

“Predictive ads are not doctors”: Mental health tracking and technology companies

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Abstract

Although using mobile phone apps to track and monitor mental health is increasingly popular, we know little about how and why people with mental health diagnoses use such technologies, nor do we know of concerns they may express about these apps. Further, automated assessments of mental health status, or digital phenotyping, are also on the rise; how people with mental health conditions feel about such technologies is also an underexplored area of research. This paper presents an exploratory interview study with 12 people that begins to address these gaps. We focus specifically on how participants, who all have been diagnosed mental health conditions, perceive tech companies' involvement with existing mental health apps and mental health digital phenotyping. We find that participants satisfice in order to interact with existing mood tracking apps, and that they are wary of digital phenotyping for mental health diagnostics. Participants raise concerns related to profit motives, distrust, and fatalism in both cases, and they recommend regulations that may be put in place to keep tech companies in check. Though participants describe regulatory policies that may mitigate their concerns, we question whether regulations can truly foster sustainable interactions with mental health apps operated by technology companies.

Introduction and background

The promotion of mental health and well-being is a significant component of the United Nations 2030 Agenda for Sustainable Development (United Nations, 2015). While mental health issues are common world-wide, they can be difficult to diagnose and treat. This is partly because of stigma, marginalization, and access difficulties (Ahrensbrak et al., 2017; Henderson et al., 2013). Mobile phone technologies like mood tracker apps and automated assessments of mental health status using mobile phone trace data, or digital phenotyping, have been touted as innovative strategies for tackling these problems (Rebello et al., 2014). There are many different types of mental health tracking technologies; in this paper, we define mental health tracking apps as either (1) apps that people use to manually log their moods and/or other data in support of their mental health; and (2) automated tracking technologies that algorithmically infer mental health status using mobile phone trace data.

In the mental health domain specifically, research on mood trackers often tests the efficacy of a specific app, provided as part of a health intervention, in order to understand the benefits and drawbacks of mood or other data tracking for a particular mental health condition. This research is clinically focused, but mood tracking and wellness apps are widely available and used without involvement from clinicians (Lupton, 2014). These apps are marketed as a method for promoting mental health and wellness by way of *sousveillance*, or self-monitoring and collecting data about one's activities, moods, or biological processes (Ajana, 2018). Apps sell the hope or promise of mental wellness to users by offering self-awareness, control, and agency over one's mental state, rendering mental health a commodity that individual people can objectively measure and control via self-quantification (Fotopoulou & O'Riordan, 2017). While some mood tracking apps refer to evidence-based treatments in their premise (e.g., cognitive behavioral therapy), a comprehensive view of mental health mobile apps found that no commercially-available apps were actually supported by empirical evidence (Ameringen et al., 2017).

Existing research on mood tracking rarely involves people who actually use these apps outside of a clinical setting. Instead, researchers design clinical interventions that typically measure the impact of a specific mood tracker on factors like one's overall mood, illness self-management, or treatment compliance (Firth et al., 2017; Gould et al., 2019). While these interventions provide valuable data about the efficacy of a given mood tracker for a particular mental health condition, their findings do not necessarily extend to people who choose to use, or not to use, mood trackers without involving their healthcare providers. There are differences between the clinical community and the general public; interventions focus only on the available clinical population (Bakker et al., 2018). To understand how mobile technologies could be or are used for mental health in the general public, data from other samples is necessary. Given their design, these interventions also have limited potential for elucidating the concerns that participants may have about using mental health apps. In a survey on mental health app use outside of the context of an intervention, patients listed privacy as their primary concern about apps (Torous et al., 2018). As this was a survey that took place in a clinical setting, the ability to contextualize or fully explicate what participants specifically meant by "privacy concerns" is limited.

