

Appendix 1: About Involve

Who we are

We're the UK's leading public participation charity, on a mission to put people at the heart of decision-making.

We're a small but passionate team focused on giving people more power over the decisions that affect their lives. We want to build a stronger democracy that works for everyone – that gives people real power to bring about change in their lives, communities and beyond.

Involve was founded in 2003 to “to create a new focus for thinking and action on the links between new forms of public participation and existing democratic institutions”. We've been promoting and practising participatory and deliberative decision-making ever since. We have worked with governments, parliaments, civil society organisations, academics and the public across the UK and internationally to put people at the heart of decision-making.

We believe that decision-making in the UK needs to be more:

- **Open** - so that people can understand, influence and hold decision-makers to account for the actions and inactions of their governments;
- **Participatory** - so that people have the freedom, support and opportunity to shape their communities and influence the decisions that affect their lives; and,
- **Deliberative** - so that people can exchange and acknowledge different perspectives, understand conflict and find common ground, and build a shared vision for society.

What we do

We demonstrate how citizens can help solve our biggest challenges.

Democracy isn't working as it should. Decision-makers are struggling to get things done. The public are frustrated that the system isn't working for them. And everywhere people are feeling divided, distrustful and powerless.

Our work seeks to create:

1. **New innovations** - to demonstrate better ways of doing democracy;
2. **New institutions** - to put people at the heart of decision-making;
3. **New norms** - to make democracy more open, participatory and deliberative.

We approach this in three ways:

1. **We set the agenda** - by developing a vision of a democracy that puts people at the heart of decision-making;
2. **We build coalitions** - by mobilising and partnering with broad, unexpected and powerful networks of allies; and,
3. **We make it happen** - by developing and supporting world-class participatory and deliberative processes.

Our recent projects have included:

- **Scotland's Climate Assembly** - the first online only citizens' assembly in Scotland charged with answering the question: How can Scotland table the climate emergency in a fair and effective way?;
- **NHS Test and Trace Public Advisory Group** - Between May and June 2021, the NHS Test and Trace Public Advisory Group brought together people from different backgrounds to inform new policies to help England come out of the coronavirus (COVID-19) pandemic;
- **Developing a citizen led Data Charter in Camden** - working with the Council to develop a deliberative process to create a Data Charter to guide the Council's decisions about the conditions under which it should collect, analyse, share and use data to inform policy, research and service delivery. Our work consisted of two components: - a distributed dialogue and a citizens' jury.
- Find out more about our work: www.involve.org.uk/our-work/

Our values

- **Collaboration** – because change comes when broad coalitions of people work towards a common vision.
- **Equality** – because everyone in society has an equal right to be listened to and participate in decisions that affect their lives. No one should be held back by societal divisions or prejudice.
- **Purpose** – because participation must have an impact. We reject tokenistic or ineffectual engagement.

Appendix 2: Interview Summary

Interviewees

- Iain Buchan
- Helen Duckworth
- Jim Hughes
- Tony Marsden
- John Whaling
- Andy Mills
- Paul Charnley
- Matt Ashton
- Amanda Lamb
- Ian Pawson
- Claire Liddy
- William Hope
- Drew Hill
- Maurice Smith
- Janet Jennings
- Rob Barnett
- Alex Chaplin

Question framework¹

Questions about their role and data

- Can you tell us a little about your role, and specifically how you use and share data?

Questions about the CDC and its role

- What role will the CDC play within the data sharing infrastructure in the city region?
- What benefits will it bring?
- What friction will it bring to the system? How can this be minimised?
- Who are the key actors in the system who need to be part of the CDC to make it worthwhile?/ What key datasets does the CDC need to hold? Why these?
 - do they see the benefits in the same way?
- What does success look like for you? How will you know if the CDC is working?
- [if time] Why a coop and not some other governance structure?
- Problem of scale - how to get the region as a whole to participate and feel a sense of ownership? Engagement with hard to reach people and communities?

Questions about public engagement and its role

- A key element of the CDC is involving the public. What role do you think the public have within the CDC?
 - What are your objectives for public engagement in relation to:

¹ This framework was used as a basis for all the interviews, however, not all interviewees were asked all questions, and the priority given to the question sets varied according to the role of the interviewee.

- The establishment of the CDC?
- The governance of the CDC - what should its governance look like?
- The use of data and public health (NHS, local government, other orgs, existing groups)?
- What public engagement around data has already taken place in Liverpool and Merseyside on data and its governance?
- Again, what does good look like in terms of public engagement process and outcome?
- Another way of asking these questions, what are the areas of risk that might reduce public trust and public engagement through the co-op could reduce? What decisions keep you awake at night? How might the CDC help you address those fears?

