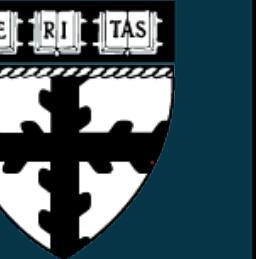


Social Computing Systems to Deepen Public Contributions to Science

Department of X
University of Y

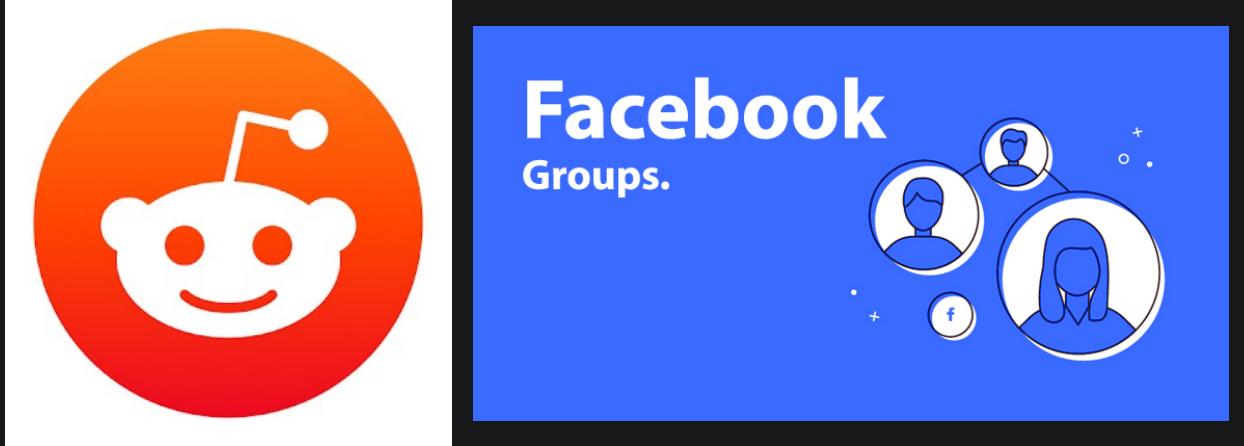
Research support: NSF, NIH; Google, SAP, Sony; Biogen; Ataxia-Telangiectasia Children's Project

Vineet Pandey
 | Harvard John A. Paulson
School of Engineering
and Applied Sciences

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How might communities
access scientific expertise
and high-quality data
using online platforms?

How might communities access scientific expertise and high-quality data using online platforms?



Patients and caregivers,
Amateur scientists

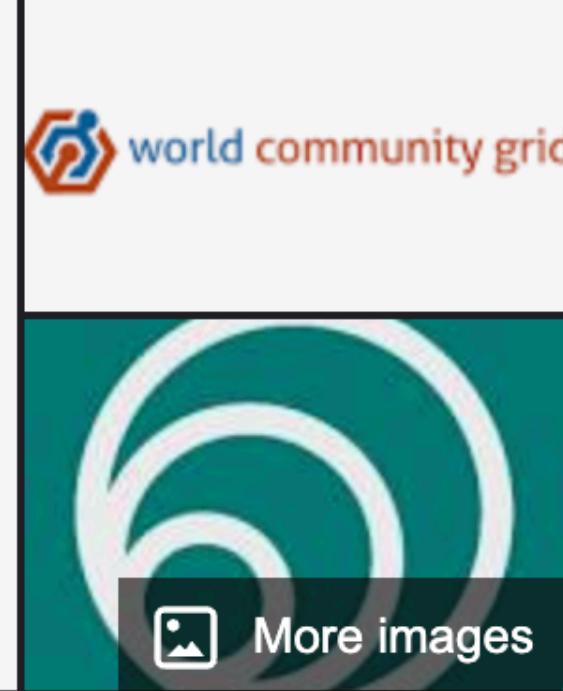
Experimentation

Support clinical
research

State of Citizen Science

2000s: Heterogenous compute resources aggregated by experts to solve computationally difficult problems

World Community Grid



 More images

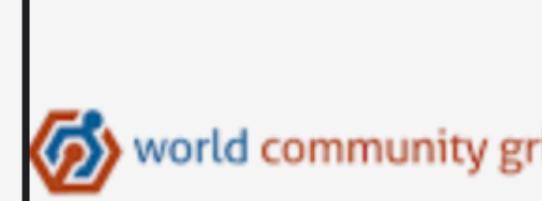
 worldcommunitygrid.org

World Community Grid is an effort to create the world's largest public computing grid to tackle scientific research projects that benefit humanity.

State of Citizen Science

2000s: Heterogenous compute resources aggregated by experts to solve computationally difficult problems

World Community Grid



[More images](#)

worldcommunitygrid.org

World Community Grid is an effort to create the world's largest public computing grid to tackle scientific research projects that benefit humanity.

My Contribution

Welcome back **vineetp**
Registered Member Since: 9/20/10 11:47:04 (UTC)

My Contribution		My Team: Dinosaur Comics - qwantz dot com	
Total Run Time (y:d:h:m:s)	0:005:06:46:39 (#587,655)	Total Run Time (y:d:h:m:s)	3856:186:10:19:08 (#46)
Points Generated (Rank)	9,198 (#561,408)	Points Generated (Rank)	4,701,139,199 (#51)
Results Returned (Rank)	26 (#553,212)	Results Returned (Rank)	8,435,289 (#53)

Statistics By Project

Statistics Last Updated: 1/8/19 00:06:02 (UTC) [4 hour(s) ago]

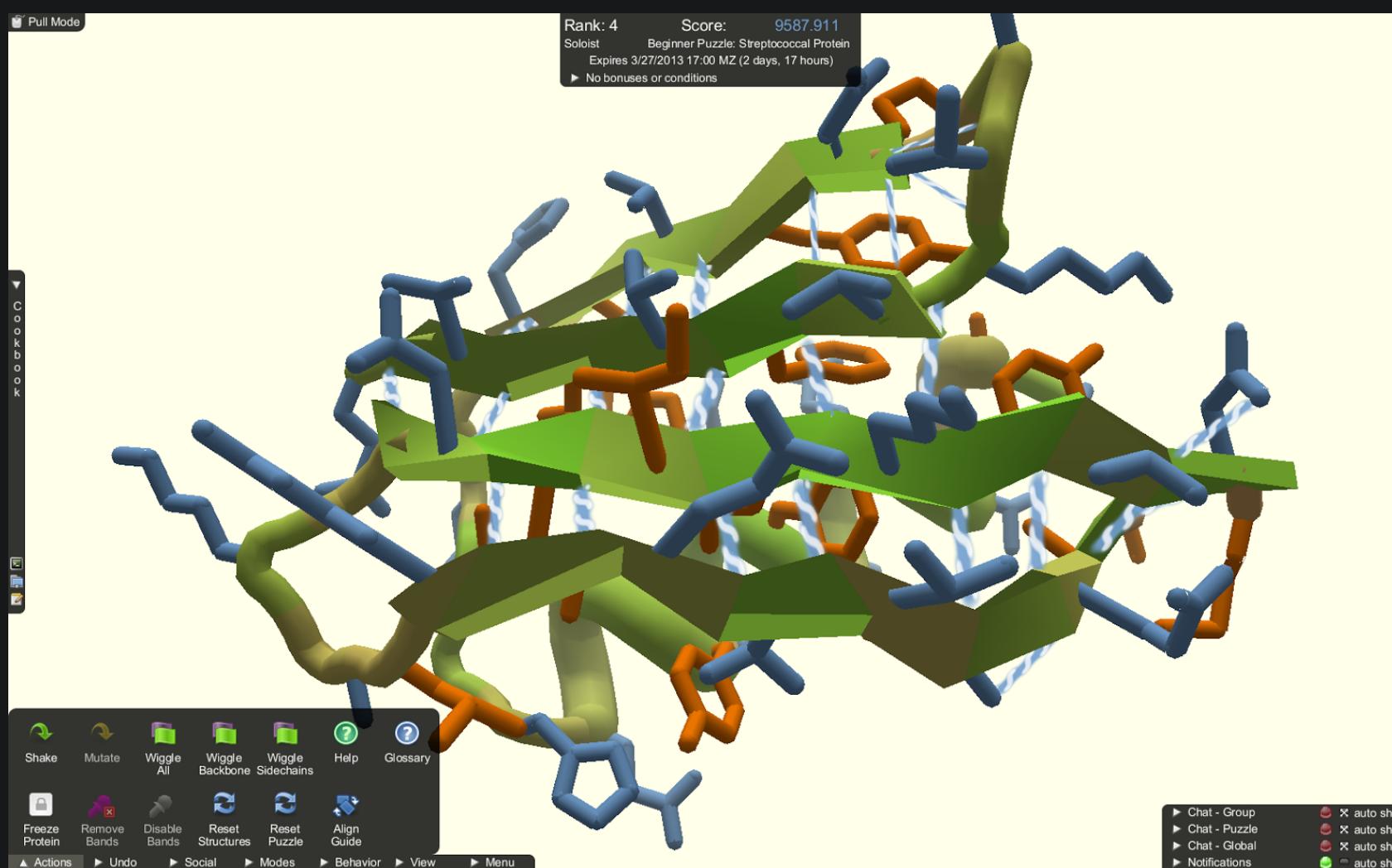
Project	Points Generated	Results Returned	Total Run Time (y:d:h:m:s)	Badges Earned
Computing for Clean Water	2,369	4	0:001:09:45:38	
Help Cure Muscular Dystrophy - Phase 2	1,327	4	0:000:17:41:23	
Help Fight Childhood Cancer	551	1	0:000:09:47:00	
Help Conquer Cancer	2,068	13	0:001:01:02:33	
Human Proteome Folding - Phase 2	2,273	3	0:001:06:43:37	
FightAIDS@Home	610	1	0:000:09:46:28	

Recruited Volunteers

Badge Earned

State of Citizen Science

2010s: People's perceptual skills aggregated by experts to solve computationally difficult problems



Folding protein structures

Foldit

Predicting protein structures with a multiplayer online game. Seth Cooper, Firas Khatib, Adrien Treuille. Nature 2010.

≡

SCIENTIFIC AMERICAN®

TECHNOLOGY

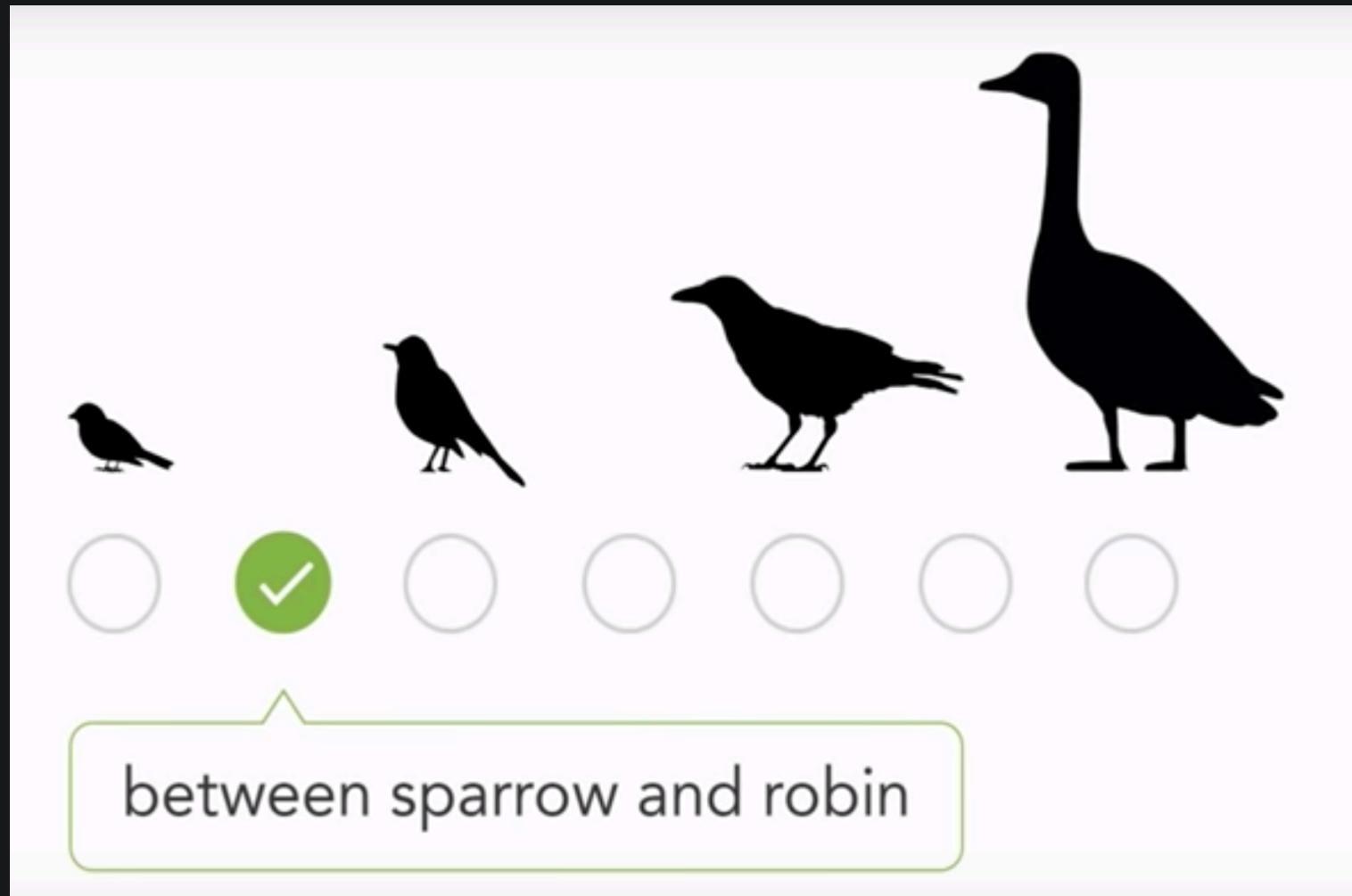
Foldit Gamers Solve Riddle of HIV Enzyme within 3 Weeks

The online game poses protein-folding puzzles, and participants provided insights recently that solved the structure of an enzyme involved in reproduction of HIV

By Michael J. Coren, Fast Company on September 20, 2011

State of Citizen Science

2010s: People's data (and geo-location) aggregated by experts to solve logically difficult problems



Tracking bird migration eBird App

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. Biological Conservation 2009.



State of Citizen Science

People's
perceptual skills
and data

Computationally or
logistically difficult
problems

Defined by
experts

State of Citizen Science

People's
perceptual skills
and data

Computationally or
logistically difficult
problems

Defined by
experts

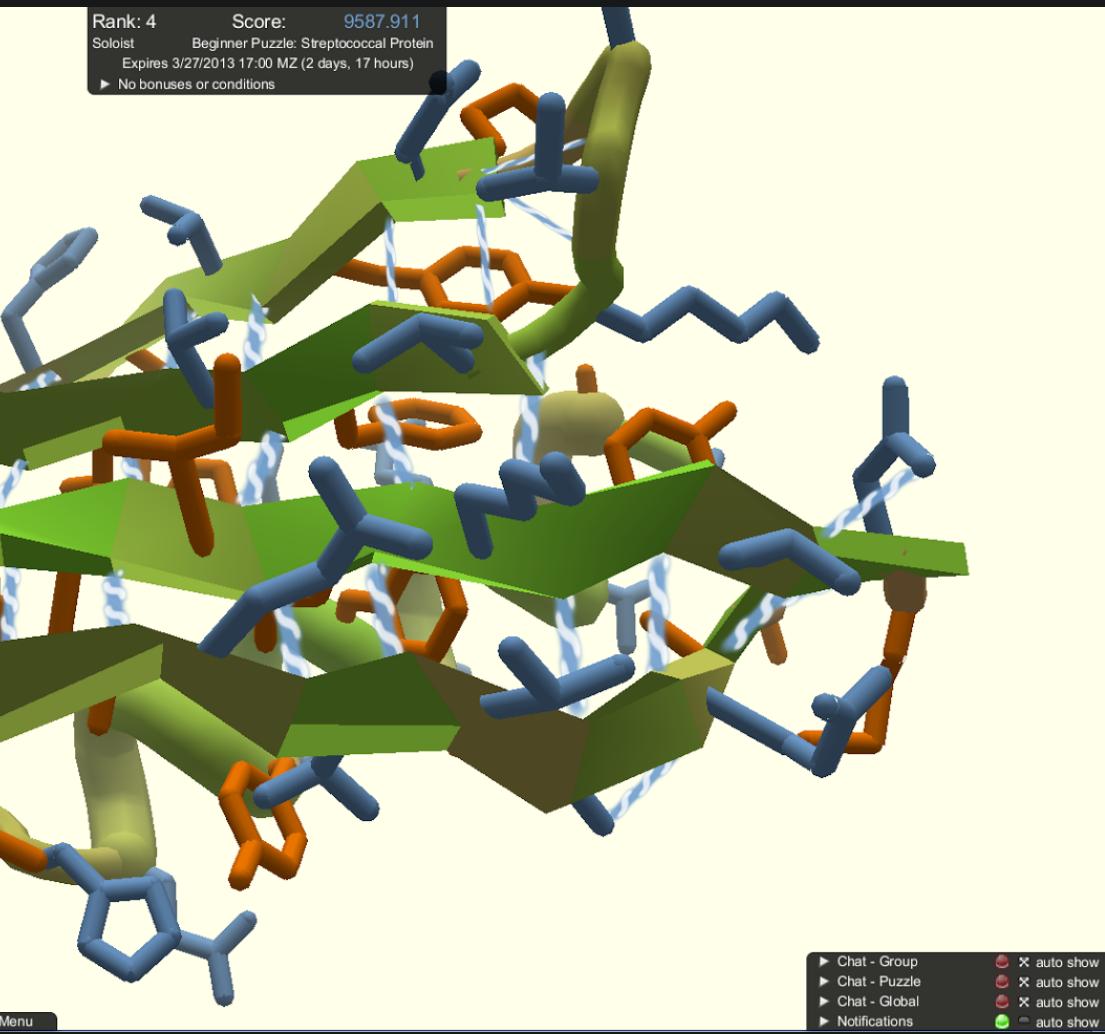
People's lived
experience

Personally-
meaningful
questions

Designed by
communities



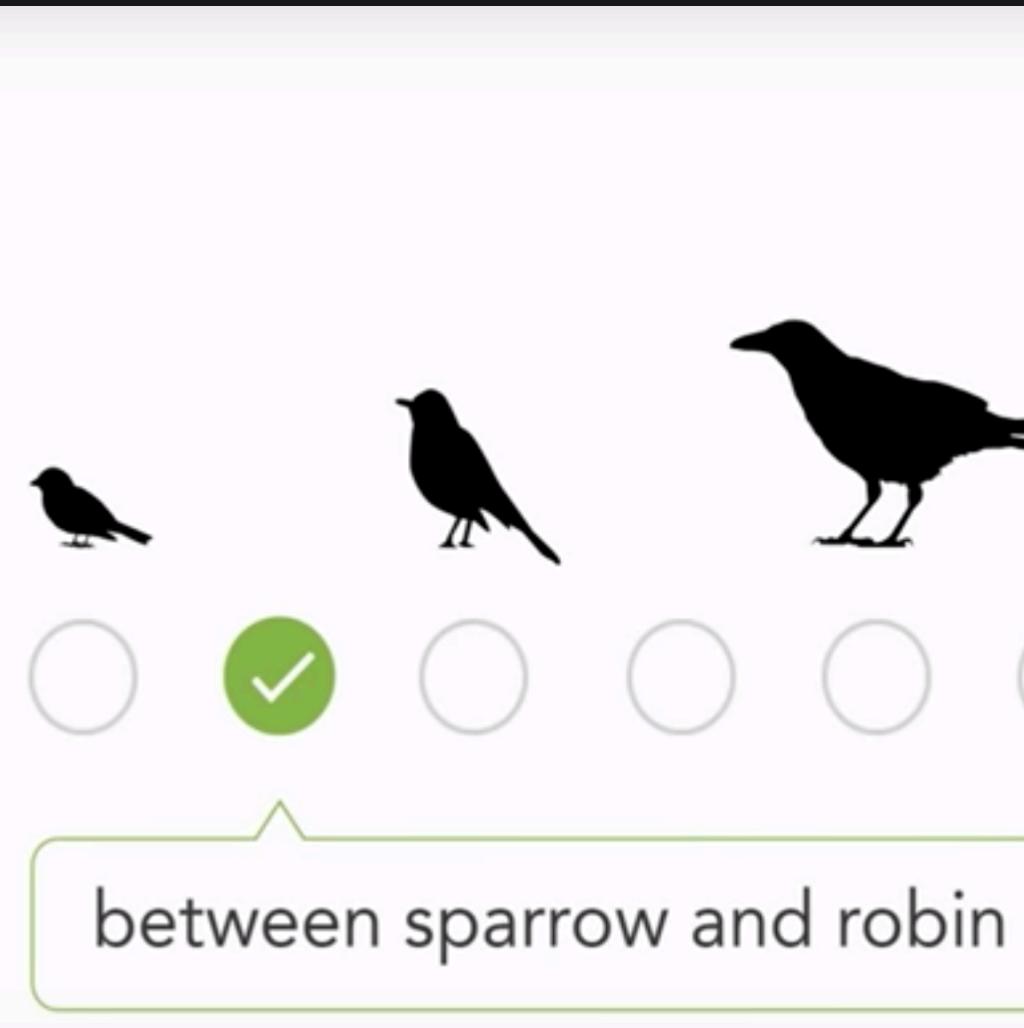
People need better knowledge support for complex work



...

