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Ethical considerations for developing pediatric mhealth interventions for teens with socially complex needs

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Abstract

Background: Mobile Health (mHealth) stands as a potential means to better reach, assess, and intervene with teens with socially complex needs. These youth often face overlapping adversities including medical illness and a history of experiencing adverse childhood experiences [ACEs].

Problem: Clinicians are faced with navigating ethical decisions when developing mHealth tools for teens who have socially complex needs. Many tools have been developed for adults from the general population. However, despite the development of thousands of mHealth interventions, developers tend to focus on designing for usability, engagement, and efficacy, with less attention on the ethical considerations of making such tools.

Objective: To safely move mHealth interventions from research into clinical practice, ethical standards must be met during the design phase. In this paper we adapt the Four Box Model (i.e., medical indications, preferences of patients, quality of life, and contextual features) to guide mHealth developers through ethical considerations when designing mHealth interventions for teens who present with a medical diagnosis and a history of ACEs. Specifically, a review of language, inclusive features, data sharing, and usability is presented using potential scenarios to guide each consideration.

Conclusions: To better support designers of mHealth tools we present a framework for evaluating applications to determine overlap with ethical design and are well suited for use in clinical practice with underserved pediatric patients.

Keywords

mHealth; underserved populations; ethical design; usability; adolescents

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Teens described as having socially complex needs often face overlapping adversities, such as adverse childhood experiences (ACEs), living in low-socioeconomic households and/or communities, experiencing food or housing insecurity, and/or multi-systems of care involvement (Bounds et al., 2020). ACEs are adversities experienced during childhood that range from child maltreatment to parental separation, mental illness, incarceration, or substance use (Anda et al., 2014; Felitti et al., 1998). Recently, ACEs have been expanded to include community violence, parental disability, or separation from a parent due to death, immigration, or child welfare involvement (Barajas-Gonzalez, et al., 2021). Ultimately these environmental factors often increase levels of toxic stress and interactions with systems of care such as homeless shelters, mental health care, and juvenile justice; situations that converge creating socially complex needs.

The COVID-19 pandemic and resulting social distancing recommendations have increased the interest in mHealth interventions, as providers seek more ways to support their patients remotely (Clipper, 2020; Stiles-Shields et al., 2020). Teens are often early adopters of mobile technologies and frequently utilize mHealth applications without caregiver knowledge, monitoring, or support (Underwood & Ehrenreich, 2017; Wartella et al., 2016). Further, the daily burden of the convergence of work, school, and home lives placed on pediatric patients and their families, and increasing time spent online, has also led more people to consider ways that technology can support them during the pandemic and beyond.

Despite the growing interest and use of mHealth tools in clinical research and practice (Cushing et al., 2019), the navigation of ethical considerations in the development of apps may seem especially complicated--particularly for teens with socially complex needs where mHealth solutions will need to be both developmentally tailored and include added protections and supports related to data privacy, consent, and safety. In addition, solutions will need to account for cultural and socioeconomic issues that often intersect with justice and equity considerations. For example, most human-centered design practices aspire to include the intended user in the process from conception. However, in doing so, marginalized populations may be overlooked and excluded (Mackey et al., 2021; Mulchan, et al., 2021; Safavi, et al., 2019; Valrie et al., 2020) due to structural racism, implicit bias, access challenges, and cost.

However, the promising effects of mobile health (mHealth) interventions on health outcomes have emerged as a potential means to reach teens, especially with their ubiquitous use of mobile devices and smartphones (Anderson & Jiang, 2018). mHealth interventions often consist of 1) continuous recording of health-related information; 2) teaching and supporting skills related to emotional regulation; 3) keeping digital diaries; 4) sending various types of reminders; or 5) momentary assessments of emotions. Because mHealth methods may support self-efficacy and adherence (Fedele et al., 2017), these interventions may be particularly beneficial for teens with socially complex needs. This population is ideally positioned to benefit from effective and well-designed digital supports given the high mental health needs identified among this group (Liu & Modir, 2020; Salerno et al., 2020; Substance Abuse and Mental Health Services Administration, 2014) and frequent contact with the health care system (Bloom, Cohen, & Freeman, 2011). Thus, the reach of care

could be extended via digital supports without further burdening families and our overtaxed health care system (Jennings et al., 2016; Ryan-Pettes, Lange, & Magnuson, 2019).

