Welcome to 2019 NAMI National Convention

Digital Mental Health: Recent Findings and New Directions

John Torous MD, MBI and Liza Hoffman, MSW, LICSW

@JohnTorousMD and @LHoffmanLICSW

Outline

- State of Smartphones and Mental Health
- Smartphones Digital Phenotyping
- Informed Decision Making For Smartphone Apps

©JimBenton.com

Our Movement. Our Moment.

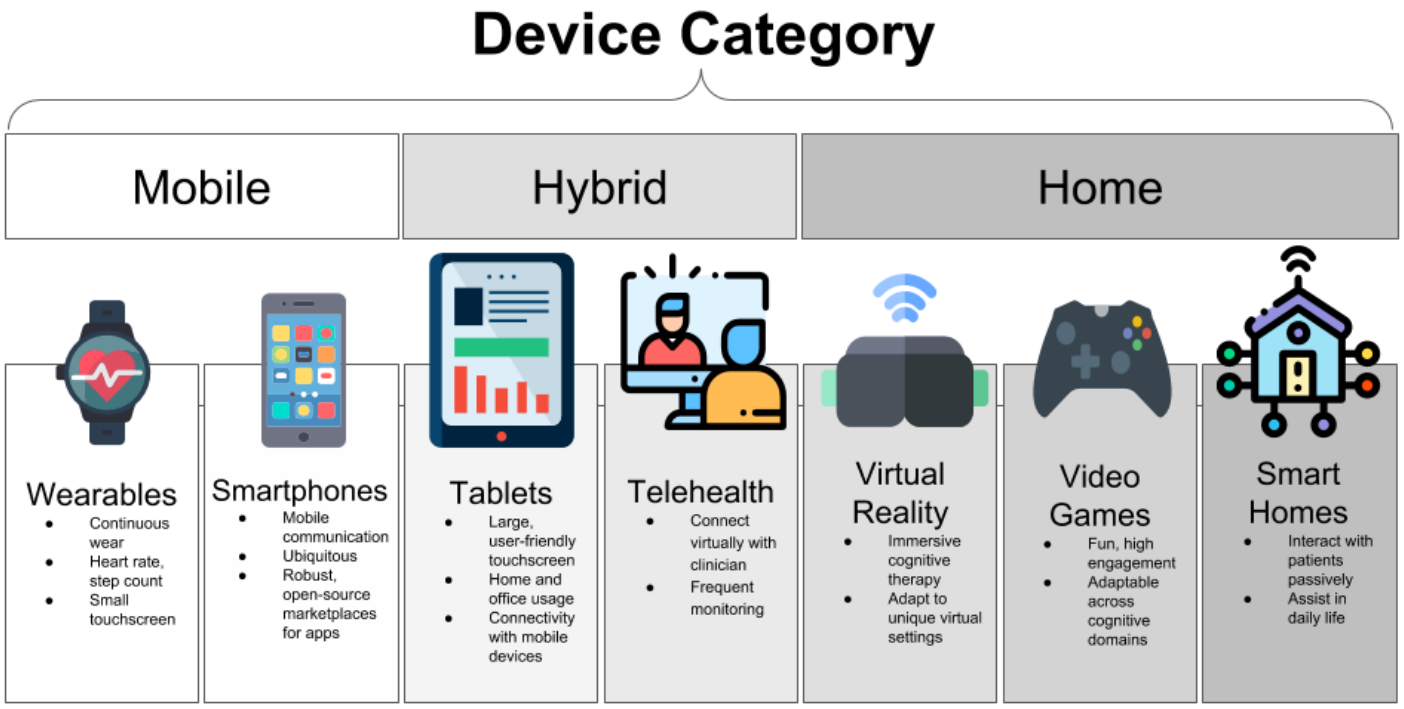
#NAMICON19

2019 NAMI National Convention

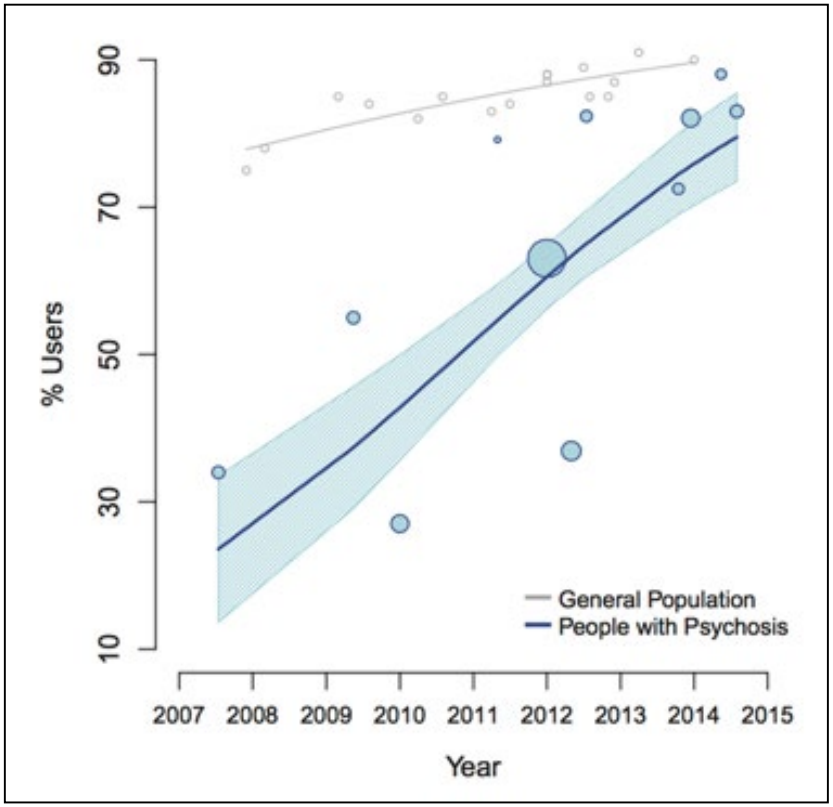
JUNE 19–22 • SEATTLE

SMIadviser.org

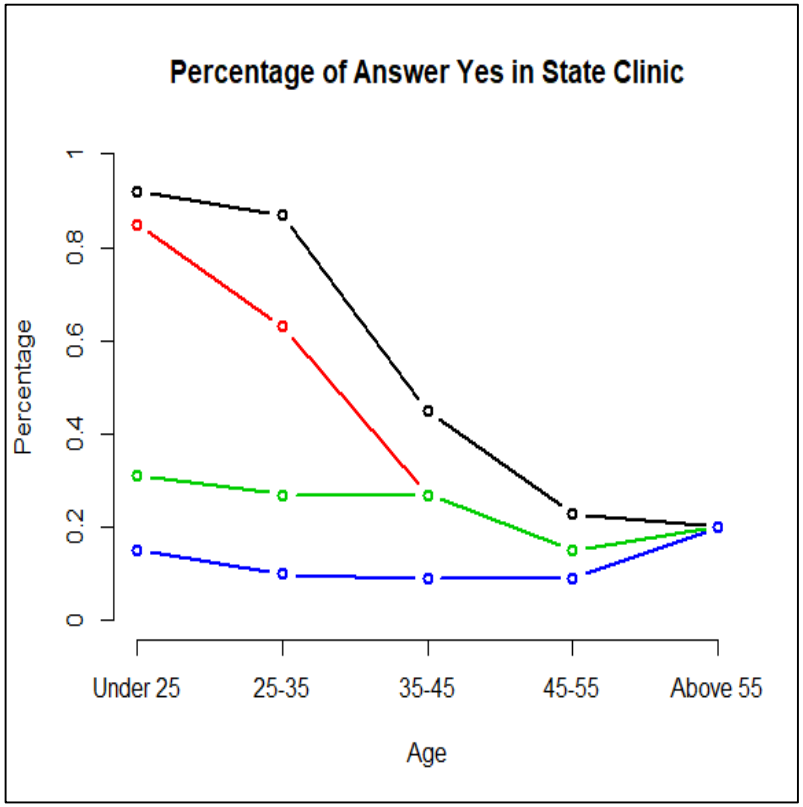
Finding Focus in Digital Mental Health



Finding Focus in Digital Mental Health

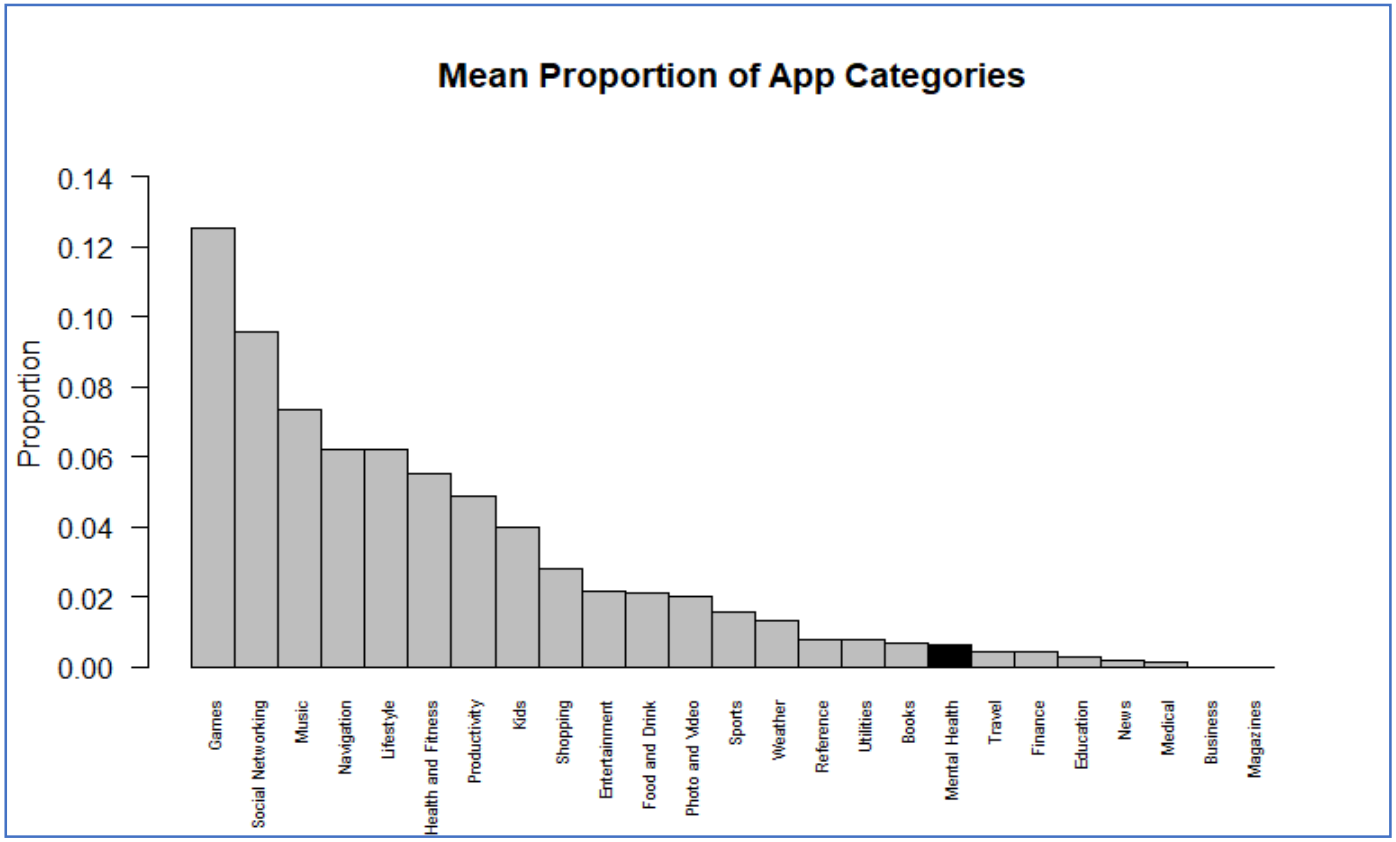


Mobile Phone Ownership and Endorsement of "mHealth" Among People With Psychosis: A Meta-analysis of Cross-sectional Studies.J Firth, J Cotter, J Torous, S Bucci, JA Firth, AR Yung. Schizophrenia Bulletin. 2016



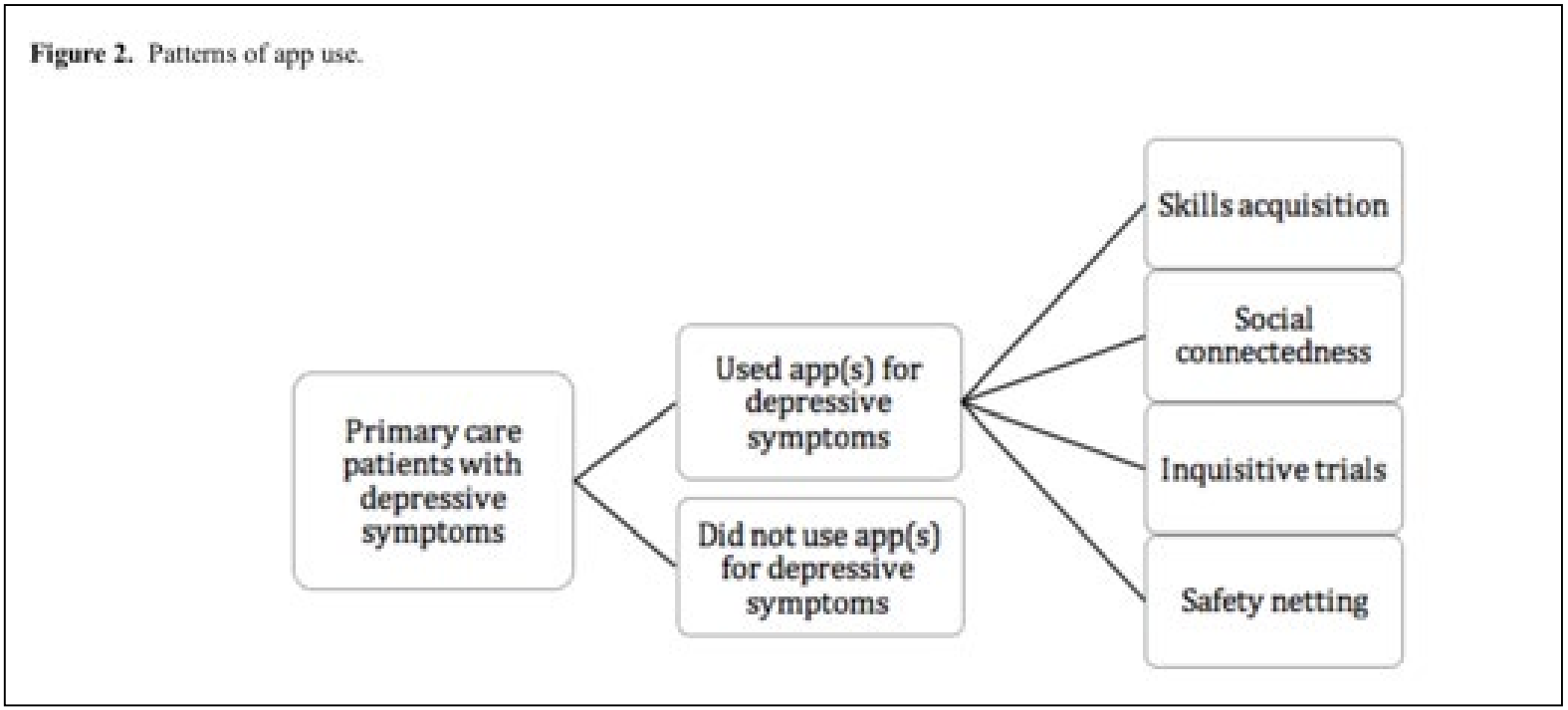
Torous J, Wisniewski H, Liu G, Keshavan M. Mental Health Mobile Phone App Usage, Concerns, and Benefits Among Psychiatric Outpatients: Comparative Survey Study. JMIR Mental Health. 2018;5(4):e11715

But What is a Mental Health App?