Beyond self-tracking one's mood, it is now also possible to algorithmically infer someone's mental health status using mobile phone or app trace data (Gomes de Andrade et al., 2018; Rickard et al., 2016; Singh & Long, 2018). There is great interest from both the commercial sector and government agencies in digital phenotyping, or automated mental health assessments that infer one's mood based on the trace data they generate when interacting with their mobile phone or other Internet-enabled devices. Such inferences are currently used to detect and intervene in serious mental health crises (Gomes de Andrade et al., 2018), in non-crisis situations, like flagging depressive states for diagnostic follow-up by a healthcare provider (Singh & Long, 2018), and for self-monitoring one's own well-being without requiring manual mood tracking (Rickard et al., 2016). Advocates of digital phenotyping for mental health say that such technologies can be used in public health interventions to promote mental health and well-being and for delivering and enhancing individual mental health services (Rebello et al., 2014). For example, for over ten years, Facebook has monitored for suicide risk (Card, 2018). In

cooperation with local law enforcement, Facebook has initiated over 1,000 wellness checks in response to proactive reports on their platform: people alerting Facebook that their friends seem unwell and at risk. Now, Facebook is moving into the reactive assessment space by developing machine learning models to identify when people are at risk, adding more automation to this process (Card, 2018).

Facebook isn't the only entity interested in advancing reactive automated mental health assessment. The United States government has discussed developing a new agency, the Health Advanced Research Projects Agency (HARPA), modeled on the Defense Advanced Research Projects Agency (DARPA), the military agency that develops military technology (Snyder, 2017). This agency plans to partner with technology companies to automatically detect and predict when people may be planning to carry out mass shootings. A recent news article named mobile phones; Apple Watches; Fitbits; and personal digital assistants like the Amazon Echo and Google Home as potential data sources for HARPA (Alemany, 2019). Using trace data as a diagnostic tool has serious implications for privacy, ethics, and justice; problems arise in automated tracking systems that use trace data in order to classify people by diagnosing them with certain health conditions (Bauer et al., 2017). Moreover, the link between the carceral state and mental healthcare in the United States is alarming; these technologies are poised to only further strengthen that link, despite calls for the contrary. The National Alliance on Mental Illness (NAMI), for example, lists unlinking the involvement of the justice system from mental healthcare as one of their three top policy priorities (NAMI Public Policy Platform, 2016). Digital phenotyping is also predisposed to discriminate against marginalized people, like Black people, people of color, and queer people (Benjamin, 2019; Huq, 2018; Keyes, 2018). Collection of tracking data, including health data, begets concerns related to financial, geographical, and technological digital divides (Ruckenstein & Schüll, 2017).

The objective of the current study, therefore, is to understand how people with mental health conditions feel about mental health apps that are owned and operated by technology companies. We ask two research questions in service of this objective:

- (1) Do participants currently use mobile apps to track their mental health? If so, how?
- (2) What do participants think about tech companies inferring their mental health status using mobile phone trace data?

The purpose of the first research question is to understand participants' current and ongoing relationships with technology companies as instantiated through mood trackers and other mental health apps. The second research question addresses what participants think about the development of automated mental health assessments made using mobile trace data. We currently understand little about what the people who will be most impacted by mental health digital phenotyping think about its development and use. It is critical to center the perspectives of people who have lived experiences with mental health issues in order to fully explicate the impact, both current and potential, of digital phenotyping in this domain.

Methods

In this exploratory study, participants with diagnoses of mental (and in most cases, co-morbid physical) health conditions were recruited on Twitter. They were directed to an intake questionnaire assessing their use of mood trackers or wellness apps on their mobile phones. Participants did not have to use a mobile phone, mood tracker, or wellness app to take part in the study. In the questionnaire, we also assessed their beliefs about the general impact of technology companies both on their personal health and on society by asking two similarly-worded questions: *Thinking about the impact mental health apps have had on [society; you personally], do you think the impact has been: more good than bad, neutral, or more bad than good?* From the 20 responses to the questionnaire, we selected 12 participants for in-depth, semi-structured phone interviews that averaged 48 minutes in length. Their ages range from 18-54 and participants are white (11), Latinx (1), and Pākehā (1). Our participants are women (6), men (3), and non-binary (3). We first asked participants about their current use, if any, of mental health apps on their phones. We then posed the following scenario to participants: *Imagine that, rather than entering your mood manually every day, your mobile phone could accurately determine your mood and record it, based simply on your interactions with the device—not the content of your phone calls or texts, but data like how often you look at the phone, the locations you visit, and the number of calls and texts you make and receive each day.* Follow-up questions like *“How would you feel if this service is owned and operated by a technology company like Facebook or Google?”* were then asked. Interviews were conducted by both researchers and transcribed verbatim. Pseudonyms were chosen by participants or assigned by the interviewers. Inductive coding and qualitative memoing were used to identify themes, and axial coding was used to develop thematic categories from the resulting inductive codes (Miles, Huberman, & Saldaña, 2014). This data is part of an ongoing grant-funded project investigating the use of mobile mental health assessment technologies; more participants are currently being recruited using theoretical sampling (Charmaz, 2014). Our study was approved by the Rutgers University IRB. Here, we present results that specifically relate to tech companies’ involvement in mobile mental health apps.

