

Gut Instinct: Creating Scientific Theories with Online Communities

gutinstinct.ucsd.edu

CSCW Doctoral Colloquium
Nov 4 2018

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The Design Lab

Inviting your feedback on..

- Missing **important questions**
- Moving **beyond current domains**
- Finding **frameworks** to better understand and present my work

Lead users have created different—and in some cases better products—than experts



Lead users have created different—and in some cases better products—than experts



1. Lived experience
2. A tight feedback loop
3. Strong personal motivation

In complex settings –*health, science*– the gap between cause and effect is large

The screenshot shows the patientslikeMe website interface. At the top, there is a navigation bar with links for Patients, Conditions (highlighted with a blue asterisk icon), Treatments, Symptoms, and Research. Below the navigation is a search bar with the placeholder "Look up a condition". The main content area displays the "ALS (Amyotrophic Lateral Sclerosis)" condition page. A prominent quote "We're all in this for good." is followed by the text "By sharing your stories and data, you will:" and a bulleted list: "• help each other live better and uncover the best ways to manage your health today" and "• help researchers shorten the path to new treatments tomorrow".

ALS patients designed a study to test a research result

Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

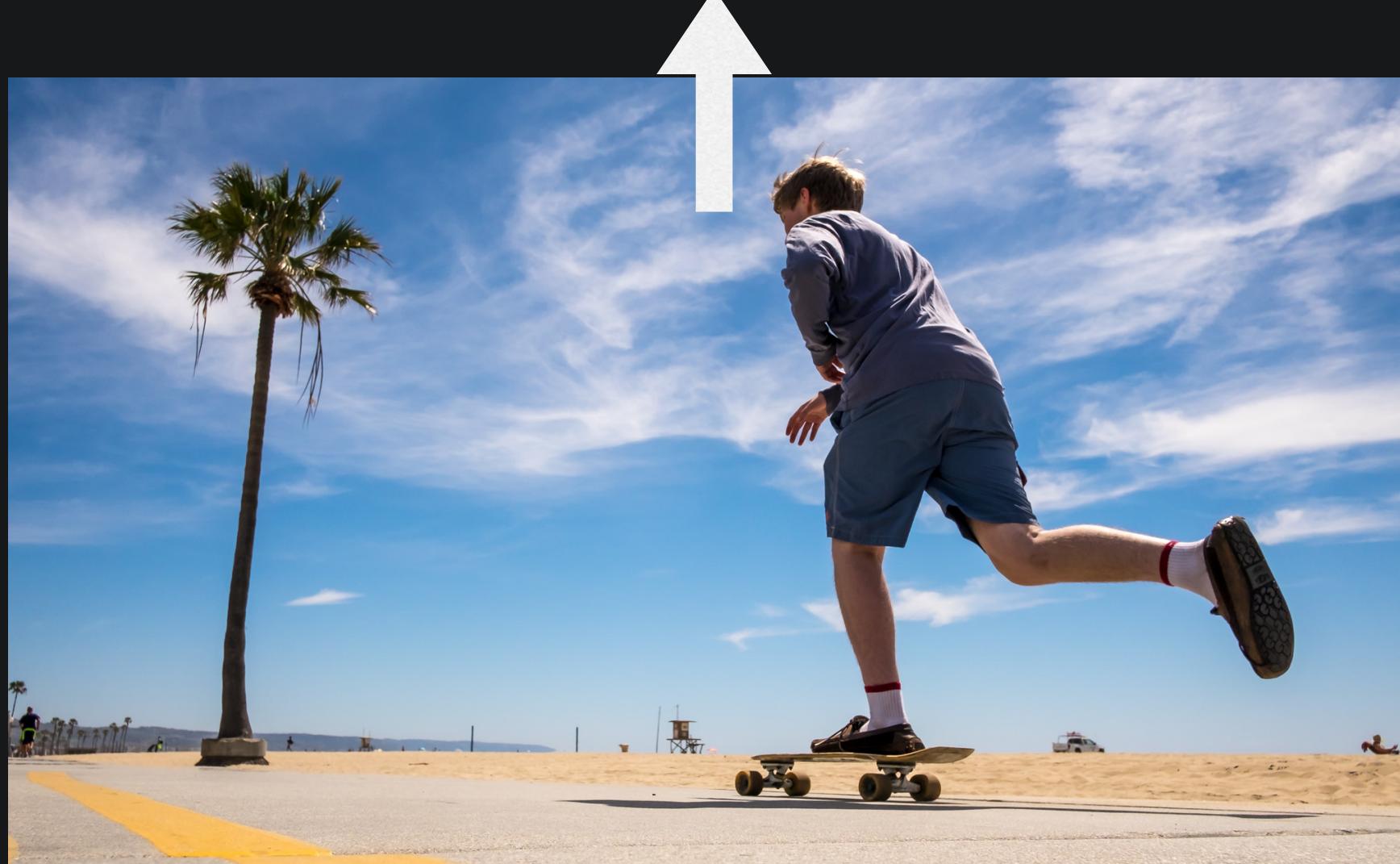
Paul Wicks, Timothy E Vaughan, Michael P Massagli & James Heywood

Published their findings

Dilemma: Potentially great insights but missing knowhow

Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

Paul Wicks, Timothy E Vaughan, Michael P Massagli & James Heywood



1. Limited training
2. Missing collaboration mechanisms
3. Limited knowledge of tools

Requires substantial time investment as well!

A domain of interest: Personalized medicine at scale needs insights from people's lived experiences

People can contribute to scientific domains that are

Nascent **Experts know little**

Contextual **Huge individual differences**

Motivating **People care**

Genomics
23andMe

Microbiome
American Gut



Thesis

**Integrating conceptual learning with
procedural training enables personally
meaningful & useful scientific work**

Gut Instinct is a collaborative citizen science platform for people to transform lived experiences into scientific theories

