

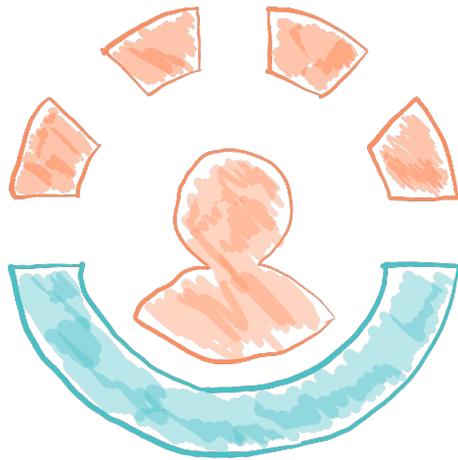
Open Humans

Data Stewardship: From the bottom-up

Mad Price Ball
Open Humans Foundation, Executive Director
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23 June 2021
HDR UK Scientific Conference: Data Insights in a Pandemic

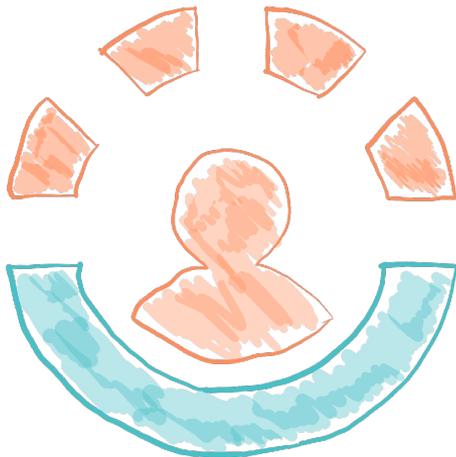
What is Open Humans?



OPEN HUMANS

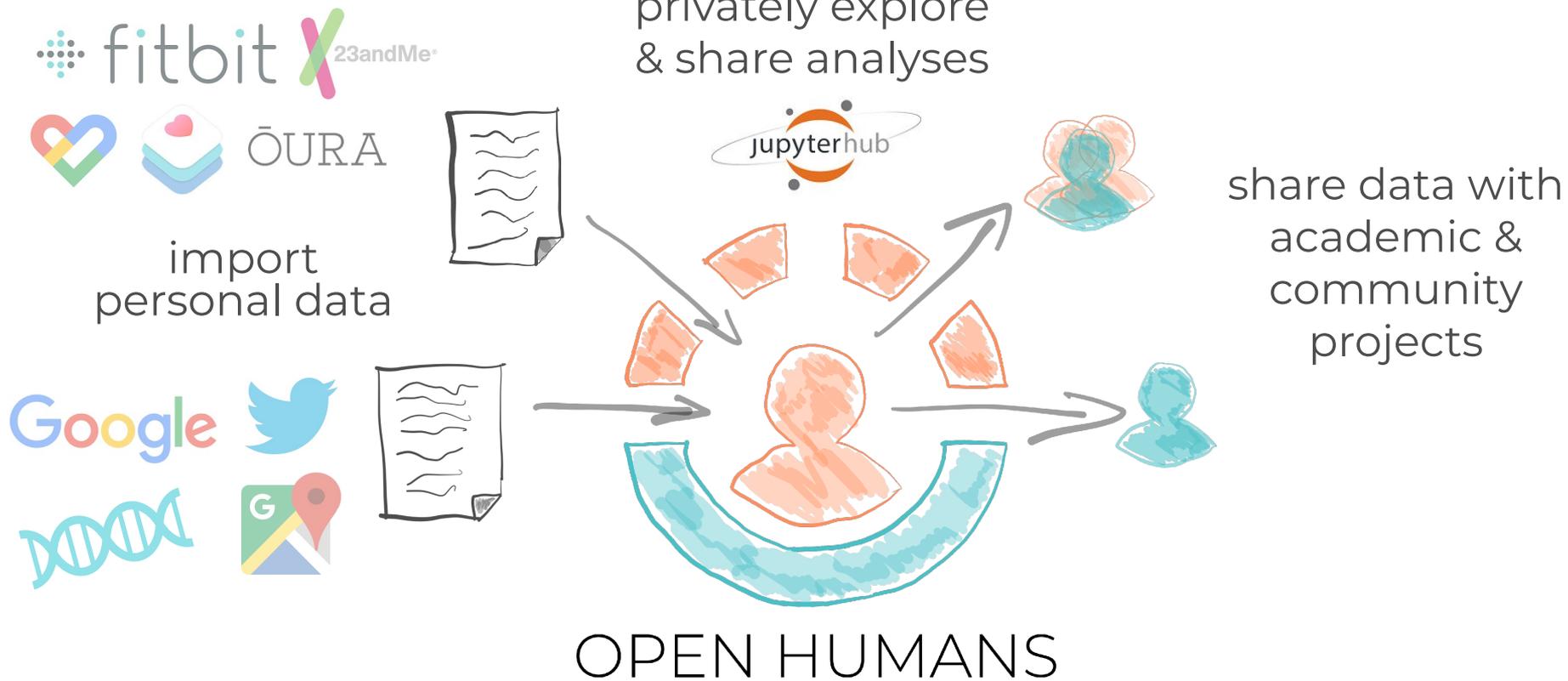
Open Humans: Platform & Community

As a **platform**, Open Humans is technology for individual-centered data.



