

OPEN HUMANS



**Empowering individuals and
communities to use personal data for
citizen science**

Bastian Greshake Tzovaras & Mad Ball
@gedankenstuecke / @madprime

2020-09-08

personal use of personal data



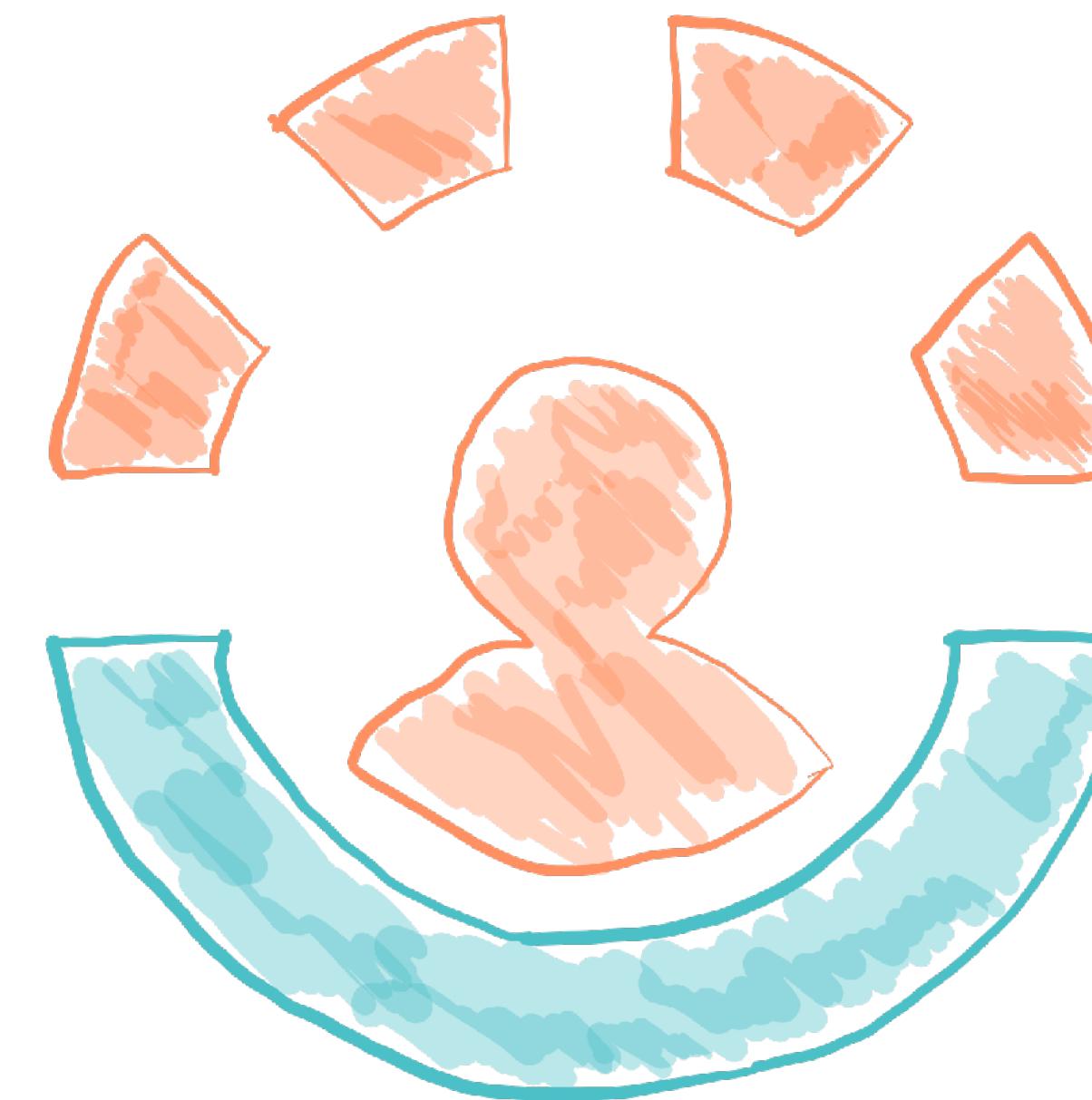
personal use of personal data



Barriers:

- data stored in silos
- lack of standardization of data
- high expertise needed for using data
- lack of shared knowledge in community⁽¹⁾ → reinventing the wheel

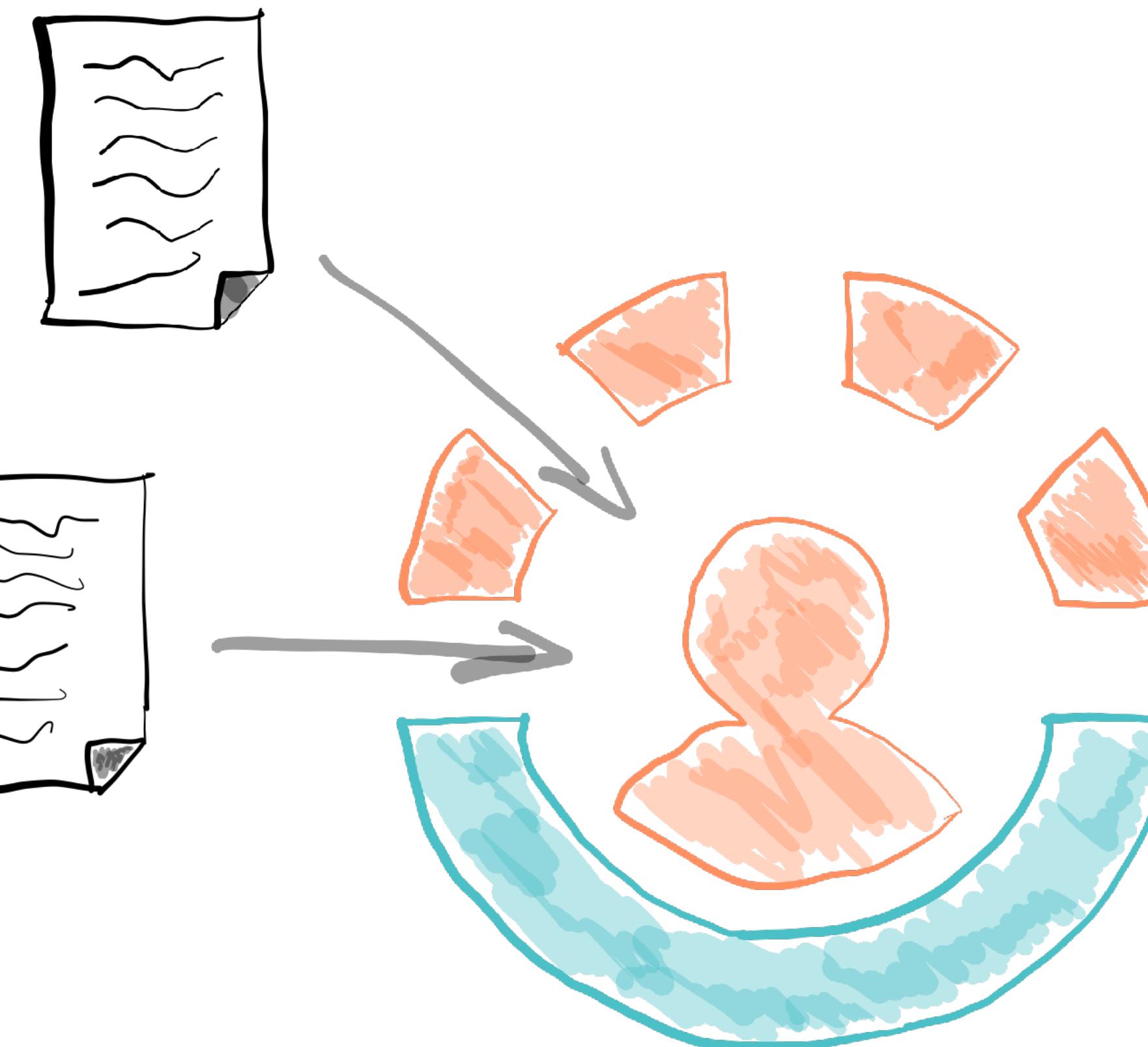
Enabling collective self-research



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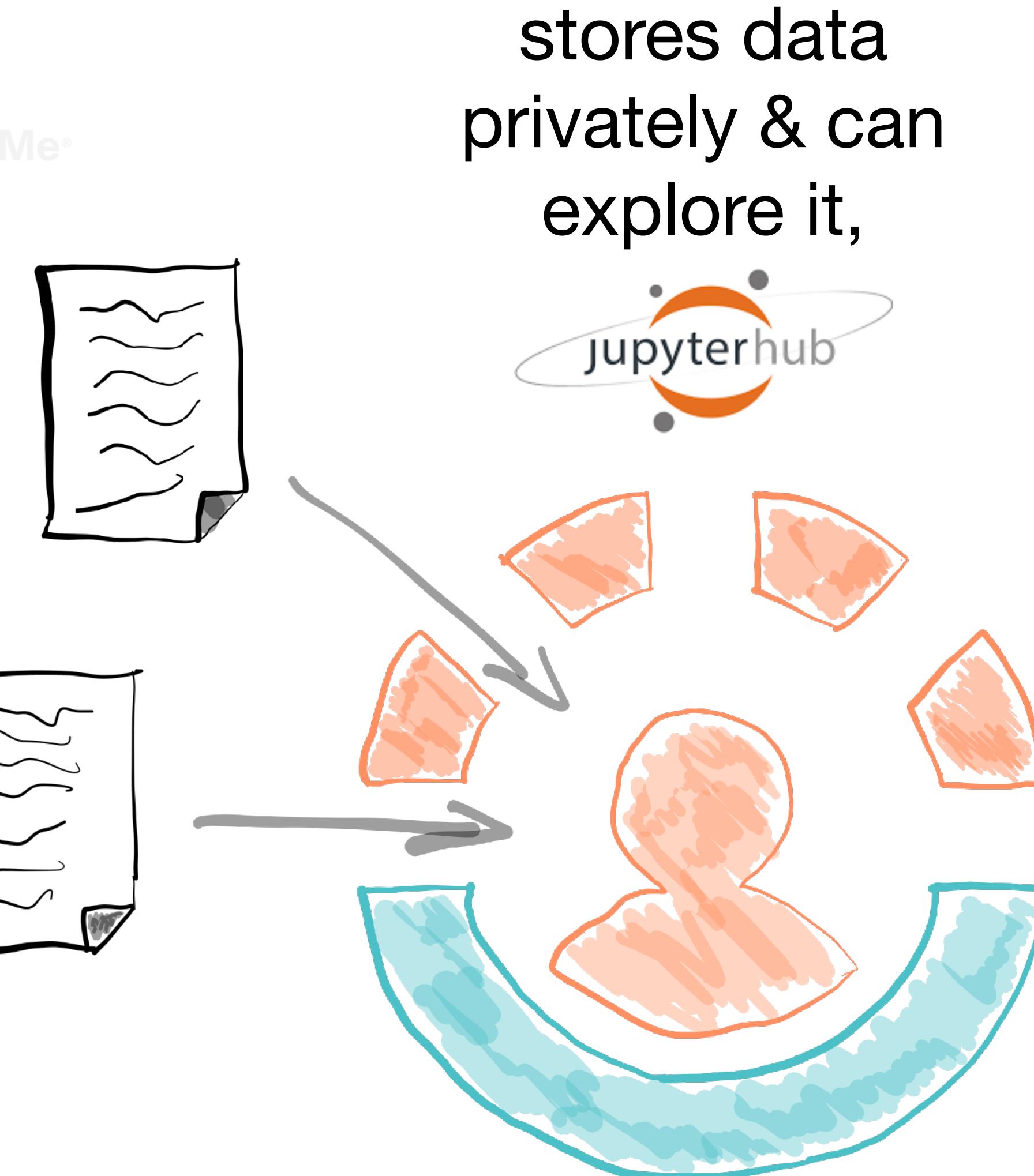
individual imports
personal data,



