



Inclusive  
Science and  
European  
Democracies

# DATA PRACTICES IN DATA COOPERATIVES, OBSERVATORIES AND ARCHIVES

Niccolò Tempini and Michael O'Grady

## GOALS AND METHODS

We were concerned with empirically understanding the state of the art in public involvement in data management and re-use. This entailed:

- ▶ A qualitative case study of governance and data practices in health data cooperatives (HDC);
- ▶ A survey of citizen scientists about data practices; and
- ▶ An usability test of open data archives.

## MILESTONES

- ▶ We drew from infrastructures and data practices debates to study governance, scalability, representation;
- ▶ We studied of Citizen Scientists and the Public's understanding, experiences, and perceptions of citizen science across Europe;
- ▶ We estimated the usability of open data repositories, as perceived by the European public.



The vision of a civic data archive (Gen AI)

## OUTPUTS

This work generated several outputs:

- ▶ *A Report on the role and responsibilities of managers of data cooperatives, citizen observatories, and open data archives;*
- ▶ *A City Leaders Guidebook* and;
- ▶ *Recommendations for Citizen Democratic Participation in Science.*

We also shared this work in academic forums:

- ▶ Roszczyńska-Kurasińska, M., Domaradzka, A., O'Grady, M., Bedessem, B., Tempini, N., Trochymiak, M., Wróblewska, N., 2023. Beyond Data: Recognizing the Democratic Potential of Citizen Science. *IEEE Technology and Society Magazine* 42, 47-56. <https://doi.org/10.1109/MTS.2023.3344904>
- ▶ O'Grady, M., Mangina, E. Citizen scientists – practices, observations, and experience. *Humanit Soc Sci Commun* 11, 469 (2024).
- ▶ Tempini, N., Doughty, T., forthcoming. Still Unproven: When are data cooperatives going to come of age?. *Manuscript under review for international journal.* <https://doi.org/10.1057/s41599-024-02966-x>

## OUTCOMES

- ▶ After more than ten years since the appearance of the first health data cooperatives (HDC), it is unclear how mature the field is. We could find no empirical literature documenting the key day-to-day challenges and best practices. Our finding is that unfortunately, the data cooperative space is still unable to prove its worth. We confirm the existence of specific data governance challenges to the day-to-day running of data cooperatives, compounded by funding instability. We also observed the lack of specific strategies to prepare and mitigate for them. Until these issues are explicitly tackled with, the sector might not mature into a tested data governance alternative.
- ▶ Practices, experiences, and perspectives of citizen science vary across the European citizen science community. While a good understanding of open research and open data is manifested, more training is needed for volunteers. Knowledge of citizen science amongst the European public is poor, and more effort should be expended to remedy this.
- ▶ Open data repositories continue to proliferate. Awareness of such repositories across Europe varies, and more effort is needed to demonstrate their potential to the public. Though initially designed by professionals for professionals, their usability is good, but more effort is required to cater for a non-traditional end-user base.



This project has received funding from the European Union's Horizon 2020 research and innovation program under Grant Agreement No. 960366