Ethical perspectives of mHealth users toward AI-enabled direct-to-consumer mHealth applications: Qualitative interview study

Katie Ryan, Justin Hogg, Max Kasun, Jane Kim

Table of Contents

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Abstract

Background: The increasing use of direct-to-consumer AI-enabled mHealth (AI-mHealth) applications presents an opportunity for more effective health management and monitoring and expanded mHealth capabilities. However, AI's early developmental stage has prompted ethical concerns related to privacy, informed consent, and bias, among others. While some of these concerns have been explored in early stakeholder research related to AI-mHealth, the limited literature suggests that the broader landscape of considerations that hold ethical significance to users may remain underexplored.

Objective: Our aim was to document and explore the ethical perspectives of users of mHealth regarding AI-mHealth applications.

Methods: We conducted semi-structured interviews with users of mHealth applications (N=21) and employed a qualitative descriptive design to document and describe their ethical perspectives.

Results: Through qualitative analysis, three major categories and nine subcategories describing users' perspectives were identified. Users described attitudes toward the impact of AI-mHealth on their health and data (i.e., influences on health awareness and management, value for mental versus physical health, and the inevitability of data sharing); influences on their trust in AI-mHealth (i.e., expert recommendations, attitudes toward technology companies, and AI explainability); and their preferences relating to information sharing in AI-mHealth (i.e., the type of data that is collected, future uses of their data, and the accessibility of information).

Conclusions: This paper provides additional context relating to a number of ethical concerns previously posited or identified in the AI-mHealth literature, including trust, explainability, and information sharing, and revealed additional considerations that have not been previously documented, i.e., users' differentiation between the value of AI-mHealth for physical and mental health use cases, and their willingness to extend empathy to non-explainable AI. To our best knowledge, this study is the first to apply an open-ended, qualitative descriptive approach to explore the perspectives of end users of direct-to-consumer AI-mHealth applications. Clinical Trial: This study addressed a supplemental aim to an ongoing study about the ethics of AI use in medicine (NCATS R01-TR-003505). This study obtained human subjects research approval from the Institutional Review Board of Stanford University on June 21, 2022 (#58118).

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Keywords: artificial intelligence; mHealth; ethics; end users; qualitative study; semi-structured interviews

Introduction

Direct-to-consumer mobile health (mHealth) applications present an opportunity for widely accessible health management and monitoring, with the integration of artificial intelligence (AI) offering immense promise to enhance the effectiveness and expand the capabilities of these applications.[1] Indeed, many direct-to-consumer AI-enabled mHealth (AI-mHealth) applications are already in widespread use by individuals seeking to address particular health concerns, obtain personalized insights into their health, promote health-seeking behaviors, and to help set and achieve wellbeing goals.[2]

While AI-mHealth applications offer potential for improving proactive health management and

monitoring, the rapid pace of AI innovation has outpaced research efforts aiming to facilitate the ethical development and adoption of AI-based applications and to maximize their benefits. Recent normative work has articulated concerns related to privacy, informed consent, and bias, among others.[3–5] For example, integral to the training of AI models and the appeal of AI use cases (e.g., personalized health recommendations and digital phenotyping based on ecological momentary assessments) is the collection of many times more behavioral data than is typically analyzed by mHealth applications that do not use AI, and this data may encompass a wider range of tracking modalities.[6,7] Mobile devices' capabilities to passively collect biometric data (e.g. motion, heart rate, sleep) and contextual data (e.g. location, browser activity) have raised novel considerations around data privacy, including users' ownership of this data, consent for data collection, AI capabilities of inferring private information, and potential for surveillance.[8–10] Another challenge for AI-mHealth is unwanted algorithmic bias, which, if inadequately addressed, could perpetuate existing health inequities and even widen health disparities, conflicting with the goals of personalized medicine.[11–13] A further set of considerations relates to how AI use cases may shape how users think and feel about their health status and health behaviors, e.g., whether self-monitoring features, depending on how they are framed and implemented, could support or threaten experiences of autonomy and agency.[6,14]

These ethical considerations relating to privacy, informed consent, bias, and autonomy have been repeatedly highlighted in the AI-mHealth literature; however, the ethical perspectives of the stakeholders in direct-to-consumer AI-mHealth who arguably stand to assume most of its benefits and risks – end users – have yet to be adequately explored in the empirical literature.[15] A scoping review of studies assessing user views of AI-mHealth applications identified a number of likely barriers to adoption related to user-centered explainability, trust, empathy, usability, privacy, AI accountability, and diversity of model training and test populations.[16] Importantly, the study revealed that AI-mHealth user research has been largely limited to quantitative studies that evaluated specific dimensions of user experience collected via structured questionnaires and performance metrics generated by the applications, which tend to rely heavily on researchers' a priori assumptions about what the major user considerations are.

