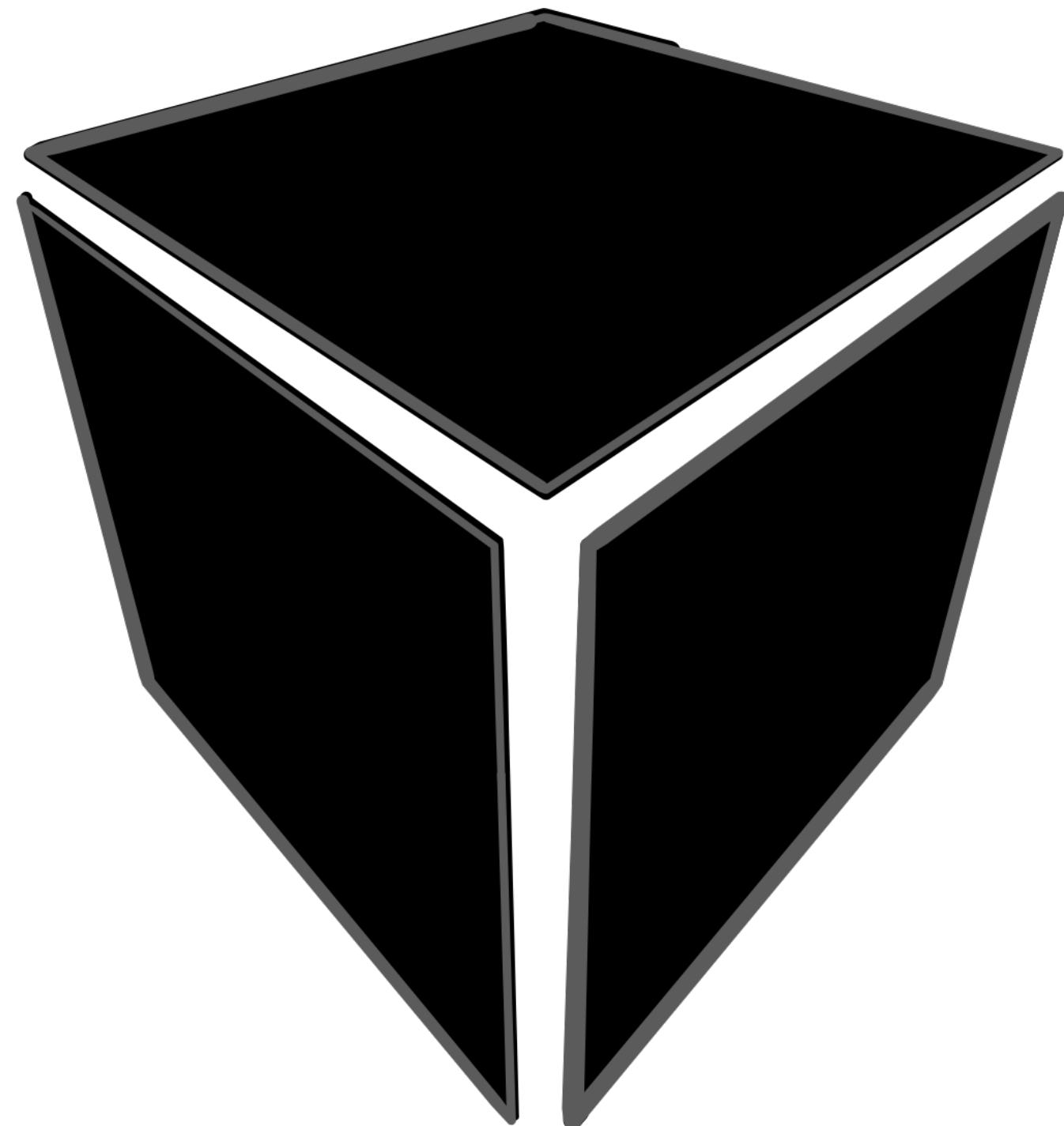


**From top-down to bottom-up:
Peer production as a means to citizen
science throughout the research cycle.**

Citizen/Community Science

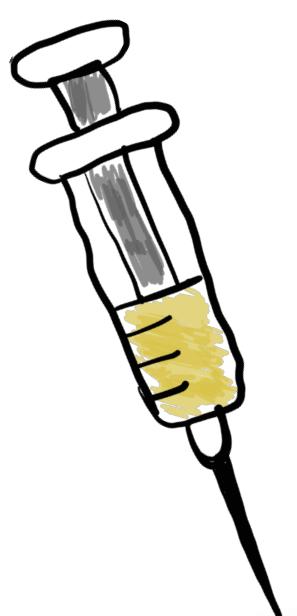
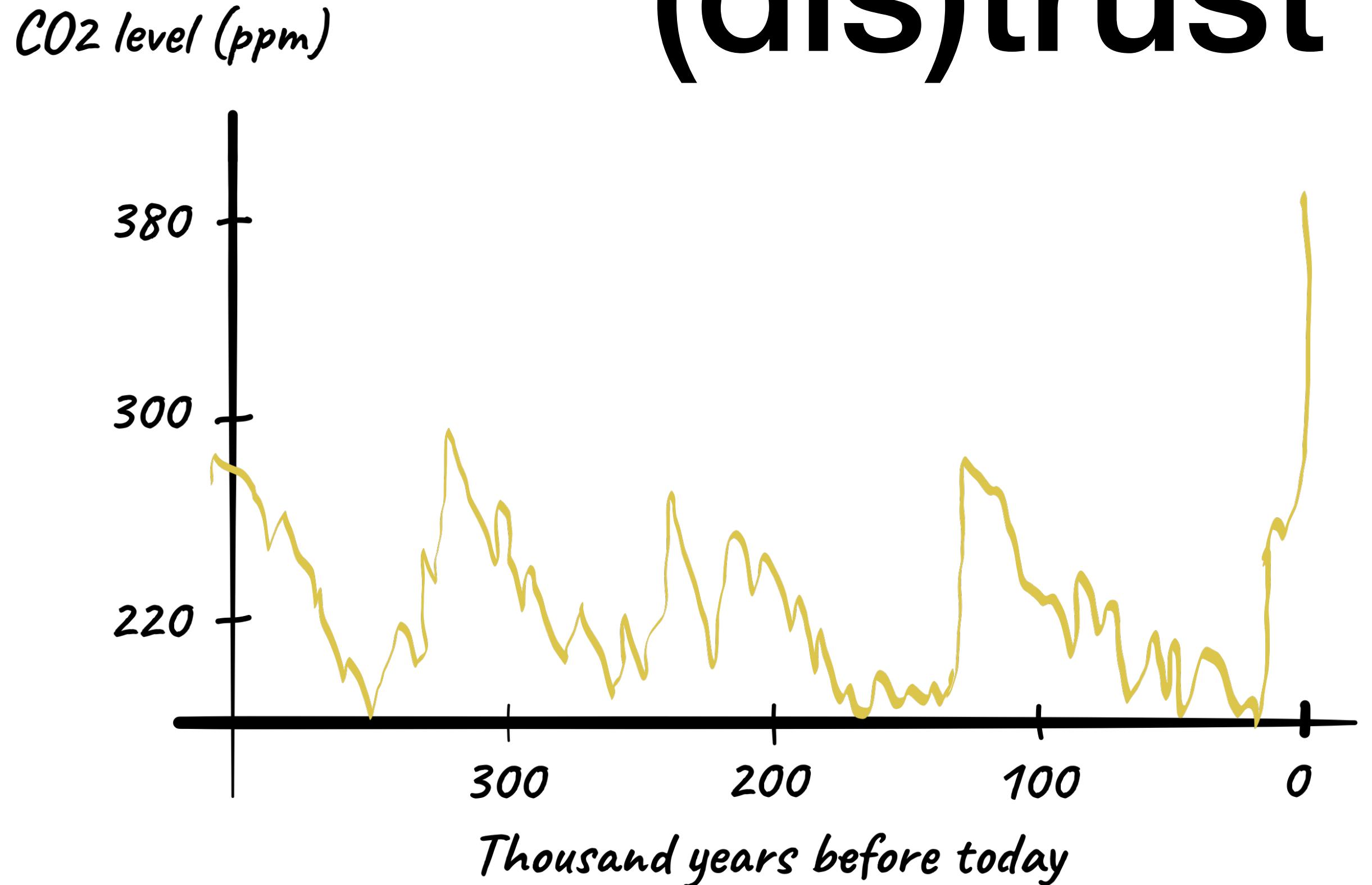


- increases public understanding...
- diversifies research...
- empowers participants...

Bonney et al. Can citizen science enhance public understanding of science? (2016)

Greshake Tzovaras et al. The Personal Data is Political (2019)

(dis)trust in science



A quarter of all kindergartners in this county in Washington aren't immunized. Now there's a measles crisis

Ken Alltucker, USA TODAY

Published 8:15 a.m. ET Feb. 11, 2019 | Updated 2:39 a.m. ET Feb. 12, 2019

Citizen/Community Science



- increases public understanding...
- diversifies research...
- empowers participants...
- **effectiveness depends on type of participation**

Bonney et al. Can citizen science enhance public understanding of science? (2016)

Greshake Tzovaras et al. The Personal Data is Political (2019)

Citizen/Community Science



What are the prevalent types of how participants are involved in the research cycle?

prevalent CCS types



- Crowdfunding
- Human Computation
- Crowdsourcing

Bonney et al. Can citizen science enhance public understanding of science? (2016)

Hecker et al. The European citizen science landscape – a snapshot (2019)

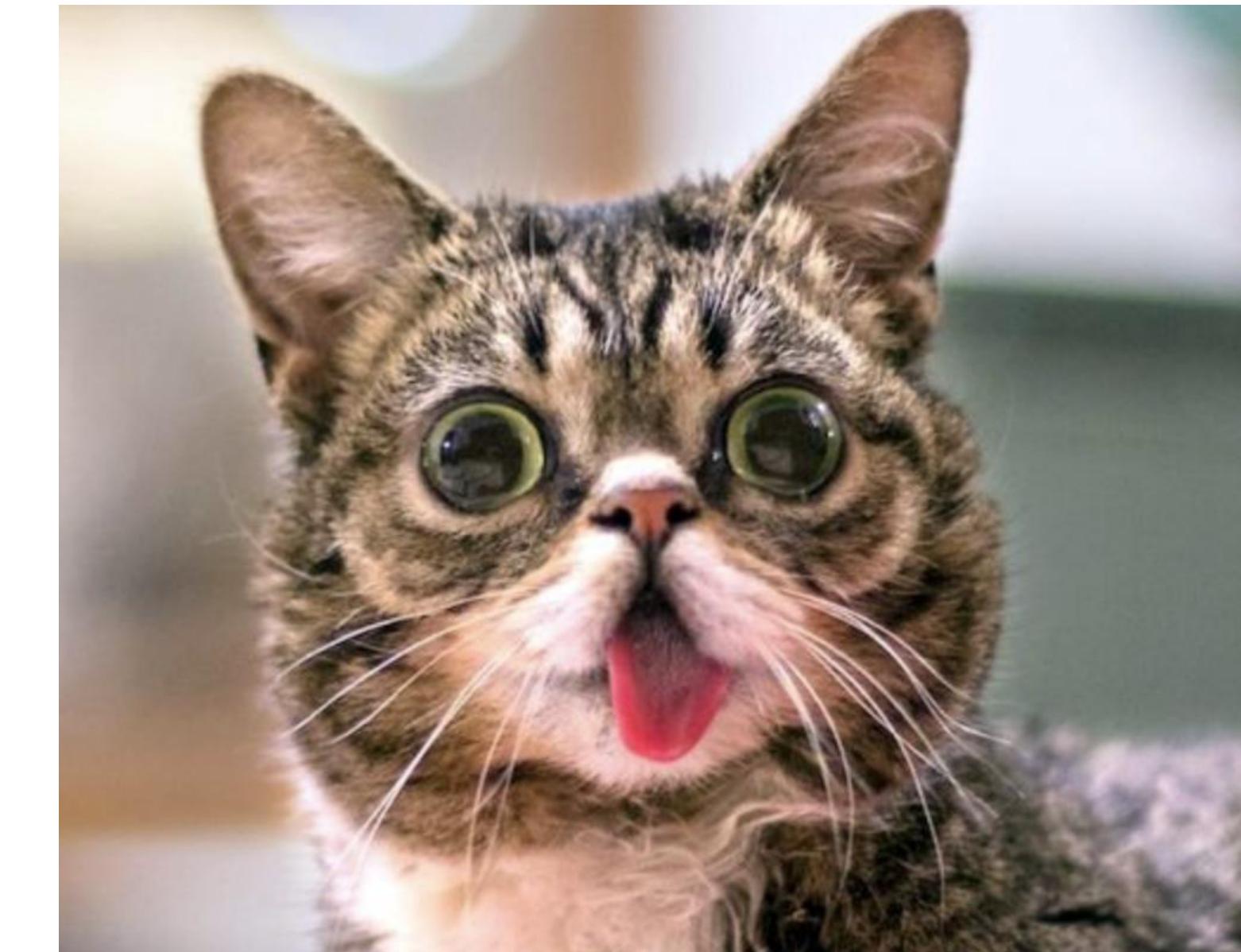
prevalent CCS types



Crowdfunded whole-genome sequencing of the celebrity cat Lil BUB identifies causal mutations for her osteopetrosis and polydactyly

