Research Topics

Digital health equity

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Digital health equity

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Editorial: Digital health equity

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Editorial on the Research Topic
Digital health equity

Digital health technologies such as smartphone apps and remote monitoring present a promising path for intervention delivery; however, equal opportunities to engage in these technologies are a challenge in science presently. Some factors contributing to these inequalities include inaccessibility, exclusivity, redlining, and more. Innovations in digital health technologies must also be distributed equitably to avoid increasing existing disparities and improve overall population health and mental health. This editorial presents the state of the science on how digital health technologies can be leveraged to reach communities that are underserved and experience health disparities. Digital health is a growing phenomenon worldwide, and we must advance how all populations can leverage these technologies. This editorial reflects studies applying a social justice framework for digital health (Figueroa et al., 2022), including populations experiencing serious mental illness (Middle and Welch), homelessness (Lal et al.), and substance use (Claborn et al.). Studies also included those who are justice-involved (Tolou-Shams et al.), people of color, veterans, and youth and families. Below we summarize recent articles that focus on digital health equity.

Digital health technologies include telehealth, teletherapy, fitness apps, text messaging, computer programs, and smartphone apps. They are all promising approaches to intervention delivery for vulnerable and often underserved populations. Yet, many populations are left behind with the growing amount of digital health services. One article addresses the effect of digital health services on juveniles. When incarcerated, juveniles have little access to support services, including their family (Tolou-Shams et al.). Tolou-Shams et al. found that when telehealth and video conferencing services were made accessible, there was an increase in attendance to court hearings and telehealth interventions for youth and families. The authors also found that those involved with digital health interventions from the start of incarceration through community re-entry had higher levels of trust, enhanced engagement, and promoted the best youth outcomes.

Barriers to accessibility still exist for vulnerable populations despite government programs like Safelink and Assurance Wireless. Making digital health accessible is not always about using the most advanced technologies, but it's about using the best-fitted technology for the target population. Buda et al. state, "socio-economic and gender biases have been identified in healthcare systems, including digital divide problems caused by inequalities in access to digital services and lack of consideration for gender differences".

Digital Redlining is a systematic process where underserved groups are deprived of equal access to digital tools, like availability to the internet (McCall et al.). Digital redlining creates inequities in access (McCall et al.) and may undermine opportunities to impact important health outcomes positively. Multiple articles in this series found that vulnerable populations were interested in digital health, but the systems in place were inaccessible. For example, Lal et al.'s article found that youth experiencing homelessness possessed the foundational skills, interests, and needs to participate in digital health interventions. However, these youth could not access digital health tools and technologies in their lived environment. Factors like internet access, access to phones/tablets, and data plans limit possibilities for homeless youth. Figueroa et al. (2021) found a similar phenomenon: Spanish-speaking women were highly interested in participating in fitness apps, yet the apps were unavailable in their primary language, making it user-friendly to only those well-versed in English.

Digital health continues to be ableist throughout our society, with limited to no accessibility options. Bunyi et al. provide several examples of ways to promote accessibility. For example, those who are deaf need in-app captions. Minimal apps offer this feature. Also, those on psychiatric medications could experience various side effects like tremors, memory impairments, and blurry vision. Most apps have text-heavy content, small print, and over-animation. This can be challenging, both visually and mentally, for many people. This article highlighted three areas of improvement that combat ableism: standards, research, and recognition. It explains that we must continue making strides to challenge and change digital health standards. Standards must be remade that is inclusive of all populations. Likewise, we must highlight the research being done into digital health delivery. Healthcare delivery must be measured with diverse populations. The only way we will change how digital health delivery is by creating new ways that are inclusive and equitable. Finally, we must transition our healthcare delivery to include user feedback. By recognizing user feedback, we create healthcare delivery methods that work for individuals vs. guessing what would work best for them.

Since the 1970s, manufacturing has shifted from engineer-centered to user-centered designs (Stiles-Shields et al.). Popular models for designing and deploying digital health technologies integrate human-centered design methodologies. These methodologies offer opportunities for users to contribute to developing technologies by co-designing and evaluating. Human-centered designs are an effective method for technology development and promote usability with the general population. However, some groups do not experience high levels of usability as they are commonly not involved in human-centered design or testing. For example, many technologies are developed for younger populations without input from these young individuals. Even adults aged 65+ increasingly use technologies that are not adequately designed for them. For example, smartwatches offer the opportunity to track steps and heart rates. They also monitor sleep, among many other things. As people age, a normal aging process is thinning the skin. Wearing a smartwatch that is not sensitive to thin skin may lead to cuts or bruises.

Incorporating a participatory human-centered design with users from populations who experience health disparities may help facilitate engagement and decrease unanticipated, technology-generated inequalities. Using feedback from intended users may minimize the gap between creating an intervention for someone and creating an intervention with someone. It allows us to work hand-in-hand with intended users to create user-friendly and relevant interventions that people want to engage with. This approach shifts the focus from the idea of "expert" or professionally driven design "for" the users to designing "with" users collaboratively (Porche, et al.) (1). Co-design can reduce potential harm or misuse by including people from vulnerable communities in decision-making (Porche et al.) (1). This allows local knowledge and expertise from marginalized voices to inform the development of more culturally relevant, trusted solutions.

Several studies show success with participatory human-centered interventions. Open2Chat is a stigma-free space for young people to articulate their concerns, share opinions and experiences with a peer, and discuss the idea of professional counseling or psychotherapy (Mittmann et al.). The results of this study showed value in co-development, like Open2Chat. Another study focused on a participatory human-centered design intervention for youth and families. This study pertained to mental health support, focusing on ways to boost self-determination. This intervention empowered participants to be informed and involved in their own treatment plans (Porche et al.). It also found that participatory human-centered design interventions created greater trust and safety among all parties involved. This fostered a more profound collaboration and community among users and researchers.

The results of these articles show a mix of benefits and concerns regarding digital health. While digital health can help reach diverse populations and create additional ways to access healthcare, it also raises concerns. Considerable research and work must be done to close the gap between healthcare delivery and issues of equity, accessibility, and inclusivity. It was shown to be successful and beneficial through participatory human-centered design, but most studies showed a lack of generalizability and raised questions of concern. Multiple forms of digital health have the potential to optimize healthcare. However, as we have new innovative ways to address healthcare, we must be conscious of populations we might be leaving behind due to inaccessibility and inequity. Throughout the editorial, we found evidence that most people will engage with digital healthcare if given access. Yet, we also found considerable concerns about how digital health is set up. We must make it a point to incorporate accessibility accommodations in every digital technology we utilize in the future. More studies should be done with these digital health interventions that eliminate the possibility of furthering inequalities. We look forward to building upon this set of studies and continuing research on digital health that centers on equity.

Author contributions

HC-C, KF, JN, AA, TM helped write and review this editorial. All authors contributed to the article and approved the submitted version.

Conflict of interest

KF works with Social Wellness and Emissary Health. 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.

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Accessibility and Digital Mental Health: Considerations for More Accessible and Equitable Mental Health Apps

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Digital mental health is often touted as a solution to issues of access to mental health care. However, there has been little research done to understand the accessibility of digital mental health, especially for those with disabilities. In this piece, we define accessibility as it relates to mental health apps, describe the current state of accessibility in the digital world broadly and in mental health apps more specifically, outline why accessibility matters in mental health apps, and identify future steps to better incorporate accessibility into research and development of mental health apps.

Keywords: digital mental health, accessibility, mental health, disability, access, mHealth

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INTRODUCTION

The number of mental health apps continues to rise. Estimates suggest that over 10,000 mental health apps are now available to the public (1). The types of mental health apps vary widely; some provide self-help resources grounded in evidence-based practices such as Cognitive Behavioral Therapy (CBT), others provide pathways to virtual care either from professional providers or lay peers, whereas still others are designed to augment therapy and increase the efficiency or efficacy of clinical care. As a subset of the broader digital mental health movement, apps are often seen as a bridge to accessing care, providing an easy and cost-effective way for consumers to get help through devices they may already use (2, 3). In short, to make mental health care more "accessible".

However, this potential to expand access to mental health care to those in need is predicated on whether such products are truly accessible for diverse, underserved, and vulnerable populations. Many believe that accessibility means "making products usable by people in a wide range of situations— circumstances, environments, and conditions" (4), and that accessible design ultimately benefits everyone. While accessibility in digital mental health has often been considered in terms of expanding access to various populations including ethnic, racial, sexual and gender minorities (3, 5, 6), individuals across the lifespan (7), individuals experiencing homelessness, or rural populations (3), it has rarely been considered in terms of people with physical, sensory, and cognitive disabilities (8, 9). This is a missed opportunity in digital mental health, where researchers and developers could be leading the way in incorporating understanding of affective, behavioral, and cognitive aspects to create mental health technologies that might truly bridge the gap between those who are able to access and receive services and those who cannot.

In this paper we will a) define accessibility, especially as it pertains to mental health apps, b) present existing work around models of accessibility as it relates to technology and digital health, c) identify considerations specific to mental health apps, and d) recommend future directions in digital mental health to better incorporate accessibility. While digital mental health is a broad field which includes many cutting-edge technologies (e.g., virtual reality, wearables), we focus this paper on mental health software which run on commonly available platforms (e.g., personal computers, tablets, and smartphones). By acknowledging all facets of accessibility in design and use, digital mental health can better meet its promise to expand access and benefit broader audiences, including those who are most vulnerable and those most in need of mental health care.

To better understand the lens of the authors of this work, we disclose that some of the authors have personal experience with disabilities including navigating attention-related challenges as a person with Attention Deficit/Hyperactivity Disorder. Much of our interest in writing this piece came from our experience with reviewing mental health apps and noticing a lack of apps that respond to system-level accessibility tools (e.g., captions, screen readers, etc.), our work in evaluating the implementation of digital mental health in various service settings, and research studying and designing assistive technologies for people with disabilities. We also consulted colleagues who are mental health providers with mobility/dexterity and visual impairments.

DEFINING ACCESSIBILITY

For a resource to be most accessible, it must be able to be used by a person with a disability for the same purpose, the same effectiveness, and with a similar amount of time and effort as someone who is non-disabled (10). In the context of the physical world, this can take the form of ramps or braille signs. In the context of the digital world, accessibility means that a website or tool is built with content and design that is understandable and navigable with or without assistive technologies. It also means that a digital resource includes back-end technical or coding considerations, such as compatibility with assistive technologies to allow for greater access for those with disabilities.

The Web Accessibility Initiative (WAI) provides an example of guidelines to define what constitutes an accessible digital resource. The POUR guidelines highlight considerations such that people with disabilities can perceive, understand, navigate, interact with, and contribute to the web (11). Considerations within POUR include: ***P***erceivable information and user interface; ***O***perable user interface and navigation; ***U***nderstandable information and user interface; and ***R***obust content and reliable interpretation (12).

One challenge with defining accessibility with regards to apps, and with developing accessible mental health apps, is that accessibility needs vary dependent on a person's disabilities. People, for example, who are D/deaf or hard of hearing, or those with learning disabilities may benefit from captioning. People who have vision impairments or those with Attention Deficit/Hyperactivity Disorder (ADHD) may benefit from text customization options such as text size, scaling, contrast, and reflow. People with color blindness may benefit from images that use additional formatting or annotations to help display information. Others who have motor impairments or people with cognitive disabilities may benefit from tools such as voice dictation and eye-tracking to help interface with technology. More examples are provided in **Figure 1**.

Accessibility for mental health apps requires making similar considerations as one would in the broader digital world. For example, a meditation app designed with accessibility for diverse needs in mind would include captions for audio-based meditations and audio indicators for visual cues such as breathing. The importance of such considerations is magnified for a population that is already dealing with layers of challenges to accessing the care they need. To better understand accessibility as it relates to digital mental health, we can start by looking at existing work in digital accessibility and in digital health.

EXISTING WORK FOCUSING ON DIGITAL ACCESSIBILITY AND DIGITAL HEALTH

In general, accessibility within the digital space has taken steps toward standardization through organizations and protocols such as WAI and its related efforts (13, 14). Researchers, organizations, and major tech companies such as Microsoft and Mozilla, have contributed to the creation of accessibility standards and the creation of guidelines for assessing the accessibility of websites and apps such as WAI's POUR guidelines (12, 15–18). Mobile platforms such as iOS and Android are also designing with physical and sensory accessibility in mind. To encourage app developers to code their apps to work with assistive technologies, Apple (iOS) and Google (Android) have been actively integrating assistive technology such as screen readers into their operating systems (19, 20). Apple, Google, and several other organizations have also created automated tools that can assess an app and check if it has integrated accessibility features or met certain guidelines (21). This helps to standardize and ease the burden of checking for accessibility in technology (although human review is still warranted). Despite all these efforts, accessibility in the digital world is still poor, including in digital health (22). However, as researchers and designers in this space, we should be leading the ways in terms of accessibility because everyone experiences mental health challenges at some point in their lives – ranging from acute to serious mental health discomfort or distress. As such, making more mental health resources available to everyone should be a common goal.

Research on accessibility remains limited in the digital mental health space. Work on accessibility in digital health more broadly is more developed (23–26) and offers some insights on how to better consider and increase accessibility in mental health apps. A number of studies in digital health have found that principles of co-design or including those with lived experience in developing an app can help identify and address accessibility issues for an app's target audience such as customization and personalization, inclusive language, or better measurements based on differing abilities (27–33).

One study looking at the use of digital health apps for vision impaired individuals found that by applying accessibility focused user experience (UX) guidelines to an app's design, information recognition and uptake increased for both those who are vision impaired, and those who are without vision impairment (27). The study's researchers also found both

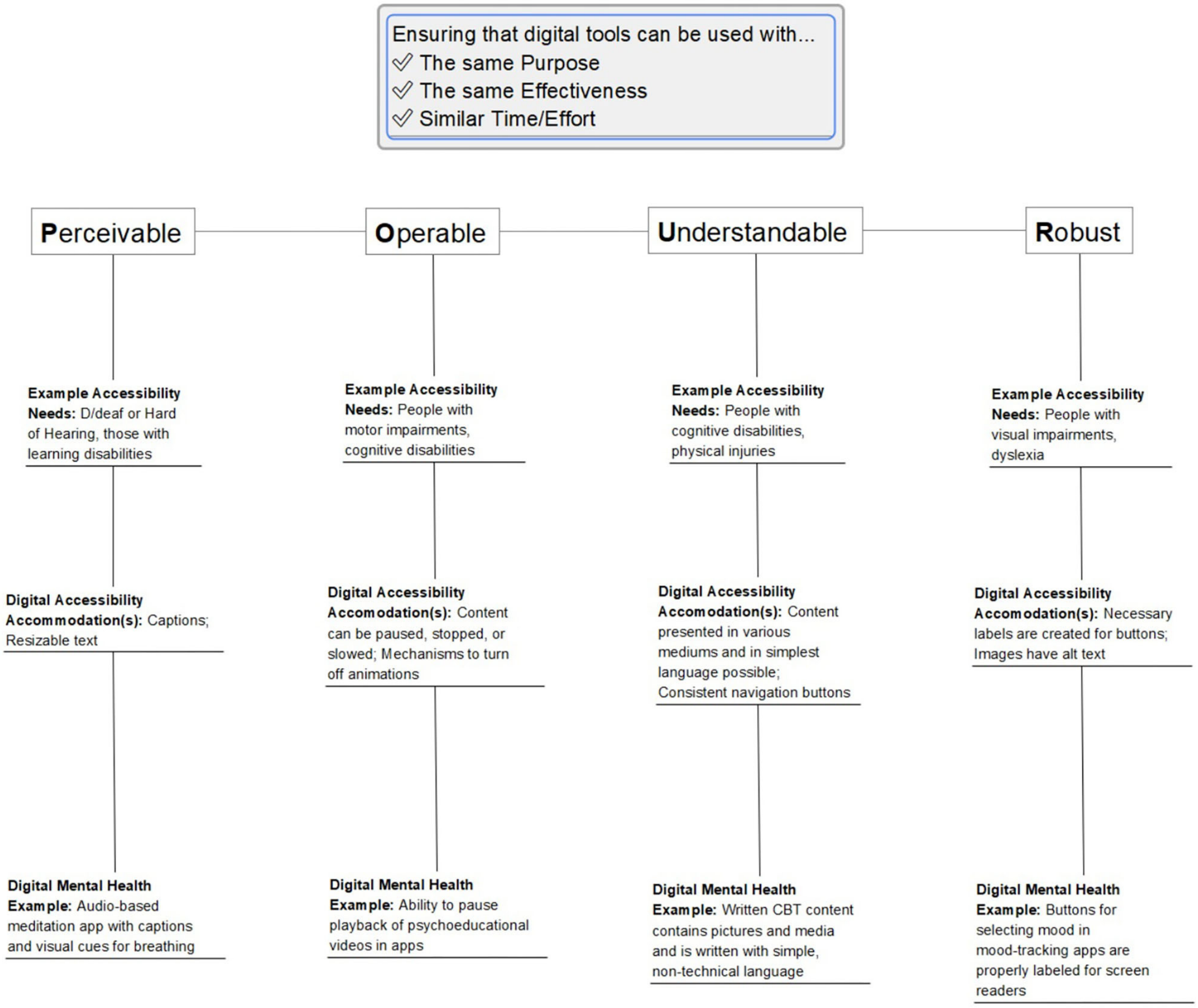

FIGURE 1 | Applying the Web Accessibility Initiative (WAI) POUR guidelines to digital mental health.

low-quality information presented in an app, as well as poor presentation and organization of valid information across other apps. Researchers point out that this can be particularly troubling especially for low-vision consumers, for whom information may already be difficult to access.

One approach in research is to include feedback from caregivers or professionals, *in addition* to feedback from disabled consumers (28). Done appropriately, which means including caregiver and professionals to provide additional, diverse viewpoints and triangulation with consumer voices, this can be useful to add context and insights (29, 34). However, professionals may have worked with other people with similar disabilities but differing accessibility needs. Thus, although work in digital health has demonstrated potential usefulness of triangulation with caregivers and professionals, it needs to be done in a way that does not diminish the involvement and voice of disabled people.

Unfortunately, accessibility research in digital mental health itself is limited. Again, there is an opportunity here to understand and address accessibility barriers for those who might use mental health apps. In the following section we look at accessibility considerations for mental health apps as they relate to a disabled person's ability to use mental health apps for the same purpose, effectiveness, and with a similar amount of time and effort as someone who is without disability.

ACCESSIBILITY CONSIDERATIONS IN MENTAL HEALTH APPS

A mental health app may not fulfill its intended purpose without weighing accessibility in design. Mental health apps are a solution for receiving treatment for those unable to access traditional forms of therapy or an opportunity to enhance treatment for those who are already receiving therapy. Accessibility considerations for mental health apps should help ensure that a mental health app can perform the same functions, achieve the same outcomes, and require the same amount of time and effort for those with or without disabilities. This includes consideration of physical, sensory, and cognitive disabilities, as well as the intersection of such disabilities with mental health concerns (35).

Mental health apps should aim to perform the same function regardless of the accessibility needs of those using them. Given that major functions of mental health apps are often around providing psychoeducation through didactic material, reinforcing skills through interactive exercises, and supporting tracking of things such as mood, symptoms, triggers, or medication, apps should attempt to ensure that functions can be performed by all. Various issues, however, may interfere with consumers using these functions. For example, those who are D/deaf or hard of hearing may greatly benefit from captioning in audio-heavy meditation apps. Alternatively, those who are vision impaired may require resizable or customizable text when navigating text-heavy content. It is estimated that almost 33% of adults with physical disabilities in the U.S. (about 17.4 million people) experience mental health issues, and those with disabilities should be afforded the same benefits from digital tools as those who are non-disabled (36).

Those with temporary disabilities must also be able to perform the appropriate tasks within a mental health app. Those experiencing common side effects of psychotropic medications such as blurry vision, tremors, or memory impairments, may have trouble reading text-heavy content that is not resizable or customizable; an accessibility feature commonly needed by those who are vision impaired. In another example, over-animated or dense app designs may make it challenging to complete and retain didactic material for those with poor working memory, a symptom found within a variety of mental health challenges (37). Physical, sensory, and cognitive disabilities often co-occur with mental health conditions (38–40), adding layers of digital accessibility concerns for individuals. Creating accessible content should serve to benefit a mental health app's reach, while maintaining or even improving the app's effectiveness at delivering information.

For a mental health app to be of the same benefit to people with disabilities, they must be able to use the app for the same or similar amount of time and effort. In addition to the examples outlined above, poor adherence to accessibility guidelines can also impact the amount of time and effort required to use and trust a mental health app (41, 42). Failing to apply accessibility guidelines to privacy policies may result in overwhelmingly complex policies written at college-level reading levels requiring additional time and effort to understand (29, 43, 44). This is especially critical for those using a mental health app, who might need clear assurances that sensitive personal data such as what is shared in a mental health app will be treated with respect.

FUTURE DIRECTIONS: MAKING MENTAL HEALTH APPS MORE ACCESSIBLE

Work on accessibility on mental health apps is sparse. Prioritizing such work, however, could provide an opportunity to expand the reach of mental health apps, especially to those who face many barriers to traditional mental health care. We note three key areas where we should work to improve the consideration of accessibility for mental health apps – standards, research, and recognition.

Various standards and evaluation frameworks have evolved for mental health apps [e.g., APA Framework (45), Enlight (46), One Mind PsyberGuide (47)] which have consensus around key areas of evaluation including evidence-base, user experience, and data security and privacy. However, none of these standards and frameworks consider accessibility. The closest aspect would be user experience, but although accessibility impacts user experience, they are not equivalent and assessing user experience may not identify accessibility issues. Accessibility should be a core area of evaluation for mental health apps. This could include accessibility as discussed in this paper, as well as other components contributing to access, such as language or system requirements, but its inclusion in evaluation would go a long way to help promote inclusion. It is beyond the scope of this paper to define specific, measurable items that define whether a mental health app is accessible or not, however, the examples provided in **Figure 1** outline some considerations that might be incorporated in such items. A recent synthesis of various evaluation frameworks identified 11 distinct questions related to accessibility covering areas of availability, offline modes, and vulnerable populations as the target audience (48). Another review has recommended the Matching Person to Technology (MPT) model as one framework to use when considering health apps for people with intellectual disabilities (30).

Accessibility research needs to be collaborative, by including those with lived experience and accessibility needs in the design and iteration of mental health apps. Although as discussed earlier, providers and caregivers can provide additional data, this should be done in a way that empowers rather than diminishes the voices of those with lived experience. Iterative research is key because the diverse accessibility needs of consumers are unlikely to be addressed or incorporated in just a few focus groups or studies. Furthermore, accessibility considerations made during various stages of iterative research should be well described and contextualized to allow other research groups to iteratively build off each other's findings. Collaboration is also required between diverse stakeholders including industry partners to make use of advances in accessible technologies more broadly in research designs and considerations.

Qualitative research and interviewing geared toward understanding accessibility in mental health apps can begin to inform specific needs in the space. Similar work has been done by Bernard and colleagues, but that was focused more on how mental illness can affect accessibility of apps and websites (29). Research design that is mindful of participants' conditions is also important. Beaton and colleagues, for example, demonstrated consideration of how the temporary disabilities caused by concussion symptoms, might impact their findings (28). Rather than limiting findings to information collected during the interview, they encouraged participants to follow up with any additional thoughts after the interview to provide time for recall and processing.

Consumer surveys, especially those done early in the process of research or design, can provide valuable understanding of potential areas to explore including needs and opportunities. However, when using surveys, recruitment needs to ensure proper representation to consider accessibility. If survey samples are small or targeted toward specific populations, that population should be well-contextualized to ensure that findings are interpreted appropriately. If survey samples are large, and intended for wide-spread generalization, an eye toward proper representation of diverse accessibility needs should be a consideration in recruitment.

Elevating accessibility to a critical consideration in the digital mental health space requires making sure it is not brushed aside by simply stating that it is already included in current evaluations. Furthermore, professional organizations and journals could do a better job of raising accessibility issues, first by making these spaces more accessible, and second by ensuring that accessibility issues are included in the dialogue.

Furthermore, while this paper focused on mental health apps, it is equally important to consider accessibility in the broader digital mental health space, as many digital mental health tools are being made available across various device form factors. Finally, while we centered around accessibility in the context of disability, it would be wrong to ignore the importance of *usability* and *inclusion*. Usability refers to considerations for efficient and satisfying design, while inclusivity includes considerations for elements such as culture, education, and digital literacy in the development of technologies (49). Both are also important to consider in digital mental health, and they often overlap with each other and with accessibility. Without being mindful of "usable" design, we risk neglecting accessible design, and without creating "inclusive" content, we are limiting others' ability to access the content.

CONCLUSION

Technology has facilitated the creation of a multitude of mental health apps. Over the past few years, accessibility has been a growing consideration in technology generally. The time is overdue for these areas to come together and promote accessibility within mental health apps. A first step to promoting accessibility would be the adoption of standards in mental health apps which follow principles from established accessibility guidelines. Second, research should explore whether mental health apps are usable for the same purpose, with the same effectiveness, and with the same time, across people. Third, the field needs to recognize that accessibility for some-but-not-all is counter to the goal of digital mental health to make resources broadly available and will only serve to entrench rather than overcome inequalities in care. Keeping the status quo and failing to prioritize the accessibility needs of consumers of mental health apps limits the quantity and quality of available treatment options. Furthermore, prioritizing accessibility may not only benefit individuals with disabilities but create better mental health apps for all users. With careful consideration and implementation of accessibility work within the field of digital mental health, we can make even bigger strides to deliver on the goals of digital mental health to increase access for all.

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/s.

AUTHOR CONTRIBUTIONS

JB wrote the first draft of the manuscript. JB, KER, and SMS wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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Conversational Physical Activity Coaches for Spanish and English Speaking Women: A User Design Study

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Introduction: Digital technologies, including text messaging and mobile phone apps, can be leveraged to increase people's physical activity and manage health. Chatbots, powered by artificial intelligence, can automatically interact with individuals through natural conversation. They may be more engaging than one-way messaging interventions. To our knowledge, physical activity chatbots have not been developed with low-income participants, nor in Spanish—the second most dominant language in the U.S. We recommend best practices for physical activity chatbots in English and Spanish for low-income women.

Methods: We designed a prototype physical activity text-message based conversational agent based on various psychotherapeutic techniques. We recruited participants through SNAP-Ed (Supplemental Nutrition Assistance Program Education) in California (Alameda County) and Tennessee (Shelby County). We conducted qualitative interviews with participants during testing of our prototype chatbot, held a Wizard of Oz study, and facilitated a co-design workshop in Spanish with a subset of our participants.

Results: We included 10 Spanish- and 8 English-speaking women between 27 and 41 years old. The majority was Hispanic/Latina ($n = 14$), 2 were White and 2 were Black/African American. More than half were monolingual Spanish speakers, and the majority was born outside the US (>50% in Mexico). Most participants were unfamiliar with chatbots and were initially skeptical. After testing our prototype, most users felt positively about health chatbots. They desired a personalized chatbot that addresses their concerns about privacy, and stressed the need for a comprehensive system to also aid with nutrition, health information, stress, and involve family members. Differences between English and monolingual Spanish speakers were found mostly in exercise app use, digital literacy, and the wish for family inclusion.

Conclusion: Low-income Spanish- and English-speaking women are interested in using chatbots to improve their physical activity and other health related aspects. Researchers developing health chatbots for this population should focus on issues

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of digital literacy, app familiarity, linguistic and cultural issues, privacy concerns, and personalization. Designing and testing this intervention for and with this group using co-creation techniques and involving community partners will increase the probability that it will ultimately be effective.

Keywords: women, mHealth, user-centered design, low-income, digital divide, chatbots, conversational agents, exercise

INTRODUCTION

Insufficient physical activity is one of the leading risk factors of death worldwide (1). Marginalized groups, such as people of lower socioeconomic status (2), women (3), and ethnic/racial minorities including Latinas (4), are particularly inactive. We need to develop interventions that help marginalized populations increase and maintain healthy physical activity behaviors.

In recent years, digital behavioral health interventions, using smartphones and text-messaging, have seen a surge in development and use (5). These tools can make interventions more accessible: people across a wide range of socioeconomic groups own smartphones in the US, and ownership continues to increase globally (6). The percentage of Latinx individuals that own smartphones is currently 85%, comparable to Blacks (83%) and non-Hispanic whites (85%), and slightly higher than low-income Americans (76%) (7). Although ownership rates are high, disparities in digital literacy and data plan limits persist for ethnic minority and lower-income individuals (8). These factors necessitate user friendly and low data solutions.

The field of digital health has seen an increase in interest in conversational agents, or chatbots, to help individuals pursue healthy lifestyles (9). Chatbots for behavior change can inform and educate, check and monitor symptoms, and improve mental health through Cognitive Behavioral Therapy (10), motivational interviewing, and other therapeutic modalities (11). Chatbots can save costs, guard anonymity, and personalize content (12). Since chatbots can communicate with text-message or voice dialogue, lower digitally skilled users can easily engage (13). Finally, chatbots using natural language processing may be more powerful than one-way messaging because individuals can interact through a natural form of communication (14).

However, most health chatbots may be unsuitable for lower-income and ethnic minority individuals including Latinxs. Most health promotion chatbots offer only English as a communication language (15) despite over 40 million people in the U.S. speaking Spanish at home (16). For example, a systematic review on health chatbots (including general health and mental health) found that out of 45 chatbot studies, only one study used a Spanish chatbot (17). Similarly, our previous review on conversational agents for physical activity identified only a handful of conversational agents for mobile delivery through apps and text messaging, and no Spanish conversational agents (15). Further, digital solutions are not often specifically designed for women (18), especially ethnic minority women, who generally have worse health outcomes than white women (19). Ethnic minority women are underrepresented in the design and testing of digital health tools (18). Because of this and the lack of adequate digital skills training, marginalized groups may underuse these interventions (20), even if health technologies target them.

Thus, developing health chatbots for marginalized populations, including low-income women and Spanish speakers, is challenging but crucial and has not been attempted often enough. We developed a prototype text-message based physical activity conversational agent for low-income English and Spanish speaking individuals, based on principles of Behavioral Activation (21), Motivational Interviewing (22), Acceptance and Commitment Therapy (23), and Solution-Focused Brief Therapy (24). We designed the prototype chatbot to help users clarify their values and motivations for physical activity, set goals and plans, and overcome exercise barriers.

The aim of this study was to understand whether low-income English and Spanish speakers want to interact with conversational agents, what their health priorities are, and how we should design these tools to meet their needs. We report the results of qualitative interviews in low-income Spanish and English speaking women, majority Latinas, during testing of our prototype chatbot, a Wizard of Oz study, and a co-design workshop conducted in Spanish. We originally opened our study to all genders, but received interest only from participants who identified as female. We recommend best practices for researchers interested in developing chatbots for low-income women in English and Spanish.

MATERIALS AND METHODS

Participants

We recruited participants through SNAP-Ed (Supplemental Nutrition Assistance Program Education) in California (Alameda County) and Tennessee (Shelby County). We consider participants low-income as the intended audience for SNAP-Ed is SNAP recipients (who are at or below 200% Federal poverty guidelines) and other low- income audiences who are at or below 185% Federal poverty guidelines.[1] SNAP-Ed extension partners distributed English and Spanish flyers and invited participants in their healthy eating groups to join the study. In addition, SNAP-Ed posted our English and Spanish flyers on their Facebook pages. We included participants 18–65 years old, English or Spanish speaking, who owned a mobile phone and desired to be more physically active. This study was approved by the University of California Berkeley Committee for Protection of Human Subjects (CPHS, ref: 2020-05-13271).

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[1] https://www.fns.usda.gov/snap/snap-ed

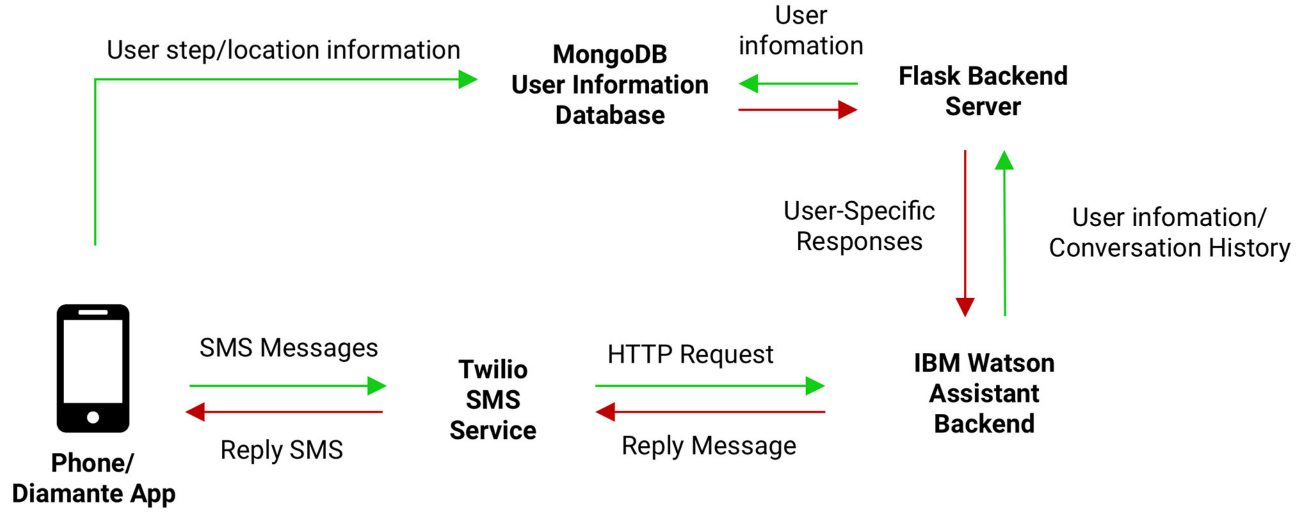

FIGURE 1 | We used a front end SMS interface for communication, through the Twilio communication service, and a backend conversational agent using a cloud-based tool, IBM Watson Assistant, for developing and managing conversational flows. We leveraged a custom server for collecting record data and managing scheduled tasks, through a backend REST API implemented in Python Flask, with a MongoDB database.

Conversational Agent Technical Development

We used a front end SMS interface for communication, through the Twilio communication service[2], and a backend conversational agent using a cloud-based tool, IBM Watson Assistant[3], for developing and managing conversational flows. We leveraged a custom server for collecting record data and managing scheduled tasks (see **Figure 1**), through a backend REST API implemented in Python Flask[4], with a MongoDB[5] database. Our dialog tree consists of over 150 conversational elements, with over 10 million possible conversational pathways.

Conversational Agent Flow Development

Our prototype conversational flows went through two iterations during the study. The first iteration included flows on core values, motivation for health behavior change, exercise goals, and activity planning. Midway through the study we added flows on weekly exercise plans and barriers to physical activity, and we addressed errors after receiving participant feedback. Examples of the dialogue flows are shown in the **Supplementary Material**.

Study Measures

Phase 1: Online Interview

We interviewed participants online between August 2020 and April 2021. After participants filled in an online informed consent form, they were directed to a short online questionnaire that assessed gender, age, socioeconomic status, depression, anxiety, perceived stress, and financial issues due to the COVID-19 pandemic. Within a semi-structured interview conducted via videoconferencing, we assessed opinions and knowledge of chatbots as personal health coaches, technology use, digital literacy, and privacy considerations of chatbots in general. We also asked participants what information and text-messages they would like to receive from chatbots, and how chatbots could help them remain active during social distancing measures.

Phase 2: Wizard of oz Procedure

After answering these exploratory questions, participants completed a 20 min text-messaging conversation with a simulated chatbot. Participants were told that they were texting an automated chatbot but were actually interacting with a second researcher who texted participants via a Google Voice phone number. This procedure allowed us to understand how a chatbot should ideally respond in conversations with humans (25). Participants were debriefed at the end of the interview about the Wizard of Oz procedure.

Phase 3: Chatbot Prototype

Participants texted with our chatbot prototype for 10–20 min. After the texting conversation, participants resumed the semi-structured interview via videoconference. Participants were asked about their opinions of the chatbot prototype's ease of use, usefulness, humanness, and sustainability, as well as their preference for the simulated chatbot vs. the automated chatbot. They were also invited to give recommendations for expanding the chatbot prototype's content and improving upon its usability. The semi-structured interviews were recorded via Zoom and audio-recordings were transcribed by a professional transcription service (3playMedia). Participants received a $40 gift card upon study completion.

Phase 4: Design Workshop

Midway through the study, two researchers facilitated a co-design session in Spanish via Zoom for Spanish-speaking and bilingual participants who had completed the online interview and tested the chatbot prototype. During the workshop, participants added ideas for chatbot use and design to a Google Jamboard

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[2] https://www.twilio.com/
[3] https://www.ibm.com/cloud/watson-assistant
[4] https://flask.palletsprojects.com/en/1.1.x/
[5] https://www.mongodb.com/cloud

(**Supplementary Material**). Participants were compensated an additional $40 for their participation.

Analysis

We show descriptives of the clinical and demographic characteristics of the sample using means, medians and percentages where appropriate.

We applied a constructivist grounded theory approach (26) to our qualitative analysis of the semi-structured interviews. TCL developed an initial codebook in English, which AM and AJ used to develop a Spanish codebook. We also employed open coding to generate codes inductively. After all co-authors met to discuss emerging themes, we revised our codebook to incorporate inductively- and deductively derived codes that captured user feedback and attitudes related to the content and physical activity motivators. The transcripts were coded independently by TCL, MM, AJ, and AM using Dedoose, a qualitative software program (27).

The codebook was divided into two distinct parts corresponding to Phases 1 and 3 of the study. The first part of the codebook was designed to analyze participants' comfort level with technology prior to engaging with the simulated chatbot and our chatbot prototype. Data from Phase 1 of the study were tagged with the following codes: "Technology familiarity" and "Privacy and security concerns." The second part of the codebook synthesized data about participants' opinions of our prototype chatbot after engaging in a 10–20 min texting conversation with it. Data from Phase 3 of the study were tagged with the following codes: "Ease of use," "Satisfaction, usefulness, and humanness," "Sustainability," "Physical activity barriers," "Content and usability recommendations." We memoed on the data tagged with these codes to generate the themes we present in this paper.

RESULTS

Participants

We included 10 Spanish- and 8 English-speaking women aged 27–41 years. Most participants ($n = 16$) were recruited by SNAP-Ed Educators. The majority were Hispanic/Latina ($n = 14$), 2 were White and 2 were Black/African-American. More than half were monolingual Spanish speakers, and the majority were born outside the US (>50% in Mexico). For most, paying for basics was hard or somewhat hard ($n = 17$). Over half of the participants had finished high school and/or college ($n = 11$). Most participants ($n = 16$) reported being in good health, and depression and anxiety scores were low overall (>2 indicates risk for depression or anxiety). **Table 1** shows participant characteristics.

Qualitative Findings

We divided the qualitative findings from the semi-structured interviews in Phases 1 and 3 into English and Spanish speaking participant feedback. Here we describe the main results. Additional quotes from participants can be found in the **Supplementary Material**.

TABLE 1 | Participant characteristics.

	Overall (*n* = 18)
Preferred language	***n* (%)**
English	8 (44.4%)
Spanish	10 (55.6%)
Age	**Mean (SD)**
	39.5 (6.01)
Race/ethnicity	***n* (%)**
Black/African-American	2 (11.1%)
White or Caucasian	2 (11.1%)
Hispanic/Latina	14 (77.8%)
Employment	***n* (%)**
Full time (more than or equal to 35 h)	3 (16.7%)
Part time (<35 h)	1 (5.6%)
Homemaker	10 (55.6%)
Unemployed	2 (11.1%)
Retired	1 (5.6%)
Other	1 (5.6%)
Education	***n* (%)**
Never went to school	1 (5.6%)
Between 1st and 5th grade	2 (11.1%)
Between 6th and 8th grade	2 (11.1%)
Some high school	2 (11.1%)
High school graduate or "GED" degree	3 (16.7%)
Some college or technical school	1 (5.6%)
College graduate	5 (27.8%)
Graduate degree	2 (11.1%)
Paying for basics (e.g., food, housing, medical care, and heating) is:	***n* (%)**
Very hard	4 (22.2%)
Somewhat hard	13 (72.2%)
Not hard at all	1 (5.6%)
Born in the US	***n* (%)**
	5 (27.8%)
Country of birth (if not US)	***n* (%)**
El Salvador	2 (11.2%)
Guatemala	1 (5.6%)
Mexico	9 (50.7%)
Peru	1 (5.6%)
Self reported-health	***n* (%)**
Fair	2 (11.1%)
Good	10 (55.6%)
Very good	3 (16.7%)
Excellent	3 (16.7%)
Impact of COVID-19 (1 = completely disagree, 5= completely agree)	**Mean (SD)**
I am running into financial issues	2.67 (1.37)
I feel more lonely	2.00 (0.970)
I feel more stressed	2.78 (1.48)
I feel more anxious	3.00 (1.41)
Psychological measures	**Mean (SD)**
Depression (PHQ-2, range 0–6)	1.06 (1.06)
Anxiety (GAD-2, range 0–6)	1.67 (1.28)

PHQ-2, Patient Health Questionnaire, 2-item scale; GAD-2, Generalized Anxiety Questionnaire, 2-item scale.

Phase 1 Findings (Prior to Chatbot Conversations)

Technology Familiarity

English-Speaking Participants. Most English-speaking participants had been sending and receiving text (SMS) and multimedia (MMS) messages for years, primarily through their phone's default messaging app but also through other messaging apps (e.g., Facebook Messenger, Google Hangouts, WhatsApp).

> Texting familiarity: "*I want to say over 10 years...15 years I've been texting, forever.*"

Some participants reported also using their mobile phones for health purposes, such as diet and activity tracking (most commonly through Apple's Health app).

> Health apps: "*I did have a fitness app… There's, obviously, the iPhone's health app, in general, for step counting. And my work handed out a health app, and I purchased Zombies, Run!*"

The majority were unfamiliar with the term "chatbot," but said to have encountered a chatbot when the researcher gave examples–e.g., for food ordering and delivery, banking, internet service, and health care.

> Chatbot experience: "*I think I might have [interacted with a chatbot]. Comcast, you know the Help Center? Yeah. I texted them and then I got a response. And then I texted something else, and I got another response. And at the end, they sent me a link to see if that could help.*"

English-speaking participants' initial perceptions of chatbots varied: some were optimistic about the potential uses of chatbots for streamlining interactions between individuals and services (e.g., "*I have no problem with it, especially with knowing the actual human technology that's guiding the technology behind it…I know that artificial intelligence is growing*").

> Others expressed doubt (e.g., "*I know that the world is evolving, and computers are being used for all types of things. But in general, I don't really like it.*").

> Some were skeptical, e.g., *"I think it's going to be frustrating. When I call to make a payment, I do it, and there's no one on the other side. And I ask a question, and [I] get something else."*

Spanish-Speaking Participants. Besides text-messaging, calling, and social platforms like Facebook's messenger, WhatsApp, Instagram, many Spanish speaking participants also used their phone for basic services.

> Common uses for phones: *"I use it a lot (default texting app), for the bank, for my close family... And the phone…for my basic services: electricity, gas, water, insurance, all that…That's what I use it for more than anything else."*

Participants used apps like YouTube as a resource for physical health, mental health, and healthy food recipes and followed doctors' advice on Facebook and YouTube.

> Fitness resources: *"I like to watch some videos on YouTube...there are some exercises that I like... They are like boxing with cardio or something... I also like the yoga ones."*

Most Spanish-speaking participants were unfamiliar with the term "chatbot," until given examples of automated machines (e.g., a phone answering machine).

Even though all had been using text-messages, some participants did not know how to send a new text message to a new number. Additionally, most participants were unfamiliar with video conferencing software and required help from a researcher and their children or partner to navigate Zoom and initiate a conversation with our chatbot.

Privacy and Security Concerns

English-Speaking Participants. Many English-speaking participants were concerned about privacy and were hesitant to share personal information such as their name, images of their face, and location. They were concerned about sharing their location and the chatbot recommending unsafe locations.

> Location recommendations: "*They [the chatbot] say you can go to this park.. but I'm going to be concerned if the park is not being cleaned often, or who gets there. Who goes there? And even though the chatbot is going to tell me this place is safe for you to go, I'm not sure if I'm going to give it a try.*"

Spanish-Speaking Participants. Privacy and security concerns mostly stemmed from limited understanding of chatbot technology. Participants' questions included: "*Do people see what the chatbot is doing? Do people review the messages? Can the chatbot see what I am doing?*"

Additionally, participants were concerned about sharing location data:

> *"I would say that [sharing location] is fine, but on the other hand it would be wrong because I would feel like they know where I am and where I'm going and everything. I would feel like I was being watched."*

Phase 3 Findings (After Testing Prototype Chatbot)

Ease of Use

English-Speaking Participants. Participants universally appreciated the chatbot's quick response times. As one participant explained, "*the thing I didn't like about the [Wizard of Oz] was that the response time wasn't as fast as the [chatbot].*"

> Others commented that they felt the chatbot *"was going more around the question and not really giving me any solutions."*

Usability issues were a common complaint. Many participants had to restart the conversation after the chatbot failed to recognize their input.

> Restarting conversations: "*I put in a lot and they sent me back: 'Hi, I am your physical health companion.' So they sent me, again, the same message that they sent me at first.*"

Spanish-Speaking Participants. Participants found the overall experience positive. After the researchers gave coaching and instructions, most participants regardless of literacy level were able to send and receive text messages. After teaching a participant how to create a new message, our team asked the participant if she found the chatbot session to be difficult, to which she replied: *"No, it's easy, I didn't find it difficult myself."*

One participant was unable to reply to the chatbot, as she had difficulties reading, writing and typing. When she needed to send a message, she would use the voice input feature on her phone instead of typing out the message.

Satisfaction, Usefulness, and Humanness

English Speaking Participants. Overall, English-speaking participants were satisfied with their interactions with the chatbot. Participants described the chatbot as *"really great," "pretty conversational," "very responsive,"* and *"very innovative."* One participant stated that the chatbot could be her support person, just like her friend. Some participants preferred texting with the chatbot over texting with a researcher. One participant noted that "*there weren't any grammatical errors in the [chatbot] responses*," as opposed to the human responses. Another user stated, "*I think this was a little bit better, the second one. Even though I had a little more problems, it was a little more specific or more detailed.*"

Participants did not find the chatbot very humanlike, especially when they compared it to their interactions with another researcher via the Wizard of Oz procedure.

> Personalization: "*It seemed like the first one was more conversational–it's more personal, kind of, than the other one. It was just like...answer this question on the second one, to get to the next thing.*"

Most participants recognized and accepted the limitations of the chatbot.

> Satisfaction: "*I mean this is cool. Like I said, I would prefer to talk to a live person, but if that's the next best thing, then it's pretty cool.*"

Spanish-Speaking Participants. Spanish-speaking participants mentioned the chatbot could give them a quick confidence boost, and help address problems when friends or family members are unavailable. Messages of encouragement and reminders were among the features most liked/requested.

> Encouragement: "*And I get a reminder (from the chatbot) and I need to get back to you (the chatbot) and I can say: 'oh, I am sorry, I am not feeling well today.' And I receive a message saying 'no, it is all right, you can do it!' In other words, a message of encouragement would be very nice."*

Another participant pointed out that humans can get tired of trying to encourage one another, or because of cultural norms, might not be the most supportive.

> Support system: *"Yes, because many times there are people who are very depressed and their relatives don't go to her because they can't go to their house or things like that...that someone (the chatbot) sent them a message I imagine they must get motivated. To say, 'wow, somebody remembered me.'"*

In contrast to the English-speaking participants, most Spanish-speaking participants found their interactions with both the Wizard of Oz chatbot and the automated chatbot to be human-like. One participant stated that she felt like she was texting a person, *"I felt comfortable with the application (chatbot) because it's like I was talking to someone, but it wasn't someone."*

Participants could not differentiate between the researcher and the chatbot and would often ask how the chatbot could be a machine.

Sustainability

English-Speaking Participants. When participants were asked how long they would use the chatbot for, answers ranged from 1 month to indefinitely. Some participants considered engaging with the chatbot daily (and even multiple times throughout the day) for workout ideas, exercise plans, and new exercise knowledge.

> Continued use: "*As long as I'm exercising or if I set a goal for like a month or two months, I think it would be great to have at least reminders or stuff like that, during the whole month, or during these two months. So it would be useful.*"

One participant found the chatbot to be more sustainable than an app or activity tracker because "*you're talking to somebody to help you work through things and think through things, and apps aren't really going to do that.*"

Some participants felt that the chatbot would lose its novelty over time, especially if its responses became repetitive or unhelpful.

> Repetitiveness: "*If they don't keep up with my goal and they keep asking the same things and not moving on to the place that I am after, probably, two months from now, that will make me stop using it.*"

Spanish-Speaking Participants. Most participants stated that they would continue to interact with the chatbot if it remained free. They also shared that they would primarily use it when they need suggestions for healthy eating and new exercises.

> Seeking advice:*"I think when I need help. Like before exercising, ask him[the chatbot] about some exercise...and also about nutrition."*

Participants also mentioned wanting to invite their family to engage with the chatbot, e.g., "*Well, not only me, I think that even the children would like it to motivate them, something like that.*"

Physical Activity Barriers

English-Speaking Participants. The majority of our participants expressed a desire to become more physically active, but also shared several barriers that prevent them from achieving their exercise goals. These barriers include work (*"This month I haven't been doing as much [exercise] because I've been a little bit busier*

TABLE 2 | Specific recommendations for content and functions.

Content	1) Providing pictures and videos of suggested exercises 2) Including healthy eating tips 3) Sending periodic exercise reminders throughout the day 4) Sending daily fitness tips 5) Describing health benefits of physical activity in more detail 6) Setting milestones for personal fitness goals 7) Including weather- and location- specific exercise suggestions (e.g., activities that can be done in the house when it's raining outside)
Functions	1) Allowing for alternative text input methods (e.g., integrating voice-to-text) 2) Allowing users to input their own barriers to physical activity 3) Giving users the option to select answers from drop-down lists 4) Integrating more opportunities for social connection (e.g., a chat room or integration to existing social platforms)

with work"); lack of companionship and social support (*"It's not motivating to start exercising by myself")*; lack of routine; injury; gym closures; and weather *(e.g., Winter is also coming, so it's like people are going to be inside even more)*.

Participants found that their daily lives were impacted due to caregiving duties. "*I have three girls of different ages and they all need something from me all the time. So I don't have much time for myself. So if I find a time to do something that I like, I just do [my errand] instead of like, stop because the park is on my way.*"

Spanish-Speaking Participants. Most physical activity barriers for the Spanish-speaking group overlapped with English-speaking participants. One participant shared how she was impacted by the stay-at-home-orders.

> Fear of infection: *"I felt very scared because the news came like a bomb...people are dying and they are getting infected, so I already imagined that we were going to get infected...it was like a trauma for me, the truth is that I stopped doing my things from one day to the next."*

For a few participants, physical injuries limited their physical activities.

> Bodily pain:*"I suffer a lot from my lower back and I like to see exercises that help me with that...I really like yoga."* Participants identified personal physical activity recommendations as a benefit of technology like our chatbot prototype.

Content and Usability Recommendations (English and Spanish Participants)

Participants gave specific recommendations to expand upon the program content and chatbot functions. We show the main recommendations in **Table 2**.

Co-design Workshop in Spanish

Background information is shown in the **Supplementary Material**. Here we report the main results.

Participants mentioned that they would like our chatbot to help with activities other than exercise, including finding health information, healthy recipes, COVID-19 vaccine information, and anti-stress tips. If they could create their own ideal chatbot, they would like it to also help them with payment reminders, advice about healthy environments, exercise and cooking tips, and recommendations for visiting new places. Finally, they would design chatbots that help young people study and go to university, and help with parenting, including activities for children.

DISCUSSION

We describe the opinions of low-income English- and Spanish-speaking women on health chatbots, and their experiences with our prototype physical activity chatbot. Overall we find that participants were largely unfamiliar with chatbots, and were initially skeptical of their use. After testing our prototype, most users felt positively about physical activity chatbots. They were concerned about the privacy of their personal information, especially involving location. Users indicated wanting a more comprehensive chatbot system that provides daily exercise goals, tips, health information and healthy food/cooking options. We found differences between English and monolingual Spanish speakers in exercise app use, digital literacy, and the wish for family inclusion. Below we provide specific recommendations for designing health chatbot interventions for this population.

Chatbots, Despite Being Machines, Can Provide Physical Activity Support

Participants were initially skeptical of communicating with a machine. After testing, most commented that the chatbot could give them support and tips when family and friends failed to provide it. Both English- and Spanish-speaking participants found the chatbot to be motivating, similar to a friend that encourages you to exercise. Previous work on automated text-messaging for mental health, also highlighted that Spanish speakers in particular perceive social support from automated text-messages (28). Thus, even if participants know they are talking to a machine, the chatbot could still provide emotional support, particularly when others are too busy or unwilling to provide it.

Pay Attention to Linguistic and/or Cultural Differences Between English and (Mono-Lingual) Spanish Speakers

In contrast to our English-speaking participants, Spanish-speakers used few health apps. Instead, they used social media such as Youtube to find health information. Further, Spanish-speakers generally had lower tech literacy and higher barriers to participating in health tech studies, in line with results from previous studies (8, 29). Several Spanish-speaking participants needed help from the researchers to set up a Zoom meeting and initiate a conversation with the chatbot. For inclusive digital health, this support should be a standard component of the research visit. Finally, though many participants indicated a wish to add a social component to the chatbot, Spanish speakers in particular wanted their family members (including their children) to be able to engage with the chatbot. Thus, differences were found mostly in exercise app use, digital literacy, and the wish for family inclusion.

Use Simple Text-Based Chatbots, Allow Voice Communication, and Provide Tech Support

Our findings combined with earlier work (30) demonstrates an advantage of a text-based chatbot rather than an app-only interface. Most participants were familiar with texting, but not all were frequent app users. Other work in Latinx parents also suggested that using tools that participants are already familiar with for chatbots, such as Whatsapp will be most effective. For participants with lower reading, writing and tech literacy, voice interactions could further increase the usability of chatbots. For example, a user co-creation study showed that older adults, who generally have lower digital literacy, prefer voice based physical activity chatbots to text based (31). The authors suggested that voice is a powerful modality for encouraging motivation among those who struggle with new technologies.

Participants also indicated they preferred short and easy-to-understand messages. In line with other work (32), we recommend that the reading level should be no more than 8th grade (13–14 years) literacy. Finally, technical issues (e.g., chatbot struggled to understand answers outside of a template) impeded smooth communication. Flexibility of bot response, dialogue length, dialogue structure, and chatbot personality are general technical challenges of chatbot design, which need to be addressed and improved in future work to avoid user frustration and drop-out (33).

Increase Transparency About Data Collection

Most users were concerned about sharing personal information, particularly their location. Users felt more comfortable with data sharing if they understood the reason for that data collection (e.g., giving more personalized tips). Informing users of the reason behind requesting information may make them feel more comfortable and willing to use the technology.

Consider Designing Comprehensive Chatbots to Help With Health and Non-health Activities

Most participants indicated they wanted help with healthy eating and finding reliable health information (including COVID-19 related information). Further, many Spanish speakers suggested chatbots should include the rest of their family into healthy living, and also provide parenting tips. Several participants envisioned chatbots also helping with practical activities such as banking, cooking and parenting. Researchers could consider comprehensive wellness chatbots that can connect individuals to other non-health related services. One drawback of this approach is the more functions a chatbot includes, the more difficult it becomes to design the chatbot, and to measure its effects (34). Factorial designs such as the multiphase optimization strategy might be helpful in this case to measure the effects of various chatbot components (35).

Consider Adaptive Chatbots to Keep Novelty

Users expressed concerns of boredom with chatbots over time if functions and recommendations remain unchanged. In our previous systematic review, we found that when program content was repetitive, users were more likely to disengage from chatbots (15). Most conversational agents included in our review lacked personalization and only communicated through multiple-choice responses. Studies also neglected to discuss safety and privacy issues, and few conversational agents acted on users' mentions of injuries, pain, or mental health symptoms. To increase engagement, chatbots should be adaptive (36–38), for example change the goals and tips based on participant behavior, and add new recommendations, weather and location specific tips and videos. Some participants also mentioned a wish to include their own exercise barriers, and be connected to others through a chatbot. Options would be to allow for more user input, and add peer support, or a human health coach when the chabot fails to provide adequate guidance.

Partnering With Community Organizations and Co-creation

Partnering with local community partners proved to be essential for recruiting typically underrepresented participants into our study. When SNAP-Ed health trainers recommended our study, participants were much more inclined to participate. Through flyers on the Facebook pages of SNAP-Ed, very few participants enrolled (only 2, both white and non-Spanish speaking). Community partners should not only be involved in the recruitment process, but also in the dissemination of health technology innovations. Our co-creation session brought unexpected participant preferences and wishes, which were useful in developing subsequent versions of our chatbot. Co-creation also helps to prevent "bad design," e.g., designing an intervention our target group won't use (39, 40). Thus, engaging both community partners and participants in the design, testing and dissemination of interventions can increase the likelihood that participants will use and benefit from health chatbot interventions.

Limitations

We included low-income women who had already demonstrated a vested interest in their health by joining the SNAP-Ed healthy nutrition program. Women were paid for their participation in the study, which may have impacted their responses and the outcomes of this study. These findings may therefore not generalize to a less motivated group who will not receive compensation. Further, the number of participants was low. This study must be considered a pilot. We divided our findings based on English- and Spanish-speaking women. However, among the English-speaking women, half were bilingual Latinas (also spoke Spanish). Cultural differences may therefore be small, though the English-speaking participants may be more acculturated. We observed differences between English- and mono-lingual Spanish-speaking participants mostly related to digital literacy and app use.

Future Steps

This research confirms that participants are interested in talking to computer-based agents about social and physical health issues. Future work should test more finalized chatbot applications in this population in larger studies, with a subsequent user-testing phase of a more finalized version of the application and ultimately in a randomized clinical trial. Most systems are currently too inflexible to personalize care because they use rule-based responses. Increasing personalization, creating chatbots that can respond flexibly, and advancing health equity by reaching marginalized populations should be major goals of future chatbot research. By tailoring this intervention to low-income Spanish- and English-speaking women-who can greatly benefit from mobile health applications but for whom they are often not designed-researchers can contribute to improving health and (digital) health equity.

Conclusion

Low-income Spanish- and English-speaking women are interested in using chatbots to improve their physical activity and general health and feel supported by these tools. Issues that researchers should take into account when designing chatbots for this population include digital literacy, app familiarity, linguistic and cultural issues, privacy concerns and novelty and flexibility. Using co-creation techniques and involving community partners will increase the likelihood that health chatbots will be effective. Future work should focus on personalization, co-creation, and ensuring health equity through digital innovations.

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 human participants were reviewed and approved by University of California Berkeley Committee for Protection of Human Subjects (CPHS). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CAF wrote the first draft of the article. TCL, MM, AJ, and AM conducted the user testing and the qualitative coding. DC developed the technical infrastructure of the chatbot. AA and JC provided feedback throughout the study. All authors contributed to the writing of the final version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fdgth.2021.747153/full#supplementary-material

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A Scoping Review on Access and Use of Technology in Youth Experiencing Homelessness: Implications for Healthcare

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Introduction: Youth are among the fastest growing subset of the homeless population. Youth experiencing homelessness (YEH) face multiple barriers in accessing health information and health care services. As such, they may best be reached through information and communication technologies (ICTs); however, limited efforts have been made to synthesize literature on this topic. In this paper, we review studies on access and use of ICTs among YEH. We also discuss the implications of the review for healthcare.

Methods: Using scoping review methodology, we searched four databases (Medline, Embase, PsycInfo, and CINAHL) for studies published between 2005 and 2019, screening 1,927 titles and abstracts.

Results: We identified 19 articles reporting on studies with YEH between the ages of 12-30, the majority of which were published in the USA. On average, more than half of the samples owned smartphones, used social media, and accessed the internet weekly to search for housing, employment, health information, and to communicate with family, peers, and health workers; however, many youths faced barriers to sustaining their access to technology. Benefits of using ICTs were connecting with home-based peers, family, and case workers, which was associated with a reduction in substance use, risky sexual health behaviors, and severity of mental health symptoms. Connecting with negative, street-based social ties was identified as the most common risk factor to using ICTs due to its association with engaging in risky sex behaviors and substance abuse.

Discussion: This review supports the advancement of research and practice on using ICTs to deliver public health information and health services to YEH, while also considering the health-related risks, benefits, and barriers that YEH face when accessing ICTs.

Keywords: digital equity, telemedicine, telehealth, cellular phone, internet, eMental health, digital health, mhealth

INTRODUCTION

Youth homelessness is a serious and complex public health issue. Factors leading to situations of youth homelessness are multifaceted, and involve the interaction of issues such as a lack of affordable housing, economic insecurity, behavioral health, violence at home, lack of positive social supports, and involvement in the child welfare system (1, 2). Various definitions have been proposed to describe homelessness. Gaetz et al. (3) define youth experiencing homelessness (YEH) as adolescents and young adults living independently from their caregivers, in unstable or inappropriate housing situations, and lacking the social and material means to successfully transition into adulthood. This definition encompasses youth living on the street, but also the hidden homeless; for example, young people living in hotels and motels, staying with friends, or sleeping in unsafe places, such as cars, tents, or in parks (4–6).

Given the transient nature of the homeless population and heterogeneity in definitions (7, 8), it is challenging to provide accurate estimates of the actual number of YEH (3, 9). Morton et al. (8) found that in the United States of America (USA), between 700,000 and 3.5 million young adults aged 18-25 experience homelessness each year, with Black youth having a significantly higher risk of homelessness. In Canada, approximately 20 percent (or 30,000-40,000 annually) of individuals experiencing homelessness are young adults aged 16-24, with a similar overrepresentation of youth from marginalized communities (i.e., youth identifying as LGBTQIA2SP+, racialized youth) (2, 9–12). In Canada and the USA, reports show that the rates of homelessness in children and adolescents are outpacing other age groups of the homeless population (12, 13).

The health of YEH is of critical concern. Without a stable and safe place to live, they often need to engage in risky activities (e.g., sex trade, selling drugs, carrying a weapon) for basic survival, which may place them at higher risk for developing health problems (12, 14–16). Health issues affecting YEH include, for example, respiratory and dermatology conditions; mood, anxiety, and behavioral disorders; psychosis; attempted suicide; and, substance abuse (11, 12, 14–19). Despite the prevalence of health and social issues among YEH, they are particularly marginalized from the health care system, facing multiple barriers to accessing timely and effective care (12, 16, 18, 20–23). Barriers they face in accessing care include: limited money, difficulties having stable contact information/address/ID, limited knowledge about health services, and negative attitudes and perceptions of healthcare professionals toward the homeless population (12, 16, 20, 22). Consequently, the mortality rates of this population are increased by up to 30 times in comparison to the general public (24–30). Such evidence provides support for the importance of creating interventions and services that are accessible and effective for this population.

Technology-enabled interventions are a promising avenue to address some of the aforementioned barriers and to help improve access to health services for YEH. However, prior to developing and delivering health information and services through technology, it is important to know the extent to which YEH use information and communication technologies (ICTs). A previous review of studies published until 2012 concluded that many homeless persons use ICTs and that there is potential for developing technology-delivered interventions aimed at improving health services among this population (31). However, this review included only a few articles that were focused on a younger population (given the nascence of the research at that time) and considering the evolution in technology development and access, the results of such a review warrant updating. Over the past decade, more studies have focused on examining access and use of ICTs among YEH (32), however limited efforts have been made to synthesize this literature. Such knowledge can be useful for informing public health practice (e.g., communicating knowledge to the homeless youth population during public health emergency situations, such as COVID-19) and health care services more broadly.

As such, we conducted a scoping review with the objective of synthesizing knowledge on access and use of ICTs among YEH and to discuss implications for public health care. Our main research questions were: (1) What is known about the rates of access and use of ICTs among YEH?; (2) what are the factors affecting access and use of ICTs among YEH; (3) why do YEH use ICTs (i.e., for what purposes); (4) what are the health-related benefits and risks for YEH in using ICTs; and, (5) what implications does the existing research have for future health care research and practice?

The scoping review method was chosen as it provides a systematic, rigorous and transparent approach for mapping a field of interest in terms of the volume, nature and characteristics of existing research (33–35). Scoping review methodology has been increasingly used in the health literature (34, 35) and is particularly relevant when reviewers are interested in questions extending beyond intervention effects or in emerging fields of research (33, 36). Given that the study of access and use of ICTs among YEH is a relatively new area of research, a scoping review is an important first step in informing future research and practice.

METHOD

Our review is based on Arksey and O'Malley's (33) five-stage framework for conducting scoping reviews and informed by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Review (PRISMA-ScR) (36). We first developed a scoping review protocol including a rationale for conducting the review, the main objectives, search strategy, inclusion and exclusion criteria, and methods for screening and data extraction, which was then piloted and discussed by the research team before finalizing. The final protocol was registered retrospectively in Open Science Framework (https://osf.io) (protocol registration accessible via: https://doi.org/10.17605/OSF.IO/6NY9B).

Abbreviations: YEH, Youth experiencing homelessness; ICTs, Information and communication technologies.

Study Identification and Selection

Information Sources and Search Strategy

A literature database search by subject, title, and abstract was applied using Medline, Embase, PsycInfo, and CINAHL. Three consultations were made with a university-based, paramedical librarian to develop a Medline search strategy, as described in **Figure 1**, which was then adapted for the other databases. The reference lists of selected articles were also screened to obtain additional articles. An initial search strategy was developed and implemented November 2nd, 2015. Given that we did not find a large number of papers to justify a full-review, we conducted a second search on April 19th, 2016 (including revisions to our keyword strategy), and an updated search on March 6th 2019, each time in consultation with the librarian. All searches involved articles published from 2005 in English and French. This date of publication was chosen given that ICTs have been evolving rapidly over the past decade; thus, literature older than 15 years would not be as pertinent to the current landscape of research and practice in this field. No other limitations were placed.

Selecting Sources of Evidence

Once the publications were retrieved and duplicates removed using Endnote, the titles and abstracts were screened (the full text was also screened for any articles identified as meeting or potentially meeting the inclusion criteria) to identify documents to be retained for the review based on the following criteria:

Inclusion criteria

(1) The publication reports on a study regarding accessibility of ICTs for YEH and/or use of ICTs by YEH; (2) the technology discussed in the document is an ICT (e.g., cell phone, social media, email, electronic case management); (3) the publication is written in English; (4) all types of study designs are included (e.g., qualitative, quantitative, mixed methods, descriptive); and (5) the date of the publication is from 2005 onwards.

Exclusion criteria

Publications were excluded based on the following: (1) the publication reports on a technology that is not included in the definition of ICTs used in this review (e.g., medical technology, diagnosis tools); and (2) the publication focuses on the use of an ICT that is only accessible by a healthcare professional (e.g., electronic medical record).

The inclusion and exclusion criteria were piloted on 10% of the documents to ensure their clarity and the ability of the research team to identify relevant articles. Revisions to the criteria were then made and applied to the rest of the retrieved titles and abstracts. A2 and A3 each screened a subset of the titles and abstracts, with any unclear articles reviewed at the full text level and discussed with A1, following which a final decision was made regarding study inclusion.

Charting the Data and Reporting Results

The selected publications were read, annotated, and entered into a Microsoft Excel spreadsheet. The data extraction sheet was piloted by A3 with two of the included studies, and then revised in consultation with A1. Next, the following information was extracted and classified by two members of the research team (A2, A3): access to technology (including methods of access), use of technology (i.e., frequency of use and purpose), impact on health outcomes, and key conclusions and implications for future research and/or practice. We also extracted basic information, including: authors, publication year, country of publication, study objectives, study design, methods, sample size, and sociodemographic characteristics.

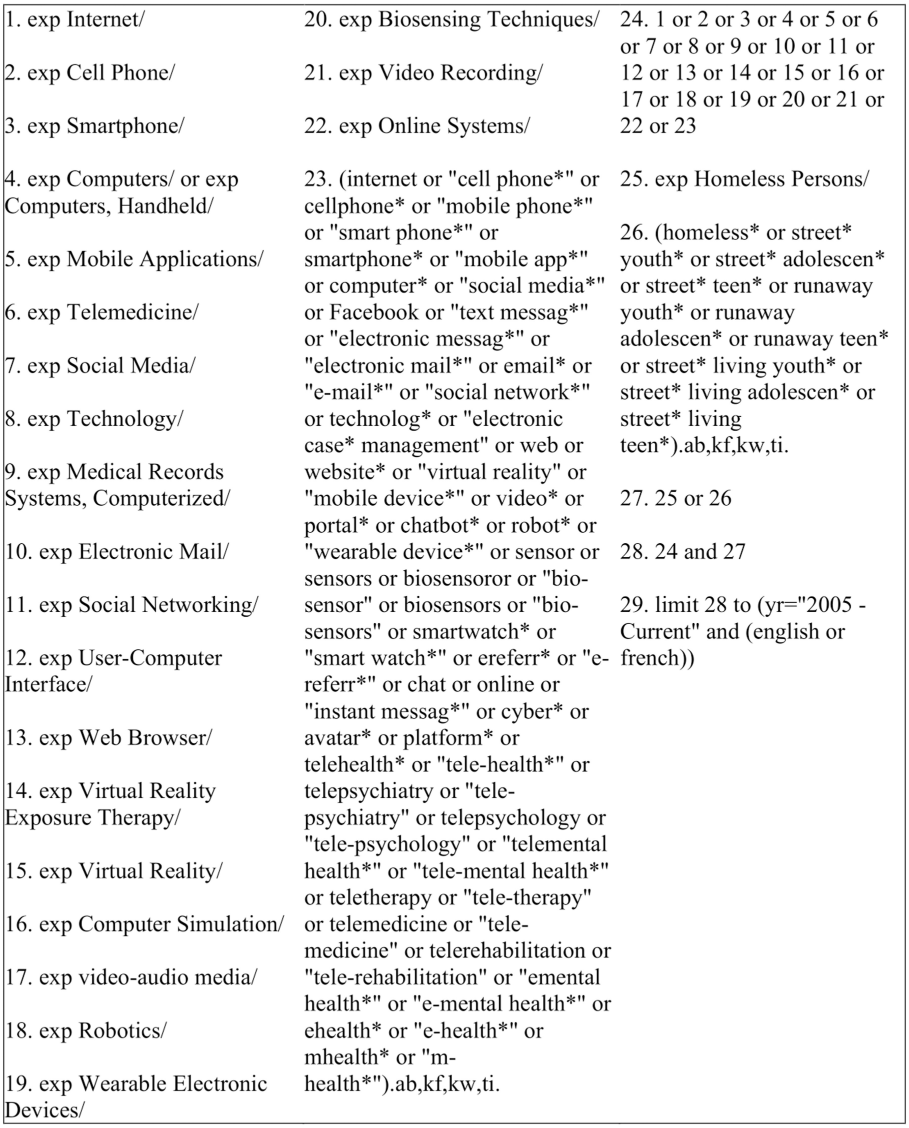
The data extraction of A3 was validated by A2, and the data extraction of A2 was validated by an additional member of the research team. Publications reporting on data from the same study sample were considered a set, and counted as one study in the PRISMA diagram. In terms of summarizing the data, where applicable, simple weighted averages were calculated by A2 in consultation with a statistician based on study sample size for data pertaining to rates of access and use of ICTs, and for sociodemographic information (i.e., studies that did not report on a category of information were not included in the weighted average calculations). The qualitative data (e.g., reasons for using ICTs, methods of access, risks and benefits to ICT use) was coded by A2 and managed using Microsoft Excel and validated by an additional member of the research team. We did not conduct a critical appraisal of the included studies given that this is not typically an objective of conducting a scoping review (33, 35, 36) and the large research design heterogeneity of the studies reviewed.

RESULTS

We identified 19 relevant peer-reviewed articles reporting on access and use of ICTs in YEH, though six of these were paired together and considered one set as they reported on data from the same study sample, resulting in a dataset of 16 study samples (see **Figure 2** for the adapted PRISMA flow diagram and details on numbers of items screened and excluded, including reasons for exclusions). The 19 articles were published between 2010 and 2018, with 17 from the USA, one from Canada, and one from Australia. **Appendix Table 1** (Supplementary Material) provides a summary of the objectives and results of each of the studies included in the review. The total sample was comprised of 3,123 participants (sample sizes ranged from 20 to 829; the majority under 200), aged between 12 and 30 years old, 2,856 (91.5%) of which were YEH living in a variety of housing situations (e.g., shelters, living on the street, temporary housing, etc.). The YEH group comprised of 1,876 (65.9%) males, 898 (31.5%) females, and 44 (1.5%) transgendered individuals, within the 18 papers in which sex was reported. Within the 16 papers that reported on ethnicity, the majority of YEH ($n = 916$; 32.6%) were Black/African American, approximately a third were White ($n = 859$; 30.6%), and the rest were Hispanic/Latinx ($n = 422$; 15%), or mixed race ($n = 367$; 13.1%). See **Table 1** for additional sociodemographic information.

Rates of Access and Use

Four studies reported on the rates that YEH access and use mobile phones; on average, 62.6% owned a mobile phone (32, 37–39). Based on two studies, an average of 68.8% specifically owned



1. exp Internet/
2. exp Cell Phone/
3. exp Smartphone/
4. exp Computers/ or exp Computers, Handheld/
5. exp Mobile Applications/
6. exp Telemedicine/
7. exp Social Media/
8. exp Technology/
9. exp Medical Records Systems, Computerized/
10. exp Electronic Mail/
11. exp Social Networking/
12. exp User-Computer Interface/
13. exp Web Browser/
14. exp Virtual Reality Exposure Therapy/
15. exp Virtual Reality/
16. exp Computer Simulation/
17. exp video-audio media/
18. exp Robotics/
19. exp Wearable Electronic Devices/
20. exp Biosensing Techniques/
21. exp Video Recording/
22. exp Online Systems/
23. (internet or "cell phone*" or cellphone* or "mobile phone*" or "smart phone*" or smartphone* or "mobile app*" or computer* or "social media*" or Facebook or "text messag*" or "electronic messag*" or "electronic mail*" or email* or "e-mail*" or "social network*" or technolog* or "electronic case* management" or web or website* or "virtual reality" or "mobile device*" or video* or portal* or chatbot* or robot* or "wearable device*" or sensor or sensors or biosensoror or "bio-sensor" or biosensors or "bio-sensors" or smartwatch* or "smart watch*" or ereferr* or "e-referr*" or chat or online or "instant messag*" or cyber* or avatar* or platform* or telehealth* or "tele-health*" or telepsychiatry or "tele-psychiatry" or telepsychology or "tele-psychology" or "telemental health*" or "tele-mental health*" or teletherapy or "tele-therapy" or telemedicine or "tele-medicine" or telerehabilitation or "tele-rehabilitation" or "emental health*" or "e-mental health*" or ehealth* or "e-health*" or mhealth* or "m-health*").ab,kf,kw,ti.
24. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. exp Homeless Persons/
26. (homeless* or street* youth* or street* adolescen* or street* teen* or runaway youth* or runaway adolescen* or runaway teen* or street* living youth* or street* living adolescen* or street* living teen*).ab,kf,kw,ti.
27. 25 or 26
28. 24 and 27
29. limit 28 to (yr="2005 - Current" and (english or french))

FIGURE 1 | 2019 search strategy launched in Medline. * refers to the inclusion of all forms of the word (e.g., plural form).

a smartphone (32, 38). The range of mobile phone ownership was wide (46.7-100%); for example, one study found that 78% of those in their quantitative analysis ($n = 41$) and 90% of those in their qualitative analysis ($n = 52$) owned a mobile phone (38), whereas another study found that their entire sample ($n = 22$) owned a mobile phone (37).

Eight studies reported on the rates that YEH access and use the internet; on average, 38.2% used the internet at least once daily, with a range of 28-86.5% (32, 40–46). Based on four studies, an average of 55.1% of YEH accessed the internet at least once a week, with a range of 45-93% (41, 43, 44, 46). Two of the studies reported that a significant majority of their sample used the internet regularly, but did not report on the actual frequency of access (32, 42).

Finally, 13 studies found that YEH access and use social media in some capacity (32, 37, 40, 43–52). Based on seven studies, an average of 77.1% used social media, with a range of 57-90.7% (32, 45–49, 52). Two of the studies reported on the frequency of YEH's social media use, with an average of 36.0% reporting daily social media use, and 26.6% reporting weekly use (47, 52).

How Youth Experiencing Homelessness Access ICTs

Ten studies described how YEH accessed ICTs (32, 38–40, 42–46, 49). Cell phones were sometimes obtained as a gift, purchased with personal money, or with money obtained from panhandling, a job, or federal benefits (32, 38, 39). The internet

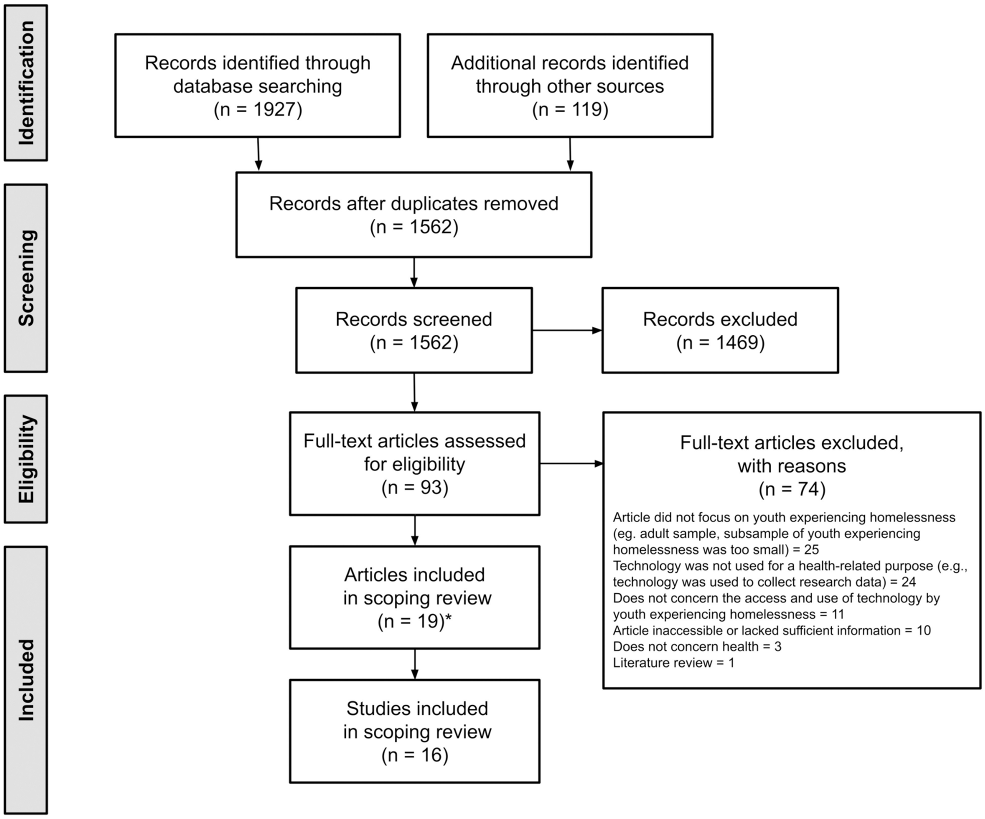


FIGURE 2 | Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) diagram. *Six of the articles were grouped together into three pairs, as each set reported on data collected from the same sample.

was commonly accessed via a friend/family member's or publicly-available device; through public libraries and Wi-Fi; and through youth service community agencies, Internet cafes, schools, and workplaces (42–46, 49).

Reasons for Using ICTs

Eighteen studies addressed the reasons for YEH's use of ICTs (32, 37–53). Reasons for use most frequently cited were to navigate social networking sites ($n = 13$), to communicate with peers ($n = 11$) and family members ($n = 9$), to conduct job-related activities ($n = 9$), for communication generally (e.g., checking email; $n = 8$), and to seek health services ($n = 5$) and health-related information ($n = 5$). **Table 2** provides additional details on the reasons for which YEH used ICTs.

Factors Affecting Access to ICTs

Eleven studies identified factors that affected YEH's access to and use of ICTs (32, 37–42, 45, 46, 49, 54). The most cited factor was the actual living situation of the youth ($n = 6$), with youth experiencing homelessness or street-based living situations reporting less access to ICTs than youth who were able to find housing more consistently (32, 39, 41, 45, 46, 49). For example, one study found that participants residing in a house or an apartment were more likely to engage in regular use of social media (90.6%) than those living on the streets (55.6%) (32). Compared to when they were housed, YEH's internet behaviors became more goal-oriented, with less time spent on leisurely activities or entertainment (46).

