

# Gut Instinct: Creating Scientific Theories with Online Communities

[gutinstinct.ucsd.edu](http://gutinstinct.ucsd.edu)

Scripps Research Translational Institute  
Oct 26 2018

Vineet Pandey  
 @vineet1pandey  
UC San Diego  
The Design Lab

# People... design, build, and track to better understand and improve their health



Dana Lewis - Created DIY Pancreas

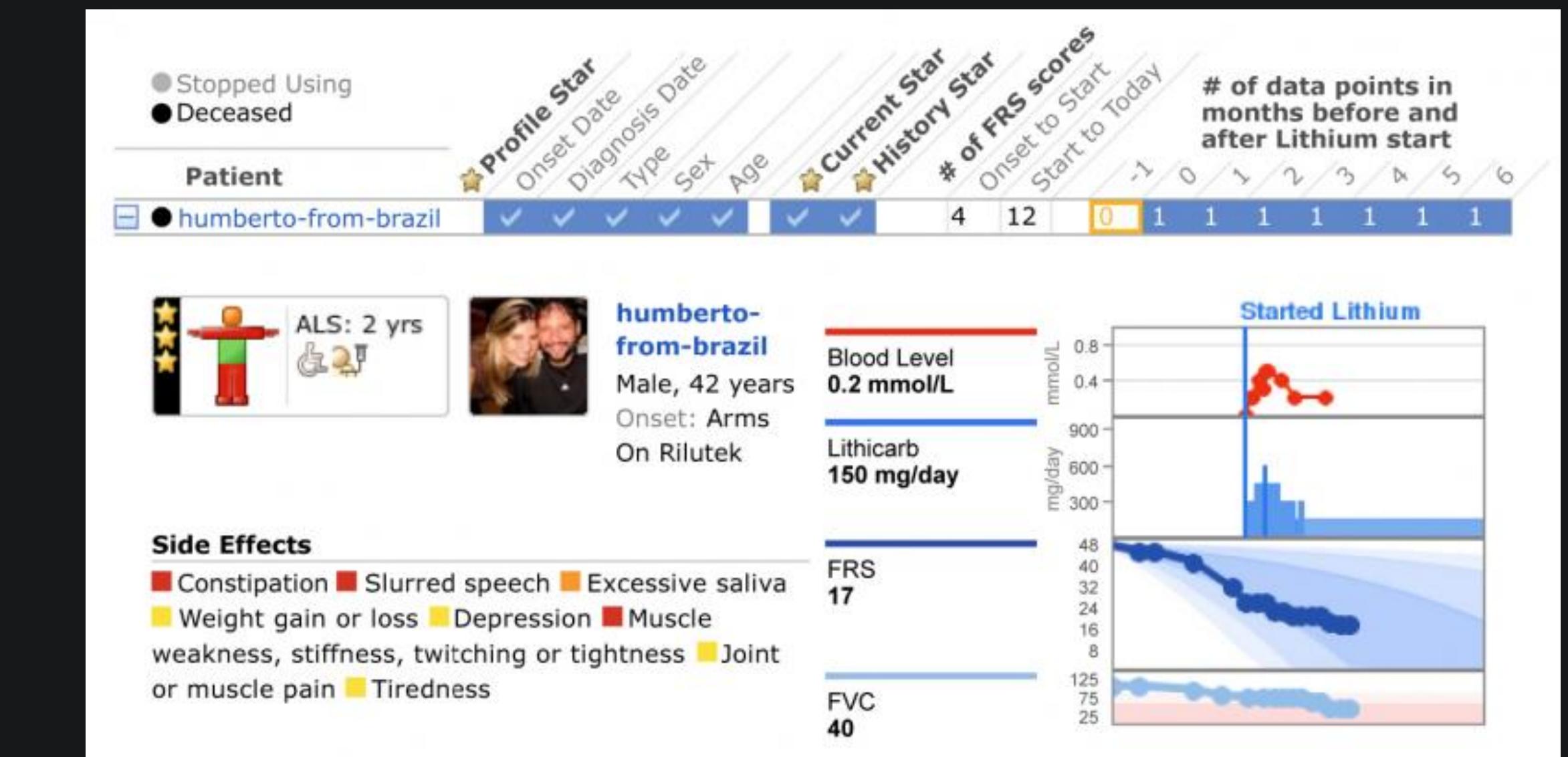
A screenshot of the patientslikeme website. At the top, there is a navigation bar with tabs: Patients, Conditions (which is selected and highlighted in blue), Treatments, Symptoms, and Research. Below the navigation bar is a search bar with the placeholder text "Look up a condition". The main content area features the title "ALS (Amyotrophic Lateral Sclerosis)". Below the title, there is a section with the text "We're all in this for good. By sharing your stories and data, you will:" followed by 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".

Ran a study to test a research paper result

# Already, people... write software, try novel hardware, and create tracking workflows



Pebble watch with constant glucose monitoring



Collaboratively-created tracking sheets

# Already, people... produce DIY Manuals, reference designs, wikis, even scientific papers

## 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)

## OpenAPS community

Reference design with algorithmic details

computational  
BIOLOGY

ANALYSIS

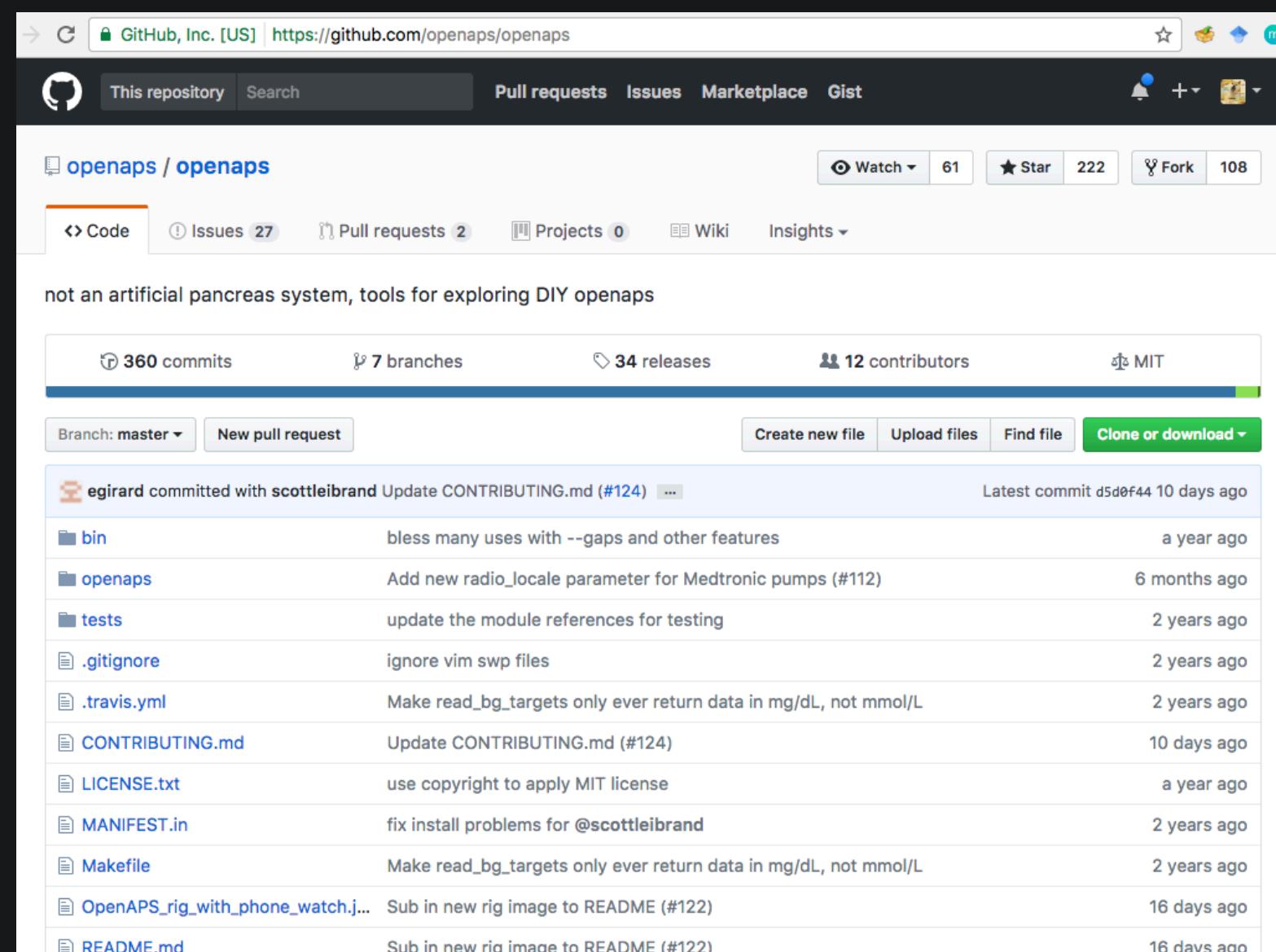
Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

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

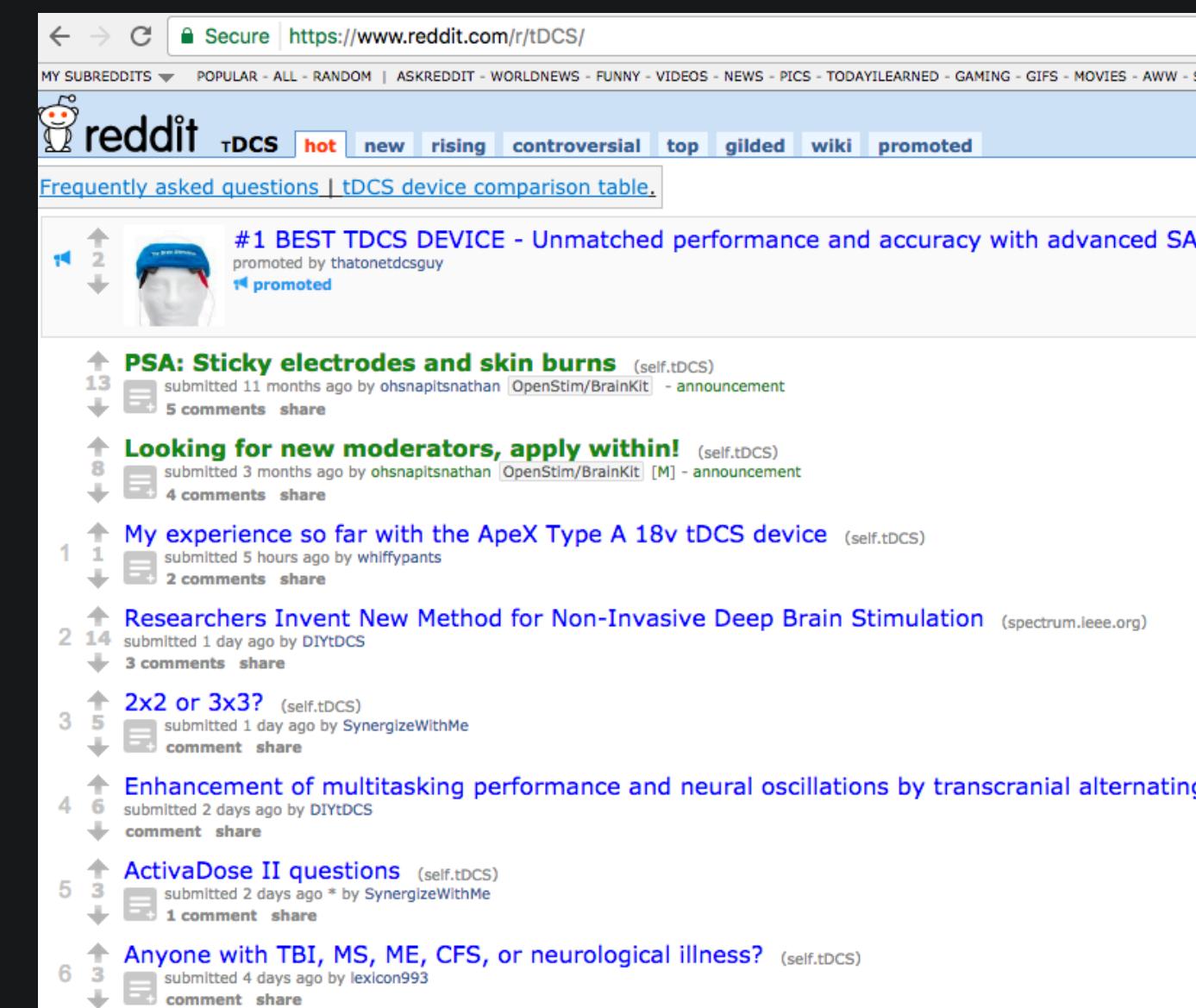
## ALS community

Ran a study to test a research paper finding

# Already, people... collaborate using online platforms to share software, manuals and personal insights



**GitHub to share code**  
[github.com/openaps](https://github.com/openaps)



**Reddit to share insights**  
[reddit.com/r/tDCS/](https://www.reddit.com/r/tDCS/)



**Social engagement**  
[fb.com/groups/658084947665356/](https://fb.com/groups/658084947665356/)

# Already, people... draw ideas from current research by reading and discussing papers

## Lithium delays progression of amyotrophic lateral sclerosis

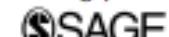
Francesco Fornai\*†‡, Patrizia Longone§, Luisa Cafaro†, Olga Kastsiuchenka\*, Michela Ferrucci\*, Maria Laura Manca†, Gloria Lazzeri\*, Alida Spalloni§, Natascia Bellio†, Paola Lenzi\*, Nicola Modugno†, Gabriele Siciliano†, Ciro Isidoro†, Luigi Murri†, Stefano Ruggieri†, and Antonio Paparelli\*

\*Department of Human Morphology and Applied Biology, and †Department of Neuroscience, Clinical Neurology, University of Pisa 56100 Pisa, Italy; §Istituto Neurologico Mediterraneo, Istituto Di Ricovero e Cura a Carattere Scientifico Neuromed, 86077 Pozzilli (IS), Italy; ‡Molecular Neurobiology Unit, Santa Lucia Foundation, 00179 Rome, Italy; and †Department of Medical Sciences, University of Novara, 28100 Novara, Italy

Edited by Thomas C. Südhof, University of Texas Southwestern Medical Center, Dallas, TX, and approved December 21, 2007 (received for review August 24, 2007)

### Letter to the Editor

## Real-World Use of Open Source Artificial Pancreas Systems

Journal of Diabetes Science and Technology  
2016, Vol. 10(6) 1411  
© 2016 Diabetes Technology Society  
Reprints and permissions:  
[sagepub.com/journalsPermissions.nav](http://sagepub.com/journalsPermissions.nav)  
DOI: 10.1177/1932296816665635  
[dts.sagepub.com](http://dts.sagepub.com)  


Dana Lewis<sup>1</sup>, Scott Leibrand<sup>1</sup>, and the #OpenAPS Community

### Keywords

artificial pancreas, APS, OpenAPS, #WeAreNotWaiting, closed loop, DIY diabetes technology

Researchers Invent New Method for Non-Invasive Deep Brain Stimulation ([spectrum.ieee.org](http://spectrum.ieee.org))  
14 submitted 3 days ago by DIYtDCS  
3 comments share

all 3 comments  
sorted by: best ▾

[-] DIYtDCS [S] 3 points 3 days ago  
And their research paper: [Noninvasive Deep Brain Stimulation via Temporally Interfering Electric Fields](#)  
[permalink](#) [embed](#)

[-] maloStak 2 points 3 days ago  
Tldr  
Neurons typically don't respond to high frequency electric signals. But they do respond to low frequency signals. Boyden and Grossman hypothesized that if they sent to a deep brain target two high frequency signals that differed by a small amount, the signals would pass through the more superficial tissues of the brain. When these signals interfered with each other at the target, they would create a field with an amplitude that oscillates at a frequency equal to the small difference between the two high frequency signals. That electrical wave would be low enough to engage neurons.

American Diabetes Association  
77<sup>TH</sup> SCIENTIFIC SESSIONS  
EXPERIENCE NEW HORIZONS IN DIABETES  
SAN DIEGO, CA JUNE 9-13, 2017

← American Diabetes Association - 77th Scientific Sessions Home  
Session LB-01 - Late Breaking Poster Session  
**127-LB / 127 - Automatic Estimation of Basals, ISF, and Carb Ratio for Sensor-Augmented Pump and Hybrid Closed-Loop Therapy**  
June 11, 2017, 12:00 - 1:00 PM Hall B

Authors  
DANA M. LEWIS, SCOTT LEIBRAND, Seattle, WA  
Disclosures  
D.M. Lewis: None. S. Leibrand: None.

