With PCORnet®, we have developed a nationwide functional research network that...

- **Engages** people, clinicians, and health system leaders throughout

- **Creates** infrastructure, tools, and policies to support rapid, efficient clinical research

- **Uses** multiple data sources including electronic health records, insurance claims data, data reported directly by people, and other data sources

- **Enables** people and systems to work collaboratively

pcornet®

Patients, caregivers, and others interested in clinical research provide leadership

- **Patients and caregivers** help identify knowledge gaps by sharing their experiences with the daily burden of disease conditions.

- **Patient and stakeholder engagement** is embodied within the PCORnet Governance Policy.

- **Patients and caregivers serve as principal investigators** for PCORnet studies and networks.

CRNs

ADVANCE

Accelerating Data Value Across a National Community Health Center Network (ADVANCE)
Oregon Community Health Information Network (OCHIN)

Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)
The Chicago Community Trust

Greater Plains Collaborative (GPC)
University of Kansas Medical Center

Research Action for Health Network (REACHnet)
Louisiana Public Health Institute (LPHI)

Mid-South CDRN
Vanderbilt University

National PEDSnet: A Pediatric Learning Health System
The Children's Hospital of Philadelphia

New York City Clinical Data Research Network (NYC-CDRN)
Weill Medical College of Cornell University

OneFlorida Clinical Data Research Network
University of Florida

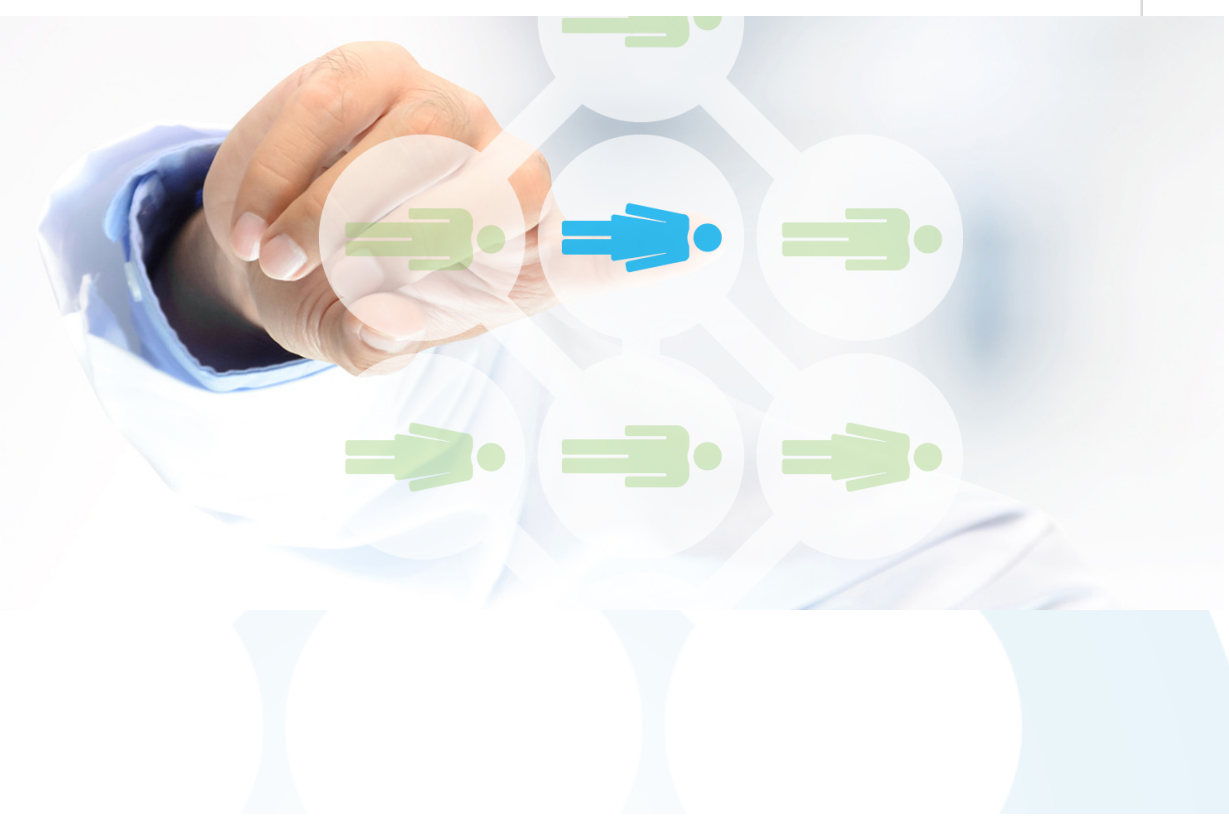PaTH: Towards a Learning Health System
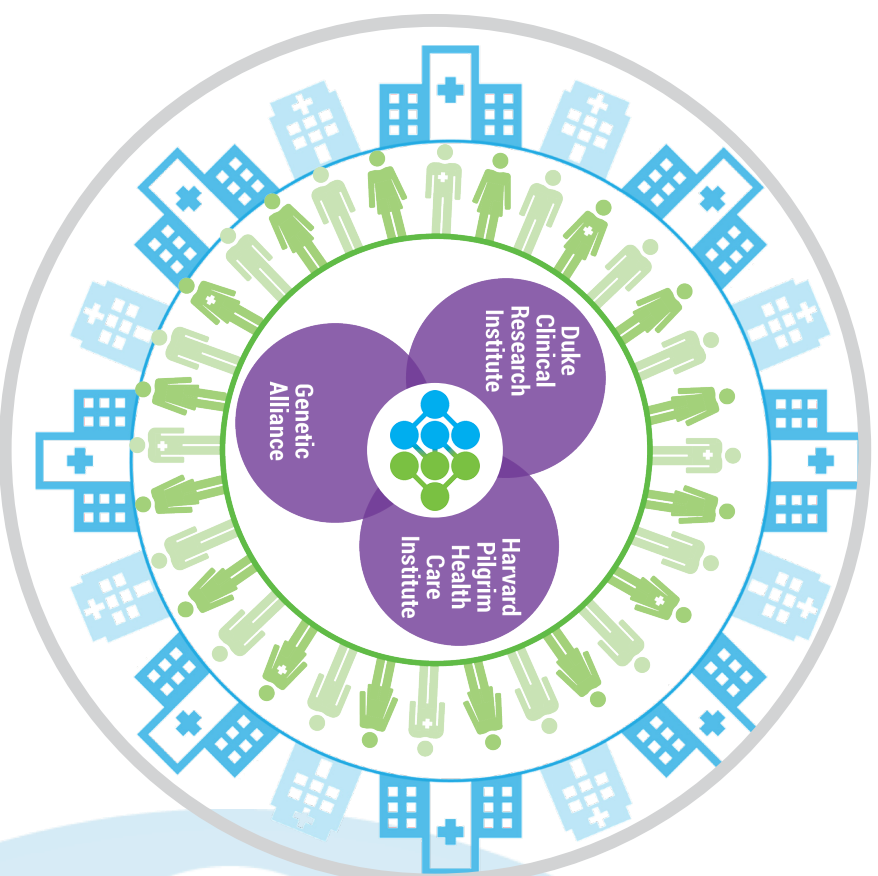University of Pittsburgh

HPRNs

HealthCore (a subsidiary of Anthem)

Humana – Comprehensive Health Insights (CHI; a subsidiary of Humana Pharmacy Solutions)

PCORnet® embodies a "network of networks" that harnesses the power of partnerships
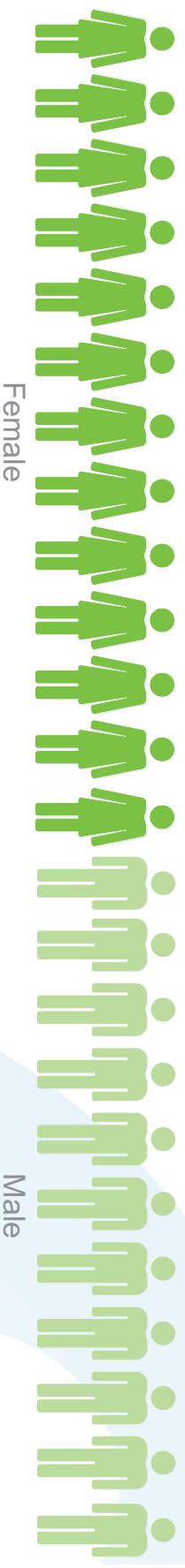