The small body of published qualitative work has employed interviews of actual or anticipated users of direct-to-consumer AI-mHealth applications to shed light on their attitudes and perspectives, yielding several ethically salient insights. An interview study of university students by Nadarzynski et al. explored their attitudes toward hypothetical conversational AI applications. The study identified several sources of hesitancy related to AI interactions (lack of empathy and understanding, especially in mental health use cases) and accuracy and quality concerns, as well as perceived advantages around anonymity, convenience, accessibility, and guidance toward relevant health services.[17] In semi-structured focus groups with young people about their attitudes toward AI-mHealth apps, Gotzl et al. found nuanced attitudes toward data sharing and safety: participants reported willingness to share their data provided that it would truly support their health interests, and expected transparency about how their data was being used, discretion in requesting more sensitive data, and user controls for personalization features.[18] In a report by Tsai et al. focusing on users' needs related to explainability in AI-enabled symptom checking tools, interviewees reported that they often felt confused by the order and content of the differential diagnosis questions asked by these applications,

and hesitated to trust the accuracy of their results due to low transparency about their reasoning procedures and underlying data.[19]

As AI advances, direct-to-consumer AI-mHealth applications may create more opportunities to improve population-wide health awareness, disease prevention, and wellbeing. In order to realize these aspirations, it is essential to engage with the end users who the tools are intended to help, and to develop a comprehensive picture of the views of the end users of direct-to-consumer AI-mHealth applications, including their own ethical perspectives and reservations or anxieties that may remain overlooked and pose barriers to adoption. Although previous qualitative study designs have focused exploration on users' views on specific use cases and/or topics of ethical importance, no single study has examined their ethical perspectives on AI-mHealth broadly. Therefore, in this paper we set out to describe, using semi-structured interviews and a qualitative descriptive approach, the topology of ethical considerations of individuals who have experience interacting with mHealth applications with respect to AI-mHealth.

Methods

Study Design

The findings presented in this paper were collected and analyzed as part of a larger study that aimed to identify and articulate ethically laden sentiments and anticipated issues of AI wellbeing applications in the workplace from the perspectives of current and future end users. This study addressed a supplemental aim to an ongoing study about the ethics of AI use in medicine (NCATS R01-TR-003505).[20] To accomplish this aim, we conducted semi-structured interviews with existing users of AI-mHealth applications (N=21) to identify and describe their perspectives relating to ethical dimensions associated with the use of such applications, specifically in the workplace.

A qualitative descriptive approach was applied to the study design, as this approach emphasizes the description and analysis of stakeholders' experiences and perceptions using language and ideas that emerge directly from the stakeholders themselves.[21,22] Whereas other methods of qualitative research and analysis prioritize the development or advancement of theory, qualitative description allows for the emergence of new knowledge that may not be readily available from theoretical deduction and are grounded in the experiences of participants.

Recruitment and Participants

Adults aged 18 years or older who reported current or prior use of a mHealth application were eligible to participate in this study. Participants were recruited for this study via an electronic advertisement posted to the Stanford Psychiatry Department's "Currently Recruiting Studies" web page. The advertisement described the study and contained a link to a web-based screening survey, and was posted from August 1 through August 29, 2022.

A total of 32 individuals completed the screening survey; 31 met the eligibility criteria for participation. All eligible individuals were contacted via email to schedule a Zoom interview; of these 21 scheduled and completed an interview. Interviews continued until the target sample size of 20 was met. At that point, interviewers jointly determined that content saturation had been reached, as no new substantive themes were emerging from additional data collection.[23] The demographic information of participants can be found in Table 1. The final cohort of participants included young adults, with a range of participant ages between 20 and 36 years old, and was primarily composed of individuals whose reported sex was female (N=15), and whose reported race was Asian (N=8), Black

(N=5), or multiracial (N=4).

Table 1. Participant demographics.

	Overall (N=21)
Age	
Mean (SD)	26.8 (4.98)
Median [Min, Max]	26.0 [20.0, 36.0]
Missing	2 (9.5%)
Sex	
Female	15 (71.4%)
Male	6 (28.6%)
Race	
Asian	8 (38.1%)
Black or African American	5 (23.8%)
White	3 (14.3%)
Multiracial	4 (19.0%)
Other	1 (4.8%)
Ethnicity	
Hispanic or Latino	1 (4.8%)
Not Hispanic or Latino	20 (95.2%)
Education	
High school degree or equivalent (e.g., GED)	1 (4.8%)
Some college, no degree	5 (23.8%)
Bachelor's degree (e.g., BA, BS)	6 (28.6%)
Master's degree (e.g., MA, MS, MEd)	4 (19.0%)
Doctorate (e.g., PhD, EdD)	1 (4.8%)
Associate, Technical, or Vocation degree (e.g., AA, AS)	3 (14.3%)
Missing	1 (4.8%)
Employment	
Employed full-time (35 or more hours per week)	10 (47.6%)
Employed part-time (up to 35 hours per week)	4 (19.0%)
Unemployed and currently looking for work	1 (4.8%)
Student	8 (38.1%)
Stay-at-home parent	1 (4.8%)

Note:

Participants were allowed to select more than 1 answer for the Education question, thus the total percentage may be greater than 100%.

