Public data for public good

A report by Involve for the Liverpool Civic Data Co-operative

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Executive Summary

One of the central questions for modern, data driven governments, is how to develop and maintain trustworthy systems of governance for the collection, use and sharing of personal data. The announcement in January 2020 by the City Region of new plans for a civic data cooperative (CDC) is an exciting development which will pilot a relatively new form of trustworthy data governance. The CDC aims to enable the analysis of anonymised health, social care and civic data for the benefit of the whole city region. If done well, in collaboration with stakeholders and residents across the city region, then it will raise the bar for effective and ethical data governance.

Involve were commissioned to help design and implement a public engagement strategy for the CDC, with an emphasis on citizen participation, clarity, understanding and collaboration.

This report lays out our recommendations and the approach we took to developing them. It takes the ambition and aspiration expressed by the CDC and its stakeholders but also challenges the CDC to be clear on the purpose, and scope of any public engagement.

The risk of presenting the public with a scenario which is too open, and which has no clear purpose or scope, is that they feel further disempowered. In the field of data sharing and consent this is of particular concern; if residents feel that they haven't been given enough detail or the promise of involvement in key decisions isn't real, then they will use the power they have - which is to withdraw consent for their data to be collected and used.

This report assumes a role for the CDC as a transparent actor and communicator to the people of the region about how their data is being collected, analysed, and shared, and of the public health benefits that accrue from that data sharing. To ensure this information is presented in a suitable format for the Liverpool City Region (LCR) residents we also make recommendations about public involvement in the development of these materials. There may also be opportunities for the CDC to develop a wider educational piece about data collection and sharing in general, as well as the specifics of civic data and the CDC.

We then think about the role of the public in the governance and ongoing development of the CDC - primarily as the gateway for researchers to access health and social care data in the LCR and hence as the trusted guardian of access to that data. The recommendations for public engagement and involvement within could be scaled up for use in Cheshire and Merseyside, but with associated resourcing implications.

Overall, we see a role for the CDC as:

- **Informing** the public about how their data is collected and analysed, who can access it, what the approval process is, and the public health benefits that accrue;
- **Involving** the public in approving and designing projects - understanding their motivations and fears and using that information to guide decision-making;
- **Collaborating** with the public to design the governance of the CDC including the role of the public;
- **Networking and learning** so that different publics inform and empower each other in understanding and benefiting from public health data;
- **Demonstrating best practice** in public engagement in the data trust environment.

Involve has been impressed by the commitments the CDC is attempting to make to the people of the Liverpool City Region and we stand ready to assist in developing these aspirations.

Introduction

In January 2020, Liverpool City Region's combined authority announced new plans for a civic data cooperative (CDC) enabling the analysis of anonymised health, social care and civic data. 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[1] participation and the principles of cooperativism. Since the plan and proposals were announced, the major shifts which were already apparent have accelerated, largely due to the COVID19 pandemic. Of particular note nationally 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 Cheshire and Merseyside, the pandemic saw the acceleration of the development and use of CIPHA (Combined Intelligence for Population Health Action), a near real-time person level linked dataset across Cheshire and Merseyside. CIPHA enables combined intelligence to be produced that can support population health analytics designed to inform both population level planning and targeting of direct care. The CIPHA Trusted Research Environments (TRE) enable researchers to access CIPHA data.

Involve were commissioned by the CDC to help design and implement a public engagement strategy to support the CDC including in its role as guardian of the CIPHA datasets. The objective is to ensure trustworthy use and sharing of clinical and care data across the region, with an emphasis on citizen participation, clarity, understanding and collaboration. Involve also asked Reema Patel to contribute to the engagement work based on her extensive work on principles for data stewardship[2] in her previous role at the Ada Lovelace Institute. This report should be read alongside the resulting provocation paper.[3] The paper broadly discusses why a participatory approach to data stewardship is crucial for developing a trustworthy and successful data stewardship model. It examines the notion of membership as implied by the term cooperative and sets out the principles for when data stewards can engage. It also lays out the need for a common and shared purpose to lie behind effective data stewardship. These principles are central to the approach taken in this report.

Our work did not take place in isolation; at the same time Matchstick Creative were commissioned to develop a marketing strategy, and Capacity were undertaking engagement work with SMEs in the region to understand how the CDC could add economic value to this sector.

To understand the needs of the CDC in relation to developing a public engagement strategy, we used the framework[4] developed as a result of Involve's work with the Open Data Institute to pilot the design of a data trust decision making process for the Greater London Authority and Borough of Greenwich.

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[1] The term 'citizen' is used in its widest form and includes anyone who has a clear connection to a place including people experiencing homelessness, asylum seekers and refugees.

[2] https://www.adalovelaceinstitute.org/wp-content/uploads/2021/11/ADA_Participatory-Data-Stewardship.pdf

[3] https://www.involve.org.uk/sites/default/files/field/attachemnt/Towards%20a%20Civic%20Data%20Cooperative%20in%20Liverpool%20-%20Provocation%20Paper.pdf

[4] The original timeline table from the ODI report is included at Appendix 4. Our revised model of proposed decision making for the CDC can be found in Part 3.

Following this model, we began by undertaking a piece of stakeholder engagement with senior figures in and around the CDC.[5]

We undertook a series of interviews, the results of which were synthesised and presented back to interviewees at a facilitated workshop. The workshop also allowed participants to discuss what public engagement might be appropriate at the different points in the life cycle identified below.

We also presented the work to NIHR Applied Research Collaborations (ARC) North West Coast Public Engagement Forum for their feedback. The findings of the stakeholder engagement, feedback from ARC and the report from Reema Patel, together with the results of Matchstick's work and ongoing conversations with the CDC team, have allowed us to develop the recommendations contained in this report. We are grateful for their input.

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[5] A full list of participants and the question framework are provided with the Interview Summary at Appendix 2

Our approach to public engagement

The first step to ensuring public engagement is useful and effective is to define the purpose and the scope of that engagement. We have chosen to focus our report on two specific areas that we heard were priorities for the CDC. This does not preclude public engagement in other areas.

These two priority areas are for the CDC to:

1. become a transparent and effective communicator about data collection, analysis and the accrued public benefit;
2. act as an ethical and trusted gatekeeper for access to the data.