Torous J, Wisniewski H, Liu G, Keshavan M. Mental Health Mobile Phone App Usage, Concerns, and Benefits Among Psychiatric Outpatients: Comparative Survey Study. JMIR Mental Health. 2018;5(4):e11715

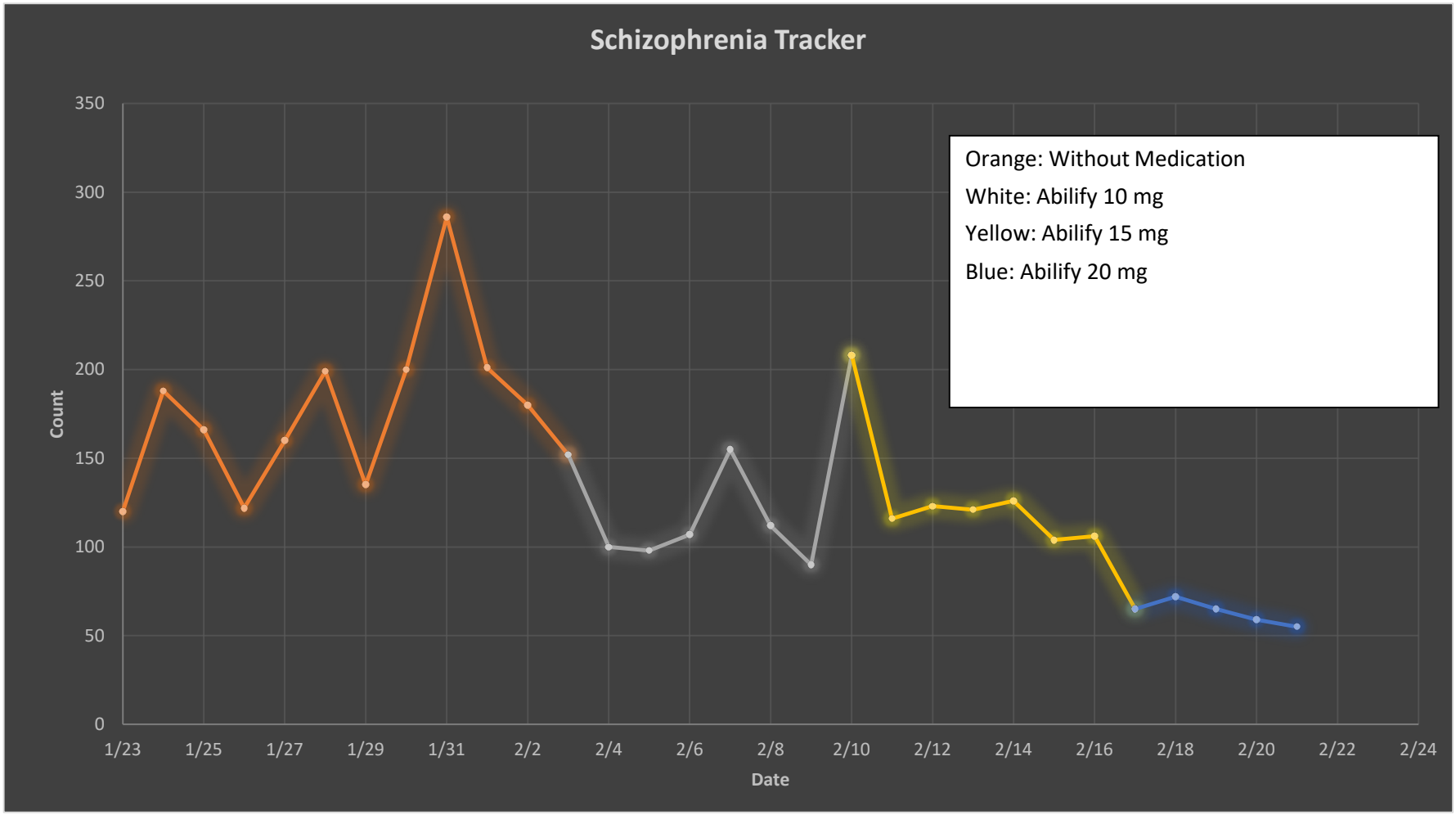
But What is a Mental Health App?



Pung A, Fletcher SL, Gunn JM. Mobile App Use by Primary Care Patients to Manage Their Depressive Symptoms: Qualitative Study. Journal of Medical Internet Research. 2018;20(9):e10035.

0123

9999
TALLY COUNTER
Count
Add/Subtract Model



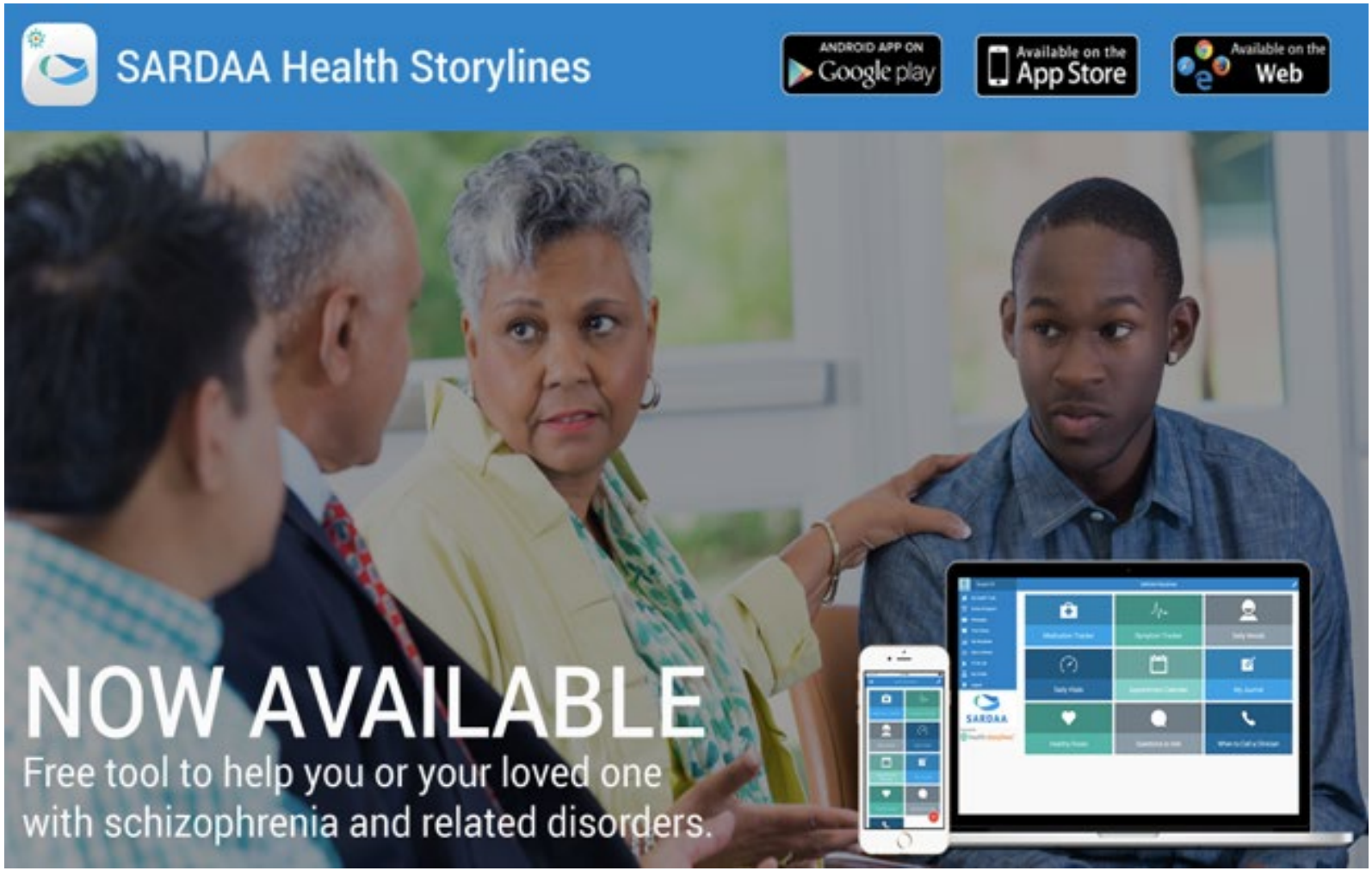
Torous J, Roux S. Patient-driven innovation for mobile mental health technology: Case report of symptom tracking in schizophrenia. JMIR mental health. 2017 Jul;4(3).

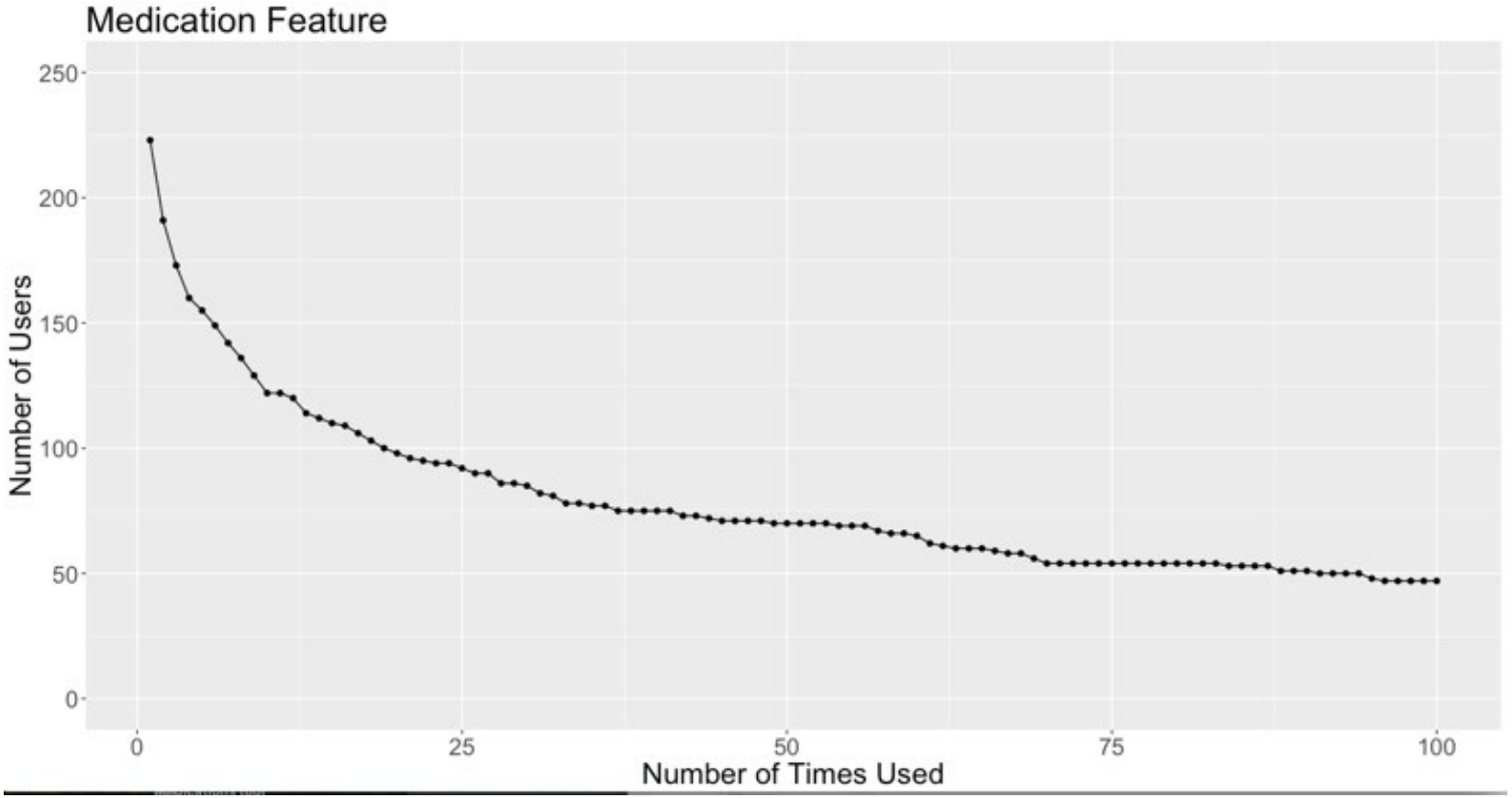
Our Movement. Our Moment.