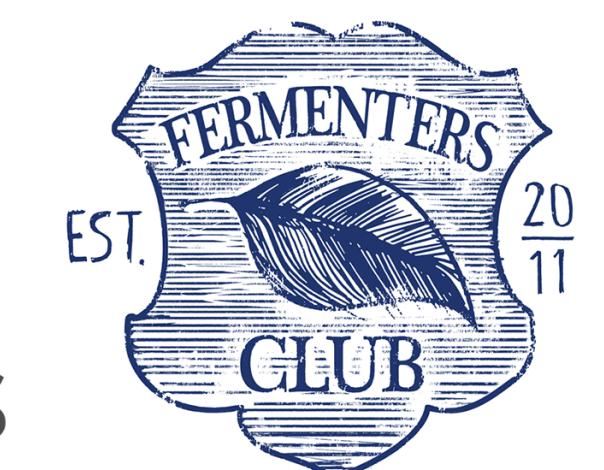


600 users
29 countries
400 hypotheses

37 novel ideas
50 experiments
5 communities



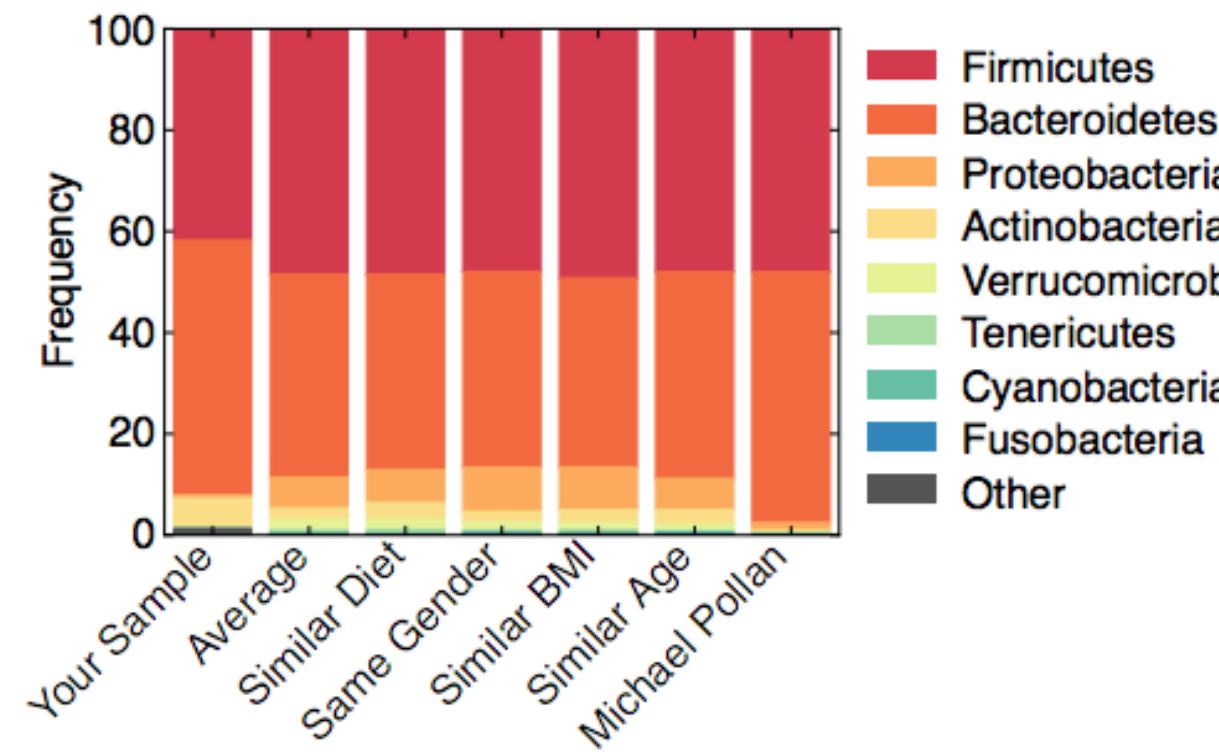
coursera



YOUR AMERICAN GUT SAMPLE

VINEET PANDEY

What's in your American Gut sample?



Your most abundant microbes:

Taxonomy	Sample
Genus <i>Prevotella</i>	50.1%
Family Lachnospiraceae	12.0%
Family Ruminococcaceae	6.4%
Genus <i>Faecalibacterium</i>	5.8%

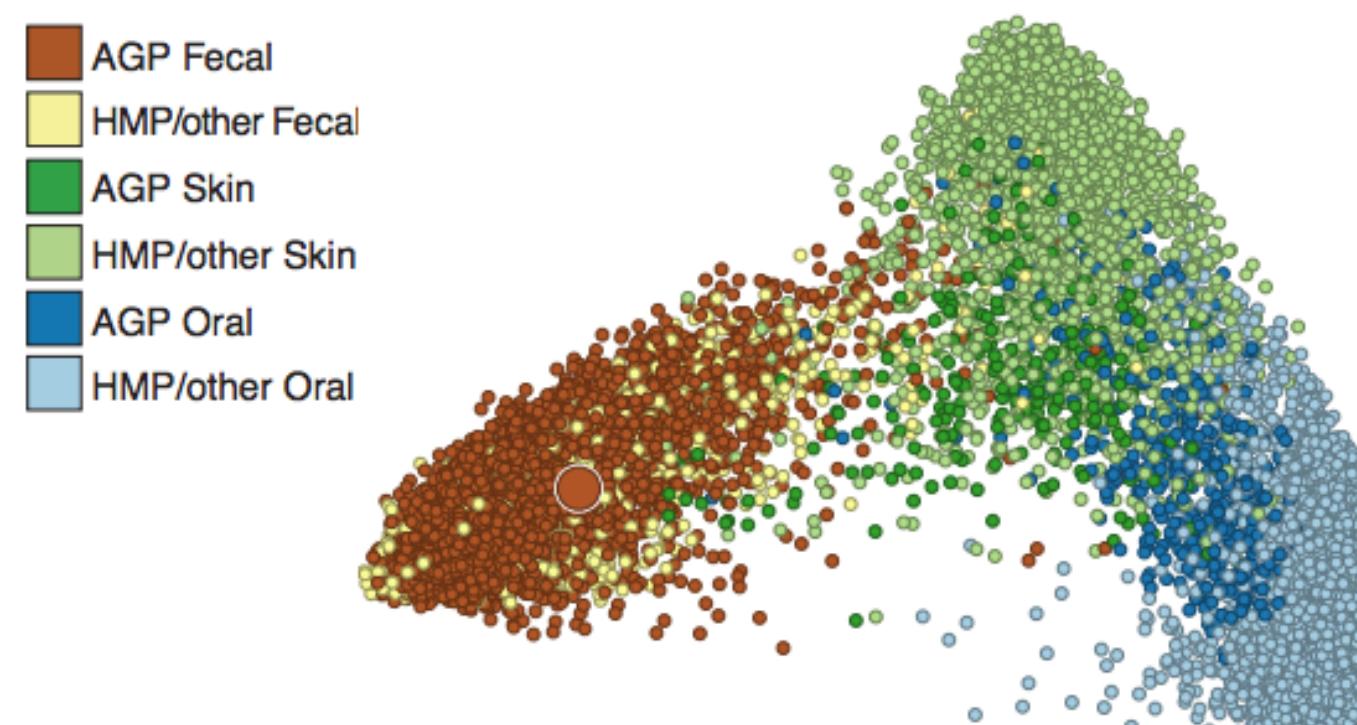
Your most enriched microbes:

Taxonomy	Sample	Population	Fold
Genus <i>Slackia</i>	0.09%	0.01%	9x
Family Victivallaceae	1.04%	0.02%	60x
Family Lachnospiraceae	12.00%	6.98%	2x
cont. Genus <i>Eubacterium</i>	1.02%	0.28%	4x

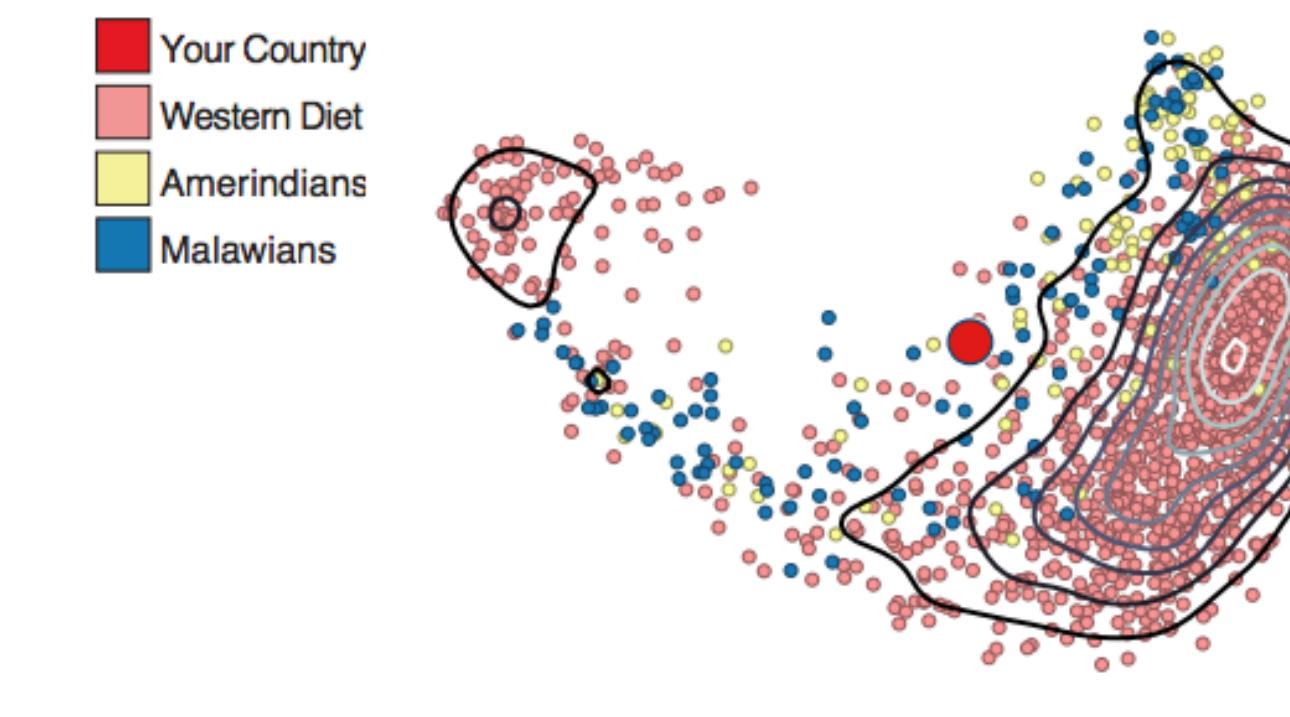
Your sample contained the following rare taxa: Unclassified Family Microbacteriaceae, Genus *Pseudoclavibacter*.