As noted above, in making our assessment and presenting these recommendations we use the report by Reema Patel as a foundation. This paper identifies many of the fundamental questions that the CDC needs to answer before it can confidently present options for its structure and governance to the public. This includes:

- developing a shared internal understanding of the terminology including *civic, cooperative* and *data beneficiaries*;
- making decisions about the geographic scope of the project; and
- defining what it means to embed public engagement in the CDC.

This report takes the ambition and aspiration expressed by the CDC and its stakeholders, but also challenges the CDC to be clear on the purpose, and scope of any public engagement.

The risk of presenting the public with a scenario for the CDC which is too open, without a clear purpose or scope, is that they feel disempowered rather than engaged. In the field of data sharing and consent this is of particular concern; if you open up the conversation, provide information and people feel that they haven't been given enough detail or 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.

This report assumes a role for the CDC as a transparent actor and communicator to the people of the region about how their data is being collected, analysed, and shared, and of the benefits which accrue from that data sharing for public health benefits. To ensure this information is presented in a suitable format for Liverpool City Region (LCR) residents, we also make recommendations about public involvement in developing these materials. There may also be opportunities for the CDC to develop a wider educational piece about data collection and sharing in general, as well as the specifics of civic data and the CDC.

We then think about the role of the public in the governance and ongoing development of the CDC - primarily as the gateway for researchers to access health and social care data in the LCR and hence as the trusted guardian of access to that data, primarily through CIPHA and its TRE but also any other civic datasets that may come under the purview of the CDC. The recommendations for public engagement and involvement could be scaled up for use in Cheshire and Merseyside, but with associated resourcing implications.

We then go on to present areas the public might be involved in, based on the timeline developed with the ODI, and the corresponding points at which coproduction and public engagement can be particularly valuable in the life cycle that are highlighted in Reema Patel's paper:

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.

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

After: In enabling data stewards 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.[6]

We would stress that whilst these are defined moments in the timeline of the CDC, we also see value in a continuous feedback loop that acknowledges a role for the public in evaluating and monitoring the CDC and making recommendations for improvements; most value will be gained from public engagement if it is seen as an iterative rather a wholly linear approach. Our revised version of the ODI framework with our recommended approach for the CDC can be found in Part 3.

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[6] As the Ada Lovelace report 'Participatory Data Stewardship' notes, the term beneficiaries includes 'data subjects', who have a direct relationship with the data in question as specified in the GDPR, and also encompasses those impacted by the use of data (e.g. workers, underrepresented and excluded groups) even if they are not themselves data subjects.

Part 1: What we heard

We interviewed seventeen stakeholders[7] across different sectors, and the region. We synthesised and themed what we heard in these interviews[8] and presented the findings to a workshop with 12 participants.

It was clear from the interviews that expectations and aspirations about the CDC were many and broad.

Expectations are many and broad

Streamlining access to data

Act as ethical and trusted gatekeeper

Facilitate access to data on behalf of the data controllers

Building TRE and managing secure, ISO accredited data lake

Supporting multi-disciplinary teams / cross-sector working

Co-ordinating and improving efficiency of the system

Improving LCR economy by supporting SMEs

Enabling investment from large corporations

Creating transparent governance of how data are used

Communicating with public and others how data has been used

Public and Patient Involvement and Engagement

- And deliver with a team of ten people…. And no official authority… And limited resources

Figure 1: slide presented to stakeholder workshop summarising the purposes for the CDC expressed during interviews

We broke down the interview analysis into three areas of purpose for the CDC and identified key themes in each area:

1. Overall purpose for CDC
    a. Co-ordinating and improving the efficiency of the civic data system;
    b. Streamlining access to data sets and breaking down silos - providing for multi-disciplinary teams to work across the system;
    c. To be an expert and trusted steward of the data;
    d. To facilitate access to the data - making that access transparent and efficient and improving public involvement; and
    e. Communicating what access to the data has allowed to be learnt.
2. The purpose of public participation
    a. To inform the public
        i. How your data is used and managed;

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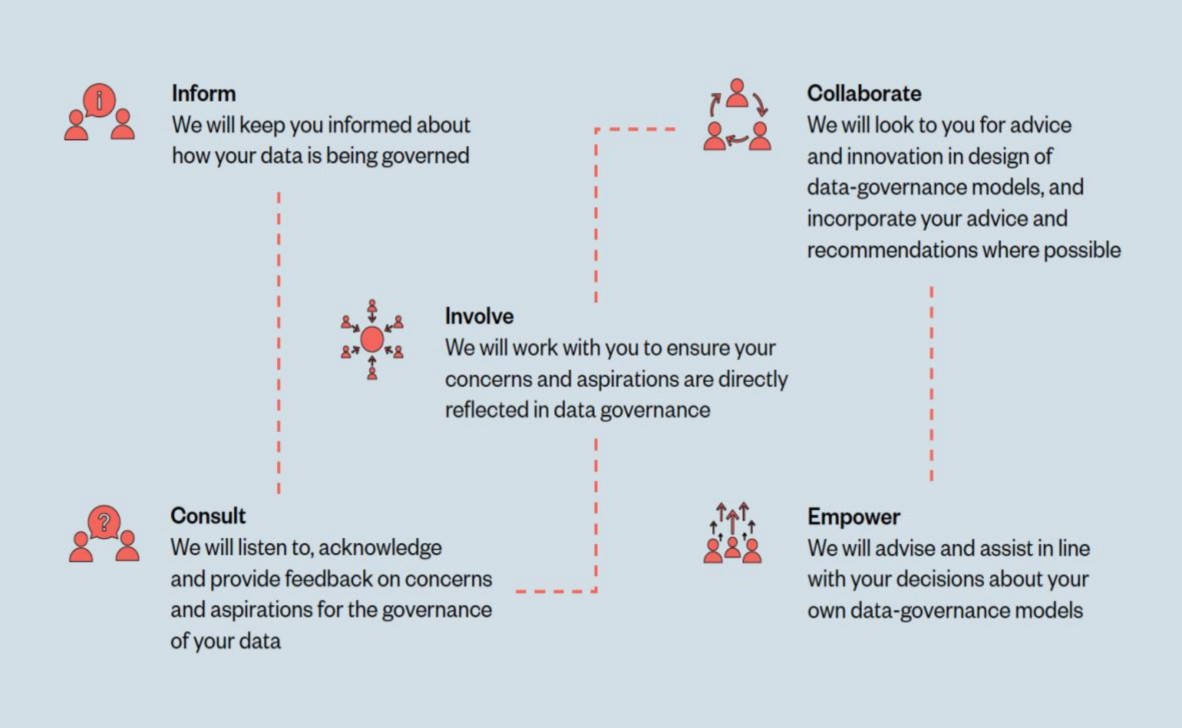
[7] A full list of interviewees can be found at Appendix 2