Other factors affecting ICT access included the youth's financial situation and the availability of public devices. Unstable financial situations often led to phone deactivation due to missed payments, to sharing devices with a friend, to having the phone stolen, and difficulties in maintaining the device's functionality (e.g., charging the phone) (37, 38, 54). Some participants reported challenges accessing ICTs through public institutions, such as specific hours of operation, long wait times, downloading or printing difficulties, and website restrictions (42).

Despite the barriers they faced in accessing technology, one study found that youth reported comfort in using ICTs (70% self-assessed their computer abilities as better than average, and 85% reported being able to use a computer), due to previous family and school experiences. In addition, youth used ICTs for a diverse range of activities, suggesting a relatively high level of digital literacy (42).

Risks and Benefits of Using ICTs With Youth Experiencing Homelessness

Eleven studies established a link between the use of ICTs by YEH and to certain risks and benefits (38–40, 42, 44, 47, 49–53). The

TABLE 1 | Participant sociodemographics.

	N	%
Total sample	3,123	100.0%
YEH	2,856	91.5%
YEH sample from studies that examined ethnicity	2,808	98.3%
Black/African American	916	32.6%
White	859	30.6%
Hispanic/Latinx	422	15.0%
Mixed race	367	13.1%
Other	345	12.3%
Unknown/missing information	2	0.1%
YEH sample from studies that examined sex	2,847	99.7%
Male	1,876	65.9%
Female	898	31.5%
Transgender	44	1.5%
Unknown/missing information	29	1.0%
YEH sample from studies that examined sexuality	2,189	76.6%
Heterosexual	1,628	74.4%
LGBTQIA2SP+	558	25.5%
Unknown/missing information	3	0.1%

YEH, Youth experiencing homelessness.

TABLE 2 | YEH's reasons for using ICTs.

Reason for using ICTs	No of Studies
Navigating social networking sites (e.g., Facebook, Twitter, MySpace, etc.) (32, 37, 42–52)	13
Communicating with peers (e.g., through email, social media, instant messaging, text message, etc.) (39, 40, 42–44, 47–52)	11
Communicating with family members (e.g., through email, social media, instant messaging, text message, etc.) (39, 40, 42–44, 47–49, 51)	9
Job related activities (e.g., job searching, resume building, etc.) (37, 41–43, 45, 46, 48, 49, 51)	9
General communication/checking email (person they are communicating with not specified) (37–39, 42, 43, 45, 46, 49)	8
Seeking health services (e.g., searching for a doctor or health clinic) (40, 41, 45, 46, 53)	5
Seeking general health-related information (e.g., looking up mental health concerns and symptoms) (40, 41, 45, 46, 53)	5
Entertainment- and leisure-related activities (e.g., listening to music, playing games, watching movies, etc.) (37, 42, 43, 46, 49)	5
Education-related activities (e.g., navigating a school's website or online portal, homework) (37, 43, 46, 48)	4
Finding a place to stay (e.g., searching for apartment listings, shelters, etc.) (41, 42, 46, 49)	4
Dating/relationships (e.g., seeking a sexual partner online, navigating a dating site, etc.) (44, 47, 48, 52)	4
Communicating with case workers (e.g., through email, social media, instant messaging, text message, etc.) (39, 47, 49, 51)	4
Seeking sexual health-related information (e.g., information about HIV prevention) (40, 45, 46)	3
Seeking general information (e.g., using Google) (37, 42)	2
Practical uses (e.g., using a phone as an alarm clock or for navigation) (37)	1

YEH, Youth experiencing homelessness; ICT, Internet communication technology; HIV, Human immunodeficiency virus.

most common benefit was the ability to connect with positive social ties, such as home-based peers, family members and case workers, which was associated with a reduction in substance use, risky sexual health behaviors, and severity of mental health symptoms (40, 44, 47, 50, 52).

However, connecting with negative, street-based social ties was identified as the most common risk factor to using ICTs due to its association with an increased likelihood of engaging in risky sex behaviors (e.g., exchange sex, sex with someone met online) and substance abuse (40, 44, 47, 52). Further, discussing drinking, drugs, and sex on social networks with street-based ties was linked to an increase in risky health behaviors, in comparison to discussions of love or goals/future plans (47, 52).

DISCUSSION

Key Findings in Relation to Access and Use of ICTs

The aims of our scoping review were to examine the ways that YEH access and use ICTs (i.e., frequency of use, purpose of use, barriers faced), and to discuss the implications of the findings for health care. We identified 16 studies (19 articles) demonstrating that there is a growing pool of evidence on access and use of ICTs among YEH, and that the use of ICTs plays an important role in their lives. At the same time, 16 studies of varying research design and sample sizes obtained through methods subject to sampling bias indicates an ongoing need for research on a highly marginalized population in urgent need for health care services (31).

In terms of our research questions, our key findings are: first, studies report high percentages of access to and use of ICTs by YEH (i.e., on average, across studies, 62.6% owned a mobile phone, with 68.8% owning a smartphone; 38.2% accessed the internet daily, with 55.1% reporting weekly access; and 77.1% used social media platforms). In comparison, surveys conducted with housed youth aged 13-17 in the USA and with youth aged 15-24 in Canada found that 92-96% of their samples went online daily, with nearly 75% of youth in the American sample reporting smartphone access (55, 56). The higher rates of ICT access in housed youth are unsurprising, considering that homelessness was linked to a decrease in internet use and access (32, 39, 41, 45, 46). However, it is important to note that the studies we reviewed are subject to sampling bias (i.e., recruitment from shelters, drop ins), and thus should be interpreted with caution. Moreover, accessibility to ICTs may differ depending on the country (e.g., prices of technology, public resources, governmental programs, etc.) and across regional areas (e.g., provinces, states, cities).

YEH diverge from youth in the general population in the methods and barriers to accessing ICTs. Many YEH rely on public computers in libraries and community agencies to access the Internet, which is accompanied by a diverse range of obstacles (e.g., wait lists, restrictions on site searches). Owning a cell phone also represents a financial burden for many YEH, who may need to panhandle or share the device with a friend to afford it, which can lead to its deactivation (38, 39, 43). These barriers can create a discontinuity in the sustainment of various social contacts for YEH and in the implementation of ICTs-based intervention.

Second, in the one study that discussed technology literacy, YEH reported confidence with their ICTs skills, due in part to exposure to technology at a young age (42). We also found that YEH used ICTs for an array of purposes, suggesting that they may be comfortable navigating and engaging with ICTs-enabled health interventions. However, given that few studies have addressed technology literacy in this population, and that research with other young populations shows that youth encounter several challenges in searching the internet for health-related information (57), this topic warrants further attention.

Third, our findings show that technology supported the maintenance of positive and healthy social contacts, which was associated with less depressive symptoms, a reduction in substance-using behaviors and more adequate sexual health behaviors (40, 44, 50, 51). This suggests that high accessibility to ICTs could also allow YEH to maintain good social relationships, influencing health outcomes. However, it should be noted that using ICTs to connect with street-based peers and to discuss drinking, drugs, and sex increased the likelihood of engaging in these risky health behaviors (44, 47, 51, 52). Thus, it is important to be cognizant of the nature of YEH's online connections, and encourage the use of ICTs to maintain positive social contacts.

Implications for Practice

The use of technology-enabled interventions with homeless populations is a new area of research and practice for healthcare professionals with several elements to consider, including: increasing access to technology, optimizing technology-based infrastructure, providing training for community outreach and health workers, and engaging service users in the development of diverse and contextually-sensitive interventions (58).

The high rates at which YEH are accessing and using ICTs for various goal-oriented behaviors indicates that technology plays a critical role in their lives. Prioritizing free and accessible technology in public settings (e.g., shelters, community centers, libraries, harm reduction centers) and free access to mobile devices, may be an important way to empower YEH, enable them to maintain connections with pro-social peers and family, and help build their awareness of public health guidelines, health services, and information.

Our findings support the notion that ICTs can improve communication with YEH for outreach purposes (31). Considering that YEH access and use a variety of ICTs, health care providers may consider ICT-based forms of communication to provide services and information. Concurrently, diversity in communicating with and disseminating information to YEH (i.e., using both online and offline methods) is an important factor to consider, given that not all YEH have regular access and use of technology, which may be further exacerbated during public health crises requiring physical distancing.

Study Limitations

This scoping review has several limitations. We did not systematically assess the quality of studies given the heterogeneity of study methods, nor did we conduct a gray literature search. Similarly, due to time and human resources, only English language publications were included. It is therefore possible that some studies were omitted by the search strategy. In addition, as there was inconsistency in the ways in which papers reported their sociodemographic information and findings (e.g., eight papers reported on daily internet use, but only four of those papers additionally reported on weekly internet use), the weighted means reported in this review may not apply to the entirety of the study sample. Finally, as the present study is not a formal meta-analysis, we did not use more complex statistical pooling methods or analyze the heterogeneity in our data; as such, our results should be interpreted with these considerations in mind.

Future Research

This scoping review highlights several research gaps, upon which we base the following recommendations: (1) international research is needed to understand YEH's access and use of ICTs, and to explore the impacts of varying infrastructures, government policies, and socioeconomic factors on YEH's experiences with technology; (2) more effort is needed to capture representative samples of the YEH population, characterizing the samples in terms of sociodemographic factors, and the role that these factors may play in their access and use of technology; (3) more consistency is needed in how access and use of technology is assessed and reported, as this will help to better synthesize the literature moving forward; (4) more research is needed on the digital health literacy skills of this population and their experiences of using technology to search for, and access health-related information and services; (5) quality appraisal will be an increasingly important consideration as more research emerges on access and use of ICTs among YEH; (6) more research is needed on how COVID-related public health guidelines affect access to publicly available ICTs (e.g., through libraries) and may further marginalize YEH from accessing critical health information and services; (7) future research should also focus on developing and evaluating technology-enabled health interventions for YEH. Indeed, we found that there is an emerging body of literature on the use of technology to deliver health related services to the homeless population, including youth. This is an important avenue to consider for a future review, to better examine the feasibility, acceptability, and efficacy of providing health services to YEH through this method of service delivery.

CONCLUSION

Our findings indicate that YEH access and use ICTs for many purposes, and they appear to have the foundational skills, interests, and needs to engage with such types of technologies for health purposes. However, barriers to access need to be considered. More research is needed on the appropriate and effective way of leveraging ICTs for public health and health related interventions tailored for YEH. Given the urgency of YEH's health care needs and their marginalization from health care systems, it is important to pursue research on the impact of these technologies on YEH and health information and services for this vulnerable population.

DATA AVAILABILITY STATEMENT

The original studies presented in this review are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

SL conceived the original idea for this scoping review, its overall methodology, and supervision of its implementation. SL and AF contributed to writing the initial protocol. SL and AH-A contributed to its revisions and finalization. SL prepared the initial draft of the manuscript, with contributions from AH-A. All authors contributed substantially to the content and approved the final version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fdgth.2021.782145/full#supplementary-material

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METHODS
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Applying the Digital Health Social Justice Guide

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Introduction: Digital health, the use of apps, text-messaging, and online interventions, can revolutionize healthcare and make care more equitable. Currently, digital health interventions are often not designed for those who could benefit most and may have unintended consequences. In this paper, we explain how privacy vulnerabilities and power imbalances, including racism and sexism, continue to influence health app design and research. We provide guidelines for researchers to design, report and evaluate digital health studies to maximize social justice in health.

Methods: From September 2020 to April 2021, we held five discussion and brainstorming sessions with researchers, students, and community partners to develop the guide and the key questions. We additionally conducted an informal literature review, invited experts to review our guide, and identified examples from our own digital health study and other studies.

Results: We identified five overarching topics with key questions and subquestions to guide researchers in designing or evaluating a digital health research study. The overarching topics are: 1. Equitable distribution; 2. Equitable design; 3. Privacy and data return; 4. Stereotype and bias; 5. Structural racism.

Conclusion: We provide a guide with five key topics and questions for social justice digital health research. Encouraging researchers and practitioners to ask these questions will help to spark a transformation in digital health toward more equitable and ethical research. Future work needs to determine if the quality of studies can improve when researchers use this guide.

Keywords: social justice, digital health (eHealth), mobile health (mHealth), racism and antiracism, equity, privacy and security

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INTRODUCTION

According to the World Health Organization, digital health strategies–the use of apps, text messaging and online interventions for health–can "promote health, keep the world safe, and serve the vulnerable" (1). Digital health can increase access to health education and management when too few professionals can provide it, or if in-person care is impossible (e.g., during the COVID-19 pandemic) (2, 3). Because mobile devices are pervasive (4), digital health interventions can reach people from all socio-economic backgrounds, with the ability to personalize content by literacy and language. Digital health strategies could revolutionize healthcare by helping people self-manage symptoms of disease, lead healthier lives through engagement in healthy behaviors such as regular physical activity, adequate sleep, and proper nutrition–and connect them to health information and resources. This can result in earlier disease diagnoses, better symptom management, lower costs and more equitable distribution of health resources (5).

However, the rapid growth of digital health apps, remote health provision, and online health information can also raise novel health equity challenges (6). Despite its potential for promoting population health and serving marginalized communities, digital health interventions are often not designed for all who could benefit from them, or may have unintended consequences. For instance, many digital health platforms and studies are designed for patients with high levels of existing digital skills, who only speak English (7). Further, as we will explain in this paper, privacy vulnerabilities and power imbalances that plague the field of medicine, including racism and sexism, influence health app design and research. We will provide guidelines for researchers to design, report and evaluate digital health studies to promote social justice in health.

What Is Digital Health Social Justice?

The most common understanding of social justice is fairness, especially in how people are treated, what opportunities they have, and how decisions are made. Social justice in *health* is not just the right to be free of disease–it is the right for all to enjoy the highest personally attainable standard of physical health, mental health, and wellbeing (8). We define digital health social justice as the equitable opportunity for everyone to access, use, and benefit from digital health, to achieve their greatest standard of health and wellbeing.

Who Is This Guide for and How Do I Use It?

The goal of this study was to develop a guide primarily for health researchers. It may also benefit developers, technology providers and (community) health organizations who work with digital health platforms. Prior to starting a project, writing a grant or paper, or evaluating earlier studies, researchers can answer questions in this framework that are relevant to their work. These questions can help to formulate current or future research questions, determine populations to study, and evaluate their results. Digital health is a broad concept that includes mobile health (e.g., apps and text-messaging), wearable devices and telemedicine (9). Though we discuss digital health broadly, we focus on mobile health.

Who Are We?

We are researchers, data scientists, clinicians, and community members funded by a University of California-Berkeley Changemaker Technology Innovation Grant. Through our vast experiences, disciplines, and backgrounds we were brought together by the common goal to give researchers, technology providers, and (community) health organizations the tools to design digital health for social justice.

METHODS

From September 2020 to April 2021, we held five unique discussions and brainstorming sessions with researchers, students, and community partners to receive feedback on the first version of our guide and the key questions (see the **Supplementary Materials** for the format of these sessions). No individual or protected health data were utilized in this process, and all participation was voluntary. We then sent out the revised key questions to six experts in digital health, data science, social justice, privacy, and education, from March to May 2021 for feedback. We conducted an informal literature review in PubMed and Google scholar, using combinations of keywords (e.g., digital health, social justice, ethics, racism, sexism, biases, discrimination).

We also identified real-world examples throughout from several studies including a mobile health study, the Diabetes and Mental Health Adaptive Notification Tracking and Evaluation (DIAMANTE) study, led by some of the authors (AA and CRL). This study seeks to increase physical activity among English and Spanish-speaking patients with lower income, educational attainment, and/or disability who receive care for depression and diabetes at a public healthcare system in San Francisco (10). In addition, we identified examples from a physical activity chatbot study in low-income English and Spanish speaking women recruited from community health centers led by some of the authors (CAF and AA) (11). The aim of the examples was to connect social justice theory to real-world strategies and methods to increase the accessibility and relevance of digital health platforms to marginalized and underserved groups. Below, we discuss the key questions and corresponding sub questions of our framework.

RESULTS

Key Topics and Questions

We identified five topics, each with an associated key question, that health researchers should ask themselves when designing or evaluating a digital health research study (**Figure 1**). These topics and questions are:

- Equitable distribution-Who is represented in my research, and why?
- Equitable design-How can I design apps for those with low digital literacy?
- Privacy and data return-What are my responsibilities in protecting and returning data to communities?
- Stereotype and bias-How might my research aggravate societal biases, sexism and racism?
- Structural racism-How can my research address societal injustices that prevent good health?

Below, we described the topics, key-questions and sub-questions in detail. These are also portrayed in **Table 1**. **Table 2** shows the key terms explained in this manuscript. In the **Table 3** we show

FIGURE 1 | The five key topics and broad questions to guide digital health researchers toward digital health social justice.

additional resources that can help researchers explore each of the key topics more in-depth.

Equitable Distribution

Who Is Represented in My Research, and Why?

No one group—gender, racial, ethnic, or socioeconomic—should receive disproportionate benefits or bear disproportionate burdens of research. Technology is often designed to be applicable to the masses in order to gain users and promote the device or platform for profit. This tendency is antithetical to medicine's goal of serving medically specific, often complex subsets of the population. The main users of digital health apps at this time are young, highly educated, tech literate, and free of chronic diseases (12). Most health apps are difficult to use for many. In one study, patients at a public hospital, of which the majority were African-American, had difficulty logging their health data in health apps, understanding the basic functions of these apps, and navigating to the app's main screen (13). Another study found that top-funded, private, US-based digital health companies rarely enroll high-cost, high burden patients with chronic diseases in their studies, or test their impact in terms of outcomes, cost, or access to care (14). Therefore, individuals with complex medical and/or psychosocial conditions may not be the primary digital health audience. All population segments commonly express high interest in digital health platforms (such as electronically communicating with providers or finding online health information), but there are large gaps in groups using digital platforms (15).

Researchers must evaluate where and for whom our interventions can make the most difference. For groups at a greater social disadvantage, such as those who lack access to education, have a low material standard of living, face severe health problems, and whose rights are not protected, the social value of digital health will have greater impact. Particularly for those interested in population-level impact of digital health, equity must be central upfront. The health burden is inextricably tied to social and demographic factors in society and is shaped by historical exclusion, racism, and resource allocation (16). By explicitly focusing on equity within our digital health work, we can better ensure that our interventions have the intended impact to improve population health and reduce disparities rather than exacerbating them. In addition to addressing a justice imperative, ensuring that the most needy are targeted can lead toward a broader social and possibly even economic benefit.

Interventions should be tailored to group's needs (equity), rather than being the same for all (equality). Instead of research starting from the perspective of those in positions of power (the researchers), we need to start from the experience of marginalized individuals. Instead of only focusing on what a community lacks, we need to empower the community to share their knowledge and experiences.

Community-based participatory research (CBPR) is an example of a tool to integrate community knowledge and input.

CBPR is a research approach that involves partnerships between academic institutions, community-based organizations and community participants (17). CBPR addresses power imbalances inherent to Western research methods by inviting community members to play an active role in all aspects of the research process, including the design, implementation, and evaluation of interventions. CBPR builds trust and rapport between the community and the researchers, before the intervention begins. CPBR can be combined with human centered design (18), an approach consisting of one-on-one interviews, brainstorming sessions, and prototype testing with community members. Nijagal et al. (18) used a Human Centered Design approach to identify gaps, opportunities, and solutions for perinatal care inequities for Medicaid insured pregnant people in the United States. The authors used the IDEO field guide to Human Centered Design. Methods included semi-structured interviews with stakeholders who received or participated in the care of Medicaid-insured pregnant people, brainstorming sessions to generate prototypes, and community events to test and improve prototypes (see additional resources in **Table 2** for the guide). Figueroa et al. (11) describes a virtual co-design session with low-income women for designing a physical activity chatbot. The session was co-led by study participants and included a digital whiteboard where participants could share their needs, wishes and design ideas for a comprehensive health app. Harrington et al. (19) conducted five design workshops to understand the health experiences of low-income African-American older adults living in a residential senior village. These workshops included poster boards to reflect on health needs—using participant's photographs of health related aspects of their environment—visualization, and brainstorming sessions related to health and technology. These studies serve as examples for creating digital tools for health equity. When using design kits or methods from other work, researchers should keep in mind to assess fit with their population of interest, particularly education, digital skills, and literacy level.

Equitable Design

How to Design Digital Tools for Those With Greater Barriers to Health Technologies?

Low Digital Literacy, Access, and Trust

Low-income and racial/ethnic minority individuals face greater barriers to health technologies, including digital literacy–the ability to find, use, and compose information through digital platforms–and lack of trust in these technologies (20–22). They less often have smartphones, laptops/computers, and internet connectivity at home (23).

Assessing Needs

Many people with low digital skills are interested in using health technology, but have trouble using health apps, because of these structural barriers and poor design (24, 25). Researchers need to assess access to technology (do participants have smartphones, laptops and internet access) and digital literacy during enrollment to determine how much help a participant needs in installing and using apps. Researchers should also ensure that effective non-digital options, such as calling on a regular phone and face-to-face care, are available and accessible (26).

Training

Researchers should train individuals with low digital skills to use their health apps at the start, and remain available to provide technical assistance throughout the study. Even if users have access, they may not have the skills to use their smartphone or laptop. We previously developed a framework for assessing digital literacy levels in situations like these (27). Other researchers developed digital skills training to help patients with severe mental illness recognize the need for digital tools, evaluate apps, and use these apps (28). The California Help@Hand project adapted this program to provide community online digital literacy training (see resources). In addition to participant training, researchers should encourage app developers to build in virtual tech support and troubleshooting guides and provide installation support when running research studies. For example, research assistants can help participants download software through phone calls or in-house visits. These types of measures will ensure that those who face high barriers to health technology can participate in digital health research.

Design

In the design phase, researchers must make sure the information is accessible for those with low digital literacy, who have often had lower levels of education and have lower reading literacy. Language used in apps should not exceed an 8th grade reading level. Researchers can use tools to check their language level such as WebFX, Grammarly, or the Hemingway App. These tools calculate readability scores, using formulas such as Flesch-Kincaid, based on the length of sentences and words. Researchers can also check with participants if the app's language is understandable and relevant to their needs/wishes in the app development phases. Further, apps should have limited text on the screen and researchers should consider adding audio, voice and video capabilities in addition to text. Adequate design can ensure that participants remain engaged with digital interventions.

Real Word Example. Prior to the coronavirus pandemic in 2020, the DIAMANTE research team was able to conduct face-to-face research visits with participants. During these visits, researchers were able to help participants understand, install, and download the DIAMANTE app. With the pandemic, we were faced with a major task to conduct this study through online means. This introduced additional obstacles, such as the need for video calling, which most participants were unfamiliar with.

We solved this by quickly developing a "digital skills protocol" (27).

- *From each participant, we mapped out digital profiles of skills and literacy in a phone call.*
- *We divided the participants into two groups: those with sufficient digital skills and those with limited digital skills.*
- *Participants with limited digital skills were then given additional guidance in Zoom calling.*

TABLE 1 | Key questions and sub questions.

Key question	Sub questions
1. Equitable distribution *Who is represented in my research, and why?*	• Who (community members/user groups) is going to inform, influence, and be influenced by my research? • What needs, but also resources or strengths do they have that could be built off of? • How might my digital health project have the most value for them? • Are the community members/users with whom I am interacting representative of the population I wish to reach?
2. Equitable design *How can I design digital tools for those with* greater barriers to health technologies?	• What does my participants' access to current digital resources (devices, broadband/cellular data) look like? • What is their level of digital, reading, numeracy, and health literacy? • What kind of support, e.g., installing apps, using them daily, do they need to use digital interventions, and how often do they need it?
3. Privacy and data return *What are my responsibilities in protecting and returning data to communities?*	• Am I collecting no more data than necessary to answer the research question? • How can I help participants understand the benefits and dangers of participating in the research? • How will data sharing occur throughout the study? • How will I measure the success of my research as a researcher, and more importantly, for my population of interest?
4. Stereotypes and bias *How might my research aggravate societal biases, sexism and racism?*	• Am I using "empowering and inclusive" language and design in my app and research? Am I refraining from using terms that may unintentionally harm? • Do my research team and/or (community) partners consist of people from different backgrounds and with different lived experiences? Are everyone's voices heard? • Do I expect differences in outcomes based on participants intersecting identities (e.g., men, women, non-binary individuals, race/ethnicity) within or between groups? How will I analyze this?
5. Structural racism *How can my research address societal injustices that prevent good health?*	• To what extent do historical societal injustices affect my (potential) participants' health? • Can digital solutions address these injustices, and how? • Can I examine how these injustices (social determinants of health) affect the success of my interventions?

TABLE 2 | Terms and definitions.

Term	Definition
Digital literacy	The ability to find, use, and compose information through digital platforms
Social justice	Fairness, especially in how people are treated, what opportunities they have, and how decisions are made
Digital health social justice	The equitable opportunity for everyone to access, use, and benefit from digital health, to achieve their greatest standard of health and wellbeing.
Digital health	The use of apps, text-messaging and online interventions for health
Equity	A situation in which resources are distributed and tailored to the needs of the recipients.
Equality	A situation in which everyone has the same resources available to them.
Community-based participatory research (CBPR)	A research approach that involves partnerships between academic institutions, community-based organizations and community participants (10).
Digital intervention	A strategy to decrease delay in receiving help and advice as well as to improve treatment strategies to be evidence-based.
Social justice point of view	Utilizing social justice as the primary lens and objective to analyze the scenario, case, project, or research at hand
Community	A group of individuals that share some commonalities. This can be based on common characteristics (such as place of living, affinity, affiliation, demographics) or by the sheer bond between the individuals.
Social justice framework	A perspective that enables evaluation of a scenario to limit inequity and empowering those who are involved.
Human centered design	An approach consisting of one-on-one interviews, brainstorming sessions, and prototype testing with community members.
Social determinants of health	An individuals' social and/or structural environment, including education, employment and poverty
Open source	Software that is made available to the greater public, usually under a license, that gives anyone the freedom to use, change, and study it.
De-identification of Data	The removal of identifiable information to mitigate privacy breaches.
Algorithm	A process that is usually on the computer that calculates
Informed consent	An agreement with open communication between patient and practitioner for the patient to undergo a medical procedure or participate in a study.
Representation	A study has ample ”representation” in its study participant pool if individuals of different characteristics are sufficiently present in the pool.
Data return	Returning data taken of participants of a study or project to those individuals to benefit and empower them.
Unintended consequences	The materialization of consequences that were not foreseen by researchers or project teams.

TABLE 3 | Additional resources to explore the questions outlined by the guide in depth.

Key question	Resources
1. Equitable distribution *Who is represented in my research, and why?*	• Brainstorming session guide: https://www.ideou.com/pages/brainstorming-resources • Field guide to Human Centered Design: https://www.ideo.com/post/design-kit • Inclusive Co-Design Toolkit: http://info.bridgeable.com/inclusive_codesign_toolkit • Experimenting with human centered design: workbook: https://www.tamarackcommunity.ca/library/experimenting-with-human-centered-design
2. Equitable design *How can I design digital tools for those with greater barriers to health technologies?*	• Assessing readability: https://www.webfx.com/tools/read-able/ • Measuring digital access and literacy: https://apha.confex.com/apha/2020/meetingapp.cgi/Paper/486628 • Digital literacy training: https://helpathandca.org/digital-literacy/
3. Privacy and data return *What are my responsibilities in protecting and returning data to communities?*	• Digital Defense Playbook: https://www.odbproject.org/tools/ • Judgment Call the Game: • AI Blind Spot: https://aiblindspot.media.mit.edu • Videos with privacy notices DIAMANTE study: iPhone (Spanish): https://youtube.com/playlist?list=PLQuqZRju5WHrV0LN_hIC-_9KJOOn6pn5k • iPhone (English): https://youtube.com/playlist?list=PLQuqZRju5WHrJS-K0fNTFPLJFBv8ljYKx
4. Stereotypes and bias *How might my research aggravate societal biases, sexism and racism?*	• A toolkit for intersectional gender analysis: https://tdr-intersectional-gender-toolkit.org/cover/0001.html?target=_self&lightbox=0 • Platform for recruiting sexual and gender minority adults into digital health: https://academic.oup.com/jamia/article-abstract/26/8-9/737/5509461 • Inclusive language: https://buffer.com/resources/inclusive-language-tech/~
5. Structural racism *How can my research address societal injustices that prevent good health?*	• A Resource to Help Communities Address Social Determinants of Health-CDC: https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/pdf/sdoh-workbook.pdf • Resources to explore the ways communities across the country are addressing social determinants of health: https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources • Framework for assessing the effect of social determinants on behavior change interventions: https://www.tandfonline.com/doi/abs/10.1080/17437199.2020.1718527

One-on-one staff-patient partnerships allowed us to continue our patient recruitment and provide unique technical assistance personalized to each patient's digital profiles. These strategies can mitigate but not eliminate digital barriers for patients without extensive technology experience.

Privacy and Data Return

What Are My Responsibilities in Protecting and Returning Data to Communities?

The difference in power, where a researcher has control over whether a participant's information is released, should not be taken lightly (29). This is crucial for marginalized communities, who have more often been victims of data abuses. As researchers, we need to increase the participation of marginalized communities by gaining and keeping their trust. To do so, we need to work for and with these communities, involving them in many aspects of the research, including the privacy and dissemination of their data. These should be long-term rather than transactional relationships. Researchers need to inform participants of their rights in study participation, think very carefully about how participants will benefit from their research, and help participants understand the benefits and risks of using health apps. Project funding should include compensation for community member's and organization's time. Finally, community members should also be able to set the research questions and priorities based on their own needs. Kimbrough-Sugick and colleagues proposed that researchers should ask themselves whether their proposed research agenda is driven by external factors such as funding opportunities, personal interests, or institutional priorities, that may not be aligned with the community's agenda (30). To respect the community's values and right to pursue its own interests, researchers should develop relationships with the community (e.g., community leaders, board members, patients, relatives) at an early stage (30). This will help to ensure that research ultimately benefits the health priorities of (marginalized) communities.

Privacy Is More Important for Some Than Others

Downloading sensitive apps that collect location, sexual health information, or discuss partner violence comes with greater risks for some. Victims of intimate partner violence, who are more often women of color (31), are vulnerable if abusers can view personal information on their phones, or have installed spyware to track their behavior. Further, location data collection in less densely populated regions increases the risk of breached privacy, putting app users living in rural areas at higher risk (32). Researchers designing sensitive apps can take extra precautions including requiring a password, giving the app an unrelated name and icon, and teaching users how to hide apps from their screens and quickly enable/disable location tracking (33). For example, the Circle of 6 safety app for preventing sexual violence encourages users to select an ambiguous name and uses discreet icons (e.g., a car to represent a need for help getting home; a phone or chat bubble to represent a need for an interruption call on an unsafe date) (34). When we study vulnerable populations or sensitive health issues, we have an even greater responsibility to help individuals protect their phones and their data.

Real World Example

In one of our digital health studies we enrolled a participant with an undocumented immigrant status. We explained to the participant that this app collects location data to track physical activity, but is optional. We wanted to track location to better understand the link between people's travel patterns and their mental health. Because of the participant's status, we advised the participant not to take part in the location tracking part of our study. We helped the participant navigate through the app and indicated where to turn off location tracking. We informed the participant that as long as the settings remain unchanged, location tracking will remain turned off. When the participant needs tech support, a team member is available via SMS or a phone call throughout the duration of the study.

Minimizing Data Collection

The more data we collect, the more potential for harm we create. Researchers and app developers have a responsibility to minimize sensitive information collection, especially when it fails to benefit individuals' health. For instance, a food-tracking app should not collect GPS data if it's unnecessary for the app's functioning. The app's audience often also includes more than the original user. Some mHealth apps request access to microphone or Bluetooth connectivity, which could accidentally collect location data, images or videos of the bystanders (35). Even de-identified data, especially when combining different data streams, can be re-identified. Only a small amount of data is needed to uniquely identify an individual—63% of the population can be uniquely identified by the combination of their gender, date of birth, and zip code (36). Researchers need to handle personally identifiable private information with additional care.

Consent Process and Privacy Notices Should Be Accessible

Consent in these studies needs to be fully informed, but privacy notices are often long, tedious, and hard to understand, especially for low digital or reading literacy users. If possible, consent should happen in person. Otherwise, researchers may consider recording video messages (see a link with examples from our team in the resources section). Notices should also be accessible for those with vision (e.g., include large font sizes or auditory notices) or hearing impairments (e.g., include subtitles). Another option is using a standardized color-coded table to give users a quick idea of what information is collected and how it is used or shared. Kelley et al. (37) showed that users achieved higher accuracy of privacy policy knowledge with the standardized tables compared to reading full privacy policies. Thus, consent and privacy notices must be accessible, engaging, and comprehensible for users with low reading literacy.

Data Collection Should Benefit the Health of the Researched Community

At the beginning of the study, researchers should plan how they will educate participants post-data collection. Oftentimes, studies benefit the individual researchers in the form of publications or increased grant funding but do not result in tangible benefit to the participants, especially if participants never see the end results of the data collection and analysis. Previous work found that only 27% of clinical trials disseminated results to the participants (38). This is partly because it is often unclear how researchers can turn data into actionable insights (39). Lack of dissemination can impede trust between community partners and researchers.

Some researchers have taken approaches of sending out a newsletter with research progress, offering participants their individual data, or giving them free study materials (such as mobile phone covers with the study logo) to make them feel included in the process. Cunningham-Erves et al. (40) recently developed a stepped framework for community research dissemination, consisting of planning and dissemination phases. There are many open questions including whether it is more informative to return group results and/or individual results, and in what format the results should be returned (articles, blogs, visualizations, or videos). This is an area of research that needs innovation. Nevertheless, researchers must consider and discuss with the community the best way for their study setting to relay the gained knowledge back to participants.

Real World Example

In the DIAMANTE study, our research group started an experiment walking participants through their app data collected throughout the study, and interviewing them about this experience. We inform participants that we are interested in answering questions such as: if people visit certain places, are they also more active? Or, does the number of places they visit relate to their mood? We then show them their most active and least active days, and walk them through the places they visited these days. We inform them that they can always stop sharing location data, or ask us to delete it. We also ask them, if, and why/or why not, they would like to receive their data on a regular basis. This will give us insights into whether participants can learn from their data, see the value in having access to their data, and have greater trust in the research process with increased transparency.

Citizen Science

Another area under debate is citizen-science, scientific research that is conducted in whole or in part by non-professional scientists. The goal of citizen science is to empower non-researchers, crowdsource data, and improve population health. Authors have proposed several frameworks, including combining community based participatory research methods with citizen science, which allows citizens to set the research agenda and have control over their own data (41). Platforms have been developed for data collection from mobile phones, with data remaining on citizen's smartphones for security purposes (for example https://md2k.org/personal). Citizen science is a promising area of research, but recruitment and retention of marginalized populations, protecting data privacy and security, and lack of internet access remain among its challenges (41).

Stereotype and Bias

How Might My Research Aggravate Societal Biases, Sexism, and Racism?

Mobile health, like other health fields, is rooted in biomedicine: a patriarchal system. Medicine has been gendered for centuries and prioritizes certain types of knowledge and practices that create barriers for feminist research and practices (42). Similarly, medicine has a long history of anti-black racism. Women, minority populations, and marginalized gender identities unequally participate in digital health because of this (43). There are gendered differences in app use behavior as well. Men more often use fitness apps and women more often use apps for pregnancy, wellness, and sexual health (44).

Another issue is the biased language and design apps use. For example, apps tend to portray white, thin, young, middle-class, and fertile female bodies as the health standard (45). They place fertility at the heart of sexuality, suggesting that reproduction is central to women's health and that sex is only meant for reproduction (45). Many women do not identify with these images and norms, and may worry that they need to conform to them or will not feel comfortable using such health resources. Digital health has also been slow to include non-binary and genderqueer people (46). Thus, apps reinforce our current, harmful gender norms and promote the idea that digital health spaces are only meant for certain groups (e.g., certain gender identities and ethnicities).

Many digital health efforts may fall short when it comes to health promotion among racial and ethnic minorities (47). This is due in part to a lack of inclusion of racial and ethnic minorities in pilot studies as well as design efforts that don't account for the aforementioned sources of bias. These oversights have produced numerous examples of racial biases built into digital health applications. For instance, a melanoma diagnostic app, trained on images of white skin, more often missed cancerous skin lesions in darker skin (48). Smartwatches have failed to measure Black people's heart rate because the built-in sensors only work on white skin (49).

Researchers and developers must tailor apps to subgroups (such as women, non-binary individuals and minorities) without reinforcing harmful societal norms or stereotypes. Determining what is harmful is challenging, but here we provide some guidelines. Technology providers can pay specific attention to language used within their apps. The Underground Scholars Initiative at Berkeley, a group of formerly incarcerated and system-impacted individuals, developed a guide (50) on using language for communicating about people involved in the carceral system. Researchers also developed guidelines for avoiding racial and gender bias in academic papers (51).

When forming a team for digital health development, team leads must recognize inequities and hire diverse teams (both in terms of social identity and interdisciplinary scholarship). A more diverse group will spot more biases and creative solutions to tackle them. Similarly, including a diverse sample of individuals for piloting and collecting feedback from a digital health product may help bring attention to potential limitations for marginalized groups. Researchers need to pay particular attention to engagement. Because of the barriers minority participants face, they may drop out of digital health research more quickly (52). Minority participants place an increased value on their relationship with the researcher or trial coordinator (53). If participants can imagine a face behind the intervention, understand why they should participate, and feel that the intervention matches their needs they will be more inclined to enroll and remain in the study. Research teams should make an effort to guide participants through this process, and match the cultural and language diversity of participants.

Finally, researchers can examine moderators and mediators to assess for whom and under what social conditions (e.g., gender, race/ethnicity, income, education and their intersections), their digital health interventions are effective (54). Currently, these factors are too often assessed in isolation.

Real World Example

African Americans have a higher risk of cardiovascular disease (CVD) and a 2-fold higher CVD mortality than whites (55). Despite this, there is a lack of suitable interventions for African Americans due to structural racism and social marginalization. FAITH! is an mHealth app based on a church educational program. An interdisciplinary research team including clinicians, technologists, social and behavioral scientists, church leaders and community members designed the app in an iterative process (56). Recommendations from community members during the design phase led to the addition of biblical scriptures and spiritual messages. Because of community involvement and trust building, the study had high recruitment and retention rates, and the app was effective in reducing cardiovascular risk factors in a pilot study (56). This intervention illustrates how researchers can integrate formative and CBPR approaches to design culturally relevant, mHealth lifestyle interventions.

Structural Racism

How Can My Research Address Societal Injustices That Prevent Good Health?

Researchers need to understand how social injustices influence health, and how their research can contribute to overcoming societal barriers that impede good health. Compared with white individuals, racial and ethnic minorities shoulder a larger burden of many chronic health conditions. For example Latinxs, Black men are twice as likely to die from prostate cancer (56); Black women are 4-times more likely to die from pregnancy related complications (57). Black Americans and Latinxs are 3–4 times more likely to contract, and die from, COVID-19.

Social determinants, including education, housing and employment (58) are the products of structural racism: "the normalization and legitimization of an array of dynamics–historical, cultural, institutional and interpersonal–that routinely advantage white people while producing cumulative and chronic adverse outcomes for people of color" (59). Racial and ethnic minority groups generally have lower education, unequal access to high quality care, and more often live in poverty–these factors all impact health outcomes (59). Chronic ethnic discrimination, acculturation stress, and chronic stress also influence health through various biological pathways, including altered immune system responses (59). Thus, the pathways leading to worse health outcomes for racial and ethnic minorities are multifactorial and multi-domain.

Health apps mostly target individual behavior and rarely pay attention to how social injustices influence health. For instance, mental health apps rarely discuss or acknowledge the role of structural or interpersonal anti-black racism, even though chronic racism is a strong influencer of mental and physical health (60). They also rarely take an individual's social and/or structural environment into account. For example, a mindfulness app might ask individuals to find a quiet space for meditation. While feasible for those living alone, people living in crowded, confined and noisy spaces may struggle to use these interventions. Similarly, an app that practices sleep hygiene, nudging users to find a quiet, dark, and relaxing place with a controlled temperature, fails to support individuals experiencing crowded housing or even homelessness (61).

To acknowledge and address societal injustices, digital health tools should be tailored to participant's environment, resources, and lived experiences. For example, mental health apps could expand beyond symptoms of anxiety and depression, discussing topics such as microaggressions and internalized and structural racism (62). Apps can also specifically target structural issues. For example, an app may connect individuals with support resources within or outside health settings, including (online) women's groups, housing advocacy organizations, food and transportation assistance programs, or education and employment agencies (63). Individuals experiencing homelessness or unstable housing can use mobile apps to participate in electronic case management sessions (64) and to identify and utilize social and health services (65). Researchers should assess how social injustices may affect the success of their interventions, and/or on which level their interventions can address societal injustices.

Real World Example

In a separate physical activity study, we developed a conversational agent (a chatbot) for low-income Latina women (66). *The app urges them to identify opportunities to walk in the neighborhood. However, our user design research reveals identifying where to walk is a small barrier for exercise. For most participants, childcare is a much larger barrier that stands in the way of regular physical activity. Women reported that they may not always be able to follow our app's suggestions, because they interfere with these responsibilities. An app providing tips about brief exercises using household items that this population can do during the day in between their busy schedules, or activities involving their family, may be more successful.*

CONCLUSION

We provide a framework with five key topics and questions to guide researchers wishing to conduct digital health for social justice. The overarching topics we identified were equitable distribution, equitable design, privacy and data return, stereotype and bias, and structural racism. We hope that encouraging researchers and practitioners to ask these questions will help to spark a transformation in digital health toward more equitable and ethical research. Remaining challenges lie in measuring social justice in digital health and comparing this between studies, and in devising strategies to quickly uncover and effectively mediate instances of injustice when they inevitably do happen. Future work needs to determine how to assess if the quality of studies can improve when researchers use this framework. This is a new and developing field. As time progresses, we plan to add to this framework with new insights, knowledge, and feedback. Working toward digital health social justice is crucial for digital health to fulfill its potential of improving health equity.

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/s.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants, in accordance with the local legislation and institutional requirements.

AUTHOR CONTRIBUTIONS

CF wrote the first draft of the manuscript. CF, CV, and VR conceptualized the study and the project. CF, HM, PA, AW, and AQ set up the discussion sessions, conducted background literature searches, and contributed to the main body of the text and the guide development. AA and CL were involved in the case studies. AS, AA, and CL helped formulate the key topics and questions. All authors contributed to the writing of the text and approved the final version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fdgth.2022.807886/full#supplementary-material

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Personalized Digital Health Communications to Increase COVID-19 Vaccination in Underserved Populations: A Double Diamond Approach to Behavioral Design

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The COVID-19 pandemic exacerbated pre-existing health disparities. People of historically underserved communities, including racial and ethnic minority groups and people with lower incomes and educational attainments, experienced disproportionate premature mortality, access to healthcare, and vaccination acceptance and adoption. At the same time, the pandemic increased reliance on digital devices, offering a unique opportunity to leverage digital communication channels to address health inequities, particularly related to COVID-19 vaccination. We offer a real-world, systematic approach to designing personalized behavior change email and text messaging interventions that address individual barriers with evidence-based behavioral science inclusive of underserved populations. Integrating design processes such as the Double Diamond model with evidence-based behavioral science intervention development offers a unique opportunity to create equitable interventions. Further, leveraging behavior change artificial intelligence (AI) capabilities allows for both personalizing and automating that personalization to address barriers to COVID-19 vaccination at scale. The result is an intervention whose broad component library meets the needs of a diverse population and whose technology can deliver the right components for each individual.

Keywords: health equity (MeSH), digital health (eHealth), personalization, behavioral science, health communication (MESH), behavioral design

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INTRODUCTION

People of all ages and races/ethnicities across socioeconomic strata were accessing and using mobile devices (e.g., cell phones, tablets, laptops) and their applications well before the COVID-19 pandemic (1, 2). The public health recommendation to social distance during the pandemic increased dependence on mobile devices for work, household maintenance, and social connections (3). People relied more on digital channels (e.g., email, text messaging) and mobile applications for maintaining relationships (e.g., Facebook), working (e.g., Zoom, Teams), shopping (e.g., Amazon), managing their health, and accessing health care (i.e., via telehealth) (4).

Also, in the United States, the pandemic brought well-established health disparities to the forefront. Vast evidence demonstrates racial/ethnic minority groups and/or those with a lower income, less education, or inadequate health insurance have worse health, limited health care, and higher rates of premature mortality relative to Whites and those of higher socioeconomic status (SES) (5). COVID-19 exacerbated these health inequities as racial/ethnic minorities and members of lower SES groups were significantly more likely to experience COVID-19 infections, hospitalizations, and COVID-19-related premature mortality compared to their White and higher SES counterparts (5).

Although COVID-19 vaccinations are effective at preventing COVID-19 hospitalization and death, fewer Blacks have been vaccinated against COVID-19 compared to White Americans (6, 7). In March 2021, three months into vaccine distribution, an absolute 6% more Whites than Blacks had been vaccinated in 43 US states. In November 2021, this disparity held with an absolute 7% more Whites (56%) than Blacks (49%) vaccinated against COVID-19 (8).

COVID-19 vaccination promotion efforts produce varying results, with few effectively closing disparities in vaccination rates (9). Personalized approaches such as 1:1 provider and patient conversations are successful, yet resource intensive (10). Digitally-delivered (via email and text messaging) interventions have been shown to effectively reach and engage lower those of lower socio-economic status (11–14). Additionally, interventions overcoming each person's barriers to doing a health behavior are effective across all populations (e.g., racial/ethnic minorities, individuals with low SES, and/or those with low health literacy) (15, 16). Promise remains in identifying and intervening on barriers of COVID-19 vaccination among diverse populations (17). To truly close gaps in health disparities, the challenge remains to provide initial and ongoing digital personalization in an equitable, automated, scalable way (18, 19).

To create scalable, equitable interventions for behavior change challenges like encouraging vaccination, we propose intentional behavioral design using the Double Diamond model of innovation to inclusively identify determinants (i.e., barriers and facilitators) for a recommended behavior, creating an evidence-based digital intervention to address those determinants, and harnessing behavior change artificial intelligence (AI) capabilities to automate and personalize the intervention to each individual within the population. Here, we share an example of a behavioral design process and behavior change AI application to address barriers to COVID-19 vaccination for the purpose of promoting the vaccine at scale.

INTENTIONAL AND INCLUSIVE BEHAVIORAL DESIGN

Behavioral science can be combined with well-established design processes such as the Double Diamond model (20) for more intentional intervention development, resulting in interventions that improve outcomes for all, particularly underserved populations (21). The Double Diamond model blends user-centered design principles into scientific intervention development by alternating exploration and solutioning stages across the development process (**Figure 1**).

In our vaccination promotion efforts, behavioral designers adhered to the Double Diamond model during intervention development to equitably promote COVID-19 vaccinations across diverse populations. Our intervention is an AI-driven behavior change platform that uses AI to select, assemble, and send message components from a behavioral science-based library to drive target behaviors. The target behaviors were scheduling the COVID-19 vaccination(s) and completing scheduled appointments. Based on recipients' actions, including interacting with the message, scheduling, and attending vaccination appointments, the intervention platform can further personalize subsequent messages to increase the frequency of target behaviors.

Designers performed a scientific literature review to identify the behavioral determinants (i.e., barriers and facilitators) for the above target behaviors. Then, as a best practice in behavioral science, designers employed an Intervention Mapping (21) process linking determinants to evidence-based behavior change techniques (BCTs) (22). Designers created a library of behavioral science message components (i.e., subject lines, body copy) and visuals suitable for both email and text messaging channels. Lastly, messages were assembled from components and delivered using a behavior change AI platform designed to personalize messages based on individual behaviors and characteristics.

Recipients were diverse in terms of race, ethnicity, income and education levels, and other demographics. The phases of the Double Diamond model (i.e., Discover, Define, Develop, Deliver) allowed for intentional and inclusive behavioral design, ensuring that library components included evidence-based behavior change strategies for the specific behavioral determinants prevalent across sub-populations, and that the AI technology was able to select the appropriate components for a given individual. To align with this objective, we outline the activities for each phase of the Double Diamond model.

Discover

The objective of the Discover phase is to deeply understand the behavior change problem. Behavioral designers searched scientific databases (e.g., PubMed, EMBASE) and relevant, credible gray literature (e.g., Pew Internet Research data, other national polls) to cast the widest net of documented historical and current determinants for vaccination adoption. Designers included both COVID-19 vaccination research and the evidence base for other communicable viruses (e.g., flu, HPV). Initiating the behavioral design process with an expansive list of determinants ensures intervention design remains inclusive for diverse populations.

In instances when the behavioral science literature is too new, as with COVID-19, to be comprehensive, partnering and learning from stakeholders who understand the behavior change problem and can provide insight into the determinants is recommended. We consulted with a variety of stakeholders specializing in population health, community health, and healthcare more broadly who provided insight into the determinants of

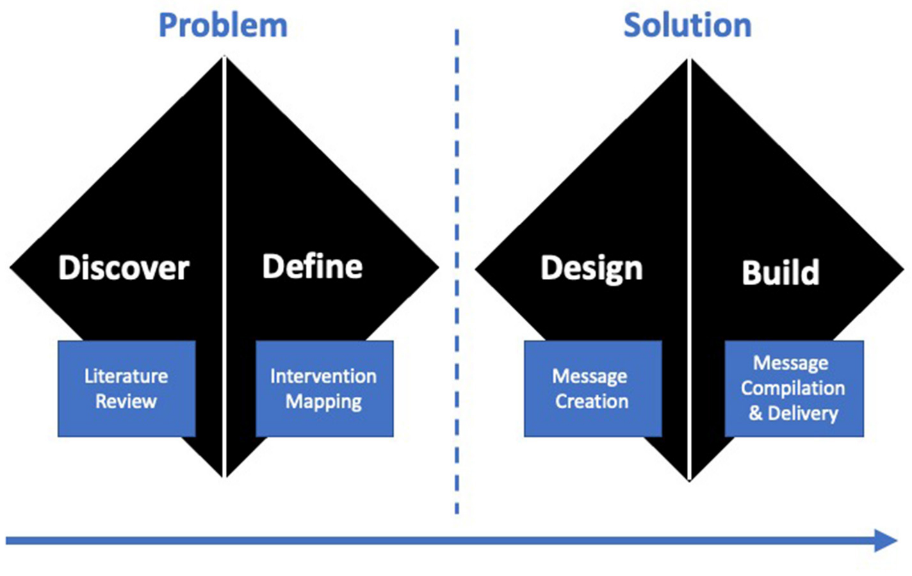

FIGURE 1 | Consistent with the UK Design Council's Double Diamond model (i.e., discover-define-develop-deliver), behavioral science can be interwoven into the model's best practice methods that alternate between divergent stages, where the focus is on gathering information and thinking broadly, and convergent stages, where the focus is on prioritization and refinement.

TABLE 1 | Unique behavioral determinants exist for vaccination adoption among historically underserved populations ($n = 10$).

Difficulty understanding health information
Unknowns about vaccine distribution, delivery and implementation
Believing in conspiracies
Negative emotions (e.g., confusion, nervousness, apathy, anger, fear)
Concern about vaccine access
Concern about vaccine cost
Concern about vaccine safety (e.g., side effects, distrust of medical institutions)
Concern about vaccine efficacy
Underestimating risk associated with opting out of vaccination
Dislike being told what to do by the government/other authorities

Our literature review captured 10 key barriers among people with a lower SES, living in rural areas, and racial/ethnic minorities, including concern about vaccine access, concern about vaccine safety and efficacy, and underestimating risk associated with opting out of the vaccine.

both patient vaccination adoption in general and COVID-19 vaccination adoption, specifically.

Define

The objective of the Define phase is to analyze and synthesize learnings from the Discover phase into themes, priorities, and design requirements. Approximately 80 publication sources revealed at least 45 determinants related to vaccination adoption (23, 24). Of these determinants, roughly 10 barriers were particularly prevalent among historically underserved populations, including people with lower SES, people residing in rural areas, and racial/ethnic minorities (**Table 1**).

In the Define phase, designers categorized and prioritized vaccination barriers for all populations. Designers flagged barriers most relevant to underserved populations as critical for inclusion in intervention design. Designers defined intervention features to specifically target these and other prevalent barriers and specified relevant demographic information to be captured to better personalize the messages.

As part of the Define phase, we identified mechanisms of action and then BCTs to best support people overcoming barriers to vaccination, paying special attention to nuances required to support the underserved. For example, racial and ethnic minority communities may have concerns about historical and unethical medical research. Leveraging credible sources is an effective behavioral strategy for changing an individual's attitudes about a health behavior. However, when using this BCT to support racial and ethnic minorities in this COVID-19 context, the use of a trusted community member as the credible source may be better received than assuming the credible source is a healthcare provider.

Develop

In the Develop phase, designers assembled requirements and created intervention content and features. The intervention content was a deliberately broad message component library written to be inclusive of the needs of a diverse population of recipients, including members of underserved communities.

Behavioral designers utilized the behavior change taxonomy and COM-B model to map determinants to mechanisms of action and then selected a single, effective behavior change technique (BCT) to address each one (25, 26). BCTs were selected based on both the strength of evidence for addressing the determinant and the ability to translate the BCT into a digital communication. Further, we carefully considered whether a particular determinant deserved to be treated separately (i.e., received its own BCT and message components), rather than consolidated with similar determinants, due to its importance to and impact on specific groups.

A creative team operationalized each BCT into a text and visual component for email and text channels that was written and displayed at a 5–8th grade reading level (27–29) to accommodate recipients with limited literacy.

Deliver

The final phase of design is Delivery, where advanced consumer technologies can use what is known about an individual to personalize intervention delivery. This allows for the selection of BCTs appropriate for an individual's needs from the broader library designed to accommodate a diverse population, as well as feedback-driven course correction based on recipient behavior. In this way, technology can address the issue that while underserved communities may experience some barriers at a greater intensity or frequency than the population at large, an individual within that community may not experience those specific barriers. In general, personalization can enhance intervention efficacy: personalized interventions or messages are more individually-relevant and, therefore, more efficacious for driving engagement, comprehension, and action (30). For our intervention, the use of an AI platform was essential to achieve this level of personalization.

Personalize and Scale With Behavior Change AI

Our team leveraged a proprietary AI reinforcement learning platform to select, assemble, and deliver the right message components for individuals based on their characteristics and behaviors. The reinforcement learning was designed to reward the AI agent for messages that yielded behavioral outcomes (i.e., opening messages, scheduling vaccination appointments, or completing vaccination appointments), so that it becomes increasingly accurate in selecting the BCTs that work for a particular individual as they interact with the intervention.

Messages were delivered via email or text message, based on recipient's available contact information and communication preference. Accommodating communication preferences is critical to an intervention's success (31). Moreover, communication channels that do not rely on broadband internet access (e.g., text message) are recommended to reach underserved populations such as people living in rural areas and racial and ethnic minorities (32). Recipients received messages via their preferred digital communication channel (i.e., email or text message) at a cadence of one personalized message per week for five weeks, followed by a break in communications to avoid notification fatigue (33). Messages ceased if the patient scheduled a COVID-19 vaccination appointment or unsubscribed from messaging.

Iterative Improvements

Real-world, just-in-time intervention improvements is a notable, persistent behavioral science challenge (34), but was necessary for this intervention to succeed as the pandemic changed over time. Designers updated the intervention at regular intervals to remain contextually relevant. These updates specifically re-evaluated known determinants for continued relevance and reviewed content for continued accuracy. For example, later versions of the messages promoted autonomy, to be particularly mindful of individuals who might be increasingly more unwilling to be vaccinated. Another example accompanied the rollback of mask requirements in many areas; we updated message visuals to include a variety of masked and unmasked figures, and updated language to de-emphasize mask wearing as an expected behavior in public contexts. A review of the behavioral data before and after these intervention updates suggests no disruption to AI agent learning or intervention effectiveness.

DISCUSSION

Intentional behavioral design that leverages evidence-based behavioral science intervention techniques, the Double Diamond model, and behavior change AI technology can address barriers to COVID-19 vaccination hesitancy, offering a way to inclusively target determinants for underserved populations and deliver behavior change messages at scale. Personalized interventions delivered through digital consumer channels have the potential to meaningfully address vaccination hesitancy at the individual level, while accommodating a broad set of behavioral determinants inclusive of those experienced by underserved populations. This blend of behavioral science and the Double Diamond model extends the best practices offered in other digital health equity recommendations into the specific realm of intervention design (31, 35, 36). We offer three critical design considerations for any behavior change intervention strategy that aims to achieve personalization and digital health equity.

First, it is vital to understand and account for everyone's barriers and facilitators to achieving the recommended health behavior, which may necessitate iterating the intervention as the recipients, behavioral determinants, and context changes over time (i.e., Discover phase). To promote health equity, behavioral design efforts must deliberately consider a broad range of behavioral determinants, contextual constraints and opportunities, and the importance of personalization. The Double Diamond's Discover phase can include conducting a broad and inclusive literature review (i.e., theoretical, historical, and practical) of the problem, its impact on health equity, and determinants of both. In doing this, it is critical to understand the origins of disparities and challenges (e.g., context, resources, barriers, facilitators) specific to social determinants of health (18, 37).

Second, once identified, designers should match the appropriate behavior change techniques to address each of the identified determinants. Each message should operationalize an evidence-based BCT (i.e., Define and Develop phase). While this requires careful translation of BCTs into the intervention medium, it also means aligning design with real-world constraints and needs. This is where partnering with stakeholders can inform the overall and equitable aspects of an intervention's design, and real-world implementation. Meaningful involvement from stakeholders (e.g., health system leadership, leaders from underserved communities) is recommended to ensure appropriate intervention design (31). Input from individuals of underserved communities holds incredible value (31), however remains rare in digital health endeavors.

Third, if feasible, technology such as behavior change AI should be applied to personalize the messages at scale during the Deliver phase. The use of AI and advanced technical capabilities offers an opportunity to achieve population-level reach with individualized content. Behavioral "nudges" distributed to diverse populations has increasing potential to promote health equity (17, 36). The more an intervention can be personalized to its recipients, the more likely it is to succeed and sustain behavior change (38). Additionally, personalization for multiple characteristics (e.g., preferences, channels, context) of an intervention enhances intervention efficacy (32, 39), and more complex personalization may require more technology support.

While AI is a relatively new tool in behavioral interventions, researchers, designers, and interventionists have already found utility in using AI to deliver context-aware digital behavior change interventions (40, 41). The use of automating technologies to leverage high-volume data points such as user inputs, behaviors, geotags, or sensor measurements may accelerate health equity efforts to ensure context is considered in digital behavior change intervention development (40). At the same time, technology that can consume and interpret such complex real-world data will yield a more accurate and complete representation of its users, supporting the design and delivery of more appropriate intervention content.

Real-world considerations are critical pieces in the behavioral design of inclusive interventions, informing iteration and implementation. As real-world contexts evolve, people's barriers and determinants change. It becomes an ethical duty for designers to improve their interventions accordingly with thoughtful design processes. Anticipating iterative improvements after implementation ensures content remains relevant and meaningful to all, and more likely to promote engagement and action with underserved populations.

Although digital health interventions have existed for decades, the marriage of behavioral scientists and traditional design teams is relatively new and can present challenges as professionals with different training and focus areas working together to build digital tools. Integrating intervention development with the Double Diamond model facilitates a new form of collaboration between behavioral scientists, designers, and technologists to create equitable behavior change interventions. We believe this aligned approach will facilitate more productive design of interventions that are both efficacious, engaging, and activating.

Despite the innovative integration of behavioral science to the Double Diamond model, limitations exist when leveraging behavioral design and AI in a real-world context. This intervention prioritized two widely used channels that are particularly accessible to members of underserved populations (i.e., email and text), but other intervention touchpoints such as chatbots or in-app notifications may be just as or more effective for some people, behaviors, and contexts (42). Moreover, any real-world implementation involves factors outside of designers' control. In this case, the lack of an accessible, unified vaccination database in the United States means interventions almost certainly undercount recipients who successfully completed their COVID-19 vaccination series. This undercount limits research insights into effective behavior change techniques for all and specifically for underserved populations. As we can augment behavioral data with additional sources, we can close this gap.

In conclusion, the COVID-19 pandemic necessitated a swift and inclusive population-based public health response. The pandemic and associated vaccination rollout emphasized health disparities, unique individual attitudes and beliefs, and the need for scalable interventions. Digital interventions, when informed by evidence-based behavioral science and design processes, offer an opportunity to engage and reach a diverse audience. The current intervention utilized the Double Diamond model to both create a COVID-19 vaccination intervention informed by a diverse set of resources (e.g., peer-review and gray literature, stakeholder feedback) and intentionally adapt to allow for in-tandem design and development responsive to the evolving pandemic. In addition, behavior change AI technology allowed for the delivery of personalized communications at scale. The combination of evidence-based behavioral design and automated personalization sets the stage for closing disparity gaps in COVID-19 vaccination at scale, and provides a template for how designers can close disparity gaps across a variety of health behaviors.

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/s.

AUTHOR CONTRIBUTIONS

KF, AW, and AB wrote the first draft of the manuscript. CO and KF revised the manuscript. All authors wrote subsections of the manuscript. All authors contributed to the article and approved the submitted version.

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PERSPECTIVE
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Researchers' Perspectives on Digital Mental Health Intervention Co-Design With Marginalized Community Stakeholder Youth and Families

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Co-design of digital mental health technology with youth and families is a relatively new but growing approach to intervention development. In this perspective article, researchers used collaborative reflexivity through duoethnography methodology to reflect and report on experiences and lessons learned conducting co-designed projects with marginalized youth and families. Researchers engaged in written reflective dialogue regarding projects designed to co-develop technology-based apps and computer programs to support mental health of youth and their families. Reflections described the barriers and challenges for sharing responsibilities with stakeholders who have extensive lived experience but limited exposure to research. Researchers shared insights about their own intersectionality and positionality from marginalized to privileged, relative to co-design participants, and what it means to share authority, authentic partnership, and responsibility in the research process. Cultural understanding may diverge, even between acculturated minority researchers and matched minority stakeholders. While there are a variety of approaches that researchers might refer to as co-design, it is important to be intentional in the implementation of these processes so that collaborations with stakeholder youth and families are neither disingenuous nor exploitative. Implications for equitable and meaningful engagement of marginalized communities in co-design projects for youth mental health are discussed.

Keywords: digital co-design, youth, families, participatory research, marginalized communities, mental health

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INTRODUCTION

Co-design of digital mental health technology with youth and families is a relatively new but growing approach to intervention development (1). Marginalized youth and families are often at a disadvantage regarding access to mental health services, due to geographic, cultural, and economic reasons that reflect, and are exacerbated by, systemic racism. These include minoritized (2). Black, Latinx, and Native American individuals, but also those pushed to the margins by socioeconomic and other inequities that limit roles in decision making and creating resources for one's community. National data on children ages 3–17 collected prior to the ongoing pandemic highlighted rising prevalence rates for anxiety (7.1%) and depression (3.2%), with reduced odds that non-Hispanic

Black and lower-income children would receive mental health services (3). Research conducted in the first year of the pandemic revealed increased anxiety and depression for essential frontline workers and their children who were predominantly of Black and Latinx background (4). The ensuing transition to telehealth visits and other digital mental health approaches underscores the urgency of developing effective platforms for service delivery for youth and families.

APPROACHES TO CO-DESIGN

Co-design involves the inclusion of potential users and stakeholders across the technology development process to ensure the end-product is feasible, acceptable, and effective (5). This approach is a shift from the "expert" or professionally driven design of interventions "for" the users to designing "with" users collaboratively (6). Co-design of interventions to advance health equity has the potential to reduce harm through inclusion and power sharing with people from marginalized communities, who have often been excluded from such processes. It draws on local knowledge and expertise, making space for marginalized voices, to develop more culturally relevant, trusted solutions (7).

A systematic overview of global studies (8) identified that clinical therapy interventions using computer-based cognitive behavioral therapy (CBT) for depression, anxiety, and stress to be as effective as face-to-face CBT, while approaches that use apps and other digital tools for treating the same conditions had mixed results. These highly scalable treatment tools for adolescent anxiety and depression offer avenues for increased access to evidence-based care. A systematic review of recent literature and clinical trials registries worldwide documented 11 mental health interventions planned for youth and families in response to COVID-19, including five designed to deliver CBT or other therapy or support through online computer or app-based platforms (9). No studies reported intervention development using co-design. Co-design processes are often used to promote engagement in digitally delivered interventions with end users, with varying levels of success. Another systematic review of studies examining digital interventions aimed at youth mental health (10) documented six modalities including websites, games and computer-assisted programs, apps, robots and digital devices, virtual reality, and mobile text messaging. This review highlighted a preference by youth for interactive features such as videos, limited text, ability to connect with others, and options to receive text message reminders. The ability to personalize features was also cited as highly desirable (10).

Limited research has been conducted on mental health digital intervention development and implementation with marginalized youth and families. Inequities and the resulting disparities that exist in mental health for a variety of socially marginalized groups have roots in persistent systemic racial bias and underrepresentation in medical and mental health research (11). Inclusion of historically excluded communities is vital to ensuring treatments, including digital interventions, improve access to mental health. The integration of community partnered participatory research, human-centeredness and co-design offers an opportunity for success in this regard (12). Community partnered participatory research stems from the traditions of action research, introduced by Kurt Lewin in the 1940s (13), which blends the social scientific experimental approach with "programs of social action to address social problems" (14). The now broad field of participatory methods includes participatory research, participatory action research, community-based research, action science, action inquiry, and/or cooperative inquiry. These terms are sometimes used interchangeably, however, participatory methods typically represent more emancipatory or transformative action methods, whereas action research is more utilitarian and problem-solving in nature (15). Strong arguments decrying the overwhelming lack of useful clinical research highlights limited patient-centeredness (16). To remedy this deficit, there are various approaches to engage patients in research, of which co-design may be the most ambitious. A review of publications that include the key word "co-design" suggests that the practice has evolved over the last two decades. Early examples include experience-based design to improve patient care through direct personal observation of patient experience (17). By moving beyond consumer reports or satisfaction measures, we gain a deeper understanding of the internal experience, in order to create digital interventions that improve what the individual feels about the tools at a deeper emotional and cognitive level (17, 18).

Participatory approaches to digital health intervention design (19) generally involve stakeholders (e.g., patients, providers, community leaders) in the design process, with the translation of designs to app creation undertaken by individuals with technical expertise (e.g., programmers). These methods are grounded in principles of user-centered design, a well-documented (20, 21) approach that centers the users' needs by incorporating user-centered activities throughout the development process (22). Allowing end users to influence the design should increase ultimate usability (23). These approaches incorporate various methods to assess intended user needs and preferences, including thorough observation and analysis of tasks and product requirements, development and testing of prototypes, analysis and resolution of usability problems, and iterative testing of features and interfaces (24). These methods are often used to create apps for populations whose users were not involved in the design process, though some approaches involve co-creation of apps for personal use (25).

Participatory informatics is one co-design approach that draws upon principles of Community Partnered Participatory Research (e.g., equity, power sharing) (26) and user-centered design (e.g., active user participation in design) (27), does not require technological expertise, and has been implemented with minoritized populations (28). This approach's aim is to democratize technology access: end users co-develop the application, including building of the app, through platforms such as Chorus (29), that require no coding expertise to design web-based applications. This method allows non-technical experts to create digital technologies designed to address the gap in availability of appropriate and effective resources that can increase access to benefits from digital health advances. While there are a wide variety of approaches referred to as co-design, researchers must be intentional in the implementation of these processes so that collaboration is not disingenuous. For example, human-centered design approaches privilege the needs of the end users and settings, guarding against over-emphasis on design for clinical trial conditions that ignores realities of complex health care settings (20).

METHODS

Duoethnography, conducted with two or more researchers, as defined by Sawyer and Norris (30) was used to guide this commentary. The authors of this article include a mixed-race Black developmental psychologist, a White clinical psychologist, a clinical psychologist from an immigrant Iranian family, and a bicultural bilingual Latina psychiatrist. As women and caregivers with careers in academic medical research, we have aimed to create opportunities for digital-based intervention development; each of us has experience working with either app-based or computer-based technology for delivery of mental health supports. Interventions include patient navigation and evidence-based treatments (CBT) for youth and families from marginalized communities. For example, the second and third authors' projects focus on co-designing a mental health services application, exclusively by and for foster care youth, leveraging participatory co-design methods to concurrently expand mental health workforce exposure and capacity by hiring former or current foster care youth as staff within an academic medicine setting. Youth co-designers have increased equity with other staff, faculty, and consultants while receiving unique mental health workforce development opportunities (e.g., resume building, making connections with mental health professionals to promote future career options).

We share a commitment to listening deeply to youth about design of these approaches and in the best of circumstances work to include them in meaningful roles on our research teams. The methodological, practical, and ethical challenges of conducting participatory action research with vulnerable populations, and its value, is well-documented (31). As we gain experience through these projects, we have begun to identify factors that facilitate this work and also areas for improvement, professionally and for the field in general. Because we each have a history of research collaboration that continues to expand, we developed this perspective article using a duoethnography methodology (30) to report and reflect on our experiences and lessons learned while conducting co-designed projects with marginalized youth and families.

After introduction of the inquiry questions and duoethnography process (30), followed by several months of self-reflection and informal conversation, researchers spent 2 months actively engaged in written dialogue, responding to each other regarding projects they are or were involved in (within the previous 5 years) that were designed to co-develop technology to support youth and family mental health. Through turn-taking, researchers responded to previous journal entries in a conversational style, adding new information and engaging in dialogue, yielding the participant data analyzed. Prompts included: What did we learn about working collaboratively with community stakeholders, working with youth and families, marginalized minoritized populations? What does it mean for a researcher to authentically share leadership and design responsibilities with a lay person? How do we address power differentials and the systemic exclusionary context that we are trained in, that is academic research?

Reflexive thematic analysis (32) was conducted with nine entries from the four researchers. A predominantly inductive and experiential orientation was used by the first author. Preliminary codes were developed after multiple readings of the journal entries and then organized into larger themes. Codes and themes as defined and named were then checked for accuracy of meaning in interpretation by the other researchers through examination of written results against codes and raw data. This review was followed by a discussion of the initial summary report and consensus coding. Final results reflect the authors' collaboratively developed interpretation of identified themes.

RESULTS

Reflections described the barriers and challenges for researchers sharing responsibilities with co-design partners who have extensive lived experience but limited exposure to research. Reflections also strongly emphasized goals of reaching end users described as racially, ethnically, and linguistically diverse from minoritized communities and families, harmed by systemic racism, silenced, and skeptical about technology use. In describing efforts to respond to apps where "graphics do not usually have individuals or characters that look like my family," researchers included observations organized into three main themes: (1) *partner characteristics*; (2) *researcher positionality*; and (3) *redefining co-design*.

Co-design partners the researchers had worked with were **characterized** as racially, ethnically and linguistically diverse, from marginalized communities, specifically identifying Latinx youth and families. They varied in interest, skills, and commitment to co-design projects, but overall youth were seen and sought after as sophisticated consumers of technology. A goal of recruitment for co-design partners was representation of the focal end user. One researcher recalled the pain of a youth partner having to grapple with "elements that are offensive" in an effort to culturally adapt an existing mobile treatment program. In acknowledging the challenges for individuals who may be alone, e.g., "the one parent" on a team with researchers, there was a realization of the reluctance partners may feel in asking questions or expressing alternative viewpoints, yet that is essential for collaboration and successful co-development. Cultural considerations were also important, as parent partners may be reluctant to say things that "might be considered disrespectful." The importance of compensation was noted, with emphasis on hiring partners as project staff. This is aligned with calls for equity in compensation to "community experts" that collaborate with academic researchers (33). There was shared concern and questions about "how do youth define their role?" and we identified the need to be intentional about having these

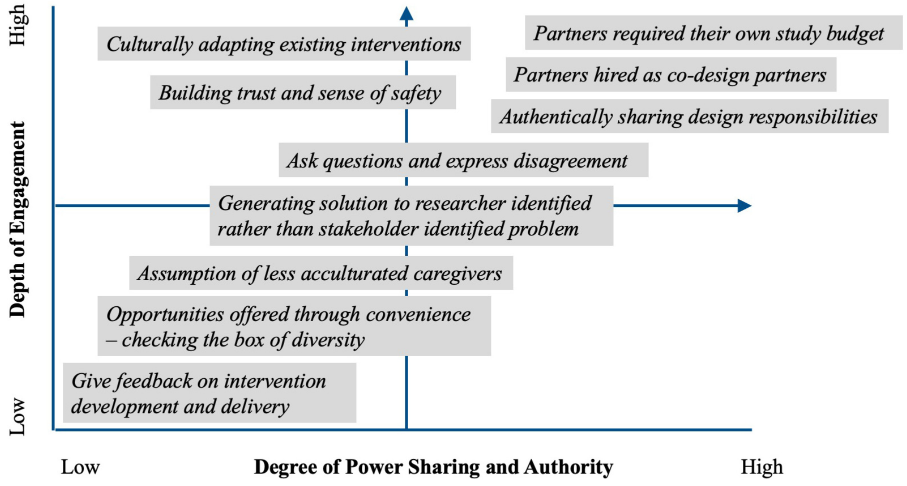

FIGURE 1 | Data from analysis of researcher reflections is used to illustrate a continuum of co-design frameworks that represent (1) the variety of roles for co-design partners and (2) growth as researchers as well as growth in the field toward more authentic and empowered partnerships. These specific examples from the duoethnography analysis are also meant to be used by the reader to reflect and situate their own co-design experiences within this framework.

conversations on our projects. The over-reliance on convenience sampling for partners "within reach" suggested the need for improved recruitment strategies.

Recalling previous and current work with co-design partners led to reflections regarding **positionality** as researchers. This included realization of privileged investigator roles where we were more simply "asking for feedback" and confirmation of research questions, with little "sharing of responsibility." Relying on our own technology expertise hampered the extent to which we tried to obtain "community identification" of both the problems and solutions. A history of researchers "dropping in to take from the community" meant being "met with initial skepticism." In stepping back, we would want to "check our own views" and more intentionally incorporate cultural humility at the start to examine whether and to what degree partners view technology as the answer.

Re-defining co-design, by examining past experiences to inform future aspirations, was a central theme of researcher reflections. Although there was increased clarity regarding the continuum of co-design at different points historically, and for varying goals of co-design for specific projects, a stated goal was for more authentic partnerships that consider both depth of engagement and power sharing by youth and family stakeholders. Codes and quotes derived from the analysis are depicted in **Figure 1** along these two continuums to contextualize previous research experiences and future aspirations for co-design. This figure is also meant to encourage the reader to situate and reflect on their own co-design experiences. Fostering authentic partnerships requires "understanding and recognizing power dynamics" that requires "willingness to let go of power and give space" to co-design partners. Researchers described the move toward "community-driven enterprises" where "work together is an exchange between partners." The boldest vision of this negotiation was with a community-based group that requested resources to investigate their own research questions that would be developed within the co-design process. Although this was a partner-driven request, there was agreement that this is a roadmap for future co-design endeavors. Timing was also a critical aspect of this theme, identifying the need for intentionality in creating guidelines about process and co-design and that these should be discussed as "close to inception" of the research as possible. And finally, there was acknowledgment that co-design, as with other research collaborations, is challenging and time consuming and requires substantial resources to be done well, despite the often-limited research budgets.

DISCUSSION

Minoritized youth and their families experience multiple barriers to accessing mainstream mental health services, thus collaborative relationships for co-designing services that are accessible, engaging, and respond to patient's needs and preferences are critical (34). The reflections allowed researchers to explore places in the co-design process where cultural understanding may diverge, even between acculturated researchers from underrepresented backgrounds and matched minoritized stakeholders. Despite a dearth of research on whether co-design improves the clinical effectiveness of interventions, a scoping review of co-design methods with culturally and linguistically diverse communities identified that the quality of the relationship between the researcher and participating community was important for maximizing the community's experience and engagement with the designed intervention or service (35). These results can facilitate interpretation of the potential of our co-design projects, in advance of end user outcome studies, e.g., the implications for the last author's implementation of an asynchronous digital evidence-based CBT therapy for childhood anxiety with Latinx and immigrant families. Substantial input from families revealed how child and caregiver would use the intervention together when English proficiency differed between them. Without co-design collaboration the intervention would have been inaccessible, unengaging, difficult to deliver and thus ineffective. Yet, involving families earlier as co-design partners could have facilitated an even more responsive intervention design from the onset.

In our defining of co-design and re-defining our aspirations for its integration in our intervention development, we build on recommendations in the field (36) by highlighting next steps for use that would advance the child and adolescent mental health equity we strive for Harris et al. (37). We suggest a more thorough and intentional practice of transparency in work with youth and families. Incorporating co-design should begin at the earliest possible stage of study design. This may lead to work with various teams in a sequence along the project period, considering youth and family availability, interest, and engagement. Every stage would benefit from explicit naming of roles and expectations for co-design partners, as well as researchers, who should reflect honestly on boundaries regarding power sharing. Part of this self-reflection by researchers should include an understanding of their willingness and ability to embrace the questions and goals of co-design partners. Finally, we encourage a broader strategy for recruitment of partners to increase representation. Networking and relationship building can start even before the proposal writing process and could be a feature of research centers working with youth and families on digital health projects.

We found the duoethnography writing process helpful for sustaining and improving our practice using co-design methods. The act of setting these reflections on paper revealed important themes on positionality and power, and important considerations for fully including youth, family and communities in co-designing technology. The process was an opportunity for increasing self-awareness and learning from colleagues committed to doing this work effectively, justly, and ethically. The central insight that surfaced from the analysis of our data is the enhanced understanding of the dimensions of co-design and what it really means to share the scientific and creative process with youth and families. Diversity and equity practices are a priority and a career-long focus for all of the authors, but frequently research requirements and pressures from academy structures may be a barrier to full participation of youth partners. Examples include limited funding and short timelines that deter potential for meaningful relationship building, as well as bureaucratic tangles that can interfere with incentives and hiring that would more fully promote fairness in co-design partnerships. We learned from this process that we can move beyond these academic norms.

We recommend other researchers engaging in co-design work use similar approaches of collaborative reflexivity. Reflective scientific journaling and dialogue by researchers and partners can evaluate these processes and qualitatively track the dimensions of co-design, positionality, and integration of youth and family prioritized perspectives as end users and scientific partners. More of our scientific reporting can include this information to build the knowledgebase in digital intervention development with marginalized stakeholders, especially if it holds us accountable to striving for optimum co-design that best serves the end user.

DATA AVAILABILITY STATEMENT

The dataset presented in this article is not readily available because analysis of authors' reflections of experiences using co-design was conducted using collaborative reflexivity methods. Questions regarding the dataset should be directed to the corresponding author.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent from the (patients/participants or patients/participants legal guardian/next of kin) was not required to participate in this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

MP conceptualized and led the duoethnography process and qualitative data analysis. JF contributed to the literature review. All authors participated in reflections and subsequent dialog regarding coding and interpretation, and writing and editing process.

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A Call to Action: Using and Extending Human-Centered Design Methodologies to Improve Mental and Behavioral Health Equity

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Mental health disparities directly tie to structural racism. Digital mental health (DMH), the use of technologies to deliver services, have been touted as a way to expand access to care and reduce disparities. However, many DMH fail to mitigate the persistent disparities associated with structural racism that impact delivery (e.g., costs, dependable internet access)–and may even exacerbate them. Human-centered design (HCD) may be uniquely poised to design and test interventions alongside, rather than "for," marginalized individuals. In employing HCD methodologies, developers may proceed with a vested interest in understanding and establishing empathy with users and their needs, behaviors, environments, and constraints. As such, HCD used to mindfully address structural racism in behavioral health care may address shortcomings of prior interventions that have neglected to elevate the voices of marginalized individuals. We argue that a paradigm shift in behavioral health services research is critically needed–one that embraces HCD as a key methodological framework for developing and evaluating interventions with marginalized communities, to ultimately promote more accessible, useful, and equitable care. The current commentary illustrates practical examples of the use of HCD methodologies to develop and evaluate DMH designed with marginalized populations, while also highlighting its limitations and need for even greater inclusivity. Following this, calls to action to learn from and improve upon HCD methodologies will be detailed. Acknowledging potential limitations of current design practices, methodologies must ultimately engage representative voices beyond research participation and invest in their active role as compensated and true collaborators to intervention design.

Keywords: human-centered design, equity, anti-racism, mental health, digital mental health

INTRODUCTION

Structural racism significantly impacts the reach of health services to diverse communities. For example, over 123 million Americans live in federally-designated Mental Health Professional Shortage Areas (1). Also, researchers continue to recruit generally homogenous samples (2), hindering our understanding of how to effectively address mental health concerns in diverse communities and further exacerbating disparities (3). The continued existence of structural racism in clinical science is problematic and reinforces decades-long distrust toward mental health researchers and clinicians. Accordingly, there are recent calls to acknowledge, address, and eradicate structural racism in mental health service delivery and research [e.g., (4, 5)].