# Problem

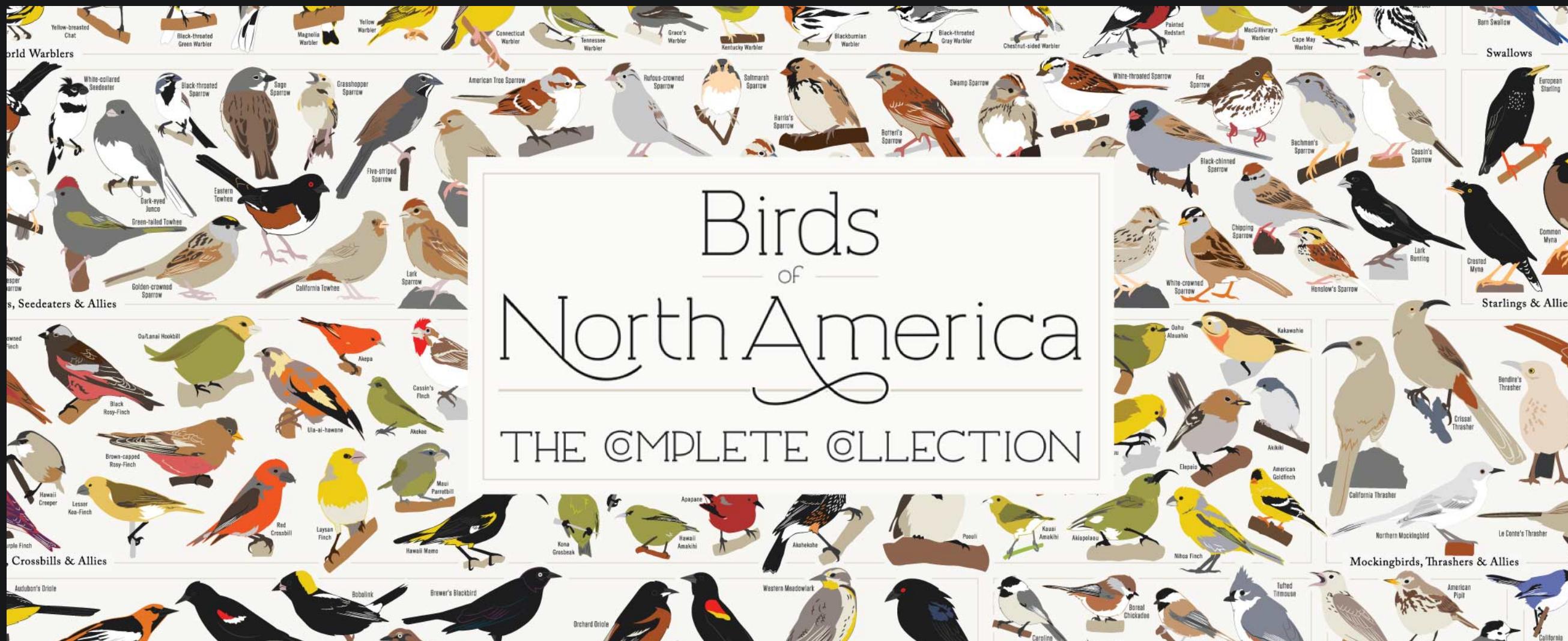
People develop intuitions of cause and effect that *might or might not* a) be correct and b) exist *in scientific literature*

# Opportunity

How might we crystallize *intuitions* to

- a) create *personally meaningful scientific knowledge* and
- b) scale up scientific work

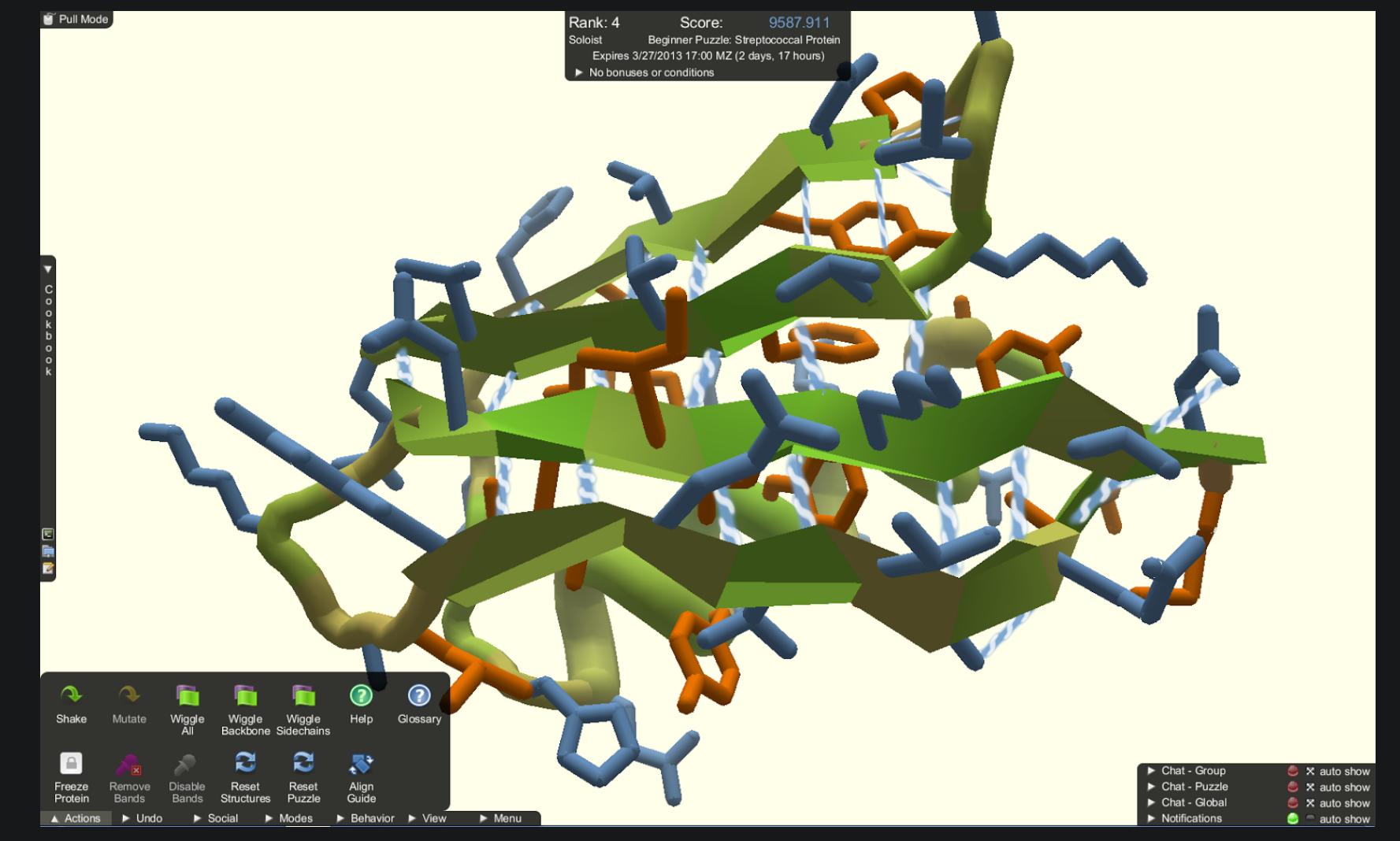
# Citizens have successfully solved expert-defined problems as sensors or algorithms



Tracking bird migration

eBird

eBird: A citizen-based bird observation network in the biological sciences. Brian L. Sullivan \*, Christopher L. Wood, Marshall J. Iliff, Rick E. Bonney, Daniel Fink, Steve Kelling. 9  
Predicting protein structures with a multiplayer online game. Seth Cooper, Firas Khatib, Adrien Treuille. Nature 2010.



Folding proteins

Foldit

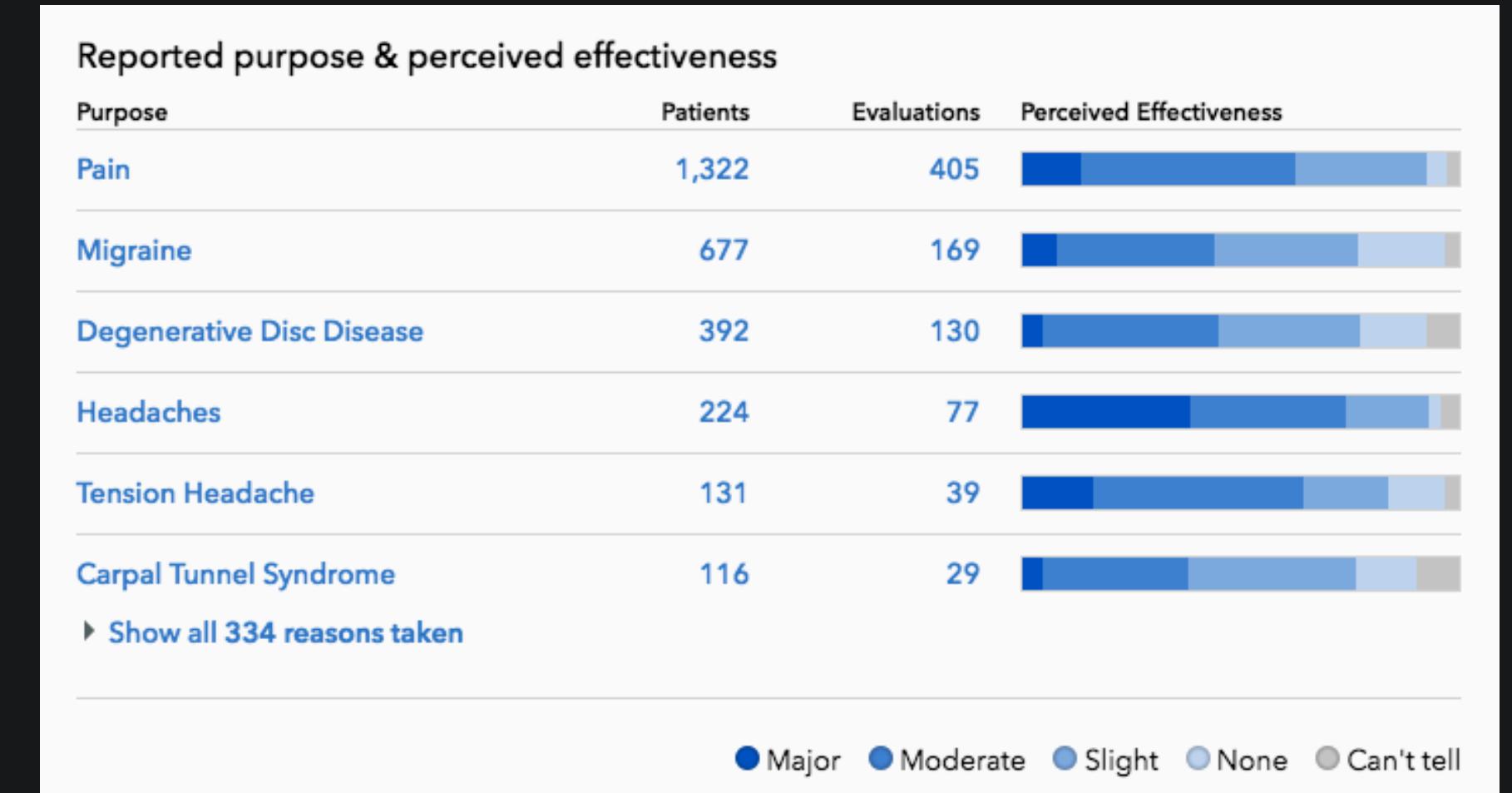
# Powerful ideas emerge when people combine personal data with insights



**Genomics**  
*23andme*



**Microbiome**  
*American Gut*



**Medicine effects**  
*Patientslikeme*

# Powerful ideas emerge when people combine personal data with insights

The image is a collage. On the left side, there is a dark blue rectangular area containing the "All of Us RESEARCH PROGRAM" logo in white, with the tagline "The Precision Medicine Initiative" below it. On the right side, there is a photograph of a diverse group of nine people of various ages, ethnicities, and abilities standing together against a solid blue background. The group includes men and women, some standing and one person in a wheelchair.

# Understanding the human microbiome requires insights into people's lifestyles

## *A Baffling Brain Defect Is Linked to Gut Bacteria,*

By GINA KOLATA MAY 10, 2017



## Are Pets the New Probiotic?

By RICHARD SCHIFFMAN JUNE 6, 2017



"Microbes are integrated into almost all aspects of our lives, redefining what it means to be human."

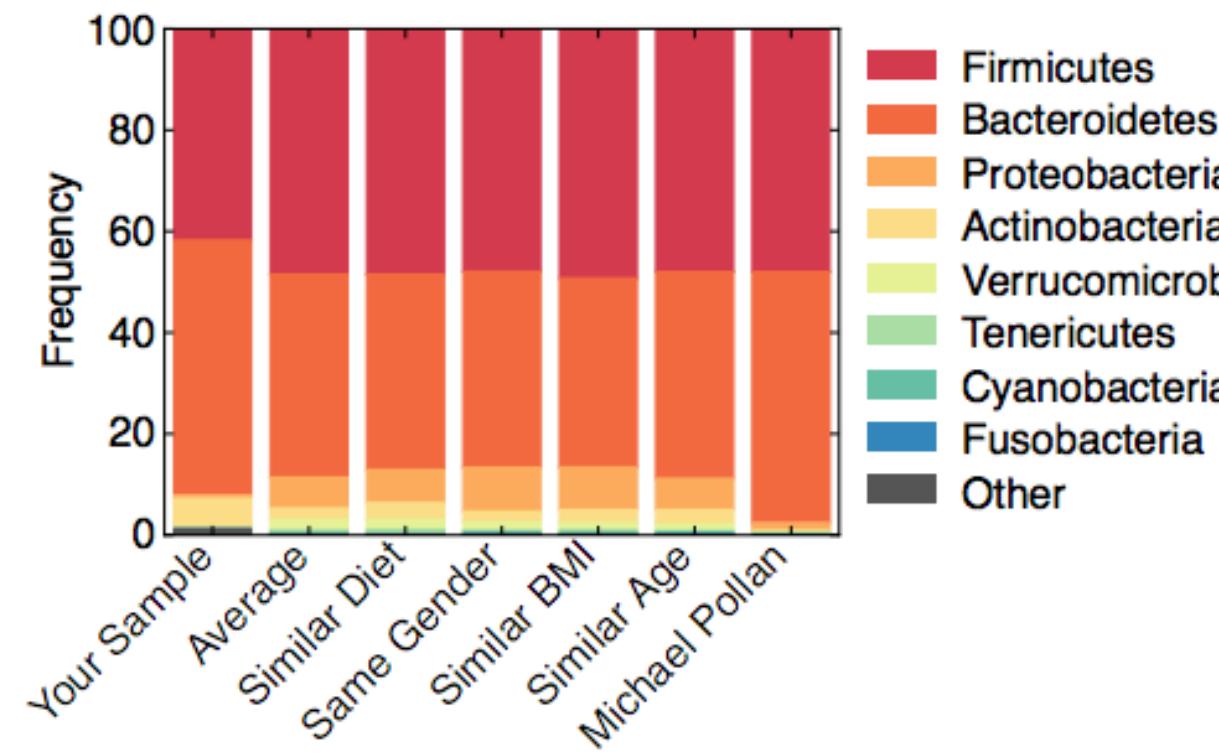
The illustration features several panels: 1) A person with a brain labeled 'OBESITY' inside. 2) A couple labeled 'MOOD'. 3) A person labeled 'IMMUNITY'. 4) A person sleeping labeled 'SLEEP'. 5) A person with a gut labeled 'DIGESTION'. 6) A person with a gut labeled 'THE ENORMOUS IMPACT OF TINY MICROBES'. The central title reads 'FOLLOW YOUR GUT'. The bottom text reads 'A TED ORIGINAL ROB KNIGHT WITH BRENDAN BUHLER'.

[Flegr et al. 1996] Induction of changes in human behaviour by the parasitic protozoan *Toxoplasma gondii*. Flegr J1, Zitková S, Kodym P, Frynta D. Parasitology 1996.