Procedures

Semi-structured interviews were used to facilitate discussion that encouraged participants to reflect on their experiences and opinions, and to allow them the flexibility to focus on topics that they found the most important. This approach allowed interviewers to ask unscripted follow-up questions where relevant, or to skip questions that did not apply in the context of the conversation. By conducting interviews via Zoom, participants outside of the local area were able to participate in the study.

The semi-structured interviews contained 4 sections: A baseline question set; two video vignettes and associated question sets; and a comprehensive question set (See Figure 1). In order to stimulate discussion of ethical considerations among a population that may not have encountered AI use cases in mHealth previously, two video vignettes demonstrating the use of example AI-enabled workplace health interventions were utilized. The presentation of these video vignettes was followed by ethically salient questions related to the presented technology (e.g., questions relating to understanding, trust, and autonomous decision-making).

[insert Figure 1]

Interviews were conducted between August and September 2022 by one of our team's 3 trained interviewers. The interviews lasted 75 minutes, 35 seconds on average (ranging from 35 to 131 minutes) and were audio recorded for the purposes of transcribing.

Data Coding and Analysis

Auto-transcriptions created by Zoom were reviewed, edited, and de-identified by a member of the research team. Data analysis was guided by the principles of qualitative content analysis.[24] This inductive approach, in which transcribed data are broken down into descriptive units that are named and sorted based on their content, allows for the emergence of codes and themes directly from the data set.[25] As we were primarily interested in identifying and describing ethical considerations of AI-mHealth users that have been under-explored in the existing literature, this inductive approach was selected over a deductive approach which would have relied more heavily on a priori assumptions about user priorities and perspectives.

An initial round of open coding was performed on each transcript by 2 authors. The authors reviewed their assigned transcripts independently, identified interview content that they felt was substantive, and suggested descriptive codes for this content. The authors then met as a group to discuss the descriptive codes that emerged during open coding and to compare the content associated with each code. They collaboratively identified topics that recurred throughout the transcripts and established preliminary code names and definitions for these topics. The transcripts were then rereviewed by the same 2 authors utilizing the preliminary codes and definitions as a guide. At the completion of this phase of intermediate coding, the authors met as a group to compare the coded units, further refine the code names and definitions, and draft the final version of the codebook.

The final version of the codebook contained 37 codes derived directly from the content of the interviews describing baseline characteristics, and tool-specific, personal, and contextual factors influencing participant attitudes toward AI-mHealth. The transcripts and codebook were then uploaded to NVivo 1.0 (QSR International) for final coding, which was completed by a single research team member and then reviewed for consistency by a different team member.

Data analysis began upon the completion of coding. A conventional qualitative analysis approach was used to guide the analysis.[24,25] At the completion of final coding, all authors met as a group to

analyze the content and meaning of the coded units, and to develop categories and themes that described the associations between units. This process resulted in the identification of three "buckets" detailing different aspects of participants' experiences and attitudes toward wellbeing AI (See Table 2). For the purposes of providing an accurate and in-depth analysis of the content of these interviews, this paper will only address the codes, categories, and themes associated with Bucket 1; Those associated with Buckets 2 and 3 will be analyzed in future publications.

Table 2. Inductive coding groups and codes describing users' perspectives toward wellbeing AI.

Number of interviews cited in (N=21)	Codes used in development of bucket
Bucket #1: User attitudes toward AI-mHealth	
21	Data collection
21	Data use and sharing
20	Availability of information
20	Experience with mHealth apps
20	Explainability of model
20	Regulation
20	Research participation
19	Potential benefits
18	Accountability
17	Attitudes toward AI
17	Potential risks
16	Trust in institutions or entities
13	Understanding of and familiarity with AI
12	Potential of AI
11	Value
9	Perceived ubiquity of technology
8	Financial or economic factors
3	Influence on mind or behavior
Bucket #2: Ethical concerns relating to wellbeing AI in workplace settings	

21	Workplace-related factors
20	Trust in tool
18	Bias
18	Data security and privacy
16	Autonomy and agency
15	Social identity and stigma
10	Trust in intentions
9	Personal health
9	Personal qualities or traits
7	Life stage
6	Social or historical context
3	Accessibility
Bucket #3: User attitudes toward features of wellbeing AI tools in workplace settings	
21	Degree of user's control
19	Intrusiveness
18	Personal context
18	User Experience
17	Optimization
17	Type of intervention
3	Physical context

Ethics Review

This study obtained human subjects research approval from the Institutional Review Board of Stanford University on June 21, 2022 (#58118). A copy of the IRB-approved informed consent form was emailed to all potential participants prior to the interview; Interviewers then reviewed and explained the content of the consent form with all participants at the start of the interview using the screen share function on Zoom. All participants signed an electronic consent form prior to the start of study-related procedures. Participants were compensated in the form of a $50 electronic gift card.

