PERSPECTIVE

Digital Phenotyping and Digital Psychotropic Drugs: Mental Health Surveillance Tools That Threaten Human Rights

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Introduction

Digital technologies and tools hold much promise. Indeed, the COVID-19 pandemic has shown us how helpful telehealth platforms and mental health applications (apps) can be in a time of quarantine and social distancing. However, such technologies also pose risks to human rights at both the individual and population levels. For example, there are concerns not just about privacy but also about the agency and autonomy of the person using mental health apps. In this paper, we describe what digital phenotyping is, how it is used to predict mood, and why we ought to exercise caution before embracing it as a means of mental health surveillance. We also discuss the United States' recent regulatory approval of the first-ever "digital" drug, an antipsychotic (aripiprazole) embedded with a sensor. Digital aripiprazole was developed in order to increase medication compliance, but we argue that it may undermine a rights-based approach in the mental health field by reinforcing coercive practices and power imbalances. The global dissemination and promotion of these apps raise human rights concerns.

Back to the future: Digital phenotyping replaces the search for genetic biomarkers

Subtle aspects of typing and scrolling, such as the latency between space and character or the interval between scroll and click, are surprisingly good surrogates for cognitive traits and affective states. I believe mental health will be the part of medicine most transformed by the digital revolution.[1]

—Tom Insel, former head of the National Institute for
Mental Health and co-founder of Mindstrong

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The lack of biomarkers, or objective measurements, to determine mental disorders has plagued psychiatry and resulted in concerns about the validity of psychiatric disorders. Rather than rely on subjective self-reports and depression scales, psychiatrists and neuroscientists are turning their attention to digital phenotyping, promoted as an objective way to measure—and supposedly predict—traits, behavior, and mood. For example, Thomas Insel, a psychiatrist and former head of the National Institute for Mental Health, left the institute to help found a tech company with the aim of improving psychiatric taxonomy and research through artificial intelligence.

Digital phenotyping is defined as the "moment-by-moment quantification of the individual-level human phenotype in-situ using data from smartphones and other personal digital devices."[3] In other words, this technology uses sensors that can track an individual's behavior, location, and speech patterns (e.g., intonation).[2] By analyzing human-computer interaction (for example, the use of a smartphone), the measurement focus is not on content (what you type) but *how* you type. These interactions—the patterns and timings of user activity on touch-screen devices—are aggregated and analyzed using machine learning.[3] The results of these interactions are referred to as digital "biomarkers." As Insel explains:

> with data from sensors, speech analytics, and keyboard use, scientists are learning how to measure cognition, mood, and behavior passively from the smartphone … offer[ing] a sort of digital smoke alarm for mental health issues … [D]igital phenotyping can provide ethical and effective biomarkers that predict relapse or recovery, much the way we monitor progress in diabetes or hypertension.[4]

Insel, along with others from technology and pharmaceutical companies, founded Mindstrong, described as a health care and tech company.[5] In 2018, the company developed a smartphone app that it claims not only can detect the worsening of symptoms but can *predict* them: "What if we can detect symptoms getting worse? What if we can predict it?"[6] The company describes this as a break-

through technology that will help users access "targeted proactive care." What is not emphasized is that mental health apps, like most apps, collect, use, and sell users' data. In fact, research has shown that the majority of smartphone apps are not transparent about what information will be collected, how it is collected, and how it will be used and sold. A recent review of mental health apps found that 81% of them sent data to Facebook or Google for use in data analytics or marketing, and 92% sent data to other third parties. The authors concluded that "users are thus denied an informed choice about whether such sharing is acceptable to them."[7]

Additionally, there is limited evidence to support the claim that digital phenotyping can predict behavior or symptoms. As previously noted, this technology is focused on how users interact with their smartphones. Scrolling, clicking, tapping, and other touch-screen behaviors are analyzed with machine learning to predict cognition and mood.[8] However, there are insufficient data to support the claim that a human-computer interaction model—analyzing the way information is presented to the user and repeated measures of a user's response time—can accurately predict an increase in mental health symptoms. For instance, one small (N=23) prospective cohort study has been registered on clinicaltrials.gov, regarding Mindstrong's model, but no study results have been posted, and no peer-reviewed papers have been published.[9] A recent review of the literature on the use of, and support for, digital phenotyping for the detection of mental health problems found that there is a clear gap between the theory that grounds this technology and the empirical data to support its use.[10]

The "first-ever" digital medication

In late 2017, the US Food and Drug Administration approved Otsuka's application for digital aripiprazole, Abilify MyCite, a version of a second-generation antipsychotic embedded with an ingestible event marker. Both the nondigital and digital versions of aripiprazole have been approved for schizophrenic disorders and for adjunctive use in bipolar and major depressive disorders. It is expect-

ed that the ingestible sensor will transmit a signal when the drug-device combination is exposed to gastric acid in the stomach, thereby allowing for real-time information about medication ingestion. The rationale behind the development of this digital drug is that it will increase medication adherence and, in turn, result in improved health outcomes and decreased health care costs. However, there are currently no clinical trial data to show that the sensor can either consistently track real-time ingestion or increase medication adherence.[11] In fact, on the company's website, the following statement is made: "There may be a delay in the detection of the Abilify MyCite tablet and sometimes the detection of the tablet might not happen at all."[12]