# 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%

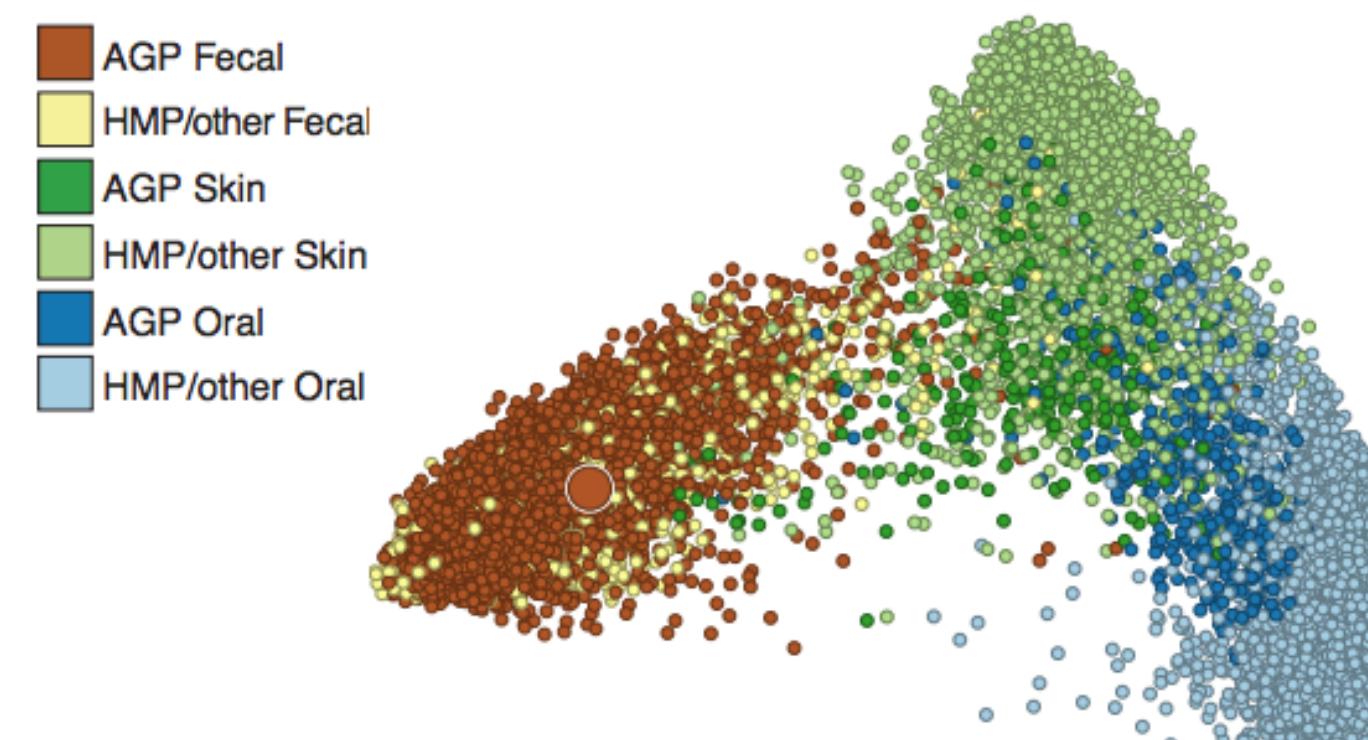
#### Your most enriched microbes:

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

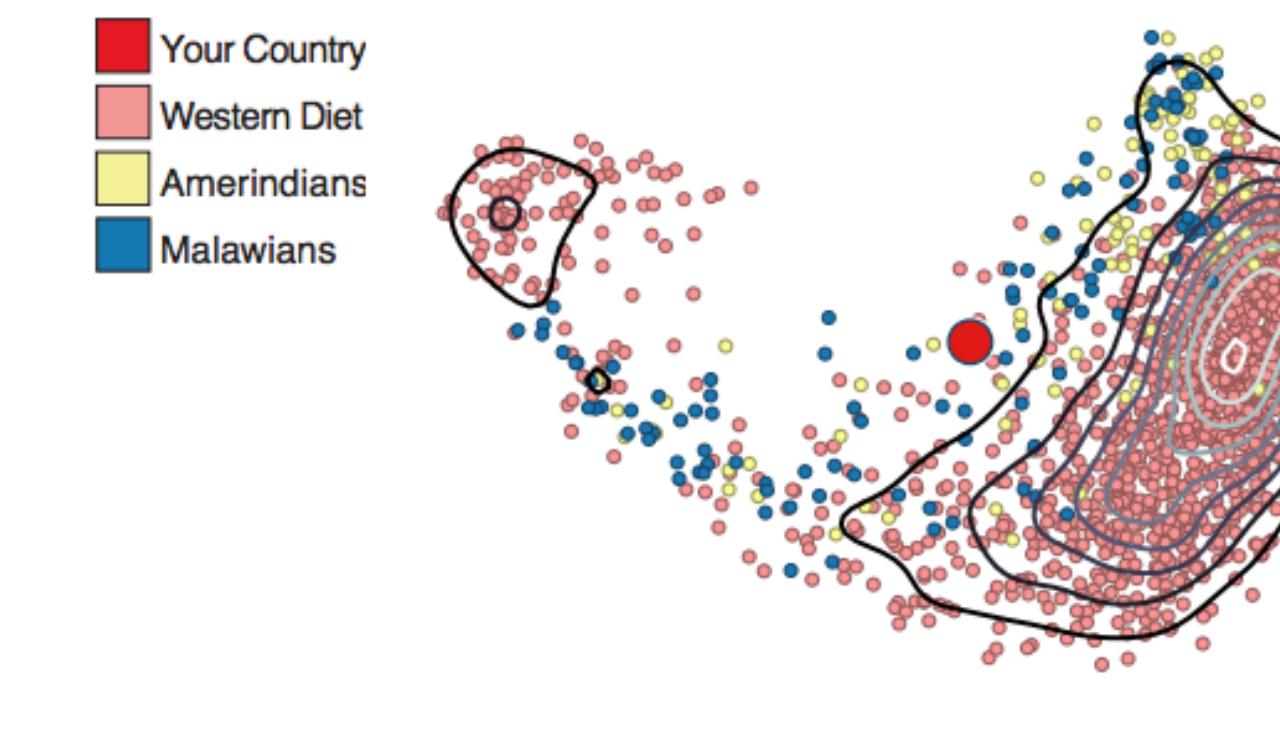
Your sample contained the following rare taxa: Unclassified Family Microbacteriaceae, Genus *Pseudoclavibacter*.

### How do your gut microbes compare to others?

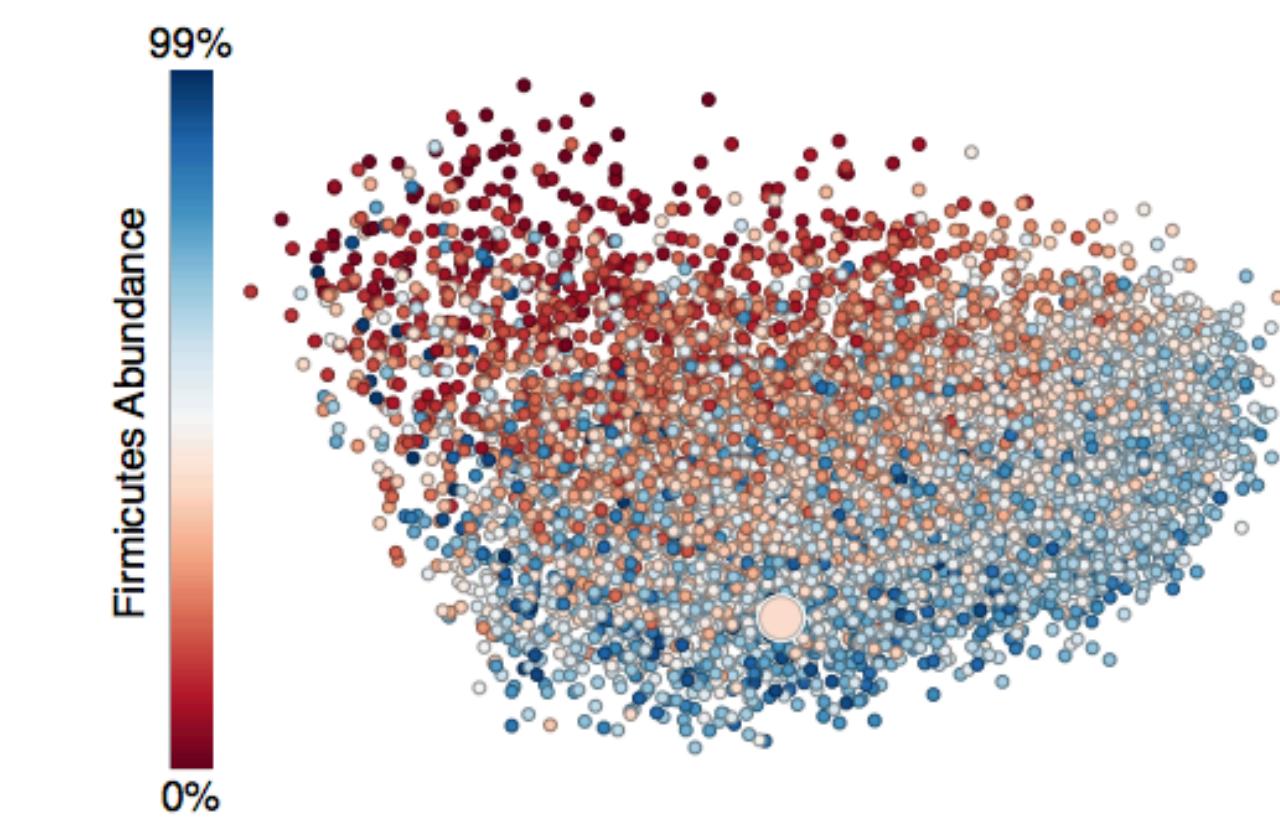
● Your sample is here • Others ◉ Unspecified



Different Body Sites

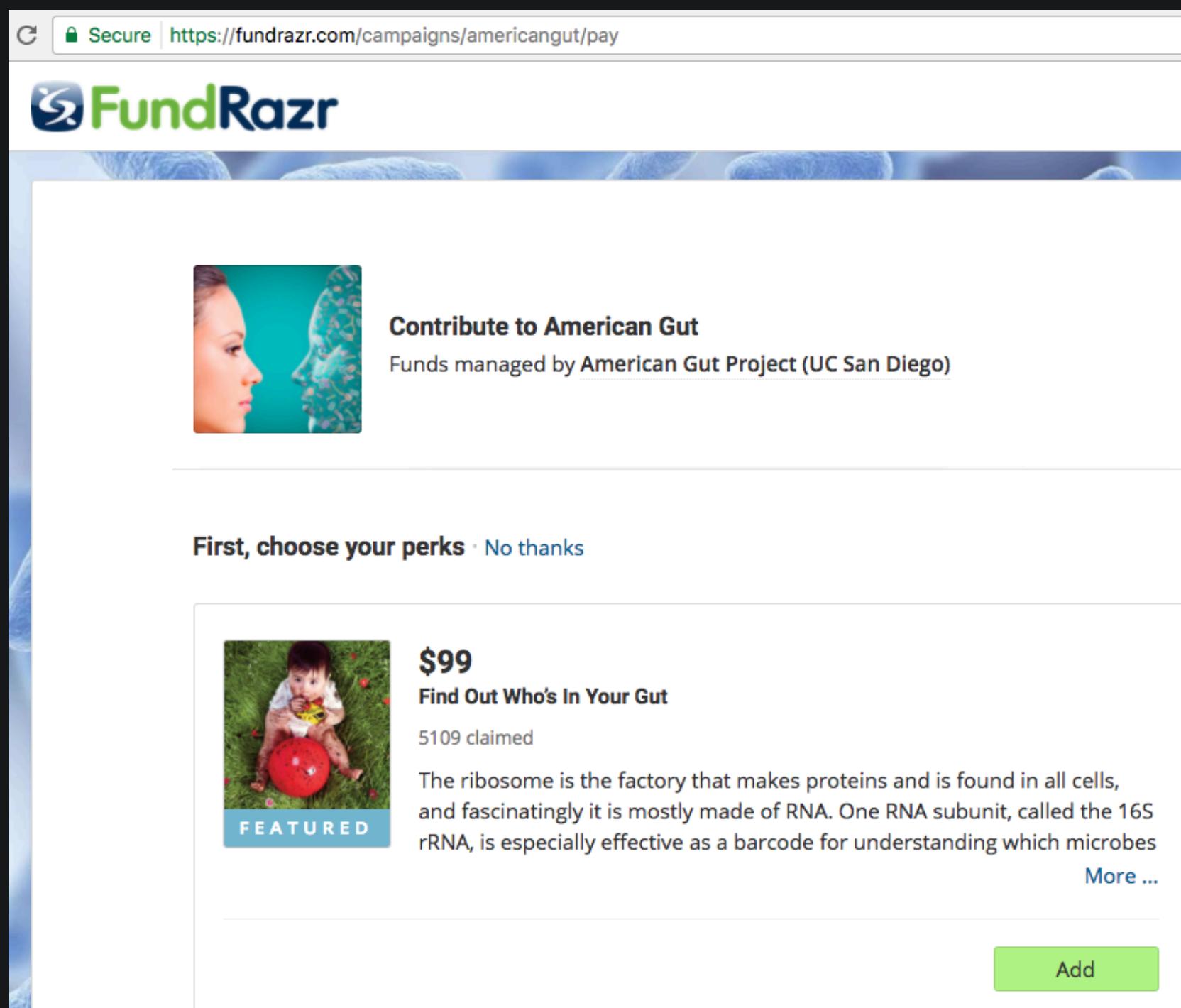


Different Nationalities



The American Gut Population

# UC San Diego's American Gut is the world's largest microbiome citizen science project



The screenshot shows a FundRazr campaign page for the American Gut Project. At the top, it says "Secure | https://fundrazr.com/campaigns/american gut/pay". The title is "Contribute to American Gut" and it's managed by "American Gut Project (UC San Diego)". Below this, there's a "First, choose your perks" section with a "No thanks" link. A featured perk is shown: "\$99 Find Out Who's In Your Gut" (5109 claimed). It describes the ribosome as a factory for proteins and mentions the 16S rRNA barcode. There's a "More ..." link and a green "Add" button.

**1: Create an online account and support the project**



**2: Send in your fecal/oral/skin samples using AGP provided swabs**

[americangut.org](http://americangut.org)

# Participants generate hypotheses by looking at the data

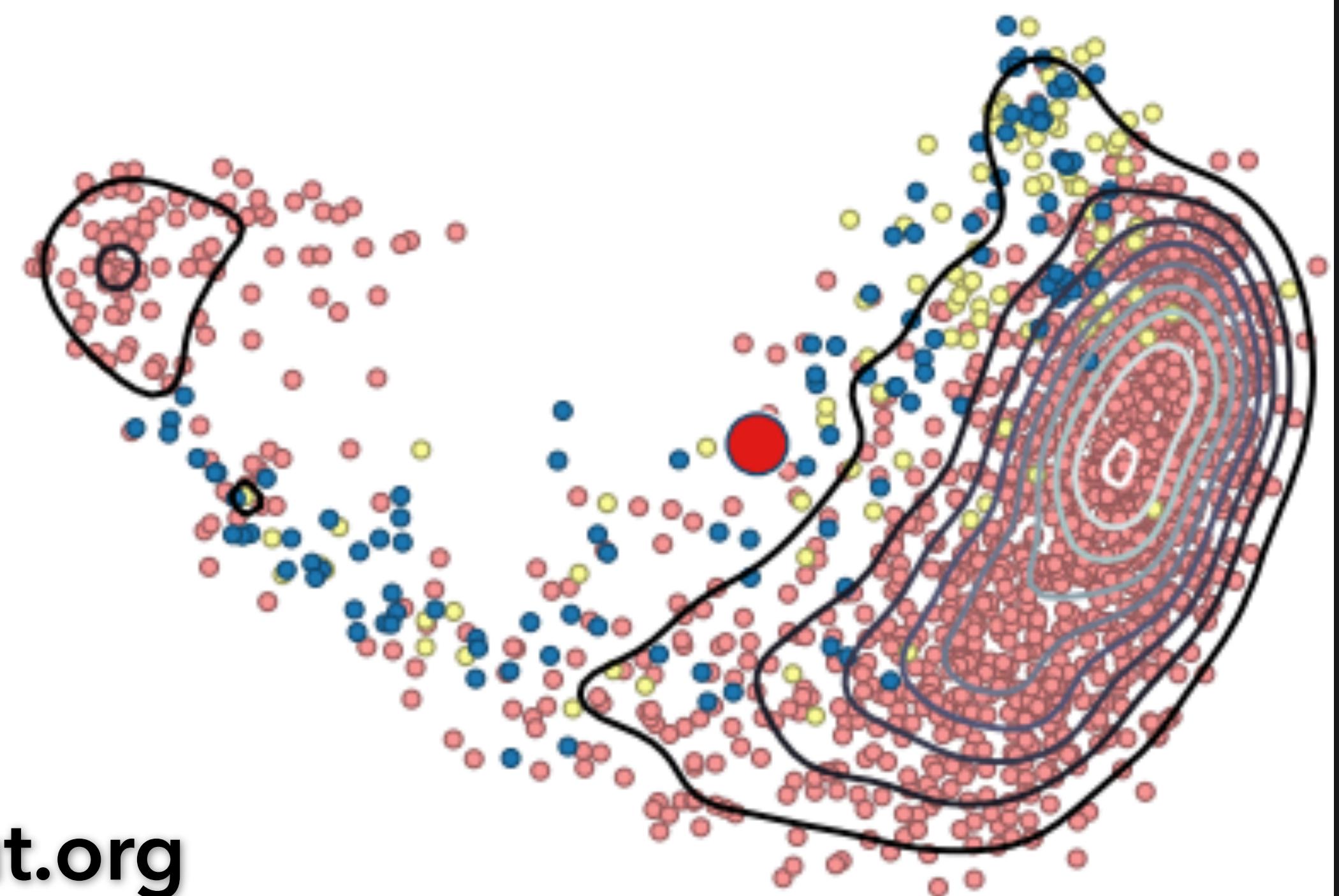


Is my data point unique because

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



[americangut.org](http://americangut.org)



# Personalized medicine at scale needs insights from people's lived experiences

People can contribute to scientific domains **Genomics**  
that are **23andme**

*Nascent*      **Experts know little**  
*Contextual* **Huge individual differences**  
*Motivating* **People care**

**Microbiome**  
*American Gut*



# How might people's situated knowledge supplement ivory-tower science? One instance: Misophonia genetic markers



[23andmeforums.com/discussion/comment/19190#Comment\\_19190](https://www.23andmeforums.com/discussion/comment/19190#Comment_19190)

I didn't realize I had this until a friend pointed me to this website: [misophonia.com/](http://misophonia.com/). Turns out my dad has the same condition. We both can not stand, with a sure hatred, when we hear food noises (crunching, chewing, slurping, gulping, etc.)