Results

All participants in this study commented on considerations related to Bucket 1: User attitudes toward

and understanding of AI-mHealth (see Table 2). These considerations primarily arose from responses that emerged in Parts 1 and 4 of the interview question set (i.e., the baseline questions at the start of the interview and the comprehensive questions at the end of the interview; see Figure 1). In discussions relating to attitudes and understanding of AI-mHealth, 3 major categories, each with 3 related subcategories, emerged (see Figure 2). The content of these categories and subcategories are described in detail below.

[insert Figure 2]

Attitudes toward the impact of AI-mHealth on user health and data.

Influence of AI on health awareness and management. Participants expressed positive sentiment toward the potential for AI-mHealth applications to support health awareness, health maintenance, and preventative care. Several users acknowledged the value of AI-mHealth in encouraging users to take steps to manage their own health, with one participant noting that 'Sometimes we can't acknowledge the moment ourselves," (101) and another noting that a major benefit of the incorporation of AI into mHealth is its ability to "[help] you know when you should be thinking about your mental health and wellbeing." (130)

While improved health awareness was perceived as a benefit of AI-mHealth applications, participants also described ways that they felt such technology could undesirably influence their health behavior. While some participants referenced having "blind trust" (096, 117) in AI-mHealth to manage aspects of their health, others emphasized that AI-mHealth applications should act as a supplement to an individual's health management, with one user noting, "Any AI use should just be a healthy sidestep to us taking control of our mental health versus taking over and trying to do it for you." (130) Another described a desire to feel in control over the management of their own health and explained how AI-mHealth could interfere with feelings of autonomy:

> "Part of me doesn't like to have too many orders. I like having the ability to choose a bit… When it comes down to health, my body and my movements, that's one of the main things that we can control, that we should control. And someone telling me to 'Do this right now,' it's just *eh*. The way I view health is as an investment in myself, but I also want to do that, I want to invest in my health. I want it to be voluntary in that sense. And just having [technology do that instead] makes me feel like a robot, just not completely autonomous." (101)

Perceived value of AI for mental versus physical health. When discussing their attitudes toward AI-mHealth applications, users differentiated between the domains of mental health and physical health. Multiple users noted that physical health could be more easily quantified than mental health, thus making mental health more complex and difficult to measure. Users commented that "Physical health is more quantitative and mental health is more qualitative…there is so much more to unpack from it than just a number for physical health," (101) "Mental health is, more often than not, harder to measure than physical health," (104), and "Technology can compensate for physical health, as opposed to, mental health can become so complicated." (130) Several users noted that, because of mental health's resistance to measurement and quantification, they would be more skeptical of AI-mHealth recommendations for mental health, and more accepting of recommendations for physical health:

> "[AI] could work for certain things but…It maybe needs more work on other aspects, especially when it comes to emotions and people's decisions. In math, it totally works. But if it can tell you when you're going to have this episode of sadness or happiness, I'm not very sure about that." (118)

"Physical health has been a lot more black and white. When I get a suggestion for my physical health, I don't question it as much. I am more likely to accept it…I am less hesitant about software that is telling me to do a physical activity." (101)

Users further emphasized that they would desire the ability for greater personalization, customization, or control of AI-mHealth applications which target mental health, with the above user noting that "With the mental health app, I want it to be more customizable. I feel like it requires more factors to consider before suggesting or working." (101)

Resignation regarding the collection of personal data. Users expressed a reluctant acceptance toward the amount and type of personal data collection that occurs while using AI-mHealth applications. Although many described discomfort regarding the volume of data collection, they acknowledged that it felt "unavoidable" due to how deeply ingrained this process is in modern technology use (See Textbox 1).

Textbox 1. User quotes regarding data collection.

097: "[Sharing data] feels unavoidable to me unfortunately. I don't feel great about this but it feels like there's some of my data that I will just have to give up."

101: "I feel like our generation is so used to using applications and we don't really question what happens with [our data]."

105: "Ideally I don't want that to happen, but I think in reality they already have access to all of our data."

106: "I am very into providing my data for research purposes, because I know that [data collection] is still happening anyway.

114: "I already know companies use my data to sell, but that's just also inevitable."

124: "I honestly just think it's so much a part of everyday life. I would not say I am 100% comfortable with all the data collection that is happening."

131: "I don't particularly want data that isn't already out there to be going out there…I deeply hate that expectation of handing over [my] data about what I am doing."

