

The Role of Participation in Shaping a Civic Data Cooperative in Liverpool - Provocation Paper

Reema Patel

1. Background and context

In January 2020, Liverpool City Region's combined authority [announced new plans for a civic data cooperative](#) enabling the analysis of anonymised health and social care data, as well as supporting innovations in healthcare. These plans aimed to join up Liverpool's work in health and social care with its work in the digital and creative sector; seeking to benefit both society and the economy by aligning this work with public and societal expectations through innovative citizen participation and the principles of cooperativism. Since the plan and proposals were announced, major shifts have accelerated in the health and social care data landscape, largely due to the COVID19 pandemic, with the first lockdown in the UK implemented in March 2020. Of particular note has been the [liberalisation of the sharing of more confidential patient data across the NHS and partner organisations](#), authorised by the Secretary of State for Health. In Liverpool specifically, there is a strong and established track record of undertaking co-design and public engagement (see, for instance the Liverpool Citizen Jury), as well as of technical delivery (see, for instance, the CIPHA Code and Health Data Repository).

2. Scope and purpose of the paper:

This paper acts as a provocation to assist Liverpool City Region and its stakeholders think through design and execution of the original vision, but it is also intended to benefit a wider network of stakeholders interested in these questions of design beyond Liverpool City Region. As a consequence, we have published it in the spirit of encouraging iterative learning in a landscape where practice is still nascent and multiple stakeholders experience similar opportunities and challenges. This paper should not be read as a description of what the Liverpool Civic Data Cooperative's plans are but rather, as an open access document that sheds light on some of the issues, questions and considerations that are live for the team at present. It also focuses primarily on how best to embed participation and engagement, rather than the narrower question of technical cooperative design.¹

3. Lessons learned from the pandemic

Whilst many efforts to use data in the pandemic have been able to assist and aid healthcare workers and scientists in better understanding the spread of the virus, the pandemic has also highlighted low levels of public confidence and trust in the use of data, as well as wider anxieties about its misuse, exploitation and appropriation. Nowhere was this more apparent than in the societal and wider public reaction to the introduction of [GDPR](#); which prompted the NHS to

¹ Work has already been undertaken by the [Mozilla Foundation](#), [Bennett Institute](#), [the Open Data Institute](#) and the [Ada Lovelace Institute on what Ostrom influenced design principles might look like when it comes to data](#) access architectures and we are keen not to duplicate but rather, build from this existing work

pause and reconsider the rollout of a centralised approach to the use of GP data. Given the context we presently operate in, measures to use healthcare data well carry high risk and require a measured and thoughtful approach to civic engagement. The GDPR 'techlash' prompted reflection on how best to enable the trustworthy use of healthcare data - and informed by a joint stakeholder workshop, [Understanding Patient Data](#) recommended six ways to move on from the debate and help build confidence and trust in the effective use of healthcare data:

1. Make secure environments the default for data access
2. Improve meaningful transparency about access to data
3. Invest in communications and media to respond to people's concerns
4. Clearly explain people's choices
5. Put new public benefit guidance (led by the National Data Guardian's Office) into practice
6. Involve the public more in decisions about health data

As the learning from GDPR above (crystallised by [Understanding Patient Data](#)) indicates, implementing civic engagement at different levels will be central to securing trustworthy data models. In particular, Liverpool City Region will need to design the cooperative to ensure that the use of healthcare data is itself secure (1), but also incorporate in the design of its architecture measures that enable continuous, and increased involvement and transparency about data including its use and people's choices (2, 3, 4, 6). It will also need to demonstrate clearly how its use of health data engenders benefits for Liverpool as a region, including (but not limited to) its patients.

4. Reimagining the civic data cooperative - what could it be, and why?

There are a plurality of possible trustworthy data models, as set out in this Ada Lovelace Institute report on [Legal Mechanisms for Data Stewardship](#) (2021). That report defines a data cooperative as 'a legal mechanism that gives members more control over their own data'. This is a specific and narrow interpretation that may work for some data cooperatives (the use case given is [Salus Cooperative in Barcelona](#)). However, we wish to offer the provocation that this definition of the cooperative highlights only some specific technical aspects of cooperatives but omits some other key considerations about *what a civic data cooperative has the potential to be*. Indeed, what is likely to be most effective will need to adapt to the needs of stakeholders in a given context or landscape - as Delacroix & Lawrence suggest, if approaches to data governance are going to be truly effective then they need to '[disturb the one size fits all](#)' approach to data governance. Data cooperatives are no exception to the rule. What other principles and approaches could a civic data cooperative engender? In the spirit of inquiry here, we interrogate three terms and concepts at play in reimagining the civic data cooperative - (a) the civic, (b) the cooperative, and (c) the beneficiary.

