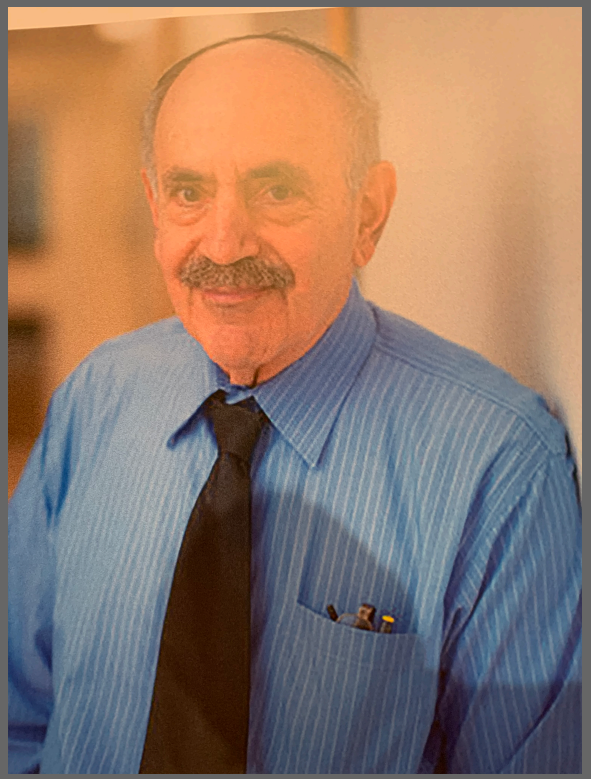
Update on how digital devices might allow us to follow symptom transitions and the effects of the fabric of life on chronic conditions

(why it will be valuable and how we might retain some self navigation)

Inspire2Live
Assembly
Jan 30, 2020

Stephen Friend MD PhD
University of Oxford
4YouandMe
Sage Bionetworks



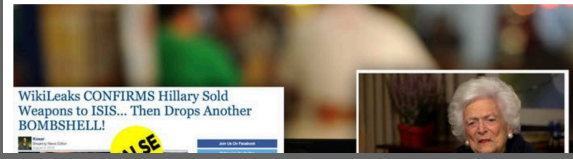
This Analysis Shows How Viral Fake Election News Stories Outperformed Real News On Facebook

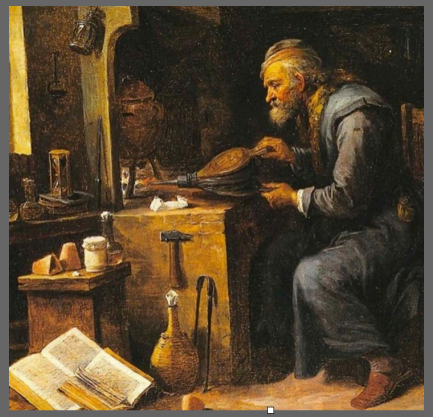
A BuzzFeed News analysis found that top fake election news stories generated more total engagement on Facebook than top election stories from 19 major news outlets combined.

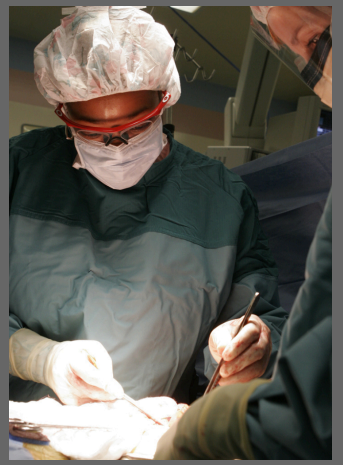
Craig Silverman
BuzzFeed Founding Editor, Canada

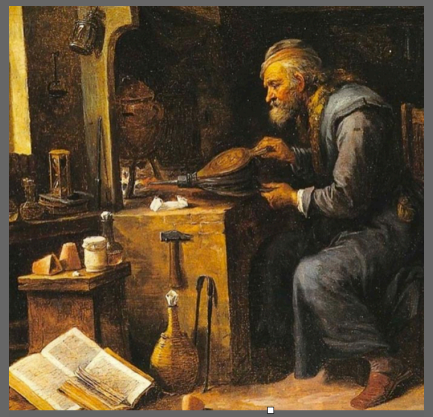
Posted on November 16, 2016, at 5:15 p.m. ET

