



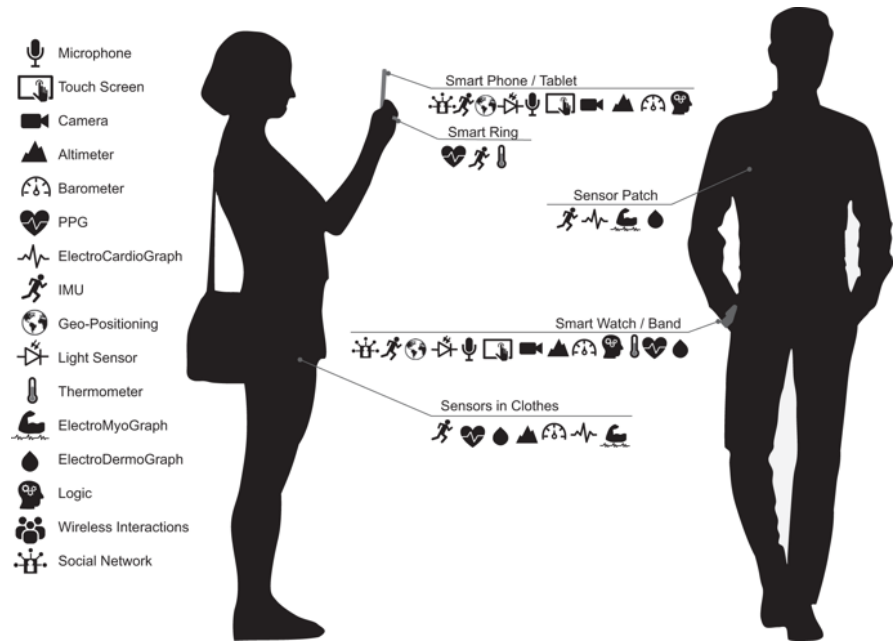
evidation

## Incorporating Person-generated Health Data and Digital Clinical Measures into PCOR Infrastructure

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Senior Director, Strategic Partnerships

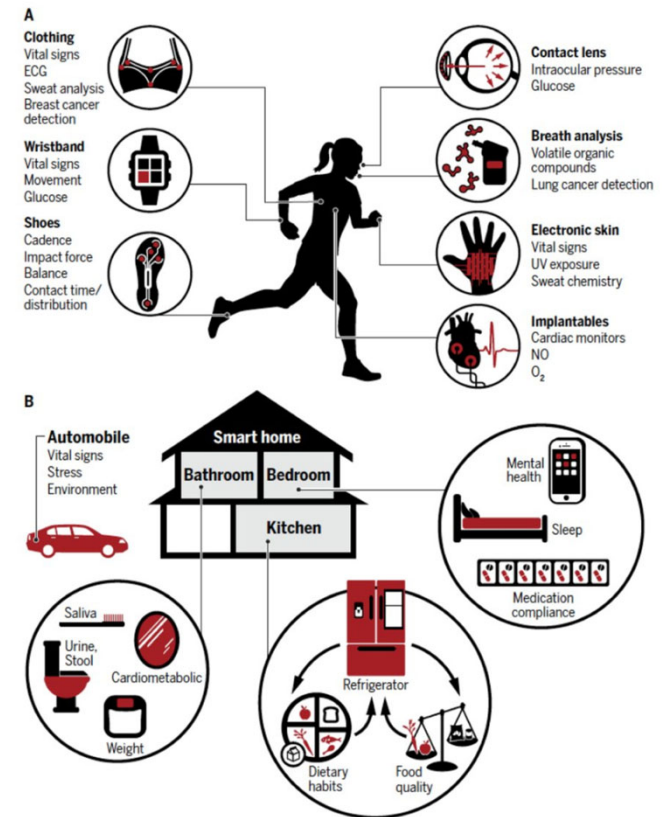
May 3, 2021

Person-Generated Health Data (PGHD) enables continuous monitoring of health outcomes at the individual level, to better understand and measure a person's experience with health and disease



KOURTIS, LAMPROS ET AL., "DIGITAL BIOMARKERS FOR ALZHEIMER'S DISEASE: THE MOBILE/WEARABLE DEVICES OPPORTUNITY" NPJ DIGITAL MEDICINE, 2(1), 9. [HTTPS://DOI.ORG/10.1038/S41746-019-0084-2](https://doi.org/10.1038/s41746-019-0084-2)

