

**“Today all of us leave behind a trove of digital breadcrumbs. That data can help catch health problems, and mobile devices are probably the most valuable source of data about someone.”**

Jennifer Esposito, “Digital Phenotyping and Healthcare,” Intel IT Peer Network, June 20, 2018.

## What is Digital Phenotyping?

Digital Phenotyping is defined as “moment-by-moment quantification of the individual-level human phenotype *in situ* using data from personal digital devices such as smartphones.” (Torous *et al*, 2015)

California tech companies are developing smartphone programs and apps that use algorithms to track and measure clients’ mental states and behaviors to make predictions about their mental health. Instead of relying on clients to report their symptoms directly to mental health professionals, these apps will use data collected from clients’ smartphones, web-connected devices, and wearable technology for mental health screening, diagnosis, monitoring, and in some cases, targeted advertising (including to pharmaceutical companies).<sup>1</sup>

## Why should I care?

- Digital Phenotyping applications monitor users through their smartphones and other Internet-connected devices. They track when and how much you use your phone, which apps and programs you use, and some can even access your location, movements, the content of your text messages, your internet searches and browsing patterns, your social networking activities, your voice data, and your facial expressions to make predictions about your mental health.<sup>2</sup> Without proper vetting, security, and client protections, the information these apps gather about you can be sold to private companies or used for improper, unethical, or illegal purposes.<sup>3</sup>
- By law, all county programs funded by the Mental Health Services Act (“MHSA”) must be developed by clients and community stakeholders from the ground up.<sup>4</sup> Counties are circumventing this requirement when they create MHSA-funded Digital Phenotyping Innovation plans behind the scenes without client stakeholder involvement.<sup>5</sup> In addition, counties pursuing Digital Phenotyping projects haven’t demonstrated how these plans meet the MHSA’s other General Standards, which require all MHSA-funded programs to be culturally competent, client driven, recovery focused, and integrated with other health and social services.<sup>4</sup>
- Despite serious concerns regarding informed consent, user privacy and data security, the appropriateness of these tech programs for target populations, and how info will be used and interpreted, several counties across the state are forging ahead with plans to spend over **\$66 MILLION** in MHSA funds – public taxpayer dollars – to implement Digital Phenotyping and other unvetted technology programs in the Public Mental Health System to be tested on public mental health clients.<sup>6</sup> And even if Digital Phenotyping programs work great, these counties are not increasing in-person direct services to meet the very mental health needs these apps are designed to uncover.
- Counties are PAYING private for-profit corporations to create Digital Phenotyping programs, diverting scarce public mental health resources to wealthy, well-connected tech companies founded by Google executives<sup>7</sup> and backed by venture capitalists<sup>8</sup> and pharmaceutical companies.<sup>9</sup> These profit-driven businesses don’t need public subsidization and shouldn’t have unrestricted access to a treasure trove of data gathered through digital surveillance of public mental health clients. Client data will be used to enhance these companies’ products and increase their profits, without any clear lasting benefits to clients and the overall Public Mental Health System.
- Most apps and programs created for commercial use by private tech companies do not need FDA approval and do not have to comply with HIPAA.<sup>10</sup> Since we already know that personal data is extremely valuable and info gathered from Digital Phenotyping can be used for targeted advertising, how safe is clients’ data, really?

## How can I get more involved?

Voice your concerns at local mental health planning meetings in your county and at MHSOAC and CalMHSA meetings where these Innovation plans are developed, discussed, and approved.

- Find local mental health planning meetings in your county here: <https://www.accesscalifornia.org/directorymap>
- Find MHSOAC and CalMHSA planning meetings here: <https://www.accesscalifornia.org/directory>

Become an ACCESS Ambassador (regional advocate), and stay connected to the only client-run statewide advocacy network in California tracking the mental health issues important to you on the state and local levels.

- Apply to become an ACCESS Ambassador here: <http://sgiz.mobi/s3/ACCESS-Ambassador-Application-2018>