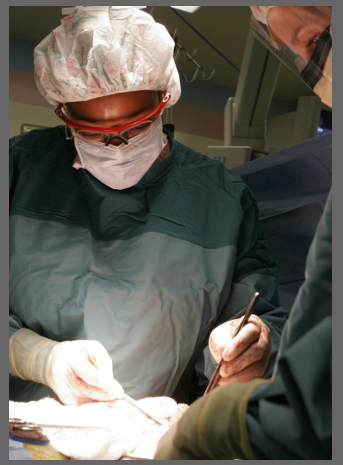
Tweet Share Copy







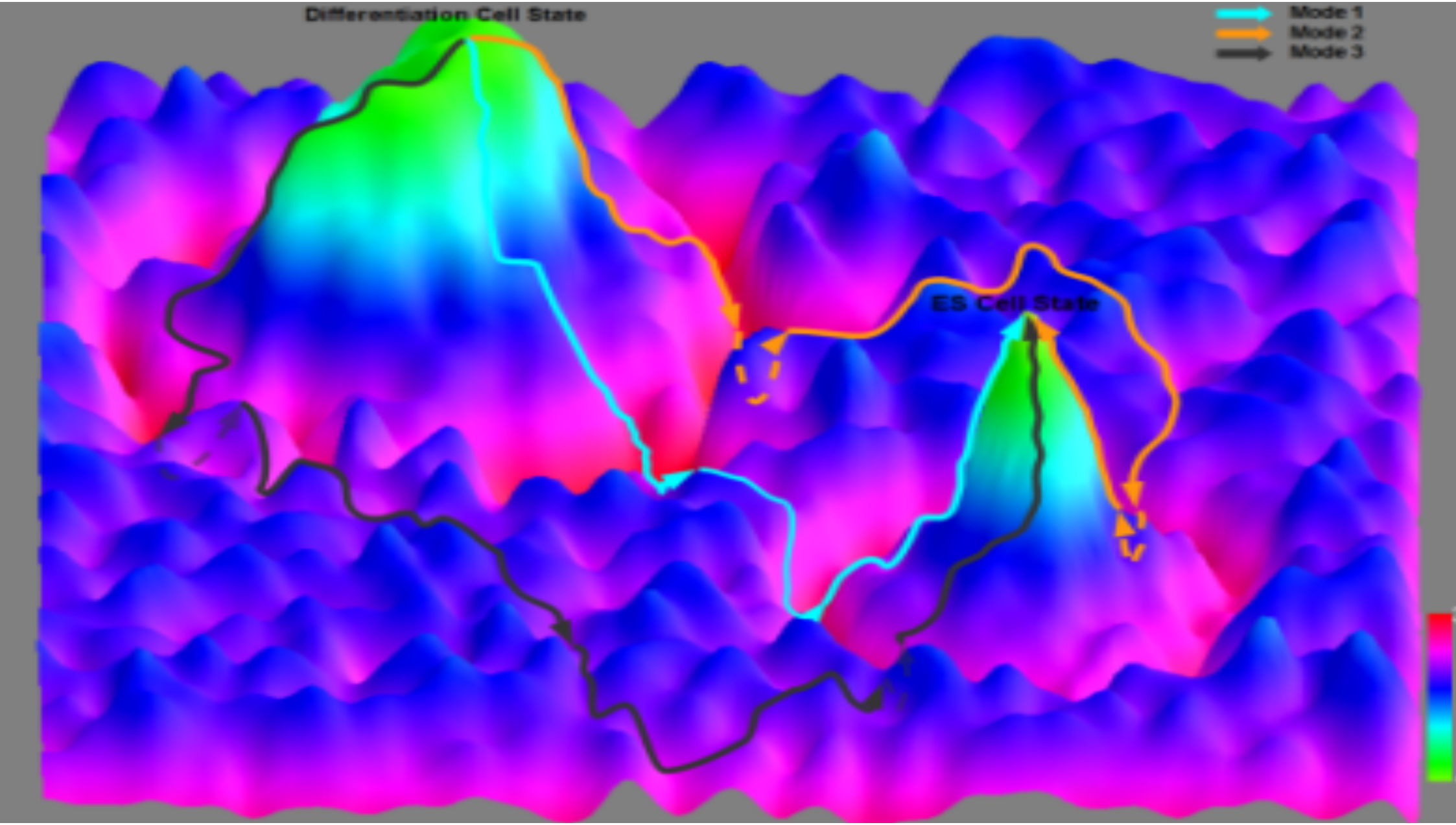



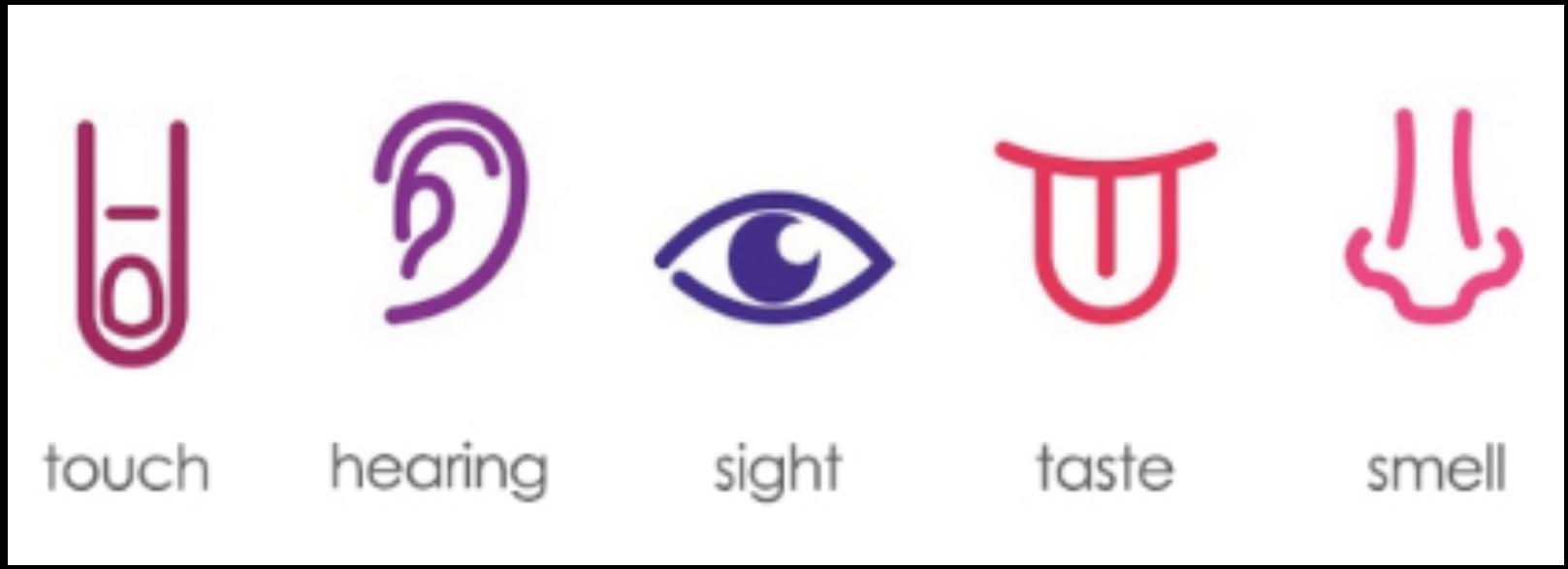



limited to linear courses of disease

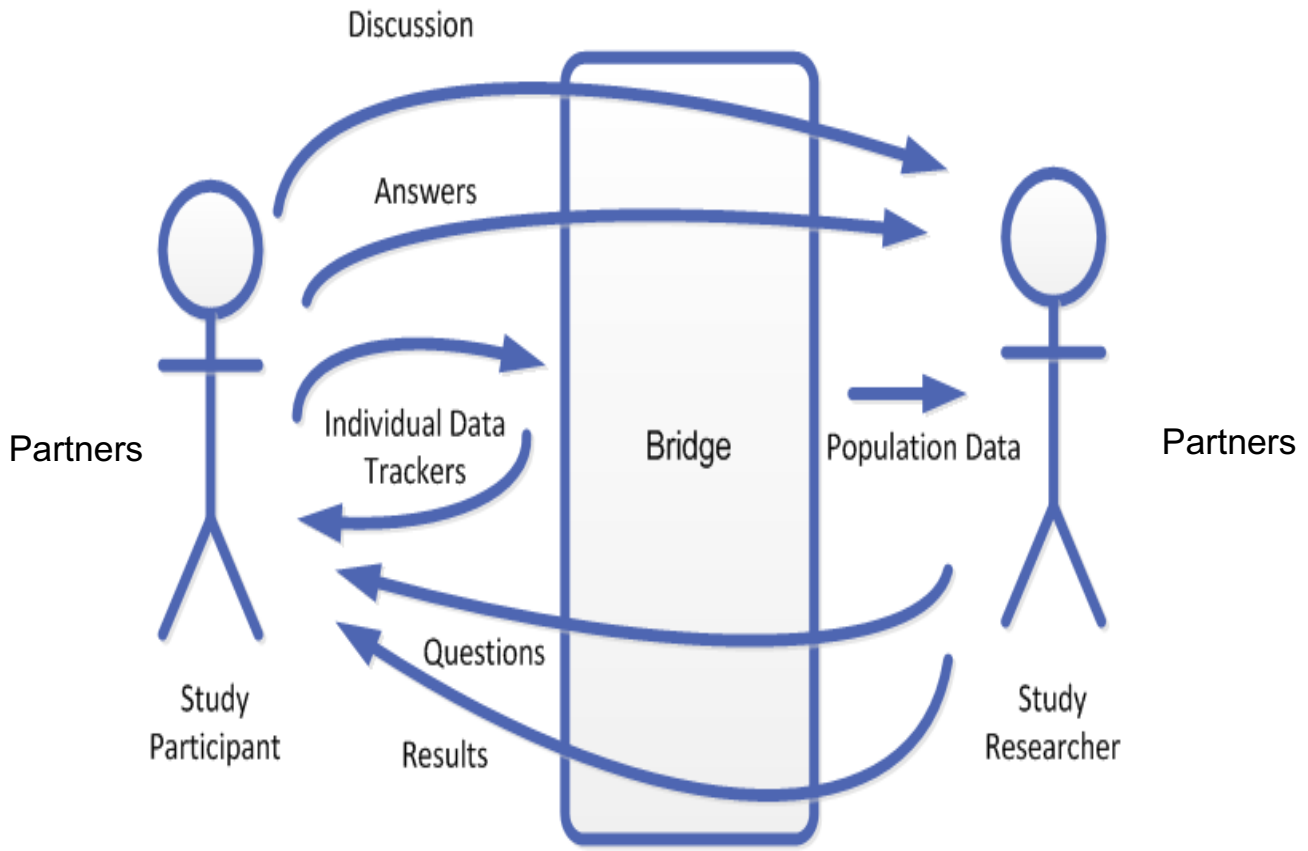
missing ability to say what will occur for an individual

assumes interventions to be provided by experts for fees

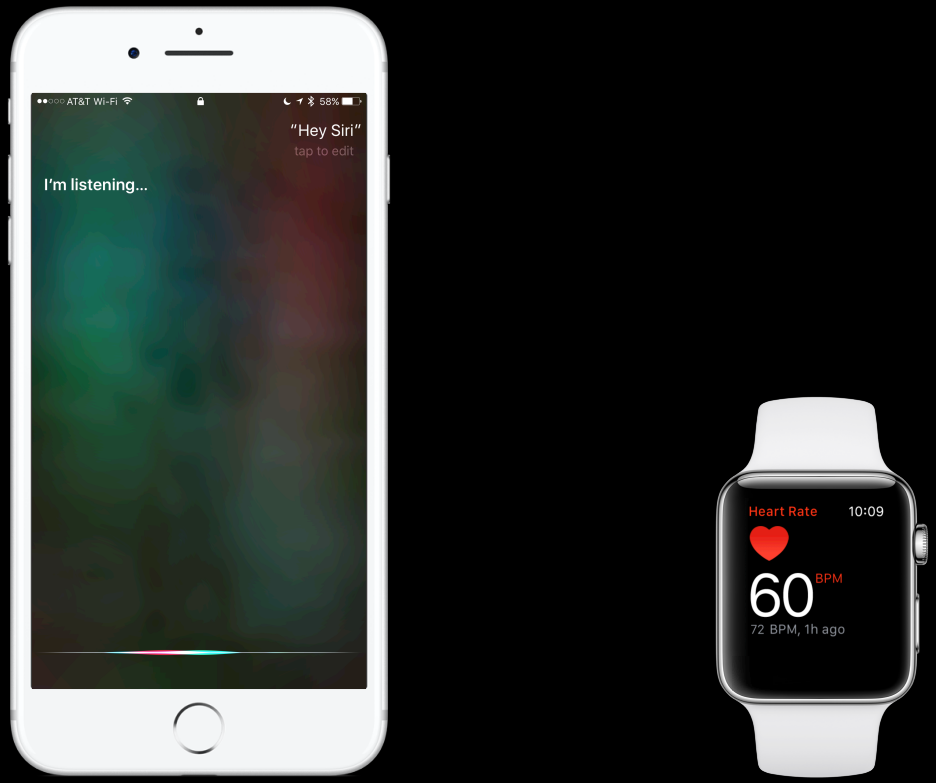

Differentiation Cell State
ES Cell State
Mode 1
Mode 2
Mode 3


touch
hearing
sight
taste
smell

Participant –Centered Research Studies with Feedback Loops



Anecdotes into Signals


AT&T Wi-Fi
58%
"Hey Siri"
tap to edit
I'm listening...

Heart Rate
10:09
60
BPM
72 BPM, 1h ago

TIM MOYNIHAN GEAR 03.09.15 02:05 PM

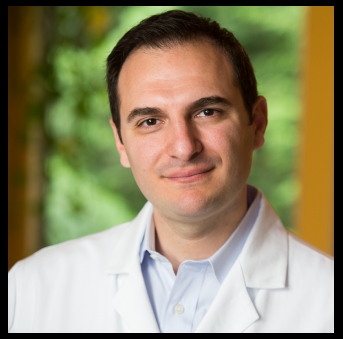
APPLE'S RESEARCHKIT IS A NEW WAY TO DO MEDICAL RESEARCH

Jeff Williams, senior vice president of operations at Apple, introduces ResearchKit at an event in San Francisco.

