



Open Humans

Sharing & Receiving Data

Nonprofit & facilitating research

Members connect data...



...and share it in a variety of ways.

Data is private by default.

Participant-oriented: sharing is always **opt-in**.

Two ways to share...

- **Public sharing**
Opt to make some of your personal data part of a public resource.
- **Direct sharing**
Share data directly with studies, projects, and other members.

Public sharing

Enrolling in our study activates **option to publicly share**.

You choose which data to make public.

RunKeeper
(GPS activity data)



14% public

23andMe
(genetic data)



47% public

American Gut
(microbiome data)



72% public

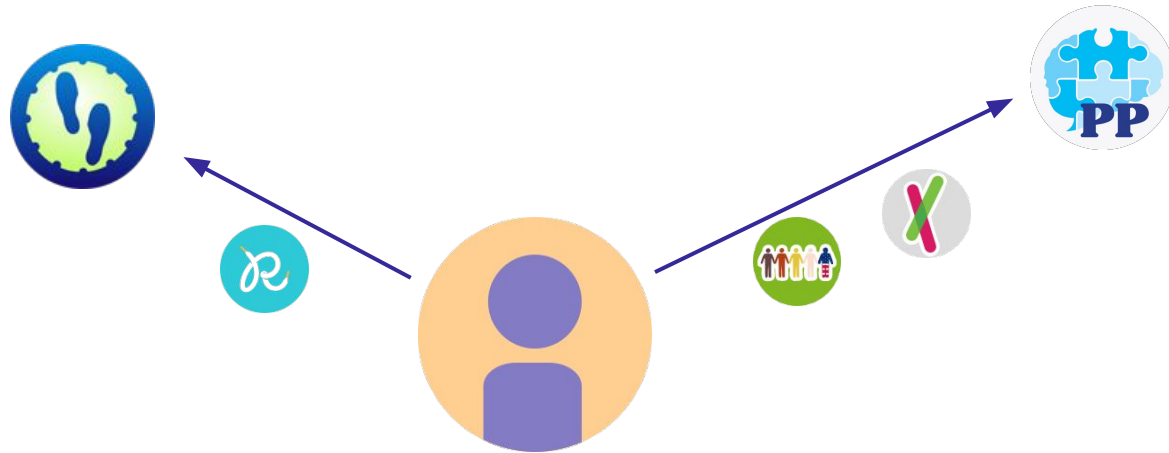
Getting Public Data



- What's public data good for?
 - Reference data
 - Project planning
 - Prototype analysis methods
 - Explore data options!
- Data is public on profiles – and on our **public data API**.
- "Can I get all public RunKeeper datasets?"
 - <https://www.openhumans.org/api/public-data/?source=runkeeper>

Direct sharing

Members can authorize **direct data access** for studies and other projects.




Projects on Open Humans

Access to data through direct sharing by members.

- Members can join a project and **authorize data access**.
- A community with **existing data**
- **Listed on the site** and featured in our communications.

Members can share data with these studies and projects. ([Learn about creating projects.](#))




Public Data Sharing
Madeleine Ball
PersonalGenomes.org
431 connected

Make your data a public resource! If you join our study, you'll be able to turn public sharing on (and off) for individual data sources on your research data page.

[Study](#)
[Academic/ Non-profit](#)
[Share data](#)

[Join project](#)




Keeping Pace
Dr. Rumi Chunara
New York University
69 connected

Keeping Pace seeks to study RunKeeper data, to understand of how seasons and local environment influence our exercise patterns.

[Share data](#)
[Academic/ Non-profit](#)
[Study](#)

[Join project](#)




The Preference Project
Christian Zuend
Department of Economics,
University of Zurich
25 connected


This study investigates the influence of the microbiome on the development of human social preferences and behavior.

[Share data](#)
[Academic/ Non-profit](#)
[Study](#)

[Join project](#)



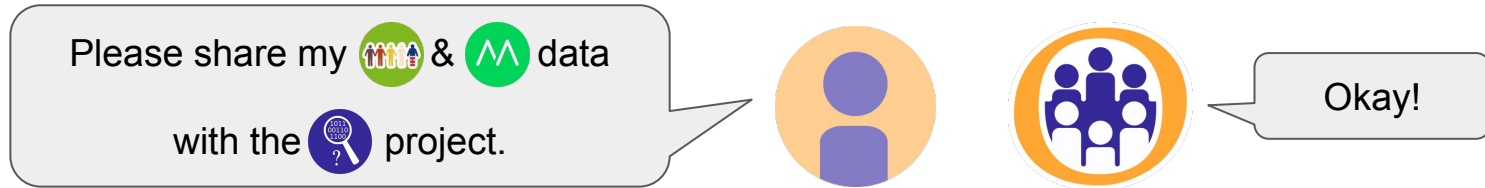
Cross-Genome Error



Circles
Cliff Tabin and Abigail Wark

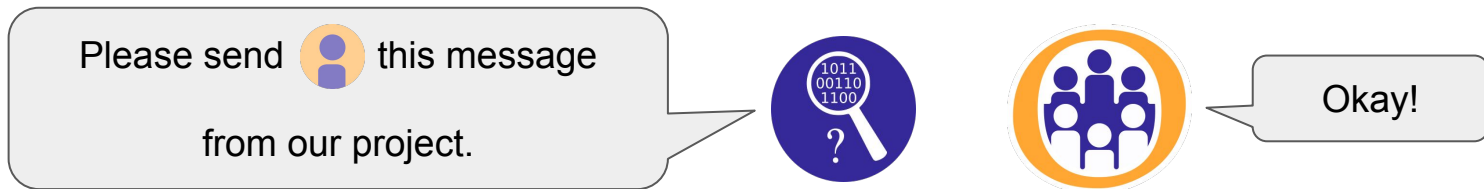
Anonymous access

- Ongoing, secure **data access via API**.
- **Anonymous access** via project member ID.



Participant access

- **Anonymous messages** via ID – ongoing study engagement!
 - Not just "data access" – it's member access!
- Members can be **sent to your study's URL**.
 - e.g. **a brief survey**
 - an **anonymous ID parameter** connects this to Open Humans data.



Works immediately

- **All features work immediately** and can be tested
 - On-site consent, URL forwarding, data access, and sending messages.
 - Facilitates rapid development!
 - Unapproved studies have a 10 user cap.
- Project approved?
 - Listed & **shared with members**.
 - IRB approval required for "study" projects.
 - **Members get a badge** for participating!

What's next?

- We've made it **fast** and **easy** to set up a study
 - We'd love to see your project on our site – prototype, explore data options!
- Closing the loop – projects that also share data with members
- Participant engagement is our new frontier...
 - Non-study projects: citizen-driven **data exploration**.
 - **Provide follow-up** – what happened with the research?
 - Go to where people are? Mobile engagement, social networks.
 - Work with researchers to **improve participant experiences**.
- Thursday: Data Dive! Take the plunge and explore real data.