Generating hypotheses
Experimentation
Data Analysis
Communication: Writing+Talks

...



People need better knowledge support for complex work



Do fermented foods
help the gut?

People need better knowledge support for complex work



Do fermented foods
help the gut?

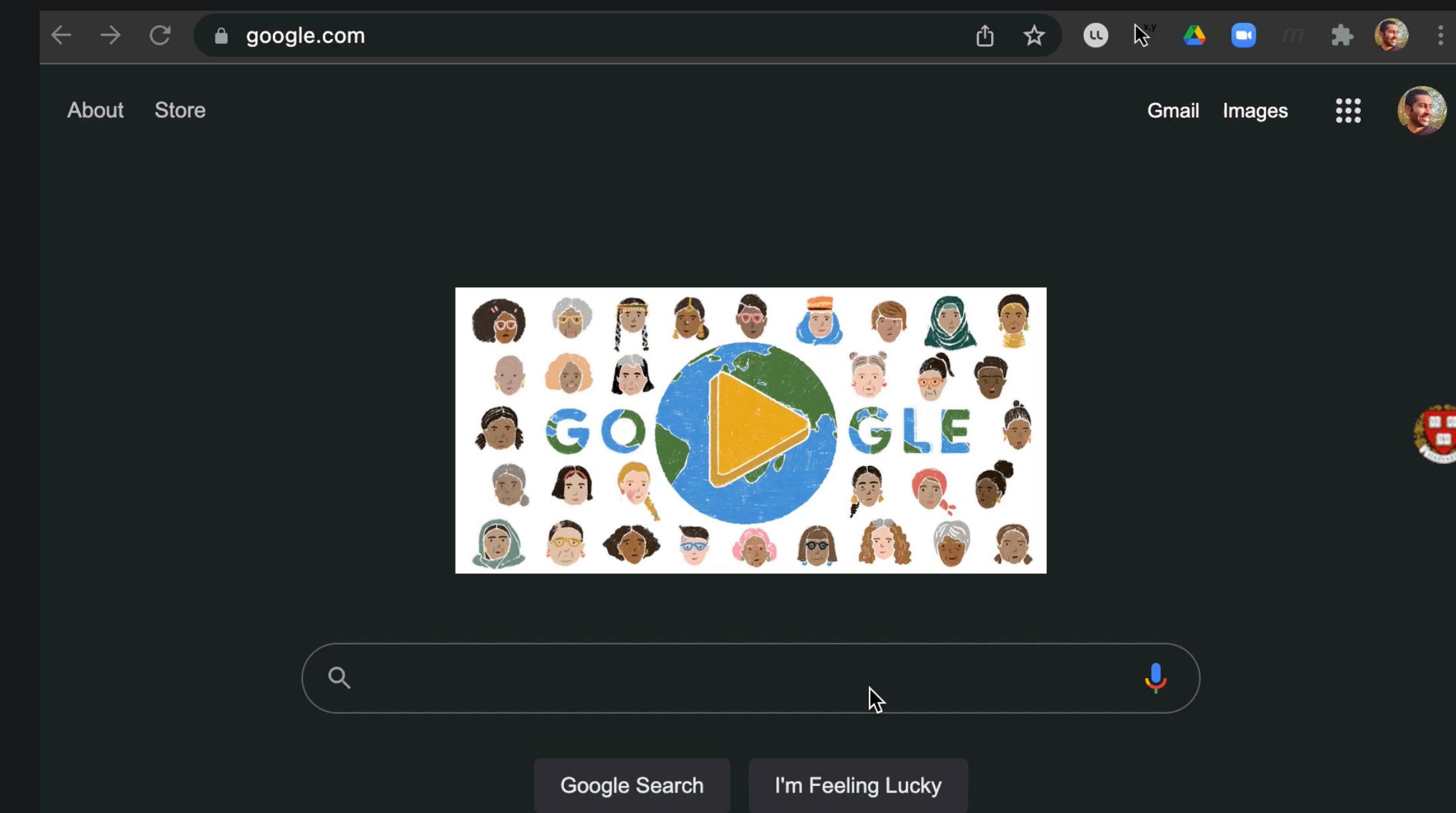
Hypothesis

- > Design an experiment
- > Review with peers
- > Recruit participants
- > Implement consistently

People need better knowledge support for complex work



Do fermented foods
help the gut?



People need better knowledge support for complex work



Do fermented foods
help the gut?

- Hypothesis
- Design
- Review
- Recruit
- Implement

People rarely start
because they don't
know what to do
and how to do it

People need better knowledge support for complex work



Do fermented foods
help the gut?

- Hypothesis
- Design
- Review
- Recruit
- Implement

WHAT (Conceptual knowledge)
Concepts, principles, theories

HOW (Procedural knowledge)
Methods, procedures, operation

People need better social support for complex work



Hypothesis

- Design
- Review
- Recruit
- Implement

Do fermented foods help the gut?

People need better social support for complex work



Do fermented foods help the gut?

Hypothesis
→ Design
→ Review
→ Recruit
→ Implement

Find motivated communities

Respect community roles, motivation, needs

Manually integrating learning material and social network makes scientific work challenging for novices



Do fermented foods help the gut?

Hypothesis
→ Design
→ Review
→ Recruit
→ Implement

Knowledge

Social capital

Collaborating for science

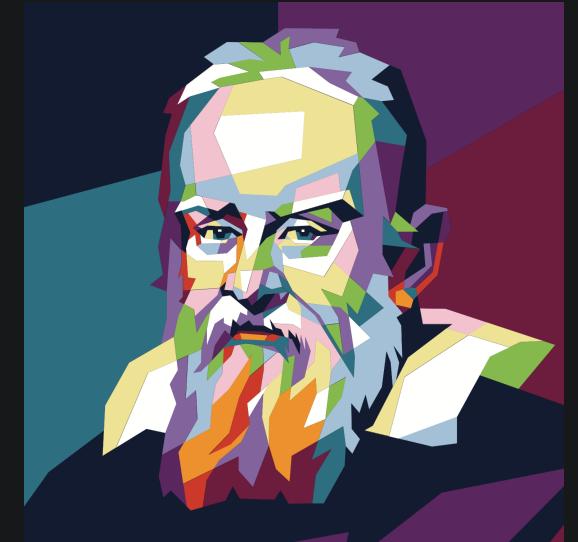
Creating
hypotheses



American Gut Project, Coursera learners

ACM CHI 2017, ACM Learning at Scale
2018

Collaborative
experimentation



Fermenters, Open science communities

ACM CHI 2021, American Society of
Microbiology

At home
assessments



Rare Disease Community,
Clinical researchers

The Cerebellum, ACM (in submission)

Collaborating for science

Creating
hypotheses



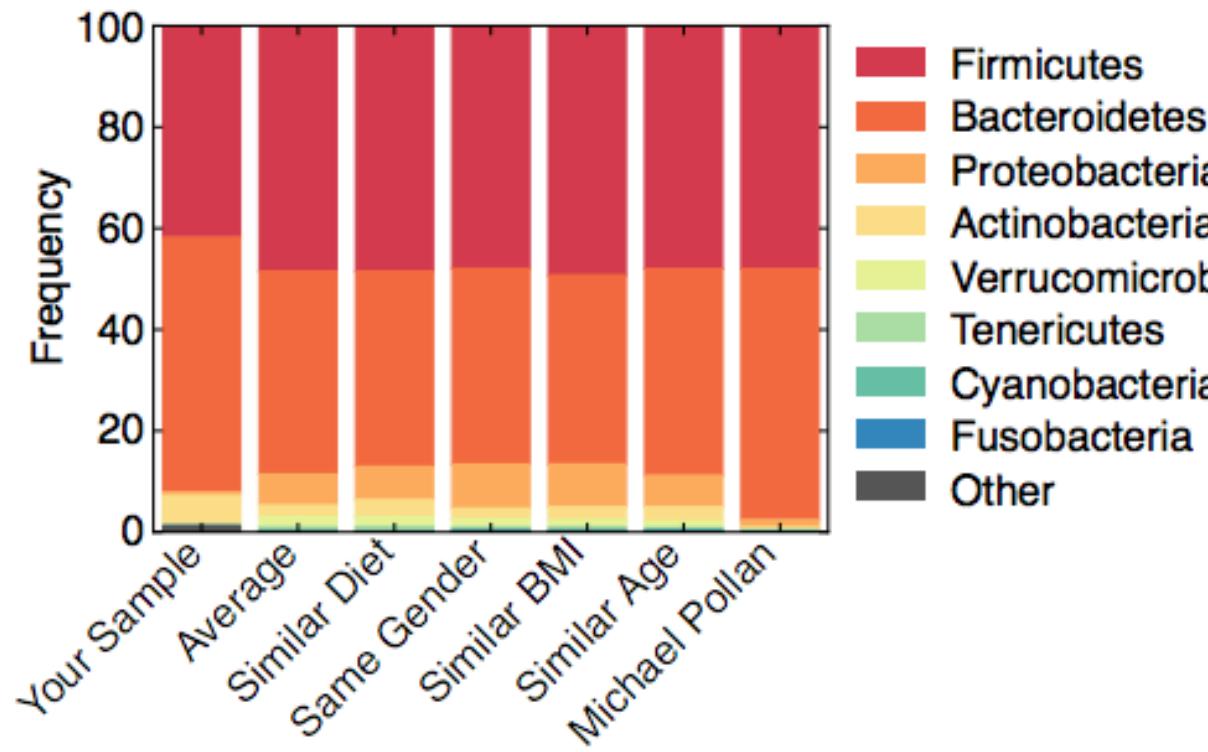
Worldwide, billions of people use online health forums to share *insights* based on subjective experiences

"I've discovered that **finding relief from IBS** is like finding a needle in a haystack. I am still searching. My faith is what is getting me through each day. **I am listing all the things that I have done or tried.** Maybe it will be someones needle in the haystack: **Upper GI, Colonoscopy, Vaginal ultrasound, Gluten and food allergy test, Gallbladder ultrasound, Stomache scoped, Abdominal CT scan, Dicyclomine, Probiotics, Colestipol...Glutten Free Diet and Special Carb Diet.** Let me know if any of these help you.

YOUR AMERICAN GUT SAMPLE

VINEET PANDEY

What's in your American Gut sample?



Your most abundant microbes:

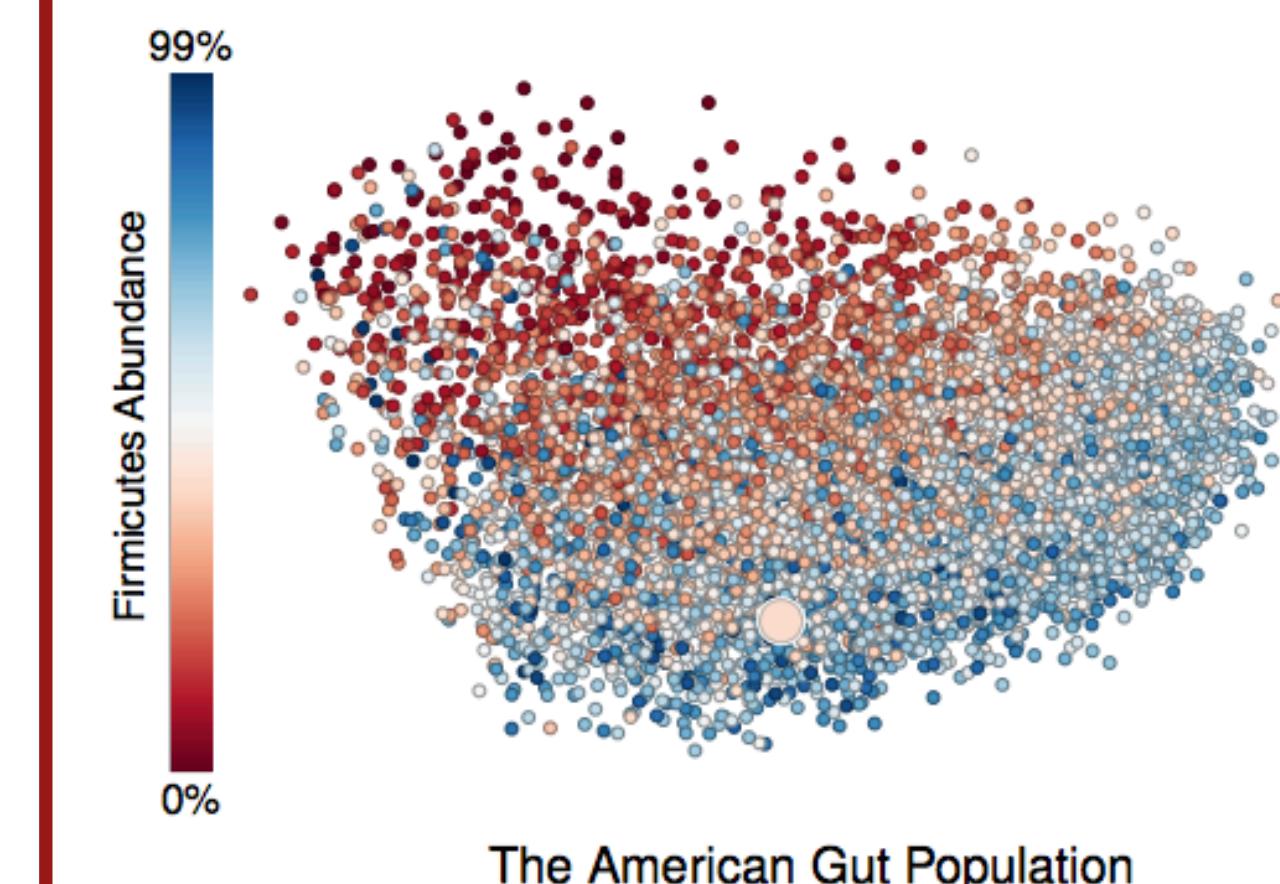
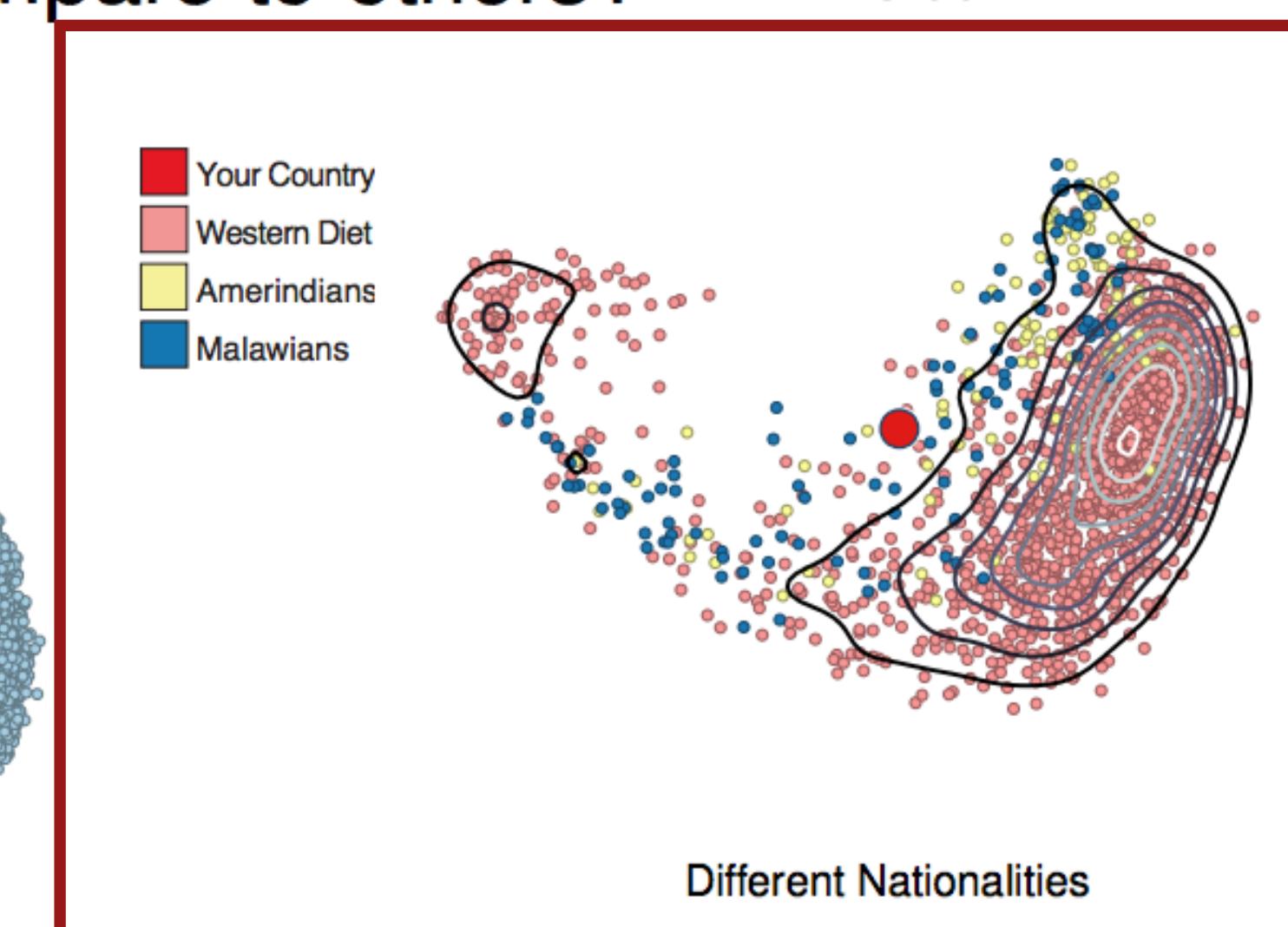
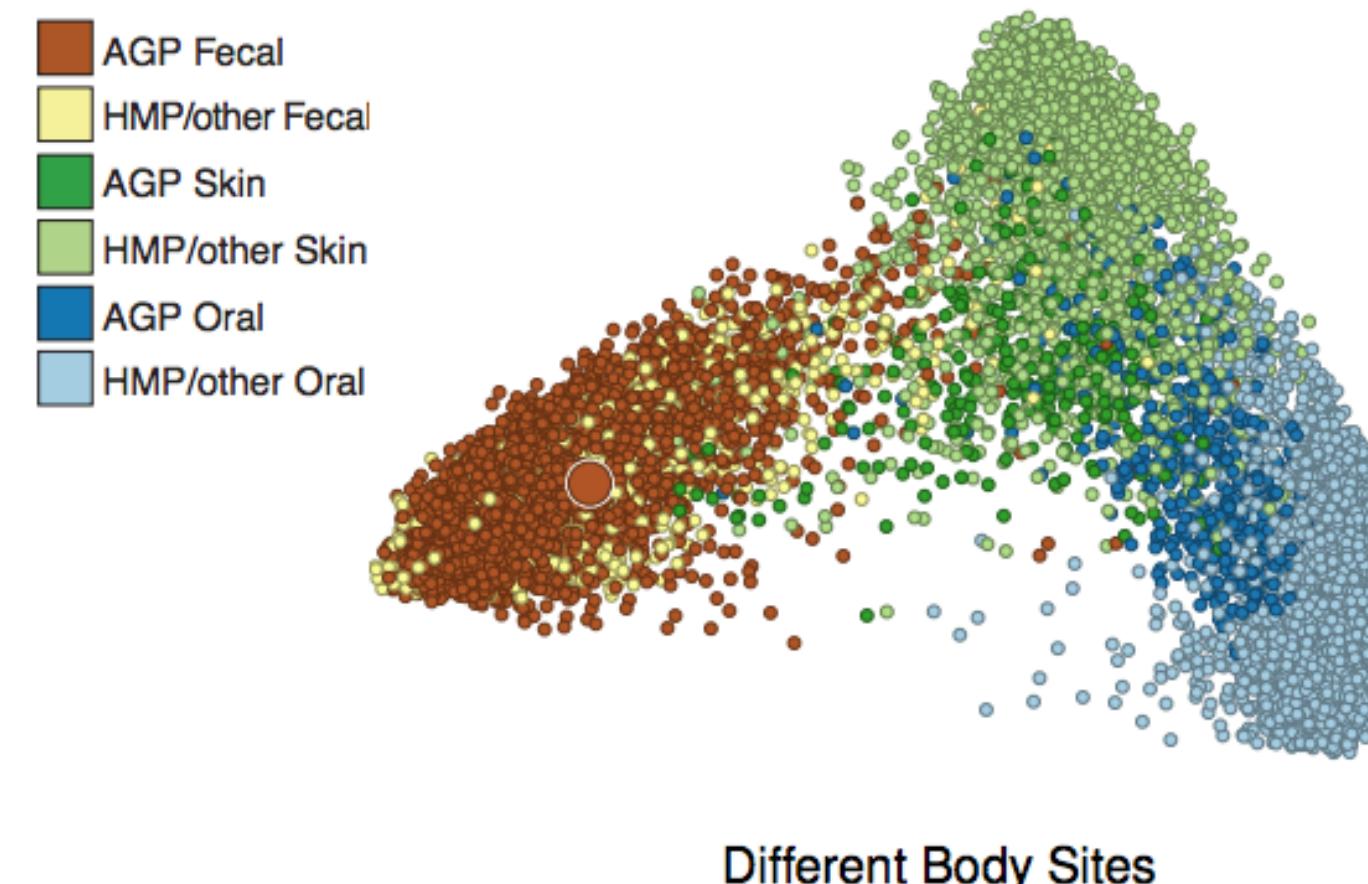
Taxonomy	Sample
Genus <i>Prevotella</i>	50.1%
Family Lachnospiraceae	12.0%
Family Ruminococcaceae	6.4%
Genus <i>Faecalibacterium</i>	5.8%