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

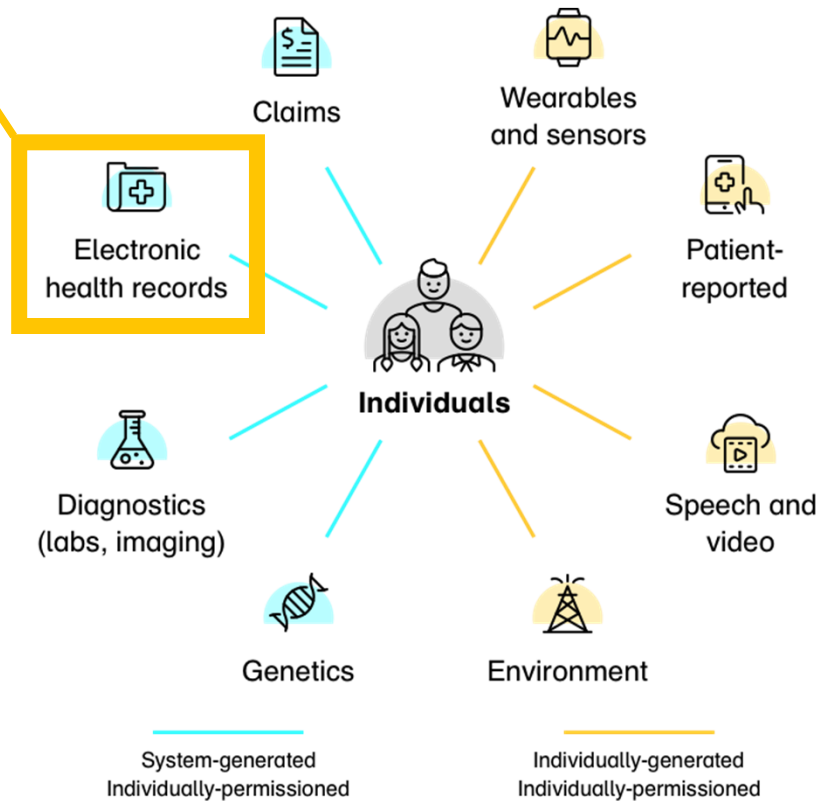
With individuals increasingly taking charge of their health, PGHD will eventually include all personal health data

**Allow or Deny Access**

Evidation Health wants your permission to access the following information:

 Allergies	 Lab Results
 Primary Care Provider	 Medications
 Demographics	 Plan of Care
 Documents	 Problems
 Health Goals	 Procedures
 Social History	 Immunizations
 Implants	 Vitals

**DENY ACCESS** **ALLOW ACCESS**



The richest data about patients' experience with disease is mostly invisible to the healthcare system

