

Participatory Discovery via Person-Generated Health Data

Luca Foschini, Ph.D.
Co-founder and Chief Data Scientist
Evidation Health, Inc.

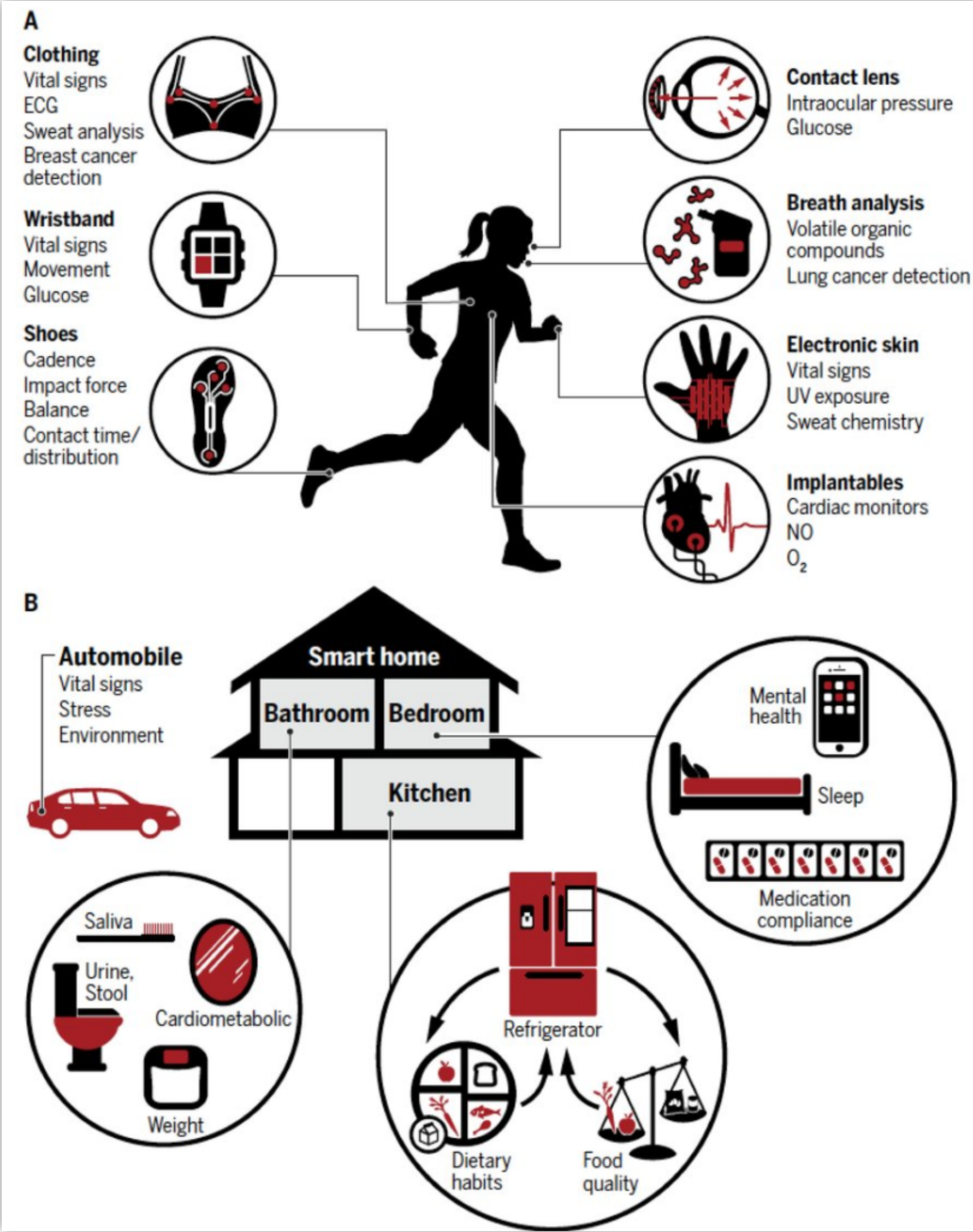
 luca@evidation.com

 [@calimagna](https://twitter.com/calimagna)