How do your gut microbes compare to others?

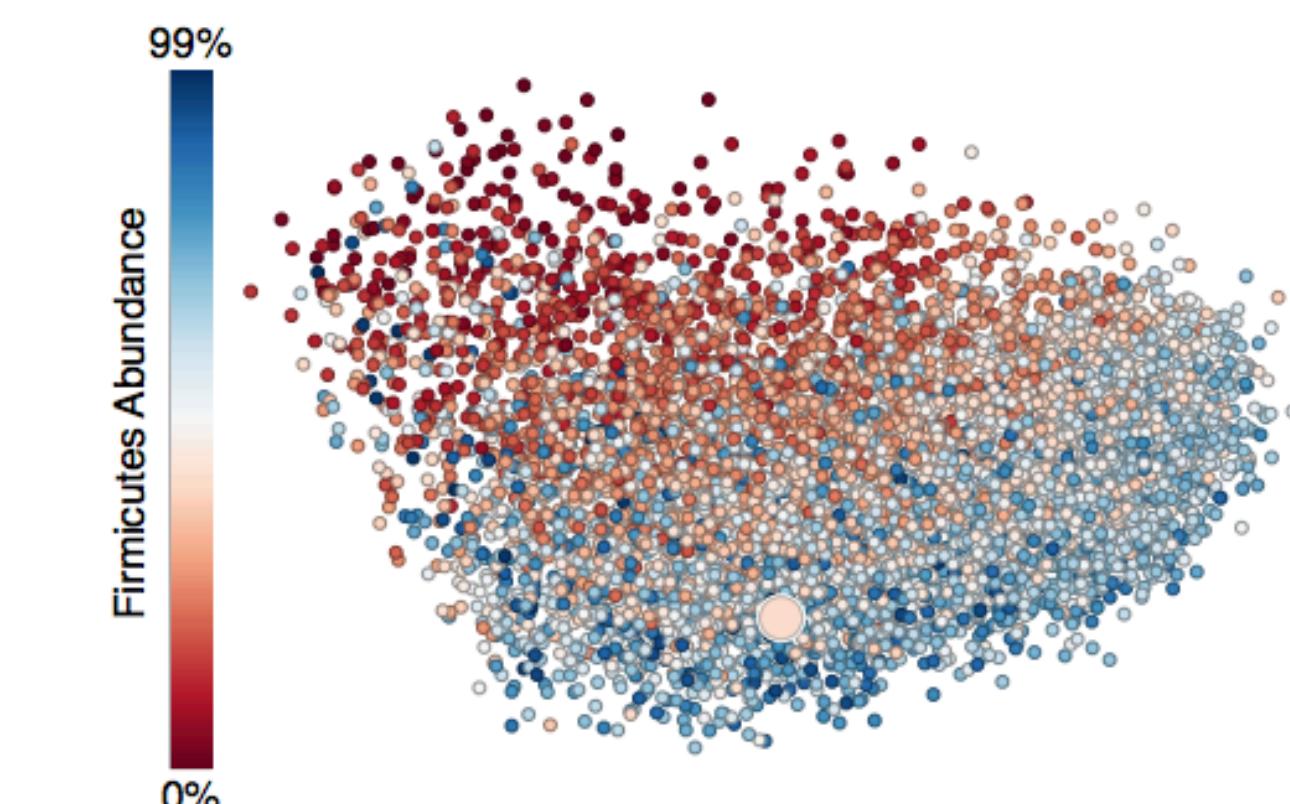
● Your sample is here • Others ◉ Unspecified