- a) **Interrogating the term 'civic'** - The use of the term **civic** evokes connotations of a place and of a set of common goals and values around a specific place (in this

instance, Liverpool); but it also evokes the concept of citizenship (the idea that people affected by data have a critical and active agency when it comes to governing their data) rather than are 'done to' or somehow ['resigned to' passively accepting](#) what happens to data. It also alludes to data having value that is societal and collective, rather than simply individual or commercial - for instance, a Bennett Institute and Open Data Institute (Coyle, Tennison et al 2020) report on the [value of data conceives of it in social welfare terms](#), and finds that 'access to data is intrinsic to its value'. When [Sidewalks Lab proposed its unsuccessful and failed 'civic data trust' in Toronto](#), it was met with criticism precisely because the design of its proposed model largely remained [proprietary and ambiguous](#) (Goodman & Powles, 2019); and had not adequately engaged city residents and stakeholders in the vision or the model.

- b) **Interrogating the term 'cooperative'** - In dictionary definitions (Oxford Languages) the term 'cooperative' has two meanings - one as a noun and the other as an adjective. As a noun, it is defined similarly to the Ada Lovelace Institute definition (above):

Noun

*a farm, business, or other organization which is **owned and run jointly by its members**, who share the profits or benefits.*

"we run the agency as a workers' cooperative"

This is one legitimate (fixed and technical) definition and certainly has been the way many data cooperatives have interpreted their role - as focused inwardly on the advantages offered to their members. But the adjective based meaning offers us some scope for increased creativity, turning towards the concept and principle of mutuality and shared, common goals and endeavours with reciprocity at its basis:

adjective

*involving **mutual assistance** in working towards **a common goal**.*

"every member has clearly defined tasks in a cooperative enterprise"

That approach to cooperativism also has strong historic roots. For instance, the mutuality principle is understood by Guerini in relation to the Italian approach to social cooperatives, rooted in norms of social solidarity as ['expanding the concept of mutuality, offering services and benefits for people who were not necessarily associated with the cooperatives.'](#) Here, reciprocal benefits aren't just by members towards other members, but rather, by the cooperative towards wider society. In Italy, this approach and model has enjoyed considerable advantages and broader engagement and support: Guerini reports that these social cooperatives are successful in 'offering services to almost 7 million citizens and employ more than 350,000 permanent employees. Among these, there are

also 30,000 disadvantaged employees, thus making Italian social cooperatives the most successful enterprise model for job placement.’

[Open Data Manchester](#)’s learning from a practical intervention (designing an energy cooperative) also leads them to a broader definition encompassing not just data subjects but also institutional actors that might have access to data - relevant in the context of where data is often gathered, collected or sits (rarely just with the individual but rather in silos or pools across a range of organisations): *‘people or organisations agree to pool and share their data, [with] the potential to bring more value back to users’*. However, Open Data Manchester’s approach to defining ‘agreement’ is also interpreted narrowly, through the concept and model of ‘individual consent’. Individual consent as a lever for engagement is itself much critiqued as many people will give by way of default; and for shifting the burden of the work onto the ‘data subject’. Various actors have proposed the concept of [‘community consent’ as an alternative](#) in the field of data governance (see, for instance, Tennison, 2021) with institutions and actors taking on more of the work to understand, listen to and respond to people’s choices and incorporate those into the work of designing the data governance model or initiative - again returning to the ideal of a mutuality based relationship.²

c) Towards a broader definition of beneficiaries?

Whilst almost all cooperatives have members, it is entirely feasible that they can intend to benefit and engender beneficial outcomes for those who are not members. Indeed, a quick scan of existing case studies of data cooperatives that take a member-centric approach highlights how requiring membership of a cooperative excludes many of the potential benefits from data that engender more broadly and have wider societal value. In the health context this is particularly significant - for instance, patients or residents in the region of Liverpool should not have to be members to benefit. Furthermore, membership may imply a choice to play an active role in the governance of the initiative - which (in isolation) can engender equity and inclusion issues - many ‘data donation’ initiatives, for instance, encounter challenges with inadequate representation of minoritised groups who may (particularly in the health context) be disproportionately impacted by the model.