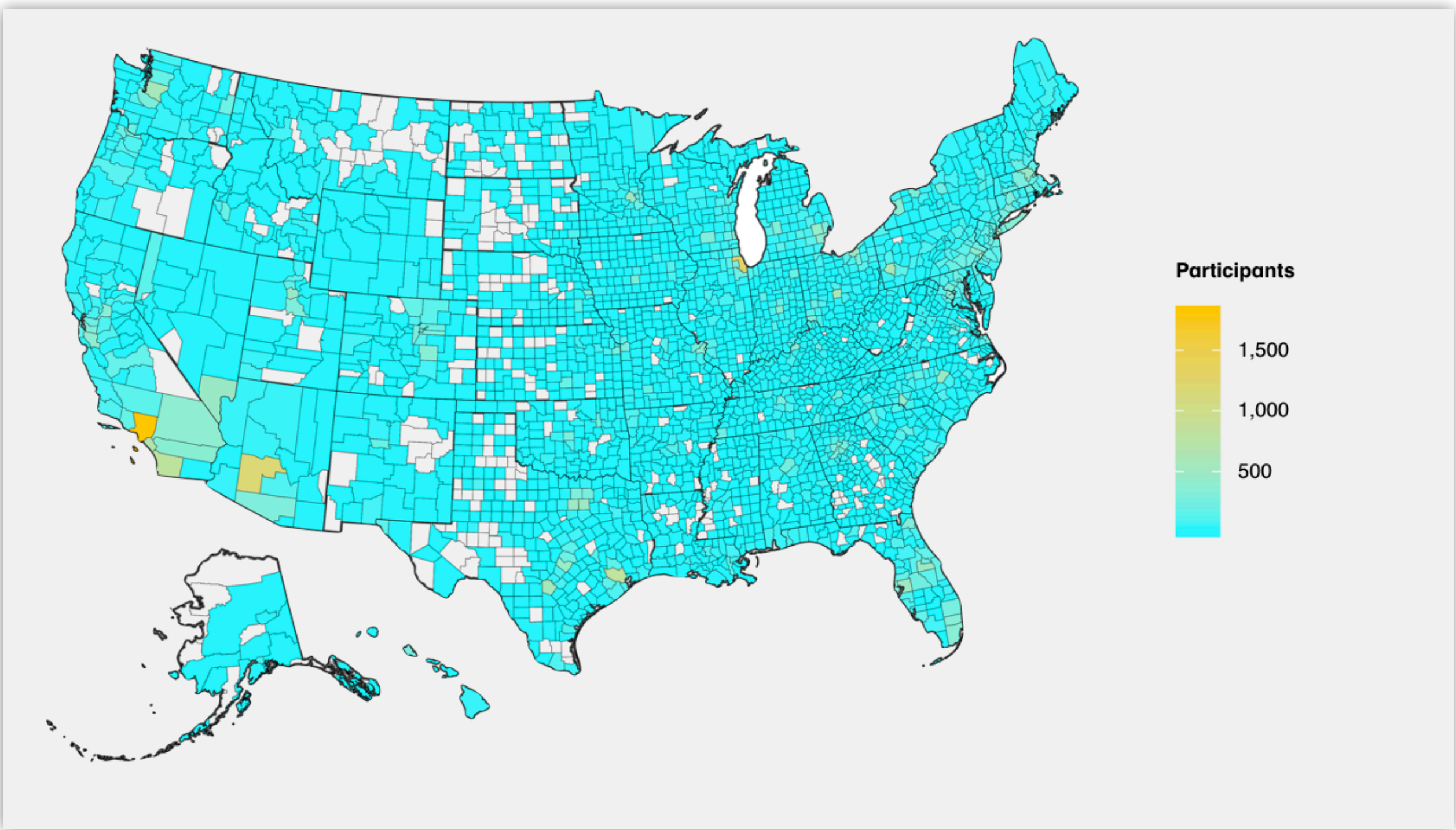
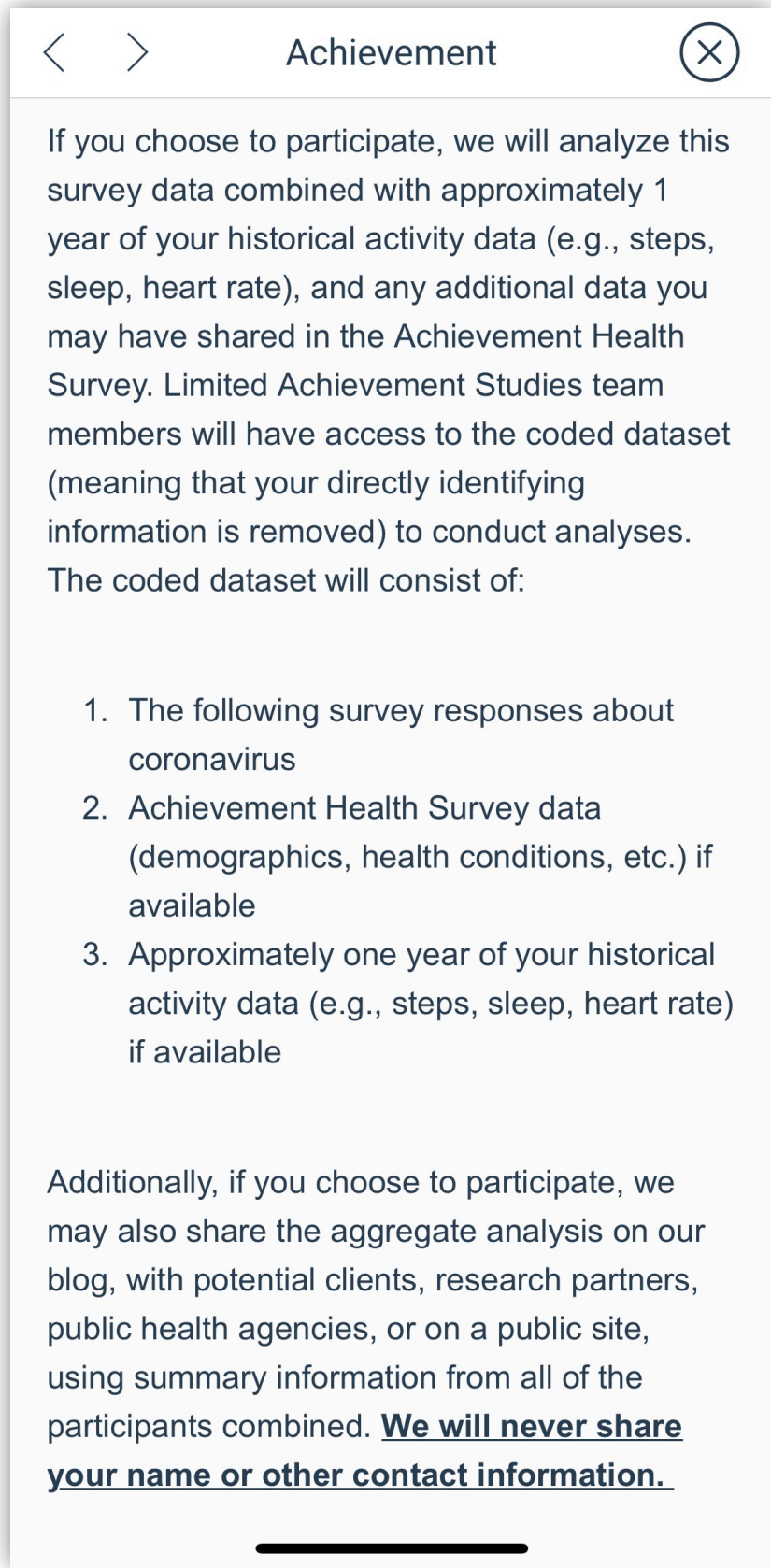
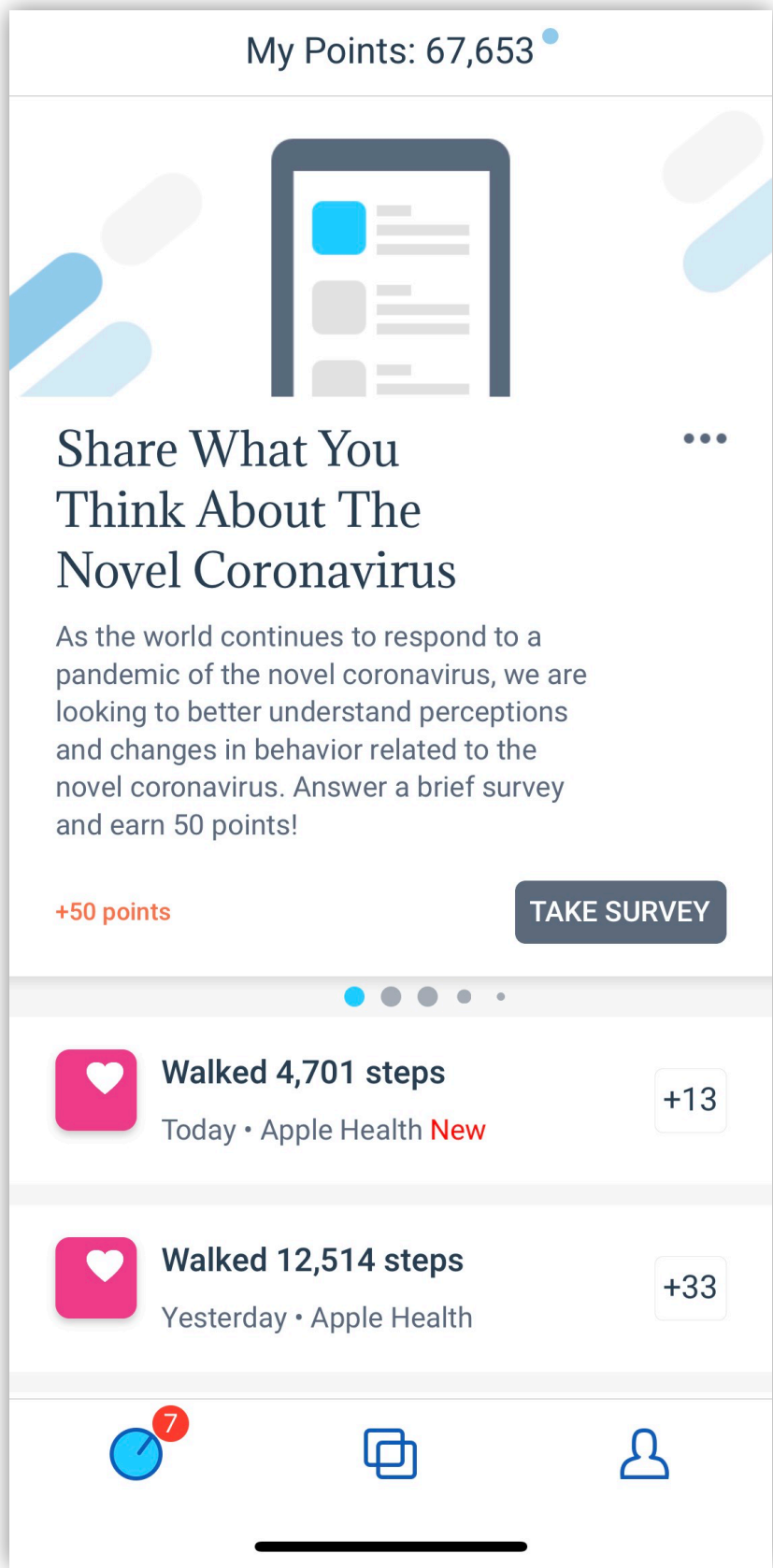
MARCH 2020