Additionally, patients diagnosed with psychotic illnesses—those most likely to be prescribed digital aripiprazole—often experience paranoia. A digital psychotropic drug, particularly an antipsychotic that is used as a treatment for people who experience paranoia, is akin to a modern-day panopticon, a disciplinary apparatus that utilizes constant surveillance to impose a form of self-discipline and internalized authority.[13] The potential for human rights violations, such as coercion (discussed in more detail in the next section), have not been adequately assessed. One could imagine that being asked to take a digital psychotropic medication could reinforce "subjectivities of disability" in people diagnosed with psychiatric disorders and, concomitantly, undermine their sense of agency. This technology may exacerbate the "subjective experience of structural stigma" that is imposed by medicalized interventions that gloss the complexity of human suffering.[14]

Many clinicians have pointed out that an antipsychotic medication was an odd choice for the "first-ever" digital drug.[15] It is noteworthy that in 2014, aripiprazole was the best-selling drug in the United States, costing, on average, over US$800 for a month's supply and generating over US$7.5 billion in sales from October 2013 through September 2014.[16] After the patent expired in the United States, sales revenues dropped by almost US$7 billion in 2015, which is when Otsuka and Proteus first submitted an application for market approval of the digital version. The generic oral version of aripiprazole costs approximately US$20 per month, while Abilify MyCite costs almost US$1,700 for a month's supply.[17]

Why both digital phenotyping and digital psychotropic drugs present threats to human rights

Advances in digital technology are transforming the capabilities of States, global tech giants, including Google, Facebook, Apple and Amazon, and private entities to carry out surveillance on entire populations to an unprecedented degree … Internet searches and social media, detailed personal information can be captured and analysed without the individual's permission or awareness. That information can then be used to categorize an individual for commercial, political or additional surveillance purposes.[18]

—Dainius Pūras, United Nations Special Rapporteur on the right to health (2014–2020)

Morality and suffering are inexorably intertwined, for emotional distress always has a political and moral aspect as well as a medical one.[19] As noted over a decade ago by the World Health Organization, "social injustice is killing people on a grand scale."[20] Unfortunately, the political and moral aspects of suffering are underappreciated, and there is an increased tendency to conflate access to psychiatric services with mental health equity.[21] Such a conflation undermines an appreciation for the profound ways that neoliberal economic policies, systemic racism, and gendered violence (among other things) can impede emotional well-being.[22] It is not only neoliberalism but also dominant ideas in psychiatry and common practices in mental health care that are profoundly shaped by institutional and systemic racism. Systemic and interpersonal racism both impede access to services (for example, for many women of color) and lead to over-representation in coercive and carceral services, as well as in forced treatment (for example, for many black men).[23] Thus, advocating for more people to be able to receive a psychiatric diagnosis and mental health treatment at the same time that such major advances in digital technology are taking place creates the

perfect storm for human rights violations. The most vulnerable and discriminated people in communities may be coerced into mental health care, leaving the societal causes of their suffering unaddressed.

The data being gathered and analyzed by tech giants through nontransparent surveillance can now be used to categorize people as "at risk" of committing crimes, including benefit fraud.[24] Now, with digital phenotyping, it is also possible to identify and categorize people as "at risk" of mental illness. When nontransparent surveillance tactics are used to identify potential criminal behavior, individuals have great difficulty achieving redress if identification errors are made.[25] Individuals who use mental health apps that employ digital phenotyping are vulnerable to such errors. For example, a bizarre but plausible outcome of using a mental health app is that when a person's digital behavior correlates with suicidality, first responders will be called in to forcibly hospitalize them, even if they did not have the subjective experience of being suicidal. Indeed, the increased use of nontransparent surveillance tactics, and the difficulty correcting errors of identification and wrong information, poses a clear threat to human rights.

Emerging research has already suggested that passive data, such as time spent scrolling or tapping on a smartphone, may be used to identify users at risk for suicidal behavior or relapse of schizophrenic symptoms and that apps which collect such data may be helpful tools for alerting clinicians to the need for intervention using an interface that "has the advantage of not requiring the collaboration of the user."[26] This "advantage" is more accurately described as a right to health violation. Additionally, it has been recommended that clinicians be prepared to act on any digital information that indicates risk for self-harm (for example, being prepared to involuntary commit the person), demonstrating the genuine possibility for such use of passive data.[27] Scholars have drawn attention to the potential for harmful iatrogenic effects in passive data collection, particularly for users who are already vulnerable.[28] Marginalized populations may be overly pathologized because of how passive data use is normed and because algorithms do not account for the

established relationship between experiences of social injustice and emotional distress.[29] It is also noteworthy that recent research on adverse events related to the use of such digital sensing technology indicates that the very use of mental health apps may actually increase some users' distress, including increased paranoia and fear of relapse.[30]