Mike Bridavsky, Heiner Kuhl, Arthur Woodruf, Uwe Kornak, Bernd Timmermann, Norbert Mages, 99 Lives Consortium, Darío G Lupiáñez, Orsolya Symmons, Daniel M Ibrahim

doi: <https://doi.org/10.1101/556761>



prevalent CCS types



ZOONIVERSE

prevalent CCS types



The Cornell Lab
of Ornithology

prevalent CCS types

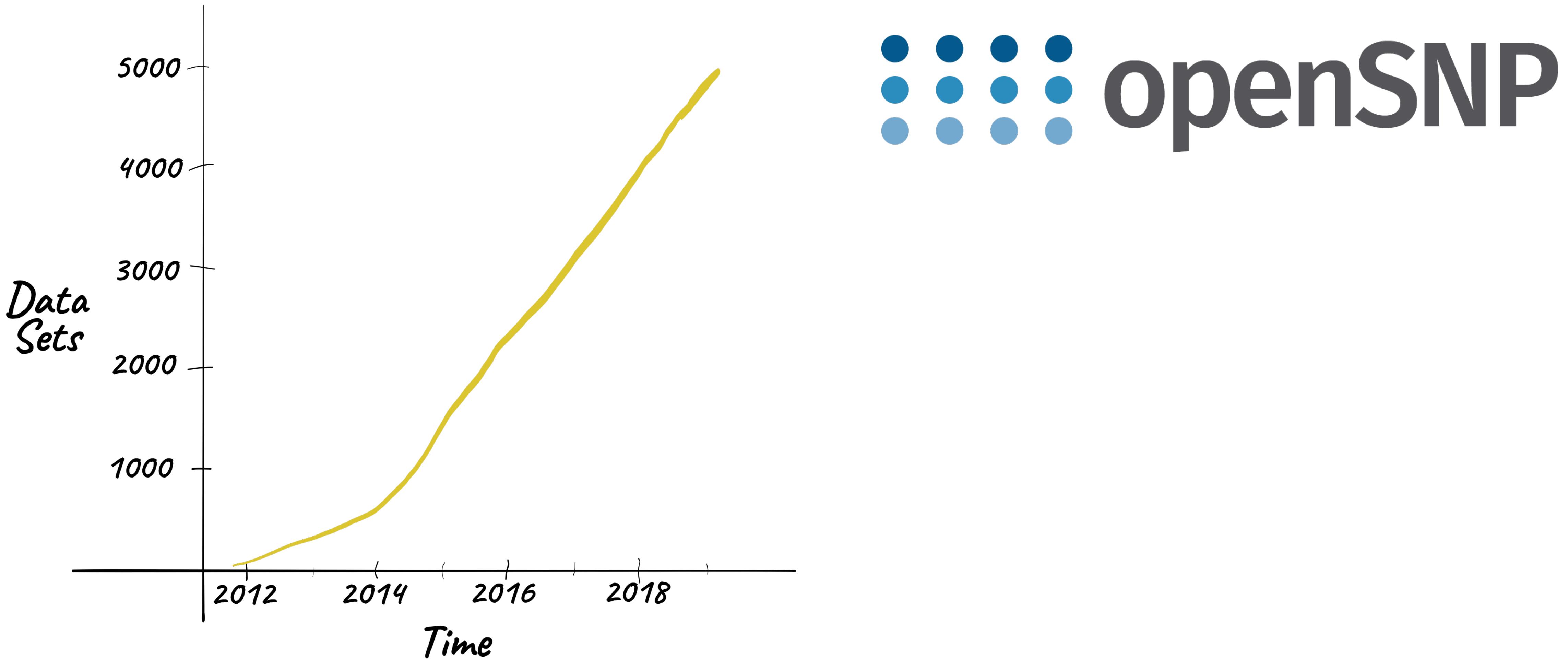


openSNP

prevalent CCS types

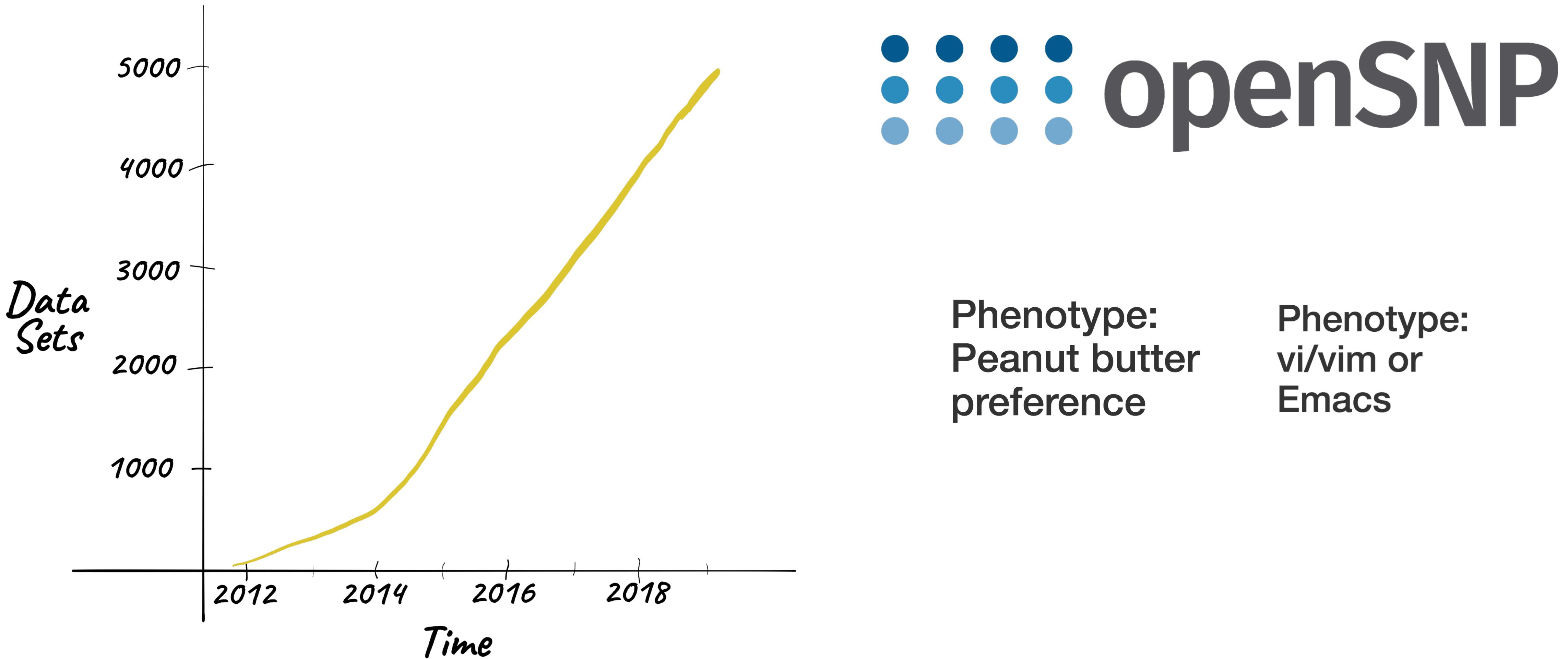


prevalent CCS types



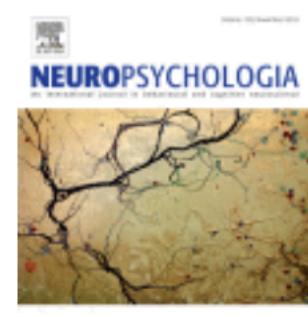
Greshake Tzovaras et al. openSNP–A Crowdsourced Web Resource for Personal Genomics (2014)
Haeusermann, Greshake Tzovaras* et al. Open sharing of genomic data: Who does it and why? (2017)*

prevalent CCS types



prevalent CCS types

Neuropsychologia
Volume 120, November 2018, Pages 97-104



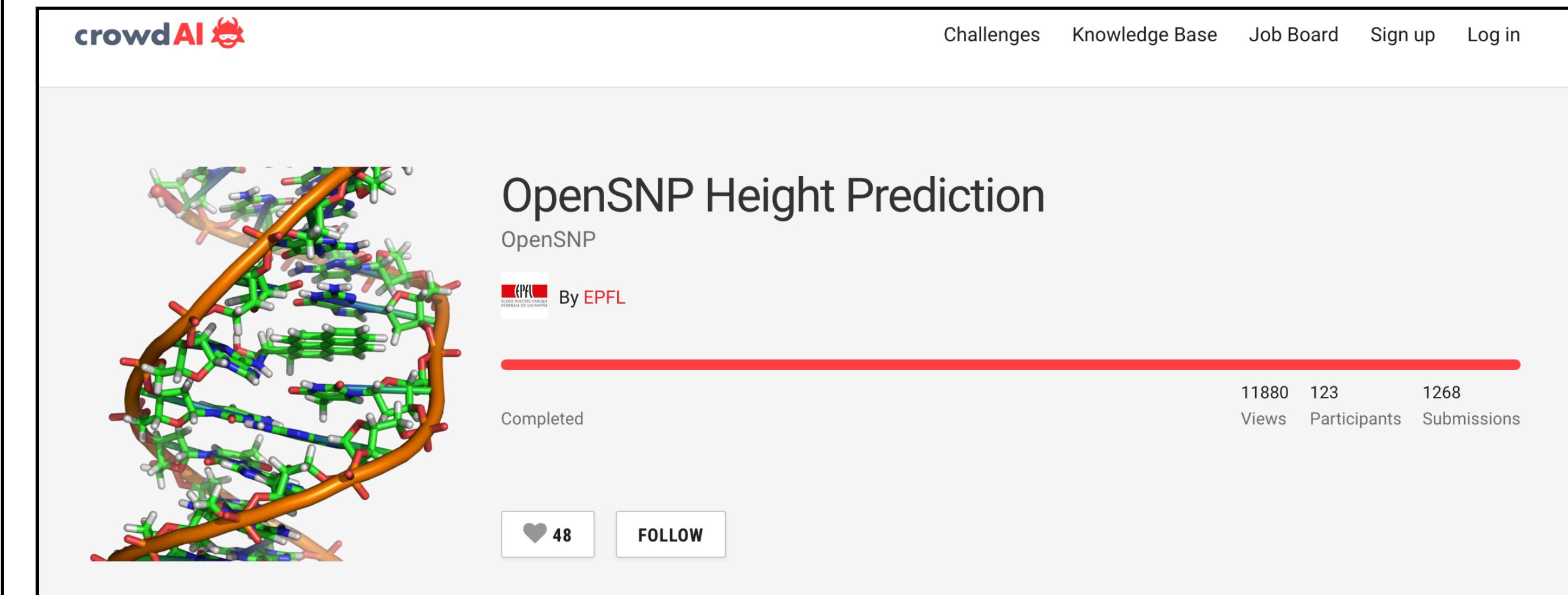
Dopaminergic genes are associated with both directed and random exploration