Person-Generated Health Data (PGHD) enables continuous monitoring of health outcomes at the individual level so we can better understand and measure a person's experience.

ADAPTED FROM: GAMBHIR, SANJIV SAM, ET AL., "TOWARD ACHIEVING PRECISION HEALTH." SCIENCE TRANSLATIONAL MEDICINE (2018)



PGHD can be collected remotely and on a large scale, enabling universal research on how individuals feel, function, and survive.



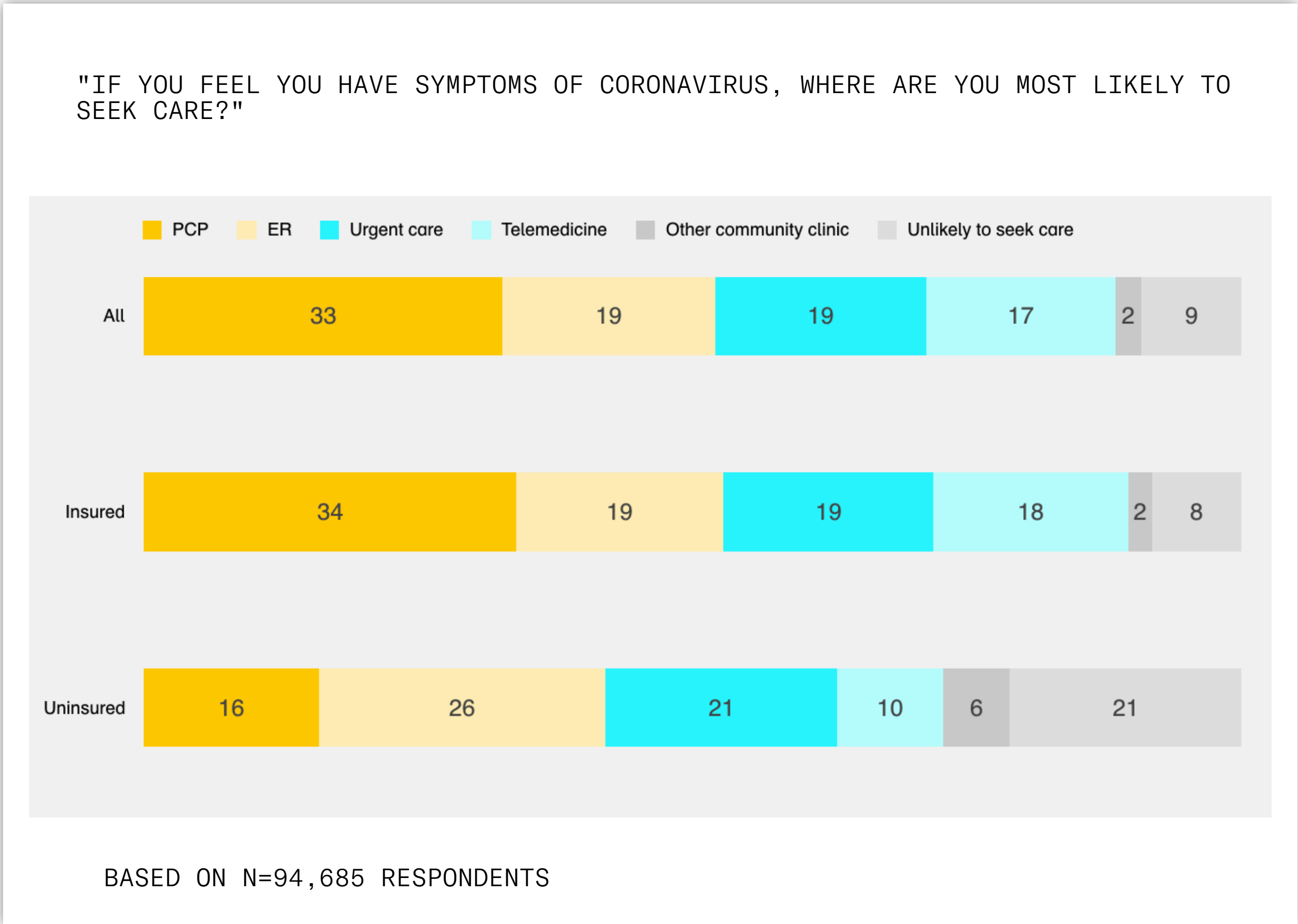
BASED 100,258 PARTICIPANTS (AS OF MARCH 15), REPRESENTATION FROM 89% OF U.S. COUNTIES

FULL STORY AT: [HTTPS://EVIDATION.COM/NEWS/COVID-19-PULSE-FIRST-DATA-EVIDATION/](https://evidaction.com/news/covid-19-pulse-first-data-evidaction/)