## What questions should I ask my county about Digital Phenotyping?

- **Is Digital Phenotyping or another Tech Suite program included in your most recent Innovation plan (or will it be included in your next Innovation plan)? If so ...**
- How was this Innovation plan developed? Did local clients and community stakeholders come up with this idea on their own or did the county create the plan and bring it to stakeholders after the fact?
- How does this tech program actually work?
- What kinds of information does this program have access to? What info does it track, collect, and store?
- Is this technology program HIPAA-compliant? Is it required to be?
- How do clients give informed consent? Can clients opt out of some or all of the program's features later?
- Who will monitor and interpret the data collected? What is the evidence-based framework for interpretation?
- How is this program culturally competent? How will cultural differences and biases in diagnostics/interpretation be addressed?
- If the data indicate an intervention is warranted, what actions will the county take to follow up and provide clients with needed services?
- How will the county address and overcome barriers for clients who:
  - Do not have program-capable devices?
  - Are not tech-savvy or are uncomfortable using this type of technology?
  - Have limited access to WIFI or cellular data service?
  - Have data restrictions or insufficient storage capacity on their devices?
  - Do not speak English as their native language (or at all)?
- How will local clients and community stakeholders remain involved in the planning, development, implementation, oversight, and evaluation of these tech programs throughout the entire Innovation project?
- Who owns the data collected from public mental health clients through these tech programs?
- Who has access to the data collected during the county Innovation project? How about after the project ends?
- Can clients' digital data **ever** be shared with or sold to data brokers or other private companies (including advertisers and pharmaceuticals)?
- Can the private tech companies developing these programs ever profit (directly or indirectly) from the data collected from public mental health clients? If so, how will they give back the Public Mental Health System in return for subsidizing their for-profit business ventures?

### Sources and Authorities Cited:

- (1) <https://www.researchgate.net/publication/266909281/download>
- (2), (3) *Id.*
- (4) Cal. Welf. & Inst. Code § 5848(a); 9 CCR §§ 3300, 3320
- (5) [http://mhsaac.ca.gov/sites/default/files/documents/2017-10/OAC\\_Los\\_Angeles\\_County\\_INN\\_%20Plan\\_Description\\_Technology-Based\\_Mental\\_Health\\_Solutions\\_10262017.pdf](http://mhsaac.ca.gov/sites/default/files/documents/2017-10/OAC_Los_Angeles_County_INN_%20Plan_Description_Technology-Based_Mental_Health_Solutions_10262017.pdf)
- (6) <https://drive.google.com/open?id=1bVeG0zfeCFMybs6713GZenkP3FCZPcRI>
- (7) <https://www.cnbc.com/2017/05/10/thomas-insel-ex-alphabet-mindstrong-track-mental-health-smartphone-use.html>
- (8) <https://www.fiercebiotech.com/medtech/ai-startup-mindstrong-bags-14m-for-mental-health-mission> and <https://www.xconomy.com/san-francisco/2018/06/14/mindstrong-adds-15m-for-tech-that-predicts-mental-health-changes/>
- (9) <https://www.prnewswire.com/news-releases/mindstrong-health-and-takeda-partner-to-explore-development-of-digital-biomarkers-for-mental-health-conditions-300604553.html>
- (10) <https://www.researchgate.net/publication/266909281/download>

**How Commercial Digital Phenotyping Apps and Programs Monitor Your Mental Health:**

Private Commercial Technology (not bound by HIPAA)	Owner/ Developer	What it Can Monitor	Purposes
Smartphone Apps and Programs	Microsoft	<ul style="list-style-type: none"> <li>SMS (text messaging), calls, email, application usage, web browsing, location</li> </ul>	<ul style="list-style-type: none"> <li>Measure mood</li> </ul>
	Nokia	<ul style="list-style-type: none"> <li>Call logs, SMS, Bluetooth scans, application usage</li> </ul>	<ul style="list-style-type: none"> <li>Classify personality traits</li> </ul>
	Intel	<ul style="list-style-type: none"> <li>Stress in voice</li> </ul>	<ul style="list-style-type: none"> <li>Classify stress in real-time conversation</li> </ul>
	Google	<ul style="list-style-type: none"> <li>Interaction with mobile phone app</li> </ul>	<ul style="list-style-type: none"> <li>Track sleep behavior</li> </ul>
	Samsung	<ul style="list-style-type: none"> <li>Classify social network user emotional states</li> </ul>	<ul style="list-style-type: none"> <li>Control interactions between users related to emotional states</li> </ul>
Internet Apps and Programs	Yahoo!	<ul style="list-style-type: none"> <li>Online queries, browsing, ad clicks, history</li> <li>Internet activities</li> <li>Generates user profile with mood gradient, friends preferences</li> </ul>	<ul style="list-style-type: none"> <li>Improve user profiles for behavioral targeting</li> <li>Update profiles daily for behavioral targeting</li> <li>Target items (song playlist, movies) to mood</li> </ul>
	Google	<ul style="list-style-type: none"> <li>Online queries, browsing, ad clicks, history</li> </ul>	<ul style="list-style-type: none"> <li>Improve user profiles for behavioral targeting</li> </ul>
	Raytheon	<ul style="list-style-type: none"> <li>Social networking and smartphones</li> </ul>	<ul style="list-style-type: none"> <li>Track movement and predict future behavior</li> </ul>
Other Hardware, Software, and Mobile Devices	Apple	<ul style="list-style-type: none"> <li>Voice, facial expression, physiologic, Internet activity, compared to a user baseline profile</li> </ul>	<ul style="list-style-type: none"> <li>Infer mood and deliver mood-based content</li> </ul>
	Microsoft Microcontroller	<ul style="list-style-type: none"> <li>Biometric data on emotional state such as heart rate, skin conductance</li> </ul>	<ul style="list-style-type: none"> <li>Mood-actuated device reacts to user mood</li> </ul>
	Microsoft Xbox	<ul style="list-style-type: none"> <li>Scan email, messages, Kinect movement sensors, facial expressions</li> </ul>	<ul style="list-style-type: none"> <li>Target ads based on emotional state</li> </ul>
	Yahoo!	<ul style="list-style-type: none"> <li>Voice analysis, speech, tone</li> </ul>	<ul style="list-style-type: none"> <li>Stream content using voice-based mood analysis</li> </ul>
	Dell	<ul style="list-style-type: none"> <li>EEG, heart rate, other physiologic sensors</li> </ul>	<ul style="list-style-type: none"> <li>Determine mood and emotion for use in education, gaming</li> </ul>