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individual imports
personal data,



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Personal Data Notebooks

Notebook	Data Sources	👁️	❤️	Last updated ▾
Daylio Analysis.ipynb by danlessa ⓘ	daylio	preview 📸	3	0 5 days ago
23andme-preeclampsia.ipynb by M_P ⓘ	23andMe Upload	preview 📸	7	0 1 week ago
fitbit-load-in-R.ipynb by gedankenstuecke ⓘ	Fitbit Connection	preview 📸	19	0 1 month ago
twitter-sentiment.ipynb by gedankenstuecke ⓘ	Twitter Archive Analyzer	preview 📸	16	0 1 month ago
twitter-archive-text-mining-R.ipynb by gedankenstuecke ⓘ	Twitter Archive Analyzer	preview 📸	16	0 1 month ago
compare_fitbit_healthkit.ipynb by gedankenstuecke ⓘ	Open Humans Healthkit Integration Fitbit Connection	preview 📸	19	0 1 month ago
Sense Of Smell and openSNP Data (New SNPs).ipynb by dnrvrdavid ⓘ	23andMe Upload	preview 📸	7	0 2 months ago
Sense Of Smell and 23andMe data (Known SNP).ipynb by dnrvrdavid ⓘ	23andMe Upload	preview 📸	6	1 2 months ago
moves-analysis.ipynb by gedankenstuecke ⓘ	Moves connection	preview 📸	7	0 2 months ago
twitter-and-fitbit-activity.ipynb by gedankenstuecke ⓘ	Twitter Archive Analyzer Fitbit Connection	preview 📸	6	0 3 months ago

Filter by data source

[23andMe Upload](#)[Fitbit Connection](#)[Moves connection](#)[Open Humans Healthkit Integration](#)[RescueTime connection](#)[Twitter Archive Analyzer](#)[daylio](#)[google takeouts](#)

Your favorite data source is still missing? Read our [About page](#) to learn how to share your own notebook!



Personal Data Notebooks

Notebook

[Daylio Analysis.ipynb](#)

by danlessa

[23andme-preeclampsia.ipynb](#)

by M_P

[fitbit-load-in-R.ipynb](#)

by gedankenstuecke

[twitter-sentiment.ipynb](#)

by gedankenstuecke

[twitter-archive-text-mining-R.ipynb](#)

by gedankenstuecke

[compare_fitbit_healthkit.ipynb](#)

by gedankenstuecke

[Sense Of Smell and openSNP Data \(New SNPs\).ipynb](#)

by dnrvdavid

[Sense Of Smell and 23andMe data \(Known SNP\).ipynb](#)

by dnrvdavid

[moves-analysis.ipynb](#)

by gedankenstuecke

[twitter-and-fitbit-activity.ipynb](#)

by gedankenstuecke

Data Sources

[daylio](#)[23andMe Upload](#)[Fitbit Connection](#)[Twitter Archive Analyzer](#)[Twitter Archive Analyzer](#)[Open Humans Healthkit](#)[Fitbit Connection](#)[23andMe Upload](#)[23andMe Upload](#)[Moves connection](#)[Twitter Archive Analyzer](#)[File](#) [Edit](#) [View](#) [Insert](#) [Cell](#) [Kernel](#) [Widgets](#) [Help](#) [Code](#) [Voila](#)

```
max=10,  
description='Loading:',  
bar_style='info', # 'success', 'info', 'warning', 'danger' or ''  
orientation='horizontal'  
)
```

```
progress.layout.visibility = 'hidden'
```

```
dropdown.observe(handle_dropdown_change, names='value')
```

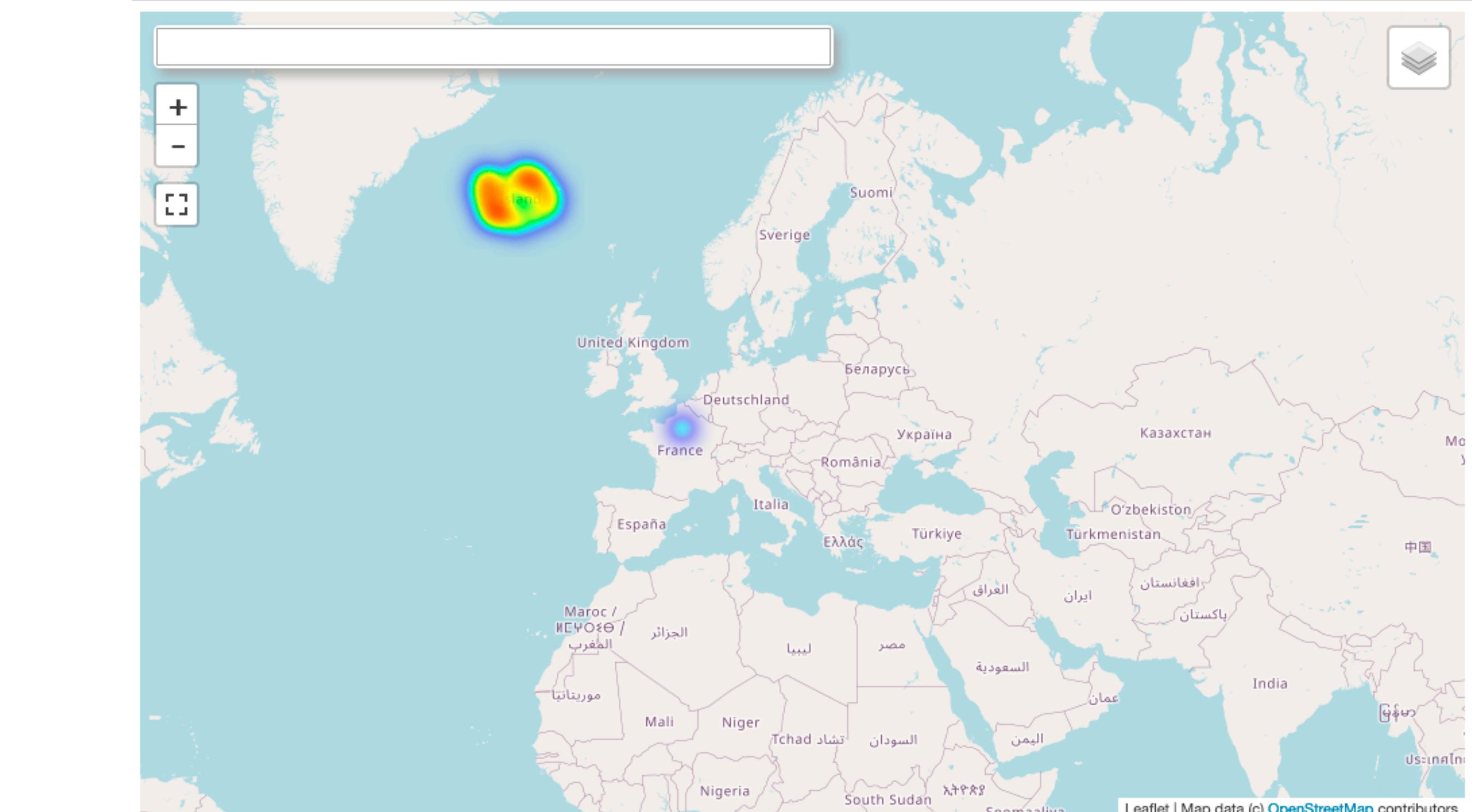
```
display(dropdown, caption, progress)
```

Month:

Loaded the data for 2020-08. It should now be on the map!

Loading:

In [11]:



Keating Memorial Self Research

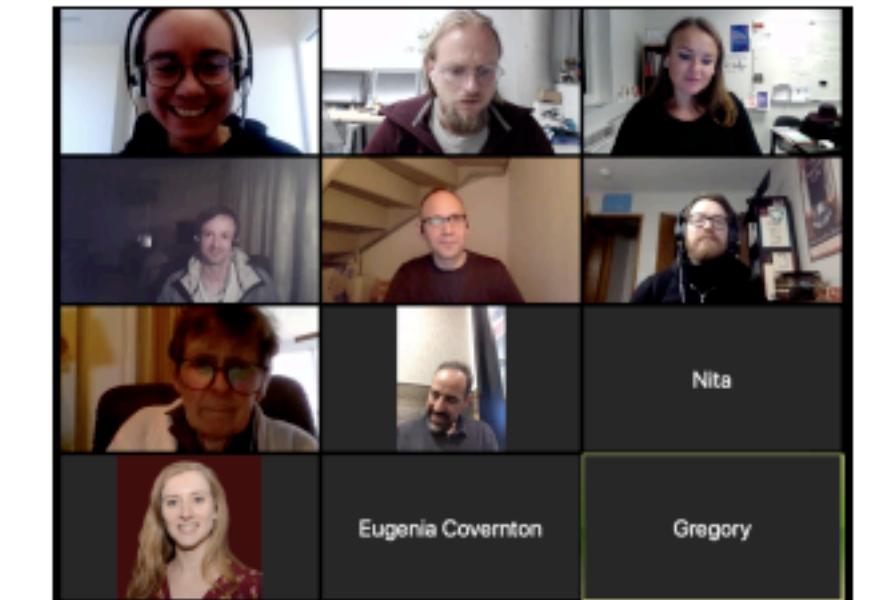


Notes & video from our self-research kickoff

⌚ February 10, 2020 📄 Open Humans, Self-research 🙋 Mad Price Ball

In case you missed it: we took notes & recorded our kickoff webinar for the [Keating Memorial Self Research](#) activity last week!

