

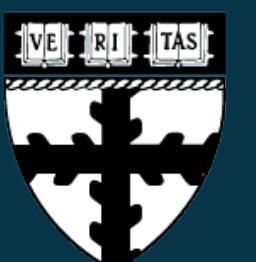
Social Computation

Supporting Intellectual Contributions from Online Health Communities

CSCW Workshop: The Future of Research on
Online Health Communities: Discussing
Membership, Structure, and Support

Oct 24 2021

Vineet Pandey



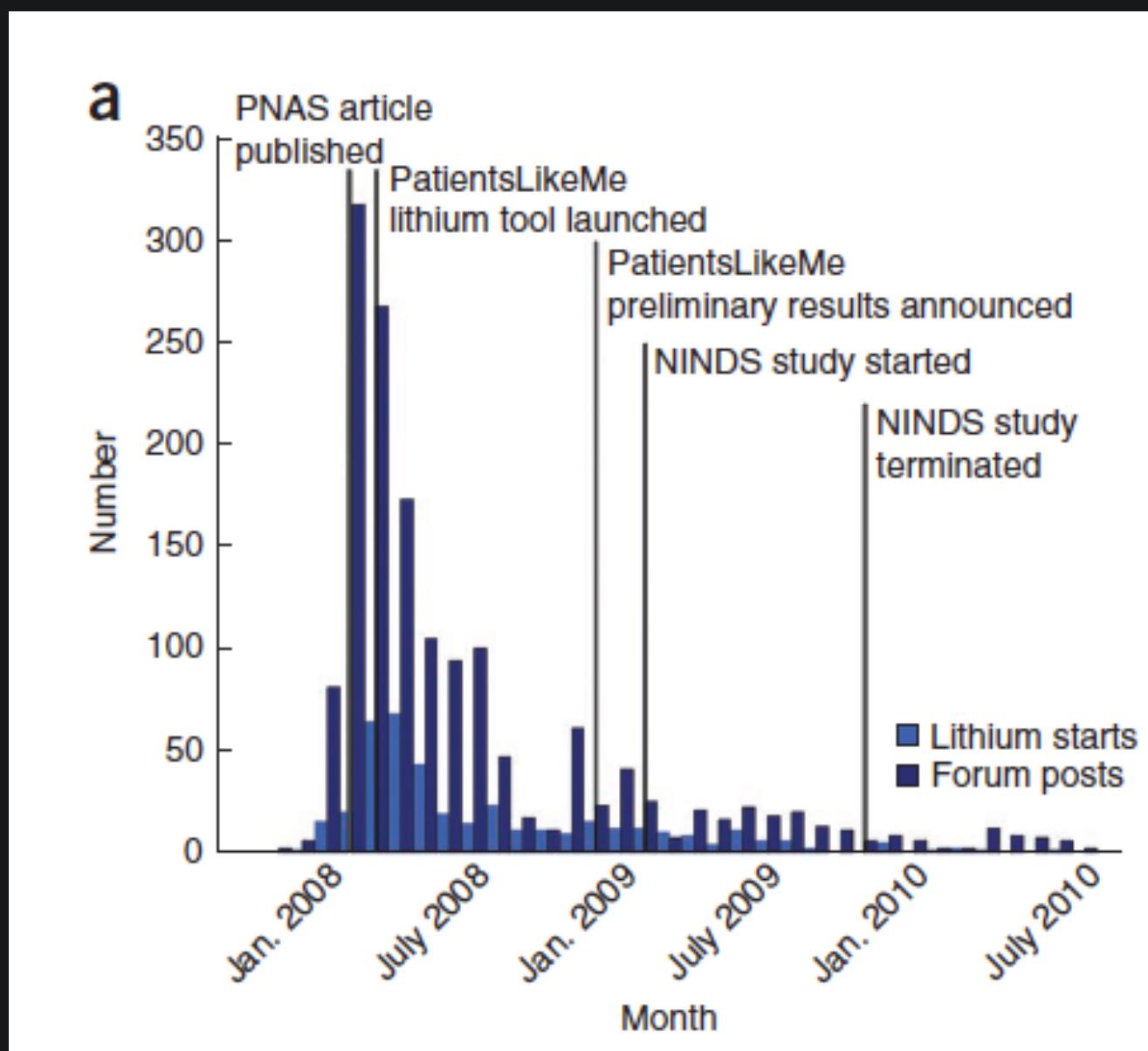
Harvard John A. Paulson
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My research purpose

Support people in performing personally-meaningful knowledge work without waiting for institutional experts to lead

Online health communities already perform such work...

