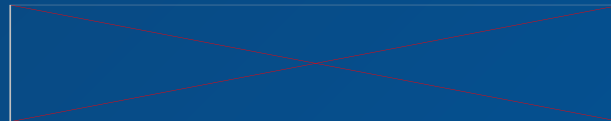
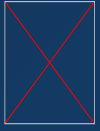


Citizen science-based data altruism practices to rethink health services and personalization

Anna Berti Suman



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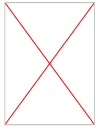
1 A recap of key concepts

What does personalization mean?

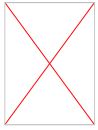
What is health citizen science?

What is data altruism?





Personalization (from below): a move from “personalized medicine” (focus on medical treatments tailored to individual needs and based on digitalized data pertaining to the individual – see [Juengst et al., 2012](#); [Maughan, 2017](#); [Prainsack, 2017](#); [Prainsack, 2018](#)) **to** more grassroots-driven approaches of health-related interventions focused on the **diversity of the individuals and communities**, including through citizen science ([Vayena et al., 2015](#)) and experimental health data governance ([Blasimme et al., 2018](#)) □
personalizing health services to the needs of unrepresented and neglected groups.



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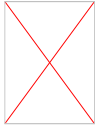
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Reimagining health services provision for neglected groups: The “personalization from below” phenomenon

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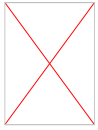


Health citizen science:

Citizen Science descriptive characteristics

AIMS	1. Investigation: aimed at answering scientific questions 2. Education: aimed at educational goals 3. Collective goods: public health, management of infectious diseases, protect and manage natural resources. 4. Action: citizens and scientists collaborate to address local concerns
APPROACHES	A. Extreme citizen science. Citizens in charge from problem definition, data collection and analysis, to interpretation and knowledge development B. Participatory science: Participation of citizens in problem definition and data collection C. Distributed intelligence a. Citizens as basic interpreters b. Volunteered thinking D. Crowd sourcing a. Citizens as sensors b. Volunteered computing
SIZE	i. Local ii. Mass

Den Broeder L, Devilee J, Van Oers H, Schuit AJ, Wagemakers A. Citizen Science for public health. Health Promot Int. 2018 Jun 1;33(3):505-514. doi: 10.1093/heapro/daw086.



Citizen Science for Mental Health

We want to identify the ways individuals manage their mental health challenges, by generating a list of self-management strategies that can enable better support in the future.

WE NEED YOUR HELP TO ANSWER
"How do people manage their mental health challenges?"

WHAT YOU WILL DO
Choose from a list, methods you use to manage your mental health.

TO PARTICIPATE YOU MUST BE

- 18 years or older
- Resident in the United Kingdom

SCAN FOR MORE DETAILS

SUBSCRIBE TO OUR MAILING LIST

The project has been funded by UK Research and Innovation (UKRI).



Figure 1. Principles of data cooperatives.

Over

6000
women participated in Isala

We found

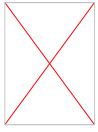
10 types
based on the most important bacteria

Determination of factors influencing the vaginal microbiome

Let's go international with sisterhood projects

ALMA Smart Underwear is the first non-invasive tool for monitoring vaginal health. It measures pH and other biomarkers in vaginal fluid and interacts with user via an app. This tool enables body awareness, prevention and monitoring of vaginal conditions such as infections and STIs.

