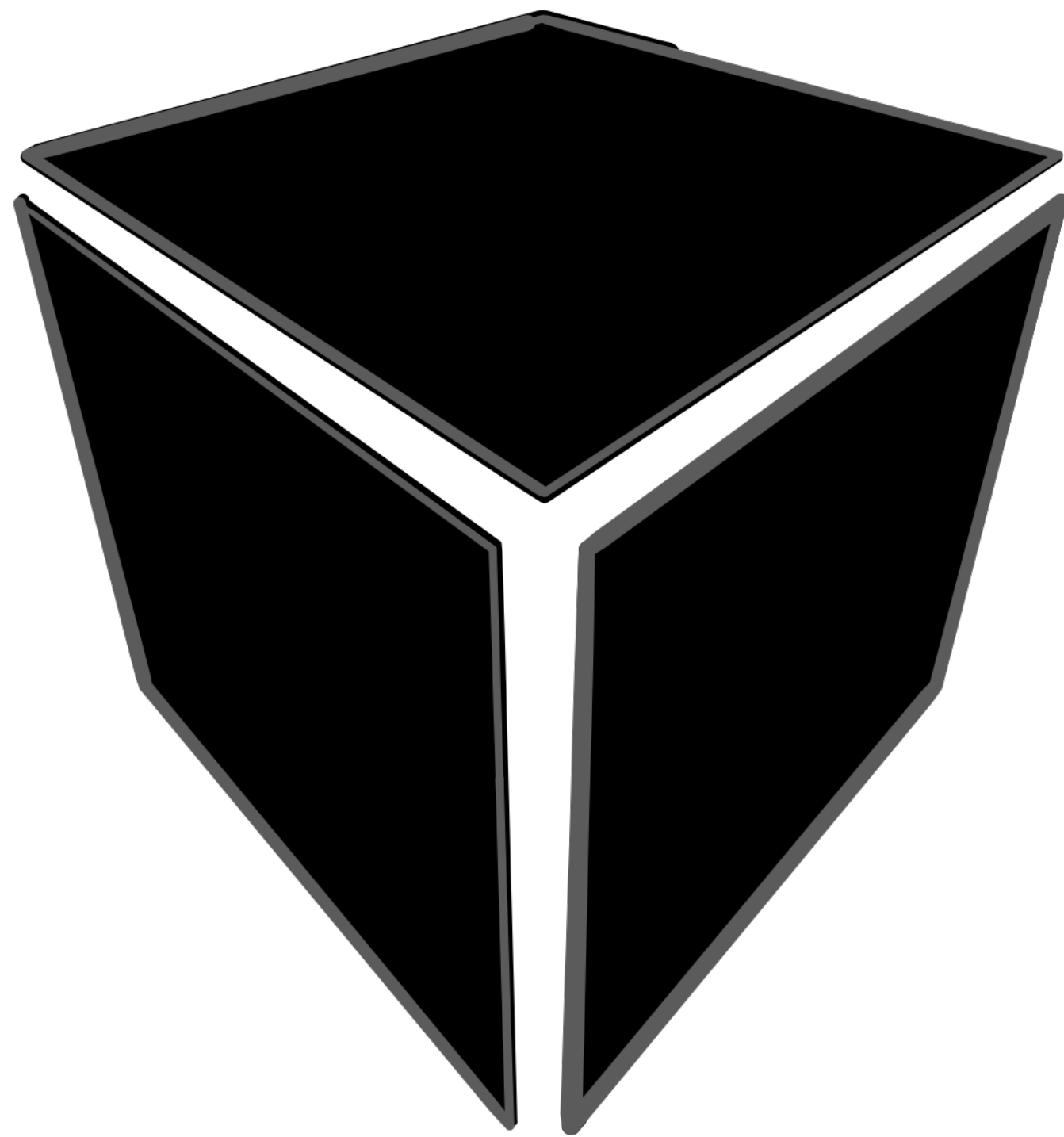


**From top-down to bottom-up:
Peer production as a means to citizen
science throughout the research cycle.**

Citizen/Community Science



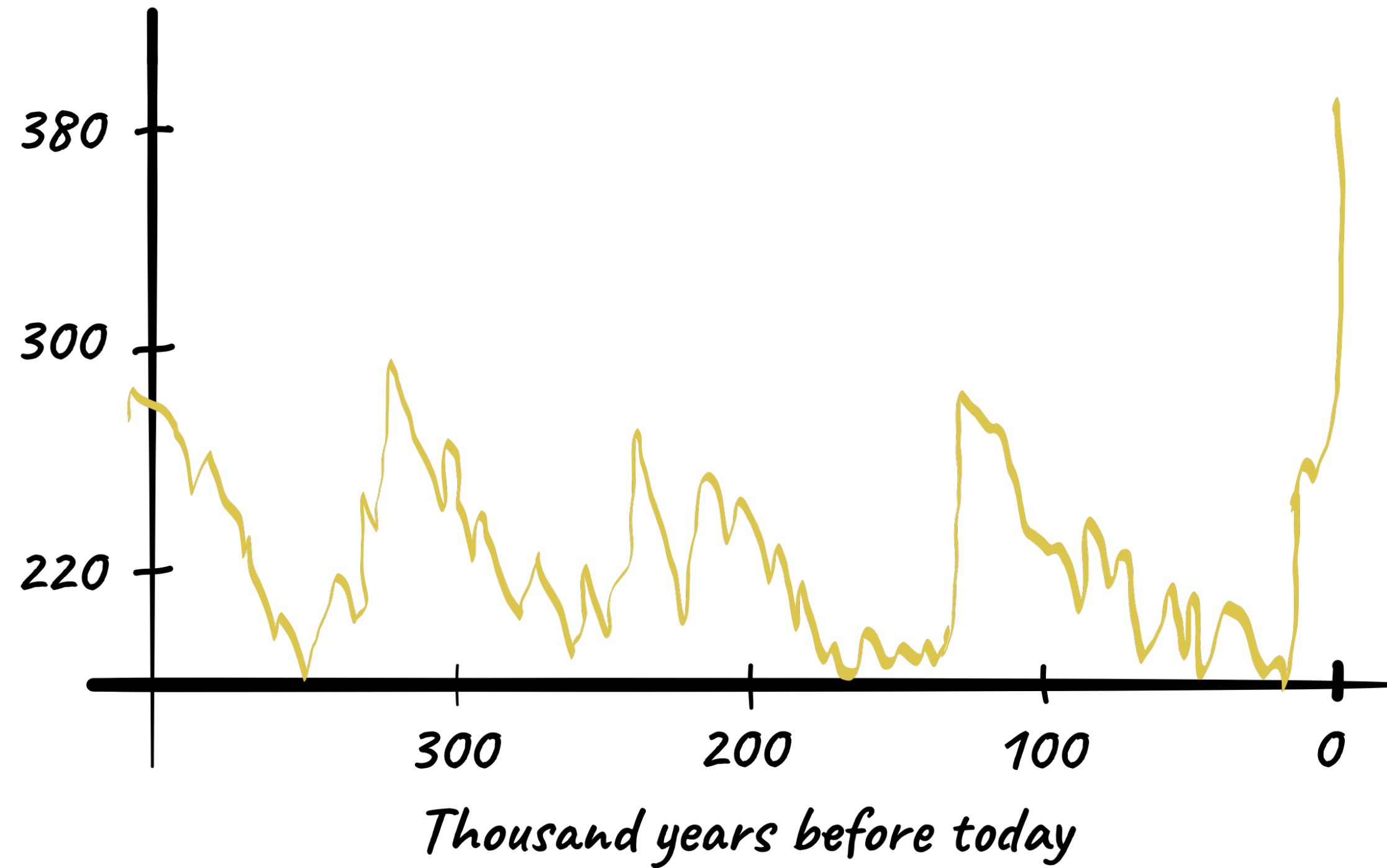
- increases public understanding...
- diversifies research...
- empowers participants...

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

CO₂ level (ppm)