On Thursday we'll have "[open office hours](#)" to [offer free expert support](#) for people getting started with questions and ideas about what they want to do. The meeting is at 10am PST / 6pm GMT on February 13 (Thursday).



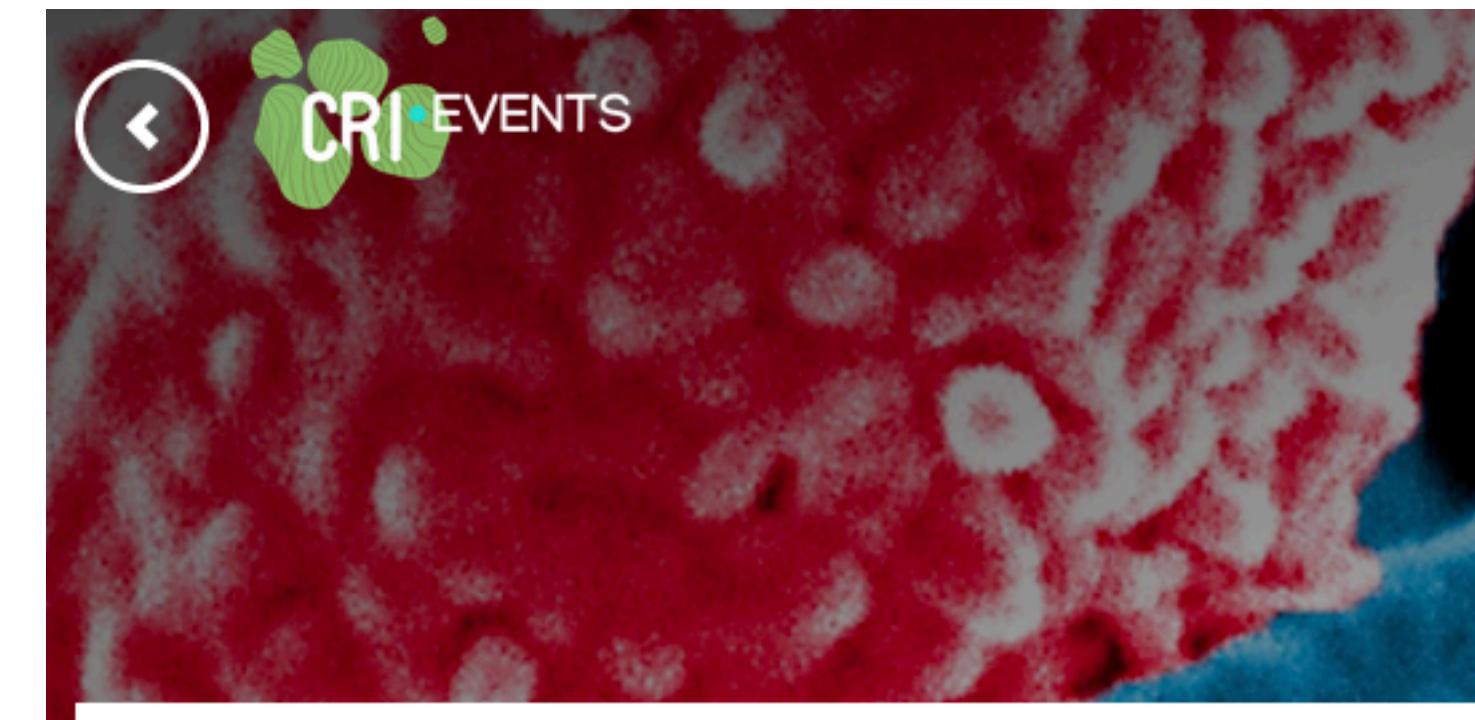
QUANTIFIED SELF
SELF KNOWLEDGE THROUGH NUMBERS

Keating Memorial

- weekly ‘group-meetings’ → lab meetings for self-researchers
 - provides space for sharing updates, asking questions, get help, find inspirations, accountability
- ended with public presentations of participants: Show & Tell
 - What did I do? How did I do it? What did I learn?

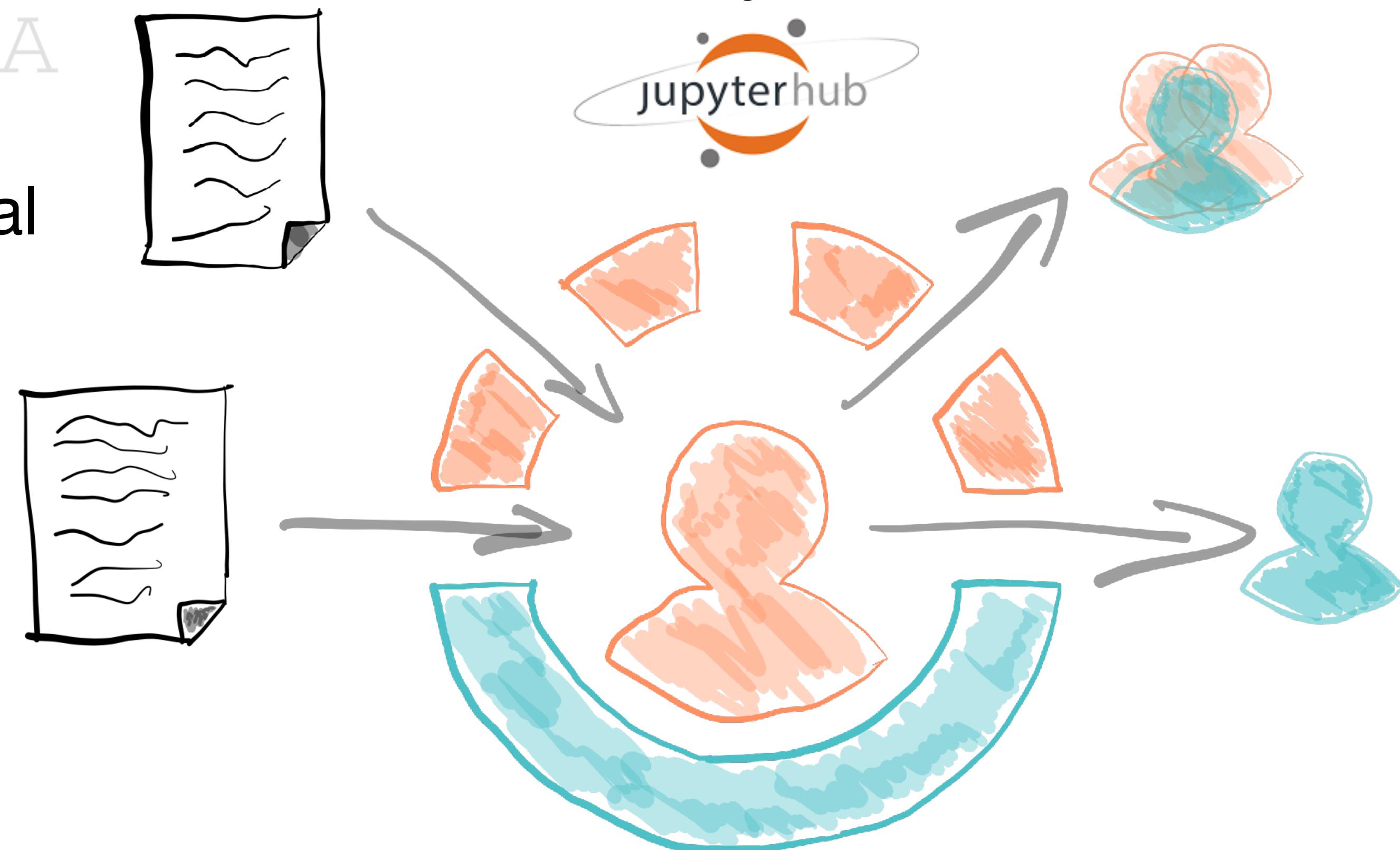
Example projects

- Life-changes due to COVID *shelter-in-place* orders in the US
- personal hay fever symptoms over time and impact of medication
- Self-Tracking of cardiac arrhythmias
- Effects of transgender testosterone therapy





privately explore
it & share
analyses



OPEN HUMANS



This is **Dana Lewis** and her
Open Artificial Pancreas System.

#OpenAPS



NIGHTSCOUT
#WeAreNotWaiting



**Data is collected by
an individual**

Nightscout

Data is collected by
an **individual**



an **individual** copies
their data through a
web app



Data is collected by
an **individual**



an **individual** copies
their data through a
web app



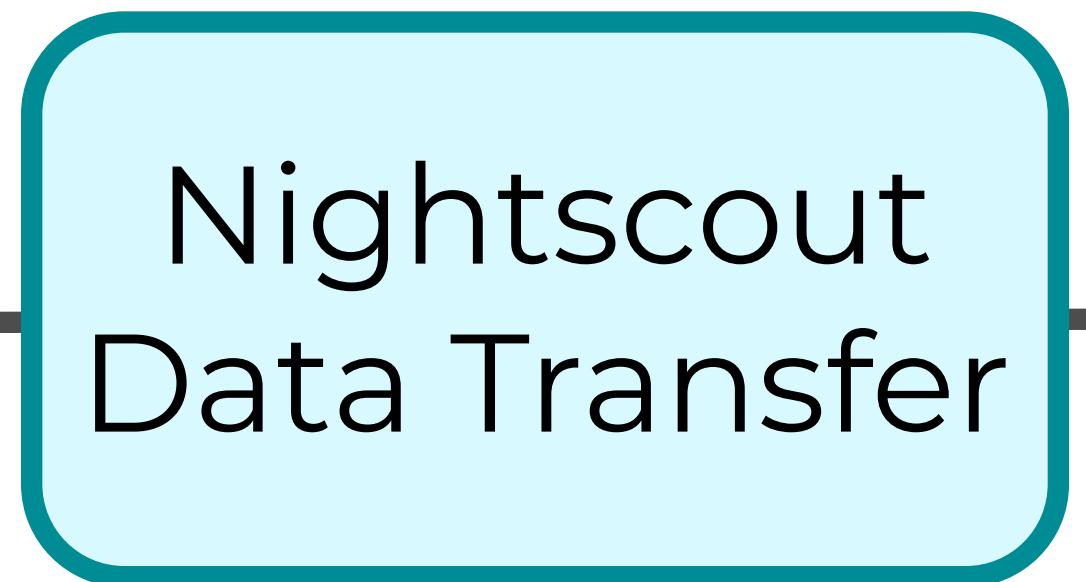
the data is **stored** in
Open Humans,
individuals decide 3rd
party access