Digital mental health tools (DMH), the use of technologies to deliver mental and behavioral health services, have been touted as a promising solution in expanding access to evidence-based services and reducing mental health disparities (6). There are initial data supporting the feasibility and acceptability of DMH in improving the mental health and wellbeing of individuals from diverse backgrounds [e.g., (7)]. Due to pandemic-related social distancing mandates, the use and relevance of DMH has increased rapidly (8) and aimed to mitigate the COVID-related psychiatric epidemic (9). However, many DMH fail to address the persistent disparities associated with structural racism that impact delivery. Indeed, DMH inherently requires access to digital technologies, dependable internet access, and an adequate level of literacy and experience with using technologies, all of which are common barriers to DMH engagement as reported by diverse populations (10). Further, DMH have often been designed from a top-down perspective that replicate in-person intervention procedures (11), which were primarily developed with homogenous participants, do not make use of the unique capabilities of digital health (e.g., using sensors to trigger specific interventions), and extend poorly to real world engagement for diverse users (2, 12). The field therefore stands at a critical crossroads in which to learn, improve, and generalize from design best-practices used in DMH development to address structural racism and promote equity in mental health interventions moving forward.

Namely, human-centered design (HCD) is uniquely poised to design and test interventions alongside, rather than "for" (i.e., designing without input or consideration of user needs, capabilities, or limitations), marginalized individuals who are directly impacted by structural racism in behavioral health services (13). Indeed, HCD shifts the focus simply from solving a user problem with participants [i.e., user-centered design; (14)] to, instead, better understanding the people who experience the problem. In employing HCD methodologies, developers may proceed with a vested interest in understanding and establishing empathy with users and their needs, behaviors, environments, and constraints where a product will ultimately be implemented and used. This is achieved through strategies such as interviews, focus groups, observing users, co-creation sessions with users, and rapid prototyping [see (15)]. As such, HCD used to mindfully address structural racism in mental health care may address shortcomings of prior interventions that have neglected to elevate the voices and preferences of marginalized individuals.

In this commentary, we argue that a paradigm shift in behavioral health services research is critically needed. It is imperative to embrace HCD as a key methodological framework for developing and evaluating behavioral health service interventions with marginalized communities, to ultimately promote more accessible, useful, and equitable health care. This commentary will illustrate practical examples of the use of HCD methodologies to develop and evaluate DMH designed with marginalized populations, while also highlighting its limitations and need for even greater inclusivity. Following this, calls to action to learn from and improve upon HCD methodologies will be detailed.

HUMAN-CENTERED DESIGN

HCD involves a group of mixed-methods approaches to attempt to match a product (e.g., technology, intervention) to the contexts of its use by people in their everyday lives (16). There are a variety of HCD approaches (17–19), but they similarly focus on: 1) understanding potential users, their needs, capabilities, limitations and goals; 2) designing to address the users' concerns; and 3) evaluating the designs with the users. HCD has roots in psychological theory due to its focus on meeting cognitive capabilities and the human experience (13, 20). Namely, HCD intends to design and evaluate products alongside, rather than "for" likely end users (e.g., through strategies such as co-design workshops). It also focuses on empathy with a user's experience, something that can hold both benefits and potential problems. Indeed, as Bennett et al. (21) describe, a designer attempting to empathize and align with a blind end user by attempting to blindfold themselves while testing a product may become distracted by their own experience compared to the daily, lived experience of a blind user. As such, while HCD principles may provide a methodological solution to addressing structural racism and promoting equitable design, its history and limitations must first be acknowledged and addressed.

Despite HCD's framing as a collaborative approach with end users, power structures are insidious to its practice history (22). Indeed, the potential for the development of the following power structure is rampant in HCD: a designer, often a cisgender, heterosexual white male, attempting to "uncover" the needs of a marginalized user and/or community to create a product (23). Marginalized users and communities may often already have strong notions of what might work for them and do not need these ideas to be "uncovered" for them (24). Rather, support from those in power is needed to amplify the community's voices and implement their ideas (25). Further, end products of HCD processes have not been equitably distributed or shared in marginalized communities after they have been developed and evaluated. In sum, HCD has typically not been practiced through the lenses of equity, cultural inclusiveness, and anti-racism. We cannot promote this group of approaches as a means to promote equity in interventions without explicitly acknowledging that it has historically not been used in this way–and will not be used for equity without purposeful and continued scrutiny of its practice (22).

Moving forward, HCD methodologies may be used to promote equity, but only if actively conducted intentionally from an anti-racist perspective [i.e., the perspective that there is nothing inherently "right or wrong" with any given racial group and that racist policies and systems drive racial inequities; (26)]. While users are considered at every stage of design, explicit recommendations for considering users' full contexts must be made to fall in line with this perspective. For example, a user of a medication adherence app to support a chronic condition must also be designed within the context of potential experiences of racism within and outside the health system. Marcu and colleagues (27) demonstrate exploring such experiences from an empathy-driven design approach with youth living with human immunodeficiency virus (HIV). Similar considerations of full contexts would create opportunities for the voices of a marginalized population to be heard, but also facilitate insight into the societal and institutional factors that contribute to power imbalances that are present in both design and healthcare systems.

Multiple actions can be taken to support more inclusive HCD methodologies–both in the development of DMH and broader behavioral health interventions and services. First, intervention designs and evaluations should be conducted by diverse research teams, with an emphasis on recruiting, retaining, and promoting team members with demographic membership that is in some way representative of potential participants and end users (28, 29). There may be various barriers to doing so, including the limited number of diverse trainees within the field of psychology (30). Some ways to increase this practice and how to invest in trainees from underrepresented groups, thereby diversifying the training-to-workforce pipeline, are described in detail below. It is also important to note that, even after increasing representation of team members, researchers may need to generate a process for managing inconsistencies between team member recommendations, especially those based on diverse team members' lived experiences and evidence-based theory, which has historically been developed based on data from primarily homogenous samples (2). Emerging work on incorporating lived experience and patient-centered care with evidence-based treatments may inform such processes (31, 32). Second, research and design teams should engage in ongoing training and education in anti-racism and pertinent contextual factors [e.g., positionality practices in equity research; (33)]. Such education would promote considerations of larger contexts for users. A recent example of expanding contextual considerations is Stern et al. (34) adaptation of Bronfenbrenner's Bioecological Model to focus on Black youth development and attachment processes. Relating to this education, teams should frequently be reflecting on whether and how the design and research are serving their potential end users and practice reflexivity in recognizing when researchers are speaking for end users (4). Third, teams should collaborate with community partners to ensure that design and intervention decisions fully reflect all contexts of potential users. Doing so would likely uncover additional relevant contexts for design [e.g., Black girls' use of an intersectional lens [race and gender] to define their health and choose health-related behaviors; (35)]. To do this successfully, community partners must be given actual and active partnership throughout the design process. Indeed, rather than viewing community partners as research participants (e.g., one time participation in a usability testing session), they should be given ample agency, compensation for their time, and credit for their contributions (e.g., authorship). Collaboration with community partners may require additional resources and time, thus funding opportunities should prioritize such work. Fourth, recruitment and retention efforts for potential participants would benefit from established community-based participatory research (CBPR) methodologies [see (36)]. Action research, a family of methodologies that are responsive to a pressing need of a group while also promoting mutual learning between those facing an internal problem and outside researchers, may also complement HCD methodologies throughout the research development and recruitment stages (37). These steps are most certainly not exhaustive. We both hope and expect that means to ensure that HCD methodologies are more inclusive and are expanded well beyond this commentary.

NARROWING THE HCD GAP TO ADVANCE DMH: CASE EXAMPLES

Though HCD methodologies have been successfully implemented in DMH research (38), the digital divide remains and so do the resulting health inequities in behavioral health (39). Marginalized communities are often left out and, subsequently, their needs remain unmet (40). These health disparities not only further exacerbate mental health, but impact users' engagement with DMH (41). Potential users are deserving of equitable design. Researchers must apply HCD design work inclusively to appropriately address varying needs of those underserved and underrepresented. Researchers and clinicians must thoughtfully approach their work with the unique needs of traditionally excluded populations in mind and the understanding that there are systems in place to reinforce structural and repressive racism (42). The following case examples demonstrate applications of HCD principles to designing, developing and implementing DMH work that takes into account the diverse needs of marginalized and traditionally excluded populations.

Centering Black Men's Mental Health Needs Using Mixed Methods and Digital Tools

Noticeably absent from DMH literature is quantitative and qualitative evidence describing HCD application and principles to mental health work focused on young, Black men. Young, Black men, especially those in college, continue to be at heightened risk of experiencing mental health symptoms; however, their utilization of traditional mental health services remains low (43, 44). Disparities in mental health services utilization among minoritized populations is well-documented in the literature (45, 46), showing that Black men overwhelmingly lack adequate access to quality care. Further, men's underutilization of mental health care is not indicative of men's unwillingness to use resources but rather due to social factors and attitudinal barriers, including masculine ideology (47, 48), medical mistrust (49), and mental illness stigma (50). Creditable research has been conducted to examine and address treatment and access disparities among minoritized populations (51, 52); however, existing interventions, though successful, lack contextual and cultural relevance appropriate for attenuating the social and attitudinal barriers influencing Black men's low engagement with mental health support and the factors that stifle their uptake of digital mental health tools. Subsequently, the HCD evidence base for promoting positive mental health outcomes and equitable design work among and with this underserved population is limited.

An HCD lens is being applied to a line of research focused on reducing mental health risk among Black undergraduate and graduate men, as well as designing DMH and social media tools that promote help-seeking. The subsequent goal of this work would be to implement and test a social media-based intervention for Black men who may or may not be experiencing anxiety and depressive symptoms and wish to seek help for such concerns. Recognizing that Black men in college are traditionally and significantly underrepresented in prevention and intervention work, a mixed-methods approach was used to quantitatively elucidate factors pervasive in increasing anxiety and depression risk among Black male students and qualitatively contextualize this risk and their willingness to engage in traditional, formal health services. Over 50% of a Black male student population experienced one or more anxiety symptoms and more than 80% experienced one or more depressive symptoms; yet their utilization of traditional, in-person, counseling services remained low compared to their male counterparts (53, 54). This data provides further evidence that Black men in college are less likely to utilize formal services and underscores the importance of examining the future utility of Non-traditional avenues in mental health promotion and prevention.

Globally, more than four billion people use social media (55) and more than 95% of young people own a smartphone (56). Further, digital tools, specifically social media, are increasingly being used, especially among Black men (57–60). A 2-fold study that quantitatively assesses Black college men's social media use and qualitatively explores how social media and mobile based apps can support their mental health needs is underway. Findings from these methods will highlight key aspects associated with social media platform preferences and stress relief practices will be determined. Additionally, these studies will provide critical context for informing the development of content and themes for social media messages to promote mental health among Black men. Development of these messages will be completed using methods such as co-design workshops and usability testing sessions, which are often highlighted in HCD work as formative processes necessary in informing the design of digital tools and products that appropriately center the needs and preferences of potential users (61). The inclusion of these methods requires collaboration with Black men in college in determining mental health needs and ensuring that messages are relevant, relatable, and acceptable for men's mental health-related, help-seeking needs.

The use of multi-method approaches establishes a unique opportunity for Black men to partner with researchers to iteratively design messages that accurately address the social and attitudinal barriers most prevalent in impacting their engagement with DMH interventions. Their input provides insight and evidence into creating digital components that promote the inclusion of contextually and culturally relevant content into interventions, increasing potential users' long-term use, engagement, and accessibility (62). This application of HCD will reflect the mental health experiences of Black men and allows us to incorporate design elements and features into design that are not only relevant to Black men but will also promote tailoring and adaptation of tools for Black men and other underserved populations. This consideration is a step toward creating useful and sustainable, digital-based, mental health interventions and technologies that are empowering and equitable (63).

Medication Taking Intervention for Diverse Adolescents and Young Adults With Cancer

Principles of HCD are being applied to develop a personalized mobile intervention for medication taking among diverse adolescents and young adults (AYA) with cancer. AYA with cancer are considered a medically underserved age cohort who experience disparities in access to developmentally-oriented cancer care (64) and experience more challenges with taking cancer-related medications than their younger counterparts (65). In addition to age, youth who identify as Black or Hispanic have demonstrated more challenges with an oral chemotherapy called 6-mercaptopurine [6-MP; (66, 67)], which is a daily medication prescribed for ∼18 months to prevent an acute lymphoblastic leukemia relapse. Racial disparities with medication taking do not reflect biological differences in abilities to manage a complex disease such as cancer, they are a proxy for structural racism and other specific forms of oppression within and outside of the health system (68).

Still, adherence-promotion interventions for AYA with cancer are lacking, and those that are available have not elevated their needs and preferences. For example, one intervention involved text messaging to prompt caregivers to supervise youth as they took 6-MP (69). While this approach had promising results for adolescents within a research context, not including AYA or their caregivers in the design process may result in limited real-world effectiveness. Supervised medication taking may undermine AYA autonomy and lead to disengagement, or have feasibility challenges for families who cannot observe medication administration due to competing work and childcare demands–the latter may be especially true for families who experience economic marginalization. Indeed, many practices derived from research have fundamental design problems that limit their effectiveness. Adopting a strengths-based view of adolescence that recognizes how youth can be transformative in the intervention design process and with their own health is consistent with anti-racist scholarship on adolescence (70).

We are developing an app to help AYA take 6-MP through personalized and daily adherence support (i.e., a just-in-time adaptive intervention). Combining principles of HCD and anti-racist practices, we have approached intervention development with the following guiding principles: 1) systemic racism and other forms of oppression influence treatment behaviors and oncology care, and can influence (implicitly or explicitly) researcher and participant perceptions; 2) AYA are the experts on their own experiences; 3) AYA are capable of engaging in the research process as collaborators (not only participants) when our research team is successful in making the research process inclusive; 4) AYA experiences with medications are not monolithic or "one-size-fits-all"; and 5) design is not a linear process and requires iterative cycles. Within this work, researchers deeply reflect on positionality and practice reflexivity in recognizing how their social positions can influence the research (including the inherent power dynamic that exists between the researcher and the participant). For example, researchers maintain ongoing vigilance for the urge to speak for participants.

The British Design Council's Double Diamond Framework has guided our HCD methodological approach (71). This process involves a combination of divergent (deep exploration about an issue and ideation of possible solutions) and convergent thinking (consolidating insights to solidify the type of solution and its design) across four iterative steps–discover, define, develop, and deliver. Fundamental to the discovery stage is a good understanding of AYA with cancer and their needs for an intervention. Toward this goal, we employed mixed-methods (e.g., qualitative interviews with AYA and their caregivers and oncology providers; quantitative surveys; ecological momentary assessment; collaborative brainstorming sessions) to understand current medication taking patterns, practices, needs and preferences for intervention, and contextual determinants (72, 73). Synthesis of these formative studies led us to define our solution as a personalized DMH.

Now, we are in the process of co-developing the intervention (e.g., app design features, message content, engagement strategies, how to link the app to other individuals and systems that impact adherence) with AYA. We formed a research advisory panel of AYA with a history of cancer where advisors serve as paid research consultants to ideate intervention content with the research team. Four advisors, either self-nominated or nominated by a member of their oncology team, were trained using Family, Youth, and Research Education (FYREworks), an interactive, web-based training that prepares youth to collaborate with researchers. We will engage with the advisors throughout the iterative intervention development process, most recently with a focus group that applied a "Blue Sky Thinking" design strategy to generate creative solutions for medication taking without imposed limits. In this activity, advisors were presented with two AYA patient stories or personas, and shared ideas for improving each patient's medication adherence. For example, advisors recommended linking medication-taking to an AYA's personal passions and goals to motivate adherence, as preventing a cancer relapse seemed too distal and focused on the AYA as a patient rather than a person. AYA end users have also developed intervention content, such as self-creating TikTok videos designed to promote adherence.

We believe that partnering with AYA in the design process in this manner is an important first step toward creating an inclusive and engaging tool for medication taking. However, an app will not completely address systemic barriers to adherence [e.g., prohibitive costs of care, patient caution about the prescription due to historical medical abuse of Black populations; (74)], nor is this intervention focused exclusively on youth who have experienced racism and other specific forms of oppression.

FUTURE OUTLOOK AND RECOMMENDATIONS

Invest in the Career Achievement and Advancement of Marginalized HCD Researchers

To ensure that HCD practices are conducted by and with diverse research teams and principal investigators, the recruitment, retainment, and promotion of researchers with marginalized identities must be an institutional priority. To achieve this goal, investing in marginalized youth cannot start early enough. Examples of such investment is the Rush Education and Career Hub (REACH), whose mission is to provide STEM training and exposure to underrepresented youth to support their academic and professional potentials from "cradle to career" (75), and the Minority White Coat Foundation, which provides mentorship, training, and support to increase the number of minorities in healthcare positions, including behavioral healthcare positions (76). Models developed by groups such as REACH and the Minority White Coat Foundation may be expanded to other institutions and supported by established researchers (e.g., provide mentoring, share data and experiences) and funding sources (e.g., funding opportunities to support HCD methodology training, mentorship, opportunities for student-led research initiatives). To extend pathway programs beyond the start of the career, the promotion of diversity, equity, and inclusion (DEI) efforts must not be placed at the feet of established researchers with marginalized identities. Indeed, such work is often uncompensated and interferes with the advancement of their own work (77). Rather, institutions should require annual mandatory curricula on anti-racism and inclusive research practices. Annual budgets for this education must also include compensation for time and effort of presenters. Finally, institutions should focus on promoting the work of HCD researchers with marginalized identities and encourage their work as compensated consultants. Due to a lack of exposure to HCD training, behavioral health specialists will often require external consultation to implement HCD methodologies into their own work. Creating pathways within institutions for HCD researchers to offer compensated consultations to behavioral health collaborators will: 1) promote the broader use of inclusive HCD methodologies for behavioral health intervention development; 2) appropriately compensate HCD researchers for their time and expertise; and 3) increase the likelihood of representation of experts with marginalized identities to behavioral health trainees and early career professionals.

Create and Recognize Active Role of Community Voices in HCD

The use of HCD methodologies must invest in creating active and compensated roles for community members in intervention design. Indeed, community members must not be viewed as "participants" but as part of the HCD research team itself. A key factor in this approach would be the practice of reflexivity and acknowledging the power imbalances that exist between and among all parties involved throughout the research process (78). Additionally, teams should collaborate with community partners and organizations to identify appropriate and preferred compensation (amount, type), venues through which to be engaged, and ways the research and its findings can invest back into the lives of community members (36, 79). Community partners should also be formally acknowledged (e.g., authorship) and welcomed to opportunities for dissemination (e.g., co-presenting at conference symposia).

Increase Funding Opportunities for HCD Research, Training, and Resources

Funding partners are needed to facilitate open access to HCD methodologies and promote their use. Federal and Non-federal funding mechanisms may provide opportunities to support this work, invest in the advancement of marginalized researchers, and promote service design aimed at systems-level changes in behavioral healthcare. Review boards are often siloed within their subspecialties and do not include experts in HCD methodologies, nor do they include individuals representative of the communities with whom the projects are intended to reach. We propose that bodies charged with disseminating funding for behavioral health research seek partnerships outside the behavioral health care field, including experts in HCD and community partners as discussed above. Additionally, funding bodies may consider HCD as a core component of any effort to increase health equity, thereby requiring researchers to include aspects of the HCD framework in their proposed work. For those specifically engaged in health disparities work, such requirements will serve to prevent the already documented phenomenon of white researchers without adequate training or understanding of these disparities capitalizing on funding opportunities without including their colleagues and community members of color (80).

To increase the use of HCD, training in this methodology needs to be accessible as well. Although experts in digital health may be familiar with user-centered design, it is imperative that they consider the more inclusive HCD framework discussed in this commentary. Though some clinical researchers are embracing HCD [e.g., (27)], most have not received formal training in HCD nor have natural pathways to form partnerships with human computer interaction researchers and human factors engineers. Providing access to training and creating a visible network of diverse scholars engaged in HCD, especially within the DMH space, will be key for the continued training of our mental health research workforce and ongoing promotion of inclusivity in our research efforts.

Apply HCD Practices to Address Structural Racism in Behavioral Healthcare

HCD practices of specifying the context of use may be harnessed to explicitly explore, identify, and address the role and impact of structural racism in behavioral healthcare through targeted and measurable means. First, interdisciplinary collaborations are needed and appropriate for determining, examining, and addressing the fundamental factors that impact underlying disparities and inequities which reinforce population health outcomes as well as policy. Second, while a primary focus of this commentary has been on employing HCD practices to co-develop DMH with community members, HCD can also be applied by clinicians and within clinics to develop: (1) DMH service protocols (i.e., how it is delivered in clinical care); and (2) implementation plans [e.g., training providers in cultural humility to recognize the limitations of DMHs and make adaptations; (81, 82)]. Indeed, clinicians and clinics may benefit from the structure of HCD methodologies as they develop service protocols, as integrating new interventions into practice poses challenges–especially for digital interventions, which differ from traditional in-person delivery. The inclusion of implementation plans in the use of HCD methodologies is also likely key, as research-based trials demonstrate poor uptake and engagement in real-world settings and there are few examples of successful digital intervention integration in existing care settings (83). Further, without designing for implementation, clinics run the risk of reinforcing inequities (e.g., bias in how tools are distributed) that DMH are purported to address [e.g., increasing access; (82)].

It is of note that while we propose that HCD methodologies may be used with intention to design DMH and broader behavioral and mental health interventions, these efforts cannot address inequities and racism alone. Systems-level changes are desperately needed, from a larger and more diverse workforce of behavioral health professionals to health care coverage for mental health services.

CONCLUSIONS

It is necessary to incorporate HCD methodologies into DMH work to achieve mental and behavioral health equity. However, changes in the practice of engaging in HCD methodologies are merely the start of changes needed to promote equity, cultural inclusiveness, and anti-racism. Steps detailed in this commentary are most certainly not exhaustive of what should and could happen moving forward. We recognize that there are critiques of HCD methods for the promotion of equity and inclusiveness and we believe that ongoing research and initiatives that we describe will lead to the growth of HCD methods for addressing the complex problem of improving mental and behavioral health equity. Advances in HCD methodology will be needed to address these problems, but HCD is an approach that can be used to improve equity in the development of DMH and broader forms of behavioral interventions.

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

CS-S: conceptualized the commentary. All authors contributed to the drafting of the manuscript and approved the final version. All authors contributed to the article and approved the submitted version.

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An Ecodevelopmental Framework for Engaging Diverse Youth in Foster Care and Their Families Into Technology-Based Family Intervention Research Trials

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Family-based interventions delivered via telehealth are a promising mode for overcoming barriers to behavioral health treatment among youth in foster care and their families. There is a dearth of research, however, regarding effectiveness of these interventions for youth in foster care, who commonly exhibit complex behavioral health treatment needs. Clinical research in this area directly relates to equity in service access and quality for these youth and families, with numerous barriers and enabling factors to consider in order to improve engagement in clinical trials and bolster the evidence base. We present a framework to better understand the multi-systemic factors impacting youth and family engagement in clinical research on family-based telehealth interventions, drawing on relevant theory, including the bioecological model and ecodevelopmental theory. We also draw on our experiences conducting technology-based clinical research through the Family Telehealth Project, an evaluation of a brief family-based affect management intervention designed specifically for youth in foster care and their families, as a case example. Recommendations for promoting engagement in clinical research on family-based telehealth interventions with diverse youth in foster care and their families are provided.

Keywords: child welfare, clinical trial, foster care, social environment (MeSH), telehealth, patient engagement

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INTRODUCTION

The Child Welfare System in the United States [sometimes referred to as the Family Regulation System (1)] is charged with investigating reports of abuse or neglect and intervening to protect children, as needed; interventions may include mandating family-based services and placing children into foster care. In 2020, 407,493 youth ages 0 to 20 years were removed from their family and placed into foster care (2). Indigenous and Black youth are at highest risk of foster care placement before age 18 (3); these inequities are driven by systemic factors (i.e., structural racism), not the commonly noted spurious "risk factor" of race (4). Youth in foster care commonly exhibit significant behavioral health treatment needs, including histories of complex trauma, mental health symptoms, and substance use. Family-based interventions are a gold-standard for youth in foster care, having demonstrated efficacy in improving mental health, substance use, educational, and delinquency outcomes (5, 6). However, geographical distance between youth in foster care and their families of origin can impede participation in family-based interventions, both in clinical practice and research trials (7, 8).

Telehealth is one promising mode for overcoming barriers (e.g., transportation) to accessing family-based treatment with youth in foster care (9, 10), however, further research regarding the effectiveness of family-based interventions delivered via telehealth is needed. Most research on telehealth service delivery has been with individual behavioral health interventions and less complex clinical presentations than commonly found among youth in foster care (11, 12). Youth in foster care are also disproportionately impacted by the digital divide, with restricted access to technology compared to their peers (13–15), which can be a barrier to participation in technology-based interventions and clinical research. As such, to maximize engagement (e.g., enrollment, retention) in clinical research on family-based telehealth interventions with youth in foster care and their families, it is crucial to attend to barriers and enabling factors specific to both system involvement and technology.

Toward this aim, we present a framework for conceptualizing factors impacting engagement in research evaluating family-based telehealth interventions while youth are in foster care (see **Figure 1**). The authors draw on the bioecological model (16) and ecodevelopmental theory (17), as well as experiences conducting technology-based clinical research with youth in foster care and their families through the Family Telehealth Project. We offer concrete suggestions for overcoming barriers and promoting enabling factors to engagement in order to advance the field of digital health equity research with underserved youth and families.

AN ECODEVELOPMENTAL FRAMEWORK FOR UNDERSTANDING AND ENHANCING ENGAGEMENT IN CLINICAL RESEARCH ON FAMILY-BASED TELEHEALTH INTERVENTIONS

Ecodevelopmental Theory (17) extends Bronfenbrenner's bioecological model of human development (16) (i.e., micro-, meso-, exo-, macro-, and chrono-system influences on development and behavior) by accounting for the role of different contexts and developmental processes. Ecodevelopmental theory is particularly relevant to understanding engagement in clinical research on family-based interventions while youth are in foster care since such system involvement occurs during key developmental periods, from childbirth through adolescence. In addition to genetic and hormonal influences *in utero* from biological parents which directly influence early childhood development (e.g., attachment, temperament), the family microsystem has a fundamental influence on youth behavior due to prolonged and frequent interactions with family members. The family microsystem also reciprocally influences peer and romantic partner microsystems, institutional systems at the meso-system level (e.g., schools), and youth-family interactions reciprocally interact within proximal contexts (e.g., peer, community, cultural).

Factors affecting engagement (e.g., barriers and enabling factors) of youth in foster care and their families in clinical research should not be understood as uniform or static but rather as dynamic and contextual (see **Figure 1**). At the individual level, youth in foster care experience elevated behavioral health treatment needs, often due to sequelae of complex trauma. They also have complex micro-systems (i.e., direct interpersonal influences) consisting of not only family, friends, and partners, but also kinship or foster caregivers, child welfare workers, case managers, family law attorneys, school staff, and behavioral health clinicians, among others. The microsystem includes both physical and virtual (18) relationships; the physical microsystem consists of activities, social roles, and interpersonal relations in face-to-face (in-person) settings, whereas the virtual microsystem involves these same features on a digital platform. Individuals within the microsystem have the most direct and frequent contact with youth; researchers must therefore sustain collaborative relationships, build rapport, and maintain consistent communication with multiple persons to facilitate engagement in clinical intervention research for this specific population.

The meso-system involves interactive influences between various micro-systems (17) (e.g., parent/caregiver of origin and child welfare staff, family law attorneys and behavioral health clinicians, foster family and service delivery systems). To promote engagement at the meso-system level, researchers must assess the strength of existing relationships and encourage collaboration between individuals and systems that may not interact regularly or effectively with one another, such as child welfare workers and caregivers of origin (19).

Exo-systemic factors (i.e., indirect, interactive influences) (17) directly influence successful clinical research, including management of youth's, caregivers', and/or clinicians' schedules when coordinating family-based intervention sessions, clinician burnout, clinician and research staff turn-over, and research and legal regulatory requirements specific to this population. Specific to telehealth intervention trials, access to technology and privacy for participation in sessions and assessments may be impacted by youth's placement (e.g., youth in group homes may be sharing devices or have rules around unsupervised use of devices needed for session participation). Further, families face multiple pressures from the child welfare system to comply with mandated reunification plans, increasing the risk of coercion to participate in clinical intervention research. Families may perceive clinical intervention research participation to be required or believe participation will look favorable to the child welfare system. Although researchers have limited control/influence on exo-systemic factors and their effects on youth and families, researchers must be responsive to them to maximize youth and family engagement, particularly when it comes to perceived coercion to participate in research.

At the broader macro-systemic level, shifting societal factors that increase the likelihood of child welfare involvement should be considered to conduct prevention and intervention research more successfully. Researchers must be aware of, and responsive

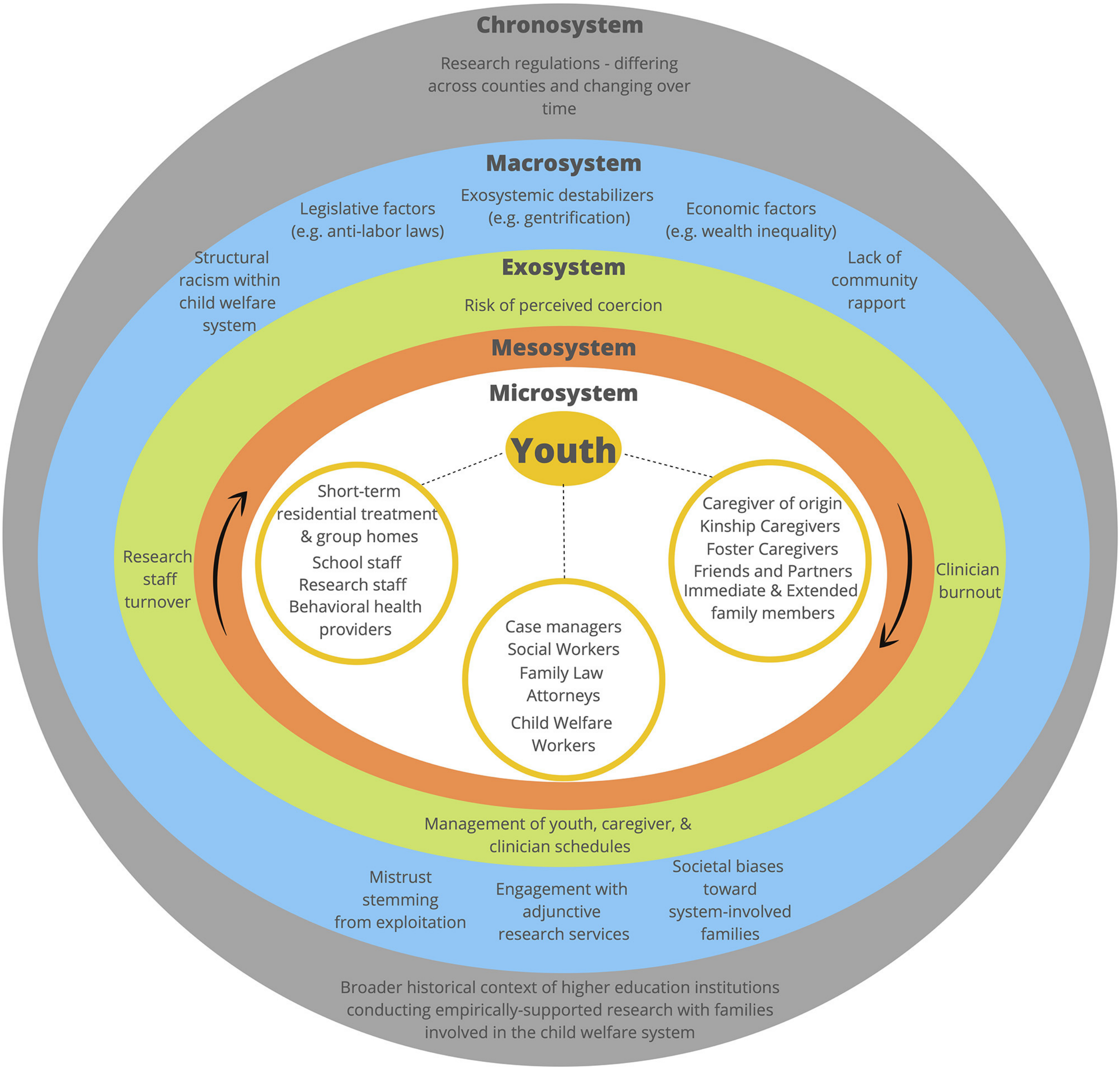

FIGURE 1 | An ecodevelopmental framework for understanding and enhancing engagement in clinical research on family-based telehealth interventions.

to, contributors to disproportionate system involvement of ethnoracial minoritized groups (3), including discrimination, structural oppression [e.g., increasingly expansive surveillance and net-widening (20), historical and ongoing effects of structural racism (4, 21)], as well as legislative and economic factors [e.g., family income, county-level poverty, and county-level income inequality (22, 23)] that contribute to child welfare system involvement, as they change over time. Macro-level factors affecting willingness to participate in clinical research may include a lack of trust toward the child welfare and affiliated healthcare systems (24–26) stemming from exploitative practices, systemic racism, and societal stereotypes and biases held toward marginalized youth impacted by the child welfare system and their families (27). Further, many youth are also dually involved in the juvenile delinquency and dependency court systems, which can result in "falling through the cracks" in timely access to needed care given challenges to information-sharing and cross-system collaboration (28); Black and Latinx youth in the child welfare system are at particularly high risk of entering the juvenile justice system (29). Specific to telehealth interventions, factors such as changes in access to technology (e.g., increasing internet access in rural areas) and wide-scale delivery of telehealth interventions which may influence their acceptability (e.g., during the COVID-19 pandemic with restrictions to in-person behavioral health services) may impact engagement in research (30). Understanding the effects of such macro-level factors can help researchers develop intervention content informed by various social, political, and cultural influences on a youth's development before and while they are enrolled in clinical research, which may facilitate engagement.

The chrono-level (i.e., temporal influences) accounts for changes that occur within and between systems at the micro-, meso-, exo- and macro-systemic levels over time (17). Interactions between multiple systems and their effects on youth and families impacted by the child welfare system are dynamic, especially those influenced by temporal changes within the family microsystem (e.g., socioeconomic mobility) and societal influences at the macro-systemic level (e.g., shifting political climate, funding priorities for services and research). Based on our own experiences, bureaucratic delays and evolving requirements when obtaining required approvals to conduct research with youth and families involved in the dependency and delinquency courts, historical contexts between research institutions and the specific populations they serve, and inequities within the higher educational system, all contribute to temporal changes impacting clinical research. Researchers must continuously identify and address gaps in the implementation of evidence-based practice, recognize how our institutions contribute to challenges engaging families impacted by the child welfare system into research and expand clinical intervention research to historically underrepresented populations.

THE FAMILY TELEHEALTH PROJECT

The authors draw on experiences conducting research through the Family Telehealth Project, which aims to improve behavioral health outcomes and reduce housing instability among youth in foster care (ages 12–18 years) through a family-based affect management intervention. Phase 1 involved the iterative adaptation of an empirically supported in-person family-based affect management intervention (31) for telehealth delivery and to meet the unique needs of adolescents impacted by the child welfare system and their caregivers of origin. The family-based affect management intervention being adapted was developed using the Social-Personal Framework (32), which recognizes adolescence is a period of significant emotional, cognitive, and physical changes. The Social-Personal Framework considers the interplay between individual, social, and environmental influences on adolescent risk, including individual factors, family context, and peer/partner influences. It has shown particular utility for understanding risk among adolescents in clinical settings and on probation (33, 34). The intervention includes an engagement session using motivational interviewing principles, four core modules, and a booster session (approximately 11 h of intervention time total). Core session content includes affect management, parental monitoring, and communication skills. Two clinicians work with each family to meet individually with the youth and the caregiver and then co-lead the family session. Family sessions allow for shared skill-building, practice, and discussion. Adaptation was conducted iteratively in collaboration with key stakeholders (youth, caregivers, child welfare supervisors, probation officers, judges, attorneys, school wellness staff) and through an open trial of the intervention. A caregiver-only version of the intervention is also available, covering the same core content and structure, when youth are unable to or not interested in participating. Phase 2 of the study involves an ongoing clinical trial to evaluate the effectiveness of the intervention.

STRATEGIES FOR IMPROVING ENGAGEMENT OF YOUTH IN FOSTER CARE AND THEIR FAMILIES IN CLINICAL RESEARCH

Researchers must actively consider the dynamic, multiple levels of influence on youth in foster care and their families when conducting clinical research on family-based telehealth interventions. This includes exploration of structural vulnerabilities and social determinants of health for minoritized youth impacted by the child welfare system. Using a justice, equity, diversity and inclusion framework can enable real-word exploration of structural vulnerabilities for minoritized youth impacted by the child welfare system and facilitate the development of strategies on how to disrupt these vulnerabilities; such strategies include examination of social determinants of health and the integration of community based participatory research. We propose key recommendations addressing each system level, that we hope will disrupt these vulnerabilities (see **Table 1**). These proposed strategies are not exhaustive and focus on considerations unique to youth in foster care and their families; we do not include standard best practices for clinical research applicable to general populations, though these certainly still apply. We highlight select recommendations using the Family Telehealth Project as a case example.

Interdisciplinary collaboration with key stakeholders working with youth and families impacted by the child welfare system is critical, starting from the preparation stage. In the Family Telehealth Project, we regularly consulted stakeholders from the child welfare, behavioral health, and legal (e.g., attorneys, family court judges) systems on research procedures (e.g., referral sources) and intervention content adaptation. Stakeholder input was gathered through formal data collection (i.e., focus groups) and informal meetings. For example, stakeholders reviewed all intervention session scripts in detail with the study team during monthly meetings in Phase 1 of the project. Stakeholders provided feedback on relevance of session content (e.g., maintain emphasis on substance use and sexual and reproductive health, addition of psychoeducational content on the impact of trauma and topics like dating violence) and suggested considerations for delivering content while youth are separated from their caregivers (e.g., how caregivers can engage in parental monitoring from a distance and within the context of supervised contact). Stakeholders also informed modification of activities

TABLE 1 | Select recommendations for conducting clinical research on family-based telehealth interventions with youth in foster care and their families.

Research Phase	Specific issue for consideration	Relevant systems and recommendations
Preparation	**Community partnerships:** • Stakeholders (e.g., child welfare, behavioral health, attorneys) have vested interest and involvement in improving outcomes for system-impacted youth and families. • Sustainable community partnerships are integral to successful clinical intervention research.	**Mesosystem:** • Identify key stakeholders from existing university partnerships, federal, state-wide, and local databases, and the youth and families directly. • Incorporate stakeholders as key collaborators in all stages of the research process, ideally from the generation of an unmet clinical need through data analysis and dissemination of findings. • Ensure relevant stakeholders understand the overall goals of the intervention, referral process, and how systems considerations (e.g., family reunification plans, supervision of contact) are being addressed. • Identify ways to promote intervention sustainability after research funding ends. • Incorporate youth, family, and other relevant stakeholder perspectives into iterative adaptation and design of interventions to ensure the approach meets local needs, is acceptable, and is feasible to implement. • When permissible, equitably compensate stakeholders for their time contributing to the research process. When stakeholders cannot accept financial compensation, provide refreshments as a gesture of gratitude for donating their time and expertise.
	Regulatory approvals: • Some counties require court petitions and/or county behavioral health approval, in addition to university IRB approval.	**Macrosystem:** • Spend ample time before study begins researching county-specific requirements for conducting clinical intervention research with system-impacted youth. • If recruiting from multiple counties, create a tracking log of all the counties of interest for recruiting families and their requirements ahead of time. • Ensure university IRB approval is obtained with sufficient time to submit alongside the required court petitions (e.g., several months in advance). • For counties requiring attorney approval to approach youth for informed consent, create attorney consent forms, a visual guide to explain study procedures, and a spreadsheet to track attorney contact information. • Initiate a conversation with each county about the "rights" to all data collected. A research team may need to draft a memorandum of understanding (MOU) or exemption form based on the county's expectations and unique history of data use in research.
	Study clinicians: • For brief interventions, partnering with community-based clinicians to deliver study interventions can reduce the number of external providers involved in a youth's care, promote long-term sustainability of the intervention, and increase likelihood stakeholders will make study referrals. • Community-based clinicians have varying experience with manualized interventions and maintaining fidelity in clinical research trials, and numerous competing demands from their primary professional role.	**Exosystem:** • Create detailed workflows outlining research protocols relevant to clinicians (e.g., checklist of steps to prepare for a session); record training to facilitate onboarding of new clinicians and allow access to refresher material. • Provide training in flexible delivery of manualized interventions, including balancing of flexibility and fidelity in approach, and any empirically supported approaches necessary to deliver them (e.g., motivational interviewing). • Provide training in use of technology for intervention delivery and ensure clinicians' feel comfortable using any special features (e.g., screen sharing). **Macrosystem:** • Partner with supervisors to support community-based clinicians in incorporating the intervention into their standard care, including outside the research trial if there is already evidence to support the intervention's effectiveness. • Identify whether and how interventions can be billed as part of clinical services when delivered by community-based clinicians to promote long-term use.
Consent, Engagement, and Retention	**Caregiver Consent:** • Caregiver consent for youth to participate in research is often required, however caregivers in system-impacted families may have had their parental rights terminated. • Caregivers may believe participation in clinical research will impact their ongoing dependency case.	**Microsystem:** • During initial eligibility screening, ask caregivers if their parental rights have been terminated for the referred youth. If so, identify legal signing guardian (e.g., supervising social worker, family court presiding judge) prior to consent appointment. • Ensure consent process and recruitment materials make clear that participation in the clinical research trial will not impact their ongoing dependency case or decisions about reunification plan. **Exosystem:** • When appropriate, obtain a waiver of parental consent from the university IRB so youth can consent to research without caregiver consent (i.e., youth 12 years+)

(Continued)

TABLE 1 | Continued

Research Phase	Specific issue for consideration	Relevant systems and recommendations
	Coordination with out-of-home placements: • Youth in foster care are separated from their caregiver and may be without access to a personal form of communication. • Out-of-home placements have varying restrictions on technology use, including for therapeutic purposes with outside clinicians.	**Mesosystem:** • Coordinate research and intervention appointments with the caregiver and the youth's placement (e.g., group home, short-term residential treatment program) to ensure youth (and caregiver, when relevant) are present. Coordination with social workers and attorneys may also be necessary for screening and consent appointments. • Communicate with out-of-home placements to coordinate availability of a private space and necessary technology prior to the first appointment and send appointment reminders.
	Clinical Intervention Accessibility: • System-impacted youth and families have diverse linguistic, cultural, and accessibility needs. • System-impacted youth and families are often separated, preventing access to family-based interventions.	**Microsystem:** • Conduct pre-intervention session with participants focused on enhancing engagement using motivational interviewing principles and troubleshooting possible barriers to session attendance and participation. • Collect data on cultural relevance/acceptability of intervention and adapt iteratively if indicated. **Exosystem:** • Hire enthnoculturally diverse and bilingual/multilingual staff and clinicians. • Budget for translation and/or interpretation services in grants. **Macrosystem:** • Ensure accessibility of intervention materials to youth and families with: • Varying visual and auditory abilities (e.g., verbal discussion of intervention materials, enable auto- and/or live closed captioning during telehealth sessions). • Different linguistic (e.g., Spanish, Arabic, Hmong) and/or cultural (e.g., Latinx) backgrounds.
	Technology Accessibility: • Youth in foster care are disproportionately impacted by the digital divide and may not have access to necessary technology to participate in sessions. • Technology literacy can vary for both youth and caregivers.	**Microsystem:** • Develop a standardized set of questions to assess technology access (e.g., what devices youth and family have available, Wi-Fi access and stability of connection) and privacy considerations prior to beginning clinical intervention sessions; consider providing devices and funds for data plan costs to promote participation, as well as headphones to promote privacy. • Provide instructional resources on how to use technology platforms, in both written and visual (e.g., video) formats and in multiple languages; provide personal tutorials to families, as needed. **Macrosystem:** • Ensure handouts and videos are viewable on small screens (e.g., phone) so large device access is not required to participate.
Intervention	**Clinical Intervention Relevance:** • Youth in foster care experience elevated behavioral health needs (e.g., mental health, substance use), often resulting from complex trauma. • Placement out-of-home disrupts familial relationships, which may have already been strained.	**Individual:** • Ensure content is trauma-responsive (e.g., providing psychoeducation about the impact of trauma on development). • Focus skill-building on transdiagnostic areas such as emotion regulation; teach skills to both you and caregivers. **Microsystem:** • Address maintenance of family connections (when appropriate) within imposed limitations by child welfare system; incorporate communication skill building to improve family relationships.

to telehealth, noting considerations around length of sessions based on their experiences with youth over telehealth. Youth and caregivers also provided feedback on intervention content through qualitative interviews and session feedback forms during Phase 1; youth and caregivers provided invaluable insights into the utility of skills taught during sessions and overall acceptability of the intervention.

Regulatory approvals are complex when conducting research with system-impacted youth and families. In addition to approval by the institutional review board, many counties require court orders and county mental health approval to recruit youth and their caregivers into clinical intervention studies. In our experience, instructions for obtaining necessary approvals are often not clearly documented and it can require significant time and resources to determine requirements and navigate the approval process. In the Family Telehealth Project, we obtained approval to recruit for our clinical research study in five California counties; three required court orders, four required county mental health approval, and one had no formal requirements for research. We were unable to obtain approval in three additional counties due to lack of resources in the court to review and approve research proposals or requirements that the county own the data collected (rather than the researcher). Each county's approval process was unique and, in some cases, required research staff to draft court orders themselves, a skill not commonly required of research assistants in academic medicine. Each county also had unique requirements for conducting the research itself; for example, one required attorneys to provide consent prior to research staff contacting youth to explain the study and screen them for eligibility; unique attorney permission forms had to be created along with materials for attorneys to understand the research and permission process. This process was incredibly time and labor intensive. Researchers should therefore budget ample time before beginning a study researching county-specific requirements and obtaining necessary approvals. However, such system-level barriers require system-level solutions. Given the clear impact of clinical research on equity in services access and quality for youth in foster care and their families, counties should prioritize developing clear and standardized processes to support researchers dedicated to improving the health of system impacted youth and their families.

Accessibility of the intervention, both for clinicians to deliver and for youth and families to engage with, is multi-faceted. In the Family Telehealth Project, we trained clinicians at a community-based agency and a short-term residential treatment program to deliver the intervention in collaboration with study clinicians. We did so to promote continuity of care for youth already in a therapeutic relationship, ensure sustainability of the intervention after research funding ends, and build capacity among community clinicians in delivering manualized, skills-based interventions. Creation of detailed workflows and protocols related to session delivery, as well as providing training in flexible manualized intervention delivery and use of technology was critical. Community clinicians all had to complete human subjects training and be added to the institutional review board application. Clinician turnover was a major impediment; in one agency, all of the trained clinicians left their position within a year and 85% of those trained never had/referred an eligible client. Clinicians with potentially eligible clients should be carefully selected, and trainings held as close to enrollment of a potential participant as possible to ensure retention and application of knowledge. Further, training clinical supervisors in the intervention and recording training sessions for later review, can help ensure knowledge is retained within an agency even if individual clinicians leave.

For youth and caregivers, we had to account for technology factors (e.g., phone vs. computer use), varying visual and auditory abilities, and cultural and linguistic backgrounds, in delivery of the intervention. We found tailoring sessions for accessibility on a phone most useful, as many families did not have a larger screen device (e.g., computer, tablet) for participation. For example, handouts were designed for readability on a smaller phone screen. We did not provide devices or internet access to families in our study, though these are other ways to facilitate access to necessary materials for participation. For youth in group home placements, coordination with clinical staff on-site was instrumental to ensuring youth had device access and privacy to participate. Other accessibility accommodations included use of closed captioning and audio for all videos in the intervention, available in both English and Spanish; live closed captioning on videoconferencing and the chat could also be used during intervention sessions for participants with limited hearing abilities. We also hired multilingual/bilingual and ethnoculturally diverse staff to deliver the intervention and conduct research procedures with Spanish-speaking families; further, we are currently culturally adapting the intervention for Latinx families.

DISCUSSION

The proposed framework and recommendations are intended to guide researchers committed to promoting equitable delivery of evidence-based behavioral healthcare for diverse youth in foster care and their families. Although the COVID-19 pandemic and restrictions to in-person behavioral health services highlighted the need for empirically supported interventions delivered via telehealth, behavioral healthcare via telehealth could reduce access barriers for families in non-pandemic times as well (e.g., overcoming challenges related to distance and transportation). Clinical research in this area is crucial as it directly relates to equity in services access and quality for youth in foster care and their families. It is crucial we identify ways to overcome barriers to delivery of empirically supported behavioral health treatment for youth in foster care and their families; failure to do so perpetuates service access inequities and engagement for racial/ethnic minoritized youth, who are disproportionately represented among youth in foster care (20, 35). Through cognizance of the multiple people, systems, and influences at play in a youth's life who is impacted by the child welfare system, we hope the collective research community can work to advance knowledge and implementation of empirically supported behavioral healthcare that is feasible, acceptable, and culturally relevant to reduce inequities for this highly marginalized group of youth and families.

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

All authors participated in the conceptualization of the proposed ecodevelopmental framework, writing, and editing process. All authors contributed to the article and approved the submitted version.

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Juvenile Justice, Technology and Family Separation: A Call to Prioritize Access to Family-Based Telehealth Treatment for Justice-Involved Adolescents' Mental Health and Well-Being

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Separating children from families has deleterious effects on children's mental health and well-being, which is highly relevant for youth in juvenile detention and other out-of-home residential placements. Despite growth in the evidence of family-based interventions in mitigating adverse behavioral health outcomes for justice involved adolescents (JIA), gaps remain in intervention dissemination for JIA; this particularly true for those leveraging digital health technologies, a need that has intensified with the COVID-19 pandemic. Use of digital health technologies for JIAs is pressing to address structural barriers in maintaining JIA-family connections, but also to improve treatment access for detained JIAs. Court systems' capacity to support use of digital health tools, such as telehealth, appear promising. Data on the use of tele-conferencing in U.S. juvenile and family courts were collected from 456 juvenile justice professionals as part of a larger study on judicial decision making. Results suggest overwhelming adoption of video-conferencing for court hearings with only 40% of respondents reporting family court use prior to the onset of COVID-19, but majority (91%) now reporting its routine use. Youth participate from a range of settings, including detention, other residential placement, community-based behavioral health and in-home settings. The COVID-19 pandemic has created a shift in the uptake of video-conferencing platforms that could hold promise for future larger scale use across the juvenile justice system. Findings underscore feasibility and acceptability of technology requirements in key settings that should be leveraged for broad scale implementation of empirically supported family-based interventions to advance behavioral health equity for JIA.

Keywords: behavioral health equity, juvenile detention, family separation, telehealth, structural intervention

INTRODUCTION

The medical field is clear: Separating children from their families has deleterious effects on children's mental health and well-being (1). There has been a significant reduction in the number of children detained or incarcerated in the United States (U.S.) over the past decade; however, over 48,000 youth remain placed out-of-home in confined settings due to involvement in the juvenile legal or criminal justice system (2). For example, in California, on any given day, almost 5,500 youth (<21 years old) who come into contact with the juvenile justice system are separated from their families and housed in residential placement facilities (3).

FAMILY CONTACT DURING YOUTH INCARCERATION

Sustained contact and meaningful connection with family during incarceration is essential to preventing worsening mental health and associated outcomes, such as substance use and recidivism (4–6). Maintaining family ties during a youth's incarceration can include in-person or virtual visits, phone calls, and mail, each with its own barriers and benefits. Visitation policies (e.g., frequency, eligibility of youth, requirements of visitors) vary substantially by jurisdiction and families often face significant costs (transportation, childcare, time off work, etc.) to visit facilities in person. Phone call policies also vary by jurisdiction, with some providing brief (e.g., 10 min) calls free of charge and others not including any allotment of phone calls, increasing the burden on families, particularly those at longer distances. Limited research on family contact during youth incarceration suggests racial inequities, with White youth more likely to report more frequent and multiple forms of contact with family than Black youth (7).

The concomitant effect of family separation and the trauma and stress of incarceration for adolescents who enter the system already with significant unaddressed mental health needs is gravely concerning (8). Family-based interventions are the "gold standard" for improving behavioral health (i.e., mental health and/or substance use) outcomes and reducing recidivism among justice-involved adolescents (JIA) (9) but nationally in the U.S., youth and families are not typically receiving the opportunity to access this type of "gold-standard" intervention, prior to and during the COVID-19 pandemic. Specifically, structural barriers to family visitation, such as physical distance between the facility and the family's location, caregiver financial inability to travel, take time off work, and/or caregiving demands (e.g., care of other family members, such as siblings) have existed for decades. These are examples of types of structural determinants that create significant barriers, disrupt family connections, and have been documented to have significant long-term consequences for JIA and their families.

Leveraging Technology to Promote Family-Based Treatment

Frameworks such as the User-Centered Design framework (10), which centers the needs and concerns of potential users during tool development and Participatory Informatics, which is derived from Community Based Participatory Research principles (11), prioritize the perspectives of those with lived experience in co-creating digital solutions. These models have been applied in various settings and can enhance the relevance and acceptability by ensuring the active involvement of target users in design phases. In line with these frameworks, Bath et al. (12) published a series of recommendations for how child and adolescent mental health professionals can and should play a pivotal role in the development and application of mobile health (mHealth) technologies to improve treatment access for JIA (12). Recommendations included, but were not limited to, the criticality of developing clinical system protocols that standardize the use of technologies for family-based interventions. Among these, the use of participatory informatics approaches to center youth and families in the development of such technologies and protocols was key to optimizing engagement. Another key recommendation was to augment workforce capacity and digital fluency by training clinicians and front-line juvenile justice system professionals in the use of mHealth technologies. Lastly, utilization of mHealth as a means to gather data to inform larger population treatment needs and reveal system level service gaps could have important policy-level and funding implications. Since those recommendations were published, the COVID-19 pandemic has intermittently halted in-person visitation in multiple juvenile detention facilities. The start of the pandemic required facilities to quickly pivot to implementing video-conferencing opportunities for brief family visitation (e.g., once per weekend) and/or attorney visitation. Yet, the use of these same video-conferencing platforms to conduct needed family-based behavioral health interventions (herein referred to as "family tele-behavioral health") appears less typical.

Telehealth expansion has been documented to support improved access to necessary behavioral health care for minoritized youth and families (13). Nationwide, the U.S. disproportionately detains Black and Latinx adolescents who have been systematically disenfranchised from access to needed behavioral health care supports in the community that could have kept them out of the justice system (14). Using existing video-conferencing tools to deliver family tele-behavioral health interventions represents a critical and time-sensitive opportunity to address an overall dearth of services, particularly while JIA are detained and separated from their families. Ideally, these services would begin during time of detention and continue from detention to community reentry/at-home placement to support best outcomes. Many of these same families are disproportionately being impacted by the COVID-19 virus, which is resulting in dramatically higher rates of severe illness and mortality among ethnoracial minoritized communities in CA and throughout the U.S. (15). The confluence of adversities potentiated by the pandemic, both economic and health, increase the risk for trauma and chronic stress, particularly for those JIA who experience the negative impact of incarceration and separation from their families and communities.

Key Structural Considerations for Implementation of Family-Based Intervention

Based on the above, it is imperative we capitalize on using technology for interventions and prioritize the development of family tele-behavioral health interventions, particularly when youth are forcibly separated from their families. This includes resolving the digital divide and addressing gaps in digital literacy and mitigating barriers unique to telehealth provision; for example, ensuring families have access to technology (e.g., access to laptops, tablets, phones with sufficient data plans, having Wi-Fi access, financial supports for technology access) and addressing linguistic barriers, accessibility considerations such as auditory and visual needs, as well as literacy concerns related to written telehealth platform directions and requirements for an email address. For example, in California, the Department of Juvenile Justice (CA DJJ) has family visitation information posted online; https://www.cdcr.ca.gov/juvenile-justice/djj-video-visiting-with-microsoft-teams/. Sites already conducting family tele-visitation should leverage this success and expand to deliver needed family tele-behavioral health therapeutic interventions. Additionally, providing technology support for families to increase their digital fluency and comfort in the navigation of online platforms is key. Systems responsible for JIA oversight, at state and local levels, must also engage in high-level realignment of facility structure and schedules to operationalize incorporation of mandated access to family-based telehealth intervention for JIA. Large-scale implementation of family tele-behavioral health intervention access requires both states and local jurisdictions (e.g., cities and counties) to partner with expert organizations (e.g., grassroot) and institutions (e.g., non-profit and academic), seasoned mental health clinicians (e.g., to train and deliver empirically-supported, family-based intervention via telehealth), digital health researchers (e.g., to study and track outcomes), policy-makers (e.g., for legislative advocacy and telehealth services reimbursement) and JIA and their families with lived experience. Justice-related stakeholders and systems are also critical to involve in this process of expanding access to family tele-behavioral health care while youth are detained. Judges, probation staff and attorneys for JIA are central players in identifying the behavioral health needs of detained youth and referring to (or in some cases mandating) mental health and/or substance use intervention. Studying the current use of video tele-conferencing in the juvenile justice system and for what purposes is a key first step in identifying how to leverage established video conferencing tools and procedures for the delivery of family tele-behavioral health services for separated JIA. We present recent data collected from a US national survey of juvenile and family courts to understand more about the current use of video teleconferencing in these settings and to inform next step considerations of ways to increase access to family tele-behavioral health services.

METHODS

Procedures and Survey Content

Data on the use of tele-conferencing in juvenile and family court settings were collected from 456 juvenile justice professionals (i.e., judges, magistrates, juvenile court officers, or juvenile probation officers) as part of a larger parent study focused on judicial decision making. Staff were recruited from across the U.S. via professional listserv and department- and state-wide emails. Inclusion criteria for the parent study included currently holding a position as a judge, magistrate, juvenile court officer, or juvenile probation officer in the U.S. who has heard or worked with at least 20 juvenile delinquency cases in their tenure. Eligible participants completed an online Qualtrics survey at one time-point between December 3, 2020 and June 23, 2021. Survey questions asked professionals' demographic and jurisdictional information (e.g., location in the U.S.). Professionals were asked he use of tele-conferencing for court hearings in the family court settings prior to and during the COVID-19 pandemic. Those who endorsed family courts' tele-conferencing use were subsequently asked to identify from which locations youth and legal staff (e.g., judges, lawyers) joined tele-conferencing hearings. Descriptive analyses were conducted with this subset of survey items to understand the utilization rate and context of tele-conferencing in family court hearings. The study was approved by the institutional review board of Drexel University.

Respondent Sample

Justice professional participants identified as male (50%), female (49%), or other/prefer not to say (1%). Participants predominantly identified as non-Hispanic (95%) and White (84%) with much less representation of Black (9%), American Indian/Native Alaskan/Native Hawaiian/Pacific Islander (3%) and Asian (1%) backgrounds. The age of participants ranged from 23 to 73 with an average age of 46 years, $SD = 9.94$. The majority of participants identified as probation officers (72%) while judges and magistrates represented 16% of the participants. Participants hailed from 28 distinct states (see **Figure 1**) and classified the jurisdictions in which they work as urban (38%), suburban (27%), or rural (35%).

RESULTS

Data suggest that prior to the onset of the COVID-19 pandemic, only 40% of respondents reported family court use of tele-conferencing, but the majority (91%) now report its routine use. Respondents were asked where various parties, including youth, were located when using videoconferencing technology for family court hearings, with the option of endorsing more than one setting for each party (e.g., youth could be located in residential settings and while at a lawyer's office; see **Figure 2**). The majority (85%) of justice system staff identified that youth attend family court from detention. Most of the participants (71%) also indicated youth participate while in smaller, more home-like residential settings, followed by next largest proportion endorsing that youth participated in family court from home (65% of participants). Interestingly, one third

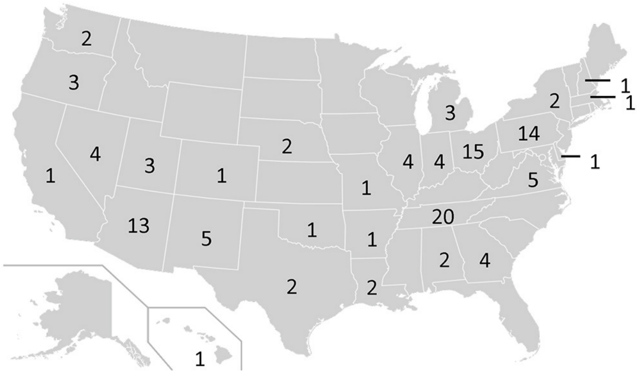

FIGURE 1 | Geographic distribution of number of survey respondents from juvenile justice systems (*N* = 456; 15 participants did not note their geographic location).

of participants (33%) indicated that youth participated in family court hearings from either a behavioral health care setting or community-based organization at the time of the remote family court hearing suggesting that these systems also have some capacity to support video tele-conferencing.

DISCUSSION

In a time of such disaster and disparity, the COVID-19 pandemic has underscored the importance of rising to the challenge to leverage video conferencing and digital technology therapeutically for JIA and their families. Survey data collected from a national sample of justice professionals across 28 states suggest significant increased use of video tele-conferencing as a successful tool for court hearings, whether the youth is in detention or home. Data also suggest approximately one-third of youth are participating in these remote court hearings from behavioral health or community-based service settings. Accordingly, it appears the basic technology logistics associated with sustained uptake of video tele-conferencing between court and juvenile detention facilities have largely been figured out; video tele-conferencing tools are available to the courts and out-of-home settings, such as juvenile detention and small, home-like residential placements, which was not true prior to 2020 and the COVID-19 pandemic. Thus, the opportunity to leverage existing technology use to expand therapeutic interventions, specifically tele-behavioral health intervention access while youth are separated from their families in detention, is promising. Next steps include determining if there are differences in what is being offered via telehealth between smaller residential homelike settings and standard detention facilities and determining specific barriers to utilization of video conferencing tools to expand access to evidence-based family interventions (and other associated family-based care navigation and supports). Our data also suggest that video tele-conferencing for court hearings is commonly occurring from within the home while the JIA is living with family. This bodes well for the opportunity to expand access to continuity of care for family tele-behavioral health intervention when the JIA has re-entered the community from detention. It also provides promise for much needed family tele-behavioral health interventions for JIA who have never been detained but need behavioral health intervention while monitored in the community (e.g., through diversion programs).

The use of video teleconferencing to provide visitation has been highlighted as an opportunity to not only close the gaps and distance between those experiencing incarceration and their loved ones, but also as a supplement to in person visits. In the adult literature, video visitation has been highlighted as a way to mitigate transportation barriers, reduce behavioral infractions, and decrease risk of recidivism post release (16). Data on the implementation of tele-behavioral health services for adults in correctional facilities is increasingly showing promise, particularly in rural areas (17). Data on detained youth are more limited, suggesting adequate acceptability and no negative outcomes associated with telehealth care (18). Future research should focus on identifying what proportion of juvenile detention facilities are using these tele-conferencing tools to deliver family tele-behavioral health services vs. family tele-visitation vs. no family-based use of video tele-conferencing. Studies should also seek to understand at the local, state and national level what the barriers to delivering such family-based therapeutic care may be (18). For example, even if the logistics and availability of video tele-conferencing and other digital health tools no longer serve as barriers, addressing workface capacity and availability of clinicians trained in evidence-based family therapeutic interventions that are tailored to the multifaceted and unique needs of JIA youth and families is key. Ethical and system-related concerns around HIPAA and other required legal protections (e.g., special protections around confidentiality) associated with providing behavioral healthcare via telehealth to detained populations that are different than standard telehealth care should be explored and addressed. Determining whether such concerns and complexities serve as a barrier to extending existing video tele-conferencing capability to provide family tele-behavioral health services will be critical to understand for successful implementation.

Our current study data are not without limitations. First, this was not a comprehensive look across all states to identify accessibility of video tele-conferencing for court hearings for youth in detention, thus generalizability may be limited and access may be specific to only certain geographical locations. In addition, this was a self-selected sample of respondents, thus professionals from states or jurisdictions who may not be using these tools for court hearings may have been more likely to decline to participate overall. We did not include a survey item that asked about prior experience in using these types of technology tools to ascertain whether those who were responding were just more comfortable or familiar with the use of technology. Queries on acceptability and ease of use were also limited, so we were unable to ascertain nuances regarding ease of uptake and an understanding of the day-to-day challenges in utilization. Lastly, survey questions did not include items that asked justice professionals about their perspective on the use of existing video-conferencing tools for anything outside of court hearings (e.g., family visitation,

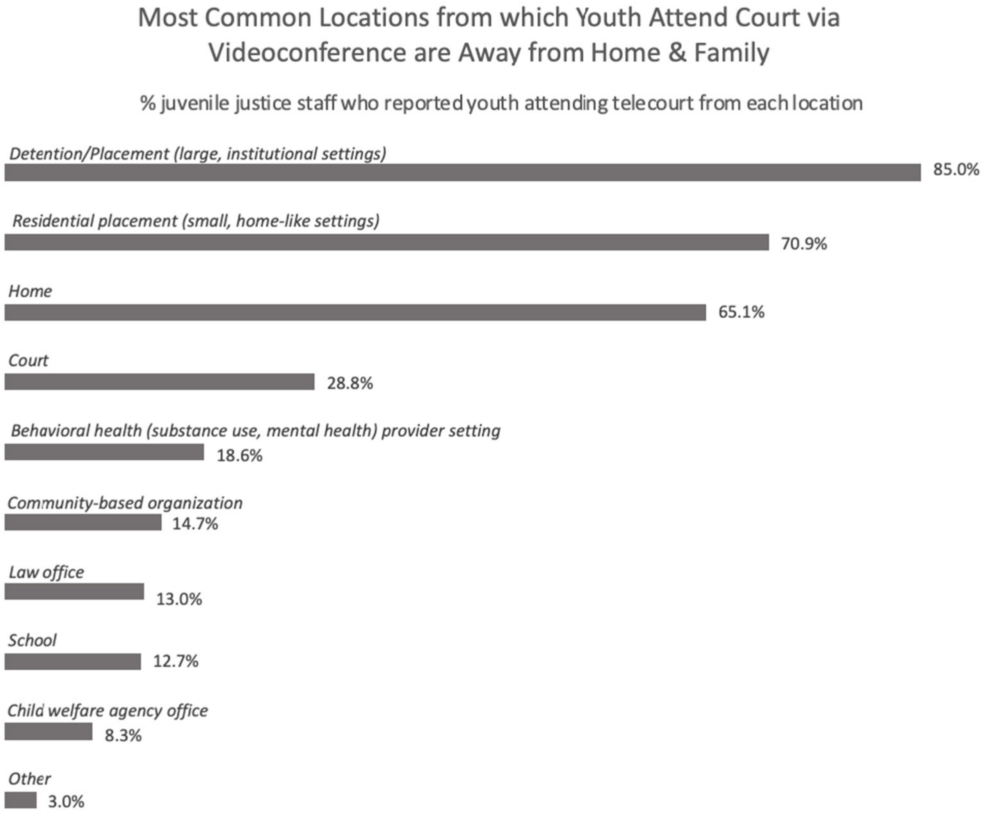

FIGURE 2 | Locations from which youth attend court hearings using video tele-conferencing.

family-based behavioral health services), which is an area for future research.

Conclusions and Recommendations

Despite the aforementioned limitations, these data provide a first-time empirical snapshot from justice professional stakeholder perspectives of the use of video-conferencing tools within the juvenile court and detention settings. These data can help the field begin to consider next steps and recommendations related to how to use these digital tools and within these particular settings to advance health equity for youth who are forced to be separated from their families due to detention and out-of-home placement. Our recommendations include a need to: (1) urgently expand family tele-visitation services to also allow for family tele-behavioral health services; (2) leverage the policies and practices that are being used successfully for tele-court hearings for tele-behavioral health interventions to promote best outcomes for youth, including upon community re-entry. Interventions that start while in detention and continue during community re-entry give opportunity for a necessary continuum of care that builds trust, enhances engagement, and promotes best youth outcomes (19, 20). Care delivered via secure video-conferencing platforms (i.e., telehealth) provides a unique opportunity to continue with the same provider "from the inside to the outside," and the field should be developing and testing outcomes associated with such interventions; (3) develop state-wide strategic plans with clear structural, fiscal and legislative aims to address juvenile justice behavioral telehealth infrastructure and implementation, and (4) make capital investments in aging infrastructure, justice staff professional development opportunities, and capacity building for community behavioral health providers to facilitate family tele-behavioral health service capacity and expansion for youth in detention.

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/s.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Drexel University Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MT-S conceptualized the manuscript topic and focus. EB contributed to the conceptualization and theoretical framework. JM provided empirical survey data, analysis, and interpretation. All authors participated in writing and editing process.

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Ethical by Design: Engaging the Community to Co-design a Digital Health Ecosystem to Improve Overdose Prevention Efforts Among Highly Vulnerable People Who Use Drugs

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Introduction: The COVID-19 pandemic highlighted significant structural barriers that exacerbated health inequities among people at-risk for overdose. Digital health technologies have the potential to overcome some of these barriers; however, development of these technologies often fails to include people who use drugs and community key stakeholders in the development and dissemination process. Consequently, this may exacerbate health inequities and the digital divide among underserved, highly vulnerable people who use drugs.

Methods: The current study employed community-engaged research methods to develop and implement a digital platform to improve overdose surveillance among harm reductionists in Texas. We used a co-design process with four community advisory boards (CABs) and conducted qualitative interviews among $N = 74$ key stakeholders ($n = 24$ people who use drugs; $n = 20$ first responders, $n = 20$ harm reductionists, $n = 10$ overdose prevention and response experts) to inform initial design and development.

Results: Several key themes emerged through the qualitative data pertaining to technical features and human factors applications. In regards to technical features, participants highlighted the importance of developing a unified system of overdose reporting and data sharing among community organizations within a county or region to better inform overdose surveillance and community outreach efforts. This system should include flexible data entry methods, have offline usage capability, be user friendly, and allow for tracking of overdose-related supply distribution. Key human factor themes included the need to use person-centered language, to preserve the established trust of the community organizations among people who use drugs, to be tailored to specific target user groups (e.g., harm reduction workers, people who use drugs, first responders), and maintain transparency of data usage. Further, participants noted the importance of developing a platform that will facilitate client conversations about overdose when doing outreach in the field. These themes were reviewed by our CABs, academic, and industry partners to design an overdose digital platform uniquely tailored to community-based organizations providing harm reduction and overdose response efforts.

Discussion: Community engagement throughout the development process is critical toward developing digital health tools for underserved people who use drugs. Dismantling the power structure among academic and industry partners is critical toward creating equity in engagement of community-based partners, particularly among persons with lived experience in addiction, a history of incarceration, or financial challenges. Our study highlights a multisectoral co-design process across community-academic-industry partners to develop a digital health tool tailored to the unique needs of community-based harm reduction organizations serving highly vulnerable people who use drugs. These partnerships are essential toward creating impact and reducing health disparities among highly vulnerable people who use drugs.

Keywords: overdose prevention, community engaged research, surveillance, human factor, harm reduction

INTRODUCTION

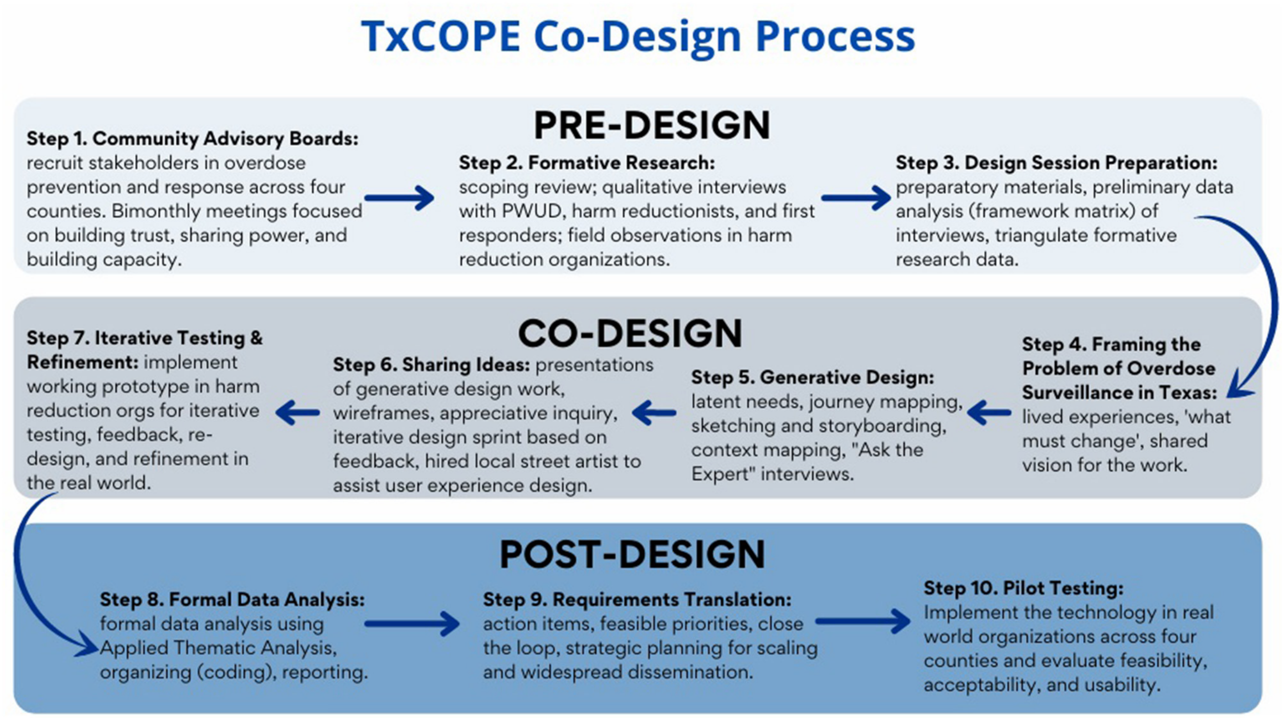
Overdoses involving opioids and other substances were declared a public health emergency in the United States in 2017 and have reached historically devastating numbers during 2021 (1). Recent data from the CDC (2) indicated that over 108,000 Americans died as a result of drug overdose during 2021, an increase of over 30% from previous years (3). It is critically important to highlight that fatal and non-fatal overdose data are likely severely underreported in the United States due to insufficient surveillance methods and systemic gaps in overdose data (2). Existing overdose estimates rely almost exclusively on data from emergency management systems (EMS), emergency departments (ED), and death records, reflecting only PWUDs who interact with the healthcare system following overdose (4). Current overdose data collection methods are fragmented, insufficient, and act to marginalize people who use drugs (PWUD) in analyses (1, 5).

These data are often housed in disparate systems which limit opportunity for integration and systematic analysis (6). Importantly, many individuals who experience an overdose do not contact the emergency management system (EMS) or interact with the healthcare system due to stigma and fear of legal repercussions. Existing overdose data sources rely heavily on data from EMS, emergency departments, and death records to calculate public health statistics. Consequently, only individuals who encounter the health care system following an overdose are recorded within these statistics. Capturing overdose data among hidden populations who do not access these systems is critical for a comprehensive and equitable strategic overdose response.

Different approaches need to be considered in digital health technology development targeting PWUD, particularly among doubly vulnerable minority populations. Employing community engaged research methods through co-collaboration with PWUD throughout technology design and development works to mitigate exclusion of the very population it is meant to serve (7). When integrating ethical considerations during the planning phase, digital health platforms can become “ethical by design” (7). Integrating the needs and voices of PWUD through community engagement and collaboration during the planning, implementation, and dissemination of a digital health platform is necessary to take “ethical by design” one step further to become “equitable by design.”

Community based participatory research (CBPR) is a co-collaborative model that re-aligns traditional “researcher-subject” hierarchies to promote partnership and respond to community priorities (8). The community through CBPR becomes a part of the research team (8). Central to health equity-oriented approaches is the inclusion of PWUD throughout planning, development, and implementation (1). Community involvement increases trust and efficacy of the resulting product within vulnerable populations (7). CBPR provides a trajectory to remedy historical racial/ethnic and socioeconomic inequities through co-collaboration with marginalized groups (8). Encompassing strategies such as community coalitions (8), qualitative interviews, and leading with a “nothing about us without us” (9) perspective, marginalized communities become co-collaborators and integral contributors to digital health and other solutions aimed at their community. Performing community level engaged research improves implementation, addresses stigma, and acts to improve the analysis and understanding of the data by providing additional context.

Texans Connecting Overdose Prevention Efforts (TxCOPE) is a digital health ecosystem developed through employment of CBPR, a community engaged research approach. Similar to other states in the United States, Texas currently does not have a unified, comprehensive digital system in place for fatal and non-fatal overdose reporting and tracking, contributing to the gap in comprehensive, real-time collection, dissemination, and analysis of overdose data (1). TxCOPE will have four interconnected platforms with each tailored to fit the needs of harm reduction organizations, the general



Step 1. Community Advisory Boards: recruit stakeholders in overdose prevention and response across four counties. Bimonthly meetings focused on building trust, sharing power, and building capacity.

Step 2. Formative Research: scoping review; qualitative interviews with PWUD, harm reductionists, and first responders; field observations in harm reduction organizations.

Step 3. Design Session Preparation: preparatory materials, preliminary data analysis (framework matrix) of interviews, triangulate formative research data.

Step 4. Framing the Problem of Overdose Surveillance in Texas: lived experiences, 'what must change', shared vision for the work.

Step 5. Generative Design: latent needs, journey mapping, sketching and storyboarding, context mapping, "Ask the Expert" interviews.

Step 6. Sharing Ideas: presentations of generative design work, wireframes, appreciative inquiry, iterative design sprint based on feedback, hired local street artist to assist user experience design.

Step 7. Iterative Testing & Refinement: implement working prototype in harm reduction orgs for iterative testing, feedback, re-design, and refinement in the real world.

Step 8. Formal Data Analysis: formal data analysis using Applied Thematic Analysis, organizing (coding), reporting.

Step 9. Requirements Translation: action items, feasible priorities, close the loop, strategic planning for scaling and widespread dissemination.

Step 10. Pilot Testing: Implement the technology in real world organizations across four counties and evaluate feasibility, acceptability, and usability.

FIGURE 1 | Community-Academic technology co-design process.

community, first responders, and healthcare providers. TxCOPE was conceptualized and is being designed with equity in mind through the utilization of community advisory boards (CABs) made up of various stakeholders with representation from people with lived experience, harm reduction, prevention, and treatment organizations throughout pilot counties, and use of qualitative interviews with PWUD, first responders, and harm reduction organizations. The CABs, in both urban and rural communities within Texas, worked to identify local challenges (5) facing PWUD while informing the design of this digital health platform. This manuscript describes key findings from our CBPR approach to develop and implement a digital platform to improve overdose surveillance and community prevention and response efforts in Texas.

METHODS

Theoretical Framework and Methodological Approach for Co-design Process

We employed principles from community-engaged research and user-centered design to inform our co-design process and formative research approach. Community-engaged research re-aligns typical researcher-subject hierarchies to involve communities, elevate their perspective within the research and solutioning process, and dismantle existing power structures (8, 10). User-centered design is an iterative process that engages a multidisciplinary team based on the active involvement of end users to improve understanding of the user and task requirements throughout the design and development process (11). Co-Design marries these approaches and extends the role of end users. Co-Design is a method for designing digital health technologies with, not for, the target user group that focuses on mutual learning, trust, shared decision-making, and open and active communication (12). Our Co-Design process included people with lived experience (PWUD), the community (harm reduction and overdose prevention stakeholders), academic researchers, and technologists working together to improve overdose reporting and surveillance methods in Texas. Our target user groups for the TxCOPE platform were harm reduction organizations and PWUD. McKercher (12) outlined four key principles for co-design: (a) share power–acknowledge and address power differentials associated with decision-making, design, delivery, and evaluation; (b) prioritize relationships–establish trust among co-designers, funders, and organizers and build a strong social connection prior to co-design; (c) use participatory means–use design methods that facilitate discovery and move people from participants to active partners; and (d) build capacity–researchers take the role of coach instead of "expert" to facilitate shared understanding and develop champions of the technology to support real world implementation and sustainability. We engaged a multisectoral group of partners across the community, academic, and technology sectors to create an immersive, highly creative environment for health innovation focused on

TABLE 1 | Summary of co-design activities and outputs.