Results

RQ1: How do participants use mobile apps to track their mental health?

Ten of our participants currently use apps to track their mental health. Alex has tried apps in the past but currently keeps a mental health journal and does not use apps. Beth has tried apps and journaling in the past, and is our only participant who does not track her mental health currently. According to our recruitment questionnaire, eight of our participants felt that using mobile apps to track their mental health caused more good than harm in their lives, three people did not answer the question, and one reported feeling neutral about their impact. When asked about the impact such apps have had on society, five people felt they caused more good than harm, four people felt neutral about their impact, and three people thought they caused more harm than good. The ten participants who use apps mentioned 18 different apps that they use to track mental health information. Only one of these was mentioned by multiple participants (3),

although two reported difficulty paying for a full subscription and using a limited, free version. Of the 18 apps mentioned by participants, 11 are owned by health tech companies, four are owned by multinational technology companies not limited to health (e.g., Google, Nokia), two are partnerships between academic or nonprofit institutions and health tech companies, and one is owned and operated by a nonprofit healthcare organization. Of the apps owned by health tech companies, four are operated by people with lived experience with mental illness, four by people with MBAs, two by healthcare providers, and one offers no information about its origins or owners to users.

While this paper focuses on what participants think about tech companies owning and operating mental health apps, our participants also describe how they find such apps and what they generally like and dislike about them. The apps that participants use do not always exclusively focus on mental health. For example, Ralph relates Google Fit to his mental health, while Lane says the apps she prefers are “more broad-based.” Some participants use certain apps because people they know or trust recommend them; Carol, for example, uses FibroMap because it was recommended by a speaker at her fibromyalgia support group. Other participants use apps because they come from trusted sources, or because they are recommended by a healthcare provider. Sammi uses SpotOn because she trusts its maker, Planned Parenthood. June sought out apps on her own; she searched the app store for mental health tracking apps and, after downloading “a batch of them,” she discovered that she likes Daylio the best.

Participants note a number of benefits they experience from mental health apps. Chris has attention-deficit/hyperactivity disorder (ADHD) and says, “with these apps, I can set them up to have reminders...So it makes it really easy to keep track of things I need to do to make myself feel better.” Chris likes gamified apps because they help “make doing tasks fun.” Mood tracking apps also help participants during times when they feel particularly anxious or depressed; Owen says, “when I was really down or anxious, it gave me kind of a perspective that things weren’t always like this and they weren’t always going to be like that.” Participants also like some apps’ affordances. For example, Owen likes the graph generated by iMood Journal, and Amanda calls the apps she uses “intuitive.” Participants also appreciate apps that grant them some control over features: June likes Daylio because it is “flexible and customizable,” while Ralph prefers apps that are configurable.