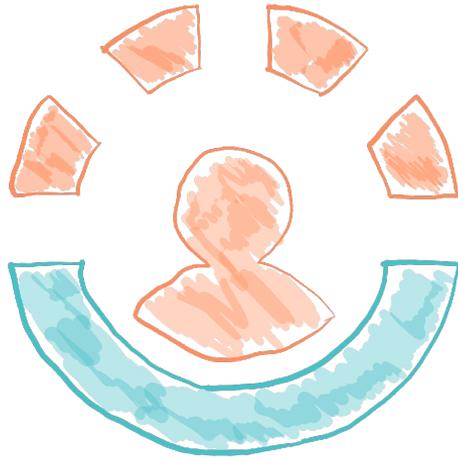
OPEN HUMANS

Open Humans: Platform & Community



Open Humans: Platform & Community

As a **community**, Open Humans is people that interact, work on projects, and share ideas.



OPEN HUMANS

Open Humans: Platform & Community

Community discussion about...

- self research, e.g. personal health
- citizen science projects
- tech development & ideas

Online chat



- openhumans.slack.com
- Anyone can join via:
slackin.openhumans.org

Online forum

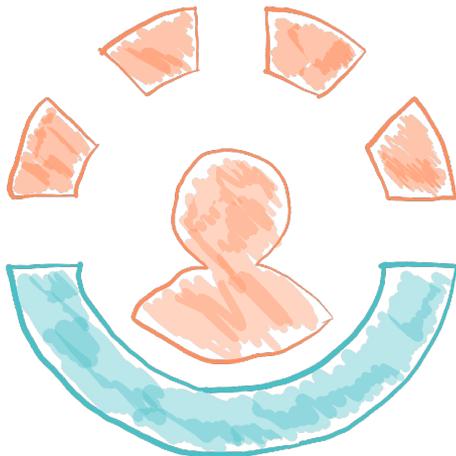


- forums.openhumans.org

Videochats

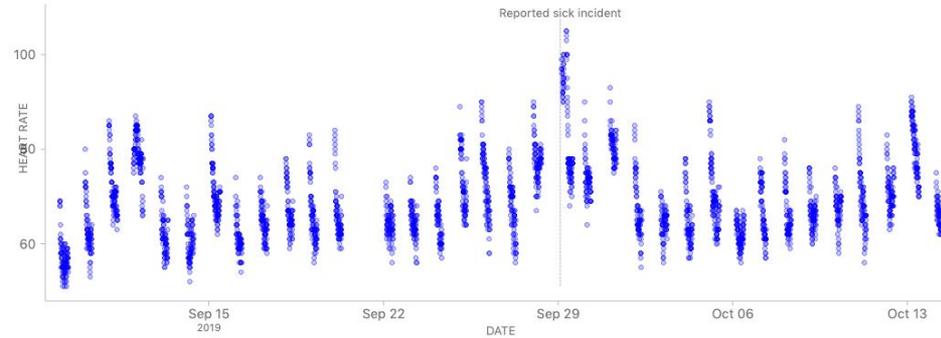


- Self research chat (weekly)
- Community call (monthly)
- Tech meetup (biweekly)



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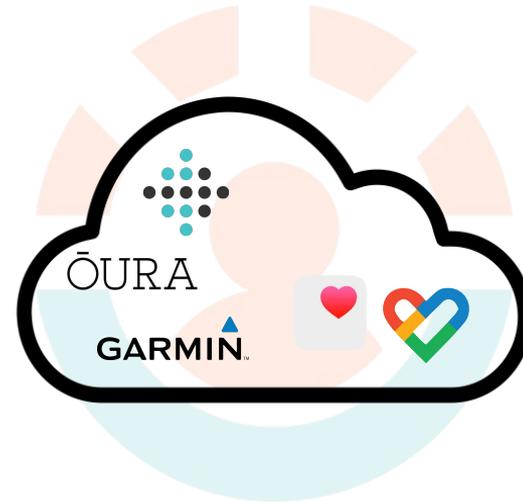
How these combined during the Covid-19 pandemic.