#NAMICON19

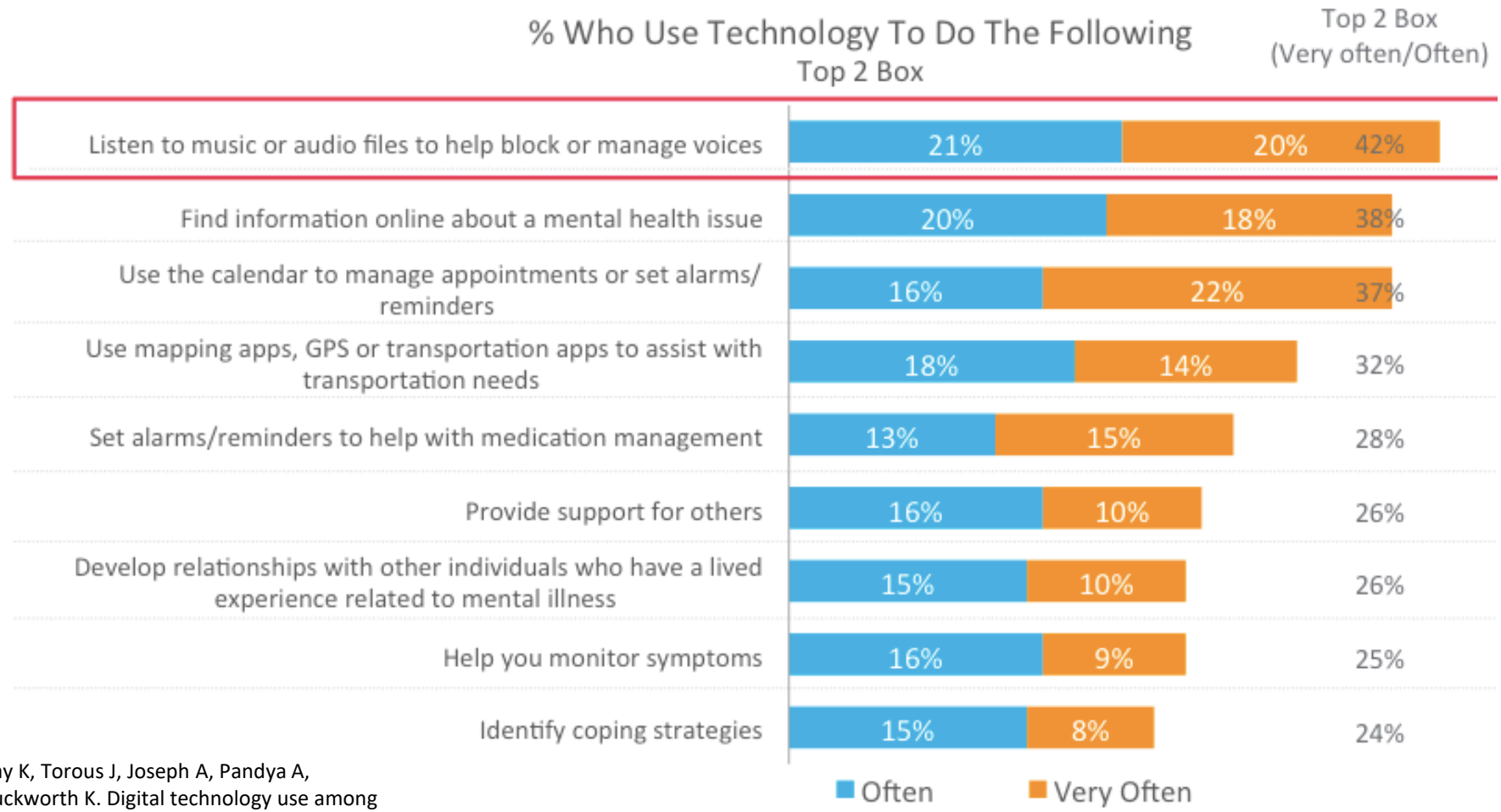
2019 NAMI National Convention

JUNE 19–22 • SEATTLE



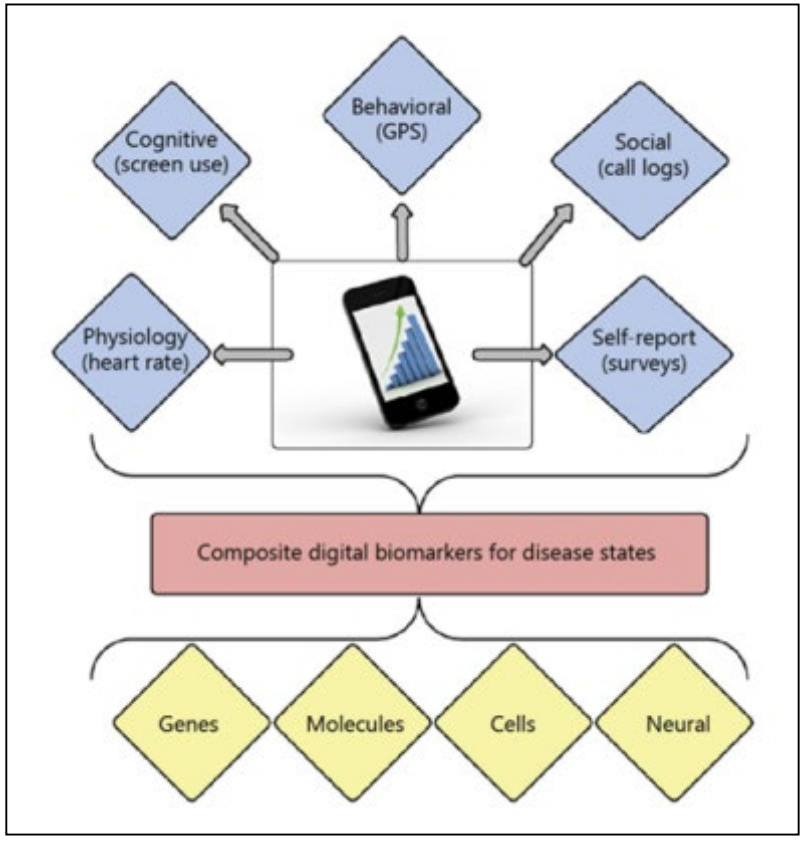


Torous J, Staples P, Slaters L, Adams J, Sandoval L, Onnela JP, Keshavan M. Characterizing Smartphone Engagement for Schizophrenia: Results of a Naturalist Mobile Health Study. Clinical Schizophrenia & Related Psychoses. 2017 Aug 4.



Gay K, Torous J, Joseph A, Pandya A, Duckworth K. Digital technology use among individuals with schizophrenia: results of an online survey. JMIR mental health. 2016 Apr;3(2).

Digital Phenotyping



What it is?

Why is matters?

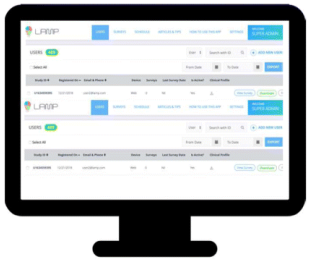
Torous J, Rodriguez J, Powell A. The new digital divide for digital biomarkers. Digital biomarkers. 2017;1(1):87-91.

Digital Phenotyping: One of Many Platforms

	Transparent	Data Driven	Translational
Trust	App co-design, full sharing and access to data, ability to delete data, remote consent built into the app	App and software support data security and privacy. Research conducted in a transparent and rigorous manner	Research conducted in ethical and transparent manner. App tools are shared to encourage research
Control	App co-design and iterative releases, ability for users to alter settings and nonfiction schedules	App data structured for access control. Users retain ultimate control of data	Personalized data collection matched to clinical needs. Ability to customize learning and interventions
Community	App, database, middleware, and data visualization code publicly available	App data shared with users. All methods and data processing code made publically available	App uses case and clinics designed to strengthen the therapeutic alliance between patient and clinician

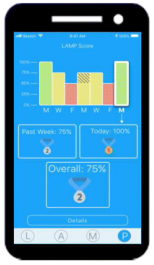
Portal (Admin)

- Create Surveys
- Schedule Surveys and Cognitive Assessments
- Download Data
- Generate Study IDs to Access Custom Configurations of the App Created in the Portal



LAMP APP (Patients)

- Learn from Articles and Tips
- Take Surveys
- Take Cognitive Assessments
- Complete Mindfulness Exercises
- View Results

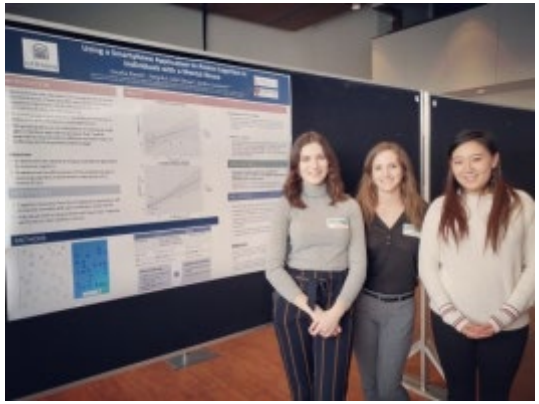


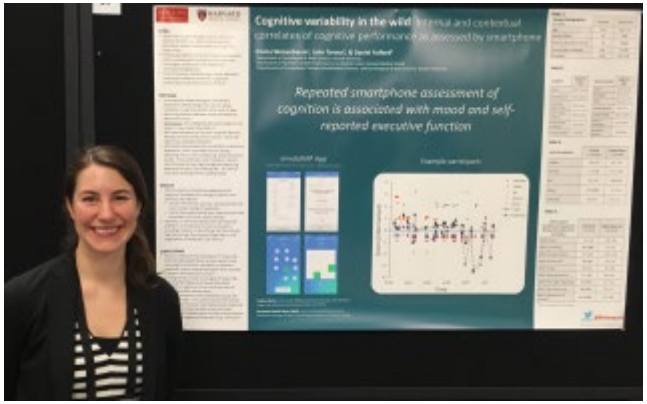
LAMP Visualizations (Admin + Patients)

- View Chart and Graphs of Results
- View Timeline of Results
- Run Custom Scripts on Results

Torous, J., Wisniewski, H., Bird, B., Carpenter, E., David, G., Elejalde, E., Fulford, D., Guimond, S., Hays, R., Henson, P. and Hoffman, L., 2019. Creating a digital health smartphone app and digital phenotyping platform for mental health and diverse healthcare needs: an interdisciplinary and collaborative approach. *Journal of Technology in Behavioral Science*, pp.1-13.

Digital Phenotyping: Sharing Tools



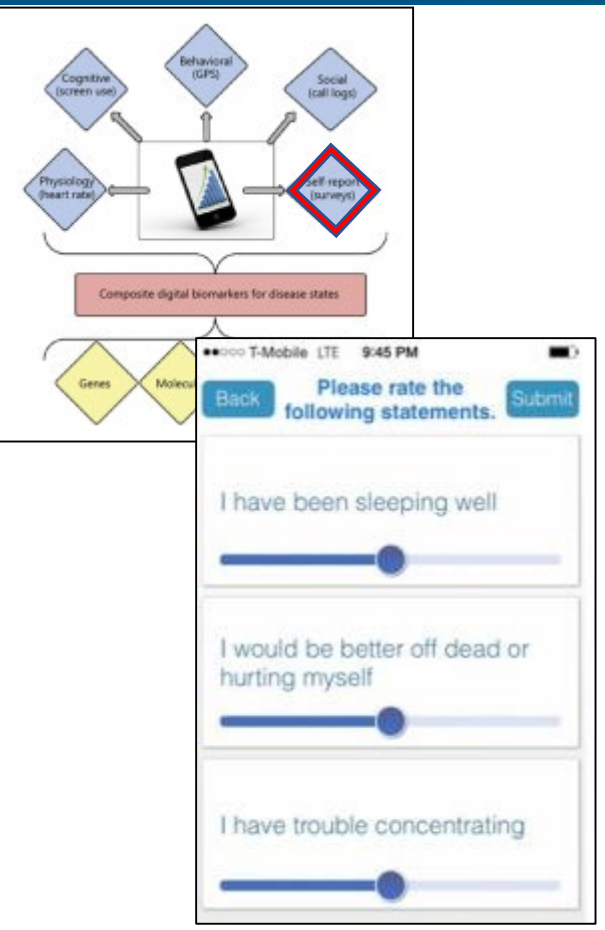


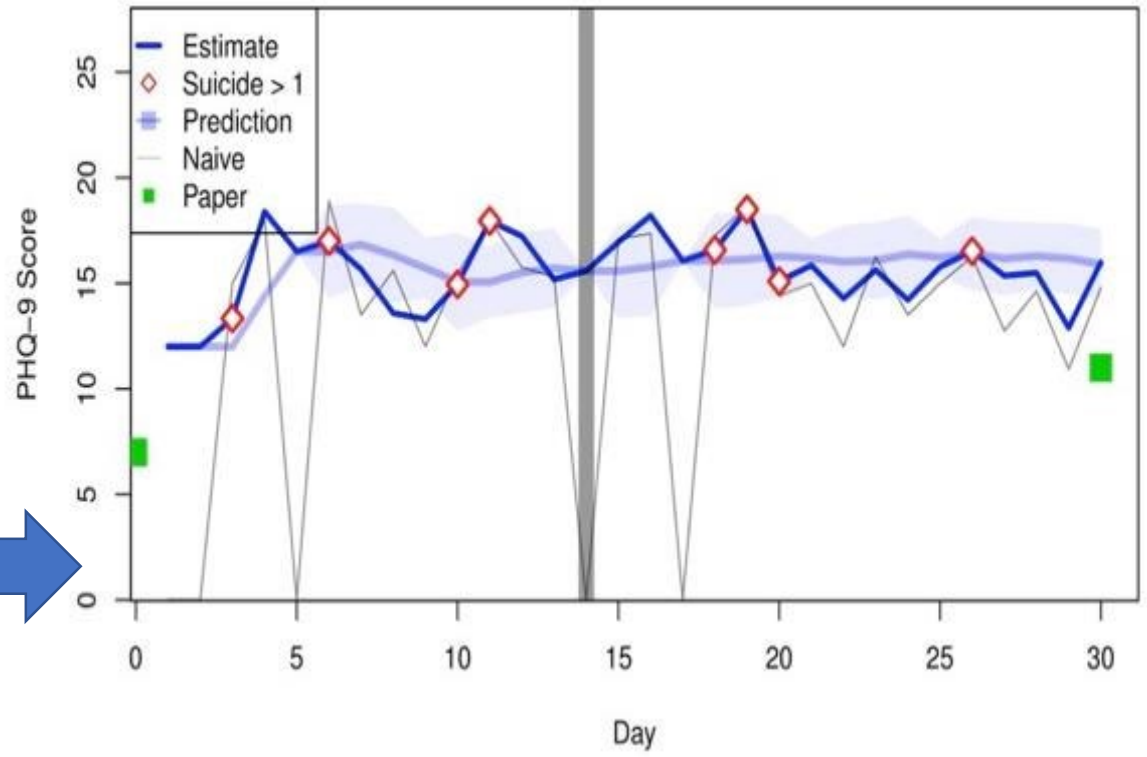
uOttawa

BOSTON UNIVERSITY

National Institute of Mental Health and Neurosciences
राष्ट्रीय मानसिक स्वास्थ्य और स्नायु विज्ञान संस्थान
ರಾಷ್ಟ್ರೀಯ ಮಾನಸಿಕ ಆರೋಗ್ಯ ಮತ್ತು ನರವಿಜ್ಞಾನ ಸಂಸ್ಥೆ

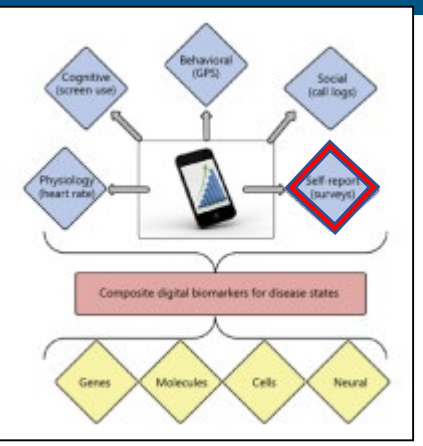
Torous, J., Wisniewski, H., Bird, B., Carpenter, E., David, G., Elejalde, E., Fulford, D., Guimond, S., Hays, R., Henson, P. and Hoffman, L., 2019. Creating a digital health smartphone app and digital phenotyping platform for mental health and diverse healthcare needs: an interdisciplinary and collaborative approach. *Journal of Technology in Behavioral Science*, pp.1-13.