Samuel J. Gershman ^a  , Bastian Greshake Tzovaras ^b



crowdAI

Challenges Knowledge Base Job Board Sign up Log in



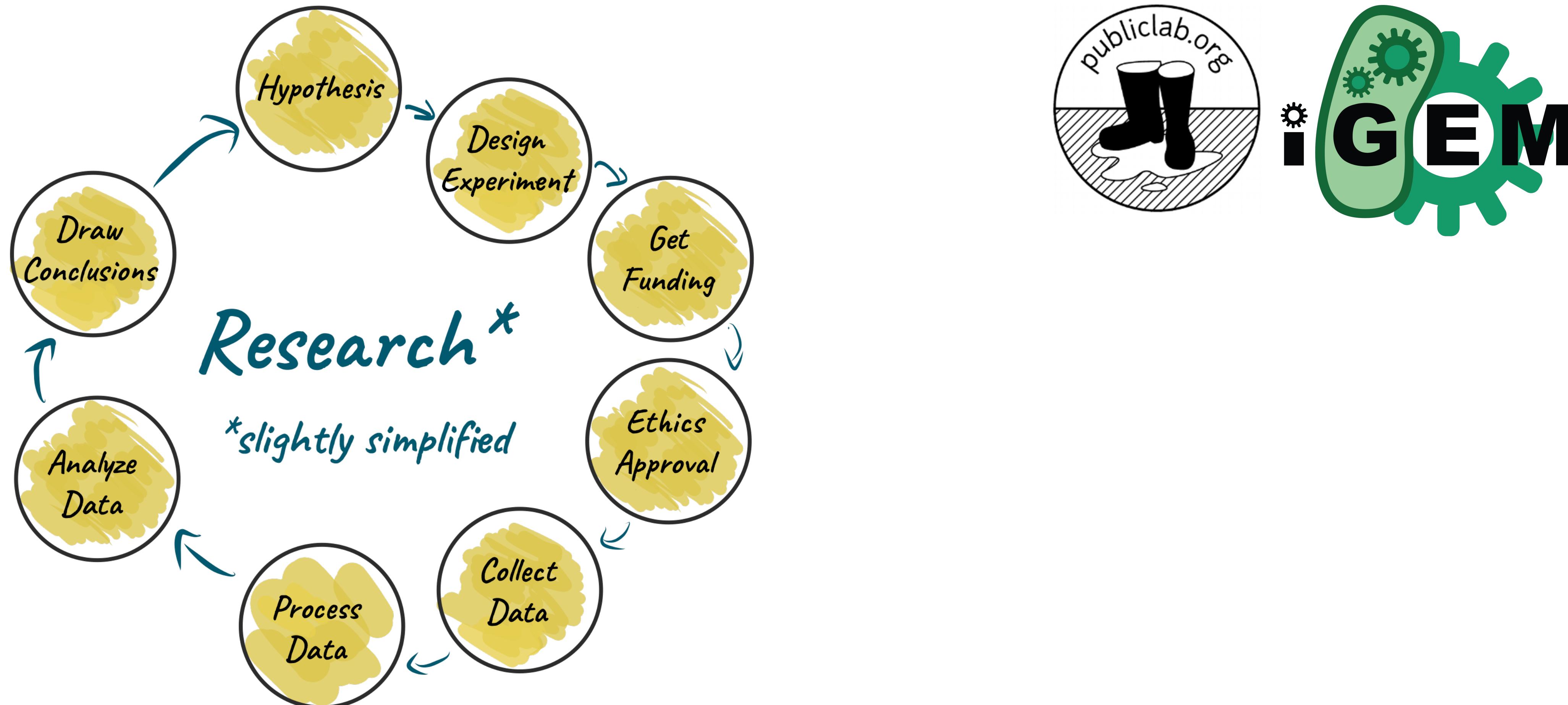
OpenSNP Height Prediction
OpenSNP
By EPFL

Completed

11880 Views 123 Participants 1268 Submissions

48 FOLLOW

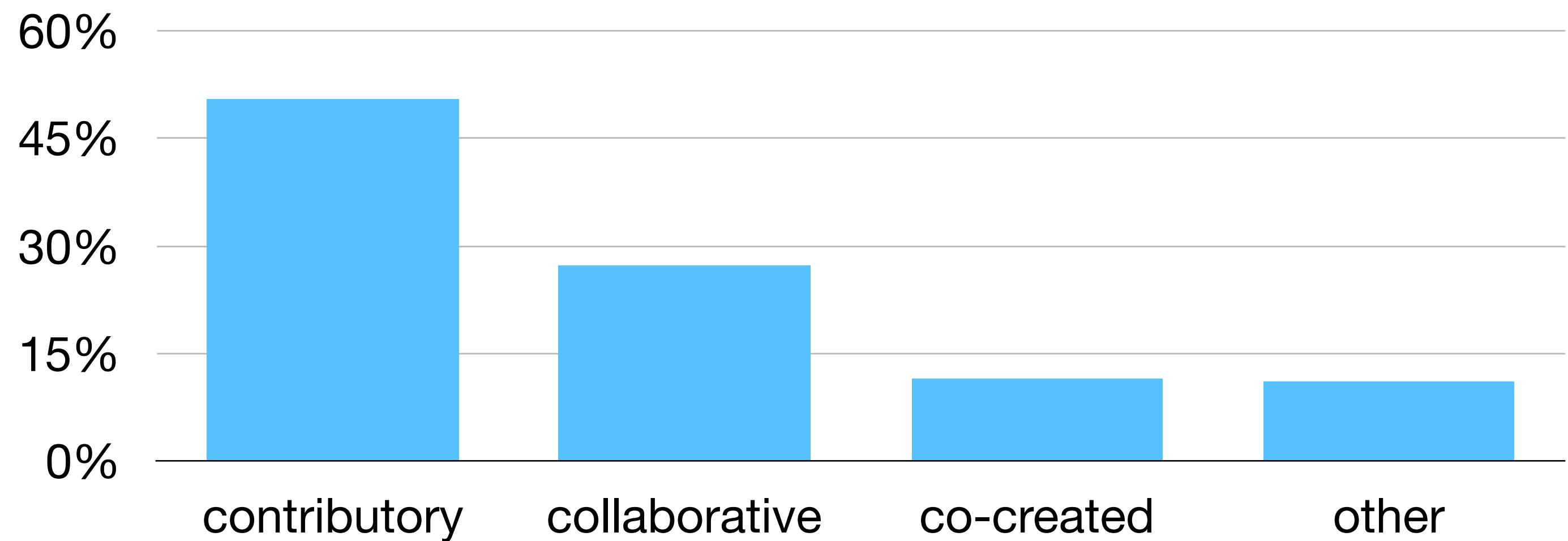
co-created community science



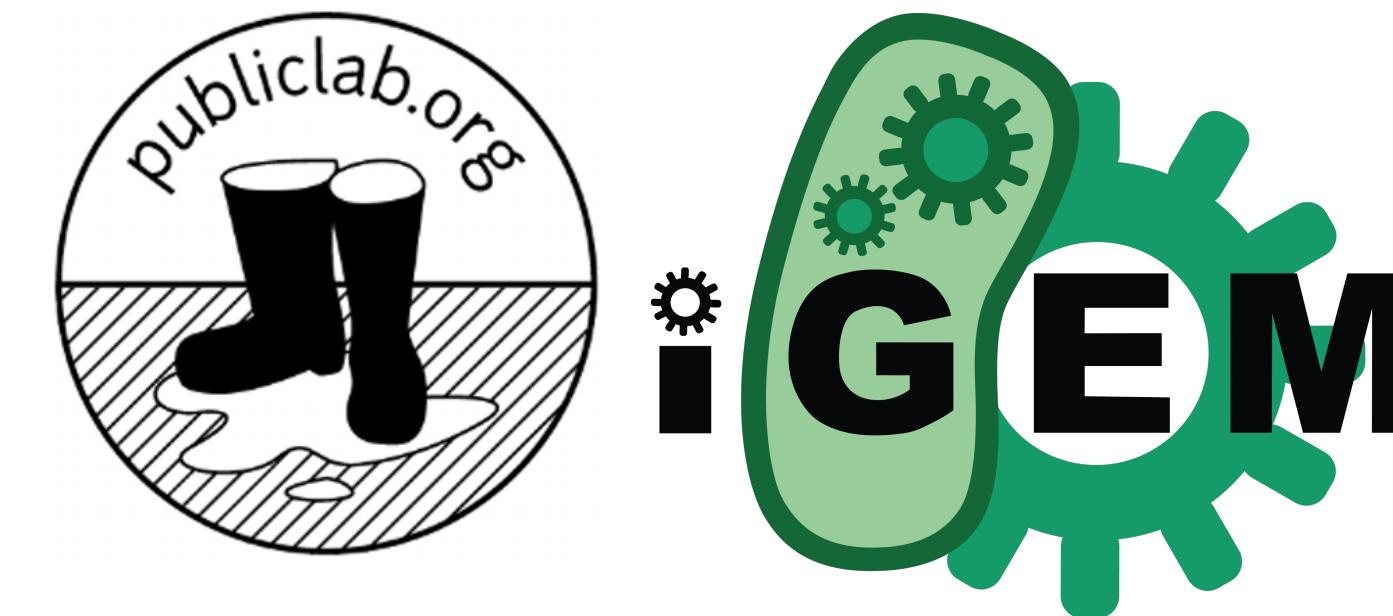
Bonney et al. *Can citizen science enhance public understanding of science?* (2016)

Hecker et al. *The European citizen science landscape – a snapshot* (2019)

co-created community science



Bonney et al. Can citizen science enhance public understanding of science? (2016)
Hecker et al. The European citizen science landscape – a snapshot (2019)



How to enable co-creation?

commons-based peer-production

“

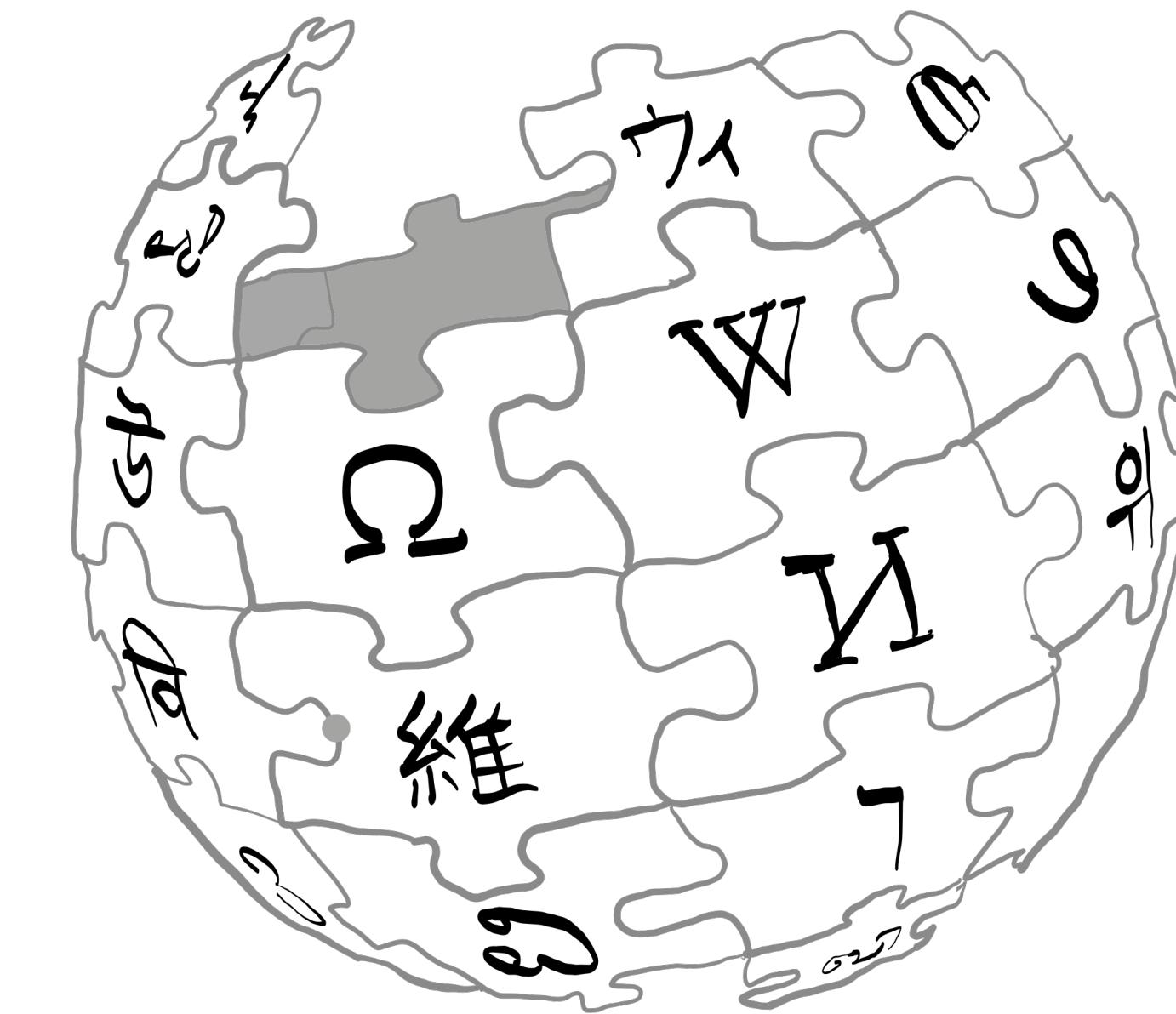
*[...] the networked environment makes possible a new modality of organizing production: **radically decentralized, collaborative, and nonproprietary**; based on **sharing resources and outputs** among widely distributed, loosely connected individuals who **cooperate with each other** without relying on either market signals or managerial commands. This is **what I call “commons-based peer production”***