Your most enriched microbes:

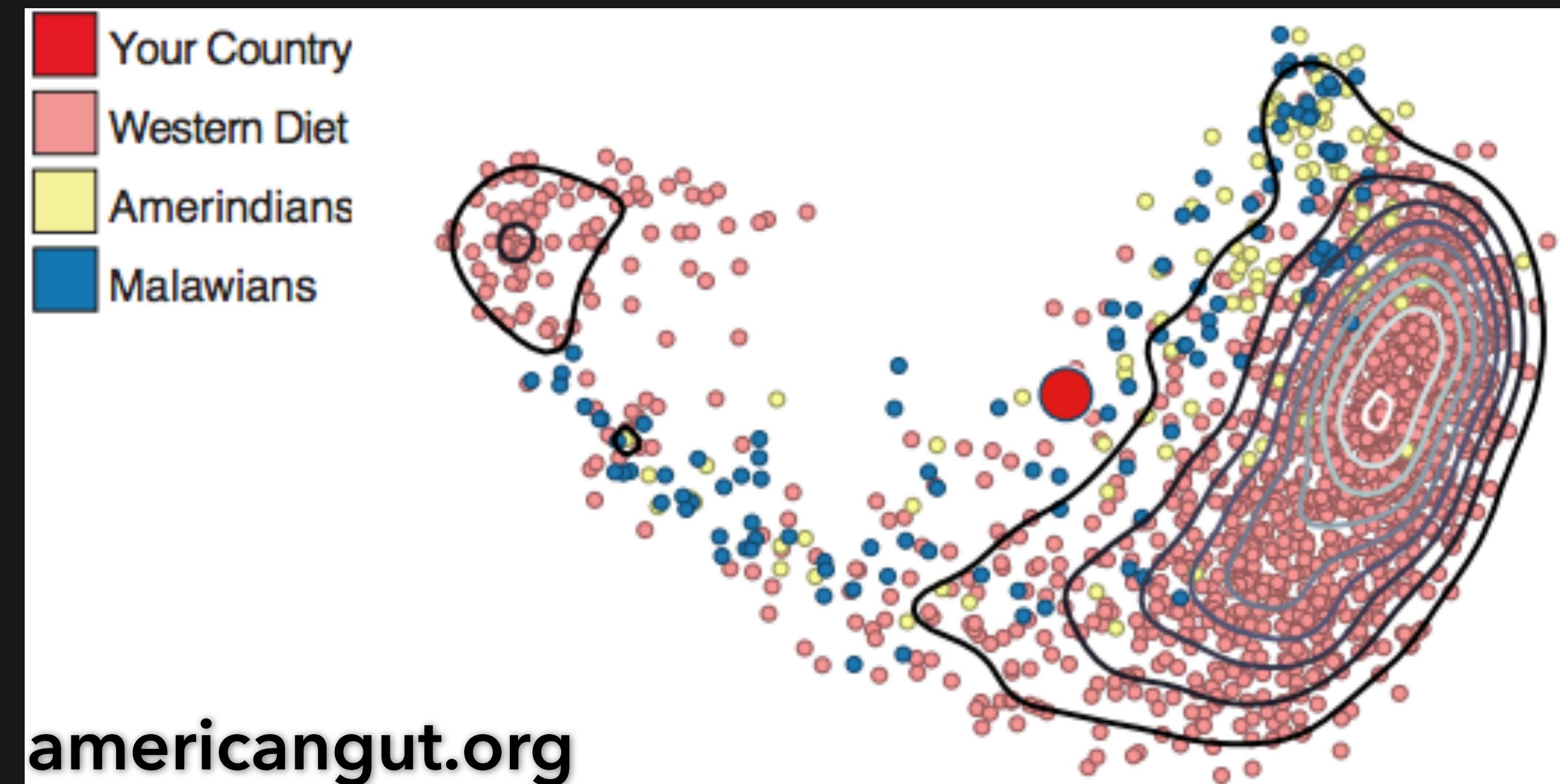
Taxonomy	Sample	Population	Fold
Genus <i>Slackia</i>	0.09%	0.01%	9x
Family Victivallaceae	1.04%	0.02%	60x
Family Lachnospiraceae	12.00%	6.98%	2x
cont. Genus <i>Eubacterium</i>	1.02%	0.28%	4x

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

How do your gut microbes compare to others?



Participants generate hypotheses by data-based comparisons



Participants generate hypotheses by data-based comparisons

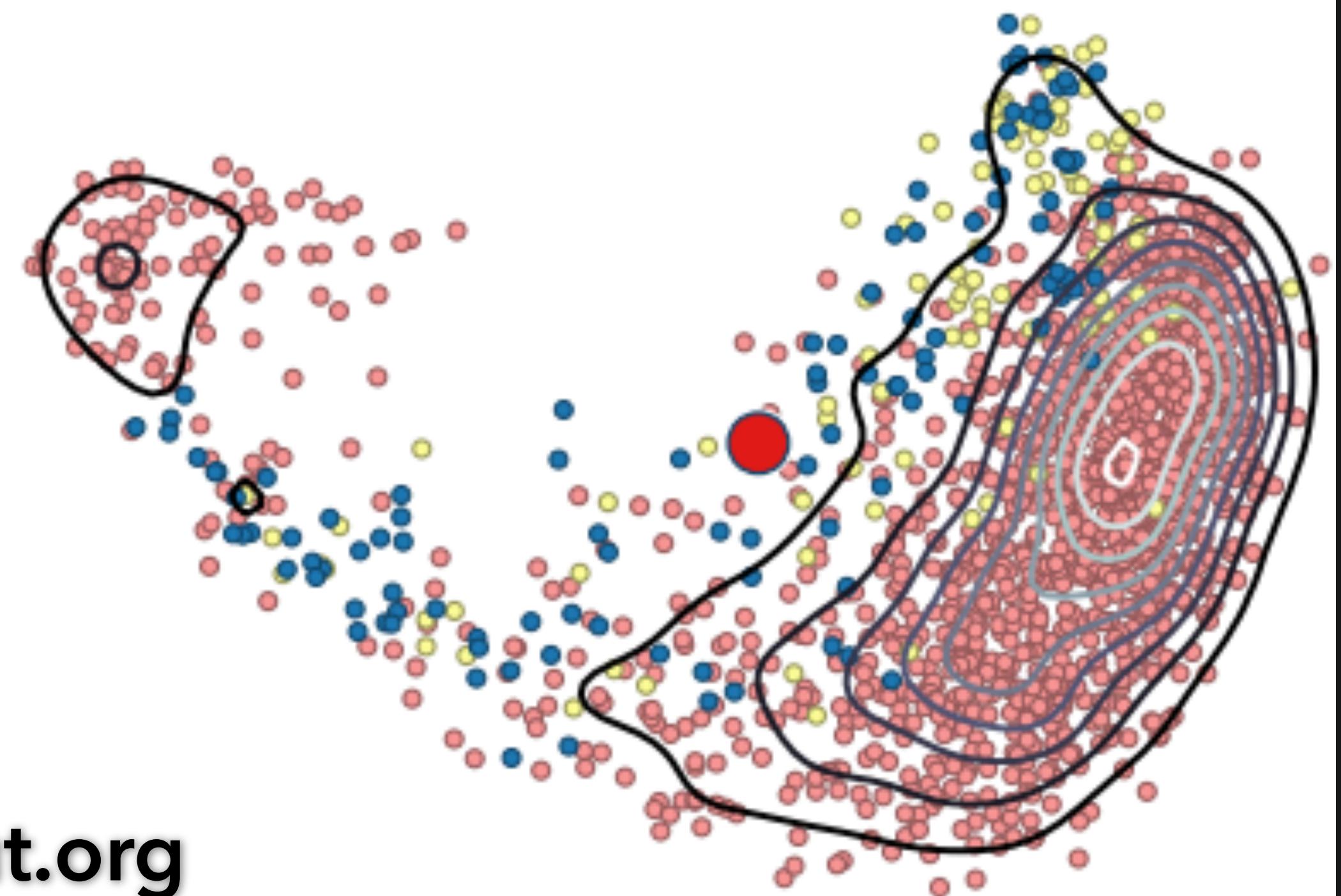


Is my data point unique
because

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



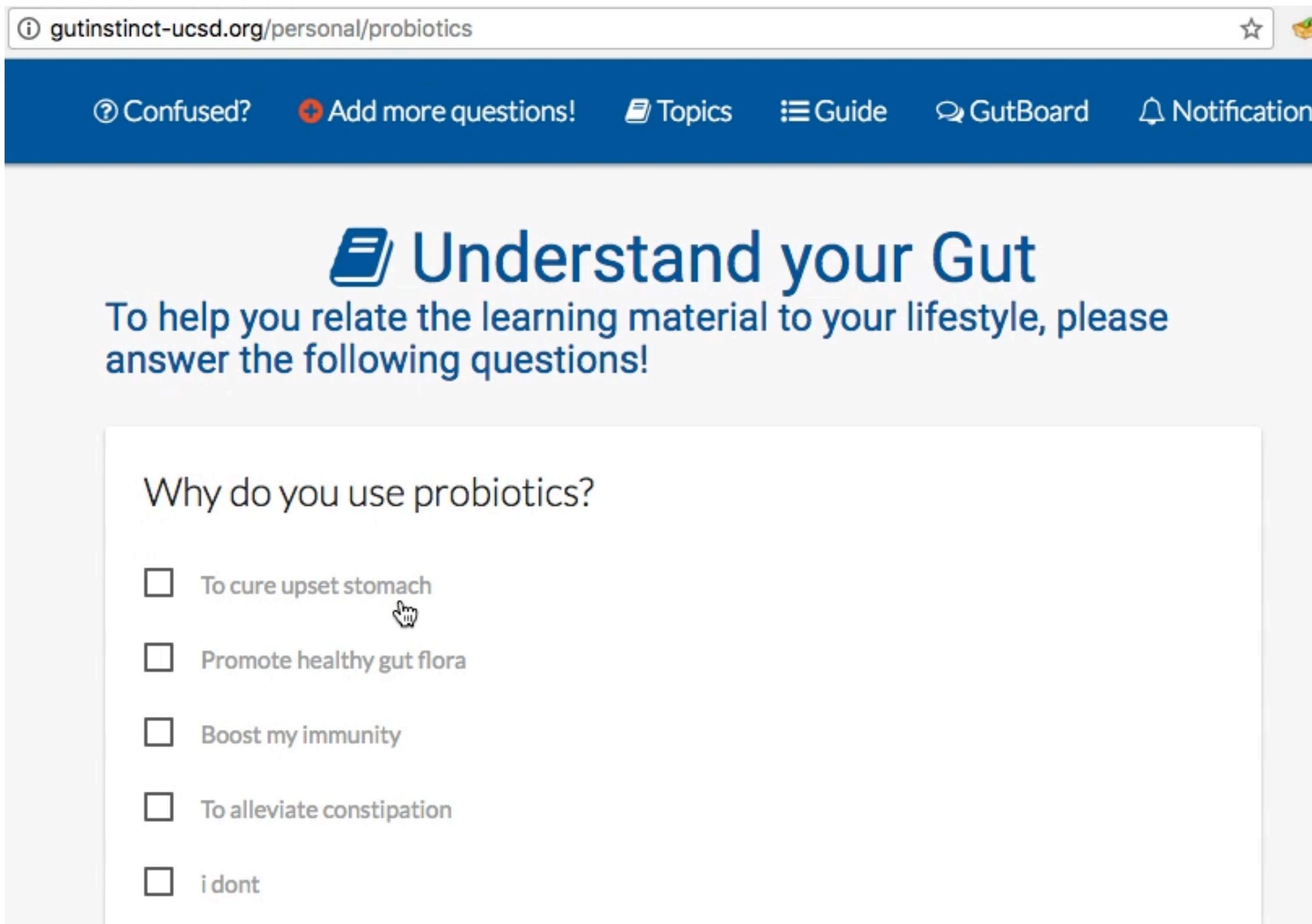
americangut.org



Insight: Scaffold domain-specific knowledge and procedural training

1. Provide domain knowledge about the microbiome
2. Teach the success criteria of sharing questions, and
3. Support these in the interface

Learn about a lifestyle topic + the microbiome



The screenshot shows a web page from gutinstinct-ucsd.org/personal/probiotics. The top navigation bar includes links for 'Confused?', 'Add more questions!', 'Topics', 'Guide', 'GutBoard', and 'Notifications'. The main content area has a blue header 'Understand your Gut' with a question icon. Below it, a sub-header reads: 'To help you relate the learning material to your lifestyle, please answer the following questions!'. A question 'Why do you use probiotics?' is followed by a list of options with checkboxes:

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

Reflect on lifestyle by answering basic questions about probiotics use

Learn about probiotics + the microbiome

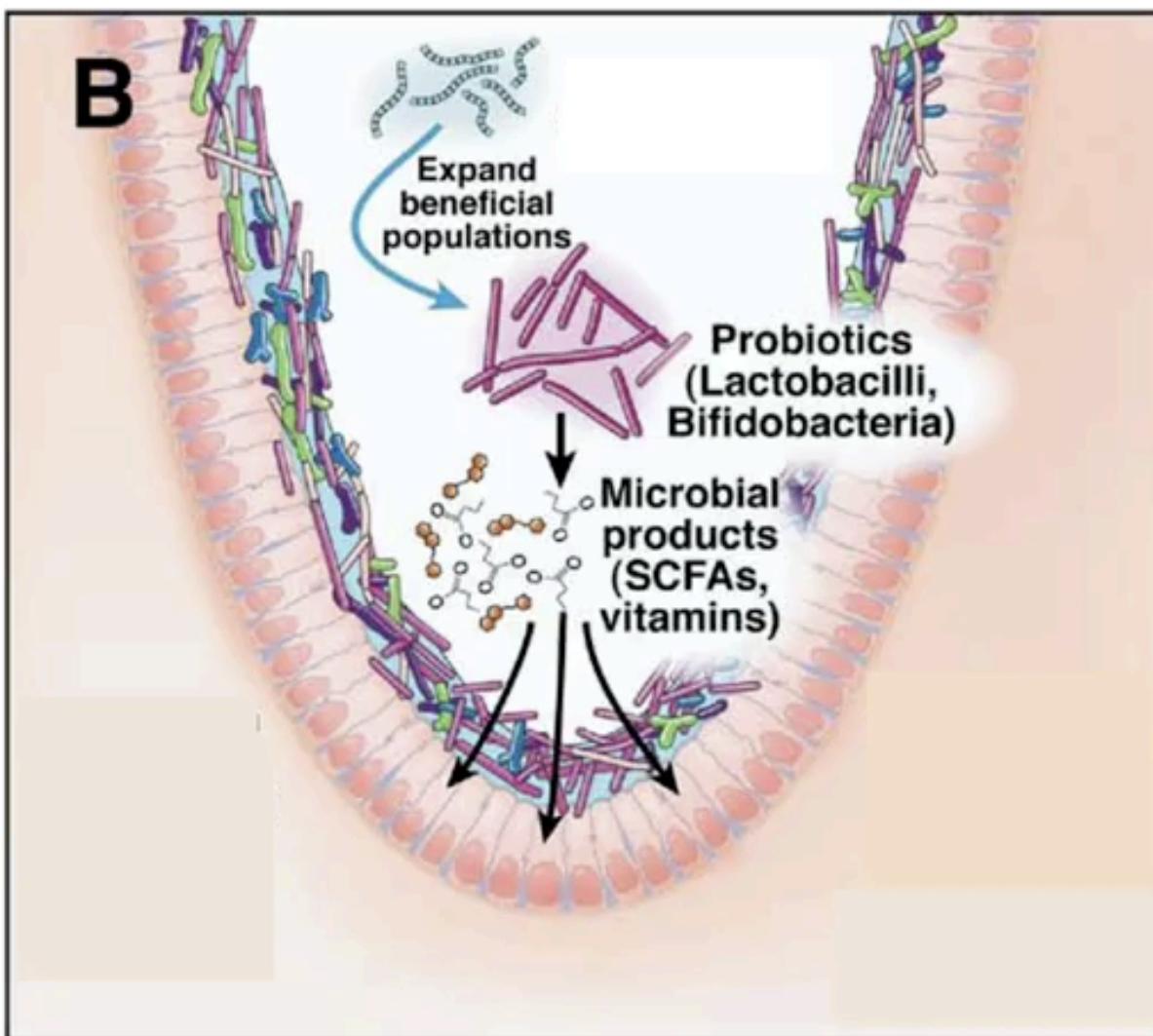
gutinstinct-ucsd.org/t/probiotics

Confused? Add more questions! Topics Guide GutBoard Notifications

Back to Topics

#probiotics

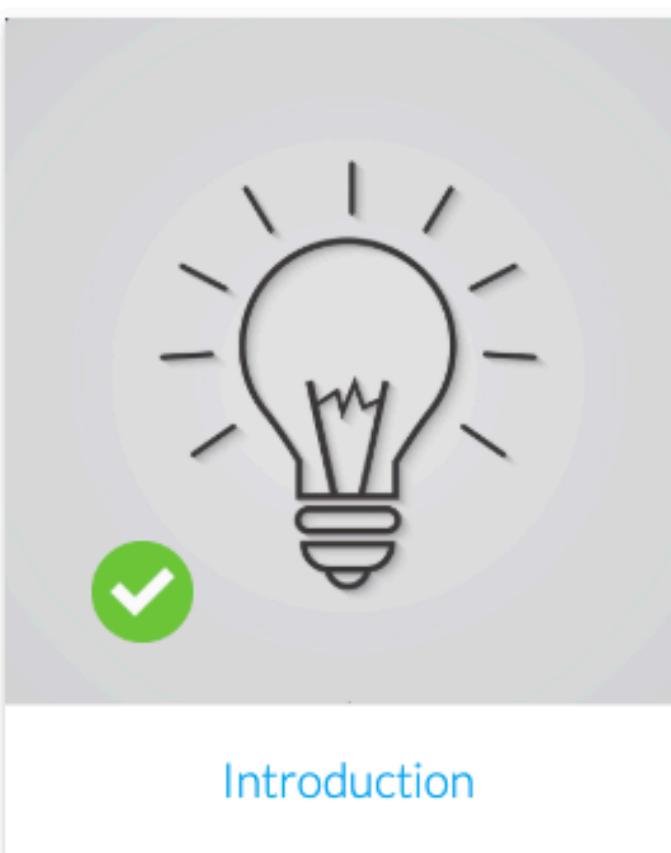
Video
Provided by coursera



Preidis and Versalovic 2009, Gastroenterology

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

Basics



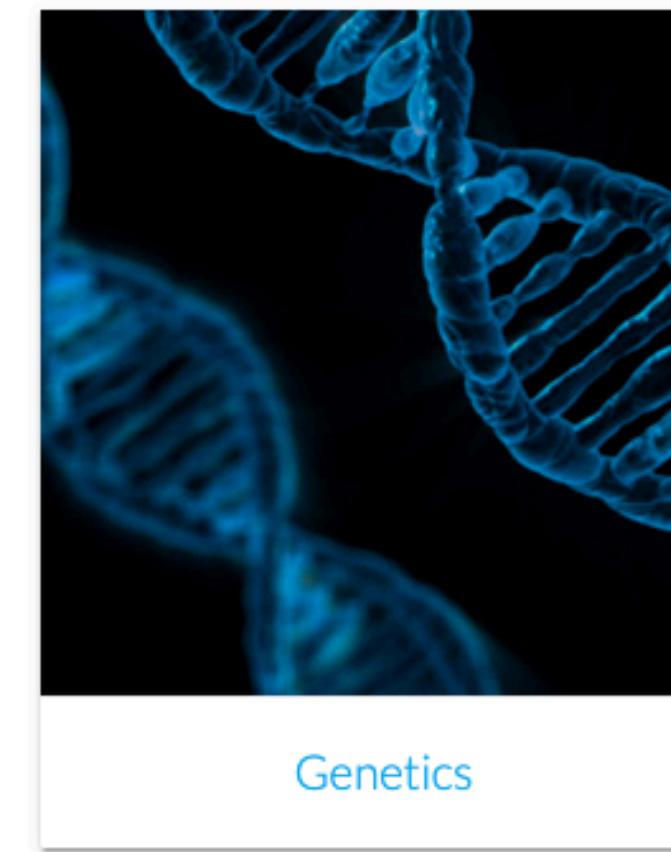
Introduction



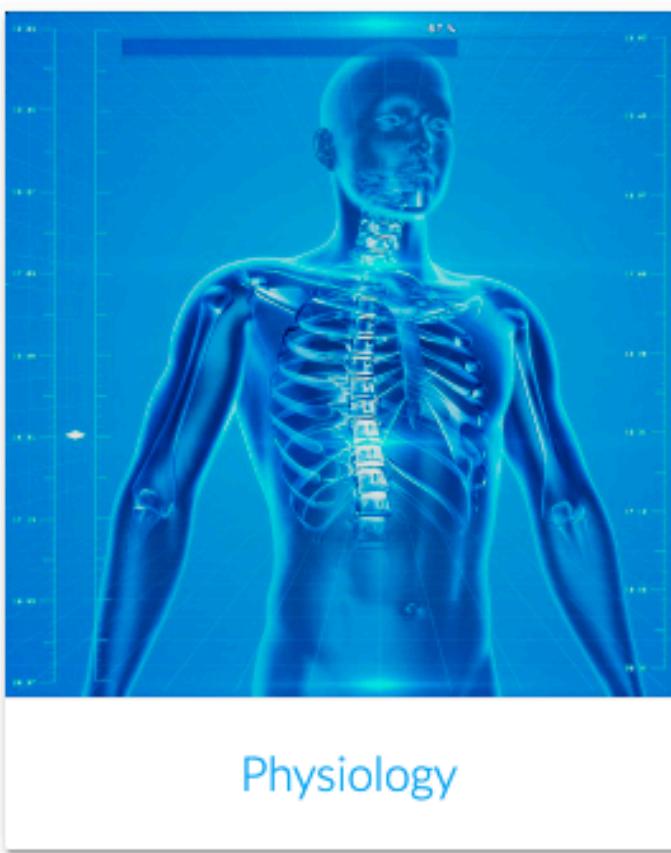
Antibiotics



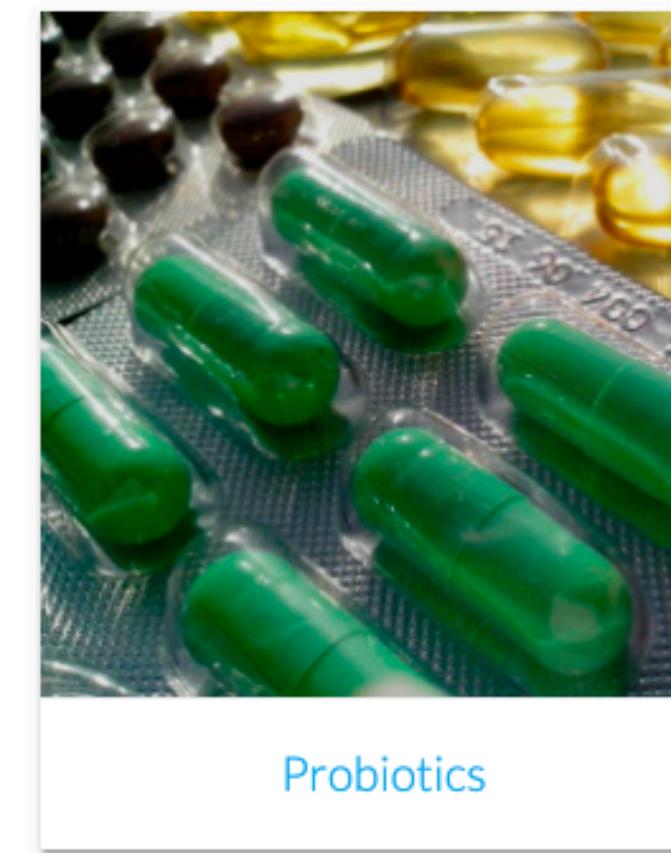
Diet



Genetics

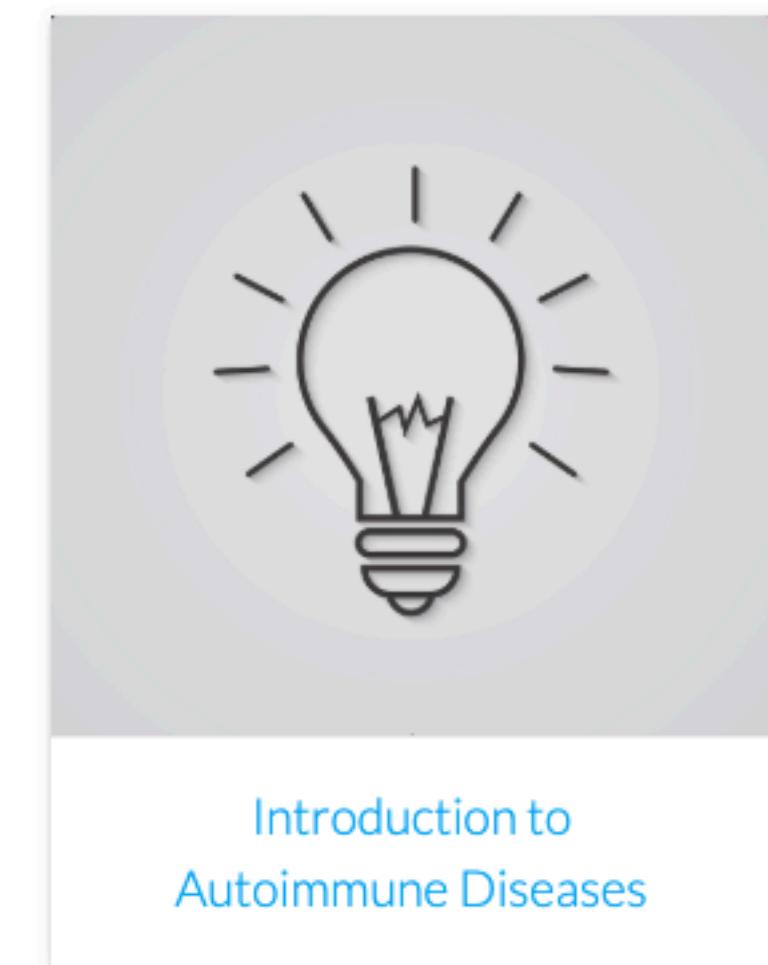


Physiology

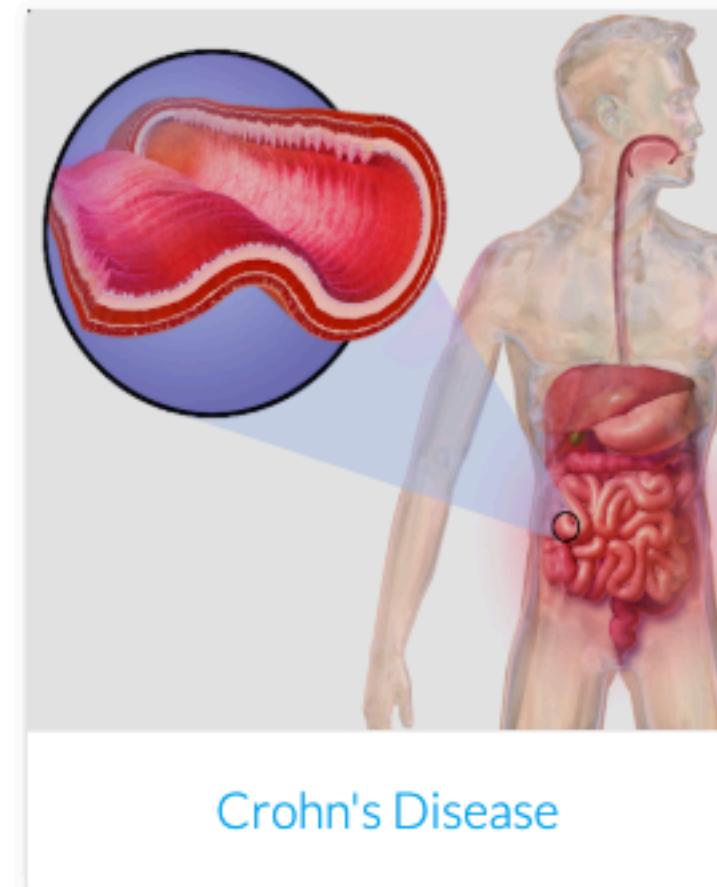


Probiotics

Autoimmune Diseases

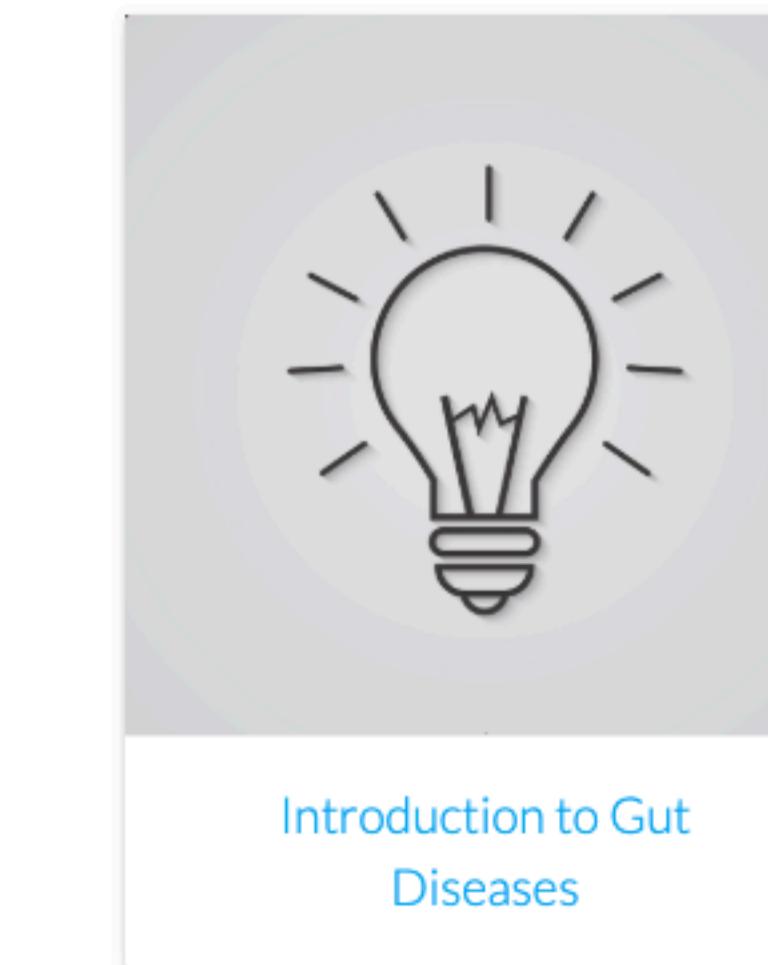


Introduction to
Autoimmune Diseases

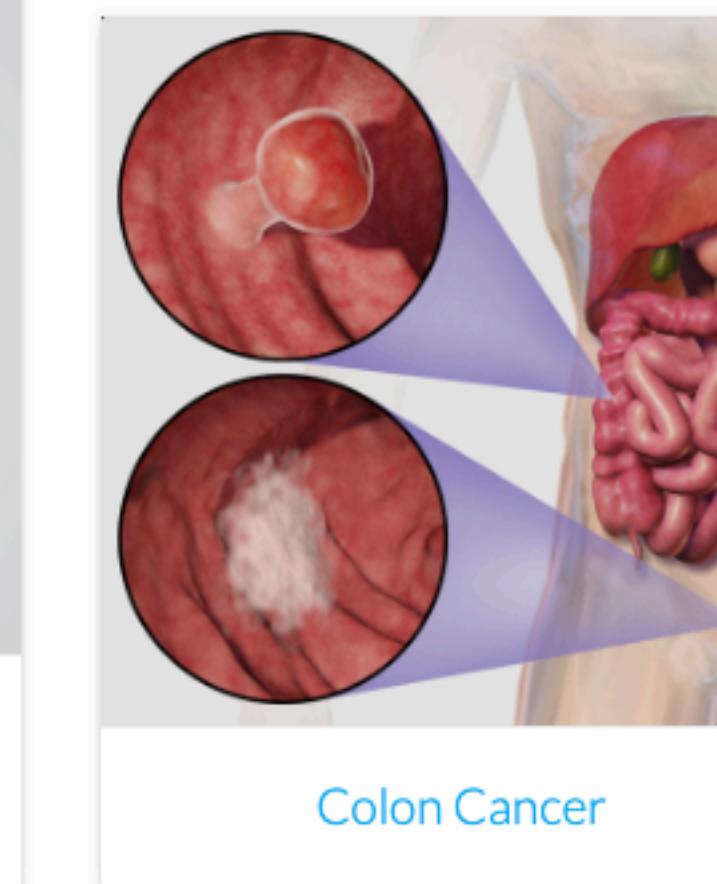


Crohn's Disease

Gut Diseases

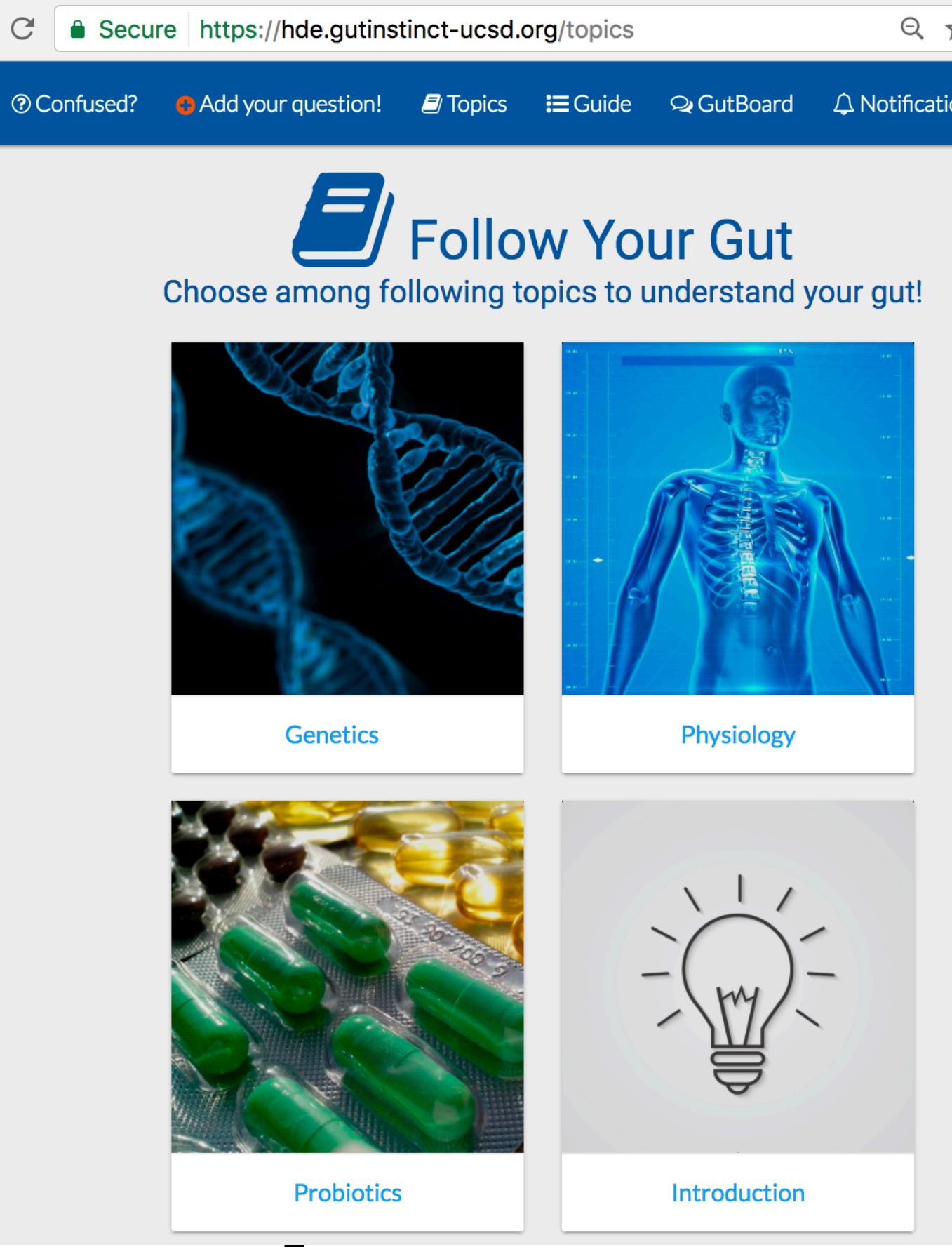


Introduction to Gut
Diseases

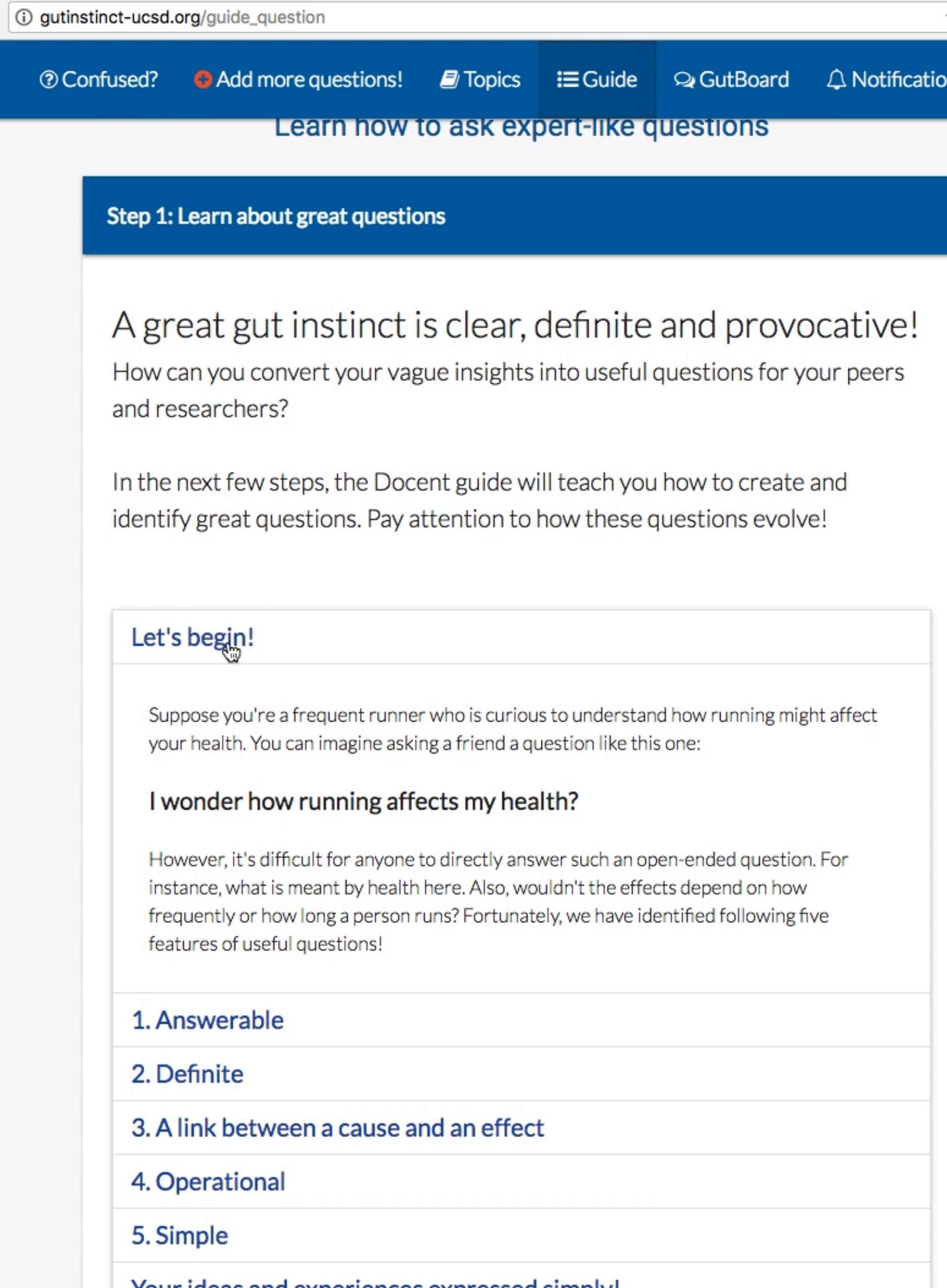


Colon Cancer

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', 'https://hde.gutinstinct-ucsd.org/topics', a search icon, and a star icon. Below this is another navigation bar with links for 'Confused?', 'Add your question!', 'Topics', 'Guide', 'GutBoard', and 'Notifications'. The main content area features a blue header 'Follow Your Gut' with a stylized 'F' icon. Below it, a sub-header says 'Choose among following topics to understand your gut!'. There are four 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). At the bottom left, the word 'Learn' is partially visible.



The screenshot shows a guide titled 'Learn how to ask expert-like questions'. It starts with a section 'Step 1: Learn about great questions' which includes text: 'A great gut instinct is clear, definite and provocative! How can you convert your vague insights into useful questions for your peers and researchers?'. It continues with 'In the next few steps, the Docent guide will teach you how to create and identify great questions. Pay attention to how these questions evolve!'. A 'Let's begin!' section follows, with text: 'Suppose you're a frequent runner who is curious to understand how running might affect your health. You can imagine asking a friend a question like this one: I wonder how running affects my health?'. It then explains: 'However, it's difficult for anyone to directly answer such an open-ended question. For instance, what is meant by health here. Also, wouldn't the effects depend on how frequently or how long a person runs? Fortunately, we have identified following five features of useful questions!'. A numbered list of five features is provided: 1. Answerable, 2. Definite, 3. A link between a cause and an effect, 4. Operational, 5. Simple. The final note at the bottom is 'Your ideas and experiences expressed simply!'. The URL in the browser bar is 'gutinstinct-ucsd.org/guide_question'.

Understand what makes a question useful

① gutinstinct-ucsd.org/gutboard_slider_addq

☆ 🍀 ⬆

② Confused? + Add more questions! 📋 Topics 📖 Guide 🔍 GutBoard 📲 Notifications

4. Guess the mechanism for your Gut Instinct

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

Add relevant tags
sample: #diet #probiotics

SAVE & SUBMIT

Ask questions

**Just-in-time
guidance using
checklist**

Contribution: Learn-Train-Ask workflow

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" (image of DNA), "Physiology" (image of a human skeleton), "Probiotics" (image of green capsules), and "Introduction" (image of a lightbulb).