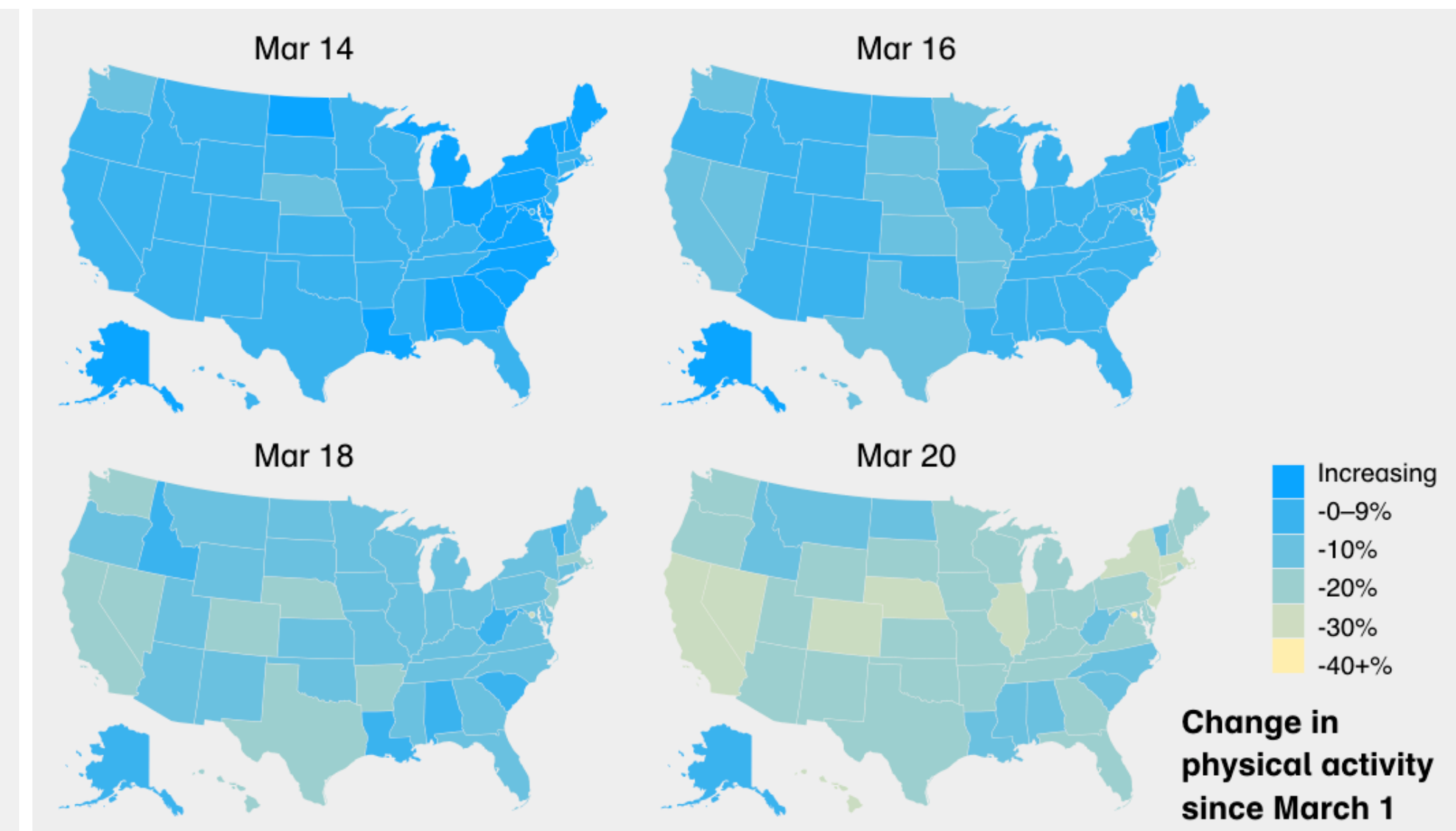
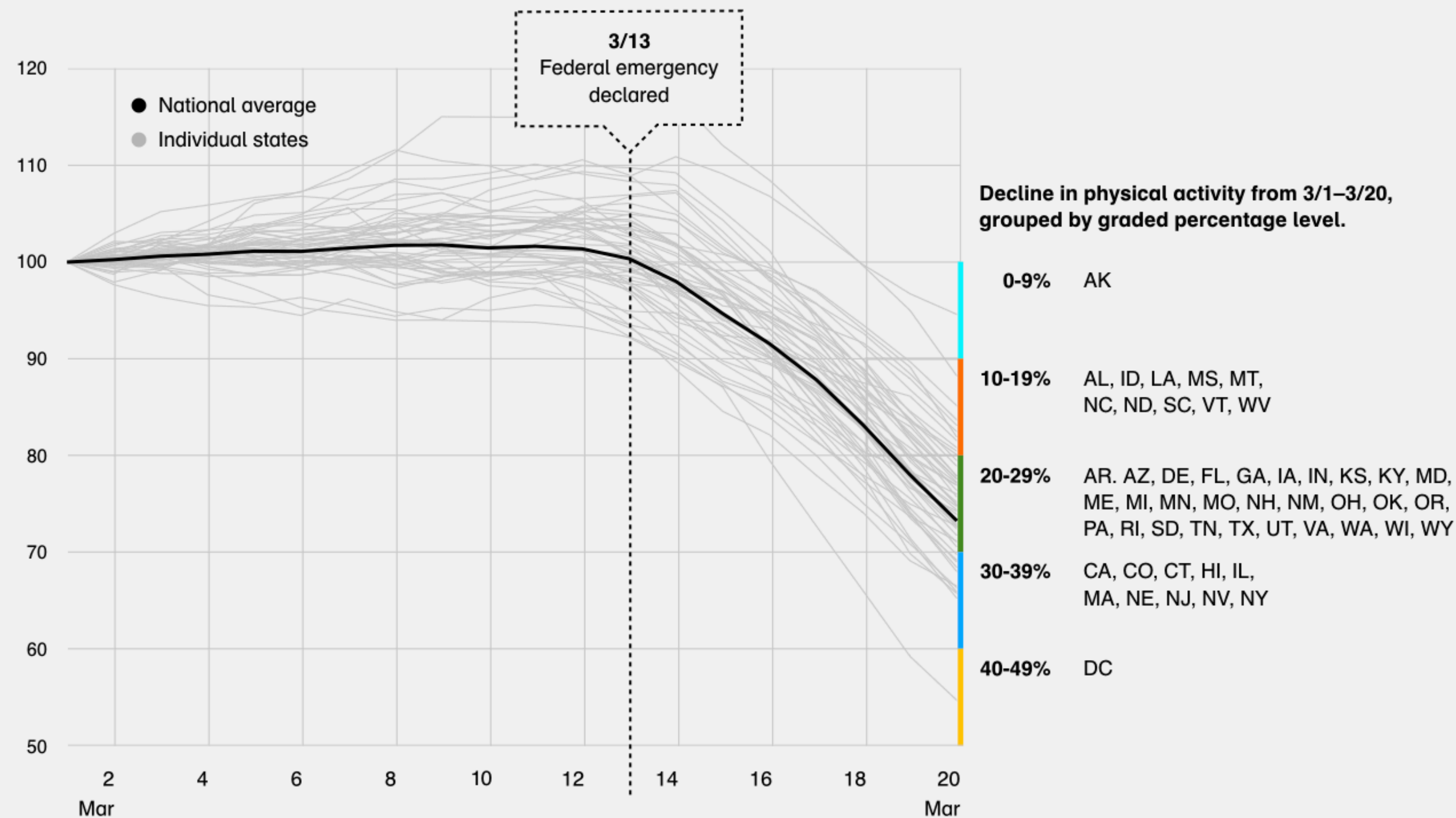
Continuous PGHD at the individual level is crucial for the development of any health intervention (drugs, devices, policies, etc.) meant to ultimately serve the individuals.