Step	Co-design activities	Outcomes and outputs
Pre-design 1: Community advisory boards	• Recruit CAB members • Establish community-based partnerships and operational structure • Bimonthly CAB meetings	• Multisectoral partnerships across four community advisory boards • Build community trust, social connections, and capacity for design & implementation
2: Formative research	• Scoping review of existing overdose surveillance methods and data dashboards • Qualitative interviews • Field observations	• Define existing technologies • Describe existing data dashboards • Data from people with lived experience • Understand existing organizational work flow and barriers/facilitators to overdose reporting in organizations
3: Design session preparation	• Preliminary data analysis • Triangulate data from Step 2 • Training project team in co-design process	• Materials for Design Session workshops
Co-design 4: Framing the problem	• *Design Session 1:* presenting formative research data to CABs for community data analysis and interpretation • Brainstorming and solutioning • Assess capacity of harm reduction partners to co-create the technology • Assess how community defines success	• In-depth understanding of the problem • Understanding shared vision for technology design and implementation • Establish community-defined success metrics
5: Generative design	• *Design Session 2:* generative design work • Journey mapping • Sketching and storyboarding • Context mapping • "Ask the Expert" interviews	• Define the target user experience • Identify steps in the user's journey • Generate preliminary features and core components of the technology • Design team uses outputs to develop wireframes
6: Sharing ideas	• *Design Session 3:* present generative design work and wireframes • Inquiry and feedback	• Low-fidelity prototype
7: Iterative testing and refinement	• Implement working prototype in harm reduction organizations • Iterative feedback and revision	• Final product design and development of high-fidelity prototype
Post-design 8: Formal data analysis	• Applied thematic analysis of qualitative interviews	• Reports and presentations of process and outcome evaluation findings
9: Requirements and translation	• Strategic planning for scaling and widespread dissemination	• Dissemination and implementation protocol
10: Pilot testing	• Implement and evaluate in real world	• Data on feasibility and acceptability

solving the problem of needing real-time, reliable overdose data surveillance. Our approach closely modeled the recently published framework of Bird and colleagues (13) which outlined the Generative Co-Design Framework for Healthcare Innovation (see **Figure 1**).

Pre-design

Our pre-design process consisted of three steps: establishing community advisory boards, conducting formative research, and preparing for the co-design sessions.

Community Advisory Boards

One method in community-engaged research is the development of community coalitions of key stakeholders and individuals with lived experience (5). In this study we established Community Advisory Boards (CABs) across four pilot counties spanning diverse cultures and urban and rural settings in Texas. CAB members were composed primarily of local harm reduction organization leaders and other representatives of community agencies active in the field such as first responders, treatment, and prevention providers. To recruit CAB members, we first identified relevant community-based organizations in each county across the following sectors: harm reduction, substance use prevention and/or treatment, first responders (EMS/Fire), and medical examiner office. We contacted leadership in each organization and described the project and the role of the community advisory board in the co-design of the overdose reporting platform. Organizations who agreed to have representation then identified a champion within their organization to serve as a CAB member. Each CAB met every 2 months for 60–90 min over a period of 2 years. CAB activities are outlined in **Table 1**.

Formative Research

Activities during this step included conducting a scoping review, series of field observations among harm reduction organizations and street outreach teams, and qualitative interviews with key stakeholders. These data were triangulated to understand existing overdose surveillance methods, gaps in data collection and reporting, and perceived solutions to improve overdose data to inform community response efforts. Qualitative interviews were conducted among a series of $N = 74$ key stakeholders and people with lived experience ($n = 24$ people who use drugs; $n = 20$ first responders, $n = 20$ harm reductionists, $n = 10$ overdose prevention and response experts) across the four pilot counties in Texas to inform initial design and development. These interviews were between 60 and 90 min in duration and participants received compensation in the amount of $30 for their time. The following research questions were addressed in interview: (1) How do stakeholders engage in the field of drug overdose perceive existing overdose and naloxone data in the State of Texas?; (2) How do stakeholders engaged in the field of drug overdose currently report opioid-related data? (overdose info, naloxone administration/distribution, etc.); (3) What are the perceived problems or negative outcomes associated with underreporting overdoses in Texas?; (4) What are stakeholders engaged in the field of drug overdose perspectives on other existing data reporting programs?; (5) What are perceived solutions to improve the tracking of overdose-related variables?; and (6) What methods should be used to implement this system to promote widespread adoption and sustainability?

In interviews with PWUD, the research questions addressed varied slightly and reflected the following: (1) Do people who use drugs currently report overdose-related data? If yes, among this population who is more likely to report and why? If no, what are the reasons this population does not report and how often do they think overdoses occur and are not reported?; (2) What methods will increase the likelihood that people who use drugs will report overdose-related data (e.g., what would incentivize reporting behavior)?; and (3) What methods should be used to increase adoption and sustainability of an overdose reporting system among people who use drugs? Semi-structured interview guides and debriefing guides were created for each interview group. The interview guides were composed of structured, open-ended question, and provided flexibility for the interviewers to adapt and clarify questions as needed. Methods and results for the qualitative interviews are described below.

Co-design Phase

During the Co-Design Phase, our academic team lead coordination of all aspects of the project and facilitated meetings with our technology team, Maven Wave an Atos company, and our community partners. This included multisectoral meetings focused on framing the problem, conducting generative design work, sharing ideas for technology design and development, reviewing wireframes and low-fidelity prototypes, and iterative testing and refinement. We completed preliminary data analysis throughout this phase using the framework matrix method for efficiency.

Post-design Process

The Post-Design Phase consisted of a pilot test across participating harm reduction organizations to assess feasibility and refine the technology. Data were formally analyzed during this phase using Applied Thematic Analysis. Finally, we developed a plan for scaling and implementation. This included hiring a local street artist to develop promotional materials and artwork. **Table 1** outlines activities and outputs for all phases of the co-design process.

Participants

Eligibility

The inclusion criteria for qualitative interviews with medical examiners, justices of the peace, harm reductionists, and other key stakeholder representatives included: (1) eighteen years or older, (2) employed in one of the target counties (e.g., medical examiner, justice of the peace, etc.) or have relevant experience that will inform statewide efforts; and (3) ability to read and speak in English. The inclusion criteria for people who use drugs (PWUD) included: (1) eighteen years or older, (2) reported misuse of opioids or stimulants in the past 3 months, (3) resides in Texas, and (4) ability to read and speak in English and/or Spanish. The exclusion criteria for all participants included: the inability or unwillingness to provide consent, being actively suicidal, or psychotic.

Recruitment

Screening for prospective participants consisted of a short (5–10 min) screening survey conducted over the phone or through email and was coordinated by the research team. When the inclusion criteria were met, the research team would then provide and obtain informed consent. During the consent process, participants were informed about the purpose of the study and all procedures. Participants were told that the interview would be audio-recorded and then transcribed verbatim. The transcripts would be cleaned and all identifying information would be removed then audio-recordings would be deleted. Participants were given time to review the consent form in-depth and ask questions. Participants were given a copy of the consent form for their records. Participants protected health information were removed and had a unique ID number assigned to them. Recruitment methods were comprised of in-person (when permitted), flyers, e-mails, telephone, snowball sampling, social media advertising, web-posting, word of mouth, and using CABs in each pilot county to assist with recruiting. In total, we recruited and interviewed 24 people who use drugs, 20 harm reductionist, 20 first responders, and 10 overdose prevention and response experts before reaching data saturation.

Data Collection

Qualitative interviews were conducted by videoconference and in-person, when permitted, with two trained researcher staff. One researcher conducted and led the interview while the other co-facilitated and took notes. After the interview was completed, the audio recordings were transcribed verbatim by a confidential professional transcription agency. Transcripts were then cleaned and scrubbed of all personal identifying information. Once returned, the cleaned transcripts and the debriefing guides were used for analysis.

Data Analysis

Qualitative interview data were analyzed using applied thematic analysis and triangulated to inform development of the TxCOPE digital ecosystem. Data from the qualitative interviews were analyzed using applied thematic analysis which was selected for its flexibility and systematic approach in analyzing text-based qualitative data while planning as well as preparing for the data collection (14). The research team identified emergent themes based on the a priori research goals. These major themes informed the development of working codebooks and framework matrices for the respective interviewee (first responder, harm reductionist, pwud, general stakeholder). The general stakeholder codebook outlined the following data: overdose, current overdose reporting, non-traditional first responders, solutions to improve reporting, digital platform structure, and digital platform implementation. The PWUD codebook outlined the aforementioned data with the addition of perceptions of organizations. The harm reductionist codebook outlined the data included in general stakeholder codebook with the addition of the following: marketing and branding and stigma.

Data analysis was conducted by six trained coders (two clinical research associates and four research assistants) using a reflexive analysis approach. The process involved assigning two team members per transcript to be coded independently using the corresponding codebook. Once independent coding was completed the two coders met to resolve discrepancies in the coding using the reflexive team approach to resolve any discrepancies. Once a consensus was met the coders finalized the coded transcript. During coding additional relevant data and themes emerged resulting in multiple revisions of the codebook. In order to organize the data collected during interviews, framework matrices were developed. The debriefing guides and cleaned transcripts were used to identify emerging themes and house direct quotations from the interviews. Once the data reached saturation, the emergent themes were collected from the coded transcripts and framework matrices. Data saturation was determined to be achieved when no new information was obtained in new interviews on key research questions (15). Several key themes in human factor (language use, trust, and transparency) and technical features (unified system, various data entry methods, and data sharing) emerged that will be discussed further within the results Section.

RESULTS

Participants

Qualitative interviews with 74 key community stakeholders ($n = 24$ people who use drugs; $n = 20$ first responders, $n = 20$ harm reductionists, $n = 10$ overdose prevention and response experts) were conducted. Participants included: emergency department and hospital employees (11.1%), EMS (22.2%), epidemiologists (3.7%), fire department (12.9%), harm reductionist (35.1%), law enforcement (1.9%), poison control (1.9%), substance use treatment providers (5.6%) and other key stakeholders (state health department official, technical assistant and workforce development, mental health peer specialist) (5.6%). See **Table 2** for Participant characteristics. Thematic analysis revealed important information regarding how the TxCOPE digital platform could be designed to meet the needs of these diverse stakeholders. Results are organized with regard to preservation of trust, preferences regarding content and digital features, and participants' perspectives of the opportunities and concerns regarding the digital platform.

Preservation of Trust

This theme emerged throughout the design process and across all community stakeholders. The harm reduction and PWUD noted that it was imperative that we embrace the mantra: "Nothing about us without us" and develop a tool that is "Informed by the community, for the community." Harm reduction stakeholders noted how important preserving trust among their clients is toward operational success of the organization. They have worked hard on the ground to develop relationships with community gatekeepers and establish their organization as worthy of trust among the drug using community. As such, any technology developed through this co-design process must put the community first, above the academic and funder's priorities.

Our community advisory boards emphasized the importance of trust in being able to capture data from "hidden populations" who do not come into contact with the healthcare system and are not captured in existing overdose surveillance methods. One harm reduction leader stated: "I would say [non-reported overdoses] are pretty high... If I was being conservative, maybe 50 to 60 percent [of overdoses go unreported]. I'd have to say [current overdose surveillance data] is very inaccurate" (120, Harm Reductionist).

The advisory boards and harm reduction organizations viewed obtaining data from this population as key to be able to have real-time, meaningful data that will inform community overdose prevention and response efforts. "I do think a more comprehensive app and website would be useful, but then like, more trust would have to be established and that there would also have to be ways to…ensure that people without access to technology would, maybe even like, maybe if there is like, an incentive for people to like, report an overdose, but I think that would definitely have to be carried out by a harm reduction organization because I just feel like that's where most trust is placed in the community" (121, PWUD).

Preferences for Content and Technical Features of the Digital Platform

In regards to technical features, participants commented on the need for ease of use, discussed the complexity of location documentation, and identified several features for the digital platform.

Ease of Use

In terms of technological features, participants highlighted a need for flexible data entry methods, offline usage capability, and for simplicity and ease. First responders requested simplicity but also repeatedly noted compliance might be poor and that pulling data from the existing system would be better because they already have systems in place. One first responder stated "don't make something complicated and I think it will piss people off if they are like, 'I already entered this'" (146, EMS). Harm reduction workers and PWUD commented on both apps and website portals. Participants highlighted the importance

TABLE 2 | Participant characteristics (*N* = 74).

	People who use drugs (*n* = 24)	First responders (*n* = 20)	Harm reductionists (*n* = 20)	Overdose prevention/ response experts (*n* = 10)	Total (*n* = 74)
	***N* (%)**	***N* (%)**	***N* (%)**		***N* (%)**
Age					
18–24	4 (16.6)	1 (5.0)	1 (5.0)	0 (0.0)	6 (8.1)
25–34	4 (16.6)	6 (30.0)	8 (40.0)	3 (30.0)	21 (28.3)
35–44	11 (45.8)	6 (30.0)	5 (25.0)	3 (30.0)	25 (33.7)
45–54	2 (8.3)	6 (30.0)	3 (15.0)	3 (30.0)	14 (18.9)
55+	3 (12.5)	1 (5.0)	3 (15.0)	1 (10.0)	8 (10.8)
Sex at birth					
Male	13 (54.2)	18 (90.0)	10 (50.0)	1 (10.0)	42 (56.7)
Female	11 (45.8)	2 (10.0)	10 (50.0)	9 (90.0)	32 (43.2)
Gender identity					
Man	13 (54.2)	17 (85.0)	9 (45.0)	1 (10.0)	40 (54.0)
Woman	11 (45.8)	2 (10.0)	9 (45.0)	9 (90.0)	31 (41.9)
Genderqueer	0 (0.0)	1 (5.0)	2 (10.0)	0 (0.0)	3 (4.1)
Race					
African American or Black	1 (4.2)	0 (0.0)	2 (10.0)	0 (0.0)	3 (3.9)
Asian	0 (0)	2 (10.0)	2 (10.0)	2 (20.0)	6 (7.9)
White/ Caucasian	19 (79.2)	17 (85.0)	14 (70.0)	8 (80.0)	58 (76.3)
American Indian or Alaska Native	0 (0.0)	0 (0)	1 (5.0)	0 (0.0)	1 (1.3)
Native Hawaiian or Pacific Islander	0 (0)	0 (0)	0 (0.0)	0 (0.0)	0 (0.0)
Other	6 (23.0)	1 (5.0)	1 (5.0)	0 (0.0)	8 (10.5)
Ethnicity					
Hispanic or Latino	10 (41.7)	3 (15.0)	8 (40.0)	1 (10.0)	22 (29.7)
Non-hispanic or Latino	13 (54.2)	16 (80.0)	11 (55.0)	9 (90.0)	49 (66.2)
Other	1 (4.2)	1 (5.0)	1 (5.0)	0 (0.0)	3 (4.1)
Religion					
Christian	6 (25.0)	9 (45.0)	6 (28.6)	5 (50.0)	26 (34.6)
Buddhist	1 (4.2)	0 (0.0)	1 (4.8)	0 (0.0)	2 (2.6)
Jewish	1 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.3)
Muslim	0 (0)	0 (0.0)	0 (0.0)	1 (10.0)	1 (1.3)
Atheist	2 (8.3)	6 (30.0)	6 (28.6)	2 (20.0)	16 (21.3)
Hindu	0 ()	0 (0.0)	0 (0.0)	1 (10.0)	1 (1.3)
Other	14 (58.3)	5 (25.0)	8 (38.0)	1 (10.0)	28 (37.3)
Education level					
Some grade school	1 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.35)
Some high school	1 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.35)
High school diploma or GED	8 (33.3)	0 (0.0)	2 (10.0)	0 (0.0)	10 (13.5)
Some college or 2-year degree	12 (50)	10 (50.0)	3 (15.0)	1 (10.0)	26 (35.1)
4-year college graduate	1 (4.2)	9 (45.0)	7 (35.0)	2 (20.0)	19 (25.6)
Some school beyond college	1 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.35)
Graduate or professional degree	0 (0)	1 (5.0)	8 (40.0)	7 (70.0)	16 (21.6)
Income					
<$25,000	11 (45.8)	0 (0.0)	4 (20.0)	1 (10.0)	16 (21.6)
$25.000–49.000	7 (29.2)	1 (5.0)	11 (55.0)	0 (0.0)	19 (25.6)
$50,000–74,999	4 (16.7)	7 (35.0)	2 (10.0)	2 (20.0)	15 (20.3)
$75,000–99,999	1 (4.2)	6 (30.0)	1 (5.0)	2 (20.0)	10 (13.5)
Over $100,0.000	0 (0.0)	6 (30.0)	0 (0.0)	4 (40.0)	10 (13.5)
Don't know/prefer not to answer role in overdose reporting	1 (4.2)	0 (0.0)	2 (10.0)	1 (10.0)	4 (5.4)

(Continued)

TABLE 2 | Continued

	People who use drugs (*n* = 24)	First responders (*n* = 20)	Harm reductionists (*n* = 20)	Overdose prevention/ response experts (*n* = 10)	Total (*n* = 74)
	***N* (%)**	***N* (%)**	***N* (%)**		***N* (%)**
Emergency department/ Hospital employee	–	4 (16.6)	0 (0.0)	2 (20.0)	6 (11.1)
EMS	–	12 (50.0)	0 (0.0)	0 (0.0)	12 (22.2)
Epidemiologist	–	0 (0.0)	0 (0.0)	2 (20.0)	2 (3.7)
Fire department	–	6 (25.0)	0 (0.0)	1 (10.0)	7 (12.9)
Harm reductionist	–	1 (4.1)	18 (90.0)	0 (0.0)	19 (35.1)
Law enforcement officer	–	1 (4.1)	0 (0.0)	0 (0.0)	1 (1.9)
Poison control	–	0 (0.0)	0 (0.0)	1 (10.0)	1 (1.9)
Substance use treatment provider	–	0 (0.0)	2 (10.0)	1 (10.0)	3 (5.6)
Other experts	–	0 (0.0)	0 (0.0)	3 (30.0)	3 (5.6)

of accessibility as it relates to equity in adoption and data reliability: "if different people are going to be using it you have to make it really easy to understand because then you get misclassification of information." (106, Harm Reductionist). Another participant noted, "It should be very practical and easy to use, uh, where they are not able—where they're able to just, um, like a one-, two-, three-step—not make it more than that because, uh, they might get fatigued, as it is, they're already using [drugs], you know—-so their patience is not too good, you know, so I think we have to keep that app very practical" (141, Harm Reductionist).

The ability to download an app in the iTunes and Google Play stores was often mentioned but responses included those who preferred to log into a web portal because some participants expressed privacy concerns regarding a mobile application: "I think that most people have phones, right? Um, even folks that are homeless out in the community have phones. So I think that, if there was a really easy, free, downloadable app that people could use to report these, I think that they would report "em"" (108, Harm Reductionist). One PWUD felt an app would be fine for their peer group but would not work for everyone because of phone access issues: "For my cohort of people, an app would be very effective. But for people that don't have or use apps, that's not gonna help them" (136, PWUD). Another PWUD commented on concerns about privacy with an app: "Not something that, like, a lot of things that you gotta sign up and put your name and put your email and create a username and a password and all that, like, no" (158, PWUD). This was echoed by other PWUD, "I don't trust the phones" (160, PWUD).

Regarding simplicity and ease of use, one EMS worker said "Yeah, I think you're gonna get a lot more use if it's kind of binary, in the sense that it's—you know, you can just—you can click through options. You know, the less that someone has to freeform an answer, and I hate to say it, but like the less somebody has to write a narrative, the more likely it is that they'll use it consistently because it's easy" (147, Firefighter).

Many participants ranging from harm reduction workers to PWUD highlighted a desire to use the platform quickly and many brought up drop down options. One law enforcement officer highlighted utility of drop downs: "I mean, guess ease of use, right. Drop-down menus are super easy. You just click-click check boxes or whatever" (144, Law Enforcement Officer). For EMS workers, integration with current systems was a highly desired technical feature. One EMS worker felt this was critical to utility: "So, having it integrated into my EPCR and makin' it to where I can't close it without doing it would be the only way to get the 100 percent compliance" (148, EMS).

Location Documentation

Preferences on overdose incident location documentation varied between those who valued granularity down to the zip code or community/neighborhood level. Harm reduction workers noted that more precise location data would allow them to make data-driven decisions for community outreach strategy. First responders noted zip codes would be helpful whereas PWUD noted areas of town or general neighborhoods where the overdose occurred, and more importantly to them, where the drugs were purchased. Taken together, there seemed to be perceived value in documentation of location of overdose, but groups viewed locations somewhat differently.

For example, one first responder (143, Firefighter) said "Oh, man. Well, if it's going up to the state, I would think some sort of, you know, uh, well, the state employees should be able to have access to it so that maybe they can see if they're having, like, a spike in, say, zip codes or that kind of thing. You know what I mean? That way they could, like, maybe have better, uh, communication with the local municipalities as far as, you know, "We've been tracking numbers and we show that in your zip code that it spiked, like, 20 percent," or whatever. You know? That kind of thing...Yeah. I think it should be local and state should have access to it. Definitely."

One harm reduction worker in an urban area said "I think at least being able to see if there are neighborhood clusters. Or a particular area. I mean that would be incredibly helpful for our services. I mean, if we could see that a bunch of people overdosed even if we didn't know from what, if there is like a spike in the map. And we–and other organizations–could figure out what's going on in that community" (105, Harm Reductionist). Another harm reduction worker highlighted the need to document where the drugs were from, not just where the overdose occurred. "if I'm still using drugs part of what I wanna know is where did the drugs come from. People get drugs from different places, so one of them is like a hotspot for someone who deals drugs that are knowingly filled with fentanyl" (106, Harm Reductionist). This was echoed by PWUD "...and they can also report whether an emergency call was made, whether Narcan was used or not used, what substance it was, just a general part of town" (122, PWUD).

Features

Features desired included components such as documentation of overdose context, polysubstance use, interventions administered such as reversals or rescue breathing, and location of the overdose incident. A popular feature among harm reduction workers was the ability to track resources such as naloxone. For example, one harm reduction worker had the idea that this could facilitate resource sharing: "sometimes, um, I ran-I ran out of testing strips or I ran out of Narcan and then, um, usually I just ask other agencies in the area, 'Hey do you—can I have some testing strips or Narcan?' And they usually have a bunch that they didn't use. So maybe a button or a link to ordering more" (140, Harm Reductionist). This was echoed by an EMS worker: "Um, I think if-if Narcan was available in the community, that would be helpful to be able to know, like, where you could get it, how you could get it. That sort of thing. And then, if you did have it and you administered it, then it would be nice, like you said, to have an app or some sort of software or internet access to where you could document like, "Yes, I did use this community, uh, resource, and it was effective." You know what I mean?" (142, Firefighter).

PWUD added additional features related to the desire for the website to include resources such tutorials on vein care or naloxone, or where to get treatment. One PWUD noted, "like some of these, um-some of these, uh, website or, um, mobile apps, um, they have, uh-they have a option on there where you can either, you know, go into like a frequently asked questions section— or you can type in, um, you know, a keyword like "help" or, um, uh, you know, "information" or "info" or something. And then you can have some kind of bot respond back to you, you know, about giving you options about what you, you know, want information on, or what you want help with. You know, and you can get all kinds of resources like that, you know, if - if you're looking to get some kind of, uh, um, recovery services or, um, emergency services, you know, poison control numbers. Yeah. Yeah, anything like that, um, I - I - I think that's definitely something that either already exists or should exist by now, but, um, yeah, that's definitely a—I think it's a good idea." (122, PWUD).

One harm reduction worker added that including treatment resources may require tailoring to each community: "Here are our services. Here are different organizations," and that kinda, like, for example—but then the problem with that is you're gonna have to regionalize it. "Cause, like, somebody in, uh, Dallas has no benefit from knowing that [harm reduction organization] does HIV testing from one through five" (138, Harm Reductionist).

Opportunities and Concerns for the Digital Platform

Participants were provided the opportunity to reflect on how overdose reporting could be improved. Themes from these questions included data accessibility, data integration, and privacy concerns.

Data Accessibility

Regarding the technology, harm reductionists and the SUD treatment providers endorsed accessibility of the surveillance data. Some harm reductionists were excited about the idea of unified data across the state, and having "Just one system where everyone could go to one place" (104, Harm Reductionist). One PWUD suggested that alerts could be used to notify users when overdose rates increase in their area (122, PWUD). Several EMS/Fire respondents noted that they already record overdose data, and so an efficient system would pull data from their records: "the system that we have right now is pretty good. I'm happy with it, and, like, it has all that stuff you need as far as drugs and-and overdose tracking" (142, Firefighter). Several EMS/Fire respondents suggested that state-mandated reporting would be helpful: "I think that if the state were to mandate collection of the data, then I could see administration either mandating us to go and fill out those forms and referrals, or just designating somebody to collect that data" (149, EMS).

Data Integration

Harm reductionists, EMS/Fire, and poison control respondents highlighted the importance of combining data sources: "there's so many different systems that trying to make sure that it isn't a duplicate or that we're not missing something or, you know, whatever it is, um, that's probably, one of the harder things" (153, Poison Control). Another participant highlighted challenges with obtaining real-time overdose data and the need for data aggregation across systems: "I don't think you can create anything that's gonna give you all the information in real time that is experiencing overdose. I don't. You're gonna need a combination of reporting" (109, Harm Reductionist).

Some harm reductionists suggested that shared data could create opportunities for collaboration across harm reduction organizations, while others suggested broader impacts of reporting for PWUD: "I feel like that should be the goal, to empower our [clients] to be able to report that information when needed and as they feel comfortable" (116, Harm Reductionist). Another harm reductionist highlighted how this might facilitate empowerment among PWUD: "That would empower them, that would make them feel like they are worthy of being cared for and better" (110, Harm Reductionist). Another harm reductionist noted, "The idea is empowering people in their own health because there is a lot of things in their life that they can't control" (106, Harm Reductionist). Similarly, one PWUD suggested that more reporting data might help people realize how much more common overdoses are, and this would allow for increased funding (136, PWUD).

When asked about their open-ended goals, harm reductionists commonly cited the need for changes to public policies in Texas: "I think it would be great if there was buy-in from all of our counties across the state.... I think you could create an amazing infrastructure and website, and then if you don't have the political will to get people to use it, then it will be similar to some of the stuff we already have [i.e., non-integrated platforms such as OD Map and TONI]" (105, Harm Reductionist). Another participant noted, "I would first have to change state policy where programs have to collect this information or are allowed to work with this population without fear of losing their funding. So I would include state policy to include harm reduction services" (107, Harm Reductionist).

Privacy

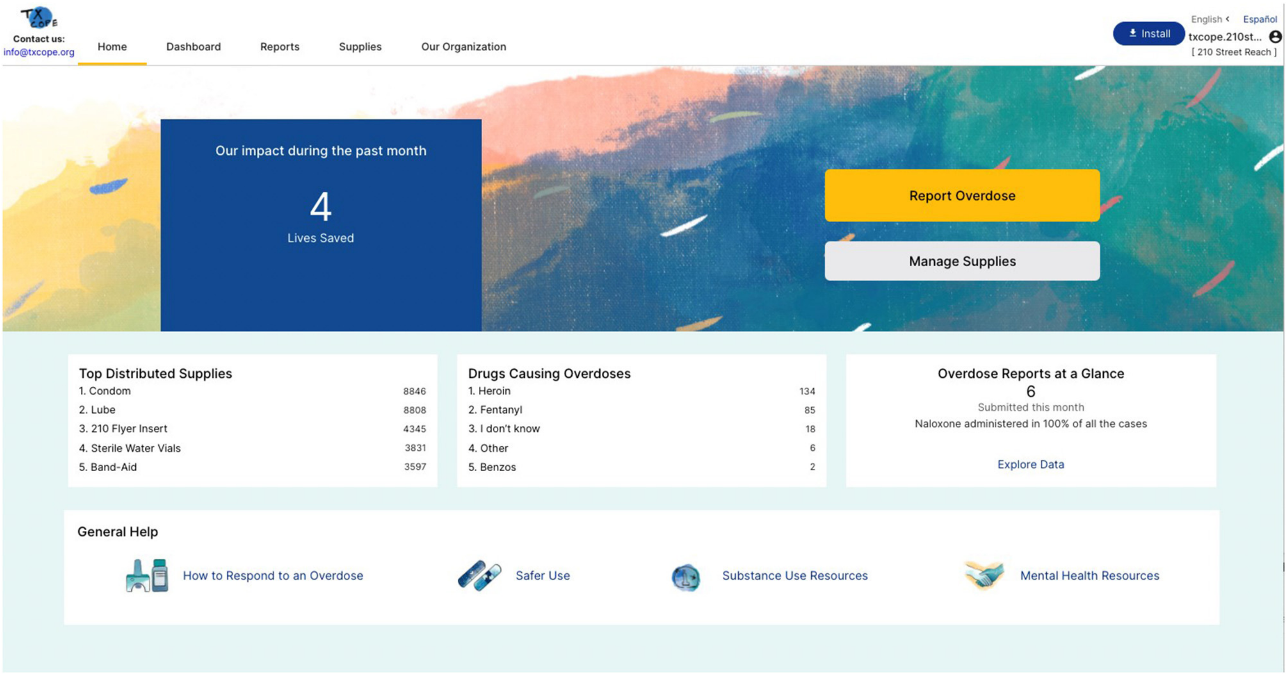
PWUD were very concerned with anonymity. Their primary concern was ensuring that law enforcement cannot access their personal information. "People don't report it because they are afraid. Because of an underlying mistrust" (136, PWUD). This mistrust was reflected in their suggestions for policy-related improvements. PWUD indicated that their peers were unlikely to report overdoses through existing channels due to mistrust, and enhancing trust would be an effective path to improved reporting: "If people started having more positive experiences when they did report it, then, you know, word would get around what really happens when you report it" (135, PWUD). This same participant then noted: "Like, that's how it happens when you report an overdose. Like, they don't frisk everybody there and threaten to throw them in jail" (135, PWUD). Notably, EMS/Fire respondents recognized this perception, but felt it was not accurate: "The perception is that if law enforcement's gonna get involved, you know, I'm gonna go to jail, or my friend's gonna go to jail. And [we need] some kind of massive public education campaign that explains to people that, you know, hey, this is not a criminal activity" (147, Firefighter).

DISCUSSION

Emerging research estimates that 50–70% of overdoses in Texas go uncounted as a result of the punitive and stigmatizing nature of policies and the fact that only 15 of the 254 counties in Texas have a medical examiner to diagnose overdose as a cause of death (16). Many PWUD experiencing or witnessing an overdose do not contact EMS nor healthcare providers due to stigma and fear of legal repercussions. This fear is well-founded. Texas both lacks a Good Samaritan Law and has more punitive drug use policies (17, 18), with the result that many people who use drugs (PWUD) are swept into the criminal justice system. Further, Black adults are more than twice as likely to be arrested for drug possession and nearly four times more likely to be arrested for marijuana possession relative to White adults exacerbating racial disparities (19–21). Accurate overdose surveillance data is needed to facilitate system and policy change. Capturing data from PWUD and the harm reduction community is necessary to better understand the overdose crisis in Texas and improve reliability of data.

This study highlighted the importance of using a co-design process in the development of an overdose surveillance digital platform to facilitate equity across multisectoral partners including harm reduction workers, first responders, and people who use drugs. Community engagement throughout the development process is critical toward developing digital health tools for underserved people who use drugs. We combined community-engaged research and user-centered design methods to serve as the foundation of the co-design process with our community, academic, and industry partners (8, 10, 11). Dismantling the power structure among academic and industry partners was a critical initial step toward creating equity in engagement of community-based partners, particularly among persons with lived experience in addiction, a history of incarceration, or financial challenges. This was accomplished through community advisory boards, qualitative interviews, and hiring paid consultants which included three local street artists with lived experience, and a first responder and harm reductionist. Results from this study highlighted several key components in developing a community-driven overdose reporting platform. First, preserving trust between harm reduction organizations and their clients is critical. This warrants a digital platform that is safe and secure, and protects their clients from potential legal repercussions. As such, PWUD want an option for anonymous reporting. Accessibility considerations should take into account community members who do not have or use mobile devices or speak fluent English. Further, reporting should be easy, quick, and simple. Less required data points may increase the number of reports. Incorporating flexible data entry methods may facilitate adoption, such as incorporating a speech-to-text feature, data capture through taking a picture of a written report on paper, having a call-in hotline, and pulling data from the backend of existing systems.

Our co-design process resulted in the development of the TxCOPE dashboard uniquely tailored to harm reduction organizations (see **Figure 2**) (www.txcope.org/harmreduction). Priorities of the community included HIPAA-compliant, secure, and anonymous reporting form. The overdose report form was designed by the community advisory board (CAB) members with detailed attention to language used throughout the report form. The community wanted to ensure data will be collected for marginalized populations with a priority among trans-people and racial/ethnic populations (see **Figure 3**). The CABs also designed a supply tracking portal that enables harm reduction organizations to manage supply distribution and map locations where supplies are given during community outreach. This allows organizations to have data to drive their supply distribution efforts and see if their community outreach efforts maps on to the same locations where overdoses are occurring. Finally, the CABs designed the data dashboard ensuring data is displayed at the organization level, county level, and state level. The data dashboard was designed to facilitate harm reduction organizations ability to demonstrate their community impact and easily insert graphs and figures from the dashboard into grant applications.



Our impact during the past month

4

Lives Saved

Top Distributed Supplies	
1. Condom	8846
2. Lube	8808
3. 210 Flyer Insert	4345
4. Sterile Water Vials	3831
5. Band-Aid	3597

Drugs Causing Overdoses	
1. Heroin	134
2. Fentanyl	85
3. I don't know	18
4. Other	6
5. Benzos	2

Overdose Reports at a Glance

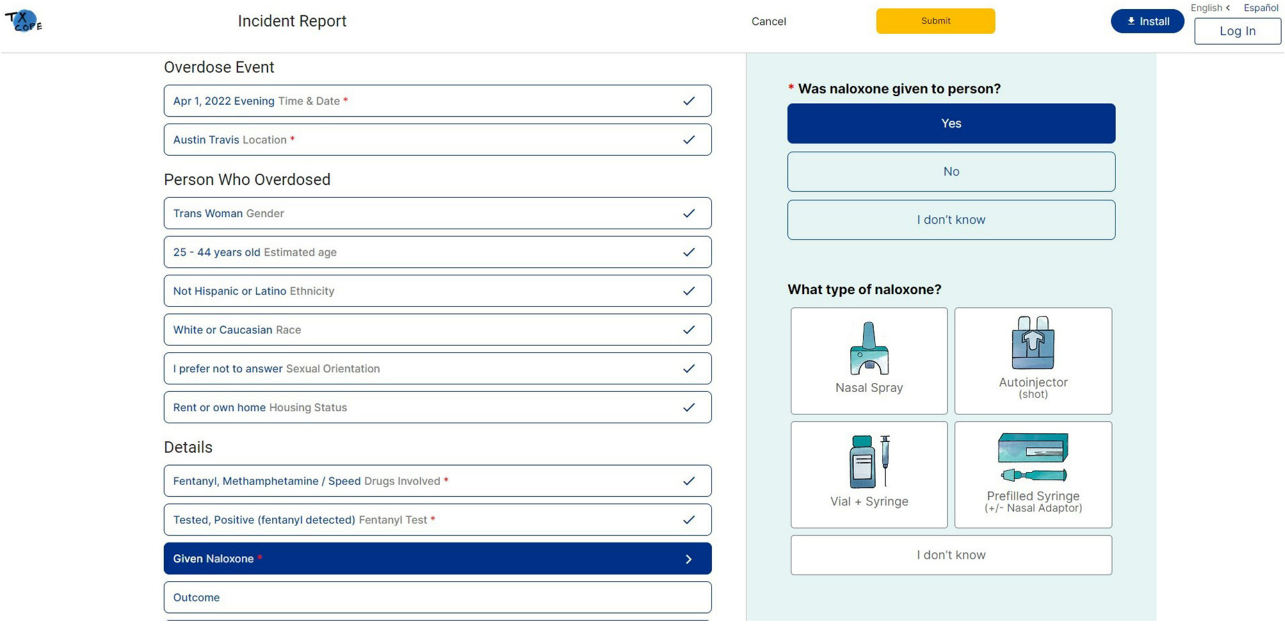
6

Submitted this month

Naloxone administered in 100% of all the cases

General Help

FIGURE 2 | TxCOPE landing page design for harm reduction organizations.



Overdose Event

Apr 1, 2022 Evening Time & Date *

Austin Travis Location *

Person Who Overdosed

Trans Woman Gender

25 - 44 years old Estimated age

Not Hispanic or Latino Ethnicity

White or Caucasian Race

I prefer not to answer Sexual Orientation

Rent or own home Housing Status

Details

Fentanyl, Methamphetamine / Speed Drugs Involved *

Tested, Positive (fentanyl detected) Fentanyl Test *

Given Naloxone *

Outcome

* Was naloxone given to person?

● Yes

○ No

○ I don't know

What type of naloxone?

FIGURE 3 | TxCOPE overdose incident report form.

Findings from this study should be taken in light of several limitations. First this study was exploratory in nature and only used qualitative methods. As such, we cannot generalize these findings of key stakeholders beyond the state of Texas. Participant perceptions likely reflect the policy infrastructure existing in Texas at the time of this study. Our sample included first responders; however, law enforcement was underrepresented in our sample. Future studies should seek to better understand perspectives on overdose reporting and use of data among law enforcement and criminal justice stakeholders.

This study highlighted a multisectoral co-design process across community-academic-industry partners to develop a digital health tool tailored to the unique needs of community-based harm reduction organizations serving highly vulnerable people who use drugs. These partnerships are critical toward creating impact and reducing health disparities among highly vulnerable people who use drugs. Incorporating non-traditional first responders into overdose surveillance methods is essential toward capturing data among hidden populations. This is a needed first step in promoting equity of overdose prevention and community outreach among highly vulnerable people who use drugs.

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 human participants were reviewed and approved by The University of Texas at Austin Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KC is the principal investigator for the study, led the conceptualization of the study, and the drafting of the original grant proposal. SC and JB are co-investigators and contributed to conceptualization of the study, contributed to writing of the original grant proposal, and successive drafts of the manuscript. QW, KC, SC, and JB developed a first draft of the manuscript. QW assisted with data collection, data analysis, and drafting the manuscript. All authors read and approved the final manuscript.

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Peer Facilitators as Core Co-developers of an Online Peer Encouragement Network (OPEN2chat) for Austrian Adolescents

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Adolescence is a crucial developmental time, and it is essential to ensure stable mental health during the transition to adulthood. Peer-to-peer networks seem to be a promising tool to support adolescents during that time. While co-development often concentrates on the end-user, this paper focuses on the peer facilitators of an online peer encouragement network (OPEN2chat), where adolescents can chat with peer facilitators about their problems. We conducted 3 group discussions with 18 peer facilitators after a testing phase to improve the process of these interactions. Thematic analysis was used to analyse the data after transcription. The four main themes were the responsibility of the peer facilitators toward their peers, especially their role of giving advice; the interaction process itself; time management; and technology aspects of the application. Including these stakeholders in the development process empowered the young people, helped eliminate problems with the application, and made the researchers more sensitive toward potential issues and emotions that peer facilitators encounter that may have been missed without a co-development process. Eliminating these problems might also help establish a better environment and support system for the actual end-users.

Keywords: adolescence, digital intervention, participatory research, co-design, young adults, peer counseling

INTRODUCTION

Adolescence as the transition between childhood and adulthood encompasses significant biological, emotional, physical, social changes and development. Social cognitive and social affective changes are especially notable as peers become increasingly important (1, 2). Adolescents need to manage the transition to adulthood in a healthy way, which can mean many things, from avoiding drugs to stable mental health (3). Positive peer support has been associated with improvements in depressive symptoms and a substantial reduction in suicide attempts (4). It has been shown to serve as a protective factor during interpersonal stress (5). Negative experiences such as bullying or victimization can harm mental health and wellbeing, with risks ranging from drug use to suicidal intentions (6). Many mental health disorders emerge in adolescence, connected to violence and (sexual) risk behavior (7). It is vital to promote healthy behavior in this period and have programs for adolescents who experience or have experienced adverse events and emotions.

A growing body of literature is calling for active investment in the health and wellbeing of adolescents (8, 9) and there is already ample evidence that preventive interventions during adolescence have beneficial effects on physical and mental health outcomes. For example, meta-analyses show positive outcomes for alcohol reduction (10), improving mental health with mindfulness (11), or reducing self-harm (12), showing that there are many possibilities to help and support adolescents overcome or prevent a variety of problems. One thing to consider when designing programs for adolescents is that adolescents' lives are more and more intertwined with the digital world and being online is part of adolescents' everyday lives (13). This has been accelerated by Covid-19 and the related lockdowns, forcing adolescents to experience both their leisure time and school lives almost entirely online. But the pandemic has not only made adolescents be even more prone to spending time in the digital world, it has also led to a strong increase of mental health problems (14). Prevention programs and interventions are not only more vital than ever, they also need to adapt to digitalization by offering online support, and some digital health interventions show promising results regarding the mental health of young people (15). Online programs seem particularly important to allow adolescents to talk about sensitive topics anonymously and confidentially (16), hence giving access to a more diverse group of users as well (17). Comparing online peer-support to face-to-face support has been shown to be equally effective in improving symptoms of users, but additional qualitative findings have shown vast benefits of the online setting in terms of accessibility and feasibility (18).

Looking at Austria specifically, adolescents' mental health service situation is far from perfect: Philipp et al. (19) found that more than 20% of Austrian adolescents between 10 and 18 years old have a diagnosable mental illness. Wagner et al. (20) confirmed this percentage, with the most common mental issues being anxiety or developmental disorders. Ego-syntonic disorders prove to be treated very rarely, with only 25% of patients receiving therapy (21). The supply of mental health professionals and institutions is alarmingly low, with only one child- and adolescent-psychiatrist available for every 30,000 children and adolescents. What is more, individuals seeking mental health support often face additional challenges such as misdiagnoses and stigma (20), which can further be exacerbated by a variety of factors such as ethnic (22) or socio-economic background (23). These findings conclude a need for a broader supply of mental health specialists and institutions for children and young adults (24). Schneidtinger and Haslinger-Baumann (25) constructed a model of Austrian adolescent patients' recovery that shows three main stakeholder groups to be able to function as both barriers and positive "facilitators" of recovery: family, treatment (institutions), and peers. In this study, peers could alleviate mental stress by providing understanding, community, and friendship. Based on this notion, OPEN2chat aims to provide peer support, especially for those who lack support from their peer group in their day-to-day lives and all adolescents who struggle to access professional intervention programs.

OPEN2chat is a web-based application for adolescents co-developed between 2018 and 2021 in close collaboration with adolescents. OPEN2chat was launched on the 1st of December 2021 and connects specifically trained adolescent peer facilitators with peers who want to share psychosocial issues, concerns, and problems anonymously. Peer facilitators undergo training for online and chat counseling. This training includes general information on mental health and mental illness, information on verbal tools, techniques for online counseling, and advice on how to deal with possible psychological stress that could arise throughout the counseling process. The training is composed of input sessions from trainers with vast experience in online counseling and opportunities to gain hands-on experience with OPEN2chat through role play.

However, OPEN2chat is not a counseling tool *per se*, but rather a stigma-free space for exchange with the possibility for young people to articulate their concerns, share opinions and experiences with a peer, and subsequently open up to the idea of professional counseling or therapy if needed. The goals are thus individual and joint reflection and the de-stigmatization of counseling services or therapeutic settings. OPEN2chat can be accessed *via* http://www.open2chat.at and is free of charge. German is currently the only supported language. Peers can register anonymously by using a token and immediately ask their questions to a peer facilitator. Peers can tag their messages with overarching themes (e.g. "school", "family", "bullying", etc.) to allow peer facilitators to handle only those messages they feel familiar with. Peer facilitators can take over newly received messages according to their time capacities and are considered responsible for this contact from then on. If necessary, they can call in supervisors for support. Supervisors are mental health professionals who are available to peer counselors *via* chat, telephone, video call and, if required, in person. They have direct insight into the current chats of the adolescents they are supervising and can intervene if necessary, e.g. when a peer counselor feels mentally burdened by the topic of a conversation. Additionally, supervisors and peer counselors meet regularly in one-on-one sessions to discuss the counsellors' experience with OPEN2chat and their overall mental wellbeing.

To ensure attractiveness for the target group and present the offer in a familiar format to young people, OPEN2chat visually corresponds to a chat tool (like SMS, WhatsApp or Facebook Messenger), e.g., offering standard digital communication tools such as emoticons. At the same time, the communicative synchronicity that is often associated with the services mentioned above is deliberately not provided in OPEN2chat. The peer facilitators are required to react to a message within 72 h at the latest. On the one hand, this is to prevent the peer facilitators from being overburdened, but on the other hand, it also encourages the peers to reflect. The time window between two text tokens in the "chat" can encourage peers to take more time to produce a single token and proceed auto-reflexively. Hence, OPEN2chat can be used in either an a-synchronous e-mail or a classical synchronous chat function.

Peer Facilitators

To be able to offer this psychosocial support to peers (help seekers) and ideally also benefit from the voluntary work themselves, the counseling young people, who in the case of OPEN2chat are referred to as "peer facilitators," must above all have the ability to empathize and feel a basic sense of security in their own lives. While neither facilitators in other online support programs like "U25" (26) nor volunteers in the German "Youth-Life-Line" classify the stresses they encountered during counseling as unmanageable (27), the former identify concrete challenges related to their counseling work. Particularly significant here is the confrontation with one's own ability to act, which is perceived as severely limited by the format of anonymous counseling. In connection with this, a lack of answers from the users is described as particularly frustrating. The interviewees in the study of Egli (26) also describe difficulties in experiencing their empathy as limited in some cases, for example when topics trigger adverse emotions in facilitators, or they do not find a typical "wavelength" with those seeking advice. These problems, which are directly related to the counseling process, mean that peer facilitators must draw on a range of coping strategies.

The facilitators at U25 point out the relevance of internal organizational support (26), which supervisors provide at OPEN2chat. While some interviewees state that they resort to external social support, such as friends or family members, others say they rely more on a strict separation of counseling and private life. Thus, it becomes clear that dissociation from the subject matter can be a valuable coping strategy for young facilitators (26). Barbuto et al. (28) also emphasize that counseling topics should be dealt with in the framework provided for this purpose. Facilitators should learn to understand psychosocial issues addressed in the counseling sessions. The facilitators at U25 also consider the training, which takes place before the first counseling sessions, as critical support. During this training, initial counseling sessions are practiced using email examples, information on mental health issues is shared, and trust within the group is strengthened. Since internal support is also seen as the leading resource later in the counseling process, this trust between all participants is particularly relevant. The training can be seen as a basis for avoiding substantial stress in the course of the counseling sessions. Later on, regular expressions of appreciation to the facilitators are important reminders of the support opportunities within the organization (26).

If these sustainable support services are available, facilitators can benefit from the experiences gained during their counseling activities even years later. In total 82% of former peer facilitators of Youth LifeLine state that they can recognize and deal with their crises, 60% accept help from professionals. In total 96% of the respondents think they can also support other people privately under challenging situations; a similar picture emerges concerning education and professional life (27). One reason for these high values can be seen in the positive experience resulting from the analogous relationship between help-seeker and counselor, which stimulates spontaneous self-reflection, trust-building, and self-identification (28).

Co-development, OPEN2chat, and the Current Study

It is not enough to develop offers for vulnerable populations such as adolescents from an external development team or mental health professionals; it is also a vital point to include the people in the process and evaluation of such offers and give them a voice (29). Participatory research is an approach that includes people in various stages of the research process. It gives them the power to be involved and make and inform critical decisions, hence breaking the hierarchy of the researcher being the "expert" by making the population co-researchers (30, 31). Co-development for mental health and wellbeing programs has recently received increased interest (32, 33). Participatory development can range from consultative to collaborative (32). Either version of involving young people, in particular, does not only have beneficial effects for the research process but also on the empowerment and capacities of the young people involved (34), leading to a positive impact on mental health and wellbeing in itself (35). Bevan Jones et al. (32) conclude that emerging studies involve young people and specific subgroups in co-design. Still, they state that specific subgroups like younger children and those with learning disabilities and specific difficulties are under-represented and have particular needs and preferences that might not be acknowledged in current approaches. Finally, in their perspective, research is required to look at technologies' developmental and implementation phases. The co-design practices might then become the new benchmark for how digital technologies of high quality are developed. Furthermore, it is essential to include the relevant population in scientific development and describe this process to evaluate the impact properly (36).

Mainly, peer-to-peer support systems' co-development focuses on end-users' perspectives of such platforms. While this is undoubtedly vital for the success of these platforms, we argue that including the peer facilitators in the co-development process will likely also influence the experience for the end-user. For example, in a literature review about peer support mental health interventions, co-design and development mainly were done with peers, i.e., those seeking support (37). In the current paper, we describe the process and influence of co-development with peer facilitators (i.e., the people who provide support) of the online peer encouragement network OPEN2chat. The webtool offers adolescents an anonymous platform where they can talk to and share their problems with specifically trained adolescent peer facilitators. These peer facilitators have been involved at various stages of the process and have co-developed the platform from users and facilitators' perspectives. First, they were involved in the needs analysis in 2018 (investigating the needs of adolescents in Austria regarding their mental wellbeing) that resulted in the establishment of a co-development team in 2019. This team was constantly involved in all phases of the development until the prototype of the web application was established in 2020.

After installing the web-tool proto-type, additional adolescents and young adults who had shown interest in peer facilitators' roles were invited to test the current version. We describe their primary input, ideas, and concerns by analyzing 3 group discussions after a single testing session of the tool for each group. Subsequently, the results of the first use of the prototype are presented. We also discuss how their input was implemented in further development.

METHODS

Population of Peer Facilitators

We actively recruited testing peer facilitators at secondary, upper secondary, and vocational schools and students at bachelor's degree programs in, e.g., psychology and social work between 16 and 21 years old. We recruited in the respective schools *via* social media and printed flyers in the year groups of the study programs and schools and asked those involved to tell friends, family members, and the classroom to join the test development group. Additionally, we promoted the program *via* social media in parent groups. We recruited for three sessions of test peer-facilitators in 2021. Adolescents were invited to test the OPEN2chat prototype and were subsequently informed about our scientific aims and data collection methods. Before the testing period, all adolescents were interviewed by a research team member to assess whether they could handle the time expenditure and potential emotional stress of using OPEN2chat. Thus, all adolescents interested in testing OPEN2chat and who passed the interview stage were included in the sample. We did not need to exclude any subjects from participation.

The sample consisted of a total of 21 adolescents (18 female, 3 male) between the ages of 16 and 22, who were interviewed in groups of 6, 8, and 7 according to their time of participation (either February, June or September 2021). Out of the 21 participants, 20 were university students of various Bachelor's programs in Austria, while one was a student in secondary school. One of the previous need analysis participants also was a test peer facilitator. Apart from this participant, none of the adolescents had any previous contact with the OPEN2chat project.

Interview Procedure and Structure

Each group participated in two online sessions, with 2 weeks testing the online application in between. The first session consisted of presenting the tool. It defined pairs of facilitators that alternated the role of test facilitator and test peers (i.e., the person who seeks help). Individuals stayed in one role for 1 week. After the test phase, a group discussion took place. Each session had two or three moderators with one designated discussion leader. Session duration was between 60 and 120 min and followed a predefined interview guideline. This guideline included questions on technical aspects of the communication and questions about the communication process and the individual experiences of each test peer facilitator. The ethics committee approved the study (EKNr: 1070-2020), and informed consent was required from all participants.

Analysis

Group discussions were transcribed *via* a word processing application with the following transcription rules: Dialectal utterances were largely transcribed as standard Austrian German, some exceptions being diminutives ("ein bissl") or contractions (e.g. "ich kann's"). Phonetic tokens not carrying a lexical meaning (e.g. "ahm") were not transcribed. Acoustically unintelligible utterances were marked with "[unverständlich]"/"[unintelligible]". While the researchers are identifiable with their first names in the transcribed files, participants were assigned numbers according to the order they first spoke during the recording.

Qualitative analysis was conducted *via* QSR International's Nvivo (38). After transcription, discussion notes were transferred to the software. We analyzed the data using thematic analysis (39) because it can describe the participants' reality and experiences without pre-existing theoretical assumptions. All data was coded by one coder (S.S.S) and reviewed by a second coder (G.M.). The ongoing discussion between all authors resolved discrepancies, which led to the restructuring, deletion, and collapse of some categories. Saturation was reached after the third focus group, as no new themes emerged. The authors translated quotes that were used in this article.

RESULTS

Four categories were the main themes of the participating peer facilitators (i.e. people who provide support): (1) Responsibility covers concerns about how to handle the sensible topics brought on by the peers; (2) The interaction process includes peer facilitators' thoughts about the whole communication process with peers; (3) Time management, including the timing between interactions and the number of peers; and (4) Technology, which covers all problems and ideas on a technical developmental level. Categories were further coded into sub-themes (see **Figure 1**).

Responsibility of Peer Facilitators

The first theme describes peer facilitators' thoughts about the (self-perceived) responsibility when interacting with peers and helping them with their problems. For peer facilitators, who are mostly teenagers themselves and not trained psychologists, this seems to be the theme related to the highest level of anxiety. Concerns related to the contents of messages, the effects of messages on peers, external support, training, and emotions.

Content(s) of the Messages

The contents of the messages were addressed frequently during the group discussions. Peer facilitators identified topics about which they already had knowledge through their own experiences to be easier to relate to. On the other hand, a lack of knowledge about an issue led some facilitators to feel overwhelmed (e.g., when asked for advice on a peer's parents' divorce while never having experienced a similar issue). This emphasizes the importance of peer facilitators choosing peers according to their problems to facilitate helpful advice and ensure that facilitators feel confident and secure. Other than just knowing the problem, uncertainty could arise because the facilitator did not have

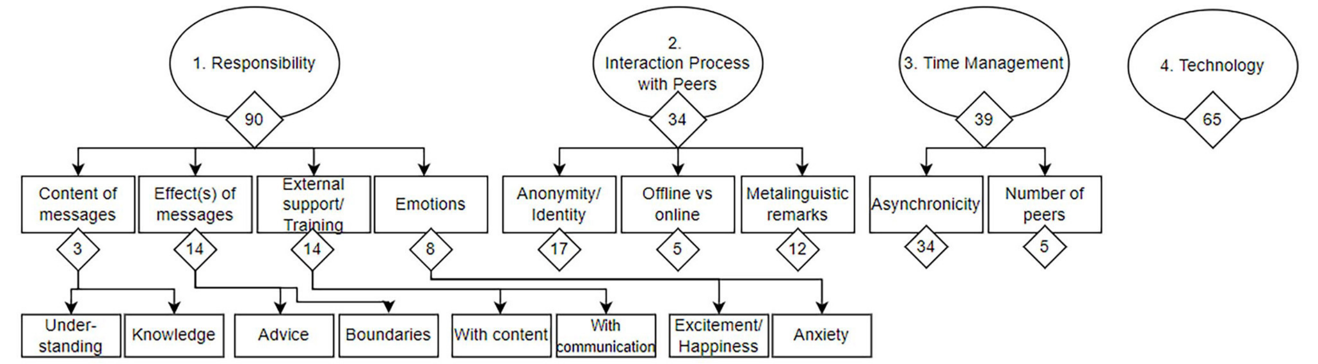

FIGURE 1 | Coding tree of themes and subthemes. The number of coded sequences per theme can be found below each node.

enough information, was unsure about the topic, or could not think of any advice for the given situation. Peer facilitators agreed that there were different difficulty levels regarding the severity and the content of the problem, which could be subjectively more complex or more straightforward. For example, "school" was seen as a relatively simple topic, though some needed time to emphasize since it has been some time since they had attended school. A topic that was perceived as more difficult was problems with other friends or peers, which involved people who were not part of the conversation.

> *"And yeah, the person also didn't know how to manage at school, when the person no longer has any friends. And yeah, I think I would definitely say that it is easier for me or that the topic is easier here. That it can help more directly than with the other topic with the friend and much more." (2-06)*

In this context, it should be noted that many facilitators felt the urge to provide their peers with pieces of advice in their first few messages and feared seeming intrusive when asking too many questions. Some voiced concern that they did not feel like they were able to tell the other person what to do. The following quote shows how a peer facilitator struggled because they did not feel confident to give concrete advice:

> *"I can understand that well [. . .], you want to say something, but [. . .] I somehow had too little information to really say / [what] the person should do now and you don't want to say: okay that would be good, and that would be wrong or that would be bad or that would be good[...]" (1-03)*

The juxtaposition of "good"/"bad"/"wrong" illustrates that the facilitator, on the one hand, feels urged to give specific advice, i.e., to directly react to the content of the user's message with ideas or suggestions on how to solve their issue. On the other hand, however, they do not want to do this due to a lack of knowledge about the user's situation. This ambivalence might lead to a conflict of interests that the peer facilitators need to resolve to proceed with the counseling process.

Effect(s) of the Message on Peers

A dominant topic throughout all three discussions was the possible effects of the peer facilitators' messages on the recipients. Some concerns were, for instance, the extent to which said messages could help the peers with their issues, how a welcoming environment could be created within the chat, how not to overstep boundaries when asking questions or giving advice and how to show empathy *via* written text messages. Peer facilitators found it challenging to find the line between asking questions and not being too intrusive and between being empathetic but still professional, for example, when disagreeing with the peer's parents.

> *"[...] it was often the case that when I suggested something, the response was "I can't do that because of my parents", and I found it very difficult not to say, "I don't think it's cool that your parents don't do that", i.e. not to condemn the person's parents [...]" (3-04)*

External Support and Training

Participants described scenarios where they would have liked to seek external support from trained supervisors. These scenarios mostly revolved around receiving messages that proved problematic in their content. Additionally, some adolescents mentioned a need for professional digital and written communication skills to feel more secure.

> *"And then, as I said, I was stuck for a while. And maybe, if it had gone in that direction somehow, I would have asked [a supervisor] at some point. That would have been the only situation where I would have asked for more ideas, creatively speaking. Somehow, I probably would have asked. Exactly. So just inventiveness, in that respect." (2-01)*
>
> *"I just think that it would be cool if you gave us a certain basic structure at this seminar for asking questions, but I guess you already have planned something." (3-03)*

Emotions

Most peer facilitators agreed that the excitement and anxiety were worst during the first interaction but diminished over time.

> *So I definitely have the feeling that this just gets easier and certainly works better the more often you do it - I'm also sure when you get more used to this medium, when you write about such things or such problems. (1-03)*

An initial feeling of being overwhelmed also accompanied this. On the other hand, they also mentioned positive emotions, especially a happy excitement when receiving an email and satisfaction after successfully replying to a peer's message.

> *"But it definitely feels good when you write a message and, as I wrote, you're somehow satisfied with it, where you have the feeling that you've somehow got it across well, so that's already / I think that feels good somehow, even when it's sent, and that's somehow so (...) and you have the feeling that you've somehow got to the heart of it then / it's a good feeling anyway." (1-03)*

Interaction Process With Peers

Anonymity and Identity

Participants discussed to what extent their and their partners' anonymity influenced their communication strategies when chatting *via* OPEN2chat. Some issues mentioned in connection to the peers' and peer facilitators' anonymity were a greater struggle to understand the peers' background and thus their problems. Another point was that communication with an anonymous other felt "strange". They further mentioned ideas on how personal identity can or could be constructed within this medium, e.g., by providing their communication partners with basic information about their gender, age, or hobbies.

The test peer facilitators acknowledged acquiring information about the peer and their respective issues as their primary aims when composing the first few messages within the chat. Due to the anonymity, the first goal would be to understand the personality, the writing style, and how much is written between the lines.

> *"So I think you have to be more careful than when you know a person personally because it's difficult to know exactly what will help the person. There are people for whom it is a great help if you are simply very direct and say what strikes you, and others are more likely to be offended or offended if you are open, and so you have to be more careful overall." (2-02)*
>
> *"But I would definitely, what we already do anyway, that you can choose the age and which gender, so the criteria you can choose. Maybe hobbies, but that you somehow, possibly also pictures somehow, so I don't exclude that now either. But I would think it would be good that way." (3-06)*

Offline vs. Online

Some participants voiced that the online environment caused additional challenges for peer facilitators, such as a lack of non-verbal elements of communication. They felt that it was harder to be empathetic due to the online anonymity, as you cannot see how the peer receives the message. They also argue that you do not have to filter what you say as much as during an online message in a face-to-face conversation because the message should not be too long. On the other hand, peer facilitators found the spatial distance and anonymity reasonable to think about the problem and their answers.

> *"So it's a bit difficult to find a middle ground, because you don't know how it will come across at the other end, because when you're sitting in front of the person, you can convey a lot that can't be expressed in words and that's kind of difficult to say - how do I convey it in such a way that it's still like / so that in the end it's just my (...) what I have from the information I have so far and how I think I would deal with it." (1-03)*

In this quote, a peer facilitator describes their struggle with a lack of non-verbal information in the chat format. They express their aim to react accordingly to the information given verbally by the user, without compensating the lack of non-verbal cues by inferring subtext to the messages that the user might not have intended.

Meta-Linguistic Remarks

When discussing the effects and contents of their messages, the test peer facilitators also reflected on the language they used, e.g., in terms of wording or structure.

> *"Then I also tried to summarize things or to keep them as open as possible, or, I think I wrote once, it is important that I know this more precisely in order to be able to help you. Yeah, to kind of explain why I do it that way." (2-05)*
>
> *"Because I just find it a bit difficult in the beginning when chatting, that you have to collect your thoughts, your thoughts a bit and then really have to pay attention to, okay, what exactly do you want to say now, what is the most important thing. Yes, I think in the chat it's better not to write too much anyway, so that it's clear." (2-06)*

Time Management

Asynchronicity

Mostly, peer facilitators agreed that the asynchronicity that comes with the online environment makes it easier for them to reply to the problem. Taking some time to think about their response, especially after receiving the first message, helped reduce anxiety in the peer facilitators.

> *"So for me, when the first request is made, I would like to be able to take my time and somehow think about it for a day or two. And you usually get a relatively long text at the beginning, and then you will answer in a relatively long text, and if there are follow-up questions or certain follow-up questions, then it can perhaps be fine that you answer relatively directly, that a conversation arises from it and that it are not somehow certain questions that are aimed at something specific." (1-04)*
>
> *"And then it wasn't so easy for me/so I spent a really long time making improvements on the message and a super long message/I also had a hard time giving my opinion, but somehow coming off too strong, too (...) too pushy with my opinion or something. So I fiddled around for a long time at the beginning, but I was similar to B and then it got better somehow and the next messages were easier." (1-03)*

A significant theme of peer facilitators during all group discussions was time management: While wanting to take enough time composing a message to accommodate their schedules and sufficiently reflect on the peer's question or problem, the peer facilitators did not want to keep their peers waiting for too long. Some preferred to reply within a 24- or 48-h window to be still familiar with the content of the chat when composing the next message. The following quote illustrates how a peer intentionally used a longer time frame to write a thoughtful response:

> *"But I also believe that it is important at the beginning just/so I also believe that it is important, to basically also have this time and to say, okay, you can think about it, because the in the chat procedure now just already shown who there already once (unintellig.) to pay attention that one doesn't communicate anything in a wrong way and therefore I also find it important that one just also knows, okay, one can think it over for 1 day or so." (1-03)*

At the same time, a different peer facilitator preferred answering immediately after receiving a message. This variety of opinions shows the importance of a tool fit for various communication styles.

> *"So it's easier for me if I answer straight away because then I'm simply confronted with the problems for the first time, and then my answer immediately contains my first helper thoughts, so to speak." (1-05)*

Number of Peers

Another topic concerned the number of peers/messages that peer facilitators could handle. There were different opinions about that, depending on the problem and personal time availability. Some said that around three other peers should be manageable for them as peer facilitators to handle at the same time.

> *"So I'm very quick with answers and yes / think so because simply at least three people at the same time would be possible as well and I could write to them because it's easy for me." (1-05)*

Technology

Even though technology was one of the most frequently discussed themes in our sample, we will only briefly describe the outputs. Most of the time, technological features are very straightforward and do not call for in-depth discussion. Instead, their implementation depends on the responsible program developers' time, money, and competencies. In our case, as a result of the group discussions, we focused on implementing the two main improvements mentioned below, which have already been implemented since the group discussions.

Participants discussed a wide range of technological features and the prototype they had tested. They described problems they had encountered, aspects they deemed neutral or positive and their wishes for improvement and adaptation of the tool. The two main ideas that the developers of OPEN2chat implemented were the function of the Enter key to start a new paragraph instead of sending the composed message right away and the improvement of the efficiency of e-mail notifications (as some have not received any).

> *"And on the mobile phone, the problem was that the messages were displayed in such a way that you couldn't read them, exactly, and the last answer was also covered by the chat bar, so I had some problems there." (3-03)*
>
> *"The only point I also want to make is this Enter key for sending. Sometimes it was annoying, especially when you wanted to go into more than one thing and needed a paragraph." (2-05)*

DISCUSSION

This paper describes the importance of including peer facilitators in the co-development of an online peer support tool to develop and improve OPEN2chat. Three groups of peer facilitators conducted a 2-week testing session of the tool, followed by an online group discussion. Four main themes were discussed during those sessions. First, peer facilitators' concerns about their responsibility of giving advice; second, the online interaction process with the peers; third, the time management of the tool; and fourth, technology.

It is difficult for trained psychologists or researchers to understand the fears and concerns of being an untrained peer facilitator without their direct input. Yet, feeling anxiety when interacting with peers as a peer facilitator might lead to a negative experience for the peer facilitator and the peer. This underlines the importance of including all stakeholders in the co-development process, especially if the group is directly using the platform with the peers. We found that peer facilitators' main point of anxiety was during the first contact with their peers, which is also discussed in previous studies (e.g. (26)). This relates primarily to peer facilitators' insecurity about writing the first message. Depending on the topic of the problem, this is perceived as more accessible or more complex and necessarily needs high-quality training programs (26).

The online environment and the resulting anonymity can heighten the anxiety (40), though it also bears advantages such as having time to think about an appropriate reply. The stress related to writing the first message and the responsibility of helping another person with their problems may be reduced if new peer facilitators get more intense help from a supervisor during their first peer interaction. As facilitators in our sample had not done this kind of helping before, they might be more confident after a few different peers to communicate with. Helping them with their peer might ease them into the process and make them more relaxed when writing with their future peers. It has also been shown that peers' counseling-based training affects the peer relationship and the quality of the support given (41). Therefore, our training can potentially improve the confidence of our peer facilitators.

Some discussion points were more straightforward to resolve than others. Time management and especially the timing between the first message from a peer and the first reply was a central discussion point for the peer facilitators. Yet, there was no consensus about the correct restrictions/freedoms. Some preferred shorter periods to be familiar with the problem, some selected more extended periods to think about the issue in-depth. Time management and overload seem to be somewhat subjective problems, so peer facilitators should have as much freedom as possible when deciding how many peers they want to accept at the same time. Other online peer support platforms have stated that creating guidelines and ground rules for all facilitators in advance has benefited everyone included. Therefore, these give a framework and confidence and guidance (42).

It is important to note that technology was the most prominent category in our sample. It became apparent that by using an interview guideline that was rather open-questioned, group discussion participants tended to talk about more obvious topics such as technical features. It seems logical that these topics are easier to think and talk about. Following this observation, it seems desirable to prepare a more detailed interview guideline before the group discussion. In that case, even if the debate is supposed to be very open (as it can have advantages to let participants speak freely), it gives the group discussion leader the possibility to steer the group to less obvious or "harder" topics if necessary.

Peer support interventions/peer-to-peer networks seem to show positive results concerning feasibility, acceptability, and effectiveness (37). We know that adolescents are confident about interacting online in a digital environment (43). Yet, the specific setting of a support tool still poses the potential for anxiety for the peer facilitators due to the responsibility they feel when advising other unknown adolescents. The main aim is to improve how confident the peer facilitators feel, especially during the first interaction. This can be achieved by giving them the freedom to choose between different peers/topics and offering support by a senior psychologist/researcher during this time. The fact that the support system is embedded in a digital environment bears both advantages, such as having more time to formulate an appropriate response, and disadvantages, such as lack of non-verbal communication cues. Adolescents nowadays are digital natives and used to navigating through an online space. Yet, intimate topics are usually discussed in an offline environment (44). Due to missing facial cues in an anonymous online conversation, it is harder to know another person's feelings (45).

The Importance of Co-development and the Future of OPEN2chat

Including young people seems to be especially important to develop mental health applications as the taste and interests and mental health problems differ between adults and young people, which makes it harder for adults to design age-appropriate programs (32). By including potential peer facilitators in the development process from the beginning and addressing their concerns in an ongoing process, peers, peer facilitators, and involved researchers/practitioners will benefit from the web application, which will undergo constant adaptations (32, 33). This paper describes the involvement of one group of stakeholders, namely the peer facilitators. Co-development is an ongoing process that involves all relevant stakeholders.

As limitations, we have to report typical problems of co-development (32). Our sample was relatively small and might not represent the population in general. Additionally, participating adolescents and young adults might underly self-selection because they are more interested in mental health issues. This is also reflected in the preponderance of women in our sample, which was constituted by only 14% of male adolescents. This low percentage is not surprising as there is a general predominance of women in the health care sector (46).

Future development of the tool will show whether the end-users of the device will report necessary adaptations. Co-development with peer facilitators (and not end-users) is a limitation and strength of this study. While it is not enough to only co-develop with peer facilitators, it also provides an essential step to including all relevant stakeholders. Even if we are not calling the peer facilitators "end users," they will use the platform just as much or even more than the peers in the end. Additionally, co-development and evaluation of the platform with peers will be done in the future.

As of November 2021, hosting the tool has been overtaken by the Caritas der Diözese St. Pölten and Caritas der Erzdiözese Wien, and the first group of peer facilitators has completed their training. Many papers and reviews describe low user engagement with digital intervention as a challenge that a rigorous co-design process might reduce through a positive relationship with users and a higher quality of the application (47). Initial user engagement for OPEN2chat (which launched in December 2021) was positive both with peers and peer facilitators, which shows the first evidence for a successful implementation. Yet, we cannot say if this is related to the user engagement throughout development, as we did not specifically address the impact of co-development as an outcome. This is a relevant problem in the literature on participatory research (33). We plan to qualitatively evaluate the impact of our co-development by addressing this question in the ongoing collaborative work with peer facilitators, who have been part of the development and are still part of the team that uses the web application.

It should be noted that we aim to continue the co-development process after the initial launch in December 2021. We plan to adapt and improve OPEN2chat based on scientific evaluation centered around adolescent users on both ends of the chat. Using quantitative and qualitative methods, we aim to collect data on the effectiveness of the intervention for peers and data on the wellbeing of peer facilitators. Based on these findings, which will be communicated to the responsible software engineers, we hope to ensure the lasting usability and appeal of OPEN2chat for our target group.

CONCLUSION

In conclusion, co-development is vital for developing online tools, especially for children and adolescents. Including all relevant stakeholders such as peers and peer facilitators add to the end product's quality. Giving that group a voice can only improve the design and content of such a tool, and we argue that co-development should be implemented whenever possible. As a next step, we will evaluate the efficacy of the application and will continue to improve based on the evaluation and implementation of our formative research approach. Only *via* such broad co-development and the following empirical assessment of the program's efficacy will it be possible to differentiate between co-developed programs and those that are not.

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 human participants were reviewed and approved by Commission for Scientific Integrity and Ethics of the Karl Landsteiner Private University for Health Sciences (EKNr: 1070-2020). Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

MB, GM, SS, and BS conceived of the presented idea. SS and MB interviewed the participants. SS and GM transcribed the audio files and analyzed the data. MB, SS, TD, and GM wrote the first draft of the manuscript. All authors discussed the results and contributed to the final manuscript and authors contributed to the article and approved the submitted version.

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A Socio-Ecological Approach to Addressing Digital Redlining in the United States: A Call to Action for Health Equity

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Physical distancing requirements due to the coronavirus (COVID-19) pandemic has increased the need for broadband internet access. The World Health Organization defines social determinants of health as non-medical factors that impact health outcomes by affecting the conditions in which people are born, grow, work, live, and age. By this definition broadband internet access is a social determinant of health. Digital redlining—the systematic process by which specific groups are deprived of equal access to digital tools such as the internet—creates inequities in access to educational and employment opportunities, as well as healthcare and health information. Although it is known that internet service providers systematically exclude low-income communities from broadband service, little has been done to stop this discriminatory practice. In this paper, we seek to amplify the call to action against the practice of digital redlining in the United States, describe how it contributes to health disparities broadly and within the context of the COVID-19 pandemic, and use a socio-ecological framework to propose short- and long-term actions to address this inequity.

Keywords: health equity, digital health equity, social determinants of health, internet access, digital redlining, COVID-19

INTRODUCTION

"Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death."—Dr. Martin Luther King Jr.

More than 50 years since Dr. King's speech, significant health disparities persist in lower income communities of color in the United Sates. Social determinants of health (SDH) primarily drive these health disparities. SDH are non-medical factors that impact health outcomes by affecting the "conditions in which people are born, grow, work, live, and age" (1). Examples include access to safe and affordable housing, educational and employment opportunities, and healthy foods, which account for 80% of health outcomes (2). Frequently overlooked as a SDH, access to broadband internet also emerged as essential infrastructure particularly during the COVID-19 pandemic (3–5). For example, various regulations enacted to mitigate community transmission of COVID-19 meant that broadband internet access became essential for people working remotely, online or distance learning, and virtual health visits *via* video or phone. Some communities, such as Black and Brown communities (6), have been disproportionately affected by the pandemic, exacerbating the existing digital divide that includes but is not limited to broadband internet access.

In this paper, we aim to increase awareness about the practice of digital redlining in the United States, its health consequences, and amplify the call to action for public health experts and advocates to support essential communications and technology service infrastructure, such as access to broadband internet, internet-enabled digital devices, and efforts to increase digital literacy in under-resourced communities. Specifically, we (a) discuss digital redlining and the impact lack of broadband internet access had on education access and quality, employment, and access to high-quality health care in the context of the COVID-19 pandemic; (b) apply a socio-ecological framework to propose synergistic short- and long-term strategies to expand broadband internet access; and (c) present existing work focused on addressing this inequity. Our perspectives draw from personal and professional experiences. We have developed digital health solutions for people who are underserved by mental health resources (7). Our patients, research study participants, family, and friends have experienced inability to participate in distance learning, inability to work remotely, or limited ability to access virtual care and telecounseling—primarily due to insufficient broadband internet access.

DIGITAL REDLINING AND THE IMPACT OF THE COVID-19 PANDEMIC

Redlining originally described a discriminatory practice in which lenders classified neighborhoods, predominantly Black and Brown communities, as risky investments and therefore denied loans to individuals wanting to purchase homes in these neighborhoods (8, 9). The Fair Housing Act of 1968 made the practice of redlining unlawful (10). However, the effects of redlining can still be felt today in many lower income communities of color: communities that were redlined endured disinvestment, resulting in food deserts, limited access to educational and employment opportunities, and fewer options to receive quality health care (11, 12).

Digital redlining, or the intentional lack of investment in broadband infrastructure and affordable service offerings in low-income communities, contributes to health inequities (13–15). A study exploring historical redlining and broadband internet access in Milwaukee showed inequities in broadband access prior to the COVID-19 pandemic; neighborhoods rated the highest "A" (predominantly White and higher income households) were significantly more likely to have broadband access than "D" rated neighborhoods (historically redlined lower income communities of color), 82 vs. 62% (15). Similarly, a study conducted by the Greenlining Institute discovered that areas in California that were redlined in the past (e.g., Oakland) currently lack sufficient broadband internet access (16).

The World Health Organization declared a global COVID-19 pandemic in March 2020 (17), as a result broadband internet access became a necessity. Low-income earners, individuals living in rural communities, elderly, and Black and Brown individuals were less likely to have broadband internet services and more likely to access the internet using their mobile devices (18). Approximately 45% of lower income households (<$25,000) and around 36% of rural households do not have access to broadband internet (19). Furthermore, the lack of access to broadband internet disproportionately affected Black (31%), Latino (31%), and American Indian/Alaska Native (34%) children (19). These communities relied on mobile device data for internet-based services during the pandemic, including schooling, work, and virtual health visits (18). Inequities related to access to quality education, employment, and health care seen pre-pandemic were worsened by no or limited access to broadband internet.

Education

Education access and quality is a SDH: higher levels of education have been linked to better health and longer life-span (20). Higher education is a pathway to obtaining higher paying jobs to improve standard of living and accumulate generational wealth. During the COVID-19 pandemic, the abrupt shift to remote learning has disadvantaged ∼16.9 million children in the U.S. who did not have access to broadband internet (19). Children unable to engage fully in distance learning experienced a "homework gap"—difficulty participating in remote learning and completing assignments—due to lack of broadband internet and inadequate computer or device access at home (21).

Children also experienced a widening achievement gap during the pandemic. For example, students in grades 8–11 without broadband internet access took longer to complete assignments and had lower grade point averages (22). Some students even sat in parking lots outside of schools, libraries, and restaurants to access internet for remote learning (23, 24). The disparity in broadband internet access is seen across education levels. College students in rural areas, lower income and Latino households were less likely to have broadband internet access at home than their counterparts (25). Individual workers with higher education levels were more likely to be able to transition to working remotely during the pandemic, reducing their possible COVID-19 exposure.

Employment

Limited educational opportunities translate into limited employment opportunities downstream. Access to safer and higher paying jobs are well-recognized SDH that were exacerbated by broadband internet access disparities during the COVID-19 pandemic. COVID-19 regulations classifying essential workers also systematized inequities by occupation. That is, possible exposure to COVID-19 varied by occupation, leading to exposure risk disparities because individuals from minoritized communities (e.g., Black and Latino) are more likely to occupy *high exposure risk* jobs (e.g., industrial, retail, and transit jobs) (26)—occupations involving close contact, within six feet, of another individual for a total of 15 min or more over a 24-h period (27).

In contrast, *lower exposure risk* occupations do not require close contact (27). This includes remote workers, office workers who do not have frequent close contact with coworkers, customers, or the public, and healthcare workers providing telehealth services only. Individuals who could pivot to remote work by utilizing broadband internet not only reduced their risk of COVID-19 exposure but also that of their household. Due to the effects of structural racism, such that more non-Hispanic Black individuals are essential workers, COVID-19 mortality was higher among non-Hispanic Black persons in comparison to non-Hispanic White persons (26, 28, 29).

Health Care

Because of limited or no high-quality, affordable broadband internet access, low-income communities, rural communities, the elderly with low digital literacy, and groups who have been historically marginalized are unable to fully benefit from contemporary evidence-based digital health services and tools. The COVID-19 pandemic accelerated individual and health system adoption of digital health tools for healthcare services (30, 31), in alignment with drastic limitations of in-person healthcare services and transitioning to virtual health service delivery that relies entirely on internet access (32). However, even though a study by the Department of Health and Human Services (HHS) revealed that there was a 63-fold increase in the use of telehealth services by White beneficiaries, Black beneficiaries were 2% less likely than whites to use telehealth services (33). Other studies show that individuals living in rural communities, the elderly, Black and Hispanic individuals, and low-income earners have been less likely to use telehealth services, predominantly due to limited/poor access to broadband internet (34, 35). These communities have greater difficulty navigating the healthcare system to find a preferred healthcare professional who is available, affordable (e.g., in-network), and accessible using a compatible device for telehealth visits and with sufficient broadband internet access. For example, lack of high-speed internet access has significantly affected the ability of Black individuals as compared to White individuals to access healthcare professionals (36).

Communities more likely to have poor internet access have experienced a decline in healthcare visits overall during the pandemic (35), but also a decline in the quality of their virtual visits if used. Because of task burden on mobile data and resultant slow internet speeds, families must choose and prioritize certain tasks over others (37). This translates into a barrier to accessing healthcare services when families choose to forgo health visits to prioritize, for example, schooling (37). Inconsistent medical check-ups are associated with high morbidity and mortality (38) and these consequences are likely to be more pronounced in marginalized groups who have a higher chronic disease burden in the absence of, but especially also during a pandemic. A recent study found that missed appointments was associated with increased all-cause mortality among those with chronic health conditions, particularly among patients with chronic mental health conditions (38).

Poor-quality internet limits families' ability to access healthcare services because of poor-quality audio or video during interactions with their healthcare professionals. Multiple interruptions from slow internet speeds during video telehealth visits interferes with rapport building, hinders patient comprehension, and frequently results in switching to telephone calls which is associated with poorer comprehension compared to video visits (39, 40). Additionally, because families may need to ration their data or internet usage, privacy may not always be able to be maintained for virtual visits. Special populations, such as individuals with mental health disorders, may be made even more vulnerable to poor mental health because they may be less likely to afford internet access as a result of unemployment and possible homelessness. This, in combination with the COVID-19 driven global rise in mental health disorder is likely to contribute to worsening of mental health care service disparities.