[8] The raw data from this exercise is available at Appendix 2

        ii. The benefits accruing from your data being used - including an educational role so that the public are making informed decisions about data sharing in different contexts; and
        iii. Feeding back to those collecting, using and sharing data – so that they can understand public preferences or behaviour better, for example.
    b. To engage the public through co-ordinating, providing and standardising engagement provision
    c. To empower the public
        i. By acting as an advocate and strengthening the public voice in how data is used;
        ii. By acting as a manager of the public voice; and
        iii. Working with the public to help them identify ways to use data to deal with problems they recognise.
3. Long term purposes
    a. Wealth generation;
    b. Open data - with the London Datastore as an example; and
    c. Improving population health and addressing inequalities in line with the Sustainable Development Goals.

In the workshop, we considered what role the public could play in achieving these objectives. We introduced the spectrum of participation, as adapted for data trusts by the Ada Lovelace Institute.[9]



Inform
We will keep you informed about how your data is being governed

Consult
We will listen to, acknowledge and provide feedback on concerns and aspirations for the governance of your data

Involve
We will work with you to ensure your concerns and aspirations are directly reflected in data governance

Collaborate
We will look to you for advice and innovation in design of data-governance models, and incorporate your advice and recommendations where possible

Empower
We will advise and assist in line with your decisions about your own data-governance models

Figure 2: The spectrum of participation adapted by the Ada Lovelace Institute in Participatory Data Stewardship

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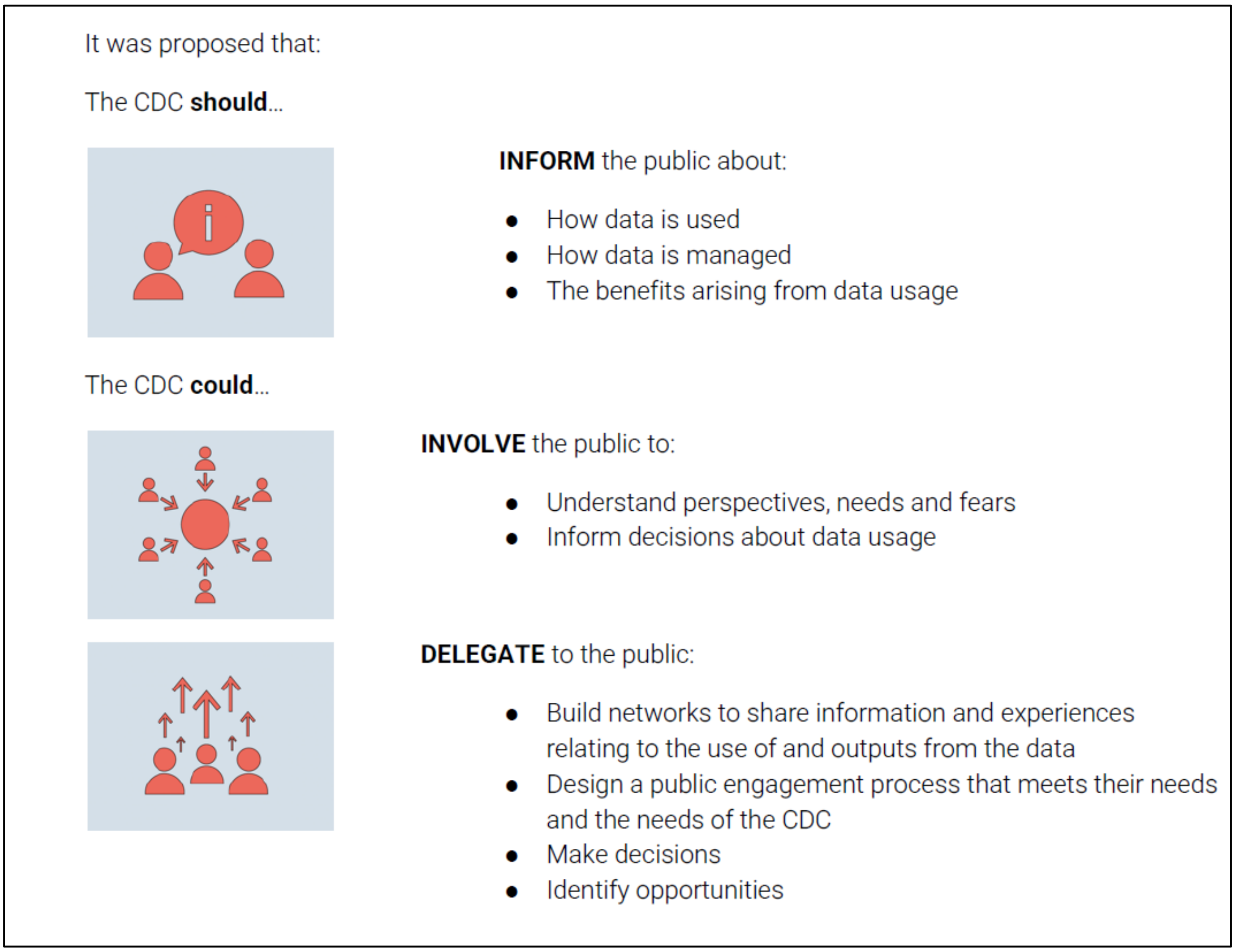
[9] After presenting this to stakeholders, for the purposes of this report we will be using the term ‘delegate to’ rather than ‘empower’ as the word empower was felt to have different meanings that could be misconstrued.



It was proposed that:

The CDC **should**...

INFORM the public about:

- How data is used
- How data is managed
- The benefits arising from data usage

The CDC **could**...

