

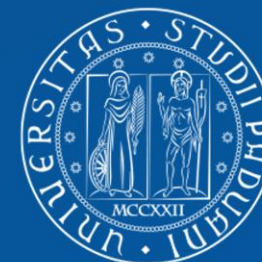


The “personalization from below” paradigm: citizen science-based data altruism practices to rethink health services and personalization

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1 Understanding the concept

What does personalization entails? And doing it from below?





Shifting 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 a **reconfiguration of this notion of personalization towards more grassroots-driven approaches** of health-related citizen science activities ([Vayena et al., 2015](#)) and health data governance ([Blasimme et al., 2018](#)).



Beyond an individual-centered view of a person's wellbeing, including **more collective and altruistic understandings of health services + overcoming the expert/practitioner-layperson divide** based on a rather “paternalistic” approach to the person that needs such services ([Chiapperino and Tengland, 2015](#); [Prainsack, 2017](#)) → **“data altruism”** aimed at personalizing health services to the needs of unrepresented and neglected groups.





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

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2 Making the concept evolve

What is data altruism about?





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.

Could grassroots-driven data altruism strategies **make health services provision more inclusive of people’s values and experiences**, bringing in a form of “personalization from below”?

Berti Suman A, Heyen NB and Micheli M (2023) Reimagining health services provision for neglected groups: The “personalization from below” phenomenon. *Front. Sociol.* 8:1052215. doi: 10.3389/fsoc.2023.1052215



The final text of the Data Governance Act (DGA)

Article 17, Public registers of recognised data altruism organisations

1. Each competent authority for the registration of data altruism organisations shall keep and regularly update a public national register of recognised data altruism organisations.
2. The Commission shall maintain a public Union register of recognised data altruism organisations for information purposes. Provided that an entity is registered in the public national register of recognised data altruism organisations in accordance with Article 18, it may use the label 'data altruism organisation recognised in the Union' in its written and spoken communication, as well as a common logo.

 <https://digital-strategy.ec.europa.eu/en/policies/data-governance-act>



Top-Down Altruism: The EU Data Governance Act

Speaker(s): Barbara Prainsack,
Katharina Ó Cathaoir

Associated with: Centre for Health, Law and
Emerging Technologies

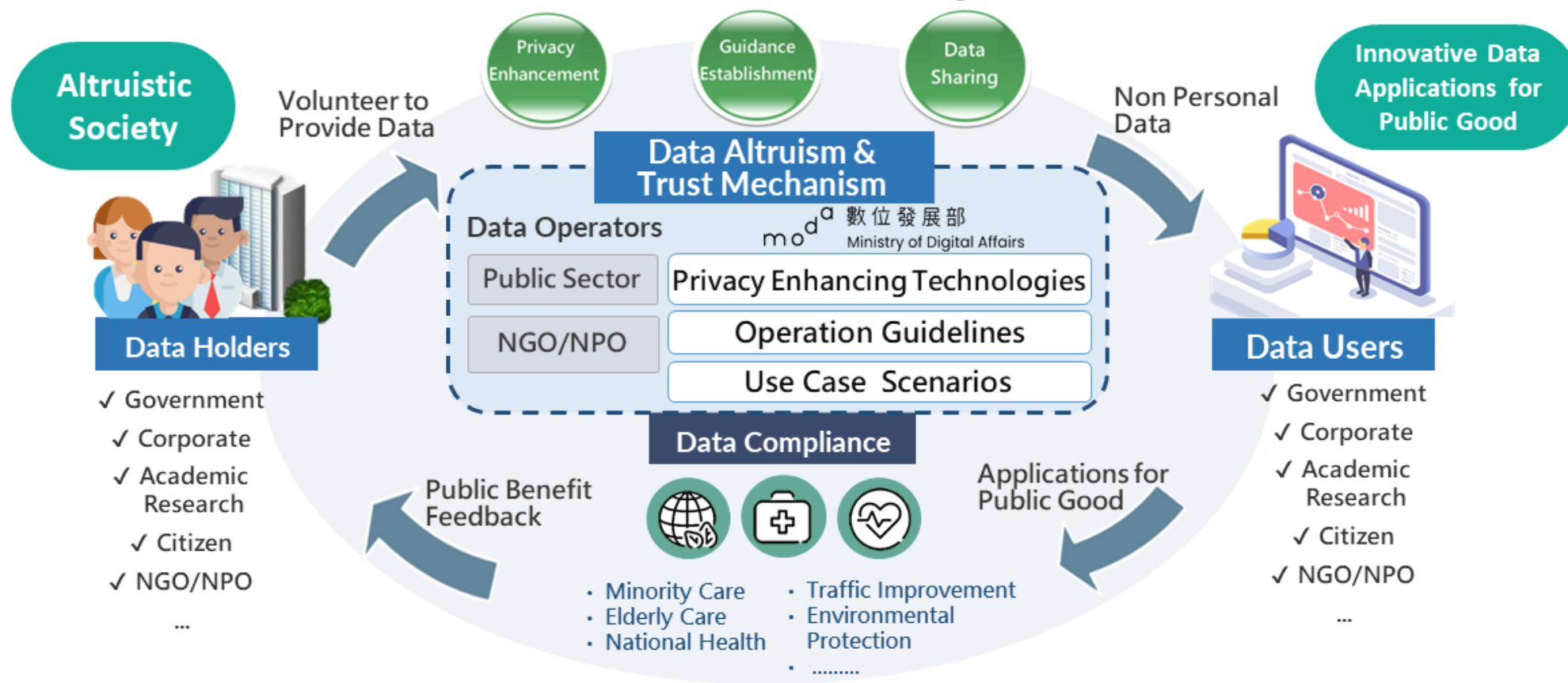
Top-Down Altruism: The EU Data Governance Act