Does anyone else have this condition? If so, do you find it is exaggerated when you are sleep deprived?

Like Flag

**1. Crowds share unique observations**

Q chew

Showing 1-1 of 1

Does the sound of other people chewing fill you with rage?

Yes  
 No  
 I'm not sure

**2. Scientists add this to the survey**

23andMe Follow

Do you suffer from feelings of rage from hearing other people chew? Misophonia might be in your genes.

We found a genetic marker associated with misophonia on chromosome 5

rs2937573 associated with misophonia

TENM2 gene Brain development

\*Findings based on responses from 23andMe research participants.

RETWEETS 36 LIKES 53

**3. Scientists unearth novel knowledge**

# Insight

**Integrating learning and collaboration  
enable people to perform personally-  
meaningful scientific work**

# Gut Instinct platform w/ 3 systems and empirical studies evaluates this contribution

1. People create novel hypotheses based on lived experiences **400 hypotheses**  
How: *Learning and Training improves quality of hypotheses* **37 novel**
2. People design structurally-sound experiments **50 experiments**  
How: *Procedural training improves experimental design quality* **900 users**
3. People can run experiments with global volunteer participants **32 countries**  
How: *Learning, collaboration, and automation supports citizen-led experimentation* American Gut Project + many communities

# Gut Instinct platform w/ 3 systems and empirical studies evaluates this contribution

From intuition..

..to questions: *Learn <-> Ask [CHI 2017]*

..to hypotheses: *Learn-Train-Ask [L@S 2018]*

..to experiments: *Design-Review-Run [In Submission]*

# Step 1: Learn about probiotics + the microbiome

gutinstinct-ucsd.org/personal/probiotics

Confused? Add more questions! Topics Guide GutBoard Notifications

## Understand your Gut

To help you relate the learning material to your lifestyle, please answer the following questions!

Why do you use probiotics?

- To cure upset stomach
- Promote healthy gut flora
- Boost my immunity
- To alleviate constipation
- i dont
- Add your own option

Which probiotics do you use?

**Reflect on lifestyle by answering basic questions about probiotics use**

# Step 1: Learn about probiotics + the microbiome

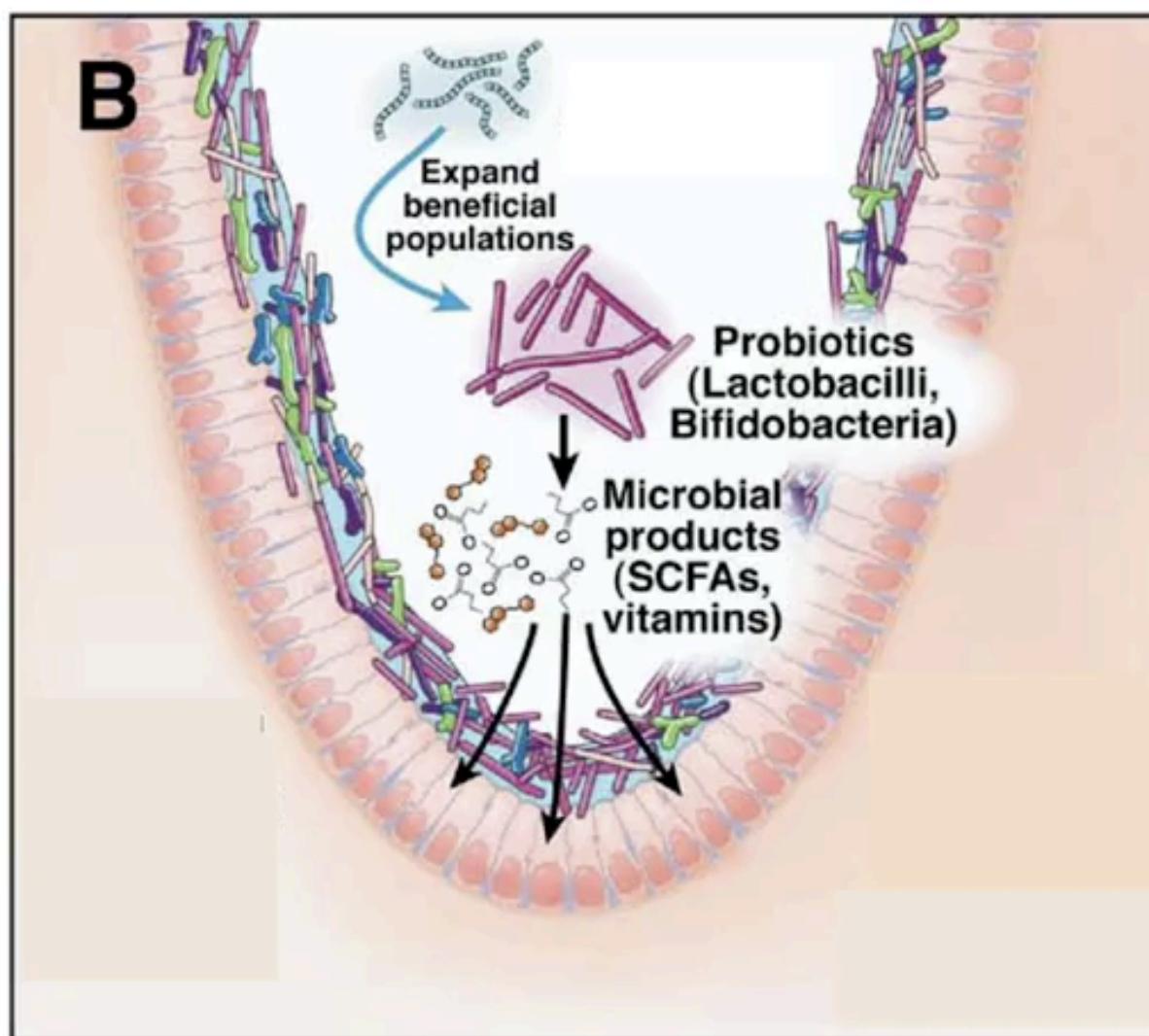
gutinstinct-ucsd.org/t/probiotics

Confused? Add more questions! Topics Guide GutBoard Notifications

Back to Topics

#probiotics

Video Provided By coursera



Preidis and Versalovic 2009, Gastroenterology

**Watch a 4-minute lecture  
that synthesizes current  
research about probiotics**

# Step 2: Train to frame useful questions

The screenshot shows the homepage of the 'Follow Your Gut' website. At the top, there's a navigation bar with links for 'Secure', 'Topics', 'Guide', 'GutBoard', and 'Notifications'. Below this is a main heading 'Follow Your Gut' with a blue icon of a notepad and pen. A sub-headline says 'Choose among following topics to understand your gut!'. There are four main topic sections: 'Genetics' (with a DNA helix image), 'Physiology' (with a human body diagram), 'Probiotics' (with a photo of capsules), and 'Introduction' (with a lightbulb icon). Each topic has a small description below it.

Learn

23

The screenshot shows a web page titled 'gutinstinct-ucsd.org/guide\_question'. The header includes links for 'Confused?', 'Add more questions!', 'Topics', 'Guide', 'GutBoard', and 'Notifications'. Below the header, a banner says 'Learn how to ask expert-like questions'. A section titled 'Step 1: Learn about great questions' contains text about what makes a question great and how to convert vague insights into useful questions. It includes a 'Let's begin!' section with an example question: 'I wonder how running affects my health?'. This is followed by a list of five features of useful questions: 1. Answerable, 2. Definite, 3. A link between a cause and an effect, 4. Operational, and 5. Simple. The page ends with the text 'Your ideas and experiences expressed simply!'. The URL 'https://hde.gutinstinct-ucsd.org/topics' is visible in the browser address bar.

Understand what  
makes a question  
useful

# Step 2: Train to frame useful questions

The screenshot shows the homepage of the 'Follow Your Gut' website. At the top, there's a navigation bar with links for 'Secure', 'Topics', 'Guide', 'GutBoard', and 'Notifications'. Below the header, the title 'Follow Your Gut' is displayed with a blue icon. A sub-header says 'Choose among following topics to understand your gut!'. There are four main topic cards: 'Genetics' (with a DNA helix image), 'Physiology' (with a human body diagram), 'Probiotics' (with a photo of capsules), and 'Introduction' (with a lightbulb icon). Each card has a small 'Learn' button at the bottom.

The screenshot shows a 'Share your Gut Instinct!' page. The URL in the address bar is 'gutinstinct-ucsd.org/gutboard\_slider\_addq'. The page features a 'Show me examples' button with a question mark icon. Below it is a numbered list of steps:

1. Add a top-level question for others to answer:  
Something that you do (*a cause*)
2. Add a follow-up question:  
Something that happens (*an effect*) due to the cause above
3. Add more follow-up questions: More effects
4. Guess the mechanism for your Gut Instinct
5. Check the criteria

**Use the criteria when adding a question**

# Step 3: Ask questions of people

The screenshot shows a web browser window with the URL <https://hde.gutinstinct-ucsd.org/topics>. The page title is "Follow Your Gut". Below the title, it says "Choose among following topics to understand your gut!". There are four topic cards:

- Genetics:** An image of a DNA double helix.
- Physiology:** An image of a human skeleton.
- Probiotics:** An image of several green capsules.
- Introduction:** An icon of a lightbulb.

Learn

25

## 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](#)

Train

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
- 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](#)

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](http://gutinstinct.ucsd.edu/topics) Please keep sharing your gut instincts, these are helpful!

## Add follow-on questions<sup>26</sup>

## Discuss questions and responses

## Receive scientific feedback

# Method

## Between-subjects experiment (N=344)

### for Learn and Train w/ 2x2 factorial study

H1 Access to learning improves question's content

	Train	Both	
Learn	<p>What type of alcoholic drinks (with sugar) affect your bowel movements?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> wine</li><li><input type="checkbox"/> beer</li><li><input type="checkbox"/> liquor</li><li><input type="checkbox"/> sugary mixed drinks</li></ul>	<p>What type of alcoholic drinks (with sugar) affect your bowel movements?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> wine</li><li><input type="checkbox"/> beer</li><li><input type="checkbox"/> liquor</li><li><input type="checkbox"/> sugary mixed drinks</li></ul>	 <p>Probiotics</p> <p>YouTube</p>
Neither	<p>What type of alcoholic drinks (with sugar) affect your bowel movements?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> wine</li><li><input type="checkbox"/> beer</li><li><input type="checkbox"/> liquor</li><li><input type="checkbox"/> sugary mixed drinks</li></ul>	<p>What type of alcoholic drinks (with sugar) affect your bowel movements?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> wine</li><li><input type="checkbox"/> beer</li><li><input type="checkbox"/> liquor</li><li><input type="checkbox"/> sugary mixed drinks</li></ul>	 <p>Probiotics</p> <p>YouTube</p>

H2 Just-in-time training improves question's structure

# Measures

## Question quality coded by blind, independent raters with microbiome expertise (max 5 points)



coursera Explore Q. What do you want to learn?

University of Colorado Boulder UC San Diego

Gut Check: Exploring Your Microbiome

★★★★★ 4.7 521 ratings • 168 reviews



Microbiome - Reddit  
<https://www.reddit.com/r/Microbiome/>  
Microbiome - an "ecological community of commensal, symbiotic and pathogenic microorganisms" found in and on all multicellular organisms studied to date ...

r/HumanMicrobiome HumanMicrobiome subscribeunsubscribe2,906 ...

How long does it take for your ... How long it takes for your microbiome to reflect the foods ...

### *Content*

**Insightful:** Does the question & discussion link to existing knowledge of the microbiome?  
**Novel:** Is there a chance the world will learn something?

### *Structure*

**Answerable:** Is it a question about the participant?  
**Specific:** Does it ask about only one topic?

### *Creativity*

**Is it reasonably interesting/ creative?**

# Measures

## Question quality coded by blind, independent raters with microbiome expertise (max 5 points)

*High-Quality*

Have you ever eaten raw pumpkin seeds to eliminate parasites?  
(Content: 1, Structure: 2, Creativity: 1)

*Medium-quality*

Do you get constipated when stressed? (Content: 0.5, Structure: 2, Creativity: 0.5)

*Low-quality*

Does day of the week influence good vs. bad microbiota? (Content: 0, Structure: 1, Creativity: 0)

*Content*

**Insightful:** Does the question & discussion link to existing knowledge of the microbiome?  
**Novel:** Is there a chance the world will learn something?

*Structure*

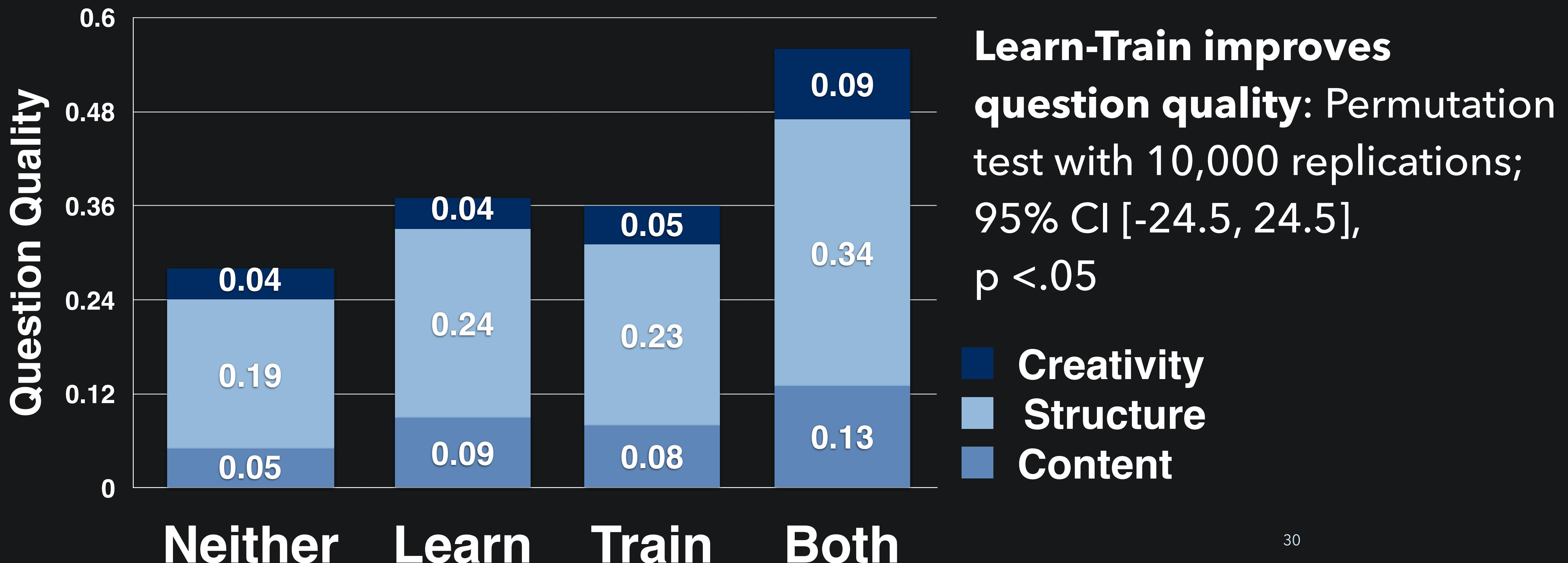
**Answerable:** Is it a question about the participant?  
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*Creativity*