Different Body Sites



Different Nationalities



The American Gut Population

Participants generate hypotheses by looking at the data

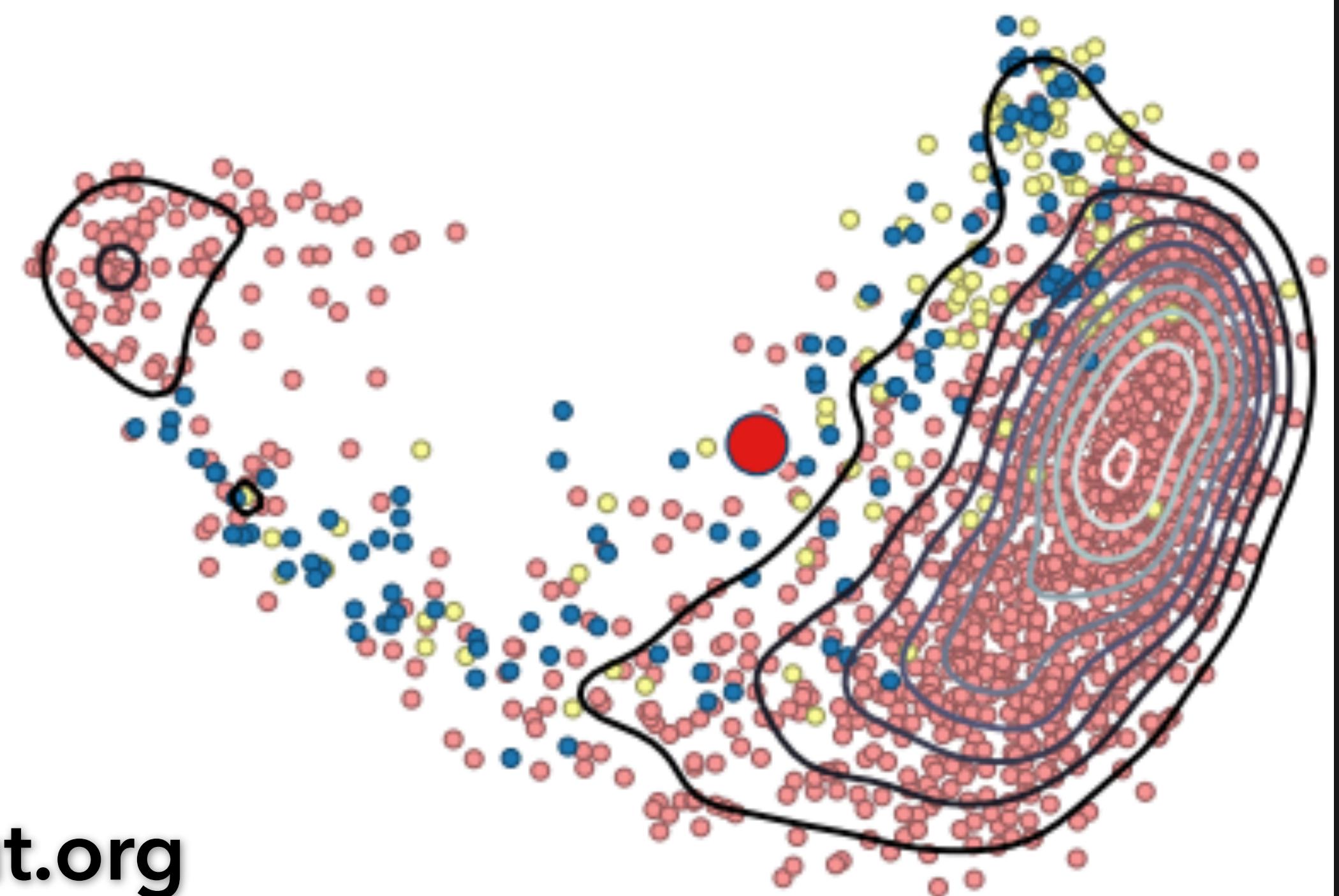


Is my data point unique because

1. My diet is vegetarian?
2. I am of Indian descent?
3. I grew up in India?



americangut.org

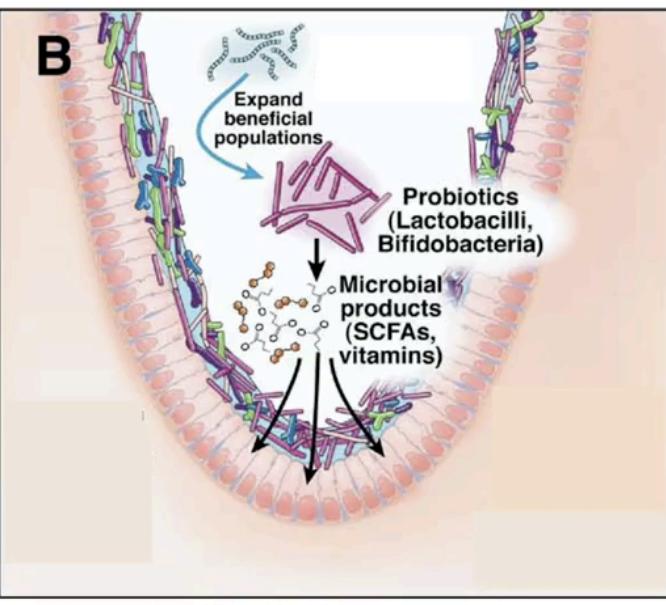


Learn-Train-Ask workflow for creating hypotheses

gutinstinct-ucsd.org/t/probiotics

Confused? Add more questions! Topics Guide GutBoard Notifications

Back to Topics #probiotics Video Provided by coursera



Preidis and Versalovic 2009, Gastroenterology

Learn

12

Train

5. Check the criteria

Make sure that the combination of your top-level and follow-up questions meets the Gut Instinct criteria!

- Answerable?**
Others should be able to answer your question
- Definite?**
A good question includes a clear timeframe
- Links a cause with an effect?**
Your question should attempt to link an activity with a specific result, allowing others to agree/disagree and share their insights
- Operational?**
Your question should avoid ambiguous terms that might be difficult to understand for most people
- Simple?**
A good question is simple to read, to understand, and to answer

Dive deeper with these follow-up questions!

What type of alcoholic drinks (ex wine, beer, liquor, mixed with sugar) affect your bowel movements?

- wine
- beer
- liquor
- sugary mixed drinks
- [Add my option](#)

Save my choice(s)

Skip

How many drinks does it take to notice a difference in your bowel movements?

- 1-2
- 3-4
- 5+
- [Add my option](#)

Save my choice(s)

Skip

Ask

Gut Instinct enables different contribution mechanisms

Dive deeper with these follow-up questions!

What type of alcoholic drinks (ex wine, beer, liquor, mixed with sugar) affect your bowel movements?

- wine
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[Save my choice\(s\)](#)[Skip](#)

How many drinks does it take to notice a difference in your bowel movements?

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[Save my choice\(s\)](#)[Skip](#)

by [phenylalanine](#) 14 days ago

0 Upvotes  | 0 Downvotes 

How much popcorn are you eating? How salty is it? Do you drink enough water with it to stay hydrated? I rarely have issues with constipation/BMs and I've never noticed any food-related changes except if I do something extreme such as eating an entire jar of hot peppers or drinking a jar of pickle juice (just a bad idea. don't do it.)

by [Cangussumicrobiome](#) 18 days ago

0 Upvotes  | 0 Downvotes 

I believe the problem here is the type or quantity of fiber in popcorn.

Receive feedback to learn about relevant science

Feedback from scientific material (?)



Updated 24 days ago  Edit

Hi DND, intriguing question! The topic video about gut-brain-axis might provide some basic information about how our microbiome state might be linked - gutinstinct.ucsd.edu/topics Please keep sharing your gut instincts, these are helpful!

Add follow-on questions

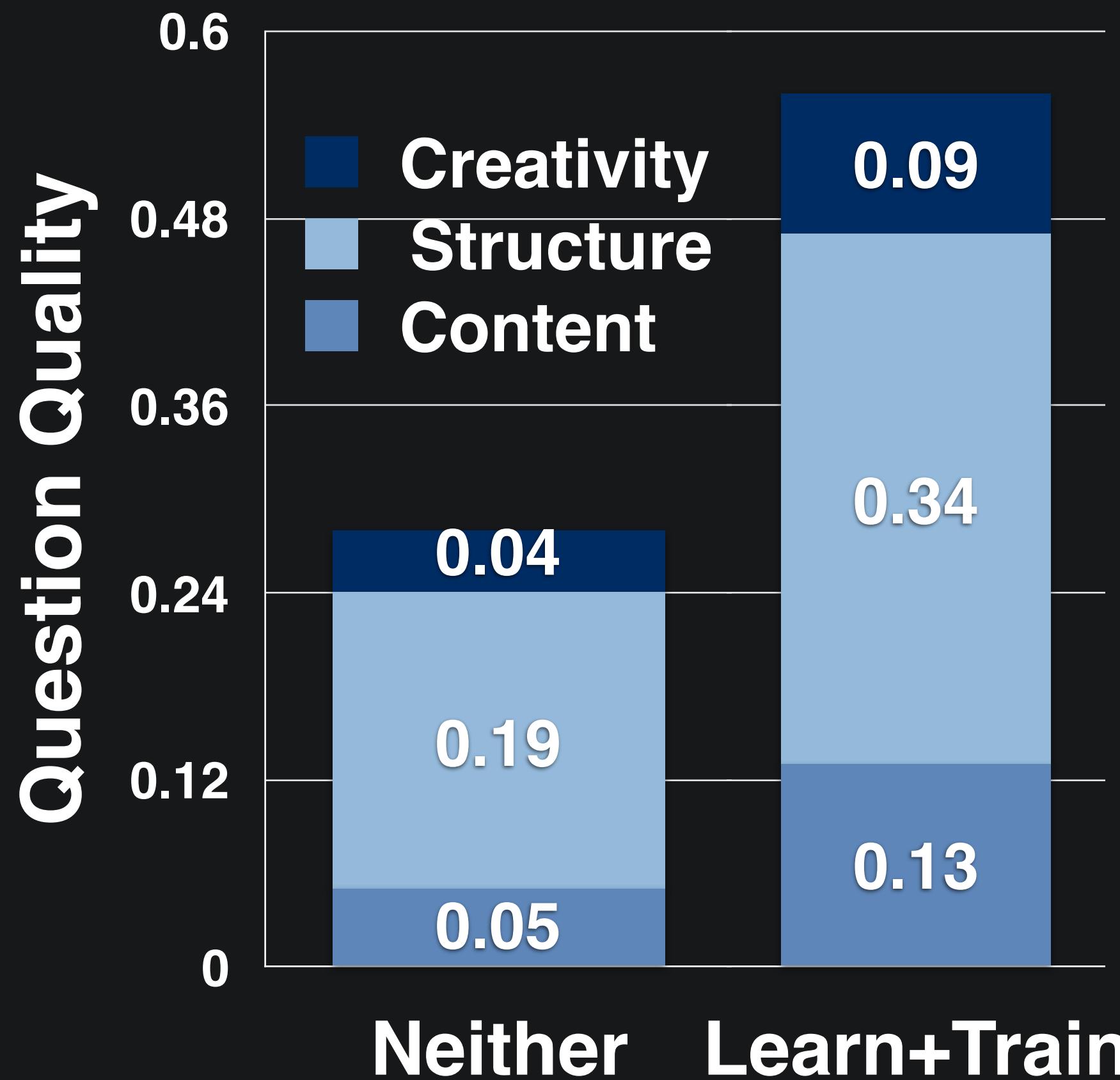
¹³

Discuss questions and responses

Receive scientific feedback

Results

The combined Learn-Train condition produces better questions
(N=344), **20% of hypotheses rated novel by experts**



Personal Insights provide novel hypotheses
Does consuming probiotics reduce your sugar cravings?
How often do you consume bone broth? Do you have better bowel movements?