INVOLVE the public to:

- Understand perspectives, needs and fears
- Inform decisions about data usage

DELEGATE to the public:

- Build networks to share information and experiences relating to the use of and outputs from the data
- Design a public engagement process that meets their needs and the needs of the CDC
- Make decisions
- Identify opportunities

Figure 3: Slide presented to workshop participants outlining the potential purposes for the CDC

Attendees agreed with the proposition that the CDC had a role to inform and indeed educate the public about how their data is collected, processed, managed and shared - and the benefits that have arisen or could arise.

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

However, precisely how that might happen and if the CDC itself had the capacity or authority to deliver, and what legal constraints there might be around the CDC taking that role, and the limits of the law in what changes any public engagement could affect, was less clear. There was broad agreement that, in order to involve the public in project-based decision making, they would also need to be involved in the design of the CDC from the beginning. Therefore, involving the public in the establishment of the CDC, including asking them the questions about how best to continue and develop the involvement of the public in its governance was felt to be the ideal approach. It was clear that this would involve slowing down, and that the exclusion of the public due to the speed of the response to the pandemic could not become the norm.

In further 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, what it meant to the public and what role there would be for public engagement in designing and in delivering the project will be important. And most critically: How are the CDC and stakeholders going to act upon what the public are advising?

Several key questions emerged from the workshop:

1. Which publics need to be engaged?
2. What is the purpose of engaging the public?
3. Where does the CDC fit in the civic / health infrastructure?
4. What is the geographic scope?

Our recommendations seek to answer the first two of these, but it is outwith our expertise to advise on the latter.

Part 2: A route to public engagement

In this section we explain the importance of establishing a clear purpose before beginning any engagement. We then reflect on the different purposes we have heard for the CDC and the implications this has for the purpose of any engagement the CDC delivers.

Establishing Purpose

What is the objective of the engagement?

Establishing a clear purpose and getting agreement on it is the single most important stage of any engagement process. Indeed, no participatory process should proceed without it.

There are, however, good and bad purposes. A good purpose will be highly focused with clear outputs and outcomes, which are easy for all to understand. A bad purpose will be poorly defined, with unclear outcomes and open to many different interpretations. A measure of a good purpose is its ability to create a commonly shared understanding of the potential impact of the project.

This does not mean that a good purpose must be narrow in its scope. Indeed, many of the best purposes are very broad. The point is that a purpose must be easy to understand and an accurate reflection of what is going to happen. Much of the best participation depends on the participants coming up with their own agenda for change, which is fine, as long as the agenda can then be implemented satisfactorily, and everyone understands what they are part of.

It is essential that all those with an interest or influence over the process are aligned to its purpose. Too often, different purposes exist within the same organisation, sometimes unspoken or assumed, and this only comes to light when the process is underway, which can be both damaging and embarrassing.

Purpose as reference point

Once established, the agreed purpose can provide a reference point throughout the process. This is especially useful if participants are likely to introduce new subjects during the process, as their relevance to the purpose will determine whether they should be included.

A clear purpose enables the commissioning body to ensure that the right mechanisms are in place to transform the process outputs into outcomes. Clarifying the purpose of a process ensures that any organisation knows what it is getting into and can then check whether participation is appropriate.

A purpose also gives participants the opportunity to make an informed choice about getting involved. Too often we hear complaints of people feeling misled or manipulated. This is often because of mis-communication between the commissioner and participants as to what the process can change.

Defining the purpose

Defining a clear purpose is not as easy as it sounds. For an organisation to develop a purpose which is shared by those inside the organisation and any stakeholders which are involved requires time. This is almost always in short supply, especially at the start of a process. External circumstances can also affect the purpose and this possibility should be anticipated. For example, the results of forthcoming research or a decision taken by others can both influence the context and the purpose of a participation process. This is a particular risk if the process is not recognised or valued by people more senior than those involved in the detailed design and delivery.

It is important that defining the purpose includes clarity about the desired outputs and outcomes. Outcomes are about what you ultimately want to achieve (for example, consensus on which uses of data should be permitted and which not); outputs are how you will achieve the outcomes (for example, a report including recommendations from participants). Making the distinction clear will contribute to defining a robust and useful purpose.

In summary, there are many possible purposes for participation, including to:

- Inform about defined activities;
- Educate about the wider context - how data is used, who uses it for what purpose, the benefits it can have and how the data is protected etc;
- Network and share ideas;
- Make a decision; and
- Explore issues and come up with new ideas.

In addition, organisations may have in mind the core participation purposes identified above (governance, social cohesion and social justice, improved quality of services, capacity building and learning).

Identifying such purposes will involve:

- Liaising internally to clarify what can be changed as a result of the process and what outputs and outcomes are sought.
- Liaising externally with those affected by a process to identify people's interests and concerns.

The key questions to help clarify the purposes of the exercise will be:

- What tangible products do you want to have produced during and after the process (outputs)?
- What do you want to have achieved at the end of this process (outcomes)?

And a checking question:

- What will you have to do with the outputs to ensure you achieve the desired outcomes?

Our sense of your purpose(s)

It has become clear that the CDC in fact has multiple purposes which public engagement could help meet. This is largely due to the different stages in the life cycle where engagement could take place.

The table identifies a number of purposes which the CDC could use to define its public engagement.

Purpose	Outputs	Outcomes
Informing the public about how their data is collected and analysed, who can access it, what the approval process is, and the public health benefits that accrue.	Stakeholder events Communications public panel Materials Public events (led by trusted stakeholders)	Knowledge of and trust in the CDC Willingness to engage more deeply
Involving the public in approving and designing projects - understanding their motivations and fears and using that information to guide decision-making.	Any access requests either meet pre-agreed criteria defined by a mini-public or are themselves tested with a mini-public	Needs and fears are better understood, informing decisions that cannot involve the public (eg for reasons of speed)
Collaborating with the public to design the governance of the CDC including the role of the public.	A role for a public panel alongside any other governance structures to monitor and inform	The CDC sets a gold standard for public engagement and involvement and demonstrates trustworthiness
Networking and learning so that different publics inform and empower each other in understanding and benefiting from public health data.	Ongoing evidence to and feedback from public panels, mini-publics, stakeholder groups and the public	Trusted relationships between data holders, data subjects and data users ensure better public health outcomes and shared understanding of risks and benefits of public data for public good
To **demonstrate best practice** in public engagement in the data trust environment.	Transparent and communicable governance and practice standards	A community of practice appreciates a gold standard of public involvement, ensuring an environment of trustworthiness

Each of the purposes for the CDC identified above implies different reasons for engaging the public. While these are not mutually exclusive, the CDC has limited resources for public engagement. Choices and priorities need to be agreed before the CDC can effectively engage the public.