**Is it reasonably interesting/ creative?**

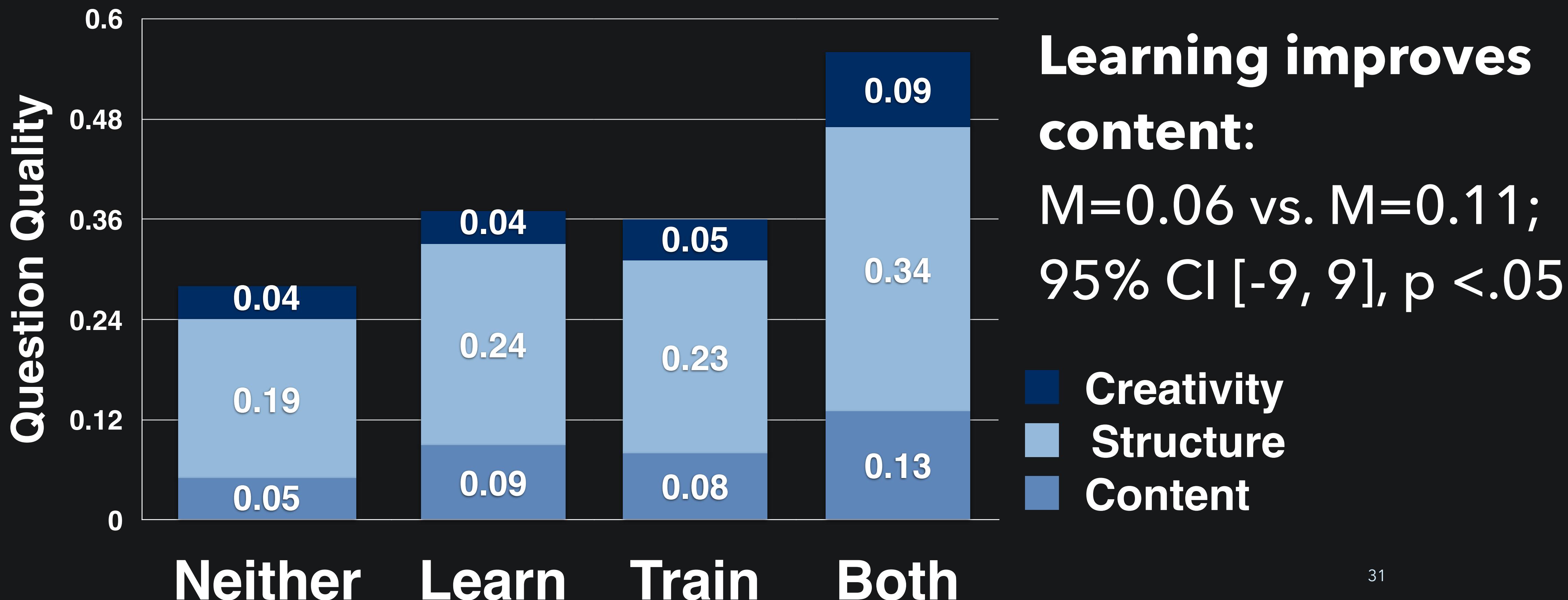
# Results

The combined Learn-Train condition produces better questions ( $N=344$ )



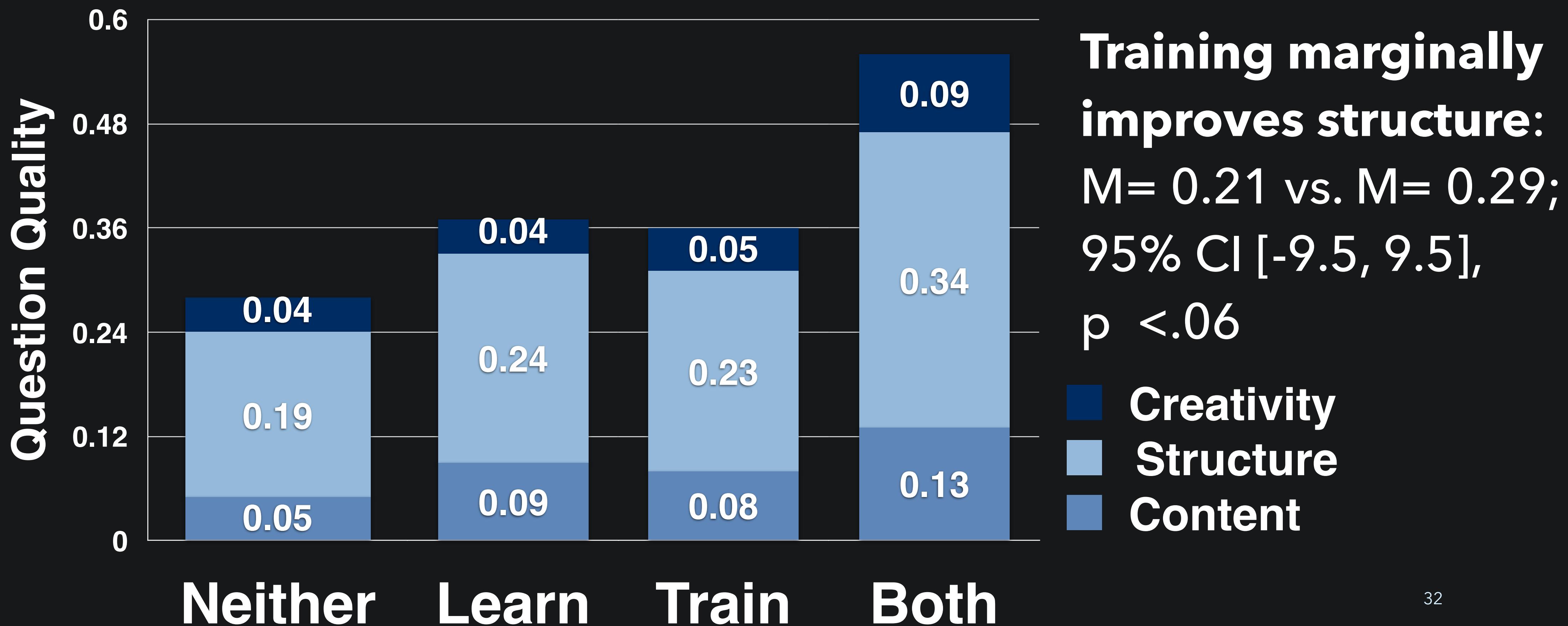
# Results

The combined Learn-Train condition produces better questions ( $N=344$ )



# Results

The combined Learn-Train condition produces better questions ( $N=344$ )



# Results

The combined Learn-Train condition produces better questions (N=344)



# Why did Learning and Training help? (Our hunch)

- Content learning engaged people
  - more time -> more questions
  - more ideas -> more questions
- Tight integration of training with question asking
  - reminder of the goal (focus on one topic + answerable)
  - makes it easy to edit in-place

# 399 hypotheses, 75 considered novel by experts; Lead users are best with need-intensive problems

*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?**

**Is yogurt better for your gut at room temperature?**

*Most Questions contained Known Facts*

**How often do you consume fermented foods?**

**Have you ever tried doing intermittent fasting?**

*Common themes*



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

## *Role and Actions*

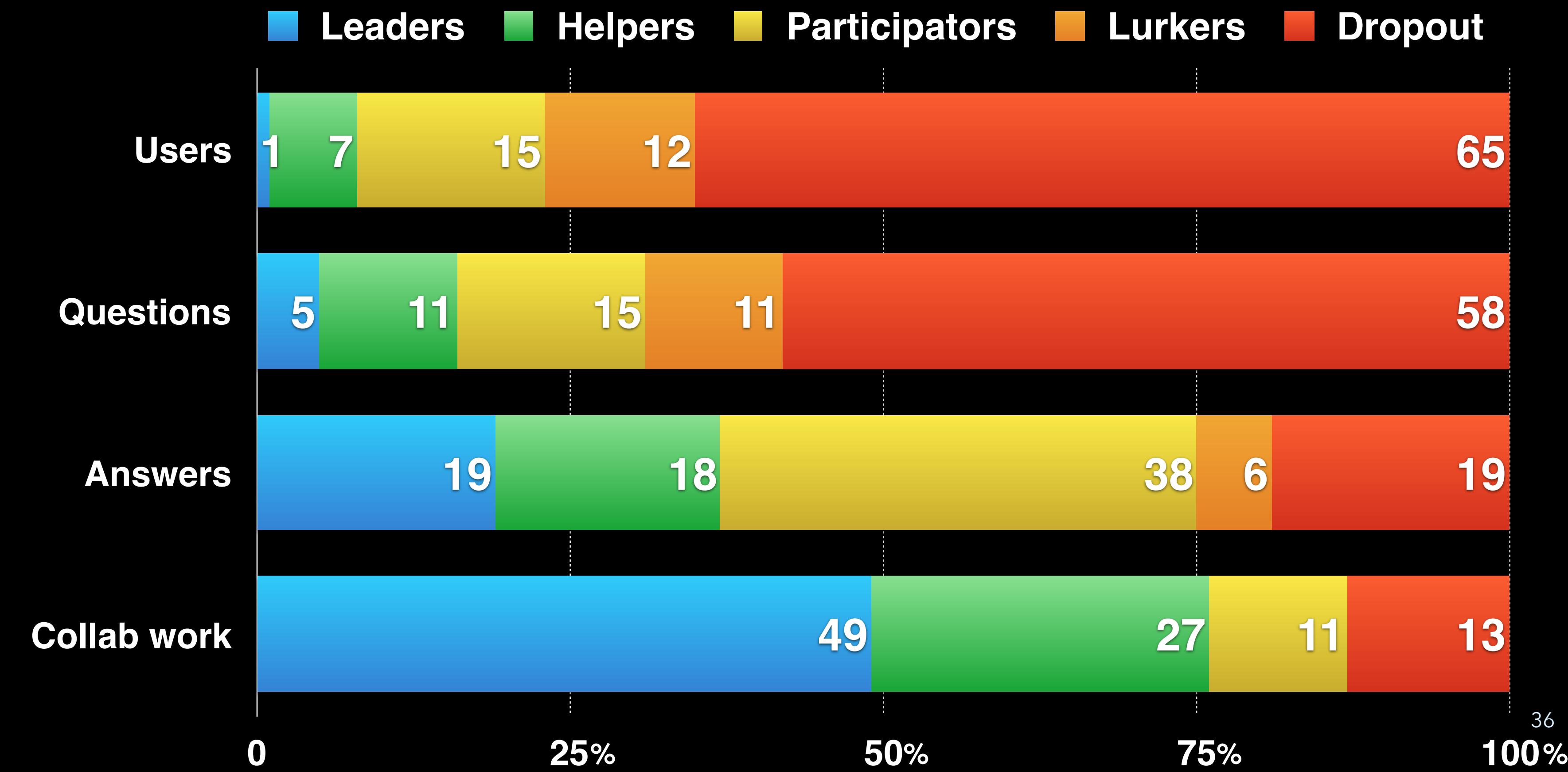
**Leader:** Add questions, answer & edit others' questions, add follow-ups, discuss

**Helper:** Add & answer questions, add follow-ups

**Participant:** Answer questions

**Lurker:** Add questions but no collaborative work

**Dropout:** Add a question; never return



# Challenge: Scientists cannot provide direct feedback

8 days ago • Added by: CITIZEN SCIENTISTS [a034]

Could an antibiotic like ciprofloxacin cure an intolerance to gluten and dairy? Seems to have done so for me.

What bacteria might be responsible for disrupting the gut's ability to digest gluten and dairy?  
 Add my option

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

 (1 comment) 

4 days ago • Added by: CITIZEN SCIENTISTS [a033]

Is the frequency of bowel movements related to the gut biome?

Is this related to diet? 1 Answer(s) / 100%  
 Is it related to age? 0 Answer(s) / 0%  
[Add my option](#)

 regularity, diet,  (1 comment) 

Dive deeper with these follow-up questions!

If so can it be changed?