JEFF WILLIAMS, SENIOR VICE PRESIDENT OF OPERATIONS AT APPLE, INTRODUCES

Dorsey

Trister



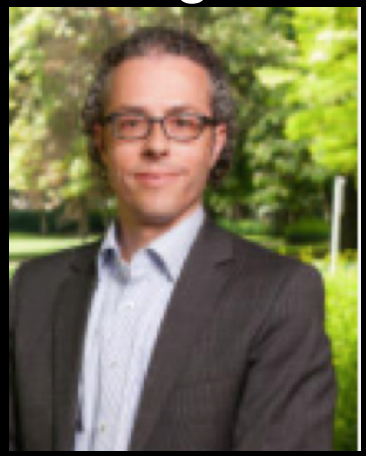
mPower

Klein

Kieburtz

Tanner

Kruger

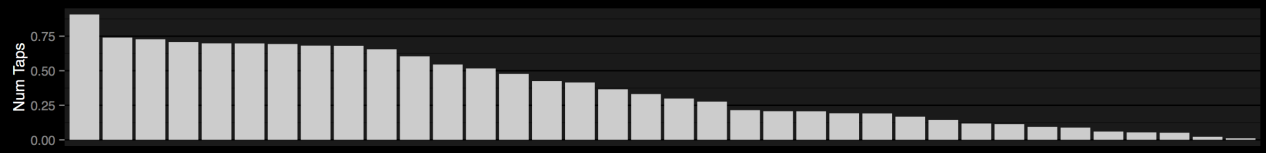


Bloem

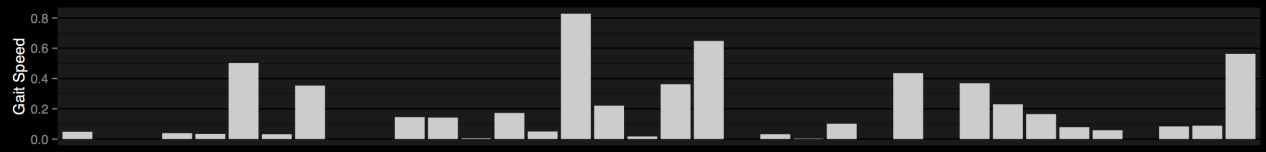
Inter-individual Diversity

no “average humans,” and no single measures for those with Parkinson’s Disease

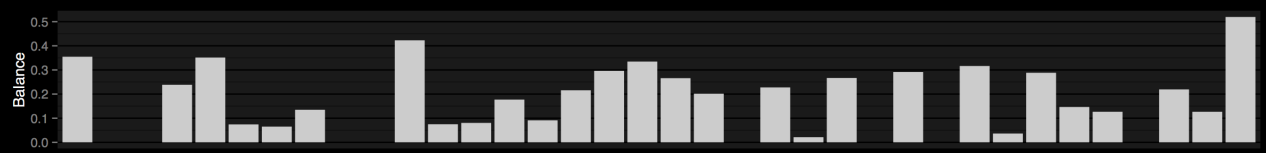
Taps



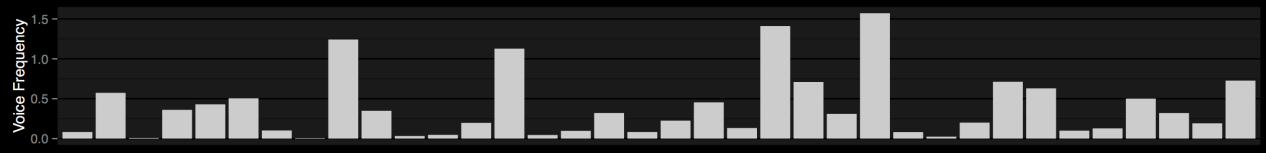
Gait Speed



Balance

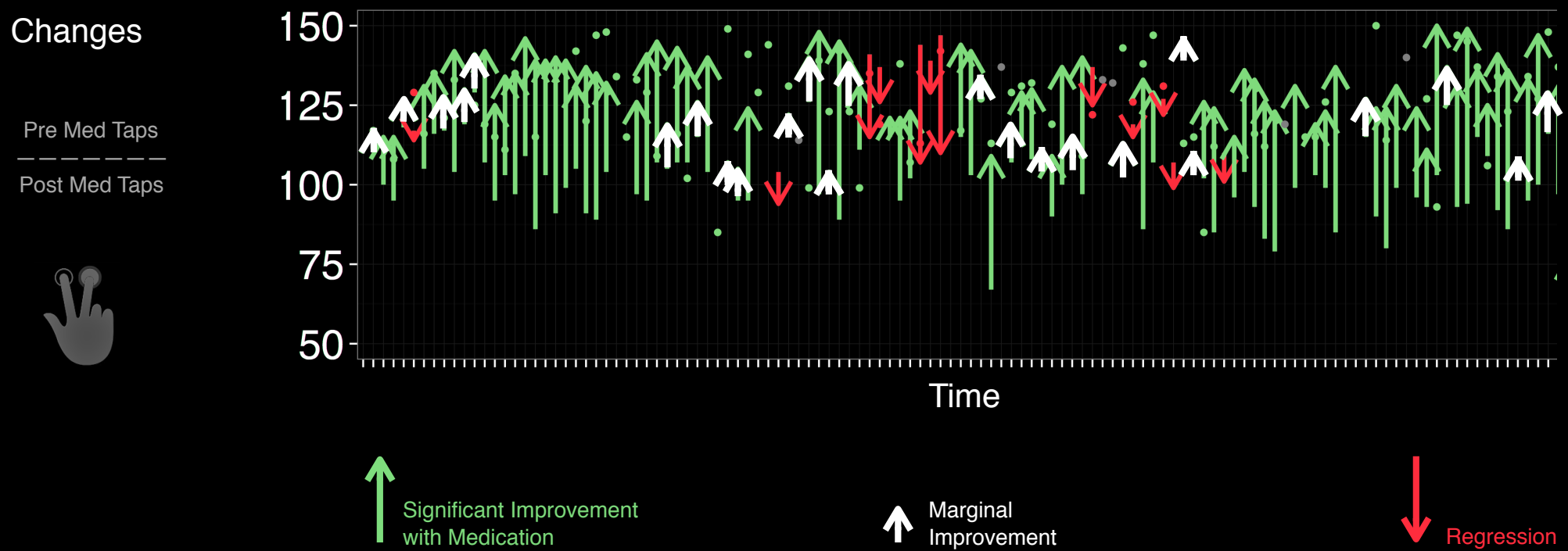


Voice Frequency



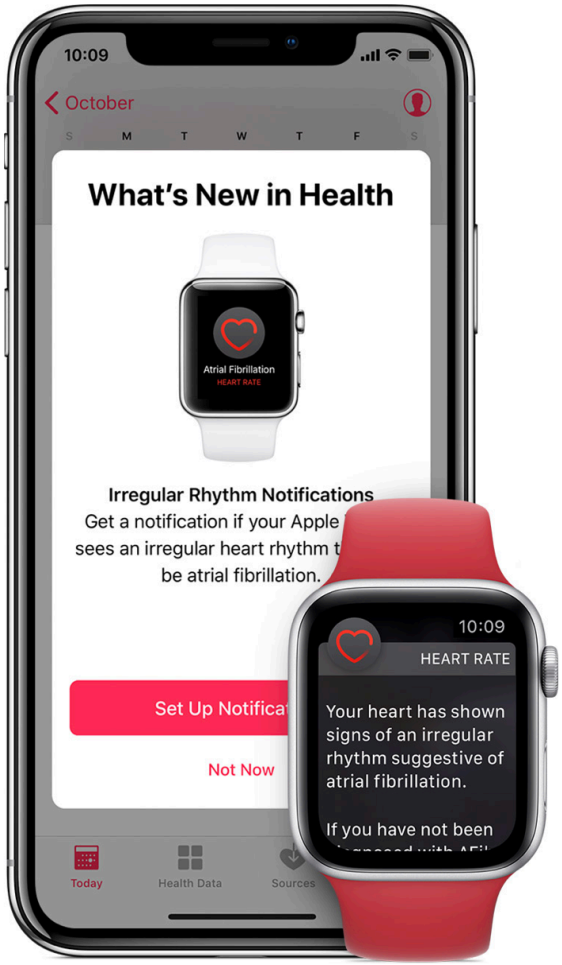
Intra-individual Diversity

among patients with Parkinson's disease



Responses to Why Changes?

Large scale beneficial alerts



Enabling irregular rhythm notifications

1. Make sure that the software on your iPhone and Apple Watch is up to date.
2. On your iPhone, open the Health app.
3. Follow the onscreen steps. If you aren't prompted to set up, tap the Health Data tab, then go to Heart > Irregular Rhythm Notifications.
4. Once enabled, you can turn irregular rhythm notifications on or off in the Apple Watch app on your iPhone: Open the Apple Watch app, tap the My Watch tab, then go to Heart > Irregular Rhythm.

What to do when you receive an alert

If you receive a notification, Apple Watch identified an irregular rhythm suggestive of AFib and confirmed it with multiple readings.

If you have not been diagnosed with AFib by a physician, you should talk to your doctor.

Benifits of large Scale longitudinal high resolution data

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Large-Scale Assessment of a Smartwatch to Identify Atrial Fibrillation

Marco V. Perez, M.D., Kenneth W. Mahaffey, M.D., Haley Hedlin, Ph.D., John S. Rumsfeld, M.D., Ph.D., Ariadna Garcia, M.S., Todd Ferris, M.D., Vidhya Balasubramanian, M.S., Andrea M. Russo, M.D., Amol Rajmane, M.D., Lauren Cheung, M.D., Grace Hung, M.S., Justin Lee, M.P.H., Peter Kowey, M.D., Nisha Talati, M.B.A., Divya Nag, Santosh E. Gummidipundi, M.S., Alexis Beatty, M.D., M.A.S., Mellanie True Hills, B.S., Sumbul Desai, M.D., Christopher B. Granger, M.D., Manisha Desai, Ph.D., and Mintu P. Turakhia, M.D., M.A.S., for the Apple Heart Study Investigators*

ABSTRACT

BACKGROUND

Optical sensors on wearable devices can detect irregular pulses. The ability of a smartwatch application (app) to identify atrial fibrillation during typical use is unknown.

Table 1. Characteristics of Participants Enrolled in the Apple Heart Study at Baseline.*