**Excerpted from:** Scott Monteith, Michigan State University, "New Measures of Mental State and Behavior Based on Data Collected from Sensors, Smartphones, and the Internet," *Current Psychiatry Reports*, October 2014.

## How Medical Digital Phenotyping Apps and Programs Monitor Your Mental Health:

Medical Technology (bound by HIPAA)	What it Can Monitor	Purposes
Cell phone or smartphone	<ul style="list-style-type: none"> <li>• Speech analysis</li> <li>• Usage patterns, app selection</li> </ul>	<ul style="list-style-type: none"> <li>• Mental health, emotion and stress</li> <li>• Monitor mood in bipolar disorder</li> </ul>
Multiple sensors and devices in home	<ul style="list-style-type: none"> <li>• Speech, activity, sleep, weight, movement</li> </ul>	<ul style="list-style-type: none"> <li>• Continuous monitoring for depression, PTSD</li> </ul>
Smartphone acceleration and GPS sensors	<ul style="list-style-type: none"> <li>• Activity and mobility</li> <li>• Location</li> </ul>	<ul style="list-style-type: none"> <li>• Mood state recognition (mania and depression in bipolar disorder)</li> <li>• Track wandering in dementia</li> </ul>
Ingestible sensor in tablets	<ul style="list-style-type: none"> <li>• Medication ingestion</li> </ul>	<ul style="list-style-type: none"> <li>• Monitor medication adherence in schizophrenia or bipolar disorder</li> </ul>
Twitter	<ul style="list-style-type: none"> <li>• Keywords and phrases in tweets</li> <li>• Usage patterns, language</li> </ul>	<ul style="list-style-type: none"> <li>• Surveillance for suicide risk</li> <li>• Predict onset of depression</li> </ul>
Internet usage	<ul style="list-style-type: none"> <li>• Traffic volume, type of activities and sites</li> </ul>	<ul style="list-style-type: none"> <li>• Passive monitoring for depression</li> </ul>
Video images	<ul style="list-style-type: none"> <li>• Facial activity and expression</li> </ul>	<ul style="list-style-type: none"> <li>• Identify depression and anxiety</li> </ul>

**Excerpted from:** Scott Monteith, Michigan State University, "New Measures of Mental State and Behavior Based on Data Collected from Sensors, Smartphones, and the Internet," *Current Psychiatry Reports*, October 2014.

## Primary Concerns About Digital Phenotyping Apps and Programs:

- HIPAA compliance
- Data ownership
- User privacy
- Data security
- Invasiveness
- Accuracy, reliability of data
- Interpretation of data
- Community collaboration and stakeholder involvement
- Whether apps are client driven, culturally competent, and wellness/ recovery focused
- Client self-determination
- Diversion of MHSA resources
- Availability of direct services and needed interventions
- Availability of alternative services/ treatments
- Opt-out policies; data deletion
- Appropriateness of apps for target populations (rural, older adults)
- Sale/use of data for marketing and advertising purposes
- Corporate subsidization
- Use of public mental health client data for profit/private gain