Yochai Benkler, 2006

commons-based peer-production



open source movement



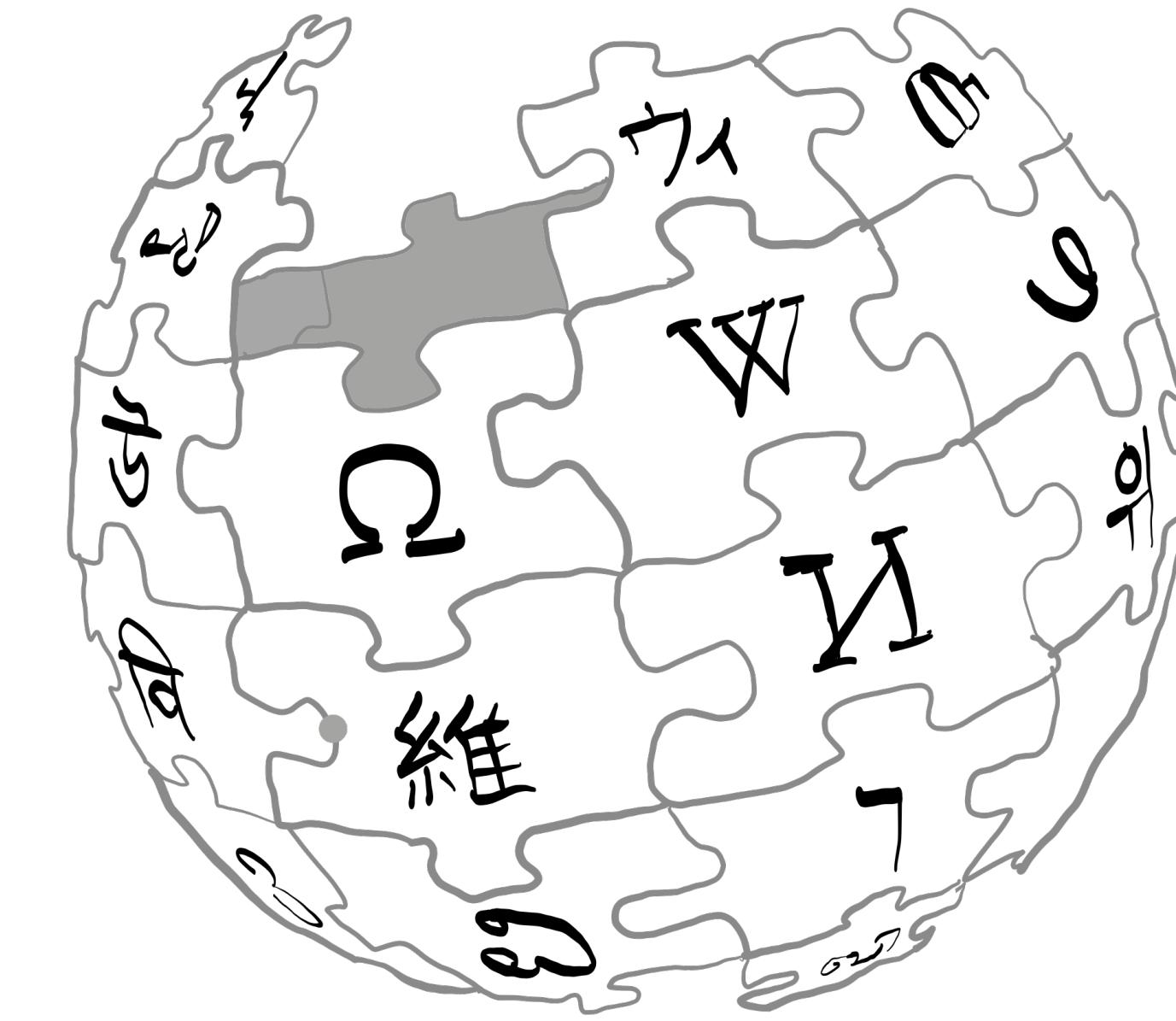
Wikipedia

commons-based peer-production



open source movement

non-hierarchical



Wikipedia

commons-based peer-production



open source movement

**non-hierarchical
negotiated coordination**



Wikipedia

commons-based peer-production



open source movement

**non-hierarchical
negotiated coordination
for-benefit**



Wikipedia

commons-based peer-production



open source movement

**non-hierarchical
negotiated coordination
for-benefit
modular tasks**



Wikipedia

commons-based peer-production



non-hierarchical negotiated coordination for-benefit modular tasks produsage



open source movement

commons-based peer-production



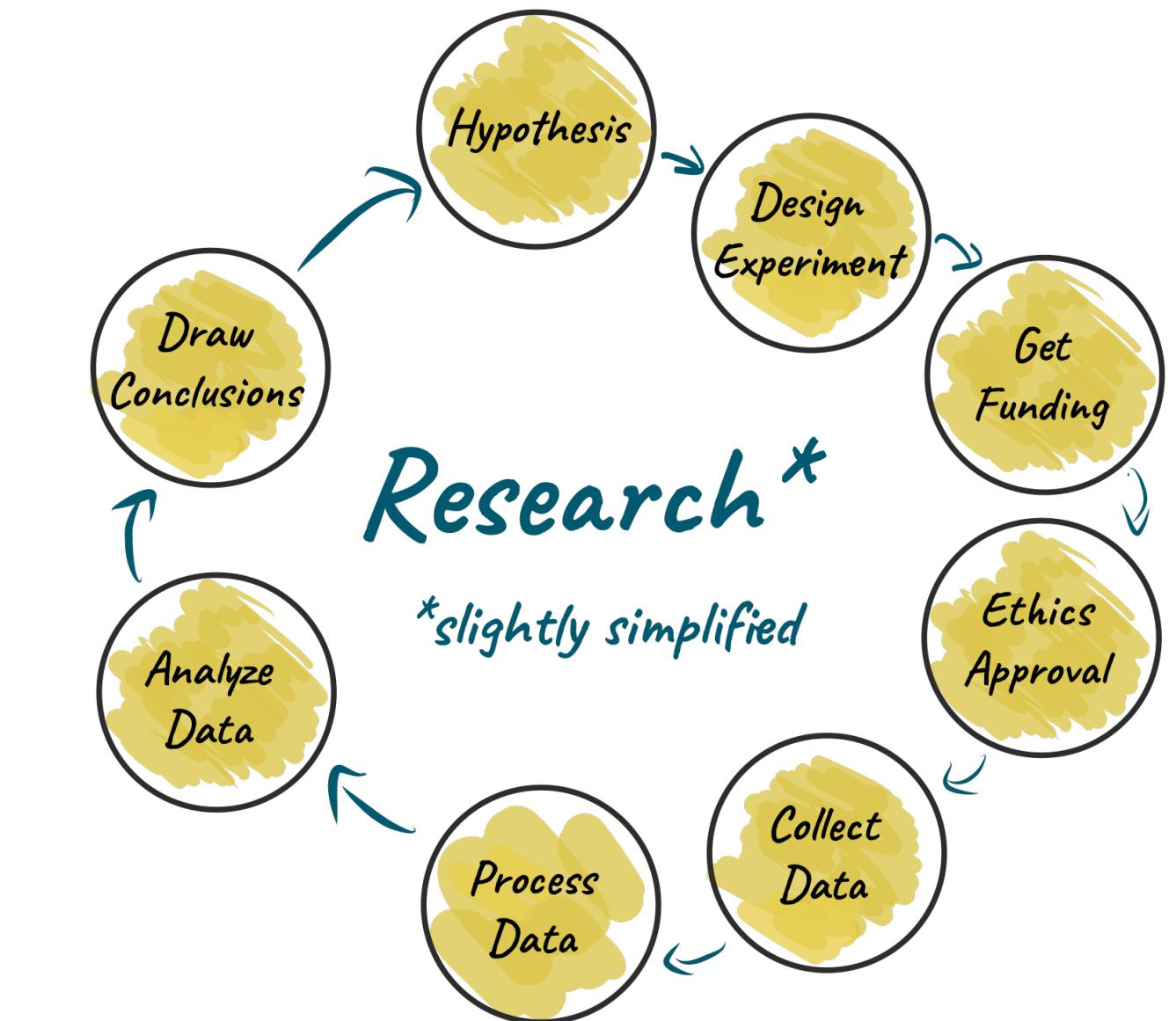
open source movement

**non-hierarchical
negotiated coordination
for-benefit
modular tasks
produsage
granularity**



Wikipedia

Hypothesis



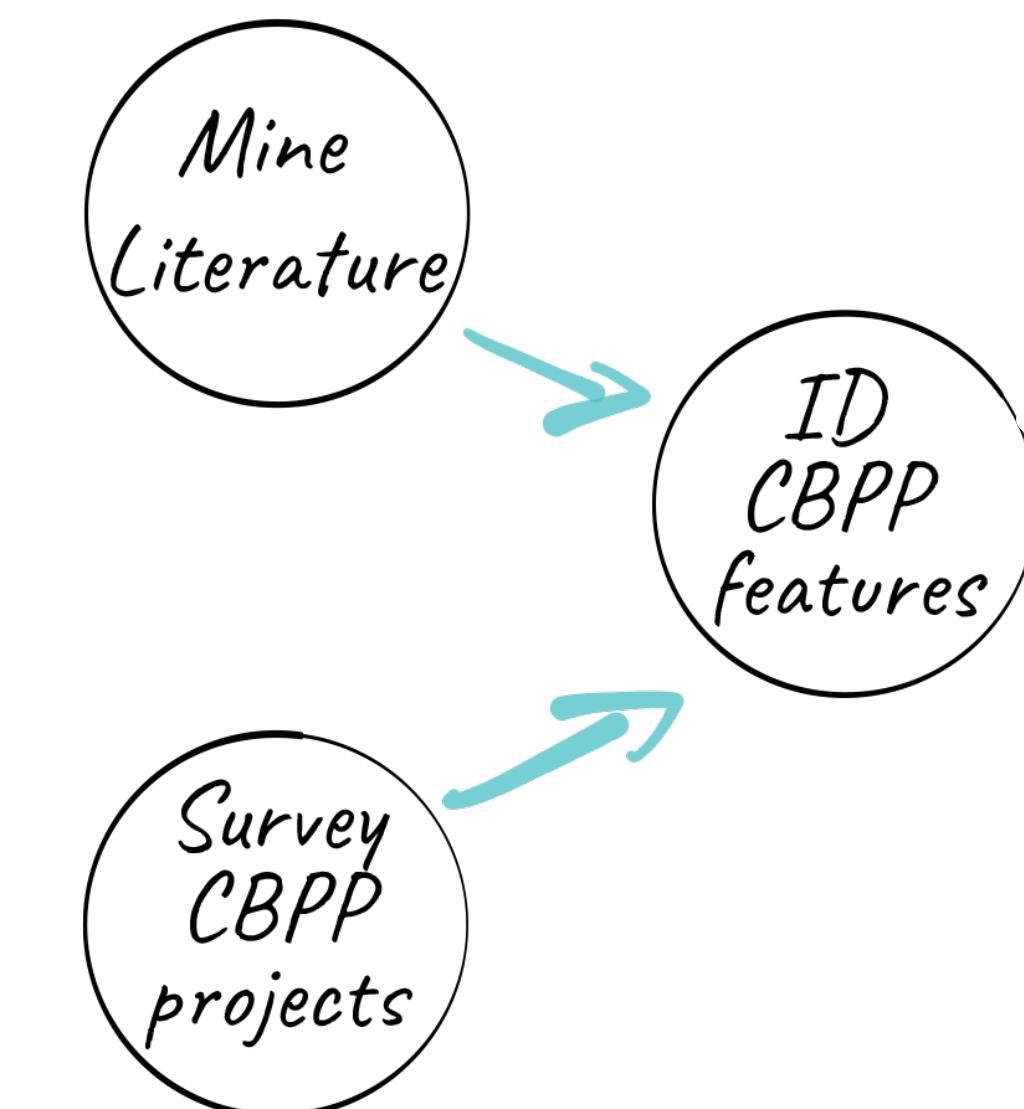
- Bringing CBPP methods to CCS leads to
 - higher involvement of volunteers, across all stages of the research cycle
 - increase opportunities for learning & innovation
 - generate research more relevant to participants
 - builds trust in research

Research Plan

1. Identify hallmarks of CBPP projects and map into CCS eco systems
2. Implement CBPP features into an existing CCS ecosystem
3. Observe how CCS projects evolve after CBPP features are available