Participants also describe a number of limitations to mental health apps. Participants note that apps cannot stand in for therapy and other mental healthcare services. Alex, who does not use apps, says, “a lot of apps either had information that didn’t really work for me or had directly conflicted with what I’d heard from the professionals who had treated me.” Lane says, “[apps] are largely stand-ins for what should be much more readily available community resources.” Particularly within a mental health domain where access to care and treatment are often stigmatized and expensive, apps may be “good enough” for participants despite their concerning elements or other limitations. Alex further notes that app features are limiting because “there were things that I wanted to keep track of or things that I wanted to know about myself that the apps wouldn’t allow for.” Ralph echoes this, explaining that a sleep app he once tried “wants you to do certain things that don’t really fit into the way that I actually live.” Amanda

is disabled, and she explains that her mood tracking app “tends to come up with a lot of irrelevant things for me to do, like tells me to make plans for work or school... And it’s like, ‘I don’t go out.’” Lane and Paul both note that apps can be cost-prohibitive.

Participants are also skeptical of apps that have chat features or that claim to connect users to actual humans. Referring to the therapy app Talkspace, Beth says, “I don’t trust that you’re actually talking to a person...they’re often chatbots.” Lane notes that such chatbots make her “feel shitty and like a failure...it’s sort of so off-base, in the same way that lots of human scripts are horrible.” Participants also note problems with mindfulness apps. June says, “that just wasn’t what I was looking for in terms of being able to record how I’m doing and mood and that sort of thing. Like yes. Thank you. I know how to be mindful. I’m good. It’s not what I came here for.” In reference to a mediation app, Paul says, “it wasn’t that magic here that was promised to me.”

Some participants also experience difficulties with apps due to their health conditions. Because Carol has fibromyalgia, she prefers to use her computer over mobile phone apps because it hurts to type on her phone. Kevin has ADHD, which causes him to “lack follow-through” when he tries to use a new app; Chris experiences similar problems due to their ADHD. Further, participants such as Beth note that apps may be less effective for people with severe mental health conditions like post-traumatic stress disorder (PTSD).

It is clear that participants *satisfice* when they use mental health apps; though satisficing is often employed in information science to describe people’s practices during situations of information overload, the construct also applies to scenarios wherein people compromise and select content when the information or information-based services they desire are not wholly available (Floegel & Costello, 2019). Though participants experience certain benefits from mental health apps, they simultaneously describe a number of reasons they dislike or distrust them. For Alex and Beth, such reasons are motivating enough to stop them from using apps. Other participants continue to use apps with the knowledge that they are settling for what they perceive to be an acceptable option among a limited pool of mental health resources.

Participants do not only *satisfice* on an individual level; their personal conditions, contexts, and opinions about apps’ technical features are not the only reasons they have to settle for apps that do not fully meet their needs and desires. Participants also identify a number of more structural problems that apps may exacerbate. For example, participants are concerned that government agencies or other entities may have access to the mental health data they generate when using such apps. Chris explains, “my major concern is that how easy would it be for the government to get its hands on that to make decisions on certain criminal proceedings and I guess, decide whether or not someone could be a threat based on their history?” Related, Ralph fears that mental health apps may lead to increased policing; he pictures “cops in riot gear” because he does not “have faith” that the government or other institutions would use data from mental health apps “judiciously or equitably.” June also fears what might happen if mental health data ends up in government hands; she imagines “a registry of all kinds of different people including but not limited to queer people and people with different mental health disturbances...I don’t

need the government making yet another list of people to discriminate against.” Further, Beth notes that any effort to glean information from mobile mental health assessments will be flawed because people would need access to technology in order to ensure the effectiveness of such interventions, and vulnerable people such as those experiencing homelessness or domestic violence may not have such access.

RQ2: What do participants think about tech companies inferring their mental health status using mobile phone trace data?

Participants express a number of concerns about tech companies engaging in mental health digital phenotyping. They dislike the role of advertising and a profit motive when it is related to their mental health; they do not trust tech companies to prioritize mental health and wellness; and they feel resigned and fatalistic about the role of technology companies in healthcare in general.

Profit motive and advertising

Participants are aware that tech companies profit off their data, be it the data they manually enter in mood tracker apps or mobile trace data. Carol says, “people who put these [apps] out aren’t doing it for free. They’re doing it because they want to collect data on you.” Chris notes, “the only reason they’re collecting the data is just so they can build better ads for me,” while Amanda says that tech companies sell mental health data to “push whatever high-price drug will pay them the most... it’s just going to be the highest bidder.” Participants identify themselves as “products” that tech companies want to sell.