Most Questions contained known facts
Does eating more plants change my bowel movements?
Do antibiotics lead to GI issues?

Diversity in roles: technical interventions are scalable, social interventions are powerful

Role and Actions

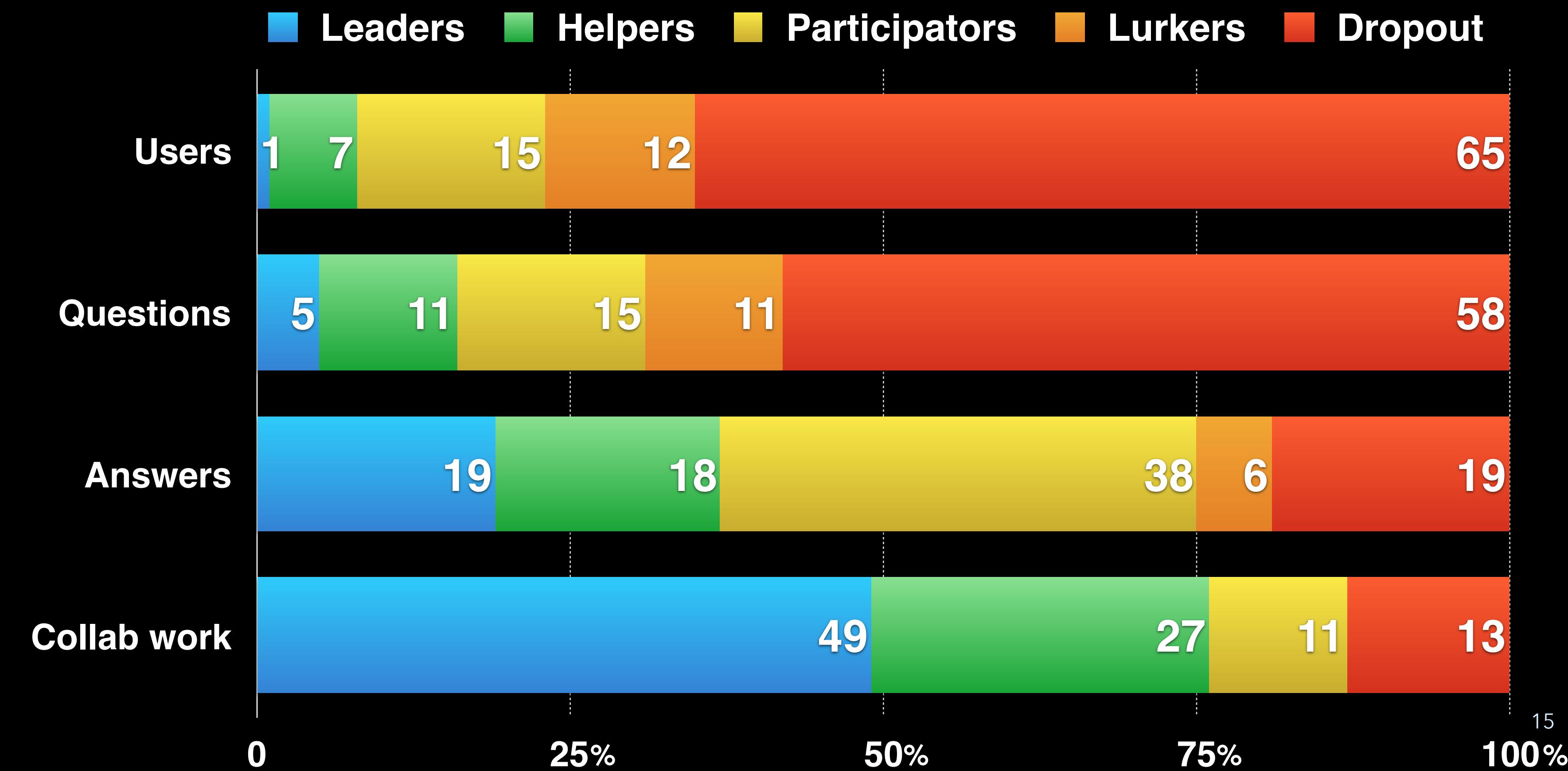
Leader: Add questions, answer & edit others' questions, add follow-ups, discuss

Helper: Add & answer questions, add follow-ups

Participant: Answer questions

Lurker: Add questions but no collaborative work

Dropout: Add a question; never return



People generated novel hypotheses.
Now what?

Experimentation is hard(er)

People need to..

1. Know what an experiment looks like
2. Know how to get the individual elements right
3. Iterate and get the design right
4. Run it correctly

(These challenges are common for creative work)

Deeper work requires leveraging (and
building) social infrastructure

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1. Understand needs

Fun? Personal health?

Curiosity/Learning?

Commercial interests?

2. Identify leaders

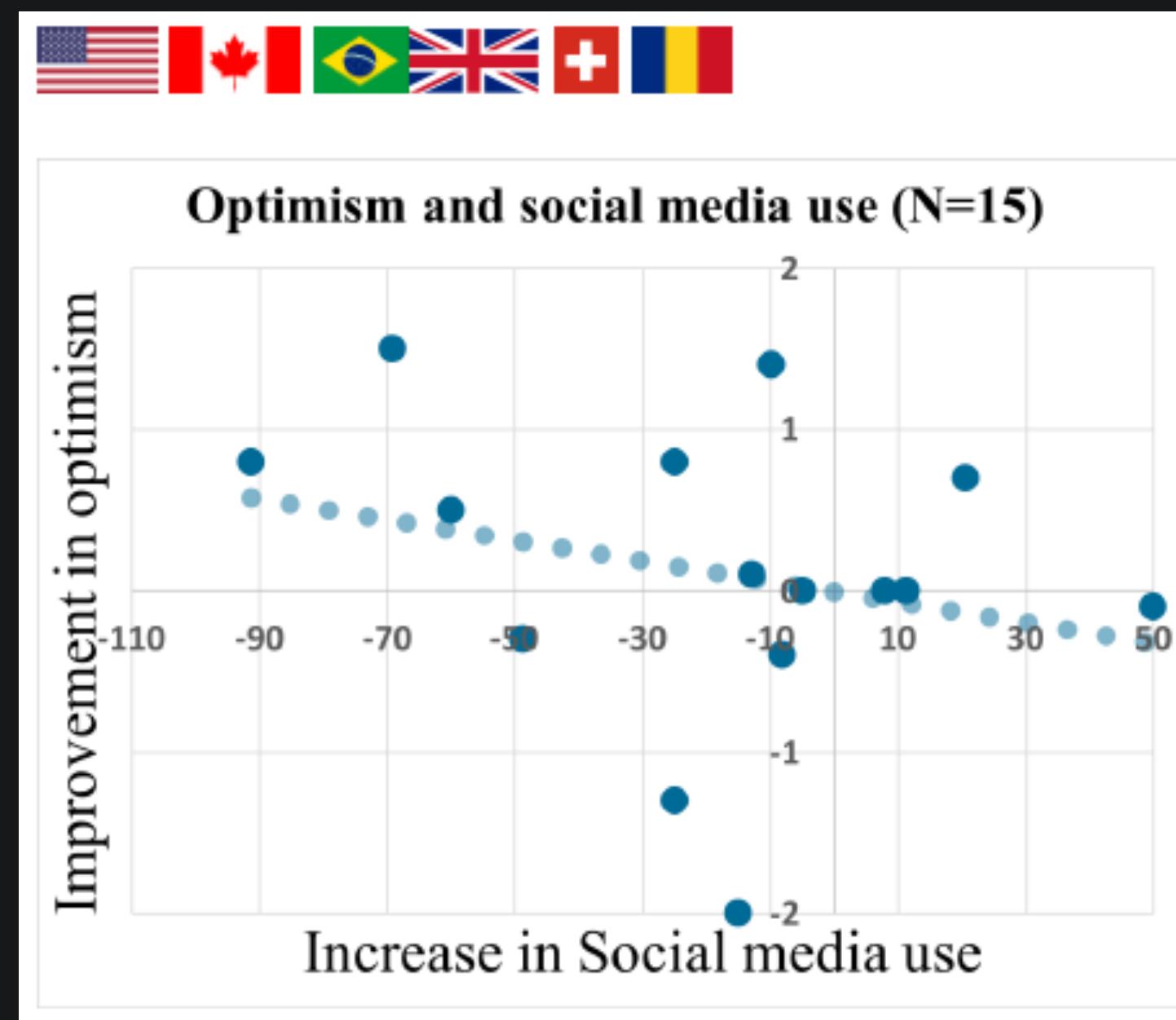
Leaders > Entirely distributed communities