Learn

32

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](#)

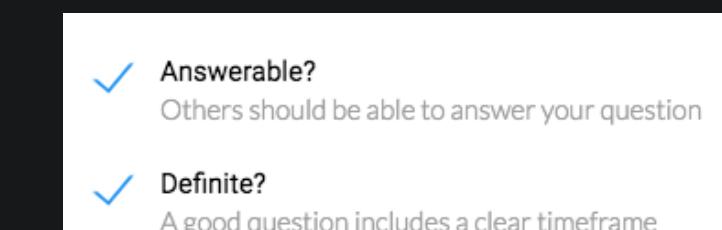
Train

Ask

Method

Between-subjects experiment for Learn and Train w/ 2x2 factorial study

H1 Access to learning improves question's content



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

Learn=No

What type of alcoholic drinks (with sugar) affect your bowel movements?

- wine
- beer
- liquor
- sugary mixed drinks

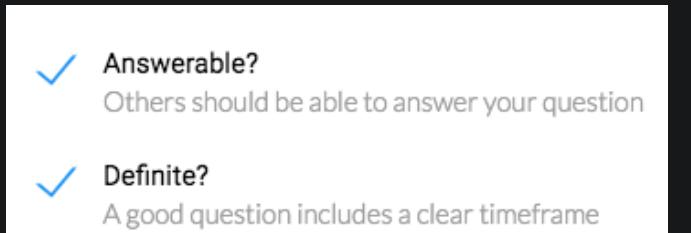
Baseline

Train=No

Both

What type of alcoholic drinks (with sugar) affect your bowel movements?

- wine
- beer
- liquor
- sugary mixed drinks



Learn=Yes

What type of alcoholic drinks (with sugar) affect your bowel movements?

- wine
- beer
- liquor
- sugary mixed drinks



Measures

Between-subjects experiment for Learn and Train w/ 2x2 factorial study

Content

Insightful	Links to existing microbiome knowledge
Novel	Contains details absent in scientific literature

Structure

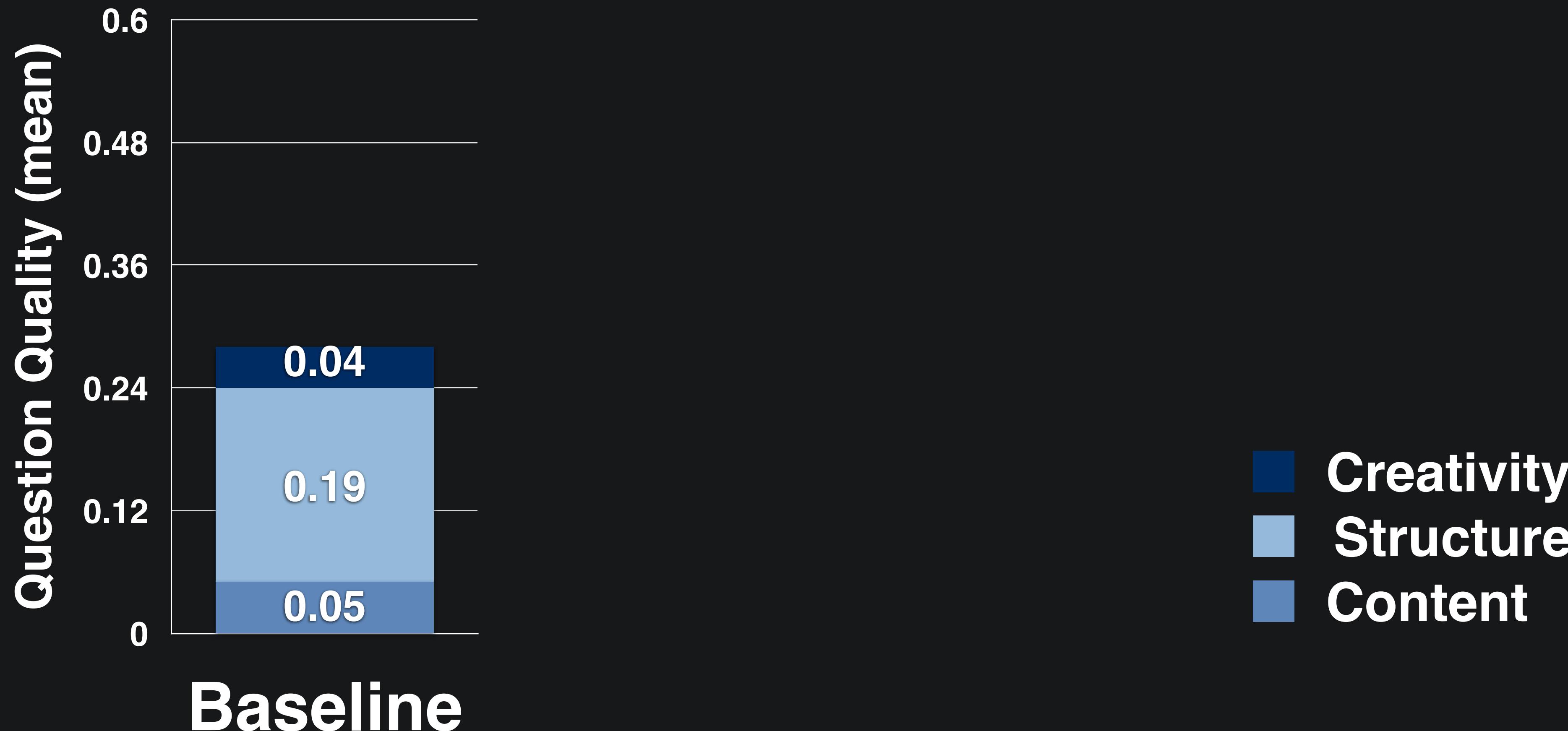
Answerable	Can be answered from lived experience
Specific	Related to only one topic

Creativity

Contains interesting/surprising details

Results

Does Learn-Train-Ask yield higher-quality questions?



Results

**Learn-Train-Ask yields higher-quality questions
(N=344)**



Results

**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

Does eating more plants change my bowel movements?

Do antibiotics lead to GI issues?

Common themes



Results

Diversity in roles: Technical interventions led to categories of users

Role and Actions

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

Helper: Add & answer questions, add follow-ups

Participator: Answer questions

Lurker: Add questions but no collaborative work

Dropout: Add a question; never returned

Results

Diversity in roles: Technical interventions led to categories of users

Role and Actions

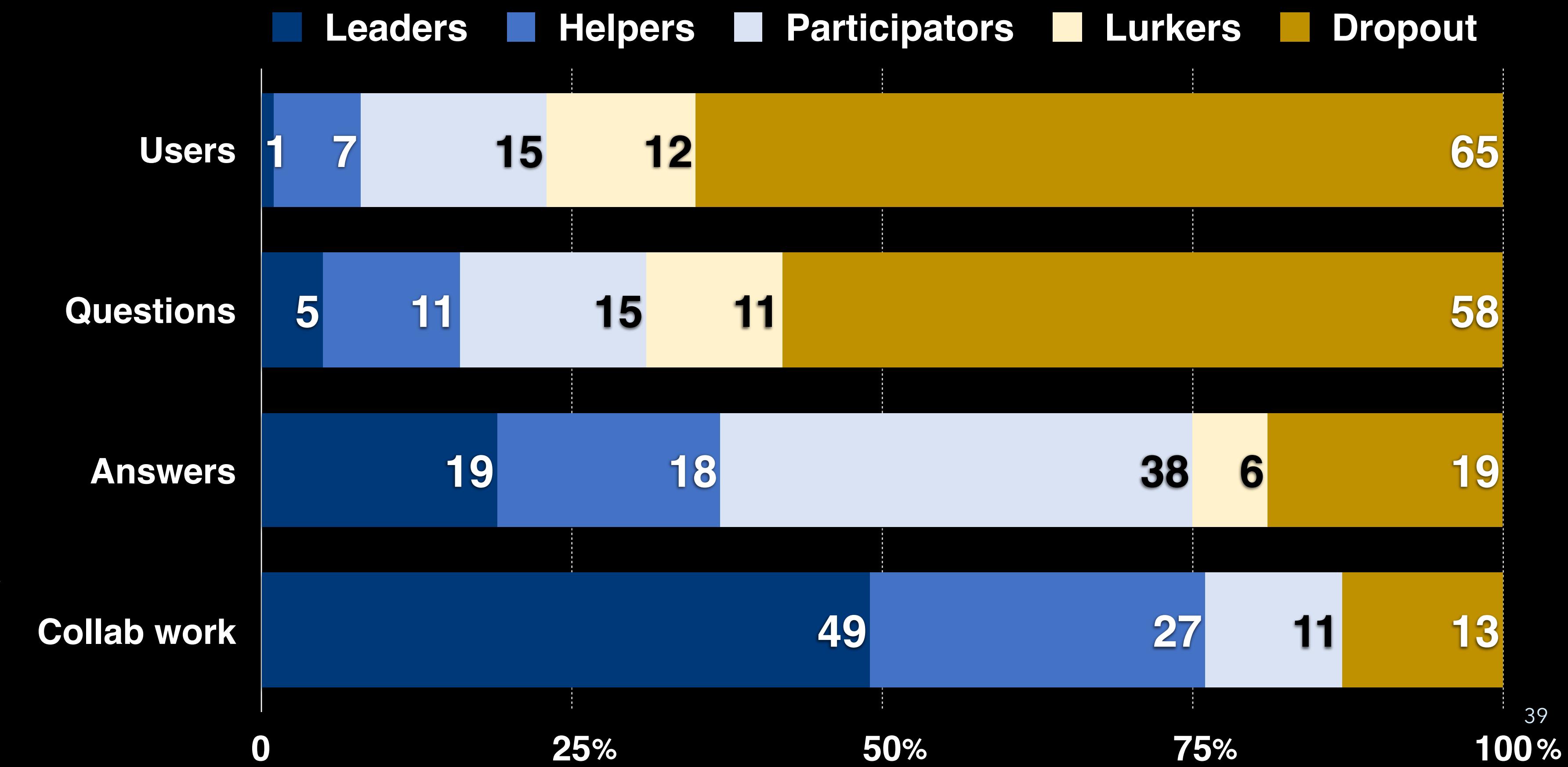
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Helper: Add & answer questions, add follow-ups

Participant: Answer questions

Lurker: Add questions but no collaborative work

Dropout: Add a question; never returned



Embedding knowledge and social support for scientific collaboration



Do fermented foods help the gut?

Knowledge

1) Just-in-time learning resources improve performance

Social capital

2) People take roles

Collaborating for science

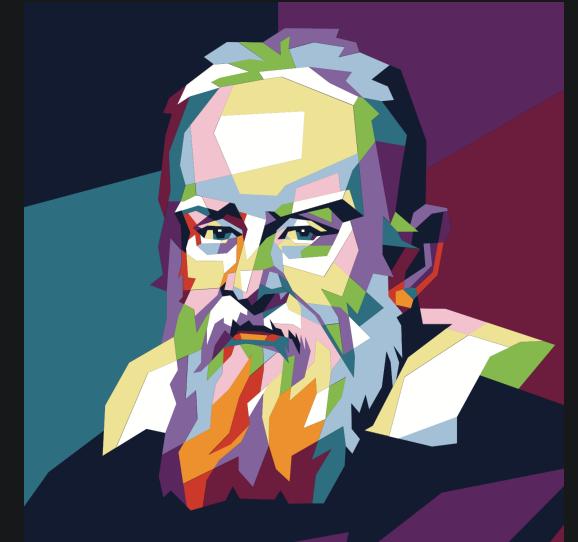
Creating
hypotheses



American Gut Project, Coursera learners

ACM CHI 2017, ACM Learning at Scale
2018

Collaborative
experimentation



Fermenters, Open science communities

ACM CHI 2021, American Society of
Microbiology

How might people design and run experiments?



Kombucha: a gut probiotic?

How might people design and run experiments?

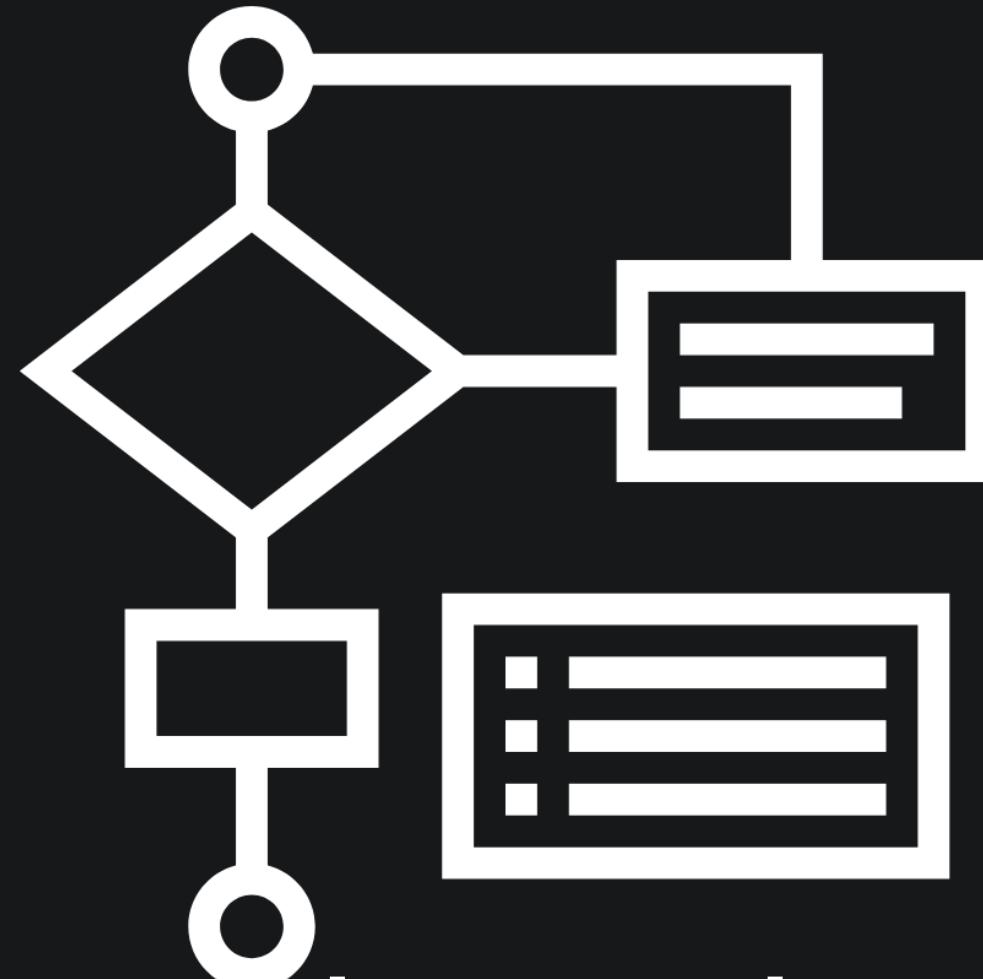


Kombucha: a gut probiotic?