Though Chris says that targeted ads are not “the worst thing in the world,” other participants oppose tech companies’ profit motivations. Beth shares, “I don’t think that tech companies should make money off people’s suffering,” while Paul states, “I definitely do not want people to try to sell me things based on a mental health score.” June notes, “I don’t need Jeff Bezos or his ilk profiting on the fact that I have a chemical imbalance.” In particular, participants are uncomfortable with tech companies accessing and selling mental health data to generate ads, because such companies are not doctors. Alex says, “I think that mental health apps are at their best when they’re used as an extension of a care provider’s tools rather than as a means to make a profit.” June explains, “predictive ads are not doctors. They’re not care professionals...they’re looking for money.” Amanda enumerates the conditions under which she might be comfortable with apps developed by tech companies:

If it’s developed by some small developers who themselves have mental illness or have experience with people close to them with mental illness and that’s why they’re working on it, that’s different. But I feel like anything Amazon, Facebook, Google does is for profit first. And they’re going to be looking to make the most money, regardless of whether what they’re doing is the most ethical.

Participants highlight the vulnerability of mental health data. Kevin says, “I think that mental health data is very valuable for marketing, and it’s also very vulnerable,” while June says that

pushing ads based on mental health data is “a good way to sort of predate upon people who are vulnerable.” Owen calls tech companies’ involvement in mental health “kind of problematic” because “there’s no profit to be made in getting people well.” Therefore, participants distrust tech companies due in part to their profit motivations.

Distrust

Participants note that mental health is both personal and stigmatized, and they do not trust tech companies with data about their mental health despite acknowledging that these companies have access to such data. Alex says, “I think mental health is and has to be a very intensely personal thing...we need to have really high barriers to who gets to access that information.” Paul says, “in terms of my mental health, I definitely do not trust any of those companies to actually have my well-being in mind...[mental health] is very private...because it’s still stigmatized.” June explicitly connects stigma to predictive ads, stating that ads can be “additionally isolating and additionally stigmatizing and again predatory.” Participants specifically distrust tech companies because, as Kevin notes, “they have a very bad track record of bad handling and of consistently misleading customers about how they will use data...they have a poor relationship with consent.” Beth echoes this: “I just don’t really trust any of those giant tech companies to do anything good with that kind of data.” Sammi worries that in the context of tech companies, “there might be some predatory use” for her mental health data.

More broadly, participants note that granting tech companies access to their data broadens the scope of who or what can access their data in general. Paul says that such surveillance “is just another tool of power. It just reinforces it. It’s not a good thing.” Related, Beth notes that tech companies’ practices may have grander consequences because “[companies] really don’t have enough willingness or ability to investigate the social impact or the ramifications of doing this sort of thing.” Alex claims:

when we start to take very granular information and share it with people...then we start running into issues just in terms of access and in terms of...continued privacy, which is kind of rapidly dwindling in the post-advertising age and especially after Cambridge Analytica.

Participants specifically highlight privacy concerns as a major reason they distrust tech companies. Ralph says, “there’s so much stigma still with mental health issues that knowing where the data is going would make me a little more comfortable.” Paul says, “we have already seen the terrible intrusions on our privacy that [tech companies] have done...every time we find something new, the intrusion onto our privacy is just somehow worse.” Amanda, however, notes, “I don’t really have big concerns about people just knowing about me.” Instead, she is chiefly concerned with companies profiting off her data.

Participants carefully weigh their own use of mental health apps, making risk/benefit calculations about their choice. Ralph says, “I feel like my own use of those apps right now is very much based on a calculus between, ‘Am I making myself more vulnerable?’ And if the answer is yes at all, I kind of don’t do it.” Kevin notes, “there’s always risks with things like this,

like outing someone to their employers or family members and so on.” Though Carol “[likes] new technology,” she is more likely to try it “if somebody I know and trust has used something”; even as a self-described early adopter, she takes some precautions.