If so, can it be changed?  
 Add my option

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

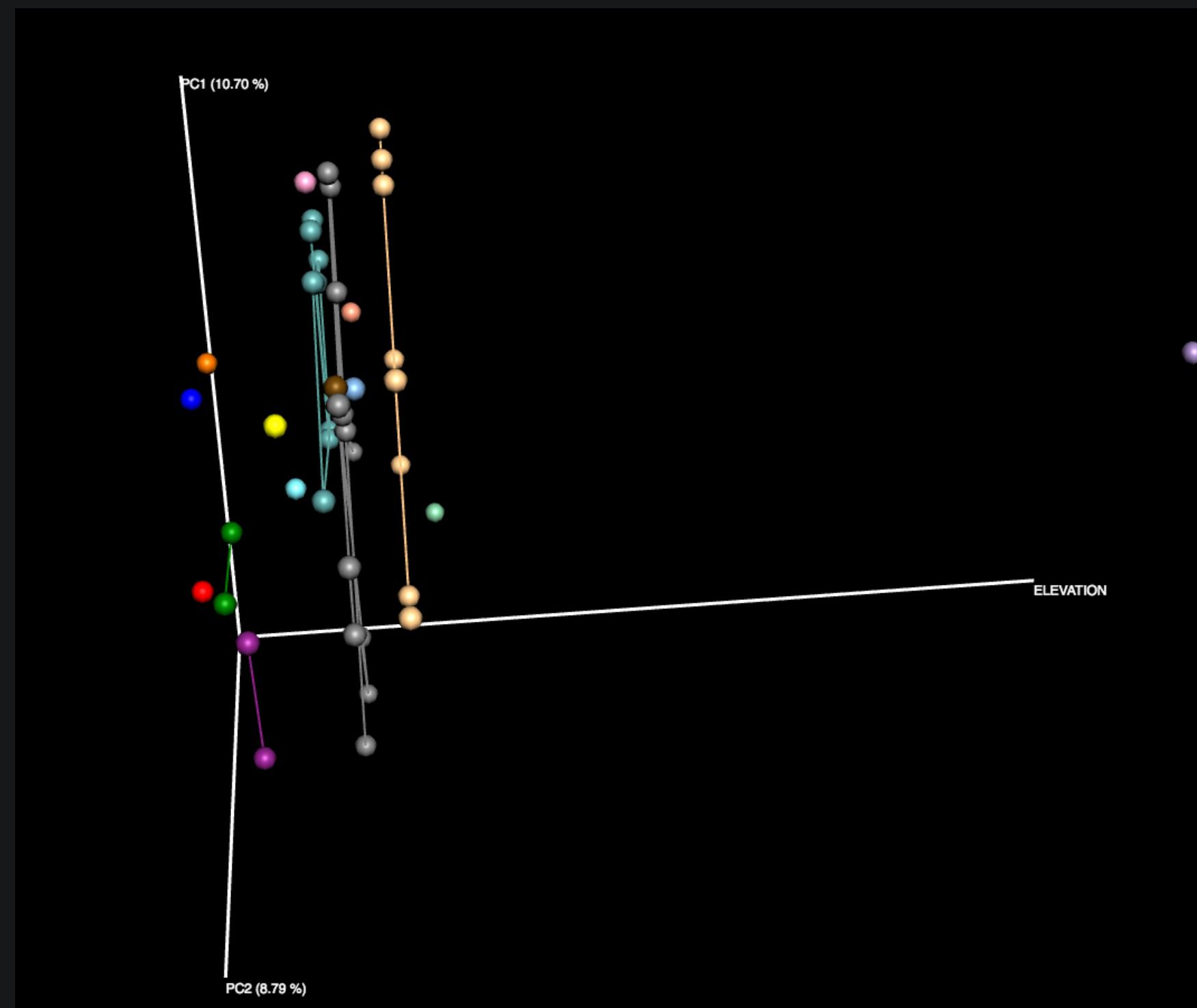
Requires clinical expertise to answer

Requires novices to understand limitations of nascent scientific domains

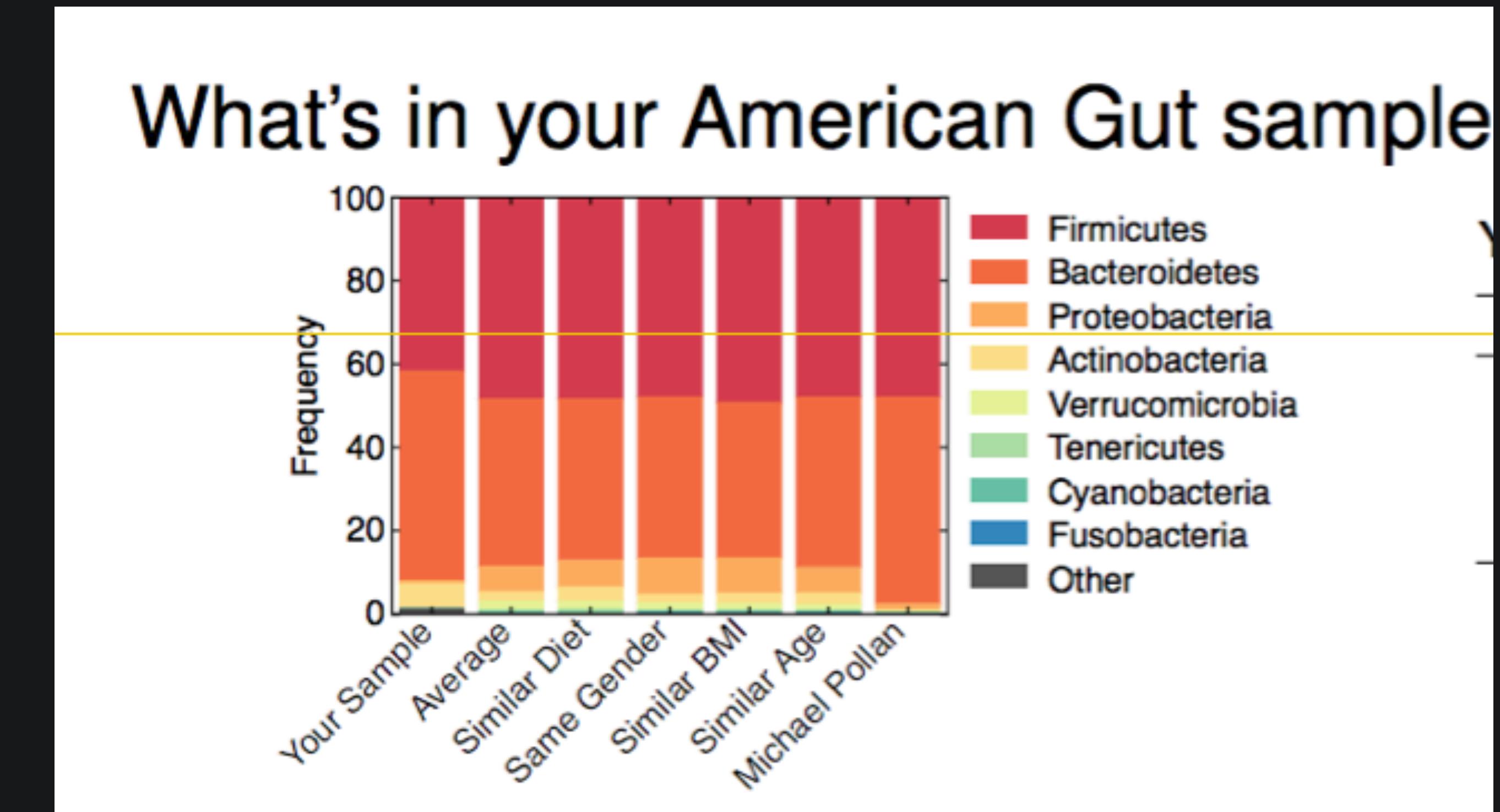
Microbiome science is far from providing prescriptive information

Requires substantial investment of time too!

# Challenge: Understanding multivariate microbiome data with crowd-responses is hard



PCoA plots confuse novices

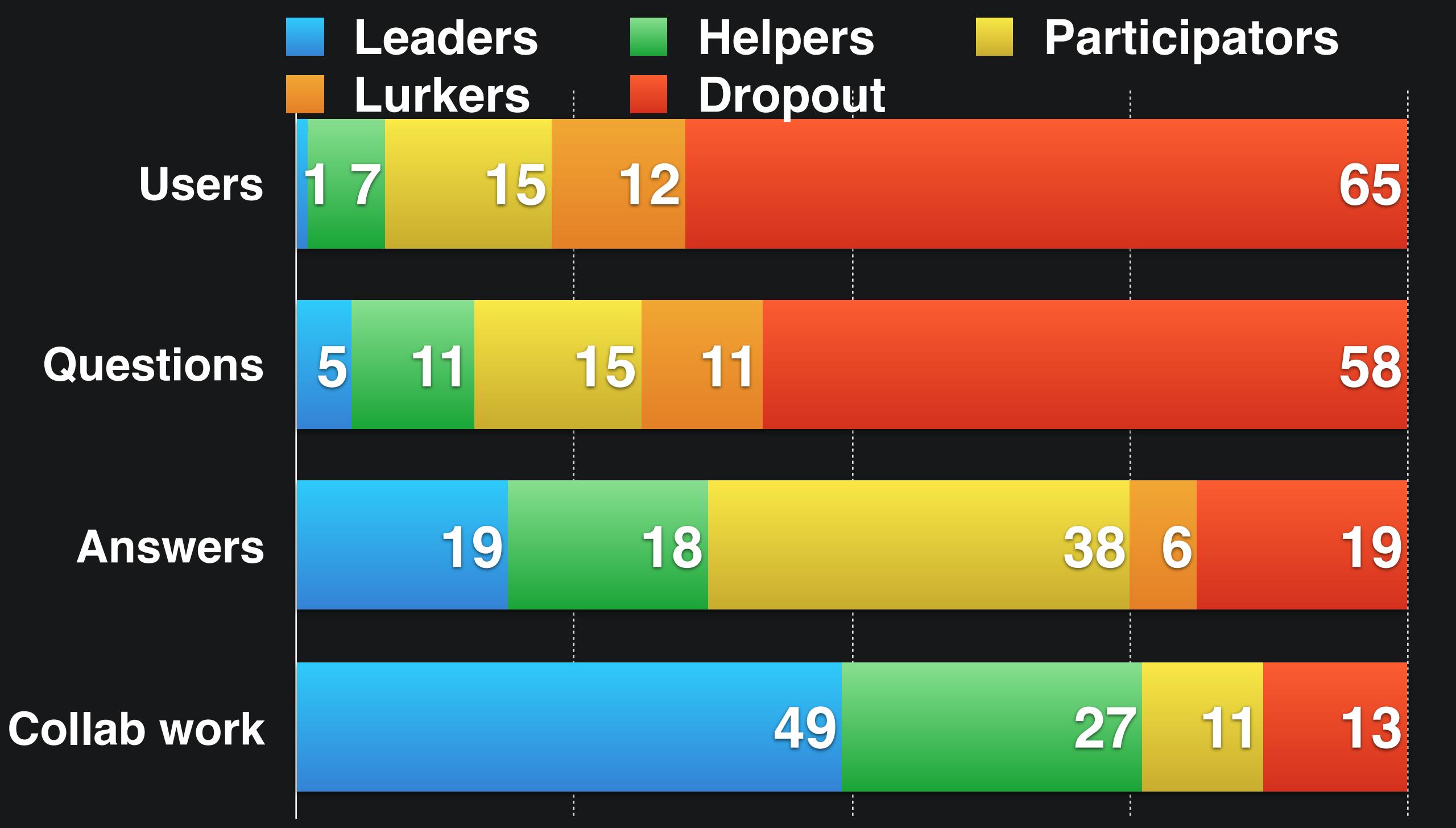


Microbiome data is difficult to interpret

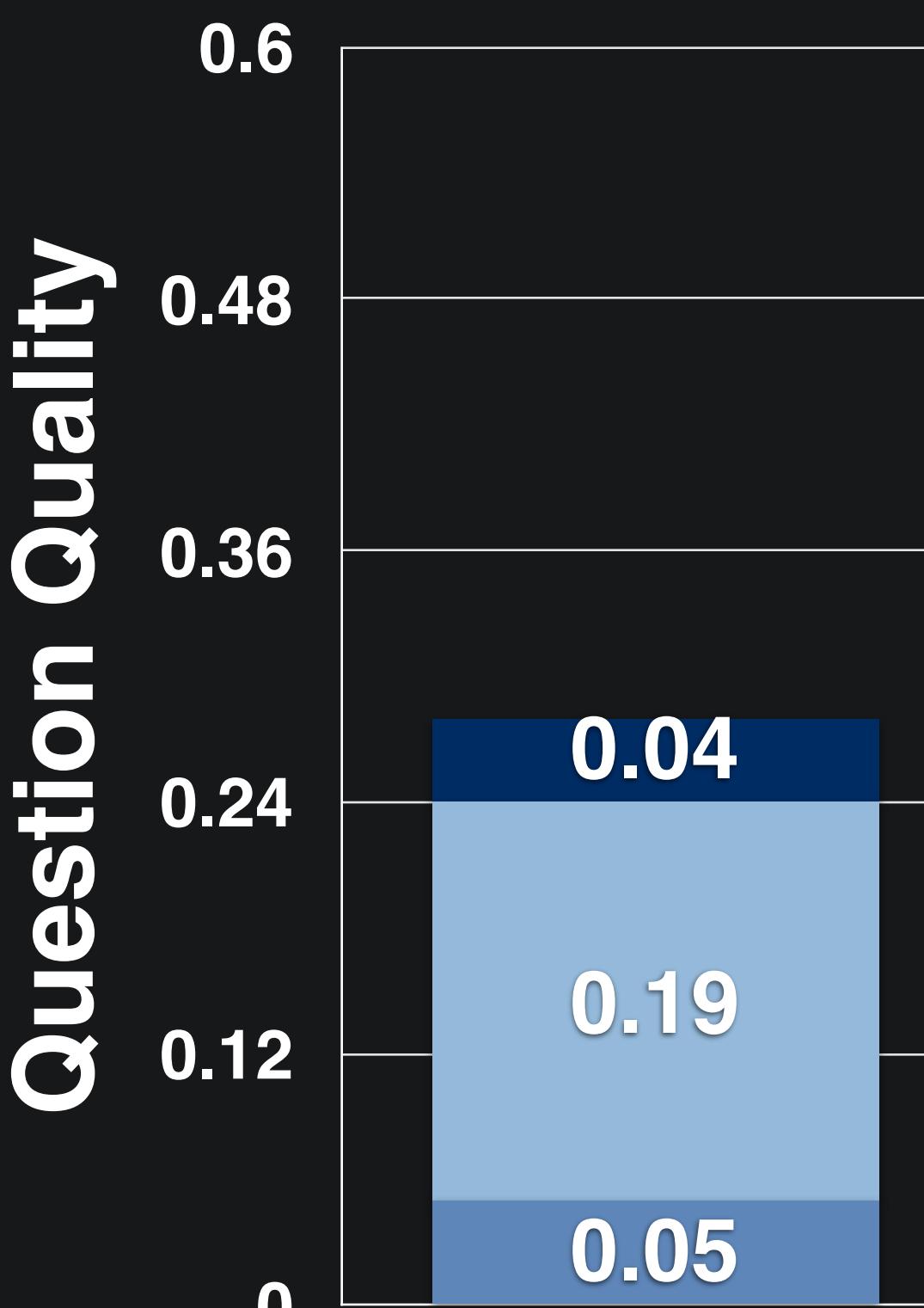
# Summary for hypotheses-generation. What next?



Novel hypotheses  
from lived experiences



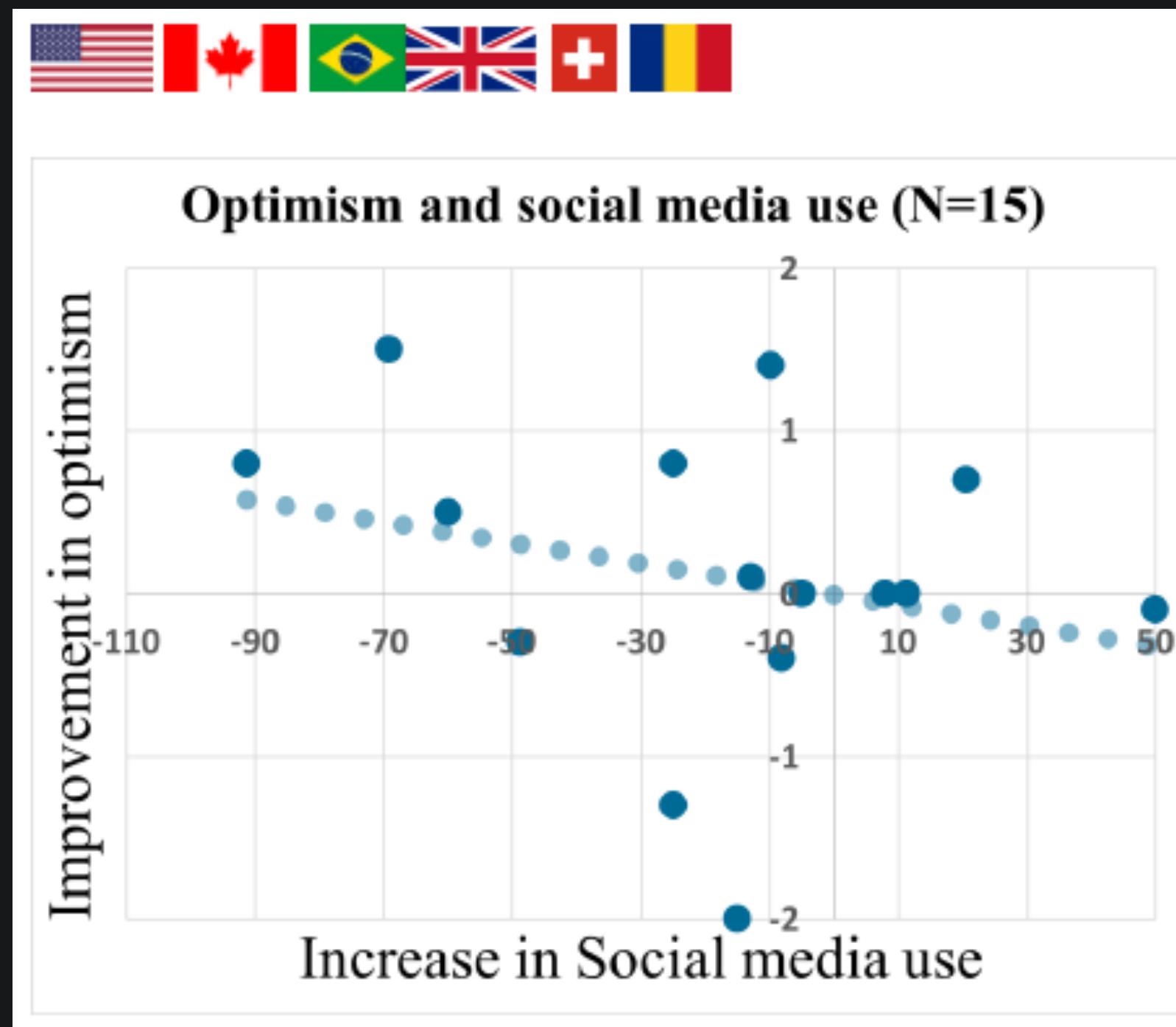
Distinct roles emerge



39

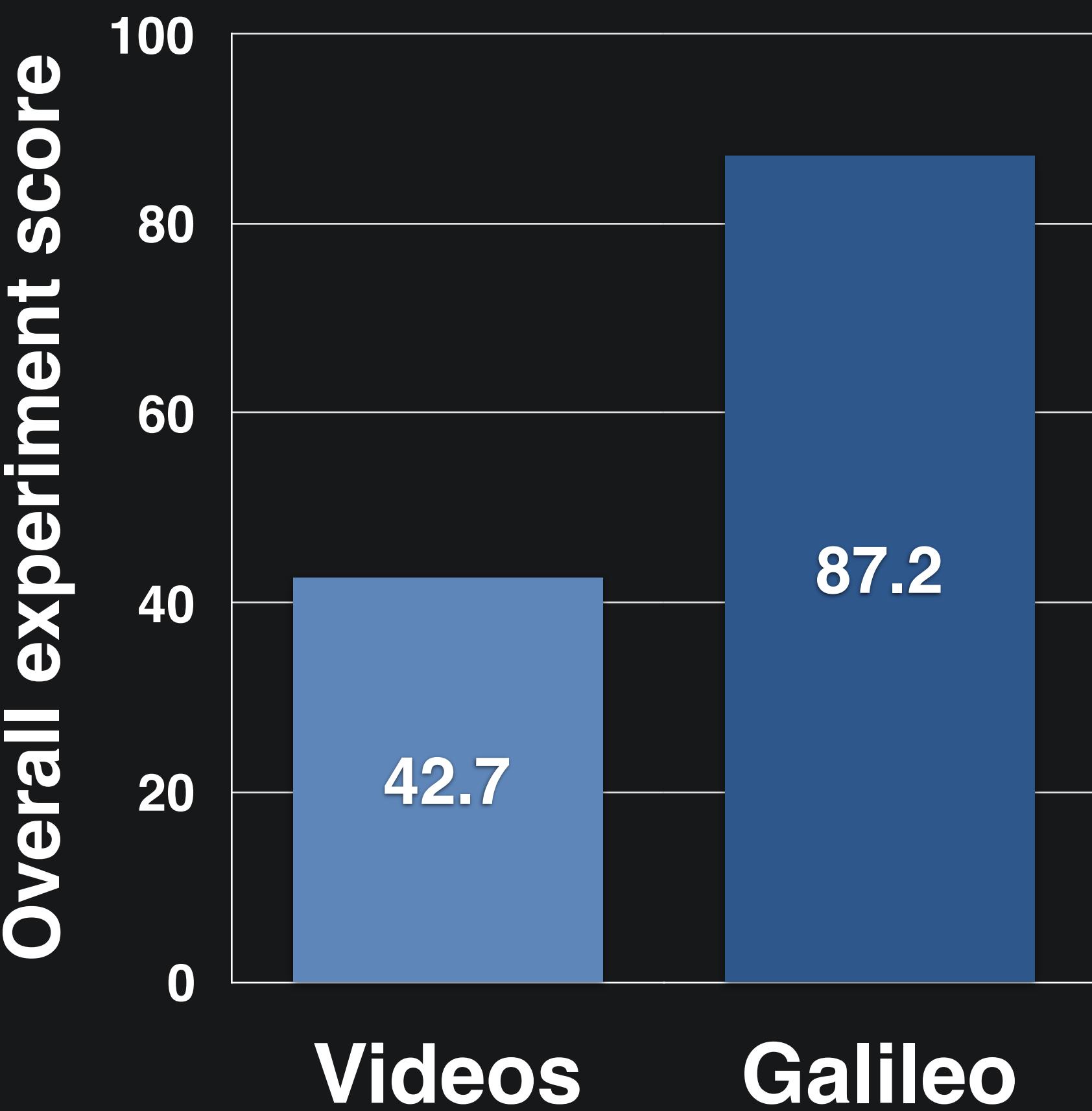
Neither

# Yes, communities can design and run experiments too!



The screenshot shows the Coursera platform interface. At the top, there's a search bar and navigation links. Below it, a course card for "Gut Check: Exploring Your Microbiome" is displayed, featuring logos for the University of Colorado Boulder and UC San Diego. The course has a rating of 4.7 stars from 521 reviews. Below the card, there are two smaller sections: "Microbiome - Reddit" with a link to https://www.reddit.com/r/Microbiome/ and "r/HumanMicrobiome" with a link to r/HumanMicrobiome.