Findings

- Countermeasure adoption: 64% of responded said they're washing their hands more frequently in the past 7 days, but only 34% have reported avoiding large gathering (up to 3/18)
- Health insurance and personal finances: 52% of the uninsured are worried about not being able to work and earn a living, compared to 36% of insured
- Anxiety: 25% reported increased level of anxiety in the past 7 days. Update: that number is now up to 40%



Continuous PGHD at the individual level is crucial for the development of any health intervention (drugs, devices, policies, etc.) meant to ultimately serve the individuals.



BASED ON N = 56,280 AND WEARABLE DATA FROM 2/23-3/20

FULL STORY AT: [HTTPS://EVIDATION.COM/NEWS/COVID-19-PULSE-FIRST-DATA-EVIDATION/](https://evidaction.com/news/covid-19-pulse-first-data-evidaction/)

PGHD as a source of Real World Data (RWD) to monitor recovery from surgery.

- 50,938 Achievement members responders responded "yes" to: "Have you had any type of medical procedure or surgery since June 2016?"
- Gave permission to access data from their Fitbit during that period

ANSWER CHOICES

▼

Vascular clip insertion

▼

Coronary bypass (coronary graft)

▼

Heart valve repair or replacement

▼

Pelvic organ prolapse reconstruction

▼

Pacemaker or defibrillator insertion

▼

Coronary angioplasty (stent insertion)

▼

Spinal fusion

▼

Knee or hip replacement

▼

Bone fracture surgery (in lower limb)

▼

Weight-loss surgery (gastric band, sleeve, or duodenal switch)

▼

Tendon or ligament repair/reconstruction (in lower limb)

▼

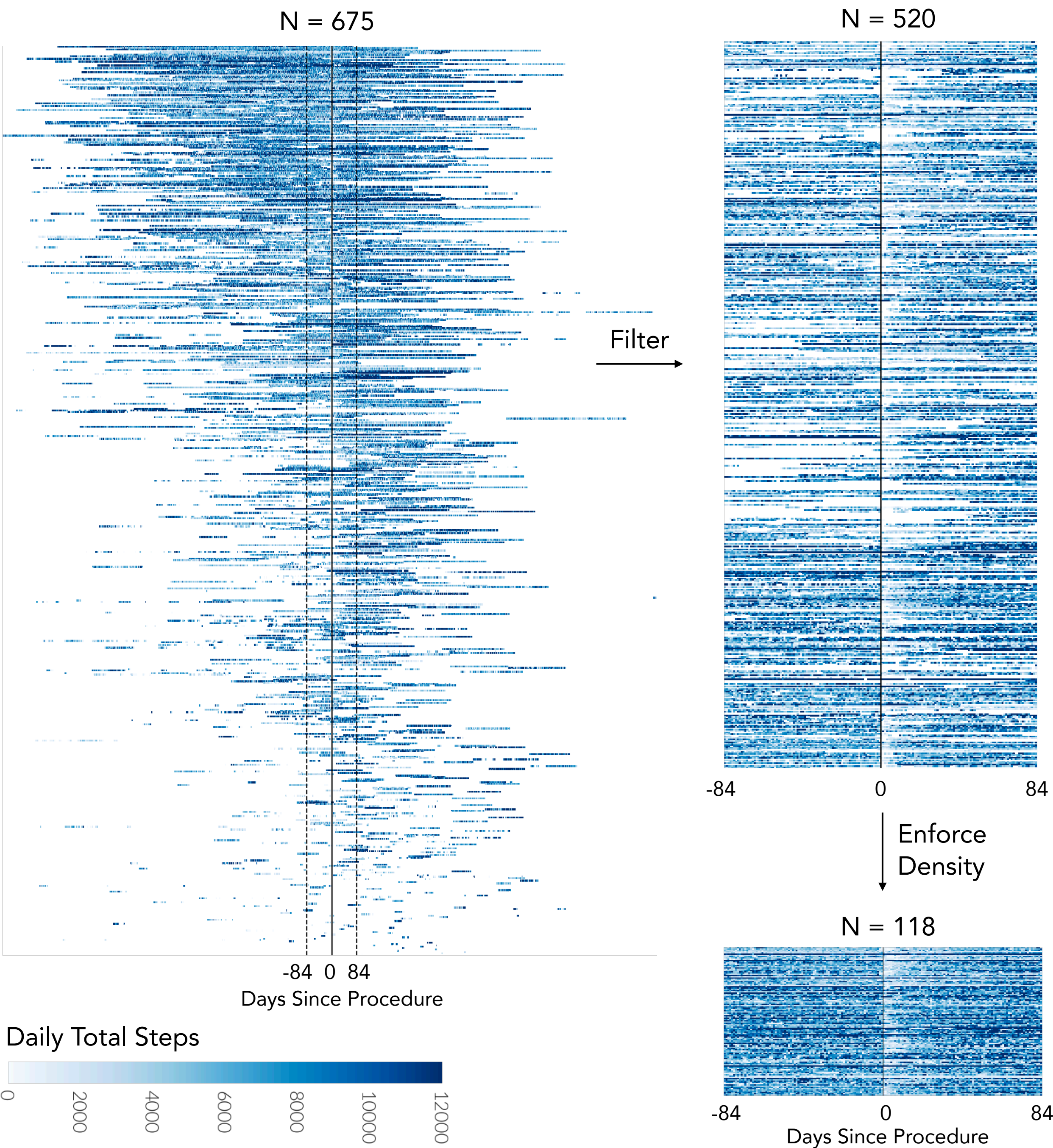
I have not had any medical procedures since June 2016.