Several users admitted a conflict between their theoretical preferences relating to data collection and sharing, and their actual use of technology, with one user summarizing: "I feel like in theory I care a lot about how my data is being used, what type of data, who it's being sold to. In practice, I feel like I don't really know what kind of data [the apps I use] collect." (097) A different participant acknowledged that, while data sharing likely would not incur any real risks, their negative feelings toward these practices were based "on principle" and their desire to feel as if they have control over information about themselves:

"When I think about data privacy, it comes more down to the principle of wanting my information to stay private and not feel like I am being tracked all the time. Because in reality when I think about it, nothing terrible seems like it is going to happen if my information is going to be used other than them telling me what to buy. It is not a huge issue, but it is almost

the principle of the thing, and wanting to feel like you have ownership over your day-to-day and it not being up to outside controlling factors." (130)

Influences on user trust in AI-mHealth applications

Doctor or expert recommendations. Multiple users agreed that recommendations from doctors or other health organizations would increase their trust in an AI-mHealth application and their willingness to use it, with one stating that "having some kind of affiliation with an actual medical professional does actually instill a little more trust and make you more willing to share your information." (130) Several users specifically mentioned that they would be more comfortable sharing personal health data with applications that were recommended to them by a trusted physician. As one user described:

"Depending on the original intent of the app, if it greatly benefits my health, if my therapist told me to use this specific app and then I saw that it had great improvements in my health because it tracked my specific triggers or mental health and it took record of everything, I don't think I'd question the data that is being collected." (114)

One user specifically referenced the FDA approval of AI-mHealth applications, commenting on how the regulatory process of FDA approval gives them confidence and has the potential to give other users more trust about using such applications:

"One of the applications I used is a FDA approved method for tracking something. That gives me a lot more trust. For AI situations where it is making recommendations based on your health, it should be like any other thing. Drugs that increase your mental wellbeing, those are FDA approved. It should go through the same scrutinizing process and the same regulatory process as well. I think the public would be more willing to use it too." (096)

Attitudes toward technology companies. Users expressed mixed levels of trust in companies that develop AI-mHealth applications. Several users saw the reputation of large companies as a reason to have trust in being a consumer there, because these companies were "reputable and reliable." (114) Two participants specifically referenced feeling more comfortable sharing their data with larger, established companies, noting that "I would feel safe…if it's a reliable company like Google," (127) and "A big company that people would know, I would feel comfortable sharing the information." (130) Although most users did not provide additional details about why they trusted larger companies, one participant acknowledged the advantages that large companies have that may keep user data safer: "The paradoxical part is I'd rather almost want it to be Amazon other than somebody I don't know, because I know that Amazon is large enough and asks the employees to do a better job at keeping my data safe from outside people." (131)

Others described mistrust in technology companies based on their perceptions about how these companies collect, use, distribute, and profit from users' data, with one user stating "they use all this data to benefit their company and they have all this money, but none of the users receive it… I feel like they are just using [our data] for personal selfish gain without it really benefiting anybody except their own company." (114) Another cited the history of such companies benefiting from the collection of personal user data as evidence against trusting them to genuinely work toward creating benefit for their consumers:

"All the mental health applications, we can see that they want to earn money. I think the consumers that are looking for mental health services in any kind of different formats, including applications, are essentially looking for a little more authenticity in their services

because it is mental health care. If the consumers can see they profit over us, once they see that, it's like, 'I don't really trust this service.'" (106)

Explainability of AI. When queried about the importance of understanding the rationale behind an AI-mHealth application's recommendation, users indicated that this type of explainability was not relevant to their trust in the application. Users acknowledged the complexity involved in AI decision-making, and did not think that having increased access to that information would be beneficial to their trust or understanding. There was agreement that they would trust AI recommendations as long as they felt reasonable (See Textbox 2).

Textbox 2. User quotes regarding the explainability of AI.

> 97: I can appreciate the fact that a complex algorithm is a black box, but as long as I know that their training sample was diverse and big enough and their results are interpretable and make sense I don't mind as much. I think it's fine that they don't know what is happening.
>
> 104: I've learned that the neural network is a black box. You can only know what you add in and what you get out of it. It's still a mystery to everybody. I have accepted that with the AI tools that I have used in the past. If the conclusion isn't outrageous and I think it's useful, I'll do it.
>
> 105: I believe the rationale for the AI is based on a bunch of different factors and I don't think I'm interested in learning which factors weigh a little bit more than the other.
>
> 124: It's the zeros and ones in the computer. How can I interpret that and equate that with the human thought process? It's not possible.
>
> 126: I honestly don't care as long as the actions and recommendations don't seem ridiculous, I would not care about the exact reasoning.