In this paper, we apply a framework for designing and evaluating mHealth interventions for teens who present to the healthcare system with a medical diagnosis but are also in need of mental health care and/or support due to the concomitant impact of multiple toxic stressors in their lives. Given that ACEs are common (Crouch et al., 2019; Giana, Wheeler, & Hubach, 2020) and have a dose dependent association with toxic stress and subsequent health challenges (Nelson et al., 2020), focusing on the intersectionality of teens' experiences in living with socially complex needs is especially relevant when developing pediatric mHealth interventions. Indeed, the overlapping layers that impact these teens' lives have implications for the social and contextual relevance and appropriateness of the intervention itself, as well as the ethical considerations that should be explored by developers early in the design phase (see Bowleg, 2012).

Initial Considerations for mHealth Designs for Teens with Socially Complex Needs

In order to support teens effectively and safely via mHealth tools we must first ensure that these tools are ready for "prime time". More specifically, there is a need to evaluate whether the diverse needs of those looking for support at this time can be met with previously developed mHealth interventions or if an entirely new class of digital solutions is required. Within these considerations, we highlight this specific population of teens for two reasons. First, while pediatric patients are already a specialized group with unique strengths and vulnerabilities, being a person with a medical condition is merely one aspect of their lives. Toxic stress associated with ACEs has been linked with a variety of medical conditions including asthma, diabetes, and cardiovascular disease (Nelson et al., 2020). Considering their needs as users in terms of overlapping identities and needs, which are often complex, increases the likelihood of appropriate application. Second, teens (i.e., 13–18) are the focus, as these ages are: 1) a high-risk time period for the onset of many comorbid psychological disorders (Merikangas et al., 2010; Merikangas et al., 2011); 2) when youth may begin to autonomously engage in interventions that could be delivered via mHealth; and 3) when youth enter a period where risky behaviors increase (i.e., smoking, alcohol use) and health promoting behaviors (e.g., healthy diet, physical activity; Champion et al., 2017) and medical adherence may decline. In fact, non-adherence is an issue of increased focus for pediatric populations due to its life-threatening consequences for certain conditions (e.g., spina bifida, diabetes, asthma, suicidal ideation; Dicianno & Wilson, 2010; Nelson et al., 2020).

As teens begin to autonomously engage in mHealth interventions, the caregivers' awareness and monitoring of their teens' engagement with mHealth interventions decreases placing an ethical obligation on mHealth developers to ensure safety. As such, we review issues of language, inclusive features, data sharing, and usability for teen patients with socially complex needs. This overview is intended to provide a jumping off point for developers, particularly as they move towards increased use of and demand for technology for patients

and the general public (Clipper, 2020; Psihogios et al., 2020). To evaluate the fit of current solutions to the needs of this population, the Four Box Model is presented as a means to guide ethical considerations for mHealth design for teens with socially complex needs

Four Box Model.

To guide the overview of these issues, we present them through the lens of the Four Box Model for ethical decision making (Jonsen et al., 2015). Within the context of pertinent case examples, the Four Box Model provides a framework through which to consider ethical design via specific clinical decisions. The Four Box Model is adapted from the four moral principles of respect for autonomy, beneficence, nonmaleficence, and justice (Beauchamp et al., 2001) to analyze the context of ethical issues through: 1) medical indications; 2) preferences of patients; 3) quality of life; and 4) contextual features (Jonsen et al., 2015). Although the Four Box Model has traditionally been used in clinical decision making, we argue for its expansion to use in mHealth intervention development. Such development has often focused on optimizing usability, engagement, and effectiveness while lacking a consideration of medical ethics despite the goal of these products to be health interventions (Van Velthoven et al, 2018). Throughout, we will provide details about inclusive design processes and apply the Four Box Model to inform ethical design decisions.