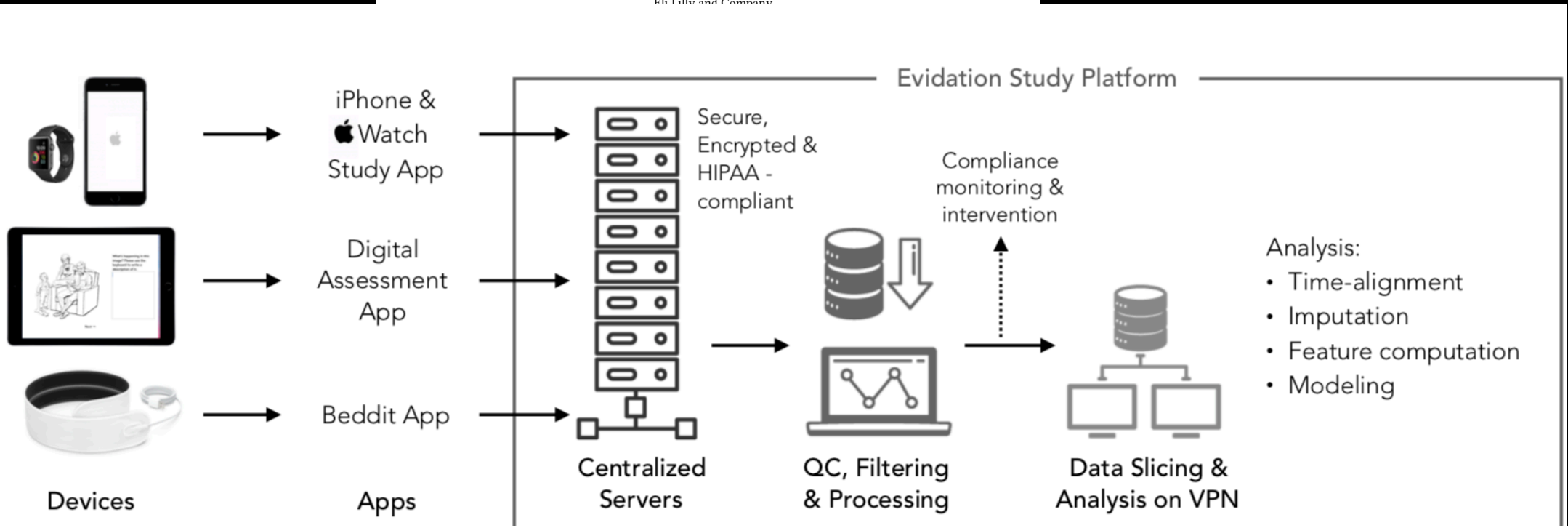
Characteristic	Total Cohort (N=419,297)	Notification Subgroup (N=2161)	ECG Patch Subgroup (N=450)
Sex — no. (%)†			
Female	177,087 (42)	461 (21)	102 (23)
Male	238,700 (57)	1672 (77)	335 (74)
Other	396 (0.1)	0	0
Not reported	3,114 (0.7)	28 (1.3)	13 (2.9)
Age — yr	41±13	57±15	59±14
Age distribution — no. (%)			
≥65 yr	24,626 (5.9)	775 (36)	181 (40)
55–64 yr	42,633 (10)	556 (26)	114 (25)
40–54 yr	132,696 (32)	488 (23)	106 (24)
22–39 yr	219,179 (52)	341 (16)	49 (11)
Not reported	163 (<0.1)	1 (<0.1)	0
Race or ethnic group — no. (%)†			
White	286,190 (68)	1747 (81)	379 (84)
Hispanic	48,775 (12)	104 (4.8)	20 (4.4)
Black	32,275 (7.7)	106 (4.9)	16 (3.6)
Asian	26,156 (6.2)	87 (4.0)	8 (1.8)
American Indian	4,696 (1.1)	20 (0.9)	3 (0.7)
Pacific Islander	1,493 (0.4)	6 (0.3)	0

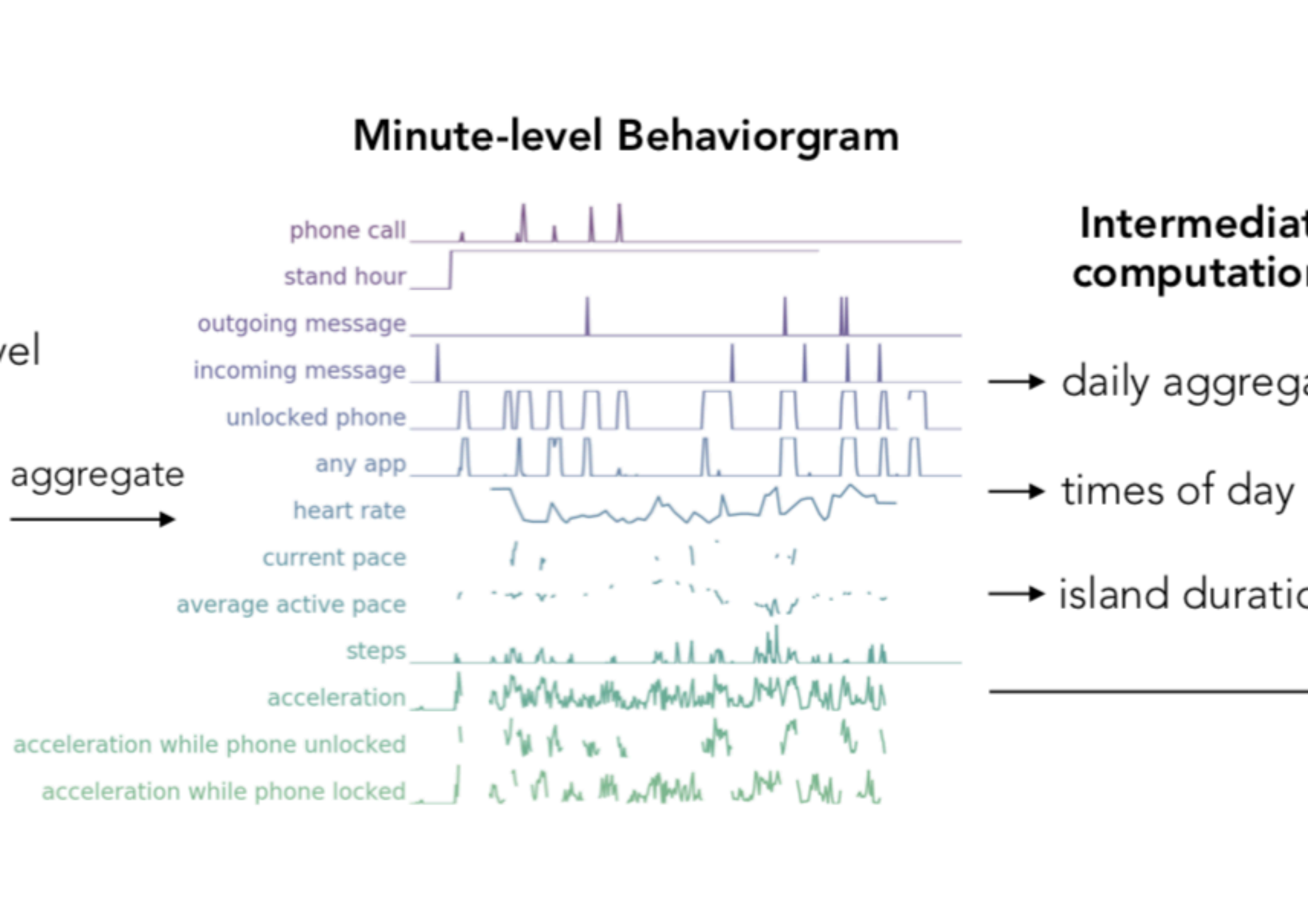
Benefits of large Scale longitudinal high resolution data to follow a symptom: cognition

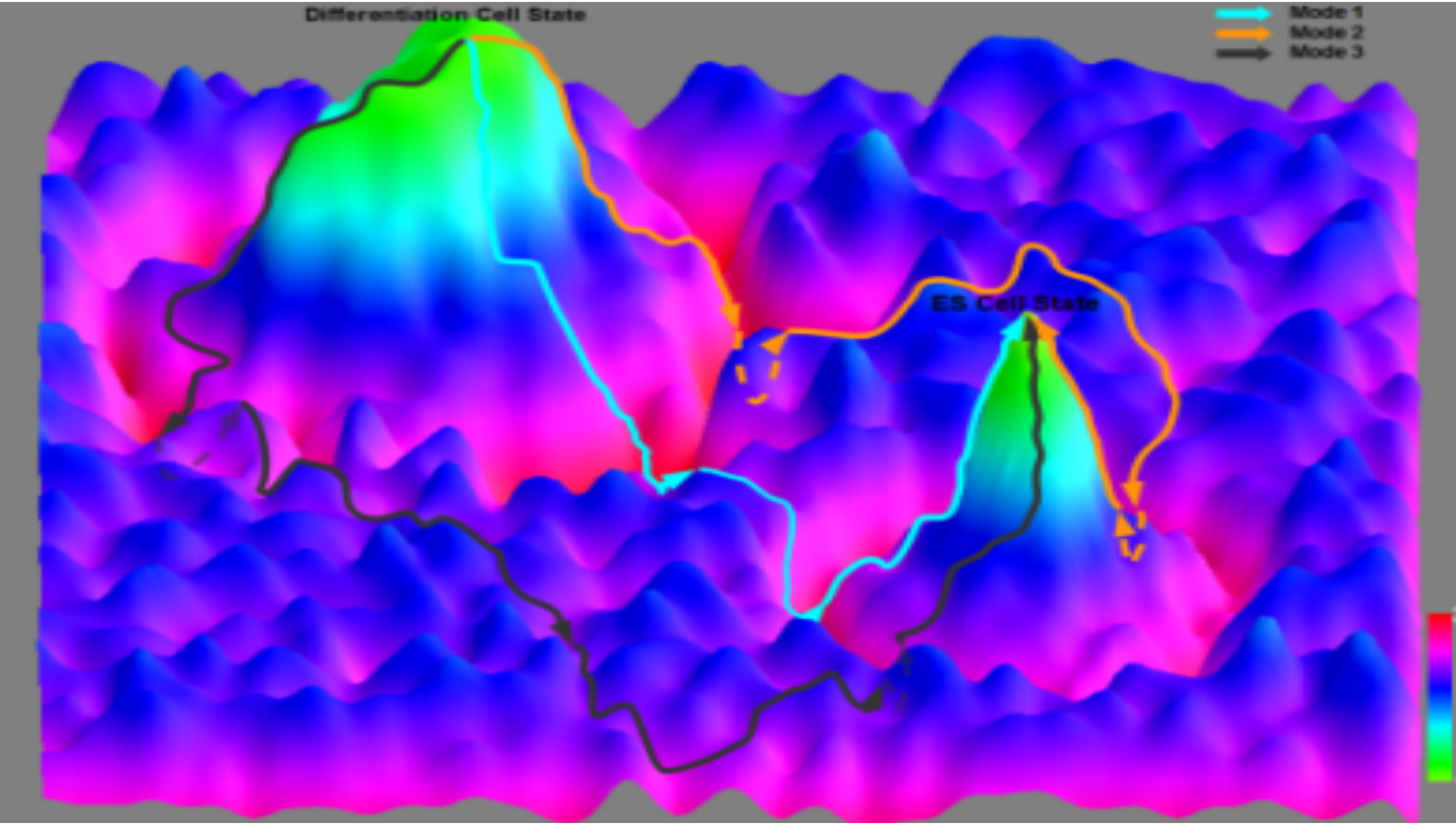
Applied Data Science Track Paper KDD '19, August 4–8, 2019, Anchorage, AK, USA

Developing Measures of Cognitive Impairment in the Real World from Consumer-Grade Multimodal Sensor Streams

Richard Chen* Apple Inc.
Filip Jankovic* Evidation Health, Inc.
Nikki Marinsek* Evidation Health, Inc.
Luca Foschini, Lampros Kourtis, Alessio Signorini, Evidation Health, Inc.
Melissa Pugh, Jie Shen, Roy Yaari, Vera Maljkovic, Marc Sunga, Eli Lilly and Company
Han Hee Song, Hyun Joon Jung, Belle Tseng, Andrew Trister, Apple Inc.