RWE Data Points

**Visible**

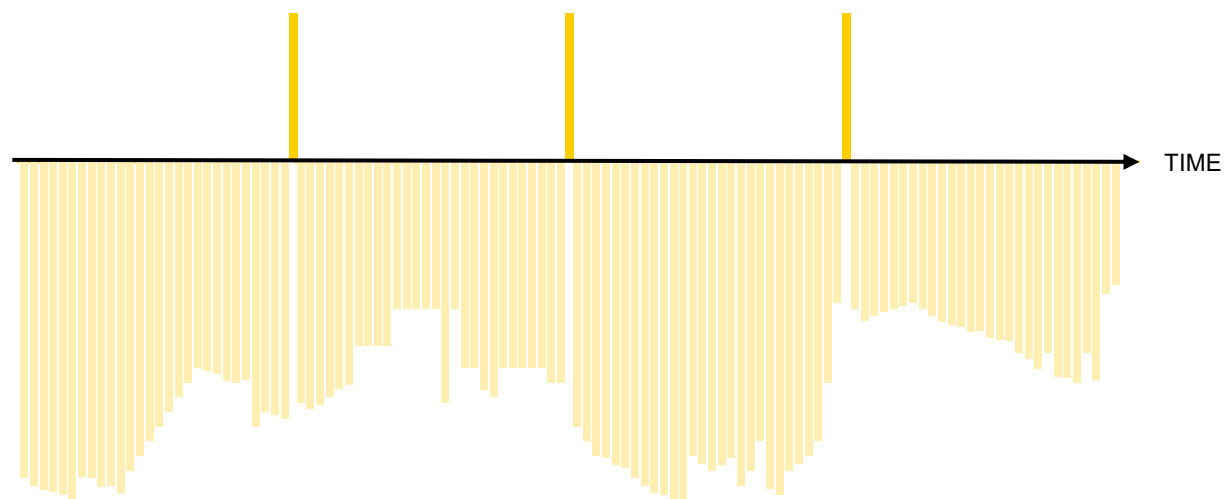
0.03%

episodic

**Invisible**

99.97%

continuous,  
passive



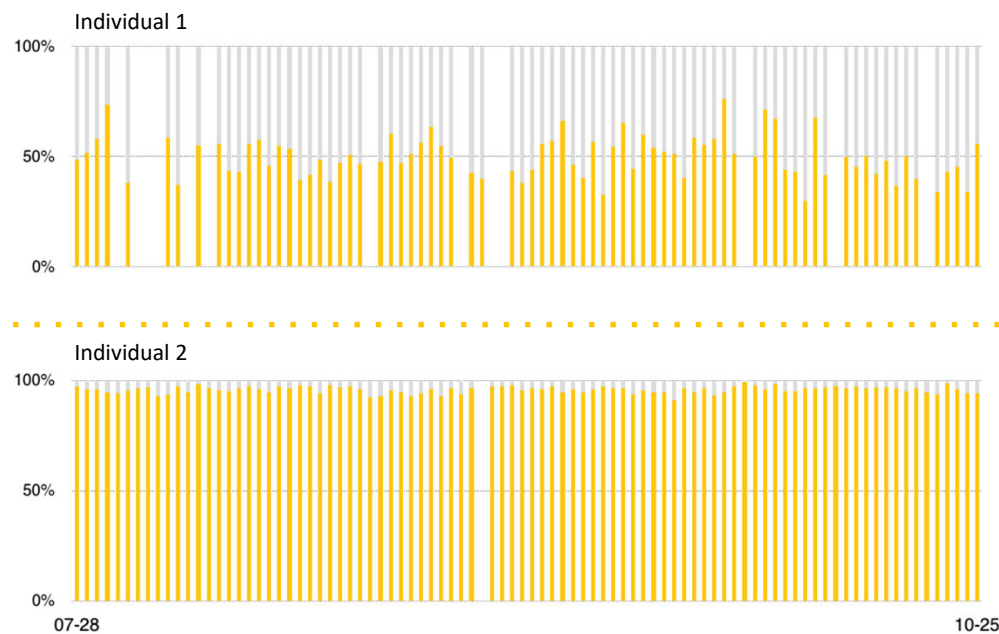
- *Better characterization and understanding of living with the disease*
- *Better understanding of disease progression*
- *Earlier identification of at-risk individuals*
- *Real world, objective QoL and ADL measures*
- *Pattern detection for public health*

## Case study: Connecting directly to patients provides unprecedented resolution into asthma control and the true disease burden in everyday life not captured by traditional RWE

### Both Individuals

- Persistent moderate/severe asthma
- Currently taking LABA/ICS
- Adhering to physician-prescribed treatment
- Non-smokers
- Use the same brand of wearable device

### Percentage of time asleep while in bed (nightly)



- Reports waking up **often (every night or almost every night)** when asked how often they wake up at night due to asthma symptoms
- **49% time asleep** while in bed over last 90 days

- Reports waking up **2 or fewer days per month** when asked how often they wake up at night due to asthma symptoms
- **96% time asleep** while in bed over last 90 days

**Note:** time asleep data is objectively-derived from wearable devices; comparison is illustrative only and not controlled for any variable

# Disease Event and Progression Modelling

- Detect, describe, and predict disease events and changes in health status
- Measure disease progression and recovery over time

## CASE STUDY: AUTOIMMUNE FLARES

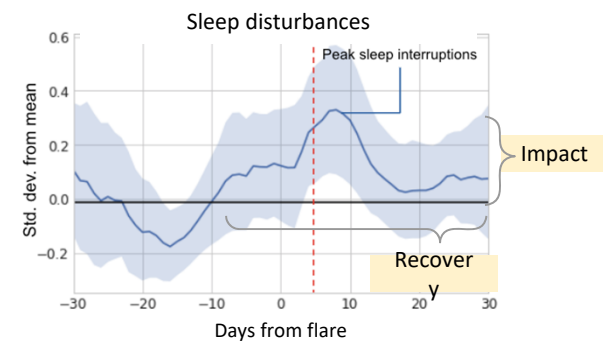
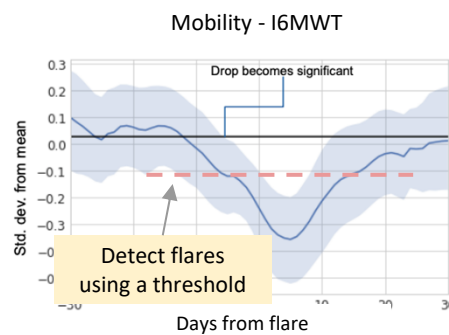
### Objective

