

# INVOLVING THE PUBLIC IN ROBUST AND TRUSTWORTHY DATA SHARING



INVOLVE & THE CARNEGIE UK TRUST

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## EXECUTIVE SUMMARY

Involve, the Carnegie UK Trust and Understanding Patient Data published the [Data for Public Benefit Report](#) in April 2018.

The key findings from this report emphasised a need for government organisations to test for **purposeful, proportionate** and **responsible** use of data should they want to increase data and information sharing in their organisations. The report developed a framework to help public service providers to do this.

Involve and the Carnegie UK Trust then invited local and central government representatives to interrogate and respond to the report and framework at a workshop in September 2018.

They identified five areas where the framework in the report could support public service providers in assessing data and information sharing initiatives: **identifying purpose, decision-making, partnership working, best practice** and **communications**.

Key research questions to explore further with the public on data and information sharing identified by attendees can be categorised around: **Purpose, Acceptability, Implementation and Resourcing**.

Core features from Citizens' Jury, Citizens' Panel & Distributed Dialogue engagement methods were highlighted as useful for engaging the public on data sharing and include: **a structured process; ability to tailor questions; simple to implement & sustain; & a grassroots approach**.

Involve and interested local authorities are now planning the next stage of this work to test these conclusions through engaging members of the public directly around potential new data sharing initiatives.

Part one of this report looks at [developing more robust data sharing proposals](#) and part two at specific [methodologies for developing trustworthy data sharing](#).

## PART 1: DEVELOPING MORE ROBUST DATA SHARING PROPOSALS

### INTRODUCTION

This briefing reviews the Data for Public Benefit [Report](#) produced by Involve, the Carnegie UK Trust and Understanding Patient Data. It reflects on the extent to which the framework within the report can support public service providers to assess the public acceptability of new data and information sharing initiatives.

Involve, with funding from the Carnegie UK Trust and support from Stephen Curtis (Centre of Excellence for Information Sharing) developed a workshop in September 2018 to bring together a group of experts from within local and central government. The workshop explored how the report and framework might be used to support more effective and acceptable data sharing. Please see Appendix A for details on attendees.

Partners were invited to explore, and stress-test the report and framework in greater detail against live data and information sharing initiatives. The overall feedback from attendees was very positive with some useful suggestions to help strengthen the report further.

This briefing paper draws out conclusions from the workshop to support organisations in how to best implement the findings and framework from the Data for Public Benefit Report.

## APPROACH & RESULTS

### Context

The Data for Public Benefit Report was published in a context where:

- More data is being produced than ever before from a variety of sources.
- There is growing awareness within government of significant potential benefits from linking, sharing and using personal data.
- There are significant financial and resource pressures on public services.
- Data sharing is sporadic and uncoordinated.
- Data sharing is sometimes not happening for purposes which would be perfectly reasonable and in other situations is occurring in ways which push the bounds of public acceptability.

The Data for Public Benefit report argues that a risk averse culture in the public sector combined with a poor understanding of the Data Protection Act and new General Data Protection Regulation (GDPR), plus limited data science skills and transparency were creating some of the above challenges. The report identified that these were being exacerbated by no clear definition of the term “public benefit” and a lack of understanding of what the public views as acceptable use of data.

### The Research

The findings in the report are based on workshops involving over 120 professionals working in Housing; Criminal Justice; Health; Social Care and Welfare. Research was carried out in the following six local authority areas:

- Greater Manchester Combined Authority/GM Connect
- West Midlands Combined Authority
- Leeds City Council/Data Mill North
- Sheffield City Council
- Melton Borough Council
- Essex County Council

These workshops were supported by The National Data Guardian’s Panel, Understanding Patient Data and Open Rights Group.

Participants were provided with case studies of projects using shared data and were asked their perspectives on the following three areas:

1. How they understood, defined and valued the ‘public benefits’ provided by data use.
2. How they identified and attributed the potential risks and harms of data sharing.
3. How they balanced benefits against risks of data sharing initiatives.