The concept of 'data altruism' will find a statutory footing in the European Union from September 2023, when the EU's Data Governance Act comes into force. Among the provisions within this heterogeneous Regulation lie the bones of new data altruism infrastructure, including registered data altruism organisations.

<https://www.law.ox.ac.uk/content/event/top-down-altruism-eu-data-governance-act>



Data Altruism Ecosystem





3 Current frontiers

What is health citizen science?

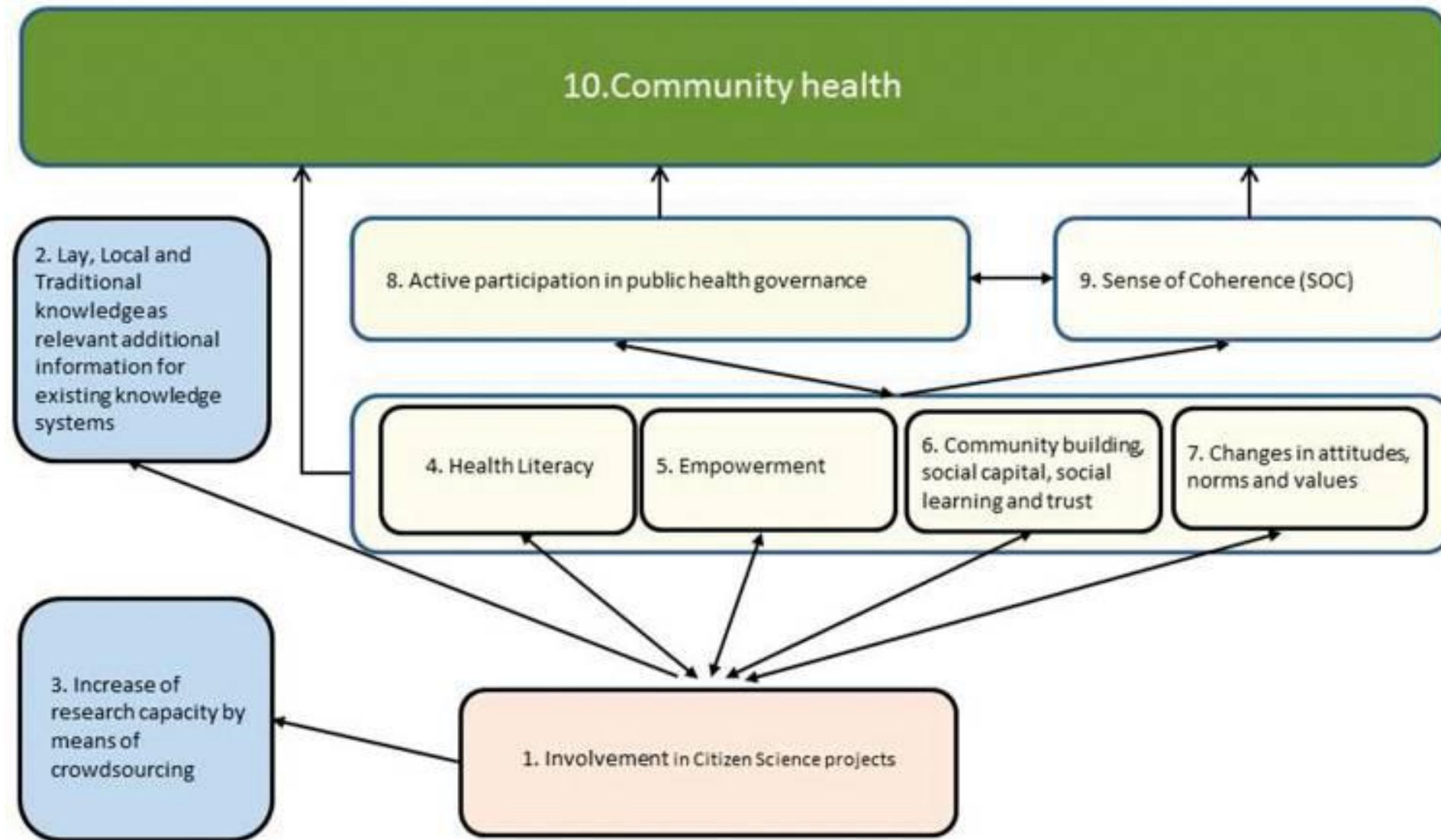




Citizen Science descriptive characteristics

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.