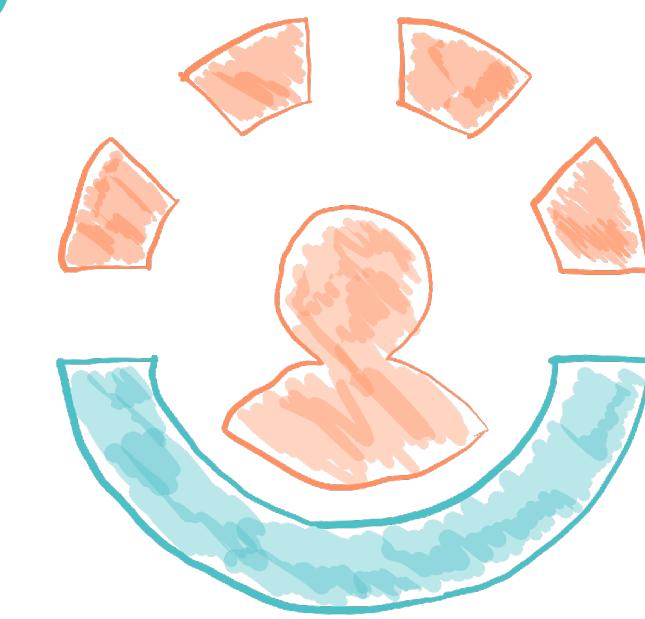
Data is collected by
an **individual**



an **individual** copies
their data through a
web app



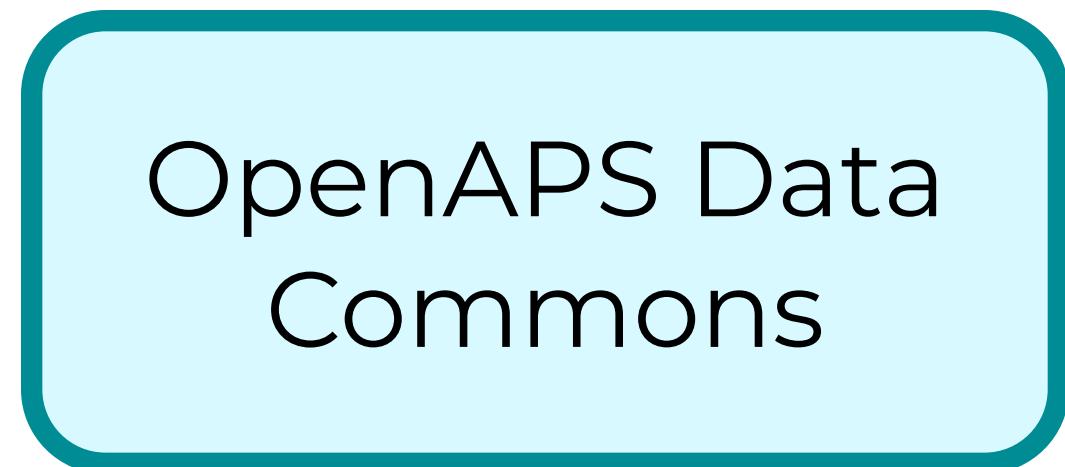
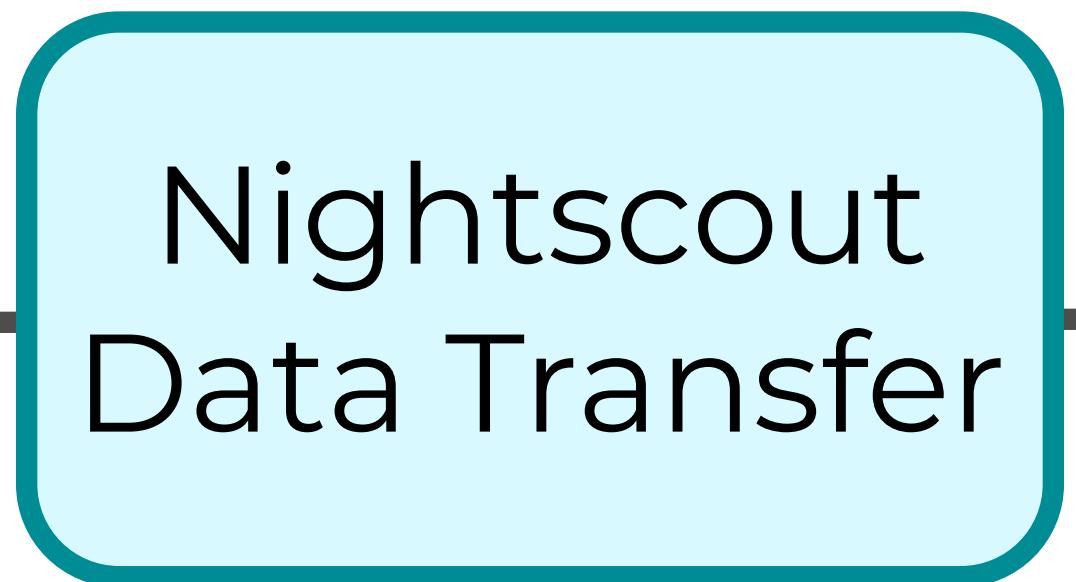
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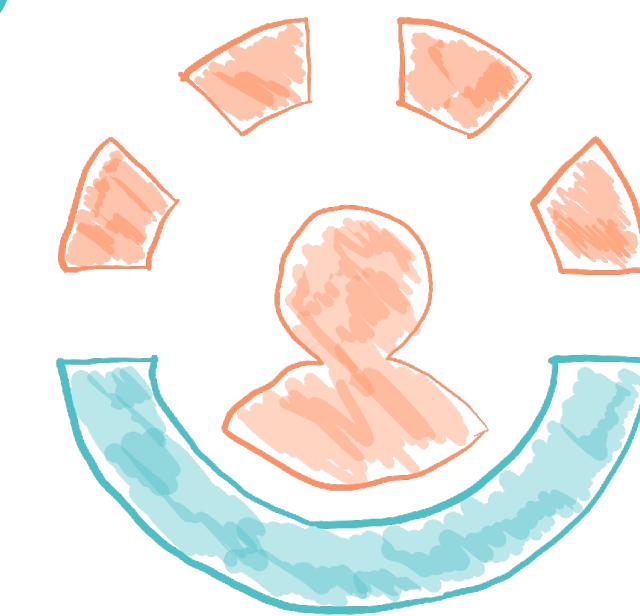
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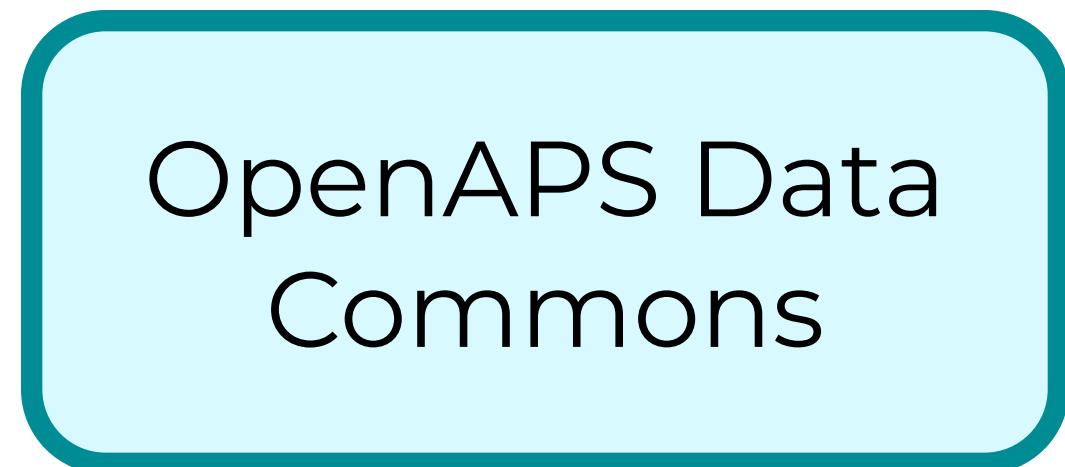