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**

Citizen/Community Science



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




prevalent CCS types

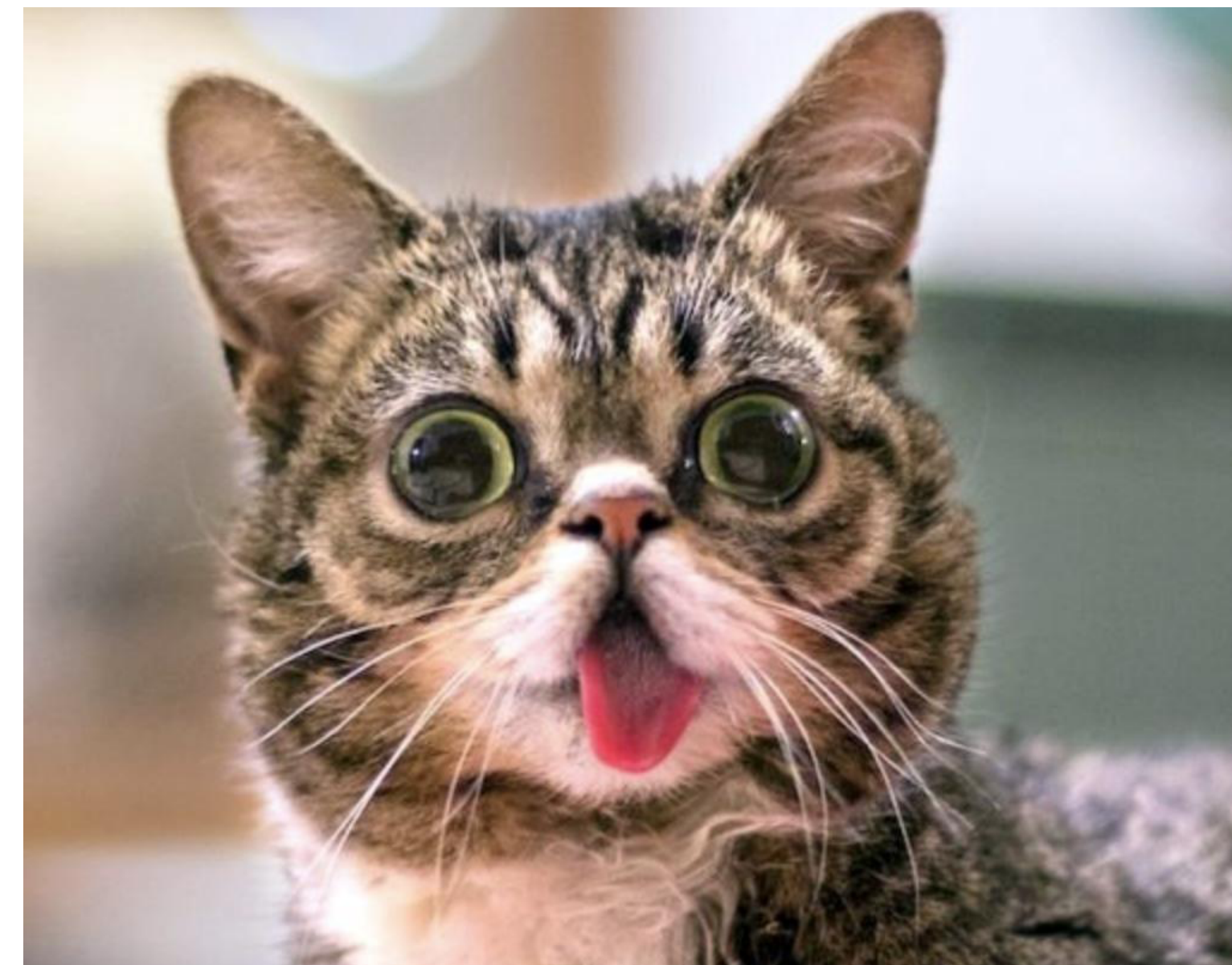


- Crowdfunding
- Human Computation
- Crowdsourcing

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



ZOO NIVERSE

prevalent CCS types



The **Cornell** Lab
of Ornithology

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

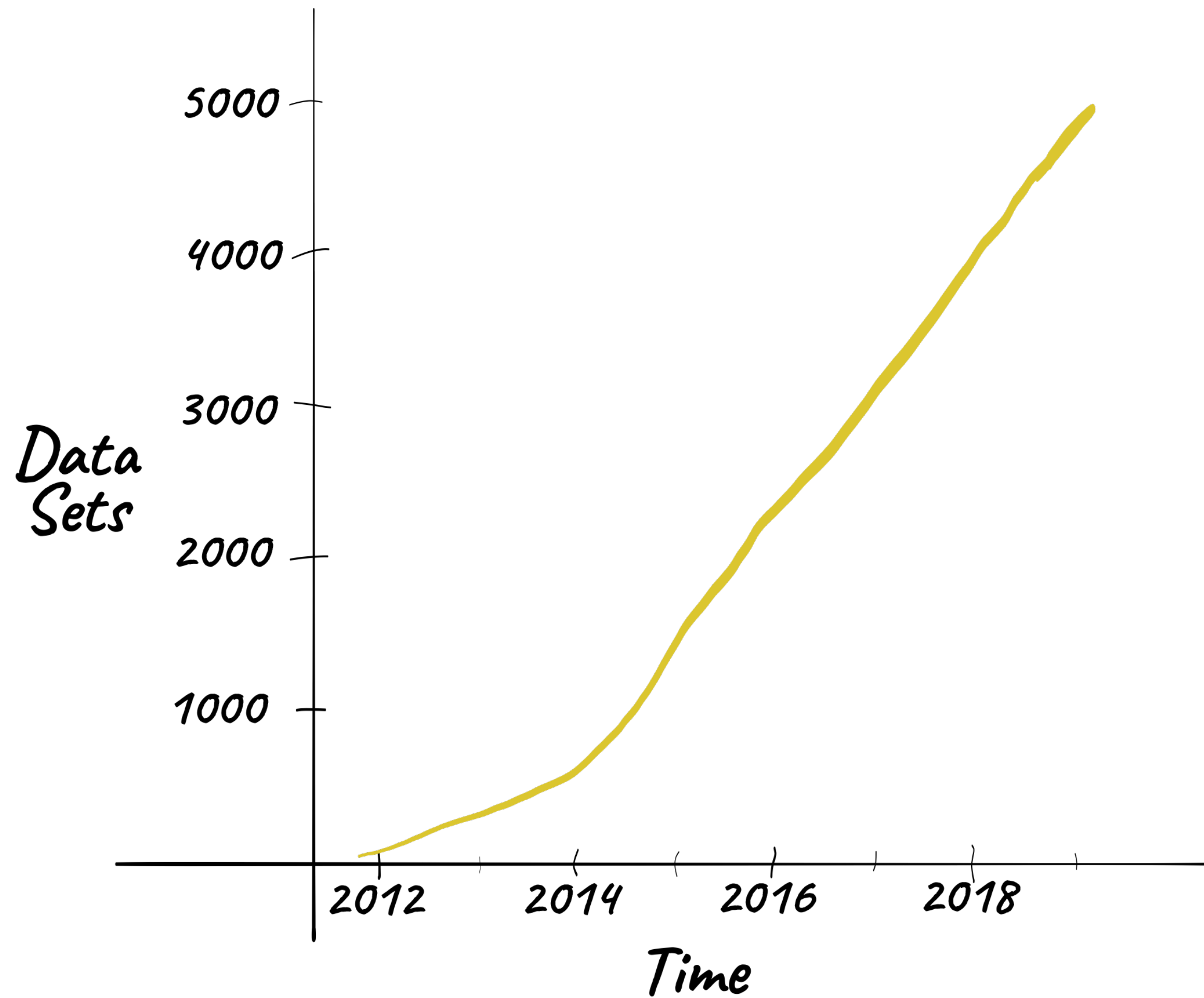


Greshake Tzovaras et al. openSNP—A Crowdsourced Web Resource for Personal Genomics (2014)
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prevalent CCS types



prevalent CCS types

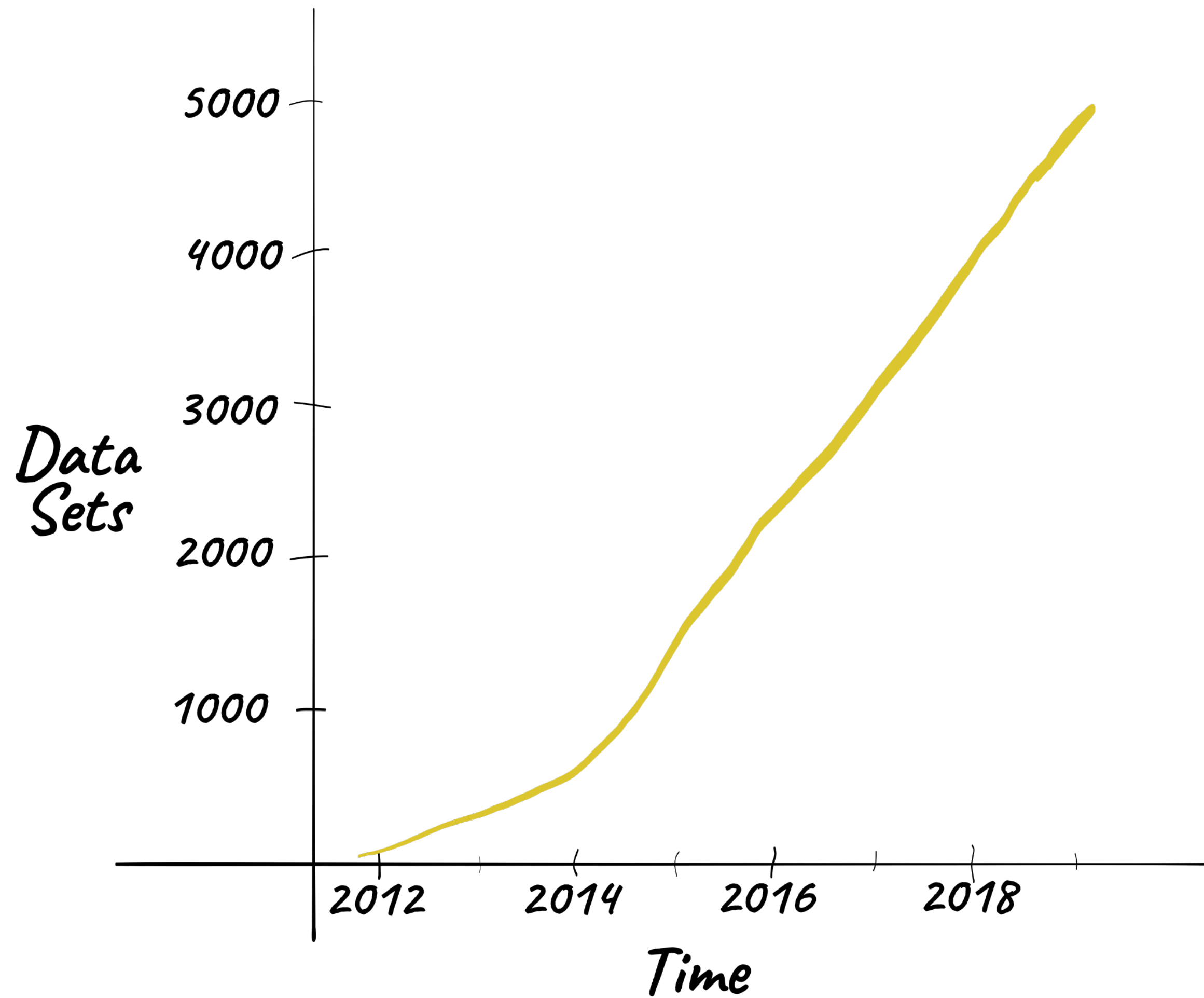


● ● ● ● openSNP
● ● ● ●
● ● ● ●

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

● ● ● ● openSNP
● ● ● ●
● ● ● ●



Phenotype:
Peanut butter
preference

Phenotype:
vi/vim or
Emacs

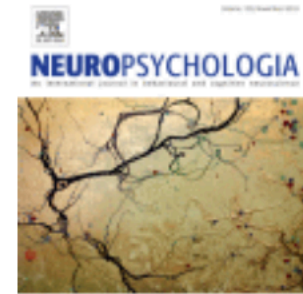
Greshake Tzovaras et al. openSNP—A Crowdsourced Web Resource for Personal Genomics (2014)
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prevalent CCS types



Neuropsychologia

Volume 120, November 2018, Pages 97-104



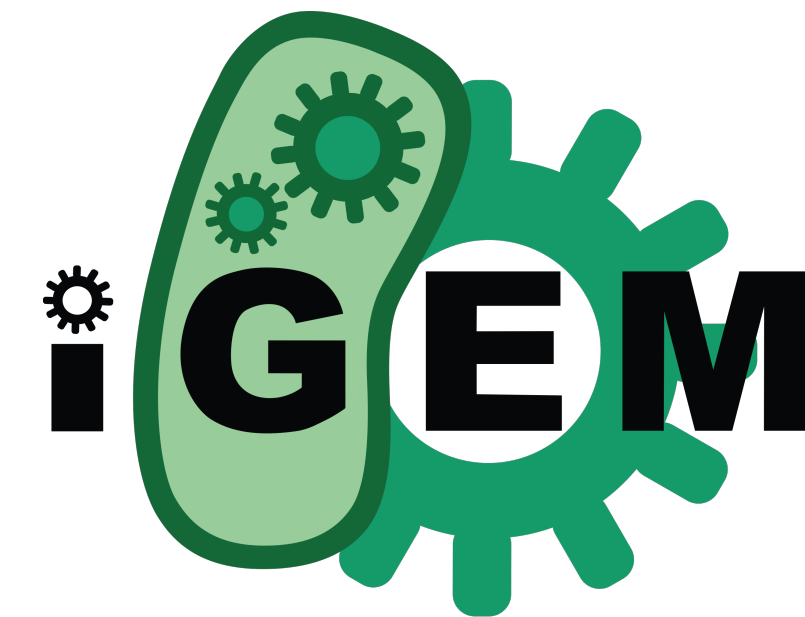
Dopaminergic genes are associated with both directed and random exploration

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

The screenshot shows the "OpenSNP Height Prediction" challenge page on the crowdAI platform. The page features a 3D model of a DNA double helix on the left. On the right, the challenge title "OpenSNP Height Prediction" is displayed, along with the OpenSNP logo and "By EPFL". A red progress bar indicates the challenge's status. Below the bar, statistics are shown: 11880 Views, 123 Participants, and 1268 Submissions. At the bottom, there is a heart icon with the number 48 and a "FOLLOW" button.

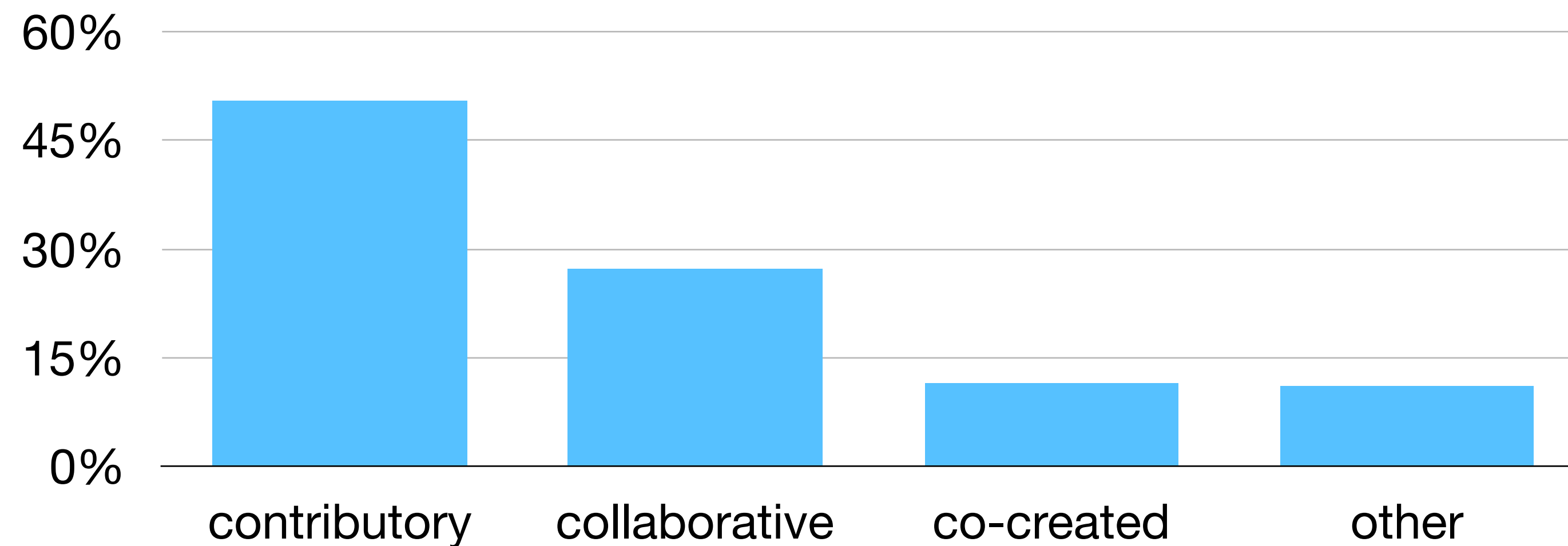
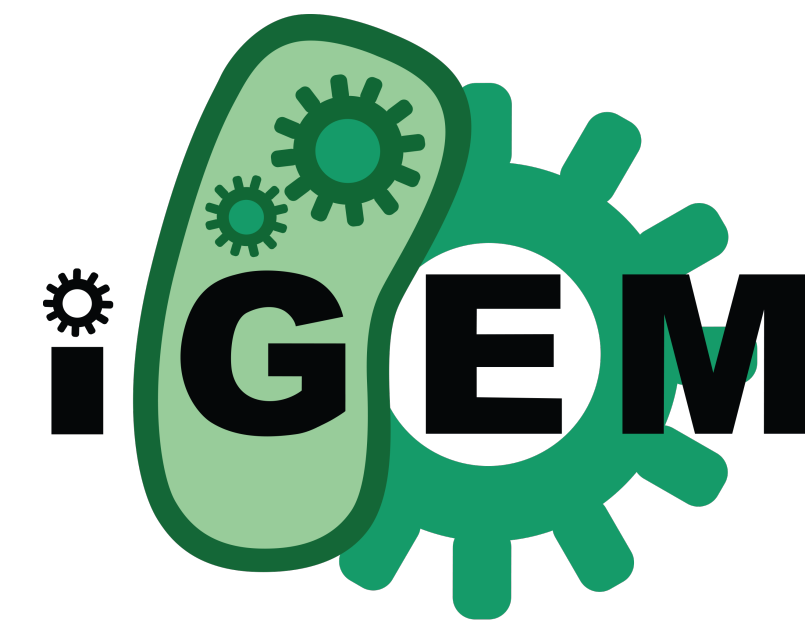
Greshake Tzovaras et al. openSNP—A Crowdsourced Web Resource for Personal Genomics (2014)
Haeusermann*, Greshake Tzovaras* et al. Open sharing of genomic data: Who does it and why? (2017)