Research Plan

- 1. Identify hallmarks of CBPP projects and map into CCS eco systems**
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commons-based peer-production *& community science*

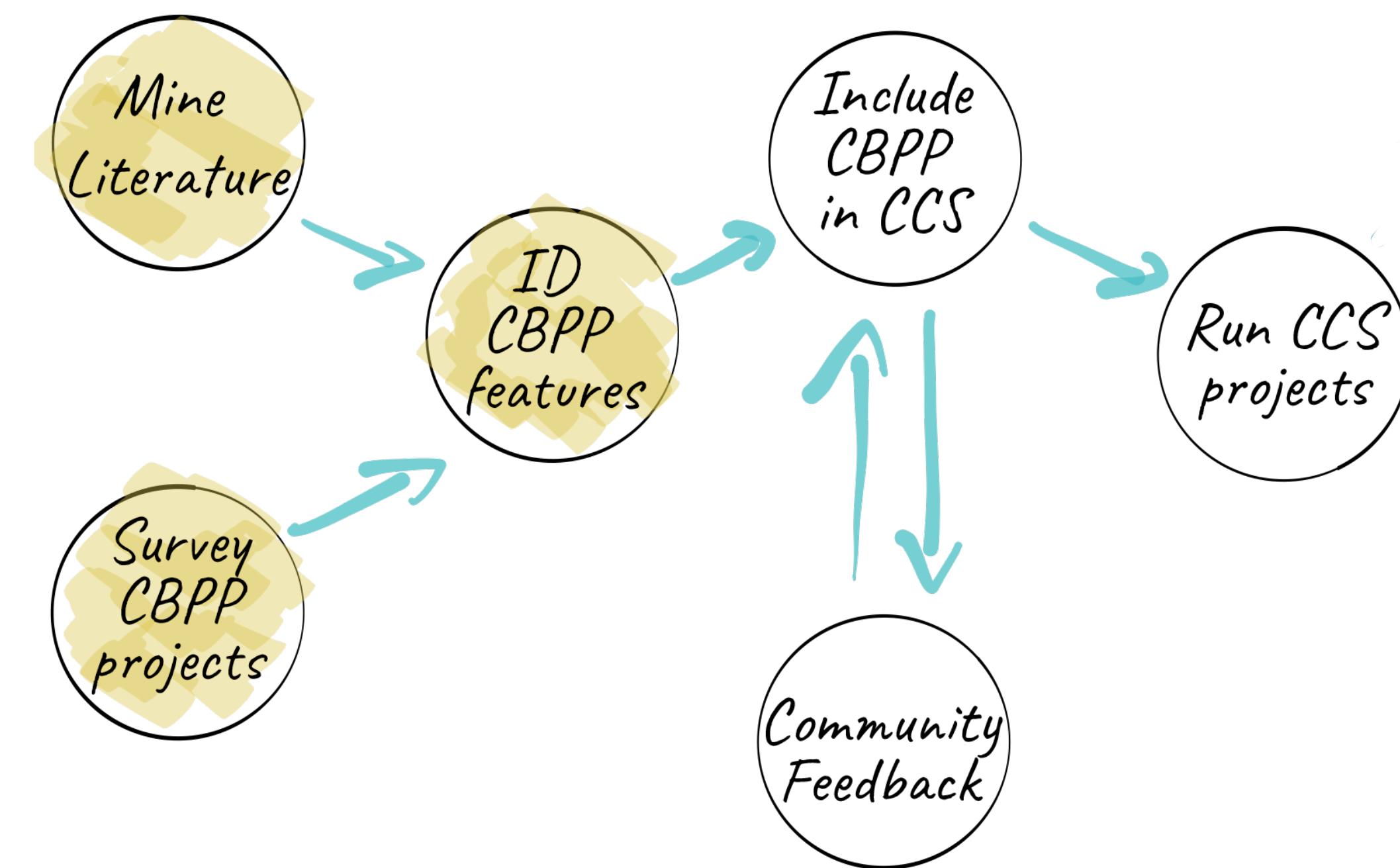
- divide researcher / volunteers
- top-down structure
- one-sided data flow



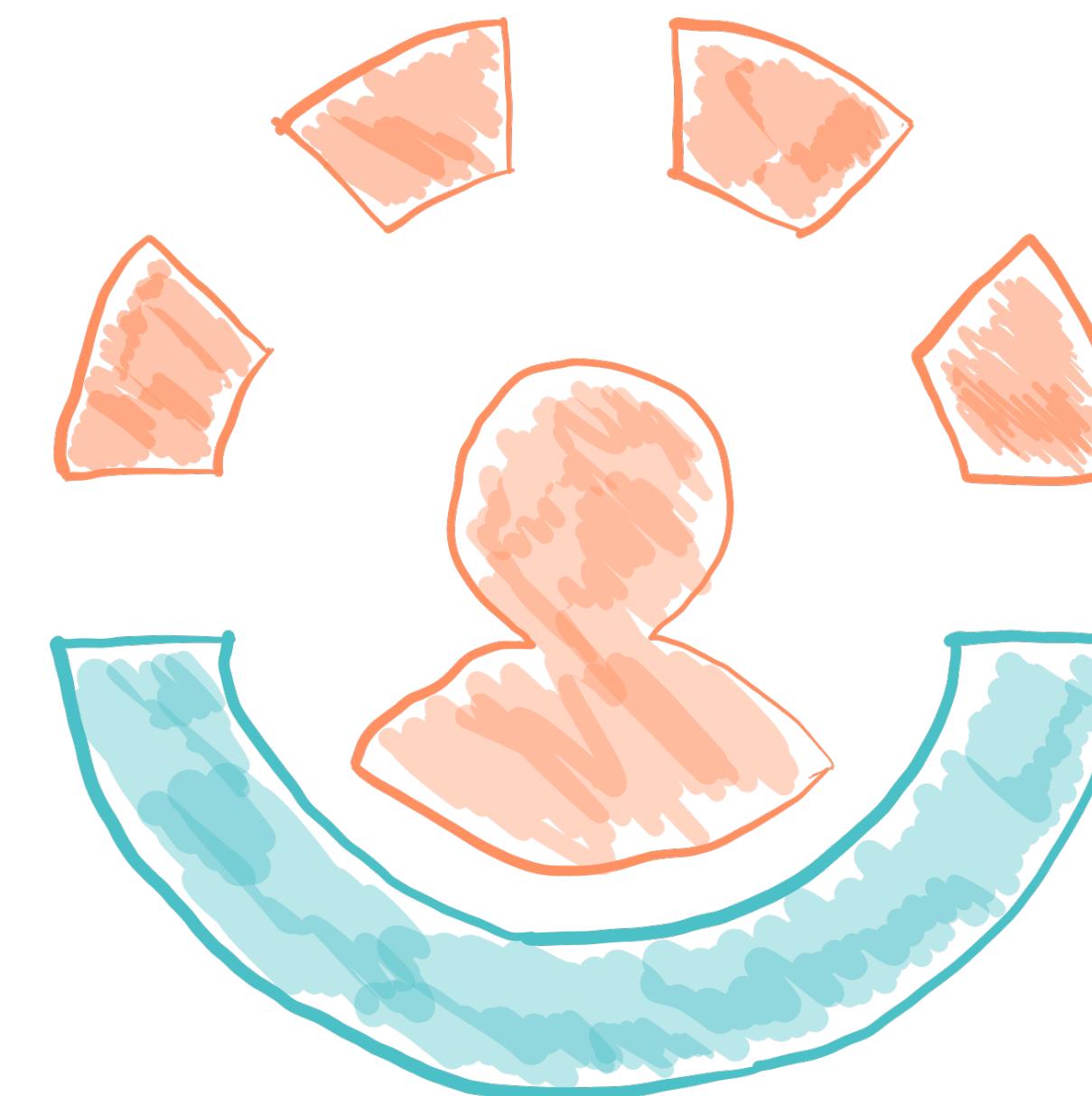
Clickworkers
Classic

Research Plan

1. Identify hallmarks of CBPP projects and map into CCS eco systems
2. **Implement CBPP features into an existing CCS ecosystem**
3. Observe how CCS projects evolve after CBPP features are available