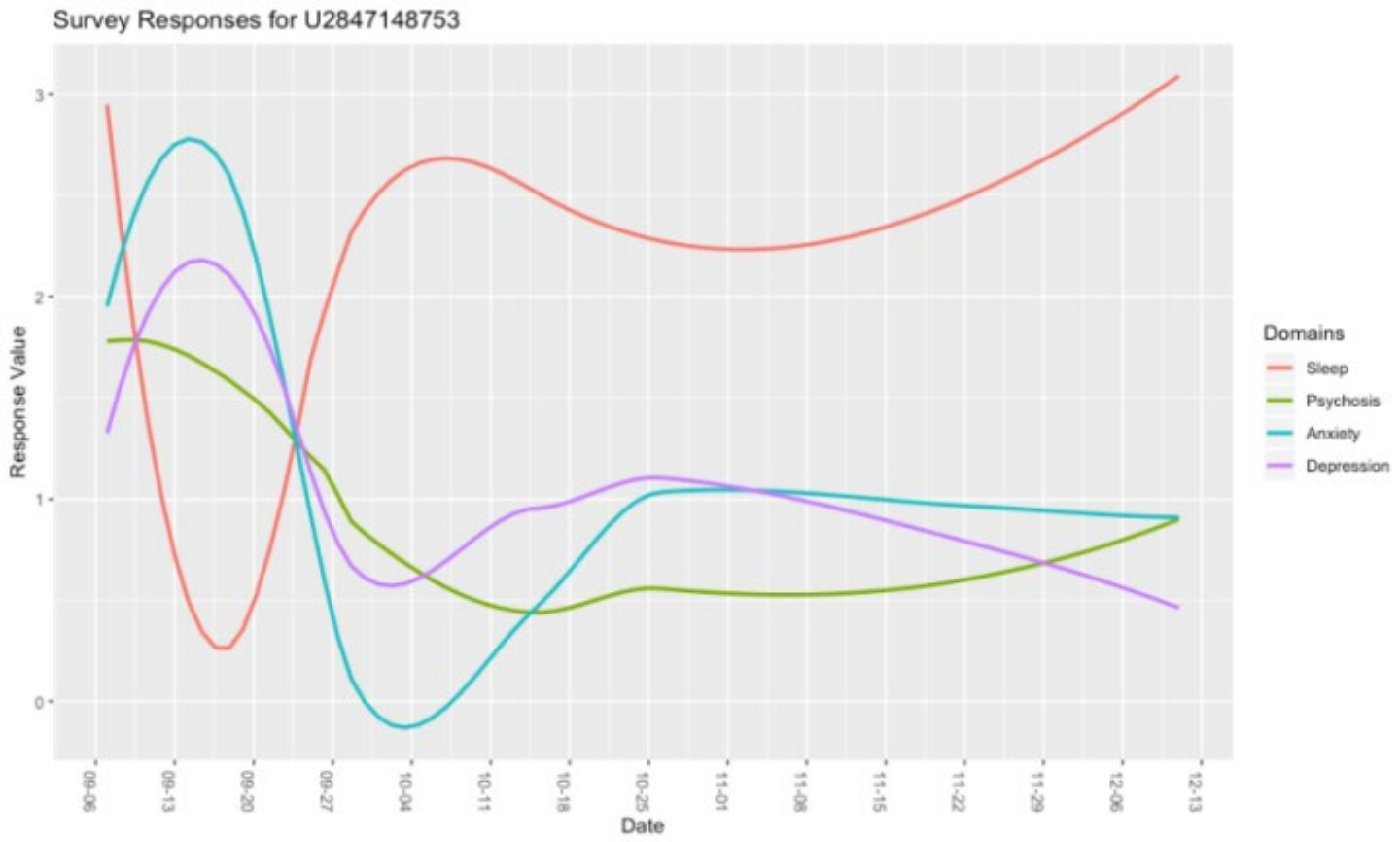




Torous J, Staples P, Shanahan M, Lin C, Peck P, Keshavan M, Onnela JP. Utilizing a Personal Smartphone Custom App to Assess the Patient Health Questionnaire-9 (PHQ-9) Depressive Symptoms in Patients With Major Depressive Disorder. JMIR Ment Health 2015;2(1):e8

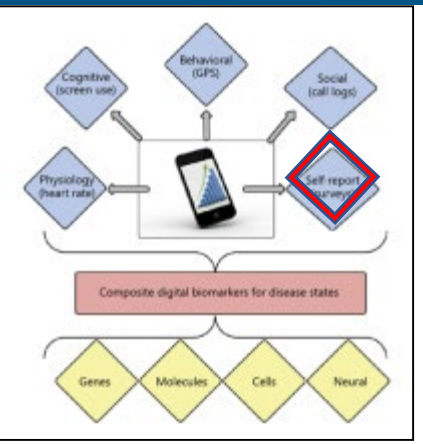
Beth Israel Deaconess Medical Center
HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

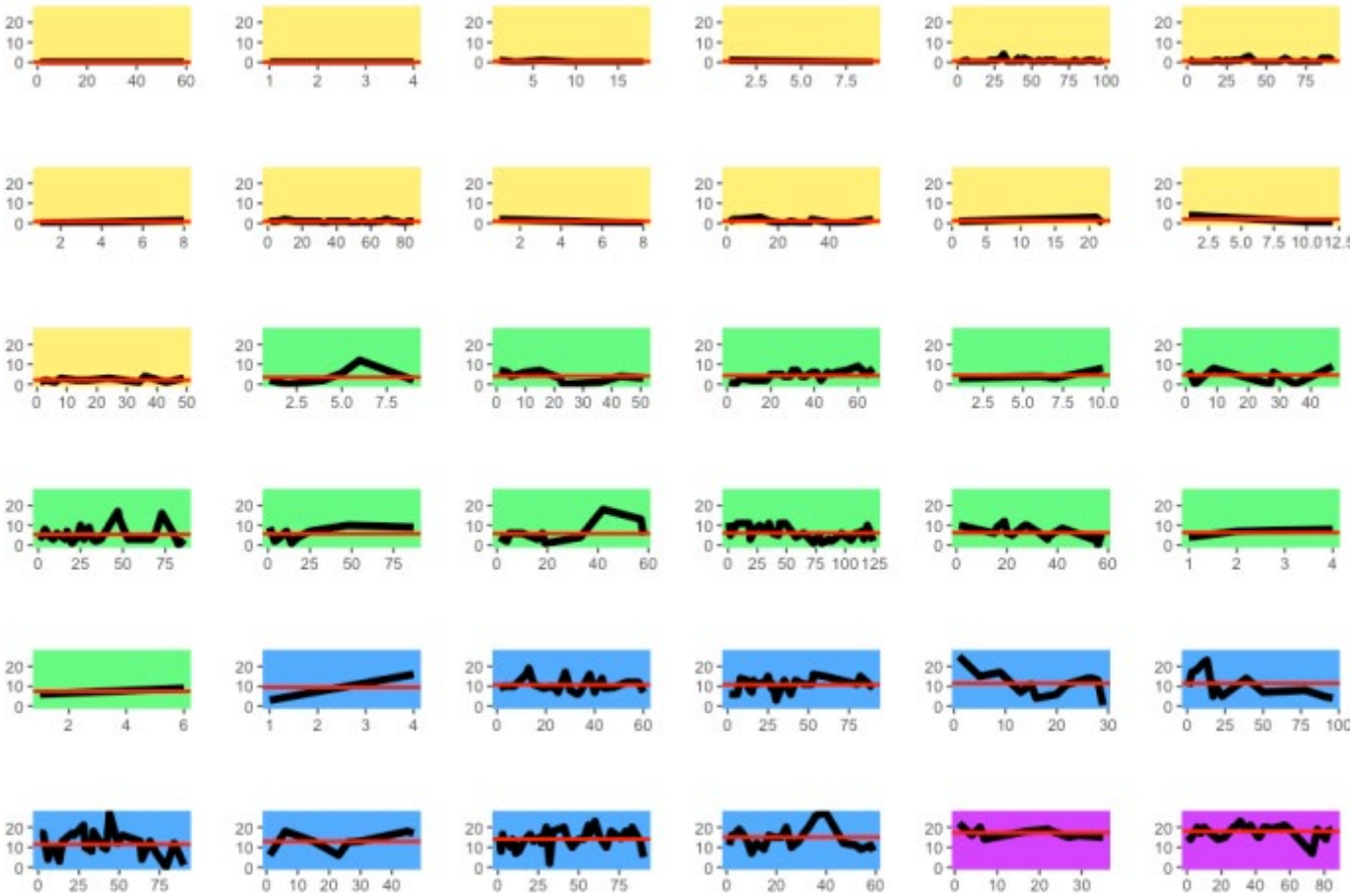


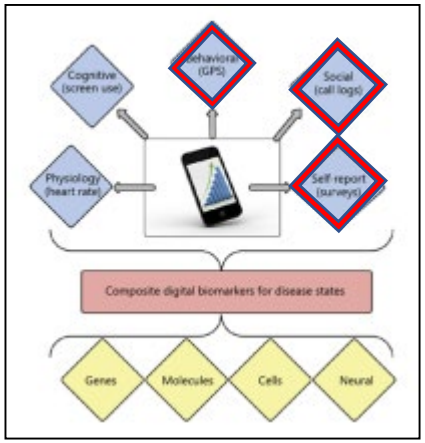


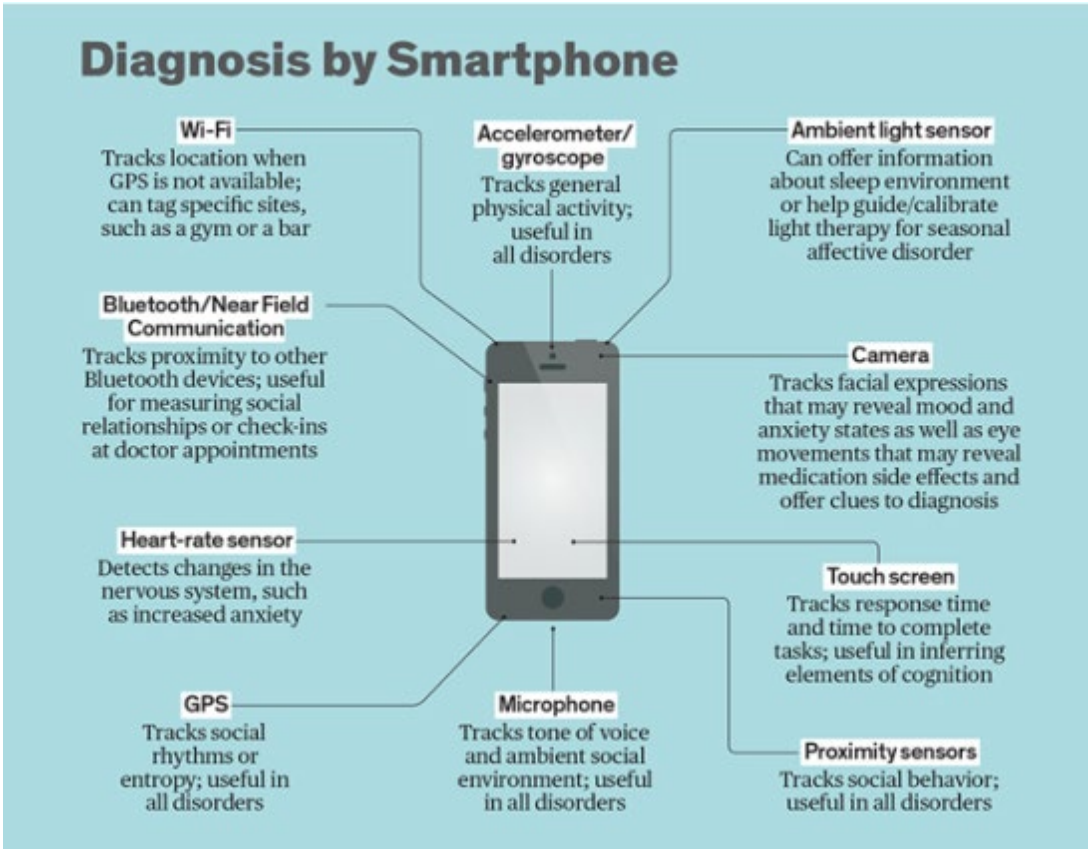
Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

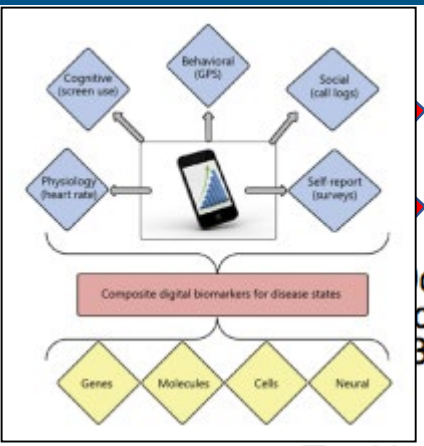

Cognitive (screen use)
Behavioral (GPS)
Social (call logs)
Physiology (heart rate)
Self report (surveys)
Composite digital biomarkers for disease states
Genes
Molecules
Cells
Neural







A Software Shrink: Apps and Wearables Could Usher In an Era of Digital Psychiatry. IEEE Spectrum. 2017.



da1206f74995a83f71
cc1206f735d849088b
3e1206f735d8490880
missed calls
Call duration
Total length of texts received
texts received
Total length of texts sent
texts sent
Circadian routine
Significant locations visited
Max distance from home
Distance travelled
Home time
GPS amount recorded