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

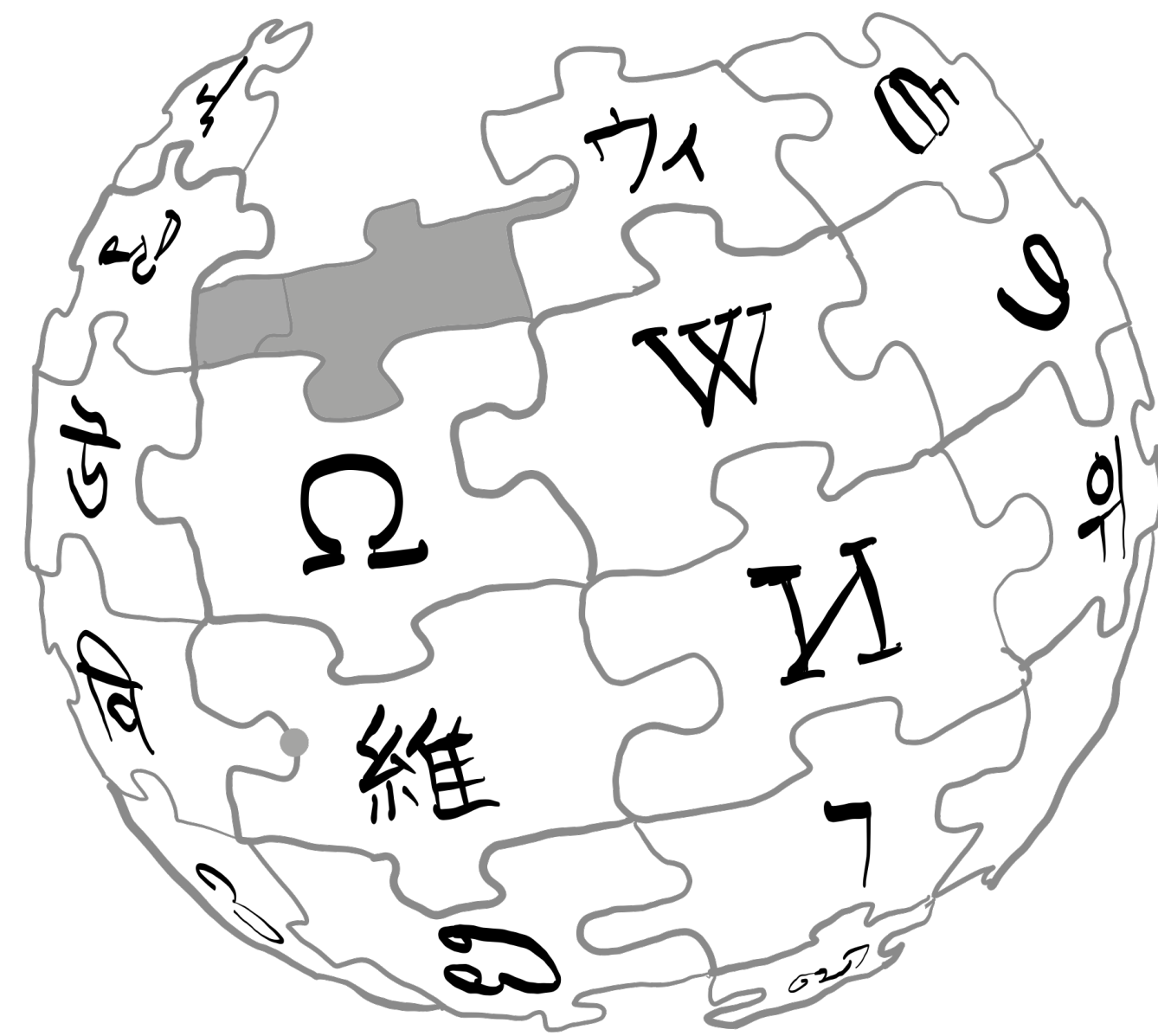
“ [...] the networked environment makes possible a new modality of organizing production: **radically decentralized, collaborative, and nonproprietary; based on sharing resources and outputs among widely distributed, loosely connected individuals who cooperate with each other** without relying on either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