OPEN HUMANS

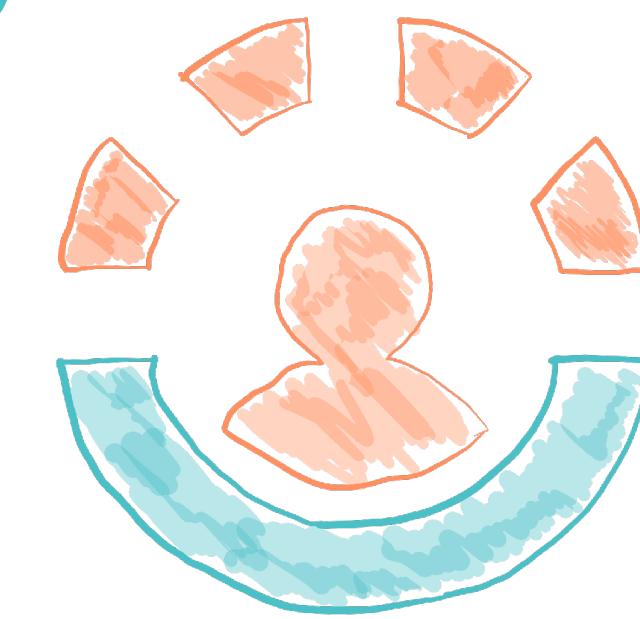
Data is collected by
an **individual**



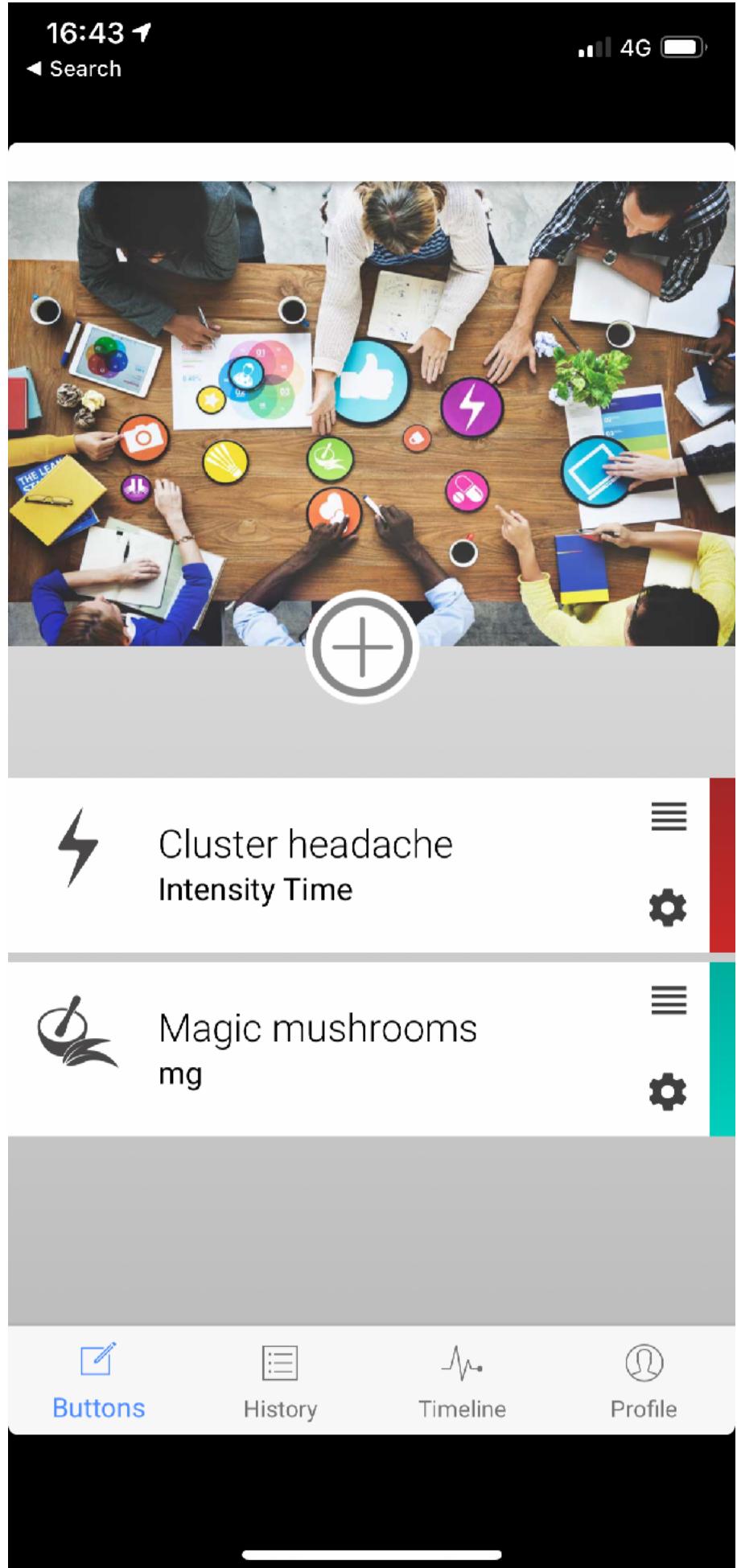
an **individual** copies
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web app

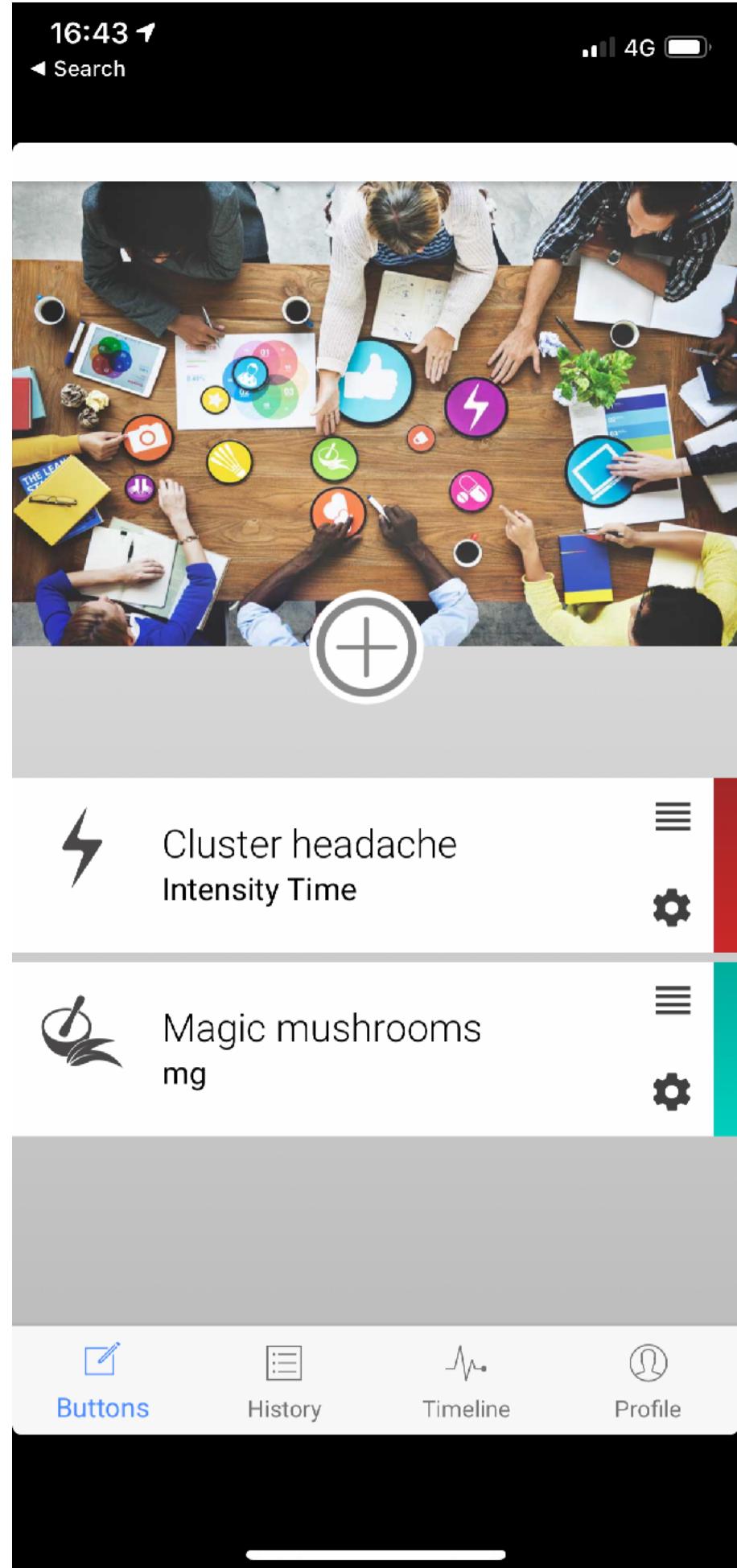


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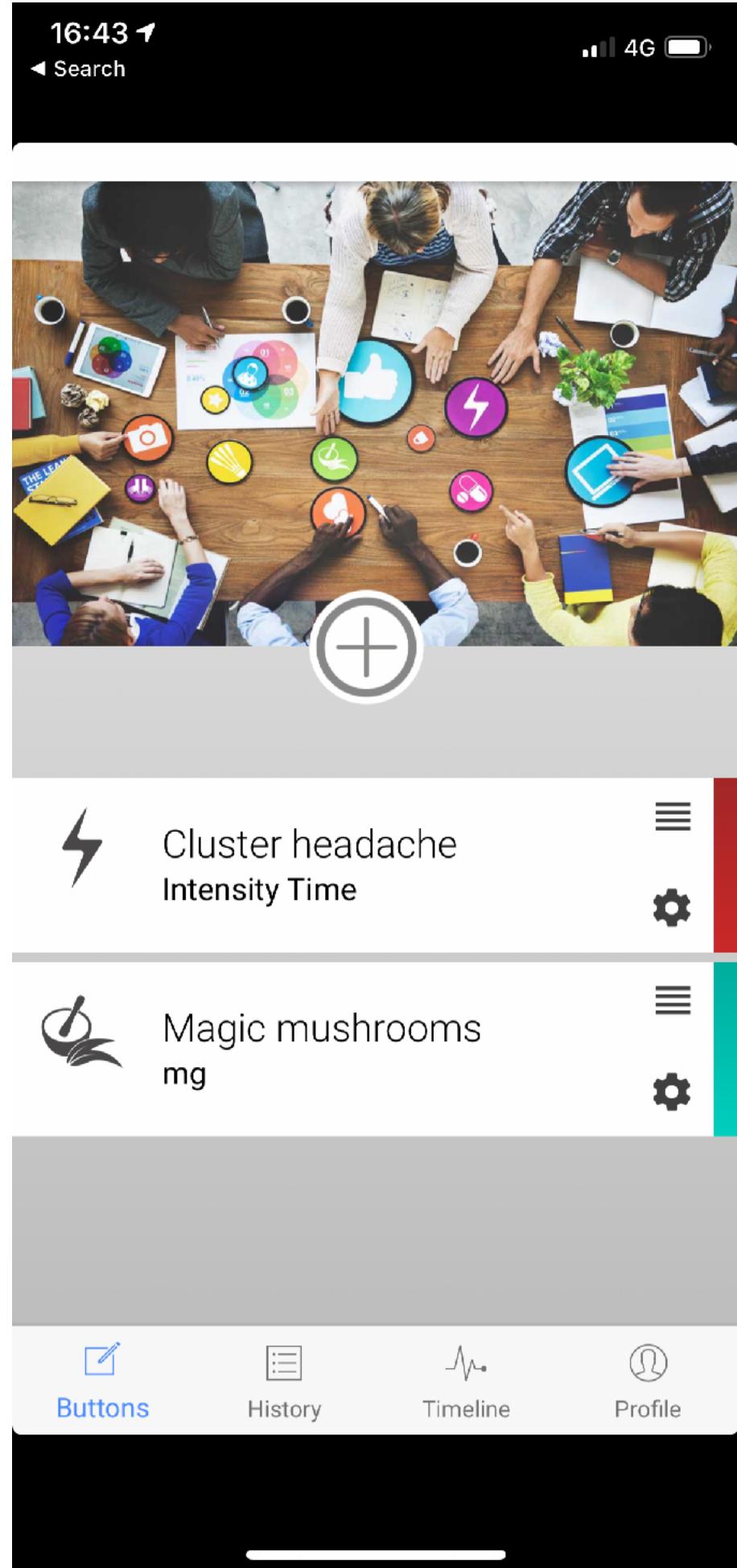
New Citizen/Patient-led
experiments!