9
Clinical Research Networks (**CRNs**)

+

2
Health Plan Research Networks (**HPRNs**)

+

Patient Partners

+

1
Coordinating Center

=

A national infrastructure for people-centered clinical research

Duke Clinical Research Institute
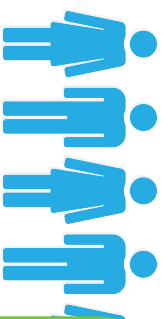
Genetic Alliance

Harvard Pilgrim Health Care Institute

pcornet®

Resulting in a national evidence system with unparalleled research readiness

Sex

Female

Male

Missing

Race

White

Missing

Age

0–4

5–14

15–2...

65+

Missing

Pool of patients

For clinical trials

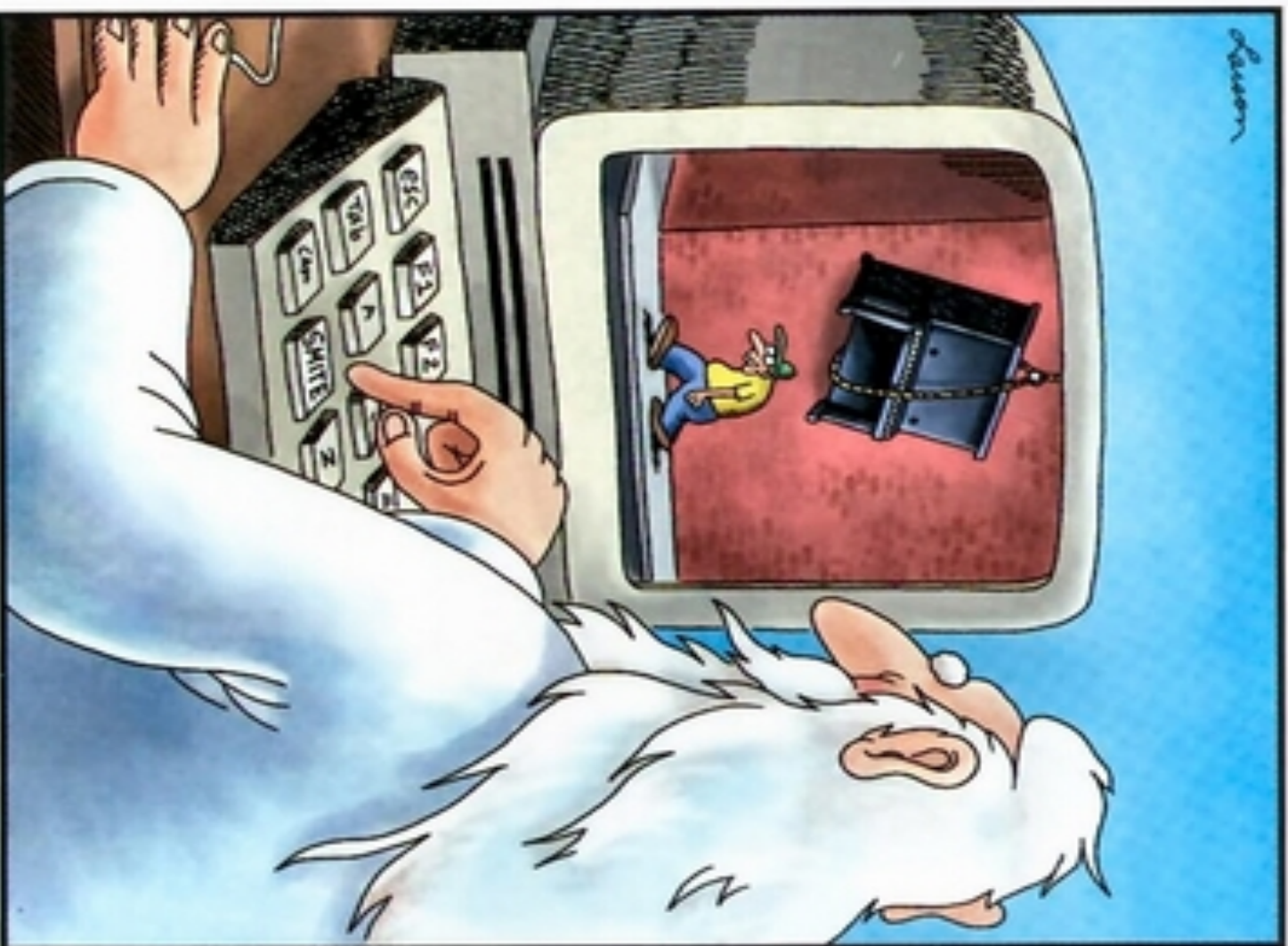more than 60 million

For observational studies
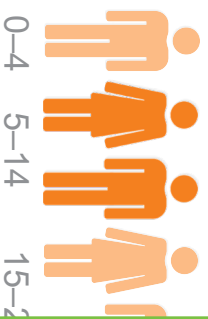
more than 100 million
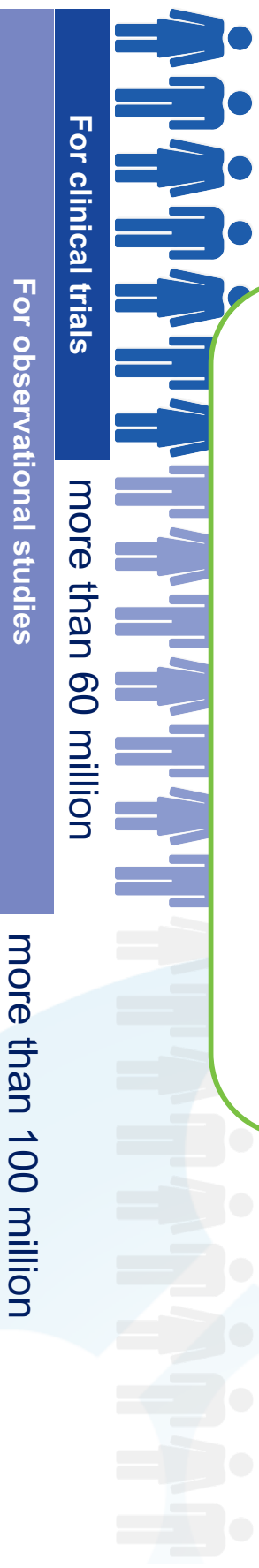
PCORnet represents:

more than
100 million patients

who have had a medical encounter in the past five years

some individuals may have visited more than one partner network Partner and would be counted more than once
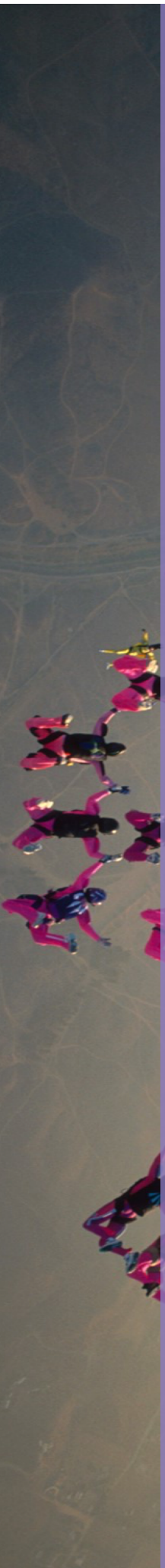
God at His computer

Single Minded Proposition based on core insight of altruism:

We can't map heart health without you. Join Us.