Yochai Benkler, 2006

commons-based peer-production



open source movement



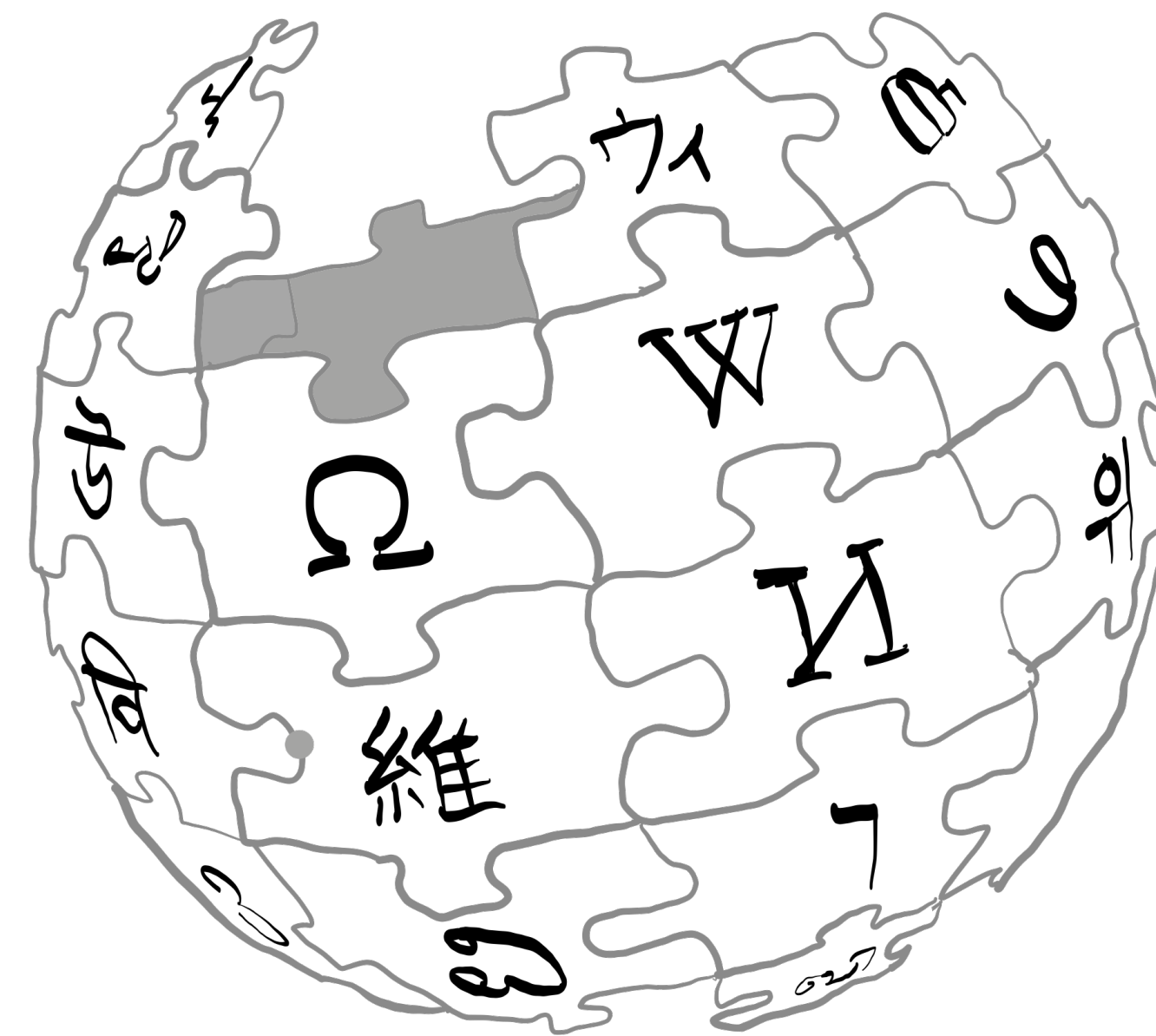
Wikipedia

commons-based peer-production



open source movement

non-hierarchical



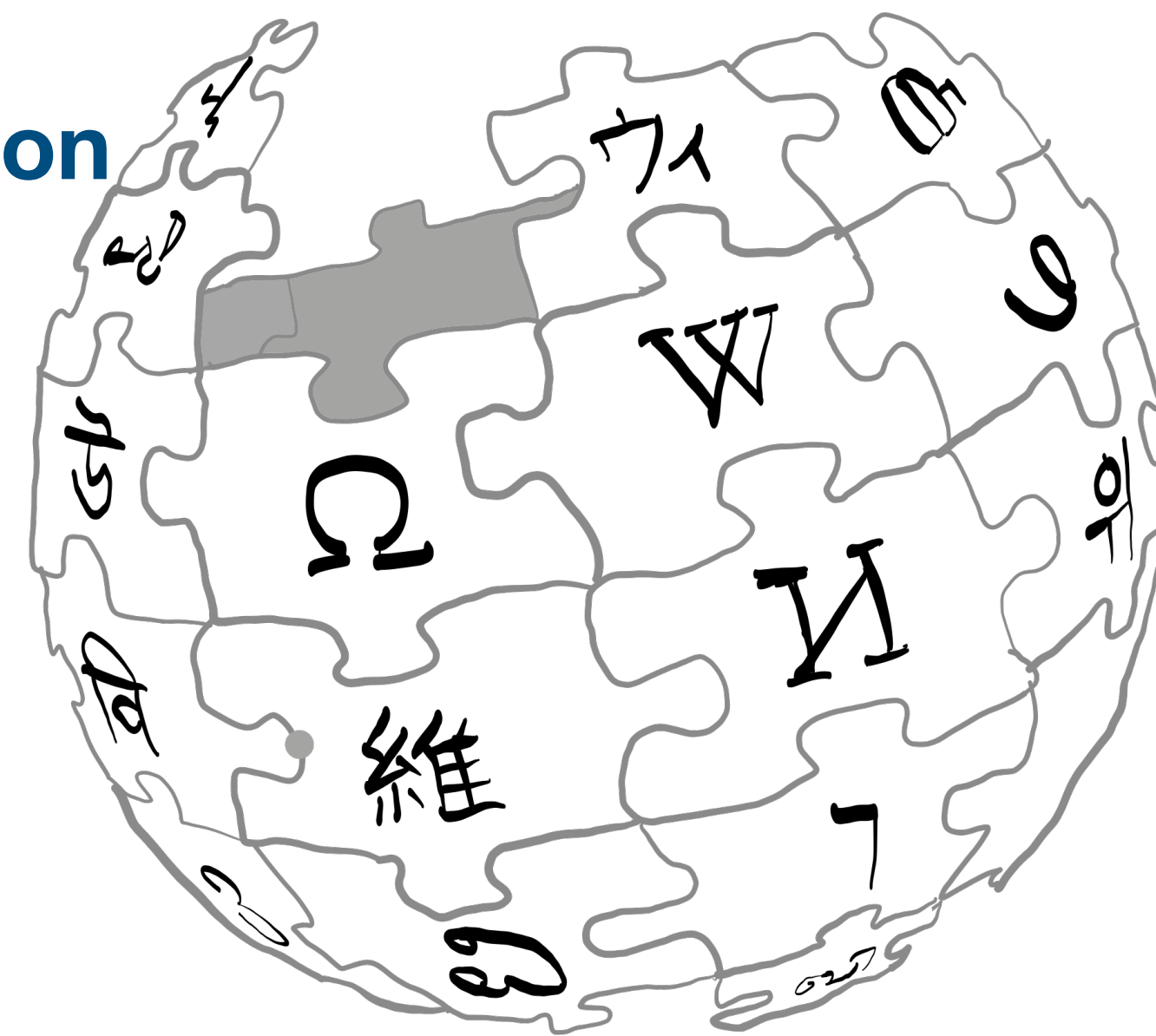
Wikipedia

commons-based peer-production



open source movement

non-hierarchical
negotiated coordination



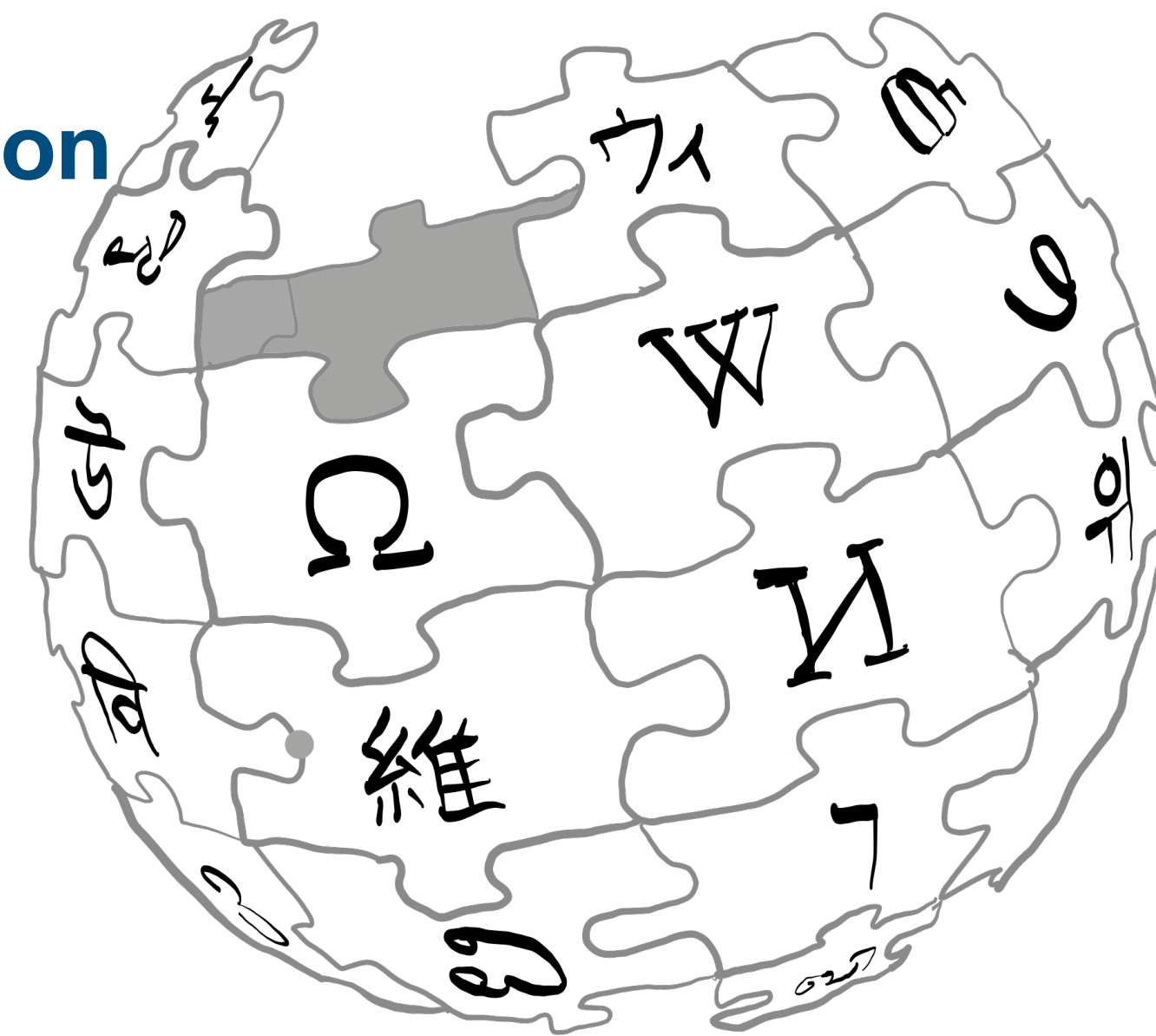
Wikipedia

commons-based peer-production



open source movement

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



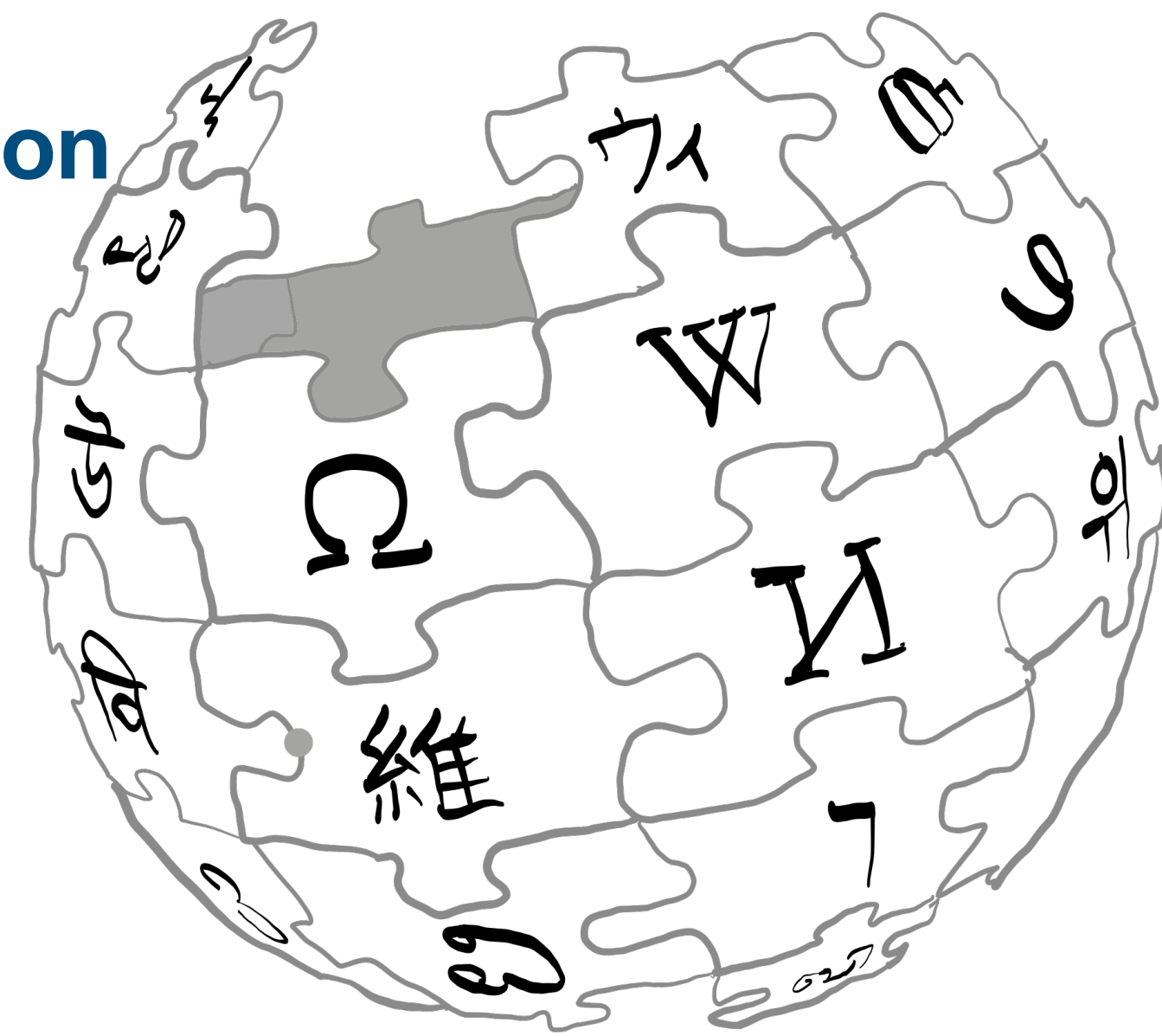
Wikipedia

commons-based peer-production



open source movement

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



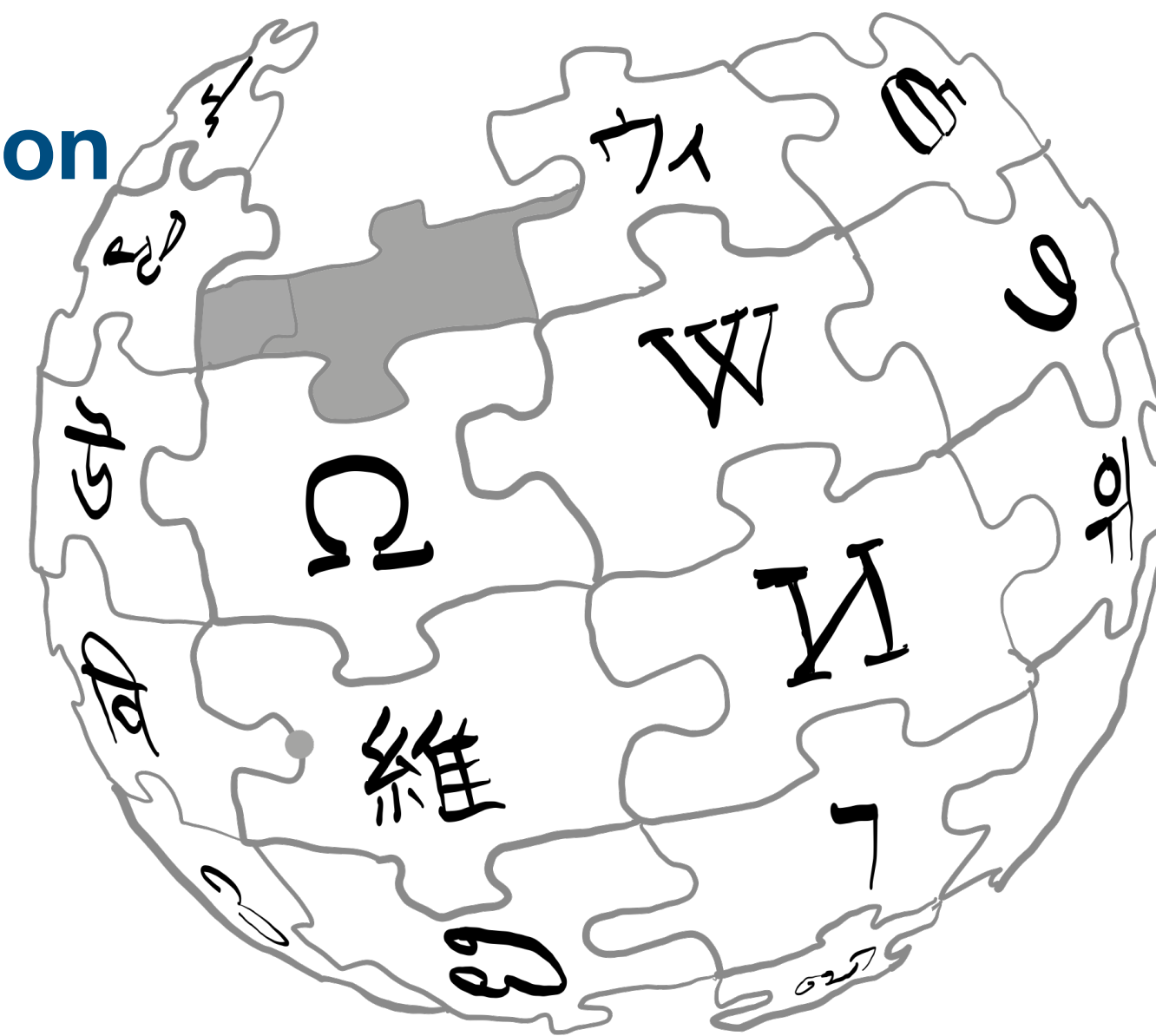
Wikipedia

commons-based peer-production



open source movement

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



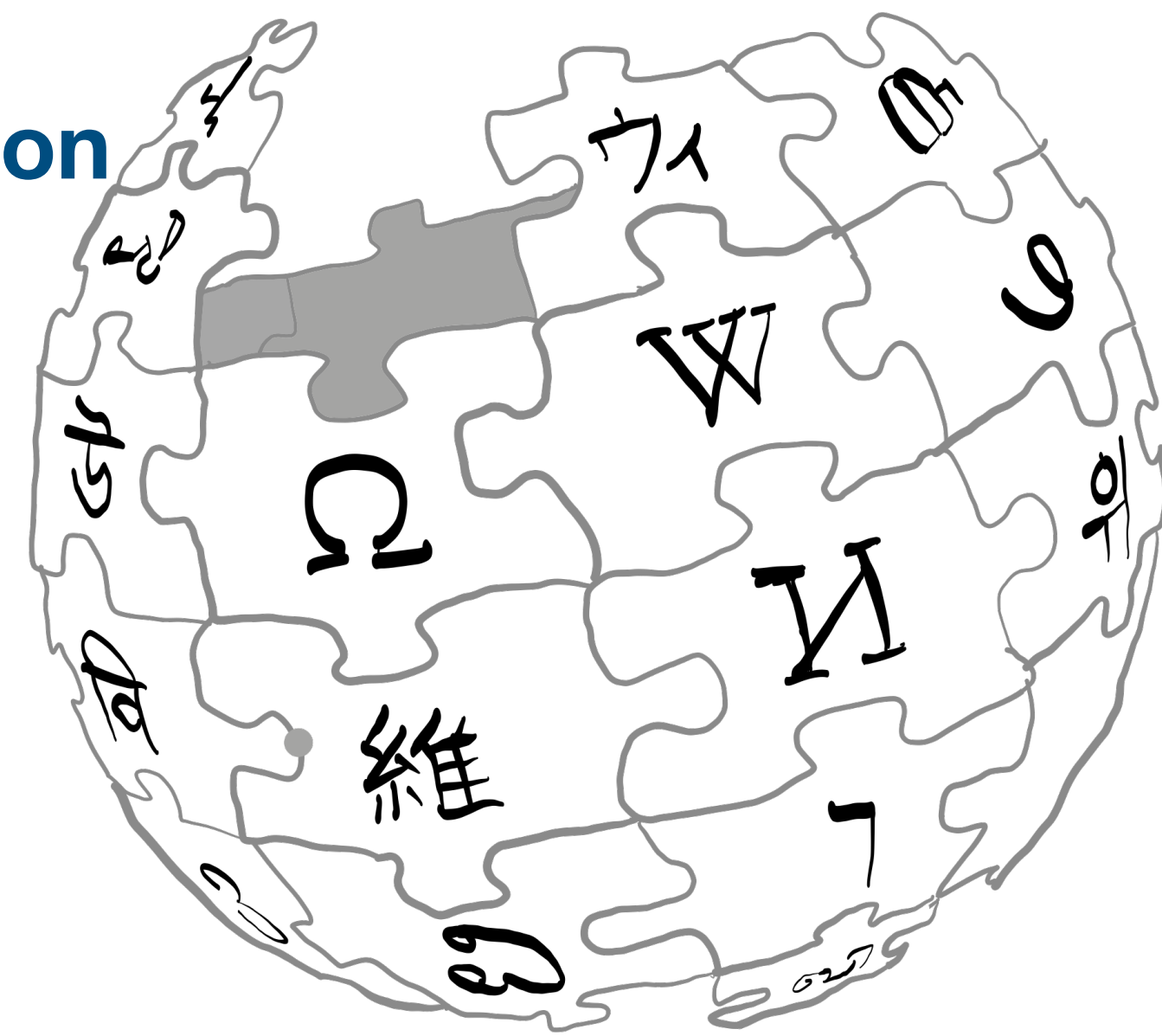
Wikipedia