STRATEGIES TO EXPAND BROADBAND INTERNET ACCESS

Broadband internet access is a SDH (4), intersecting and exacerbating other SDHs such as access to education and employment opportunities and access to high-quality healthcare services. The Social-Ecological Model can offer a clear roadmap of potential solutions to address digital redlining and expand broadband access to communities that have been structurally marginalized and minoritized. The Social-Ecological Model is a framework that acknowledges multiple levels of influence, guiding the development of solutions toward equitable access to broadband internet (41). We outline short- and long-term strategies with action points to address digital redlining (**Table 1**), including strategies at the societal, community, relationship, and individual levels (**Figure 1**).

Societal Strategies

Societal strategies with high potential to increase equity in internet access are federal changes in the definition of broadband, broadband infrastructure expansion, and telecommunications regulatory policies. Redefining broadband access is a short-term solution that addresses inequities in the quality of broadband which limits access. The Federal Communications Commission (FCC), the agency responsible for defining broadband, defines it as 25 megabits per second download and three bits per second upload. This definition sets the standard for broadband access. However, this definition is misaligned with the current needs and how people use internet today. Broadband access is central to societal functions as aforementioned, such as supporting access to education, employment, health care, and socialization (42, 43). The current broadband standard set by the FCC is insufficient to provide quality access given how integral broadband is to our daily lives (44) and serves to mask racial and ethnic inequities in quality of broadband access which matters for broadband to be useable.

The expansion of broadband network infrastructures is a critical long-term strategy, particularly for rural and

TABLE 1 | Key solutions and action points for addressing digital redlining.

Socio-ecological domain	Key solutions	Action points
Individual	1. Increase access to digital devices	• Establish programs (local, state, and federal) that subsidize cost of digital devices for individuals/populations that cannot afford these devices. • Health systems can develop digital health platforms that are accessible across multiple mobile operating systems and types of mobile devices.
	2. Increase digital literacy	• Providers and health systems should assess the level of digital literacy of their patients, i.e., ask if patients have clarity on how to use their devices for health-related purposes such as signing in for a doctor's visit, scheduling a lab test, reviewing their test results, sending a message to their provider. • Create handouts and videos that can walk patients through steps needed for digital device use.
Relationship	1. Employ community-based digital navigators	• Each clinic and hospital service should have access to a digital navigator who is available to explain to a patient, if needed, steps to using their mobile device or computer in accessing services. • The Information Technology (IT) department in each health system should be available at all times to respond to questions that patients may have about using their devices to access services. For systems or clinics without IT departments, a plan for accessing a digital navigator after hours should be in place. • Train current staff to provide services relating to digital navigation of technology for health services.
	2. Increase awareness of and access to digital navigators	• Part of the initial assessment and orientation to a clinic or hospital service should include information provided to the patient about how to access digital navigators. • Information about accessing digital navigators should be easily found on hospital/clinic websites.
Community	1. Increase financial support for under-resourced schools	• Local and state governments should include in their school budget funds for digital devices that includes internet access.
	2. Access to equitable health platforms	• Create digital health platforms that are accessible across multiple mobile and computer operating systems
Societal	1. Expand internet infrastructure and access	• Funding should be provided to internet companies to install adequate internet infrastructure in areas that are lacking, including cell towers, fiber, fixed wireless, digital subscriber lines (DSL), or cable • Expand WiFi hotspots to provide free WiFi for individuals who primarily access the internet using their mobile devices. • Subsidized cost of WiFi for specific individuals who cannot afford it.
	2. Redefine broadband	• Continuously review if the current definition of reliable high-speed internet meets current individual needs and update as needed. • Monitor internet maps to assess if residents are connected at the minimum requirement for high-speed internet.
	3. Regulatory policies	• States should use the Federal Communications Commission definition of reliable high-speed internet (download speeds of at least 25 Mbps and upload speeds of at least 3 Mbps). • Create regulations that ensure Internet Service Providers build infrastructure that meets the minimum requirement for high-speed internet.

Tribal areas (45–47). Some urban areas still lack infrastructure; however, evidence shows that rural and tribal communities account for the majority share of households that lack broadband access (46, 48). The lack of infrastructure barring these communities from accessing specialty healthcare services, job opportunities, and opportunities for educational growth have implications for health and wellbeing (5, 49). Beyond broadband access, building infrastructure that allows for expansion of internet access (e.g., WiFi), particularly if free, will go a long way in ensuring equitable access particularly in areas where consumers rely predominantly on use of mobile phones for internet access. Polices that promote digital health equity will decrease the likelihood of disparities arising from digital redlining. The recently signed Infrastructure, Investment and Job Act (IIJA), is a step in the right direction (50).

A third societal-level solution is to reinstate policies regarding net neutrality, which would require internet service providers (ISPs) to provide access to website content at the same speed and under the same conditions (51). These policies would result in broadband service providers treating all services equally; thereby preventing companies from providing different levels of service driven by factors such as the quality of internet speeds or location. The ability of providers to distinguish levels of service, tied to different costs, creates a structure in which usable broadband is unaffordable to groups that have been structurally marginalized and minoritized (52). This structure perpetuates inequities in access broadly and most importantly, access to quality broadband. This also limits growth or emergence of new broadband providers which could disrupt the monopolization of broadband service and lead to lower cost (52).

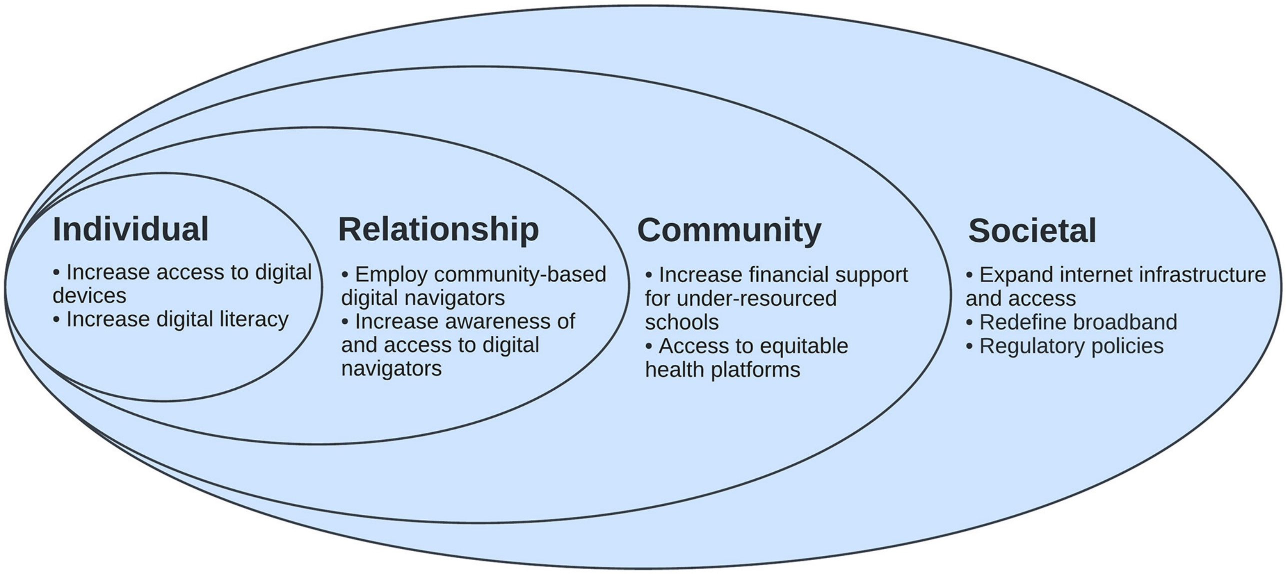

FIGURE 1 | Socio-Ecological Model for Addressing Digital Redlining.

There has been recent bipartisan effort to invest in affordable broadband in the United States (53). Current efforts such as President Biden's $65 billion investment earmarked for broadband infrastructure (54), the State of New York passing a law that requires all ISPs to offer high-speed internet plans to low-income families for $15 a month (55), Representative Yvette Clarke (NY) introducing an anti-digital redlining act (56), and the FCC's Digital Health Symposium on advancing broadband connectivity as a social determinant of health (57) are great attempts to address this issue.

Community Strategies

At the community level, solutions that focus on schools and neighborhoods are key to achieving progress. The 1996 federal E-rate program, which made telecommunications and internet access more affordable to schools, provided a basic level of broadband connectivity (58). The common use of digital tools to facilitate learning and prepare students to function in an increasingly digital society makes access to quality broadband paramount. A 2014 benchmark set by the FCC recommended schools have an internet speed of 1 Mbps per student to support digital learning (59, 60). Only 33% of America's schools meet this goal (61) and likely to be lower given the rapid increase in digital teaching and learning due to the COVID-19 pandemic has outpaced broadband growth and quality (61, 62). Building internet infrastructure in school locations and allocating funds specifically toward expanding internet access will increase the likelihood that schools can meet and exceed this goal.

Additionally, the increase in the number of devices demands more robust broadband infrastructure at schools. Less resourced school districts and those that serve children of color are more likely to face these challenges (43, 46, 62). Increased financial and technical support for school districts and re-examination of provisions of the E-rate program are needed to increase equity. School districts also experience hidden costs associated with providing broadband internet access, like network security and management. State support can help ensure that all districts have adequate and high-quality access. Solutions that expand broadband internet access in certain neighborhoods could also be impactful in reducing health inequities, for example, in rural neighborhoods. Existing evidence demonstrates the success of public-private partnership solutions in providing broadband access to rural communities (45, 63). The creation and execution of a municipal broadband access strategy that provides access to all members of a community is another potential solution. In addition, we must create digital health platforms that are accessible across multiple mobile and computer operating systems.

Relationship Strategies

Solutions at the relationship level are important to facilitate the diffusion of information relevant to digital access. As many transactions and interactions have moved online *via* digital collection tools and apps (i.e., registering for classes, searching for jobs, and accessing materials for school, job performance, or health), people often struggle to engage with information and communication technologies. For example, digital navigators, are individuals who can work with community members to increase digital inclusion and equity through sustained, direct interaction with individuals (64). They can be individuals who work in the social services sector, based within community organizations, and have the skills to facilitate community residents' access to online services and information. Digital navigators provide guidance on access to social needs, such as food, transportation, education, and health care; facilitate skills in app use for telehealth services or other myriad online services (64, 65). However, a key limitation currently is the lack of widespread employment of community-based digital navigators. Roles for digital navigators can be embedded within local public health departments and libraries to make them widely accessible to communities.

Individual Strategies

Increasing access to digital devices and digital literacy are individual-level solutions that are critical to narrowing the digital divide. Relevant solutions should leverage school infrastructures to establish 1:1 device programs. These are programs where schools or districts provide each student with a device (e.g., tablet or computer). As of 2019, 51% of schools did not have a 1:1 device program (66). Providing 1:1 devices will help to standardize access to reliable online learning and increase students' families' exposure to digital tools (67, 68). Investment in digital literacy is a second area for targeted solutions that address digital redlining. Digital literacy is the ability to use information and communication technologies to find, evaluate, create, and communicate information, requiring both cognitive and technical skills (69). A 2018 report showed that Black adults were twice as likely as White adults to have limited digital literacy (60). Findings also show disparities according to rural residence and show that digital illiteracy is more prevalent in rural areas (49). Progress in digital literacy can be achieved with investments in digital navigators, community programming in areas of high need, and by leveraging educational systems to reach surrounding communities that are under-resourced (64, 65, 70, 71).

CONCLUSION

The practice of digital redlining has contributed to the COVID-19 pandemic disproportionately affecting Black and Brown communities, precipitated by the rapid transition to virtual platforms for education, occupational and health purposes. Minoritized communities that have experienced disinvestment in necessary resources, such as broadband internet, have seen higher COVID-19 infection and mortality rates than their White counterparts (6). Individual strategies alone are insufficient to overcome the systemic inequities that are enumerated throughout this perspective piece. A synergistic multi-level approach, engaging community members about the strengths and needs of their communities must be employed in all efforts to make access to broadband internet equitable and decrease the negative impact of digital redlining exacerbated by the COVID-19 pandemic.

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

TM, CO, TL, and KW conceptualized the topic for this perspective piece. KA drafted the initial version of the Socio-Ecological Model for Addressing Digital Redlining which was further refined by a graduate student assistant (see Section Acknowledgments). All authors conducted literature searches and contributed to the writing, editing, and approval of the final version.

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Perspectives from leadership and frontline staff on telehealth transitions in the Los Angeles safety net during the COVID-19 pandemic and beyond

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Objectives: The start of the COVID-19 pandemic led the Los Angeles safety net health system to dramatically reduce in-person visits and transition abruptly to telehealth/telemedicine services to deliver clinical care (remote telephone and video visits). However, safety net patients and the settings that serve them face a "digital divide" that could impact effective implementation of such digital care. The study objective was to examine attitudes and perspectives of leadership and frontline staff regarding telehealth integration in the Los Angeles safety net, with a focus on telemedicine video visits.

Methods: This qualitative study took place in the Los Angeles County Department of Health Services (LAC DHS), the second-largest safety net health system in the US. This system disproportionately serves the uninsured, Medicaid, racial/ethnic minority, low-income, and Limited English Proficient (LEP) patient populations of Los Angeles County. Staff and leadership personnel from each of the five major LAC DHS hospital center clinics, and community-based clinics from the LAC DHS Ambulatory Care Network (ACN) were individually interviewed (video or phone calls), and discussions were recorded. Interview guides were based on the Consolidated Framework for Implementation Research (CFIR), and included questions about the video visit technology platform and its usability, staff resources, clinic needs, and facilitators and barriers to general telehealth implementation and use. Interviews were analyzed for summary of major themes.

Results: Twenty semi-structured interviews were conducted in August to October 2020. Participants included LAC DHS physicians, nurses, medical assistants, and physical therapists with clinical and/or administrative roles. Narrative themes surrounding telehealth implementation, with video visits as the case study, were identified and then categorized at the patient, clinic (including provider), and health system levels.

Conclusions: Patient, clinic, and health system level factors must be considered when disseminating telehealth services across the safety net. Participant

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discussions illustrated how multilevel facilitators and barriers influenced the feasibility of video visits and other telehealth encounters. Future research should explore proposed solutions from frontline stakeholders as testable interventions towards advancing equity in telehealth implementation: from patient training and support, to standardized workflows that leverage the expertise of multidisciplinary teams.

KEYWORDS

telehealth, telemedicine, digital divide, digital health disparities, safety net, vulnerable populations, COVID-19, community-partnered participatory research, qualitative research

Introduction

Digital health care has expanded over the past decade, largely driven by the financial incentives of the Health Information Technology for Economic and Clinical Health (HITECH) Meaningful Use program, part of federal health care reform. In the last few years, *safety net systems* (1), health systems that provide a significant level of care to minority, low-income, Limited English Proficient (LEP), and other patients from under-resourced backgrounds, have implemented digital tools for the first time. Since safety net patients already face social barriers related to the effort and cost of accessing in-person care such as taking unpaid time off from needed work, and transportation costs—digital health is an important tool for improving health equity in this group (2–9). Telehealth services like patient portals and telemedicine phone and video visits have the potential to augment access to health care and improve outcomes (10–16).

\Coupled to this, the Coronavirus-19 disease (COVID-19) pandemic propelled telehealth into the forefront as a clinical mechanism towards maintaining access to health care during a global shut down (as has occurred during other times of crisis) (17–29). However, this forced and uncharted transition immediately raised concerns about equitable access for safety net patients (3, 30, 31). Health leaders and researchers have documented how the abrupt shift from in-person visits to telemedicine with COVID-19 left many safety net health systems ill-prepared to support digital uptake (3, 31–33), especially among historically and contemporarily underserved patient groups (3, 31, 33, 34). Among those most left behind in the digital health waves are the 22.3 million LEP residents of the US (35), who already experience health access barriers due to language and literacy (36–40) that place them at higher risk for inadequate disease control, higher utilization of acute care, and poor health outcomes (41–43). A study examining Kaiser Permanente patients from 2016 to 2018 found that populations with non-English language preference were significantly less likely to access a telehealth visit than English-speakers, and that patients living in low SES areas were less likely to have a video visit than those living in higher SES neighborhoods (44). Early evidence during the COVID-19 pandemic confirmed lower rates of telehealth visits for older, non-White, and LEP patients (3, 31–33, 45).

With no established digital guidance in place for safety net settings prior to the pandemic, the evidence demonstrates that telehealth in health settings that care patients from underserved backgrounds will have to be monitored as implementation evolves—to understand and mitigate barriers to use. As such, studying telehealth implementation within safety net settings is critical for developing multi-level solutions that advance digital health equity. Therefore, to explore strategies and barriers to telehealth implementation in the safety net, we focused on the highest quality synchronous telehealth modality as the study case example—video visits—within the Los Angeles County Department of Health Services (LAC DHS), the second largest municipal healthcare system in the US. The objective of this study was to interview health system leadership and frontline clinical staff to understand their perspectives on, and experiences with the delivery of video visits during the COVID-19 pandemic, and to also inform subsequent telehealth implementation efforts in this safety net, and nationwide.

Methods

Study design and setting

LAC DHS forms the core of the health care safety net for indigent populations in Los Angeles County—the largest and most ethnically diverse county in the US. Over 50% of the primary care patient population is LEP (46–49). This safety net health system serves more than 10 million residents and provides over 2.5 million ambulatory visits every year across Los Angeles County. Between August and October 2020, we conducted in-depth individual interviews with LAC DHS stakeholders who, at the time, were implementing some of the first telemedicine video visits in their respective Los Angeles safety net clinics.

Participants and recruitment

Individuals were recommended for interview by a study co-investigator (AA) who is the LAC DHS medical director for patient engagement and population health. Participants were nominated given their role in the implementation of video visit "pilots" at clinics across LAC DHS (spring 2020). Potential participants were emailed to inform them about the study. Participants could also nominate other stakeholders involved or leading the pilot video visits (e.g., snowball sampling). Those who responded and accepted were scheduled for a 1-hour video or phone interview. Each participant was offered a $50 Amazon gift card for participation. The study was approved by the UCLA and LAC DHS Institutional Review Board.

Data collection and analysis plan

We based our interview guide on the Consolidated Framework for Implementation Research (CFIR), a conceptual framework that guides systematic assessment of multilevel contexts to identify factors that might influence implementation and effectiveness (50). The questions were also based on the published digital health literature among safety net patients in the United States (AC and CL) (32, 51–67), and further amended by our study team, which included LAC DHS stakeholders (AA, GG, CM). The interviews (conducted by AC) included questions on: the debut of video visits in clinics, the preparation and process for clinics, staff, and patients to offer, schedule, and conduct video visits, and how these video pilots evolved or changed over time, and adaptions. Questions probed around issues surrounding technology platform, usability, staff resources, clinic needs, and stakeholder perceptions of facilitators and barriers. We asked interviewees to consider these discussions for the unique strata of patients served by LAC DHS: LEP, digital/health literacy challenges, and limited access to Internet and/or Internet-connected software and devices. Interviews were digitally recorded and transcribed. Transcriptions were independently read by 3 members of the research team (AC, EW, CV) to develop a codebook. Two coders analyzed the interview transcripts (AC, CV) to organize participant quotes under unifying themes.

Results

Of 27 stakeholders that were nominated, 20 individuals accepted and these semi-structured interviews were conducted between August–October 2020. Participants included physicians, nurses, medical assistants, and physical therapists with clinical and/or administrative roles (**Table 1**). Participants were either: primarily based at one of five major hospital/clinic medical centers that are part of the LAC DHS health system (DHS site) or worked within LAC DHS' network of 26 non-hospital affiliated community health centers and community clinics all over Los Angeles (Ambulatory Care Network, ACN). Narrative themes surrounding telehealth implementation in the Los Angeles safety net are organized into patient, clinic/provider, and health system levels that correspond to constructs in the CFIR, with accompanying exemplar quotations (**Table 2**).

Patient level themes (CFIR Outer Setting)

Patient level themes corresponded to the CFIR "Outer Setting" construct, detailing conversations regarding patient needs and resources and patient influences in implementation feasibility.

Patient preparedness

Conversations about *patient preparedness* encompassed digital health barriers in the patient's context that could affect the feasibility of telehealth for the safety net. Stakeholders described barriers to use of existing digital health tools due to a "digital divide" for their populations, characterized by low digital literacy, limited broadband and/or cell phone data plans, and lack of access to Internet-connected personal devices (and/or high quality digital devices). Other technology-specific challenges included patient usability of the LAC DHS telehealth interface and the English-only language of the current platform. Stakeholders noted that the current video visit system required multiple steps on behalf of the patient (see **Figure 1** process map), which were challenging for most patients. Furthermore, a "successful" (i.e., completed)

TABLE 1 Safety-net Stakeholders' clinical role/training and operational/leadership role relevant to telehealth implementation ($n = 20$).

Clinical training	Operational role
Physician	Medical Director of Dermatology at DHS site
Physician	Chief Medical Information Officer at DHS site
Physician	Medical Director of Ambulatory Specialty Care at DHS site
Physician	Medical Director of Ambulatory Specialty Care at DHS site
Physician	Medical Director of Primary Care at DHS site
Physician	Medical Director of HIV Primary Care at DHS site
Physician	Chief Operating Officer at DHS site
Physician	Medical Director of an ACN community health center
Physician	Medical Director of an ACN community health center
Physician	Medical Director of urgent care in ACN community health center
Nurse	Clinical Nursing Director of Specialty Clinics at DHS site
Nurse	Neurology clinic nurse manager at DHS site
Nurse	Supervising Staff Nurse of Specialty clinics at DHS site
Nurse	Nurse Manager, ACN Population Health
Nurse	Clinical Nursing Director of Ambulatory Care Services at DHS site
Medical Assistant	Outpatient Care Health Education at DHS site
Medical Assistant	Outpatient Care Health Education at DHS site
Physical Therapist	Physical Therapy Clinical Supervisor at DHS site
Physical Therapist	Director of Speech Therapy and Audiology at DHS site
Physical Therapist	Director of Rehabilitation Technology at DHS site

TABLE 2 Multilevel themes addressing telehealth implementation in the safety net.

LEVEL cfir construct	Theme	Exemplar quotation by safety net stakeholder
PATIENT Outer Setting	Patient preparedness for telemedicine	*Some are very tech-savvy, some can't get an email on their phone or don't even have a phone. So that has been one of the challenges.* -Physician
		I'm going to say 50, 60% of patients or more have challenges getting it set up. And in our communications with the nurses who have done it so far, they said sometimes it can take 30 min to an hour just to walk a patient through getting set up if they have to have them download Zoom and they have to send them a link and they have to literally walk them through the process. –Physician
		Now we have to look at the IT literacy of our patients as well. And I think that's probably even more challenge than our health literacy for a lot of patients. –Physician
		There's no sense in developing a really great workflow … when the patient doesn't know the technology. –Physician
		So access is a challenge and then just knowing how to use the basic functions of the phone. Most of what we do over FaceTime or Zoom is using a front-facing camera, but if you're working with a dermatologist or a podiatrist, you actually want to use the rear-facing camera and point the device towards your foot and so, in the middle of a Zoom call, how do you move to the other camera? Or another example that comes to mind is, okay, I've got you on the phone and you want me now to click on the message that I got as a text? I don't understand how I'm supposed to app-switch from being on the phone to now going to messages and now going to Zoom and often patients will ask, "Am I supposed to hang up now and go to messages? -Physical Therapist
		But they were really basically, first, do you have a smartphone or a computer or a tablet that has a video capability that you could use for a video session? Second question is, are you functioning on data minutes or do you have Wi-Fi capability and you have unlimited data? Because of a concern that sometimes people might be paying for data per megabyte or whatever and if we're going to have a 60-minute call, then we don't want them to come away with a $60 phone bill as a result of it because it's data intensive. Really, it's do they have the technology? Are they able to download the software and let's try out the software and make sure that you succeeded at it. And is this your phone? So if they grab their friend's phone and do the whole and then on the day of, they don't have a phone anymore, that's a bit of an issue. -Physical Therapist
		Well, one of the things we really tried to impress upon the providers is you will have a successful video visit based on your patient selection. Right? Because there's so many things involved. The patient has to be a little tech-savvy. –Nurse
		… couldn't even figure out how to open the text messages app on his phone to see a text message. There was no chance he was going to be able to run a video visit. And he hung up on me like ten times and I was unclear whether he was purposely hanging up on me or not. And then eventually we called his daughter because we're like, "Maybe his daughter can help him do this" –Physician
		… the barriers for our patients are the email issue and then in terms of the app, a lot of them have phones with very limited capacity. So either they don't want to, or they can't add an app … It's doable, but it's another technical barrier for them. -Physical Therapist
		… but the more I talk to patients and the more I've heard from our staff, with the pandemic I feel like it's internet and Wi-Fi, or data, it almost needs to be a public utility. Our patients struggle with that. And being a pediatrician, I hear a lot of stories of students having troubles keeping up with school because they can't connect, which is unfortunate. It shouldn't be in this—at least in a major metropolitan city that we're in, I think that's one of our major connections. That's probably what we're going to struggle with as far as when it comes to video visits. –Physician
		Some patients, when found out they may be charged carrier fees, declined right off the bat because of that. Some patients, even though we chose them, didn't feel comfortable doing the video visit. They were more comfortable doing a telephone visit …And ensuring the proper platforms to support the video visit, their phone, yeah. –Nurse
		Again, quality of the client's internet can be challenging because sometimes it's very glitchy. Their equipment sometimes the video quality—especially, for example, like for [derm] you're looking at an atopic rash or you're looking at some other dermatological issue that you need a close-up on and it's pixelated and you can't really see well—I think that is a challenge. –Nurse
		… the issue I have with it is like an equity issue that I think that some of the patients that are probably least capable of setting up video visits or some of the people most in need of that resource and it's kind of unfair and not cool to say like, hey, here's this great clinical resource, but we're just going to deny it to a big swath of the patient population just because it's too hard for us. So I think it's on us to figure out how to make it work, not on us to figure out which patients to and to not give it to. –Physician
		It's, how can we make this work for people? And someone said, "You know what? We should actually have IT like the Apple Genius Bar. We need a genius bar in DHS just to help people enroll in an email and get all of that." –Physician
		Is there a packet that we should be giving to patients head of video visits or to advertise for video visits to get them prepper? Are there maybe two different packets, one for folks that are gung-ho like, "Yeah, I want to do a video visit. I know how to do that"… and then another one would be the patient who's questioning or if they're going to do a video visit, they really need a family member to be with them during the visit to almost accompany them to the video visit. –Physician
	Patient acceptability of telemedicine	*In the beginning, patients were like, "Well, I don't know if I feel comfortable about this." They were unsure about having their information getting out. And we assured them that we were confidential in all of our information, just like as if they were here.* -Nurse
		Maybe if it's spreading, just if the patients are willing to do it. Some want to be seen, some want to come in, or some are afraid of this technology stuff or some just don't have the patience to do it." -Medical Assistant

(*continued*)

TABLE 2 Continued

LEVEL cfir construct	Theme	Exemplar quotation by safety net stakeholder
		I think the biggest challenge for us first is just changing the culture …And I think just that lack of coming face to face and seeing the nurse and having your vital signs taken and all of that was really a culture shock for a lot of our patients that they still haven't recovered from. And they want to come in and see us. And we keep trying to encourage I can do most of the same stuff over the phone or even over a video visit, but culturally I think that's where we haven't gotten to the point where we've really said it's acceptable and the norm in medicine to see you over a video visit and that I can give you almost the same care … And I think there is a lot to be said just for the human connection when you're in the same room, but the culture I think is the hardest part of sell. –Physician
		If you can't push them into a video or a telephone visit, let them come in, it's okay." We will see you and then let's slowly develop the rapport and say, "Look, okay, Mrs. Jones, I can do all of this stuff and I know I'm used to seeing you four times a year, but realistically I can see you maybe once a year and the other three times I'll do over the telephone. We can talk about the same stuff. I can order the same stuff. If you have a concern that you want me to examine, obviously I'll need to see you or look at it on video or actually see you. But most of this stuff we can do." And I think the most powerful message comes from their doctor who they trust, but we are going to have to sell that to them probably face to face at first. And that's what we're advocating for. –Physician
		We're actually saying, when you start talking to your patient about their patient experience that's coming up in their initial evaluation, your messaging really needs to be "We will be doing almost half of the visits by video and we need to do this in order to be able to keep the environment safe for you when you come for your in-person visits." So we are going to have a very different approach to how we structure our in-person visits vs. the video visits. The in-person visits really need to be deliberate and intentional. -Physical Therapist
		There's a lot of people who said, "I would [do video visit] if I had to, but I'd still prefer in-person." And that's the group of people that we're going to have to circle back to and say, notwithstanding that, we're going to be doing it by video. -Physical Therapist
		…even though we think clinically it's okay to do a video visit, we realize that on the patient side, there may be some hesitancy. And also a matter of perspective of whether they're getting the same quality of care. We've also been learning that they actually do like video visits much better than phone visits for those that can do it, which has been good. –Physician
		I think it's going to be a culture shift for our patients. It's been a culture shift for the nursing staff and providers. It's going to be a culture shift. Many of them want to be seen face-to-face …So it's getting them comfortable in realizing it's the same level of care. -Nurse
		There's so much more work around educating patients and staff. And really not just educating patients and staff, but making sure that patients desire, feel comfortable with, and can benefit and engage in a video visit. And have the technology and tech literacy, as well as the health literacy to do so that we think warrants a lot more work upfront maybe. –Physician
		And some of the older folks, too, they're very traditional, they're very leery about technology. They don't want their "information" out there, so they don't want anything to do with our video visits. They're afraid it's going to go viral somehow, so they absolutely do not want video visits. So that's a challenge, educating them that it's a secure link, that their information won't go anywhere, so that's another bit of education. -Nurse
CLINIC/ PROVIDER Inner Setting	Staff telemedicine training/ empowerment	*… we quickly discovered that this was a new technology. People had not tried it yet. And they really needed to have mentoring experiences at least for the first one and if not for more.* -Physical Therapist
		… we still have staff members a month later that have not yet done a video visit. And it's partly because of their own fear and fear of new and fear of technology. And really just it's not something that we learned in school. Is two hours of training really enough? It really isn't. It's really about learning a language. -Physical Therapist
		The second bucket is we have a digital divide within generational workforces. So not everyone who's working in our integrated health systems in terms of our employees—from nurses to providers to clerks—not everyone's at the same digital-savviness level. So not everyone can learn texting or understand Zoom in the same manner. So they also need an update. –Physician
		I think one of the biggest barriers is going to be staff readiness and comfort with it. Because even if patients are excited and want to do it, if the staff aren't comfortable, it's not going to go well; and if we don't train them well enough, if we don't equip them with the right personal skills as well as technology to do these well, they're going to get frustrated with it and not see the value in it and it can flop. If the staff don't want to do it or don't feel comfortable doing it, then it's not going to work. So I think that's one of the areas we need to focus a lot on is proving the value, giving them the skills and the training, and giving them guidance on how to select which visits are best and then how to optimize those visits when you're doing them, and how to do them efficiently so that you don't feel like, oh, I did a phone visit with a patient, but I still need to see them in person. That defeats the purpose of what the video visits are supposed to do. –Physician
		Because it was a small group, I was assigned do the actual training and implementation. So I actually went out and trained the nurses on how to access and how to actually use the Zoom because there's some technology that they have to maneuver through. -Nurse
		We didn't ask that it [champions] be an RN, an LVN. It could have been a CMA. In the original area it happened to be my LVNs that stepped forward and I think they just wanted to be that subject matter expert. I think for them it had an internal award, not an external reward. And to get to go to another clinic and share their knowledge, I think it was just their personality. –Nurse
		Remember like each clinic, we base it—based on their attitude and the willingness—number one, willingness to participate. They're, of course, technology savvy. So that's how we—each clinic we already know who they are. What we do is just after the implementation, those nurses that participate then go to the next clinic just to support them and to train them in the beginning. It's like train the trainer, you know? –Nurse

(*continued*)

TABLE 2 Continued

LEVEL cfir construct	Theme	Exemplar quotation by safety net stakeholder
		Because they're very savvy, technology savvy, that's one. And second, great attitude and team player attitude and just, yeah. We know who they are. –Nurse
		It's like certain staff that you know are always pioneers, always trying to champion through just other things that they were asked do you want to be part of this, and they say yes. So it's more like the people that have the good rapport already, have already championed in different aspects. And we just select them and they carried it on very well. They are very strong. -Medical Assistant
		… I made available to anyone who was interested and our telehealth accelerator team basically laid it out very clearly saying, "This is an imperfect science. Okay, there's not a standard, if you want to do it, we're going to expect you to develop the standard, but you have to work through all the challenges.' So we had a set of individuals who took on that role and they were magnificent. They were unbelievable. I mean, I was there for them, obviously, but I consider them the heroes of the pandemic. So they're very good. -Physician
	Standardized clinic workflows to facilitate telemedicine uptake	*But in terms of dermatology, podiatry, ophthalmology, I don't exactly know how they're deciding which patients are—which disease states are good for Zoom and which ones would need to come in person. I think in pediatrics it's just anybody who doesn't need to come in person like for a physical exam. And a lot of times in primary care basically we've just been using the telehealth visit as a way to filter out face-to-face, so we don't make that face-to-face decision until the telehealth visit has been done. But in peds, that's basically been the model, unless we know that you need certain vaccines or a newborn exam or a well-child physical exam for back to school, et cetera.* –Physician
		So the determination of whether a visit is appropriate for virtual, phone, or video vs. face-to-face is made by the provider, which is either a resident trainee or a faculty attending. –Physician
		We had to ensure that the providers would scrub the list of patients prior, to see which ones were actually appropriate for a video visit as opposed to a face-to-face visit. Because obviously, depending on what the condition or diagnosis was and what information needed to be—whether or not a face-to-face was more appropriate or a video was appropriate. –Nurse
		Yeah, that process [patient selection for telemedicine] is more like the provider and leadership. They made an outline of what's a good criteria to select these patients. I'm not part of that—yeah, we just get the list. But it is through leadership with providers. They do have a criteria that makes them qualify for it, because not everyone is qualified to do the Zoom, apparently, yeah. -Medical Assistant
		Well, that's when we can send them the link with the information on how to download the Zoom. In the beginning though, the nurses, like I said, we were just learning; the nurses were doing it themselves. Walking the patient through. And then, as I said, it was all about patient selection. If patient said "Well, I'm not comfortable with that," then we moved on and found a patient who said, "Oh yeah, I already do Zoom because of school or my child does, I know all about it." In those patients, it was easier to work with. –Nurse
		But what we are doing is the providers in that particular specialty clinic are identifying patients who they feel are appropriate for a video visit. When we first started, what the nursing staff had to do was actually reach out to the patients that the providers identified. And call the patients and ask them if they would be willing to do a video visit as opposed to either a phone visit or a face-to-face. And we tried to explain to the patient the benefit of the video visit. That it would be easier on them because they wouldn't have to drive all the way over here. They wouldn't have to find parking. You know, just selling all of the positive points. As patients agreed and consented to video visits, then the nursing staff had to go in and actually change the appointment time to a video visit appointment time. –Nurse
		And what we're actually going to try doing too is—and we're not sure about how this will work, but this is something we're looking to see is screening for level of appropriateness. It's one thing to think clinically that, yes, a video visit is fine. But the other part is on the patient side—if they don't have someone that help them manage a smartphone or manage a video visit, it's not going to be successful and it's only going to frustrate the patient and the staff. So we don't want to set that up. So we're actually trying to figure out like is there a screening tool that we could use. -Medical Assistant
		And what I'm hearing from the staff in terms of the workflow, that had to be part of our clinical workflow, that we don't know is do they have Wi-Fi? Do they have a cellphone? Do they have a computer? So we don't know that. We don't know that kind of demographic. It becomes a responsibility of the clinic. And how do you know? And even if you had all that, like they miss their visit. They don't know. Their battery ran out. How do you do that? So that part of the workflow is two or three boxes on a swim lane. That should be a massive (challenge? @ 00:27:42). So that's missing. So to me that's a whole different category. And who are the owners of that? Who would be the best to really assess that? We don't have a workflow for that. So I think with a better understanding and segmentation of those type of patients, it would make our workflow a lot easier. –Physician
		And I believe that all the training material was really done nicely, but it was done by a team of nurses—very good nurses, by the way—and great material, but it was material that was not developed by maybe getting some end users, some nurses that are on the line to bring those kind of questions. Is there an assessment criteria that we can kind of screen our patients with to see who are the candidates, rather than just kind of doing a cold call. So that I believe lacked, but not minimizing that the development of the training material and all the job aids and things that—I want to say the DHS nurse informatics from ORCHID did were wonderful, wonderful, great material. When we do really go back to—and we're getting close to going back to the drawing board, bringing all those materials in, but also adding, you know what? We need not a cold-call list. We need to be able to really identify when we go to that end user and say, "Hey, let's talk first before I tell you you're going to implement something. How would you stratify your patients that could qualify or be willing to do a video visit with you?" And that way they don't feel so unsuccessful. –Nurse
		… we're actually trying to see if there's a more objective way to do an assessment in advance so we know the patient's level of readiness in advance. There are some that are out there and there are some that other sites around the state that are part of the grant have used. I don't know that any of them are validated or anything like that. And some are I think too long to really be useful. So my goal out of this

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TABLE 2 Continued

LEVEL cfir construct	Theme	Exemplar quotation by safety net stakeholder
		would be for us across DHS that we can come up with a three- or five-question screener that even a nonclinical person like a call-center staff could provide so that if someone calls and says, "I want to do a video visit," the scheduler, who's separate from the clinic, could say, "Okay, do you have a cellphone or a device that has internet? Do you have Wi-Fi in-home or do you have somewhere where you can go to do it? Are you comfortable doing it on your own or will you need some advance help to make sure you're ready?" Something very simple like that and it wouldn't keep someone from being able to schedule a video visit as long as they have at least the phone and Wi-Fi, but it would at least give the team a heads-up as to what the person's level of comfort is with doing the video visit so they know in advance whether it'll be a quick logon and just go or whether they may need some extra time to make sure the person's ready or maybe they need to do a practice session in advance of the scheduled visit, something like that. –Physician
		So I'm working on developing criteria of let's say you identify a patient that you're scrubbing a chart and clinically it makes sense to do this as a video visit because there's something you want to see visually. And once you have identified that patient, rather than saying, "Oh, this is a good candidate for a video visit or not and deciding accordingly," saying, "This is a good candidate for video visit versus this is a candidate for a video visit that is going to probably need some help and let's make sure we provide whatever help and resources are needed," or be prepared that they're going to need help -Physician
HEALTH SYSTEM Process	Technology planning	*It's like lighting has to be good, the quality of the video, so that the appointment or whatever the doctor needs to do as far as visually seeing it, can maybe get a better plan for care.* -Medical Assistant
		As long as you have the equipment and enough equipment to make these video visits happen, then that'll be more beneficial. And then it's like scheduling because then if you have the equipment, then you can schedule more patients to do it. But if you have one or if you have none, or if you just have a tablet, it's harder too. Luckily we were able to get these WOWs (workstation on wheels), which are very beneficial because it has a better screen, it has better video quality, and its sole purpose for this whole computer is just for video visits itself. And it's easier for the staff to just recognize, oh, this is for the video visit. And just this morning, I'm using one but the staff already knew where to go. They just knew that you just pick it up from this designated area. -Medical Assistant
		Like I said before, no matter how much we've been doing it, or even the superusers for each clinic, there's always an issue with sound or it's something about "I can't hear you," or "Can you hear me and is the volume of the screen up?" Because we actually came across that where many times the reminder call from the staff nurse would call the patient and they said, "Everything's fine, okay, we'll see you tomorrow." And then come the day of, something happens with the volume. And it's just a bunch of troubleshooting like that. -Medical Assistant
		Facility-wise it's just as far as if they have the equipment to do it, which I hope isn't an issue if they do want to spread it clinical-wise. And then the manpower for the teams to support, to teach these things at every—because whenever we do a go-live, we all have to be there—and let's say we're at our fifth go-live but yet there's still four of the other clinics that are still continuously doing video visits, it's like, well, we need to focus on the go-live, but then we also want to help with these four other clinics. How do you spread the manpower to help with all this stuff? So that might be a barrier as far as staffing goes on that. And then teams, multiple teams will be involved, so IT and stuff, so their manpower, nursing manpower, leadership manpower. -Medical Assistant
		And we are still struggling with the best way to check in patients and have the CMA and the ancillary staff involved in the visit. Because some of our providers, actually two days out of the week our providers are actually at their houses doing telephone visits. And eventually we'll have to figure out, okay, are we going to do video visits while they're at their house? But when they're not on site, my staff, their ancillary staff, is actually on site. So the handoff between the two is still challenging. And I know some of the clinics are a little bit more I would say maybe ahead of us as far as involving the CMAs and the LVNs and they're doing the same intakes that they were doing face to face. And I don't know what the best way is to do that yet. –Physician
		So setting up space or the reengineering of space has been rather involved, because these spaces were not necessarily readily available. So we've really had a domino effect of really reengineering the use of space and also a lot of clinical moves themselves to best utilize the space available within our hospital building. So stakeholders who I—thankfully, I think we had the necessary support to move this forward and as element come along or as needs come along, ad hoc members such as facilities and IT are brought in. –Physician
		One of the challenges I think, though, is because we still are having a combination of face-to-face, phone visits, and the video visits, it's again a provider thing where they need to figure out, well, who's doing telemed, who's doing the face-to-face, who's doing the phone. It's that on their end where it might be a little difficult because you still have your patients that are here face-to-face and they need to be taken care of just as well. So it's the juggling act of finding that happy medium of how to assign out and how to get all of that taken care. It's, to me, a little difficult, just like our nursing assignment. We have to figure out who we're assigning for phone visits and the face-to-face that we still have, and that there's visits and all of that. It's just a new normal that we're all trying to figure out right now. -Nurse
		One thing we've been doing here is trying to create nonclinical spaces to do telehealth, so like telehealth hubs. And so that I think is a big piece of it is you want people to be on campus and not be remote at their house. You have to build these computer labs or telehealth labs so that the expensive clinical spaces that are designed for clinic use don't have to be used for telehealth. Or, alternatively, you do make remote work more possible and equip at least providers with the equipment to be able to do this from home. And then have a support structure on the nursing side. That would probably still require telehealth hubs for nursing to support the providers who are remote. And then I think the other piece of it is probably the software. I don't think Zoom for Health has been scalable software for DHS because it's a lot of management of the licenses and the accounts. And so having a separate system is always added work. So not only do you have to schedule an appointment in the EMR, but you have to schedule a license and you have to link the two. –Physician

(*continued*)

TABLE 2 Continued

LEVEL cfir construct	Theme	Exemplar quotation by safety net stakeholder
		So what are the standard elements to creating a telehealth workstation, whether it be having a dual monitor, a singular monitor, having headsets, landline versus, I guess, voice, or having Wi-Fi versus wired connection, all of those elements to kind of understanding what is the best set up for telehealth so that it can be replicated in these kind of shared remote locations. –Physician *Well, we're going to need to do video visits, let's place some orders," everything was already backordered. We had to get DHS as a system just to meet the needs of our system. We already had a big delay in getting the hardware available. I want to say when we were looking at placing the order early on in the pandemic, it was probably a two-month, maybe three-month backorder. And so that took some time to even just get the hardware in. So even if you had licensing to do a visit, you didn't have the camera.* -Medical Assistant *There are also challenges with connectivity. The Wi-Fi is not optimal. Even when we have our own internal meetings on Zoom or on Teams … we'll have times when we're on some meeting and the person suddenly is talking all garbles. And you know they're talking, but you can't understand a word. So there's just all those types of things. And I think at DHS, at least at Harbor the Wi-Fi isn't really up to the level that it needs to be to be able meet the challenges.* -Physician *And so it took that long for us to be able to interface effectively with the medical records system. They had to do a completely new build for us for the billing part of it, but it is now done. There's a lot of stuff on the scheduling side that's still not working properly, but it's at least not preventing us from billing.* -Physical Therapist *So we wanted to make sure that if we put forward a video-visit model, that it would be compliant with HIPAA and whatnot going forward. So I think that's why we went with the license model that we have and that obviously when you go with that kind of license model, albeit, that kind of said we had to prioritize who needed to go first … and also to train everybody to do this workflow. So that right there probably set the tone like where things had to go.* -Medical Assistant *And so having a separate system is always added work. So not only do you have to schedule an appointment in the EMR, but you have to schedule a license and you have to link the two. And so I think this is where DHS is moving is to more of an integrated solution for the EMR so it's more simple and you can just click on the patient chart and open a video platform and, on the patient side, they've downloaded whatever they need to download. I think that would be a little bit more scalable* -Physician *I think probably bringing in some of the end users to develop some of the—or just have an open conversation with some of the end users to really see what do they think. Especially bringing in the ones that we implemented already; not bringing in people that don't know, but people that—like the three sites that I'm—especially the two sites—maybe interviewing those care managers, bringing them in on a session and saying, "Hey, look it, we have this plan. What do you think we could do?" The end user is always so vital in this conversation for success. We can always make the decision that we're going live, but if we're not there on the ground, you know.* -Nurse
	Leadership communication and goal setting	*Secondly is I think it's very important to have a bidirectional understanding of who's really going to be your implementation teams and give them channels to give you really quick feedback on things that practically can and cannot happen as you implement. I think we're in a pattern of actually just rolling things out and specifically I think in probably the initial rollouts, we already have very clear signs of what is probably going to be problematic and not and we're not agile enough to process that information to really change either our approach or maybe potentially our overall strategy, but instead we will just focus on the outcome.* -Physician *I think the big barrier is just that if there's no leadership buy in or it's not organized, then the people will not buy in. That's one. We have to make sure that every key stakeholder are right there from the beginning and the expectations from each and every one of them, clear expectations and then support. What do I mean by "support?" Being there, being present, communicating, providing them with the tools if they need it. One of the support is just having educators a lot. It's a big support, knowing that they're there, that they're not alone. The bottom line is we explain the why, and people understand that this is for—this enhancement and also good for our patients. So we do a lot of explanation. We communicate a lot at Harbor as far as my team is concerned, a lot of checking in with them. That's very important to me. To me, any project that we implement at Harbor, we do the same thing.* -Nurse *The other related issue is that strategically the way that the DHS highest levels of leadership have really pushed to see the implementation rolled out I think has been—I understand why they made the decisions they made, but from a practical implementation perspective, it doesn't make any sense.* -Physician *And I see that as a resource-utilization mistake because if the goal is to get this high-value clinical resource to as many patients encounters as possible, giving it to the people who are really excited about using it and are going to make it work will get it to the most patient encounters as possible. Giving it to whatever specialty you deem through some esoteric process was high priority, yeah, sure, if there are providers in that specialty that are really excited about, go for it.* -Physician *So when you say "telehealth," are we trying to get to standard ubiquitous implementation? Are we trying to address use case on our needs? And those have to be well thought out from the beginning so that people know how to resource and design the appropriate outcomes and the KPIs to keep all the downstream teams understood. So communication I think is key. So that's number one, I think just having the appropriate mission and scoping it appropriately.* -Physician *So one of the things that I would say—and hopefully this doesn't go too far throughout anywhere else, but often we come up with a solution before we've really found the problem.* -Physician

TABLE 2 Continued

LEVEL cfir construct	Theme	Exemplar quotation by safety net stakeholder
		And then the other thing for success is being very clear, what is the goal? What are we trying to achieve? And who's going to benefit the most? Are we just looking at numbers or are we really looking at what is our goal to reach this patient and see improvement in their relationship with us and trusting us? And one day when we go back to real clinic time again, keeping them engaged and keeping them healthy. Yeah, I think that's a lot that we need to look at first. -Nurse
		So we need to understand before the in-person visit even happens what it is specifically that we are trying to accomplish in person that we could not accomplish by video, because those things should happen by video. -Physical Therapist

video visit usually depended on many staff phone calls in advance of the encounter. This was noted as not sustainable for staff given constrained resources and time. Some clinic staff indicated that their clinics had resorted to "selecting" for patients who they thought could complete a video visit, and promoted it among these groups. However, they also noted that this was not equitable, as it was unfair to promote video visits among a subset of patients—when potentially all safety net patients could benefit from the service.

Patient acceptability

Stakeholders also discussed *patient acceptability,* with specific conversations centering around a culture shift with regards to telehealth. Stakeholders shared how so much has been taken away from the large proportions of racial and ethnic minority communities served by the Los Angeles safety net—due not only to COVID-19, but also because of historical and contemporary systemic injustices. The threat of losing a personal connection to their doctor and health system was a perceived fear from their patients. Stakeholders suggested eliciting and directly acknowledging concerns about telehealth with patients, and then following up with discussions about benefits as a way to assuage misconceptions while shifting the patient culture about expectations for clinical visits. The goal would be to normalize telehealth visit offerings as part of high quality clinical practice.

Clinic/provider level themes (CFIR Inner Setting)

Clinic and provider level themes corresponded to the CFIR's "Inner Setting" construct—detailing issues regarding clinic characteristics such as networks and communications, workflows, culture and climate.

Staff telemedicine training and empowerment

Participants felt that leadership assumed that frontline staff, who interface the most with patients, would be familiar with telehealth and able to promote it. However, this was not always the case, as some staff were not comfortable with the technology and had not used telehealth visits or a patient portal themselves. Participants discussed the need for more recognition of the different comfort and electronic health literacy levels of staff and medical providers and endorsed a need for effective training during implementation (including "refreshers" or updates about the technology) and immediate contacts for troubleshooting problems. In these discussions, participants talked about identifying ideal staff to serve as telehealth "champions," delineated characteristics of champions, and ways to support/reward champions, that would help in telehealth promotion and facilitation within clinics.

Standardized clinic workflows to facilitate telehealth uptake

Stakeholders discussed the informal use of workflows to identify appropriate clinical scenarios for telehealth. In the video visit pilots, this was being done *ad hoc* by physicians and other medical staff. It was stated that systematic identification of clinical visit types ideal for telehealth (medicine reconciliation, diabetes coaching, treatment discussions) could potentially be created, with algorithms or workflows to automatically match these to telehealth offerings (especially within each clinical specialty). Participants mentioned that such efforts could save time for nurses and doctors. Staff thought that automatized offerings could promote telehealth uptake, as patients would probably be less proactive about asking for video visits, given their low baseline awarenes and knowledge about telehealth in the safety net. The other major operational workflow that participants mentioned was the need to integrate digital readiness patient screening or assessment tools as part of clinical care. During early phases of implementation,

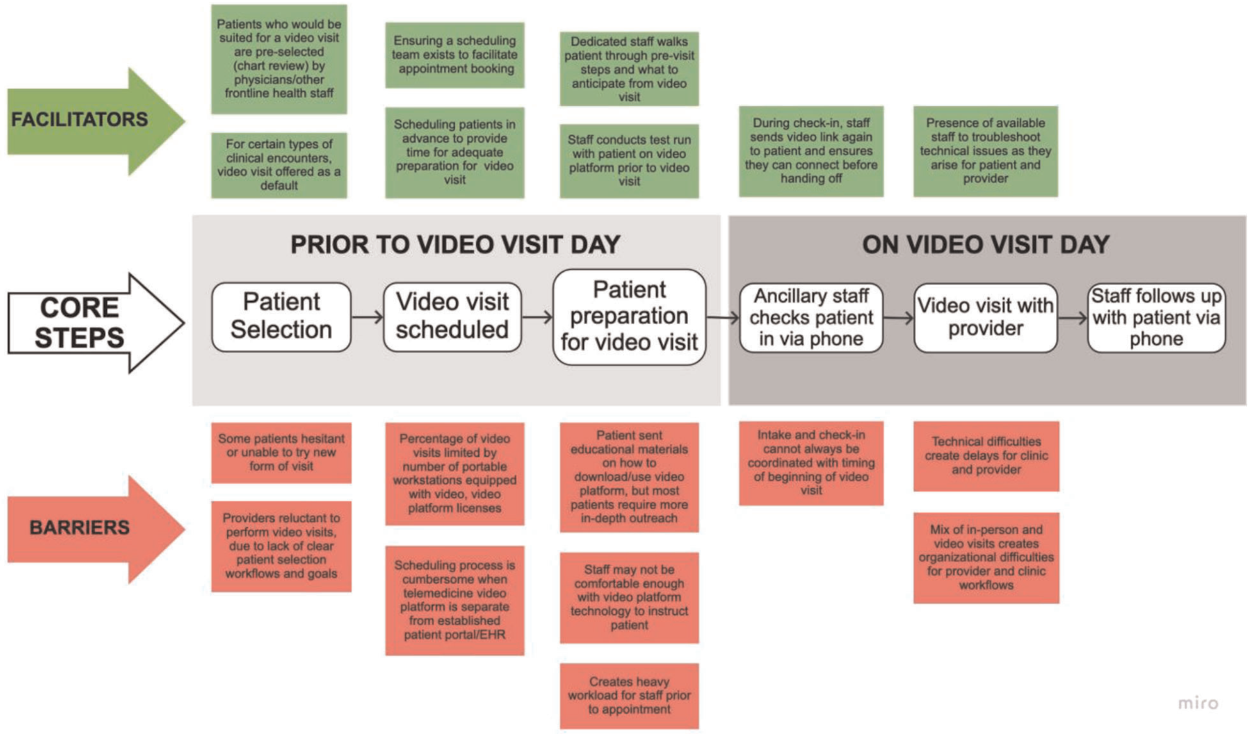

FIGURE 1
Process map for typical LAC DHS clinic video visits.

providers spent time trying to "identify" ideal candidates to offer a telehealth visit to (e.g., those registered to a patient portal, had an email account on file in the health record, or who used apps on their phone). While this identification process was somewhat helpful to increase the yield on completed telehealth video visits, obtaining this information required extra time during the visit and limited the service to subgroups of patients. Participants brought up the potential of digital screening tools to increase immediate yield of visits and help identify patient needs and allocate resources for support. For example, a pre-visit preparation session could help make video visits more accessible to those who most needed it and troubleshoot connectivity and other problems. However, participants noted that this screening process would require a standardized tool, such as a set of validated predictor questions that could quickly and easily identify patient's needs for support. Without a uniform approach and systematic guidance, too high a burden would be placed on staff and providers.

Health system level themes (CFIR Process)

Themes that corresponded to the health system mostly reflected CFIR factors regarding the planning, engaging, execution, reflection, and evaluation over telehealth implementation.

Technology planning

Among the barriers cited were lack of planning for needed equipment and ancillary resources: such as not enough computers with cameras in the clinic, lack of physical space to expand telehealth given constraints of a simultaneous in-person and telehealth visit schedule for providers in a county clinic with a shortage of clinic rooms, need for differentiating telehealth visit procedures from in-person visits (e.g., a required "nurse intake" for a telehealth visit may not be useful), challenges with broadband Internet access in clinic such as poor Internet reception in some of the county clinics, lack of systemwide IT support to facilitate early implementation, and video visits not integrated with the system's current patient portal.

Leadership communication and goal setting

Participants endorsed the importance of routine telehealth discussions between leadership, IT, and front-line staff, especially for the sharing of best operational practices, digital educational tools for patients (and staff), and patient-centered digital engagement across different sites in this large county health system. Most participants recommended that the health system invest more to support patient education that impacted preparedness for telehealth access and high quality utilization. They described feeling like they were designing these processes in real time. Additionally, although tailoring to their specific settings is needed, they would have benefited from learning about other clinical sites' models, approaches, and "mistakes," particularly those sites that started earlier with telehealth implementation. They called for LAC DHS to develop more centralized patient and staff telehealth educational resources.

Participants also discussed being "unclear" about the goals of the implementation, expectations from leadership and what telehealth "success" looked like in the safety net. Did this mean that all patients should be using video visits or a goal number or percentage of visits by some date? Would these metrics be uniform across specialties and clinic sites? The stakeholders we interviewed felt it would be important to have staff partner with leadership in asking these questions and in goal setting. They also emphasized the importance of transparency about specific telehealth goals and regular updates to their frontline staff. Participants also mentioned that these metrics should be set with the overarching aim of offering the highest quality of care possible to their patients and not for the sake of simply reaching some arbitrary telehealth uptake or usage metric at LAC DHS. Finally, participants noted that without measurable telehealth goals, objectives and metrics, there was less incentive and accountability to continue the use of video visits beyond the pilot phase.

Discussion

This qualitative study of informed safety net stakeholders presents some important multilevel lessons learned around telehealth implementation in settings caring for historically and contemporarily underserved patient populations. Of note, thematic narratives from these interviews highlighted the following takeaways: patients' longstanding risk for and history of the digital divide must be addressed up front, with the aid of trained multidisciplinary teams, established workflows tailored to each clinical setting that facilitate telehealth, and with clear communication and partnership between safety net leadership and on-the-ground staff about the objectives and goals for telehealth care for their patients. Most participants stressed the need for the health system to invest more resources to support patient engagement and education that impacted preparedness for telehealth access and high quality utilization. If these challenges are not addressed, this could be a set-up for worsening health disparities for these patients (not only LA safety net patients, but all over the US), already at higher risk of poor disease management outcomes.

Our study does reinforce the findings of prior digital health literature regarding the need to better understand patient preparedness for telemedicine. This includes several dimensions for digital access and uptake which have been described in the digital divide literature addressing safety net patient populations—(51–67) including devices and data plans as well as clear expectations for digital skills from more basic (opening an app) to more sophisticated skills like finding, sending, and/or interpreting health information digitally (68–73). Discussions of digital health equity must also address patient acceptability of telemedicine, with specific conversations centering around a culture shift for patients. The safety net serves a large proportion of minority patients, with populations that value a personal relationship with the doctor (i.e., "*familismo*" in the Latina/o/x community, a primary ethnic minority population served by LAC DHS) (74). The introduction of video or phone visits is an adjustment for patients, and requires reassurance that their patient-doctor relationships would be conserved, something that has been noted in early patient portal studies within the safety net, especially among Black patients (75).

Our study adds new content around the readiness and culture of providers and staff to deliver telemedicine, which is not actively explored in previous literature. Participants discussed that there was almost an assumption made by leadership that frontline safety net staff interfacing the most with patients would be comfortable using these new telehealth tools. Future implementation will have to focus on the technology needs and understanding of the workforce, and staff telehealth training and empowerment for those at the front lines of the health technology implementation in the safety net (76). Also, much of the discussion at the clinic and provider level revolved around the extra use of resources to identify high quality clinical scenarios and appropriately identifying what support patients needed to use the video visit service, to meet these unmet digital needs (52, 77–79). In a busy and under-resourced setting, the concept of standardized clinic workflows to facilitate telehealth uptake is an approach for this, and has been recommended by other organizations who have focused on digital health uptake in safety net settings (79).

Health system-specific challenges in the discussions encompassed technology planning barriers like usability and the English-only language of the video visit platform, which has also been previously discussed in the literature as major factors (80–83). Participants mentioned the lack of infrastructure in clinic spaces and the incompatibilities with concurrent in-person and telehealth visits functioning efficiently for a provider in the same clinic workrooms and nurse teams. In terms of leadership communication and goal setting, there was a clear need for more partnered goal setting around telehealth implementation, and transparency of process. Of note, these early stakeholder discussions have led to the development of the LAC DHS Virtual Care Workgroup, a consortium of LAC DHS primary care clinic directors, patients and community advocates from Patient Family Advisory

Councils (PFAC's), interpreter services, social work and chronic disease health educators. This workgroup has been meeting every week since the spring of 2021 to help shape LAC DHS local telehealth policy and determine the evidence-based interventions needed to appropriately deliver effective telehealth. Some recent innovations borne out of this workgroup include: addition of telehealth (video visits, patient portal) tutorials into educational content delivered by health educators in their chronic disease self-management classes for LAC DHS patients, and the development of a health technology navigator community health worker corps with health technology navigators "stationed" at various LAC DHS clinic waiting rooms—helping patients enroll and use their portal and become familiar with other telehealth offerings while they wait for their in-person appointments.

Study limitations included the small sample size of staff and leadership who were nominated to participate in the interviews, and limited generalizability to safety net health systems outside of Los Angeles County. This study focused on workforce and leadership stakeholder perspectives in the implementation—however, research centered around patient perspectives will be needed to validate changes, and advance substantial progress. In addition, this study did not address the relevant role of external policies like Medicaid reimbursement of phone and video visits, impact of patient-centered staff such as health educators and community health workers (who have been shown to improve digital health uptake in these settings), and availability of telehealth platforms and technology support in multiple non-English languages—all of which have been shown to be critical factors in the sustainability of telehealth in the safety net (84). Future research will need to more fully explore these in safety net settings to ensure that evidence-based factors that affect long-term high quality telehealth for these patients are addressed.

Overall, the purpose of this formative study was to generate initial health stakeholder insights regarding meaningful telehealth implementation for safety net patients and settings, as all health systems around the country are integrating remote strategies to reach out to patients, even beyond COVID-19. Although telehealth is not a full replacement for all in-person health care, it is important to note that telehealth is an added and complimentary clinical tool to address longstanding and continued health access inequities among underserved patients, if implemented appropriately in these settings. Because Los Angeles County is the largest and most ethnically diverse county in the country, these unique insights will be applicable to safety net systems across the US who are working to augment access to care and prevent worsening of chronic disease conditions among their patients. This augmented access will be especially needed after the disproportionate physical and mental health traumas inflicted upon this safety net population from COVID-19—effects that will resonate years beyond the end of the pandemic.

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 human participants were reviewed and approved by UCLA. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

All authors listed have contributed sufficiently to the project to be included as authors, and all those who are qualified to be authors are listed in the author byline. To the best of our knowledge, no conflict of interest, financial or other, exists. AC conducted the study. AC and AA designed the study. AC, CV, and EW carried out the analysis. CRL, CM, GG, and AB guided all aspects of the study from a research and operational/stakeholder perspective. AC wrote the manuscript with secondary writing from CV and EW. All other authors edited the manuscript. All authors contributed to the article and approved the submitted version.

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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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Longitudinal high-frequency ethnographic interviewing to simulate and prepare for intensive smartphone data collection among veterans with homeless experience

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Objective: While Veteran homelessness has steadily declined over the last decade, those who continue to be unhoused have complex health and social concerns. Housing instability interferes with access to healthcare, social services, and treatment adherence. Preventing unwanted housing transitions is a public health priority. This study is the first phase of a larger research agenda that aims to test the acceptability and feasibility of smartphone-enabled data collection with veterans experiencing homelessness. In preparation for the development of the smartphone data collection application, we utilized ethnographic methods guided by user-centered design principles to inform survey content, approach to recruitment and enrollment, and design decisions.

Methods: We used a case study design, selecting a small sample ($n = 10$) of veterans representing a range of homelessness experiences based on risk and length of time. Participants were interviewed up to 14 times over a 4-week period, using a combination of qualitative methods. Additionally, 2 focus group discussions were conducted. Interviews were audio-recorded and transcribed. Data were synthesized and triangulated through use of rapid analysis techniques.

Results: All participants had experience using smartphones and all but one owned one at the time of enrollment. Participants described their smartphones as "lifelines" to social network members, healthcare, and social service providers. Social relationships, physical and mental health, substance use, income, and housing environment were identified as being directly and indirectly related to transitions in housing. Over the course of ~30 days of engagement with participants, the research team observed dynamic fluctuations in emotional states, relationships, and utilization of services. These fluctuations could set off a chain of events that were observed to both help participants transition into more stable housing or lead to setbacks and further increase vulnerability and instability. In addition to informing the content of survey questions that will be programmed into the smartphone app, participants also provided a broad range of recommendations for how to approach recruitment and enrollment in the future study and design features that are important to consider for veterans with a range of physical abilities, concerns with trust and privacy, and vulnerability to loss or damage of smartphones.

Conclusion: The ethnographic approach guided by a user-centered design framework provided valuable data to inform our future smartphone data collection effort. Data were critical to understanding aspects of day-to-day life that important to content development, app design, and approach to data collection.

KEYWORDS

digital health tools, homelessness, veterans, user-centered design, qualitative research, smartphone, apps

Introduction

U.S. military veterans are at high risk of homelessness because of a variety of social, structural, and health-related factors. Through efforts of the U.S. Department of Veterans Affairs (VA) and other public and private entities the number of veterans who are homeless decreased from 74,000 to 40,000 between 2010 and 2016 (1). While the substantial reduction is praiseworthy there are persistent trends in homelessness between veterans and non-veterans and among subpopulations of veterans. Veterans make up only 6% of the U.S. population, but 11% of adults experiencing homelessness (2). Research conducted over the last three decades has also called attention to disparities within the population of veterans experiencing homelessness (VEH). For example, African American or Black veterans of all genders are overrepresented among VEH (3, 4), and are more likely to experience prolonged or chronic homelessness once an initial episode occurs (5). Other subpopulations within the veteran population that are at increased risk for homelessness include transgender veterans, who are nearly three times more likely to report housing instability than cisgender (i.e., non-transgender) veterans (6). Veterans with cognitive and behavioral health issues, such as substance use disorders or suicide attempts are 4–5 times more likely to be homeless than veterans without these conditions.

Among VEH, there is also considerable variation in the pathways leading to and out of periods of residential instability. Homelessness is often episodic, occurring once or twice for some, many times and for long duration for others. There are also many more Veterans who are at risk of homelessness because of previous life circumstances. In response to the both the prevalence of and risks related to homelessness, the VA implemented a clinical screener for providers to assess patients' housing status. This screener indicates about 300,000 Veterans served by VA are at risk of losing their housing (7). Homelessness and housing instability are characterized by frequent residential transitions, such as from transitional housing to shelter, or from doubled up with family/friend to living out of a car (8). Disruptions caused by such transitions likely contribute to this population's poor health by interfering with access to care and treatment adherence (9–13). Understanding how different experiences with homelessness intersect with disparities among veterans who are homeless or at risk of homelessness is critical if we want to provide meaningful assistance to meet their housing goals (14).

Methodological limitations of research on homelessness

Prior research has drawn attention to a range of factors underlying homelessness among veterans (15–18). These studies have examined more distal determinants such as adverse childhood events, mental health, social support, unemployment, and housing costs (16–20). However, there is a gap in understanding of the experiences and life circumstances leading up to, during, and immediately after transitions among this diverse, veteran population. This includes in-the-moment emotions (21), behaviors (22), geographic movements (23), and changes in social support (24) which have been linked with housing stability. For example, substance use in residential programs is often treated as a rule violation that can lead to being discharged from the program and thus a transition in housing. While substance use is often attributed to the cause of transitions like this, there are likely other factors that precede the decision to use drugs and alcohol, such as feelings of loneliness or lack of social support, frustration with bureaucratic processes, discrimination, and/or a perceived lack of control over life circumstances.

Prior work on residential instability and homelessness over time has been limited by the methodological difficulty of retrospectively gathering data about distinct points of time in the past surrounding a housing transition (25–27). In part, many studies on homelessness are limited by cross-sectional research designs. These studies may be most useful for understanding major events that participants are able to recall about prior transitions in housing. However, retrospective studies are less useful for generating a nuanced understanding of the chain of events, emotions, or experiences that may lead up to a transition in housing.

Longitudinal studies with repeated data collected over time offer greater insights into patterns of residential instability and factors contributing to these patterns. There have been a few high-quality longitudinal studies conducted with individuals experiencing homelessness. For example, the 2011–2014 Australian Journeys Home is a large-scale longitudinal cohort study of persons who are homeless or at high risk of homelessness (28). The HOPE HOME study based in Oakland, California, US is a longitudinal study of older persons who are homeless (29). There are also several longitudinal studies focusing on specific conditions or risks, such as Roy et al.'s study of HIV risk among a cohort of youth experiencing homelessness in Montreal, Canada (30, 31). Many of these studies have complicated findings from cross-sectional studies that identify risk factors such as substance use, unemployment, and mental illness as predictors of homelessness (32). Nevertheless, even when people experiencing homelessness are surveyed every 6 months, the ability to retrospectively recall and understand what may have led to an event 4 months ago, for example, is still limited (33). Gathering in-the-moment/real time data about emotions, social interactions, experiences with bureaucratic systems and processes, changes in health and mental health, and other experiences that come into play in the hours and days before a transition in housing occurs may provide insights that can be used to inform the development or tailoring of homeless prevention and intervention resources (34).

Mobile technologies as a research tool

Mobile technologies, such as smartphones, have the potential to aid in the collection of real- or near real-time information about the sequence of events leading up to and immediately after housing-related transitions. These increasingly ubiquitous technologies may help identify "early warning" signals based on self-reports of mood, activities, social support and activity spaces (constructed from passively collected GPS data) that may presage increasing housing instability, a homelessness episode, or a major health event. However, technology enabled studies conducted with individuals experiencing homelessness are few, in part because of concerns about their feasibility. Recent research has shown that mobile phones are commonly used by people experiencing homelessness (35, 36) and that these devices are used for a broad range of purposes (35, 37–41). This has led to increasing interest in studies that explore how to deliver services *via* smartphones and meet the differing needs of this population (18).

Fewer studies have made extensive use of smartphones to facilitate the collection of real time data from people experiencing homelessness, such as brief surveys that are transmitted *via* email, text, or application ("app") (42–44). Other tools available on smartphones such as global positioning system (GPS) also have had limited use in research (36–38). For example, GPS-enabled smartphones may be able to provide information about the mobility patterns, suggesting linkages between spatial context, day-to-day experiences and emotions, and pathways into and out of homelessness (45, 46). Researchers increasingly recognize the potential of smartphones for real time data collection in populations at risk of or experiencing homelessness (45, 46). However, the utility of studies collecting data *via* smartphone, depend on generating interest in participating and being able to ask the right questions at the right time.

User centered design

Principles of User Centered Design offer guidance throughout the phases of designing, developing, evaluating, and refining a product, such as a data collection app for research purposes. At the heart of the process is a deep understanding of the users, the contexts or conditions of use, and factors that might influence tasks associated with product use (47, 48). Applied to a research study, cultivating an understanding of potential users or participants requires learning what is relevant and important to ask in relation to the central research question(s). Learning about the contexts of users' lives can provide valuable information for design and use features. Eliciting feedback on user preferences and potential challenges or limitations associated design features can improve the completion of tasks and activities associated with the product. Investing time early in the research process, to learn about the study population in relation to the data collection, product or tool is critical to the conduct of meaningful and useful research.

This paper draws on data collected during the formative phases of a larger research initiative to engage VEH in longitudinal research studies using smartphone applications or "apps" to facilitate real-or near-real time data collection. The formative phase used an ethnographic case study approach, guided by user-centered design principles, to gain a nuanced understanding of the daily lives of VEH in one urban geographic area of the United States. Specifically, we sought to learn about factors influencing transitions in housing that might be amenable to capturing through a smartphone app. We sampled veterans to include variation in types of homelessness (chronic, recent, at risk) to gain insights into how these different circumstances might influence use of smartphones and other related technologies (e.g., computers, tablets). Finally, we explored factors that could influence tasks associated with smartphone-aided data collection, ranging from concerns with privacy and confidentiality to design considerations (e.g., reminders, font size). Our formative ethnographic work is being used to guide the content, design, and approach to data collection *via* a smartphone app in the next phase of our research.

Materials and methods

Overview

The formative phase of this larger study entailed the use of an ethnographic case study methodology focusing on the experiences of a diverse sample of VEH, including those who were at risk of homelessness, newly homeless, and experiencing chronic homelessness. A case study is a detailed examination of a single or small number of individuals, sites, or event aimed at generating context-dependent knowledge that is useful for developing theories about social phenomena of interest (49, 50). In this study we sought to learn about the relationship between events, activities, and emotional states related to transitions in housing and health, and the day-to-day use of smartphones and technology. A mix of long and brief qualitative interviews and observations conducted over multiple weeks allowed for exploration of historical and current factors that influence transitions in housing (Phase 1). Phase 1 interviews and Phase 2 focus groups also collected information on design and methodological considerations. User Centered Design principles (47) and the Uniform Theory of Adoption and Use of Technology (UTAUT) (51) guided inquiry into factors that may influence willingness to engage in and participate fully in a smartphone-enabled data collection study. Figure 1 provides an overview of the study phases and goals.

Setting

The U.S. Department of Veteran Affairs (VA) provides healthcare and aligned social services for over 9 million military veterans annually. It is the largest integrated healthcare system in the U.S., and one of the largest providers of services to persons experiencing homelessness. This study was conducted in two locations in the northeast region of the U.S. Site 1 is one of the VA Healthcare System's 141 medical facilities, located about 15 miles north of a major city. It provides a range of health and social services to veterans living in suburban and rural areas. The second site was located in the center of a dense, urban area. Here we recruited veterans from a multi-service residential program serving veterans who are experiencing homelessness and at risk for homelessness. The [City] Healthcare for the Homeless Program, which offers low barrier, low threshold services in the metropolitan area, also referred veterans in their care to the study.

Participant sampling and recruitment

A convenience sampling strategy was used to recruit ten participants with a range of experiences with homelessness, including chronic homelessness, a recent onset of homelessness, or at-risk for homelessness. The study team purposely recruited at least three veterans from each category to learn from people with diverse experiences with housing instability. For the purposes of this study, we defined these three groups as follows: *Chronically homeless* means having a pattern of multiple episodes (or a single long episode) of homelessness over an extended period of time (i.e., a year or more). This could be, for example, a person who lives primarily on the street and/or in a short-term shelter for long periods of time. *Recent onset* means newly homeless, with the period of homelessness having begun in the last 6 months, but not having a history of being chronically homeless. *At risk* refers to being at imminent risk of losing one's housing. At risk was determined in one of three ways: (a) a case manager knows that an individual is about to lose housing or is likely to lose housing; (b) a Veteran seeking Supportive Services for Veteran Families (SSVF) prevention services from a community based organization; or (c) a veteran was identified as at risk in response to a health provider's use of the VA Homelessness Screening Clinical Reminder which asks if a Veteran is concerned about not having housing in the next 60 days. These categories and definitions were adapted from the U.S. Housing and Urban Development's annual Point-In-Time count and report to the US Congress (52).

A multi-pronged effort was used to recruit participants. For the Phase 1 longitudinal case studies, the study team hosted informational sessions and posted flyers at residential programs in Site 1 and 2. Those that expressed interest were approached by study team members during informational sessions or later contacted by telephone. They were then screened for their current homeless experience (chronic, recent-onset, and at-risk) to confirm that they met eligibility criteria. Participants who met criteria provided written informed consent and assessed for cognitive functioning using the Montreal Cognitive Assessment (53). The results of the assessment were not used as part of the

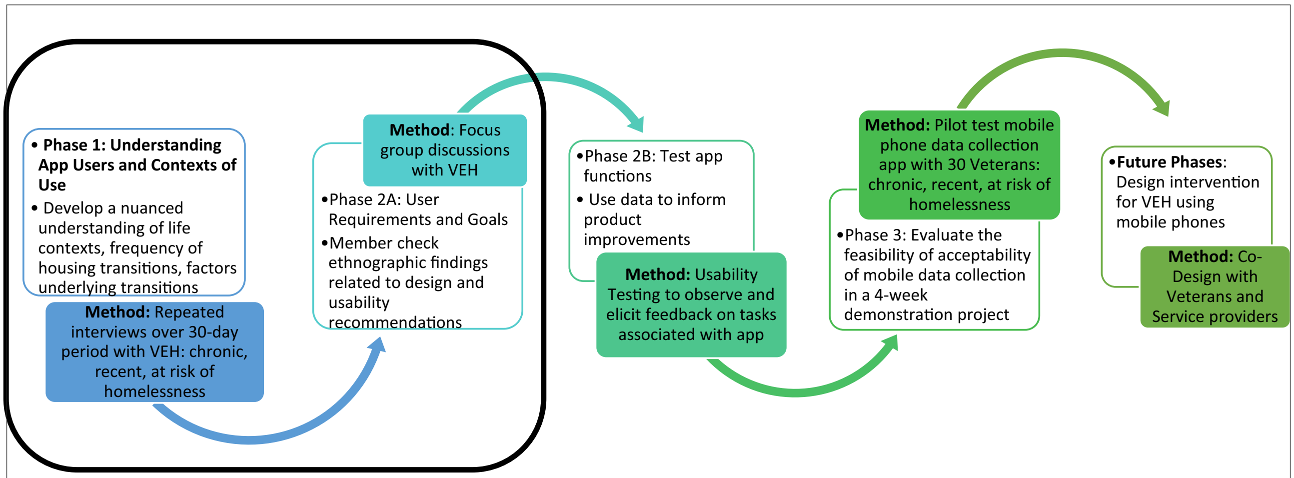

FIGURE 1
Ethnographic-informed user-centered design data collection app. *Black box represents phase of the study reported on in this manuscript.

TABLE 1 Schedule of phase 1 ethnographic data collection.

Week 1				Week 2			Week 3			Week 4		
Baseline	**RQI-S**	**RQI-S**	**RQI-L**	**RQI-S**	**RQI-S**	**RQI-L**	**RQI-S**	**RQI-S**	**RQI-L**	**RQI-S**	**RQI-S**	**Final**
Interview 1	Interview 2	Interview 3	Interview 4	Interview 5	Interview 6	Interview 7	Interview 8	Interview 9	Interview 10	Interview 11	Interview 12	Interview 13

study criteria, but to identify the potential need to spend more time reviewing informed consent procedures or potentially tailor the approach to collecting interview data.

Phase 2 focus group participants were recruited from Site 2. Focus groups took place at a nearby VA hospital and on-site at the residential program. Only veterans with recent onset and chronic homelessness were included in these group discussions. In part, this was due to challenges identifying and recruiting veterans who were at-risk for homelessness in Phase 1. Through rapid qualitative assessment of Phase 1 data we found few differences in the themes emerging between those at risk and those with recent onset of homelessness. We therefore used the focus groups to collect feedback on topics important to the app design and research approach.

Methods: Ethnographic case study

Phase 1 included repeat interviews over a 4–6 week period. This study period is consistent with the planned timeframe for the Phase 3 pilot study of smartphone-enabled data collection and offered a proof of concept for engagement in this later work. Four different types of interviews were conducted during this period (see Table 1): (1) a baseline, historical interview that lasted between 60 and 90 min; (2) Rapid Qualitative Interviews focused on a "special topic" of interest to the study that lasted ~60 min (RQI-L); (3) a general Rapid Qualitative Interview, twice a week, that lasted ~15 min (RQI-S); (4) a final interview to obtain feedback on participation in a multi-week study. The baseline interview was designed to gain a deeper understanding of participants' housing history, using a modified Residential Time-Line Follow Back Inventory (54, 55). Key social relationships, military experiences, and employment opportunities that may have influenced each individual's life course were explored. Demographic information was also collected and recorded on a short survey form during this initial interview. Longer "special topic" interviews (RQI-L) provided an opportunity to gain insights into three different topics over the course of participation: (1) physical and mental health (e.g., perception of overall health, experience with physical and mental health conditions and the extent to which they impact everyday life, perceptions of the impact of health conditions on housing stability); (2) Access to and use of social services (e.g., places participants go for financial, logistical, and/or social support to meet needs, facilitators and barriers to accessing different types of support, and perceptions of how support influences housing stability; and (3) Use of technology (e.g., type and uses of phone, including common apps and phone features). In between the longer special topic interviews, participants were called ~2–3 times each week for short interviews (RQI-S) to explore (a) how were feeling, (b) where they slept the night before, (c) any changes in their lives since the last conversation. These were meant to be brief conversations (~15 min) to identify and document any abrupt changes in participants' lives. At the end of the study period, a final 60-min interview was conducted to obtain feedback from participants on the experience of engaging with a research team over a prolonged period of time. These interviews also provided an opportunity to ask their opinions about the most important things to ask on a regular basis that might influence stability in housing, how to ask about sensitive topics like substance use, and about potential concerns with answering questions through a smartphone app. Experienced qualitative researchers conducted all interviews, with one interviewer assigned to follow each participant, to build rapport and knowledge. The interviews were conducted in a location of the participants' choosing, including a private room in Site 1 or Site 2, outdoors, or *via* phone.

Phase 2 entailed two focus groups with veterans who met Phase 1 inclusion criteria. The first focus group had two participants and the second had seven participants. These discussions provided an opportunity to build on the Phase 1 findings and further explore how to recruit, enroll, and retain VEH in a future study such as ours. The focus group participants were asked for their general perceptions of taking part in a research study that uses a smartphone app for data collection and recommendations regarding how to: (1) introduce and explain a study that uses the collection of data through a smartphone app, (2) explain the ways in which privacy and confidentiality will be maintained, (3) ask about potentially sensitive topics, such as substance use and relationship conflict, and 4) assess capacity to participate using a smartphone app. Participants were also provided a brief questionnaire to obtain specific information about their access to and use of technology generally, and specifically smartphones. Focus group discussions lasted ∼60 min and were facilitated by one of the anthropologists on the study team.

Ethical considerations

Study procedures were approved by the VA Bedford Institutional Review Board. Participants provided written informed consent and received up to $185 USD reimbursement over the course of the study ($25 for the baseline, follow-up, and long RQI interviews, and $10 for each brief RQI interview) for Phase 1. Participants in Phase 2 received $25. Randomly generated ID numbers were assigned to participants to ensure confidentiality. No personal identifying information were used in the audio-recordings.