Scope - who do you want to engage with?

1. What is open to change (and what is not)?

Defining the scope of any engagement in the CDC involves clarifying what the boundaries are, what is achievable in practice – and whether engagement is appropriate at all. This allows you to begin to determine what level of engagement is right for your purpose

In order to effectively engage, in a way that adds value to both the CDC and the public, it is necessary that:

- The public can influence, to some degree, the decisions they are being invited to engage on
- The public participation will bring in something new
- The public are interested in being involved
- There are sufficient resources to support the process and ensure it works properly

Understanding what you can offer and why leads to your 'promise to the public'.

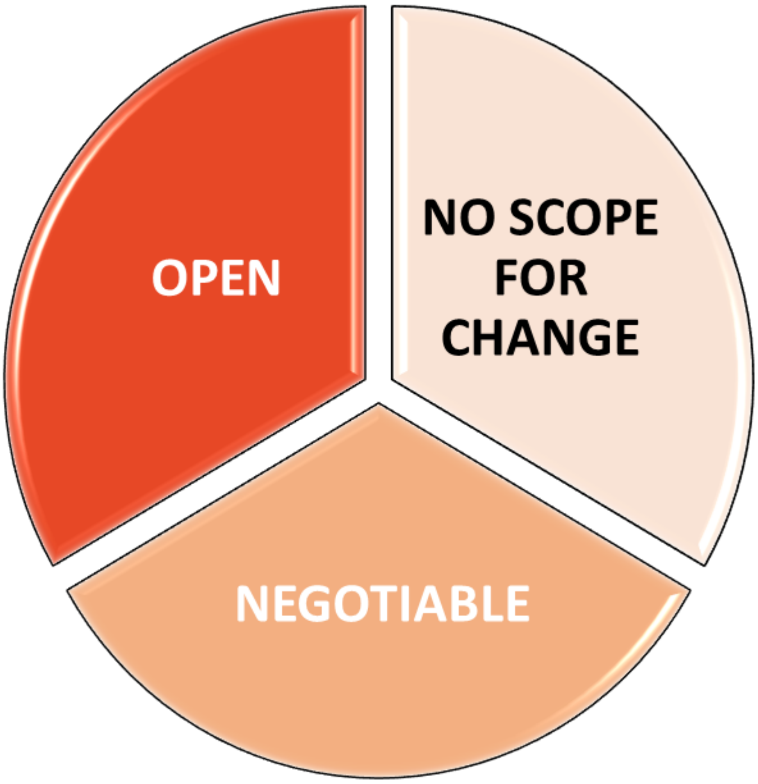


Figure 4: what is open to change

With this in mind, we have identified what we think can change for each of the identified purposes, and therefore what your promise to the public is.

Purpose	What could change?	What can't change?	Your promise to the public
Informing the public about how their data is collected and analysed, who can access it, what the approval process is, and the public health benefits that accrue.	● Target groups ● Content of materials	● The data collection ● Access to the data	We will communicate accessible, timely and accurate information about the work of the CDC
Involving the public in approving and designing projects - understanding their motivations and fears and using that information to guide decision-making.	● Amendments to project design ● Comms about the project	● No public veto - a collaborative approach ● Who proposes the project(?)	You can help us shape the projects we deliver using your data. We commit to explaining to you if and how you have had an impact on the project
I) Collaborating with the public to design and deliver the governance of the CDC including the role of the public. **II) Collaborating** with the public to design and deliver data projects	Level I ● Who is involved in governance? ● The structure and purpose of governance structure ● Key decisions including potential contribution to veto Level II ● Shape and structure of data projects ● Proposal for projects ● Potential veto over projects	● Decisions subject to legal restrictions (There will also be a set of decisions that are guided by partner requirements, funding stipulations etc where you will need to clearly articulate the scope for change)	If you decide to involve the public in design of the governance structure and then within this you will be promising: **Level I:** You will have a clearly defined role within the design and delivery of the governance of the CDC including the power to shape decisions. **Level II:** We will work with you to design and deliver data projects that meet your needs

Purpose	What could change?	What can't change?	Your promise to the public
Networking and learning so that different stakeholders and the public inform and empower each other in understanding and benefiting from public health data.	● Who finds out about the project and how? ● Who is at the table	● Decisions subject to legal requirements including privacy. ● The scope of the projects (this is a reporting and learning stage, not a decision making stage).	We will facilitate conversations between the public and different stakeholder groups so that you have an informed understanding of how your data is being used, and that stakeholders have an understanding of your priorities.
To **demonstrate best practice** in public engagement in the data stewardship environment.	● Membership of the network	● Decisions subject to legal requirements including privacy. ● The scope of the projects (this is a reporting and learning stage, not a decision making stage).	We will share what we learn from you with others in the sector to ensure our learning is cyclical and embedded across data actors.

Once purpose and scope have been identified, the final questions start thinking about methods. Which method can best achieve the purpose within the scope without exacerbating risk and in a cost effective manner:

1. How might you involve the public in order to achieve the purpose and when?
2. What are the risks which could be mitigated by effective public engagement / might be exacerbated by ineffective public engagement?
3. What level of expenditure on engagement is proportionate given the possibility for change and the risks identified? (Cost / Benefit)

Part 3: How to develop and embed public engagement in the CDC

Who needs to be involved?

The use of civic data for civic outcomes brings with it a wide range of stakeholders as well as the public. We would suggest that stakeholder groups be considered as a complementary part of public engagement, and that the CDC seek to embed cross-fertilisation between stakeholders and the public.

Our overarching suggestion for how the CDC might approach public engagement is to take a staged approach which will progressively become more embedded in the decision making processes of the CDC. This will allow the engagement with the public to move from 'Inform' to something deeper. In taking a staged approach, how much decision making is devolved can be assessed at each stage to ensure efficiency, effectiveness, and appropriateness. We believe this will allow the CDC to better understand the needs of the public and their interest in engaging as well as providing for the development of trust between the public and the CDC as you progressively delegate more of the decision making.