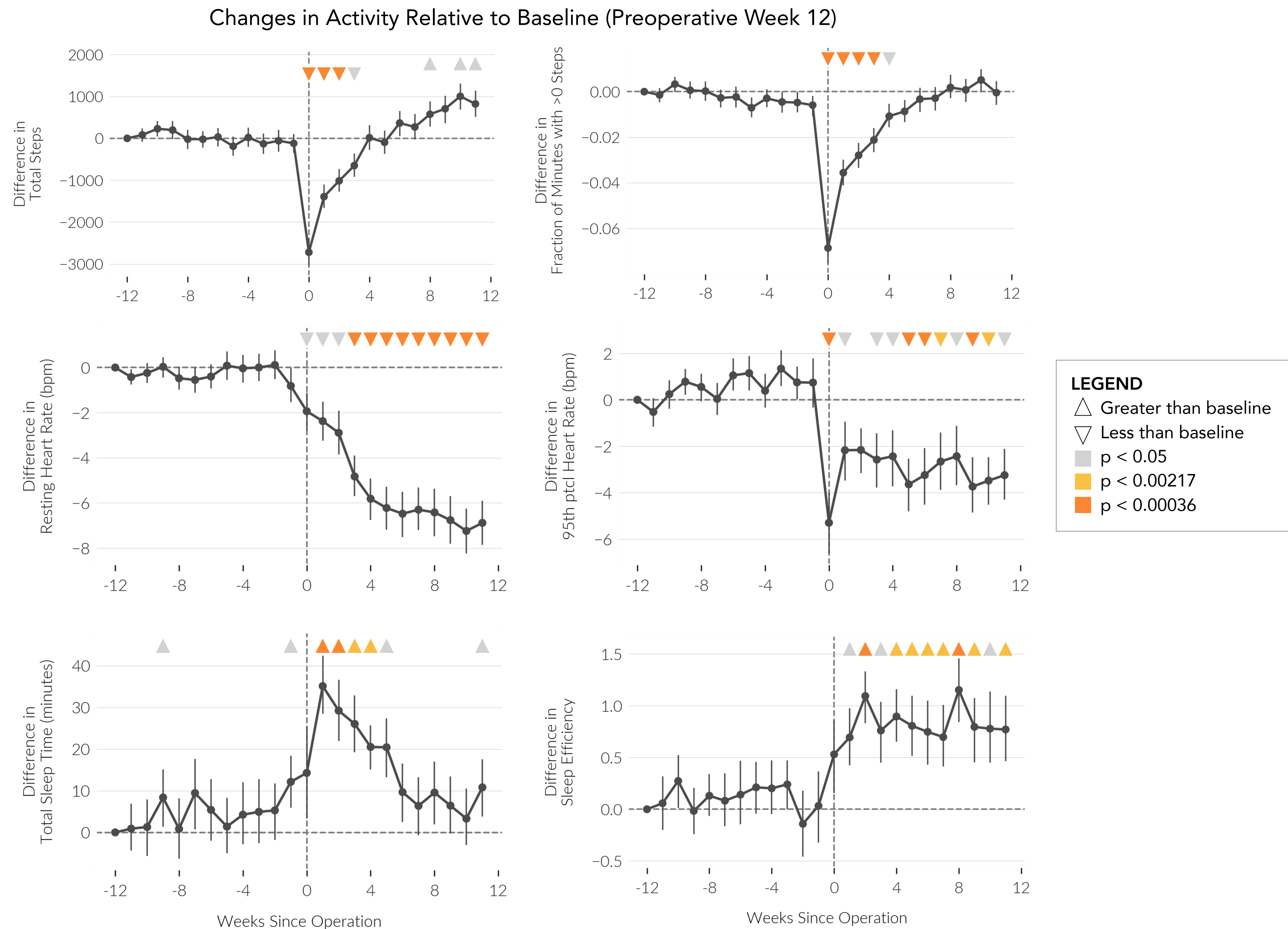
▼

Other (please specify the procedure)

- 1,203 reported undergoing a weight loss procedure.

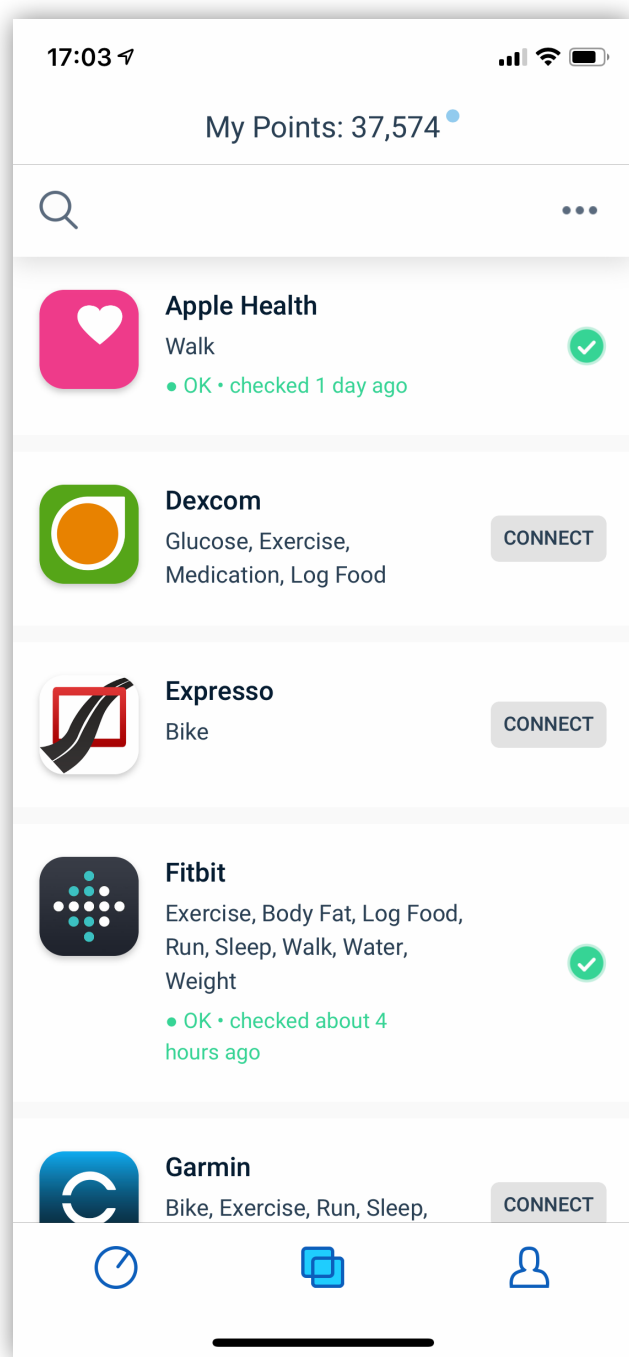
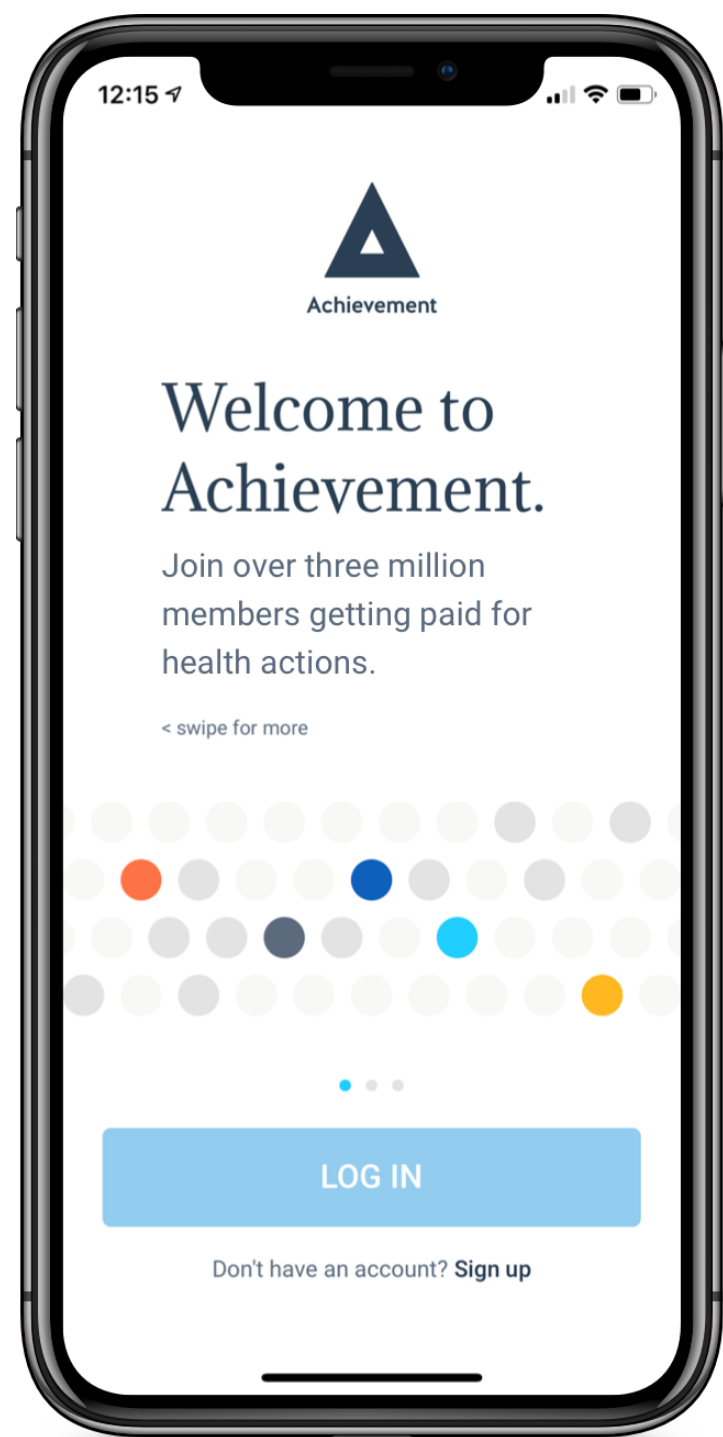
SOURCE: **CONTINUOUS DIGITAL ASSESSMENT FOR WEIGHT LOSS.** RAMIREZ ET AL., KARGER
DIGITAL BIOMARKERS (IN PRINT)