Quantified Flu

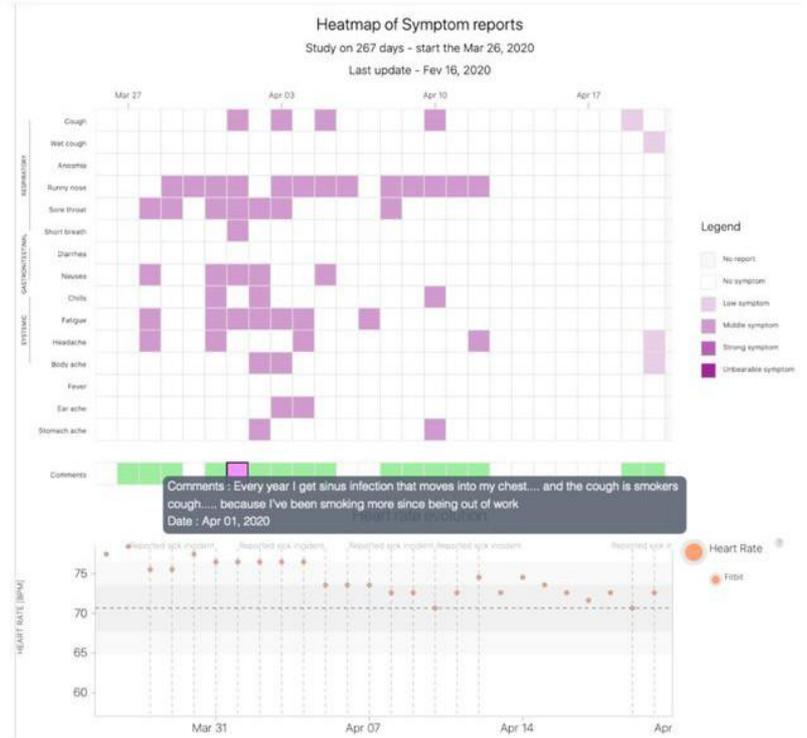
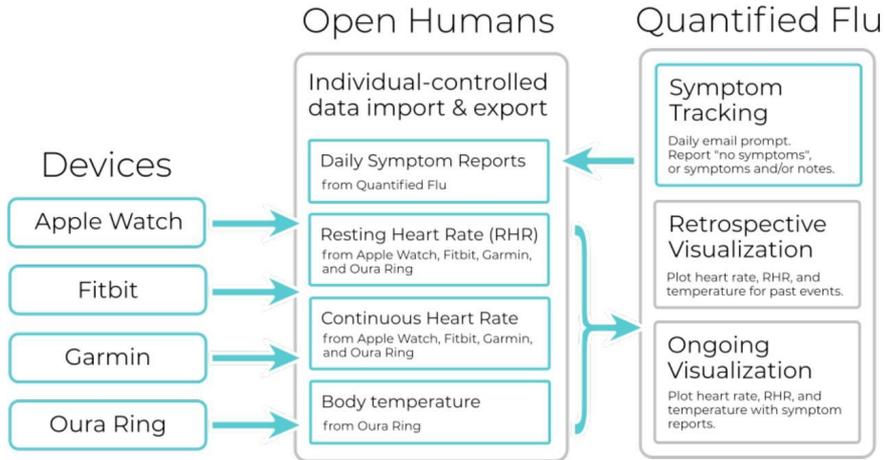
Quantified Flu: self-tracking & co-creation

Quantified Flu began in community discussion, in April 2020...



The question: Can my wearable help predict if I am getting sick?

Quantified Flu: self-tracking & co-creation



Device data + Symptom tracking → Visualization + Data sharing

Quantified Flu: self-tracking & co-creation

What was remarkable about it?

- **high skill contributions** from various people
 - (e.g. interactive visualization, Apple Health & Garmin data)
- **utility and learning** for individuals contributing & collecting data
- high rate of **sustained use**

Pre-print about the project & co-creation process:

<https://www.medrxiv.org/content/10.1101/2021.03.10.21252242v2>

What is the value of
"small data"?

Small data matters: for health

- For **individuals**:
 - Managing health, e.g. chronic complex conditions
 - Learning the potential of data
- For **communities**:
 - Creating & sharing solutions
 - Pooling effort & data to explore what matters to them

Some communities using
& pooling their data:

#OpenAPS



NIGHTSCOUT
#WeAreNotWaiting

Diabetes (esp. CGM data)



Cluster headache
(symptom & trigger tracking)

Small data matters: for democracy

Big data is powerful – but it needs **democratic legitimacy**.

When stories & tools are shared, others gain...

- A **sense of power**, even for those that will not exercise it.
- **Awareness** of our own potential data.
- **Interest** in what our data might do.

We become: **empowered, informed, and engaged**.

Link & Acknowledgements

Open Humans: <https://www.openhumans.org>

Particular thanks to people I've worked with closely in the last year:

- **Bastian Greshake Tzovaras**
 - Co-leads Open Humans & leads lab at the CRI in Paris
 - At CRI: Enric Senabre, Katharina Kloppenborg, Clara Lehenaff
- **Gary Wolf**
 - Open Humans board member & Quantified Self co-founder