Several users additionally conveyed tolerance for the "black-box" limitations of AI recommendations, noting that humans often cannot explain exactly what drives their intuitions and judgments and extending this idea to AI: "There are some things that we think about and we can't really explain our reasons for it…We don't really know how to quantify certain things, so I can't completely blame the AI for having a black box concerning my data either." (114) Multiple other users similarly compared the limits of explainable AI to the covert processes of the human brain:

> "It is sometimes really hard for even the software engineers to design the specific algorithm to know exactly what is going on in that thought process. It is really hard for even us to walk someone through, 'I thought about this and then this thought led to that, because of the specific factors...' It is really hard even for ourselves to talk that through." (106)
>
> "[Humans] can't always pinpoint exactly where something comes from, where an idea comes from, where feelings come from. If I'm being empathetic to the AI, I would be like, 'Yeah I get that. You don't know where this suggestion is coming from but you feel like it's correct.' I would probably trust that." (115)

Preferences related to information sharing in AI-mHealth

Type of data being collected and used. Several participants clarified that, while they felt comfortable with not knowing *how* an AI application makes a decision, it was important for them to

understand *what personal data* was being collected and used in such decisions. As described by these participants: "The initial information they are collecting I would want to know. How those decisions are made, I definitely can understand that that would be too complicated to be explained. That I don't really mind," (130) and "It wouldn't be too much of an issue if they can't explain how it's making the decision, but at least knowing what is being considered in the process would give me some peace of mind." (101)

One of these users wanted to know "What information do they need from me to decide?," (130) while other users summarized " I would love to know what kind of data is being taken in," (127) and "I would really appreciate knowing what behaviors and responses they are using to create that output…I think people 100% deserve to know every piece of data they are using and knowing what that is for." (097) Several others described how being provided with information regarding the type of personal data that is being collected and used in an algorithm's decisions would increase their willingness to consistently use an application. (096, 117, 120)

Future uses of personal data. Many users expressed a desire to have access to information regarding the potential future uses of data collected via their use of AI-mHealth applications. Specifically, they wanted to know if personal data collected by an application would be sold to or shared with other corporations or entities (See Textbox 3).

Textbox 3. User quotes regarding future uses of personal data.

097: "I would like to know if the applications that I'm sharing data with have plans to sell that data."

104: "[I want to know] what it's being used for. And I think it should only be used for the optimization and my de-identified data should be used for the training of the model to make it more accurate, better for future uses."

106: "I really would like to know what data are being collected and how exactly they are being used. Because I don't want my health data to be floating around."

111: "I would love to know who is the end user of my data. Has my data been sold to another person?"

114: "I really want to know specifically how they use it. Are they selling my data, what agencies or companies have access to that? What is the background of these companies? Are they just going to spam email me, put it on the dark web? I really want to know the security of that."

120: "How are you using my data, is it going anywhere where it's identifiable?"

127: "We are hearing stories that they are selling data. I would love to know if the data that is collected, is it being sold to hospitals or is it being sold to the black market? If it is sold to a hospital for further research then I will be okay with it, but if the app is using it for other malicious activities, that would be very wrong."

Multiple users discussed how the collection of highly sensitive health data increased their level of concern about its potential sharing or selling to third parties and their desire to know whether this was occuring. Three users specifically mentioned menstruation tracking applications as examples of

health applications where concerns of data being shared or sold involved additional and/or elevated risks (097, 114, 115). One participant argued that exposing sensitive health data to third parties could lead to serious social, legal, and medical harms:

> "[I would want to know] who has access to that data. I read some discourse about the banning of abortion and then they were telling people to delete period tracking applications because if they're able to detect when you're on your period or trying to get an abortion, you could legally be arrested for that…If [the company is] able to sell that data or give the government access to that, it could potentially put certain people in danger." (114)

Accessibility of information. Users expressed a range of suggestions about how companies might better communicate to users about the collection and use of their personal data. Multiple users described the lack of engagement that users have with traditional terms and conditions pages, noting that "Many people just don't read them, and I am one of those people usually," (115) "For me, and probably a lot of people, [when] reading those small text notices, I always push 'agree' and move on, " (096) and "A lot of people blow through that stuff and are like, 'Yes, yes, accept.'" (120) The length and complexity of these agreements were frustrating to users, with one commenting that "I just don't like how a lot of us aren't really informed how our data is being used, and then they make it so complicated to the point where we don't really look through it." (114)

Several users described wanting to receive clear and digestible information regarding the risks and benefits of AI-mHealth applications as a more straightforward way to understand considerations related to their data. As described by two users, "It would be good to know the risks and benefits," (096) and "[I would like] an explanation of pros and cons, rather than a sales pitch-type view of it," (124). Other participants commented that companies should provide a "condensed version" of the terms and service agreement that "just gives the bullet points," (101) with one participant noting how a shift toward providing more accessible information could demonstrate a company's concern for and efforts to safeguard users:

> "Privacy policies are often not very accessible. I want to see, not just do you provide the information, but do you provide it in a way that is clear with its language which to me also expresses that you care about what you are doing with the data? [To see] if you take the time and energy to make something that people understand because you care about conveying that information." (131)

One participant further expanded on their request for more accessible information regarding the risks, benefits, and data policies of an AI-mHealth application, and posed an analogy to the informed consent process they completed for the present interview study:

> "I want the app to highlight the very important data that they will be collecting and to put that into layman's terms so that I can just understand it very easily. Not in a 3-page article, those 10-point fonts. No. I am thinking of something like the informed consent procedure that you just did to me. The document itself looked pretty intimidating honestly. It is full of study research terms that the general public would not be willing to understand. But what you did when you started this interview is like, 'I am going to point out some important things that you need to know.' You highlighted the components I really needed to know as a study participant. I was given the opportunity to understand it in more precise and simple terms and also, if I have to, I can ask follow up questions. If the app could do something like that, like 'these are the comprehensive things you need to know about risks and benefits of the app, here are the key points,' if it can be that transparent and simple, that will definitely boost my

trust and credibility as the app's consumer." (106)

Some participants suggested technology- and media-based alternatives to the current text-based terms of service agreements that they felt would provide information relating to risks, benefits, and how personal data is collected and used, in a more digestible and accessible format. Two suggested videos as an alternative to text, (096, 115) with one noting that this format could be useful for "forcing" users to engage with the information: "If it were presented in a really digestible way where you were basically forced to read it or hear it if you use the app, like a video where you couldn't move on unless you play the whole thing." (096) Multiple other participants commented that applications could have associated websites where users could look up information if questions arise through their use of the application, with one noting "It would be great to have a resource that is just live all the time. A website where you can access that information and then contact them if you have questions that aren't answered on their website." (120)

Discussion

Principal Findings

In this semi-structured interview study, users expressed attitudes and concerns about a number of ethical considerations related to the use of AI-based mHealth applications, including considerations related to autonomy, privacy, trust, transparency, and information sharing. The major findings are discussed in detail below.

The value of AI-mHealth: Perceived limitations of applications for mental health. Interviewees expressed comfort with the idea of using AI-mHealth applications to supplement their health management, citing their value in organizing and tracking health data, and providing users with prompts or knowledge that could benefit them. Several users were adamant that AI-mHealth should supplement rather than replace healthcare services, and preferred technologies that encouraged informed and autonomous health decision-making, as opposed to more assertive recommendations, which they felt could be perceived as orders that could ultimately detract from health awareness. This finding aligns with prior research by Almourad et al. (2021), which found that users' feelings of increased self-awareness and a sense of control over the usage were acceptance factors in their use of mHealth technologies.[26]

Users in our study notably distinguished between the potential value of AI-mHealth applications designed for physical health and those intended for mental health. Strikingly, some were less confident that AI could be as effective for mental health use cases compared to physical health use cases. They perceived mental experience as highly personal, intimate, and resistant to observation and measurement (admitting also the limits of human introspection), and therefore did not feel that AI-mHealth applications could "know" them well enough to make accurate inferences that lead to helpful predictions or guidance. These attitudes have not been previously identified in the existing literature on user views of AI-mHealth applications, and suggest that users may be more hesitant to accept predictions and guidance that rely on AI inferences regarding more subjective and phenomenal mental processes (e.g., underlying emotions or affective states) compared with applications that target physical health. The design and implementation of AI use cases for mental health will benefit from additional empirical inquiry to help understand how users think AI can benefit this domain and to develop a clearer picture of ethically salient factors that may influence adoption.

AI use of personal data: Resignation and mistrust. There was a general admission among interviewees that, as users of modern technology, they often must concede control over their data and

its future uses. They expressed discomfort with the fact that personal data is systematically collected through their devices partly to help advance corporate and business interests, but expressed resignation about their ability to prevent or change this reality. These attitudes have been documented frequently in the technology literature, having been described as privacy cynicism,[30] digital resignation,[31] privacy apathy,[32] and privacy fatigue.[33]

Participants in this study further described how the pervasiveness of data collection and sharing influence their trust in not just with specific technologies, but with the corporations or entities associated with them as well. Some expressed greater trust in large companies that they believed were better suited to protect their data, while others asserted no trust in these same companies due to their historical collection of user data. This too is consistent with findings from the technology literature, which have found mistrust in corporations which users associate with data sharing. As was described by Lutz et al. (2020) in their survey study, the potential benefits of an individual technology or application may be trumped by "mistrust and powerlessness in relation to those platforms ostensibly providing the infrastructure." [34] Although a recent user-review analysis found an overall high degree of public trust in individual AI-mHealth applications for mental health, our results along with findings from the technology literature indicate that there are users whose attitudes toward AI-mHealth are influenced by their existing trust, or lack thereof, of large technology companies.[35] More research is needed to assess how the systematic collection and distribution of personal data has contributed to users' trust or mistrust in technology companies, and the impact that this may have on their trust in and adherence to AI-mHealth applications.