Analysis

Quantitative data analyses

Demographic data were entered into a Microsoft excel spreadsheet and analyzed to generate descriptive information. The participants' ages were described using median and interquartile ranges and the descriptive data was summarized using counts, frequencies, means and percentages.

Qualitative data analyses

All interviews (one-on-one and focus groups) were professionally transcribed verbatim. Data were analyzed using a Rapid Assessment, Response, and Evaluation (RARE) approach (56), which uses a multi-disciplinary team to collect different types of data that can be synthesized and analyzed iteratively and efficiently to generate an understanding of critical health and public health issues. Each participant in Phase 1 comprised a "case" and had a portfolio of data from their multi-week study period. Analysis entailed attention to both the cumulative story and key changes that might impact housing transitions or health. Analysis of qualitative data began with interviewers preparing an analytic memo summarizing key impressions, immediately following the baseline interview to summarize information from the qualitative and quantitative questions (e.g., residential history, important relationships, and circumstances currently affecting housing stability, etc.). This memoing processes was then built on over the course of data collection, adding analytic memos to the baseline document, capturing key learnings about factors influencing physical and mental health, social relationships, use of social services, and use of technology. Adjacent to these open-ended memos, which capture information from participants and analytic insights, each interviewer identified categories of information (e.g., events, relationships, and perceptions) that were salient in participant's lives.

Once the transcripts of each interview became available, the interviewer reviewed the transcript and added detail to the analytic memos, including illustrative quotes. A standardized template was created to systematically summarize data related to transitions in housing and health for each participant. The summarized information was examined to identify patterns, common concepts, and emerging ideas about current events and experiences that influence transitions in housing and health. The lead interviewer and one other team member paired up to review the analytic memos and the resultant summaries for each template to assure consistency. These were then discussed by the full team. Phase 2 focus group data was analyzed using a similar process. Templates for these interviews focused in specifically on recommendations for improving the introduction of the study and approach to data collection *via* smartphone app. We also captured information related to recommendations for asking about sensitive topics *via* an app-based survey, such as substance use or loss of housing.

Data summaries were reviewed to both identify factors related to historical and current housing transitions, focusing specifically on understanding the chain of events that lead to transitions. Similarly, we explored the contexts or environments of participants' lives, which influence the ability to use and maintain smartphones and other technologies. Building off Phase 1 findings about how technology is used to navigate and access resources, social support and connection, and other uses, Phase 2 focus group transcripts were reviewed to dive deeper into specific topics relevant to smartphone use and issues related to our future data collection effort *via* an app that are important to build into the design and content of questions.

Results

We collected ethnographic data from 10 veterans who met inclusion criteria (chronic, recent, at risk for homelessness). In addition, 9 veterans actively experiencing homelessness (chronic or recent) took part in focus group discussions. Across 10 veterans who participated in Phase 1 ethnography, we had 45 transcribed interviews and dozens of brief notes from RQI-S interviews. The majority of participants participated in all data collection activities; 2 did not complete the final debrief interview and 1 was lost to follow up after completing 2 of the longer interviews. The participant lost to follow up was unsheltered and did not have a mobile phone at the time of enrollment. We provided him with two phones during the short time he was engaged in the study, both of which he reportedly damaged.

Below we provide an overview of key insights from our ethnographic research and the influence of these insights on the development of our Phase 3 pilot study. Following a description of the sample, we present findings related to the ubiquity of smartphones and uses among the sample. We then describe common circumstances and events observed or reported on during the study period and how they may influence transitions in housing. Finally, we highlight factors that may influence smartphone-enabled data collection with a population of veterans who are experiencing or at risk of homelessness. After each section, we provide an overview of how these key findings are influencing decisions about the content, approach, and design of the smartphone data collection app we are developing.

Sample characteristics

Table 2 provides an overview of key demographic characteristics of our Phase 1 and 2 samples. Although small, the sample mirrors the demographic characteristics of VEH in the region where the study was conducted. The sample included nine men and one woman. They ranged in ages from their 30–70s with most being between the ages of 40 and 60 years. Four were African American and six were white. The majority ($n = 6$) were staying at Site 2, a housing program and multi service non-profit for veterans experiencing homelessness. Several ($n = 3$) were in a VA domiciliary program (Site 1); one was unsheltered, living on the street. Half ($n = 5$) reported experiences of homelessness or unstable housing as a child. Less demographic information was obtained from focus group participants. All 9 focus group participants were categorized as being either more recently homeless or chronically homeless; no veterans who were at risk for homelessness were able to be recruited for these discussions. Among the nine participants, all (9 of 9) were male. The majority (6 of 9) were white and 3 were black or African American.

TABLE 2 Demographics of Phase 1 and 2 participants.

	Phase 1 interviews ($n = 10$)	**Phase 2 focus groups ($n = 9$)**
Gender, *n* (%)		
Males	9 (90%)	9 (100%)
Females	1 (10%)	
Age range, years, *n* (%)		
30–40	1 (10%)	
40–50	3 (30%)	
50–60	4 (40%)	
60–70	2 (20%)	
Race/ethnicity, *n* (%)		
White	6 (60%)	6 (67%)
Black / AA	4 (40%)	3 (22%)
Type of homelessness experience		
Chronic	5 (50%)	
At-Risk	3 (30%)	
Street	1 (10%)	
Current housing type, *n* (%)		
Shelter (Veterans only)	6 (60%)	9 (100%)
VA Substance Use Treatment Facility (Domiciliary)	3 (30%)	
Other	1 (10%)	
Number with childhood housing instability, *n* (%)		
Self-reported	5 (50%)	
Number with Military-Related Trauma, *n* (%)		
Self-reported	3 (30%)	

Frequency of residential transitions during study period

We captured variation and changes in housing status across the 10 participants over the 30-day study period. The data collection period for Phase 1 of the study was designed to last ~30 days, which is the length of time proposed for the Phase 3 pilot study that will entail smartphone-enabled data collection. During this formative phase, half (5 of the 10) of the study participants had transitions in housing. Three of these participants moved from transitional housing or shelter into permanent housing. One of these participants reported not wanting to work with case managers at the transitional program he was in because there were too many rules and requirements to follow. He preferred and successfully did find housing on his own. The other two moved into a Single Room Occupancy unit that was managed by the transitional housing program they were living in when first enrolled in the study. Two participants had to leave their residential treatment and shelter programs due to rule violations. One was found with an over-the-counter medication in his room that was not reported upon entry into the program. During the study period, he moved to one short term transitional housing program before finding another treatment program. He was able to maintain a full-time job throughout these transitions. The other was asked to leave after getting into a fight with other residents. This was at the end of our study period and we do not know where he transitioned. Two other participants were very close to moving out of a transitional housing program and into their own subsidized apartment, but this did not occur until after the study period ended. Three of the remaining participants were interested in finding their own housing at some point in the future, but for a variety of reasons (e.g., needed to feel more stable in recovery) this was not a priority at the moment. Only one participant indicated that he was not looking for more permanent housing. This individual was unsheltered and lost to follow up during the study period.

Besides these major transitions, such as moving out of a transitional or shelter program and into more permanent housing, the majority of participants who were homeless at enrollment stayed in the same residential program each night. A few participants noted that they would occasionally “take a break” from their temporary housing program to sleep in a hotel for a night or two. This allowed them some privacy, a greater sense of safety, and a better night’s sleep. These “respites” typically happened around the beginning of the month, when VEHs receive their disability or other benefit payments. There was also a seasonal component to the “first of the month” phenomenon, which one participant referred to as the “curse of the first.” During the Spring and Summer months in New England, the consequences of losing one’s housing were perceived to be less concerning because it is warm enough to sleep outside. A few participants noted they were more likely to take risks with their shelter or transitional housing bed (e.g., stay out past curfew) during these warmer months. However, regardless of season, most participants surviving on a fixed income (i.e., benefits) reported that they have dwindling income to live on over the course of a month. As noted below, this often coincided with fluctuations in levels of stress, frustration, and depression.

Implications for phase 3 pilot

Content

A 30-day data collection period may be long enough to capture real time transitions in housing for at least a subset of participants. Although we planned on frequently asking information about where a person slept the night before, we may consider adding a question to explore whether changes were temporary/short-term or permanent/long-term. Additionally, the events surrounding a transition were relatively stressful and time-consuming for participants. Capturing fluctuations in moods and behaviors through ecological momentary assessments (EMA) will be critical to learning how participants perceived and manage these changes.

Approach

There was some temporary loss of responsiveness to interviewers during the week leading up to and following a transition. Although Phase 1 data collection was more time intensive for participants (i.e., repeated interviews, lasting 15–60 min), we may anticipate a drop in participation in daily data collection surveys during a housing transition. This has led to thinking about ways to accommodate a busy period by either shortening surveys or allowing participants to pause participation or extend participation to allow for 4 full weeks of data collection.

Design

Interviews indicate that there may be fluctuations in activity spaces over the course of a month and by season (at least in places with highly seasonal weather patterns, like New England). Those who mentioned taking a break from shelters by staying in a hotel indicated that this entailed taking public transportation to an outlying suburb of the city where hotels are less expensive. Similarly, having more money at the beginning of the month may mean they are able to get to and purchase goods in locations further away from their current housing. GPS features on smartphones will be useful for exploring fluctuations over the course of a month. We will also want to ensure that recruitment of participants happens across seasons to explore climate-related variation in activity spaces.

Factors underlying fluctuations in housing

Most participants described a long history of residential instability that began in childhood. These experiences continue to influence their lives, particularly their physical, mental, and behavioral health, social relationships, and income. Below we highlight how historical experiences continue to influence participants' everyday lives and housing stability.

Trauma

In baseline interviews, the majority of participants described their housing instability as starting in childhood. Abuse and neglect, familial substance abuse, and frequent moves due to divorce and/or poverty were common. Joining the military at age 18 was perceived to be one of the few ways for participants to change their circumstances. However, entering military service with fairly significant and unaddressed trauma histories often posed more challenges for participants. Many were discharged before completing their service and returned to similar circumstances, routines, and habits. Residential instability shortly after separation from military service was commonly reported.

A few also identified traumatic incidents that occurred during their military service, such as military sexual trauma, which continues to affect their mental and physical health into the present day. As one black male participant noted, the sexual trauma he experienced while in the service filled him with shame and guilt. There was little recognition of military sexual trauma in the 1980s when he separated from service. Similar to others with histories of trauma, he spent nearly two decades coping with drugs and alcohol, which affected his personal relationships, employment, health, and housing.

Participants' prior trauma experiences are important to understand as they impact their housing transitions and residential instability in direct and indirect ways. In the Baseline and RQI interview focused on health, participants described how symptoms associated with trauma, such as chronic nightmares, hyper vigilance, depression, and anxiety, interfere with one's ability to engage in everyday activities. For example, one participant who was unsheltered and living on the streets described in his first interview a broad range of social support services he avoids because they are full of "skinners and rippers" (people who molest children and rape people). He was molested as a child and continues to feel the reverberating effects of these experiences more than 50 years later. For him, isolation and detachment have become strategies for self-protection. His avoidance of social and health services was on the extreme end of the spectrum. Most were accessing some support services, mainly housing support. A few participants were engaged in individual and/or group therapy for trauma and substance use. These participants generally felt that these supports provided a buffer against recurring trauma symptoms, while also offering them tools to manage symptoms when triggered.

In their everyday lives, participants also faced a broad range of challenging and often traumatic events. Being mugged and having belongings stolen was common across participants who were chronic and recently homeless. Many described their living situations as constantly chaotic and stressful, requiring hypervigilance.

> *It's not really tents. I just pull a tarp over me. I am a Marine, we just lay on the ground and pull a tarp over… It's camping yeah but it's incognito. That way you don't get knocked in the head. I got knocked in the head many times. And they steal your stuff. You got to sleep with one eye open. It's kind of like combat. 24/7. (V-104, chronic)*

Violence on the street and seasonal cold weather led many to seek out shelters and transitional housing programs. While these locations were relatively safer, violence, verbal harassment, and theft within group living environments was commonly reported. For many, the unpredictability of these environments and hypervigilance was exhausting.

Implications for phase 3 pilot

Content

The intensive longitudinal approach to data collection shed light on the potential relationships between prior experiences of trauma and current transitions that impact housing stability. Among participants with these experiences, fluctuations in stress, anxiety, frustration, and depression emerged as critical to capture on a daily basis. Negative changes in these emotions have a strong ripple effect for those with histories of trauma as they can be triggers for coping mechanisms such as drug and alcohol use and violence (verbal and physical). We will also have an opportunity to learn if engagement in professional support or treatment serves as a buffer to these stressors, including activities or strategies that are used to manage challenging situations.

Approach

A second implication of understanding participants' prior histories of trauma and military experience is related to trust. Participants with prior histories of trauma were more likely to note throughout our engagement that they do not trust many people, if anyone at all. In our final Phase 1 RQI-Long interview and focus group discussions, participants noted the importance of taking time up front in the Phase 3 study to build a relationship with participants. They specifically recommended having the study be introduced in person, with a clear explanation of study purpose and how the data would be used. They also recommended having an initial long interview at baseline so that participants get to know more about the kinds of questions we have and who (study team) will be looking at their data.

Design

With high levels of trauma anticipated among the study sample, we are also looking into principles of trauma-informed app design (57, 58). Although a new concept for User Centered Design practitioners, there are key principles that are aligned with feedback from Phase 2 focus group participants.

> *You gotta put all these questions into short-form. Make it quick, to the point. If you drag it out, you'll lose the concentration of the servicemen. With post-traumatic stress, you're looking around all the time, you get that in the streets too cuz you're worried about that guy stabbing you, stealing your wallet… None of these long-drawn-out things that we need to read forever. Get it to the point and then check it off. I recommend that for all men and women who have been to war and have trauma in their life. (Focus group 1 participant)*

Key principles of trauma-informed design include: (1) take time to build trust with participants, (2) be clear about the purpose of the study and how information will be used, (3) have a recognizable logo for the app so that when push notifications appear people know they can be trusted, (4) be mindful of the cognitive burden associated with each question and minimize complexity and volume of response options, and (5) offer choice to participants to not answer questions they are uncomfortable with and to provide open text fields if more information wants to be shared.

Physical, mental and behavioral health

Nearly all participants reported managing a range of physical, mental, and behavioral health issues. Chronic physical conditions included hypertension, diabetes, chronic obstructive pulmonary disorder, cancer, and HIV/AIDS. Mental health conditions commonly reported included post-traumatic stress disorder, anxiety, depression, and bipolar disorder. Behavioral health concerns were largely linked to alcohol and drug use.

Participants who experienced chronic homelessness had the greatest number of health concerns and struggled the most to manage them. These individuals were more likely to report a lack of trust in healthcare providers and poor prior experiences trying to access care. At the other end of the spectrum, those who were at risk of homelessness tended to be in treatment programs and receiving the healthcare they wanted. This group and the recent onset of homelessness group also tended to be younger and had fewer reported physical health problems.

The longitudinal nature of our study allowed us to capture a number of instances when physical, mental, and behavioral health issues interfered with housing or other goals that participants had on a day-to-day basis. One participant's experiences demonstrate the intertwined nature of housing, health and poor adherence. This participant had several complex chronic conditions, including diabetes, high blood pressure, asthma, neuropathy, and an alcohol use disorder, found it difficult to leave her room at the shelter on many of the days we spoke with her. On some days she missed appointments because she was not feeling well or she was unable to figure out how to get to her medical appointment on foot. Missed appointments meant that she was not able to communicate with her care team as her health was deteriorating. It also meant that she missed her substance use treatment appointments, resulting in a lapse in medication she took to deter her alcohol use. In addition, her fiancé who was staying in a different shelter became increasingly agitated and verbally violent over the phone on some weeks when she was not able to meet him and provide him with money. With others in the shelter drinking, she found herself joining them on some days to cope with the stress. Under these circumstances, it was difficult to do things she needed to do to complete her application for subsidized housing, such as get her state identification card and complete paperwork.

Unaddressed mental and behavioral health issues were associated with a bundle of problems that influenced housing stability, including job loss, incarceration, and strain in personal relationships. Specific substances of concern included alcohol, heroin, and cocaine. Marijuana use was frequently mentioned, but not generally perceived to be problematic. Several talked about their substance use as a way of managing their mental health needs. Veterans with more extensive histories of homelessness also talked about using drugs and alcohol to cope with symptoms of post-traumatic stress, which was frequently triggered as their current circumstances required hyper-vigilance ("you can never let your guard down"), an ability to handle unpredictability ("it's total madness here"), and a tolerance for challenging social dynamics. A few were new to mental health treatment and just beginning to reflect on their personal pattern of drug and alcohol use as a way to self-medicate and manage symptoms.

> *I smoked pot. That's what I was using to self-medicate my bipolar before I was on medication but, and then alcohol, I drank alcohol, but I wouldn't say it's like a substance abuse problem. You know, it's more me trying to manage my bipolar and the times I've had too much to drink, it's usually I'm in a manic state and trying to suppress it, and it just like, it comes out, you know, and I think a lot of, you know, the problems I've had with alcohol stem from me being bipolar.*
> *(Vet-315, at risk)*

Vet-315 had recently been released from jail and was in a treatment program where he was getting the mental health care he felt he needed. He was optimistic that the medications he was on to help manage his bipolar disorder would result in not feeling the need for other drugs. A few participants indicated their choices were to isolate themselves as much as possible to avoid others or to give in and join them. Although most wanted to isolate themselves and do what they needed to move into more permanent housing, we observed fluctuations in mental health, particularly depression, over the course of a month. Worsening physical health, repeated bureaucratic delays, and interpersonal conflicts were among the common "flashpoints" that led some participants back to drug or alcohol use.

Most participants described abstaining from drugs and/or alcohol for periods of time. In general, these were times when they had more stability in their housing and thought of themselves as doing pretty well. However, many also experienced changes in their circumstances that led them back to drug and alcohol use, which set off a chain of events that affected their housing stability. For many participants in our study, the COVID-19 pandemic was a recent example of this fluctuation. For example, one participant who was at risk for homelessness was working two jobs and living in his own apartment prior to the pandemic. His job gave him meaning and purpose in his life and kept him busy. Shortly after the pandemic caused a major shut down of many non-essential services, he was laid off one job and then his second one shortly after. He suddenly found himself isolated with a lot of time on his hands. His social network became much smaller, comprised largely of other Veterans who were living in his housing complex. They were "all drinking and doing drugs." Without a "purpose and reason to get out of bed in the morning" he started using again to fill the void. Over the course of 6 months, his use escalated and led to several substance-related hospitalizations. He was at risk for losing his housing and entered a substance use treatment program, which is where he was when he enrolled in the study.

A third group indicated that they do not see their alcohol or drug use as a problem at all. They described using these substances to either deal with the monotony of everyday life or to manage the chaos that is around them at a shelter or transitional housing program. They push back on the notion that if you have a drink or two at night you have a problem or that this is the underlying reason for homelessness. This perspective came up most strongly in focus group discussions about how to ask questions about sensitive or stigmatized issues through an app. Participants pressed group facilitators on why questions about substance use were important and how the information would be used if participants answered them.

Implications for phase 3 pilot

Content

Physical, mental, and behavioral health conditions are intricately linked to fluctuations in participants' mood, sense of hope for change, and motivation to work toward housing and other goals. In baseline interviews it will be important for the research team to gain an understanding of all the health conditions participants are living with and their perceptions of how well they are able to manage them. Throughout the pilot phase, we will include brief questions about perceived physical, mental, and behavioral health status (e.g., How is your physical health today? Did you use drugs today?) and the extent to which they believe their health impacted the ability to do the things they wanted to do. We will use Ecological Momentary Assessments to understand fluctuations in mood throughout the day. At the end of each day we will also ask about engagement in health services (e.g., services accessed, appointments missed) and the extent to which participants feel they received the professional support they needed to help manage health conditions.

The salience of drug and alcohol use and the ways in which directly and indirectly influenced participants' housing stability makes it an important topic to ask about in the Phase 3 pilot. However, participants expressed hesitation with sharing information through an app about their substance use. Among some participants, their experience is that when they mention using drugs or alcohol to a professional health or social service provider, it tends to become the lens through which all other circumstances and behaviors are understood. They are labeled as "drug addicts" or "alcoholics" and substances become the main focal point for services.

> *We don't want to be stereotyped as having "that issue" [drug or alcohol problem] bringing us down to where we are, cuz I know a lot of people that don't have issues at all that are lost and homeless due to circumstances… Because it [being labeled] really affects you if you're homeless… (Focus Group 1)*

Others expressed some legal and privacy concerns with sharing detailed information about drug use in particular. This was particularly true for participants who were on probation or parole. One other potential barrier to asking about substance use was related to participants' readiness to admit it. For example, one participant noted that he would have no problem answering questions about his substance use because he was not currently using drugs or alcohol. When asked to think about a time when he was using and the extent to which he would feel comfortable answering the same set of questions, he noted "*that would be a different story*" *(V-314, At-Risk)*. For this participant, the shame of using drugs and alcohol usually leads him to feel reluctant to share this information with others until he is ready to stop again.

Approach

As already mentioned in the section on trauma, investing time during the initial study enrollment period in getting to know participants' life experiences, circumstances, and perspectives in relation to their health will be important. Not only will it inform our interpretation of daily survey data but will also give participants a chance to learn who we are as a research team and form an opinion about the importance of the research.

If we are able to do this well, both through a thoughtful informed consent process and a meaningful baseline interview, we may improve our chances of participants responding to questions about highly stigmatized or sensitive topics, such as drug and alcohol use, trauma, and mental health challenges.

Our team discussed how to ask questions in ways that are psychologically safe, non-judgmental, and low burden. In addition to using neutral, person-centered language, we are also considering what we actually might need to know about things like drug and alcohol use. For many participants, it may be sufficient ask two questions about drug and alcohol: (1) use of drugs/alcohol today, and (2) perception of if use (or not) influenced their ability to do what they wanted to do. For each question, we will also include a "decline to answer" choice option.

Finally, findings from this formative phase have led us to consider adding questions to our enrollment screener to help identify individuals for whom participation in a smartphone-enabled study would not be appropriate for participation. Examples of individuals who may not be appropriate include those who believe they are under constant government surveillance through technologies like smartphones or who have a deep mistrust of government institutions (such as the U.S. Department of Veteran Affairs).

> *"We don't like to be tracked, we don't like to be watched, basically most of us are a little paranoid. We don't want anyone asking where I'm going, what I'm doing." (V-104, Chronic)*

The Phase 3 pilot study has a relatively small sample size ($n = 30$). Given the sensitivity of some questions we want to ask about (e.g., mental health and substance use) and data collection features we want to try out through the smartphone app (e.g., GPS location data), we want to assess our "proof of concept" with a sample of individuals who are willing to participate from the outset.

Design

As a research study, the research team is required to ensure that all data collected through the smartphone app is securely obtained and stored on HIPAA compliant servers, with access only granted to members of the research team. In addition, the app will use end-to-end encryption to send survey, GPS, and other data to the HIPAA compliant server. Finally, we have obtained a Certificate of Confidentiality from the National Institute of Health to comply with Section 2012 of the twenty-first Century Cures Act (42 U.S.C. 241). This adds a layer of protection to our data to ensure that identifiable data cannot be provided to legal or other non-research parties. While these precautions are relatively standard for a research study, it is important that we are able to clearly communicate these precautions and educate participants on the many ways we will protect the privacy and confidentiality of the information they provide.

Social relationships

There were three types of social relationships that participants described as influencing their everyday lives in both positive and negative ways. The most influential were family and friends, followed by professionals, such as case workers and clinical providers. Participants were also influenced by the people that lived in residential or transitional housing programs, whom many referred to only as "acquaintances." The majority of participants relied almost exclusively on their smartphones to maintain relationships with family members and professionals, with some (mostly older participants) preferring to talk by phone, while others preferred text or video applications. Phone theft and/or phone damage was a common occurrence and a major stressor for participants. The loss of a phone often meant the loss of important information such as contacts, upcoming appointments, and electronic documents. Participants who reported the fewest personal and professional relationships were also more likely to report the greatest frequency of phone loss over the last year.

Relationships with family members varied significantly across the sample. On one end of the spectrum, there were two male participants who reported no contact with family members, including siblings and children. These participants were chronically homeless and described extensive instability and trauma from an early age. A second group of participants ($n = 6$) described maintaining some relationship with family members, mostly their adult children and/or mothers. Some in this group reported that these relationships can be emotionally supportive, but no one reported that they offered financial or logistical support. On the other end of the spectrum, two participants reported they frequently speak with family members, who provide substantial emotional support. One female participant reported the greatest contact with family members, connecting with her mother and kids nearly every day. Participants noted that they were better able to maintain contact with family members when they were housed. These connections diminished when they begin using drugs or alcohol, experience a downturn in their physical and emotional health, and/or lose housing.

Participants in our sample frequently described connections to other individuals in their day-to-day lives that provided social support. They included other veterans, romantic partners, social service workers, and sobriety sponsors. For some, these relationships were a key source of support as they navigated homelessness. Some described receiving access to hot showers, food, laundry, and temporary sleeping accommodations, as well as physical, emotional, and spiritual support.

> *"She [friend who was once homeless with participant] helped me out as she could. She let me take showers, let me spend the night over there. She fed me, hooked me up with some weed… my own family members would ride by me… But people who actually help me, that was there for me, that call me [and ask] How you doin?, How's things goin?, What do you need?, Are you all right?, There's only like four or five people that do that." (V-102, Chronic)*

A few participants also described forming relationships with other veterans experiencing homelessness. These veterans were often living in the same transitional housing or treatment program. Similar to social service providers, these relationships provided information about potential housing opportunities, financial assistance, sobriety support, and support for trauma resulting from military service (e.g., PTSD, military sexual trauma):

> *"Veterans tell me this is a place you can go to if you got an unpaid bill and you can't pay it, they might help you out, stuff like that… they might have a resource where if you owe an electric bill from an old apartment and you're trying to move to a new apartment, they might have funding…" (V-315, At-Risk)*

During the study period, we also observed frequent turmoil and disruptions in these relationships. One participant broke off his engagement with a woman who he described in the baseline interview as "my number one" (*V-101, Chronic*). Several others talked about arguments they had with romantic partners that led to them to feeling more depressed and isolated within the span of just a few days. Some personal relationships were particularly difficult to navigate. This was especially true among participants who were working on making changes so that they could obtain housing, employment and/or address health concerns. For example, one participant with a significant substance use history frequently expressed a desire to limit interactions with her close knit "street family" because their frequent drinking and drug use threatened both the participant's sobriety and current housing placement.

> *"It's particularly people that I hang with of my street family, the ones I've been hanging with and they do drink a lot… You know, I'm doing what I have to do. I'm staying away from, you know, people, places and things" (V-110, Chronic)*

Although this was something she felt like she needed to do, it was also difficult for her to distance herself from this part of her social network. During the study period she was often isolated in her room at the shelter. Her emotional state, as well as her health, fluctuated a lot during the study period, and often from one interview to another.

Finally, the contexts within which participants were living put them in social relationships that were often described as unhealthy and challenging. Staying in shelters or residential programs meant that a person's de facto social environment was comprised of other individuals they had not have chosen to be with. Many reported tense relationships with the peers in their shelter or transitional housing program. Concerns about violence, theft, and exposure to drug use frequently reported.

> *"I come to this building… I wasn't planning on it being – I'm surrounded by addicts. I'm surrounded by drunks. I'm surrounded by everybody using, actively using stuff… that's why I'm trying to get out of there as fast as I can." (V-102, Chronic)*

The desire to leave the shelter and move to a stable, individual housing unit, without substance use exposure, was frequently expressed by participants. Participants also reported feeling a lack of meaningful social attachment to many people in their lives, including social service workers who were supposed to help them. At the same time, some participants expressed concerns with feeling lonely and isolated when they are finally able to leave their transitional housing or treatment program. As one participant noted, *"I've seen some get up off the streets and get an apartment and die because of loneliness." (V-315, At-Risk)* It was not uncommon for participants to express very different opinions about their readiness and confidence to move into more stable housing throughout their engagement in the study.

Finally, a few participants discussed their relationship with social and health professionals that provide some kind of support in their lives. Most felt that these relationships were relatively distal and inconsistent. The COVID-19 pandemic likely played a role in this, as restrictions on in-person meetings, requirements for social distancing, and precautions taken when someone was ill (or potentially exposed) disrupted preferred ways of connecting and communicating. Some engaged in services through telehealth, or virtual care. Although convenient, the structure of virtual appointments led many to feel like their providers did not know them or understand their circumstances. A few participants also talked about the stresses posed by reduced access to social and medical services during the pandemic, leading people to feel frustrated, trapped in unhealthy or unsafe living circumstances, and unable to get the kinds of support they needed.

Implications for phase 3 pilot

Content

Findings from this formative phase suggest that social relationships are critical to ask about frequently through a mobile app. We observed that some relationships change relatively quickly, especially romantic partnerships and acquaintances within temporary housing programs. Social relationships are also not perceived to be consistently positive or negative but may fluctuate in relationship to a participants' personal goals, health status, and behaviors. Finally, variation in perceptions of one's social circumstances highlights the need to not make assumptions about size and composition, especially in relation to social support. Questions about preferences and satisfaction with social network are needed in order to understand patterns in communication.

Approach

Nearly all participants in both phases of the study emphasized the importance of meeting participants face to face when the study begins and spending time building rapport and trust with them. Their willingness to engage and provide honest answers hinges to a large extent on whether or not they can formulate a sense of trust in the researchers and believe in their motives. As one participant who took part in the Phase 1 ethnographic interviews explained,

> *"Talking to you and meeting you, it makes it easier, now we actually had a face-to-face. So, now when I do talk to you [by phone], I know who I'm actually talking to, to give you the feedback that you need instead of some person just sitting on the computer." (V-102, Chronic)*

Most participants placed a high value on in-person encounters. Although the goal of Phase 3 is to use smartphones for data collection, findings highlight the need to nest this data collection effort into a broader approach that includes taking time to get to know participants and their current circumstances before launching the smartphone data collection effort.

Design

With permission from participants, we will be leveraging smartphone capabilities to track patterns in communication with others through phone calls and texts. The app will be programmed to encrypt numbers so they are not traceable to individuals. As noted above, there will be a need to gather other information regarding preferences for size and composition of social networks and satisfaction with support provided to assist with interpretation of communication patterns.

Income

The majority of participants reported little monthly income during the study period. About two-thirds of participants relied to some extent on military service benefits (e.g., physical or mental health disability stemming from time in service), with half relying solely on these benefits. A few relied on state disability benefits. One person held a full-time job at a VA hospital throughout the study period. Although he had a steady income, he depended on subsidized housing vouchers to make ends meet in a high-cost area. A few also talked about work they did in the informal economy, such as asking for spare change or selling alcohol, cigarettes, or drugs.

Most participants relied on public benefits for some or all of their monthly income. Over the course of a month, fluctuations in money contributed to feelings of stress, anxiety, and perceived loss of control over one's life. In particular, the beginning of a month meant that participants had money to pay for public transportation to leave the dense urban area they were living or to pay for a hotel room for a night or two to take a break from shelter life. As the month proceeded, money dwindled and participants had to rely more on public and social services to meet their basic needs. These fluctuations in income were common. We observed and participants reported that they felt more depressed, angry, and frustrated near the end of each month. In situations like this we observe that participants were less likely to be able to cope with unexpected events or flashpoints when they occurred, which could lead to unanticipated setbacks or transitions.

Implications for phase 3 pilot

Content

In baseline interviews we will ask open-ended questions to gain an understanding of the amount and type of income participants typically rely on each month. We will ask about the extent to which they feel this income allows them to meet their needs. We will explore other resources or services that provide assistance. This baseline understanding will help us learn about fluctuations in income over the course of a month. A few times a week we will ask questions through the app about work (e.g., type) and perception of having enough income to meet one's needs. Asked repeatedly over the course of a study period, we will be able to explore how changes in income and perceptions of adequacy of income are related to mood, stress, depression, substance use, and other factors that can influence housing stability.

Approach

Given that there are a variety of income sources (e.g., benefits, formal wage labor, informal or illicit labor) that participants may rely on, it will be important for us to be inclusive in how we phrase our question(s). Concerns with confidentiality and privacy have prompted discussions about what is important to learn about income and work. We tentatively decided to ask about participants' engagement in work each week and whether or not the work was for: (a) money, (b) trade or barter, (c) without pay (e.g., volunteering), (d) did not work, and (e) prefer not to answer.

Design

With the smartphone-enabled data collection app we are able to program questions about income and work that might have daily and weekly fluctuations. For example, at the end of each night we are considering asking a single question about whether a participant worked that day. On a weekly basis, we can explore activities that might occur over a longer period of time, such as looking for work or participating in a work-training program. Total income and perceptions of adequacy of income to meet needs can be asked at random times throughout the study period and programmed to capture variation across a given month.

Factors that may influence smartphone-enabled data collection

In addition to identifying key elements in the day-to-day lives of veterans experiencing homelessness, we sought to understand the feasibility of collecting research data *via* a smartphone app. Nine of the ten individuals who enrolled in the Phase 1 study and all nine individuals who participated in Phase 2 focus group discussions had their own smart phone. The veteran who did not have a phone upon enrollment in the study purchased phones somewhat regularly. However, he frequently damaged them when frustrated or mad. This veteran was provided two mobile flip phones by the research team to take part in the study. He damaged the first one shortly after our first interview and was provided a second one. After the second interview we lost communication with him.

Among those who had mobile phones, there was wide variation in how they were used in everyday life. On one end of the spectrum, a few participants indicated that they use the phone primarily to make phone calls and occasionally check email. These individuals tended to be older and more likely to report that they do not know how to use their phones to the full extent.

> *"That there're no classes for the phone. That really ticks me off. How are you supposed to learn – like, I bought this phone, and it didn't even come with directions." (V-104, Chronic)*

In addition to knowledge about how to use their phones, a few participants called our attention to the importance of language when introducing a study that involved smartphones and applications. For example, when asked about what kind of applications or "apps" he used on his phone, one participant indicated he did not know what an app was. Upon explanation, he told the interviewer that he had always referred to the app icons on his phone as *"little squares" (V-102, Chronic)*.

A few participants who described more limited uses of their phone noted physical challenges that impeded use. One person had limited dexterity with several fingers. Performing certain functions, like typing texts or emails, was reported to be difficult given the small screen and keyboard. Others had impaired vision that made it difficult to see small font and images.

On the other end of the spectrum, some participants consider their phone a lifeline in the world. They used it to stay in contact with people, including social and professional relations, for telemedicine appointments, geographic navigation, to identify services and resources, and for entertainment. For these individuals, their phones were critically important. *"Staying in communication depends on me having my phone, you know*?" *(V-314, At-Risk)*. One participant described the anxiety he felt when he temporarily lost his phone:

> *"[At] the time I had my team or workers, my social worker, my therapist, my housing worker, my case workers, everybody in my phone was helping me to get where I'm at today and now I had to reestablish all my phone numbers on my finder and got my team back together. I was having an anxiety attack. Without my phone I was literally, I didn't realize how much I needed it." (V-102, Chronic)*

The loss or theft of a phone, which was commonly reported, could mean the loss of important connections, setbacks in progress toward housing, and missed health or social service appointments. Loss of a phone is another type of flashpoint that can have ripple effects. In general, those who reported having their mobile phones lost or stolen in the past have been successful in obtaining new ones relatively quickly and tend to have access to support to get them back "up and running" with their digital connections. Some did rely on email or social media apps that they were able to access through a computer to stay in touch with others when they were without a phone.

The issue of trust emerged again in conversations about technology use and the potential of collecting data through a smartphone app. Many participants had smartphones that were free or subsidized through a governmental program (nicknamed "Obama phones" after the US President at the time of a policy to subsidize phone access). They had inexpensive phone plans. However, these lower cost options had drawbacks. Many reported getting a lot of spam texts, phone calls and emails. Repeated spam made it difficult to discern what incoming information was trustworthy.

> *"Anybody who texts me, how do I actually know who's on the other end? How do I actually know the person is really sincere with what they're saying?..." (V-102, Chronic)*

These types of communications heightened concerns with surveillance and lack of privacy among some. For others, it meant they only responded to messages from recognizable numbers (i.e., in their contact list).

Finally, we explored perceptions of using additional features on a smartphone, such as global positioning systems (GPS) and phone logs to gain a better understanding of participants' mobility (i.e., how far people travel each day), activity space (i.e., types of places people go), and social contacts. Participants in the Phase 1 ethnographic interviews raised fewer concerns about GPS and phone log features. This may be due to our asking specific questions about the use of these features near the end of our data collection period, after we had repeated encounters with them. Focus group participants had more questions about why this information was needed, how much detail would be transmitted, and who would be seeing the data. Concerns were raised about the potential use of this information to track or monitor drug deals or other illicit activity. Of note, concern was anticipated primarily when someone was active in their drug use.

Implications for phase 3 mobile app

Content

These findings did not have major implications for the content of our survey questions. However, we will incorporate a series of questions into our baseline interviews to learn about participants' comfort with and uses of their smartphone. This information will be useful to members of the research team to inform the type and extent of training that participants may need to participate in the app-based data collection.

Approach

Exploration of participants' use of and concerns about their smartphones over time highlighted a number of important considerations for how we approach enrollment in the Phase 3 pilot study. Clear communication about the purpose of the study and what participation entails will be important to enrolling people who are interested and willing to provided data through an app. While this is a required ethical practice, we think that this information needs to be shared before the formal informed consent process. For example, when introducing the purpose of the study at the initial recruitment phase, research members may need to use visual aids, such as showing example questions on a smartphone and pictures of activity spaces generated from GPS location data, so that potential participants have a good understanding of the study. If they remain interested, then a formal informed consent process can begin. Through this process we need to reiterate the purpose of the pilot study, how the data will be used, who will have access to their data, and how privacy and confidentiality will be maintained. Although this is standard ethical practice, the novel approach and time intensive nature of the study needs to be explained thoroughly prior to enrollment. This may also reduce the risk of recruiting people who are not a good fit for this phase of the study (i.e., are reluctant or opposed to sharing personal information through an app).

With the high level of theft and phone loss reported among participants, it is important to create ways for participants to stay engaged with the study. For example, we will have one research team member be the primary point of contact for the study. His contact information will be sent in email, text, and hard copy form. Participants will be asked to contact him with any questions or if they have lost their phone. We are also considering creating a way for people to respond to questions through other means, such as a tablet or link to a website. Finally, upon enrollment we will also ask participants to inform us of how to reach them if they have not responded to survey questions for a week. This will allow us to connect with them to learn about their situation and how best to get them re-engaged (if interested).

Design

Concerns with high volumes of spam communication, privacy and mistrust have highlighted the importance of branding the smartphone app and making it very clear when push notifications or requests to respond to daily or weekly questions are from the study. In a future focus group, we will provide several different logos and ask participants to identify which one is preferable. This may help participants decipher between a trusted communication and an unknown one.

Another design feature that was recommended by participants was the ability to make decisions about what information to share with the research team. For questions, they recommended an option to "refuse" or "decline" a response. For GPS data transmission, they recommended transmitting periodic requests to continue to sharing GPS location data or, if location data was turned off, to request turning it on again. We are considering a similar approach to requesting access to phone logs. This provides participants with the ability to know what personal data the smartphone app is accessing and allows choice over what and when to share.

> *"... as long as you have that prompt where you can say yes and no [for sharing GPS data], I mean, everything is fine." (V-316, At-Risk)*

Providing choices like this will allow the study team to learn more about the features of smartphone data collection that are acceptable to participants. If enough participants provide consent to use these other types of data, we will have the opportunity to determine their value in understanding dynamic factors that contribute to housing instability and homelessness.

Discussion

Ethnographic research guided by a user-centered design framework provided our research team with a depth of information to inform the content, approach, and design of our planned smartphone-enabled pilot study with veterans experiencing and at risk of homelessness. Frequent data collection using questionnaires distributed *via* a smartphone app at regular intervals may provide information traditional survey research have been unable to do—identify the sequence of events and experiences that precede and follow the transition from one housing status to another. Such an effort may facilitate early identification of potential problems, offering service providers a chance to prevent or intervene quickly enough to mitigate them. The planned pilot study will explore the feasibility and acceptability of using smartphone apps to identify or detect near real-time events, activities, moods, and triggers that presage negative outcomes such as housing instability, loss, or serious health events. To our knowledge, this will be among the first test of active and passive smartphone-enabled data collection applied to the study of homelessness among veterans.

While our sample of veterans experiencing homelessness was relatively small, we were able to gather extensive, longitudinal data about their daily patterns. We collected up to 30 days of data across ten participants, providing a depth of information about fluctuations in their daily lives. The participants represented a range of housing situations, including transitional housing, residential treatment programs, shelters, and one individual was street homeless. More than half of participants had a major transition in housing during the 4–6 week study period. This finding lends support for our initial study design which aims to develop and test a smartphone app over a limited period of time for "proof of concept." Further, the ethnographic data provided insights into the types of transitions that might be made, catalysts for these transitions, and potential fluctuations we might detect based on season and time of month.

Similar to other studies conducted with individuals experiencing homelessness (36, 38, 59), we found near ubiquitous ownership and use of smartphones among participants in our sample. The one individual who did not have a phone at the time of enrollment in the study, reported recent and frequent smartphone ownership (reportedly buying 40 phones a year, all of which were lost or damaged). Although phone theft or damage was frequently reported, the majority of participants secured new phones quickly. For many, it was their "lifeline" to family, friends, healthcare providers, and social services. Many used their phones to access needed medical and social services, navigating from one location to another, and for entertainment (e.g., games, movies). Technological competency did vary however, with older veterans less likely to report using a broad range of functions on their smartphones and more likely to report challenges with use (e.g., dexterity to type, impaired vision to read small fonts).

A key lesson learned about our *approach* to implementing the Phase 3 pilot study is the need account for a range of technology user expertise by tailoring an initial training on how to answer questions through the smartphone app. Attention to the wide variation in digital literacy will be important for consistent participation (38, 60–62). We are considering incorporating a series of digital literacy screening questions when introducing the study so that the research team is able to tailor training on how the smartphone app functions and how to provide responses to different types of questions. We expect that some individuals will be familiar with how apps work and quickly know how to use the app. Others may need an overview of how apps work, including where and how information is stored, how to adjust settings to increase ease of use (e.g., increase font size), and how to answer each type of question. In addition, we will provide a single point of contact on the study team who is available to answer questions and provide technical support. Investment in this type of tailored training and on-going support may help reduce frustration with technology. Individualized training can also contribute to building trust and rapport with participants so they feel comfortable reach out for assistance. Notably, the response to our questions about trust varied between the Phase 1 participants who got to know their assigned researcher, while the Phase 2 focus group participants were more circumspect.

With respect to *design* of the app, findings highlighted the need to offer choices that allow participants to participate. For example, we can design options for font size and help participants select one that is best suited for them. We are also considering offering "voice to text" options for open-ended questions to accommodate participants with limited dexterity or comfort typing on a smartphone keyboard. Designing the app to include choices to opt in or out of data requested was highly recommended among participants. Issues related to privacy and trust were of concern, particularly with respect to questions about sensitive issues (e.g., drug use) and passive data sources, such as GPS location data and call logs. Providing participants with an option to turn off or refuse to transmit information may improve willingness to participate in the novel research study. In addition, we are developing robust procedures to protect privacy and data security of any data submitted or tracked. Our *approach* to explaining these safeguards and providing adequate training on how to opt in or out of a data request will be critical.

The dynamic fluctuations in the lives of participants over the course of the Phase 1 study highlighted the potential value of using a smartphone app to collect information about the day-to-day experiences that influence transitions in housing and health. However, building a digital health tool offers very little if people do not use it or the quality of response data is poor. For people experiencing homelessness, lack of trust in people generally, and certain entities in particular (e.g., "government"), can be a major barrier to engagement in many services (9). Trust was found to be important to decisions about participating in a study like ours that aims to collect personal information *via* a smartphone app. Attention must be paid to how creators of digital health tools and/or those who want to implement them can build a sense of trust with a potential tool user. In our study, our team discussed the need to meet participants in person to introduce the study and to be prepared to offer one or more introductions and enrollment sessions. Clearly communicating the purpose of the study and how we are safeguarding the information they share through the app will be critical to participation. Participants will need to have a clear understanding of the purpose of study and the rationale for different types of questions we might ask (i.e., "We ask about substance use because it may mean there will soon be changes in social relationships and housing"). Importantly, they will need options for what to share and when to share data.

Use of a smartphone app for data collection has some limitations, especially in regard to the number of questions that can reasonably and feasibly be asked at a given time. As with any questionnaire, this means that it is important to understand what is relevant and meaningful to ask about (i.e., *content*) and the frequency with which to ask. Our ethnographic data provided a number of examples of how transitions in housing are rarely linked to a single event. For many, conflicts in relationships, unmanaged health conditions, and repeated challenges securing documents or completing paperwork for housing subsidies were often catalysts for changes in mood, which sometimes led to substance use as a coping mechanism. Some temporary housing environments were also stressful and unpredictable, with high levels of substance use and violence reported. For some, the options were to isolate as best they could, or join others to get by; these options had pros and cons for different participants which would be important to discern. Frequent data collection allowed us to see changes in mood and health over the course of a month as a person's fixed income dwindled. Options to take a break from a shelter by staying in a hotel or to exercise choice over their meals were greatest at the beginning of the month when many received benefit payments. As income declined over the month, stress, anxiety, and depression seemed to increase. These changes in mood affected participants' response to key events, such as an altercation in a personal relationship or bureaucratic barrier. Sometimes this influenced decisions to use drugs and alcohol, which also had variable impacts on participants' housing, health, and general sense of well-being.

While the ethnographic methods employed during this formative phase of our pilot study offered rich and nuanced insights to guide the content and design of the smartphone data collection app, there are a number of limitations worth noting. First, there are limitations related to the study sample. Given the intensity of data collection (volume and period of time) and need for rapid analysis to inform subsequent phases, formative data could only feasibly be collected from a small sample of Veterans experiencing homelessness. The research team understands the heterogeneity of the population of veterans who are homeless or at risk of homelessness. However, we had to make decisions about what qualities or perspectives would be important to understand for the pilot study, which is a "proof of concept" that near-real time data can be collected from people experiencing homelessness through a smartphone app. Drawing on our prior research with veterans with unstable housing and conversations with our veteran research consultants, we opted to prioritize sampling based on variation in homeless experiences; our goal was to recruit Veterans whose housing situations ranged from at risk to long-term and chronically homeless. We anticipated that these different circumstances may influence access to and use of smartphones. Although we did not specifically recruit for other types of diverse experiences, our sample reflected some, but not a full range of diversity among this population in the metro area, including 40% who identified as Black and 10% as female. We also had a range of age groups, although the majority were over the age of 50 years. To our knowledge, our sample does not include veterans who identify with racial/ethnic groups other than White/Caucasian or Black/African American or as gay, lesbian, bisexual, transgender, or non-binary. The sample also does not account for variation in experiences with homelessness based on geographic location. It is likely that transitions in housing and decisions about housing more generally are affected by cost of living and seasonal variations in weather. The metro area is both expensive and seasonally cold for approximately half of the year, both of which influenced housing decisions in our sample. Diversity with respect to race, ethnicity, gender, age, and geographic location are important to understand before we scale up a smartphone-enabled study approach, particularly as they influence our thinking about what is important to ask about (i.e., content of our questions) and how best to ask (i.e., approach).

A second limitation related to our sample is with the narrower diversity of focus group participants in Phase 2. Our intention was to leverage our success with recruiting veterans from one shelter (NECHV), which housed veterans with recent and chronic homeless experiences, to provide rapid feedback on specific questions related to approach and design, such as how to explain our interest in GPS location data and call logs. The sample did not include one of our three priority groups, veterans at risk for homelessness. This was a difficult group to identify and recruit for Phase 1 interviews. This perspective is missing from the initial focus groups. As we move into the usability testing phase, greater attention to including representatives from all three groups will be important.

Finally, we offer our perspectives on a challenge as researchers gathering and analyzing data from individuals who have a broad range of experiences and opinions related to using smartphones to collect data in near real time (63). This challenge is what Oliver et al. (63) refer to as "the dark side" of co-design work. As with any user-centered design approach, our team must decide how to prioritize the range of events, experiences, physical and emotional states that participants shared as being important in their everyday lives. We must also manage divergent opinions about approach and design features. There is no playbook for how to approach this variation. Our qualitative team has spent hours reviewing notes and transcripts, identifying salient and unique themes. We have shared these insights with the broader team, some of whom are focused on survey development and others on app design. Decisions about what questions to ask, design features, and approach are necessarily iterative, tacking back and forth between figuring out what content is important, what is reasonable and feasible to ask in an app format, and what options are needed to increase acceptability. The work requires a multi-disciplinary team to move a project like this from concept to product.

Conclusion

Our findings highlight the value of bringing together ethnographic methods and user-centered design frameworks to develop digital health tools. Smartphones offer a variety of benefits for people experiencing homelessness, including connecting them to people and services (35, 64). The ubiquity of smartphones in people experiencing homelessness potentially present novel methodological options for research. This formative study is part of a larger research agenda to understand the extent to which smartphones can also be used to facilitate a variety of different types of data collection from people experiencing homelessness. Collecting data *via* smartphones may allow us to gather almost real time data, which may support interventions to intervene in a timely manner if we can identify key indicators that lead to a housing transition. If we are able to demonstrate the feasibility of smartphone-enabled data collection, additional formative research with an expanded diversity of veterans experiencing homelessness is needed. This includes veterans who are vulnerable to homelessness or may have different experiences related to homelessness because of their sexual and gender identity, race and ethnicity, and geographic location. This is a critical step to take before launching a large-scale data collection effort using smartphone applications. Similarly, engaging a highly diverse sample of veterans in usability testing, which is our next phase of work, will be important to creating a relevant, user-centered digital data collection tool.

Data availability statement

The datasets presented in this article are not readily available because this will need to be approved by the VA IRB, requiring a modification. Requests to access the datasets should be directed to DM: Keith.Mcinnes@va.gov.

Ethics statement

The studies involving human participants were reviewed and approved by VA Bedford Healthcare System. The patients/participants provided their written informed consent to participate in this study.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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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/fdgth.2022.897288/full#supplementary-material

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Challenges and opportunities for implementing digital health interventions in Nepal: A rapid review

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Background: In recent times, digital technologies in health care have been well recognized in Nepal. It is crucial to understand what is works well and areas that need improvements in the digital health ecosystem. This rapid review was carried out to provide an overview of Nepal's challenges and opportunities for implementing digital health interventions.
Methods: This study is reported according to PRISMA guidelines and used telehealth, telemedicine, e-health, mobile health, digital health, implementation, opportunities, challenges and Nepal as key search terms to identify primary studies published between 1 January 2010 and 30 December 2021 in four databases, namely PubMed, Google Scholar, Scopus, and CINAHL. Initially, identified studies were screened against predetermined selection criteria, and data were extracted, and the findings were narratively synthesized.
Result: The review identified various challenges, opportunities, and benefits of implementing digital health initiatives in Nepal. The most expressed challenge was inadequate technical facilities (lack of electricity and internet) and rugged geographical distribution, which makes transportation difficult in hilly and mountain areas. Shortage of skilled workforce and supportive policies were also notable challenges documented. Meanwhile, major opportunities identified were education and training of the students and health practitioners and increasing awareness among the general population.
Conclusion: This review identified various factors associated with the successful implementation of digital health initiatives in Nepal. Our findings may guide the formulation of digital health policy and interventions to improve mass health outcomes using digital health services.

KEYWORDS
challenges, digital health, implementation, opportunities, telemedicine, telehealth, e-health, Nepal

Introduction

In the 21st century, digital health can connect healthcare systems and deliver health services to promote health outcomes for people of all ages (1). The field of knowledge and practice are essentially associated with the development and use of digital technologies to improve health (2). The World Health Organization defined telemedicine as "*the delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for the diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities*" (3). Similarly, Jacob et al. (2020) defined mobile health (mHealth) as the medicinal practice conducted through any portable gadget like a cell phone or patient monitoring device. Digital health encompasses a comprehensive approach to providing health care services to the patients in different forms like synchronous and asynchronous or through remote monitoring and mobile health (4). The advantage of deploying telehealth is enhancing the ease of access to health services (1). Most developed countries have effectively used digital health, and many developing countries follow the pattern of adopting digital health (5)

In Nepal, a lower-middle-income country situated between China and India, 83% of the population lives in rural areas. One-fourth of the population is classified as "under the poverty line" (6–8). Recent data from 2021 shows that 92.54% of the Nepalese population takes 15 min with motorized travel mode and 94.63% take 60 min of walking distance to have to access health care facilities in Nepal (9), health infrastructure is poorly developed, and the country has a low health human index (10). In rural areas, establishing well-equipped health care centers with specialized health services is an ongoing challenge for the government (10). A poor economy is an important but not the sole barrier to healthcare access in Nepal. Nepal's rugged terrain, especially in the mountains, makes transportation, and installation difficult; consequently, access to visiting health facilities is limited (7). With multiple challenges surrounding effective health care delivery, the government's plan to make universal health coverage is not fully illustrated. Therefore, digital health is considered one of the promising resources to make health care accessible cost-effectively, especially in tough-to-reach areas (5, 10).

In the context of rural Nepal, telehealth offers great opportunities such as remote consultation of medical practitioners (otherwise practicing in urban areas) (11, 12), remote delivery of specialized services, distance education and training of local health care providers, and collaboration of local health workers with other national and international experts. Such distance learning and collaboration can bring positive changes among the health care providers regarding their skills and the services they provide (4). Additionally, using information and communication technology (ICT), digital health may help to improve health literacy and bring positive change in people's health behaviours (13). Digital health also connects patients electronically with the health care providers so that personalized medical plans can be developed to deliver better health care for improved health outcomes (14)

In Nepal, the Telecommunication Act and National Telecommunication Policy were established in the late 1990s. The digital health system was introduced as HealthNet in 1995 (11, 15) by a non-governmental organization (NGO) to provide affordable internet services for people to access health care facilities. After that, in 2002 the "Nepal wireless project" and "hello-health" were established to provide ICT access and digital health services in remote settings of Nepal. Similarly, the National Health Education, Information and Communication Centre (NHEICC) started using cell phones to educate people on sexual and reproductive health. Additionally, there are many digital health information systems including HIV Surveillance, eTB register, mental health counselling in Nepal, being supported by World Health Organization (WHO), United Nations International Children's Educational Fund (UNICEF), and Save the Children (6, 16).

Though the internet service is accessible to less than 35% of the overall population in Nepal, the subscription of smartphones has increased from 0.043 per 100 people in the year 2000 to 139 per 100 people in 2020 (15). In a nutshell, various small-scale digital health programs are operational in Nepal but are often vertical in approach (6). Although digital health is not a silver bullet when offered as a stand-alone solution, deploying digital health intervention has successfully addressed public health issues in LMICs and can potentially do so in Nepal (17). There is an ongoing body of work in Nepal that has unearthed opportunities and challenges in rural digital health ranging from community health care centers to specialists in tertiary hospitals (18). All of them are based on specific health issues and carried out as pilot projects in specific regions of Nepal. For example, collaborative care for psychiatric patients in a rural setting (19), capacity building and text messaging intervention in the Dhanusha district (20), and dengue prevention through mobile SMS (21).

While the importance of digital health has been well acknowledged, it is imperative to understand the barriers and enablers for implementing digital health in Nepal that may guide the development and implementation of digital health intervention in Nepal. Therefore, this narrative review aims to provide a synopsis of Nepal's challenges and opportunities for implementing digital health initiatives.

Methods

This review method was developed by following the guidelines and criteria set in Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) (22). The rapid review protocol was registered in PROSPERO (CRD42020199056).

Search strategy

An electronic search was conducted between 1 January 2010 and 30 December 2021 through PUBMED, Scopus, CINAHL, and Google Scholar using the keywords: Telehealth, Telemedicine, e-health, digital health, challenges, implementation, and Nepal. These keywords were searched in Medline using the Boolean operators "AND" and "OR" (a detailed search strategy is provided in Box 1.

Inclusion criteria:

I. Primary studies focusing digital health in any setting in Nepal.
II. Primary studies regardless of study design (e.g., qualitative, quantitative, observational, pilot study, case study, and Randomised controlled trial (RCT)) were included in the study.

Exclusion criteria:

I. Studies on public health issues that did not consider digital health approach
II. Conference abstracts, commentaries, reviews, and letter to editor
III. Studies published in a language other than English.

BOX 1 List of search items

Challenges: "Challenges" OR "Problems" OR "Difficulties" OR "Chance" OR "Possibilities" OR "Potential" OR "Scope" OR "Issues" OR "Concerns" OR "Obstacles" OR "Barriers."

Digital health: "Digital health" OR "Telehealth" OR "Mobile health" OR "mHealth" OR "Telemedicine" OR "eHealth" OR "telehealth" OR "Remote medicine" OR "Teletherapy" OR Distance medicine."

Nepal "Nepal" OR "Rural Nepal" OR "Urban Nepal" OR "Developing country."

Study selection

Initial records retrieved from each of the four databases were imported into Mendeley, where duplicates were removed. On the title and abstract screening, studies were excluded based on the selection criteria. Two authors (RP and DB) did the abstract screening, whereas title screening was done by all three authors (RP, DB, and MKC). After those studies were subjected to full-text screening to determine their eligibility for inclusion, which was done independently and later discussed for confirmation in a group. Any reviewer discrepancies were resolved by conducting a group meeting and further discussing them with the supervisor (UNY).

The PRISMA (22) diagram illustrates the screening process for the study selection (**Figure 1**).

Data extraction

Data from the selected articles for final inclusion was divided among three reviewers (RP, DB, and MKC). The extracted data include the region, year, and authors of the publication. It also consists of the study design, service offered, the digital device/ technology used, the challenges faced, and the opportunities to deliver health services through digital devices /technologies. A data extraction sheet was developed (**Table 1**), and data were extracted from the information based on the selected 19 articles, and the results were discussed with the study team members.

Data synthesis

Data synthesis was done for both quantitative and qualitative data that highlighted the challenges and opportunities related to digital health interventions in Nepal. Both primary and secondary studies, including digital health interventions, were included in this review. Content analysis (23) was performed for descriptive evaluation of the selected articles, based on which specified outcomes were identified and arranged into two themes: challenges in implementation digital health, and future opportunities in digital health implementation.

Results

The final literature search was conducted on 30 December 2021, which yielded 35,789 results through four different databases (CINAHL 28,046, Google Scholar 3650, Scopus 3884, and PubMed 209). After removing duplicates and screening the titles and abstracts of the articles using

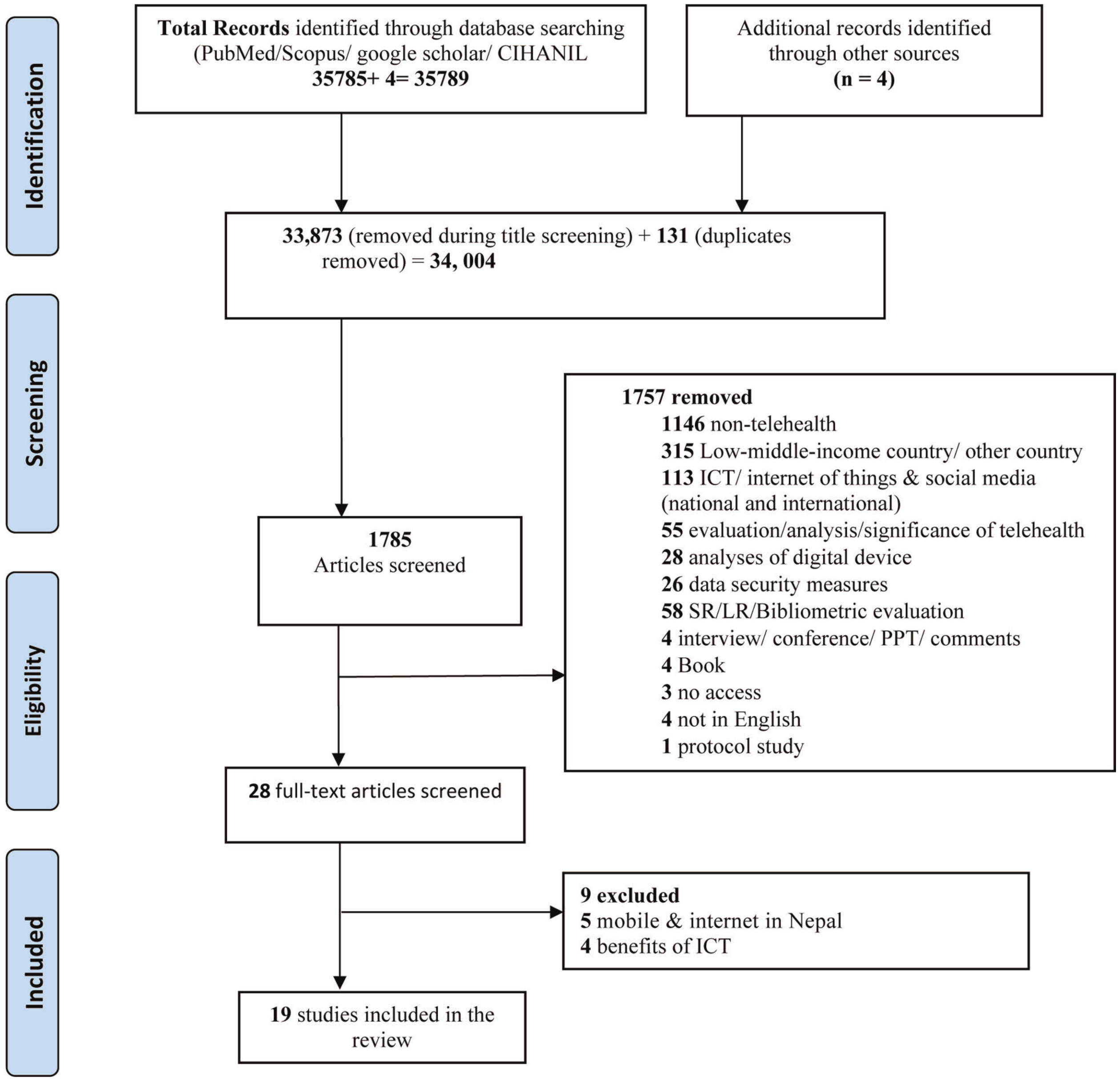

FIGURE 1
PRISMA 2009 Flow Diagram.

exclusion criteria, only 28 papers were selected for full-text screening. Of these 28 studies, 9 studies were excluded because of the following reasons: four mentioned the benefits of using ICT in Nepal, five were excluded for only focusing on the efficacy/ use of mobile phones and internet in Nepal. A total of 19 articles that met the eligibility criteria were included for data extraction. The characteristics and findings summary of all the selected 19 papers are mentioned in the Table 2, highlighting various challenges and future scope/ opportunities in implementing digital health services in Nepal.

As only a few studies reported, the enablers for implementing digital health are merged with the benefits and opportunities. The first enabler was that the stakeholders of rural areas were likely to adopt digital health services if supplied with good technical equipment (13, 24) and motivations (organizational and governmental support for digital health (programs) (24, 25). Second was the sustainable relationship between patients, paramedics and consultants which will further help sustain the digital health programs (19, 24, 26, 27).

TABLE 1 Data extraction sheet.

Data to be extracted	
Study outline	Reference details (title, authors, year) Research Question Digital Intervention Region Key findings
Study design and aim	Study design (qualitative, quantitative, Case studies, RCT & mixed methods) Aim of the study
Ethics	Discussion of ethical issues: No
Setting	Study area/setting Intervention delivery (community health workers/ Nurse/ GP/Hospital based Used technique/device
Representativeness	Number of participants included in analysis/ Target population

Challenges in the implementation of digital health

In this context, challenges are defined as the problems or barriers faced by stakeholders (health care providers and patients) during the implementation of digital health programs in Nepal. Different challenges faced by stakeholders are categorized into six sub-themes: technical challenges, geographical challenges, policy challenges, lack of skilled workforce, funding challenges, and other challenges. All those themes and sub-themes were developed by analyzing various themes illustrated in **Figure 2**.

Technical challenges

Technical challenges are defined as technical issues faced during the implementation of telemedicine in Nepal. Technical challenges include network problems, frequent power cuts/ lack of electricity, blurred image, poor sound quality/cut- off the sound during video consultations due to slow internet connection, and interrupted service due to poor network quality. These technical issues were mentioned in 14 papers (10, 13, 19, 21, 24–26, 28–34), of which network connection problems (13, 21, 24, 31) and frequent power cuts (29, 31) were the major technical challenges for implementing digital health successfully.

Geographical challenge

Five studies (10, 13, 24, 27, 32) mentioned rugged geography as one of the challenges faced in implementing digital health services in Nepal. The geographical factors identified by the authors were uneven geographical distribution like hilly and mountainous regions, which have made transportation difficult due to the lack of roadways in these areas. Also, the rough terrain has made the installation of mobile towers and other computer devices difficult and facing maintenance difficulties (21).

Lack of supportive policies

Lack of supportive policies was mentioned in four studies (10, 13, 24, 25) which were political instability, frequent transfer of trained doctors/ health workers, and lack of government support like lack of motivation by the government to their staff in terms of compensation and bonus salaries (24) have become a reason to end the telemedicine program.

Skilled workforce challenges

Five studies (10, 13, 24, 25, 28) mentioned the lack of skilled workforces, such as the lack of IT specialists, who could provide technical training to health workers about video consultations, and the lack of technical knowledge among health workers. Piya (24) also mentioned the lack of basic internet use and video consultations among health professionals. Furthermore, there was insufficiently trained staff at the local health care centers who could encourage the public towards digital health. Thus, the lack of specialists for teleconsultation has discouraged the program and interrupted the whole digital health project.

Funding challenges

Funding challenges in terms of buying costly equipment, high installation charges, and training staff were identified by four studies (10, 24, 26, 33). Digital health programs in Nepal depend on funding and volunteers; when funding stops, the whole project gets disturbed and terminated (24). Similarly, installing new and advanced technologies is expensive in a resource constrained country (26). Moreover, Basu et al. 2015 (32) mentioned the lack of IT specialists in Nepal, and it was financially challenging to recruit the experts from overseas.

Other challenges

Four studies mentioned that adaptation challenges and misdiagnosis are categorized as other challenges (13, 19, 24, 33). Adaption challenges make it difficult to train senior doctors who believe in face-to-face consultation rather than video consultations, and it was also challenge to convince patients about the benefits of digital health. Furthermore, one of the papers mentioned a case of misdiagnosis, which occurred through the conveyance of wrong messages due to an interrupted phone connection (13).

Opportunities

For digital health services, opportunities are defined as the service or facility provided by digital health to the public to deliver medical services regardless of distance and time

TABLE 2 Data extraction on challenges and opportunities from the included studies.

Author	Intervention	Challenges	Benefit	Opportunities
Rai, 2013	**Type of study:** A case study. **Study area/ Setting**: Nangi village, Kathmandu, Model Hospital **Participants No./Target population**: 13 health workers and 96 patients. **Type of service offered:** dermatology, maternity, e-learning **Used technique/device:** video consultation **Intervention delivery through:** nurse, doctors, community health workers	– Staff turnover – Lack of IT skills – Lack of infrastructure – Uneven geographical distribution – No electricity/internet – Sometimes unavailability of specialist for teleconsultation – Lack of government support – Sometimes misdiagnosis	– Better diagnosis and treatment – Reduced child and maternal death – Increased patients concern for health care	– No extra cost – Better diagnosis and treatment – Telelearning by interns & other health workers
Morrison et al., 2013	**Type of study: Pilot study** **Study area/ Setting: Gulmi district** **Participants No./Target population: 24 health workers & 3 GP** **Type of service offered: phone consultation with the GP** **Used technique/device: landline phone/ Mobile Phone** **Intervention delivery through: mid-level health workers.**	– Frequent power cuts – Network problem – Technical difficulties	– Easy consultation – Patients are more concerned towards health care.	– Stakeholders are positive
Piya, 2010	**Type of study**: A case study **Study area/ Setting**: OM hospital and research centre, Kathmandu, Nepal **Participants No./Target population**: 6 (out of 8 responded) health officers of OM Hospital. **Type of service offered:** not limited to single service/ consultations have been done for various types of illness Used technique/ device: video consultation **Intervention delivery through:** Doctor and consultant	– Lack of IT knowledge of experienced doctors – Patients also need to know the usage technique – Sometimes, doctors are not willing to learn the new techniques – Sustainability (usually after execution of donor support, the program also gets terminated due to lack of resources) – Lack of availability of equipment – High installation cost – The poor and disturbing connection – Government support – Motivation	– Better health care facilities	– Low treatment cost for those who had to travel abroad for treatment. – Enhance technical skills among health professionals – Patient literacy about telehealth
Bhattarai et al., 2015	**Type of study**: A comparative-cross sectional **Study area/ Setting**: Manahari VDC and Hetauda, Makawanpur, Nepal. **Participants No./ Target population**: 40 people of age group 30 to 70 years (20 from intervention and 20 from non-intervention group) **Type of service offered:** Diabetic care **Used technique/ device:** tele-consultation **Intervention delivery through:** local doctors	N/A	– Reliable and better diabetic care – Management of diabetes care in rural area is feasible and comparable with urban areas.	– It can be used on a large scale in rural areas
Shrestha et al., 2018	**Type of study**: A case study **Study area/ Setting**: Semi-Urban Kathmandu, Nepal **Participants No./ Target population**: 2 patients infected with *Tinea Incognito* **Type of service offered:** Dermatology **Used technique/ device:** mobile phone **Intervention delivery through:** medical officer	N/A	– Successful treatment of long persistent skin problems	– Reliable, useful & cost-effective means of dermatological consultation

(*continued*)

TABLE 2 Continued

Author	Intervention	Challenges	Benefit	Opportunities
Ghimire et al., 2019	**Type of study: A cross-sectional study** **Study area/ Setting: Siddharthanagar Municipality, Bhairawa, Nepal** **Participants No./Target population: 100 participants of Siddharthanagar Municipality.** **Type of service offered: Tele stroke** **Used technique/ device: videoconferencing and image sharing technology** **Intervention delivery through: community people residing in Siddharthanagar Municipality, one member of one household who had heard about stroke was selected.**	– Technology level – More work on individuals – Installation time and cost for it. – Management issues include plasminogen activators' effects. – Some individuals prefer to visit clinicians physically. – The concern of online data' store and confident	– Benefits to stroke patients – Useful to physicians and the community regarding stroke education	– Improve diagnosis and treatment of acute stroke. – Useful in research of emerging stroke medications. – Enhance physicians and community education.
Cai et al., 2016	**Type of study: Prospective study** **Study area/ Setting: Department of plastic & reconstructive surgery at Kritipur Hospital Kathmandu, Nepal** **Participants No./ Target population: 17 individuals with healed burn scars** **Type of service offered: outpatient burn care** **Used technique/device: live video-conferencing** **Intervention delivery through: local occupational/physical therapist**	N/A	– Improve scar management	– Feasible – Sufficiently accurate for clinical assessment
Bhattarai et al., 2019	**Type of study**: Non-randomised quasi-experimental design **Study area/ Setting**: Ratnanagar Municipality (ward no.2) Chitwan District, Nepal **Participants No./ Target Population:** 300 participants from 50 households of Ratnanagar Municipality **Type of service offered:** Dengue prevention **Used technique/device:** Mobile Short Message Service (SMS) **Intervention delivery through:** District (Public) Health Officers, health workers and Female Community Health Volunteers (FCHV).	– Poor networks in geographically rural places.	– Can be taken as a tool for educating health against dengue and other diseases. – Improving preventing practices and behaviors regarding dengue in the community. – Perceived as enjoyable, informative, and trustworthy. – Acceptable and appropriate media.	– Can provide instant access to information to a large population – Effective measure devices in health knowledge and practices reduce transmission cases. – It can be considered a crucial public health advocacy tool to improve people health-related behavior.
Mandavia et al., 2018	**Type of study**: A cross-sectional **Study area/ Setting**: outpatient clinic of Sahodar Hospital, Lamjunj District, Nepal **Participants No./Target population**: 56 patients including adults and children **Type of service offered:** Otoscopy **Used technique/device:** Cupris device was used for ontological history and examination, and a recorded video was sent to the specialist. **Intervention delivery through:** trained non-medical workers	– May lead to less quality of the video and can impact results. – Requires more training and experiences	– It is a simple, quick, and valid tool for diagnosing ear-related diseases. – Based on the device result can plan of referral for further assessment. – Reliably screen and evaluation tool for ear diseases. – Simple and highly portable for images and history data capture rather than another tool (otoscope linked to a computer)	– Low cost, significantly less than the cost of an otoscope.
Hong et al., 2019	**Type of study**: Pilot study **Study area/ Setting**: Various District of Nepal (Ramechhap, Jiri, Dolakha & Charikot) **Participants No./Target population**: 346 participants from the four districts **Type of service offered:** Ophthalmology **Used technique/ device:** Paxos scope ophthalmic camera system attached to an iPod Touch 6th generation **Intervention delivery through:** ophthalmic technicians	– Uploading issues and lack of Wi-Fi access.	– Cost-effective, portable, hand-held design. – Durability, affordability, and their ability to take high-quality images.	– The opportunity to access health care

(*continued*)

TABLE 2 Continued

Author	Intervention	Challenges	Benefit	Opportunities
Swar et al., 2019	**Type of study:** Pilot study. **Study area/ Setting**: General Clinic, Accham Hospital **Participants No./Target population**: 300–400 patients per day **Type of service offered:** Mental health care **Used technique/ device:** videoconferencing **Intervention delivery through:** primary care providers (PCPs)	– Unreliability to electricity – Technical issues – Lack of trusting relationship between psychiatrists and patients due to remote communication or no face-to-face contact – A mismatch between psychiatric recommendations and the site's capacity to implement them due to limited capacity	– Teleconsultation in rural parts of far western Nepal to improve the quality of mental health services – Solar back up/Gasoline generators for power cut problems	– Video-based training for primary care providers in mental health issues
Shrestha PL & Ellingsen, 2016	**Type of study:** Qualitative Case study. **Study area/ Setting**: Dhulikhel Hospital and 14 outreach clinics **Participants No./ Target population**: patients at 14 outreach clinics. **Type of service offered:** Dermatology, Gynecology **Used technique/ device:** Global System for Mobile Communications (GSM) based phone, Code Division Multiple Access (CDMA) phones, and Email. **Intervention delivery through:** paramedics	– Technical problems – High maintenance cost	– Management of dermatology, gynecology, and emergency cases through telemedicine in 14 outreach clinics – User friendly technology leads to a sustainable system	– Paramedics also learned through teleconsultation – Building relationships among paramedics, people, and specialists
Bhandari, 2016	**Type of study:** Cross- sectional study. **Study area/ Setting**: Sahid Gangalal National Heart Centre (SGNHC) **Participants No./Target population:** 80 cardiac patients from outpatient department who are 18 years and above. **Type of service offered:** tele-cardiac rehabilitation **Used technique/ device:** mobile-based telehealth **Intervention delivery through:** primary care physicians.	– Limitations in access to the Internet	– The substantial willingness of patients towards mobile-based telehealth/ use mobile calls for consultation/disease management.	– Promising measure to fill the gap in the existing health care and to increase the access of health care to rural people in Nepal – Opportunities to launch a large telehealth project with a target to cardiac and chronic patients requiring Continuous monitoring.
Mercado et al., 2017	**Type of study:** Pilot study. **Study area/ Setting**: Tilganga Institute of Ophthalmology (TIO) in Kathmandu, Nepal, Geta Eye Hospital and rural outreach centers **Participants No./Target population:** Patients at hospital and outreach clinics **Type of service offered:** mobile ocular imagining **Used technique/ device:** Paxos Scope smartphone camera adapter coupled with an iPhone 5. **Intervention delivery through:** two cornea specialists	– connectivity issues with use of digital software	Empowering community eye hospitals to relay information back and forth with tertiary eye centres, Tilaganga Eye hospital	Affordable, high-quality, mobile ocular imaging option for under-resourced parts of the world.
Bhatta, 2013	**Type of study:** Qualitative research method. **Study area/ Setting:** Rural Sindhupalchowk, Darchula district hospital and Patan Hospital. **Participants No./Target population:** Patients visiting Sindhupalchowk and Darchula district hospitals. **Type of service offered:** sexually transmitted diseases (STDs), HIV/AIDS, general medicine, podiatric, orthopedic, gynecology, dermatology and surgical cases **Used technique/ device:** video conference **Intervention delivery through** health workers of the respective hospitals	– Insufficient infrastructure resources and technology. – Difficult geographical distribution. – A weak policy of the government on rural-telemedicine programs. – Lack of funds and skilled manpower. – Frequent transfer of health workers.	– Underserved people from rural Nepal get an approach to health service. – Affordable and cost-effective health care service to countryside people. – Improve the health care system in rural Nepal.	– The government get an opportunity to look at health policy for future need. – Make to realize the challenges and limitations faced in providing health services in rural Nepal for improvement. – Connects rural districts hospital to tertiary level hospitals for medical support.

(*continued*)

TABLE 2 Continued

Author	Intervention	Challenges	Benefit	Opportunities
Adhikari et al., 2020	**Type of study:** Retrospective study design **Study area/ Setting:** Manekharkha and Bahunepati in rural municipality Banepa. **Participants No./Target population:** 15/ patients meeting eligibility criteria. **Type of service offered:** Tele physiotherapy **Used technique/ device:** mobile phone **Intervention delivery through:** local health assistants	– They could not measure exercise adherence. – Barrier to accessing health care service in rural people.	– Participants feel a significant reduction in perceived pain due to various musculoskeletal conditions. – There is no significant difference between TPT and face-to-face physiotherapy.	– Telephone-based tele-therapy seemed a feasible option for pain management where high technology is beyond reach and has a literacy rate. – It could be a choice to deliver home-based rehabilitation to enhance the older population's wellness.
Lama, 2011	**Type of study:** A Participatory Action Research method. **Study area/ Setting:** Dhulikhel Hospital and 3 remote health centres. **Participants No./Target population:** Three group of participants; Doctors from Dhulikhel Hospital, Village health worker from Dhulikhel Hospital's outreach and government health from from Dhulikhel health centers) **Type of service offered: Dermatology, Eye care** **Used technique/ device:** mobile phone and email **Intervention delivery through:** remote health care workers	– Participants refused to answer the questions and get involved in the discussion. – Difficult geographical distribution.	– People get supportive and affordable care services.	– Got the opportunity to observe and experience the dynamic changes in the knowledge, attitude, and practice of all the stakeholders. – Led to a completely different understanding of the difficulties between telemedicine interventions.
Meyers et al., 2017	**Type of study:** Pilot study **Study area/ Setting:** Rural Achham **Participants No./Target population:** 9 community health worker leaders (CHWL), 81 CHWs across nine village clusters serving 25,000 people. **Type of service offered:** data collection of the conditions like pregnancy and diarrhea. **Used technique/ device:** mobile phone **Intervention delivery through:** community health workers	– Staff turnover and technical difficulties. – Problem to access required telephone network. – Lack of training and inappropriate technical partner. – Poor process planning and management.	– Due to inadequate management and planning, the program failed to achieve its goal and collapsed.	– Provide information for future mHealth interventions in similar contexts. – Failure of the project makes them to realize what factors prevent them from achieving goal of m-Health management.
Basu et al., 2017	**Type of study:** A case study. **Study area/ Setting:** 2015 Earthquake affected areas of Nepal. **Participants No./Target population:** A large set of doctors for you (DFY) who exchanged messages from different earthquake relief operations. **Type of service offered:** supply of medical resources during different phases after the earthquake. **Used technique/ device:** Mobile phone **Intervention delivery through** medical experts (doctors)	– Information was only obtained and shared among DFY (Doctors for You) after a disaster. – The problem is in the transportation of medical personnel and supplies. – Electricity and save drinking water problems during that time.	– Real-time analysis of such online data helps to decision makers in forming resources and mapping strategies dynamically. – Provide medical aid and other needs to needy people during disaster crises.	– Provide a lesson that government should always be on standby to help in critical disasters.

through information and communication technologies. Opportunities are also categorized into four forms education, training and awareness; cost-effective treatment; equity and increased health access and future use (**Figure 3**).

In the context of digital health, opportunities are not just limited to using technology remotely to deliver health care services but also simultaneously adaptation by staff to the new working practices. Firstly, the professionals (health care providers) need to trust the digital system, reassure the patients of the privacy and confidentiality of collected health information, and ensure affordability for individuals and health care organizations (13).