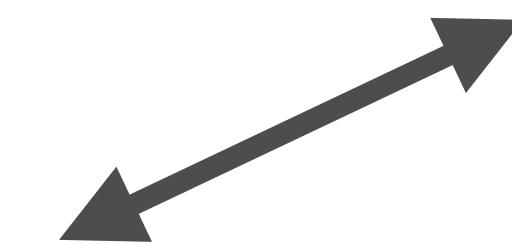


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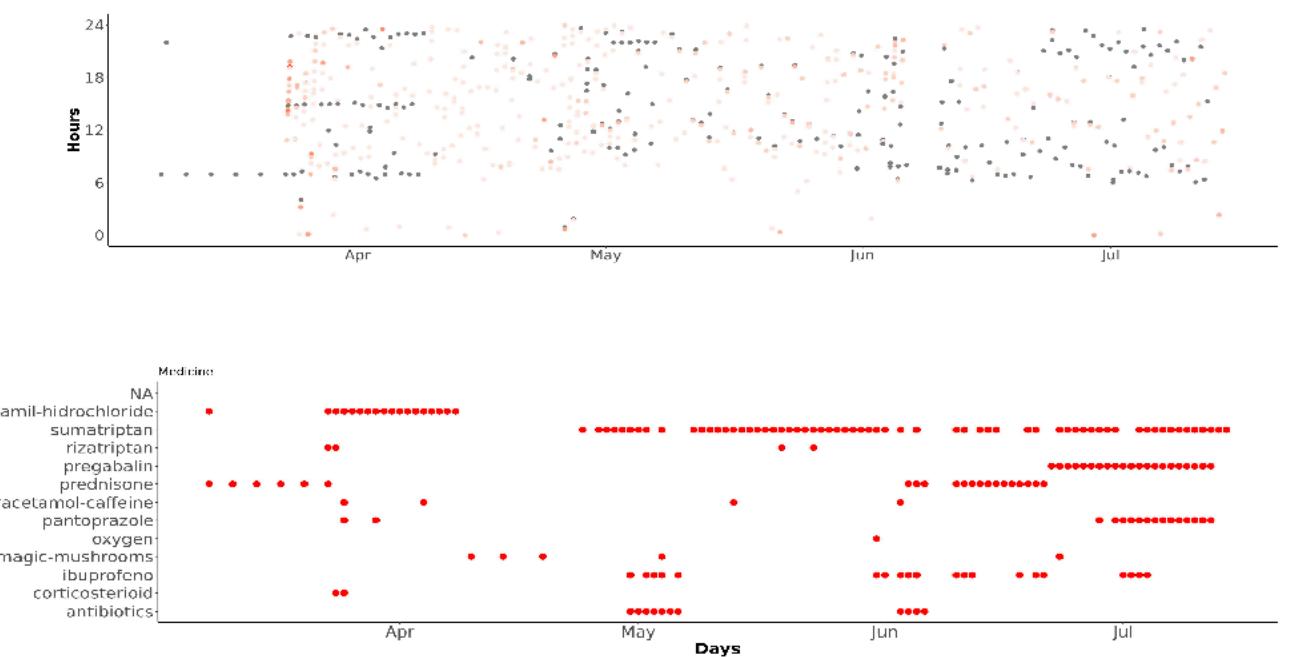


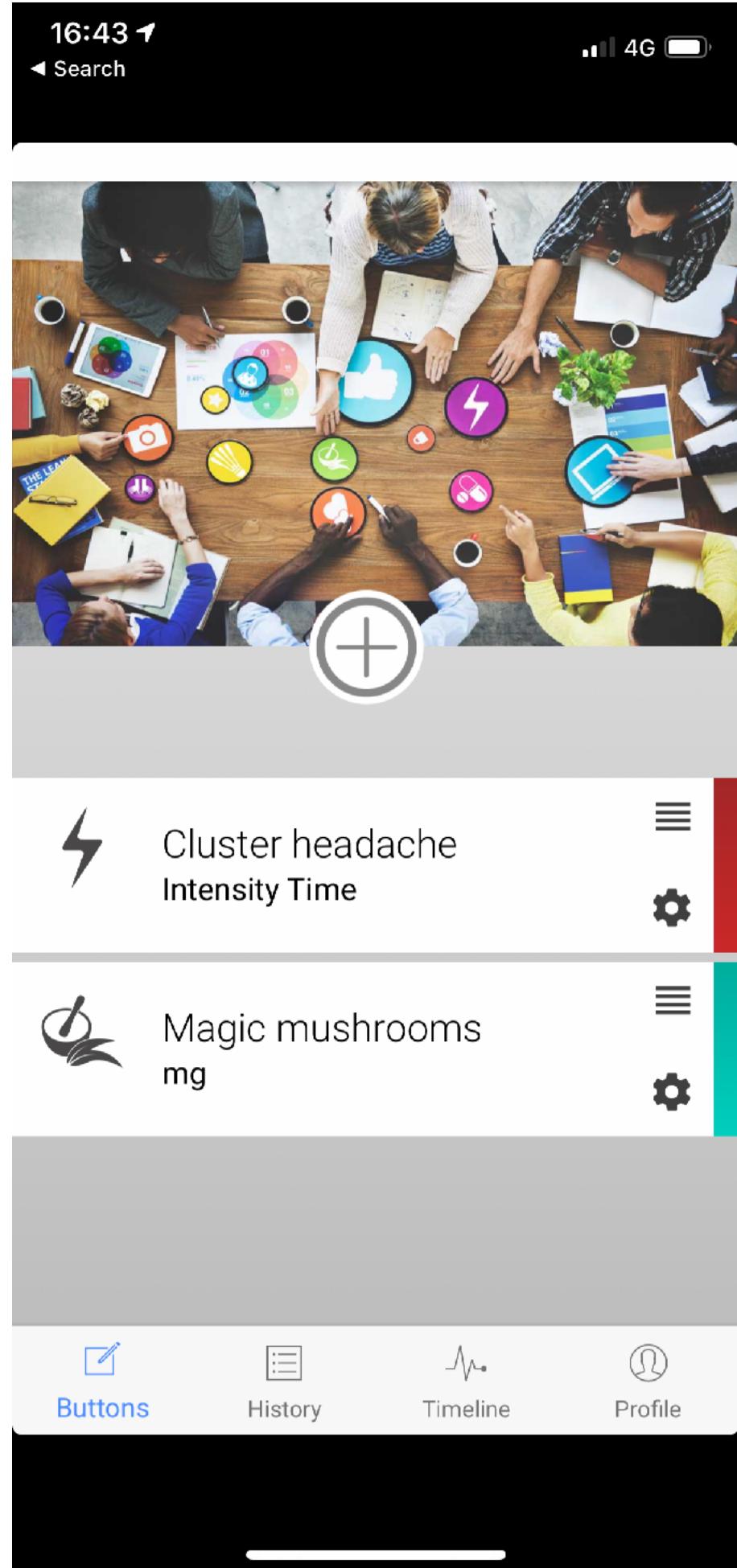


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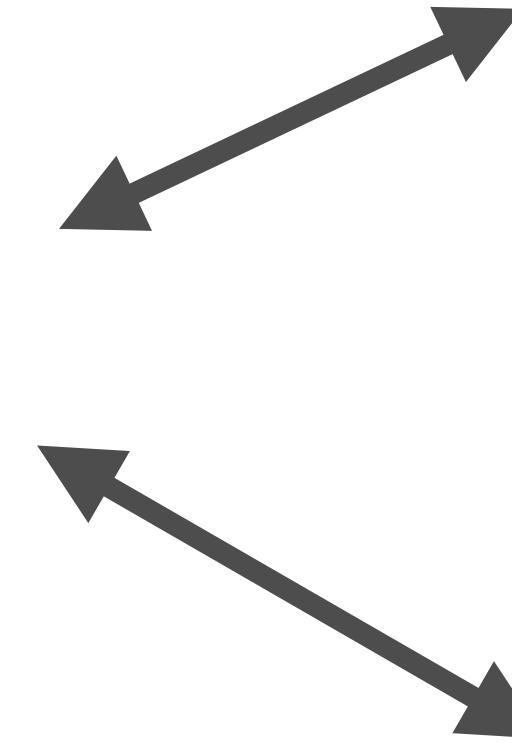


It's interesting to know what treatments you took, its also good to see when you took these treatments and how your attacks responded to it. So we display here a timeline of attacks together with a timeline of your treatment intake.