User desire for information: Understanding *what,* not *how*. Prior interview studies with users of AI-mHealth identified their desire for clearer information about applications' AI, as well as an explanation for how, and how well, they work.[36] Participants in our study expanded on this finding, as they distinguished between the specific types of information that they preferred. While they were not concerned with *how* an AI-mHealth application was making a decision, many users had questions about what type of data it was collecting and using to make its recommendations, and whether this data was going to be shared or used for other purposes in the future. This distinction was consistent throughout interviews, and demonstrated that users may have less interest in the explainability of an AI algorithm, and more concern regarding what personal data is being collected and used. Although prior research has elevated the necessity of explainability for establishing user trust, especially in healthcare contexts, experimental studies with users of AI technologies both inside and outside of healthcare have demonstrated that increased explainability is not always beneficial to user understanding, decision making, or trust. [37–39] Our results provide additional context for these findings, and further indicate that explainability may not be necessary for user trust, provided that answers to users' questions about the collection and use of their personal data are available. Future studies testing these factors specifically will be useful for determining whether users do benefit from increased explainability, or whether simply providing more information about their data confers the same benefits.

Beyond noting that understanding an AI's decision making process was not important to their trust in a tool, several participants in this study further expressed empathy toward black-box decision making, relating it to human intelligence and decision making processes. A qualitative interview study by Gkinko and Elbanna previously documented the tendency of humans to extend empathy to AI chatbots in the workplace, however, the relating of black-box AI decision making to human intelligence appears to be a novel finding that has not been previously documented in the literature.[40] This finding is especially interesting in the context of understanding user attitudes toward explainability, for although it has been assumed that users will require explanations from technology in order to establish trust, this finding provides a reminder that humans are accustomed to decision

making processes that cannot be fully explained, and that willingness to accept decisions that are reasonable yet not explainable may extend to their interactions with AI.

Informing users: Concerns and recommendations. Users in this study repeatedly acknowledged that they do not read terms and conditions pages, which they felt were overly lengthy and not designed for the purpose of informing users. Participants offered a range of alternatives for how they would prefer to be informed about the use and future distribution of their personal data. Instead of lengthy terms and conditions pages, lists containing a summary of the risks and benefits or pros and cons of an application were suggested, as were videos or accessible websites. As highlighted by several participants, the inclusion of easily digestible lists or videos regarding risks and benefits of use is a fairly minor addition to an application that could be incorporated before or after existing terms and conditions pages. These changes could have an impact on users' trust in a tool and willingness to use it and incorporate its recommendations.

One participant referenced the informed consent method that is typically used in medicine and research when discussing how information sharing in digital health technology could be improved. Informed consent forms share similar downsides to Terms and Conditions documents, in that they often require the inclusion of specific language which is intended to protect the institutions funding and completing the research and is not necessarily relevant to participant understanding or decision-making. Studies testing shorter consent forms have found that participants were more likely to fully read shorter forms, and that those exposed to shorter forms comprehended more of the information, indicating that length of the terms and conditions pages could be a primary factor in users' tendency to bypass them without engagement.[41] Furthermore, the accompanying informed consent process in which the information in informed consent forms is distilled into accessible language that highlights the risks and benefits are often positively rated by participants, indicating the terms and conditions pages which are followed by summaries highlighting the information relating to specific risks and benefits may be well-received by users of AI-mHealth applications.[42,43] Informed consent processes are established within medical practice and research and could provide a useful roadmap for AI-mHealth applications which may require both templated legal disclosures and access to product information which encourages participant engagement and understanding.

Limitations

This study has several limitations relating to its sample. Most notably, all participants were between the ages of 20 and 36 at the time of the interview. It is documented that attitudes toward technology are influenced by age and life stage, so the findings from this study should therefore not be generalized to older populations.[44,45] Our sample was furthermore primarily female and minorities. As we did not specifically intend to prioritize the interviewing of these populations, the attitudes documented in the interviews and analysis should not be assumed to be representative of all users of mHealth applications.

Conclusions

In this qualitative study utilizing semi-structured interviews, users expressed their attitudes and concerns about a number of ethical considerations in the use of AI-mHealth applications, including considerations related to autonomy, privacy, trust, transparency, and information sharing. Notably, users distinguished between the potential value of mental and physical AI-mHealth applications, cited existing feelings of loss of control and ownership of their data in everyday use of technology that appeared to influence their trust in AI-mHealth broadly, and expressed a desire for more proactive and accessible information sharing about aspects of AI-mHealth applications. These findings present recommendations for consideration in the development and distribution of AI-mHealth applications that may enable greater ethical alignment between producers and consumers of

AI-mHealth applications. Future evidence-based research examining the intersections between mHealth and AI with the attitudes of relevant stakeholders is still needed, as is research that analyzes how the actual use of AI-mHealth applications aligns with the ethical perspectives identified in this study.

Acknowledgments

Conflicts of Interest

None declared.

Abbreviations

mHealth: mobile health
AI: artificial intelligence
AI-mHealth: AI-enabled mHealth

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