Describe, detect, and predict flare events in an autoimmune condition using wearable and survey data

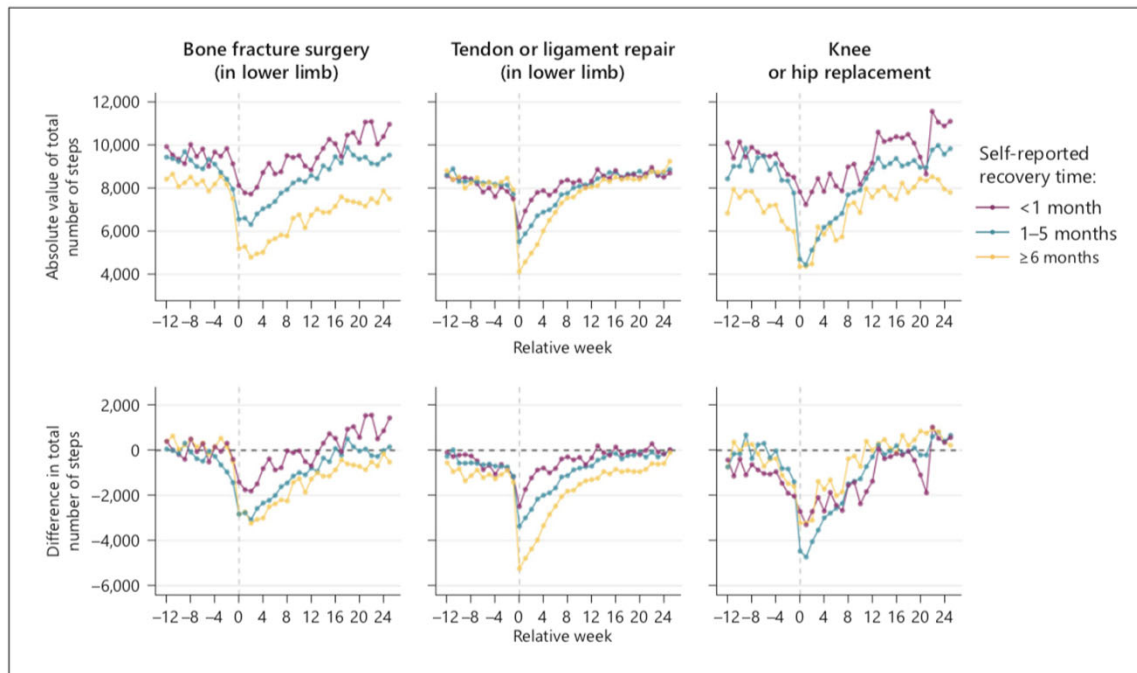
- Identify behavioral changes leading up to and following a flare
- Assess whether behavioral deviations can detect and predict flare events

### Results / Impact

- Enabled **flare detection** using easily measured changes in behavior
- Quantified flare **impact and recovery** over time