commons-based peer-production



open source movement

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



Wikipedia

Hypothesis



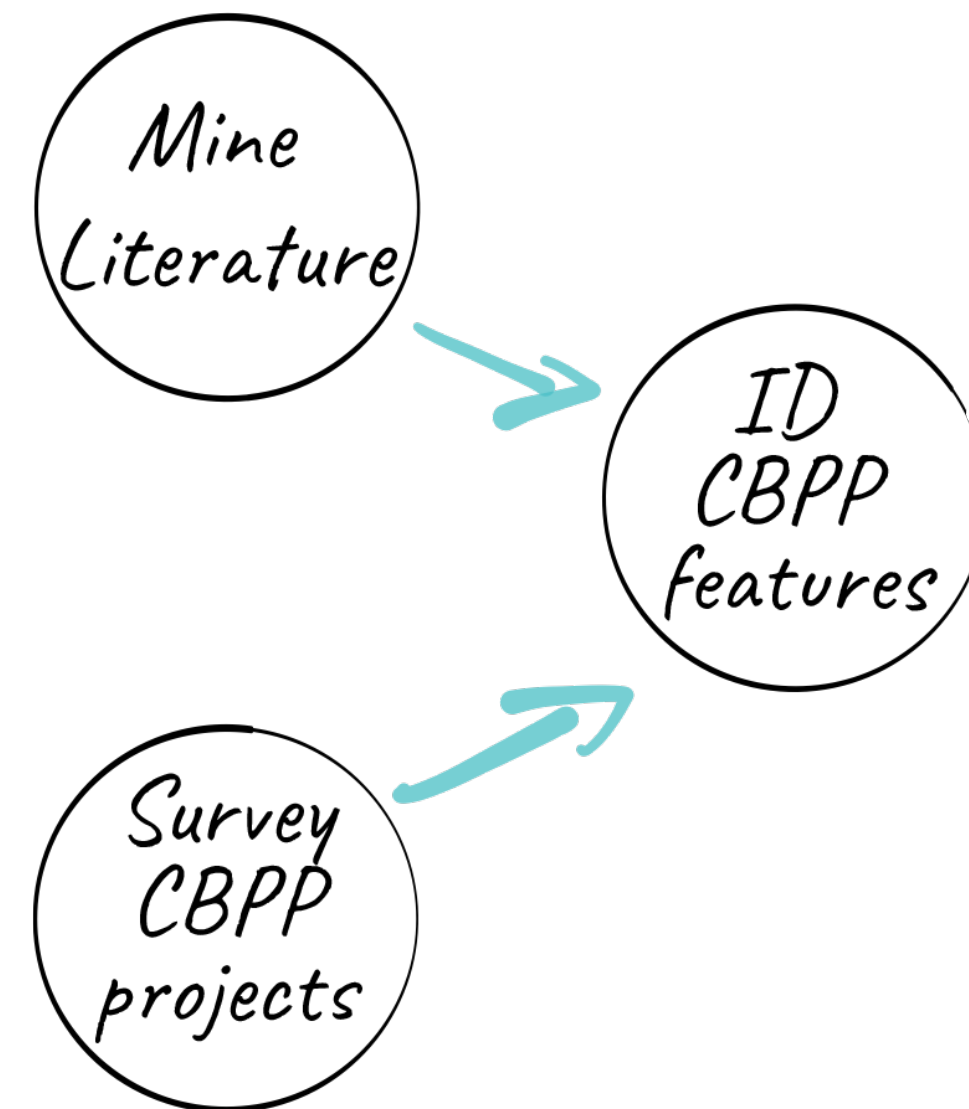
- Bringing CBPP methods to CCS leads to
 - higher involvement of volunteers, across all stages of the research cycle
 - increase opportunities for learning & innovation
 - generate research more relevant to participants
 - builds trust in research

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**
2. Implement CBPP features into an existing CCS ecosystem
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commons-based peer-production & community science

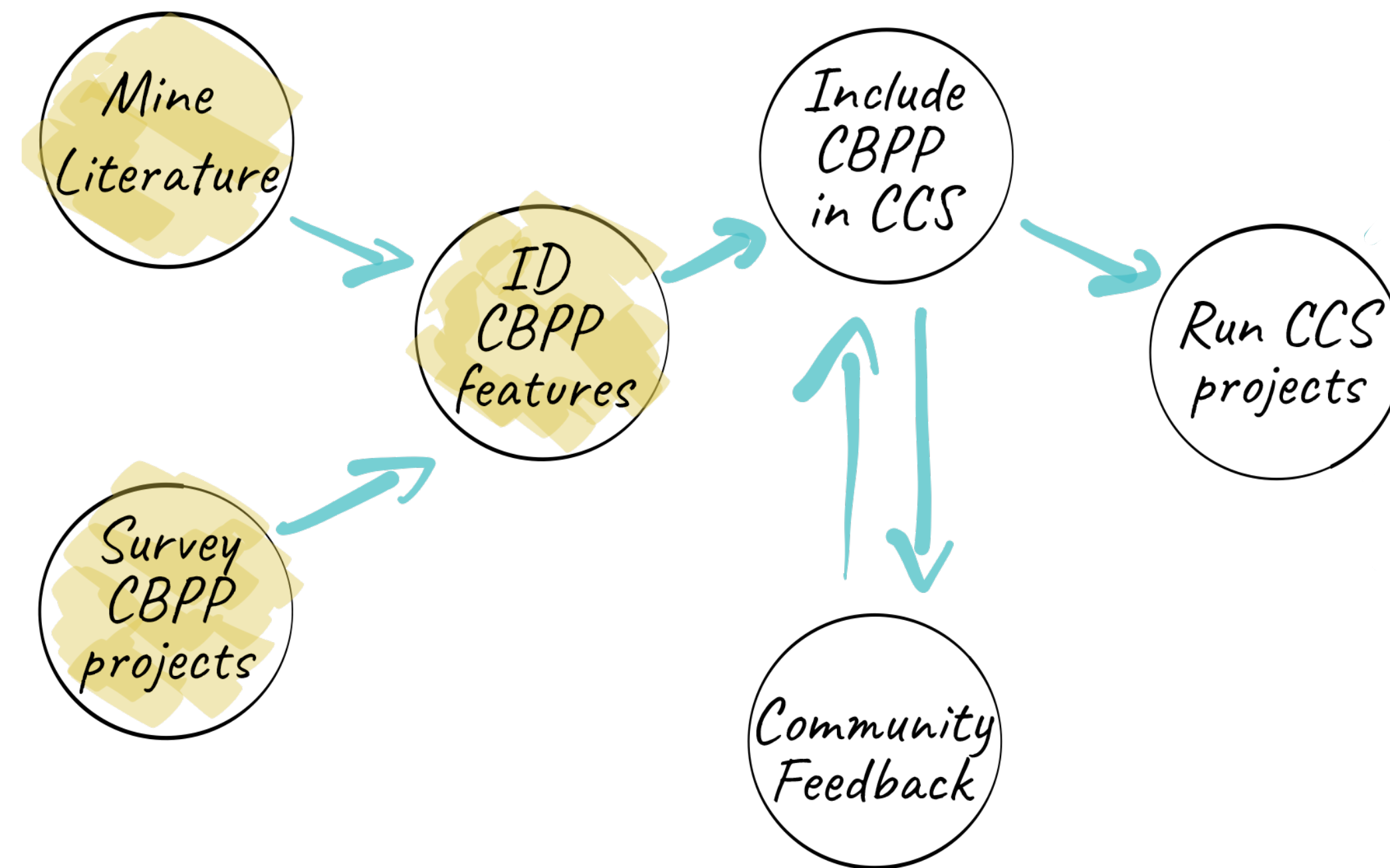
- *divide researcher / volunteers*
- *top-down structure*
- *one-sided data flow*



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**
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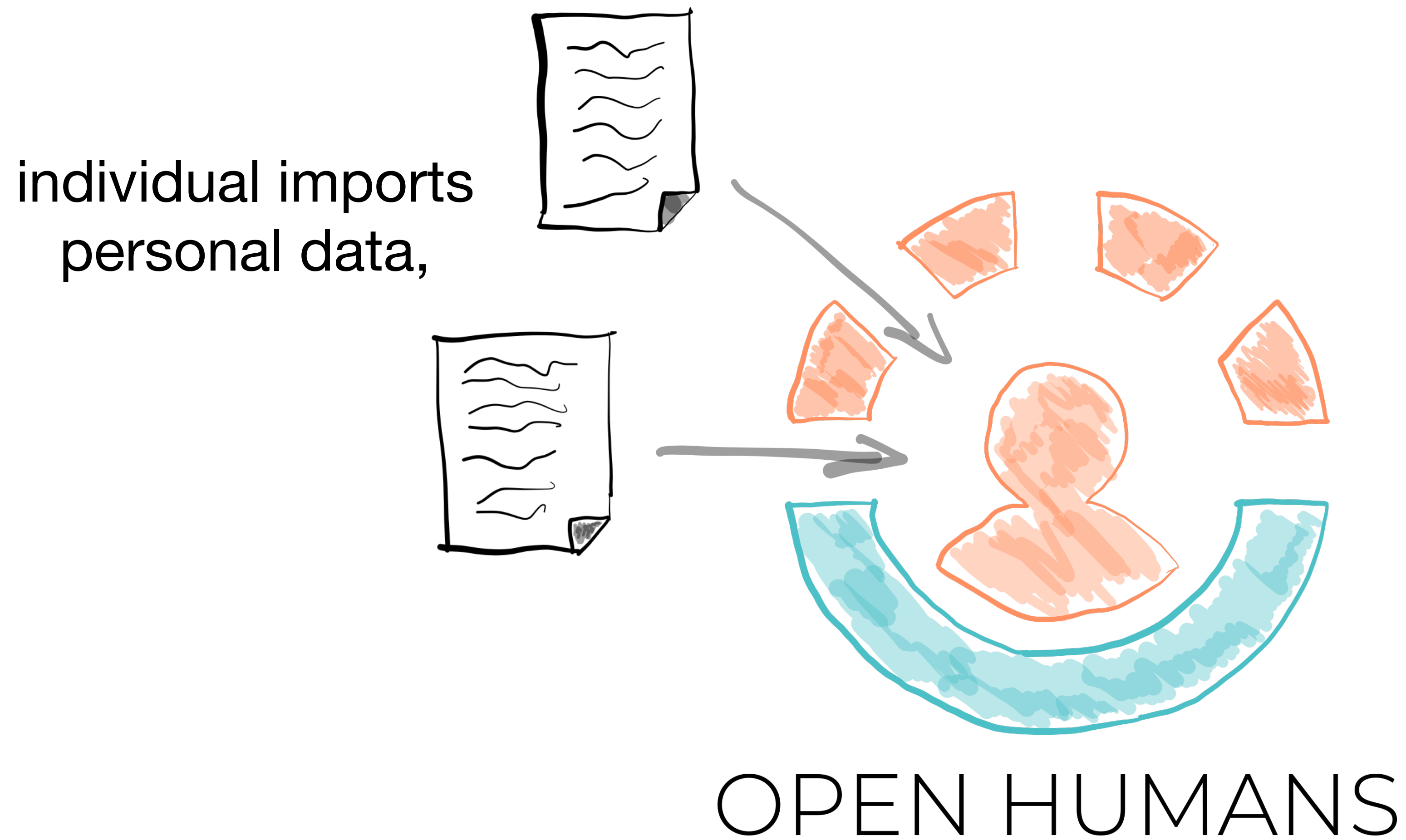