Case Example

The first author is currently designing an mHealth intervention for pediatric patients who have been identified as high risk through the Adverse Childhood Experiences (ACEs) screening process. The mHealth intervention delivers psychoeducation via Zoom to teens and their caregivers. It is focused on self-regulation during health coaching sessions. Why seek to address ACEs exposure within a psychoeducation application? ACEs are associated with negative health and social outcomes, such as comorbid trauma spectrum disorders, multiple risk behaviors (e.g., risky sexual behaviors, alcohol, and substance abuse), mental health symptoms (e.g., anxiety, depression, angry outbursts), sleep disturbance, and chronic illness (e.g., cardiovascular disease and cancer; Anda et al., 2014; Felitti et al., 1998; Nelson et al., 2020). Therefore, the proposed mHealth intervention uses Cognitive Behavioral Principles alongside foundational health information identified by the ACEs Aware Campaign (Office of the California Surgeon General, 2022) to promote healthy habits, such as stress management and sleep hygiene. Focusing on pediatric patients who present with comorbid health challenges and socially complex needs due to their ACEs exposure(s), we will explore the development of the mHealth intervention described above. The Four Box Model will be used to explore ethical considerations for developing this intervention. Table 1 displays mHealth design considerations using a checklist to guide mHealth developers through the Four Box Model.

How can mHealth interventions be developed to benefit the pediatric patient without causing harm?

Medical indications, or identification of medical problems, diagnoses, and goals of treatment, is the first step in the Four Box Model. Principles of beneficence and nonmaleficence guide the exploration of medical indications (Jonsen et al., 2015). While

developing an mHealth intervention for youth who have been impacted by multiple ACEs, considering how to benefit the patient without causing harm is a challenging endeavor. For instance, pediatric patients impacted by ACEs may be system-involved due to their history of abuse and/or neglect and therefore may have restrictions around who it is safe to interact with (e.g., a parent or caregiver with a history of abuse). And so, on one hand, developing supportive relationships with caregivers is crucial, but on the other, it is important not to facilitate increased contact with an abusive caregiver.

It is also critical to define and assess potential harms (e.g., Rozental at el, 2014). Too often developers consider harm only from the vantage of lack of intervention effect or a negative effect, whereas an mHealth intervention could introduce other harms such as risks to safety or privacy, or delaying other service receipt. Thus, there is a need to assess, measure, and evaluate potential negative effects or unintended outcomes early in the development process. Next, we define constituent parts of mHealth interventions while considering what inclusive features (i.e., indications, problems, and goals), might be indicated as the first step of ethical decision making in the Four Box Model.

Inclusive Features.—It is important to ensure that mHealth features match the needs of the likely users—something that is highly dependent on their developmental stage, symptom profile, and cognitive capacity. Given our focus on teens with comorbid conditions, accessibility is an important consideration (Stiles-Shields et al., 2019). The constituent parts of mHealth interventions have been defined as including elements, characteristics, aims, and workflows (Mohr et al., 2014). In parallel, Marwaha & Kvedar (2021) organize cultural adaptation considerations into content, methods, and procedures. The elements refer to the "what" of the intervention, which we refer to here as *content*. The characteristics refer to the "how" of the intervention, which we refer to as the *form*. Aims refer to the "why" of the intervention, which we refer to here as the *function*. We do not discuss aspects of workflow here as that focuses more on when different technological elements appear to users, including time-based or task-completion rules.

<u>Content.:</u> Content should be reflective of not only the age and stage of development (as is typically considered for teens in the general population), but also other important characteristics of the target population. This includes ensuring diversity in names, photos, and videos (e.g., sexual/gender identities, racial/ethnic minorities, able bodied vs. ambulating by wheelchair, etc.). Tailored mHealth intervention content that reflects the needs and characteristics of sub-populations has been demonstrated to be more effective than generic information for various conditions (see Anderson-Lewis et al, 2018 for a review of tailored mHealth interventions developed for underserved populations). Additional examples of tailoring include Bath and colleagues' (2019) work with justice-involved youth and recent work developing messaging to minoritized communities during COVID-19 (Kamal et al., 2021). Given that: 1) teens will often seek out older peers for advice and model their behaviors on older peers that they feel connected to on or offline (Silva et al., 2016); and 2) positive effects have been noted in peer mentoring in teens with chronic health conditions (Jerson et al., 2013; Merianos et al., 2016; Raphael et al., 2013), harnessing near-peer mentorship and representation (DiClemente et al., 2014) may also be beneficial.

Thus, mHealth interventions should ensure that teens with socially complex needs can see themselves in them--whether this means creating content that is ambiguous and could be interpreted to represent diverse groups or specifically calls out aspects important to the target group.