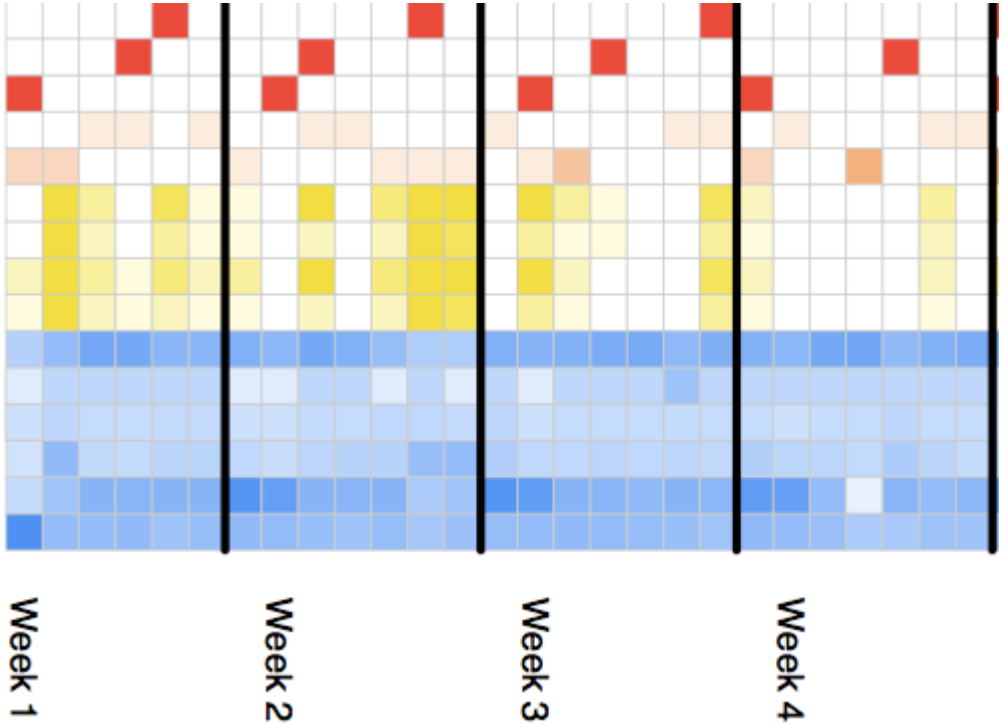
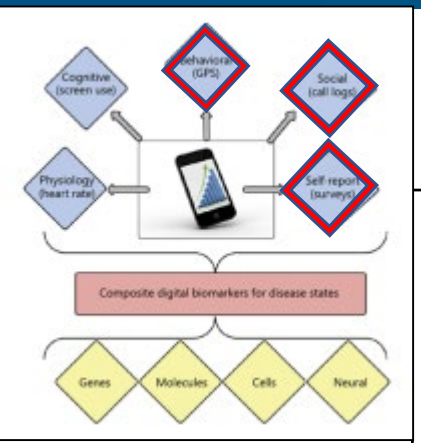
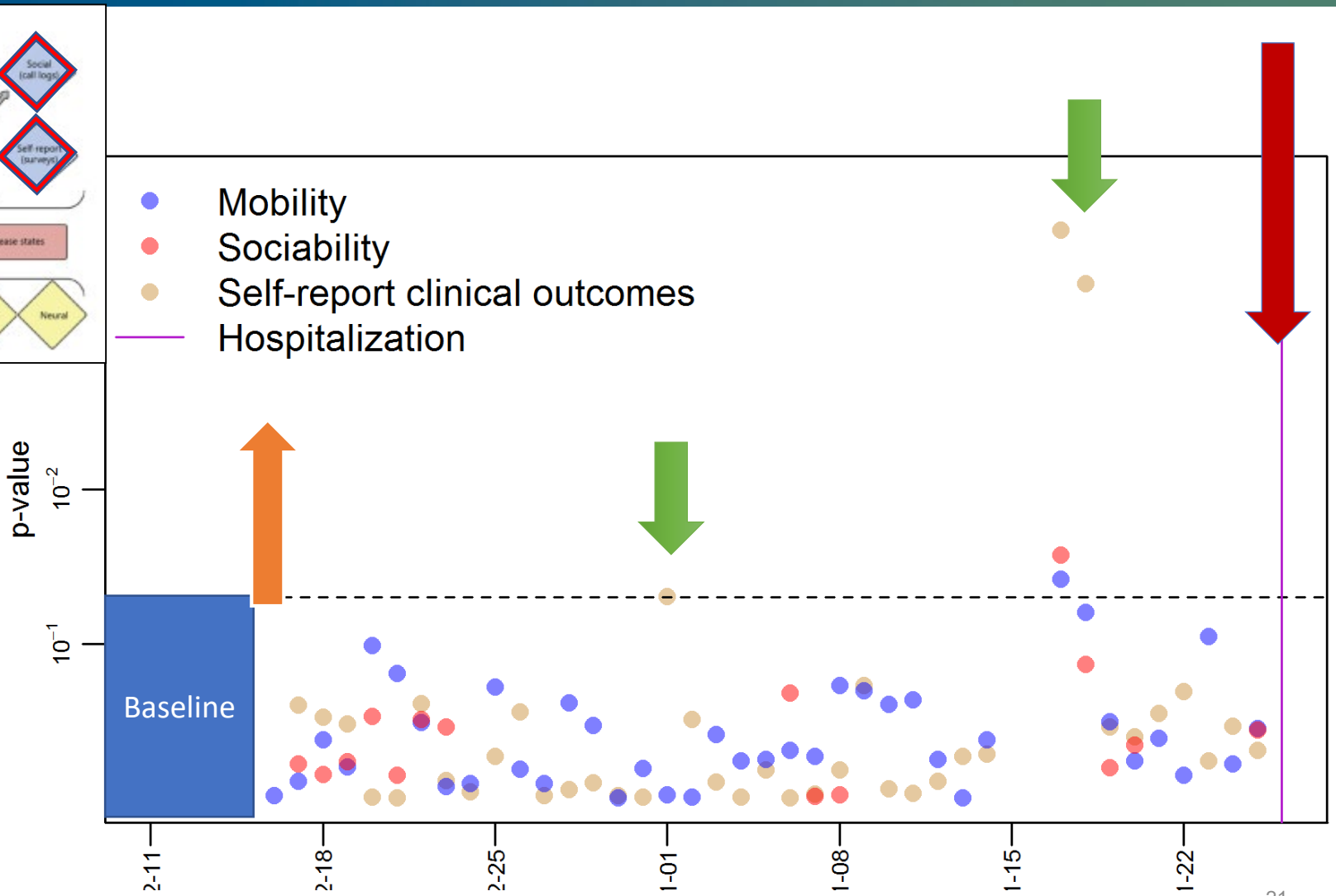
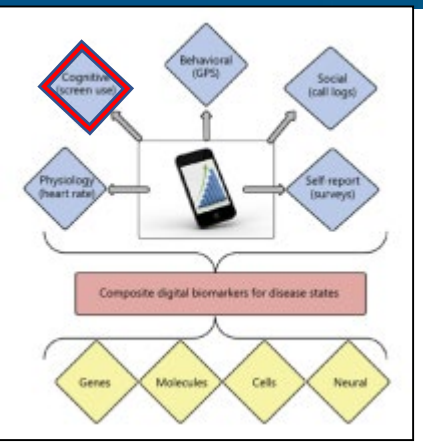


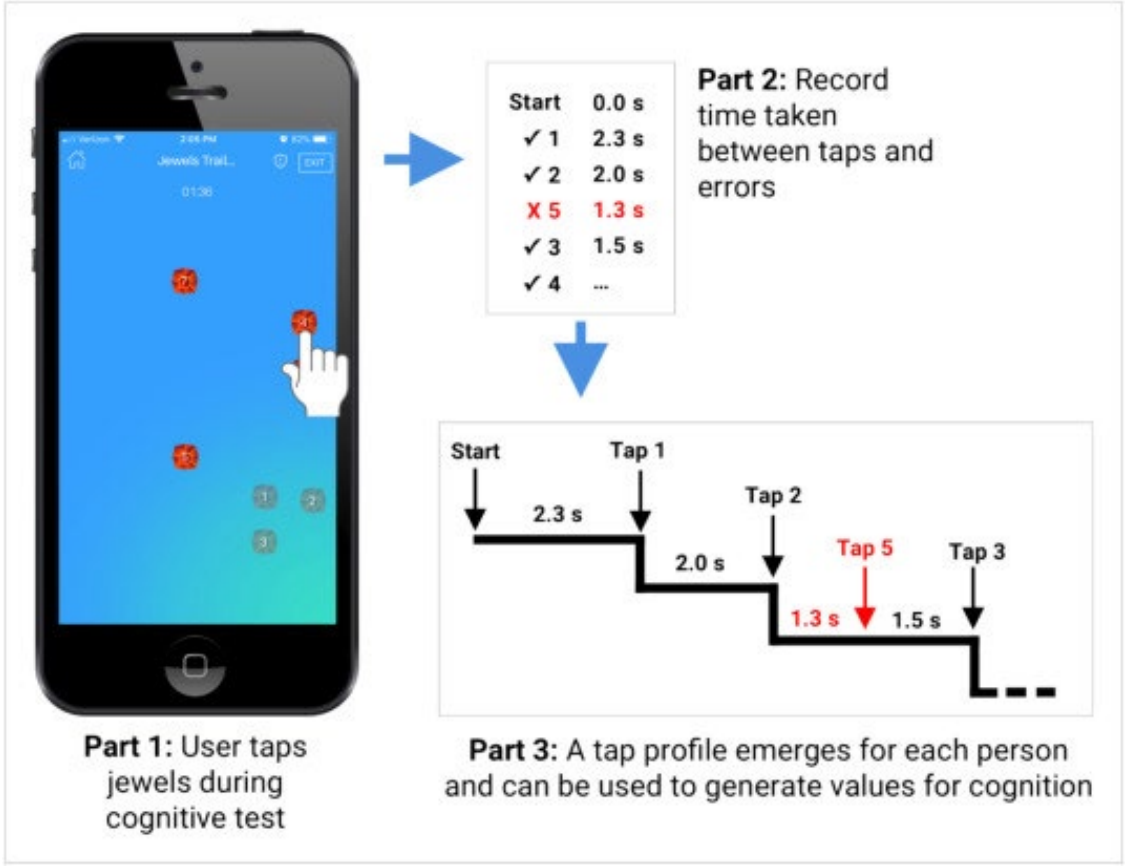
Image by Ian Barnett PhD, UPenn



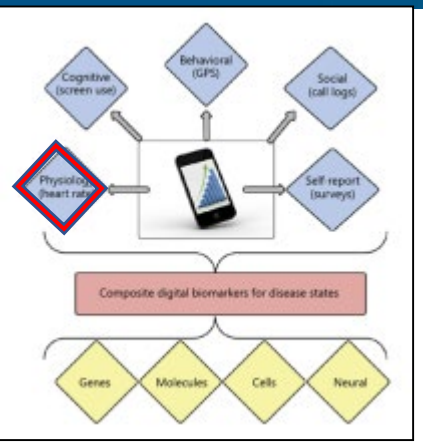


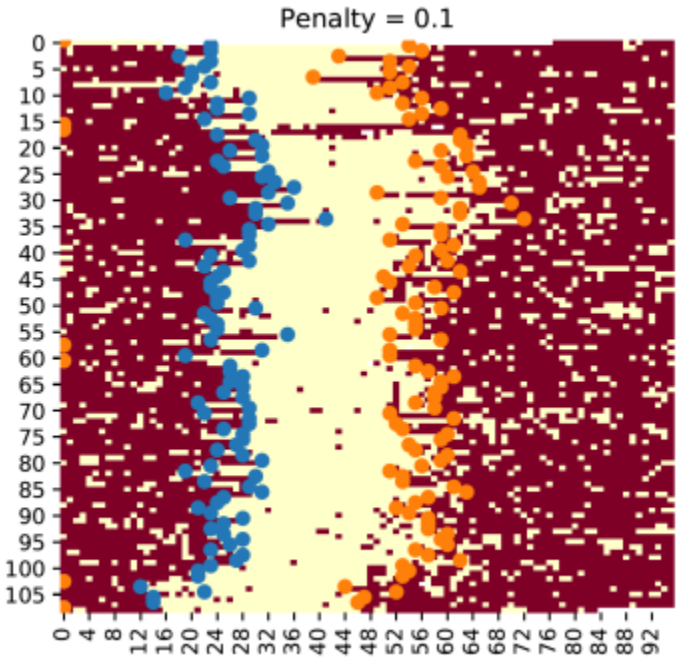
Barnett I, Torous J, Staples P, Sandoval L, Keshavan M, Onnela JP. Relapse prediction in schizophrenia through digital phenotyping: a pilot study. Neuropsychopharmacology. 2018 Feb 22:1.

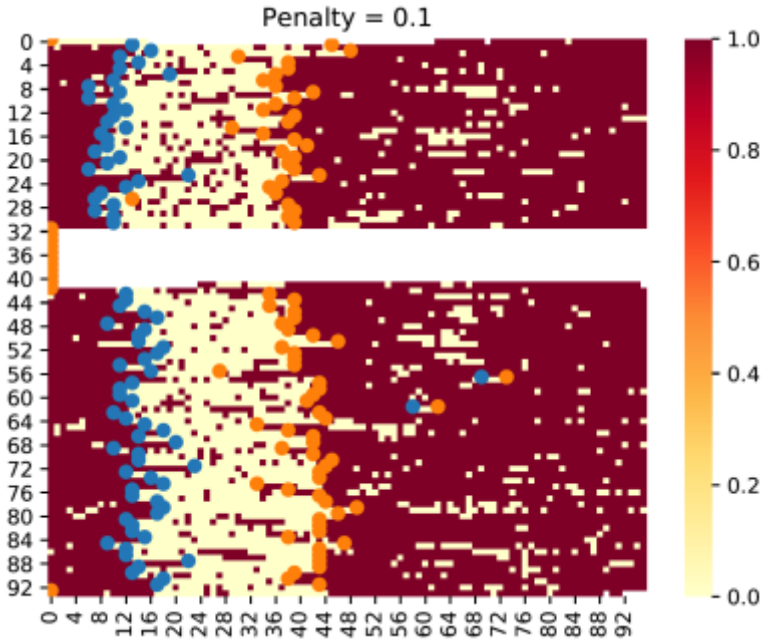




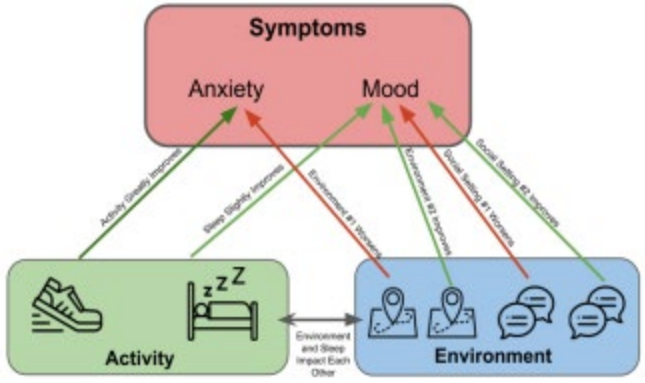
Liu G, Henson P, Keshavan M, Pekka-Onnela J, Torous J. Assessing the potential of longitudinal smartphone based cognitive assessment in schizophrenia: A naturalistic pilot study. Schizophrenia Research: Cognition. 2019 Sep 1;17:100144.