The definition of who the Civic Data Cooperative in Liverpool is intended to benefit, therefore, must surely be wider than just those who sign up to a membership role or function. In a recent Ada Lovelace Institute report on

² Later on in this paper (see Table 1), we set out a wide range of mechanisms that do not rely heavily on individual consent that together can help build a social licence to operate. The key is to ensure that these mechanisms are not ‘tokenistic’, but rather do shape and influence outcomes in the design, delivery and accountability of the data cooperative - Arnstein (1969) describes this scope to influence as the basis for meaningful engagement as opposed to tokenism or manipulation.

participatory data stewardship, Patel, Peppin et al propose the term 'beneficiary' instead to denote this wider set of legitimate and significant stakeholder and societal interests. Whilst 'data subjects', who have a direct relationship with the data in question as specified in the GDPR are included, the Institute has sought also to encompass those impacted by the use of data (e.g. workers, underrepresented and excluded groups) even if they are not themselves data subjects or self selecting members. The beneficiary is thus understood as a person who has the *potential* to benefit from the civic data cooperative - helping to move beyond a compliance-based approach to a model truly underpinned by social license.

As set out in that report, beneficiaries can include:

- The data subjects – the people to whom the data directly relates, for instance, when processing mental health data; patients or those with mental health conditions. They may or may not be a member.
- The wider public – for instance, those who might have an interest in how mental health data is governed or used ethically, as well as those who might have lived experience of an issue or disadvantage (such as mental health patients); but also more broadly, the residents of the city of Liverpool with a shared interest in improving their local area. Sortition is one method that may enable the sampling of the wider population of beneficiaries.
- Minoritised groups: people at risk of being oversurveilled, underrepresented or missing from the data itself, e.g. migrant populations, members of low income communities, people from racialised or otherwise minority groups such as people with mental health conditions, LGBTQI, disabled people and people experiencing intersectional and overlapping discrimination/oppressions
- Developers, designers, policymakers, charities and clinicians: stakeholders working in technology or related policy/charitable organisations, or workers of a global supply chain. e.g. those engaged in collecting and processing data, or who have an interest in data to secure their own collective workplace rights.

In defining beneficiaries it will be important to concentrate on these three questions in considering who should be involved (at various stages), rather than necessarily seeking to narrowly predefine the engagement or close it down to 'members':

1. Who is a stakeholder - who has a stake in the outcomes that emerge? Who might lose or be affected adversely by the change?
2. Who is most likely to be directly affected and impacted, either benefiting or being adversely impacted?
3. Who is most likely to be overrepresented and/or underrepresented in the data and by the data use?

In the context of health within the region of the city of Liverpool the 'civic' is place based but also sector specific - referring to patients, GPs and clinicians, and the wider public bodies engaged in delivering improved mental health outcomes. The 'cooperative' can be understood as benefiting not just the members, but a wider set of interests and stakeholders - beneficiaries. That list includes patients, those with lived experience of health conditions, clinicians, GPs and health professionals, the NHS, and a range of public bodies coordinated in delivering health services. It can be extended to involve a cross-section of the Liverpool population; as well as the organisations (technical and otherwise) tasked with the delivery of mental health support and services.

4. Institutionalising and embedding public engagement - principles and mechanisms

The Liverpool City Region Data Cooperative can therefore be understood as an opportunity to institutionalise the ethos of taking a civic, participatory, beneficiary-oriented and mutuality based approach to access, governance and use of mental health data. The data life cycle is the process that the Civic Data Cooperative will need to be a part of and as depicted on the right hand side offers various opportunities to involve people in the conceptualisation, execution and evaluation of the use of mental health data (source [Mosconi. Data Life Cycle Model](#)).

The involvement of the public can start with the planning and purpose definition stage - articulating what would be most beneficial, and clearly defining the purpose and parameters for data use and governance.

The first step, therefore, in order to elicit meaningful input would be for a range of **transparency-based approaches** (working options or models) to be surfaced relating to the civic data cooperative, and its intended approaches to mental health data use, for wider societal and public input (see 'Inform' in table 1 below). In **curating and/or collecting or synthesising data**, there is the need for engagement to understand appropriate parameters, but also the need to design mechanisms that enable individual and/or collective consent (see 'Consult' and 'Involve' in table 1 below). With regards to **processing, analysing, publishing, sharing data and re-using**, there are opportunities to involve people in articulating or helping to shape potential interventions that can be better informed by mental health data, as well as in enabling



people to make the best possible use of data (see 'Involve, Collaborate and Empower' in table 1 below).