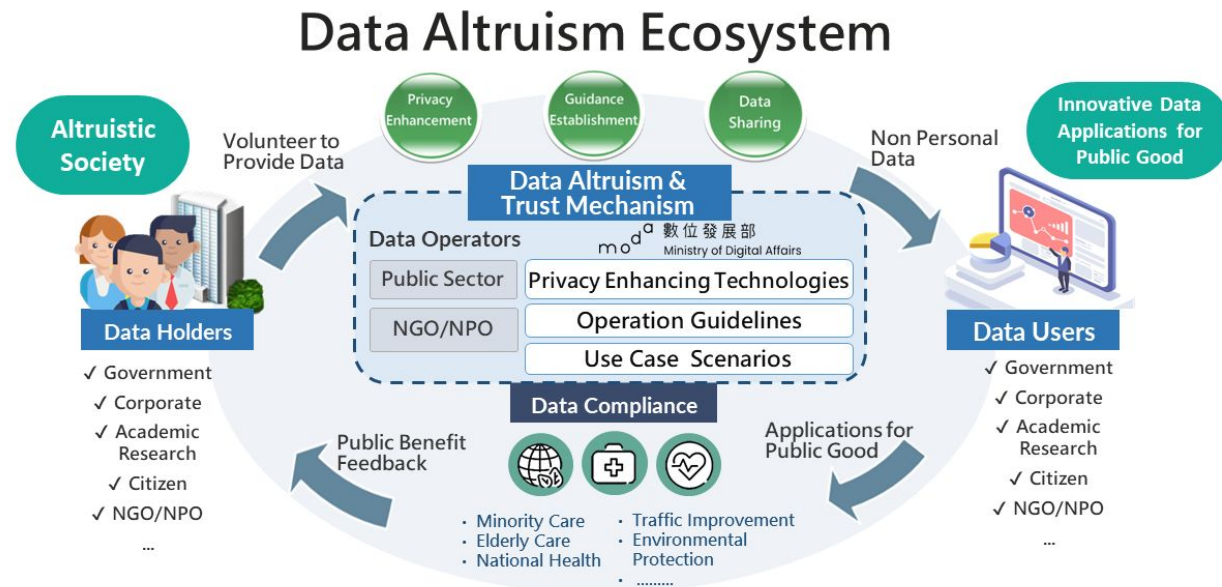
Learn more about the **Transbiome** study

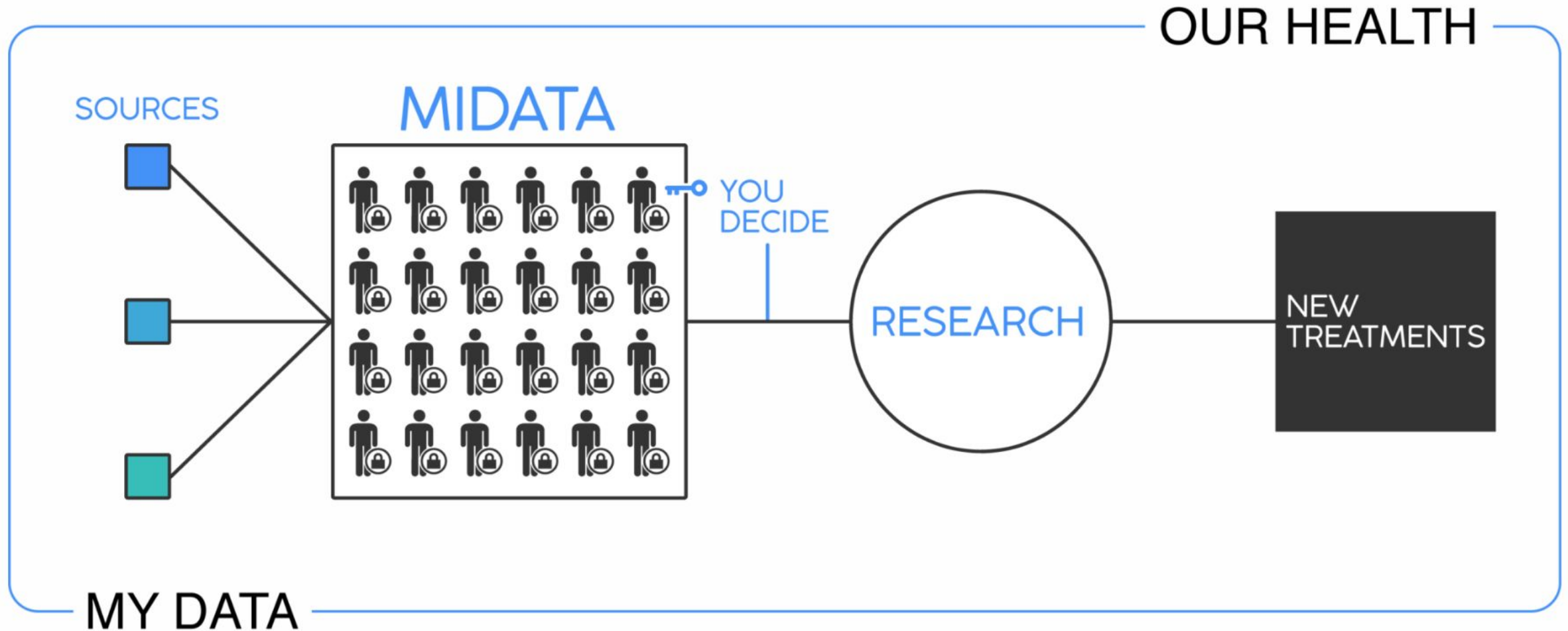
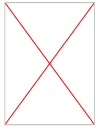


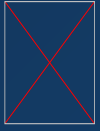
Data altruism is understood as the situation in which some people decide to **voluntarily donate their personal data for a common goal such as improving health services.**

Health services include:

- those organized by the government or any other institutional body to the benefit of a particular society or community,
- and those that are “auto-organized” from below, by grassroots actors that complement or substitute “official” service provisions.