ADAPTABLE Study Design

15,000 patients with known ASCVD + ≥ 1 "enrichment factor"

Patients identified by research networks through EHR searches

Computable phenotype identifies pts via inclusion/exclusion criteria

Patients able to learn, provide e-consent, and self randomize on a web portal

Treatment assignment provided directly to patient

RANDOMIZATION

ASA 81 mg QD

ASA 325 mg QD

Electronic patient follow-up: Every 3 or 6 months
Supplemented with EHR, health plans, Medicare

Primary endpoint:
Composite of all-cause mortality, hospitalization
for MI, or hospitalization for stroke

Primary safety endpoint:
Hospitalization for major bleeding

ClinicalTrials.gov:
NCT02697916

To develop and refine the
infrastructure for
PCORnet to conduct
multiple comparative
effectiveness trials in the
future

Adaptable

Site Approach and Enrollment

CDRN	Total Number Eligible	Total Number Approached	% of Eligible Approached	Golden Tickets Entered Approached	% Golden Tickets entered per Approached	Total Enrolled	# Non-internet Enrolled	% Enrolled Per Approached	% Enrolled Per Golden Ticket Entered
CAPriCORN	18,389	12,251	67%	821	7%	516	203	4%	63%
GPC	92,053	62,365	68%	3594	6%	1690	119	3%	47%
HPRN	160,914	160,914	100%	1,551	1%	358	2	0%	23%
LHSNet	128,981	35,342	27%	1493	4%	865	115	2%	58%
Mid-South	92,714	43,629	47%	7,283	17%	3942	491	9%	54%
NYC-CDRN	22,141	6,575	30%	1339	20%	710	253	11%	53%
OneFlorida	59,373	5,220	9%	749	14%	593	154	11%	79%
PaTH	47,594	41,187	87%	3682	9%	1279	58	3%	35%
pScanner	15,669	6,855	44%	253	4%	131	8	2%	52%
REACHnet	33,299	20,583	62%	1801	9%	773	240	4%	43%
TOTAL	671,133	394,921	59%	22,566	6%	10,857	1,643	3%	48%

Adaptable

What if a choice made over the counter prevented...

19,000 Deaths/Heart Attacks

Or

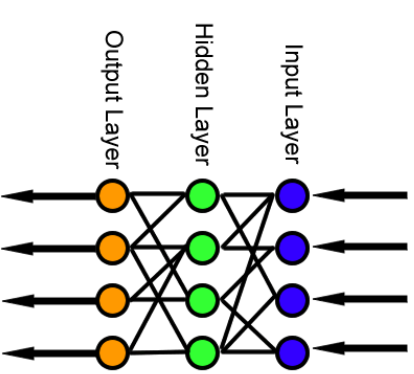Thousands of Bleeds

Annually in the United States

- Machine learning is a subset of artificial intelligence in the field of computer science that often uses statistical techniques to give computers the ability to "learn" (i.e., **progressively improve performance) on a specific task) with data, without being explicitly programmed.**

- Artificial neural networks (ANNs) or connectionist systems are computing systems vaguely inspired by the biological neural networks that constitute animal brains. Such systems **"learn" to perform tasks by considering examples**, generally without being programmed with any task-specific rules.

- Natural language processing (NLP) is an area of computer science and artificial intelligence concerned with the **interactions between computers and human (natural) languages**, in particular how to program computers to process and analyze large amounts of natural language data.

Input Layer

Hidden Layer

Output Layer

Innovations jointly deployed by Google + Verily

Healthy

Diseased

Hemorrhages

| No DR | Mild DR | Moderate DR | Severe DR | Proliferative DR |

Sensitivity, %

1 - Specificity, %

n = 9,963 images
AUC 99.1% [98.8, 99.3]

Development and Validation of a Deep Learning Algorithm for Detection of Diabetic Retinopathy in Retinal Fundus Photographs
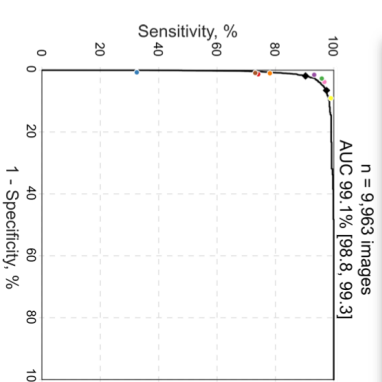
Admission Risk Prediction Model