To manage these risks, participants desire more control over their data. Ralph wants to see his data in its “raw form,” while Kevin thinks there should be more options for opting into and out of certain services. Owen notes that though cloud-based services also have privacy problems, he backs his data up on Dropbox “for essential accounting control.” Participants especially desire such mechanisms of control because they believe that, in many contexts, they cannot escape tech companies’ grasp.

Ubiquity and fatalism

As noted throughout, we discussed two topics with our participants. First, we discussed how they currently use (or do not use) apps to manually track their mental health. We then posed a digital phenotyping scenario wherein their mobile trace data (GPS, number of contacts via phone and text, screen time) was used to predict their mental health status. While we did pose this as a hypothetical scenario, our participants do not consider it to be: “Bold of you to assume that’s not already happening,” June laughs. Our participants feel resigned at the ubiquity of big tech, and share a general sense that such companies “already have” their personal data. Ralph says that big tech companies “are the institutions that have resources to develop these programs, so they’re the ones offering them to us presently.... It’s sort of a done deal... we already swim in those waters.” Owen describes how his own use of tech companies’ services amounts to tacit endorsement: “Judging from past behaviors, in the course of today I’ve used Twitter, Facebook, Google. I’m probably okay with it.” Lane recounts a certain fatalism in their ubiquity: “They already do own everything, and all of that information would get to them anyway. And so there is a sort of fatalism about that.... I don’t use Facebook. But it has its tentacles everywhere. And so I don’t feel like there’s really-- it’s not like I would feel more safe. I would be like, ‘Oh. Well, that was where this was all going anyway.’” The tentacles of big tech are deeply rooted, demonstrated by how attached participants feel to their mobile devices. Carol jokes: “I call my phone my brain [laughs]. It is always with me.” That her phone serves as an extension of her brain helps to describe why Carol feels resigned: “Google already has enough of my information. It actually probably wouldn’t matter.” This resignation at the ubiquity and long reach of technology companies may explain why so many participants currently use mobile apps to track their mental health despite having serious reservations about the companies that produce them.

Regulation as proposed solution

In response to the quandaries posed in the results for RQ1 and RQ2, participants often mention regulations as a method for managing the negative effects of technology companies owning mental health tracking apps and their associated data. Participants express a desire for more robust and readable privacy policies, often mentioning HIPAA, or the Health Insurance Portability and Accountability Act, as a regulation that should apply to data in this context. Like Sammi says: “It’s something that people should be able to protect. There’s a reason that there’s HIPAA and everything. I wouldn’t want everybody’s information to be readily shared.” Stronger

privacy policies would engender trust; as Alex describes, “I think that a lot of privacy concerns can be fixed with an upfront, clear, and strong privacy policy. It’s just that right now, a lot of mental health care apps just don’t have that.... Having a clear and strong commitment to privacy that is easy to reference and easy to read into their trust, I think would be a way to make me feel way more comfortable using that kind of service and providing that kind of data.” Others elaborate on more specific regulations that they desire; for example, Kevin wants the use of data to be limited so that companies cannot easily profit off of it: “I’m not sure that, necessarily, it should ever be appropriate to use somebody’s health status to advertise products because it’s too easy to go from there to using that to discriminate against people.” Amanda says that she wants limits to be placed on what data the app is able to transmit to third parties, and Chris is particularly concerned about data confidentiality. Kevin also notes that enforcing such regulations will likely require human intervention:

We’re all trained to click through things right away, but using plain language to explain how data will be used, using, again--there can’t be any use of the data that is against what a person could reasonably expect. It’s kind of difficult to do that with an automated system.

Human intervention is not just necessary in the enforcement of regulations; having people involved throughout the process is itself a regulatory mechanism. Ralph brings up the importance of having people involved in the process of mental health diagnostics: “Judging the mental health of a group of people without talking to them directly just seems so weird and terrifying to me that I can’t see anything like this ever being used for anything good.” Automating mental health assessments implies the removal of a necessarily human element of care, which Paul fears will result in the reduction or outright removal of ethics from the process.