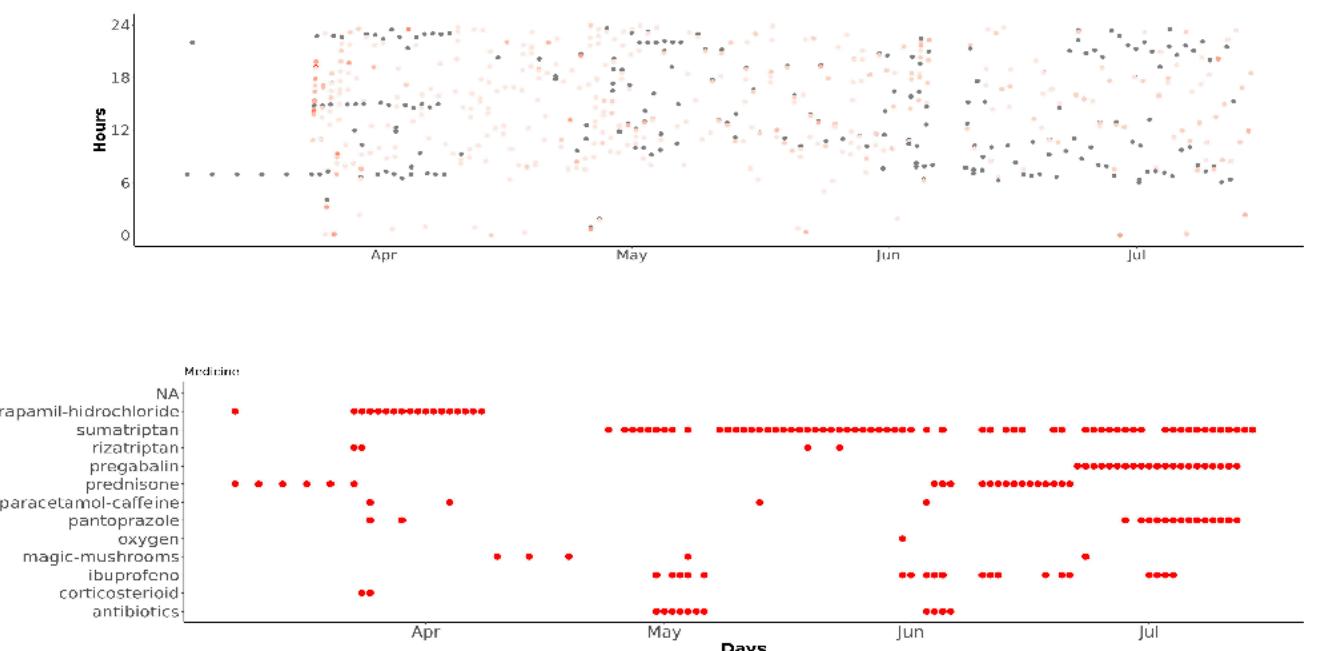




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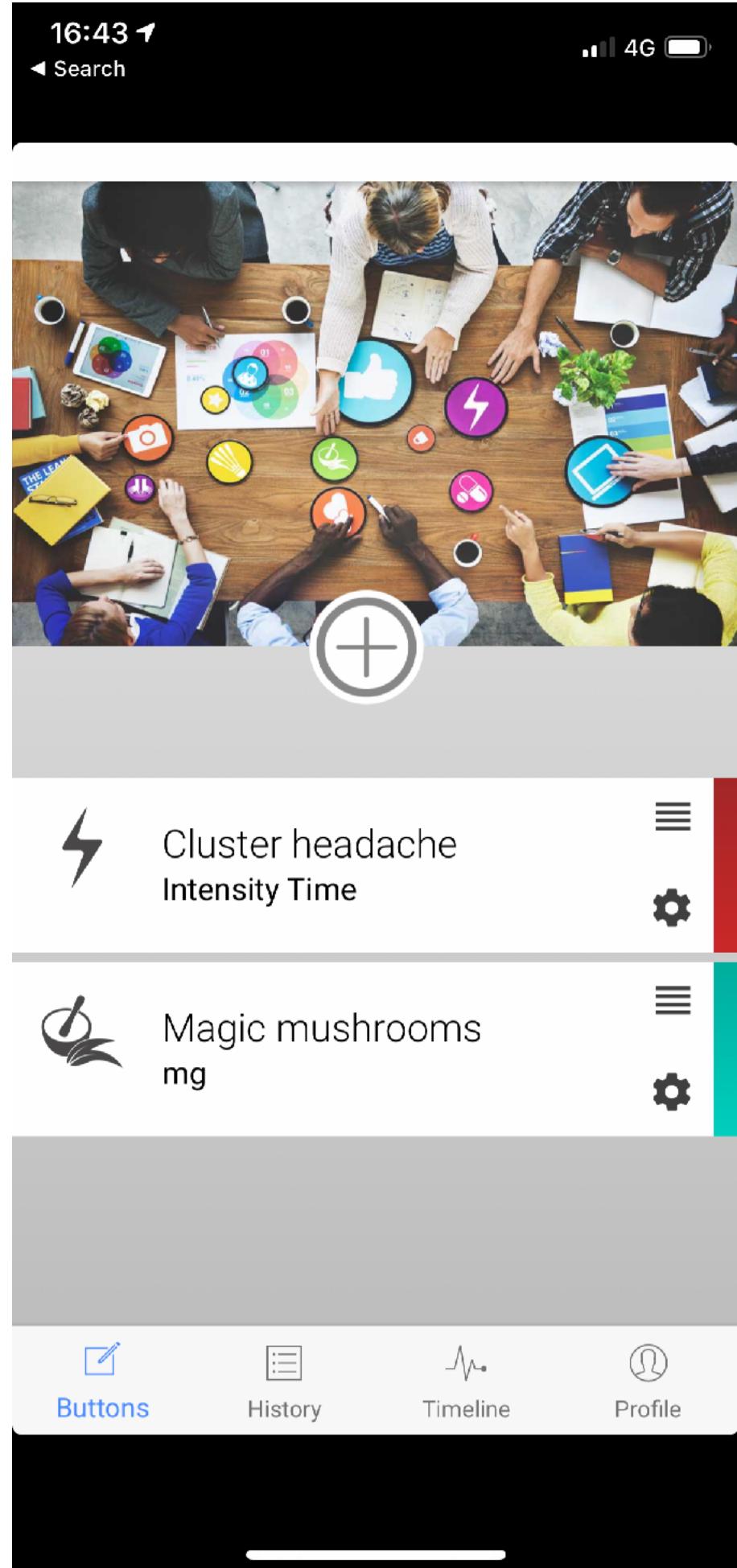


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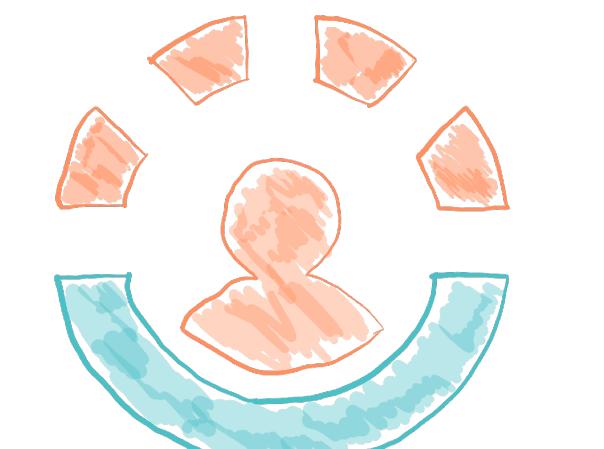


**Donate reports for
Patient Advocacy**

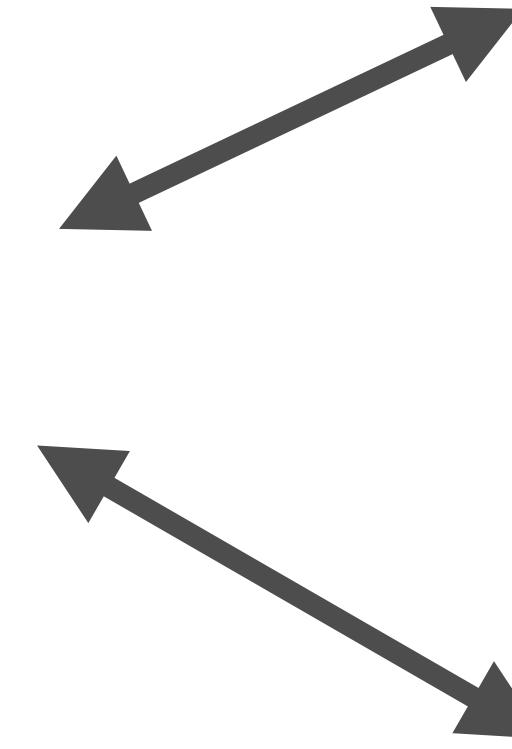




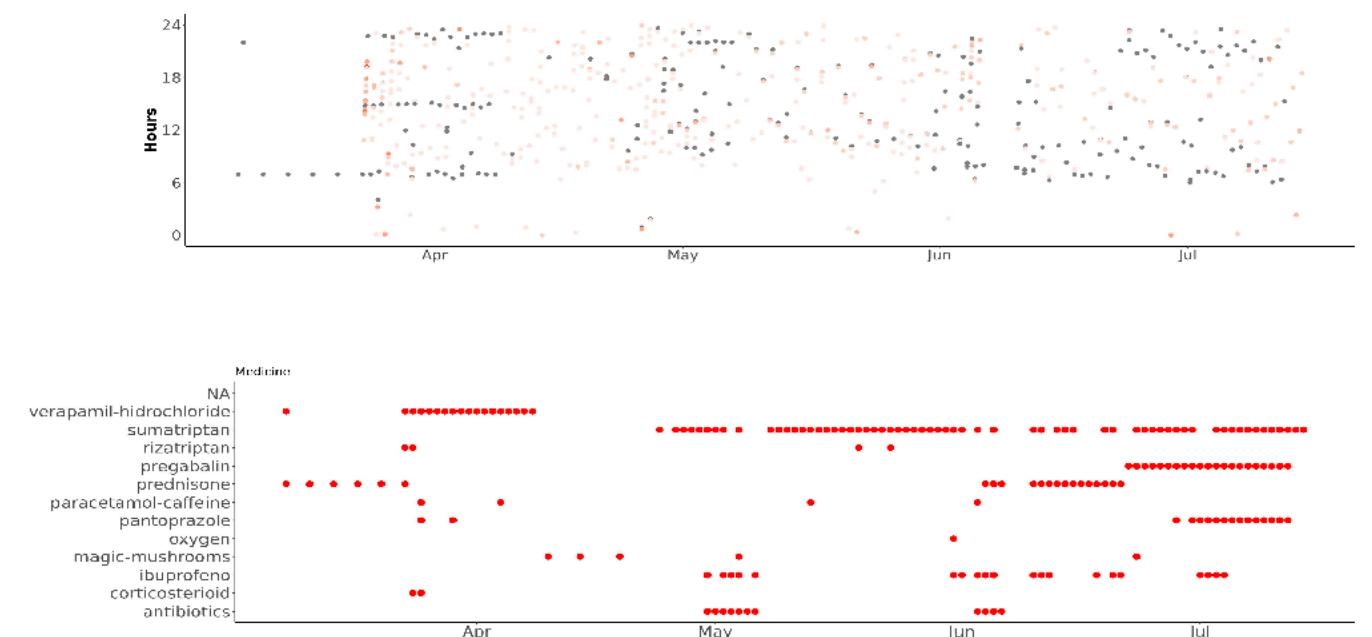
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**patient-led
experiments**



It's interesting to know what treatments you took, its also good to see when you took these treatments and how your attacks responded to it. So we display here a timeline of attacks together with a timeline of your treatment intake.



**Donate reports for
Patient Advocacy**



Governance: Building **trust** & **community**



Governance: Building trust & community

I'm posting a review request for the [Genetics of Personality Type](#) project [3](#) which is applying for project approval. The project is part of a research study led by Dr. Denise Cook. [The whole documentation of the study's IRB approval is available here](#) [1](#)!

Should this project be visible and available for all Open Humans members to join?

Please vote **Approve** or **Deny**, and/or comment.

Quick links

- **Activity page:** <https://www.openhumans.org/activity/genetics-of-personality-type/> [2](#)
- **Project review guide:** [Project Review Guide](#) [3](#)
- **Project guidelines:** <https://www.openhumans.org/community-guidelines/#project>

Governance: Building trust & community

I'm posting a review request for the [Genetics of Personality](#) approval. The project is part of a research study led by Dr. [the study's IRB approval is available here](#) !

Should this project be visible and available for all Open Humans?

Please vote **Approve** or **Deny**, and/or comment.