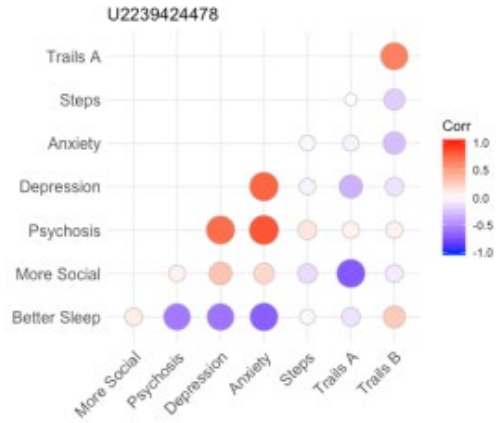

Cognitive (screen use)
Behavioral (GPS)
Social (call logs)
Physiology (heart rate)
Self-report (surveys)
Composite digital biomarkers for disease states
Genes
Molecules
Cells
Neural


Penalty = 0.1

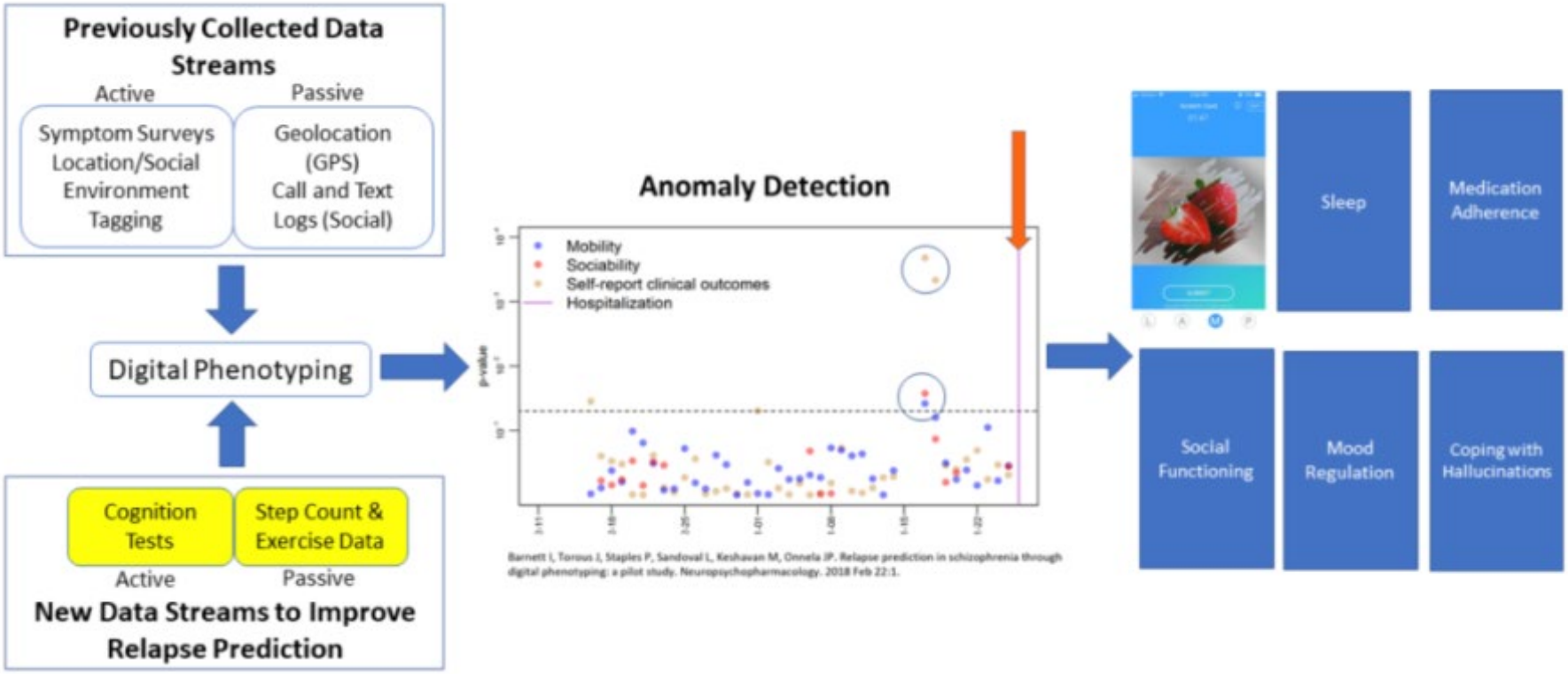

Penalty = 0.1

Putting it all Together: 'Digital' Clinics





Beth Israel Deaconess Medical Center | HARVARD MEDICAL SCHOOL TEACHING HOSPITAL



1. LAMP creates a baseline digital phenotype for users based on active + passive data. New data to improve phenotyping will be added to the model.

2. LAMP monitors users' digital phenotype at all times for anomalies in surveys, behaviors, cognition, and activity patterns, and identifies relapse risk.

3. LAMP prompts users to complete intervention activities to reduce relapse risk. Intervention will be based on published evidence and created via co-design at all study sites.

Our Movement. Our Moment.

#NAMICON19

2019 NAMI National Convention

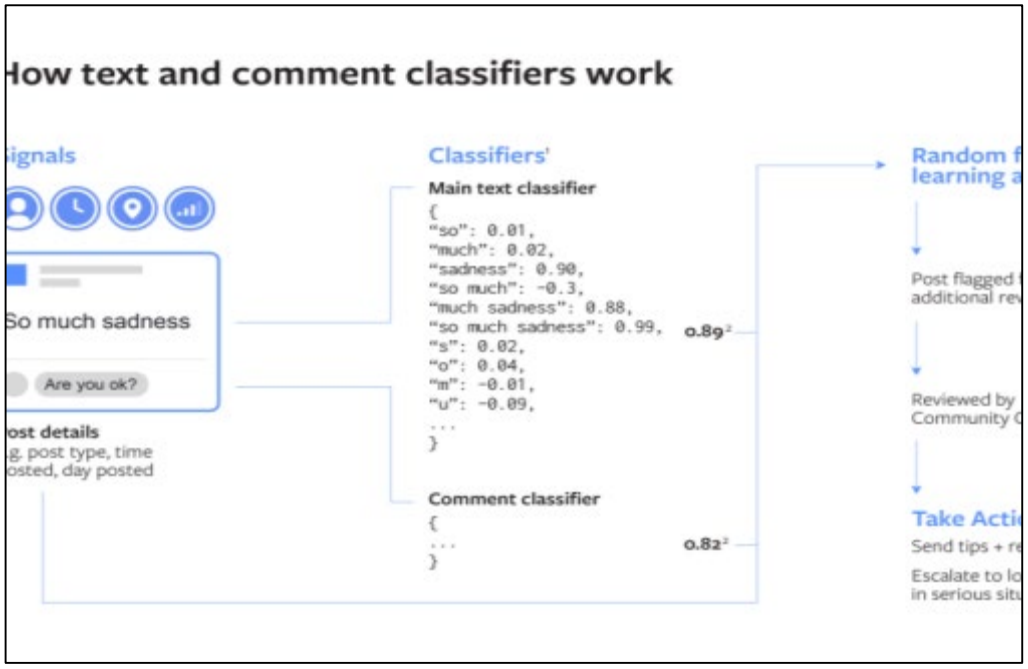
JUNE 19–22 • SEATTLE

Important to be aware of what is being collected and why

The New York Times

In Screening for Suicide Risk, Facebook Takes On Tricky Public Health Role

January 1, 2019

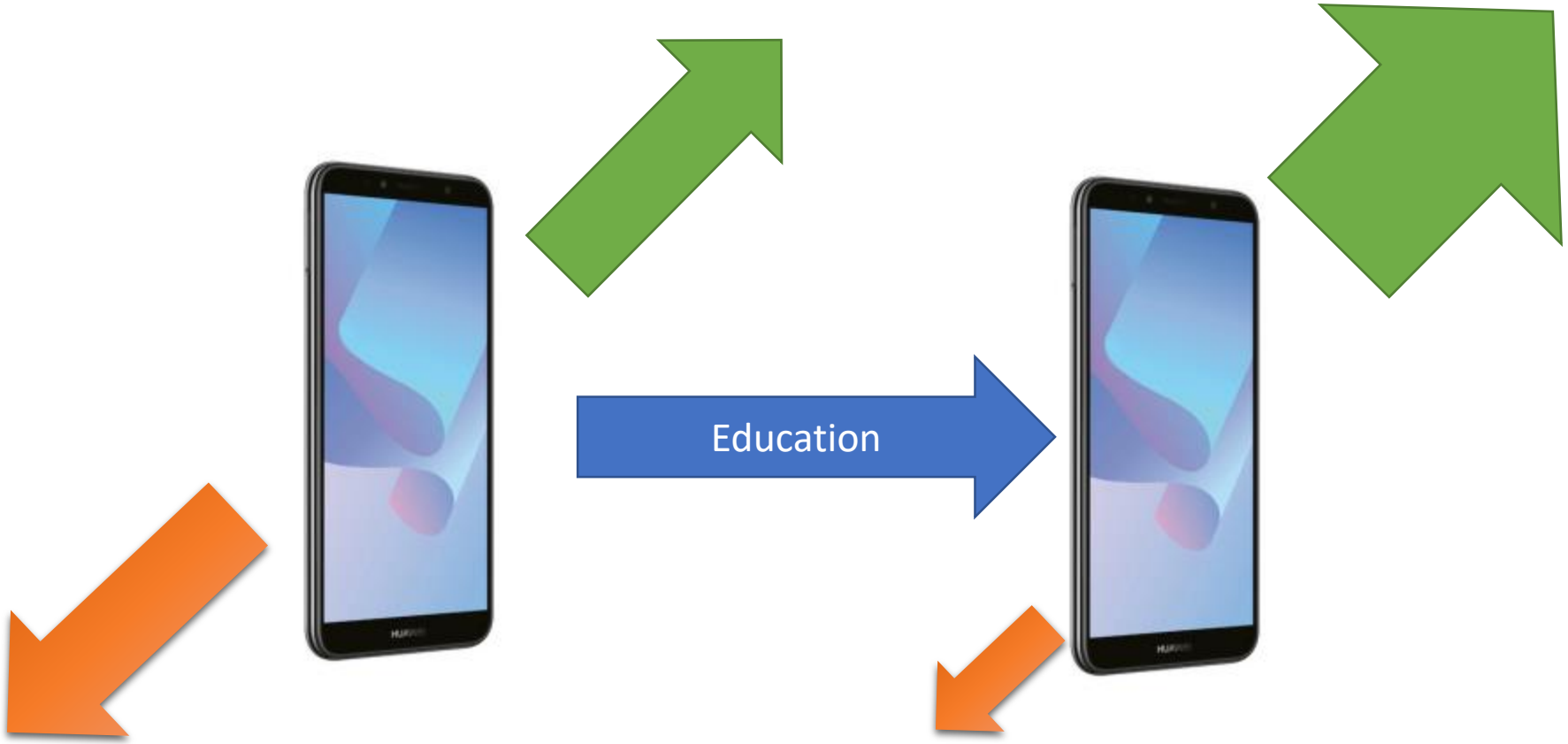


https://newsroom.fb.com/news/2018/09/inside-feed-suicide-prevention-and-ai/

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

Helping People Use New Tools



Helping People Use New Tools

DOORS
DIGITAL OPPORTUNITIES FOR OUTCOMES IN RECOVERY SERVICES

Session 1: Smartphone Fundamentals and Your Health Goals

Learn how apps may help you towards your health goals // Learn about mental health apps and other digital resources // Access and download apps // Keep your personal data secure //Remove harmful apps // Use alarms, maps, and reminders on the phone available for

Session 2: Smartphones for Health and Wellness

Set up mental health apps // Collect your own data on mood, anxiety, sleep, and steps // Learn to use wearables and smartwatches // Learn to explore and discover local services via apps // Learn how to connect with peers and family with apps (without a data plan)

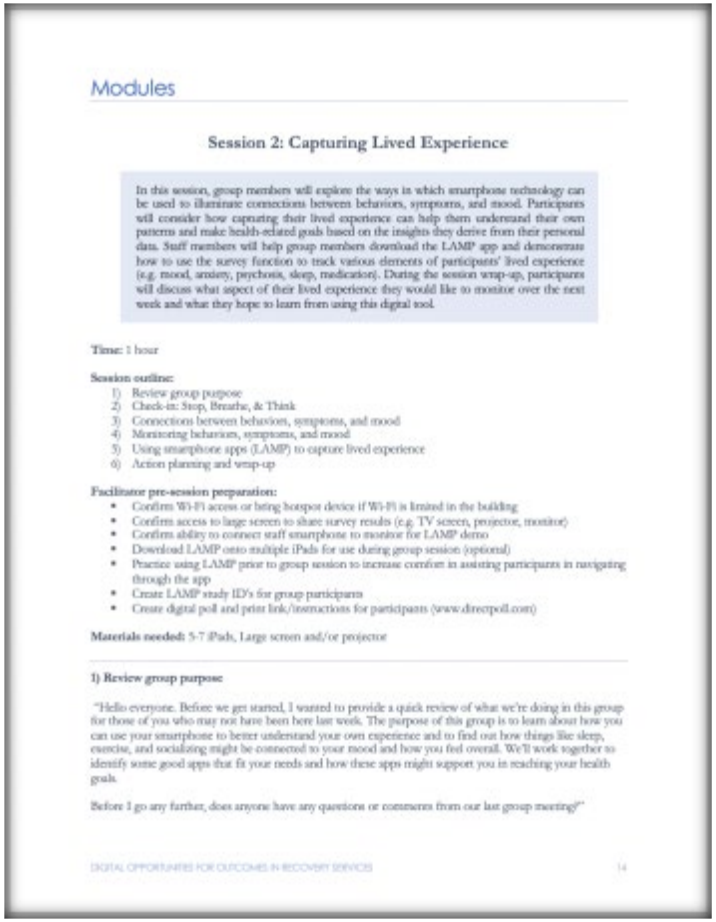
Session 3: Smartphones for Personal Health

Access and learn from your personal data // Learn how to share your data with who you want and how to protect what you don't want to share // Customize apps to your needs // Develop a digital mental health toolkit to support your recovery // Evaluate apps that may be of help

Session 4: Smartphones for Your Recovery

Develop insights into your recovery with digital data and smartphone tools // Finalize your digital toolkit // Help peers with technology // Use apps to access community resources and services // Action planning with apps // Identify barriers and solutions to technology use

Helping People Use New Tools



Modules

Session 2: Capturing Lived Experience

In this session, group members will explore the ways in which smartphone technology can be used to illuminate connections between behaviors, symptoms, and mood. Participants will consider how capturing their lived experience can help them understand their own patterns and make health-related goals based on the insights they derive from their personal data. Staff members will help group members download the LAMP app and demonstrate how to use the survey function to track various elements of participants' lived experience (e.g. mood, anxiety, psychosis, sleep, medication). During the session wrap-up, participants will discuss what aspect of their lived experience they would like to monitor over the next week and what they hope to learn from using this digital tool.