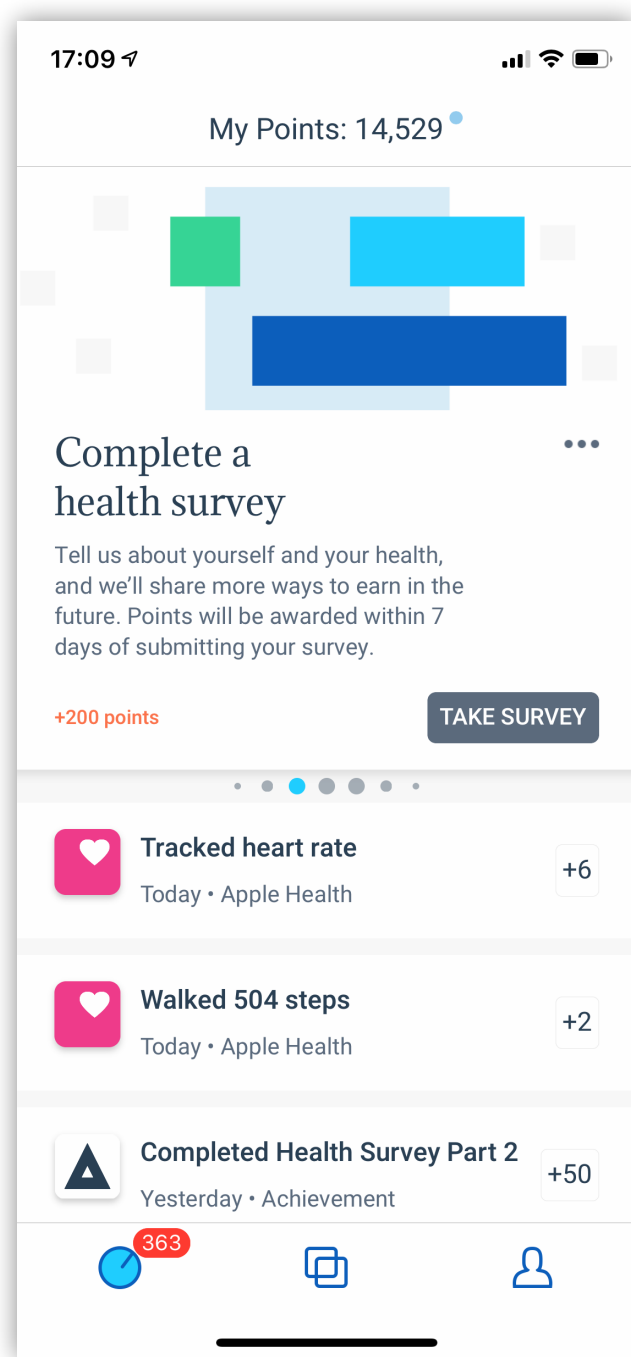


Achievement allows members to earn rewards, connect health sensors and apps, and participate in research—it is the largest virtual site in the U.S.

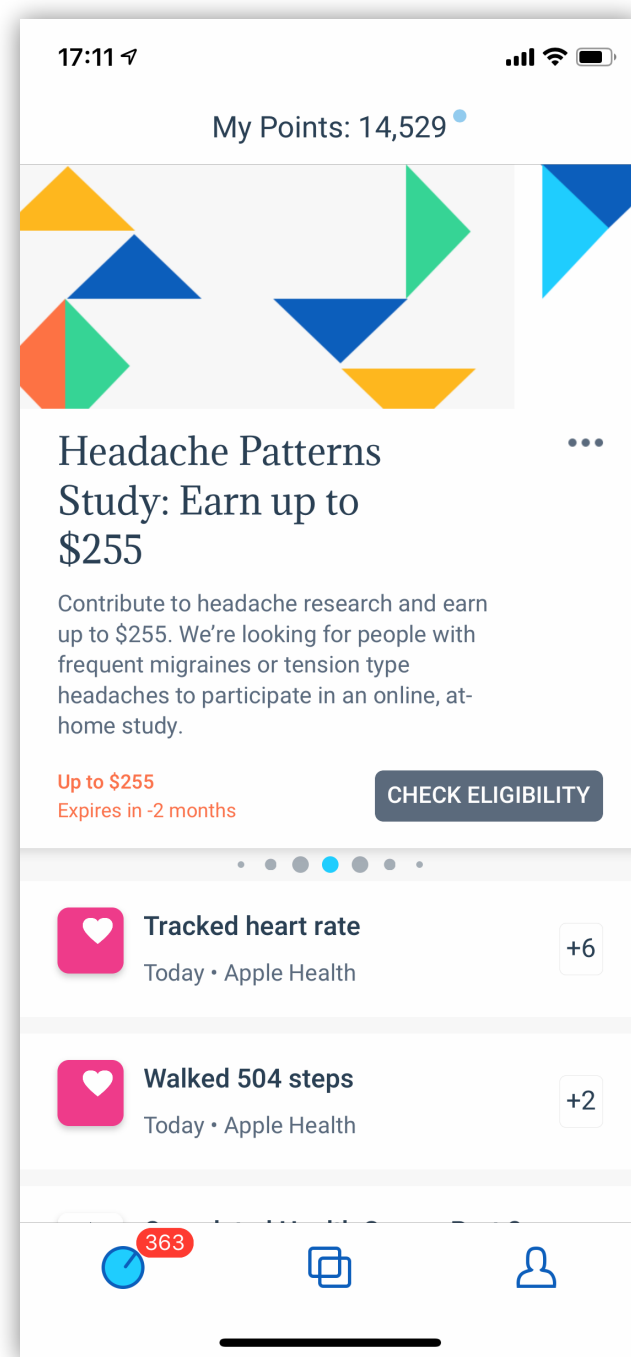
- Completely virtual
- Open to any U.S. adult, multi-platform (web, iOS, Android)
- Data is collected via individual permissioning
- Only accessible to Evidation and our partners via a per use consent
- Privacy-safe and secure