### The Results

The report drew the following conclusions from this research:

- There is no common framework that public service providers draw on to identify the risks and benefits of data and information sharing.
- There are significant differences in the way different stakeholders understood the concept of public benefit.
- This has a significant impact on considerations of acceptable uses of data.
- If public confidence and support for increased data sharing is to be translated into the social licence for organisations to use data more widely, then the public needs to have the opportunity to contribute to discussions about the appropriate uses of data.
- Five key features of a data sharing initiative for public benefit were identified: **high quality service delivery; benefit to wider public; respects the individual; supports effective use of public resources & creates tangible benefits.**

The report presents a framework, based on the above findings, for public service providers to use when testing new data sharing initiatives. The framework can be found in Appendix B.

Overall, the key findings from this report emphasised a need for government organisations to test for **purposeful, proportionate** and **responsible** use of data should they want to increase data sharing in their organisations. The framework aims to support local organisations make this test an active element of the development of all proposals to share and use data.

## LOCAL & CENTRAL GOVERNMENT RESPONSE

***“I will take the Data Sharing Framework and implement it across North West London.”***  
*Kwesi Afful, Digital Citizen & Innovation Lead, North West London Collaboration of Clinical Commissioning Groups.*

In September 2018, local and central government representatives working in this area were invited to explore and stress test the report and framework. These discussions were held in the context of the question: “To what extent will building a better understanding of public perspectives help support public service provider data sharing initiatives?”

Their responses are categorised into three key areas below: value of public engagement, areas for further exploration and how the framework could help service providers.

### What is the value in engaging with the public about data and information sharing?

When asked whether it was important to engage with the public, attendees provided the following arguments for why it was important for their work on data sharing:

*“Yes - there is an erosion of trust in public institutions & private organisations in relation to collection, use & sharing of data. Engagement, communication & deliberation at the earliest possible stage will help create trusted frameworks & realise benefits.”* **Maeve Walsh, the Carnegie UK Trust Associate**

*“It is important as it ultimately affects them. It's most important.”* **Kwesi Afful, Digital Citizen & Innovation Lead, North West London Collaboration of Clinical Commissioning Groups**

*“We have huge potential for improving people's lives with data in Scotland: world leading datasets and academic power informatics. We have a good reputation for safe and fair use of public data. Having public engagement in decision making is key in maintaining trust, enabling the value from data to be realised: saving time, money and lives.”* **Roger Halliday, Chief Statistician & Data Officer, Scottish Government**

### Areas for further exploration

During the discussion attendees identified several areas which will need to be explored further as the framework is tested inside organisations and with the public:

- How can the framework be most effectively used in partnerships or with multiple stakeholders?
- What does meaningful public engagement look like? Especially with high population numbers in a region? How do we build something sustainable and cost effective?
- Could you run a process to get the public to weight scores/give confidence so that you can then assign a score to acceptability?

### How can the framework help public service providers?

Participants provided some very positive feedback to the overall report and around how they could see the framework being helpful for public service providers to use. It was identified that the framework would be beneficial in the following areas:

- **Identifying purpose:**
  - Helps identify priorities for public service providers– the point to negotiate.
  - Helps articulate the concerns: the things we would need to see improved – quicker than we would have.
  - Supports engagement with multiple publics and the identification of the communities which are relevant and need to be engaged in decisions about the acceptability of data sharing.
- **Decision-making:**
  - Creates nuance for decisions.
  - Provides a tool to focus on where key leadership decisions need to be made.
- **Partnership working:**
  - Supports a staged approach to partnership, focusing internal discussions about the purpose of sharing before entering partnerships.
  - Facilitates quick assessments of whether to proceed or not.
- **Best practice:**
  - Provides a mechanism for thinking about the development of Data Protection Impact Assessments (DPIA).
- **Communications:**
  - Prompts effective discussion.
  - Helps inform communications and messaging on data sharing purposes from gatekeepers to the public on what they want/need through developing a better understanding of public perspectives.
  - Provides a focus thus highlights the need to engage the public on the acceptability of data sharing in different contexts.

## NEXT STEPS

The next steps for this work are to test the findings of the report and the responses from local government against real life potential data sharing initiatives directly with the public. This work is still being explored by Involve with several interested local authority areas.

If this is something that you are interested in finding out more about or exploring further, don't hesitate to contact Simon Burall ([simon@involve.org.uk](mailto:simon@involve.org.uk)) or Lizzie Adams ([lizzie@involve.org.uk](mailto:lizzie@involve.org.uk)) at Involve.