Additionally, telehealth interventions' experiences and outcomes depend on the design details and factors like health literacy, digital literacy, and the quality of integration with clinical care pathways. To realize the long-term benefits of

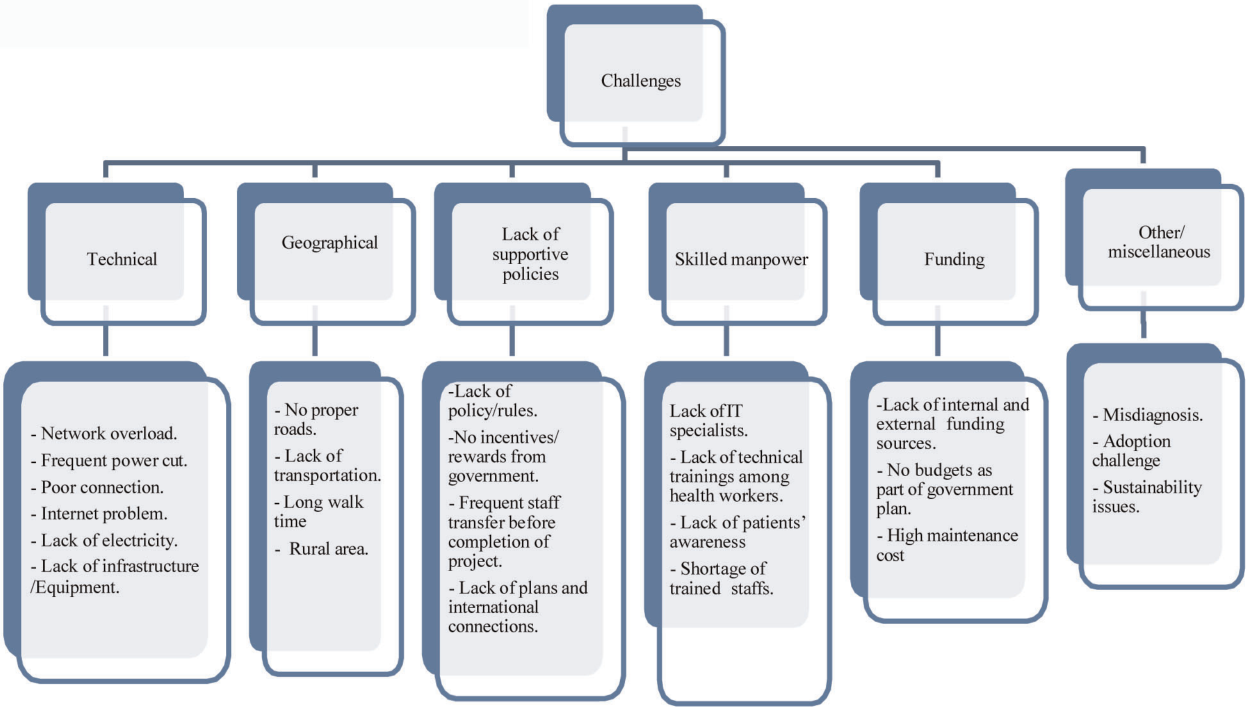

FIGURE 2
Challenges for implementing digital health interventions in Nepal.

digital health, organizations need to collaborate and learn what, where, when, why and how it works well (24).

Education, training, and awareness

Digital health is a platform for all health stakeholders that provides an opportunity for health education, training, and awareness. Opportunities were mentioned in 10 studies- (13, 19, 21, 24–26, 32, 33, 35, 36) through different forms such as telesurgery and teleconsultation by medical students. It was mentioned that doctors learned about IT skills during health care delivery (13, 26), and patients also got the opportunity to learn about the use of technical devices (24).

Cost-effective Treatment

Cost-effective treatment was mentioned by four studies (10, 27, 29, 35). Cost-effective treatment in terms of reduced traveling costs with no excess consultation fee was mentioned in these articles. Patients from rural areas had to visit hospitals in the city for specialist consultations, which was reduced when they started getting digital consultations in their locality. As mentioned in a case study (37), untreated patients with face-to-face consultation were found to be adequately treated through mobile tele dermatology. Thus, patients were found satisfied and attracted to the quality of service they obtained through digital consultation, where they did not have to pay an extra for the specialist service.

Equity and Increased health access service

As mentioned in 12 studies (10, 13, 19, 21, 24, 26, 31–34, 36, 38), patients from rural areas were found to be more focused on their health issues and were interested in using digital health services. Similarly, another study by Sikhar Swar et al. (19) showed improvement in patients' mental health status in far western regions. Digital health services delivered for diabetic care, childcare, and maternal health care in rural areas showed similar outcomes compared with urban health care facilities. Thus, telehealth service was more affordable and accessible to the public, and assistance was provided by the health professionals as required, which encouraged patients to use this service (38).

Future use

Future use of digital health was mentioned in four studies (10, 21, 34, 38) in different forms, like the opportunity to review digital health care policy and implementation on a large scale. Lots of successful pilot projects by Morrison et al. (31); Hong et al. (29), and case studies by Shrestha et al. (37) and Basu et al. (32), among few, have been conducted in various parts of the country yielding major positive outcomes with some drawbacks also. From all those outcomes, the government, including other

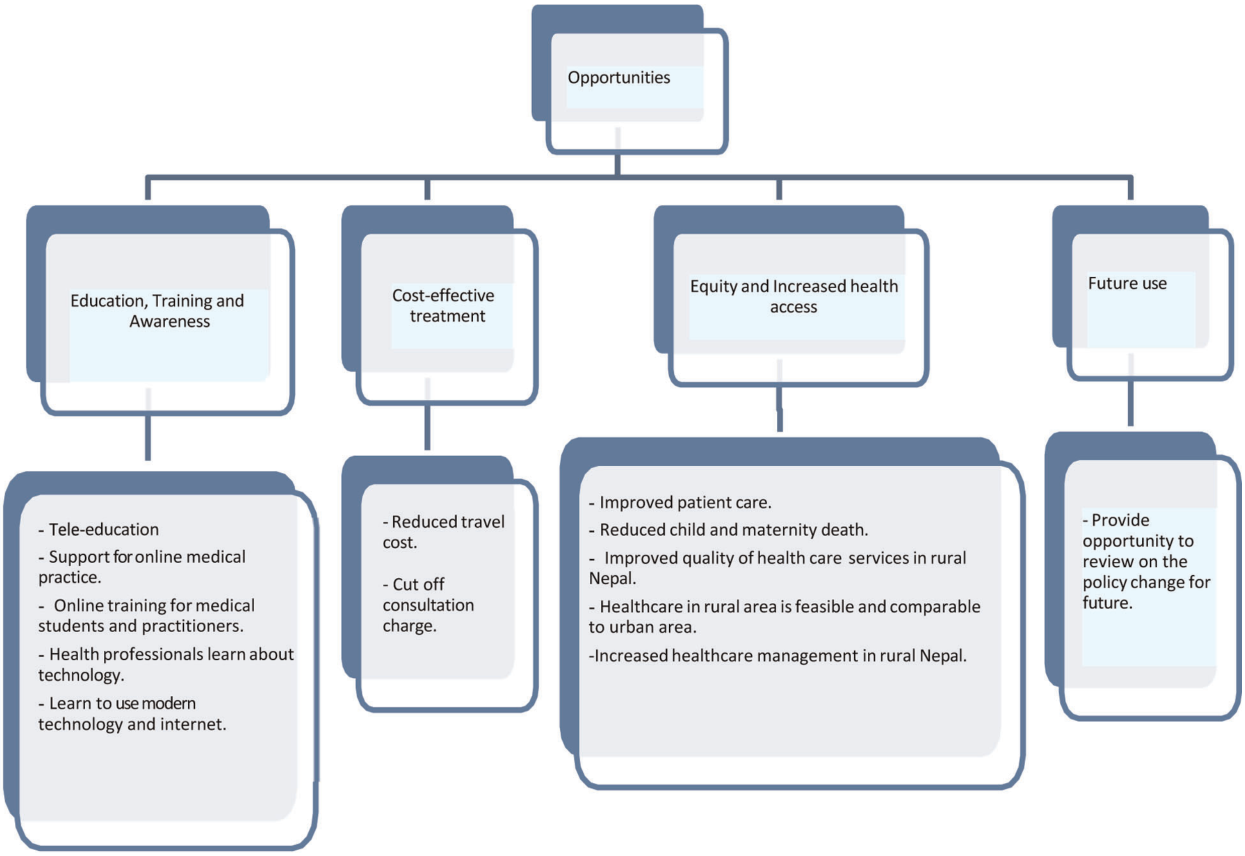

FIGURE 3
Opportunities for implementing digital health interventions in Nepal.

stakeholders, can use the results for implementing those projects in revised form on a large scale. Doctors, nurses, and even patients need to be trained regarding digital health use and its translation into their workplace without any technical hassle (39).

Discussion

This review explores the challenges of implementing digital health programs in Nepal before Covid 19 and future opportunities. The most recognized barriers were technical barriers such as network overload, frequent power cuts, lack of electricity, and internet problems (13, 19, 24, 29, 31, 34). Similarly, the lack of sufficient technology and infrastructure crisis (inadequate telephone network, Wi-Fi connectivity, and mobile phone penetration) for running digital health has also become a huge barrier to its implementation in Nepal (10, 21, 25). A study conducted in Bangladesh by Hoque et al. (39) found similar technical issues like lack of ICT infrastructures (lack of electricity and network problems), and a study done in India (40) mentioned the lack of broadband for quality of video consultation. Less than 85% of the houses in Nepal have access to electricity, which are facing rolling blackouts commonly known as load shedding for several hours and multiple times a day. Industrial production is also dependent on this limited power supply. Remote Nepal is mainly affected and has compelled the citizens to use alternate sources like small solar power systems or diesel for power supply (41). Some papers also found a lack of IT skills among doctors, nurses, and other health care workers. Younger doctors and interns are willing to learn about the new technology, but for senior doctors, it is hard to convince them to be tech-friendly (24). A similar pattern was also found in a study done by Hoque, M. R., Maximum, M. F. A., & Bao, Y. (39) among the older administrative staff who were found to be a bit resistant to adapting to new technology.

Apart from technical issues, a skilled workforce plays an important role in the smooth functioning of digital technology, but many lagging factors were found. On one side, there was a lack of operational skills among health care staff (10, 13, 25), and on another side, the literacy gap among people in the rural-terai region was found (20). Thus, training should be provided to the staff and awareness-raising initiatives among the patients (21, 28). A study from India (40) also emphasized the lack of technical training among paramedics. Lack of technical illiteracy in digital health intervention was also identified as a hindering factor among Pakistani citizens in a study by Ittefaq, M., & Iqbal, A (42).

Additionally, funding plays a vital role in supporting digital health services and, in the context of Nepal, is a major motivational factor for its sustainability. The WHO also has mentioned the lack of funding as a major factor for lagging digital health services in developing countries (43). Though the government has planned to expand the digital health facilities, a separate budget in this sector is not allocated, and does not fall into a top priority list. Thus, reimbursement can also be used as a motivational factor to support the volunteers/digital health in the long run. Studies from Bangladesh (39, 44) also found similar funding-related problems, including access to digital tools that affect the adaptation of digital health.

The new information and technology era may lead to new hope and more services for the public in Nepal, where geographically varied places and their landscape become barriers to health care delivery. Due to a lack of infrastructure and other facilities, people lag in accessing health services and have died from curable and preventable diseases. So, digital health and modern medical technology offer treatment, cure, and awareness in addressing health needs without traveling out of hometowns. Developing countries like Nepal, India, and Bangladesh and even developed countries like Australia have shown the cost-effective benefits of digital health in aged care centres and disability centres in remote areas (45).

Digital health interventions conducted in remote villages of Nepal have shown equal consultations and treatment benefits as received by urban patients (38). Hence, digital health empowering community hospitals and tertiary centers has shown fruitful application (25), thus extending to larger areas. Medical students were found learning through tele-education. The intern doctors of Kathmandu model hospital were virtually experiencing the surgery conducted in Korea through telesurgery. They were eager to learn about the techniques (13). In addition, mid-level health workers and volunteers also had telephone for video consultations to care for the patients (20, 31).

Furthermore, most of the digital health interventions we have included in our review were conducted in small areas or specific locations, with a positive outcome. This has the potential to expand digital health services in a broader context by empowering community health care centres through relaying information to and fro with the tertiary hospitals. For instance, a study carried out by Mercado et al., (30) at Tilganga Institute of Ophthalmology (TIO) in Kathmandu, and rural eye hospital in Dhangadi, and a rural cataract camp in Hetauda showed the potential of digital health further to expand their impact in other areas (30).

Digital health literacy is the most among doctors, and patients play an essential role while implementing digital health. Few papers (13, 21, 24) have mentioned the importance of digital literacy among the stakeholders. The confidentiality of patients' information is also a significant concern. Morrison et al. noted that confidentiality might not be considered an essential factor for telephone-related consultations (31). Pradhan et al. mentioned that Nepal has no specific data protection law (46). Additionally, the negligence in patients' data protection systems while conducting digital health programs was mentioned by Rai (13).

A quantitative study shows equal access to diabetes care in rural and urban areas. Teleophthalmology also has reduced the travel cost (29, 38). Patients were eager about digital health (34) and were found equally satisfied whet her they were treated face to face or through tele ophthalmic means (29). Additionally, the majority of the patients' were comfortable with telephone consultation (34). Phone-based SMS was also used as a health promotion tool for dengue control and increased awareness about nutrition (21).

Nepal's government should take heed to developing a national digital health strategy that may guide the effective implementation of digital health interventions in Nepal. Evidence has highlighted the importance of digital health education among health care providers (34). Moreover, a center for digital capacities and knowledge should be established to train, coach, and facilitate the human resource to digitalize the health system (46), which motivates them to uptake new technology without hesitation (34). It may allow the government to deliver services in a people-centered approach improving digital health literacy and the quality and safety of health services, thereby helping the country to achieve universal health coverage.

Strength and Limitations of the study

Like other studies, this paper does have strengths and limitations. The strengths include: (i) findings based on the review of peer- reviewed journal articles, and (ii) findings might guide the policy and practice for digital interventions in Nepal. This study had some key limitations. First, the literature search was done in selected databases using key search terms which might not have captured all the published evidence. Secondly, the study only reviewed articles published within a particular time framework and did not include grey literature; therefore, findings should be interpreted carefully. Thirdly, the search was limited to English, meaning this study did not consider articles published in Nepali.

Conclusion

The study identified various challenges and opportunities that can guide the development and successful implementation of digital health interventions in Nepal. Moreover, decision-makers should involve wider stakeholders including information technology experts and the developmental partners in building the capacity of public health facilities, and workforces to effectively tailor and deliver digital health interventions in Nepal. While digital transformations have great potential to benefit population health, they may exacerbate social inequalities. Therefore, future research should focus on social and cultural determinants of digital health literacy at the professional level (those who develop, deploy, recommend, and prescribe digital health services) and community level (those who use digital health services). This may guide the development of people-centred digital health information that can address the practical, comprehensive needs of the people.

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/s.

Author contributions

RP, DB, and MKC conceptualize and design the study under the supervision of UNY. RP, DB, and MKC analyzed and prepared the first draft. UNY revised paper for its intellectual content and provided significant inputs to improve the quality of the work. UNY, SKM and SS provided significant inputs, edited, and approved the final version to be submitted. All authors contributed to the article and approved the submitted version.

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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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Foundations for fairness in digital health apps

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Digital mental health applications promise scalable and cost-effective solutions to mitigate the gap between the demand and supply of mental healthcare services. However, very little attention is paid on differential impact and potential discrimination in digital mental health services with respect to different sensitive user groups (e.g., race, age, gender, ethnicity, socio-economic status) as the extant literature as well as the market lack the corresponding evidence. In this paper, we outline a 7-step model to assess algorithmic discrimination in digital mental health services, focusing on algorithmic bias assessment and differential impact. We conduct a pilot analysis with 610 users of the model applied on a digital wellbeing service called *Foundations* that incorporates a rich set of 150 proposed activities designed to increase wellbeing and reduce stress. We further apply the 7-step model on the evaluation of two algorithms that could extend the current service: monitoring step-up model, and a popularity-based activities recommender system. This study applies an algorithmic fairness analysis framework for digital mental health and explores differences in the outcome metrics for the interventions, monitoring model, and recommender engine for the users of different age, gender, type of work, country of residence, employment status and monthly income.

Systematic Review Registration: The study with main hypotheses is registered at: https://osf.io/hvtf8

KEYWORDS

digital mental health, algorithmic fairness, case study, undesired bias, algorithmic discrimination

1. Introduction

Concerns about potential bias in the application of automated systems have been increasing over time, in particular in domains that are considered to be in highly-regulated, high-risk areas (e.g., health, crime, employment or housing as per the European AI Act of 2021 (1)). However, it is far from trivial to ensure that the service, as well as the algorithms powering such service, are free from discrimination (consistently disadvantageous) for all the sensitive groups, particularly because it requires developers and designers to engage with the social, legal and ethical facets of algorithmic fairness in a given context (such as mental health); and to design and develop solutions which incorporate these values.

In its technical usage in data modeling, the word bias indicates a preference for certain kinds of models over others, and it is indeed essential for obtaining an effective model in an efficient way. There are two types of bias: desired and undesired. In the domain of digital health, the former is the type of bias that allows for recommendations to be based on evidenced factors or drivers that maximize health and/or wellbeing. The latter is the type of bias that causes recommendations to be based on gender, race, ethnicity, sexuality, age, belief, or other characteristics protected under anti-discrimination law except in narrowly defined cases related to characteristics that indeed play a relevant role, in some specific types of recommendations. Undesired bias is articulated with greater precision in the literature as "algorithmic discrimination." This occurs when results are systematically disadvantageous against already disadvantaged and/or legally protected groups[1] (3). While algorithmic undesired bias in general cannot be completely avoided, it is important to dedicate preventive efforts in an attempt to investigate potential disparate impact.

In this work, we assess *Foundations*,[2] a mental health application (app) designed to help people improve and maintain their mental wellbeing. By design, *Foundations* is built on evidence-based interventions, which are meant to be effective regardless of gender, race, ethnicity and other protected attributes. It consists of a library of content grounded in science and designed by experts in the fields of Psychology and Psychiatry to help users deal with topics such as stress, poor sleep, worry and anxious thoughts, low self-esteem, among others. Nevertheless, in this paper we argue that evidence-based tools designed not to discriminate need to be regularly evaluated in practice. In this paper, we propose applying a 7-step fairness framework to evaluate:

1. whether there is any disparate impact in the response to treatment for our digital health app, *Foundations*, and
2. whether there is any undesired bias in automated algorithms, in particular, (a) in our predictive model of deterioration in well-being and depression severity (step-ups), which can be used to passively monitor our users' symptoms, and (b) in our recommendation engine which can be used to suggest activities that are relevant for the user.

This paper is structured as follows: **Section 2.1** presents some background on fairness in mental health apps and algorithm, as well as product auditing. **Section 2.2** presents the app audited in this study, *Foundations*. **Section 2.3** introduces the 7 step process to assess fairness in automated systems. **Section 2.4** presents the details of the randomized controlled trial (RCT) previously conducted, as well as the demographics of the participants. **Section 3** presents the results of applying the 7 step process, per step, for (1) evaluating fairness in *Foundations* (**Section 3.1**), (2) evaluating fairness of a wellbeing step-up monitoring model (**Section 3.2**), and (3) evaluating fairness of a recommender system (Recsys) (**Section 3.3**). **Section 4** presents the discussion where we provide the interpretation of the results, mention limitations of this analysis and ethical considerations. Finally, **Section 5** concludes the paper.

2. Materials and methods

2.1. Background

Work-related stress is the first cause of long-term sickness absence and the second reason for sickness leave shorter than four weeks in public service workers in the UK (4). Moreover, the literature has revealed that chronic exposure to hostile working conditions leads to stress (5) and several mental disorders and physical diseases, which have differential impacts on protected groups (6–9). Stress accounts for 45% of all working days lost due to poor health (Health and Safety Executive, 2016). It has also been shown that the roots of stress are more related to personal factors for females in the UK IT sector (10). Moreover, according to Health and Safety Executive (HSE), women aged between 25–54—who are likely to be juggling many roles, including worker, mother, carer for elderly parents and homemaker, experience significantly higher stress than men (11). According to WHO, workplace burnout should be approached as a multivariable phenomenon. Therefore, in creating apps for mental health and recommender algorithms to improve mental wellbeing, the literature demands that enterprises pay attention to various structural factors at both social and organizational levels.

2.1.1. Fairness in mental health apps

Mobile technologies and apps for mental self-care have been supported by the WHO, in its Mental Health Action Plan 2013–2020, and by other public organizations such as the UK National Health Service (NHS). Socio-economic and gender biases have been identified in such systems, including possible digital divide problems or lack of consideration of gender differences in wellbeing, which are influenced by complex relationships between both biological and socio-economic factors (12, 13).

Some of these mobile technologies are powered by machine learning models. Such AI systems can determine that a person belongs to one of the above protected groups through proxies, such as zip codes for a specific ethnicity. Moreover, the use of these proxies for protected attributes can sometimes be intentional (see example of zip code for race in a loan eligibility system in (14)). Removing these attributes from the data, the so-called "color-blind" approach, does not reduce

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[1] The liability and (un)intentional character of discrimination determines differences concerning its legal disparate treatment (deliberate) or impact (unintentional) over individuals (2).

[2] https://foundations.koahealth.com

risks of algorithmic discrimination, and instead can make things worse, by hampering detection and mitigation efforts (15). In addition, some of these technologies are powered by recommender systems, which can be biased for different salient groups. Specific recommendations could be considered biased (due to undesired discrimination) when recommended more to one group than another. For example, if in similar contexts an app routinely recommends women an activity such as taking cooking lessons while recommending to men that they practice an outdoors sport, this would be reinforcing stereotypical gender roles. This sort of problems affect many information access systems, including search engines and recommender systems.

2.1.2. Algorithmic and product auditing

A common response to the concerns about the application of automated systems has been to codify ethical principles that are intended to govern their application. Frameworks of principles include the Ethics Guidelines for Trustworthy AI by European Commission et al. (16) and the Principles for Responsible Stewardship of Trustworthy AI by OECD (17). Indeed, ethical frameworks abound; Mittelstadt (18) found that at least 63 public-private initiatives had produced statements describing high-level principles related to ethical AI, and the number has surely grown since then.

Ethical principles are only as good as their implementations. Audits, and particularly algorithmic audits are increasingly being used to understand whether ethical principles are in fact adequately implemented in practice. A number of auditing frameworks have been developed, such as the End to End Framework for Internal Algorithmic Auditing by Raji et al. (19).

However, all such audits suffer from the same challenge—namely, their post-hoc nature. This is particularly problematic when audits discover problems that arise from choices made, unconsciously or otherwise, at the early stages of creating a product or algorithm. With respect to the implementation of ethical principles, the biggest challenge is that ethical principles can exist in tension with each other, such that trade-offs must be made on how much to follow one principle at the expense of another. A pertinent example is the trade-off between privacy and avoiding bias. In Clavell et al. (15), some of the authors of this paper found, through an algorithmic audit, that an overemphasis on data minimization can in practice hinder efforts to avoid bias. This is because the goal of data minimization means that data relevant to understanding bias, such as gender, age, ethnicity, etc. is not collected, thereby forcing auditors to rely on indirect evidence of bias.

To avoid *driving by looking in the rear-view mirror*, step-by-step guides are required that allow the potential for bias to be considered right from the conception of a product or algorithm, through to its deployment and, of course, auditing.

2.2. About *Foundations*

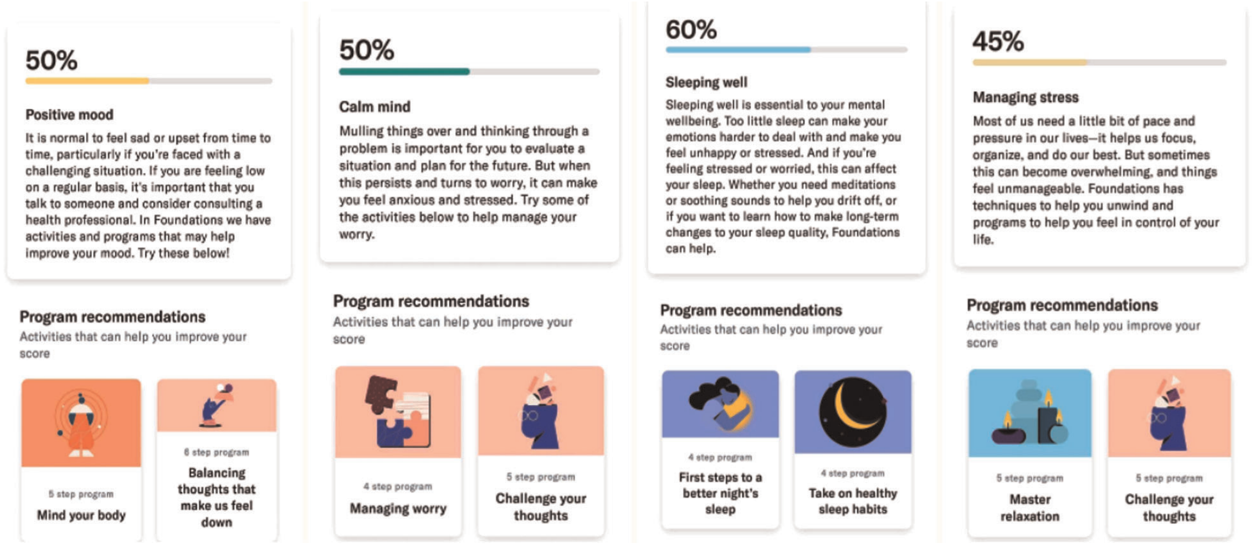
Foundations is a mental wellbeing app, available on iOS and Android, with interactive, evidence-based programmes and activities to help users build resilience and manage stress. *Foundations* is offered as a Business-to-Consumer (B2C) product to employers as part of their Employee Assistance Program. It is designed to help work organizations support their teams, enabling people to take care of their mental wellbeing on their own terms in a cost-effective manner. Employees interact with the app, its programmes and activities to build resilience. The areas of focus are anxiety, depression, stress and trouble sleeping. The efficacy of *Foundations* was previously evaluated in a randomized control trial, where the intervention group ($n = 62$) showed significant improvements compared to the control group ($n = 74$) on measures of anxiety (GAD-7 score), resilience (CD-RISC score), sleep (MISS score), and mental well-being (WHO-5 score) within 2 weeks of using *Foundations*, with further improvements emerging at week 4 (20).

Foundations offers programmes to help improve mental wellbeing through several activities (i.e., units of content): "Relax and unwind," "Sleeping," "Challenging negative thoughts," "Positive thinking" and "Boosting self-esteem." Activities are either *in the moment* (can be accessed at any time) or part of a *programme* (can be accessed only through the programme). The programmes are locked sequences of activities, delivered in daily steps designed to teach a skill, for example, to teach healthy sleep behaviours. In total, the app offers over 150 different activities to help the users manage their stress. **Figure 1** illustrates sample activities and programmes included in *Foundations*.

To improve its engagement levels, *Foundations* recommends activities that users should explore outside of their active programs. For the current model version, the recommendations are presented in the *Today explore* widget. We further refer to this recommendation engine as the *Today explore* RecSys. The recommendation engine is based on the popularity of different activities during certain hours, depending on whether it is day or night. The recommendations are optimized for clickthrough rate by showing the user activities that the engine deems most relevant. The app has gone through several iterations since this analysis; the one here analyzed is the version from March 2021. The model training takes into account all the impressions and clicks. However, no data on gender, age, or other protected characteristics is used for training nor collected for *Foundations* everyday users as part of data minimization since this data is not needed for the functioning of *Foundations*.

2.2.1 Risks of bias in *Foundations*

Within the focus of *Foundations* on mental health at a subclinical level, the main class of tasks is information access



50%

Positive mood

It is normal to feel sad or upset from time to time, particularly if you're faced with a challenging situation. If you are feeling low on a regular basis, it's important that you talk to someone and consider consulting a health professional. In Foundations we have activities and programs that may help improve your mood. Try these below!

Program recommendations

Activities that can help you improve your score

50%

Calm mind

Mulling things over and thinking through a problem is important for you to evaluate a situation and plan for the future. But when this persists and turns to worry, it can make you feel anxious and stressed. Try some of the activities below to help manage your worry.

Program recommendations

Activities that can help you improve your score

60%

Sleeping well

Sleeping well is essential to your mental wellbeing. Too little sleep can make your emotions harder to deal with and make you feel unhappy or stressed. And if you're feeling stressed or worried, this can affect your sleep. Whether you need meditations or soothing sounds to help you drift off, or if you want to learn how to make long-term changes to your sleep quality, Foundations can help.

Program recommendations

Activities that can help you improve your score

45%

Managing stress

Most of us need a little bit of pace and pressure in our lives—it helps us focus, organize, and do our best. But sometimes this can become overwhelming, and things feel unmanageable. Foundations has techniques to help you unwind and programs to help you feel in control of your life.

Program recommendations

Activities that can help you improve your score

FIGURE 1
Foundations app screenshots.

tasks such as search and recommendation. In particular, in the *Today explore* area of the app, users can access activities recommended to them, based on a mix of app usage and contextual data, such as the time of the day.

While developing *Foundations* we need to evaluate the process of monitoring or profiling users for bias (e.g., determining a health risk score) and then potentially provide this information to other algorithms, such as a decision support process as part of a dosage or intervention delivery mechanism. In a future extension of the app, we aim to passively monitor the severity of symptoms of users through models trained on smartphone sensing data. Undesired bias in categorization could affect a group of users who receive the wrong kind of care, as the algorithm can make inappropriate decisions based on biased or low-quality information. Potential issues in this task include providing less dosage or improper interventions to a group of individuals who need it the most when compared to others based on a protected attribute (such as disability status or gender). Depending on the algorithm design, such profiling could be, to some extent, caused by proxies for protected attributes.

Furthermore, undesired bias in recommendations could mean that some users do not receive any benefit from an activity or have adverse effects due to this activity. *Foundations*' recommendations include suggestions for changing habits, behaviors, or the development of specific practices to improve users' health. These have contextual implications from a societal standpoint, and in addition to having no benefit or being harmful, they might also reinforce stereotypes or stigmas.

2.2.2 Sources of bias in *Foundations*

There are several potential sources of bias, including training datasets that encode past discrimination, or the actual design of models containing undesired bias, sometimes due to developers' failure to acknowledge, or their unawareness of, issues of structural discrimination (21). Considering *Foundations*' main goals, two primary sources of bias should be considered:

- *Expert-provided data*: Expert-provided data includes experts' categorizations or rankings. These experts may be professionals in a relevant area or trained data annotators. Expert-provided data must be examined for categorizations that are strongly dependent on protected attributes or rankings that routinely place some items above others in an unjustified manner.
- *User-provided training data*: User-provided data includes explicit feedback as well as observed interactions (behavioral data) obtained from end-users in the operation of a system, including passive collected data. Systems trained on user-provided data containing undesired biases are susceptible to reinforcing biases existing in society or predominant within target groups. In a recommender system such as the one developed in *Foundations*, explicit feedback may be obtained from surveys, and behavioral data may include clicks or ratings of recommendations. Unwanted bias may be present in behavioral data if, for instance, a majority group of users (e.g., younger users) always rejects some recommendations that are actually very beneficial for a minority group of users (e.g., older users)—in this case, the minority group may experience less relevant recommendations.

2.3. 7 step process to assess fairness in automated systems

We leverage a step-by-step framework and present below the processes to assess fairness in automated systems, focusing on algorithmic bias detection. General recommendations introduce decisions to be made in order to properly conduct risk assessments and use appropriate methods at each stage of the process.

2.3.1. Step 1: Contextual analysis

Establishing a solid basis for the analysis of algorithmic processing requires revisiting the rationale and theories behind the model design. This analysis includes aspects such as: (a) intended use and purpose of a (sub)system: determining users' characteristics, categorizing users or items, generating recommendations, etc.; (b) theoretical basis of the model: are all variables or drivers associated with the target outcome captured adequately, considering the literature about the phenomenon? (c) fit-for-purpose features: are features appropriate for characterizing people from all groups? Does the system need to process more or different data from women, people with disabilities, or other groups? Is there any data or feature concerning a protected group which is missing? (d) characteristics of the ground-truth: is the ground truth an objective, physically measurable quantity, or does it contain some subjective elements? Is it obtained directly by observation or via inference? Is the ground truth the "real" target, or a proxy chosen for convenience? (e) completeness of training data: whether different groups are well represented in training data, particularly minorities. As a result of this examination, initial hypotheses about potential biases involving protected groups may be stated.

2.3.2. Step 2: Mapping the user population

At the initial stage of development, it is also crucial to identify which protected groups might be at risk of bias. Therefore, the social context where the system will be used needs to be examined both within its envisioned context of use as well as with respect to its training data, if available. This includes a description of its targeted population at a sufficient level of detail in order to understand which protected groups it contains, including data on age-sex groups, age cohorts or other relevant factors (ethnicity, nationality, education level, etc.).

2.3.3. Step 3: Prioritizing protected groups

The third step starts with identifying a reference group, which can be a structurally privileged or majority group (e.g., male, white). Next, protected groups within the population identified in Step 2 can be identified based on attributes or intersections of attributes. This includes particularly vulnerable groups (e.g., children with disabilities), large minority groups, women, and groups of particular concern with respect to the specific application at hand. The choice of protected groups and intersections of groups to analyze depends on the context and purpose of the algorithm. Potential harms (or lack of benefit) for disadvantaged groups must be hypothesized considering model outcomes and expected results since absolute algorithmic fairness measures will focus on differential effects of treatments between the protected and unprotected groups. Note, resource limitations may mean that we will not be able to prioritize all groups that we might wish to or need to undertake analysis in series. Such trade-offs should be described.

2.3.4. Step 4: Selecting algorithmic fairness metrics

This step consists of choosing the most suitable metric for measuring identified disparities or potential adverse outcomes of the system regarding disadvantaged groups.

In theory, it could be possible to undertake a cost-sensitivity analysis in which each deviation from perfect parity is given a cost in arbitrary units or even in monetary ones. For instance, each additional percentage point of false negative rate disparity against a group might be equivalent to two additional percentage points of false positive rate disparity against another. However, in most cases, there is no reference point for performing this cost-sensitive assessment and no clear justification for the chosen costs. Hence, a possible hierarchy of metrics, in which some algorithmic fairness metrics are considered more important than others, can only be achieved in practice in a broad qualitative sense, if ever.

An additional task on this step is to determine the level at which the metric will be measured. For instance, a metric such as "satisfaction" can be computed at the level of the entire app (e.g., via a survey) or at the level of a specific recommender system (e.g., by observing whether users accept or do not accept the recommendations by that system).

2.3.5. Step 5: Calculating the selected algorithmic fairness metrics

Various tools are available for this purpose, two popular tools are described next. Aequitas, an open-source toolkit of the Chicago University, is easy to use and includes a web-based tool to generate a report, configure bias metrics of interest and reference groups. It also has a Python Library to calculate bias and fairness metrics on data and predictions. Another tool is IBM AI360, a more feature-rich tool that includes methods for generating classifiers that satisfy algorithmic fairness criteria, usually at the cost of small decreases in terms of accuracy.

2.3.6. Step 6: Analysing results, interpret using qualitative information

Identified differences for applied metrics between groups must be examined. Results should be checked against initial hypotheses, including the usual culprits such as training data representativeness or appropriateness of features for different groups. Some disparities could be justified through a careful application of, for instance, "business necessity"[3] or another normative framing (23, 24). Other disparities may provide an advantage to a disadvantaged group and might not be as troubling as cases where a disadvantaged group is negatively impacted.

It should be noted that disparities in AUC or false negative rates are expected and fairly common in most deployed recommender systems. Quantitative results must be appropriately placed within the overall qualitative analysis to decide in which cases an action is necessary. To facilitate decisions on possible mitigation actions, the following warning levels are suggested: (1) *Most severe*: The analyzed algorithm or system harms a group or has no beneficial effect on a group who may be in harm's way. (2) *Intermediate severity*: The algorithm or system has a positive effect but is substantially less effective, either in terms of performance or errors, for a vulnerable group (e.g., people with disabilities) or for a large group (e.g., women, people under 25 years old). (3) *Least severe*: The algorithm or system fails with respect to some algorithmic fairness criterion between a protected group and the reference group, or between two protected groups, however the disparate impact is relatively small. Whether a disparate impact (such as a discrepancy is false positive rates between two groups) is large or small, needs to be defined contextually within a specific application and with respect to specific groups, depending on factors such as how consequential the recommendations are and how vulnerable the group that experiences the disadvantage is.

2.3.7. Step 7: Mitigating bias

Mitigation actions should be decided on the basis of severity, considering to what extent the criterion is violated and who the negatively impacted users are. Patterns of discrimination need to be identified, e.g., when both quantitative and qualitative analysis agree that the application has issues for some specific group.

In the case of risk assessment, learning models can be adjusted through in-processing changes, or their scores can be post-processed, or training data can be pre-processed (e.g., resampling, reweighting, or changing labels). This may lead to losses of accuracy that can be to some extent compensated with more training data, particularly for the group that exhibits less accuracy. It may also require additional features targeting specific characteristics of people in protected groups that can be good predictors of positive/negative outcomes for them.

Disparate impacts (Step 6) should be documented alongside the methods to mitigate them and any limits to mitigation efforts imposed by trade-offs with other goals, such as accuracy. Any remaining disparate impacts, where they affect end users, should be disclosed to them as limitations of a tool. For instance, if the app performs poorly for people over 65 and training data for that group is scarce, and/or for some reason that group is not within the scope of the app, the app should not be marketed to that group and a warning of this limitation should be made clear to potential users.

2.4. A randomized control trial

The primary aim of the RCT was to evaluate the efficacy of *Foundations* in improving the mental wellbeing during the COVID-19 pandemic, after 2 and 4 weeks of usage.

A 4-week RCT randomized controlled trial (RCT) was conducted which explored psychological and social wellbeing measures for London School of Economics students. Two apps were used in the trial, *Foundations*, a mental wellbeing app with interactive activities and programmes designed to build resilience, manage stress and improve sleep and LSEasy, an app designed to measure experiential subjective wellbeing.

Upon entry into the trial, all students were randomized to one of four groups: (1) *Foundations*, (2) LSEasy, (3) *Foundations* + LSEasy, or (4) control. Wellbeing measures were collected at baseline and weeks 2 and 4.

Participants were randomized individually with equal allocation to the 4 arms, stratified by gender (male, female, or

TABLE 1 Sensitive attributes analysed.

Sensitive attribute	**Values**
Gender	Female, Male
Working position	Do not work, Entry level, Internship
Employment status	Unemployed (not searching for job), Unemployed (searching for job), Employed
Location of origin	South and East Asia (incl. India and China), UK, Other Western Europe
Age	18–19, 20–26
Level of work	Full time, Part time, Other
Monthly income	<£1,000, £1,000–£2,000

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[3] For instance, as Raghavan et al. (22) explained, some vendors of algorithmic hiring assessments avoid disparate treatment solely by assuring that protected attributes such as race are not used as inputs to their models. However, with regards to disparate impact, vendors can still fail, and such limitations may be legal within some legal frameworks. Even if the screening algorithm does produce a disparate impact, it can be justified as assisting a legitimate business objective if it is accurate enough.

TABLE 2 Distribution of participants per arm, total and for each value of sensitive attribute.

Sensitive attribute	Attribute value	Group 1	Group 2	Group 3	Group 4	Total
		153	153	151	153	610
Gender	Female	105	106	105	106	422
Gender	Male	46	46	45	45	182
Working position	Do not work	81	85	77	84	327
Working position	Entry level	25	19	20	16	80
Working position	Internship	19	20	20	22	81
Location of origin	South and East Asia	43	48	35	40	166
Location of origin	UK	42	48	49	45	184
Location of origin	Other Western Europe	24	23	26	31	104
Age	18–19	17	20	24	19	80
Age	20–26	112	105	97	112	426
Level of work	Full time	28	32	29	32	121
Level of work	Part time	60	54	51	51	216
Level of work	Other	62	67	68	67	264
Monthly income	<£1,000	110	121	115	116	462
Monthly income	£1,000-£2,000	28	26	22	25	101
Employment status	Unemployed (searching for job)	48	56	49	48	201
Employment status	Unemployed (not searching for job)	32	33	38	36	139
Employment status	Employed	44	42	41	38	165

other) and baseline WHO-5 score (≤ 12 or >12), using a random permuted block design.

The distribution of participants per arm, including the partial counts of participants for each sensitive attribute in Table 1, is shown in Table 2.

Participants were paid £30 upon completion of the trial. Participants who were assigned to a group that included the use of *Foundations* were offered access to the app for free. Those in group 1 were considered to have completed the trial if they completed at least one programme and four activities in *Foundations*, and filled in both the onboarding and exit questionnaires. Participants in group 2 were considered to have completed the trial if they answered at least 70% of questionnaires and filled in both the onboarding and exit questionnaires. Participants in group 3 had to complete the completion requirements of both group 1 and group 2. Participants in group 4 were required to answer only the onboarding and subsequent check-up questionnaires at week 2 and 4 of the trial.

Participants were recruited from London School of Economics between March and April 2021. Upon the apps installation, they were first presented with a consent form detailing the objective of the RCT and data collected (in compliance with the GDPR regulations). The trial was reviewed and approved by the London School of Economics Ethical Board. Moreover, participants had to agree to a privacy policy for the onboarding questionnaire.

The pre-registration of the RCT can be found in https://osf.io/hvtf8.

3. Results

3.1. Evaluating fairness in *Foundations*' effectiveness

3.1.1 Step 1: Contextual analysis

Foundations is an application designed to be marketed to large organizations for their employees. Organizations licensing the app would provide it to their employees, which means that our target groups included adults who are employed full-time and are between 18 and 66 years of age. As such, some groups of users are explicitly excluded from using *Foundations*, such as the unemployed, school-aged children or students, and the retired. Within the scope of employees in the US and UK, there is a vast variety, although businesses in the following sectors are more likely to be buyers of *Foundations*: healthcare, education (teacher not students), finance, telecommunications, and industrial organisations. Nevertheless, in the study conducted, we enlarge the population characteristics to evaluate differential impact across extended protected groups.

3.1.2. Step 2: Mapping the user population

Given the study use case of *Foundations*, we analyzed its impact across the following protected characteristics, age, gender, income and employment attributes, and location of origin. The relevant arms for this analysis were *Foundations* and *Foundations* + LSEasy (groups 1 and 3, as defined in Section 2.4).

3.1.3. Step 3: Prioritizing protected groups

In *Foundations*, women were identified as the protected group for the bias analysis. This decision is based on the contextual analysis conducted within step 1 framing women as a potential disadvantaged population regarding *Foundations*. Beyond gender, we analysed the sensitive attributes presented in Table 1, for the values reported by at least 10% of the participants.

3.1.4. Step 4: Selecting an algorithmic fairness metrics

Since *Foundations* is a mental wellbeing app, designed to help people take care of their mental wellbeing on their own terms, we are interested in measuring users' satisfaction as measured by the progress in their mental wellbeing (WHO-5 score).

The following measures are used to monitor users' progress in wellbeing during the usage of *Foundations*:

- *Step-up over 4 weeks*: WHO-5 scores can be categorized as corresponding to low (<28), regular (≥28, <50) or high (≥50) wellbeing levels. The values reported at on-boarding and 4 weeks later are compared and those participants that decreased at least one level are deemed to have stepped up (e.g. regular wellbeing at on-boarding and low wellbeing 4 weeks later).
- *Increment over 4 weeks*: An increment in wellbeing over 4 weeks has occurred when there is an increase of more than 10 points in the WHO-5 score.

We consider that there is no disparate impact in *Foundations*' effectiveness when the probability of a user stepping up or having an increment is similar across protected groups.

3.1.5. Step 5: Calculating the selected algorithmic fairness metrics

To assess bias in the metrics described in Step 4 we use Fisher's exact test on contingency tables where the participants are split both by their metrics score and whether or not they belong to a protected group.

3.1.6. Step 6: Analysing results

For each one of the metrics (step-up and increment) and each value of a sensitive attribute reported in Table 1 a contingency table was calculated as described in Step 5 and the Fisher's exact test was applied.

For the gender attribute, the contingency tables related to the step-up and increment metrics are reported in Tables 3 and 4, respectively, and the corresponding Fisher's exact tests yielded *p*-values of 0.359 and 0.169, respectively. We observe a large gender bias, which corresponds to an odds ratio of 1.80 for WHO-5 step-ups and 0.54 for WHO-5 increments between females and not females; however, the detected bias was not statistically significant.

TABLE 3 Contingency table for WHO-5 step ups (in the original data), split by gender values.

	WHO-5 step up	
Gender	**Yes**	**No**
Female	7 (8.23%)	78
Not female	6 (13.95%)	37

TABLE 4 Contingency table for WHO-5 increments (in the original data), split by gender values.

	WHO-5 increment	
Gender	**Yes**	**No**
Female	33 (38.82%)	52
Not female	11 (25.58%)	32

In summary, the (minimum) *p*-values for the Fisher's exact tests for each sensitive attribute and metric (step-up and increment) are shown in Table 5, line 1 and 2, respectively. We illustrate the percentage of WHO-5 step-ups, defined as the number of step-ups divided by the total number of participants in that category, for each sensitive attribute in Figure 2, given its importance in clinical usage, namely in triage.

While three of the statistical tests yielded statistically significant results (*p*-value <0.05) we need to take into account that multiple tests were performed (18 for each of the targets, i.e., WHO-5 increment and step-ups) and correct for multiple hypotheses. Using the correction by Benjamini-Yekutieli (25) we conclude that, after correction, none of the results is statistically significant.

3.1.7. Step 7: Mitigating bias

No mitigation actions were further taken, given that the results from Step 6 were not statistically significant.

3.2. Use case results: Preliminary analysis on the disparate impact of step-up monitoring models in WHO-5

Continuous monitoring of users' mental health state is a pre-requisite for delivering the right intervention at the right time. Asking users to frequently report their mental health states is not sustainable, which is the area where passive detection of symptoms can provide a breakthrough. Smartphone sensor data provides a proxy to everyday behaviours, such as diurnal patterns, sleep,

TABLE 5 Minimum p-values for Fisher's exact test on contingency tables involving a sensitive attribute and the following targets: WHO-5 step ups in the original data, WHO-5 increments in the original data, and WHO-5 step up events as predicted by the step up model.

	Sensitive attribute						
	Gender	**Working position**	**Employment status**	**Location of origin**	**Age**	**Level of work**	**Monthly Income**
WHO-5 step up Minimum p-value (original data)	0.346	0.258	0.033*	0.213	0.059	0.546	0.690
WHO-5 increment Minimum$p$-value (original data)	0.169	0.292	0.171	0.031*	0.011*	0.200	0.614
WHO-5 step up Minimum p-value (step up model)	0.091	0.549	0.049*	0.049*	0.112	0.517	0.338
Today explore Minimum p-value (RecSys model)	0.035*	0.399	0.102	0.270	0.343	0.613	0.257

*Statistically significant p-values are marked with *.*

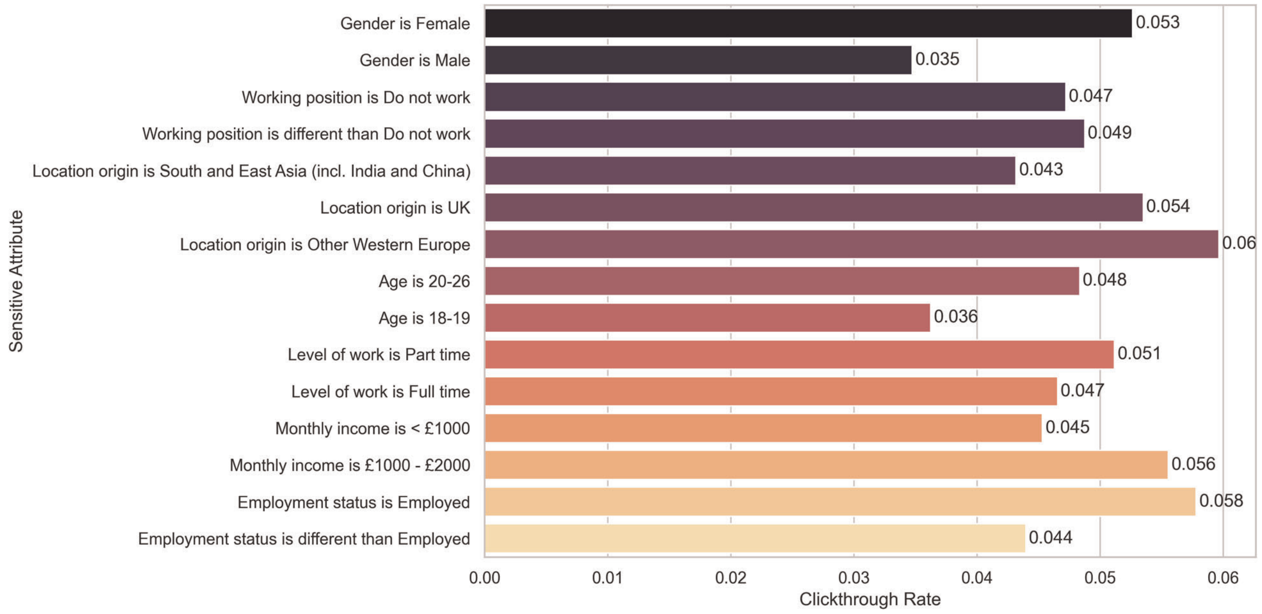

FIGURE 2
Percentage of WHO-5 step-ups for each sensitive attribute. None of the differences remain statistically significant after correcting for multiple hypotheses testing.

mobility, physical and social activities—all correlated with mental health symptoms. Based on such data, we developed a machine learning model to detect important changes in wellbeing, reported by using the World Health Organization's Well-Being Index. The 5-item World Health Organization Well-Being Index (WHO-5) is a short self-reported measure of current mental wellbeing (26). WHO-5 scores range between 0 and 25. They are rescaled to 0–100 and the following intervals are used to classify the scores into levels of wellbeing: *Low wellbeing*: [0, 28), *Regular wellbeing*: [28, 50), and *High wellbeing*: [50, 100].

WHO-5 questionnaire results taken at two different points in time are compared per individual as follows: *"step-up"* if the second result is in a higher severity level than the first one (equivalent to a lower score in WHO-5, denoting a deterioration in wellbeing); *"no change"* if both results are in the same severity level; and *"step-down"* if the second result is in a lower severity level than the first one (equivalent to a higher score in WHO-5, denoting an improvement in wellbeing). Note that this includes the following cases: (a) when a user steps up by one level between the two points in time (e.g., from regular to low); or (b) when a user steps up by several levels between the two points in time (e.g., from high to low).

The intended use of the algorithm is to passively monitor wellbeing outcomes and detect deterioration in wellbeing level. Enabling a continuous assessment of the user state would open the door to changing the mental healthcare paradigm towards the continuous and stepped-care model—delivering appropriate interventions timely and with a proper dosage, and ultimately improving health outcomes.

We utilize the gradient boosting library called XGBoost to train a machine learning algorithm to predict step-up events of deterioration in WHO-5, according to standard labelling of low, regular and high at the two different points in time. We compare its performance against two other machine learning models, namely Logistic Regression and Random Forest (using $n = 500$ trees), using the following metrics: Area Under Curve for the receiver operating curve (AUC), sensitivity, specificity, precision, recall, balanced score and Kappa score. We utilized a mixture of tree-based and linear models to explore models of different complexities, with the tree-based ones having a low bias and high variance, while the regression has a high bias and low variance. The model that performs best across the majority of the evaluation metrics is the XGBoost one. The models were trained using passively collected data, which was transformed into features that capture the variations between the individual's behaviour between two different moments in time. These features are designed to reflect behaviour and cognitive state changes between the start of the period and the end of the period. In that sense, the data was aggregated at a daily level over the period of time that the system is meant to detect the state change, such as average across days, total sum, standard deviation across days, variance across days, minimum value, etc. In the second stage, the set of variables is transformed into the change-based features that are used in the following step for modeling (e.g., similarity between the mean number of steps during week 1 and 2, compared to week 3 and 4).

3.2.1. Step 1: Contextual analysis

The intended use of the step-up model is to function as a triage model with the purpose of detecting users that decrease their well being significantly, and hence, enable a stepped care model where the user is given the next level of care, within their consent. For instance, a different mental health app may be prescribed to them, or the therapist may be notified about the deterioration, should this be within the scope of the app and their consent. The ground truth of the stepped care model is computed based on a threshold obtained by literature. WHO-5 score was self-reported by the users.

3.2.2. Step 2: Mapping the user population

As in the analysis of *Foundations*' effectiveness the protected characteristics that we will pay attention to are: age, gender, income and employment attributes, and location of origin. We utilized data coming from users who had installed the LSEasy app for passive monitoring, since we build the predictive model based on passive signals from the phone. This includes users who installed only the LSEasy app, as well as LSEasy and *Foundations* apps (groups 2 and 3, as defined in **Section 2.4**.

3.2.3. Step 3: Prioritizing protected groups

As in the analysis of *Foundations*' effectiveness, women were identified as the protected group for the bias analysis. Beyond gender, we again analysed the sensitive attributes presented in **Table 1**, for the values reported by at least 10% of the participants.

3.2.4. Step 4: Selecting an algorithmic fairness metrics

We consider that the model for monitoring a user's state is fair when the probability of stepping up is similar across protected categories. Therefore, we utilized Fisher's exact test to compare the probability of stepping up is statistically significant across protected categories.

3.2.5. Step 5: Calculating the selected algorithmic fairness metrics

We performed a pairwise Fisher exact two-tailed test for subgroups within each category. Given the small sample size we decided not to create new subgroups out of the protected attributes (e.g. Male with an income of <£1,000).

TABLE 6 Step up in WHO-5 level (e.g. regular to low = Step up) with a machine learning model.

Model	Confusion matrix	AUC	Sensitivity	Specificity	Precision	Recall	Balanced score	Kappa
XGBoost step up model	[47, 6], [7, 5]	0.66	0.42	0.89	0.45	0.42	0.65	0.31
Logistic regression step up model	[47, 6], [8, 4]	0.69	0.33	0.89	0.40	0.33	0.61	0.24
Random forest step up model	[50, 3], [10, 2]	0.74	0.16	0.94	0.40	0.16	0.56	0.14

3.2.6. Step 6: Analysing results

We present the results of the step-up model in **Table 6**. Moreover, for each protected attribute, we computed the contingency table related to the step-up events detected and the corresponding Fisher's exact test *p*-values. In summary, the (minimum) *p*-values for the Fisher's exact tests for each sensitive attribute are shown in **Table 5**, line 3.

While two of the statistical tests yielded statistically significant results (*p*-values <0.05), their value was at the border of significance (0.049), and we need to take into account that multiple tests were performed (18 per metric) and correct for multiple hypothesis. Using the correction by Benjamini-Yekutieli (25) we conclude that, after correction, none of the results is statistically significant.

3.2.7. Step 7: Mitigating bias

No mitigation actions were further taken, given that the results from Step 6 were not statistically significant.

3.3. Use case results: Preliminary analysis on the disparate impact of *Today explore* RecSys

3.3.1. Step 1: Contextual analysis

The intended use of the *Today explore* Recsys is to improve the engagement levels in *Foundations* by providing better activity recommendations. In particular, it recommends activities that users should explore which are outside of their active programs. For the version of *Foundations* used during the study (3.2.0), the recommendations are presented in the *Today explore* widget.

The recommendation engine is based on the popularity of different activities during certain hours, depending on whether it is day or night. This model aims to optimize for clickthrough rate on activities, by showing the user activities that it classifies as most relevant. No data on sensitive attributes is used for training nor collected for *Foundations*' everyday users as part of a data minimization strategy since this data is not needed for the functioning of *Foundations*.

3.3.2. Step 2: Mapping the user population

As in the analysis of *Foundations*' effectiveness, the protected characteristics that we will consider are: age, gender, income and employment attributes, and location of origin. We selected the study participants from the *Foundations* and *Foundations* + LSEasy arms (groups 1 and 3, as defined in **Section 2.4**) who completed at least one programme and four activities in *Foundations* ($n = 219$).

3.3.3. Step 3: Prioritizing protected groups

As in the analysis of *Foundations*' effectiveness, women were identified as the protected group for the bias analysis. Beyond gender, we again analysed the sensitive attributes presented in **Table 1**, for the values reported by at least 10% of the participants.

3.3.4. Step 4: Selecting an algorithmic fairness metrics

Today explore Recsys was designed with the goal of improving engagement levels in *Foundations* through additional clicks in the *Today explore* widget. Therefore, a key indicator to evaluate its performance is the click-through rate, measured as the ratio between activities selected and activities recommended.

As a fairness metric we use the related binary variable which takes the value 1 when a user selects the recommendation and 0 when a user does not select it. The click-through rate can be computed as the average value of this metric.

3.3.5. Step 5: Calculating the selected algorithmic fairness metrics

To assess bias in the fairness metric described in Step 4 we use Fisher's exact test on contingency tables where recommendations are split by the fairness metrics value and whether they were shown to a user with the relevant sensitive attribute or not.

3.3.6. Step 6: Analysing results

For each value of a sensitive attribute reported in **Table 1**, a contingency table was calculated as described in Step 5 and the Fisher's exact test was applied.

In **Table 7** we show the contingency table related to the fairness metrics for the gender attribute. The corresponding Fisher's exact test yielded a *p*-value of 0.035, with female participants benefiting more than male participants from the recommendations of *Today explore* Recsys. In summary, the (minimum) *p*-values for the Fisher's exact tests for each sensitive attribute are shown in **Table 5**, line 4. We illustrate the clickthrough rates for each sensitive attribute in **Figure 3**.

While the statistical test for female participants yielded a statistically significant result we need to take into account that multiple tests were performed (in particular 18 tests) and correct for multiple hypothesis. Using the correction by Benjamini-Yekutieli we conclude that, after correction, the result is not statistically significant.

3.3.7. Step 7: Mitigating bias

No mitigation actions were further taken, given that the results from Step 6 were not statistically significant.

TABLE 7 Contingency table for Today Explore Recsys outputs, split by gender values.

	Activity selected		
Gender	**Yes**	**No**	**Clickthrough rate**
Female	128	2,303	5.27%
Not female	27	762	3.42%

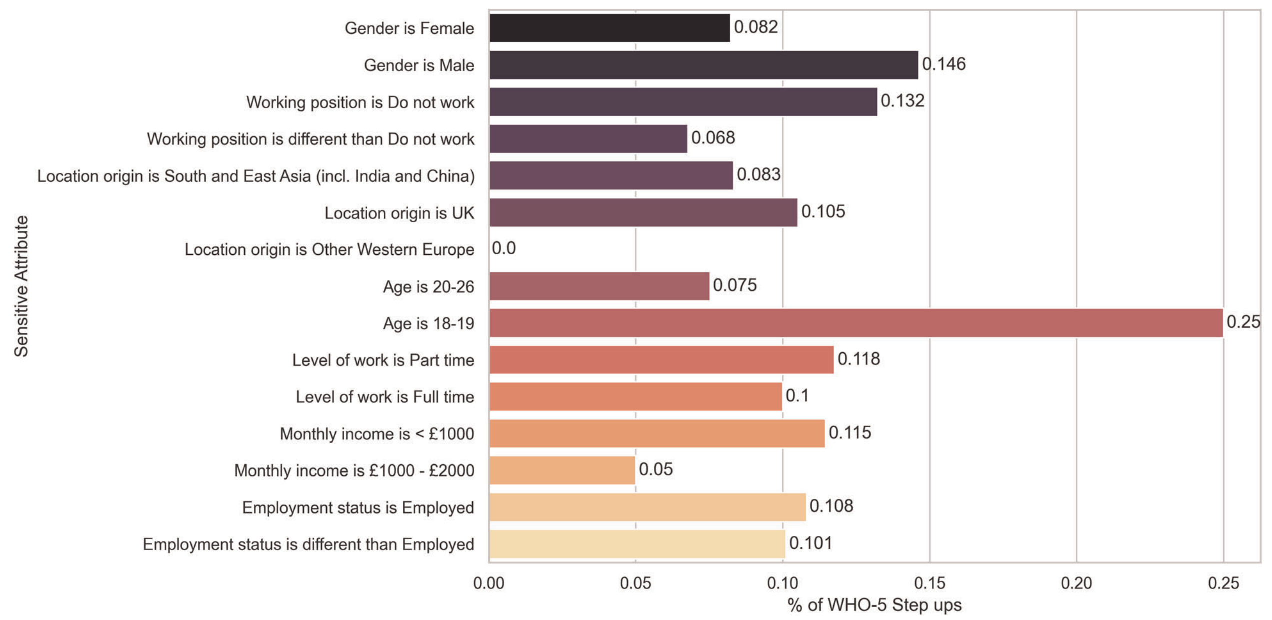

FIGURE 3
Today explore RecSys Clickthrough rate for each sensitive attribute. None of the differences remain statistically significant after correcting for multiple hypotheses testing.

4. Discussion

As digital mental health services are expanding, it is becoming increasingly important to understand fairness in the provision of those services. Existing literature provides little guidance on this topic in the domain of digital mental health services. In this paper, we shed light on the process of auditing digital mental health services and their algorithms as an integral part of digital mental healthcare delivery. We advocate for a greater focus on fairness analysis in this domain in which sensitive user groups (based on age, gender, ethnicity, etc.) may be impacted differently by mental health services and their embedded automated systems.

4.1. Overall *Foundations*' impact in wellbeing

At the overall app level, we found that there is no difference when analysing four of the protected groups: gender, working position, level of work and monthly income. In the other three groups (i.e., employment status, age, and location of origin), we did find some small differences regarding *Foundations* efficacy, but only before correcting for multiple hypotheses testing. In the case of employment status, we found that the people who had selected "Unemployed (not searching for job)" ($N = 27$) benefited less from the app, and had a higher percentage of step-ups (odds ratio: 0.266 compared to the rest; 22.22% in this category stepped up, compared to 7.07% for the rest). Moreover, in the case of "Age," we found that people between 18 and 19 years of age ($N = 16$) had less benefits from the app in terms of WHO-5 increments (odds ratio: 9.35; 6.25% of increments in this category, compared to 29.46%). The majority of people of this age included in the study were unemployed (62.5%). In the case of "Location of origin," we found that people from "Other Western Europe" ($N = 17$) benefited less from the app and had a lower rate of WHO-5 increments (odds ratio: 5.09, compared to the rest; 11.11% of increments in this category, compared to 38.88%). In this subgroup of participants 47% of them were unemployed. This is somehow expected and in line with an app that targets a working population. It is within reason to expect that unemployed people will benefit less than employed people within such a short time frame (4 weeks). Nevertheless, none of these results remained significant after correcting for multiple hypotheses.

4.2. Overall impact of the *Step-up* monitoring models

We found two results which were at the limit of statistical significance, since their p-values were 0.049, in the categories "Employment status" and 'Location of origin." In the case of "Location of origin," we observed that the model was particularly accurate for people from South East Asia ($N = 18$), correctly categorizing 17 out of 18 cases. This was the second largest group in our training sample. Moreover, this group had only 2 step-ups. Similarly, in the case of "Employment status," we observed that the model was particularly accurate for people who were "Unemployed (searching for a job)," correctly categorizing correctly 17 out of 18 cases. Moreover, this group had only 1 step-up. The results are not surprising given that these groups represent a large portion of the training data and have a low number of step-ups, meaning that the majority of people did not deteriorate in well-being, which is easier for the model to learn. Nonetheless, none of the results remain significant after correcting for multiple hypotheses. In conclusion, in a potential future extension of *Foundations*, where the step-up model would be deployed for monitoring users' wellbeing passively, we do not expect significant disparate impact in any of the seven studied salient groups.

4.3 Overall impact of the *Today explore* RecSys

The *Today Explore* recommender system is only a part of the *Foundations* app, and there are other elements of the app with which users interact. In particular, for this study, participants were required to complete at least one programme within *Foundations*, which may have limited the time they invested in other parts of the app. However, the recommender system is a specific element that we identified as having a potential risk of algorithmic bias and this is why we analyze it. Nonetheless, the click through rate for the RecSys was below 5% during this study, hence, having little impact on the overall engagement and efficacy. Nevertheless, we established a protocol for evaluating the algorithm fairness of the RecSys in the future, we assessed its current bias and found no statistically significant results after correction in any of the seven studied protected groups and finally, we are completing a model card that will be used before deploying models in production.

4.4. Difference between the study population and *Foundations*' active users

Currently and in the foreseeable future, there is no plan to collect sensitive attributes from the active users of *Foundations* (e.g., gender or age) due to internal privacy policies within Koa Health. Therefore, we have less information about our users which in turn leads to fewer ways to personalize *Foundations*, and can also delay the discovery of bias against protected groups. For these reasons, it is difficult to compare the sample population from the study with the active users of *Foundations*. Nevertheless, we plan to discover biases when running randomized control trials with a large sample population.

4.5. Ethical considerations

The research presented in this paper has been reviewed against Koa Health's ethical commitments in its Ethics Impact Assessment (EIA)[4] framework. In terms of ethical concerns with respect to *Foundations*' efficacy and the algorithms presented in the two use cases (WHO-5 step-up model, and RecSys), the most important are:

- Ensuring that there is a positive impact on users' happiness, health and wellbeing.
- Avoiding biases that discriminate against protected groups.
- Maximising privacy of users' personal data.
- Ensuring that the algorithm does not lead to users becoming addicted to *Foundations*.

The first three of the above points were all considered within the analysis on discrimination, intended use, subgroups, trade-offs and limitations.

Addiction is not considered to be a challenge at this stage in the maturity of the algorithm, nor of *Foundations* more generally. This is because the app does not use features that can lead to addiction, such as infinite scroll, social validation, etc.; and the algorithm does not support these. See the *Foundations* EIA for more details.

5. Conclusion

Mobile technologies and apps for mental self-care have became prominent in recent years. Socio-economic and gender biases have been identified in such systems, including digital divide problems caused by inequalities in access to digital services, and lack of consideration for gender differences. Moreover, some of these mobile technologies are powered by machine learning models, which can perpetuate existing biases and present risks of algorithmic discrimination. In this paper, we assess *Foundations*, a mental health app, that aims to help people deal with stress in the workplace, regardless of gender, race, ethnicity and other protected attributes, and by design should have no disparate impact, since it is built on evidence-based interventions meant to be effective for all. We argue that evidence-based tools still need to go through an ethics impact assessment and we cover the following evaluations in practice: (a) whether the content of *Foundations* has any disparate impact on protected groups, (b) whether a future extension of *Foundations* offering a passive monitoring service has any undesired bias, and (c) whether the existing

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[4] https://koahealth.com/ethics˙audit˙koa˙health˙apps.pdf

version of RecSys at the time of the study had any undesired bias. In this study, we found no disparate impact and no undesired bias in our evaluations.

Data availability statement

The datasets presented in this article are not readily available because **the data used for this study can be shared only under a data sharing agreement**. Requests to access the datasets should be directed to aleksandar.matic@koahealth.com.

Ethics statement

The studies involving human participants were reviewed and approved by London School of Economics Ethics Board. The participants provided their written informed consent to participate in this study.

Author contributions

TSB, JG contributed to writing the paper, hypotheses generation, producing the results, and critical revisions of the paper. AM contributed to the study conception, interpretation, critical revisions and ideas in abstract, introduction and discussion. JOI contributed to writing in abstract, introduction, discussion and producing results for the RecSys and WHO-5 use cases. CC contributed to the analysis framework. OS contributed to drafting the background, establishing the collaboration among the authors, and refining the scope of the paper. All authors reviewed the manuscript.

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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Experiences of digital exclusion and the impact on health in people living with severe mental illness

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Background: The covid-19 pandemic has accelerated the use of digital tools within health and social care services. However, for a range of different reasons, across the UK there continue to be people who are digitally excluded. People living with a disability have been identified as being more likely to be digitally excluded and many of these people, including people with severe mental illness (SMI) already experience health inequalities. Therefore, understanding the perceived impact digital exclusion has on health and potential facilitators of increased inclusion is an important area for research. This study had two aims: 1. To understand experiences of digital exclusion and the impact on health in people with SMI. 2. To explore the influences and mechanisms which would increase engagement with digital health tools.

Methods: This was an observational qualitative study, conducting focus groups (with the option of a 1:1 interview for those uncomfortable in groups) with nine people with severe mental illness.

Results: Participant's responses were themed in to four key areas in relation to digital exclusion and impact on health: 1. Reduced social connectedness, 2. The impact on wider determinants of health 3. Negative perception of self, 4. Disempowerment. Key facilitators for increased engagement with digital tools included, local digital skills support with mental health lived experience involvement in the delivery, digitally engaged social referents, access to digital tools and data, personalised and straightforward digital tools. In addition, increasing health and social care staff's awareness of digital exclusion was also viewed as important in promoting inclusion.

Conclusion: The research findings suggest that digital inclusion should be viewed as a wider determinant of health. Many of the identified consequences of exclusion are particularly important in relation to mental health and mental health recovery. This research suggests that identifying and addressing digital exclusion should be viewed as a priority for mental health services.

KEYWORDS

digital, SMI, exclusion, health, inequalities

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Background

The covid-19 pandemic has rapidly accelerated the use and adoption of digital technology in health and social care services (1). In addition to video consultations, digital tools in health and care services can also include, the use of apps, wearable devices, smartphones for accessing health information and smart technology (Artificial Intelligence) (2). While there are many potential benefits from increased use of digital tools, including more rapid access to information and personalized care, more control, and empowerment (3), there is also an acknowledged risk of some people being excluded (4).

This is because, despite the pandemic and subsequent increased use of digital tools, 29% of the UK population still has "very low digital engagement (5)." The UK consumer index measures digital engagement through establishing levels of engagement with a range of digital activities. Individuals with "very low digital engagement" are generally not using digital tools such as email. This data is particularly relevant for those with severe mental illness, in light of both the documented benefits of self-management for this population (6), and aspirations for people to manage their own health through the use of digital tools (7). For those who are not able or willing to use digital tools in this way there may be a risk of being digitally excluded and not having the same opportunity (or parity) to utilise the benefits of digital tools for their health.

Digital exclusion could lead to worse health outcomes through both indirect and direct routes (8). Direct routes relate to health services using digital technologies in ways some individuals cannot access and or benefit from. Indirect routes are related to the wider determinants of health, when, for example, housing or employment opportunities, become dependent on digital access routes (8). For people with severe mental illness (SMI), being digitally excluded could exacerbate existing health inequalities. Heath inequalities in people with SMI are driven by factors such as, diagnostic overshadowing (when new symptoms/physical health issues are wrongly attributed to the persons mental health condition), the link between mental illness and poverty, stigma, social isolation and a lack of support to access health and preventative care (9). In England, these inequalities contribute to people with SMI dying on average fifteen to twenty years earlier than the general population. The issue of digital exclusion impacting on people already at increased risk of health inequalities has been described as the "digital inverse care law" with those who most need the benefits that come with digital health tools also being the least likely able to access it (3).

When examining the reasons for digital exclusion, research by Borghouts et al. (10) found that people with SMI can experience additional barriers to engagement with digital tools associated with their mental health condition. For example, symptoms such as fatigue, paranoia and depression can make consistent engagement with digital tools more challenging. This further highlights the importance of exploring and addressing the needs of this population specifically, as they are likely to have different experiences and need a different type of digital support to other groups of people accessing health care.

Berry et al. (11) conducted individual interviews with people living with SMI in 2016 focused on perceptions of self-guided interventions delivered via websites and smartphone apps. Within this research, participants, who reported good levels of digital literacy themselves, expressed concern that there were others who would not have the technology and skills needed to benefit from digital healthcare interventions. This suggests that digital exclusion is an area of importance for this population.

When considering where the gaps in the research are, Helsper (12) concluded that research in to why or how individual's positions around digital exclusion might change is lacking. This was echoed in a scoping review of digital technology and health inequalities (8). This scoping review concluded that there is a need for further research into what factors influence engagement with digital health technology.

In addition, much of the research previously completed in the area of SMI and digital management of health was conducted prior to the covid-19 pandemic. Therefore, considering digital exclusion and health in the context of the covid-19 pandemic is important due to the potential opportunities to use the findings to influence the delivery of mental health care services going forward. Publications such as, "Build back fairer: The covid-19 marmot review" (13) have helped drive an increased recognition of inequalities and the impact of social determinants on health. The Marmot review provides the impetus for services to "do things differently" and "build back fairer" when resuming services post covid. Therefore, this empirical research focused on two key areas, important in supporting mental health services to "build back fairer"; these are;

To understand experiences of digital exclusion and the impact on health in people with SMI.

To explore the influences and mechanisms which would increase engagement with digital health tools.

Materials and methods

Study design

This was an observational qualitative study design. This study utilised focus groups and interviews (14) as a way of eliciting and exploring participants experience of digital exclusion and its impact on health. A qualitative approach was selected as it facilitates an in-depth exploration of participants own behaviour, beliefs and opinions as well as the meaning they attach to their views and experiences (15). Facilitating this was an important aspect of the research, given the hypothesised complexity and nuanced nature of digital exclusion in people living with severe mental illness. In addition, qualitative research is recognised as a valuable method in generating new knowledge in order to enhance evidence based healthcare design (16).

Ethical approval was obtained from University of Southampton, ERGO II number: 66928.There were two members of the research team with lived experience of severe mental illness who acted in an advisory (PPI) capacity. They advised on the research design and participant documents as well as attending the focus groups.

Sampling and recruitment

Participants were recruited via community organisations supporting people with severe mental illness on the Isle of Wight. The researcher contacted organisations *via* email, attaching the approved study advert and participant information sheet. Two organisations responded to say they had participants who would be interested, and the researcher then followed this up with a face to face discussion to talk through the study.

Ten participants consented to participating in the study, nine participants were recruited via one mental health support group and one participant via a mental health focused housing organisation. However, one participant (recruited *via* the mental health support group) did not attend the focus group and did not leave contact details, so the researcher was unable to follow this up. Therefore, nine participants participated in the study. Of these nine participants, four participants stated that they did not feel comfortable communicating about this topic in a group setting. Therefore, these four participants were offered, and completed, an interview instead of attending the focus groups. Of the remaining five participants, four attended two focus groups and one participant, due to ill health, attended only the first focus group.

The eligibility criteria were:

Inclusion	Exclusion
Severe mental illness- “psychological problems that are so debilitating that ability to engage in functional and occupational activities is severely impaired” (9)	Mental illness which does not severely impact on ability to engage in functional and occupational activities.
Self reported digital exclusion and rating themselves with a score of 1–7 on a digital inclusion scale (17)	Self-rating of 8 (confident) or 9 (expert) on a digital inclusion scale (17)
Over 18 Years Of Age	People with moderate/severe/profound cognitive impairment were not included in the study due to the likely impact of this level of cognitive impairment on the use of digital tools.

Screening questionnaire

The digital inclusion scale (17) was used as a tool for screening level and type of digital exclusion (**Supplementary Appendix A**). This scale was chosen due to its simple accessible format and the ability to differentiate between the different levels and types of exclusion. Mental health diagnosis and socio-demographic information (age, gender, education level and employment status) was also collected. This information was collected as it is known to influence digital use.

Procedure

Two focus groups were facilitated by the lead researcher. Focus groups were selected primarily due to findings that focus groups can facilitate the sharing of sincere attitudes and beliefs due to their less formal nature, compared to one-to-one interviews (18). The decision to run two focus groups was made to ensure that participants had long enough to discuss their views but also to mitigate against the potential impact of fatigue. All participants were made aware of the role of the researcher, (employed by Isle of Wight NHS Trust within a mental health clinical improvement role). They were also made aware that this research was conducted through a research initiation award with “Wessex Applied Research Collaboration” with support from University of Southampton.

Each focus group lasted approximately 45 minutes and was held at the community location, in a private space, that participants would usually meet to attend their mental health support group. Five participants attended the first group and four participants attended the second, one participant was not able to attend the second due to experiencing a deterioration in his mental health. Four participants met with the researcher to complete a 1:1 interview, these were offered to be inclusive of those participants who stated that they were not comfortable sharing their experiences in a group setting. The interviews lasted between 10 and 20 minutes and were completed at the location of the community support group ($n = 3$) and at the persons home address ($n = 1$).

The focus groups and interviews followed a topic guide (**Supplementary Appendix B**) which was developed for the study based on a review of the literature (10, 11, 12, 19).The topic guide was also discussed and agreed with the two members of the research team with lived experience of SMI. The first focus group asked participants about their experiences of digital exclusion and how digital exclusion has impacted on their health. The second focus group asked participants to discuss what might have to change in their lives to enable increased use of digital tools and how any support needed in relation to this might be delivered.

Prior to the focus group and interviews starting the lead researcher talked to participants and explained what is meant by the term digital tools and what this can include so all participants were interpreting this term in the same way.

Data analysis

The focus groups and interviews were audio-recorded and transcribed verbatim by the lead author. Thematic analysis, as a six phased method (20), was used as the method for examining the perspectives of the research participants and identifying themes. The data was viewed from an interpretivist standpoint (21).

Following audio transcription, the lead author listened back again to the recording while reading the transcript in order to familiarise themselves with the data. Initial coding was then completed, every line of the data was coded. While acknowledging the active role of the researcher and their epistemological position, social constructionism (21), an inductive approach to coding was taken, driven by the data. The next three steps involved theming the codes, then refining and naming the codes. Several thematic maps were generated as part of this refining process. Peer debriefing (22) was utilised throughout the coding and theming steps, with three members of the research team (NC, RE, LW). Once the themes were identified and named, member checking, checking the preliminary researcher findings and interpretations with the research participants, was completed with eight of the participants in order to generate the final themes and thematic map. Peer debriefing and member checking are recommended steps in achieving trustworthiness when using thematic analysis (22). These steps were also important elements of the process of engaging in reflexivity (23).

Results

Participants' age ranged from 32 to 73 years ($M = 54$, SD = 14.73). As shown in **Table 1**, there were slightly more female participants ($n = 5$;55%) than males. The majority of the sample had a diagnosis of anxiety and/ or depression ($n = 7$; 78%), and no participants were currently working, two participants were employed but signed off sick. The participant's self-reported level of digital inclusion ranged from "never have never will" ($n = 1$) through to "task specific" ($n = 3$).

In relation to digital exclusion and health four key themes were identified: social connectedness, wider determinants of health, negative perception of self and disempowerment. The key themes as well as participants identified factors contributing to digital exclusion and factors which may alleviate the impact of exclusion/promote inclusion are presented in a thematic map (**Figure 1**).

TABLE 1 Participant demographic information.

Demographic Information	Frequency	Percentage
Gender		
Male	4	44%
Female	5	56%
Primary Mental health diagnosis		
Anxiety	4	44%
Depression	2	22%
Panic disorder	1	11%
Hearing voices	1	11%
Borderline personality disorder	1	11%
Employment status		
Sick leave	1	11%
Retired	3	33%
Volunteer	1	11%
Unemployed	3	33%
Student	1	11%
Level and type of digital exclusion		
1-never have, never will	1	11%
2-was online but no longer	1	11%
3-willing and unable	1	11%
4-reluctantly online	2	22%
6-task specific	4	44%
7-basic digital skills	0	0
8-confident	0	0
9-expert	0	0
Additional medical information provided		
Hearing difficulties	2	22%
Autism	2	22%

The key themes and additional factors are elaborated on below, with quotes from the participants. Participants who contributed via the focus groups are recorded as participant numbers 1–6. Participants who inputted via 1:1 interview are recorded as participant letters A-D.