This approach will involve embedding public engagement in different communities (of place and of interest) across the city region, so could be scaled up to Cheshire & Merseyside if desired. This approach aims to also develop ties within and between communities and to ensure that the CDC is both utilising and supporting existing networks.

Our rationale for this approach is as follows:

Purpose

Your purposes are diverse and depend on the stage in the life cycle of the engagement and the public(s) you wish to engage with. Our approach seeks to build from the fundamental purpose of informing the public about how their data is used and the benefits that accrue. We feel building in this way will help avoid misunderstanding and disappointment about the role of the public. It will also demonstrate trustworthiness.

Publics

Your publics are also varied, and will have different incentives for participating, and different levels of influence. Our proposed approach seeks to embed cross-fertilisation across your publics, so they are informing and empowering each other as well as contributing to the development of an ethical and transparent CDC.

Scope

The scope of the engagement and the promise to the public varies depending on the level of decision making that is possible to be devolved. In some areas of the CDC operation the public will be able to have a stronger influence than in others. Our proposed approach allows you to be clear where change is possible, and where it is not, enabling you to answer the following questions about the purpose of the engagement:

- Is it to invite the public to inform decision making? To what extent?
- Is it to invite the public to 'authorise' (or refuse) something?
- Is it to find out the public's thinking on the trade-offs around ethics and public good?

It is also intended to deliver a transparent CDC which we believe will help you build an engaged audience who will want to participate. Effective public engagement requires your public(s) to want to be engaged.

Our approach also acknowledges that there is much that is not open to change. It seeks to provide a growing role for the public in the work of the CDC, such that the public understand the aspirations for their involvement, but also its limitations. It provides for strengthening feedback loops within and across the public and stakeholder groups so that as the engagement becomes more collaborative it remains fit for purpose for the CDC, stakeholders, and the public.

Our proposed methods[10] for this approach.

This approach aims to build engagement from the bottom up. The final stages will require the CDC to choose between developing a way of engaging in some areas which currently are not open to change or deciding to limit the involvement of the public in order to ensure that they are not asked to make recommendations which subsequently have to be declined. We would suggest that co-creation and a full public voice is a more sustainable approach which is more likely to build trust over the long term.

1. *A community conversation with communities of interest and / or place, including stakeholder groups.*

Aim: to ensure the principles of the CDC are fit for purpose and that all communications about the CDC are useful, accessible, and understandable across a wide variety of demographics and stakeholders.

Methodology: A community conversation methodology would partner with groups and organisations with existing networks. This could include:

- Providing resources and support for organisations to host their own conversations and provide an appropriate honorarium to participants to support their participation;
- Developing a pack to guide community hosts through the process, including a common conversation guide and options for different ways they might run the conversation tasks including online and face to face, together with an introductory PowerPoint presentation;
- Providing support for engaging different groups, such as:
    - Resourcing to provide British Sign Language translation and live captioning;
    - Alternative text simple picture descriptions (Alt Text) and fuller picture descriptions for the presentations;
    - Providing the presentation in different formats – e.g., large text and printed versions for visually impaired participants; and
    - The offer of translation into Easy Read format.

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[10] More information about different methodologies can be found on the Involve website https://www.involve.org.uk/resources/methods

- Providing a common feedback mechanism to collate the results from the conversations.

2. *An iterative development of people's panels that widen the community conversation to additional operational and decision making aspects of the CDC, including developing requirements for data access and whether that access should be contingent on public engagement within research projects.*

Aim: to begin to offer representative public involvement in setting the engagement standards for the CDC.

Methodology: This would involve the participation of a representative sample of the public which would be engaged in a deliberative process that would seek to develop and extend the community conversations. There would be a number of dialogues across the region over a period of months. This would build a picture of the aspirations of the public for the CDC and their role within it.

3. *Representatives from the panels and communities come together to decide the terms of a standing mini public which will act alongside any ethics / access committees of the CDC. These committees should be regularly and continually testing their approach with the group.*

Aim: to ensure the voice of the public is heard at all levels of governance and decision making within the CDC

Methodology: The precise method used to co-create this mini public will be decided by the representatives.

4. *The board (or other governance committee), any ethics and / or access committees will report regularly to the representative group and will receive updates from the group.*

Aim: to maintain lines of communication between levels of governance and the public.

Methodology: The precise method used for reporting will be decided by the group.

5. *The representative group will be responsible for reporting back and seeking feedback from the panels and communities.*

Aim: to keep the information flowing to all levels of the community and back to the centre.

Methodology: The precise method used for reporting will be decided by the group.

6. *As the knowledge and interest of the public grows, the CDC could consider commissioning a citizens' assembly to bring together a cross section of the region to review the operation of the CDC and make recommendations as to the future approach. It is suggested the assembly be asked to consider how best the Liverpool City region can use public data to improve public health outcomes and address inequality (with a view to meeting the SDGs).*

Aim: to publicly and fairly have a conversation with the region about the role of data in public health outcomes and tackling inequality in order that:

i. The public understand and see the value in data sharing and research access to that data; and
ii. Decisions about data sharing do not have unforeseen consequences that damage public health, increase inequality, and decrease trust.

Methodology: Best practice suggests that the design of a citizen's assembly should be a co-production process, with the stakeholders identified by a steering group. It is also possible to include members of the assembly in this process. Below we propose a potential wider public engagement to establish the remit and design of the assembly.

6.1 The citizens assembly's remit and design will be determined by the public in a facilitated workshop that is broadly representative of the panels and communities. It should be permitted to include consideration of the role of the public in:

a. Setting research priorities;
b. Approving research proposals;
c. Establishing criteria for access to the data;
d. Contributing to requirements for public engagement within research projects
e. Initiating research proposals;
f. Designing the communication about research - as it happens and any outputs and outcomes;
g. Suggesting areas for increased funding or attention from the CDC (ie identifying calls for research interest as well as reacting to incoming proposals); and
h. Identifying unintended consequences of research and suggesting mitigation strategies

Alternatively, you could skip straight to the citizens' assembly, but the risk is that without having done the groundwork with communities you do not stimulate interest. Aside from potentially impacting participation in the assembly itself, this would mean that the work of the assembly risks going under the radar and therefore being easy to dismiss. It would also mean that the stated aim of including all Liverpool Region residents in the CDC would be harder to achieve.