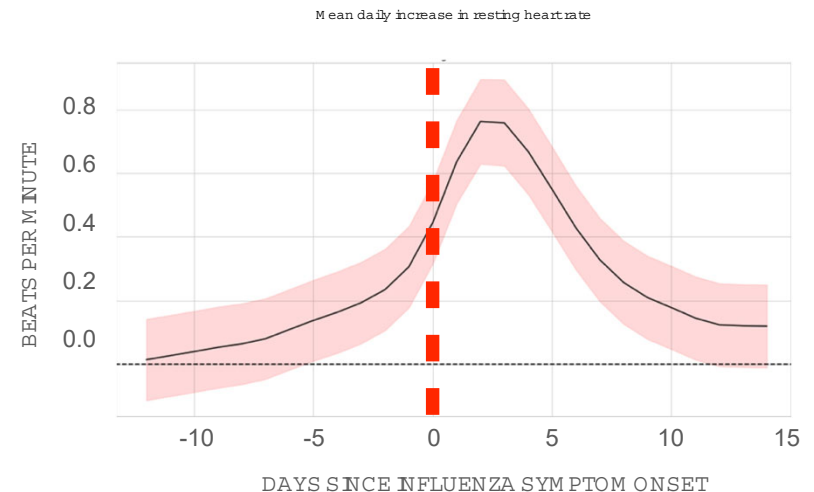
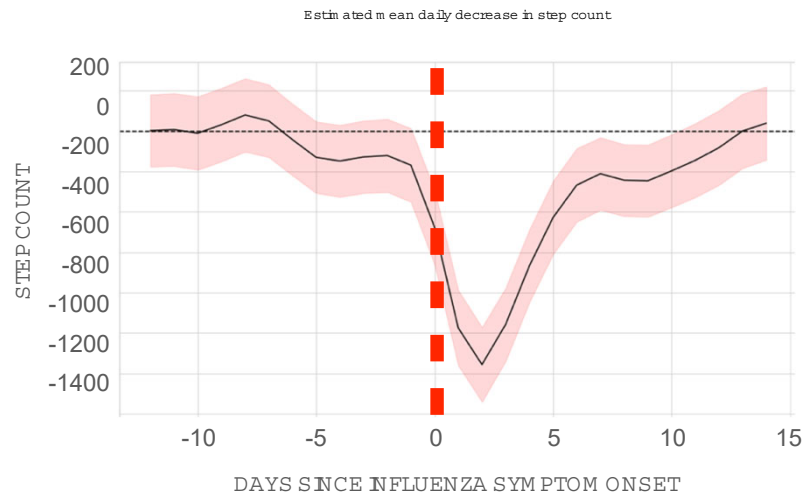
**Fig. 3.** Estimated trajectories of daily number of steps across 3 self-reported recovery time groups in subsequent weeks from 12 weeks before to 26 weeks after surgery. The upper plots show absolute values of activity, the bottom plots show change with respect to the model-estimated baseline. Vertical plot panels correspond to 3 lower limb surgery types: bone fracture, tendon or ligament repair, and knee or hip replacement. The color of a point/line corresponds to the self-reported recovery time group. The “week 0” label (x-axis) denotes a 7-day period starting on a self-reported surgery day.

## Recovery Modeling:

The most discriminative variable between faster (0-2 months) vs. slower (>3 months) recovery at 4 weeks follow up is the 95-th percentile of 30-min rolling sum of steps over week 1 as compared to baseline, which can be seen as a continuous and individualized version of the 6-min walk test

SOURCE: PREDICTING SUBJECTIVE RECOVERY FROM LOWER LIMB SURGERY USING CONSUMER WEARABLES. KARAS ET AL., KARGER DIGITAL BIOMARKERS

PGHD allows measuring burden of acute conditions invisible to the healthcare system, and its unfolding through time.




ADAPTED FROM: INFLUENZA SURVEILLANCE USING WEARABLE MOBILE HEALTH DEVICES.  
BRADSHAW ET AL., ONLINE JOURNAL OF PUBLIC HEALTH INFORMATICS, MAY 2019

NOTE: BASED ON 124K SURVEY RESPONDERS WHO REPORTED INFLUENZA SYMPTOMS IN 2018





Study goal: Understand utility of Person-generated Health Data (PGHD) for early detection, monitoring, and management of COVID-19 in everyday life




ARTICLE | VOLUME 2, ISSUE 1, 100188, JANUARY 08, 2021

Characterizing COVID-19 and Influenza Illnesses in the Real World via Person-Generated Health Data

Allison Shapiro<sup>5</sup> • Nicole Marinsek<sup>5</sup> • Ieuan Clay • ... Yuedong Wang • Tim Althoff • Luca Foschini<sup>6</sup> •  • 

Show all authors • Show footnotes

Open Access • Published: December 12, 2020 • DOI: <https://doi.org/10.1016/j.patter.2020.100188> •  Check for updates

Picture

Summary

Data Science

Maturity

Keywords

Introduction

Results




Highlights

- We use data from smartphones and wearables from ~7,000 people to compare flu and COVID-19
- While symptoms have some overlap, patients report longer COVID-19 illnesses than flu
- Elevated resting heart rate measures are more frequent around illness symptoms onset
- It is important to consider flu as a confounder in COVID-19 real-world studies