(Some) People in OHCs design, build, and track to better understand and improve their health. They create novel scientific and technical knowledge in the process.



Example 1: Online ALS community tested the effects of Lithium before a NINDS study

OpenAPS Design Details

Medical device communication

OpenAPS periodically (i.e. every 5 minutes) reads new data from the CGM as it becomes available. It also periodically (every few minutes) queries the insulin pump for current settings and recent activity, such as current (scheduled or temporary) and maximum basal rates, recent boluses, IOB (if available), ISF, DIA, carb ratio, BG target/range, etc. If that query is successful, OpenAPS updates its bolus wizard calculations (detailed below) and determines whether any action is required (canceling or issuing a temporary basal).

If action is required, OpenAPS issues the appropriate insulin dosing command to the pump, confirms that it was received and acknowledged by the pump, and then performs another query for recent activity to make sure any new temporary basal successfully took effect.

Algorithms

Basic overnight operation (`oref0`)

Example 2: Type 1 diabetes community shares design for Open Artificial Pancreas with algorithm details on their blog

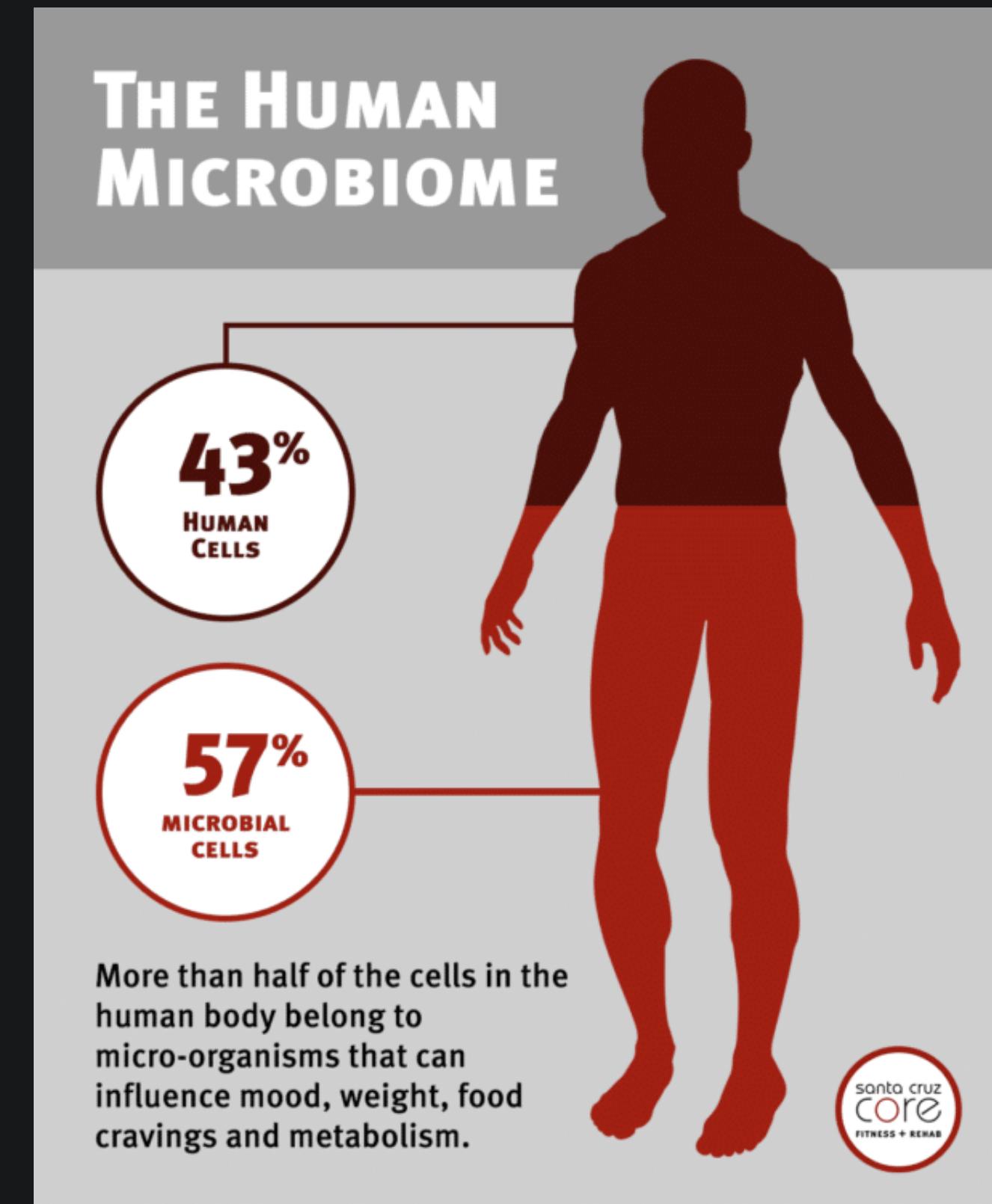
The problem: Success is uneven.