Form.: Content refers to what features contain; form refers to what medium the features take (i.e., text, videos, images, or icons). This might refer to the overall look and feel of an mHealth tool (e.g., layout, graphics, colors), as well as what the various forms contain (i.e., text, videos, images, or icons). Different populations might be more likely to prefer different forms. These preferences might serve functional purposes, as individuals with visual disabilities might prefer audio as opposed to text, or those with lower literacy may prefer voice-to-text/text-to-speech options. However, preferences might also come from learning or cultural differences, as some groups might be more likely to use text messages or messaging apps over other types of mobile apps and prefer information in text that is short and frequent. Indeed, research has demonstrated the success of text messaging strategies to reach and improve the health of underserved and marginalized groups (Anderson-Lewis et al., 2018). Pediatric researchers have also demonstrated success in engaging representative patient groups to create their own content for text message interventions. For example, Seid and colleagues (2012) utilized this approach with minoritized teens from low-income families with asthma and Thompson and colleagues (2016) did so with minoritized teens with obesity-related behaviors. However, more research is needed to understand whether text messages are the preferred form for teens with socially complex needs or if this is what researchers have tended to employ with such groups.

Function.: The function refers to what these features are meant to accomplish. This might be didactics or education, communication, or other interactive tools meant to reinforce learning or build skills. For mHealth interventions targeted towards teens with socially complex needs, the form, content, and function need to be appropriate for the population(s), which might include tailoring to consider personalization and inclusion or accessibility concerns to account for physical barriers (e.g., poor fine motor dexterity), cognitive impairments, or developmental delays (Stiles-Shields et al., 2019). Function for mHealth interventions should reflect the ways that youth are accustomed to using mobile devices. For example, youth frequently use mobile devices for communication, but communication in the context of mHealth interventions has to convey safety and promote trust, especially for teens with socially complex needs. Many teens may use technology to create or find safe spaces as well as to help navigate challenges that might occur in offline spaces (Scheuerman et al., 2018). As a result, communication is especially important to ensure that teens can trust to safely use and disclose in online spaces (Sheoran et al., 2016).

Teens particularly emphasize confidentiality as a key concern around apps that address mental health content (Kenny et al., 2016). Thus, it is crucial to consider the lack of safe spaces in the home environment that may prohibit teens from accessing needed mental health services, for example. Additionally, navigating parents' access to records may also pose privacy concerns that could potentially decrease teen utilization. It is also important to acknowledge challenges with certain functions for specific sub-populations. As an example,

findings from working with homeless teens have demonstrated that maintaining mobile connectivity over time was challenging due to inability to maintain consistent data plans, to have reliable access to WiFi, or have the ability to regularly and safely charge one's phone (Jennings et al., 2016). It is important to acknowledge that although national surveys might uncover trends in teens' smartphone and app use, these trends might not hold across all subpopulations and for individuals with specific disorders. Therefore, patient preferences require further exploration.

How do the preferences of pediatric patients impact engagement with and adherence to mHealth interventions?

The second consideration of the Four Box Model, preferences of patients, is guided by respect for autonomy (Jonsen et al., 2015). Underlying the respect for autonomy is the need to seek to better understand the context of the target populations' preferences. For teens impacted by ACEs, they may have experienced abuse or neglect at the hands of a parent. In the case example, if the intervention intends to include a caregiver, the developer might build in how the preferences of the pediatric patient could be considered and honored. Considering and honoring the pediatric patients' preferences might mean that they get to choose the caregiver who participates in the intervention with them. It might also mean that if a caregiver is required that the term caregiver or family is defined broadly to include other parental figures such as older siblings, aunts, uncles, or godparents. Next, we explore preferences from the lens of use of language in mHealth design.

Language.—Consistent with core competencies for psychological practice (McDaniel et al., 2014), mHealth tools must use language that is appropriate for teens' needs. Language has been linked to engagement (Bakker et al., 2016; Schueller et al., 2019) and multiple considerations must be made in this domain. First, language must be simple and relatively jargon-free, while not condescending (teens are sensitive to overtly juvenile or patronizing text that contrasts with their budding autonomy; e.g., Jones et al., 2019). Teens and their families are likely to have highly variable health literacy (Davis et al., 2013) and English may be a second language (Flower et al., 2017). Second and related to the simplicity of language, brevity is also critical. Any text displayed in the mHealth tool is constrained to the size of the device screen on which it is accessed. Reliance on scrolling through text may push the limits of a teen's working memory capacity, which is impacted by age and diagnosis (Compas et al., 2017). Third, mHealth language that avoids clinical/diagnostic language may further increase accessibility and decrease possible user concerns around stigma (Bakker et al., 2016; Titov et al., 2011).