Galileo: Citizen-led experimentation

In Submission

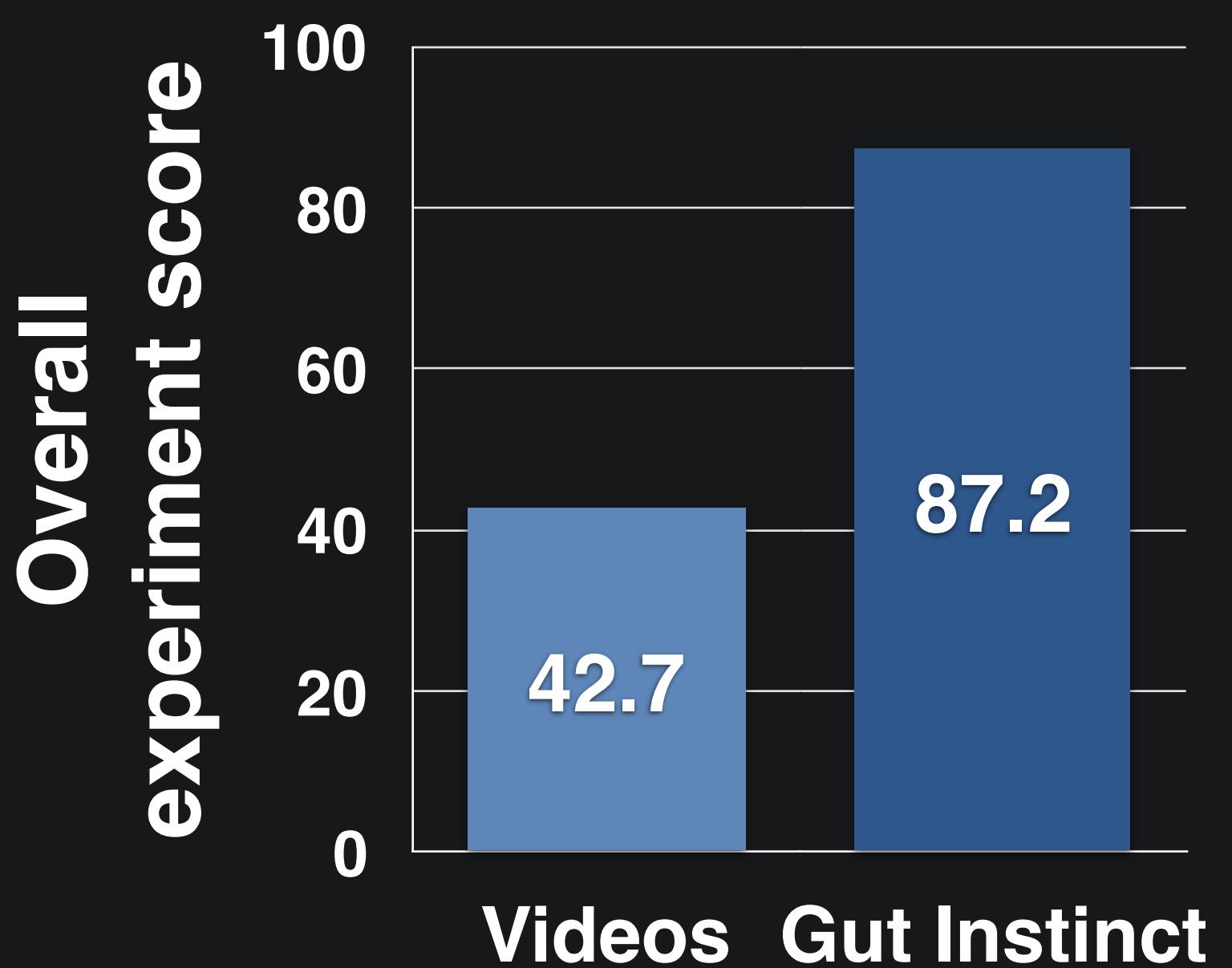
Communities can design and run experiments!



Open Humans community studied the effect of social media on optimism



People design structurally-sound experiments



People design better with procedural training

Online Architecture for Experimentation:

Design → Review → Run

Design using procedural training cues baked into the interface

Experiment Design Summary

Hypothesis: Drinking lassi decreases bloatedness 

Cause

Drinking lassi

Relation

decreases

Effect

bloatedness

Mechanism:

How is Drinking lassi manipulated? 

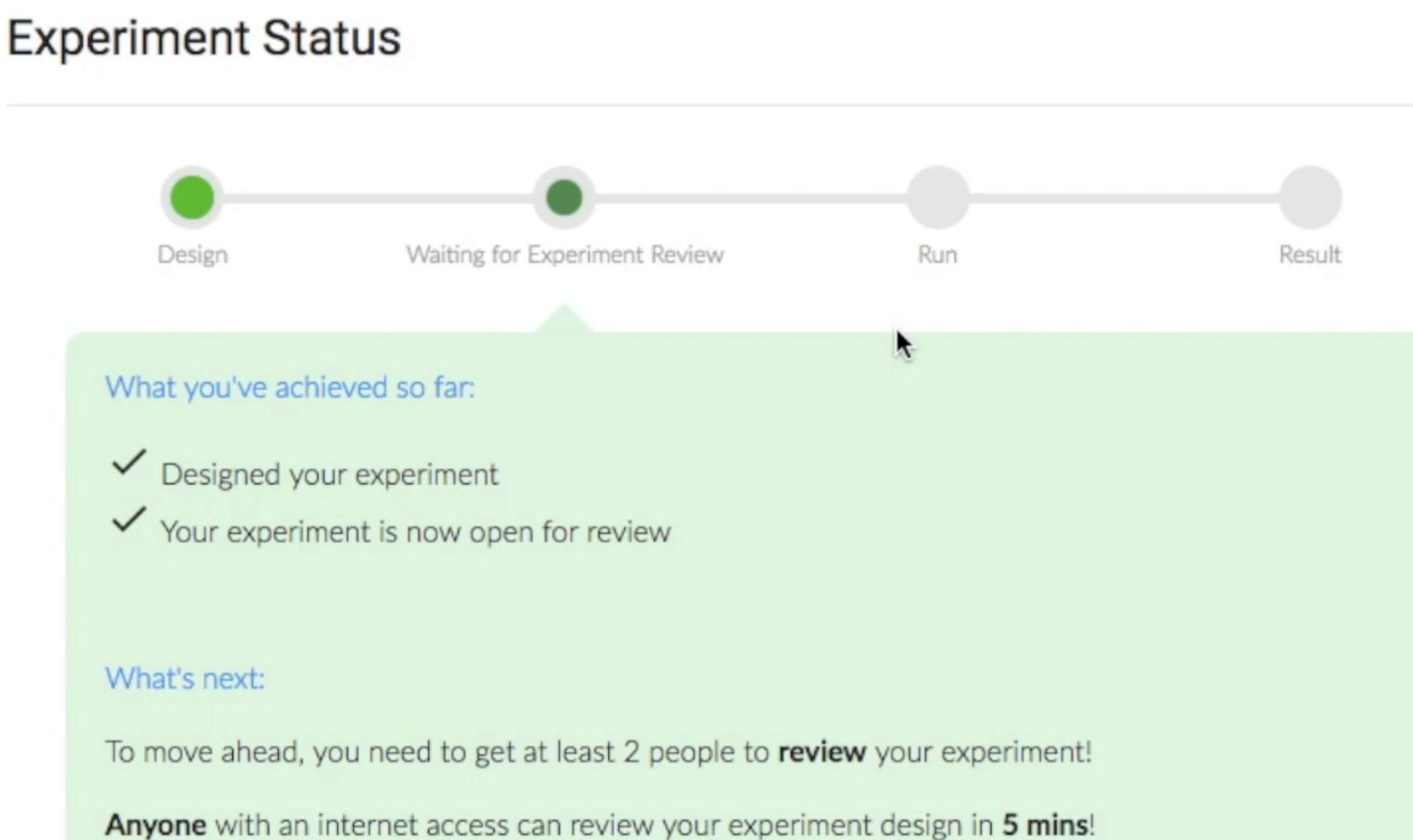
- Participants measure Absence/Presence of Drinking lassi
- Reminder sent every day at 8 pm with