Minute-level Behaviorgram
vel
aggregate
phone call
stand hour
outgoing message
incoming message
unlocked phone
any app
heart rate
current pace
average active pace
steps
acceleration
acceleration while phone unlocked
acceleration while phone locked
Intermediat
computatio
daily aggrega
times of day
island duratio


Differentiation Cell State
ES Cell State
Mode 1
Mode 2
Mode 3

A nonprofit founded to tackle the fundamental unknowns using smart phones and wearables to enable individual forecasting of symptom transitions and how to effectively return it to individuals wishing to navigate with health and disease where all data, findings, algorithms, and apps as possible will be put in the public domain.

4YouandMe

PARTICIPATORY STRATEGIC FUNDERS

cohorts

device & apps

VECTOR INSTITUTE

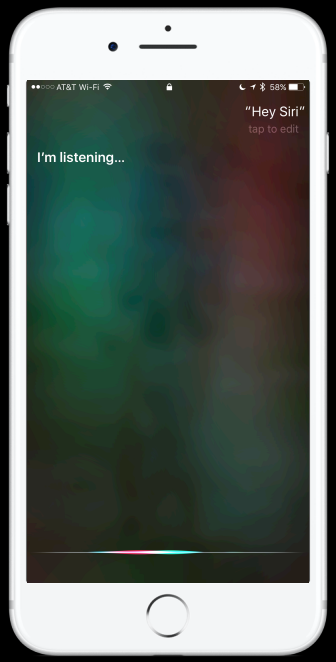
evidation

assessments

data flow

suggestions

all-day sensing & recording



- heart rate
- breathing
- voice
- facial expressions
- app usage
- motion & orientation

Health Assessments | Signals to Symptoms (examples)

FATIGUE

COGNITION

EMESIS

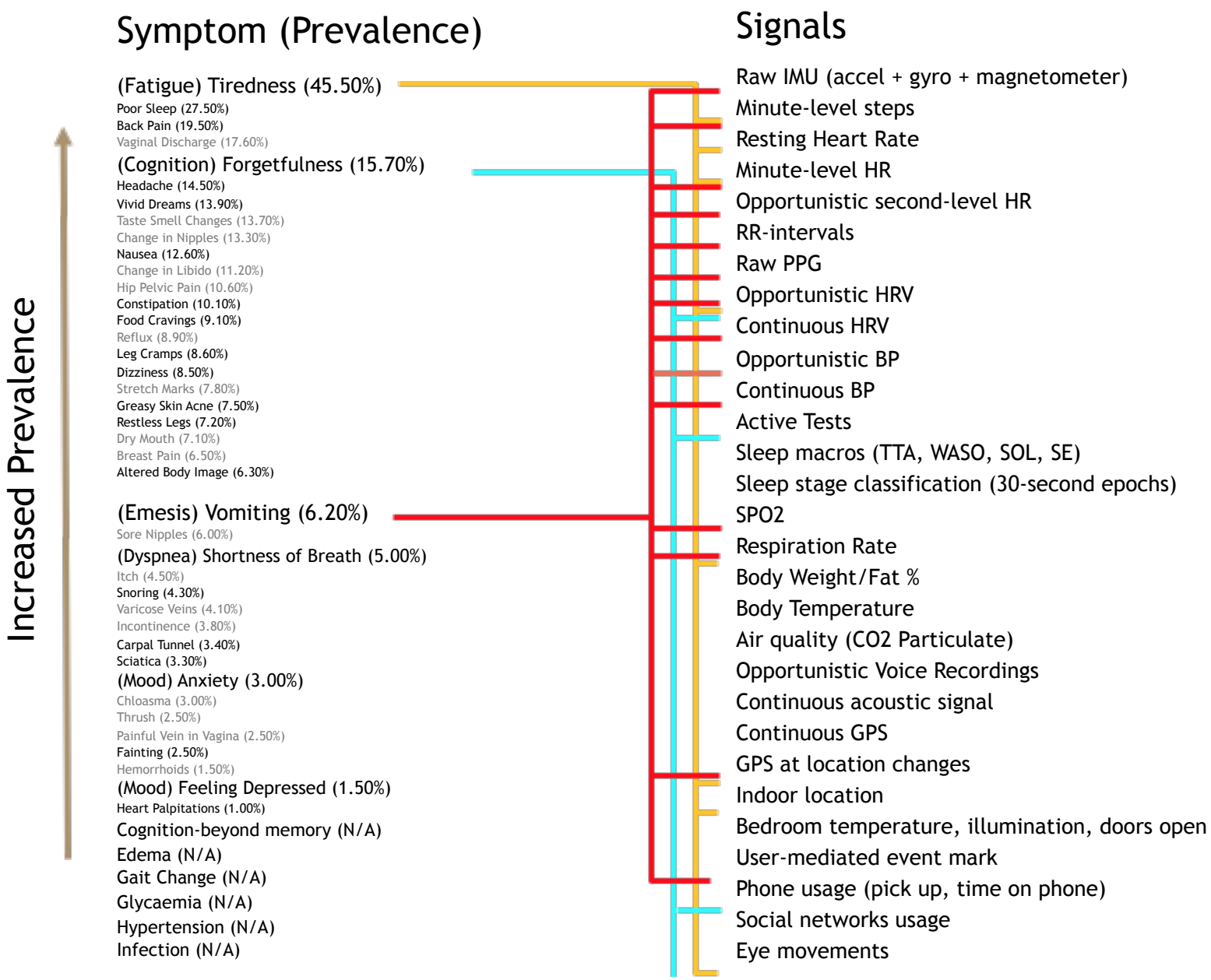
GAIT

EDEMA

MOOD

HYPERTENSION

STRESS


Symptom (Prevalence)
Signals
Increased Prevalence
(Fatigue) Tiredness (45.50%)
Poor Sleep (27.50%)
Back Pain (19.50%)
Vaginal Discharge (17.60%)
(Cognition) Forgetfulness (15.70%)
Headache (14.50%)
Vivid Dreams (13.90%)
Taste Smell Changes (13.70%)
Change in Nipples (13.30%)
Nausea (12.60%)
Change in Libido (11.20%)
Hip Pelvic Pain (10.60%)
Constipation (10.10%)
Food Cravings (9.10%)
Reflux (8.90%)
Leg Cramps (8.60%)
Dizziness (8.50%)
Stretch Marks (7.80%)
Greasy Skin Acne (7.50%)
Restless Legs (7.20%)
Dry Mouth (7.10%)
Breast Pain (6.50%)
Altered Body Image (6.30%)
(Emesis) Vomiting (6.20%)
Sore Nipples (6.00%)
(Dyspnea) Shortness of Breath (5.00%)
Itch (4.50%)
Snoring (4.30%)
Varicose Veins (4.10%)
Incontinence (3.80%)
Carpal Tunnel (3.40%)
Sciatica (3.30%)
(Mood) Anxiety (3.00%)
Chloasma (3.00%)
Thrush (2.50%)
Painful Vein in Vagina (2.50%)
Fainting (2.50%)
Hemorrhoids (1.50%)
(Mood) Feeling Depressed (1.50%)
Heart Palpitations (1.00%)
Cognition-beyond memory (N/A)
Edema (N/A)
Gait Change (N/A)
Glycaemia (N/A)
Hypertension (N/A)
Infection (N/A)
Raw IMU (accel + gyro + magnetometer)
Minute-level steps
Resting Heart Rate
Minute-level HR
Opportunistic second-level HR
RR-intervals
Raw PPG
Opportunistic HRV
Continuous HRV
Opportunistic BP
Continuous BP
Active Tests
Sleep macros (TTA, WASO, SOL, SE)
Sleep stage classification (30-second epochs)
SPO2
Respiration Rate
Body Weight/Fat %
Body Temperature
Air quality (CO2 Particulate)
Opportunistic Voice Recordings
Continuous acoustic signal
Continuous GPS
GPS at location changes
Indoor location
Bedroom temperature, illumination, doors open
User-mediated event mark
Phone usage (pick up, time on phone)
Social networks usage
Eye movements

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Equipment Needed

Three wearable devices will be provided to study participants

Fitbit Versa

- 3-axis accelerometer
- 3-axis gyroscope
- Optical heart rate monitor
- Altimeter
- Vibration motor
- WiFi Antennas (802.11 b/g/n)
- 4+ days battery Life

Oura Ring 2

- Heart Rate, Resting Heart Rate (RHR)
- Heart rate variability (HRV)
- Respiration rate, breathing variance
- Sleep stages and quality metrics
- Body temperature variation
- Duration, intensity, and timing of activities
- Inactivity, sedentary time

BodyPort Smart Scale

- Weight
- Pre-ejection Period
- BMI
- Ejection Time
- Impedance
- PEP/LVET
- Peripheral Fluid Content
- Pulse Wave Velocity
- Balance
- Pulse Transit Time
- Pulse Rate
- Pulse Arrival Time
- Heart Rate Variability
- Ejection Force

4YouandMe

Study Visit Schedule

Visit 01	Visit 02	Visit 03	Visit 04	Visit 05	Visit 06	Visit 07
~8 wks	12 wks	16 wks	20 wks	24 wks	28 wks	30 wks

Visit 08	Visit 09	Visit 10	Visit 11	Visit 12	Visit 13	Visit 14
32 wks	34 wks	36 wks	37 wks	38 wks	39 wks	40 wks

Visit 15
3 months

4YouandMe

Participant Mediated Health Data

Through a combination of passive trackers and active tests administered through the 4YouandMe Study App, participants provide objective data with minimal burden