Just as a pediatric provider working with a family that has expressed concerns around seeking mental health care may choose to discuss how "stressful days" rather than "anxiety" impact an adherence regimen similar language choices may increase teens' comfort in interacting with an app. Special emphasis on inclusive language must be made (Bakker et al., 2016; Schueller et al., 2019). For example, ensuring that didactic examples do not solely portray heteronormative situations and traditional family compositions (Rozbroj et al., 2015) or providing personalization options such as choosing a preferred name and/or pronoun are ways to use inclusive language. Finally, language selections should be reviewed

by representative teens with socially complex needs to help support the areas outlined above and to additionally bring important cultural and contextual information to the design process. This point is further discussed more broadly below, in the context of Quality of Life and Usability Testing. In sum, many of the ethical decisions that pediatric providers make in selecting their own language in face-to-face settings with diverse patient populations should be extended to mHealth tools.

How can the design be the most usable for pediatric patients so that they can reap the potential benefits of use?

Combining both beneficence and nonmaleficence with respect for autonomy is the consideration for the impact on quality of life (Jonsen et al., 2015). As the third step in ethical decision-making, considering how the development of the mHealth intervention impacts quality of life in our case example might explore the relevance and function of actual components of the intervention. For instance, considering if the teen will use special functions of an app because they are relevant and functional means that the teen is easily able to see the benefits from doing so. Next, we walk through the importance of usability testing to ensure the mHealth intervention is congruent with improving the quality of life of its users.

Usability Testing.—The ideal way to ensure that a mHealth intervention is effective and applicable to teens with socially complex needs is to ask them and to include them in all stages of the design and testing of the digital intervention. As such, formative and summative usability testing that includes the targeted population in the design and determining if the resultant tool is usable for them are critical to ensuring quality of life. Many mHealth tools might not be usable for the intended targeted population, such as was demonstrated in the case of apps for people with diabetes and depression self-management (Sarkar et al., 2016). Specifically, Sarker and colleagues (2016) identified three themes from participant comments that encompassed: 1) a lack of confidence with the technology; 2) frustration with design features and navigation; and 3) interest in having technology support their self-management.

Formative usability testing refers to testing during the development process that is used to inform the eventual form, content, and function of the mHealth intervention (Stiles-Shields & Montague, 2017). For example, usability testing might include gathering youth feedback on initial mock-ups, wireframes, or low-fidelity prototypes before coding or development is complete. Summative usability testing refers to determining the issues, problems, or benefits of an existing system (Stiles-Shields & Montague, 2017). Within a teen-friendly environment to encourage participation, summative usability testing can combine established methods, including: 1) observational methods, such as the "cognitive walkthrough," where users interact with a product while talking aloud and an observer codes for usability dimensions such as errors or task completion (Nielsen & Mack, 1994); and 2) quantitative data collection, such as the widely used System Usability Scale (SUS), that asks users to reflect on their perception of the efficiency, effectiveness, and satisfaction with a mHealth intervention to reach its desired goal (Brooke, 1996). Failure to address these issues across

diverse populations will likely result in tools that are not relevant or functional to meet their issues and needs (Psihogios, Lane-Fall, & Grahmam, 2022).

Formative usability testing with teens with socially complex needs requires special considerations to ensure that their perspectives are properly incorporated. The first instinct of many researchers and developers is to conduct focus groups to quickly gather feedback from many people. Group settings may be difficult for some youth to share, particularly around sensitive topics (Farquhar, 1999). As such, individual sessions might be necessary, presented as opportunities to follow-up on group sessions or as alternatives to focus groups. Conducting in-person group sessions might also create logistical challenges and it is especially worth noting that requiring in-person parental consent may restrict some teens' access to participation. It is also worth noting that protocols to obtain online parental/ guardian consent are also needed and may represent another barrier to participation among this population (Odgers, 2019).