Duke | FORGE
HEALTH DATA IN ACTION

EHR

Claims

Poisson Deep Factor Network

31 Diagnostic Categories
(rolled up from ICD codes)

Any Diagnosis
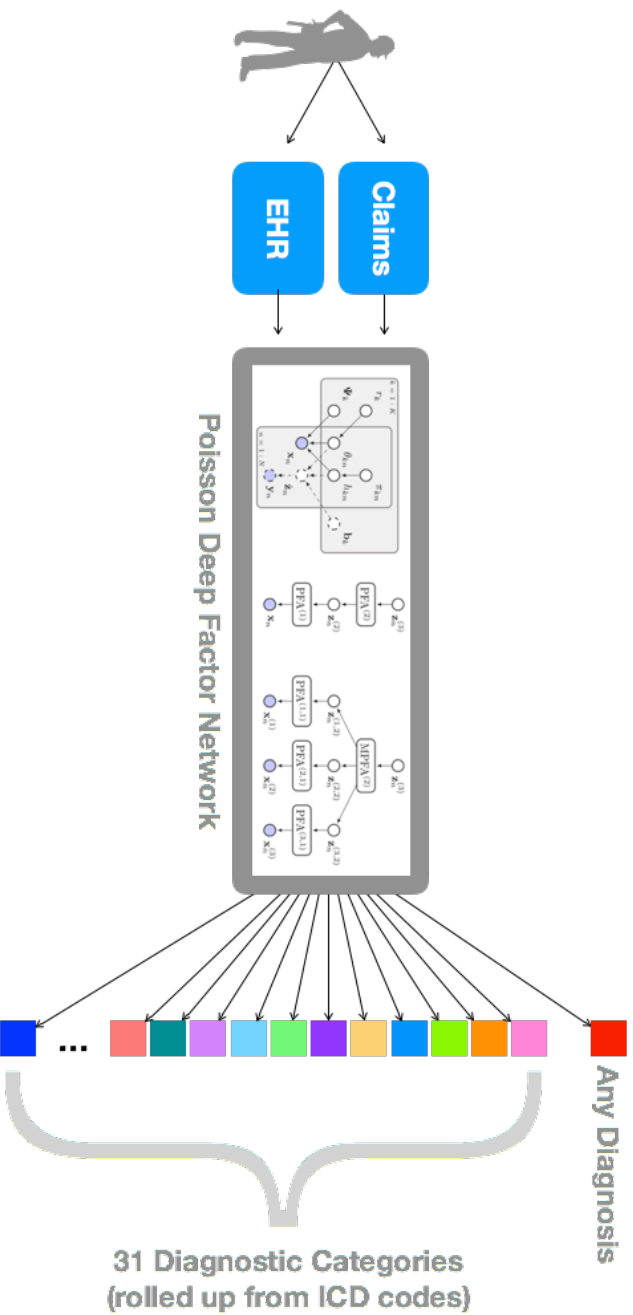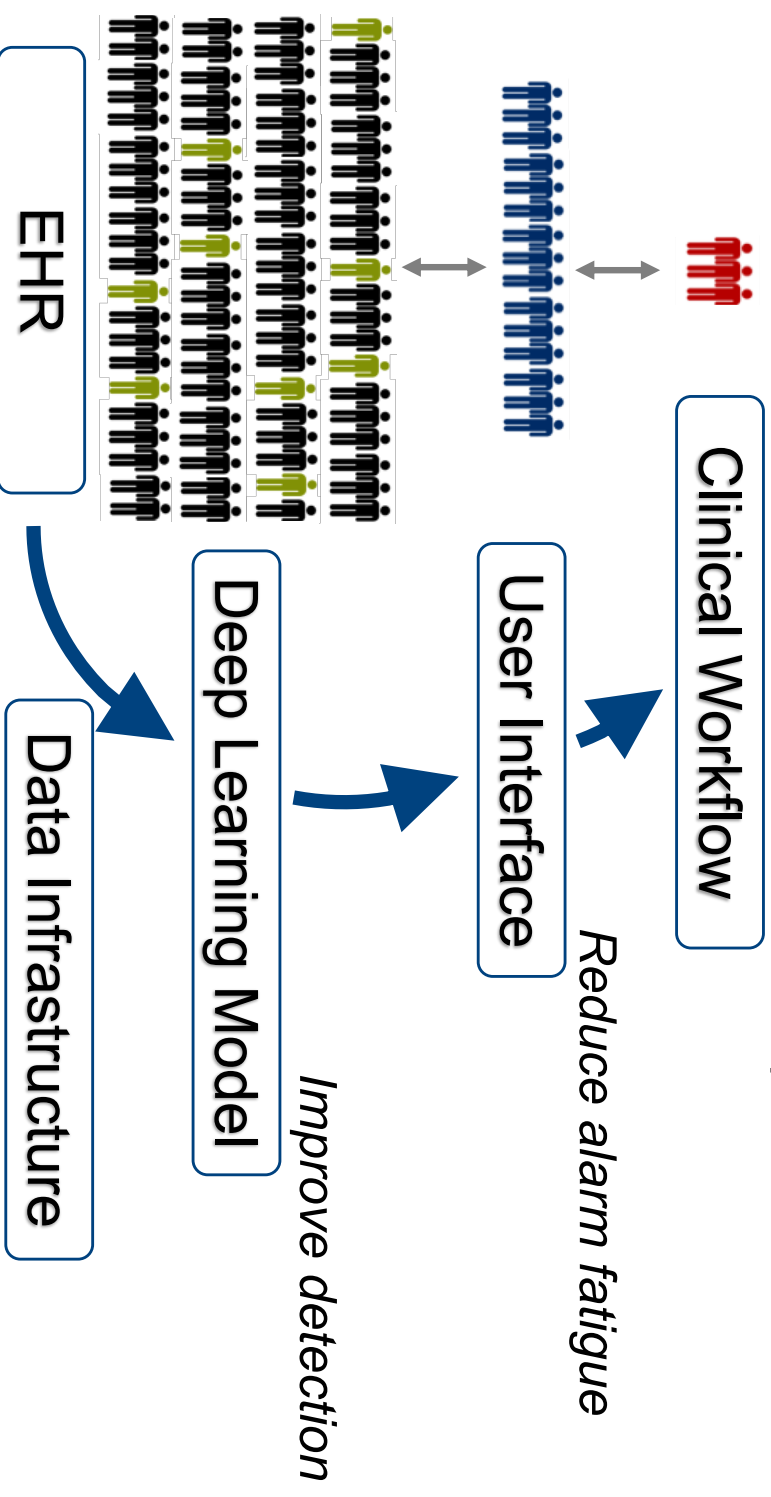
Expressed as absolute
6-month probability
and percentile risk
(e.g. 73% and 87th %-ile)