Bringing CBPP to a CCS ecosystem



OPEN HUMANS

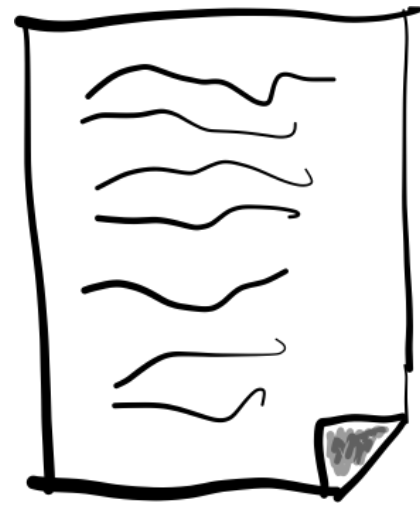
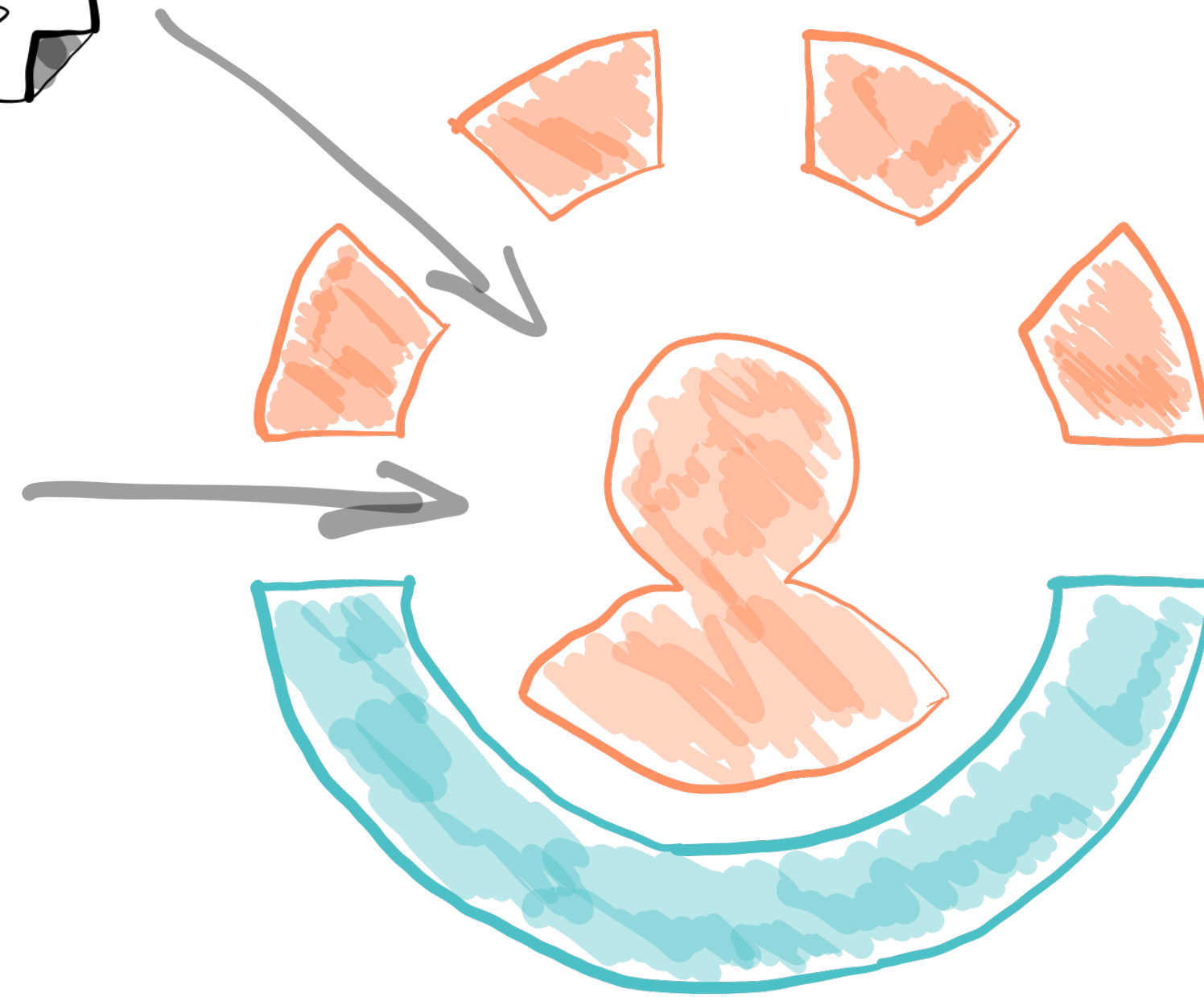
Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)



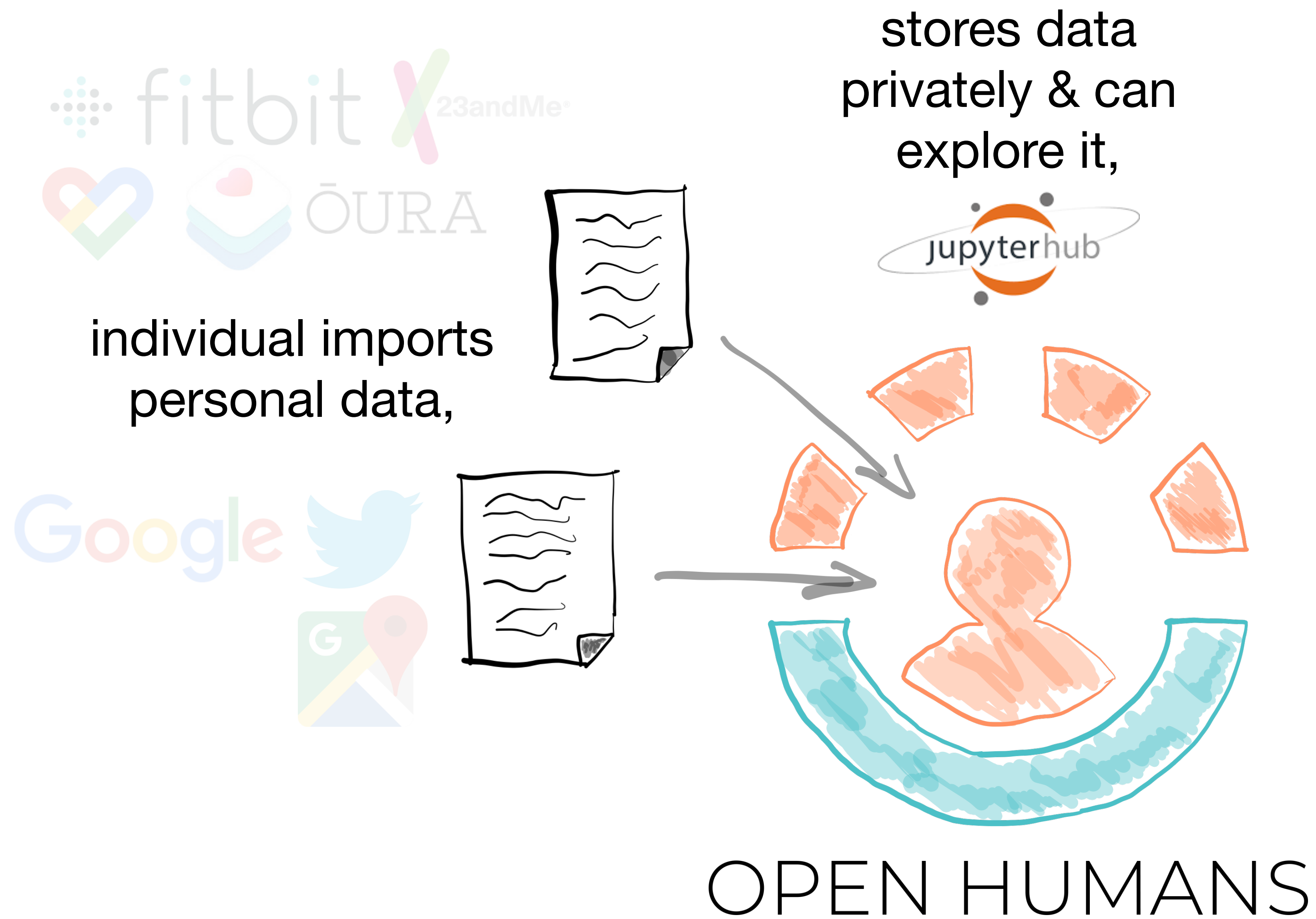
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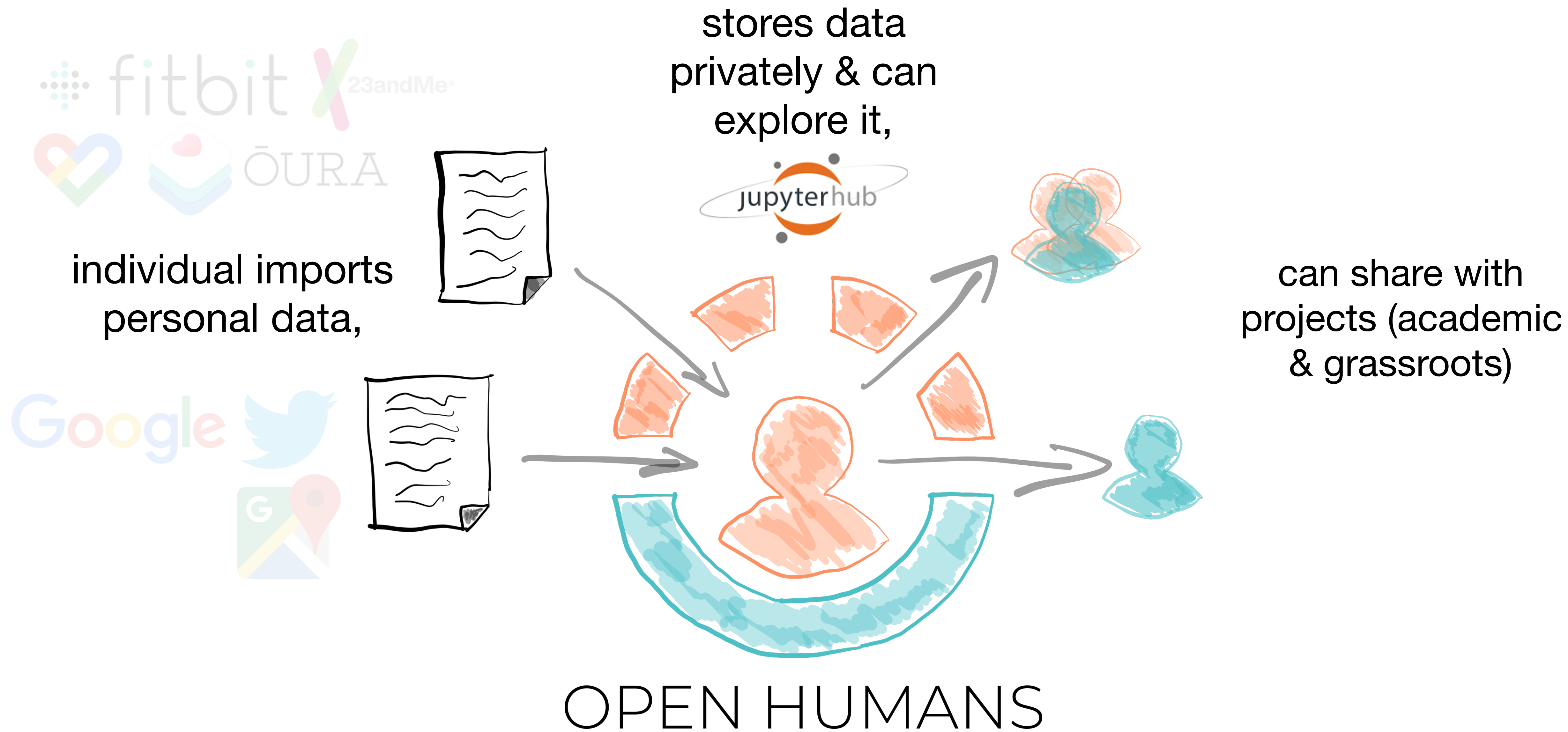
individual imports
personal data,