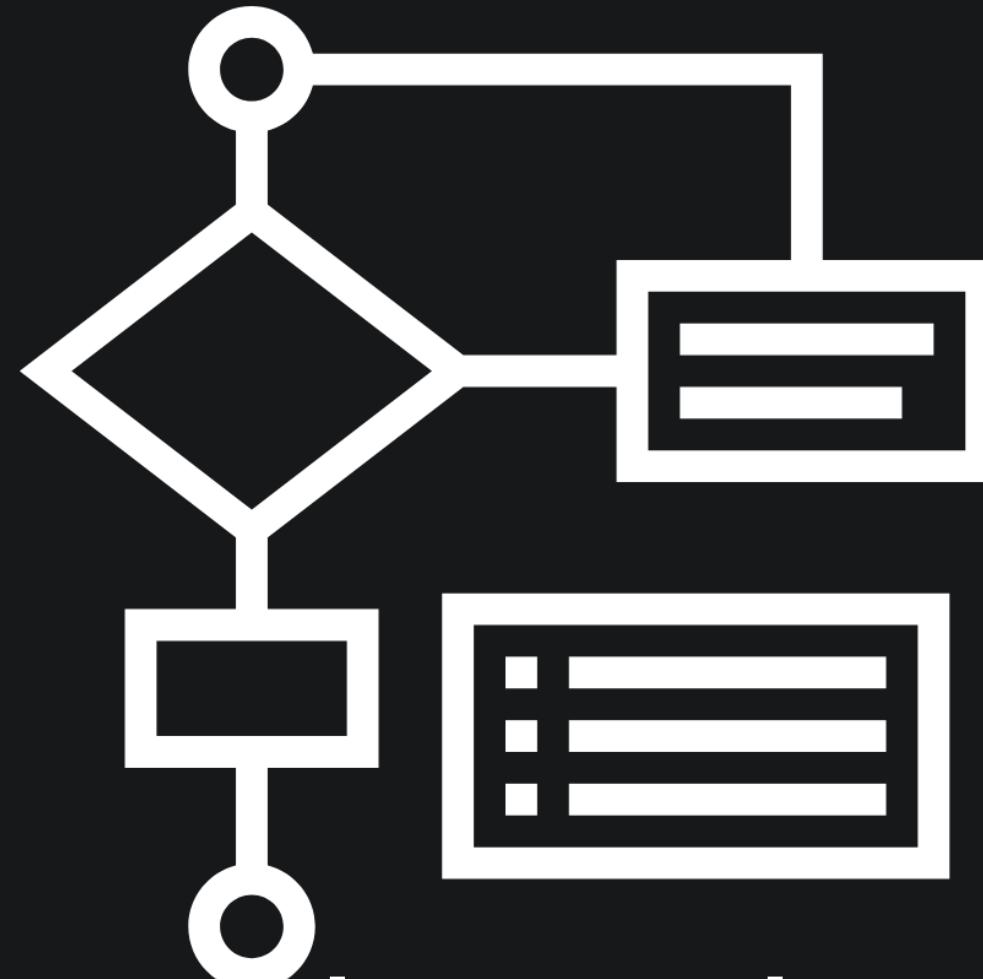
Adriana: Kombucha producer from Rio

Experimentation is difficult

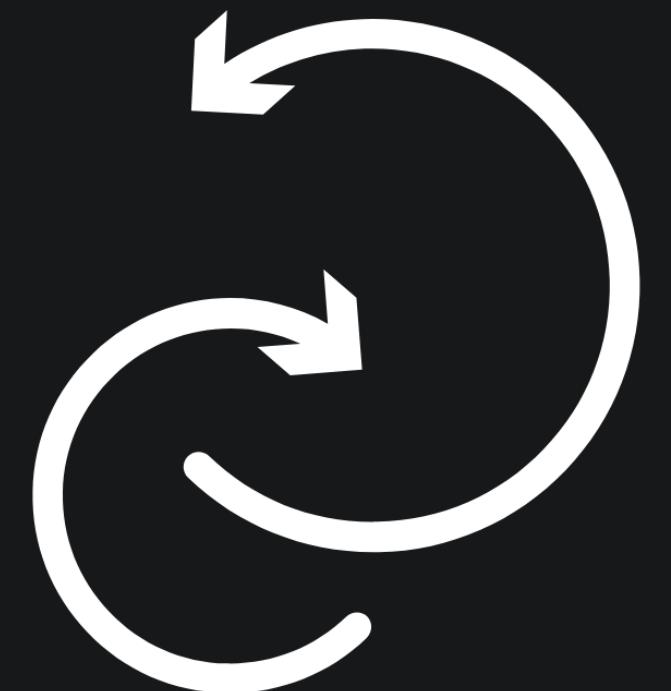


Know about the
components +
Get them right

Experimentation is difficult

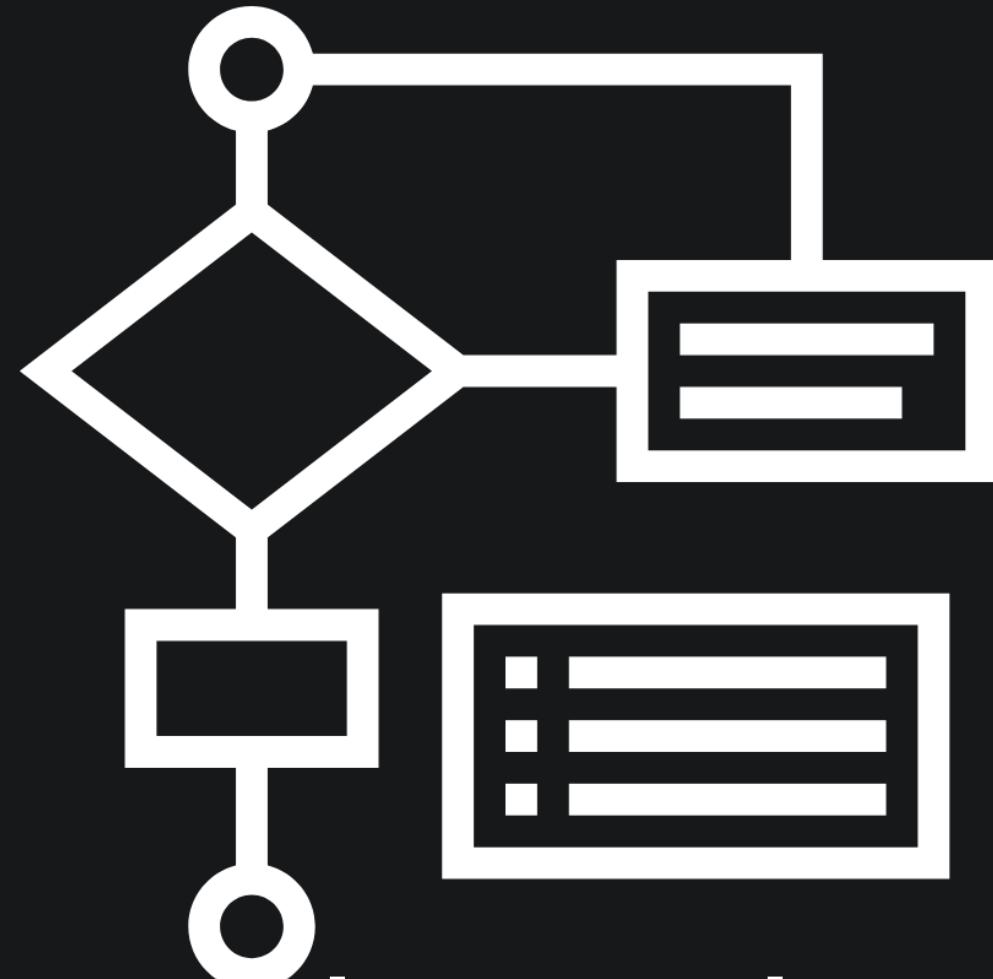


Know about the
components +
Get them right

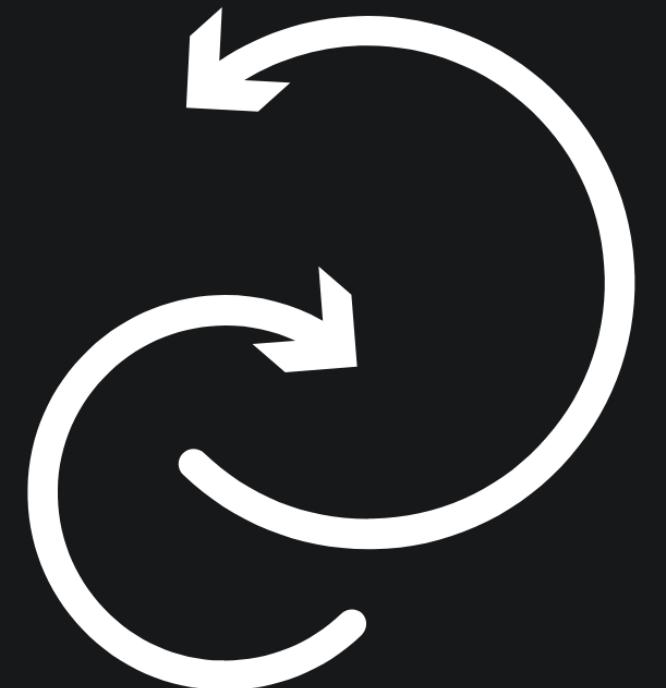


Iterate to improve
the design

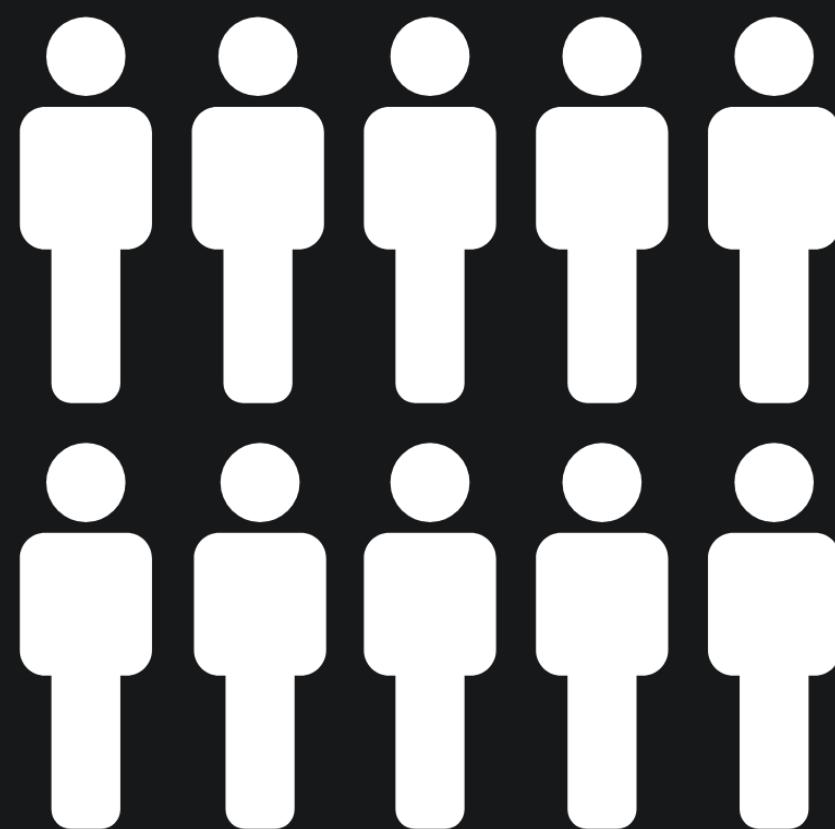
Experimentation is difficult



Know about the
components +
Get them right

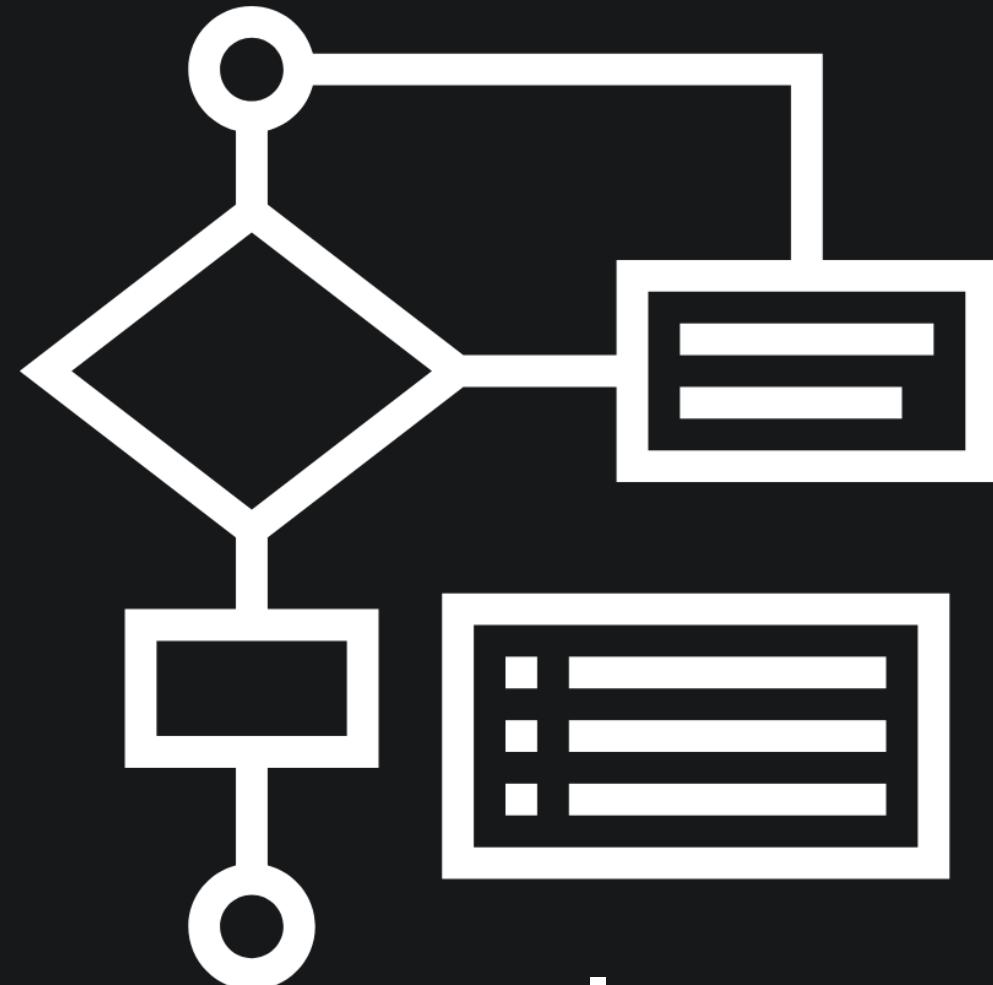


Iterate to improve
the design

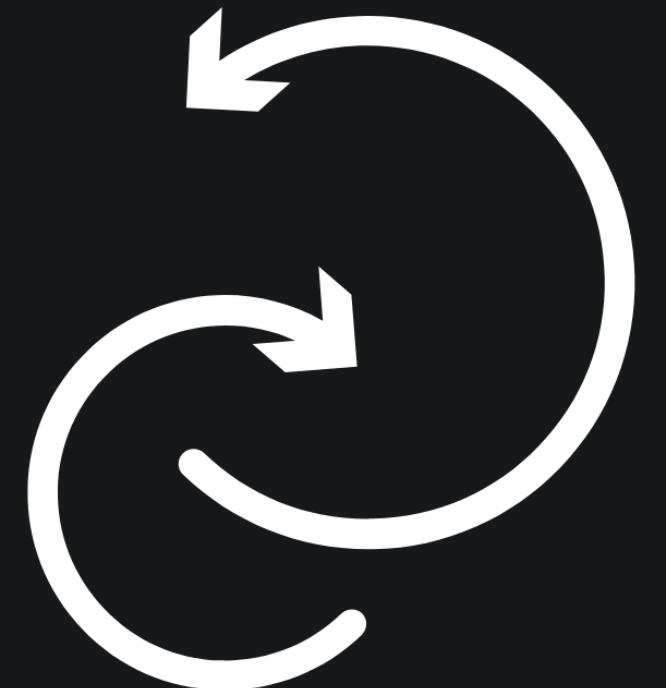


Run it correctly

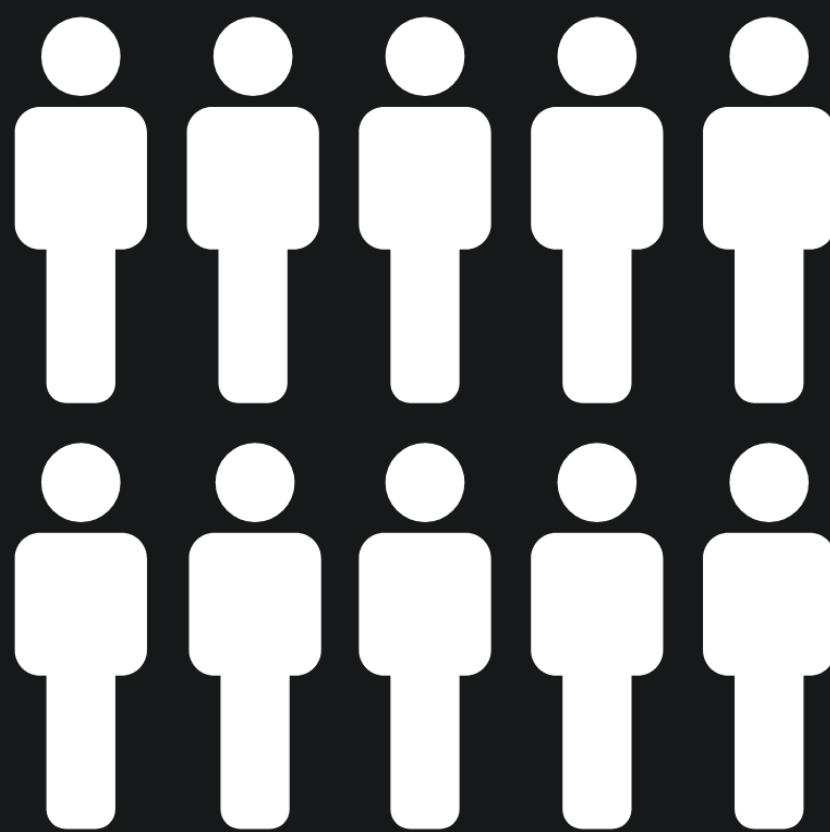
Experimentation is difficult



Conceptual +
Procedural support



Contextual insights



Consistent
implementation

Galileo

Community-designed and run experiments



Vineet Pandey

Tushar Koul

Chen Yang

Scott Klemmer

Daniel McDonald

Rob Knight

Mad Price Ball

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 **OPEN
HUMANS**



Design using procedural training cues integrated into the interface

1 Start with an intuition

Drinking kombucha makes me less bloated

These examples might help:

Drinking coffee	increases	alertness
Eating raisins every day	decreases	number of bowel movements
Not brushing teeth	results in	bad breath

Cause **Relation** **Effect**

Drinking kombucha improves stool consistency



EXAMPLES

2 Measure the cause

Drinking kombucha improves stool consistency

To conduct an experiment, you need to

1. change the cause (called manipulation) and then
2. record the effect.

How will you manipulate **Drinking kombucha** in your experiment?

(To keep your experiment simple, choose **one** option)

Absence or Presence

E.g. Milk in your diet could be present or absent

E.g. Exercise in your day could be present or absent



TEMPLATE

3 Set up data collection messages

Send all participants a reminder to provide **Bristol Scale Value** of **stool consistency** at

edit the content for the reminder text message to track **stool consistency** at 8:00 pm ...

Hello from Galileo! This is your 8:00 pm reminder to measure "stool consistency" today.

How would you classify stool consistency on the Bristol Stool Chart? Please refer to the chart (https://en.wikipedia.org/wiki/Bristol_stool_scale) and reply with a value between 1 to 7.



4 Set up exp/control conditions

Your Hypothesis: **Drinking kombucha improves stool consistency**

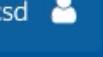
Your Experimental Group:

Drinks Kombucha

Your Control Group:

Does not drink Kombucha

Reviewers use a scaffolded interface that enables boolean and open-ended comments

Kombucha and Kefir Experiments Design An Experiment Dashboard Help us improve!  vipandey_ucsd

Experiment Details

Hypothesis: Drinking Kombucha improves stool consistency

Cause	Relation	Effect
Drinking Kombucha	improve	stool consistency

Mechanism:
kombucha has beneficial probiotics to help keeping a normal stool consistency

Related Work:
There are papers about Kombucha benefits but they do not look specifically at stool consistency. Dufresne and Farnworth (Tea, Kombucha, and health: a review) gives an overview of kombucha benefits (mostly from drinker's testimony) and indicates the need to investigate it with a more scientific approach. This is an old paper, though (from 2000). We have more recent papers, but I could not find one specifically related to stool consistency. There are some related to diabetes, for example.

How is Drinking Kombucha manipulated?

- Participants measure Absence/Presence of Drinking Kombucha
- Reminder sent every day at 6 pm with the following message:

"Hello from Austin! This is your 6:00 pm reminder to measure "Drinking Kombucha" 🍶 today. Was Drinking Kombucha absent or present in your day today? Reply Yes for present, No for absent."

How is stool consistency measured?

- Participants measure Bristol Scale value of stool consistency

The Bristol Stool Chart

Type	Looks like	Consistency	Indicates
Type 1		Separate hard lumps	Very constipated
Type 2		Lumpy and sausage like	Slightly constipated
Type 3		Sausage shaped with cracks in the surface	Normal
Type 4		A smooth, soft sausage or snake	Normal
Type 5		Soft blobs with clear-cut edges	Lacking fibre

Feedback request from the creator of the experiment:
none

People's review of the hypothesis

Is the cause specific?
Yes  1 | No  0

Is the effect specific?
Yes  1 | No  0

Is the relation between cause and effect clear?
Yes  1 | No  0

Is the hypothesis concrete i.e. it either holds or it does not hold?
Yes  1 | No  0

Is this mechanism the most plausible explanation?
Yes  0 | No  0

Is the related works description comprehensive?
Yes  0 | No  0

NEXT SECTION

Participants join online and provide data via text reminders



People join and provide data using text messages



Kombucha and Kefir Experiments

Design An Experiment

Dashboard

Help us improve!



vipandey_ucsd



Ongoing Experiment

Ready-to-run Experiments

Under-review Experiments 2

Incomplete Experiments 2

Completed Experiments 1

All Experiments 3

My Contributions

Reviewing Experiments 1

Participating Experiments 2

Account

Notifications

Edit My Profile

Log out



Design



Review



Run



Under Analysis

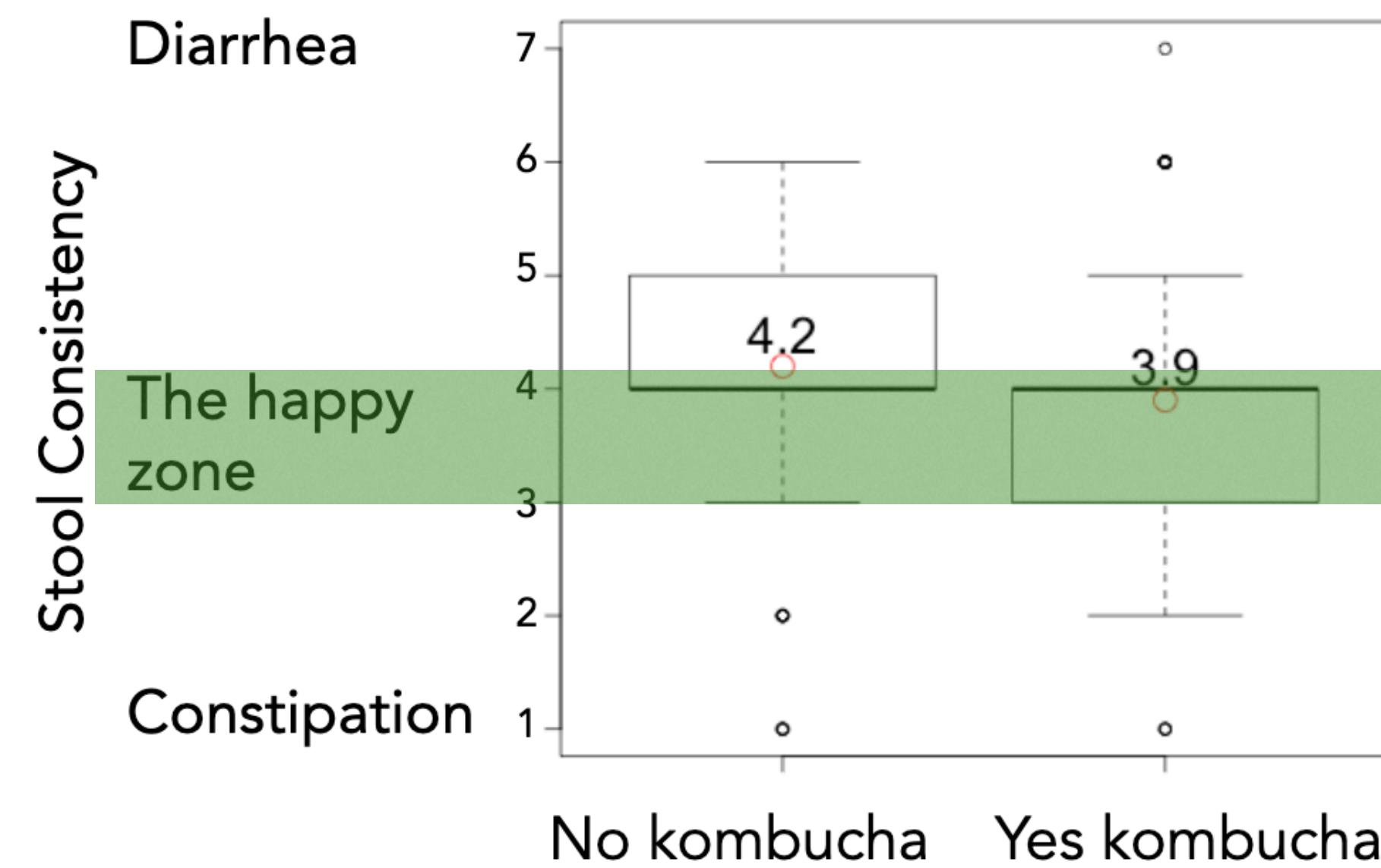
Congratulations, your experiment is under analysis!