How is bloatedness measured? 

- Participants measure Rating of bloatedness on a scale of 1 to 5 (1 being no bloatedness and 5 being

Experimenter designs

Get unstuck by following instructions provided by the system



Community reviews

Others review using a scaffolded interface that enables boolean and open-ended comments

People's review of the hypothesis

Is the cause specific?

Yes  4 | No  0

Is the effect specific?

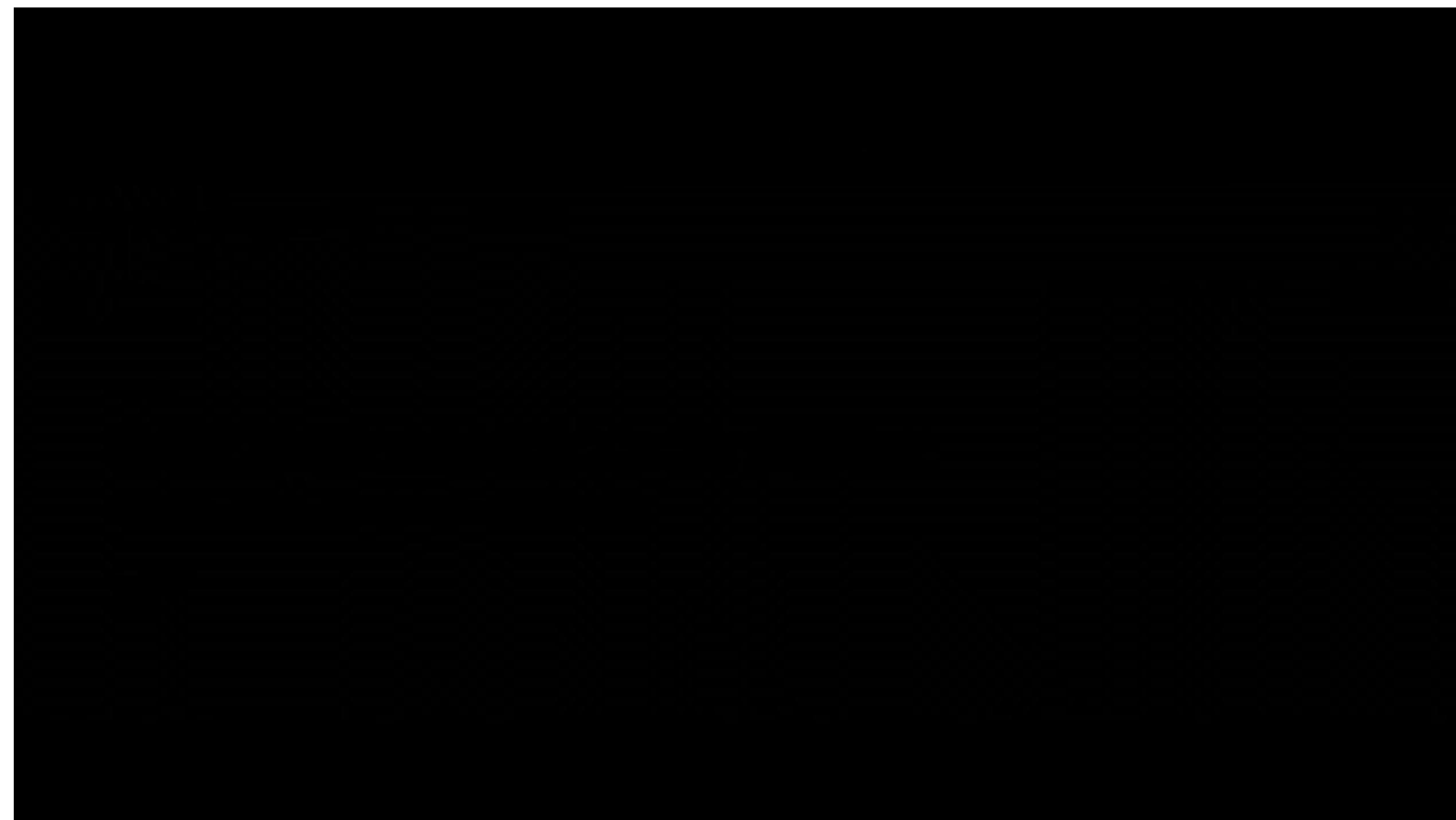
Yes  3 | No  1

Dbear: The description includes both optimism and depression as possible effects. Optimism isn't the opposite of depression. One might also state that using more social media might make one more depressed, but my impression is that this isn't exactly what the experimenter means.

NEXT SECTION

Community reviews

Join online and provide data via text reminders



People join

Galileo | Beta x +

← → C <https://galileo-ucsd.org/galileo/entrance> 🔍 ☆ Bookmark Up

Select the appropriate community below to design your own experiments and to view others' experiments

Knight Lab

Experiments: 10



If you are affiliated with the Knight Lab,
click here to design, review, and
participate in experiments.

Diet (including Coffee)

Experiments: 6



If you are interested in Diet (incl Coffee),
click here to design, review and
participate in experiments [\(?\)](#)

American Gut Project

Experiments: 7



Join the American Gut Project
community to design, review, and
participate in experiments! [\(?\)](#)

Coursera Gut Check

Experiments: 7



Join the Coursera Gut Check
community to design, review, and
participate in experiments! [\(?\)](#)

Open Humans

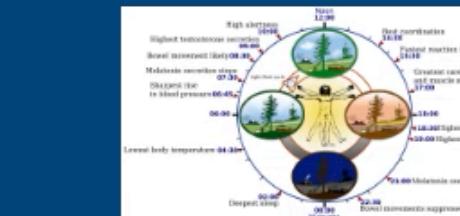
Experiments: 5



If you are interested in Open Humans,
click here to design, review and
participate in experiments [\(?\)](#)