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.



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(Not Just) Another Manifesto: Postdigital Feminist (Citizen) Science in Patriarchy–Capitalist Ruins

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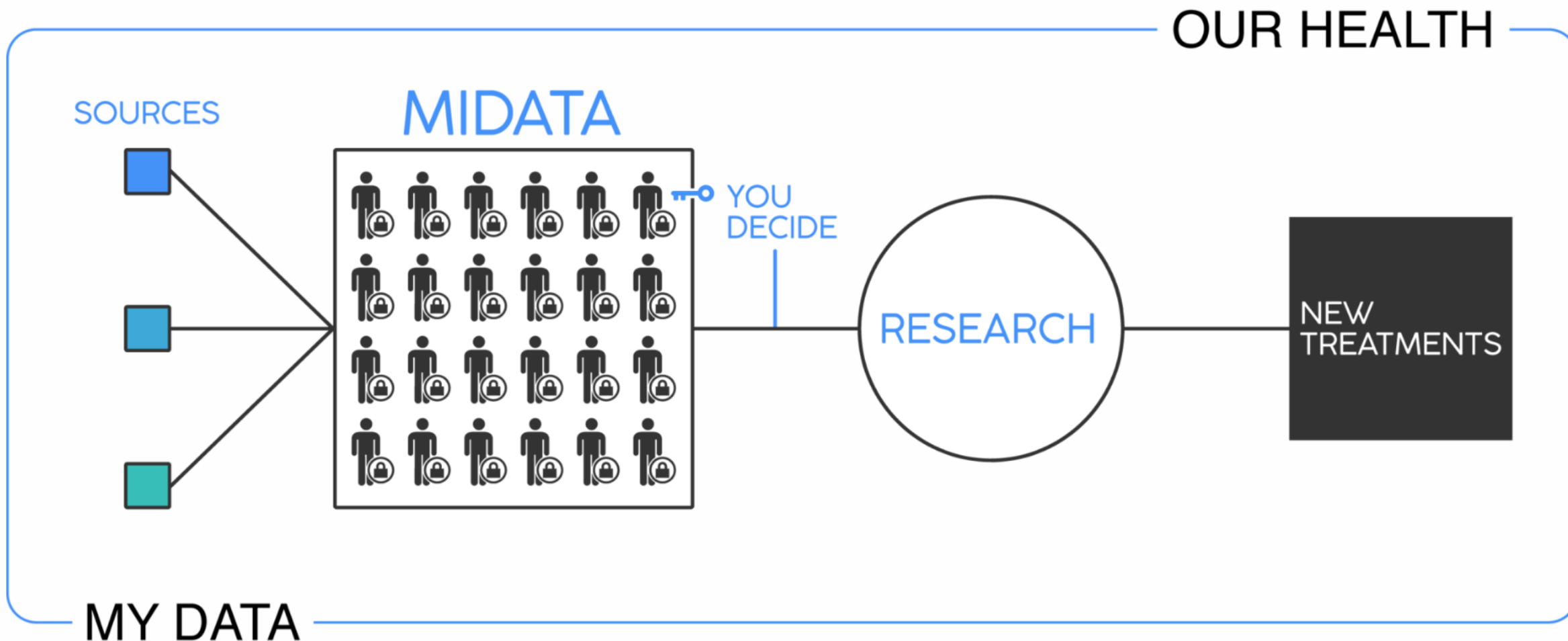
[Postdigital Science and Education](#)



4 Looking at real cases

What is health citizen science?







 **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.

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

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

TO PARTICIPATE YOU MUST BE

- 18 years or older
- Resident in the United Kingdom

SCAN FOR MORE DETAILS



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



SALUS.COOP

Elements of a Data Cooperative



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



5 Sketching conclusions

Discussing key results and future avenues





- Small-scale initiatives shape the debate on health data governance and **shed light on under-represented health concerns or disparities** that are not prioritized by policy or market agendas.
- They push for **regarding data as a common resource** for the benefits of civil society at large
- In a near future people might increasingly **shift from demanding data and services from “official” channels to openly providing data and even services** that can be of value for institutions and other citizens.
- Institutions in charge of services provision should look at these practices as possible **models of alternative public health interventions** and design appropriate “policy uptake” strategies ([Berti Suman, 2021](#)).
- **Institutional support** to these initiatives would entail a twin transition, pairing socially just interventions with data-driven innovation, and shaping both according to civic values.
- These practices will need **regulation, validation and standardization** to avoid abuses and misinformation masked under the vests of “good data.”



Thank you for your attention. Questions?

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