Experiment Participants

HIDE USER INFO				Day 1		Day 2			
MORE DETAILS				Cause	Effect	Cause	Effect	Cause	
Ctry	Participant	Location	Timezone (rel. to GMT)	Value	Value	Value	Value	Value	
Control Condition									
BR	cont01	Belo Horizonte	-3	No	2,4,6,6	No	5,5	Yes	
US	cont02	Sunnyvale	-8	false	3	true	3	true	
IN	cont03	Bangalore	5	No	4	Absence	4	-	
US	cont04	Spring Valley	-8	No	3	No	3	Yes	
US	cont05	San Diego	-8	false	3	false	4	false	
US	cont06	Ann Arbor	-5	-	-	-	-	-	

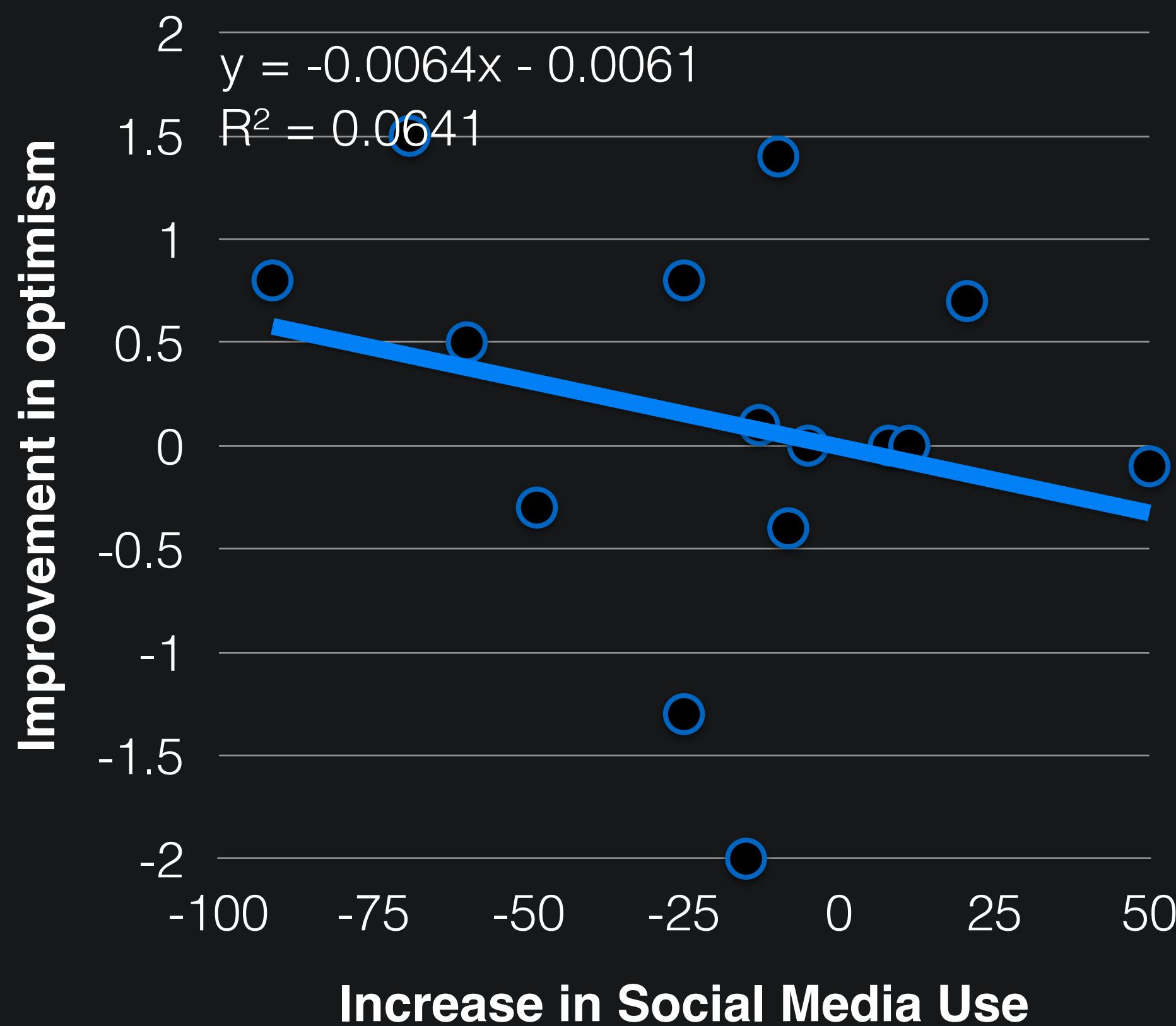
N=36

Kombucha community: Does drinking kombucha improve stool consistency?



**between-subjects
experiment; $p<0.03$**

Open Humans community: Does using less social media increase optimism? ($N=15, r=0.25$)



- 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

Collaborating for science

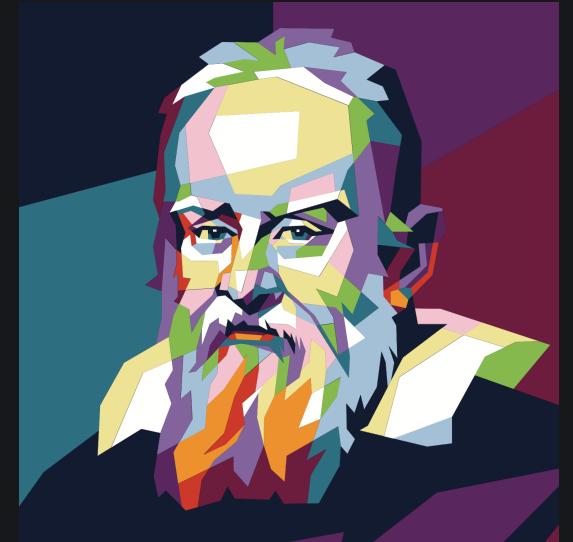
Creating
hypotheses



American Gut Project, Coursera learners

ACM CHI 2017, ACM Learning at Scale
2018

Collaborative
experimentation



Fermenters, Open science communities

ACM CHI 2021, American Society of
Microbiology

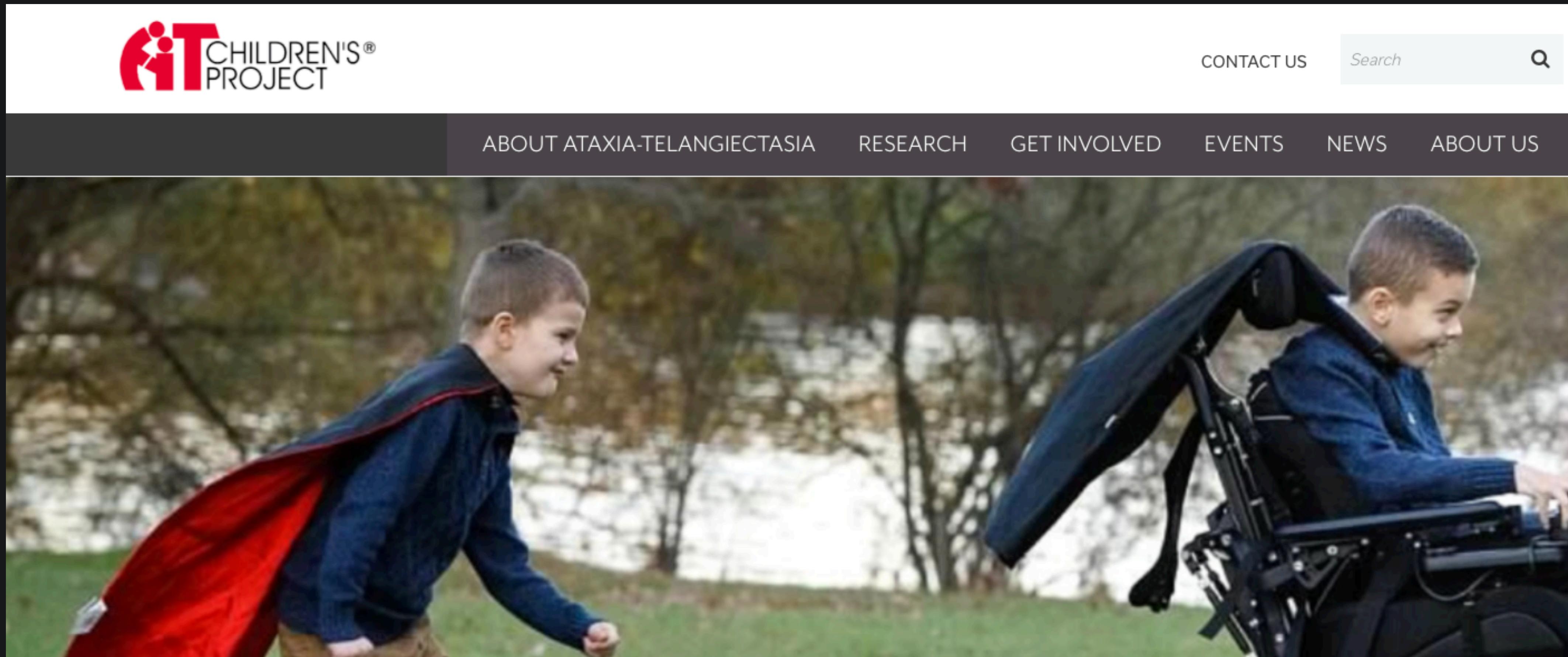
At home
assessments



Rare Disease Community,
Clinical researchers

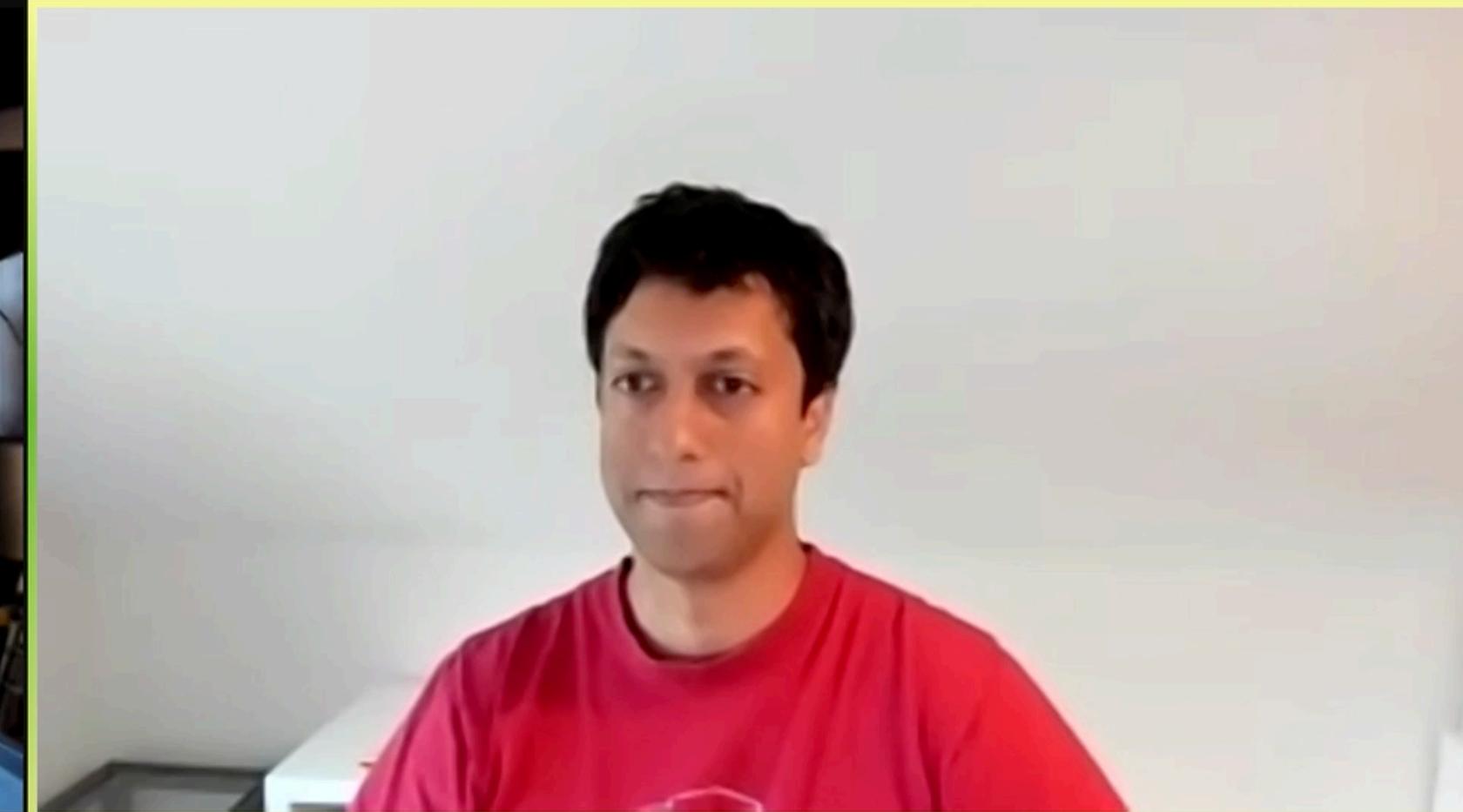
The Cerebellum, ACM (in submission)

How to perform valid, reliable motor impairment assessments from home?



The screenshot shows the homepage of the Children's AT Project website. At the top left is the logo 'AT CHILDREN'S® PROJECT' with a red stylized 'AT' icon. To the right are links for 'CONTACT US', a search bar with a magnifying glass icon, and a navigation menu with tabs: 'ABOUT ATAXIA-TELANGIECTASIA', 'RESEARCH', 'GET INVOLVED', 'EVENTS', 'NEWS', and 'ABOUT US'. Below the header is a large photograph of two young boys. On the left, a boy in a blue jacket and red superhero cape runs towards the right. On the right, another boy in a blue jacket sits in a black wheelchair, smiling. They are outdoors in a park-like setting with trees.

Problem: Assessing motor impairment is difficult



Problem: Assessing motor impairment is difficult



12. Finger-to-nose test: decomposition and dysmetria (Left and Right scored)
- 0: Normal
 - 1: Oscillating movement without decomposition of the movement
 - 2: Segmented movement in 2 phases and/or moderate dysmetria in reaching nose
 - 3: Segmented movement in more than 2 phases and/or considerable dysmetria in reaching nose
 - 4: Dysmetria preventing the patient from reaching nose.

More challenging over video

Requires contextual expertise

Categorical assessment on a 5-point scale

Problem: Assessing motor impairment is difficult

Use mouse trajectory from interactive, online tasks

More challenging over video

Automated comparisons to normative data across age

Requires contextual expertise

Draw objective, quantitative measures from mouse trajectories

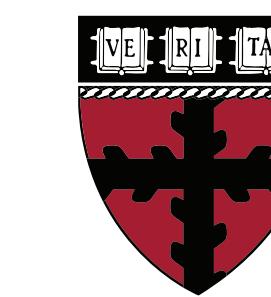
Categorical assessment on a 5-point scale

Hevelius at home

A motor impairment assessment tool for remote use



Vineet Pandey
Krzysztof Z. Gajos



Harvard John A. Paulson
School of Engineering
and Applied Sciences

Nergis C. Khan
Anoopum S. Gupta



MASSACHUSETTS
GENERAL HOSPITAL

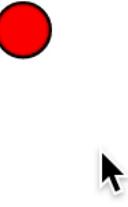
2020. Movement Disorders. Gajos, Gupta et al. Computer mouse use captures ataxia and parkinsonism, enabling accurate measurement and detection.

2020. ACM ICT4S LIMITS. Pandey et al. From novices to co-pilots: Fixing the limits on scientific knowledge production by accessing or building expertise

2021. The Cerebellum. Khan, Pandey et al. Free-Living Motor Activity Monitoring in Ataxia-Telangiectasia

2022. In Preparation. Pandey et al. At-home Use of a Computer-based Pointing Task Accurately and Reliably Estimates Motor Impairments.

Task 5 out of 8

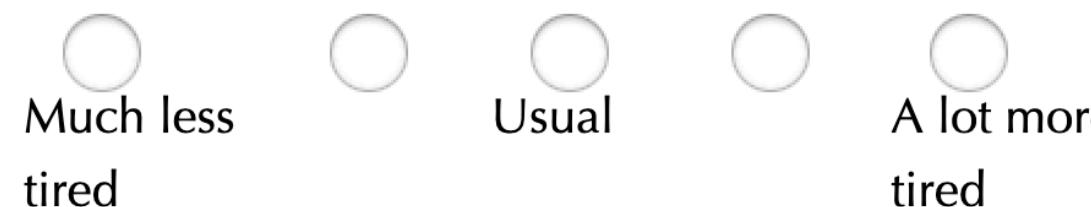


Pointing task

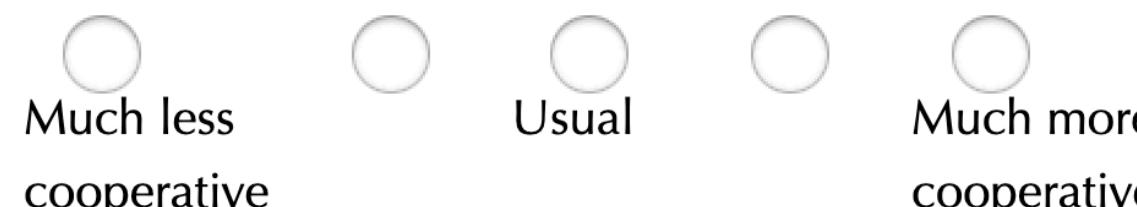
Tool

The Hevelius system includes caregiver inputs, dot clicking tasks, and follow-up questions

How tired is your child right now compared to most other times?



How cooperative is your child right now compared to most other times?



How many times has your child stumbled or tripped in the past week?



What have been some current events for your child since they last used this tool?

Any information that you provide will help researchers better understand the data.
E.g. a trip, a big family gathering, tummy troubles, social or school events

What is your mood right now?



How alert do you feel right now?



How well did you sleep last night?



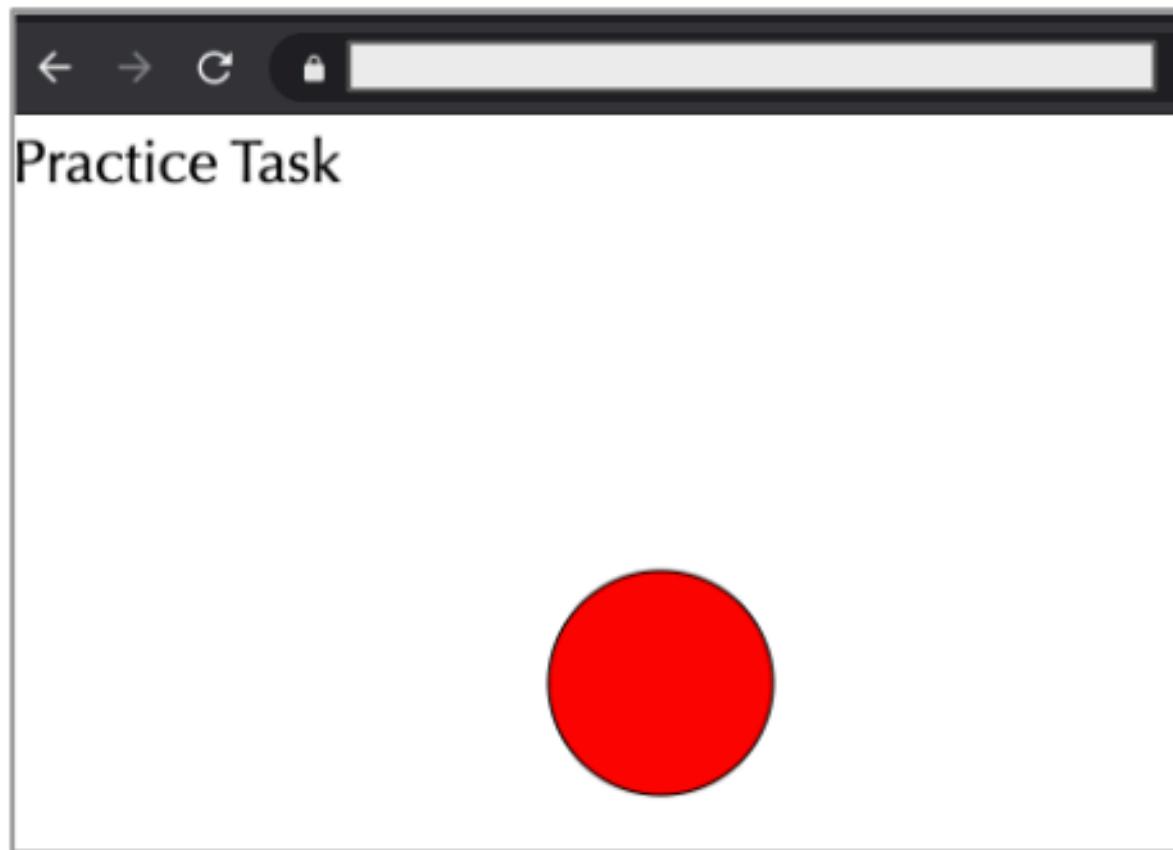
Participant self-reports

Caregiver reports

Tool

Movement features provide estimates of clinical severity

Participant clicks on dots
for a few mins



Neurologist-approved features
drawn from mouse trajectories



```
movement_time:  
4084 msec  
execution_time: 2100  
msec  
num_pauses: 6  
Duration of longest  
pause: 1137msec  
...
```