## PART 2: METHODOLOGIES FOR DEVELOPING TRUSTWORTHY DATA SHARING

### 1. Summary of Key Conclusions

- This section outlines findings from discussions between local authorities and devolved administrations interested, in principle, in exploring public engagement around data and information sharing initiatives.
- The discussions are from a workshop delivered by Involve in September 2018, funded by the Carnegie UK Trust, for those interested parties.
- Key research questions attendees wanted to explore with the public on data and information sharing can be categorised around: **Purpose, Acceptability, Implementation and Resourcing.**
- The key features from Citizens' Jury, Citizens' Panel & Distributed Dialogue engagement methods identified as useful for engaging the public on data sharing include: **a structured process; ability to tailor questions; simple to implement & sustain; & a grassroots approach.**

### 2. Introduction

Local authorities and devolved administrations across the UK are exploring better ways to engage the public for many different reasons. In doing so, they face the ongoing challenge of engaging in ways that are sustainable whilst still feasible to resource and implement. This is just as true for those concerned about engaging the public in decisions about when to share data and information as in other areas of their work.

This paper outlines findings from discussions between local authorities and devolved administrations interested, in principle, in exploring public engagement around data and information sharing initiatives.

This paper identifies key research questions that these local authorities and devolved administrations would like to ask the public. It then outlines selected features from engagement methods that were identified as robust and beneficial aspects that should be used when looking to test new data sharing initiatives with the public.

This paper concludes by outlining the next steps for this work looking at how these attendees (and others) can continue to work together and explore a common approach to public engagement in this area.

### 3. What are the research questions to explore with the public?

We have summarised the shared research questions that participants would like to investigate with the public into the following themes:

- **Purpose**
  - Testing individual projects: what are the intended actions – do the public want it?
  - Do the public recognise that the specific issue is one to be addressed?
  - What would the identified “at risk” groups want from this data sharing intervention?
    - Is there a concern around potential for stigma/unintended consequences of data use/self-fulfilling prophecy scenarios if pigeon holing “at risk” status groups?
  - What does the public know that data doesn't know?
  - What are the limitations of data sharing, how to manage public expectations?
- **Acceptability**
  - What are the conditions under which data sharing becomes more acceptable?
  - What level of transparency do the public need?
  - How do the public understand risk/benefit of data sharing – and how should systems be set up to take account of this?
- **Implementation**
  - What are the “problems” the public think data should be used to solve?
  - What do the public think about their health data being used in ways that won't directly benefit them as individuals?
  - Do the groups targeted think using data to do this is good?
  - What is the right timing of engagement? Are we making a prior assumption of public interest? How to avoid retrospectively including the public?

- Should predictive modelling at individual level be used (even if highly secure)?
- Potential for different levels of public engagement depending on risks?
- **Resourcing**
  - What do the public think about using data to support people to use alternative services which might be better suited to their needs?
  - Linked to above: How do the wider public view the resultant shift in resources that will be required?
  - What are public views on linking data & secondary uses? What are the implications for consent?

#### 4. Features of the methodology

The following three public engagement methodologies were shared with participants at the workshop: Citizens' Jury, Citizens' Panel and Distributed Dialogue processes. Attendees then had a chance to explore and ask questions on each methodology. Various positive and negative features of each methodology were analysed in the context of engaging the public on data and information sharing initiatives.

The conclusions drawn by participants on each methodology were as follows:

##### *Citizens' Jury*

Participants thought that this is a recognised brand that could be tailored and straightforward to deliver. The limitations on scale and representation were highlighted as impacting on the outcome of the engagement process in some circumstances.

##### *Citizen's Panel*

Discussions focused on the benefit of working with existing panels using this method but questioned the reliability of the results and thought that questions could be less nuanced and therefore findings less detailed.

##### *Distributed Dialogue*

Participants appreciated the focus on dialogue, building of trust and grassroots nature of this method. Several key risks were also highlighted including a lack of control over the quality of the process and write ups and the risk of a low up take from potential participants.

Overall, there was support for a more structured process as some identified that this provided greater sense of control, helped build legitimacy for the process and allowed for combining useful elements of different methods to answer specific questions.