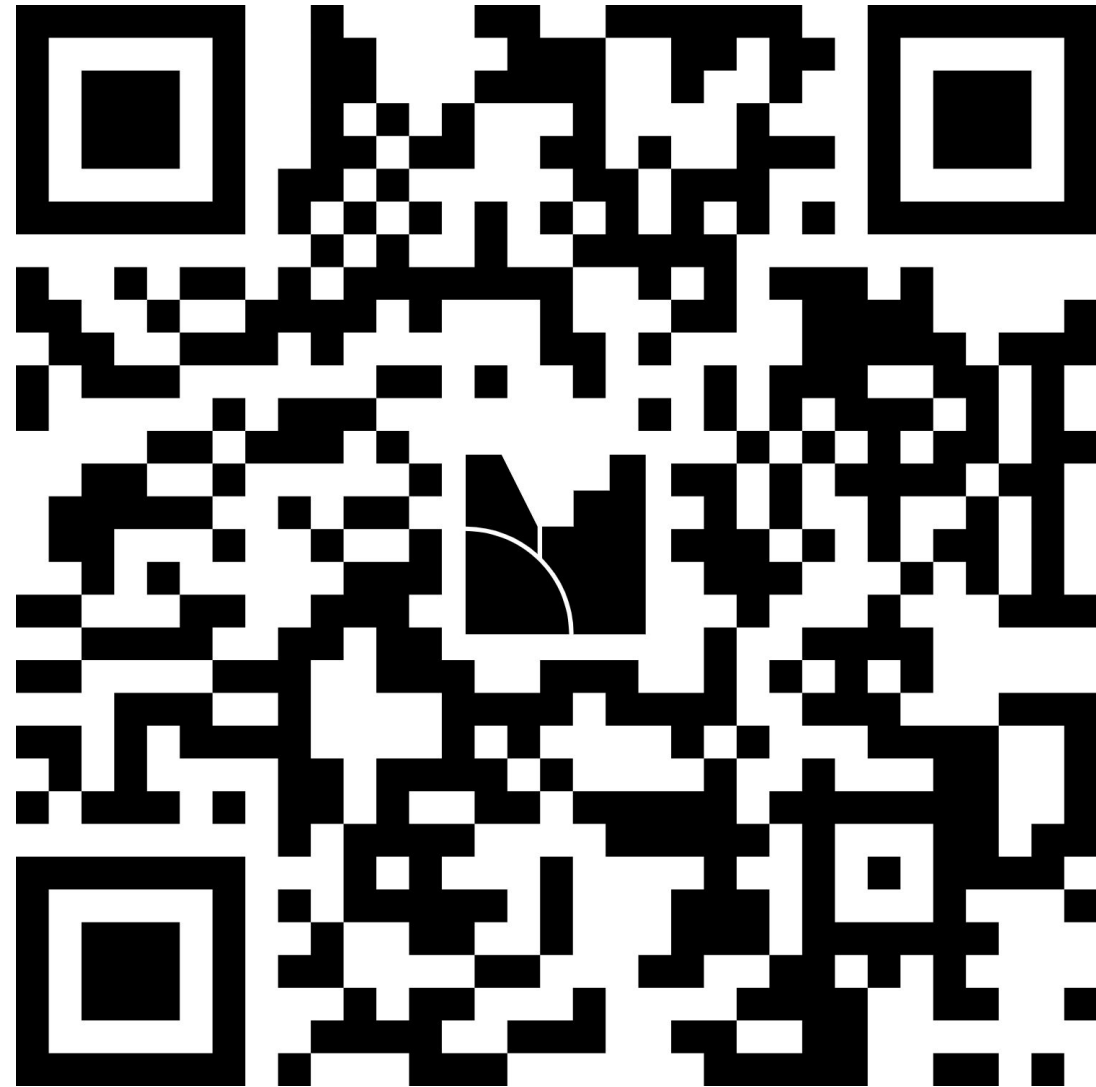
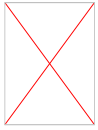




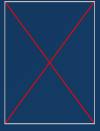
2 Enriching these notions

What does all this mean to you?