How do we improve this situation?

1. Which scientific domains to target?
2. Which tools/platforms to build?
3. Which communities to support?

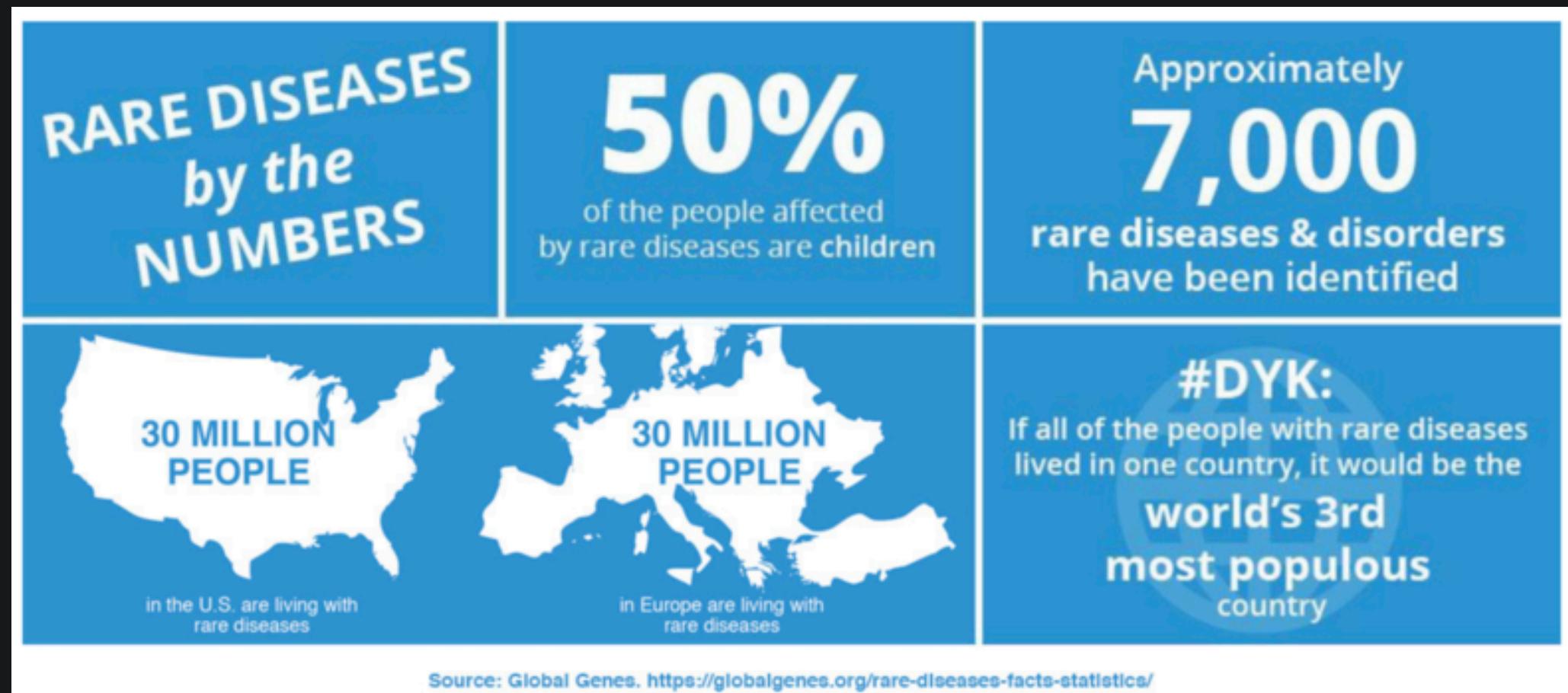
Q1: Which scientific domains to target?