FLAGGING ACUTE INPATIENT ISSUES

EHR → Deep Learning Model → User Interface → Clinical Workflow

Data Infrastructure

Improve detection

Reduce alarm fatigue

Shorten time to treatment and better patient outcomes

"The Boeing 737 Max and the Problems Autopilot Can't Solve"
- New York Times

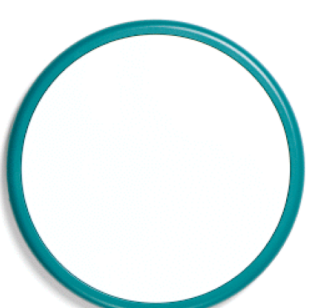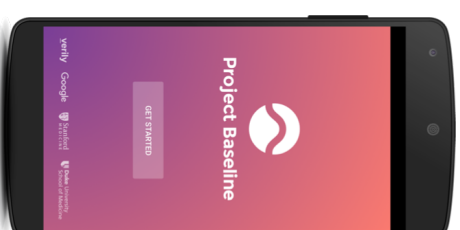"Trump Laments Modern Airplanes as 'Too Complex to Fly' in Wake of Deadly Crashes" *- Chicago Tribune*

Continuous data with wearable sensors

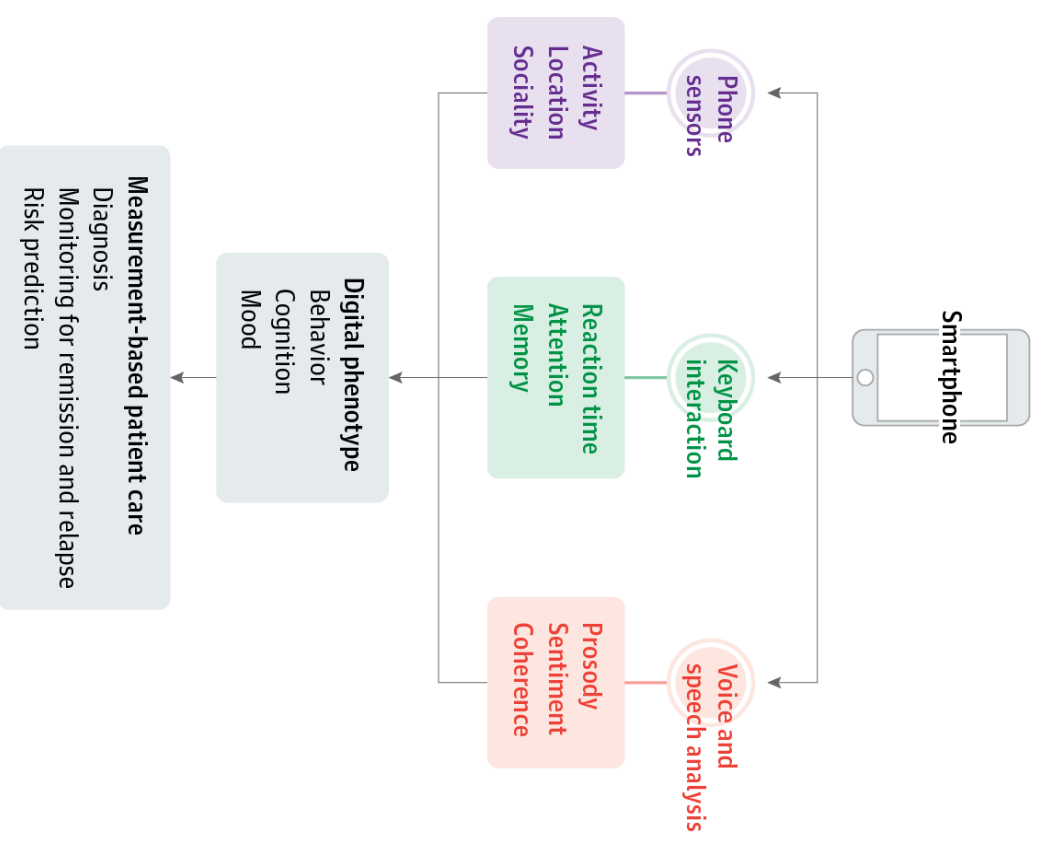Sensors and devices for passive collection of large quantities of real world data

Project Baseline

GET STARTED

verily   Google

verily
Study Hub

12:18
Thu Jan 5
Please sync

*investigational device

Duke | FORGE
HEALTH DATA IN ACTION

The process of digital phenotyping

Digital phenotyping involves collecting sensor, keyboard, and voice and speech data from smartphones to measure behavior, cognition, and mood.

JN The **JAMA** Network

Smartphone

Phone sensors
- Activity
- Location
- Sociality

Keyboard interaction
- Reaction time
- Attention
- Memory

Voice and speech analysis
- Prosody
- Sentiment
- Coherence

Digital phenotype
Behavior
Cognition
Mood

Measurement-based patient care
Diagnosis
Monitoring for remission and relapse
Risk prediction

1 in 20

Google searches are health related