The CDC could reconvene a refreshed assembly annually or bi-annually to reflect on the work of the CDC and to hear from the panels (also regularly refreshed) established in 1-5. As time went on this could take the role of an AGM, with residence in the city region gifting membership of the CDC and the right to apply for membership of any of the public engagement processes.

Alongside this, a complementary piece of work with the identified communities of interest would seek to ensure that under-represented and easy to ignore groups were supported to both contribute through trusted intermediaries from inside the spaces where they felt comfortable and to be encouraged to participate in the wider engagement processes, with appropriate support, mentoring and pastoral care.

Additionally, the CDC could develop a pilot study or studies utilising either an existing research cohort - like C-GULL (a birth cohort study tracing the lives of over 10,000 Liverpudlians to understand more about what influences the health and wellbeing of children and their families living in the region), or by introducing the digital twin concept. However, we would suggest these are seen as additional defined projects within the overall approach. This would enable the CDC to test what sort of project level engagement might be possible.

Finally, the CDC should consider if it has a role in delivering wider education about data collection, processing, management and sharing. Certainly, by instigating transparent and effective communication about its own work, the CDC could demonstrate best practice about what the public should expect from those who seek to access their data. Equally, individual projects or pilots could be used as a wider educational tool by demonstrating principles, approaches and recommended public actions that could be applicable across the data stewardship environment and not just in the context of civic data.[11]

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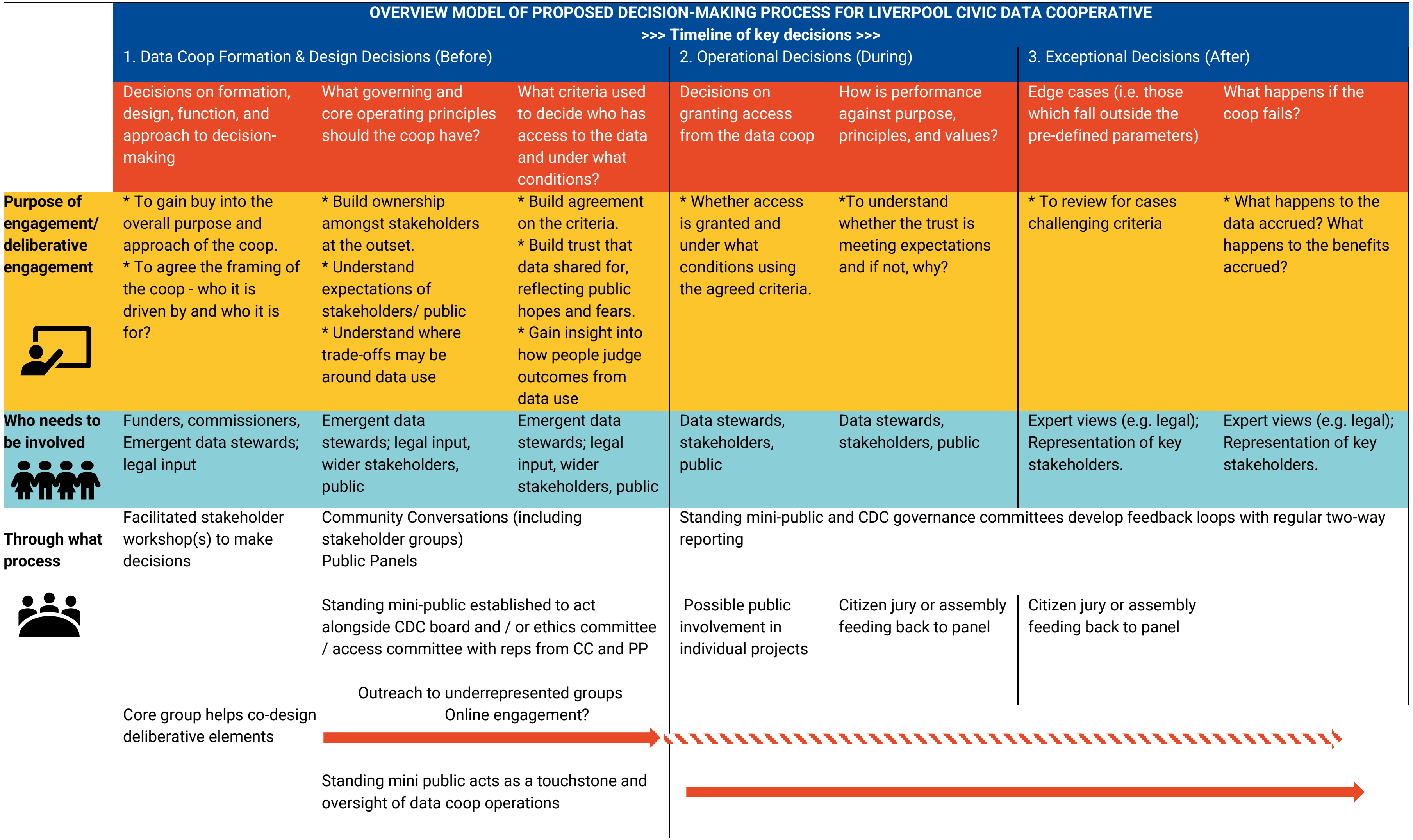
[11] Here we are imagining that, for example, in empowering the public to understand what happens to their data in the process of consenting to share it for civic purposes, the CDC could also offer guidance on how to interpret and apply cookie consents and other common data trawling tools.

An overview of the proposed decision making process, adapted from the [model Involve developed with the ODI](), revised to reflect our recommendations above.