Passively Collected

- Oura Ring
  - Temperature
  - Sleep Quantity
  - Sleep Quality
  - Resting Heart Rate
  - Heart Rate Variability
  - Respiration Rate
  - Activity
- BodyPort Smart Scale
  - Pulse rate
  - Heart rate variability (HRV
  - Cardiac waveforms
  - Systolic time intervals
  - Body weight
  - Body impedance
  - Balance analysis
  - Temperature and humidity
- Fitbit Versa
  - Steps
  - Activity Level
- Smartphone
  - RealizD
    - Phone pickups
    - Screen time
  - Study app
    - GPS
    - WiFi
    - Battery level
    - User-app interactions
- Facebook, Instagram
  - Bio, posts, likes

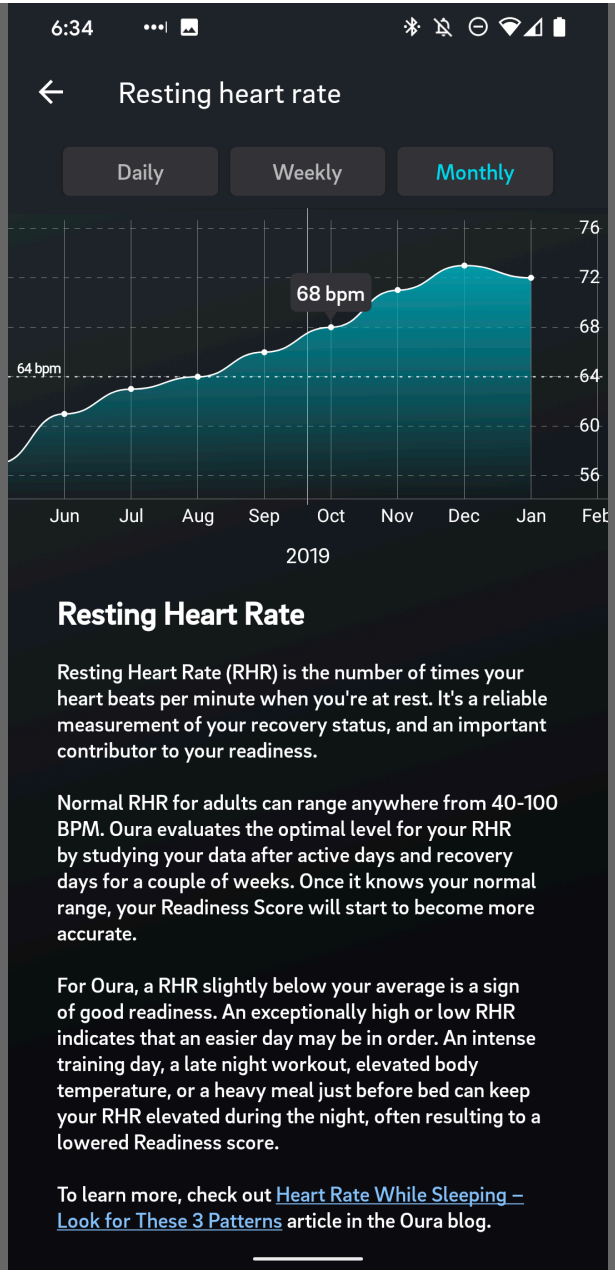
Active Tests

- Gait Active Task
- Video Diary
- Memory Active Task
- Psychomotor Vigilance Test
- Executive function active Task

4YouandMe


6:32
Sleep efficiency
Daily
Weekly
Monthly
96
94
92
90
88
86
84
91%
90%
Jul
Aug
Sep
Oct
Nov
Dec
Jan
Feb
2019
Sleep Efficiency
Sleep efficiency is the percentage of time you actually spend asleep after going to bed.
For adults, a generally accepted cut-off score for good sleep efficiency is 85%. It's common for sleep efficiency to slightly decrease with age.
For a maximum positive contribution to your sleep score, your sleep efficiency needs to be 95%. You'll see a lowered sleep score if it has taken more than 20 minutes for you to fall asleep, or if you experience one long or multiple shorter wake-ups during the night.


6:33
Sleep score
Daily
Weekly
Monthly
90
87
84
81
78
75
83
79
Jul
Aug
Sep
Oct
Nov
Dec
Jan
Feb
Mar
2019
Sleep Score
Ranging from 0-100, the sleep score is an overall measure of how well you slept.



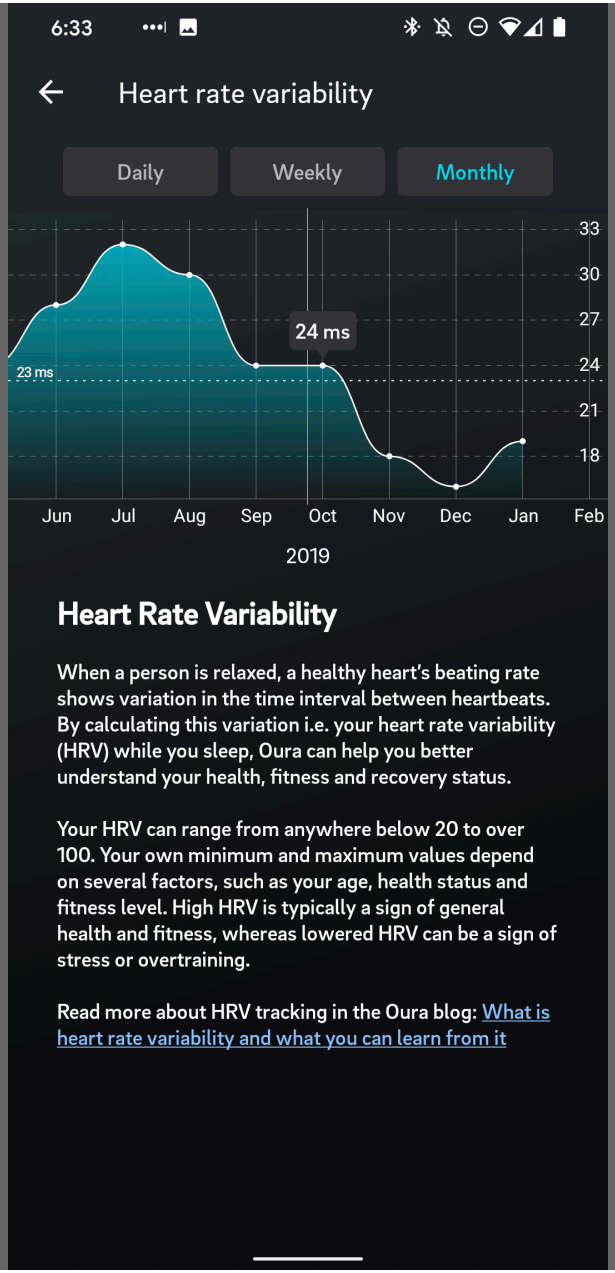
Resting Heart Rate

Resting Heart Rate (RHR) is the number of times your heart beats per minute when you're at rest. It's a reliable measurement of your recovery status, and an important contributor to your readiness.

Normal RHR for adults can range anywhere from 40-100 BPM. Oura evaluates the optimal level for your RHR by studying your data after active days and recovery days for a couple of weeks. Once it knows your normal range, your Readiness Score will start to become more accurate.

For Oura, a RHR slightly below your average is a sign of good readiness. An exceptionally high or low RHR indicates that an easier day may be in order. An intense training day, a late night workout, elevated body temperature, or a heavy meal just before bed can keep your RHR elevated during the night, often resulting to a lowered Readiness score.

To learn more, check out Heart Rate While Sleeping – Look for These 3 Patterns article in the Oura blog.



Heart Rate Variability

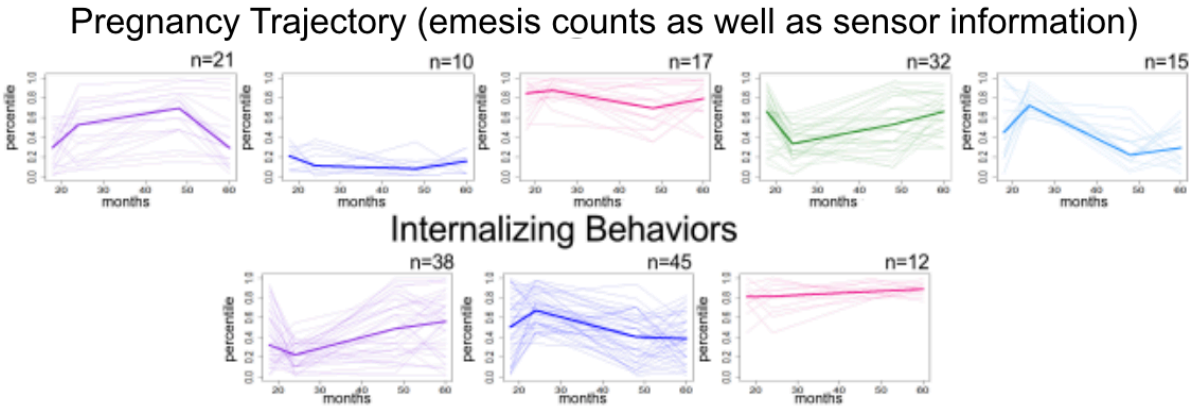
When a person is relaxed, a healthy heart's beating rate shows variation in the time interval between heartbeats. By calculating this variation i.e. your heart rate variability (HRV) while you sleep, Oura can help you better understand your health, fitness and recovery status.

Your HRV can range from anywhere below 20 to over 100. Your own minimum and maximum values depend on several factors, such as your age, health status and fitness level. High HRV is typically a sign of general health and fitness, whereas lowered HRV can be a sign of stress or overtraining.

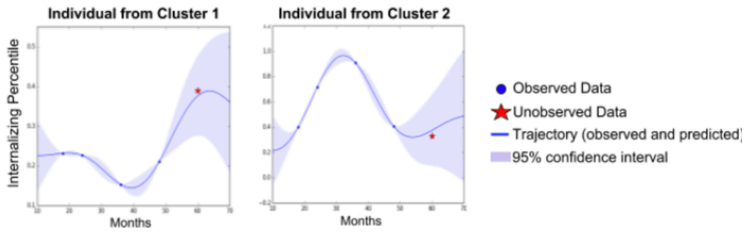
Read more about HRV tracking in the Oura blog: What is heart rate variability and what you can learn from it

Trajectory clustering

1. Identify trajectories of individuals (using clinical measures over time/ continuous sensor measures/active monitoring data through apps)
2. Use a similarity measure and cluster e.g.