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Your Apple Watch could soon tell you if you've got coronavirus

Millions of people are already wearing smart devices that can measure heart rates, sleep patterns and oxygen saturations. They might also tell us when we're getting ill

By SANDY ONG  
Updated 3 September 2020



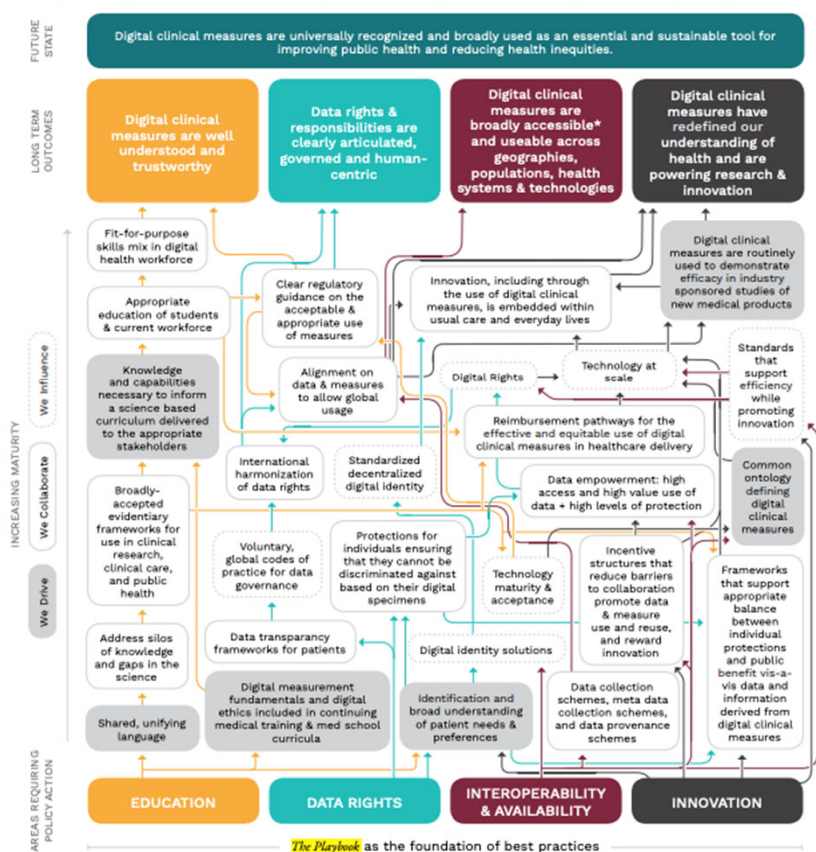
Credit: Apple / WIRED

In the middle of March, Luca Foschini began to feel unwell. He had a high fever, cough, a light head and a lot of bone fatigue. His wife had just returned from London which was experiencing a spike in Covid-19 cases at the time, and the couple feared that they both might have contracted the disease too.

CELL PRESS PATTERNS: [HTTPS://WWW.CELL.COM/PATTERNS/FULLTEXT/S2666-3899\(20\)30258-0](https://www.cell.com/patterns/fulltext/S2666-3899(20)30258-0)  
TWEETORIAL: [HTTPS://TWITTER.COM/CALIMAGNA/STATUS/1267250624678096896?S=20](https://twitter.com/CALIMAGNA/STATUS/1267250624678096896?S=20)

## The Pathway to a Future State of Healthcare Powered by Digital Clinical Measures

Today's healthcare system is struggling to meet the needs of today's population. As poor health outcomes and health economics persist alongside widening health disparities, there is no strategy in place to ensure that the new toolbox of digital technologies is intentionally deployed to reimagine a safe, effective, ethical, and equitable healthcare system for the 21st century. This is our theory of change:



## In order for PGHD and digital clinical measures to achieve their potential in accelerating clinical research, enhancing clinical care, and improving public health we must:

- Ensure digital clinical measures are well understood and trusted
  - common ontology, standards, data collections schemes, meta data collections schemes, and data provenance schemes
- Develop broadly accepted evidentiary frameworks for clinical care, clinical research, and public health
- Develop incentives that reduce barriers to collaboration – promote data and measure use and re-use, reward innovation
- Advance data rights and ELSI work to support the appropriate balance between individual protections and public benefit, ensuring that individuals are well informed and protected against discrimination from their digital specimens

[playbook.dimesociety.org](http://playbook.dimesociety.org)

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