OPEN HUMANS

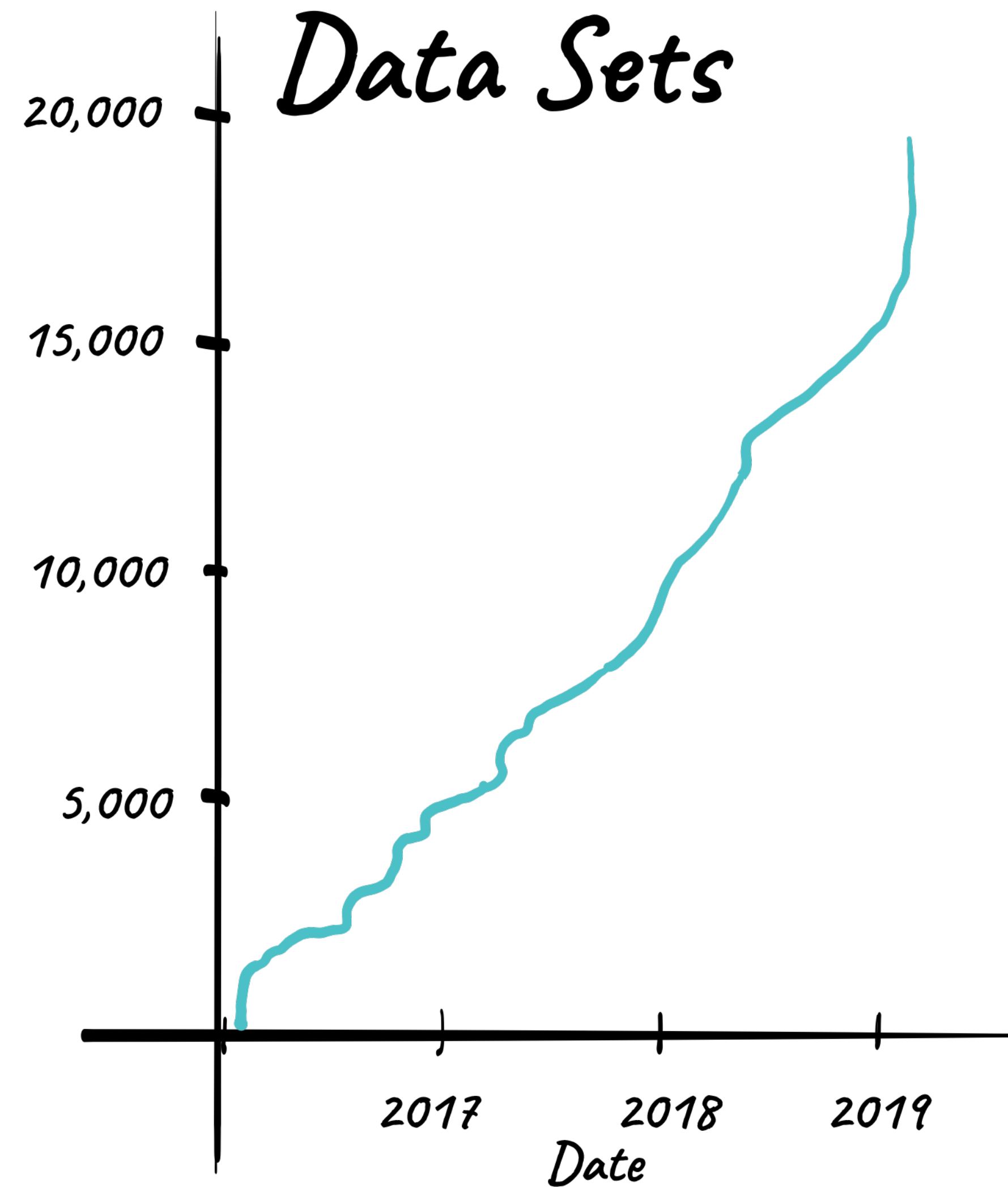
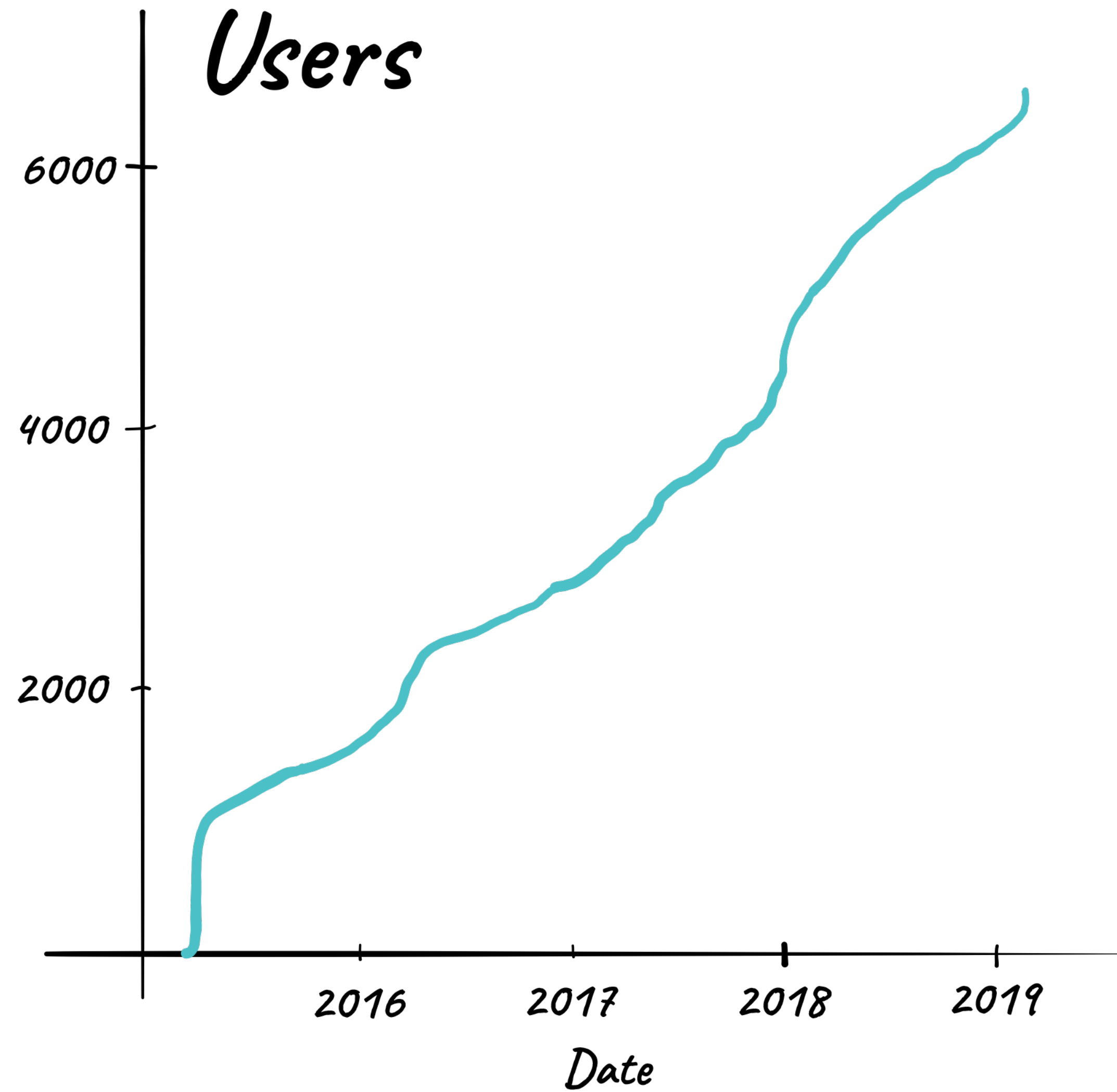


Greshake Tzovaras et al. Open Humans: A platform for participant-centered research and personal data exploration (2018)



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

Existing Community



Existing Community

18 projects running

academic-led



co-created

range of *CBPP-ness*

academic-
led



co-
created

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*

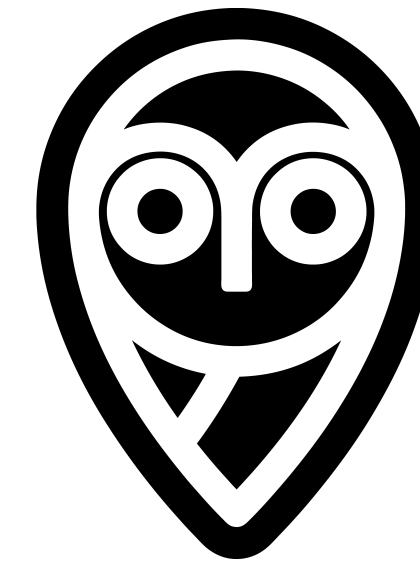


Quantified Self



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

range of *CBPP-ness*



NIGHTSCOUT
#WeAreNotWaiting

academic-
led

co-
created

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



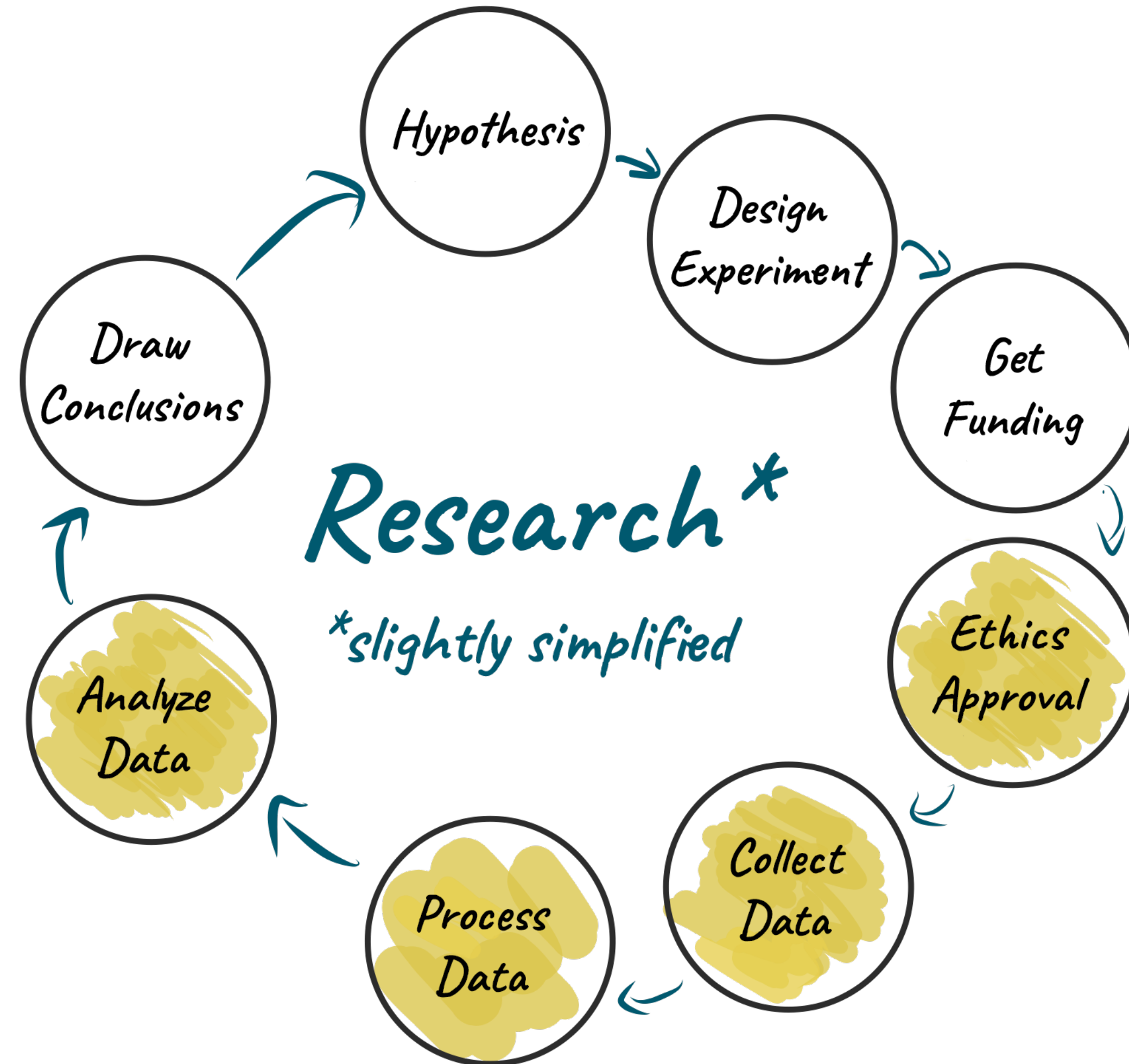
Quantified Self



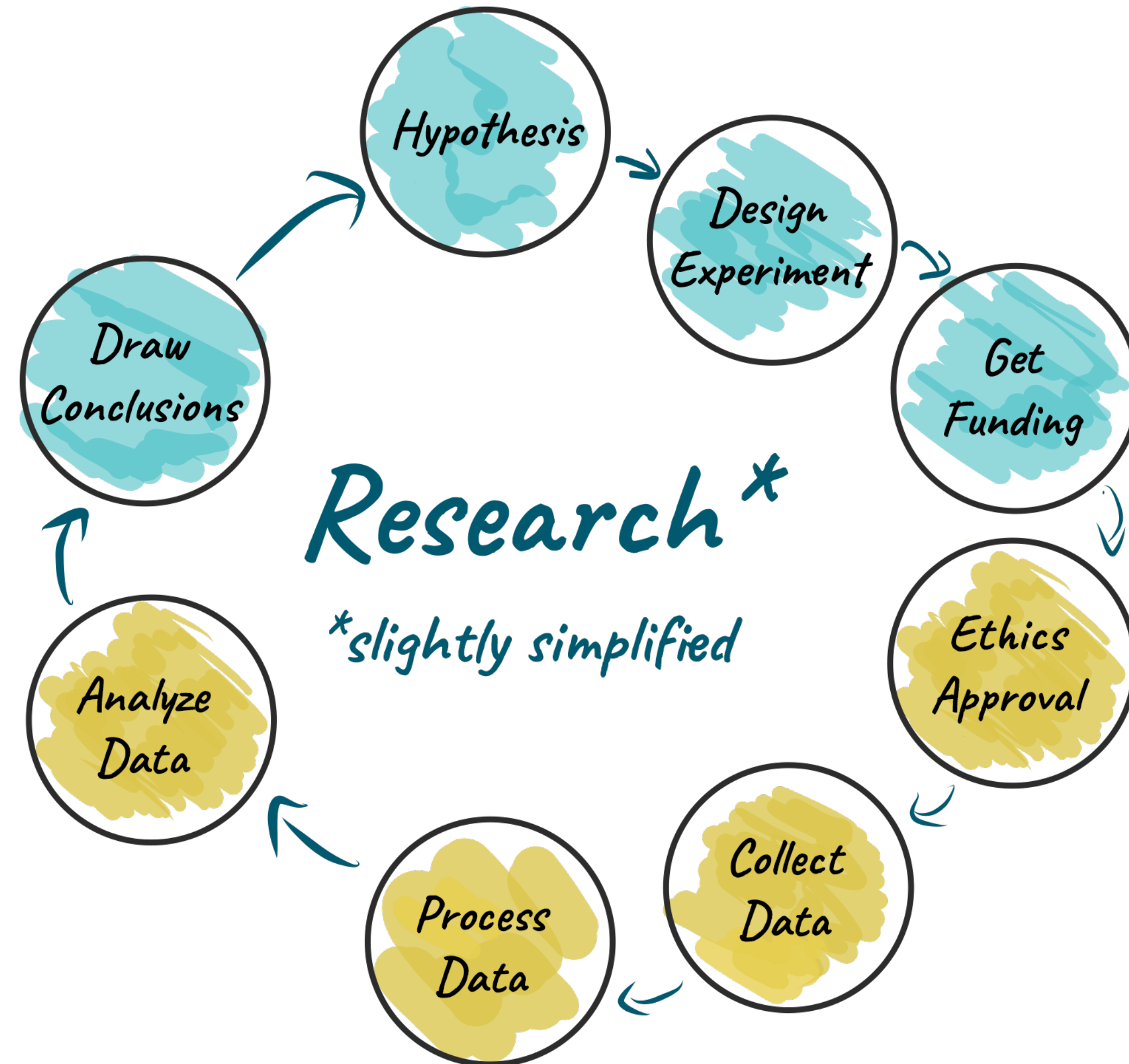
QCycle
*participant-led research on
physiological change across the
ovulatory cycle.*