1. **Nascent:** Experts have much to learn
2. **Contextual:** Heterogeneity in function/phenotype
3. **Actionable:** Possibility of better outcomes



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Q2: Which tools to build?

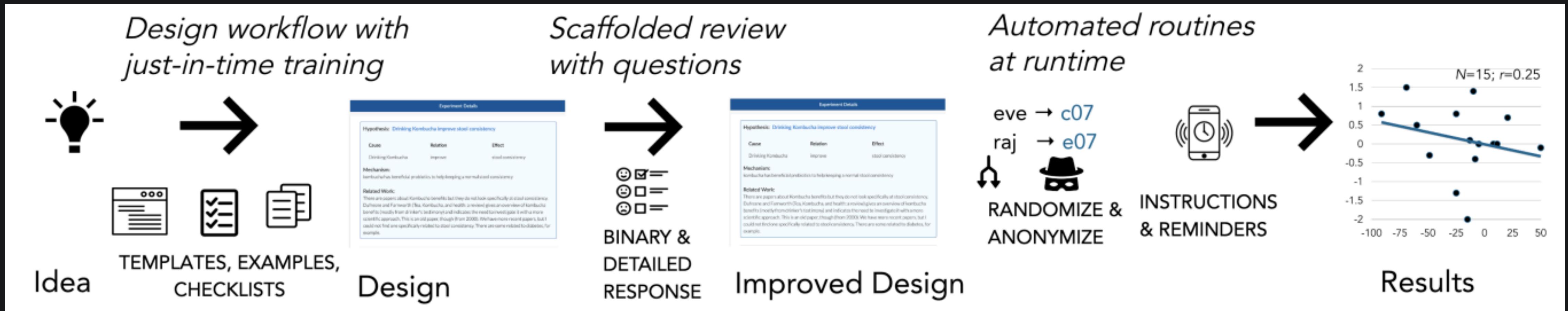
1. (Natively) Support learning
2. (Natively) Support collaboration

Conceptual (WHAT)
and Procedural (HOW)

Create different roles

Q2: Which tools to build?

An example for citizen-led experimentation



Vineet Pandey et al. Galileo: Citizen-led Experimentation Using a Social Computing System.
CHI 2021.

Q3: Which communities to support?

Support communities of practice.

Why?