Other methods, such as the Asynchronous remote communities (ARC) method, might be useful--especially to overcome access barriers like geography or transportation (Maestre et al., 2018). The ARC method leverages the online environment, such as a private social media group, to engage hard-to-reach populations in research activities (Maestre et al., 2018). Further, all of these methods might better adopt platforms that teens are used to engaging, such as social media (MacLeod et al., 2017), or methods that are modified to meet accessibility concerns, such as allowing individuals with visual impairments to enter information in a mobile phone, call a phone number, or send a text (Kientz et al., 2006). Increasing the diversity of people who might be helped by an mHealth intervention requires increasing the diversity of ways people can contribute to its development. Ultimately, there's a trade-off in efficiency for depth and accuracy of stakeholder feedback in human-centered design (HCD) and because HCD is meant to be an iterative process, fast really should not be the goal. Evaluating mHealth interventions within their intended setting may efficiently accelerate evaluation in a way that does not compromise the process (Mohr et al., 2017).

Once an mHealth intervention is developed, summative usability testing can help determine its potential to be an effective conduit for health behavior change. Summative usability testing can help uncover why an mHealth intervention may not be ultimately effective for a given population. For example, a behavioral activation app intended to reduce depressive symptoms that provides a suggestion to "go for a walk when feeling blue" could be ineffective for youth: 1) with difficulty ambulating; 2) with fatigue related to a disorder or treatment; 3) who do not have a safe space to go for a walk; or 4) who do not have consistent and/or private access to their mobile device (e.g., parents limiting screen time, sharing phone with siblings). Consequently, typical usability procedures might need to be adapted to better reflect *why* teens make certain "errors." Indeed, such information might better be captured by reviewing data collected in cognitive walkthroughs with participants to allow them to help the researcher better understand why they did certain things and whether these "errors" reflect issues with technology, stem from issues related to their condition(s), or an interaction between the two.

Will the design impact the fairness and clinical decisions of pediatric patients and their families?

Finally, contextual features, guided by the ethical principle of justice, are concerned with factors that might impact patient decisions as well as access to mHealth interventions (Jonsen et al., 2015). In our case example, designing a mHealth intervention for youth impacted by ACEs must consider the context within which these youth live. For example, if the intervention is delivered via an online platform, will reliable internet be necessary to gain access and if not how can fair access to the platform be achieved? Additionally, as data are being collected within mHealth applications for clinical decision making, how might that data be protected or not protected within the intervention are all important considerations. In the case example, for instance, youth disclosures of abuse or neglect that occur online might have similar limits of confidentiality. In the context of mHealth, this is illustrated through design decisions involving data sharing.

Data Sharing.—Sharing of pediatric mental and behavioral health data is dependent on a number of factors (US Department of Health and Human Services, 2017). Data sharing links to important ethical considerations regarding autonomy and privacy of information and the ability for individuals to make decisions. The Children's Online Privacy Protection Act (COPPA) provides federal guidelines and protections for children under the age of 13 (Topelson et al., n.d.), but does not extend to teens. General practices allow for teens to provide assent for many types of research and to also participate in clinical decision-making along with their parents or guardians. Yet, the partial autonomy allotted from these practices makes data sharing a complex area, especially when considering digital tools. For these reasons, providers often feel unprepared to address issues of data sharing and lack the technical expertise required to ensure that the data collected from their patients is handled in ways that are compliant with current standards of medical care and privacy.

While it is important to remain vigilant about patient privacy and protections for pediatric patients, teens may be open and knowledgeable about data sharing to some degree. Older teens have been found to understand the majority of informed consent language regarding privacy in interventions using smartphones (e.g., Meter et al., 2019). Yet, understanding the nuances of data privacy and when confidentiality can or should be breached is difficult for teens--and even for parents--to surmise (Alper & Goggin, 2017; Odgers, 2019). More research and protocols in the design of data privacy for teens with socially complex needs is required.