Quick links

- **Activity page:** <https://www.openhumans.org/activity/1234567890>
- **Project review guide:** [Project Review Guide](#) 3
- **Project guidelines:** <https://www.openhumans.org/community/guidelines>

Project info

- **Title :** Genetics of Personality Type
- **Managed by:** Dr. Denise Cook
- **Description:** Current academic research looking for personality genes measure personality traits using questionnaires for the “Big 5”: Extraversion, Openness, Conscientiousness, Agreeableness, Neuroticism, traits that have been found to vary continuously in the human population. While these studies have successfully identified genetic variants associated with each of these traits, each polymorphism has only a small effect on the phenotype and explains only a tiny fraction of the genetic variance in each trait. Consequently, none of the SNPs or combinations of SNPs identified so far can predict someone’s personality traits. Instead of using the Big 5, this study will use the Myers-Briggs Type Indicator, which categorizes people into 16 different groups that share similar behavioural tendencies, and we hypothesize, similar patterns of genetic variants as well. The goal is to use this framework to isolate genetic variants that are strongly correlated with personality type.
- **Project website:** <https://www.personalitygenie.com/consent> 3
- **Connections:** 13 members
- **Data received:** [23andMe Upload](#), [AncestryDNA Upload](#), [FamilyTreeDNA integration](#), [Imputer](#)
- **Data added:** This project will return a person’s personality type (i.e., INTJ, ESFJ) as determined using three personality questionnaires.

Governance: Building trust & community

I'm posting a review request for approval. The project is part of the study's IRB approval is

Should this project be reviewed?

Please vote **Approve** or **Do Not Approve**.

Quick links

- **Activity page:** <https://www.reddit.com/r/IAmA/comments/1000000000000000000/>
- **Project review guide:** [Project review guide](#)
- **Project guidelines:** [Project guidelines](#)



wolfgang8741

May 22

Approve - Nothing about the IRB or project are raising any flags for concern about the project content.

As a note: I sent their contact email a message outlining minor [personalitygenie.com](#) 1 website server configuration improvements so https is more reliably accessed. Such as additional redirects and addition of HSTS header. Trivial to fix.

1 ... Reply



blackbearnh

May 22

Do Not Approve - The Myers Briggs is considered pretty much junk pop psychology these days. I can't see this as doing anything but providing data to enable a commercial site to deliver data of questionable value. The authors are specifically rejecting the generally accepted instrument of personality measurement, the "Big 5". This is akin to saying that they are choosing not to test for an infection with a white blood cell count, but instead measure the relative amounts of the 4 bodily humors.

using three personality questionnaires.

Governance: Building trust & community

OHF Board of Directors: Self-nominations invited



- Community-Elected
- Board-Elected

I'm also delighted to share that we have restructured our organization's governance to create "community seats". One of the three seats this round will be chosen by Open Humans members!

Anyone may apply to our board. The process involves a self-nomination, and nominees should be seconded by a current member of the Board of Directors.

Being a director of this organization is a position of trust. While I manage day-to-day operations, the board is our highest tier of governance – our ultimate decision-making authority. Many board members also contribute to the organization as officers, e.g. as secretary or treasurer. As Executive Director, I serve at the board's behest.

tl;dr



- Using our personal data is pretty hard with many barriers
- *Open Humans* aims to minimize these by allowing
 - individuals to import their data and explore it themselves with peer-support
 - make per-project decisions on how to share their data with academic or participant-led projects
- Members of *Open Humans* play an active role in the governance of the ecosystem
- Check us out at <https://www.openhumans.org> and join our slack at <http://slackin.openhumans.org/>

thanks to:



Mad Ball

Mairi Dulaney, Mike Escalante,
Tim Head, Rosy Gupta,
Manaswini Das, Jasmine
Tamak, Tarannum Khan

**& over 9,000 community
members!**

QUANTIFIED SELF

SELF KNOWLEDGE THROUGH NUMBERS

Gary Wolf, Steven Jonas, Azure
Grant



talk to me:

bastian@openhumans.org
twitter: @gedankenstuecke

Download slides at <https://tinyurl.com/OH-ECSA>

Quantified Flu

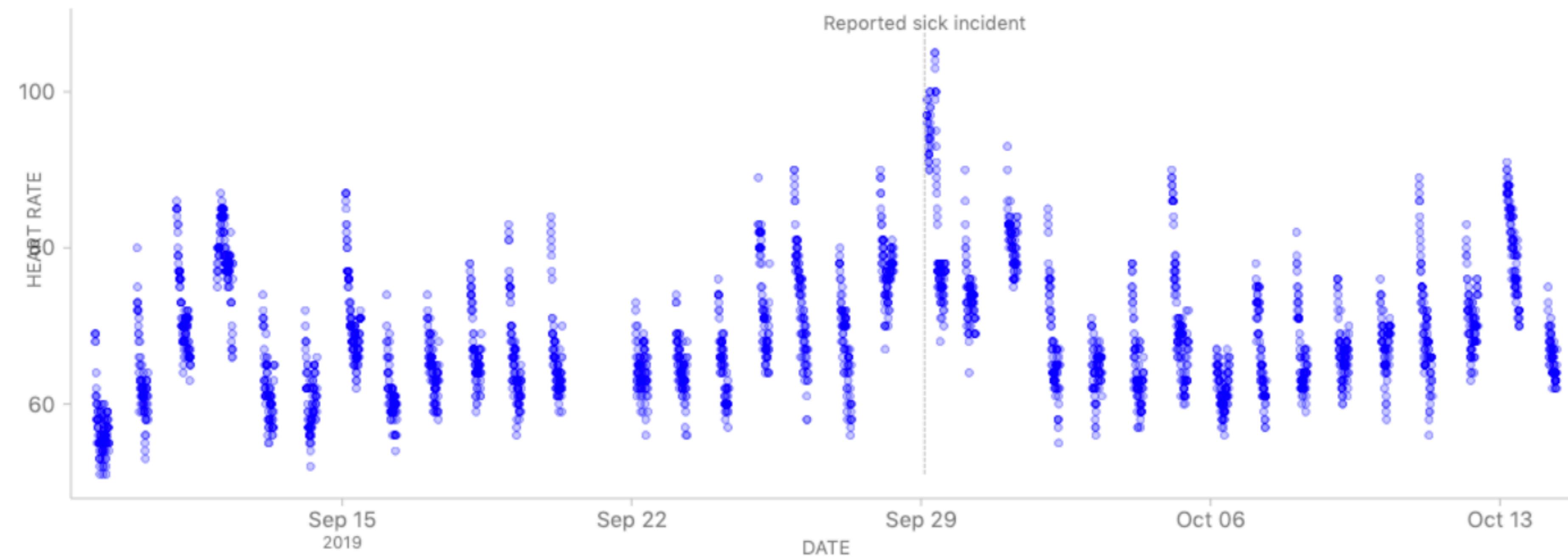
QF Quantified Flu

Public data About & Contributing

Log in

Welcome to the *Quantified Flu!*

Whether the flu or the common cold: Can wearables warn us when we're getting sick? Help us find out!



We have two ways you can contribute...

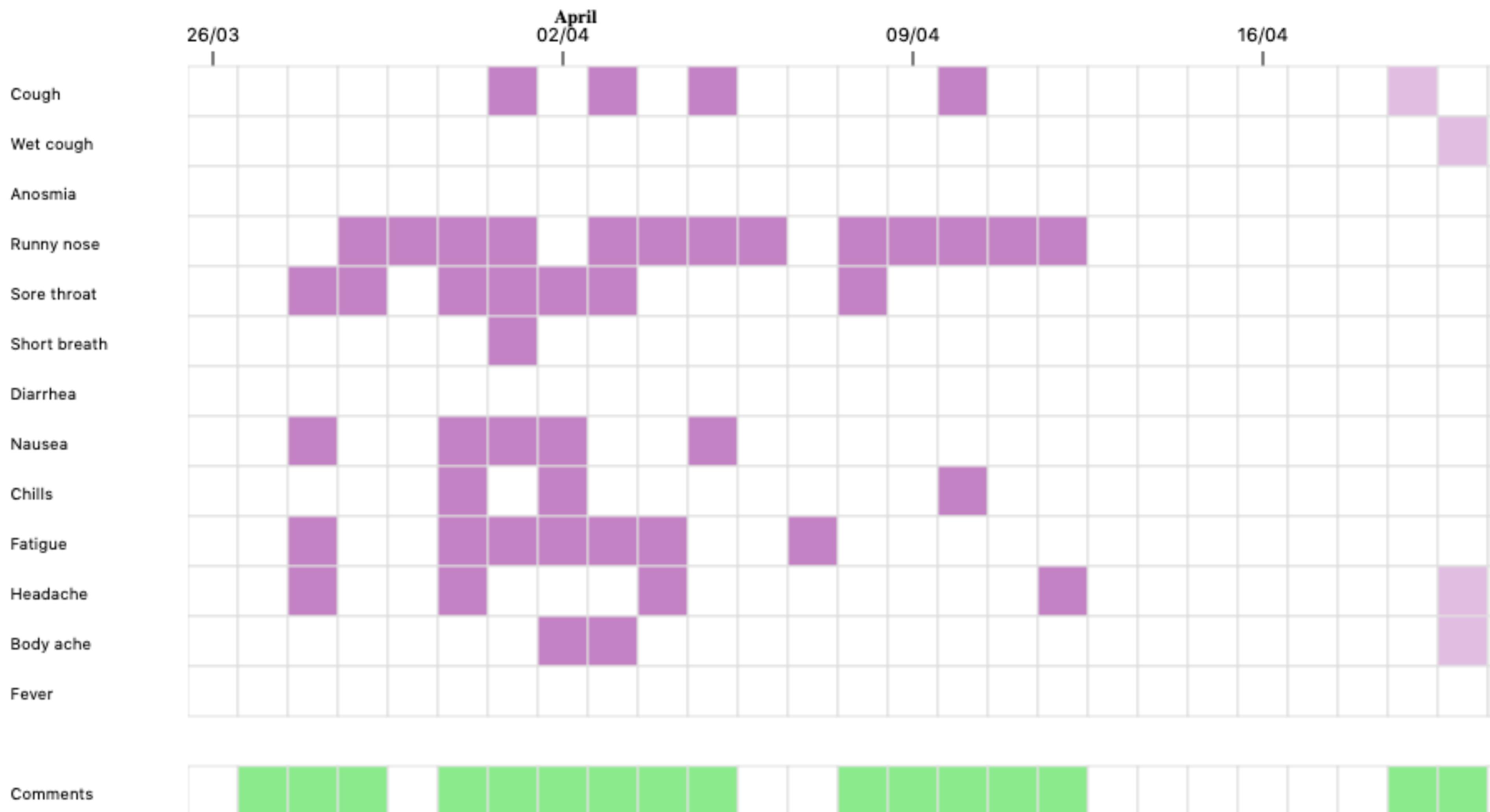
Report past illness

Report when you got sick and share your wearable device data. **We'll plot your data for you!** Currently we support *Fitbit* & *Oura Ring* wearables. [Ask us to add support for your wearable](#), if yours is missing so far.

Heatmap of Symptom reports

Study on 75 days - start the 26/03

Last update - 08/06



Legend

- No report
- No symptom
- Low symptom
- Middle symptom
- Strong symptom
- Unbearable symptom