1. They actually do things
2. They have an organizational structure
3. They have a clear(er) sense of their needs

Fermenters



Rare Disease Foundations like
Ataxia-Telangiectasia

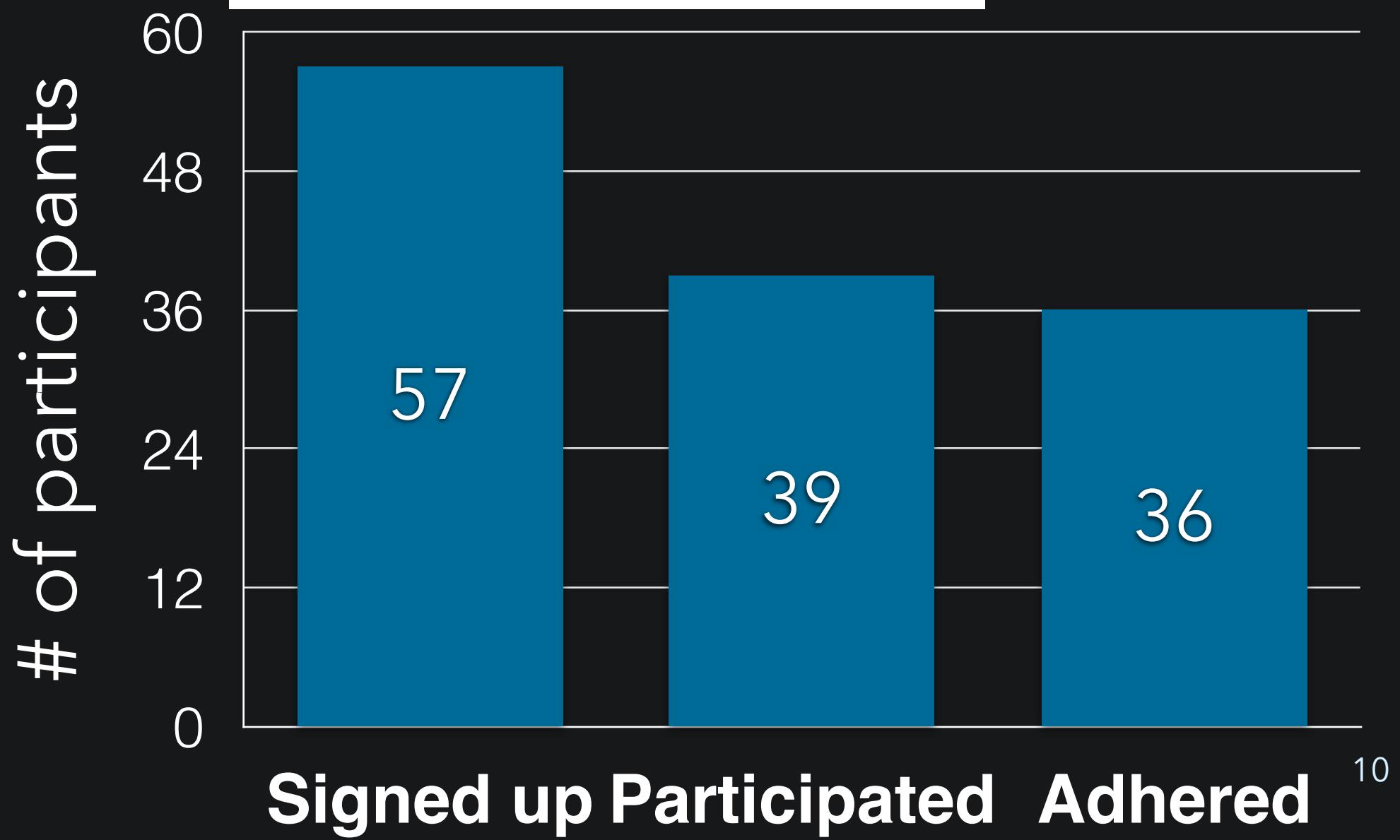
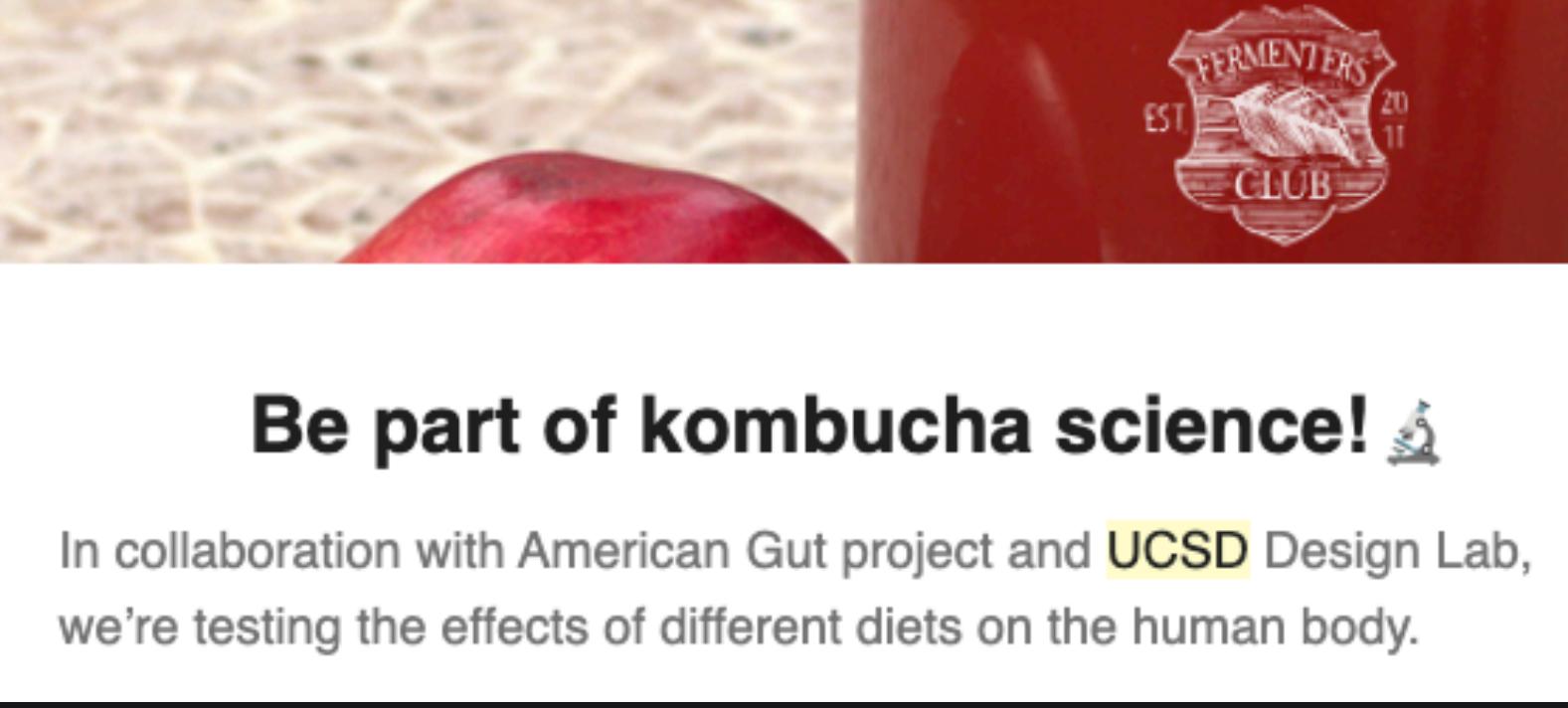
Example 1: A community of fermenters designed and ran a between-subjects experiment to test whether drinking kombucha improves stool consistency