With that said, teens generally appear to be open to health-related data sharing with parents, peers, and/or providers, provided that they are in control of what is shared and when (Jeminiwa, et al, 2019). Indeed, ad hoc data sharing may be a potential solution to this issue, particularly for pediatric populations who may rely on their parents for support with issues such as adherence. For example, youth with diabetes have expressed an interest in sharing of lab results and other disease-specific stats with their parents, finding their input on such data to be valuable (Cafazzo et al., 2012). Other populations, such as those with juvenile arthritis and overweight/obesity, have noted the benefits of such data sharing options with parents and providers (Gabrielli et al., 2017; Waite-Jones et al., 2018). However, pediatric patient

feedback indicates the importance of user choice in sharing and desire for clear protections from privacy threats when data are shared (Beierle et al., 2020; Lopez, et al., 2017). Further, some pediatric populations report that if they decide to share data, they want it to occur automatically to improve simplicity in mHealth interactions; this is something that may be of particular interest for those with more complex and/or multi-system chronic conditions (e.g., cystic fibrosis, spina bifida; Bendixen et al., 2017; Vilarinho et al., 2017).

Taken together, data sharing is possible and even welcomed if the privacy protections are clear. However, data sharing options should be: 1) easily accessible (e.g., an "on" or "off" switch in settings); 2) modifiable (e.g., allowing the user to select if all of her blood sugar checks for the week are shared with her mother, as opposed to just sharing the checks from Tuesday); and 3) should be clear on what data are being shared (e.g., the user should be clear on whether she is sharing her medical vs. mental health data with her mother).

Conclusion

There have been increasing calls to better address the behavioral health needs of teens with a history of adverse childhood experiences and related challenges (Bath et al., 2018; Becker et al., 2016; Cheng et al., 2015; Hughes-Reid, 2019; Teachman et al., 2019). Digital tools, such as smartphone apps or health tracking wearables, stand as a means to help access, assess, and intervene with pediatric patients with socially complex needs in their real-world environments. Yet, teens with socially complex needs require special consideration as mHealth users. As such, a focus on majority populations in the development of mobile tools have left many youth vulnerable to the growing digital divide and potentially exacerbated health disparities (Schueller et al., 2019; Psihogios, Lane-Fall, & Grahma, 2022; Williams et al., 2016). To serve as a guidepost to mHealth designers during the COVID-19 pandemic and beyond, the current work stands as a starting point to an overview of ethical development considerations for mHealth tools targeting teens from such pediatric populations. Using the framework of the Four Box Model to understand mHealth design through the context of medical indications, preferences of patients, quality of life, and contextual features (Jonsen et al., 2015), an emphasis on inclusive content and collaboration with teens with socially complex needs in the design process is noted. As mHealth quickly evolves, new ethical considerations might not neatly fit in the Four Box Model and therefore additional ethical frameworks may need to supplement this model to guide future considerations. In reviewing these considerations and using the checklist provided in Table 1 as a starting point, pediatric providers may increase their aptitude in discerning how well mHealth tools are designed to meet the needs of their teen patients. At the same time, researchers and interventionists can use this framework to expand the inclusivity of their development approaches and check to ensure fundamental concerns are addressed in the design of their mHealth products and interventions.

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Table 1.

mHealth design considerations from the Lens of the Four Box Model

Medical Indications *Beneficence and Nonmaleficence*	**Preference of Patients** *Respect for Autonomy*

Inclusive Features Checklist:
⇒ Do features match the needs of the users including cultural adaptations?
   ○ Content – "what?"
   ○ Form/Methods – "how?"
   ○ Function/Procedures – "why?"
⇒ Are features accessible, developmentally and cognitively appropriate?
⇒ Have potential harms been defined and assessed?
	Language Checklist: Is the language used…
	⇒ Simple?
	⇒ Jargon-Free?
	⇒ Not condescending?
	⇒ Inclusive?
	⇒ Relevant?

Quality of Life *Beneficence, Nonmaleficence, & Respect for Autonomy*	**Contextual Features** *Justice*
Usability Testing Checklist: Have we ensured relevance and functionality through… ⇒ Formative usability testing? ⇒ Summative usability testing?	⇒ Has equitable access been ensured? ⇒ Are there features/elements that may limit access, marginalize or exclude certain populations, or further health inequities? **Data Sharing Checklist:** ⇒ What is the assent/consent process for data sharing? ⇒ How will privacy of data be maintained? ⇒ Have limits to confidentiality been established and clearly explained?

Note. mHealth = mobile health. Adapted from <u>Clinical Ethics, 8th Edition: A practical approach to ethical decisions in clinical medicine</u>, by A. R. Jonsen, M. Siegler, and W. J. Winsdale, 2015, McGraw Hill Professional.