Synthesis of the interviews

The jamboard slides below show the themes that developed from our synthesis of the interviews.



Figure 9: Theming of what we heard in the interviews around the overall purpose of the CDC

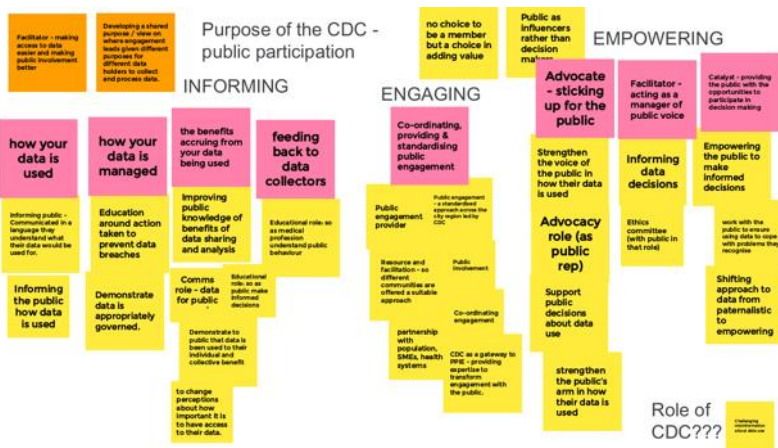


Figure 10: Theming of what we heard in the interviews around the purpose of public participation in the CDC

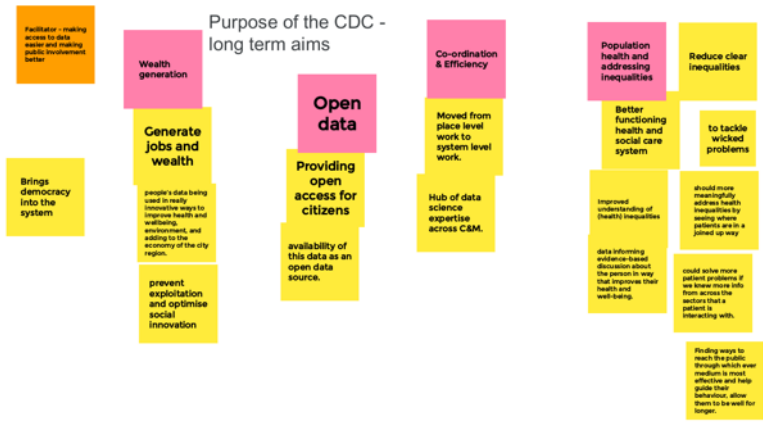


Figure 11: Theming of what we heard in the interviews around the long term aims of the CDC

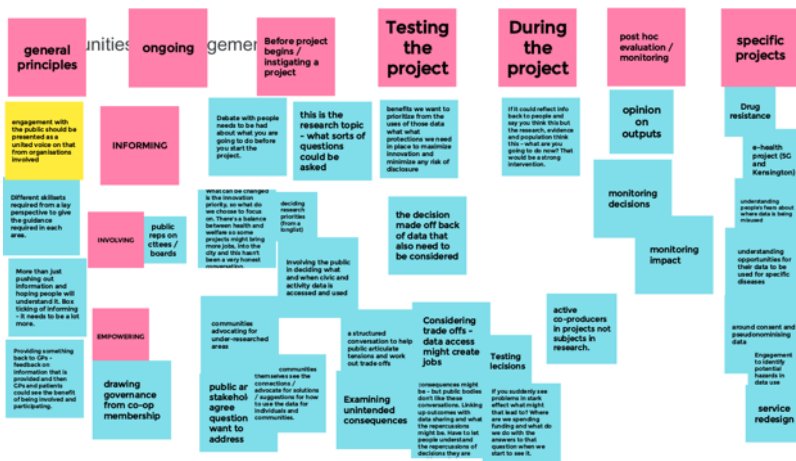














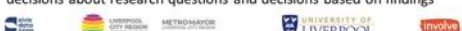

Figure 12: Opportunities for public engagement identified by interviewees

Appendix 3: Workshop Summary

Attendees

- Helen Duckworth
- Iain Buchan
- Rob Barnett
- John Whaling
- William Hope
- Lisa A'Hearne
- Gary Leeming
- Emma Lord
- Claire Smith
- Jim Hughes
- Amanda Lamb
- Andy Mills
- Saah Wright
- Angela Johnson
- Reema Patel
- Greg Macoy
- Ellie Fielding