Time: 1 hour

Session outline:

1) Review group purpose
2) Check-in: Stop, Breathe, & Think
3) Connections between behaviors, symptoms, and mood
4) Monitoring behaviors, symptoms, and mood
5) Using smartphone apps (LAMP) to capture lived experience
6) Action planning and wrap-up

Facilitator pre-session preparation:

- Confirm Wi-Fi access or bring hotspot device if Wi-Fi is limited in the building
- Confirm access to large screen to share survey results (e.g. TV screen, projector, monitor)
- Confirm ability to connect staff smartphone to monitor for LAMP demo
- Download LAMP onto multiple iPads for use during group session (optional)
- Practice using LAMP prior to group session to increase comfort in assisting participants in navigating through the app
- Create LAMP study ID's for group participants
- Create digital poll and print link/instructions for participants (www.directpoll.com)

Materials needed: 5-7 iPads, Large screen and/or projector

1) Review group purpose

"Hello everyone. Before we get started, I wanted to provide a quick review of what we're doing in this group for those of you who may not have been here last week. The purpose of this group is to learn about how you can use your smartphone to better understand your own experience and to find out how things like sleep, exercise, and socializing might be connected to your mood and how you feel overall. We'll work together to identify some good apps that fit your needs and how these apps might support you in reaching your health goals.

Before I go any further, does anyone have any questions or comments from our last group meeting?"

DIGITAL OPPORTUNITIES FOR OUTCOMES IN RECOVERY SERVICES 14

Helping People Use New Tools

4. I know **where** to find helpful health resources on my smartphone

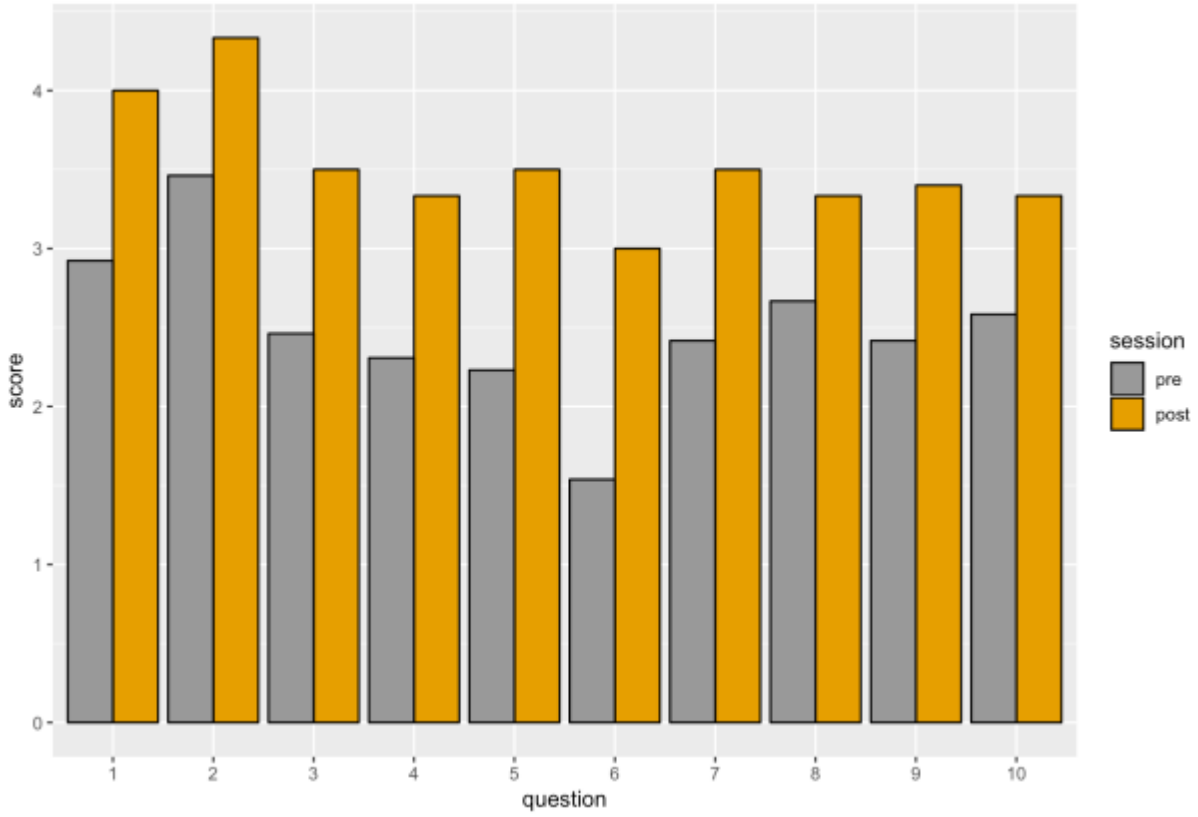
1) ❑ Strongly Disagree
2) ❑ Disagree
3) ❑ Undecided
4) ❑ Agree
5) ❑ Strongly Agree

5. I know **how** to find helpful health resources on my smartphone

1) ❑ Strongly Disagree
2) ❑ Disagree
3) ❑ Undecided
4) ❑ Agree
5) ❑ Strongly Agree

6. I know **how to use** my smartphone to answer my questions about health

1) ❑ Strongly Disagree
2) ❑ Disagree
3) ❑ Undecided
4) ❑ Agree
5) ❑ Strongly Agree

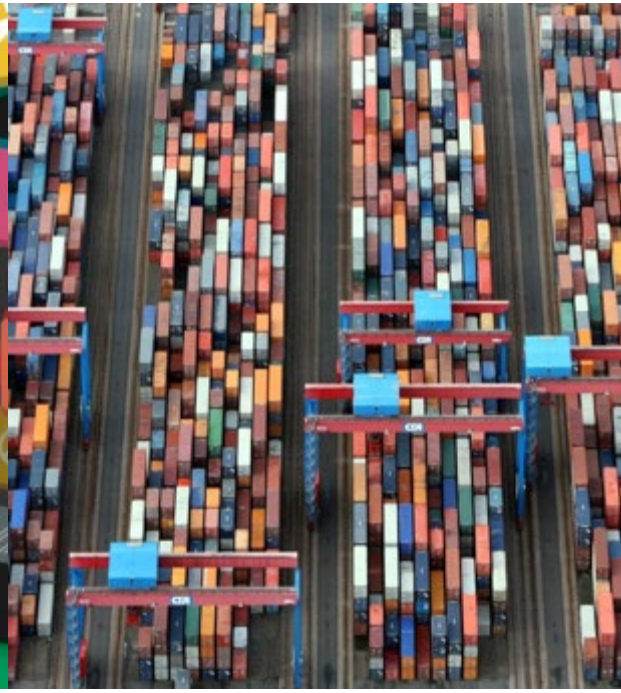


Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

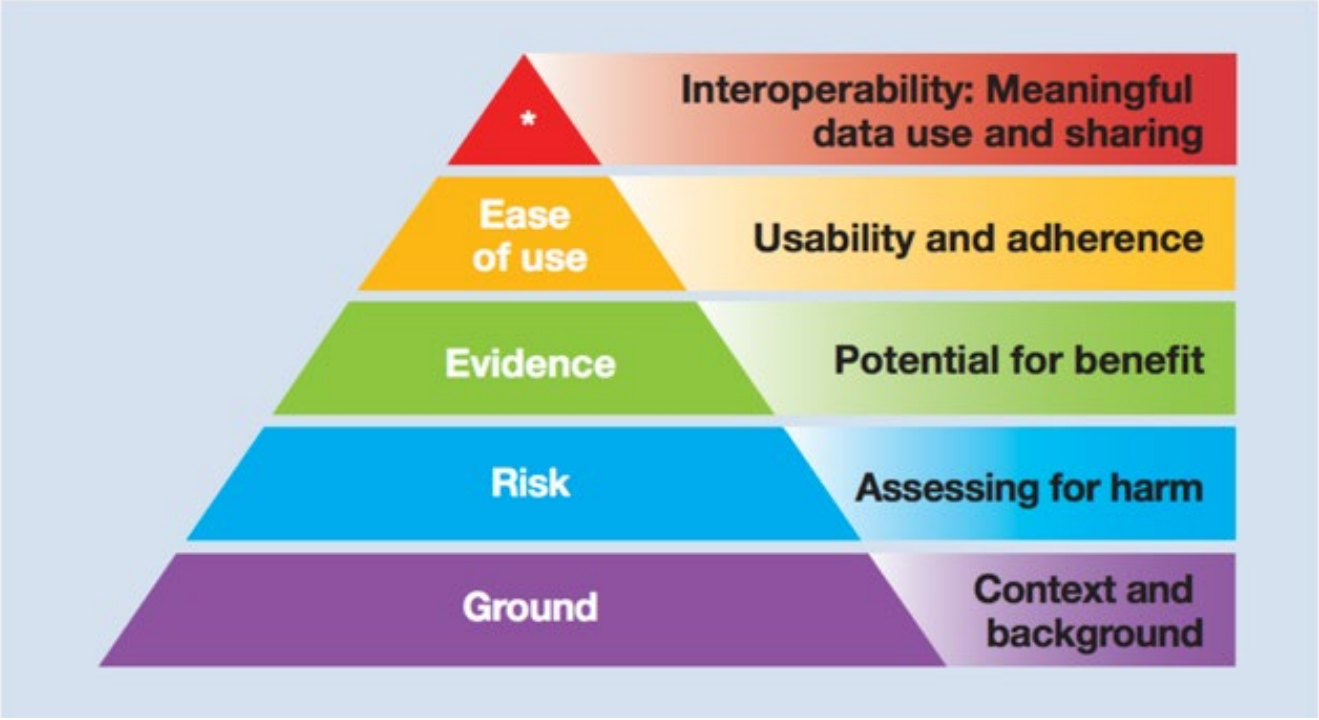
Helping People Find Apps

- Estimate to be over 10,000 mental health related apps



Torous J, Roberts LW. Needed innovation in digital health and smartphone applications for mental health: transparency and trust. Jama psychiatry. 2017 May 1;74(5):437-8.

Magic Formula For Safe and Better Apps?



Torous J, Roberts LW. Needed innovation in digital health and smartphone applications for mental health: transparency and trust. Jama psychiatry. 2017 May 1;74(5):437-8.

Our Movement. Our Moment.

#NAMICON19

2019 NAMI National Convention
JUNE 19–22 • SEATTLE

Up to 48% of NHS mental health patients are re-admissions - don't be one of them

In 2014 the National Audit Office reported that each year the NHS deals with one million emergency readmissions within 30 days of discharge, costing an estimated £2.4 billion.

What can you do to change this?

Dedicate yourself to your own healing, and thereby avoid being readmitted.

This will help save the NHS some of the £2.4 billion, which they urgently need to help others like you.

Help others by helping yourself.

Be your own NHS.

Created in England by 365 Positivity

Disclaimer: The information within this app is not

Close

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

https://www.nytimes.com/interactive/2018/12/10/business/location-data-privacy-apps.html

Table 2. Counts and Proportions of Apps Transmitting Data to a Third Party and Whether This Was Disclosed in a Privacy Policy

Destinations	No. (%)			
	Apps With Privacy Policy			Apps Without Privacy Policy
	Transmission Occurred, Disclosed in Policy	Transmission Occurred, Not Disclosed in Policy	Transmission Occurred, Policy States Won't	Transmission Occurred
Any destination type[a]	16 (44)	5 (14)	3 (8)	9 (25)
Advertising or marketing services	10 (28)	2 (6)	2 (6)	8 (22)
Analytics services	14 (39)	5 (14)	1 (3)	4 (11)
Google destinations	13 (36)	5 (14)	3 (8)	7 (19)
Google advertising services[b]	6 (17)	2 (6)	1 (3)	6 (17)
Google analytics services[c]	12 (33)	5 (14)	1 (3)	4 (11)
Facebook analytics	9 (25)	2 (6)	0 (0)	1 (3)
Others	15 (42)	1 (3)	0 (0)	4 (11)
Mixpanel	3 (8)	0	1 (3)	0
AppNexus	2 (6)	0	0	1 (3)
Twitter Mopub	3 (8)	0	0	0
Yahoo Flurry Analytics	3 (8)	0	0	0
AdColony	1 (3)	0	0	1 (3)
AppsFlyer	1 (3)	0	1 (3)	0
Kiip	1 (3)	0	0	1 (3)
Branch	1 (3)	0	0	0
AddThis	1 (3)	0	0	0
Amplitude	1 (3)	0	0	0
Manage.com	1 (3)	0	0	0
Singular/Apsalar	1 (3)	0	0	0
UserVoice	1 (3)	0	0	0
Unknown destination[d]	0	0	0	1 (3)

JAMA Network Open. 2019;2(4):e192542. doi:10.1001/jamanetworkopen.2019.2542

Huckvale K, Torous J, Larsen ME. Assessment of the data sharing and privacy practices of smartphone apps for depression and smoking cessation. JAMA network open. 2019 Apr 5;2(4):e192542-.

Search term	Identified in searches (n=1435)		Screened (n=350)	
	Android	iOS	Android	iOS
Anxiety	249	200	40	40
Depression	250	200	40	40
Schizophrenia	250	32	40	32
Self-harm	85	29	40	29
Substance use	131	9	40	9
Total	**965**	**470**	**200**	**150**

Larsen ME, Huckvale K, Nicholas J, Torous J, Birrell L, Li E, Reda B. Using science to sell apps: Evaluation of mental health app store quality claims. npj Digital Medicine. 2019 Mar 22;2(1):18.