3. Build a model for each of the clusters to predict future trajectory for specific individuals within a cluster



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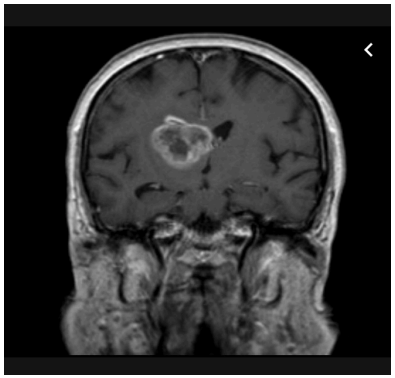
Detection of and forecasting symptom transitions and consequences of stress and lifestyles impacting those symptom transitions in chronic diseases

Why not?

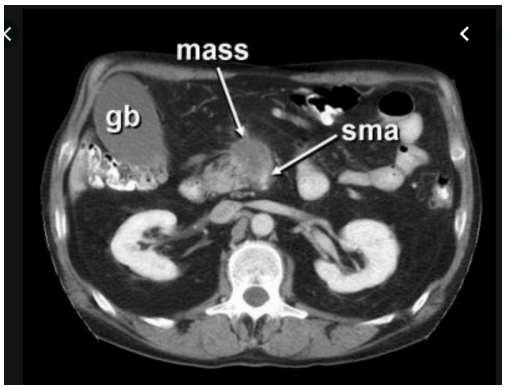
Can we devise continuous early warning systems for tumors?

Helping Enable Real time Observational Studies
"HERO" Studies

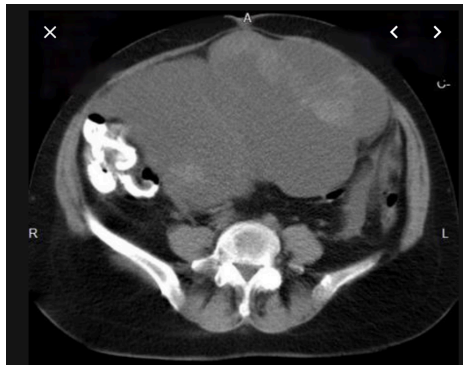


CNS

Mark Foundation



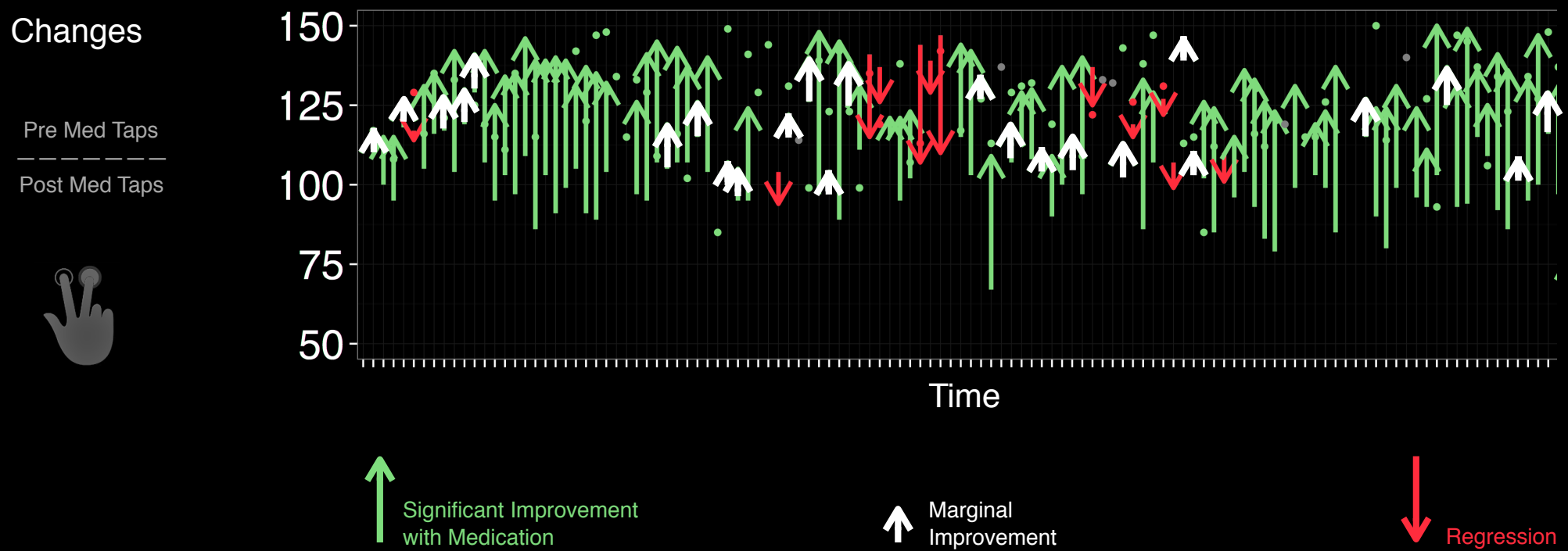
Pancreas



Ovarian

Intra-individual Diversity

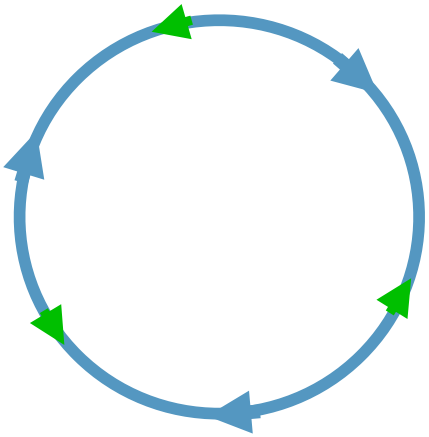
among patients with Parkinson's disease



Responses to Why Changes?

subjective vs objective

Immediate Stress



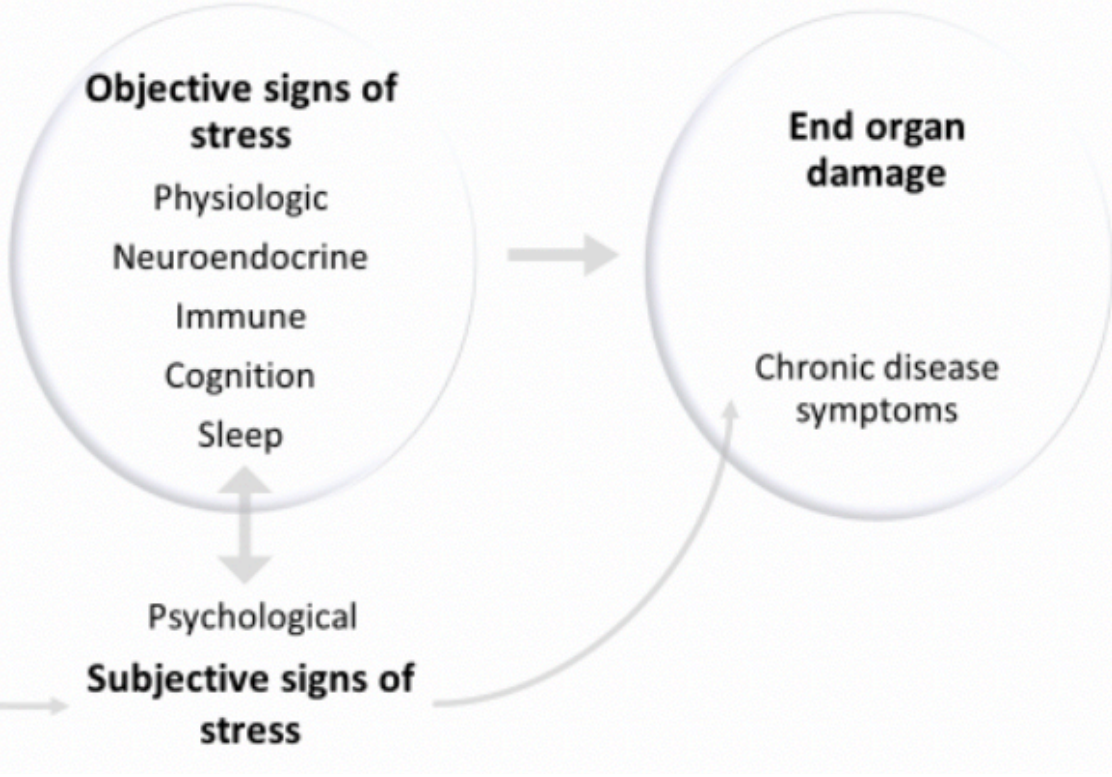
End Organ
Deterioration

Intermediate
Consequences

Engineering signals from wearable devices to signs of stress to end organ damage

Machine learning and artificial intelligence

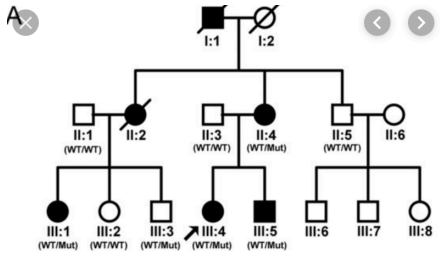
Engineering signals	
Smart rings, watches, scales and body patches	Temperature Sleep quantity/quality Sleep quality Resting HR HRV Respiration rate Breathing variance Activity (duration, intensity, frequency) Relative BP EDA Pulse rate Cardiac waveforms Systolic time intervals Body weight Body impedance Balance Cortisol Cytokines
Smartphone passive	Google Takeout – Online interaction RealizD – Phone usage Facebook/Instagram – Social activity Apps – GPS, WIFI, battery, app usage
Smartphone active	Cognitive tasks Video diaries – facial and speech EMA surveys – subjective symptoms, life events