Discussion

The development and ownership of mental health apps by technology companies provides one context in which we can further explore the reasons participants make compromises when they interact with such apps. Participants satisfice when they use mental health apps, and are wary of automated mental health assessments generated by tech companies because they dislike profit motives and advertising; they distrust such companies; and they feel fatalistic towards the ubiquity of big tech.

To date, automated mental health assessment efforts have largely been initiated or planned in partnership with big tech companies like Google and Facebook, and our participants report using apps to track their mental health that are mostly owned by health tech firms. At their core, these platforms are advertising companies (Zuboff, 2019) that promote mental health as a commodity that individual people can objectively measure or control via self-quantification or automated tracking practices (Fotopoulou & O’Riordan, 2017). This, in turn, promotes normative assumptions about mental health, obscures sociopolitical dimensions of healthcare, and further industrializes healthcare as a for-profit industry (Lupton, 2015). As our participants discuss, these apps belie a serious perversion in the definition of “mental health” as a construct. Instead

of being focused on care, technology companies have made mental health into a commodity that exemplifies the neoliberal ideals of market logic, individual responsibility and agency, and consumer choice (Esposito & Perez, 2014).

Our data reflect a strong preference for different types of regulation as a means to build trust and curb the profit motive of tech companies involved in mental health assessment. Privacy policies and user controls over privacy were often mentioned; however, these solutions are individually focused and place the onus of responsibility on the end user rather than the tech companies. Individually-focused solutions are problematic because they tend to provide an *illusion* of choice rather than sustainable and ethical changes (Zong & Lee, 2019). Furthermore, apps conceptualize privacy and consent as events rather than processes (Madden et al., 2017). This means that people are often faced with binary choices, like whether or not to use an app, without acknowledging that use of self-tracking apps is not continuous (Epstein et al., 2015).

Participants who use mood tracking apps say that they are better than nothing for managing mood, although they do not think they should replace doctors. Participants satisfice in multiple ways when using apps; for example, they feel they have to accept a lengthy privacy policy that they may not fully understand and that can be changed at any time in order to gain the benefits of using a mood tracker. Self-tracking may even be framed as a form of advanced capitalist digital labor that allows companies to extract people's data without payment (Till, 2014). Participants also recognize that even if they do not use mood tracking apps, they likely cannot opt out of mental health profiling entirely if they use a mobile phone. They believe that tech companies are already creating profiles of their mental health, in addition to many other forms of digital phenotyping, whether or not they use a mood tracker. This is of particular concern in mental health, as mental health diagnostics and treatment are historically fraught with questions about power, normativity, and inequity (Bergin et al., 2008; Frances, 2013). Inferring mental health status using mobile trace data is a form of surveillance, which also exacerbates inequities (Benjamin, 2019; Browne, 2015; Lupton, 2014).

Participants also desire ways to place limits on tech companies' ability to sell data or to use data to advertise products. While these regulations are less individually focused than privacy policies, they are also limited because they do not necessarily account for the broader regulatory systems in which tech companies reside (Scholz, 2016). For example, efforts have been made to curb what tech companies can legally do with people's data. However, technology companies are often able to circumvent these measures. Facebook, for example, is frequently fined for violating regulations around data privacy and security, but the company's capital resources allow it to circumvent both user protections and legal fall-outs (Srinivasan, 2019). Though Facebook was fined a record-breaking \$5 billion as part of a 2019 settlement with the Federal Trade Commission for violating people's privacy rights, the sum is paltry in comparison to Facebook's revenue (Snider & Baig, 2019). While Facebook provides only one case, other technology companies with significant resources are positioned to take similar actions. Essentially, such companies may consider breaking the rules and being fined as a result of regulatory measures to be a cost of doing business. Regulatory measures are only as strong as their enforcement. Per Scholz (2016), "not much is done in the face of these companies flouting

federal law and municipal regulations” (p. 9). There has been only one penalty imposed on a major tech company (Google) for violating the General Data Protection Regulation (GDPR) law in Europe; the fine was for 50 million euros, or about 10% of Google’s daily revenue (Satariano, 2020). The Facebook settlement discussed above curbed Mark Zuckerberg’s executive power; however, media policy advocates argue that this regulation provides neither structural change in the tech industry, nor consequences for Facebook’s other transgressions (Snider & Baig, 2019). Weak regulatory measures are in part a product of alliances between tech companies, governments, and other institutions because these bodies often work together to own, control, and monitor people’s data online (Fuchs, 2014).