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

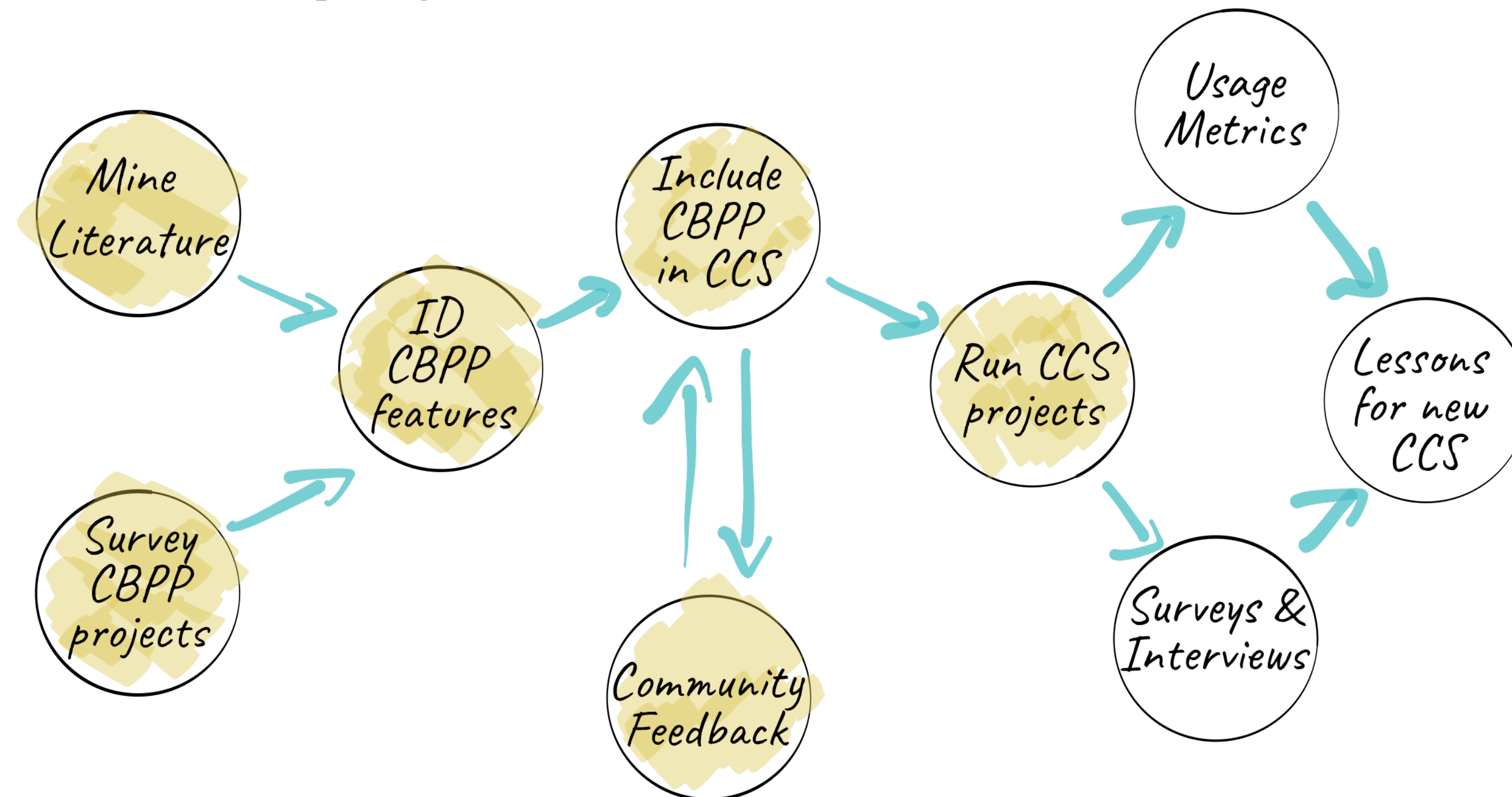


Types of CCS in Open Humans



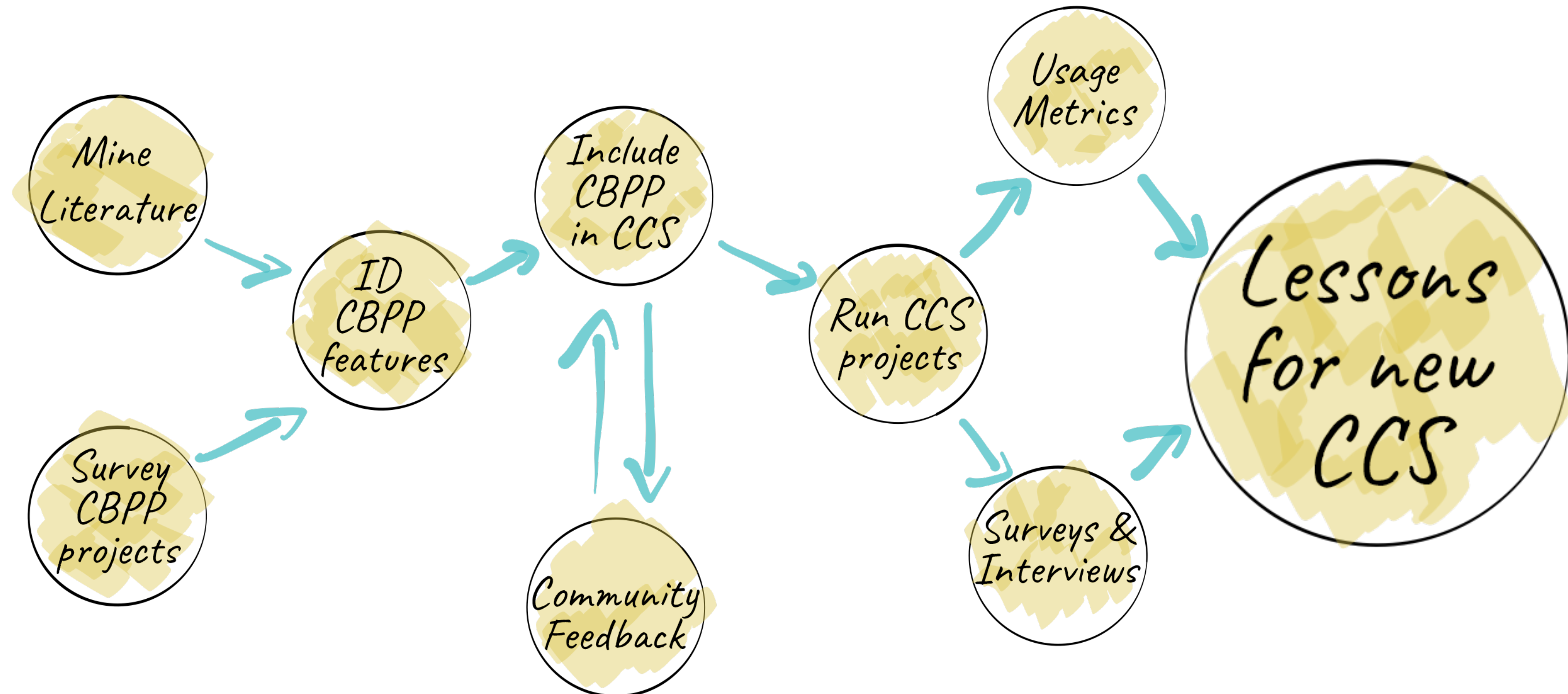
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Research Plan

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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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Mike Escalante
Rosy Gupta (Outreachy)
Manaswini Das (Outreachy)
Jasmine Tamak (Outreachy)
Tarannum Khan (Outreachy)



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Nomi Harris
Deepak Unni



OPEN
HUMANS

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Vivek Raj (GSoC)
Graham Dyer (GSoC)

With support from:



Google
Summer of Code



Ext. Collaborators: Samuel Gershman (Harvard)
Marcel Salathé (EPFL)
John Wilbanks (Sage Bionetworks)
Effy Vayena (ETH Zurich)

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
Open Humans
Bastian Greshake Tzovaras
Connected by **519** members

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

[Learn more](#)



AncestryDNA Upload
Open Humans
Open Humans Foundation
Connected by **411** members

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

[Learn more](#)



Open Humans Healthkit Integration
James Turner
self
Connected by **183** members

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

[Learn more](#)



Data Selfies
Open Humans
Open Humans Foundation
Connected by **124** members

Upload Data Selfies

[Learn more](#)



Nokia Health (Withings) Connection
Open Humans
Open Humans Foundation
Connected by **101** members

Add your Nokia Health (Withings) data to Open Humans

[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](#)



Fitbit Connection
Open Humans
Open Humans Foundation
Connected by **398** members

Connect your Fitbit account to add data from your Fitbit activity trackers and other Fitbit devices.

[Learn more](#)



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.

[Learn more](#)



uBiome Upload
Open Humans
Open Humans Foundation
Connected by **69** members

uBiome is a company based in San Francisco that performs microbiome sequencing

[Learn more](#)



FamilyTreeDNA integration
Bastian Greshake Tzovaras
Connected by **74** members

Upload your FamilyTreeDNA data to Open Humans

[Learn more](#)



Imputer
Kevin Arvai
Connected by **55** members

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

[Learn more](#)



Runkeeper connection
Open Humans
Open Humans Foundation
Connected by **210** members

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

[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](#)



Genome/Exome Upload
Open Humans
Open Humans Foundation
Connected by **209** members

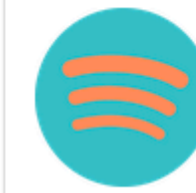
Do you have genome or exome data? You can upload genome, exome, and genotyping data in VCF format.



Google Location History Upload
Open Humans
Open Humans Foundation
Connected by **46** members

Upload your Google Location History archive

[Learn more](#)



Spotify integration
Open Humans
Open Humans Foundation
Connected by **47** members

Collect the songs you listen to on Spotify

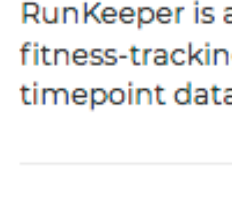
[Learn more](#)



Oura Connect
Open Humans
Open Humans Foundation
Connected by **38** members

Connect your Oura to Open Humans

[Learn more](#)



Overland connection
Open Humans
Open Humans Foundation
Connected by **15** members

Import GPS data from Overland

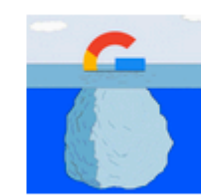
[Learn more](#)



RescueTime connection
Bastian Greshake Tzovaras
Connected by **31** members

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

[Learn more](#)



Google search history analyzer
Athina Tzovara
Connected by **12** members

Google search history analyzer

Projects using Data



Genevieve Genome Report

Mad Ball

Connected by **807** members

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

[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](#)



Keeping Pace

Dr. Rumi Chunara
New York University

Joined by **400** members

Keeping Pace seeks to study data about how we move around, to understand how seasons and local environment influence our movement patterns.

[Learn more](#)



Juno's Personal Data Exploratory

Bastian Greshake Tzovaras
Open Humans Foundation

Connected by **96** members

Showcase and share your Personal Data Notebooks with others

[Learn more](#)



UbiQomix Microbiome Exploration

Orit Shaer, Mad Price Ball,
Oded Nov
Wellesley College, Open Humans,
NYU

Joined by **123** members

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

Vineet Pandey
UCSD Design Lab

Connected by **93** members

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

[Learn more](#)



Circles

Cliff Tabin and Abigail Wark
Harvard Medical School

Joined by **316** members

Circles is a research study that aims to discover the genetic basis for a mysterious and remarkable human trait: the areola.

[Learn more](#)



Personal Data Notebooks

Bastian Greshake Tzovaras
Open Humans Foundation

Connected by **466** members

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

[Learn more](#)



GenomiX Genome Exploration

Orit Shaer & Oded Nov
Wellesley College & NYU

Joined by **356** members

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

[Learn more](#)



Imputer

Kevin Arvai

Connected by **55** members

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

[Learn more](#)



Galileo

Vineet Pandey
UCSD Design Lab

Connected by **54** members

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

[Learn more](#)



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.

[Learn more](#)



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.

[Learn more](#)



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

[Learn more](#)



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.