



Inclusive  
Science and  
European  
Democracies

Policy Brief Series  
Promoting Deliberative Participation in Europe

**SUPPORTING HEALTH  
DATA COOPERATIVES IN EUROPE**

January 2024



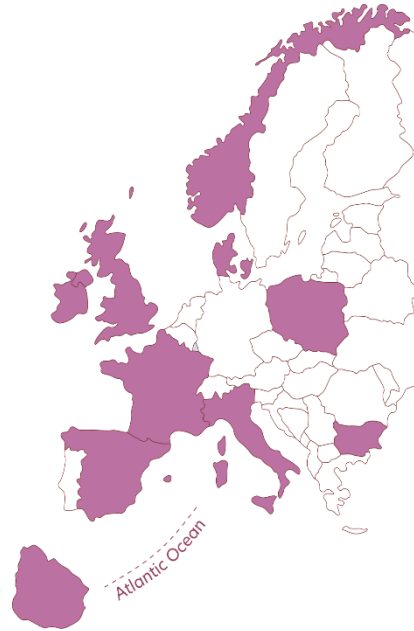
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## Innovation Targets

- Taking **Citizen Science** initiatives, in all their diversity, as a **Methodological Toolbox** to improve participation and deliberation in Democracy.
- Taking the **role of science-based knowledge** in public policy and democratic decision-making – central to knowledge societies – to improve **Participatory and Deliberative Processes** and to complement **Representative Democracy**.

## Consortium

<b>UNIVE</b>	Ca'Foscari University of Venice – Lead Partner	Italy
<b>UNIFI</b>	University of Pisa	Italy
<b>UNIPA</b>	University of Palermo	Italy
<b>UNITN</b>	University of Trento	Italy
<b>Observa</b>	Science and Society	Italy
<b>MNHM</b>	Museum National d'Histoire Naturelle Paris	France
<b>ENS</b>	L'École Normale Supérieure	France
<b>UNIWAR</b>	University of Warsaw	Poland
<b>NTNU</b>	Norwegian University of Science and Technology	Norway
<b>IRMiR</b>	Institute of Urban and Regional Development of Warsaw	Poland
<b>DBT</b>	Danish Board of Technology	Denmark
<b>UCD</b>	University College Dublin	Ireland
<b>UPF</b>	Pompeu Fabra University	Spain
<b>ARC</b>	ARC Research Fund Sofia	Bulgaria
<b>MEC</b>	Ministry of Education of Uruguay	Uruguay
<b>UNEXE</b>	University of Exeter	United Kingdom



## Supporting Health Data Cooperatives in Europe

Health Data Cooperatives (HDCs) present an innovative approach to data management and utilization that could, in principle, significantly shift the status quo in health research.

HDCs operate on the fundamental principles of individual agency and autonomy over personal data, providing a model that empowers individuals and communities while potentially enhancing the quality and scope of health research. In a health data cooperative, a constituency comes together to collectively manage health data to produce new knowledge about health in alignment with the membership's priorities.

The key advantages of HDCs are many, ranging from fostering a culture of data awareness and responsibility, to enabling inclusion and the proactive participation of patients in health management. Some see in HDCs the potential to cultivate a sense of community and shared purpose among individuals, thus fostering a culture of data awareness and responsibility, which also supports connection and wellbeing.

## OUR POLICY RECOMMENDATIONS

1. **Ensuring** transparent 3rd party data sharing: it is crucial to maintain transparency with members regarding the potential secondary uses of their personal data, in alignment with existing legislation (GDPR) and principles for Responsible Research and Innovation.
2. **Prioritizing** the public good in research: data cooperatives should give precedence to research that serves the greater public good and aligns with the collective interests of its members.
3. **Enforcing** strong accountability and governance principles: implementing robust accountability and governance principles is essential for the effective operation of health data cooperatives. This includes the development of a strong human resource management function capable of steering projects towards a proficient use of the data. Accountable managers should strive to provide the deep and diverse scientific expertise needed to meet the data quality requirements of collective data management efforts.
4. **Promoting** bottom-up development: involving stakeholders and members from the early stages of cooperative formation and growth is a vital practice for health data cooperatives.
5. **Establishing** an ethics oversight function: Creating an elected ethics oversight committee stands as another crucial best practice in the governance of health data cooperatives.
6. **Providing** stable sources of long-term funding (for funders and public agencies): it is mission critical that data cooperatives are well funded. Constrained temporary funding can fatally undermine the growth and management of a cooperative, and potentially expose data and the membership to security risks, especially once the project folds.