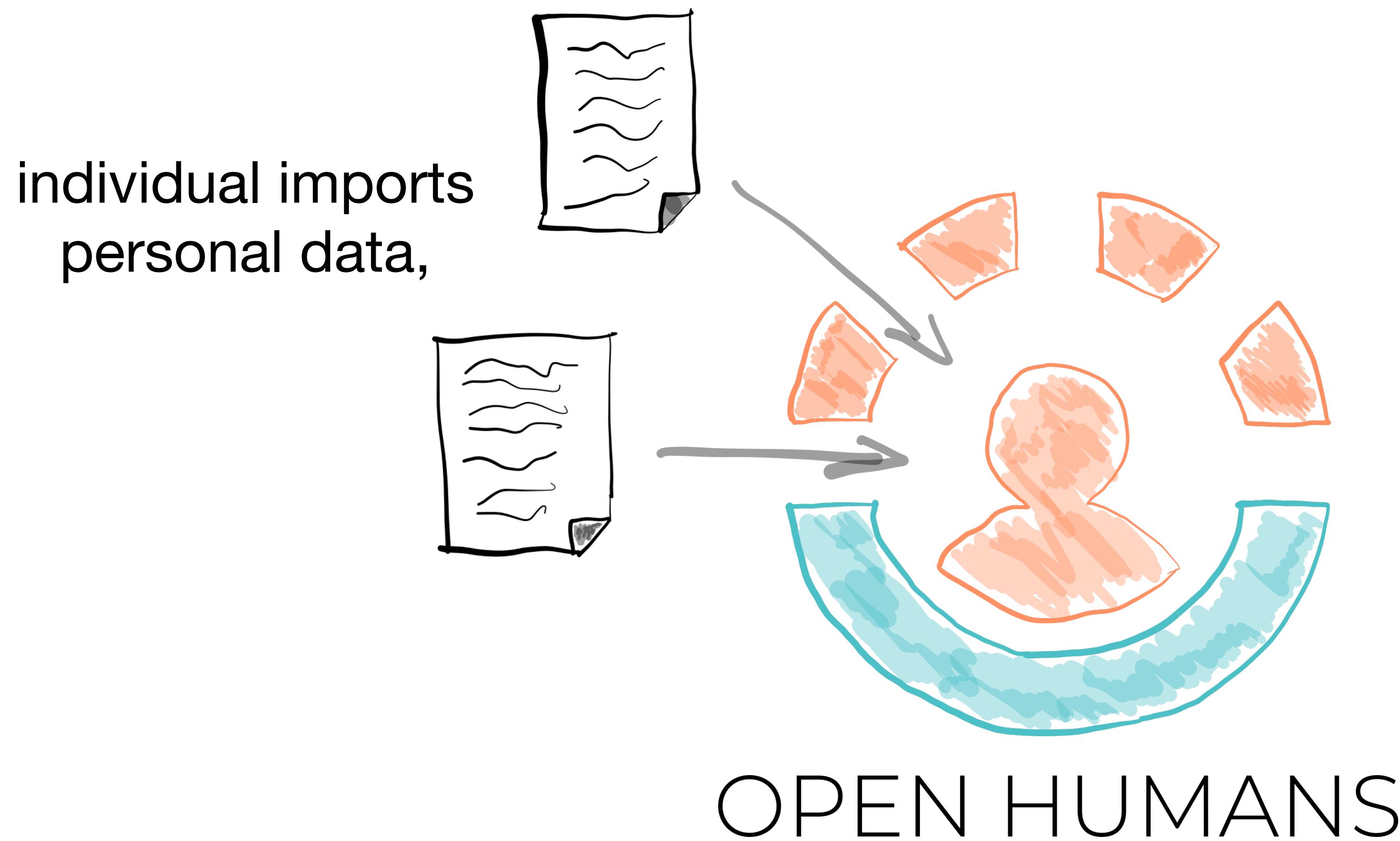


Bringing CBPP to a CCS ecosystem

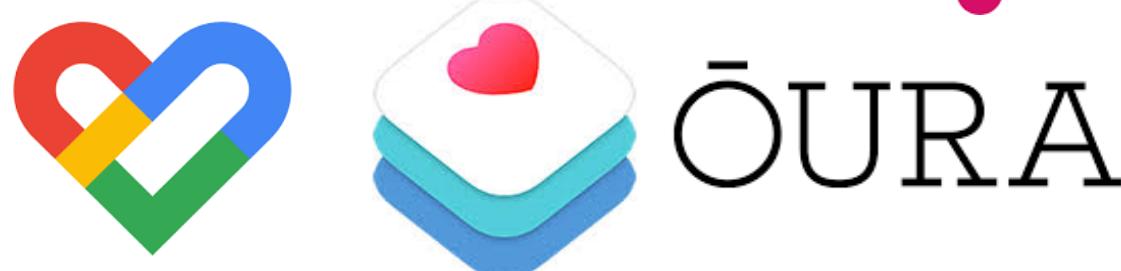


OPEN HUMANS

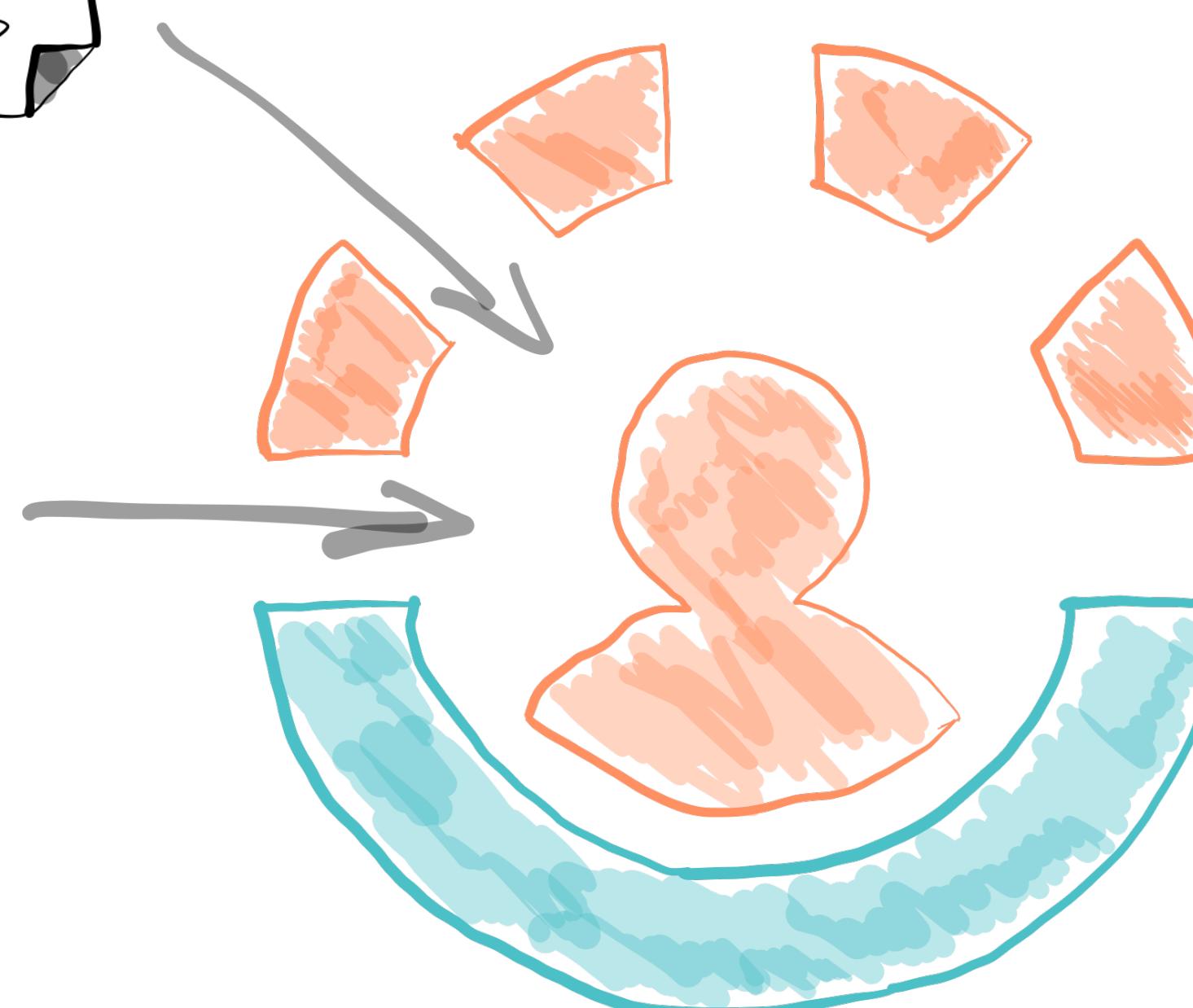
Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)



Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)



individual imports
personal data,

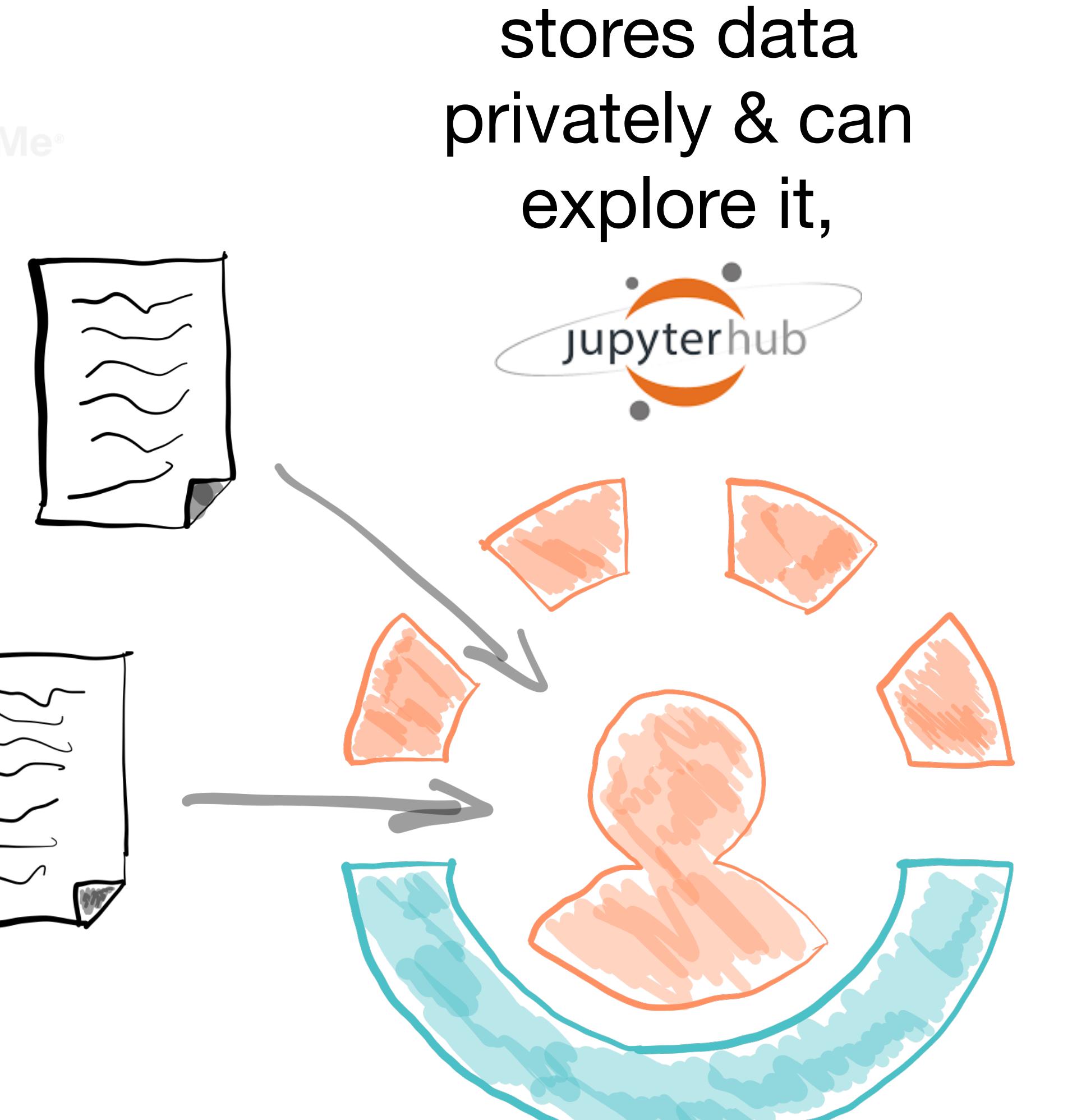


OPEN HUMANS

Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)



individual imports
personal data,



OPEN HUMANS

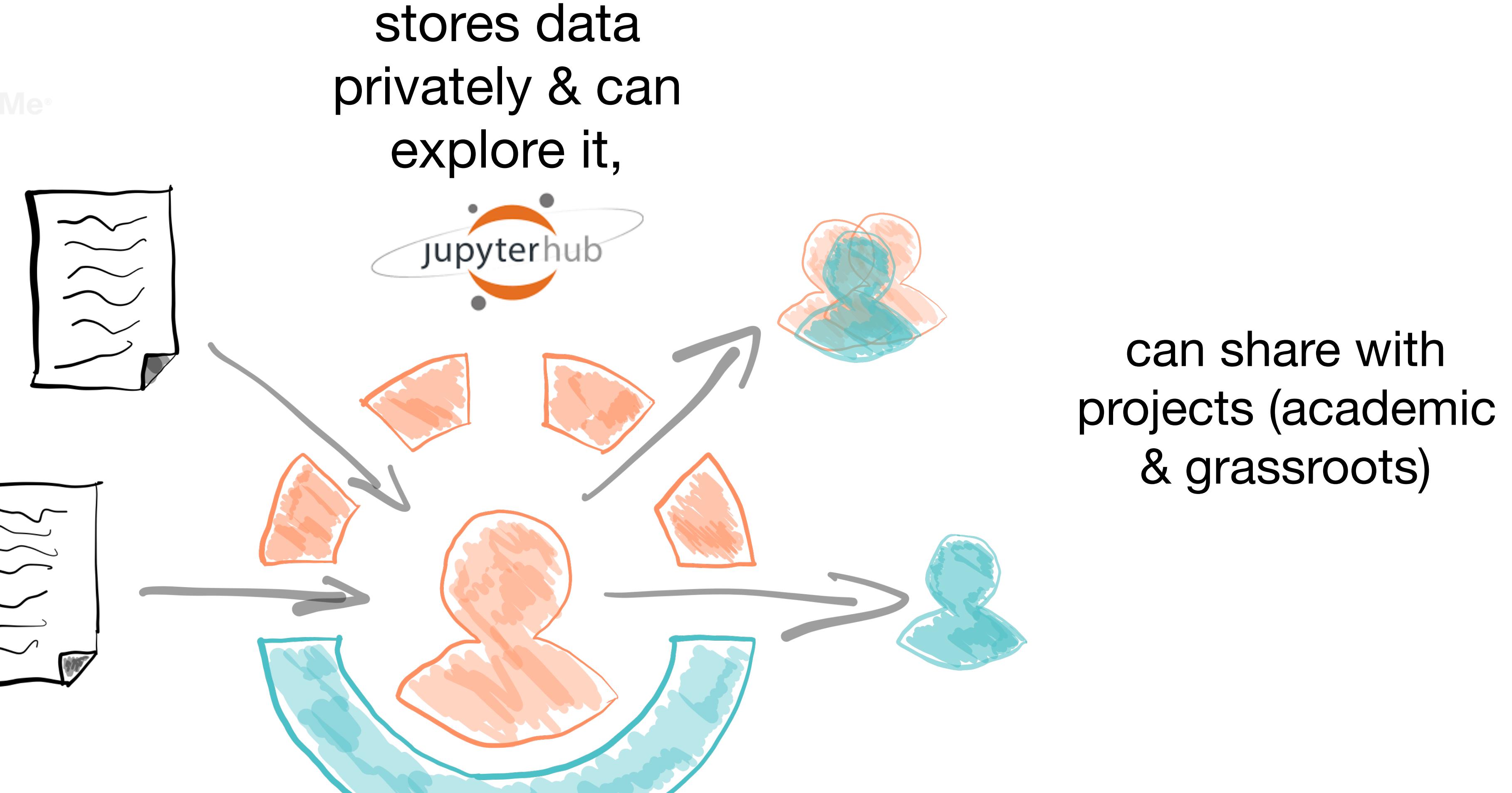
Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)