In this way, digital surveillance is antithetical to basic principles of human rights—namely, individuals' inherent dignity, as well as their autonomy and independence. Not surprisingly, proponents of digital technology argue that the opposite is true: that using this technology will enhance the ability to detect symptoms and increase adherence to treatment, thereby improving the quality of life for individuals who use mental health apps and drugs with sensors embedded in them.[31] However, we should be cautious about such claims when they come from the developers of this technology who stand to profit from its uptake in the general population, and when such claims have not undergone robust empirical investigation. People with lived experience have long recognized that psychotropic drugs can be experienced as a form of chemical incarceration; the uncritical use of digital technologies may turn out to be a virtual form of incarceration.[32]

Concerns about institutionalization and other coercive practices were a major focus of child psychiatrist Dainius Pūras during his six-year tenure as the United Nations Special Rapporteur on the right to health. He emphasized the urgent need to abandon outdated practices in mental health care, including medicalization, coercion, and institutionalization.[33] Medicalized approaches undermine an appreciation for the social realities, structural violence, and health inequities that produce emotional distress.[34] In his thematic reports, the Special Rapporteur consistently highlighted the importance of attending to structural and systemic issues, focusing on the global burden of *obstacles* to achieving good mental health rather than the global burden of disease in order to bring a robust rights-based approach to mental health to fruition. In addition to deflecting attention away from structural and systemic obstacles that undermine

the right to health, digital technologies, insofar as they are not transparent, also undermine a genuine informed consent process.[35] The lack of attention paid to maximizing informed decision-making for service-users parallels the ongoing controversies in psychiatry over consent to treatment. Traditional medical-model approaches to mental health care are premised on the assumption that service-users often "lack capacity." As a result, policies have prioritized access to medical interventions over informed consent and the right to refuse treatment.[36] However, rights-based approaches to mental health, rooted in an alternative "social model of disability," have contested this prioritization and advocated for individuals' right to determine their own treatment decisions.[37]

Therefore, we must take seriously the concern that digital phenotyping and digital psychotropic drugs, like other medicalized approaches, run the risk of further entrenching coercive practices. Such practices may undermine the autonomy and agency of persons using (or being forced to use) these technologies. Indeed, the boundary between predicting mood and shaping behavior is tenuous. It is noteworthy that Shoshanna Zuboff, author of *The Age of Surveillance Capitalism*, quoted one scientist working on digital technologies as saying, "We can engineer the context around a particular behaviour and force change that way … We are learning how to write the music, and then we let the music make them dance."[38] The end goal of surveillance technology is never above suspicion, even when it is cast in rhetoric about improving mental health or quality of life. Although digital technologies are promoted as tools, we must remember that tools are at *our* service; they neither demand anything of us nor manipulate us.[39] Digital technologies, on the other hand, are designed to shift and direct the behavior of the user, often without the user's knowledge.

These technologies also reinforce the commodification of health care and promote practices that violate the right to freedom, including freedom from coercive or degrading treatment.[40] For example, if patients are incentivized to take the digital version of a psychotropic drug (such as by being offered outpatient treatment as an alternative to compulsory inpatient treatment, or as a condition of parole), the line between incentivizing and coercion becomes blurred.[41] Vulnerable populations—such as people in prison, in marginalized groups, or who use illicit drugs—are more likely to be coerced into using surveillance-based diagnostic technologies (for example, mental health apps) and taking surveillance-based psychotropic medications.

Such risks must be assessed seriously because people with psychosocial disabilities and other vulnerabilities have a long history of experiencing discrimination and inequality, and they have not enjoyed the freedom to make their own treatment choices.[42] It is not yet fully researched or understood why individuals stop taking antipsychotic medications, although such medicines' high discontinuation rate and difficult side effects have been well documented.[43] Unfortunately, the burden of antipsychotics is underappreciated, and the biomedical focus instead is on "increasing medication compliance." But creating short-term technological solutions to increase medication compliance is anathema to a rights-based approach to mental health, which instead promotes and respects the autonomy and agency of all people, including those with psychosocial disabilities.

Conclusion

The efficacy of digital phenotyping to predict mood states has not been established, nor is it known whether a drug embedded with a sensor can track real-time ingestion, let alone improve medication adherence and improve quality of life. Even if these interventions achieve their stated objectives, digital drugs and phenotyping are part of a wider pattern of technological solutions—often profit-making quick fixes—that do not resolve the real causes of mental distress. Promoting these short-term fixes over societal transformation maintains the status quo and does not address inequality, discrimination, or other human rights failings. Not only are the unvalidated digital tools being promoted, but these mental health apps are using people as unwitting profit-makers. The apps gather data from people when they are vulnerable and makes them

part of a hidden supply chain for the tech giants' profits, while potentially compromising their agency and autonomy.[44] Similarly, the advent of digital psychotropic drugs marks a new age in surveillance and poses risks to privacy and human rights, possibly in ways yet unimagined.

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