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)
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 News Editor, Canada

Posted on November 18, 2016, at 5:15 p.m. ET
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
Participant–Centered Research Studies with Feedback Loops

Discussion → Answers → Bridge → Population Data → Partners

Partners → Study Participant → Individual Data Trackers → Questions → Results → Study Researcher

Anecdotes into Signals
Apple’s ResearchKit Is a New Way to Do Medical Research

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

A software framework made specifically for medical research

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

no “average humans,” and no single measures for those with Parkinson’s Disease
Intra-individual Diversity
among patients with Parkinson’s disease
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

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 Rajmone, 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.
Benefits of large scale longitudinal high resolution data to follow a symptom: cognition.

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

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

Evidation Study Platform

Analysis:
- Time-alignment
- Imputation
- Feature computation
- Modeling
Minute-level Behaviorgram

- 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

Intermediate computation:

→ daily aggregation
→ times of day
→ island duration
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
all-day sensing & recording

- heart rate
- breathing
- voice
- facial expressions
- app usage
- motion & orientation
# Health Assessments: Signals to Symptoms

### Patients with Neurodegenerative Disease

<table>
<thead>
<tr>
<th>Cognition</th>
<th>Decreased ability to navigate</th>
<th>Driving slowly</th>
<th>Decreased vocabulary</th>
<th>Change in grammar</th>
<th>Disruptive speech cadence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood</td>
<td>Typing speed</td>
<td>Decreased vocabulary</td>
<td>Disruption of normal cadence</td>
<td>Reduced social engagement</td>
<td>Apathy</td>
</tr>
<tr>
<td>Sleep</td>
<td>Sleep disruptions</td>
<td>Sleep fragmentation</td>
<td>Lower amount of REM</td>
<td>Heart rate variability</td>
<td></td>
</tr>
<tr>
<td>Gait</td>
<td>Gait speed</td>
<td>Variability of gait</td>
<td>Arm swing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>Heart rate</td>
<td>Total activity</td>
<td>Reduced mobility</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Smart Phone</th>
<th>Gyroscope</th>
<th>Steps</th>
<th>Pedestrian Distance</th>
<th>GPS Vectors</th>
<th>Background HR</th>
<th>Device lock history</th>
<th>App in focus</th>
<th>Messages</th>
<th>Calls</th>
<th>On-wrist</th>
<th>Stride</th>
<th>calibration</th>
<th>Exercise &amp; breathe minutes</th>
<th>Voice samples</th>
<th>Typing speed</th>
<th>Typing corrections</th>
<th>Language content</th>
<th>Typing</th>
<th>Language content</th>
<th>Sleep Time</th>
<th>Nighttime HR</th>
</tr>
</thead>
</table>
FATIGUE
COGNITION
EMESIS
GAIT
EDEMA
MOOD
HYPERTENSION
STRESS
Symptom (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%)
Reflex (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%)
Snoring (4.30%)
Varicose Veins (4.10%)
Incontinence (3.80%)
Carpal Tunnel (3.40%)
Sciatica (3.30%)

(Mood) Anxiety (3.00%)
Chloasma (3.00%)
Thrash (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)

Signals
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
Equipment Needed

Three wearable devices will be provided to study participants

<table>
<thead>
<tr>
<th>Fitbit Versa</th>
<th>Oura Ring 2</th>
<th>BodyPort Smart Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>● 3-axis accelerometer</td>
<td>● Heart Rate, Resting Heart Rate (RHR)</td>
<td>● Weight</td>
</tr>
<tr>
<td>● 3-axis gyroscope</td>
<td>● Heart rate variability (HRV)</td>
<td>● Pre-ejection Period</td>
</tr>
<tr>
<td>● Optical heart rate monitor</td>
<td>● Respiration rate, breathing variance</td>
<td>● BMI</td>
</tr>
<tr>
<td>● Altimeter</td>
<td>● Sleep stages and quality metrics</td>
<td>● Ejection Time</td>
</tr>
<tr>
<td>● Vibration motor</td>
<td>● Body temperature variation</td>
<td>● Impedance</td>
</tr>
<tr>
<td>● WiFi Antennas (802.11 b/g/n)</td>
<td>● Duration, intensity, and timing of activities</td>
<td>● PEP/LVET</td>
</tr>
<tr>
<td>● 4+ days battery Life</td>
<td>● Inactivity, sedentary time</td>
<td>● Peripheral Fluid Content</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Pulse Wave Velocity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Balance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Pulse Transit Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Pulse Rate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Pulse Arrival Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Heart Rate Variability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Ejection Force</td>
</tr>
</tbody>
</table>
Study Visit Schedule

Visit 01 ~8 wks
Visit 02 12 wks
Visit 03 16 wks
Visit 04 20 wks
Visit 05 24 wks
Visit 06 28 wks
Visit 07 30 wks
Visit 08 32 wks
Visit 09 34 wks
Visit 10 36 wks
Visit 11 37 wks
Visit 12 38 wks
Visit 13 39 wks
Visit 14 40 wks
Visit 15 3 months
## 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.
**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.

**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.

Pregnancy Trajectory (emesis counts as well as sensor information)

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

Changes
Pre Med Taps
Post Med Taps

Time

Significant Improvement with Medication
Marginal Improvement
Regression

Responses to Why Changes?
Immediate Stress

End Organ Deterioration

Intermediate Consequences

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

Machine learning and artificial intelligence

<table>
<thead>
<tr>
<th>Engineering signals</th>
<th></th>
</tr>
</thead>
</table>
| **Smart rings, watches, scales and body patches** | Temperature  
Sleep quantity/quality  
Sleep quality  
RestingHR  
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 |

**Objective signs of stress**
- Physiologic
- Neuroendocrine
- Immune
- Cognition
- Sleep

**Subjective signs of stress**

**End organ damage**
- Chronic disease symptoms

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

Crohn’s
(The Helmsley Trust)

Li-Fraumeni Syndrome

Diabetes

“modifyable factors”
Building better ways to objectively assess Stress

“Scan Scare”

Marlene Kok
Sabine Linn
EmielRutgers
Luis Diaz
What is needed
What is needed
What is needed

COMMUNITIES

trust
knowledge
support
privacy


"Our Menopause"

Thematic example for passive collection of mood and vasomotor symptoms

Passively collected symptoms
- Mood
- Cognitive deficits
- Energy
- Activity
- Irritability
- Sleep impairment
- Anxiety
- Vasomotor
- Weight

Actively collected symptoms
- Headache/migraine
- Menstrual cycle
- Urinary
- Musculoskeletal
- Well being
- Vaginal dryness
- Dyspareunia
- Other symptoms?

Engineering signals
- Raw IMU (accel + gyro + magnetometer)
- Minute-level steps
- Raw PPG
- Resting Heart Rate
- Minute-level HR
- Opportunistic second-level HR
- Opportunistic HRV
- Continuous HRV at night
- Active Tests
- Sleep macros (TTA, WASO, SOL, SE)
- Sleep stage classification (30-second epochs)
- Respiration Rate
- Body Weight/Fat %
- Speech patterns from video diaries
- Continuous acoustic signal
- GPS at location changes
- User-mediated event mark
- Phone usage (pick up, time on phone)
- Social networks usage
- Eye movements from video diaries
- Facial processing from video diaries
- Accelerometer
- Body temperature
- EDA
- EMAs

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
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
Surveillance Capitalism, 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 instrument of social control and exploitation.