fitbit X 23andMe®

OURA

individual imports
personal data,

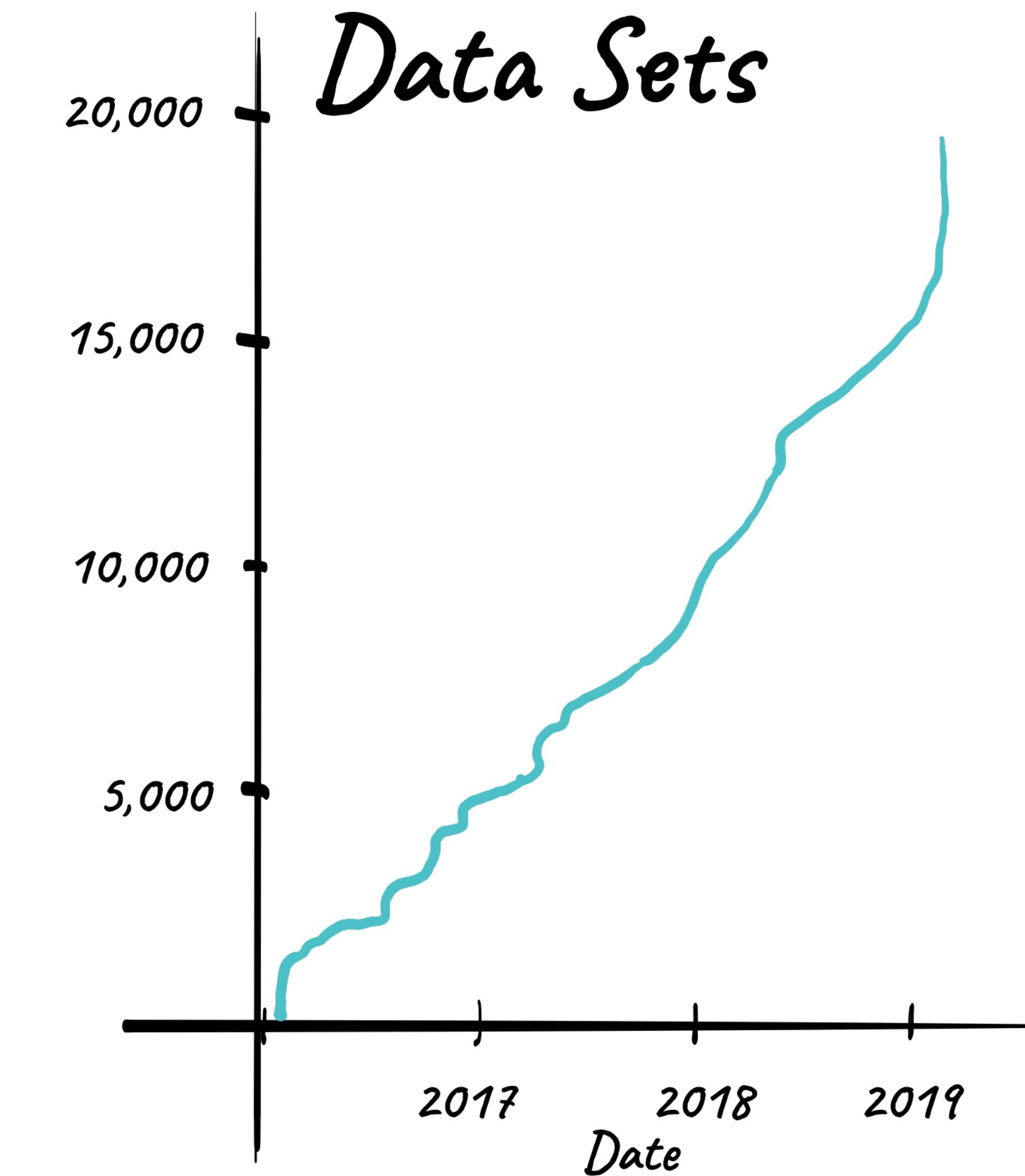
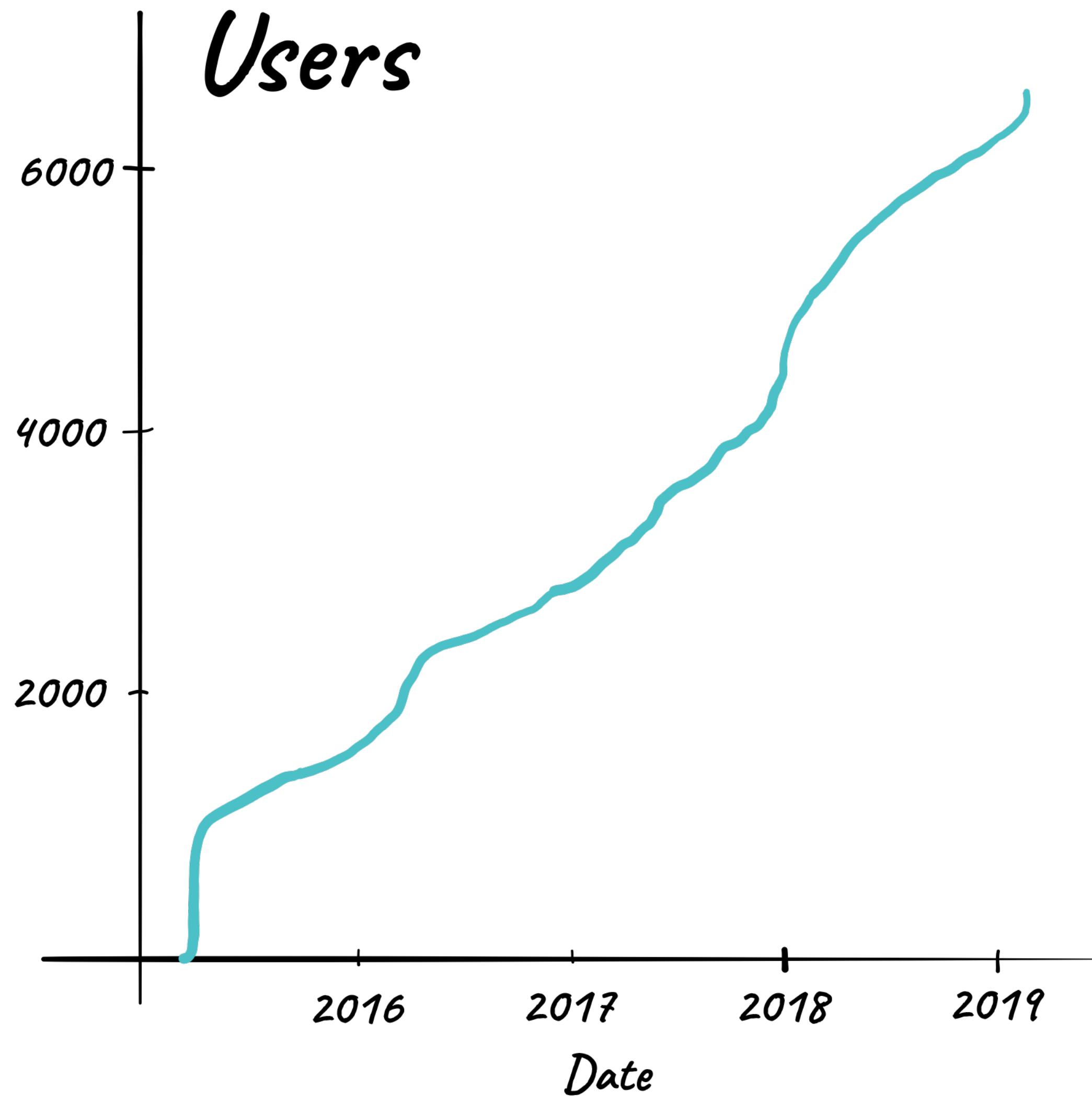
Google



OPEN HUMANS

Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)

Existing Community



Existing Community

18 projects running



range of *CBPP-ness*



range of CBPP-ness



academic-
led



co-
created

**Personal Genomics Human
Computer Interaction Research**
*design effective interaction
techniques to empower nonexpert
users*

range of CBPP-ness



academic-led



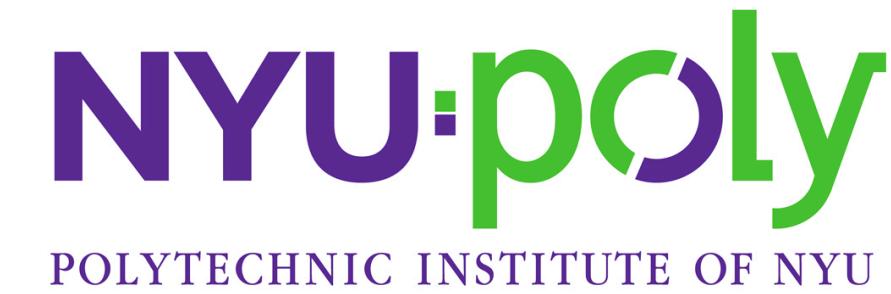
co-created

**Personal Genomics Human
Computer Interaction Research**
*design effective interaction
techniques to empower nonexpert
users*



QCycle
*participant-led research on
physiological change across the
ovulatory cycle.*

range of CBPP-ness



academic-led



Personal Genomics Human Computer Interaction Research
design effective interaction techniques to empower nonexpert users



Quantified Self



NIGHTSCOUT
#WeAreNotWaiting

co-created



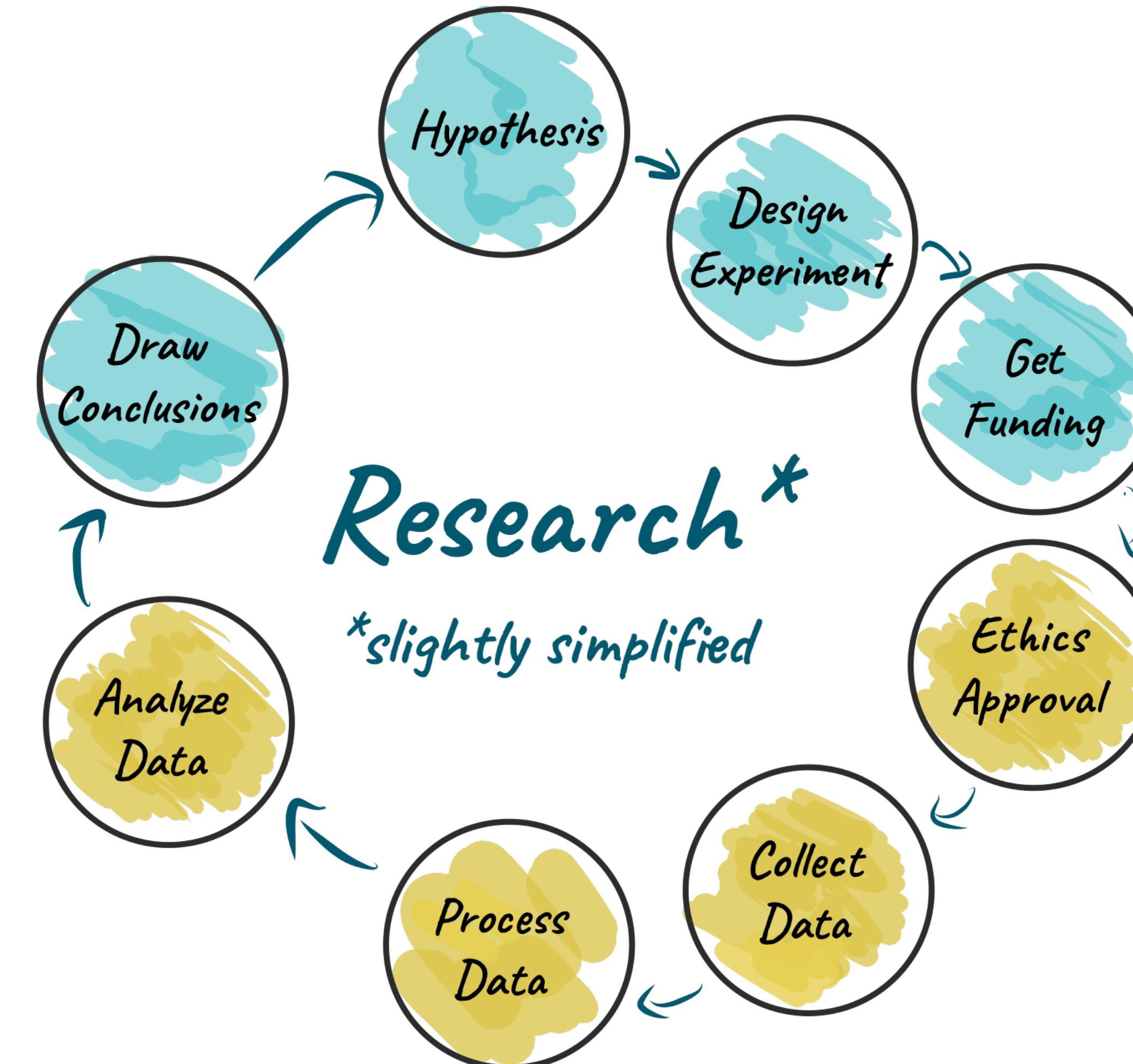
QCycle
participant-led research on physiological change across the ovulatory cycle.