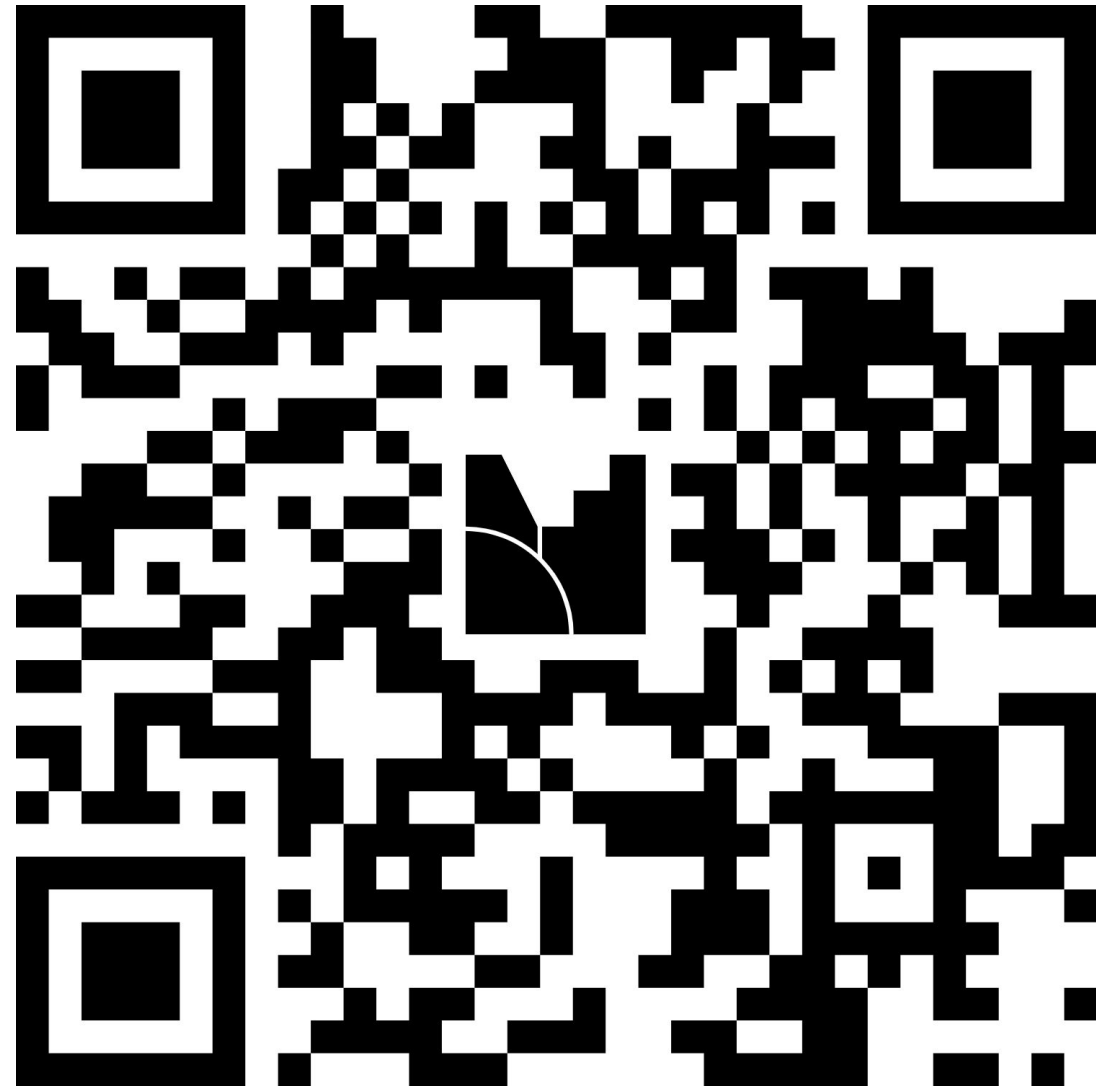
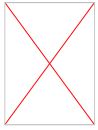
We go to Mentimeter <https://www.menti.com/al6vv3jgopn1> (part I)



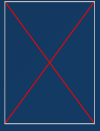
3 Hands-on part

Co-designing practical pathways toward improved personalization and citizen-driven health services





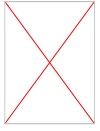
We go to Mentimeter <https://www.menti.com/al6vv3jgopn1> (part II)



4 Some final reflections

Discussing our results and future
avenues





Thank you for your attention.
Questions?

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