OVERVIEW MODEL OF PROPOSED DECISION-MAKING PROCESS FOR LIVERPOOL CIVIC DATA COOPERATIVE

>>> Timeline of key decisions >>>

	1. Data Coop Formation & Design Decisions (Before)			2. Operational Decisions (During)		3. Exceptional Decisions (After)	
	Decisions on formation, design, function, and approach to decision-making	What governing and core operating principles should the coop have?	What criteria used to decide who has access to the data and under what conditions?	Decisions on granting access from the data coop	How is performance against purpose, principles, and values?	Edge cases (i.e. those which fall outside the pre-defined parameters)	What happens if the coop fails?
Purpose of engagement/ deliberative engagement	* To gain buy into the overall purpose and approach of the coop. * To agree the framing of the coop - 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 stewards; legal input	Emergent data stewards; legal input, wider stakeholders, public	Emergent data stewards; legal input, wider stakeholders, public	Data stewards, stakeholders, public	Data stewards, stakeholders, public	Expert views (e.g. legal); Representation of key stakeholders.	Expert views (e.g. legal); Representation of key stakeholders.
Through what process	Facilitated stakeholder workshop(s) to make decisions	Community Conversations (including stakeholder groups) Public Panels		Standing mini-public and CDC governance committees develop feedback loops with regular two-way reporting			
		Standing mini-public established to act alongside CDC board and / or ethics committee / access committee with reps from CC and PP		Possible public involvement in individual projects	Citizen jury or assembly feeding back to panel	Citizen jury or assembly feeding back to panel	
	Core group helps co-design deliberative elements	Outreach to underrepresented groups Online engagement?					
		Standing mini public acts as a touchstone and oversight of data coop operations					

Figure 5: Overview of decision making process for Liverpool CDC

Part 4: The CDC in 2032

As public engagement becomes embedded and normalised, we envisage the CDC moving from a series of interlocking and cross-pollinating groups to an organisation with the public voice at its heart. The structures of the CDC would be democratic, transparent, and accountable.

2023

If the approach we recommend above is implemented, we envision a number of complementary activities feeding in to and back towards each other, whilst also embedding a core structure centred on the Board, Ethics Committee and the representative mini-public, with an overlapping membership and co-operative relationship.

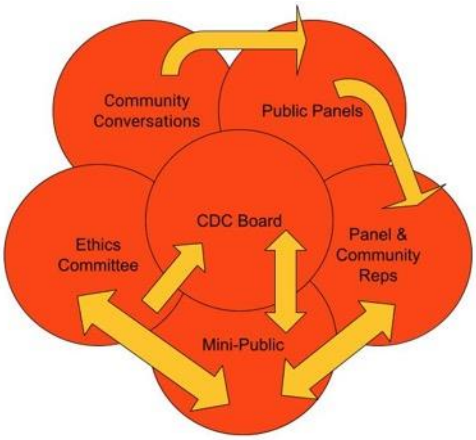


Figure 6: Potential model of the connections between public engagement and governance in 2023

2024

As the CDC develops, this core structure will be able to commission a Citizens Assembly to test current ways of working and discuss the future of the CDC, including ongoing, deepening, and embedding public participation.

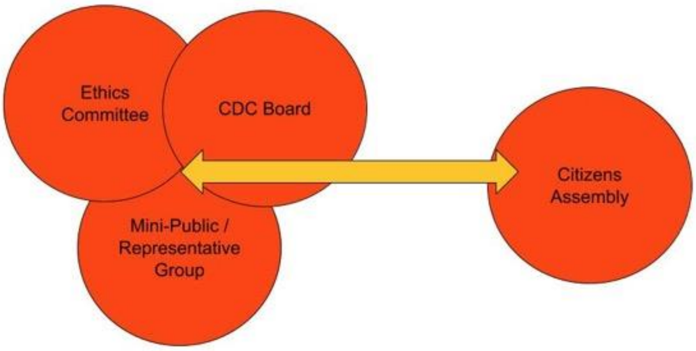


Figure 7: The next iteration of the public engagement – governance model is 2024

2032

Finally, one of the possible outcomes of this ongoing collaboration could be that the core structure remains, with mechanisms for membership open to all members of the co-operative (and membership of the co-operative open to all residents of the region), and accountability being met through an AGM.

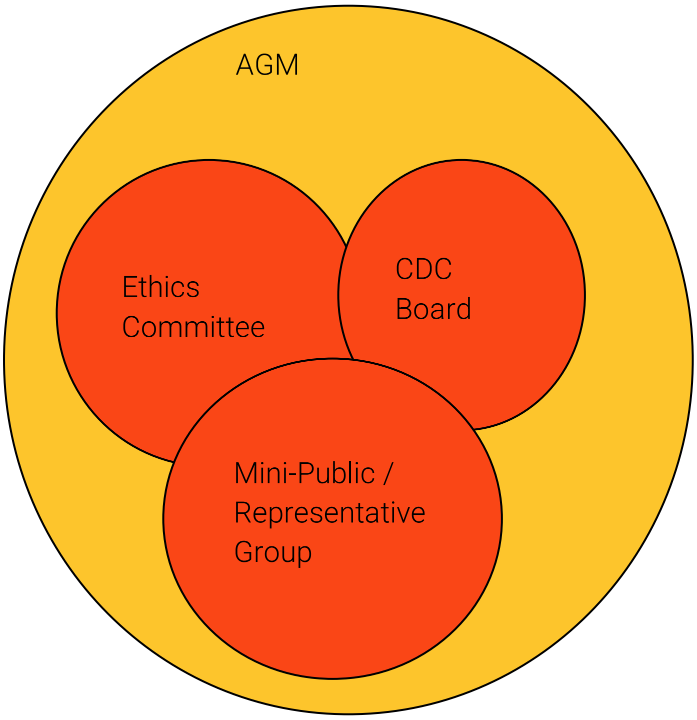


Figure 8: A potential end point for the public engagement governance model in 2032

Part 5: A Final Recommendation

The role of data in improving civic outcomes is growing exponentially. How data is collected, used, analysed, and shared is complicated and can be opaque. Poorly explained or overly technical methods of providing 'choice' for the public are prevalent. As our lives become increasingly governed by what data says about us, it is vital that the public not only are informed about how data about them is collected, analysed, and shared, but that they actively understand the implications and are able to participate in decision making, and possibly shape how the data is managed and used.

The growth of data trusts and data co-operatives, and their ambitions to demonstrate the public good that well managed data can deliver, as well as a desire to include the public in understanding trade-offs and making decisions around data collection, analysis and sharing is generating many different models and approaches.

Therefore, our final recommendation to the CDC is that it seeks to establish a Community of Practice around the role of the public in data stewardship and the use of civic data. The collection, management and use of data is changing and growing incredibly quickly. If we are to best understand how to act ethically and in the public interest; take the public with us; and delegate decisions to them about how data is managed, it is vital we learn from each other as well as testing our assumptions with our data subjects.

Involve has been impressed by the commitments the CDC is attempting to make to the people of the Liverpool City Region and we stand ready to assist in developing these aspirations.