The screenshot shows a post in the r/HumanMicrobiome subreddit. The title asks, "How long does it take for your microbiome to reflect the foods ...". The post has received 2,906 upvotes.

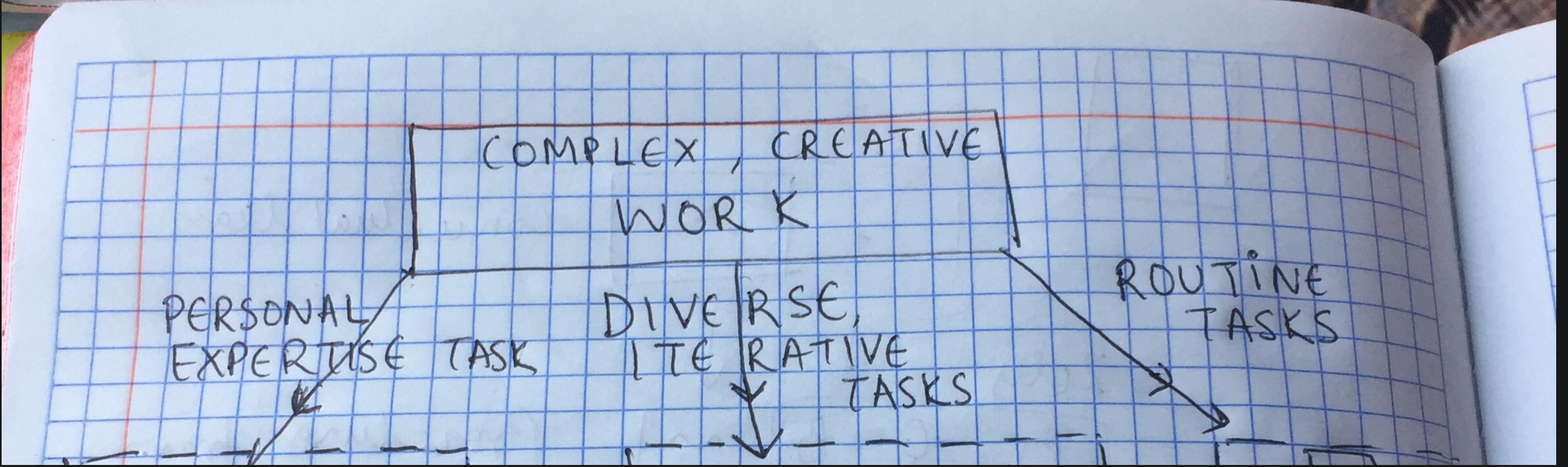


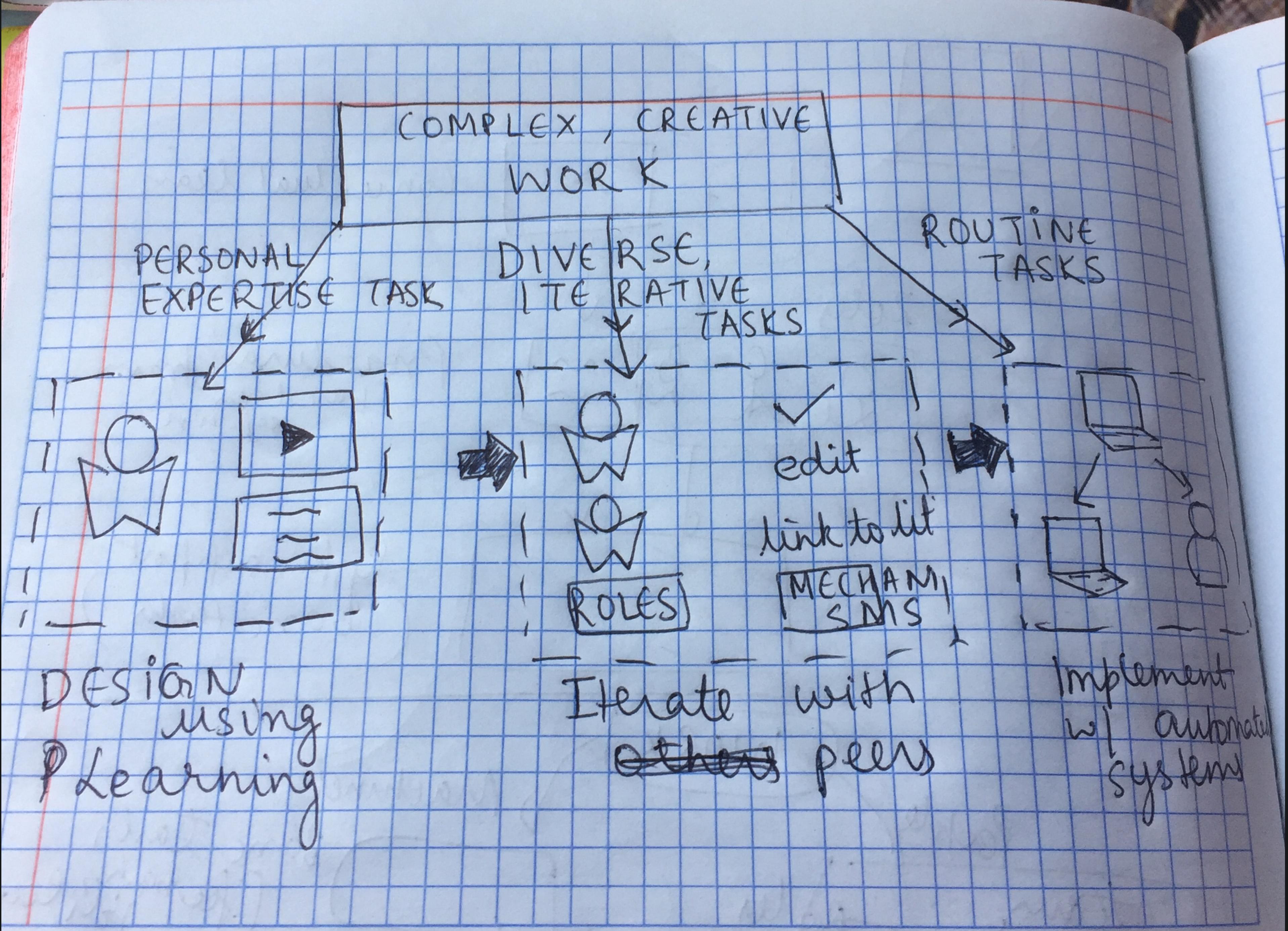
# Experimentation is hard(er)

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 similar to any creative work





# Insight

**Divide the activity of experimentation  
into tasks that exploit complementary  
strengths of creator, community, and  
computers**

# System Architecture for Experimentation

**Experiment Design Summary**

Hypothesis: Drinking lassi decreases bloatedness

Cause	Relation	Effect
Drinking lassi	decreases	bloating

Mechanism:

How is Drinking lassi manipulated?

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

How is bloating measured?

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

**Experiment Status**

What you've achieved so far:

- ✓ Designed your experiment
- ✓ Your experiment is now open for review

What's next:

To move ahead, you need to get at least 2 people to **review** your experiment!

Anyone with an internet access can review your experiment design in **5 mins!**

Does Drinking Kombucha affect bloatedness?

Created by / 2 months ago  
Reviewed by: 3  
Participant(s): 2

1 I would like to   
2 suffer from bloatedness  
3 are under 18 years of age  
4 are pregnant  
5 are potentially cognitively impaired  
6 are a prisoner or incarcerated

✓ I will begin following the instructions when I receive a notification about the experiment's start date  
✓ I will follow the experiment instructions every day for the duration of the experiment  
✓ I will provide quick responses to text messages to collect experiment data  
✓ I consent to using my data towards analysis to answer the study's question  
✗ I cannot review this experiment's design because that might bias my responses during the experiment  
✗ I cannot participate in any other experiment on Galileo during the course of this experiment

Once the experiment begins, you must follow these steps

1. DO NOT consume Kombucha
2. Continue performing your daily activities as usual
3. Measure effect: in the evening write down your bloatedness on a scale
4. Send you measurements to Gut Instinct

Measurement Scale (Bristol Stool Scale) for step 3

**The 7 types of poop**  
According to the Bristol Stool Scale

Type 1 Separate hard lumps, like nuts (hard to pass)

Type 2 Soft, shaped but lumpy

(EXPERIMENT DAY 2)  
Hello from Galileo! This is your 8:00 am reminder to measure "Drinking Kombucha" today. Was Drinking Kombucha absent or present in your day today? Reply Yes for present, No for absent.

Tue, Aug 28, 09:51  
Text Message  
No

1) Design (by creator)

2) Review (by peers)

3) Run (Machine)

Figure 4: 1) Participants can view a list of experiments. When they elect to join one, they 2) answer inclusion criteria, 3) consent to following the provided steps, and 4) receive instructions. 5) Participants receive daily, condition-specific requests, and respond with data and/or clarifying questions.

# Results: 1) Running Experiments

## Open Humans: Does using less social media increase optimism? (N=15)

Experiment Details	Review						
<p>Hypothesis: Using less social media increases optimism</p> <table><thead><tr><th>Cause</th><th>Relation</th><th>Effect</th></tr></thead><tbody><tr><td>Using less social media</td><td>increases</td><td>optimism</td></tr></tbody></table> <p><b>Mechanism:</b> there is some research into how consuming a lot of news will make you unhappy and that excessive Facebook consumption makes people miserable and depressed. And intuitively one could assume why: Being bombarded with bleak political news and seemingly overachieving friends boast about their achievements might not make you feel very optimistic about yourself and the state of the world.</p> <p><b>Related Work:</b> There is conflicting evidence about the impacts that social media has on our mental well-being. Some studies find that the use of e.g. Facebook increases people's satisfaction, social trust, civic engagement, and political participation. Other studies find the opposite, i.e. that quitting Facebook lead to a higher wellbeing. It seems that more research is clearly needed</p> <p>How is Using less social media manipulated?</p> <ul style="list-style-type: none"><li>Participants measure Amount of Using less social media in minutes spent on social media platforms</li></ul> <p>How is optimism measured?</p> <ul style="list-style-type: none"><li>Participants measure Rating of optimism on a scale of 1 to 5 (1 being 😢 (very low optimism) and 5 being 😊 (very high optimism))</li></ul>	Cause	Relation	Effect	Using less social media	increases	optimism	<p>Feedback request from the creator of the experiment: <b>I am not 100% sure whether the difference between different kinds of social media is clear enough. Basically I want to tell people that chatting is okay, but please stay away from the likes of Twitter, Facebook &amp; co.</b></p> <p><b>People's review of the hypothesis</b></p> <p>Is the cause specific? Yes  4   No  0</p> <p>Is the effect specific? Yes  3   No  1</p> <p><b>Dbear:</b> 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.</p>
Cause	Relation	Effect					
Using less social media	increases	optimism					

# Results: 1) Running Experiments

## Open Humans: Does using less social media increase optimism? (N=15)

Experiment Details

Hypothesis: Using less social media increases optimism

Cause	Relation	Effect
Using less social media	increases	optimism

Mechanism:

there is some research into how consuming a lot of news will make you unhappy and that excessive Facebook consumption makes people miserable and depressed. And intuitively one could assume why: Being bombarded with bleak political news and seemingly overachieving friends boast about their achievements might not make you feel very optimistic about yourself and the state of the world.

Related Work:

There is conflicting evidence about the impacts that social media has on our mental well-being. Some studies find that the use of e.g. Facebook increases people's satisfaction, social trust, civic engagement, and political participation. Other studies find the opposite, i.e. that quitting Facebook lead to a higher wellbeing. It seems that more research is clearly needed

### How is [Using less social media](#) manipulated?

- Participants measure [Amount of Using less social media](#) in minutes spent on social media platforms
- Reminder sent every day at [7 pm](#) with the following message:

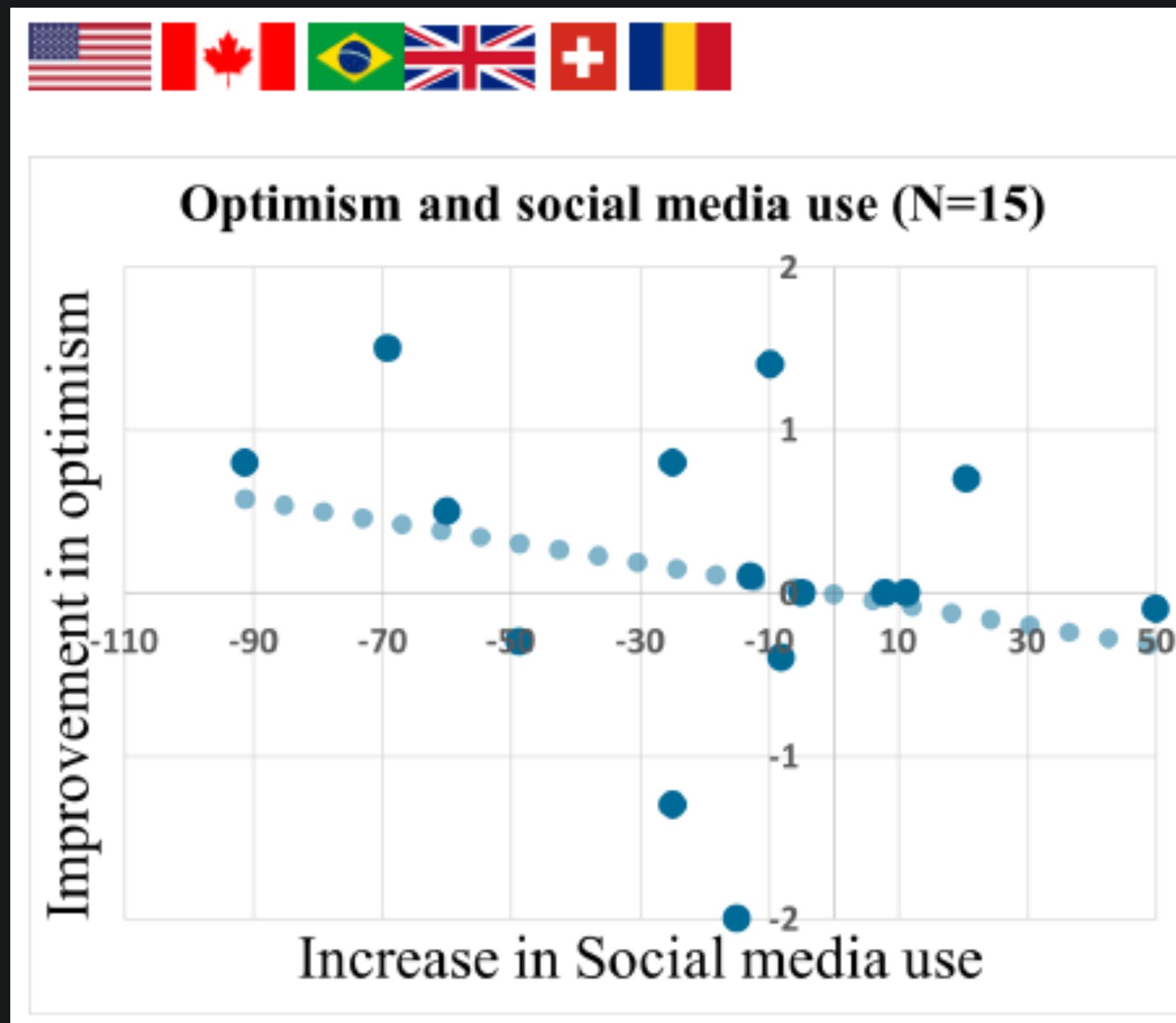
### How is [optimism](#) measured?