Exploring the effects of “the fabric of our lives” on us

Crohn’s

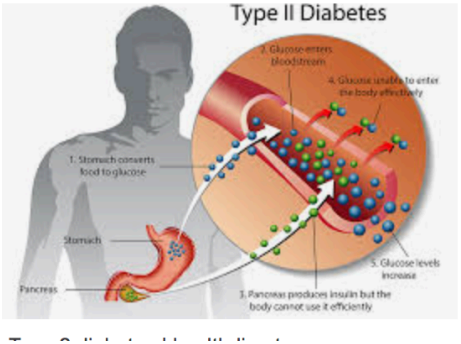
(The Helmsley Trust)



B

ID	Age in 2014	Tumors
I:1	Deceased	Liver mass at 46 y
II:1	40 y	None
II:2	Deceased	Breast cancer at 32 y
II:3	35 y	None
II:4	35 y	Breast cancer at 34 y
II:5	30 y	None
III:1	13 y	Adrenal pheochromocytoma at 3 y, and kidney cyst at 12 y
III:2	10 y	None
III:3	6 y	No
III:4	5 y	Medulloblastoma at 5 y
III:5	3 y	Choroid plexus papilloma at 3 y

Li-Fraumeni Syndrome



Diabetes

“modifyable factors”

Building better ways to objectively assess Stress

“Scan Scare”

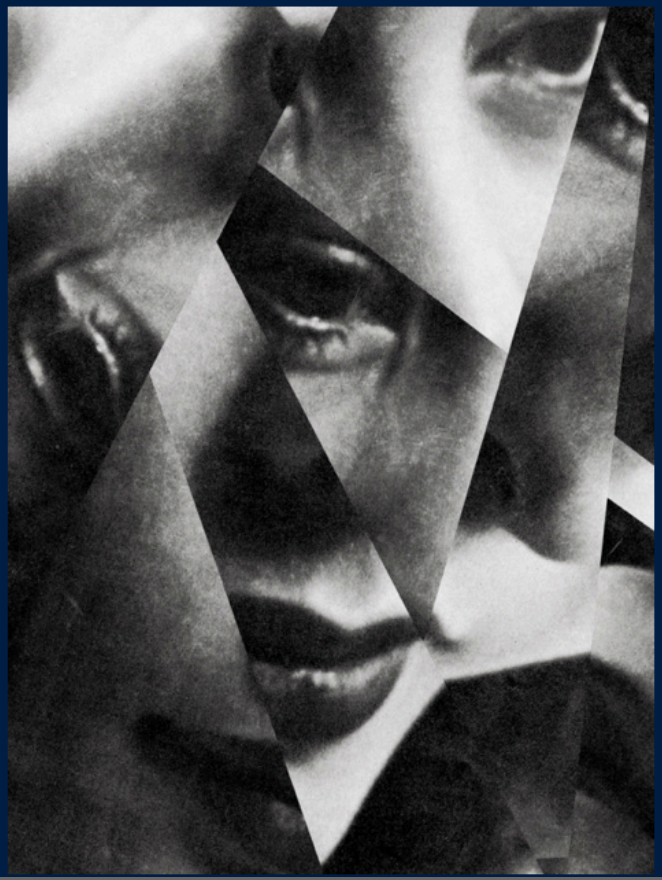
Marlene Kok

Sabine Linn

Luis Diaz

EmielRutgers

What is needed



What is needed

What is needed

COMMUNITIES

trust

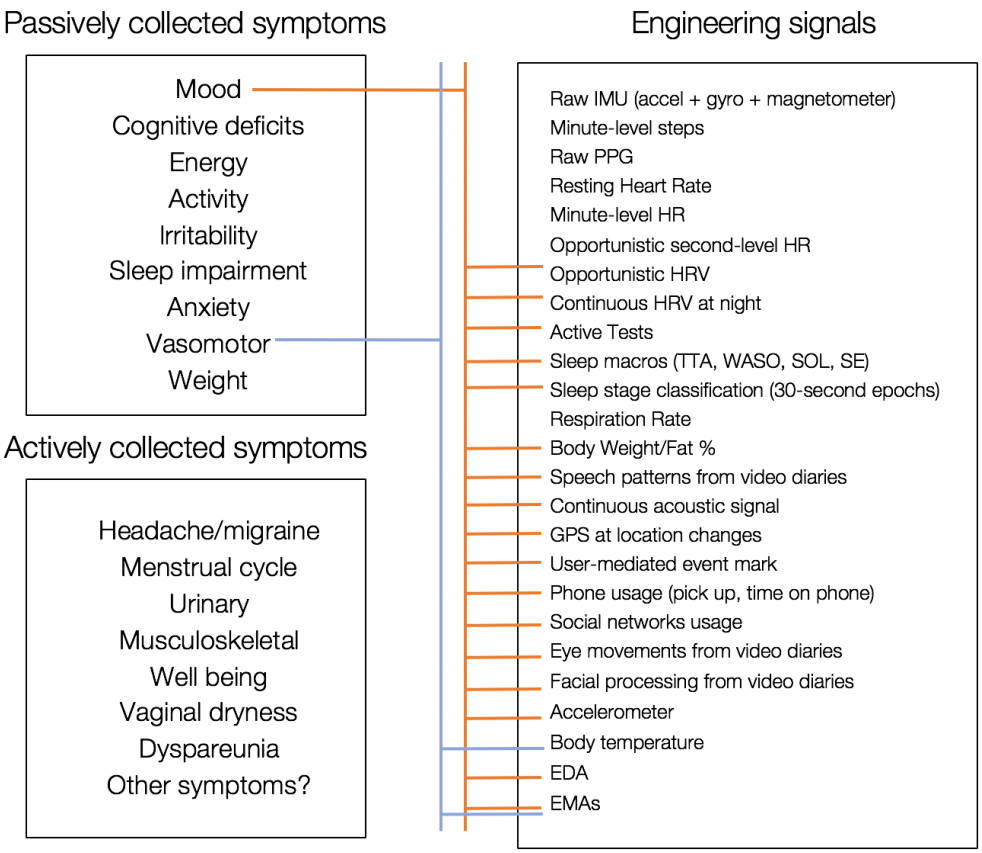
support

knowledge

privacy

:"Our Menopause"

Thematic example for passive collection of mood and vasomotor symptoms



participant designed and funded - built by each other for each other

“Our digital century was to have been democracy’s Golden Age. Instead, we enter its third decade marked by a stark new form of social inequality best understood as “epistemic inequality.”

It recalls a pre-Gutenberg era of extreme asymmetries of knowledge and the power that accrues to such knowledge, as the tech giants seize control of information and learning itself.”

Shoshana Zuboff

Open Band Project

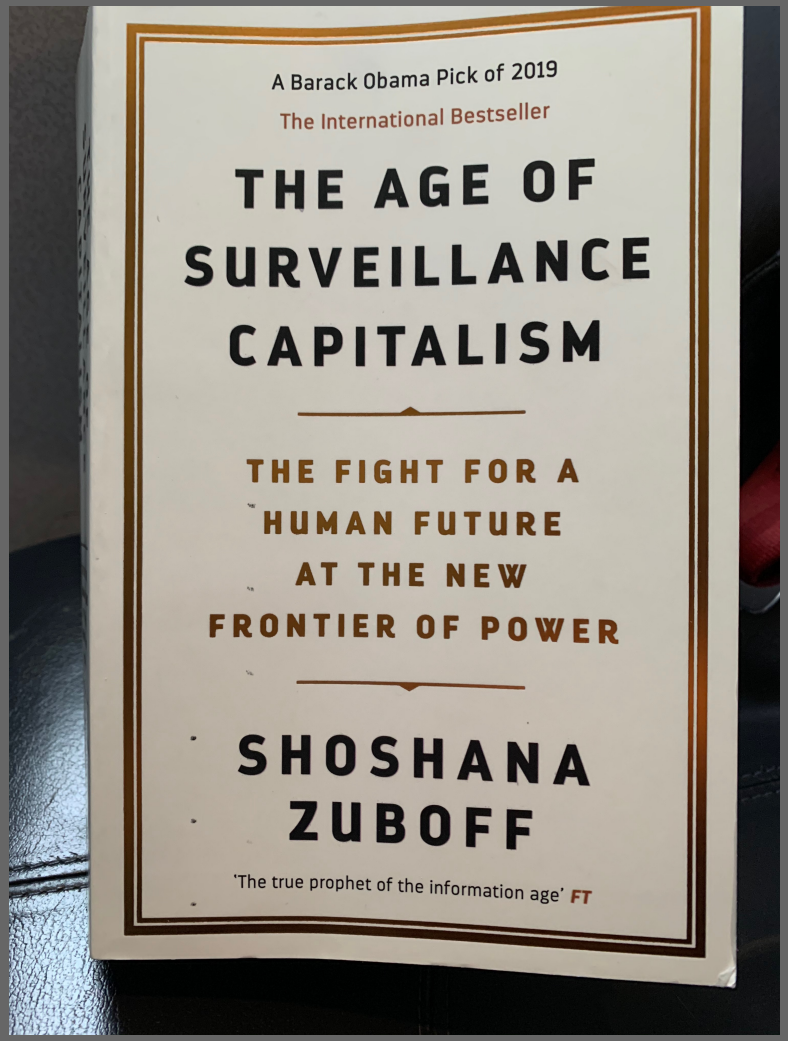
evidation

OPUSLOGICA™

Centre de Recherches Interdisciplinaires

SageBionetworks

4YouandMe


A Barack Obama Pick of 2019
The International Bestseller
THE AGE OF SURVEILLANCE CAPITALISM
THE FIGHT FOR A HUMAN FUTURE AT THE NEW FRONTIER OF POWER
SHOSHANA ZUBOFF
'The true prophet of the information age' FT

Sur-veil-lance Cap-i-tal-ism, n.

1. A new economic order that claims human experience as free raw material for hidden commercial practices of extraction, prediction, and sales; **2.** A parasitic economic logic in which the production of goods and services is subordinated to a new global architecture of behavioral modification; **3.** A rogue mutation of capitalism marked by concentrations of wealth, knowledge, and power unprecedented in human history; **4.** The foundational framework of a surveillance economy; **5.** As significant a threat to human nature in the twenty-first century as industrial capitalism was to the natural world in the nineteenth and twentieth; **6.** The origin of a new instru-