Design +
Pilot

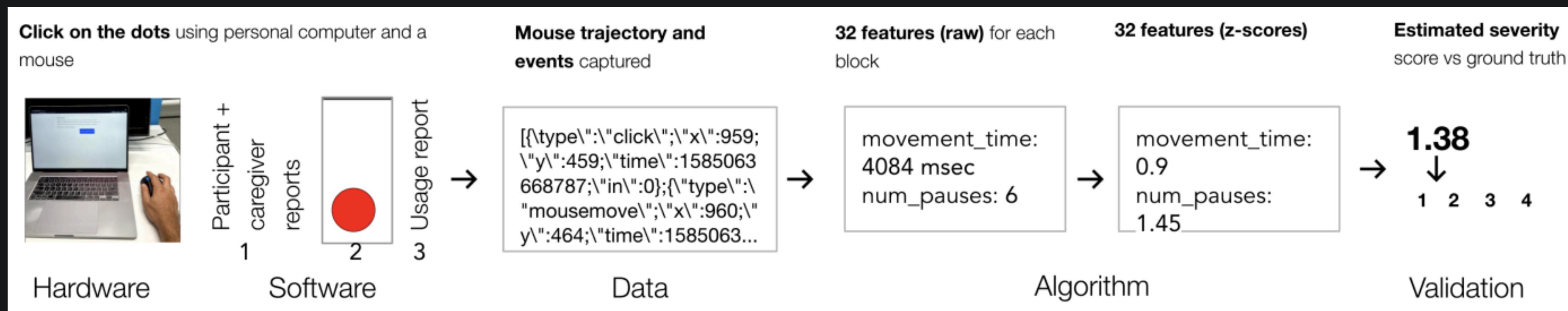


Gathering
participants



Example 2: A rare disorder community generates data that can better characterize the condition and generate evidence for treatments that work

Example 2: A rare disorder community used a web-based motor performance measurement tool to generate data that can improve our understanding of different phenotypes and heterogeneity of the condition.



Thoughts?

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