These realities of regulation ensure that technology companies, especially those with a large market share, can effectively avoid responsibility for the consequences of commodifying health data. They are able to do this in part because they are not technically gathering health data in the legal sense: HIPAA, for example, only applies to protected health information gathered specifically by healthcare entities. Tech companies, even health tech firms, are gathering data that is not necessarily classified as health data and are therefore not subject to such regulations (Katuska, 2018). Questions about what data is health data are evolving: for example, contact tracing apps, which are currently being discussed as a mitigation method for the COVID-19 pandemic, necessitate the use of mobile trace data to operate (Calvo et al., 2020). Our whereabouts are not classified as protected health information, but they may be used to infer health status. It could be argued that all data is health data. These terminological tangles make regulation all the more difficult.

Therefore, we argue that regulatory policies that place the onus of responsibility on individual people or that wealthy technology companies can easily circumvent are not sustainable solutions because they uphold the very neoliberal principles that underlie the commodification of mental health (Esposito & Perez, 2014; Fuchs, 2014). Further, these regulatory proposals do little to address the inequities that participants note underscore and are exacerbated by mental health apps; power dynamics involved in the formation, buying, and selling of people’s trace data require deeper structural interventions (Thylstrup, 2019). Centering, serving, and empowering people with mental health conditions will necessarily involve meaningful community engagement and the use of participatory design and other democratic methods, rather than those that commodify mental health, for solving the issues posed by our participants (D’Ignazio & Klein, 2020).

Conclusion

As with any study, there are limitations to our work. First, this is an exploratory study with a small number of participants, all of whom were recruited online. Most of our participants are white, formally-educated people who live in the United States. Although we attempted to recruit people with a range of preconceived notions about mental health apps, our participants were largely skeptical of such apps despite the fact that the majority of them do use a mood tracker on their mobile device. As this is an exploratory study, generalizability was not the goal of our analysis; instead, we are more interested in the transferability of our results to other domains

(Lincoln & Guba, 1985). Investigating whether participants have these same reservations about using mobile apps to track contagious diseases, or less stigmatized conditions, is warranted, particularly given the increasing global interest in developing contact tracing apps to slow the spread of COVID-19 (Strickland, 2020). Future work in the mental health app domain should engage a more diverse sample of participants, including more people of color, people who do not use mood trackers, and people who are excited about the possibilities of mental health prediction using mobile trace data. Data from these types of users will enhance the depth and trustworthiness of our findings, allowing for negative case analysis and a more robust theoretical understanding of this phenomenon.

The current existence of mood trackers and the burgeoning use of trace data to assess and predict mental health status does not preordain their continued existence. At the very least, our data indicate that automated, reactive assessments about mental health should not be further developed by technology companies, and that data about mental health that is collected or inferred from mobile trace data should not be sold or used to advertise products to people. To make this argument seriously requires a profound shift in how health data and technology are understood. The ethics of tech companies are clearly at odds with the ethics of medical care: for example, Facebook's oft-quoted ethos to "move fast and break things" is extremely harmful when applied to someone's mental health, which requires, by necessity, time and care. To break things implies doing harm and violence and directly counters the central tenant of the Hippocratic Oath: to do no harm. Further, designers of mental health apps make dangerous assumptions regarding apps' ability to treat people with mental health conditions. In order to obtain meaningful mental healthcare, patients need strong, continuous relationships with their healthcare providers (Green et al., 2008). Given our findings, it is dangerous hubris to suggest that digital phenotyping should be used at any point in the process of diagnosing and treating mental health conditions. The risks simply outweigh the benefits, particularly when the private sector is involved.

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