Z-scores after comparing to
normative data

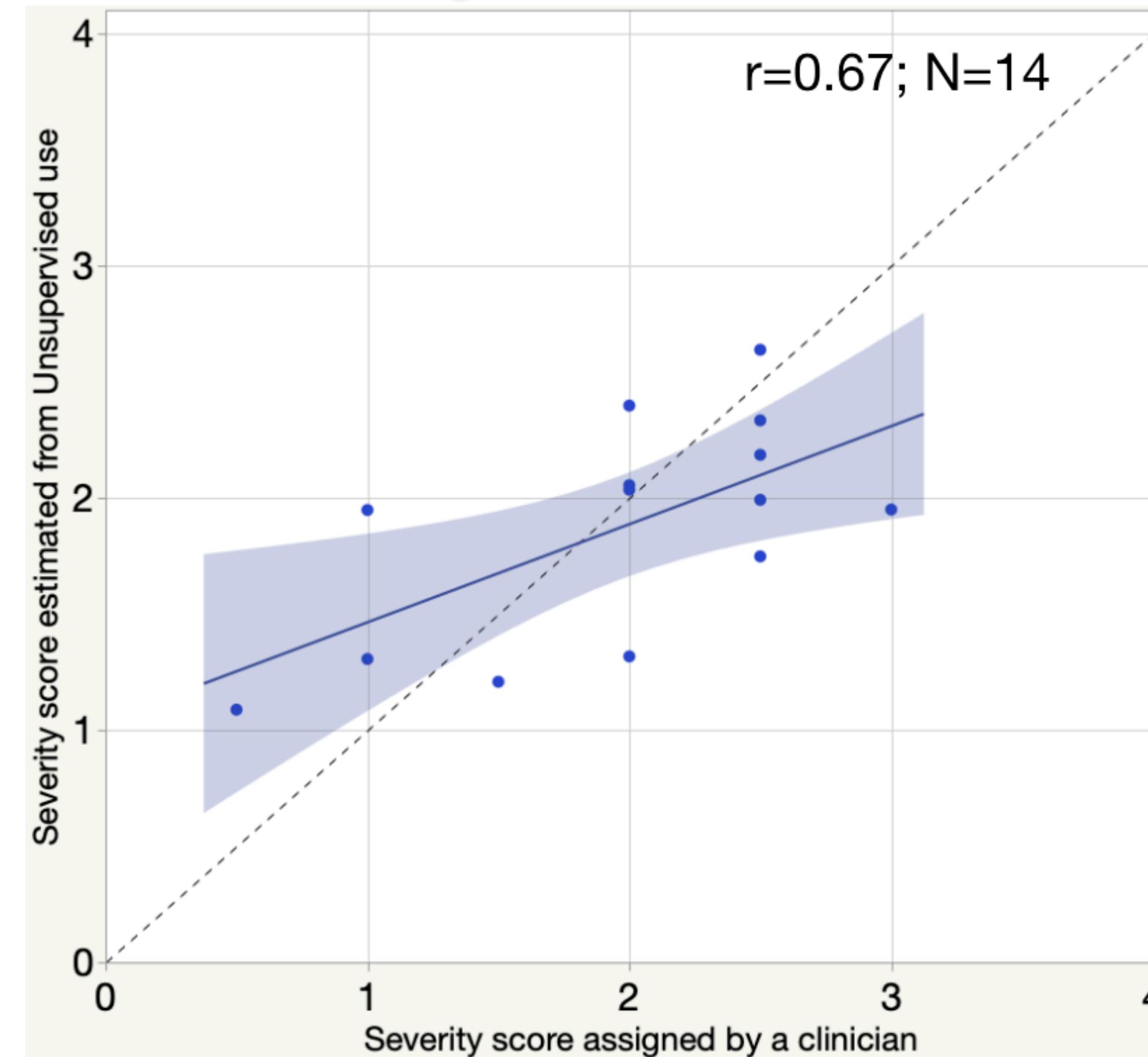


```
movement_time: 2.4  
execution_time: 3.57  
num_pauses: 5.03  
...  
...  
...
```

→ Severity
score

Results

Severity score estimated from tool usage correlates well with clinician-assigned severity



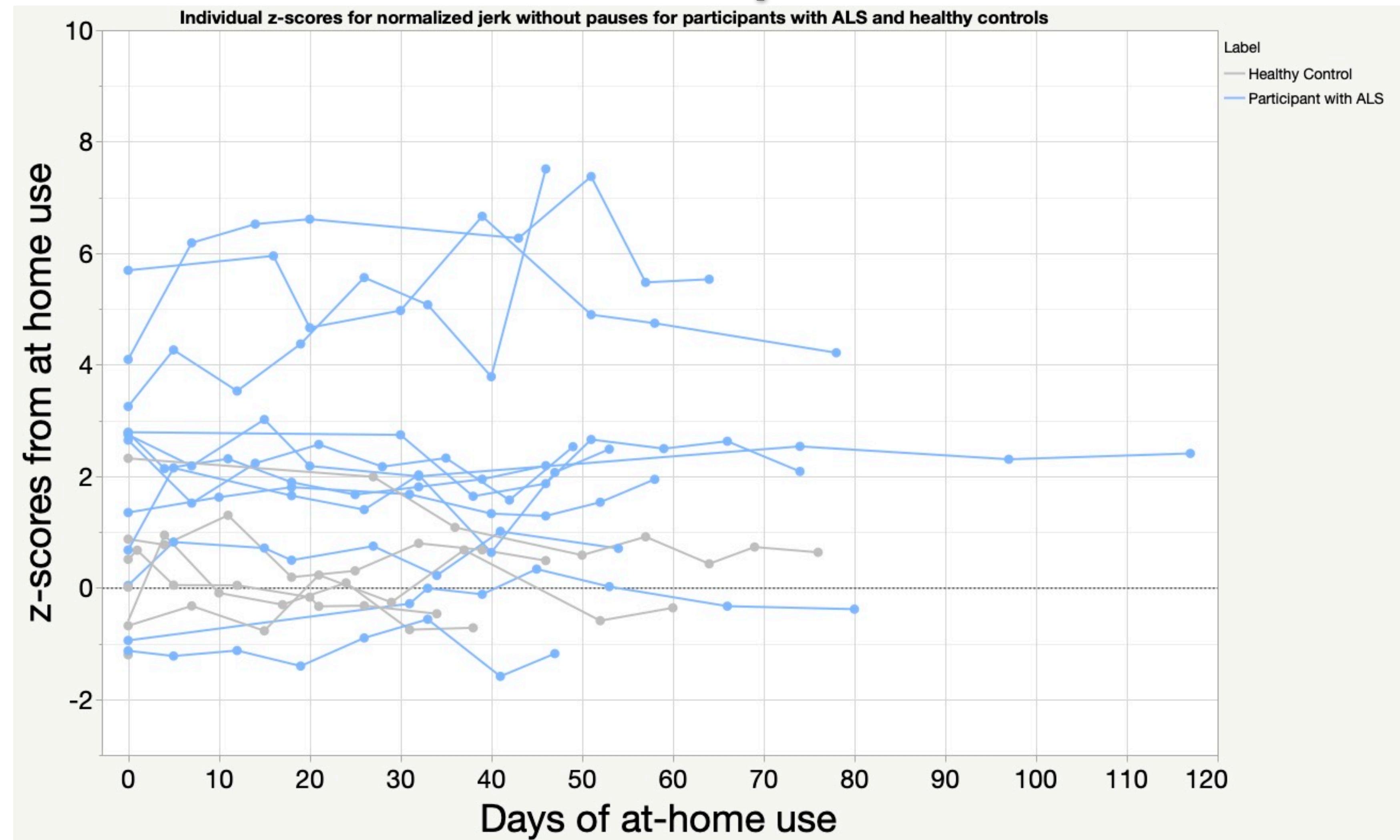
Results

Many measures are reliable over eight weeks

#	Feature name	Feature description	ICC (A-T)	ICC (Con- trols)
1	Duration of the longest pause	Duration of the longest pause of 100ms or longer. If not such pause occurred, 0ms is recorded for this measure	0.988	0.899
2	Number of pauses	Number of pauses of 100ms or longer	0.987	0.906
3	Movement time	Complete movement time from target onset to the end of the successful click on the target	0.985	0.931
4	Verification time	The time interval between the end of a movement inside a target and the beginning of the click (i.e., the time when the mouse button was pressed)	0.909	0.9
5	Click duration	The time between mouse button press and release during the correct click on the target	0.907	0.94
6	Execution time	Time from the first to the last mouse movement (excluding any movement that occurred while the mouse button was pressed)	0.887	0.951
7	Click slip	Distance between the point where the mouse button was pressed down and where it was released during click on the target	0.825	0.758
8	Execution time variability	Coefficient of variation of execution times in a block of trials	0.808	0.899
9	Verification time	Standard deviation of verification times in a block of trials	0.799	0.915
10	Normalized jerk [4, 10]	$\text{normalized jerk} = \frac{(ET)^3}{v_{max}^2} \int_t \left(\frac{da}{dt} \right)^2 dt$ <p>where $\frac{da}{dt}$ is the jerk, ET is the execution time without pauses and v_{max} is the peak speed during the movement.</p>	0.799	0.95

Results

Participants for ALS show distinct profiles

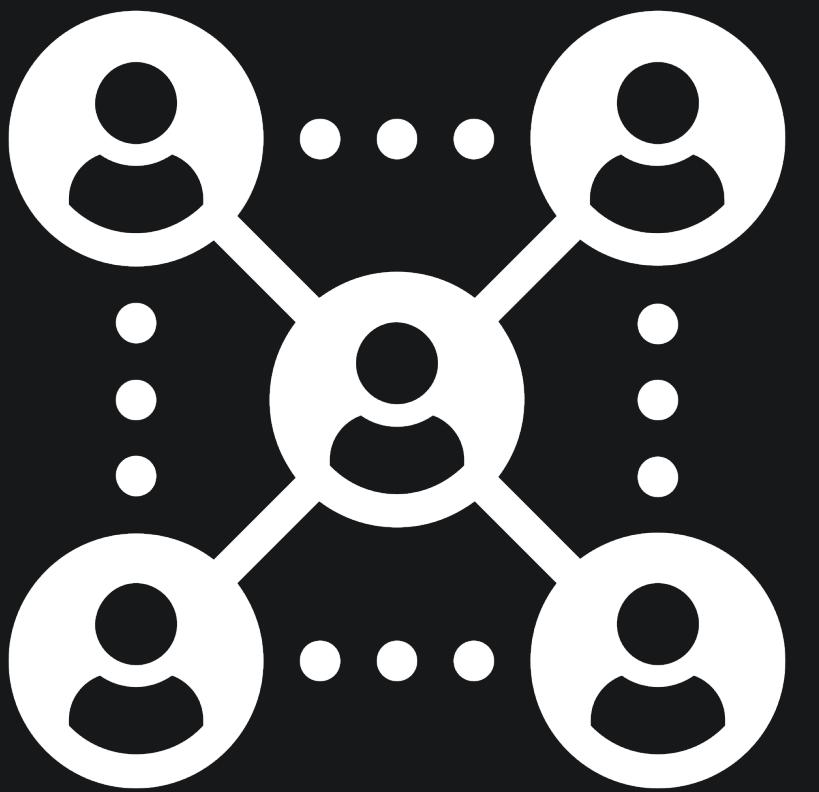


How might communities
access scientific expertise
and high-quality data
using online platforms?

Creating knowledge with social software builds on interventions at three levels



Deepen
Individual
contributions



Leverage
Community
structures



Support
Institutional
outcomes

Short-term: Novel representations of health assessments

Example Approach Outcomes

Diagnostically-
useful topics

Dysmetria
Dysarthria

Short-term: Novel representations of health assessments

Example

Diagnostically-useful topics

Dysmetria
Dysarthria

Approach

Co-design with patients, doctors, and physical therapists

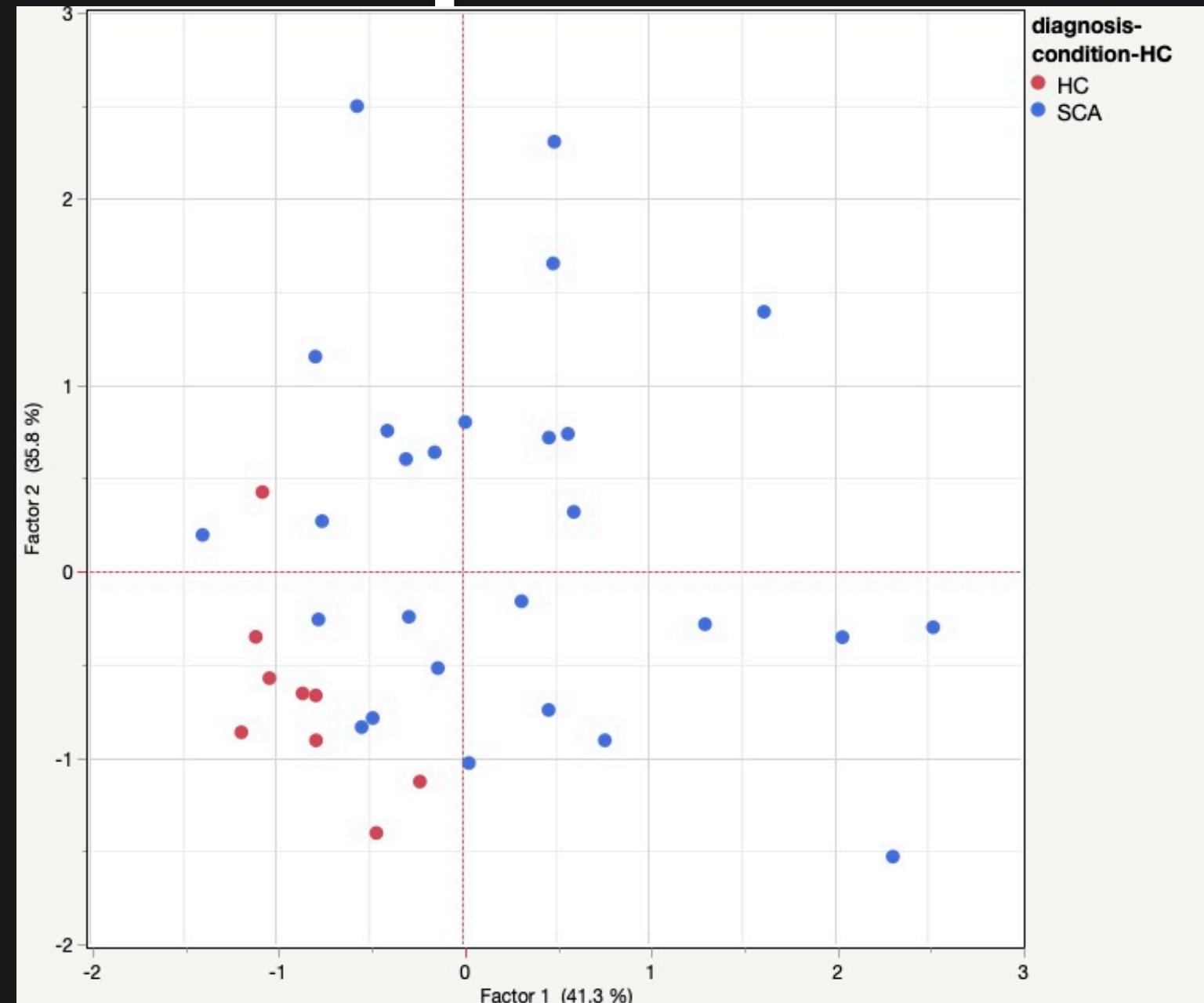
Outcomes

Web-based behavioral biomarkers

Asynchronous telemedicine for complex conditions

Mid-term: Social representations of knowledge

Example

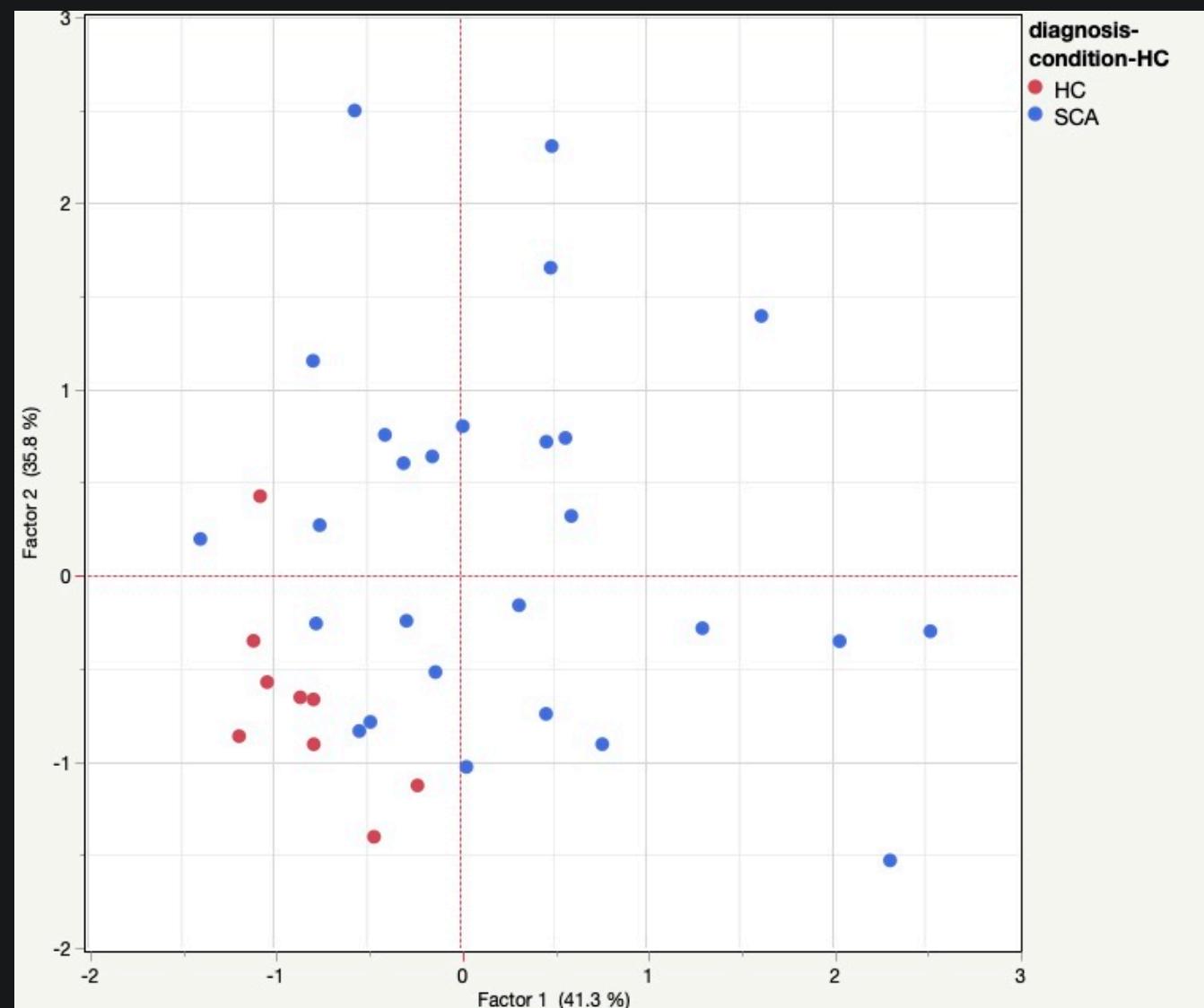


Approach

Outcomes

Mid-term: Social representations of knowledge

Example



Approach

Collaborative,
low-effort
visualization and
annotation tools

Outcomes

Social visualization
platforms for rapid
hypotheses testing

Collaborative decision-
making

Long-term: A science of community-expert collaboration

Example Approach Outcomes

Communities of practice: roles, processes, means

Science: Nascent, Contextual, Actionable

Long-term: A science of community-expert collaboration

Example

Communities of practice: roles, processes, means

Science: Nascent, Contextual, Actionable

Approach

Co-design of experiments

Integrate people at different steps of the scientific process

Outcomes

Patient-partnered research

Lifelong learning and collaboration tools

Vision for teaching and engagement: **Solve personally-meaningful problems**

Introductory

Intro to HCI
(needfinding ->
prototype evaluation)

Intro to Data Science

Social Computing Systems

Design of Social
Computing Systems

Social Computing
seminar

Healthcare

Interactive systems
for health
assessment

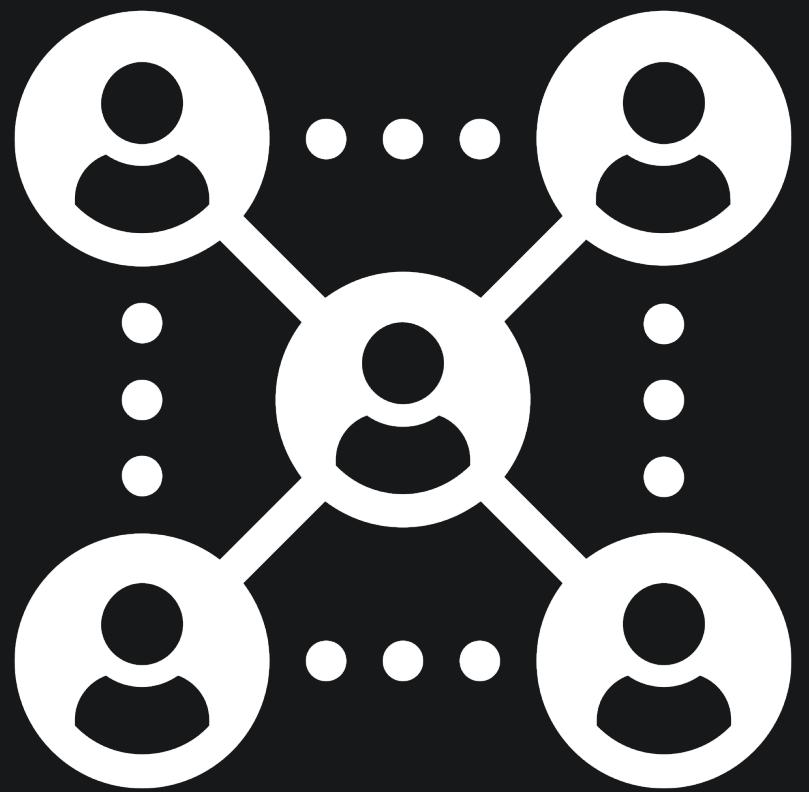
+

HCI gaps in clinical
success

Thank you



Deepen
Individual
contributions



Build on
Community
structures



Support
Institutional
outcomes

Complex work: learning & collaboration