- Participants measure [Rating of optimism](#) on a scale of 1 to 5 (1 being 😢 (very low optimism) and 5 being 😊 (very high optimism))
- Reminder sent every day at [8 pm](#) with the following message:

- Design to launch: 13 days**
- Experimenter: Community leader (Germany)**
- Review**
  - Community members added 76 boolean responses and 16 comments**
  - Themes: Make details specific & improve data quality**

# Results

## Open Humans: Does using less social media increase optimism? (N=15)



- **Pilot: Participants did not want to be randomly assigned + Forget instructions sent early in the morning**
- **Publicity**
  - OH emails
  - Online posts
- **Result**
  - Reduced social media correlating with increased optimism ( $r=0.25$ )

# Results: 2) Designing Experiments

## What kind of experiments do people design?

(N=50 experiments)

# Measures Question quality coded by independent raters

*Structure (13pts)*

*Hypothesis: Is the hypothesis concrete?*

*Measurement: Are the cause and effect properly manipulated/measured?*

*Conditions: Are the conditions designed correctly?*

*Steps: Are experimental steps clear?*

*Criteria: Are the participation criteria appropriate?*

*Run: Can the overall experiment be run as is?*

# Results: 2) Designing Experiments

## Do people design structurally sound experiments? Yes. ( $N=50$ experiments)

*Structure (13pts)*

**Hypothesis:** *Is the hypothesis concrete?*

**Measurement:** *Are the cause and effect properly manipulated/measured?*

**Conditions:** *Are the conditions designed correctly?*

**Steps:** *Are experimental steps clear?*

**Criteria:** *Are the participation criteria appropriate?*

**Run:** *Can the overall experiment be run as is?*

*Mean structure score for the experiment was 10/13*

*People scored more than 90% on 10 of 13 measures*

*Fewer participants created*

- \* *a minimal-pairs experiment (50%),*
- \* *providing clear steps (75%), and*
- \* *providing criteria (75%)*

# Results: 2) Designing Experiments Do people draw from personal insights?

(N=50 experiments)

*Content (3pts)*

**Novelty: Is there a chance the world will  
learn something? 28%**

**Popularity: Is the world already curious  
about this hypothesis? 82%**

**Diet (dietary styles, alcohol, fermented  
foods), Medicines, Alternative treatments**

**Lived experience?: Did the hypothesis  
come from personal experience? 86%**

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**Lived experience?: Did the hypothesis come from personal experience? 86%**

*Avoiding foods high in lectins cures long-term post-infectious diarrhea,  
Drinking kombucha regularly reduces joint inflammation/arthritis symptoms*

*Having dry mouth (or Sjogren's Syndrome) promotes the growth of less beneficial gut microbes*

*Eating yogurt makes a person have a more regular bowel movement  
Personal health and performance: 90%*

# Results: Designing Experiments

## What kind of feedback do people

provide? (N=50 experiments)

*Three types*

**Improving structural  
correctness**

**Providing domain-specific  
knowledge**

**Participant's experience**

*"A simplistic Likert scale seems like a bad idea. There has to be something better than this. At least a couple questions? Like, optimism, excitement, depression, anxiety?"*

*"A1C is measured monthly and won't change after 1g. You mean the BG value?"*

# Results: 3) Designing Experiments

## Does Galileo's procedural training enable better experimental designs?

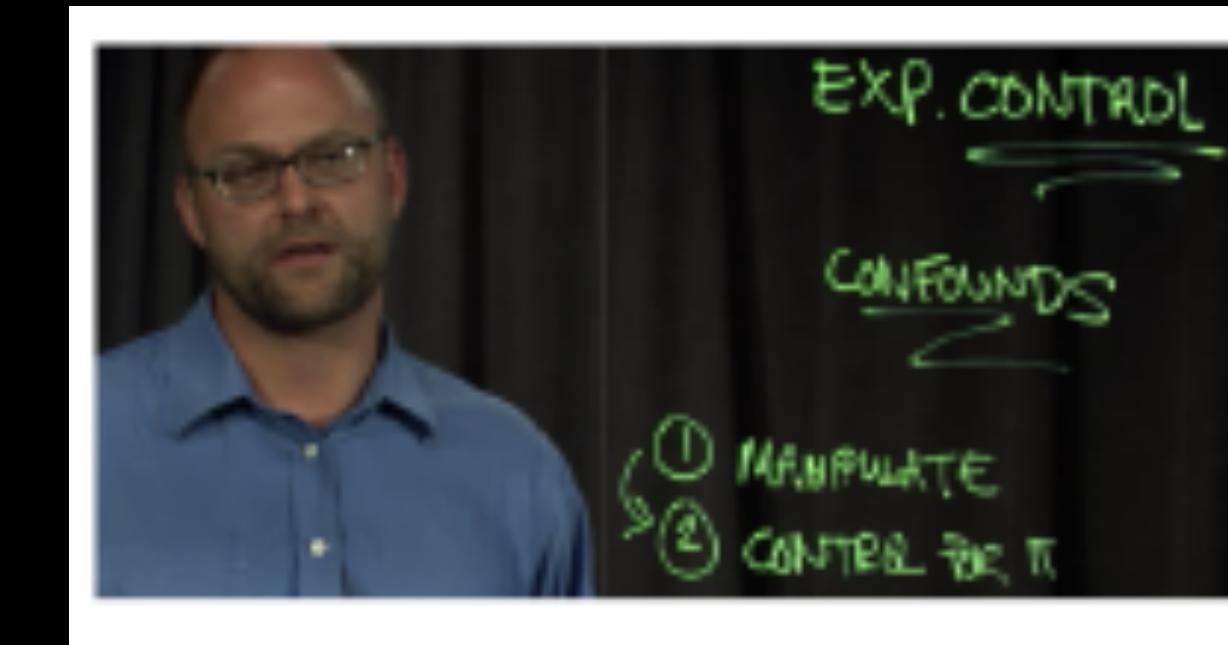
# Method

## Between-subjects experiment (N=72)

### with two conditions: Videos and Galileo

Hypothesis

**Structured procedural training yields higher quality experimental designs than learning from lecture videos**



- Minimal pairs: The experimental steps in the two conditions should differ in only one step. Your experiment should strictly manipulate only one behavior for a [true minimal pairs experiment](#) ↗
- Minimize confounders: Participants should not perform other activities ([called confounders](#)) ↗ that might contribute to the cause and/or effect

# Measures Question quality coded by independent raters

*Structure (13pts)*

*Hypothesis: Is the hypothesis concrete?*

*Measurement: Are the cause and effect properly manipulated/measured?*

*Conditions: Are the conditions designed correctly?*

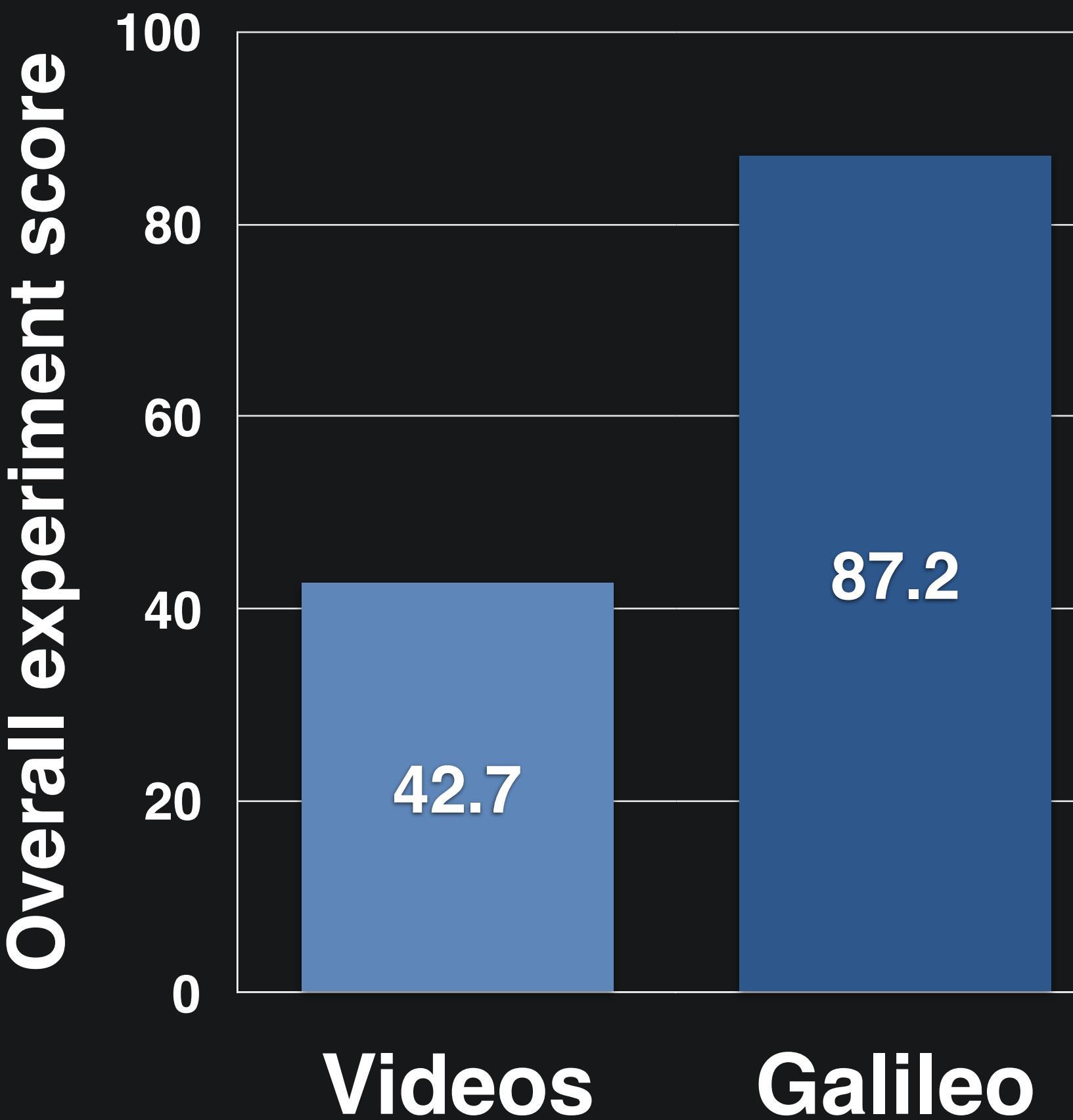
*Steps: Are experimental steps clear?*

*Criteria: Are the participation criteria appropriate?*

*Run: Can the overall experiment be run as is?*

# Results

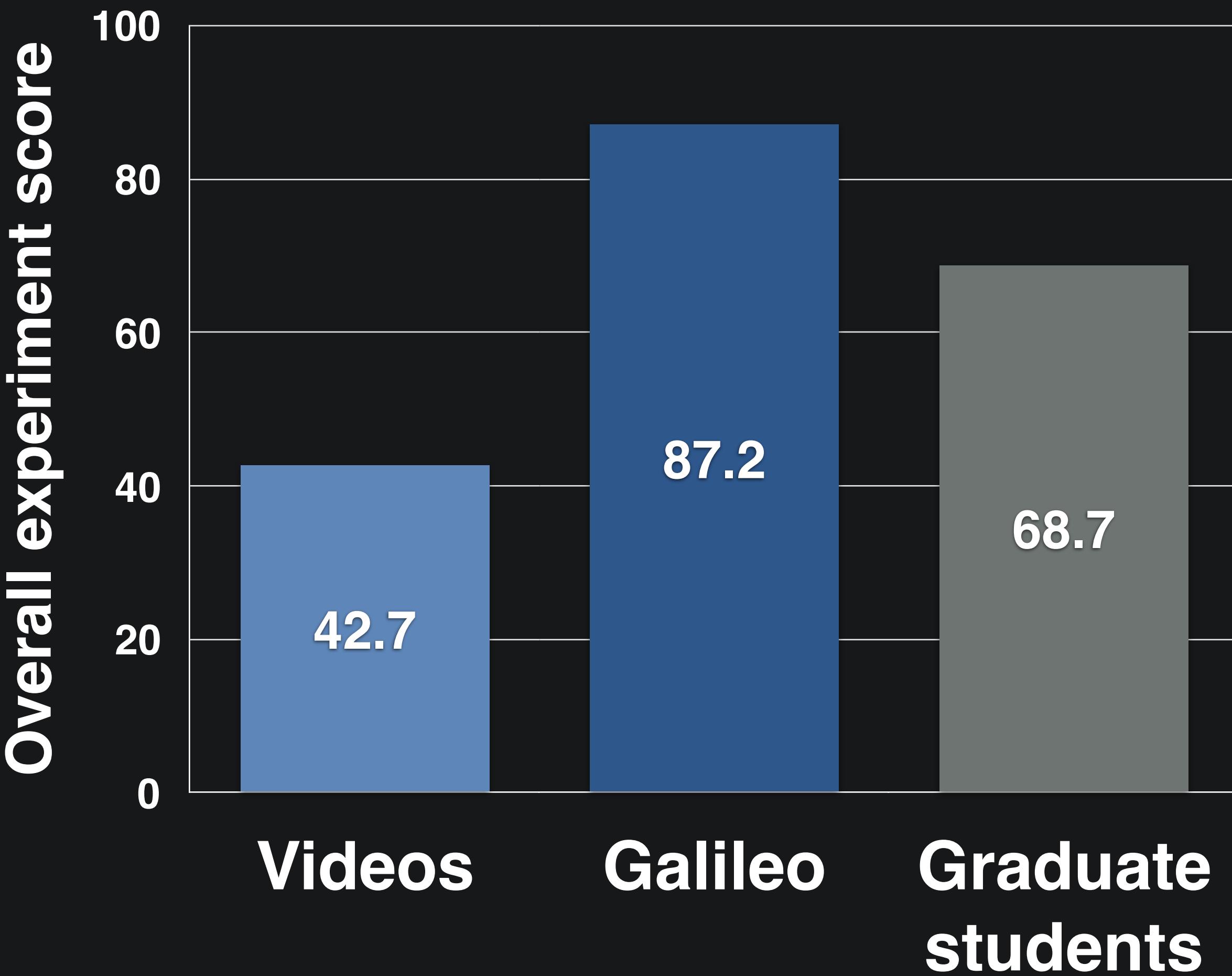
Galileo participants created higher-quality experiments ( $N=72$ )



**Galileo improves experimental design.**  $M=11.3$  vs.  $M=5.6$ ;  
Mann-Whitney  $U = 108$ ,  $n_1 = n_2 = 36$ ,  $p < 0.005$

# Results

Galileo participants created higher-quality experiments (N=72)



**Galileo improves experimental design.** M=11.3 vs. M=5.6;  
Mann-Whitney U =108, n<sub>1</sub> = n<sub>2</sub> = 36, p < 0.005

**Novices with Galileo created better experimental designs than experts without Galileo.** M=11.3 M=8.9;  
Mann-Whitney U=104, n<sub>1</sub>=15, n<sub>2</sub>=36,  
p<0.005

# Why did Galileo help?

- Two strategies when watching videos:
  - all-at-once watching: floods the mind, making retention difficult
  - search-when-needed: interrupts people's flow, replacing the attention on design with a task of locating needed information
- Galileo provided in-context help
  - the interface provided sufficient examples
  - videos were slow
- 25 minutes to reach full productivity
  - 27 mins to design an exp

# FUTURE PLANS: JOIN US!

1. **Scaling up** to make experimentation richer and seamless  
e.g., placebo-controlled experiments
2. **Scaling out** to multiple domains  
e.g., Circadian rhythms..
3. **Deploying in classrooms** and scientific outreach program

# Gut Instinct: Creating Scientific Theories with Online Communities

[gutinstinct.ucsd.edu](http://gutinstinct.ucsd.edu)

Scripps Research Translational Institute  
Oct 26 2018

Vineet Pandey  
 @vineet1pandey  
UC San Diego  
The Design Lab