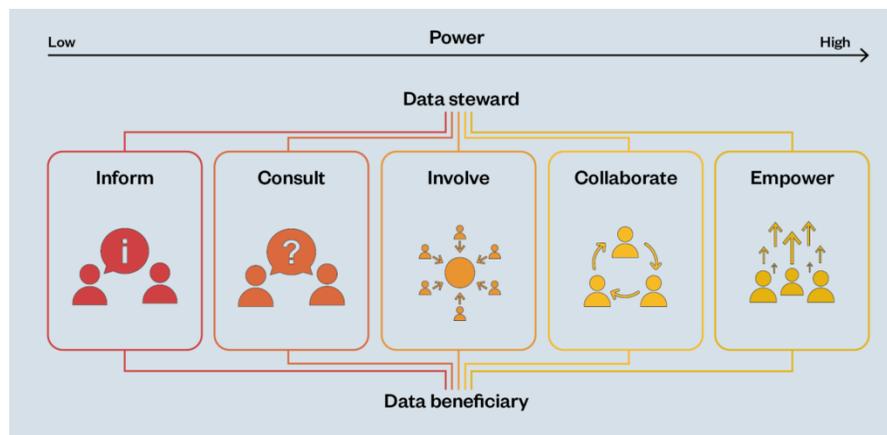
Thus, in addition to three questions about who to involve; there are three key points at which co production and public engagement can be particularly valuable:

1. **Before:** To help shape and inform the design of the cooperative, working closely with technical and policy stakeholders around scoped and potential options and working models. There must be sufficient information to permit 'intelligent consideration', as well as adequate time to incorporate reflections into the design of the initiative.
2. **During:** Institutionalised as part of the mechanisms of the data cooperative itself (this is likely to involve people in how the data itself is curated, collected and used and decisions made by the cooperative) and
3. **After:** In enabling actors such as Liverpool City Region, NHS and other bodies to understand how best to act in ways that use that data effectively, to help aid assessment of how the initiative is working and how it might be able to be improved; and to act as a sense check that the data is being (re)used in the interests of beneficiaries.

5. What could this public engagement and participation look like in practice?

The form this engagement takes is likely to vary depending on the purpose of the engagement; and the actors engaged may also vary, although there may also be role and scope for continuous engagement- see the below for the range of objectives possible for engagement, ranging from informing through to collaborating with and empowering publics.

Figure 2: The spectrum of engagement in data governance



Source - Ada Lovelace Institute

A useful way to think about the different mechanisms available at different stages and for different purposes is set out in the below table (this is a simplified table that derives originally from [Participatory Data Stewardship, Patel, et al 2021, Ada Lovelace Institute](#) p 18-19) and influenced by Arnstein's ladder of participation (1969):

Table 1: Mechanisms for Participation

Purpose	Description (drawn from Arnstein's 'ladder of participation')	What people can expect from Liverpool City Region (IAP2 Participation Spectrum)	Relevant options and mechanisms
<i>Informing</i>	'A one way flow of information'	'We will keep you informed on how your data is being used'	<ul style="list-style-type: none"> - Open data portals available for public access and use - Model cards and data sheets - Good communications about the cooperative with residents - ensure it is more accessible and inclusive
<i>Consulting</i>	'Inviting people's opinions, through attitude surveys, neighbourhood meetings and public hearings'	'We will listen to, acknowledge concerns and aspirations, and provide feedback on how public input influenced us'	<ul style="list-style-type: none"> - Community networks and forums (go to already established ones) - User experience (UX) testing and co-design - Surveys and public attitudes research - Community engagement and consultations
<i>Involving</i>	'Allow beneficiaries to advise, but retain for powerholders the continued right to decide'	'We will work with you to ensure your concerns and aspirations are directly reflected in data governance...'	<ul style="list-style-type: none"> - Public deliberation and deliberative democracy initiatives such as citizen juries, public dialogues and stakeholder dialogues - Lived experience panels - Participatory horizon

			scanning, design thinking and futures thinking
<i>Collaborating</i>	Enables beneficiaries to negotiate and engage with tensions and trade-offs; define public benefit	'We will look to you for advice and innovation in design of data-governance frameworks... and incorporate your advice and recommendations to the maximum extent possible'	<ul style="list-style-type: none"> - Public deliberation and deliberative democracy initiatives - Bottom-up 'data governance initiatives' managed by an independent fiduciary (e.g. data cooperative design itself) - Participant panels and data donation mechanisms based on active understanding/genuine consent
<i>Empowering</i>	'Citizens obtain decisionmaking seats or managerial power'	'We will provide advice and assistance as requested in line with your decisions for designing/developing this cooperative'	<ul style="list-style-type: none"> - Data governance rules shaped and routinely reviewed by beneficiaries and data donors (engagement is institutionalised) - Voting on governance board / patient engagement board - Managerial control of data cooperative - Setting terms of data licensing and access, with permissions overseen by citizens