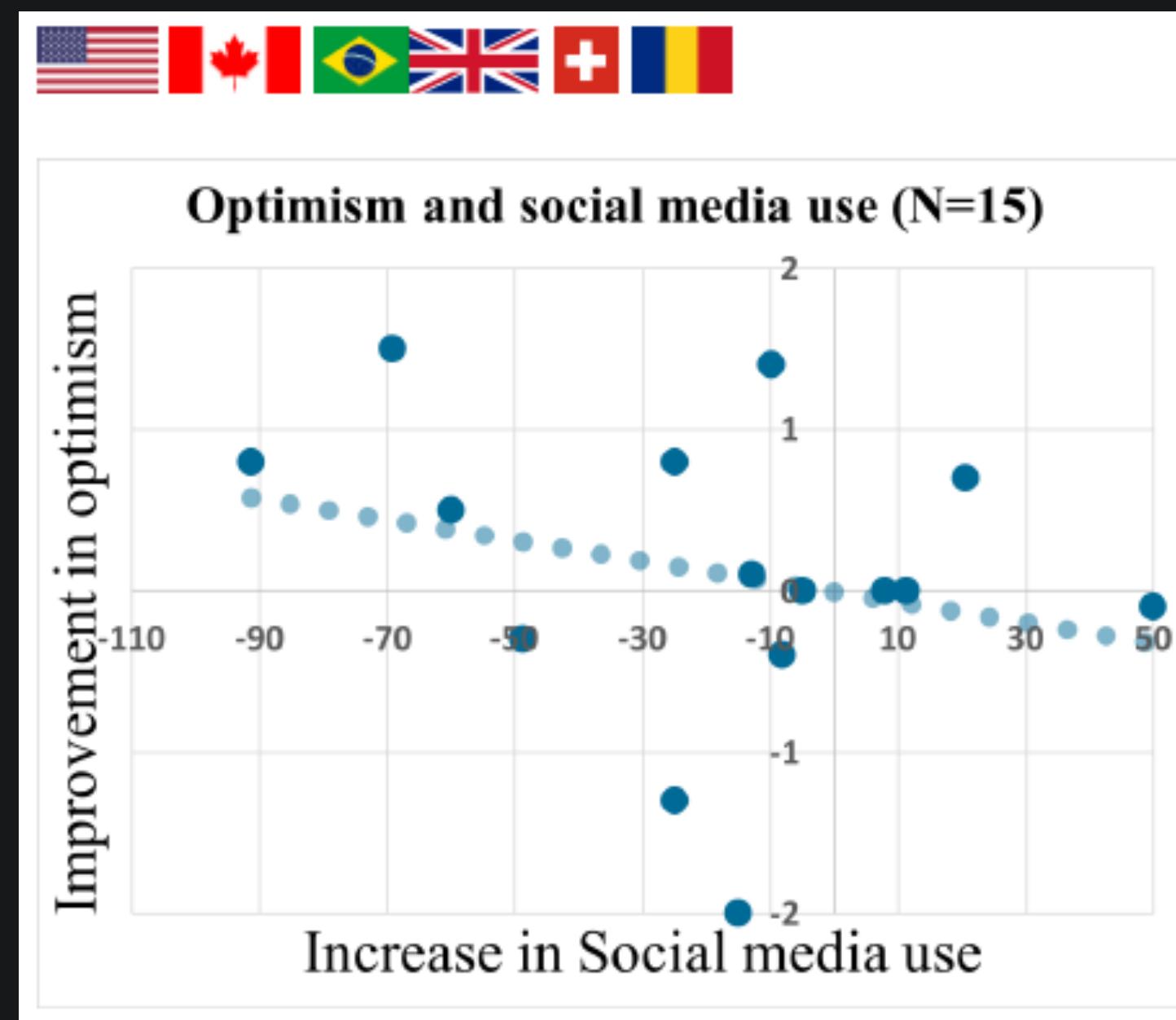
Circadian Rhythms

Experiments: 4



Join the Circadian Rhythm community
to design, review, and participate in
experiments! [\(?\)](#)

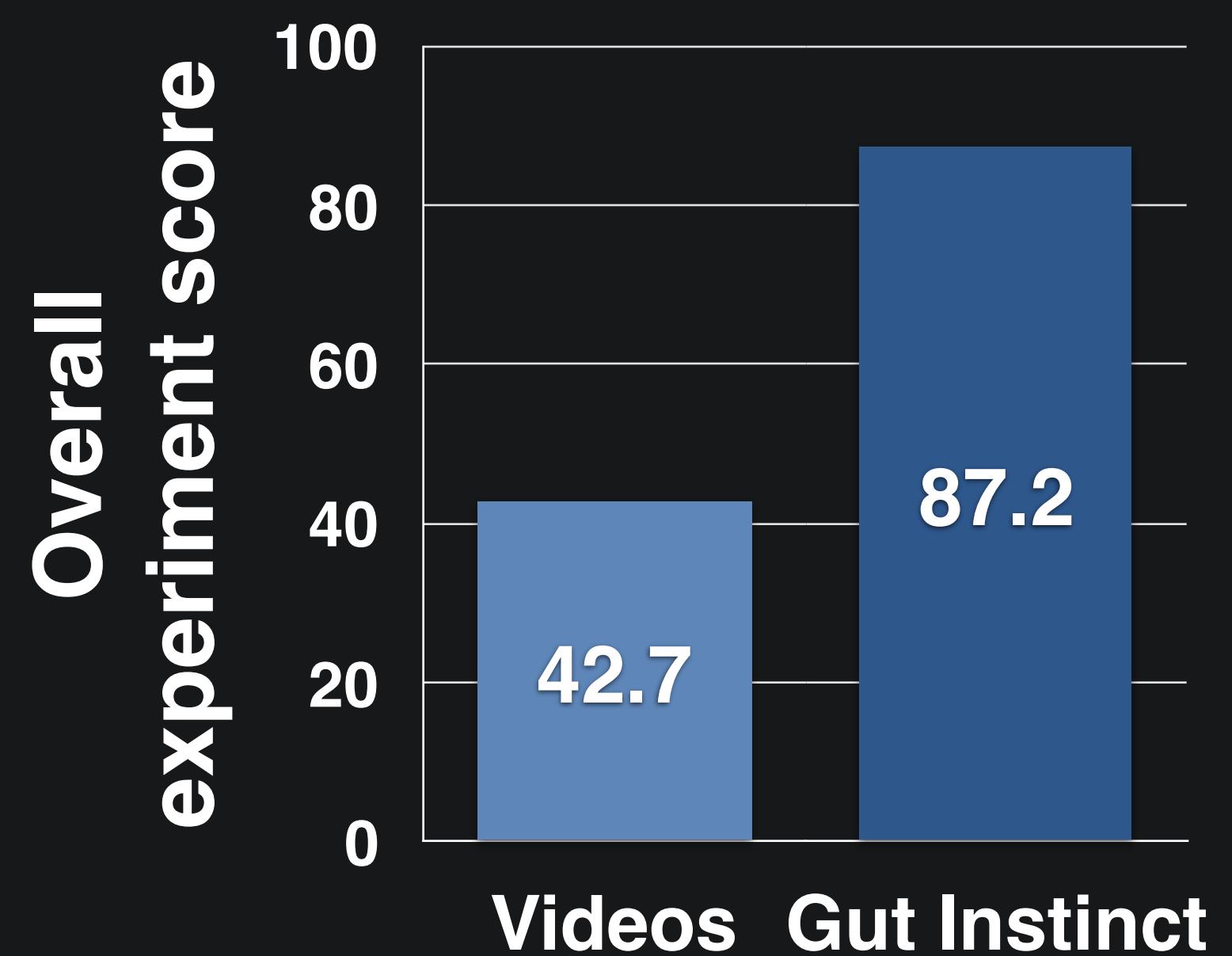
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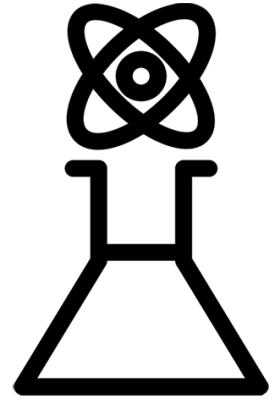
People design better with procedural training



→ Questions
Gut Instinct
CHI 17

→ Hypotheses
Docent
Learning@Scale 18

→ Experiments
Galileo
Coming Soon



Thank you! Inviting your feedback on..

- **Missing important questions**
Being a scientist is more than following xyz steps. Which things should I focus on next?
- **Beyond scientists and skateboarders**
Where else can just-in-time learning systems augment people's abilities and knowledge?
- **Frameworks** to better understand and present my work