Presentation to stakeholder workshop

<h2>Liverpool Civic Data Co-op</h2> <p>The role of the public</p> 	<h3>Why create the CDC?</h3> <p>Harnessing data's value for economic and social benefit needs:</p> <ul style="list-style-type: none"> public trust data to be available to those who need it <p>To be effective decisions need to be made about:</p> <ul style="list-style-type: none"> who should have access for what purposes for whose benefit the role of the public <p>CDC is at the forefront of the debate about data stewardship</p> 
<h3>Changing context ... adapting purpose?</h3> <p>Evolution of form as it has developed</p> <ul style="list-style-type: none"> Trust or Co-operative <p>The pandemic</p> <ul style="list-style-type: none"> Covid and CIPHA <p>Wider governance reforms</p> <ul style="list-style-type: none"> Integrated Care Systems 	<h3>Expectations are many and broad</h3>  <p>• And deliver with a team of ten people.... And no official authority...</p> <p>And limited resources</p> 
<h3>Emerging consensus about core functions</h3> <p>Facilitation not IG</p> <ul style="list-style-type: none"> Open data Processes for accessing closed data (in partnership with CIPHA) <p>Identifying value</p> <ul style="list-style-type: none"> Public support, ethical status, benchmarking Cross-sector consortia (including industry) to solve wicked problems Sustainable Development Goals 	<h3>The public are critical, but what is their role?</h3>  <p>Graphic: Ada Lovelace Institute</p> 
<h3>The role of the public – different perspectives</h3> <p>The CDC must ...</p> <p>INFORM the public about:</p> <ul style="list-style-type: none"> how data is used how data is managed the benefits arising from data usage <p>The CDC could ...</p> <p>INVOLVE the public to:</p> <ul style="list-style-type: none"> understand perspectives, needs, hopes and fears inform decisions about data usage <p>EMPOWER the public to:</p> <ul style="list-style-type: none"> use data make decisions identify opportunities 	<h3>The role of the public – in what?</h3> <p>Three different options</p> <ul style="list-style-type: none"> In the formation of the CDC In the governance of the CDC In the development and delivery of individual data projects 
<h3>When: Developing the CDC</h3> <p>Question: "What legal form should the CDC take and what conditions should be placed on who it should and shouldn't work with, and how should it prioritise projects?"</p> <p>Who: A citizens' assembly, formed of a large representative sample could be presented with evidence and given time to deliberate</p> <p>Outcomes:</p> <p><i>Involve:</i> Recommendations considered, responded to but not necessarily implemented.</p> <p><i>Empower:</i> co-creating the governance and the mechanisms for permitting access and project prioritisation</p> 	<h3>When: In the governance of the CDC</h3> <p>Question: What key principles should be applied in the governance framework of the CDC, including how it makes decisions about access to datasets and prioritisation of projects?</p> <p>Who: A People's Panel of a smaller representative sample meeting regularly both to discuss data access requests</p> <p>Outcomes:</p> <p><i>Involve:</i> Panel comments on data access requests against agreed principles, these are considered, but may not be implemented</p> <p><i>Empower:</i> Panel can veto data access requests</p> 
<h3>When: Project by project</h3> <p>Question: How can we ensure individual data projects meet the needs of residents?</p> <p>Who: Using a distributed dialogue process, community groups are engaged to consider individual projects</p> <p>Outcomes:</p> <p><i>Involve:</i> Residents provide input into their perspectives on the problem and potential solutions, these taken into account as data project delivered</p> <p><i>Empower:</i> Residents involved in scoping projects and making key decisions about research questions and decisions based on findings</p> 	<h3>In your groups</h3> <p>Consider at least two of the options</p> <ol style="list-style-type: none"> What level of public engagement is appropriate for this option? Why? What would you need to see to give you confidence to act on what the public says? Is this a priority area for CDC to invest in engaging the public? Why? Does the CDC have the authority to offer the level of engagement proposed? If not, should it have it? 

Report from workshop

The Liverpool Civic Data Cooperative (CDC) was introduced in 2020 with a view to being a trusted third party to facilitate research access to health and social care data in the Liverpool City Region (LCR).

Involve was commissioned in 2021 to work with the CDC to advise on the public engagement needed as part of the process to design the CDC as well as the ongoing engagement likely to be needed.

The first stage of our work involved interviewing key stakeholders across the LCR.