Objective data collection from consumer and clinical-grade devices and apps



Ongoing phenotypic labeling via both digital and self-reported methods



Targeted offers to participate in research based on known inclusion/exclusion criteria

Conclusion and Future Outlook

The unprecedented ability to build a trusted relationship with individuals creates new opportunities for the discovery and rapid development of interventions that have the individual at the center, spanning the gamut from public health policies to drugs, devices, and digital therapeutics.

What is needed to get us there:

1. Interoperability: Need to agree on a common data format for PGHD among individuals, providers, and regulators.
2. Common analytic framework: Need to standardize analytical validation, decouple from sensor verification/validation.
3. Governance: PGHD is as identifying as DNA, and straddles research, care, and consumer experiences.
4. Representativeness: PGHD can really reach all of us, provided we strive to reduce the technological divide.

Continuous Digital Assessment for Weight Loss Surgery Patients *Ramirez E, Marinsek N, Bradshaw B, Kanard R, [Foschini L](#)*, KARGER DIGITAL BIOMARKERS 2020

Adversarial Examples for Electrocardiograms, *Han X, Hu W, [Foschini L](#), Chinitz L, Jankelson L, Ranganath R*, NATURE MEDICINE 2020

Machine Intelligence in Healthcare – Perspectives on Trustworthiness, Explainability, Usability and Transparency" by *Sharma K, Cutillo C, [Foschini L](#), Kundu S, Mackintosh M, Mandl K*. NJP DIGITAL MEDICINE

Large-scale influenza vaccination promotion on a mobile app platform: A randomized controlled trial. *Lee WN, Stück D, Konti K, Rivers C, Brown CR, Zbikowski SM, [Foschini L](#)*. VACCINE 2019

Quantifying the Impact of Influenza Among Persons with Type 2 Diabetes Mellitus: A New Approach to Determine Medical and Physical Activity Impact. *Samson SI, Konty K, Lee WN, Quisel T, [Foschini L](#), Kerr D, Liska J, Mills H, Hollingsworth R, Greenberg M, Beal AC*. JOURNAL OF DIABETES SCIENCE AND TECHNOLOGY 2019

African American Participants Experience Greater Pain Severity and Pain Interference Compared to Non-Hispanic Whites in a Large-Scale Virtual Study on Chronic Pain. *Cerrada C J, Tai C, Kumar S, Scherer K, Eulogio R, Ramirez E, [Foschini L](#), Juusola J*. SMDM 2019

Effect of Different Financial Incentive Structures on Promoting Physical Activity Among Adults. *Bachiredy C, Joung A, John LK, Gino F, Tuckfield B, [Foschini L](#), Milkman KL*. JAMA NETWORK OPEN 2019

Developing Measures of Cognitive Impairment in the Real World from Consumer-Grade Multimodal Sensor Streams. *Chan R, Jankovic F, Marinsek N, [Foschini L](#), Kourtis L, Signorini A, Pugh M, Shen J, Yaari R, Maljkovic V, Sunga M, Hee Song H, Joon Jung H, Tseng B, Trister A*. KDD 2019

At Home Cognitive Testing (CANTAB Battery) in Healthy Controls and Cognitively Impaired Patients: A Feasibility Study. *Maljkovic V, Pugh MAM, Yaari R, Shen J, Juusola, JL*. AAIC 2019

A systematic review of feasibility studies promoting the use of mobile technologies in clinical research. *Bakker JP, Goldsack JC, Clarke M, Coravos A, Geoghegan C, Godfrey A, Heasley MG, Karlin DR, Manta C, Peterson B, Ramirez E, Sheth N, Bruno A, Bullis E, Wareham K, Zimmerman N, Forrest A, Wood WA*. NPJ DIGITAL MEDICINE 2019

Pain Management Strategies and Activity Tracker Utilization in a Large-Scale Chronic Pain Study. *Tran JLA, Kumar S, Eulogio R, Ramirez E, [Foschini L](#), Juusola JL*. ISPOR 2019

Reproducibility in Machine Learning for Health. *McDermott M, Wang S, Marinsek N, Ranganath R, Ghassemi M, [Foschini L](#)*. ICLR 2019 workshop

The association between medication adherence for chronic conditions and digital health activity tracking. *Quisel T, [Foschini L](#), Zbikowski SM, Juusola J*. JMIR PUBLICATIONS 2019

Comparison of Heart Rate Measurement Between the Fitbit Charge 2 and OMSignal Smart Garments: A Free-Living Study. *Wildman M, Eulogio R, Singh R, Ramirez R, [Foschini L](#), Nadarajan A, Booth B, Mundnich K, Ferrara E, Lerman K, Narayanan S*. SOCIETY OF BEHAVIORAL MEDICINE 2019

Longitudinal Changes in Activity and Sleep Behaviors from Activity Trackers Are Associated with Change in Depression Severity. *Ramirez E, Tran JL, Bradshaw B, Kumar S, Tai C, [Foschini L](#), Juusola JL*. SBM 2019

Digital biomarkers for Alzheimer's disease: the mobile/wearable devices opportunity. *Kourtis LC, Regele OB, Wright JM, Jones, GB*. NPJ DIGITAL MEDICINE 2019

Influenza Surveillance Using Wearable Mobile Health Devices. *Bradshaw B, Konty K, Ramirez E, Lee WN, Signorini A, [Foschini L](#)*. INTERNATIONAL SOCIETY FOR DISEASE SURVEILLANCE CONFERENCE 2019

Interested in participatory research?

Reach out to: research@evidation.com

Luca Foschini, Ph.D.

Co-founder and Chief Data Scientist

 luca@evidation.com

 [@calimagna](https://twitter.com/calimagna)