## RESEARCH OVERVIEW

There were three main research questions that motivated this ISEED study:

- How can we empower citizens by involving them in citizen science initiatives such as collaborative data collection, analysis, and interpretation?
- What are the main challenges in successfully conducting such initiatives?
- What conditions must be met to ensure the success of citizen science initiatives? The study was conducted by Niccolò Tempini from the University of Exeter.

## METHODS

The fieldwork centered on qualitative data collection from two leading international data cooperatives, Salus.coop based in Barcelona, and Liverpool City Region's Civic Data Cooperative (LCR CDC). Data collection involved one-to-one interviews with informants, who were selectively chosen based on their familiarity and involvement with the cooperative. In total, data was gathered from a minimum of ten oral informants, each offering unique perspectives and insights. Interviews were recorded with informants from both participating cooperatives. Additionally, a literature review of 57 scientific articles on data cooperatives was conducted.

## RESULTS

We identified the following challenges in the operation of data cooperatives:

- The challenge of achieving economies of scale and establishing robust datasets, as data cooperatives manage to gather a limited amount of data, which might be difficult to reuse.
- Trust issues: Citizens tend to associate data innovations with exploitative practices. A lack of awareness and expertise in understanding complex data models can hinder trust and willingness to share data with the organization.
- A difficulty in recruiting qualified and experienced members: Data cooperatives demand a high level of expertise in data management, data science, cybersecurity, and a knowledge of international and local regulations. The methodological intricacies surrounding data re-use, and dataset bias and fitness for purpose is often underestimated. Traditionally, data cooperative management has been absorbed by the development of collective decision-making structures, neglecting to prioritise the creation and support of a strong culture around ensuring the data are high quality, and maintained and used well.
- Securing a stable source of funding, crucial for maintaining high standards of data storage and security.
- Implementing a clear management structure capable of effectively addressing management challenges, including conflicts between members and managers that may erode trust in a data cooperative. 6) Ethical considerations and conflicts of interest, particularly in deciding whether to use financial incentives and generate profits, as well as determining the ethical use of data.

## DISCUSSION

Early in research on data cooperatives, it becomes apparent that despite the concept trending for more than 10 years, it is difficult to point out to breakthrough projects that have achieved undeniable impact and proved the feasibility and long-term sustainability of the model. Empirical information in the literature is very scant. Many of the projects that are most promising and have the best momentum

in terms of resources and progress, such as Liverpool City Region's Civic Data Cooperative (LCR CDC), were founded only recently and have not reached a stage of maturity or completed flagship projects to prove the model.



Collective data governance models such as data cooperatives face high startup costs, and in order to give returns, they need to have appropriate and firm financial support. The *status quo* of small, uncertain, short-term funding is inadequate and leads to wasted opportunities. Scientific data governance is complicated even when centralized, always requiring multiple kinds of expertise, and it becomes more complicated in data cooperatives where there are many more decision-makers.

Data cooperatives need deep scientific expertise to be able to meet data quality requirements. And, in a climate of public diffidence towards long-term custodianship of individual data, data cooperatives need to make an extra effort in demonstrating trustworthiness, transparency, accountability and robust research ethics governance.

## RELEVANCE TO POLICY-MAKING

These results are of relevance to different stakeholders:

- **Members of parliament:** data cooperatives have potential to succeed and make a lasting mark on science-based policy making. But they need much deeper institutional support than what is currently given to them.
- **Business stakeholders:** there is clear potential to engage SMEs with data cooperatives as DCs can help SMEs address local needs and create niche market solutions addressing them.
- **Local municipalities:** local administrations have been fundamental in setting up a few of the most important examples of DCs and they can see in them a key way to renew local governance and inform local policy making. Clearly more local administrations could benefit from experimenting with data cooperatives.

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- ▶ **International organisations and cooperations:** economies of scope and scale in the development of socio-technical infrastructure required for running data cooperatives could be enabled through the leadership of international organisations, with the potential outcome of lowering costs.
  - ▶ **Research administrators:** data cooperatives have been of interest to debates of research administration and governance but there is a lack of empirical research in what works and what does not. Research institutions might be attracted to experiment with collective data governance, as a data cooperative-based model of research would enable.
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ISEED maps and explores how inclusive science can support European democracies.

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This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No 960366.