The stakeholder workshop was the second phase of our work seeking to understand how best to engage the public in the Liverpool Civic Data Cooperative. It involved a number of the stakeholder interviewees from across different sections of the infrastructure within which the CDC seeks to operate.

The main purpose of the workshop was to explore what level of engagement attendees thought was most appropriate, and at what stage of the development / operation of the CDC.

The specified objectives were:

1. To develop a shared understanding of the role of Liverpool City Region residents within the CDC
2. To develop options for public engagement within the CDC

After a short presentation from Simon Burall and a Q&A, attendees discussed in small groups at what level the public might be engaged at each defined stage of the CDC's development and operation.

It was clear from the discussion that attendees had the aspiration to fully involve the public, and to hand over some power to them to make decisions about the development and operation of the CDC.

This is a cooperative approach so any individual or any member of the network could have an actionable idea.

However, precisely how that might happen and if the CDC itself had the capacity, authority, or legal standing to make it happen remained unconfirmed. This brief report seeks to provide an overview of the discussions.

The role of the public

Based on Involve's previous work, including with the ODI, we identified three moments when the CDC might choose to engage the public - at each moment that could be at the perspective of 'inform', 'involve' or 'empower'.

It is clear from the nomenclature that the CDC should include the public voice to some degree.

Coop means involving the public. structure. But there do have to be appropriate controls to manage that whilst also maintaining transparency. It will be important to have methods to empower and involve the public.

At minimum the public wants to be informed and have a say around that.

Cooperative implies putting some power into the hands of the public.

It was also evident from the discussion that to do this will mean giving the CDC the time and capacity to implement effective processes.

If we really want to do this, we have to slow down decision making processes, think about how the public will add value and how to reach out to them.

However, it was less clear what the purpose and scope of the public's involvement would be.

Also, the question of why are we doing it? We're looking to get public opinion but also to educate.

We want to explain to people what we do with data. Question is how much do we act on the opinions we hear. That is quite different. And in any one room there will be a spread of views. Maybe it is about getting the tone – there will be a spectrum of opinions.

We need to define what the scope might be – involve and empower – answers might be different depending on where applied – e.g. ICS/NHS obligations to use data in a certain way/treat patients/improve services. We can't change the COPI notice but we can surface opinions and inform people why we cannot do these things.

We also heard that there were challenges in the authority the CDC would have to act on what it heard from the public, and that it was being asked to navigate a complex array of brokers.

CDC doesn't have authority to take decisions on data. It has authority to raise the profile of data and start the debate/ ask questions on what data can do for unheard communities or people with particular conditions. Groups across the NHS and the local authority need to come together in a coop to have integrated governance to better serve our communities.

Original point that if we do this, will set expectations and we haven't got legitimacy therefore set up to fail if we don't set parameters in advance within the legal framework – need to understand this. Empower **and** set the scope.

From Involve's perspective, given the creation of the CDC, and the use of the word 'cooperative', it seems clear that the intention was that at the very least the CDC would seek to 'inform' the people of the Liverpool City Region about how their data is used and managed, and the benefits that accrue to the region from the ways the data is used.

The risk facing the CDC is that if you open up the conversation, provide information and people feel that they haven't been given real power or that they realise how little power they do have, then they will use the power they have - which in regard to data is to withdraw consent.

It is therefore vital that the CDC understands what it can offer the public before it begins to engage. The purpose and scope of any engagement must be clear. In this respect the workshop raised more questions than answers.

Issues identified by participants

1. Who is the public?

Questions that were raised during the workshop included what the definition of 'public(s)' includes - and this is important to understand. The CDC will need to engage different publics, from institutional stakeholders and GPs to community representatives and elected officials, as well as the general public. And of course, in any given instance each individual will in fact be representative of several different publics. The question is whether the CDC has the capacity to coordinate across such a wide

range of actors. There are also challenges in reaching under-represented groups - this would require specific resourcing.

Next steps: The CDC team needs to identify its priority audiences and why it needs to engage them.

2. Where does the CDC fit in the civic / health infrastructure?

Concerns were raised about both the legal identity of the CDC and how it fits into the existing frameworks in the region. The CDC is attempting to work across both democratic and civic infrastructures and the complex infrastructure of the health and social care system, including the medicalised approach taken by the NHS.

Next steps: Working with its key stakeholders, the CDC team needs to identify its role within the civic/ health infrastructure. One way of doing this is to more clearly identify the value it will bring to the system.