Coding element	n (%) of apps
3. Positive claims	**59 (81%)**
3.a. Claims of effectiveness	47 (64%)
3.a.i. Detection or diagnosis	7 (10%)
3.a.ii. Improvement in symptoms or mood	22 (30%)
3.a.iii. Improvement in self-management	26 (36%)
3.b. Claims of acceptability	33 (45%)
4. Supporting statements	**47 (64%)**
4.a. Scientific language	32 (44%)
4.a.i. Specific technique described	24 (33%)
4.a.ii. Evidence from study using app	2 (2.7%)
4.a.iii. Citation to scientific literature	1 (1.4%)
4.b. Technical expertise	23 (32%)
4.b.ii. Prizes or awards	2 (2.7%)
4.b.iii. Credible developers	18 (25%)
4.b.iv. Credible endorsements	3 (4.1%)
4.c. Lived experience design	10 (14%)
4.c.i. Lived experience involvement	6 (8.2%)
4.c.ii. Lived experience developer	5 (6.8%)
4.d. "Wisdom of the crowd"	14 (19%)
4.d.i. Download, usage or popularity statistics	11 (15%)

Meta-Analysis of Smartphone Apps for Anxiety

Firth & Torous et al., April 2017

JOURNAL of AFFECTIVE DISORDERS

9 RCTs for Anxiety: 1,837 participants

Effects on Anxiety	Hedge's (g)	P-value
All RCTs	0.33	<0.001
Smartphone vs. Waitlist	0.45	<0.001
Smartphone vs. Active Control	0.19	0.003

Meta-Analysis of Smartphone Apps for Depression

World Psychiatry

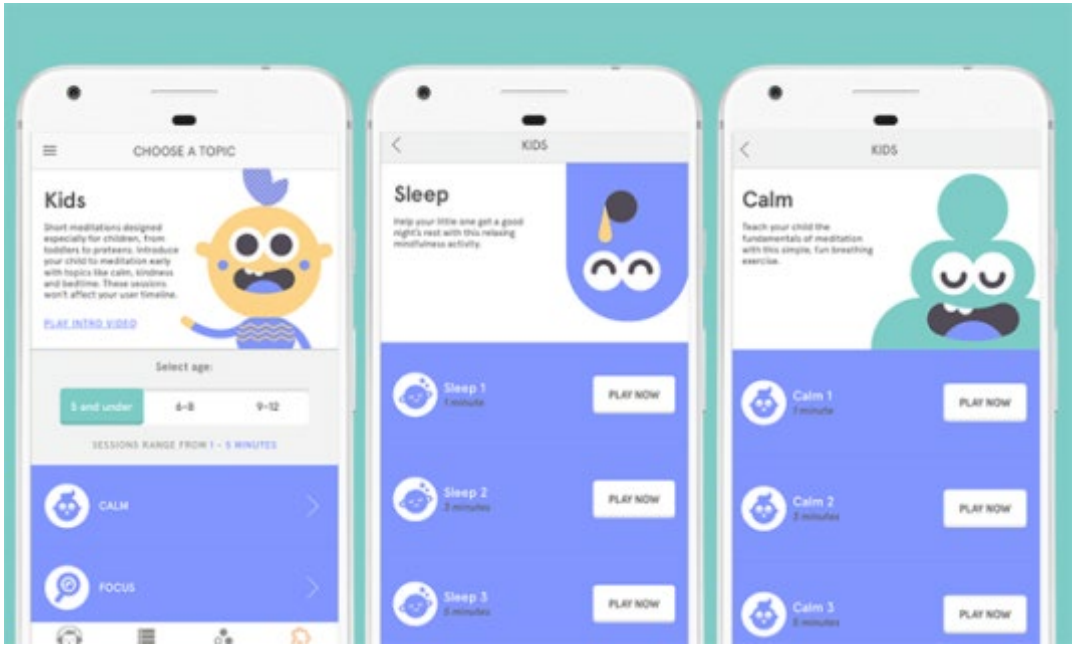
Firth & Torous et al., October 2017

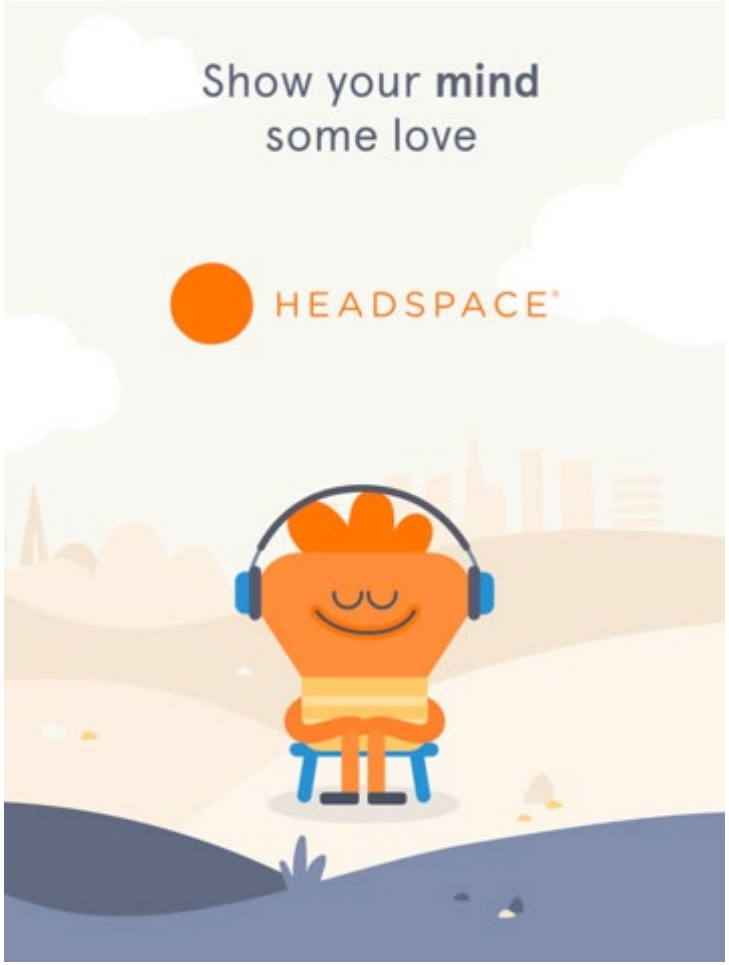
18 RCTs for Depression: 3,414 participants

Effects on Depression	Hedge's (g)	P-value
All RCTs	0.38	<0.001
Smartphone vs. Waitlist	0.56	<0.001
Smartphone vs. Active Control	0.22	<0.001

Eligibility Criteria
(i) RCT's in any population
(ii) Smartphone-based psychological interventions
(iii) Assessed changes in anxiety/depression

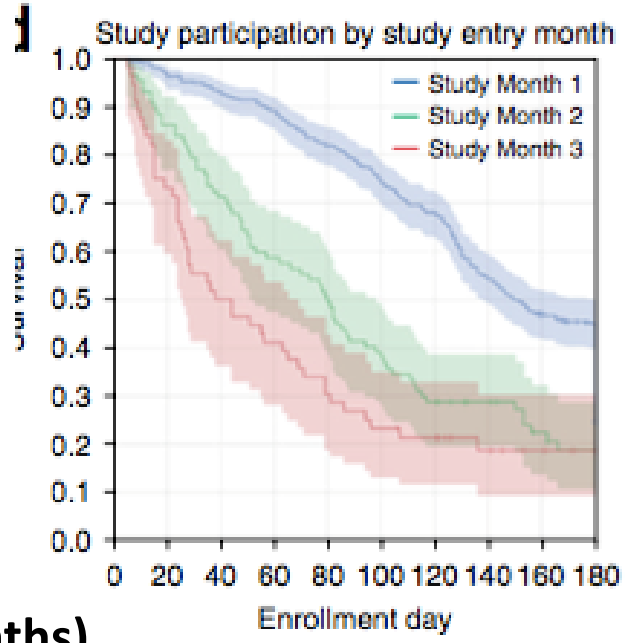
Firth J, Torous J, Nicholas J, Carney R, Pratap A, Rosenbaum S, Sarris J. The efficacy of smartphone-based mental health interventions for depressive symptoms: a meta-analysis of randomized controlled trials. World Psychiatry. 2017 Oct 1;16(3):287-98.

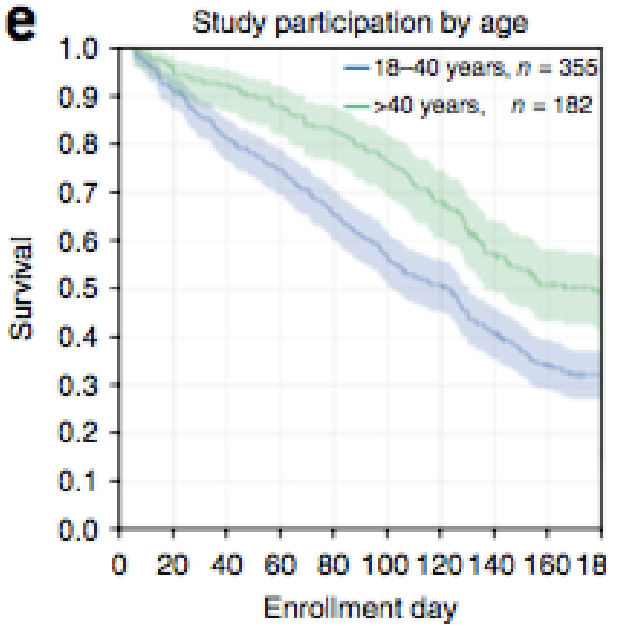




Noone and Hogan. A randomised active-controlled trial to examine the effects of an online mindfulness intervention on executive control, critical thinking and key thinking dispositions in a university student sample. BPJ Psychology. 2018

Eligible = 8,524
Enrolled = 7,953
Participants = 6,370
Robust Users = 2,317
(>=5 total surveys)
Milestone Users = 175
(completed survey at 6 months)





Chan YF, Wang P, Rogers L, Tignor N, Zweig M, Hershman SG, Genes N, Scott ER, Krock E, Badgeley M, Edgar R. The Asthma Mobile Health Study, a large-scale clinical observational study using ResearchKit. Nature Biotechnology. 2017 Mar 13.

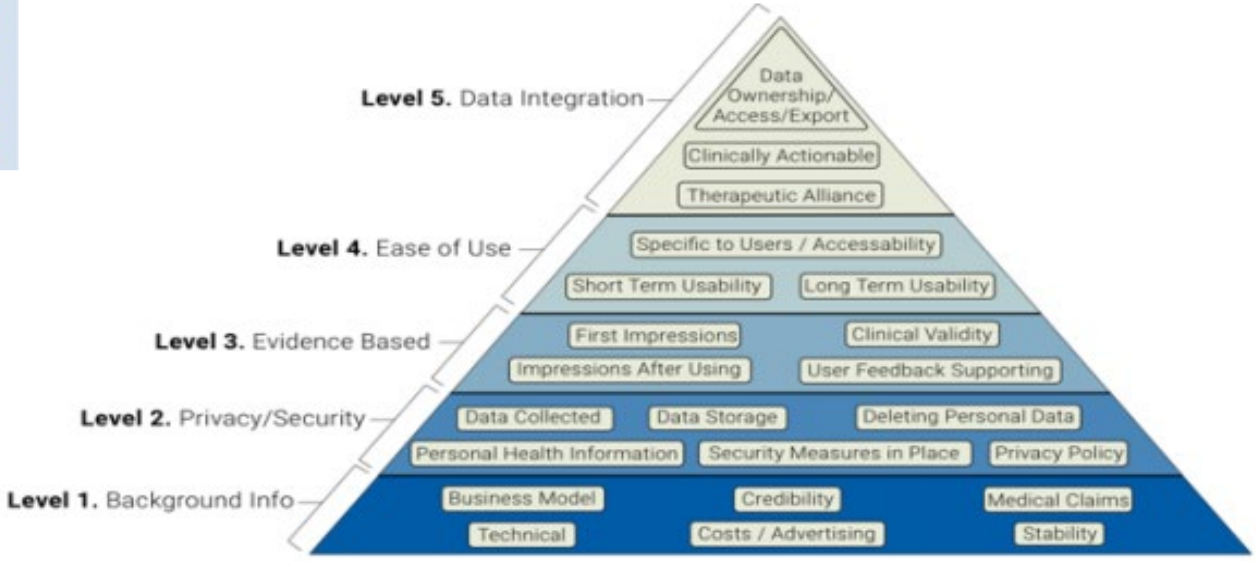
Our Movement. Our Moment.

#NAMICON19

2019 NAMI National Convention
JUNE 19–22 • SEATTLE

-

Beth Israel Deaconess Medical Center | HARVARD MEDICAL SCHOOL TEACHING HOSPITAL



Level 1: Background Info
- Does the app identify funding sources and conflicts of interest?
- Does the app identify ownership?
- Does the app come from a legitimate source?
- Where does app info originate?
- Are there additional or hidden costs?
- Does the app need an active internet connection?
- On what plaforms does the app operate?
- Has the app been updated in the last 180 days?

Level 2: Privacy/Security
- Is there a privacy policy?
- Does the app declare data use and purpose?
- Does the app describe use of PHI?
- Can you opt out of data collection or delete data?
- Are data maintained on the device or the web?
- Does the app explain security systems used?

Level 3: Evidence Based
- Does the app do what it claims to do?
- Is app content correct, well-written, and relevant?
- Are references included with the app?
- Is there evidence of benefit from end user feedback?

Level 4: Ease of Use
- Are there potential barriers to access?
- Can the user easily undertand how to use the app?
- Is the app easy to use on a long-term basis?
- Does the app clearly define its functional scope?

Level 5: Data Integration
- Do you own your data?
- Can you easily access your data?
- Can you easily share your data?
- Does the app lead to any positive behavior change?
- Does the app improve therapeutic alliance between patient and provider?

Henson, David, Albright, Torous. Deriving a practical framework for the evaluation of health apps. Lancet Digital Health. June 2019

Our Movement. Our Moment.

#NAMICON19

2019 NAMI National Convention

JUNE 19–22 • SEATTLE

Digitalpsych.org

jtorous@bidmc.harvard.edu

lhoffma1@bidmc.harvard.edu

Please take a few minutes to give us your feedback about this session

There are **two ways** you can give us your feedback:

1. Download the NAMI Convention App and rate the session in real time:

App Download Instructions

Visit your App Store and search for the "Aventri Events" app. Download the app and enter Access Code: 778151 or scan the following QR Code:

2. You can also evaluate the session on your computer. Go to: www.nami.org/sessioneval, select the session and click "Rate This Session."