Nightscout / OpenAPS
Type1-Diabetes patient community: open source, DIY project for real time access to a CGM data and Artificial Pancreas System (APS)

Types of CCS in Open Humans

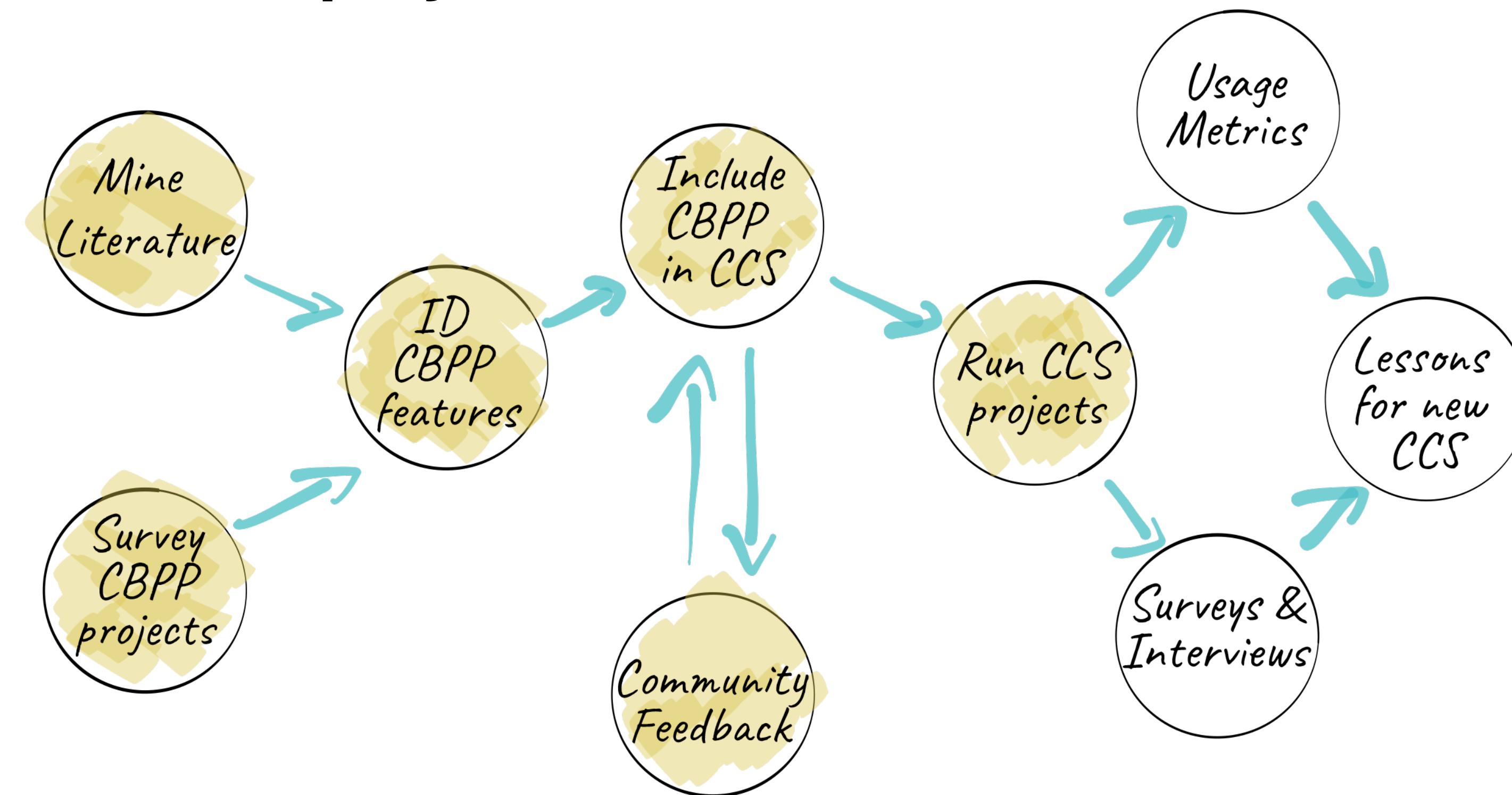


Types of CCS in Open Humans



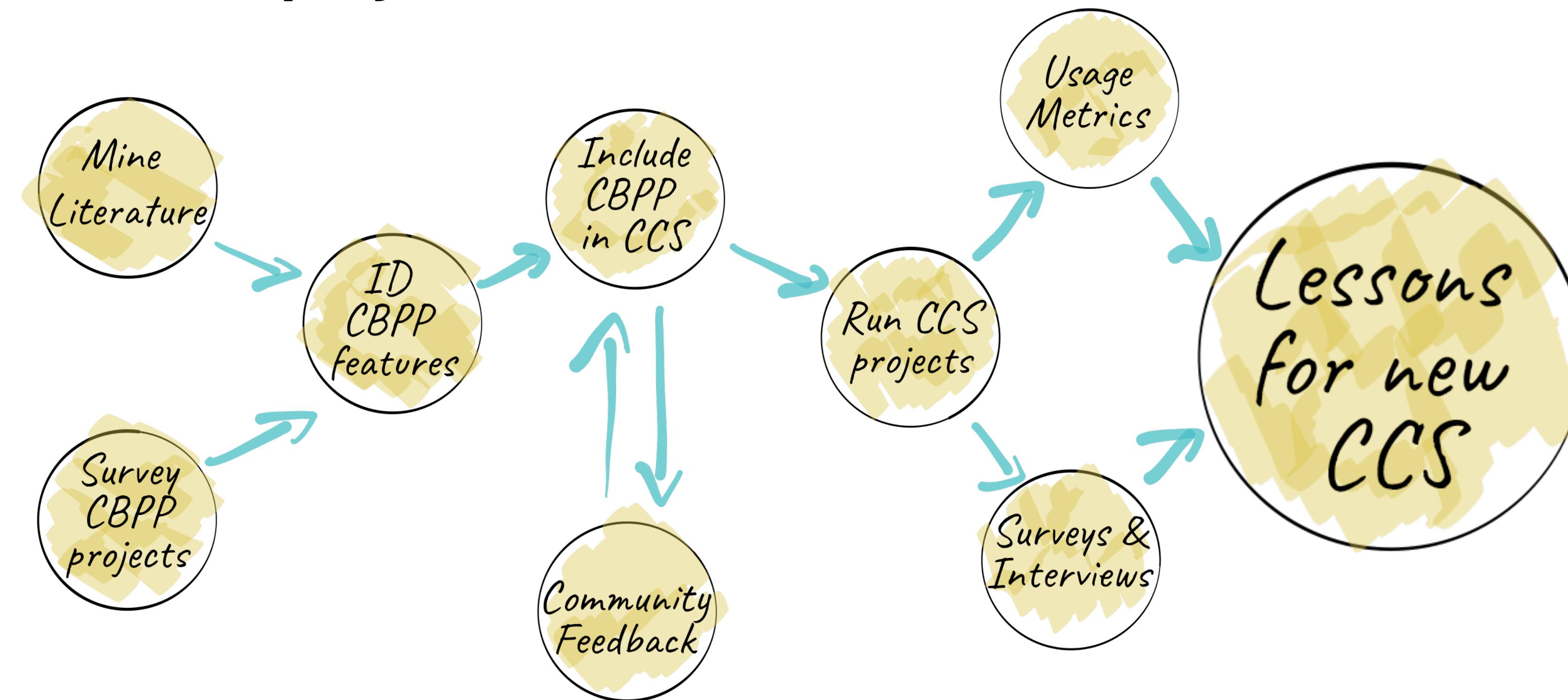
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Research Plan

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Summary

- Can commons-based peer-production design lead to co-created community science which facilitates public understanding of science & combats distrust in science?
 - Currently there are few examples of using CBPP methods in community science projects
 - Building out an existing CCS community to facilitate CBPP-interactions offers a unique opportunity to understand how both concepts can be used synergistically

Acknowledgements



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OPEN
HUMANS

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Graham Dyer (GSoC)

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With support from:



KNIGHT
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Google
Summer of Code



Robert Wood Johnson Foundation



Data Sources



23andMe Upload

Open Humans
Open Humans Foundation

Connected by 1152 members

23andMe is a direct-to-consumer genetic testing company that tests about one million genetic locations.

[Learn more](#)



Twitter Archive Analyzer

Bastian Greshake Tzovaras

Connected by 519 members

The TwArxiv is a Twitter Archive Analyzer. Upload your Twitter archive and get new insights.

[Learn more](#)



Gencove

Joseph K. Pickrell
Gencove, Inc.

Connected by 295 members

Your genome app - get your ancestry, microbiome, and more! Contribute your data to OpenHumans.

[Learn more](#)



Nightscout Data Transfer

James Wedding, P.E.
The Nightscout Foundation

Connected by 280 members

A tool to easily enable upload of data from individual Nightscout databases to the Open Humans platform

[Learn more](#)



Runkeeper connection

Open Humans
Open Humans Foundation

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RunKeeper is a free smartphone app for GPS fitness-tracking. You can use it to record GPS timepoint data for runs, walks, bicycling, and other activities.

[Learn more](#)



AncestryDNA Upload

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Ancestry.com's AncestryDNA is a direct-to-consumer genetic testing product that tests about 700,000 genetic locations.

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openSNP

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openSNP allows you to put your genetic and phenotypic data into the public domain. Connect your openSNP account to Open Humans.

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Google Location History Upload

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Upload your Google Location History archive

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Genome/Exome Upload

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Do you have genome or exome data? You can upload genome, exome, and genotyping data in VCF format.

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Overland connection

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Import GPS data from Overland

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RescueTime is a web service tracks your productivity and computer usage over time.

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Nokia Health (Withings) Connection

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Open Humans Healthkit Integration

James Turner self
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Install this third-party app on your iPhone or iPad to upload HealthKit data to Open Humans.

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FamilyTreeDNA integration

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Imputer

Kevin Arvai
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Imputer will perform imputation on user's genotype data to estimate genotypes at missing loci.

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Google search history analyzer

Athina Tzovara
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Google search history analyzer

Projects using Data



Genevieve Genome Report
Mad Ball
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Genevieve matches your genome against public variant data, and invites you to contribute to shared notes.

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Twitter Archive Analyzer
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New York University
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Keeping Pace seeks to study data about how we move around, to understand how seasons and local environment influence our movement patterns.

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Juno's Personal Data Exploratory
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Showcase and share your Personal Data Notebooks with others

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UbiQomix Microbiome Exploration
Orit Shaer, Mad Price Ball, Oded Nov
Wellesley College, Open Humans, NYU
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This research survey study aims to gain insight into user needs as they engage with their personal and social microbiome data.

[Learn more](#)



Gut Instinct
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Learn about current science of the gut microbiome with expert-curated learning materials.

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Personal Data Notebooks
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Play with code for analyzing personal data! Your data stays private on a personal virtual machine.

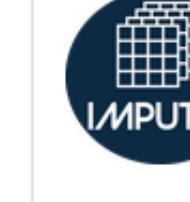
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Is your 23andMe data public? Register interest in a study of how folks interact with their genome data using GenomiX, our visualization tool

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Imputer will perform imputation on user's genotype data to estimate genotypes at missing loci.

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Galileo
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UCSD Design Lab
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Learn about current science of the gut microbiome with expert-curated learning materials.

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Nightscout Data Commons
The Nightscout Data Commons Committee
The Nightscout Foundation
Joined by 66 members

The Nightscout Data Commons collects data from Nightscout users and facilitates research in partnership with the DIY diabetes community.

[Learn more](#)



Data sharing and ethical oversight
Prof. Dr. Effy Vayena
ETH Zurich
Joined by 210 members

Through a quick survey we aim at understanding what the Open Humans community thinks about ethical oversight.

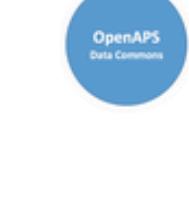
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openSNP
Bastian Greshake Tzovaras
openSNP
Connected by 290 members

openSNP allows you to put your genetic and phenotypic data into the public domain. Connect your openSNP account to Open Humans.

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OpenAPS Data Commons
Dana Lewis
OpenAPS
Joined by 128 members

The OpenAPS Data Commons collects data from DIY closed loopers and facilitates research in partnership with the DIY closed loop community.

[Learn more](#)



lineage
Andrew Riha
Scedastic Software, LLC
Connected by 35 members

lineage provides tools for genetic genealogy - find shared DNA and genes between individuals, merge raw data files, and remap SNPs

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Resilience Project Study
Jason Bobe
Icahn School of Medicine at Mount Sinai
Connected by 6 members

The Resilience Project aims to discover why some people are more able to overcome challenges to their health and escape disease.