In order to assist the CDC team, these key stakeholders need to decide what power, if any, they are willing to share with the CDC.

3. What is the geographic scope?

This leads on to another aspect of the discussion which questioned the geographic scope of the CDC. CDC is funded by LCR but clearly the health system is larger than that and it might be desirable to work at a Cheshire and Merseyside scale. However, the discussion also included the value of working at a PLACE level, understanding the hyper local needs of communities. The benefits of establishing the CDC as a local / sub-regional player to challenge the trend towards centralisation was noted.

Next steps: The CDC team and its key stakeholders have a number of options for the geographic footprint of the CDC. It will be tempting to try to operate within different geographic scales. However, this will make the decisions needed around purpose (see below), much more challenging. It will be more effective to identify a clear focus and grown from there over time. A decision needs to be made about the geographic scope - and how that fits into the national conversation and a trend towards centralisation.

4. What is the purpose of engaging the public?

As identified above, there was a lack of consensus on the purpose of engaging the public, including a conversation about trustworthiness and the extent to which engaging the public can help with this.

Next steps: The CDC needs to be clear on why it is seeking to engage the public and to what extent. Without a clear understanding of why you want to involve the public you cannot be clear on the offer you are making to them.

Conclusions

Overall, attendees acknowledged that information provision was a critical element in the role of CDC. It was also proposed that in order to have the public involved in project-based decision making, they would need to be involved in the design of the CDC from the beginning. They would need to be the ones deciding who was asked what and when. Involving the public in the establishment of the CDC, including asking them the questions about how best to involve the public in its governance would be the ideal approach. It was clear that this would involve slowing down, and that the exclusion of the public in the speed of the response to the pandemic could not become the norm.

In considering individual data projects attendees saw a real role for the public in decision making. However, establishing principles and rules of engagement and what the public could and couldn't be consulted on was vital. Defining a project and what it meant to the public would be of importance, is a project collecting data in CIPHA or doing something additional with the data? And, of utmost importance: How are you going to act upon what the public are advising?

We must not lose the ambition to empower but need to do it slowly. There is room for it but it is difficult e.g if we empower patient care it would be framed differently – ask people on waiting lists 'what will you do' – this is potentially disruptive to the NHS but could save lives and reduce costs.

Appendix 4: ODI model timeline

Overview model of proposed decision-making processes for a data trust - Taken from Involve (2019) [Greater London Authority/Royal Borough of Greenwich data trust pilot: Design of a decision-making process](#)

		Timeline of key decisions >>>						
		1. Data Trust Formation & Design Decisions		2. Operational Decisions		3. Exceptional Decisions		
		Decisions on formation, design, function and approach to decision-making	What governing and core operating principles should this trust have?	What criteria used to decide who has access to the data and under what conditions?	Decisions on granting access from the data trust	How is performance against purpose, principles and values?	Edge cases	What happens if the trust fails?
Purpose of engagement/deliberative engagement		* To gain buy into the overall purpose and approach of the trust. * To agree the framing of the trust - who it is driven by and who it is for?	* Build ownership amongst stakeholders at the outset. * Understand expectations of stakeholders/ public * Understand where trade-offs may be around data use	* Build agreement on the criteria. * Build trust that data shared for, reflecting public hopes and fears. * Gain insight into how people judge outcomes from data use	* Whether access is granted and under what conditions using the agreed criteria.	* To understand whether the trust is meeting expectations and if not, why?	* To review for cases challenging criteria	* What happens to the data accrued? What happens to the benefits accrued?
Who needs to be involved		Funders, commissioners, Emergent data steward; legal input	Emergent data steward/ trustees; legal input, wider stakeholders, public	Emergent data steward/trustees; legal input, wider stakeholders, public	Data steward/ trustees, stakeholders, public	Data steward/trustees, stakeholders, public	Expert views (e.g. legal); Representation of key stakeholders.	Expert views (e.g. legal); Representation of key stakeholders.
Through what process		Facilitated workshop(s) to make decisions	Core stakeholder group co-production process Mini public used to gain insights for core stakeholder group to develop Outreach to underrepresented groups Online engagement?		Stakeholder/ public reference panel input	Review by stakeholder public/ reference panel; Mini public/ citizen jury or assembly feeding back to reference panel	Review by stakeholder /public reference panel; Mini public/ citizen jury or assembly feeding back to reference panel	Review by stakeholder /public reference panel;
		Core group helps co-design deliberative elements						
			Establish public /stakeholder reference panel as a touchstone and oversight of data trust					