Theme 1. Digital exclusion impacts on social connectedness

Family

Participants all discussed the role and importance of digital tools in connecting with others, in particular family, with one participant explaining how crucial this is:

> *"during two spells in hospital when I had to put things in a bag umm you know like some spare socks and boxers and*

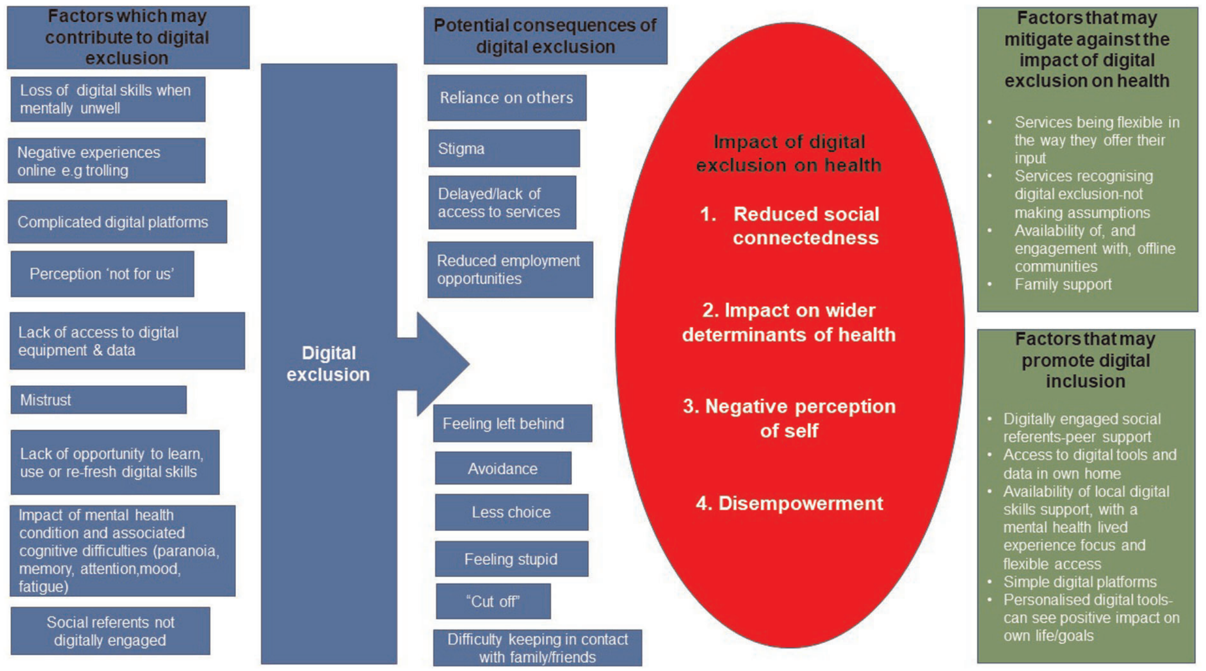

FIGURE 1
Thematic map.

> *things like that to get in the ambulance, I would always make sure I had my phone charger with me … even when so unwell and feeling this is the end of the road now, that went into the bag, because its communication isn't it with your family …"* (Participant 5)

One participant discussed how even experiencing some digital exclusion (not using social media) can make maintaining this connection more challenging:

> *"Umm it makes some communications difficult, like my entire family are on Facebook and I'm not and a lot of them don't live over here so it's harder to keep in touch coz no one wants to go through the effort of a phone call these days"* (Participant A)

Local community

Another participant discussed that not being on social media, makes it more difficult to hear about community events:

> *"… it's good for messages or if you see there's an event, good for that side of it, that's the sort of things you might miss"* (Participant D)

There was agreement across participants that digital inclusion can be important in reducing social isolation and feeling "cut off". Participants expressed that being enabled to have the ability and choice to use digital tools in their own home is an important part of feeling connected to others.

However, in contrast, there was also concern that the accelerated use of digital tools in society is in part to blame for perceived loss of local community infrastructure:

> *"I feel it's a bad thing sometimes … I think you know the high streets disappearing, lots of people are losing their jobs because of the internet …"* (Participant 1)

Society

There was a consensus that being digitally excluded can lead to a feeling of disconnect with wider society:

> *"I think a lot of us we're scared to use technology but at the same time we feel we're being left behind because we're not in that group if you like"* (Participant 1)

However, there was also concern that with increased digital inclusion comes reduced opportunities for face to face contact in society and that this has a negative impact on people with mental illness:

> *"And I know everything seems to be going over to this but I can't really see how it would work really umm it just can't*

> *because we're human beings not a machine and we require reassurance all the time, especially if we've got mental health problems, that's the whole idea of mental health is talking to some body and getting some feedback"* (Participant 6)

Peer support and offline communities

The group placed value on connecting with offline communities, such as their mental health support group:

> *"… Its why this groups so successful, it's not technology its people talking which makes you feel better, it's the personal touch if you know what I mean, you can bounce off each other, you suffer like I suffer and all that but you don't get that, not on the internet I don't think anyway"* (Participant 1)

There also appeared to be a feeling of increased connection from a shared group identity around digital exclusion:

> *"… We're not expected to do something on the computers or on our phones we can just sit with each other"* (Participant 2)

Nearly all participants felt that there was a role in this connection, with others with lived experience of severe mental illness, acting as a potential bridge to increased digital inclusion:

> *"… I don't have many (friends) so their opinions are very valued to me and a lot of them have mental health disorders too, so you know they've been through a lot of the same things as me, and I think if they have positive experiences with it (digital tools) maybe I can"* (Participant A)

This also applied to any potential training courses offered around use of digital tools:

> *"Ideally this person doing the 1:1 will have had depression not just know about it but actually lived it, unless you've actually lived it you don't realise how crippling and restrictive it can be, you know"* (Participant 1)

"you'd feel comfortable with people a bit more like yourself that, you know, know what it's like" (Participant 4)

Theme 2. Digital exclusion and social determinants of health

Participants discussed the affect digital exclusion can have on some of the social, economic and environmental factors which influence physical and mental health and wellbeing.

Employment and benefits

For one participant, not having adequate level of digital skills and appropriate digital equipment impacts on her employment options:

> *"… the technology that I've got moving forward isn't enough … so yeah in that way me moving forward I need that really"* (Participant D)

Limited employment options then exacerbate her financial stress:

> *"I get £57 per week, I'm struggling, (becoming upset) … sorry"*

The participant explained that she has recently had an offer of help from someone in the local community to support her to learn the digital skills she needs and considers this help to be "*a lifeline*".

Another participant explained the challenges associated with applying for benefits without the digital skills needed to use email and how much longer this takes when he has to ask his employer to assist with this.

Housing

One participant explained that not having the digital skills needed to access online services meant that there has been delays in addressing issues with his housing situation, negatively impacting on his mental wellbeing:

> *"I felt err, nothing, I was getting nowhere; nothing was changing and the problem wasn't going away and I was stuck if you like"* (Participant 5)

Access to services

Participants discussed that being digitally excluded has altered the type of health input available to them:

> *"I was once trying for some treatment over the phone, like a consultation you know, health wise, over the phone, not over the phone over the internet and I couldn't cope with it at all, just couldn't cope with it"* (Participant 5)

Participants also discussed how the combination of inaccessible digital platforms and cognitive difficulties associated with their mental health condition (e.g., memory difficulties) can create barriers to access. This has resulted in participants not being able to access services they have needed.

Some participants reported that covid-19 had made access to health services more difficult due to increased use of digital platforms:

> *"And I understand about covid but it is a bit like since covid it does feel a bit like the doctors and mental health services have all gone there you go do it online don't bother us"* (Participant 4)

However, two participants, with hearing difficulties, discussed the potential for digital tools, such as the use of text messaging and emailing, to support improved access to services.

> *"I used to have a support worker but I don't anymore, last month it took me two weeks to phone up the GP surgery for hearing aid batteries, but I did speak to them and explained how anxious I get phoning and they have for the first time ever, I am 42 now and have seen them since I was 4, they have given me an email address that I can contact them on"* (Participant 2)

Offering email as a form of contact, is an example of the potential positive impact the acceleration in adoption and use of digital tools during the covid-19 pandemic can have on health care accessibility. However, participants emphasised that in their experience services are not consistently adopting the flexible and individualised approach needed to facilitate digital inclusion.

Theme 3 digital exclusion can contribute to a negative perception of self

Stigma

Most participants discussed awareness and experience of stigma associated with having a mental illness:

> *"I think the mental health is the Cinderella because people tend to think that we're useless don't they, that we shouldn't be a burden to society"* (Participant 6)

In addition to the stigma associated with mental illness, participants also described experiencing a second layer of stigma associated with digital exclusion:

> *"Maybe there's a bit of a stigma as well where you don't really want to say you don't understand because you feel stupid you know"* (Participant 1)

> *"… everybody's on social media using apps and things like that aren't they? It's literally the simplest thing and it's taken for granted mostly, but when I tell people that I don't have social media they kind of look at me as if I've got two heads or something"* (Participant A)

The impact of this perceived stigma appears to be reinforced by others assuming a certain level of digital inclusion. Participants all expressed experiencing services demonstrating a lack of awareness around digital exclusion:

> *"I think there's far too much assumption by, umm the support, the health support and things that we can all just automatically use technology. I think that seems like a given now, well you just go online … and I'm afraid they have to realise that isn't the case"* (Participant 5)

> *"They take it for granted … they just usually say oh just go on the computer, I haven't got one, oh you know, just go on the internet"* (Participant 2)

Self-esteem

Nearly all participants commented that not having the ability/access to utilise digital tools has impacted on the way they feel about themselves:

> *"I suppose it makes you feel vulnerable using technology that you're not sort of fully or you don't understand it fully"* (Participant 6)

> *"Frustrating, feel as though I'm backward, horrible"* (Participant C)

However, for one participant, coming offline, after negative experiences with online support forums, social media (trolling) and search engines on health anxiety, can have a positive impact:

> *"it's good to have those things limited so I'm exposed to triggers as little as possible … if I'm having a particularly bad mental health day I have to disable the internet on my phone so the temptations not there to make myself worse"* (Participant A)

Social identity

The participants also discussed how not using digital tools can influence how they perceive themselves to be viewed by others and their place in society:

> *"they get frustrated don't they"* (Participant 2)

> *"It's a bit embarrassing as well though isn't it? like you're out of touch, don't you use these things?"* (Participant 2)

> *"you're sorta left behind aren't you"* (Participant 1)

Theme 4. Digital exclusion contributing to a feeling of disempowerment

Self- efficacy

Participants discussed previous attempts to engage with digital tools which had not been successful. They described how this had negatively affected their wellbeing and their motivation to engage with digital tools again in the future. This lack of belief and motivation (self efficacy) in their ability to engage with digital tools, appeared to contribute to a general sense of disempowerment

> *"The very fact that you struggle with technology makes your anxiety even worse in a way, because you're frustrated that you can't do it so you tend to avoid it because you know you're going to get annoyed with it"* (Participant 1)

> *"You just find yourself saying I can't do it…"* (Participant 5)

Self-determination

Participants agreed that digital exclusion can result in a loss of choice and control when accessing health services.

> *"It's a backward step isn't it really… it seems to limit your choices then doesn't it of what sort of help you can get"* (Participant 5)

Some participants felt that their digital exclusion was driven by a lack of opportunity to learn how to use digital tools:

> *"We weren't taught it… we've had to learn it bit by bit and perhaps if you do a job which you have to use a computer there, but otherwise you're left to your own devices aren't you"* (Participant 6)

All recognised that having control and choice over your own level of digital inclusion was important associating digital competence with "power" (Participant 4)

Reliance on others

Many participants highlighted that not having digital skills or access to appropriate digital equipment leads to increased reliance on others, particularly family:

> *"my phone is my brothers ex contract phone, he got a new contract and he gives me his old one, otherwise I wouldn't have one, no way"* (Participant 2)

> *"my mum helps me with it"* (Participant B)

> *"… you have to ask people all the time you know"* (Participant 1)

Sometimes this can be challenging if the person does not have family/friends with the digital skills needed to support:

> *"I don't have anyone else to ask to help me, coz my mum bless her she's useless with technology, I have to help her and I don't know much… but so then sometimes you end up giving up because you're just like, oh no its too much"* (Participant 4)

Two participants discussed the positive impact good digital skills support can have, associating their new skills with a feeling of increased independence.

> *"I've actually got the banking app, only coz my bank were lovely I went in and explained everything and he actually sat down downloaded it with me, it worked, miracle, and then showed me how to use it and everything so I know how to do that now, I'm confident to do that, but that's him taking time out to show me, you don't always find someone"* (Participant 2)

This was in contrast to other experiences of digital support. These were described as disempowering and were characterised by a "one size fits all", rushed approach with digital support being "done to them" rather than with them.

Discussion

The aim of this study was to view the experiences of digital exclusion in people with SMI in the context of health as well as the mechanisms and influences of increased digital inclusion. This study found that digital exclusion can impact on the health of people with SMI both directly and indirectly, through the wider determinants of health. Digital inclusion could be increased through understanding and addressing the complex relationship between digital skills, access to equipment and the role of local community and digitally engaged peers.

Digital exclusion and health

The data and themes from this study highlight the broad and complex relationship between digital exclusion and health. This relationship is particularly pertinent when viewed from a mental health recovery perspective (24). Three of the themes identified in this study, relating to social connectedness, perception of self and empowerment, are viewed as important components of mental health recovery. The acronym CHIME has been used to describe five components of personal (mental health) recovery, connectedness, hope and optimism about the future, identity, meaning in life and empowerment (24). The positive impact of belonging and meaningful connections on wellbeing and mental health in people with SMI was also highlighted by Barut et al. (25).

Participants discussed the value of their links with, and support from, offline communities, which may provide some of this belonging and connectedness and mitigate against the loss of social connectedness arising from digital exclusion. However, even with these offline connections, participants discussed difficulties forming or maintaining other connections when experiencing digital exclusion. The potential for digital exclusion to lead to a feeling of disconnect with wider society was evident through participants conveying a sense of "us and them" when discussing digital use.

In addition, there were concerns from participants that accelerated use of digital tools across society was leading to a loss of community infrastructure. The presence of local community infrastructure is known to be important in fostering a sense of belonging in the community. This has been found to be important in relation to promoting good health and mitigating against conditions such as, stress, depression, addiction, and chronic physical ill-health (26).

This experience of accelerated digital use in society and perceived loss of local community infrastructure, likely exacerbated by restrictions on social contact and mobility during covid-19, may be leading to a sense of mistrust and apprehension about engaging with digital tools. The areas most likely to have seen the loss of community infrastructure are also areas with highest levels of social disadvantage, with southern coastal towns (this study was located in a Southern Coastal town) highlighted as being more likely to have areas of intense social deprivation compared with other parts of the UK (27). This is relevant to this research, given the location of the participants and the relationship between mental illness and poverty (28).

Participants discussed the feeling of stigma that comes from their mental health diagnosis. They also reported an additional layer of stigma attributed to their digital exclusion. The anticipation of discrimination associated with stigma can lead people to use strategies of avoidance and concealment (29). This links with experiences relating to digital exclusion stigma described by participants in this study. For example, the participants talked of being reluctant to tell people they struggle with using technology and avoiding using it. This perceived stigma also appeared to create or exacerbate negative feelings about themselves, arising from not being able to access/use digital tools and the subsequent increased reliance on other people. This is important when considering impact on health, as a good quality of life in people with mental health problems has been found to be characterised by elements including control, autonomy and a positive self-perception (30). In contrast low control is associated with poorer health outcomes (13) and regular experiences of enacted or perceived stigma and self-stigmatising has been found to have a negative impact on areas including engagement with services and self-management (31).

Digital inclusion is one aspect of life, and there are other influences on positive self-perception, belonging and control. However, participants did equate digital skill/access with concepts such as "independence" and "power" while reporting that digital exclusion can result in a loss of choice and increased reliance on others. Therefore, supporting people to be in a position to make informed decisions about their level of digital engagement through addressing barriers could have a positive impact on perceived quality of life and on health more broadly.

Health is also influenced by social determinants and participants in this study discussed the ways in which being digitally excluded can negatively impact on this area. For example, they reported experiencing, delayed, altered or a lack of access to housing, employment, benefits and health services. This supports the model put forward by Davies et al. (3) outlining the ways that digital exclusion both directly and indirectly impacts on health inequalities and arguing for the need for digital exclusion to be recognised as a social determinant of health.

Mechanisms and influences of increased digital inclusion

When discussing factors that may increase engagement with digital tools, participants echoed the need to consider factors identified in previous research such as cognitive difficulties associated with their mental health condition, financial barriers and the complexity of the digital tool (10, 11, 19). In addition to these several other factors were identified, including the importance of access within the local community and the presence and influence of digitally engaged peers.

The experiences and thoughts expressed by participants in this study indicated a strong feeling of connection with others experiencing severe mental illness. This connection appeared key to influencing their possible future engagement with digital tools. Participants talked about the role of others with mental illness delivering digital skills support and the benefits of this in facilitating accessible digital skills support where mental health related reasonable adjustments are built into the design and delivery. Participants also talked about the role of others with mental illness, with higher levels of digital engagement, sharing their positive experiences as being a motivator to increasing their own level of digital engagement.

The importance of social referents supports the findings of Helsper (12) who discussed the importance of social identity and group comparisons in digital inequalities, with some individuals possibly viewing their digital exclusion as "the norm" for them and those they view as their referents. This may then foster a feeling of acceptance of their current situation, reducing the individual's motivation to change. Mental health peer support is a recognised role in NHS mental health services, and there is evidence to support the positive impact this role can have on levels of hope, empowerment and quality of life (32). The provision of peer support in the area of mental health and digital skills support could be beneficial in building on the value of shared social identity as a way of increasing digital inclusion.

Participants stated that health and care professionals do not ask about their level of digital inclusion and as a result often make assumptions of digital access and competence. This may perpetuate a perception of stigma around digital exclusion and suggests that there is under recognition of digital exclusion within services. Recognising and identifying digital exclusion needs is an essential first step in increasing digital engagement.

Participants gave examples of how health services using digital tools flexibly, based on an individuals need, could have a positive impact on access to and engagement with services. For example, the use of text messaging to confirm appointments and or communicate basic health information. However, their experiences suggest that often the availability and implementation of digital tools can be too rigid meaning that the benefits of digital are not accessible to all.

Participants valued local community and connection with others, and described a perception that society's increased use of digital tools/services has contributed to a loss of local community infrastructure. Participants also reported they have not had the opportunity to learn and or maintain digital skills through education or employment. Therefore, local community based digital support services may provide a positive way of reinvigorating local highstreets and fostering a sense of belonging for local people. This could also provide opportunity to learn, refresh and maintain digital skills. The potential for this type of support to have a positive impact was highlighted by one participant who had received beneficial support characterised by "time" and "patience" from a digital support service at a bank. However, choice and control over how and where they use digital tools was seen as important with participants also discussing the need for this to be available in their own homes.

Limitations

This study was a small qualitative study, exploring the experiences of nine people with severe mental illness on the Isle of Wight. The small number of participants, somewhat limits the generalisation of findings across the whole population. However, there was a range of ages represented and mix of males and females. In addition, the findings from this study are in line with findings from other research carried out in the area of mental health and digital exclusion which adds to the validity of the findings.

Nearly all participants were recruited from the same mental health support group. This possibly enabled more open interaction within the focus groups as participants were familiar with each other. However, the homogenous geographical location may have an influence on the experiences of digital exclusion for this group of people.

Some socio-demographic data was collected as part of this research (age, gender, employment status and education level). However, data around housing status and ethnicity was not collected.

This study looked specifically at the experiences of people digitally excluded, therefore it is not possible to draw conclusions relating to which factors in particular lead to some people with severe mental illness being digitally excluded and others not. However, it was noted during this study that none of the participants were currently in full or part time employment (although one person was on long term sick leave). Future research could look to establish the factors which influence digital engagement most within a population.

Further research would also be beneficial in evaluating the delivery of digital support, addressing areas raised in this research, and its impact on an individual's health. This is important in understanding the effectiveness of models for addressing digital exclusion and the impact on health.

Conclusion

This study identified four overarching themes that relate to digital exclusion and health in people with severe mental illness: social connectedness, wider determinants of health, negative perception of self and disempowerment. These themes highlight the relationship between digital exclusion and health and support arguments that digital inclusion should be viewed as a social determinant of health. These themes appear particularly pertinent when viewed in the context of mental health and mental health recovery.

This suggests, that for mental health services, enabling informed choice around digital engagement should be viewed as an important part of their role in promoting good health. Addressing identified barriers to digital inclusion, through considering facilitators to engagement such as; access to local digital skills support with a mental health peer support component, awareness of digital exclusion amongst mental health staff and access to equipment and data. Furthermore, flexible and individualised use of digital tools by services should be viewed as a priority for mental health services.

Data sharing

Access to the underpinning research data set can be obtained by contacting the lead author of the paper.

Data availability statement

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

Ethics statement

This study involving human participants was reviewed and approved by University of Southampton, ERGO II number: 66928. The participants provided their written informed consent to participate in this study.

Author contributions

RM- led on design of study, ethics application, recruitment, led focus groups, led analysis of data and creation of thematic map. Primary author of paper. LW- supported with design of study and ethics application, supported with analysis of data, creation of thematic map and writing of paper. All authors contributed to the article and approved the submitted version.

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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

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fdgth.2022.1004547/full#supplementary-material.

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Exploring social determinants of health: Comparing lower and higher income individuals participating in telepsychiatric care for depression

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Background: Telemental health may increase access to care; there has been little research on efficacy with those at the lower end of the income distribution. The purpose of this study was to determine whether lower vs. higher income patients receiving telepsychiatric care for depression achieve: (1) effective symptom reduction and (2) similar outcomes.

Methods: Data utilized were obtained from a national mental health telehealth company and consisted of 5,426 U.S.-based patients receiving psychiatric care for moderate to severe depression between October, 2018 and January, 2022. Propensity matching was used to create lower and higher income samples (n = 379 in each) using 22 covariates. These samples were then compared using repeated measures ANOVA on Patient Health Questionnaire-9 (PHQ-9) scores at start of treatment, 6, 8, 10, 12, 14, and 16 weeks.

Results: Both lower and higher income groups made significant improvement over time, with groups averaging mild symptom severity by week 16. There was a significant group x time interaction, such that the lower income group had significantly greater depression severity at the last two timepoints.

Conclusion: Lower and higher income groups both made significant improvement in depression symptom severity over time following initiation of psychiatric treatment via a telehealth platform, though higher income individuals, all else being equal besides employment, tend to do better. These findings suggest that when lower income individuals do participate in care, good outcomes can be achieved. Further research is needed to better understand the role social determinants of health (SDOH) play in outcome disparities.

KEYWORDS

social determinants of health (SDOH), depression, antidepressant, low income, SDOH, telepsychiatry, outcome, United States

Introduction

Major depressive disorder (MDD) is one of the most prevalent (1) and consequential health disorders in the country. It is one of the leading causes of disability in the United States, though only about 65% of people with depression receive treatment (2). Due to fewer resources and access, barriers to care may be even greater in lower income patients. It is conceivable that those with lower incomes may lack digital literacy or high-quality internet connection and may further have lower awareness of telepsychiatry.

In general, lower income individuals have worse health and mental health outcomes (3–6). Some have posited this is due to lower medication adherence, greater mistrust of healthcare providers, and lower quality of care (7, 8). While evidence is mounting that digital mental health care options are effective and can help eliminate structural barriers to evidence-based care, (9–19) there is a consensus that more research is needed with respect to providing telemental health services to lower income patients (20).

The goal of the current study is to determine whether lower income patients being treated for depression via a telemental health platform achieve: (1) effective symptom reduction and (2) similar outcomes as higher income patients.

Materials and methods

Participants

Participant data utilized in the current investigation were obtained from a national mental health telehealth company (i.e., Brightside) and consisted of 5,426 U.S.-based adult patients, aged 18 to 80 (mean age = 33.67, sd = 9.72) receiving psychiatric care for depression between October, 2018 and January, 2022. These data were a subset from another study (21) examining the impact of age. Participants were eligible if they (a) were diagnosed with Major Depressive Disorder by their provider (b) had moderate to severe symptom severity at intake (PHQ-9 $\geq$ 10) (c) had complete income data, (d) were prescribed at least one psychiatric medication (described below), and (e) had complete outcome data. Patients at high risk for suicide, and patients with psychosis or in need of emergency psychiatric services at the initial evaluation were not eligible.

Procedure

All study procedures were approved by the WCG Institutional Review Board for the retrospective analysis of patient data obtained by Brightside as part of routine clinical care. Enrolled Brightside patients complete an initial digital intake that includes clinically validated measures of depression and anxiety, as well as questions about clinical presentation, medical history, and demographics. All Brightside patients are required to complete baseline and intake questionnaires. During a patient's first session, a licensed professional prescribed psychiatric medication(s) for each patient. Over the course of treatment, patients communicated with their provider both asynchronously via messaging and synchronously via video telehealth sessions. Brightside also uses a measurement-based approach to tracking long-term outcomes by prompting patients to complete periodic assessments during treatment. Assessments were completed at baseline/intake, and periodically thereafter. Surveys were administered digitally through an email prompt. Survey completion at baseline, 6 weeks, 8 weeks, 10 weeks, 12 weeks, 14 weeks, and 16 weeks were required for participation.

Measures

The Patient Health Questionnaire-9 (PHQ-9) is a 9-item self-report measure used to assess the severity of depressive symptoms present within the prior 2-weeks as outlined by DSM-5 criteria. Respondents rate items on a 4-point Likert scale (0-3) and total scores range from 0 to 27, with >9 indicating mild-to-low symptoms and 10 + indicating moderate-to-severe symptoms (22). Sample items include: "Little interest or pleasure in doing things," and "Feeling down, depressed, or hopeless." The PHQ-9 shows strong reliability, demonstrating 88% sensitivity and 88% specificity for Major Depressive Disorder (22). There is also evidence that the PHQ-9 can be used as a measure of antidepressant response (23). It has demonstrated reliability and validity across various cultures and settings (24–26). PHQ-9 scores were collected via self-report electronically at baseline, and at weeks 6, 8, 10, 12, 14 and 16 and served as the outcome measure of interest. As part of the PHQ-9, patients were asked to what extent, if they scored >0, these problems have made it difficult for them in four areas – social, family, work, and activities, on a scale from 0 to 3, with 0 indicated "not difficult at all," 1 – "somewhat difficult," 2 – "very difficult," and 3 – "extremely difficult" (27). These were summed to create a measure of the functional impact of depression (27).

The GAD-7 is a 7-item self-report measure of Generalized Anxiety Disorder (GAD) symptoms with a four-point Likert scale and a total score ranging from 0 to 21. Sample items include: "Feeling nervous, anxious or on edge," and "Trouble relaxing." Like the PHQ-9, a higher score corresponds to a greater anxiety severity. The GAD-7 has good psychometric properties with 89% sensitivity and 82% specificity for GAD (28, 29). It was included in this study to equate groups on anxiety severity.

Other standard demographic, health, and clinical information was also collected at baseline, such as age, sex, education, race/ethnicity, employment status, census-based geographic region of the country, prior episodes of depression (none, one, or more than one), duration of the current episode, any prior mental health treatment (yes/no), primary non-mood symptom complaint (agitation, concentration, motivation, sleep, none), frequency of social media use from 0 to 4 (i.e., never, rarely, several times/week, once/day, several times/day), current participation in concurrent psychotherapy, frequency of technology use on a scale from 0 to 4 for personal (non-work) use (e.g., phone, tablet, computer, gaming console), and total number of chronic health conditions endorsed (including arrhythmia, asthma, cancer. hypercholesterolemia, diabetes, heart condition, irritable bowel syndrome or Crohn's disease, lung disease, obesity, thyroid disease, eating disorder, and chronic pain/fibromyalgia).

Interventions

Because this is a naturalistic sample, participants were prescribed a variety of medications. The most commonly prescribed medication category of the sample (61.5%) was selective serotonin reuptake inhibitors (SSRIs), followed by norepinephrine and dopamine reuptake inhibitors (NDRIs, 20.7%), serotonin-norepinephrine reuptake inhibitor (SNRI, 5.5%), trazodone (or trazodone + SSRI) (4.9%), SSRI and NDRI combination (4.4%), mirtazapine (or mirtazapine + SSRI) (1.5%), and atypical antipsychotics and SSRI combination (1.5%). The dosage of index antidepressants remained relatively consistent throughout the study period and were prescribed in standard therapeutic ranges. Dosage adjustments were made based on participant responses to the PHQ-9 and other assessments, as well as virtual visits between participation and providers. Because specifics about treatment were not the focus of this study and because this was a naturalistic study, medications and dosages were not controlled and therefore varied to meet individual needs. 26% of the sample was concurrently engaged in psychotherapy.

Data analyses

Data analyses were performed via SPSS, Version 28. Two income-defined groups were created, one group with annual incomes below $30,000 and one group with annual incomes above $60,000. Comparisons between groups were made using t-tests for continuous variables and chi-square analyses for categorical and evaluated at $p < 0.01$. Propensity-matching of the two groups using 0.0009 caliper was done based on *a priori* variables collected at baseline that might potentially affect outcome (30). This approach attempts to replicate a randomized trial by obtaining treatment groups with similar distributions of known covariates (31). Included variables were: age, sex, race/ethnicity, education level, employment status, census-defined region of the country, primary non-mood symptom complaint (agitation, concentration, motivation, sleep, none), past/present use of antidepressant medication, history of any prior mental health treatment, total number of chronic medical conditions (arrhythmia, asthma, cancer, hypercholesterolemia, chronic pain, diabetes, fibromyalgia, heart condition, irritable bowel syndrome/Crohn's disease, lung disease, thyroid disease, obesity), current smoker, prior depression (yes/no), duration of depression, baseline depression and anxiety symptom severity, functional impact of depression rating at baseline, frequency of social media use from 0 to 4 (i.e., never, rarely, several times/week, once/day, several times/day), current participation in concurrent psychotherapy, and frequency of technology use on a scale from 0 to 4 for personal (non-work) use (e.g., phone, tablet, computer, gaming console). Repeated measures analysis of variance (ANOVA) was used to compare the groups over time (at baseline, and at weeks 6, 8, 10, 12, 14, and 16) on total PHQ-9 scores over time. Mauchly's test was used to test the sphericity assumption, with the Greenhouse–Geisser correction (32) used for violations.

Results

In the entire sample, there were 3,186 individuals in the higher income group and 2,240 in the lower income group. Besides income, these groups differed significantly on several variables. The lower income group had significantly more severe depressive symptoms at baseline, $t = 14.40$, more severe anxiety symptoms at baseline, $t = 7.69$, greater reported functional impact of depressive symptoms, $t = 7.26$, fewer average number of chronic medical conditions, $t = 4.51$, and was significantly younger than the higher income group, $t = 35.90$, all $p < 0.001$. The lower income group also had a greater proportion who were female, $\chi^2 = 30.29$, $p < 0.001$, less degree of education/number of graduate degrees, $\chi^2 = 1112.68$, $p < 0.001$, greater number of minorities, $\chi^2 = 73.67$, $p < 0.001$, more people who were unemployed, $\chi^2 = 1642.97$, $p < 0.001$, fewer who had had one prior depressive episode, $\chi^2 = 43.61$, $p < 0.001$, fewer who had had prior mental health treatment, $\chi^2 = 13.43$, $p < 0.001$, longer duration of depression, $\chi^2 = 117.29$, $p < 0.001$, more people endorsing motivation/low energy, $\chi^2 = 10.02$, $p = 0.002$, fewer people endorsing agitation, $\chi^2 = 33.61$, $p < 0.001$, more who endorsed smoking, $\chi^2 = 67.58$, $p < 0.001$, fewer people currently receiving psychotherapy, $\chi^2 = 82.50$, $p < 0.001$, more people endorsing technology use multiple times per day, $\chi^2 = 173.50$, $p < 0.001$, and more people endorsing social media use once per day, $\chi^2 = 34.07$, $p < 0.001$. The two income groups did not significantly differ on region of the country, or endorsement of sleeping or concentration difficulties. Please see **Table 1** for a summary of the initial sample.

A repeated measures analysis of variance (ANOVA) comparing the lower and higher income groups on depression severity across time revealed that PHQ-9 scores differed

TABLE 1 Characteristics of lower and higher, entire sample (*N* = 5,426).

Characteristic	Lower income	Higher income	t or χ^2	Effect size[a]	*P*-value
Age	28.59 (8.25)	37.24 (9.06)	35.90	8.73	<0.001
Sex			30.29	0.08	<0.001
Male	27%	35%			
Female	73%	65%			
Education:			1, 112.68	0.45	<0.001
No high school	3%	0.1%			
High school diploma	49%	14%			
Some college	14%	11%			
College degree	27%	44%			
Graduate degree	7%	31%			
Race/Ethnicity			73.67	0.12	<0.001
White/Caucasian	73%	81%			
Asian	4%	4%			
Hispanic	11%	6%			
Black/African American	5%	5%			
Other	7%	4%			
Employed			1, 642.97	0.55	0.000
Full time	31%	85%			
Part time	26%	3%			
Unemployed	43%	12%			
Region of the country			8.84	0.04	0.03
Midwest	15%	13%			
Northeast	17%	20%			
South	40%	39%			
West	28%	28%			
Prior episodes of depression			43.61	0.09	<0.001
None	40%	37%			
One	9%	14%			
More than one	51%	49%			
Prior mental health treatment	25%	29%	13.43	0.05	<0.001
Number of chronic medical conditions	0.53 (0.85)	0.64 (0.89)	4.51	0.87	<0.001
Baseline PHQ-9	19.11 (4.24)	17.43 (4.22)	14.40	4.23	<0.001
Baseline GAD-7	15.14 (4.56)	14.14 (4.80)	7.69	4.70	<0.001
Functional impact total	9.95 (1.93)	9.54 (2.08)	7.26	2.02	<0.001
How long depressed			117.29	0.15	<0.001
Less than 2 weeks	<1	%1%			
2 weeks to 2 months	10%	13%			
2 months to 1 year	24%	32%			
1 to 2 years	16%	18%			
More than 2 years	50%	36%			

(Continued)

TABLE 1 (Continued)

Characteristic	Lower income	Higher income	*t* or χ^2	Effect size[a]	*P*-value
Primary non-mood symptom					
Sleep	5%	5%	0.02	0.00	0.88
Motivation/Low Energy	37%	32%	10.02	0.04	0.002
Agitation/Irritability	9%	15%	33.61	0.08	<0.001
Concentration	5%	7%	5.53	0.03	0.02
None	<1%	<1%	0.16	0.01	0.69
Current smoker	15%	8%	67.58	0.11	<0.001
Current treatment			82.50	0.12	<0.001
Medication	80%	70%			
Medication + Therapy	20%	30%			
Frequency of technology use, 0-4			173.50	0.18	<0.001
Seldom, Never	2%	3%			
Rarely	5%	11%			
Few times/Week	13%	21%			
Once/Day	17%	19%			
Multiple times/Day	63%	46%			
Social media use, 0-4			34.07	0.08	<0.001
Seldom, Never	8%	9%			
Rarely	14%	18%			
Few times/Week	10%	11%			
Once/Day	63%	55%			
Multiple times/Day	5%	7%			

[a] Effect sizes are Cohen's d for continuous variables and Cramer's V for categorical variables. Effect sizes are interpreted as small (0.2), medium (0.5), and large (0.8) (38).
Mean values are presented for continuous variables (with standard deviations in parentheses) and frequency counts are presented (with%) for categorical variables.

significantly across time, $F = 4913.54$, $p < 0.000$, $\eta^2 = 0.48$, such that scores significantly decreased over time. There was no significant group x time interaction, $F = 1.53$, $p = 0.17$, $\eta^2 = 0.000$, though the low income group reported significantly greater depressive symptom severity overall, $F = 149.69$, $p < 0.001$, $\eta^2 = 0.03$. Please see **Figure 1** for an illustration of these results.

Due to the many differences between groups at baseline, propensity matching was used to create matched groups with 379 in each group. Despite matching, the groups still significantly differed on employment, $\chi^2 = 59.83$, $p < 0.001$, such that the lower income group had fewer fully employed individuals. There were no other differences between the groups on assessed variables. Repeated measures ANOVA comparing the lower and higher income groups on depression severity across time revealed that PHQ-9 scores differed significantly across time, $F = 696.88$, $p < 0.001$, $\eta^2 = 0.480$, such that scores significantly decreased over time. There was a significant group x time interaction, $F = 7.43$, $p < 0.007$, $\eta^2 = 0.01$, such that the lower income group had significantly greater depression severity over time at the last two timepoints. Please see **Figure 2** for these results. As can be seen in **Figure 2**, both groups had PHQ-9 scores less than 10 by week 10 and beyond.

Discussion

This study demonstrates that individuals with both lower income (i.e., below $30,000 per year) and higher income (i.e., above $60,000 per year) receiving completely virtual treatment for major depression achieve significant symptom reduction across 16 weeks, going from a moderate to severe level of symptom severity to a level considered mild (22). While there may be an assumption that lower income individuals will not benefit from telepsychiatry services due to poorer access, this assumption must be tested by distinguishing between access and outcome. Contrary to this assumption, in the current sample of individuals being treated for depression by a national mental health telehealth company, the lower income group reported using technology (e.g., phone, tablet, computer, and gaming console) more than the higher income group. It is unclear why that may be the case, but the greater rate of unemployment

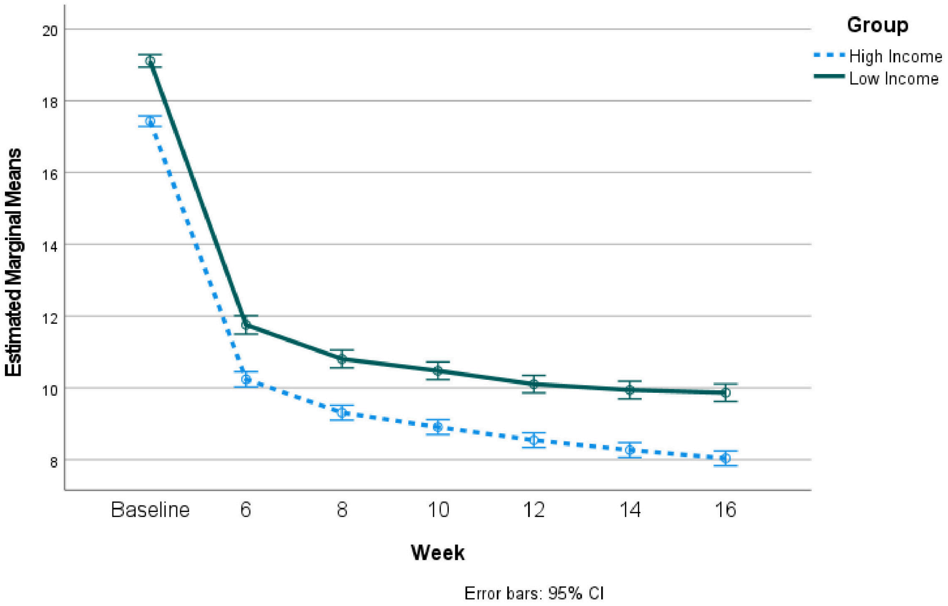

FIGURE 1
Repeated measures results comparing depression severity over time during telepsychiatry treatment for high vs. low income groups: Non-matched groups.

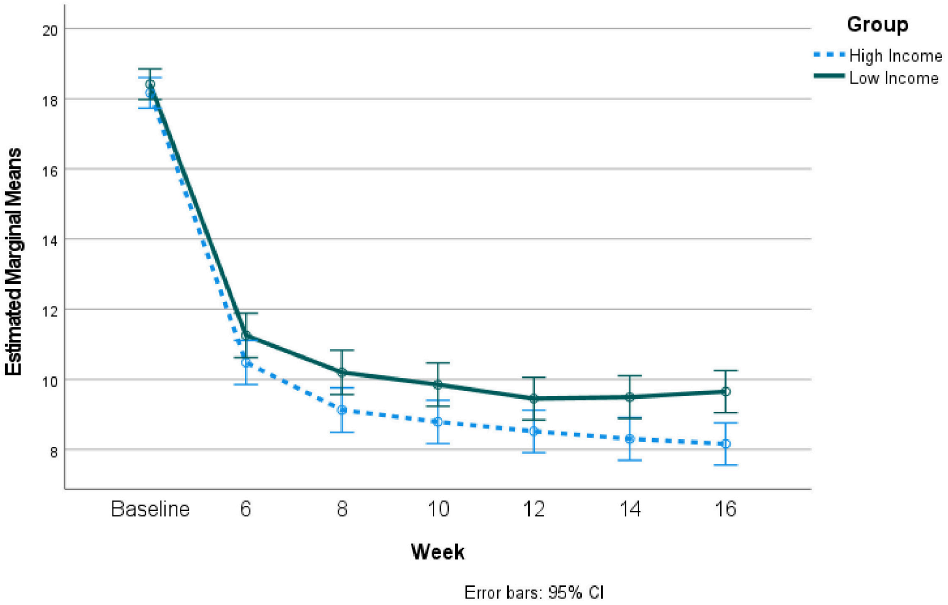

FIGURE 2
Repeated measures results comparing depression severity over time during telepsychiatry treatment for high vs. low income groups: Propensity-matched groups.

among the lower income group may provide them with more time. Notably this is a group of individuals who elected to pursue telemental health platform for their care, so this particular group of lower income individuals were obviously able to access it, which may not be the case for some (33). However, a recent study, in accordance with this sample, found that people with lower incomes (less than $25,000 annually) were more likely to use telehealth services during the pandemic than people with higher incomes (34) suggesting that telehealth increases access for lower income individuals. Given that this study was conducted during the pandemic, the results may have altered the proportions of low vs. high income individuals accessing these services, though it is impossible to know with certainty.

Despite both groups showing significant improvement over time, the higher income group showed significantly greater improvement in the latter time periods, relative to the lower income group. There is very little research on efficacy of telemental health with lower income individuals. Studies of depression treatments conducted with lower income, homebound older adults, have demonstrated efficacy in reducing both depression and disability among disabled older adults (35–37), though these studies did not compare lower with higher income individuals. Further research is needed to better understand the role social determinants of health (SDOH) play in outcome disparities. For example, medication adherence was not addressed by this study and may be explanatory, as just one possibility. A prior study (21) using some of the same participants suggested no difference in outcome based on age. This study, in contrast, suggests that unlike age, socioeconomic status may affect outcome. A trial with only low-income individuals, randomized to different levels of intensity, therapeutic approach, etc., might elucidate ways to improve outcomes for lower income individuals.

Limitations of this study include selection bias, such that results may not apply to all adults. Conceivably those who opt into treatment by a telemental health provider are inherently more comfortable with technology and may therefore be in a better position to benefit from it. In addition, this study lacked a control condition not receiving care, preventing any comparative conclusions regarding the effect of treatment. Additionally, the number of asynchronous and synchronous messages was not controlled which could have impacted results.

In conclusion, lower and higher income groups both made significant improvement in depression symptom severity over time following initiation of psychiatric treatment via a telehealth platform, though higher income individuals, all else being equal besides employment, tend to do better. Further research is needed to better understand the role social determinants of health (SDOH) play in outcome disparities, as well as how best to increase access and engagement among lower income individuals.

Data availability statement

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

Ethics statement

The study involving humans were reviewd and approved by the WCG Institutional Review Board for the retrospective analysis of patient data obtained by Brightside as part of routine clinical care. The ethics committee waived the requirement of written informed consent for participation.

Author contributions

HB contributed to the manuscript development, writing, and analyses. MW contributed to the manuscript development and writing. Both authors contributed to the article and approved the submitted version.

Conflict of interest

HB and MW were employees and partial owners of Brightside Health Inc.

Publisher's note

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Modeling the impact of digital readiness in recruiting and sustaining underrepresented groups: Data from the *All of Us* research program

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The All of Us Research Program (*All of Us* or Program) is an ongoing longitudinal data collection operated by the National Institutes of Health (NIH). The Program aims to improve healthcare for all through the development of a biomedical research resource reflective of the diversity of the United States that includes Underrepresented in Biomedical Research (UBR) groups. Federally Qualified Health Centers (FQHCs) are a key recruitment stream of UBR participants, which are community based and provide primary care and preventive services in medically underserved areas. Over 90% of FQHC patients enrolled in *All of Us* to date are UBR. The COVID-19 pandemic caused a pause in *All of Us* activities. Re-starting the activities was a challenge, especially due to the digital divide faced by FQHC participants, and that most Program activities are primarily completed *via* web-based portal from a computer or a mobile device. This paper investigates the extent to which digital readiness impacted recruitment and sustainment of a pre-pandemic sample of 2,791 FQHC participants to the Program. Digital readiness was defined by access to home-based or other internet-accessing devices, and participants' comfort level using such devices. Results from multivariable logistic regression models showed that lower age, more education, female gender identity, and higher income were associated with higher digital readiness ($p \leq 0.01$). Race, rurality, and sexual orientation status were not significant factors associated with digital readiness. Older participants had higher odds of completing Program activities, even though less digitally ready than their younger peers, as they often completed the activities during their in-person clinical visits. A subsequent weighted model demonstrated that FQHC participants who were digitally ready had 27% higher odds of completing Program activities than those not digitally ready. The data highlight the need for improved connectivity and sustainment between longitudinal data collection, research programs, and UBR participants, particularly among those facing the digital divide. Quantifying digital challenges provide operational insights for longitudinal data collection (*All of Us*, or others), and broadly, other aspects of digital medicine such as telehealth or patient portals by recognizing digital readiness of participants and patients, and the level of support required for success.

KEYWORDS

longitudinal data collection, underrepresented in biomedical research (UBR), national institutes of health (NIH), diversity, *All of Us* research program, healthcare, health disparities, health equity, digital readiness

1. Introduction

The *All of Us* Research Program (*All of Us* or Program) is an ongoing longitudinal data collection operated by the National Institutes of Health (NIH) to collect lifestyle, health, socioeconomic, environmental, and biological data from 1 million United States-based participants (1). Diversity is a core tenet of the Program, which aims to ensure those who are typically Underrepresented in Biomedical Research (UBR) are the majority of those enrolled and retained (2).

The Program has defined specific UBR categories that include racial identity, age when consented to Program participation, biological sex at birth, sexual orientation, gender identity, income, educational attainment, access to care, disability and rurality. Three site types are responsible for enrolling and retaining these participants: Regional Medical Centers, Veterans Administration Medical Centers, and Federally Qualified Health Centers (FQHCs). FQHCs are a key recruitment stream of UBR participants and are centrally coordinated and supported by The MITRE Corporation (MITRE) (3). FQHCs are community based and provide primary care and preventive services in medically underserved areas regardless of ability to pay (4). Over 90% of the FQHC patients are low income, over 80% are publicly insured or uninsured, and the majority are members of racial and ethnic minority groups (5). Individuals and families served by FQHCs are among the most economically vulnerable in the nation and often have complex health and social challenges. Enrollment activities for the Program are primarily completed *via* a web-based portal from a computer or a mobile device. Therefore, digital readiness plays a key role in the FQHC *All of Us* team's ability to enroll and retain participants in the Program. Barriers for utilizing digital devices among patients at FQHCs include cost and lack of information, access to technology, and broadband connection. Digital health device adoption at FQHCs requires education, investment, and high-touch methods (6).

While the Program intends to ensure enrichment of UBR populations, historically the recruitment of UBR populations (particularly racial and ethnic minorities, and low-income communities) to clinical studies is largely viewed as a challenge (7). For example, where race and ethnicity are concerned, though African Americans and Hispanics represent 13% and 16% of the United States population, respectively, only 5% of clinical trial participants are African American and 1% of participants are Hispanic (8). Socially and economically disadvantaged groups are least likely to have access to a smartphone, computer, home broadband, or internet. For example, a 2021 study published by the Pew Research Center found that 13% of low-income adults do not have access to a smartphone, computer, or home broadband, in comparison to 1% of those with incomes over $100,000 (9). Populations that discontinue internet use due to cost and disability are more likely to be Hispanic, Black, or low income. Telemedicine is also less adopted by UBR groups, including those who are older, are racial and ethnic minorities, have a rural residence, and are publicly insured (10). A Brookings Institute report published in 2020 found that, when examining the issue by income groups, 38% of households earning less than $20,000 lack a broadband subscription (11). This is a typical manifestation of the digital divide, defined as the gap between those who have and those who do not have access to information technology. Digital exclusion can limit participation in clinical research studies, innovative clinical trial design, and the collection of patient-reported outcomes. Furthermore, while digital exclusion is concentrated among the poorest, least educated, disabled, and socially isolated, these groups also gain less benefit from the use of digital technology in their health outcomes than do their more privileged peers. In this manner, digital exclusion compounds poor health outcomes, and is now termed a new social determinant of health (12–16).

This paper investigates the extent to which digital readiness impacts recruitment and sustainment of participants to the Program who are patients at FQHCs, particularly among UBR groups. Analyses contained in this paper provide operational insights for NIH, healthcare providers, and researchers on developing and adopting a digital inclusion-informed strategy that recognizes the digital readiness of participants and patients, and the level of staff support required for a broad range of activities, such as recruiting for longitudinal data collection and studies, telehealth, telemedicine, or patient portals.

2. Methods

The analyses utilize quantitative data on adult FQHC patients who are *All of Us* participants; data are housed at the Data and

Research Center (DRC) Program Data Repository. The DRC is located at Vanderbilt University Medical Center and is funded by the NIH Program (17). Quantitative data used in this paper include participant demographics, *All of Us* operational data, and a participant survey questionnaire called the Minimum Common Metrics (MCM) collected by the following six FQHCs from across the country that reflect the diversity of the United States: Community Health Center, Inc. located in Connecticut; Cherokee Health Systems located in Tennessee; Cooperative Health located in South Carolina; Jackson-Hinds Comprehensive Health Center located in Mississippi; Sun River Health located in New York, and San Ysidro Health located in California. Two additional FQHCs located in Hawaii and Puerto Rico have since been added in 2021 and 2022, respectively. These two FQHCs had not begun collecting MCM data at the time of writing this paper and are therefore excluded from the analysis.

On March 16, 2020, NIH paused in-person Program activities to assist in preventing the spread of COVID-19 (23). UBR participants were disproportionality impacted during the COVID-19 pause of in-person activities. FQHCs adopted virtual strategies using Computer Assisted Telephone Interviewing (CATI), which was launched by *All of Us* in January 2021. CATI has presented a new opportunity for FQHCs to contact participants *via* phone and record participant responses to surveys in real time. Follow-up research is underway to characterize the *All of Us* participants who utilized CATI at FQHCs as well as to explore the relationship between retention activities *via* CATI and UBR status. The quantitative data collection methods were performed in accordance with relevant guidelines and regulations and approved by All of Us Research Program Institutional Review Board (IRB00010472). The participants included in this paper have provided consent to having their data used for research. All data used were derived from participants who provided written consent on or before April 28, 2022, which is the freeze date for the dataset used in this study. Variables in the dataset are described in the sections below.

2.1. Participant demographics and recruitment data

Participant demographics include data that the Program considers for determining UBR and are collected from FQHC patients at the time of registration. They include racial identity, age when consented to Program participation, biological sex at birth, sexual orientation, gender identity, income, educational attainment, and rurality at the time of writing this paper. Participants are considered UBR if one or more of the definitions provided in **Table 1** is true.

Recruitment data include participants who are considered retained per the Program definition at the time of writing this paper, by completing the activities outlined in **Table 2**. In *All of Us*, retained participants complete follow-up surveys at least once every 18 months after their enrollment. In this context, retention provides a measure for the ability of the FQHCs to sustain engagement with participants after recruitment to the Program. All activities, except submitting bio samples to the Biobank, are completed by participants on a web-based portal when they come in-person to the FQHCs or virtually from a computer or a mobile device.

TABLE 1 *All of Us* definitions for participants that are Underrepresented in Biomedical Research (UBR).

UBR Category	Program Definition for UBR
Racial identity	Participant has identified as other than White. Also includes participants who self-identify as Hispanic, Latino, or Spanish
Age at consent	Participant is 65 years or older when they consented to Program participation
Sex at birth	Participant self-reports intersex as their biological sex at birth
Sexual orientation	Participant selects any sexual orientation choice other than straight
Gender identity	Participant selects any gender identity choice other than man or woman
Income	Participant's annual household income is less than $25,000 a year
Educational attainment	Participant does not have a high school diploma or General Educational Development (GED)
Rurality	Participant is a resident of an established rural and non-metropolitan ZIP code, based on the Health Resources and Services Administration Federal Office of Rural Health Policy data files

2.2. Minimum common metrics data

MCM is an Institutional Review Board (IRB)-approved questionnaire collected by FQHCs for MITRE. It contains participant responses on their enrollment experience, digital readiness, access to a fitness tracker, and level of FQHC staff assistance required for completing *All of Us* activities. Answers to these questions are collected throughout the participant journey (**Table 2**), with a goal of understanding FQHC participant experiences and resources available for them to participate in the Program. **Table 3** provides all questions asked of participants in the MCM data at the time of writing this paper. The MCM survey questions were asked by FQHC staff to all participants at their time of enrollment in *All of Us*. However, per the IRB requirements, participants were given a choice to decline responding to the MCM survey entirely or skip any of the questions. A subset of responses to the MCM questions that pertain to participants' digital readiness were used in the analysis contained in this paper.

TABLE 2 Required Actions to be Completed by the Participant in the *All of Us* Research Program.

Action	Activity Type
Create an account (i.e., *has a participant ID*)	Enrollment
Consent to program participation	
Consent to EHR data sharing	
Complete the Basics Survey	
Complete the Overall Health Survey	
Complete the Lifestyle Survey	
Have Biobank receipt of sample (blood, urine or saliva)	
Complete Physical measurements	
Complete the Social Determinants of Health Survey	Retention
Complete the Health Care Access Survey	
Complete the Family Health Survey	
Complete the Medical History Survey	
Complete the COVID-19 Participant Experience Survey (*retired in 2021*)	
Consent to return of genetic results	
Update consent for Program participation	
Complete the Minute Survey on COVID-19 Vaccines (*retired in 2022*)	

2.3. Qualitative data from FQHCs

In addition to quantitative data described in the previous sections, the MITRE team engaged the FQHC staff to collect qualitative data about their experiences and strategies in engaging population groups for retention activities. The MITRE team held a focus group with the FQHC staff in June 2022 to gather inputs. *All of Us* staff members from all six FQHCs participated in the focus group. Focus group discussion included open-ended conversations on the following topics: strategies FQHCs used to retain participants with low digital readiness into *All of Us*, and data sources FQHCs utilized to be better informed and to develop strategies for engaging population groups with low digital readiness. The discussions were focused on pre-pandemic scenario, given the scope of this paper. The MITRE team recorded the conversation upon consent from the FQHC staff members participating in the meeting and transcribed notes summarizing the conversations. Information collected from these questions were analyzed alongside quantitative results to develop insights on whether specific population groups that the model found significant for indicating low digital readiness influenced the FQHC engagement strategy.

TABLE 3 FQHC MCM questionnaire.

Category	What Is Asked
Enrollment Experience	•How did you first hear about the Program? •What would you say is your main reason for wanting to join the Program? •Research assistant created email account to enroll (*filled out by FQHC staff member*)
Digital Readiness	•Do you have access to a computer, tablet, or mobile phone at home? •Do you have access to the internet through Wi-Fi or mobile data at home? •How comfortable are you using technology, such as navigating emails, answering survey questions, or navigating a patient account portal?
Fitness Tracker Access	•Do you have a fitness tracker (such as a FitBit, an Apple Watch, an app on your phone, etc.)? •[If yes] Have you linked/connected your fitness tracker to the *All of Us* Research Program Portal?
Level of FQHC Staff Support (*filled out by FQHC staff member; answer choices: assisted, facilitated, independent on-site, independent off-site, assisted virtual, facilitated virtual)*	•Level of FQHC staff support required to complete consent form for Program participation •Level of FQHC staff support required to complete consent form for EHR data sharing •Level of FQHC staff support required to complete consent form for return of genetic results •Level of FQHC staff support required to complete various required participant surveys

2.4. Study population

The study population included 2,897 *All of Us* participants who responded to questions on digital readiness (three questions, Table 3) for the time-period between June 2019 and March 2020 when they completed required actions to become an enrolled participant (Table 2). This time-period was selected based on when the digital readiness questions were first asked by FQHCs (June 2019) to newly enrolled participants until the start of the COVID-19 pandemic (March 2020). The COVID-19 pandemic significantly changed the operational workflow at the FQHCs when NIH paused in-person *All of Us* activities. Therefore, data collected during the COVID-19 pandemic were not included in this analysis. Demographic variables, retention data, and participant responses to the MCM technology access questions were additional fields associated with the participants in the study sample.

2.5. Analytical methods

For purposes of this study, digital readiness was defined by access to home-based or other internet-accessing devices (computers, tablets, mobile phones, and other devices) and participants' comfort level using such devices. Responses to the three MCM technology access questions shown in **Table 4** were utilized to define digital readiness. Participants who skipped or selected the "Prefer not to answer" option to any of the three questions were excluded from the analytic sample within the study time-period range since it was not possible to infer the digital readiness disposition for these participants. This reduced the final analytic sample from 2,897 to 2,791 participants. FQHC participant demographic distributions of those included in the analytic sample were compared with those who were excluded from the study sample to verify that the analytic sample was not a biased set relative to the larger FQHC *All of Us* population. All analyses in this paper were conducted using R and RStudio (18, 19). Any group with less than 20 participants were included in "Other" group to stay consistent with the Program data suppression levels to support data privacy.

Participants who responded with a "Yes" or "Intermittent" to Questions 1 and 2, and "Very comfortable," "Somewhat comfortable," or "Neutral" to Question 3 were considered as digitally ready and transformed as such in the analytical data set. Participants who responded with a "No" to Questions 1 or 2 or "Somewhat uncomfortable" or "Not at all comfortable" to Question 3 were considered as not digitally ready and transformed as such in the analytical data set.

TABLE 4 Answer choices for the MCM technology access questions.

Question #	Question Wording	Answer Choices
1	Do you have access to a computer, tablet, or mobile phone at home?	☐ Yes ☐ Intermittent ☐ No ☐ Prefer not to answer
2	Do you have access to the internet through Wi-Fi or mobile data at home?	☐ Yes ☐ Intermittent ☐ No ☐ Prefer not to answer
3	How comfortable are you using technology, such as navigating emails, answering survey questions, or navigating a patient account portal?	☐ Very comfortable ☐ Somewhat comfortable ☐ Neutral ☐ Somewhat uncomfortable ☐ Not at all comfortable ☐ Prefer not to answer

Retention data was transformed into a Boolean (1 or 0) variable, which was equal to 1 if the participant had ever been retained by completing the required activities outlined in **Table 2** at some point during their involvement in the Program, and a 0 if the Participant was never retained because they did not complete any of the required activities since becoming an enrolled Participant during the study period.

2.5.1. Characteristics of digitally ready groups in the program at FQHCs

The characteristics of the *All of Us* groups that are digitally ready (vs. not digitally ready) at FQHCs were explored using a multivariable logistic regression model (Model 1) with UBR variables of racial identity, age at consent, sex at birth, sexual orientation, gender identity, income, educational attainment, and rurality.

2.5.2. Digital readiness impact on the retention of participants in the program at FQHCs

The effect of digital readiness on retention was measured using a second multivariable logistic regression model (Model 2). Inverse probability of treatment weights (IPTW) propensity score methods were used to create a weighted synthetic population. IPTW utilizes propensity scores to balance baseline characteristics in exposed and unexposed groups. Applied to the current study, IPTW balances UBR characteristics in the digitally ready and not digitally ready groups, therefore minimizing the impact of confounding due to those measured UBR characteristics (20). With this approach, one cannot attribute differences in retention outcomes due to differences in UBR characteristics between individuals who are digitally ready and those who are not digitally ready.

UBR variables significant at the 0.05 level from Model 1 were used in the propensity score model. Multivariable logistic regression was used to model participants' probability of retention as weighted by the previously described IPTW. Propensity score modeling was conducted using the WeightIt and Survey R packages (21, 22). Results from both weighted and unweighted models are included in the results.

3. Results and discussion

3.1. Digital readiness landscape of the program participants at FQHCs

The analytic sample included 2,791 *All of Us* participants who responded to the three MCM digital readiness questions between June 2019 and March 2020 when they completed the required actions to become an enrolled Participant. Applying the definition of digital readiness described earlier in this paper to this sample resulted in 1,527 participants who were considered digitally ready and 1,264 participants who were considered not digitally ready, as shown in **Figure 1**.

Figure 1 indicates that, among the 1,264 Program participants who were not digitally ready, about 31% (391) were comfortable using technology but did not have access to the internet or a computer at home; and 22% (283) of participants were comfortable using technology and had access to the internet but did not have a computer, tablet, or mobile phone at home. These observations indicate that a majority of the participants (53%) were not digitally ready due to lack of a device, which they may not have been able to afford considering that over 90% of FQHC patients are low income (5).

Prior to setting up the model, FQHC participant demographic distributions of those included in the analytic sample were compared with those who were excluded to verify that the analytic sample was not a biased set relative to the larger FQHC *All of Us* population. The two groups were very similar in distribution (χ^2 test $p \geq 0.13$ for all comparison groups), indicating that specific demographic groups were not over- or under-represented in the analytic sample. Examination of demographic characteristics, to the extent they might result in collinearity, showed that gender identity and sex at birth were strongly associated (Cramer's $V = 0.65$). Therefore, gender identity was used in the final model as it represented the participant's self-identification; sex at birth was excluded.

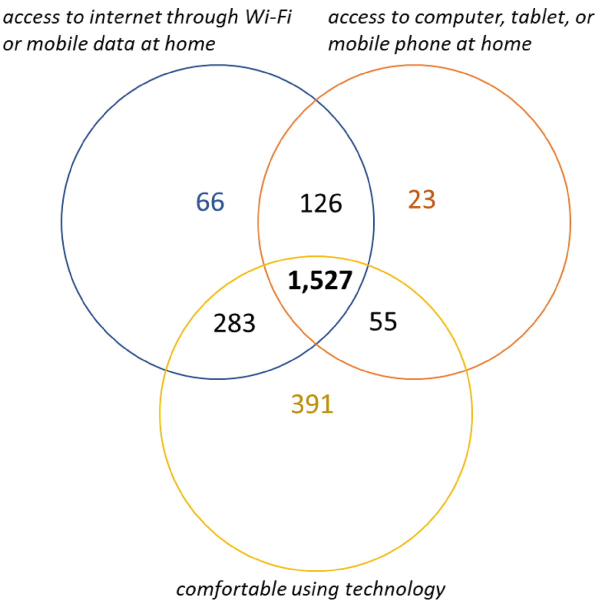

FIGURE 1
Digital readiness disposition among the *All of Us* participants at FQHCs. [Total number of participants = 2,791. Digital readiness was defined by access to home-based or other internet-accessing devices (computers, tablets, mobile phones, and other devices) and participants' comfort level using such devices].

Results from a multivariable logistic regression model relating to characteristics of groups that are not digitally ready at FQHCs are shown in **Figure 2** (Model 1). A complete table containing Odds Ratios (OR) and 95% Confidence Interval (CI) values is included in the Supplementary Table S1 of this paper.

Age at consent, gender identity, income, and educational attainment were the significant variables associated with digital readiness ($p \leq 0.01$). Race, rurality, and sexual orientation status were not significant factors associated with digital readiness. Participants who were 26–35 years of age when completing their primary consent had 46% lower odds of being digitally ready (OR 0.54) compared with their 18- to 25-year-old peers. This trend continued with every decade of age at consent increase. For example, participants who were 36–45 years of age at consent had 71% lower odds (OR 0.29) and those 46–55 years of age at consent had 81% lower odds (OR 0.19), peaking at 76 years or older of age at consent, who had 95% lower odds (OR 0.05) to be digitally ready.

Participants who identified as females had 60% higher odds of being digitally ready (OR 1.58) than those that identified as males. Further analyses showed that FQHC *All of Us* participants who identified as females were more digitally ready than males at all age groups, races, rurality, incomes, and education levels (data not shown).

Higher income levels were associated with higher digital readiness; participants with income levels greater than $50,000 had 6.5 times higher odds of being digitally ready (OR 6.47) than those with incomes under $10,000. This was the highest OR among all the other demographics included in the study. Educational attainment followed a similar trend as income levels. Participants with a high school degree had 53% higher odds of being digitally ready (OR 1.53) than those without a high school degree, and those with a college degree or more had five times higher odds of being digitally ready (OR 5.89) compared with their less-than-high-school participants.

3.2. Digital readiness impact on retention of participants in the program at FQHCs

As described earlier, most of activities required by *All of Us* that qualify a participant to be considered retained (except submitting bio samples to Biobank) are completed on a web-based portal. The online portal can be accessed by the participants when they come in-person to the FQHCs or virtually from a computer or a mobile device. The instructions for participants to complete the retention

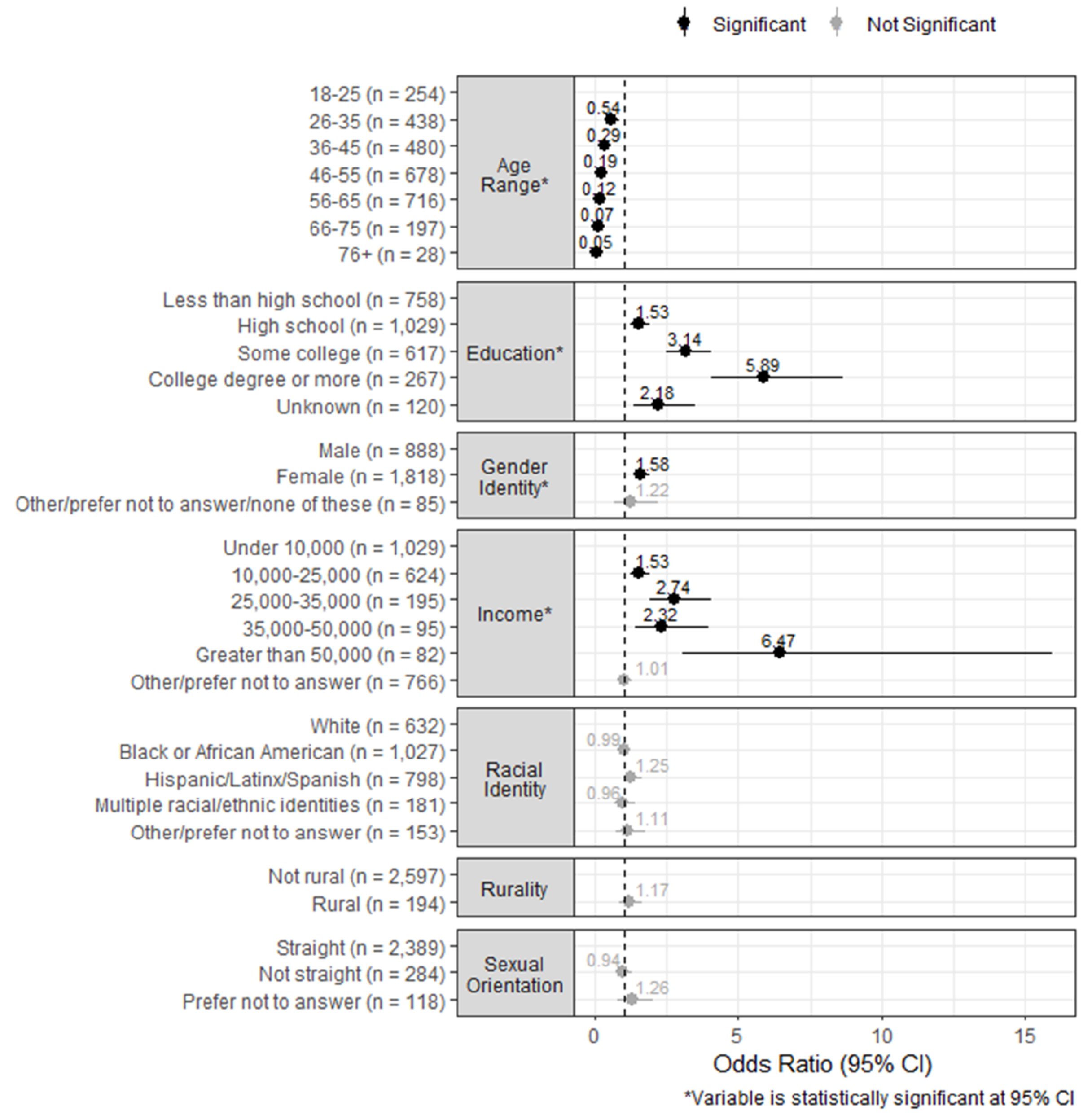

FIGURE 2
Results from the model to understand characteristics of groups that are not digitally ready at FQHCs. (Outcome variable: Digital Readiness. Coded as 1 if the participant was digitally ready, and 0 if the participant was not digitally ready. Digital readiness was defined by access to home-based or other internet-accessing devices (computers, tablets, mobile phones, and other devices) and participants' comfort level using such devices).

activities are often sent *via* mail as paper copies, or electronically by email or text messages, based on the participant's preferences indicated when joining the Program. Therefore, digital readiness plays a key role in the ability to retain participants in the Program.

Results showing the retention impact of digital readiness on FQHC participants in *All of Us* are shown in **Figure 3** (Model 2). Significant variables from Model 1, which included age when consenting to the Program, income, educational attainment, and gender identity, were used for propensity score weighting in Model 2. Results from both unweighted and weighted (using IPTW propensity score methodology) models are shown. A complete table containing OR and 95% CI values for both unweighted and weighted models is included in the Supplementary Table S2 of this paper.

Digital readiness significantly increased the odds of a participant being retained in the Program; the odds were *21% higher* with the unweighted model (OR 1.21) and *27% higher*

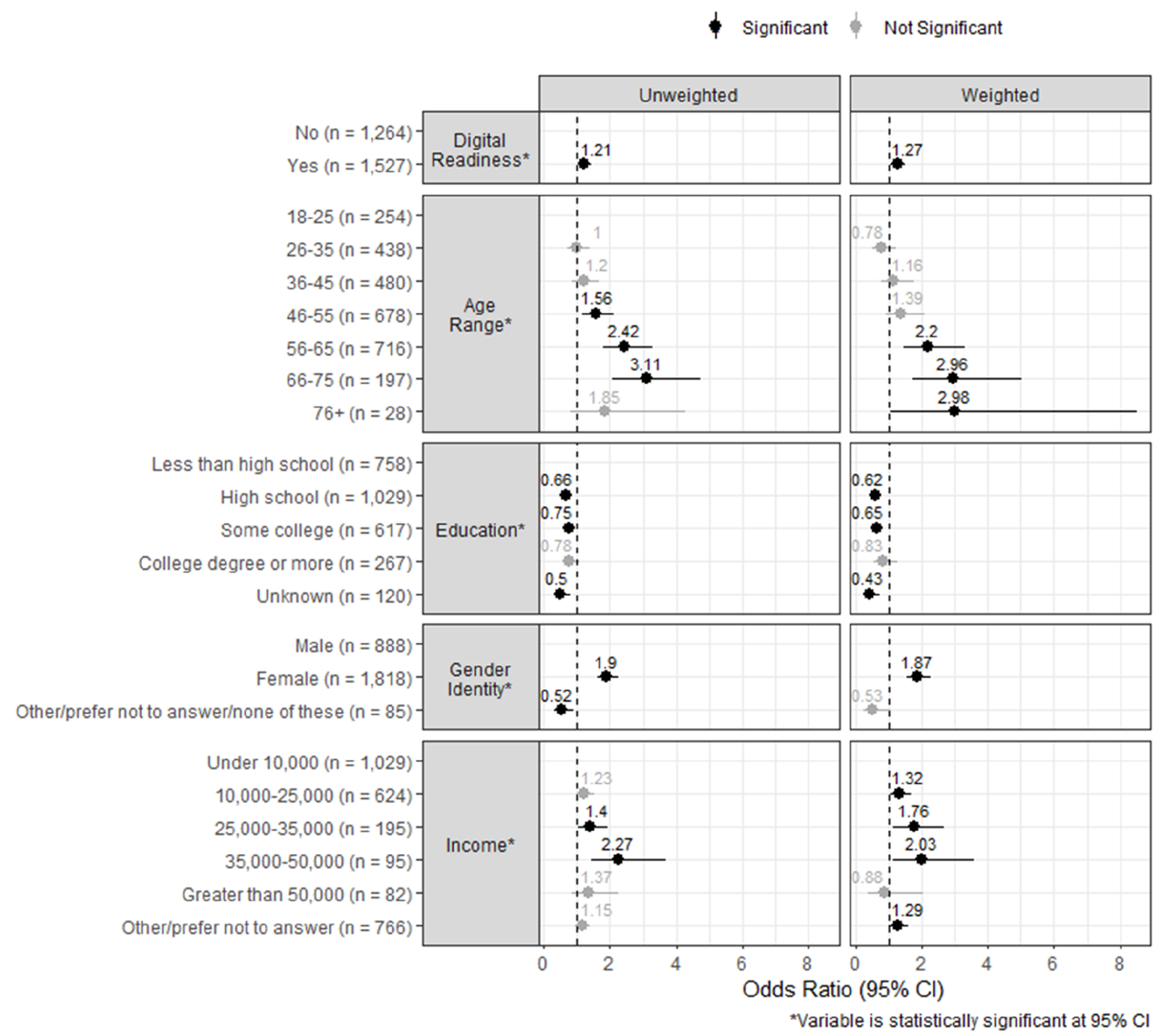

FIGURE 3
Results from weighted and unweighted models to understand the impact of digital readiness on retaining participants at FQHCs. (Outcome variable: Retention Status. Coded as 1 if the participant was retained, and 0 if the participant was never retained. Retained participants complete follow-up surveys on a web-based portal at least once every 18 months after their enrollment, indicating sustained engagement after recruitment to the Program).

in the case of IPTW model (OR 1.27). Additionally, the odds of never being retained were significantly associated with lower age at consent, lower income, and participants identifying as male.

The odds of being retained in the Program overlapped with participant groups with higher digital readiness (i.e., higher income and participants identifying as female), except for age at consent and educational attainment. Older participants had higher odds of being retained, even though they were less digitally ready than their younger peers. Participants who were 56–65 years of age at consent had *two times higher* odds of being retained (OR 2.2) than those who were 18–25 years of age at consent; at 66–75 years of age at consent, they had *three times higher* odds (OR 2.96). This observation suggests that older participants often completed retention activities through in-person appointments with FQHC staff during their clinical visits. Older participants might be making more frequent in-person clinical visits to the FQHCs and/or may have more time available, thereby providing more opportunities for the *All of Us* staff to engage them in-person for completing retention activities. Increase in education level did not increase the odds of being retained.

Findings from Models 1 and 2 indicate that participants who were digitally ready had 27% higher odds of being retained in the Program than those who were not digitally ready. Participants with higher income, higher educational attainment, and from lower age groups were all associated with digital readiness. While the odds of digital readiness increased with increase in education level, it did not increase the odds of being retained. Participants who were not digitally ready, such as those from older age groups, but made in-person clinical visits to the FQHCs benefited from *All of Us* staff supporting them in completing retention activities, thereby compensating for their lack of digital readiness. The models also suggest that younger participants, despite their association with being digitally ready, had lower odds of ever being retained, indicating that motivating participants from younger age groups to complete the Program retention activities at FQHCs is a significant challenge, particularly as they may be making less frequent visits for healthcare.

3.3. Qualitative findings on the strategies FQHCs are using for retaining participants in *All of Us*

In June 2022, 11 FQHC *All of Us* staff members participated in a focus group to share their strategies for retaining participants in the Program. The strategies were focused on pre-pandemic scenarios given the scope of the analysis included in this paper, but some of the findings could be applicable during the pandemic. The key takeaways are summarized in **Table 5**.

TABLE 5 Summary of Strategies used by FQHCs for Retaining Participants in *All of Us*.

Strategy	Description
Continuity	Continuity strategies, such as sending birthday/Program anniversary cards to participants, or having FQHC *All of Us* staff members who initially enrolled participants call the same participants, helped build and strengthen connections. This encouraged participants who were not digitally ready to complete retention activities in-person.
Align with clinical appointments	Aligning the completion of retention activities with clinical appointments enabled completion of retention activities in-person. This strategy also saved time, as the participants could complete the activities while waiting in the lobby prior to getting called in for their clinical appointment. If the participant had more activities to complete, the nurse brought the participant back to the FQHC *All of Us* staff member after the clinical appointment concluded.
Familiarity	Familiarity with the FQHC *All of Us* staff member made a significant difference in scheduling in-person appointments to complete retention activities. Participants were more open to visiting the FQHC and resulted in fewer missed appointments with All of Us staff members.

Many of the strategies described in **Table 5** further strengthen the findings from quantitative analyses. FQHC focus group members shared that aligning *All of Us* activities with clinical appointments was an especially effective strategy for older participants since they typically made more frequent in-person visits to FQHCs. They added that older participants enjoyed the company of having someone to talk to, liked to stay longer, and appreciated the service and personalized attention. This point further strengthens findings from the quantitative analysis that digital accessibility disposition for older participants had low to no impact on being retained into the Program at FQHCs.

Familiarity with a participant's digital readiness was another strategy that provides additional insights on the quantitative results. FQHCs shared that the *All of Us* staff recorded detailed notes from prior appointments about whether the participant completed all retention activities independently (vs. needing staff assistance) and their comfort using technology to determine the level of assistance needed. This allowed for the staff to be well prepared to support participant needs for completing Program activities.

4. Conclusions

The data presented in this paper demonstrate significant overlap between participants who are not digitally ready and those with low income, who are less educated, and of increased age. The representation of these UBR groups in clinical trials, along with longitudinal data collection, is critical to designing medical countermeasures that benefit the entire United States population and can potentially provide inference for populations around the globe. Longitudinal data collection efforts can embed measures to mitigate this disproportionate impact on UBR populations. Opportunities exist in the provision of culturally sustaining outreach and engagement to support retention, mitigating lack of digital readiness by ancillary services that bridge the gap between *All of Us* and participants who are not digitally ready, or provision of internet or internet-accessing devices to vulnerable groups.

5. Limitations

There were some limitations to this study, primarily due to constraints on the study design. The MCM survey questionnaire was not developed specifically for this research study. It was developed to understand the general characteristics of the population groups that FQHCs enroll. Therefore, our study was limited by the data that was already collected.

The MCM survey questions were asked by FQHC staff to all participants at their time of enrollment in *All of Us*. However, per the IRB requirements, participants were given a choice to decline responding to the MCM survey entirely or skip any of the questions. This may have introduced bias in our study sample. Out of a total of 3,552 participants enrolled by FQHCs during the study time-period, 2,897 participants chose to respond to MCM survey (82% response rate). Of the 2,897 that responded, 106 participants skipped one or more of the three MCM technology questions and were excluded (3.6%), potentially introducing selection bias. For example, these participants could have skipped the questions because they may not have access to technology devices (computers, tablets, mobile phones, and other devices) and were not comfortable stating it on the survey. Had these limitations not existed, we hypothesize that the magnitude of the quantified impact would only be greater.

The three MCM questions on technology access and participants' comfort level to using technology were used to develop a definition for digital readiness. While there is no universally established definition for digital readiness, the definition used in the study deviates from previous studies, which may limit the study's comparability with others. Some studies have used the term "digital divide", focused on the gap between those who do and do not have access to information technology, regardless of their comfort with technology (24). Another definition of digital readiness is based on technology access, comfort level and trust (25).

Finally, the results of this study must be considered in the context of this longitudinal data collection effort, and may not generalize to other research efforts, each of which has its own definition of retention, incentive structure, and may have a vastly different study population. However, despite the limitations, the study provides timely and insightful contribution by quantifying the impact of digital readiness in recruiting and sustaining UBR population groups in longitudinal data collection.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: The datasets generated during and/or analyzed in this study are available from the corresponding author on reasonable request, and subject to approval from NIH. Requests to access these datasets should be directed to skini@mitre.org.

Ethics statement

The studies involving human participants were reviewed and approved by All of Us (AoU) Institutional Review Board (IRB). AoU IRB Protocol Number: 2017-06. The patients/participants provided their written informed consent to participate in this study.

Author contributions

SK and DD: contributed to conceiving the study, authored the manuscript and are equal contributors. SK: led the data analytics team, engaged FQHCs for qualitative inputs on retention strategies, and wrote the manuscript. DD: led the data clean up, validated study population, and contributed to model development. JW: contributed to the Propensity Score Weighted Model methodology development. All authors contributed to the article and approved the submitted version.

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Conflict of interest

SK, DD and JW were employed by The MITRE Corporation when this work was carried out. 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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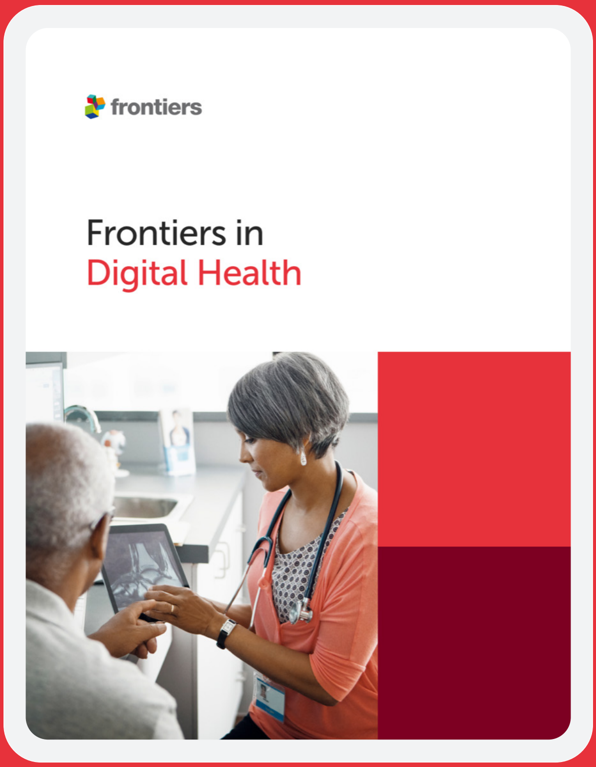

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