There was however a split in the room over this conclusion. This demonstrated the tensions and trade-offs that local authorities need to consider when designing an engagement process. They must consider how prescriptive they make the process versus how much control they share with the public and other stakeholders over the design and structure of engagement.

Please see the appendix document for more detail on these discussions, an explanation of each methodology which was shared with participants before the workshop and the list of attendees.

#### 5. Next steps

There was clear interest and support expressed in the room for continued discussion and momentum around the identified synergies between participants. It was agreed that a joint approach moving forward would help with sharing learning and providing increased output, but equally the importance of context for each party was acknowledged. The conclusion from the afternoon session was for Involve to work with interested parties to continue these discussions. The aspiration from those in the room was to turn the above features into a methodology for testing data and information sharing initiatives directly with the public.

*Authors: Lizzie Adams & Simon Burall, January 2019*

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## APPENDIX

### Appendix A – Attendee Organisations

Kent County Council

Melton Borough Council

Information Commissioner's Office

West Midlands Combined Authority

Corsham Institute

North West London Collaboration of Clinical Commissioning Groups

Scottish Government

Understanding Patient Data

Department for Education

Involve Foundation

The Carnegie Trust UK

Centre of Excellence for Information Sharing

THE INVOLVE FOUNDATION (KNOWN AS INVOLVE)

REGISTERED CHARITY NO: 1130568 (ENGLAND & WALES)

REGISTERED CHARITY NO: SC047314 (SCOTLAND)

CARNEGIE UNITED KINGDOM TRUST

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## Appendix B - Data Sharing for Public Benefit Report Framework

### Framework for assessing the merit of a data sharing activity to deliver 'public benefit'

Checklist covering key elements of 'public benefit'		Where does your data sharing proposal lie on the scale?			
<b>1. That the use of data enables high quality service delivery which produces better outcomes for people, enhancing their wellbeing.</b>	Does the individual's whose data is being used directly benefit from improved service provision?	No direct benefit provided to the individual			Clear and direct benefits provided to the individual
	Is the use of data able to deliver long term, life changing benefits to individuals?	Unlikely to deliver long term benefits			Very likely to deliver long term benefits
	Will the use of data have punitive impacts on individuals?	High risk of punitive impacts for individuals			Very low risk of punitive impacts
	What is the risk that individuals or communities will suffer unintended negative consequences as a result of the data sharing i.e. as a result of stigma, discrimination or inappropriate targeting?	High risk of unintended negative consequences			Very low risk of unintended negative consequences
<b>2. That the use of data delivers positive outcomes for the wider public, not just individuals;</b>	Does the use of data deliver wider social benefits?	The benefits are just for individuals			There are multiple types of beneficiaries
	Does the initiative address the root causes of social problems/issues?	The approach addresses the symptoms			It addresses the root cause
	Can the use of data inform strategic service changes in ways that could have significant impacts on both public service providers and community wellbeing in the future?	Limited strategic value to inform service changes			High strategic value to inform service changes
<b>3. That the initiative uses data in ways that respects the individual, and their privacy, not just in the method of sharing but also in principle.</b>	Is only data that is necessary to achieve the purpose being shared?	Wide data sets shared without filtering			Sharing strictly limited to necessary data
	Does the use of data respect the privacy of the individual data subject?	Data routinely shared in personally identifiable forms			Data anonymised where possible and/or proactive steps taken to reduce privacy intrusions
	If data is being shared without consent, is it practical to gain informed consent without compromising the value of the data?	No efforts have been made to seek consent			Gaining informed consent is not viable
	Could the public reasonably expect data about them to be used for this purpose?	Very unlikely to expect data to be used this way			Very likely to expect data to be used this way
	How compatible is this use with the reason the data was originally collected?	Very incompatible			Very compatible
<b>4. That the use of data both represents, and supports, the effective use of public resources (money, time, staff).</b>	Does the use of data enable the delivery of 'better' public services, able to respond to what the majority of people need/want?	Unlikely to lead to more responsive service provision			Likely to deliver better, more responsive public services
	Does the use of data enable strategic planning that will deliver long-term efficiencies?	Unlikely to deliver efficiency savings			Likely to deliver efficiency savings
<b>5. That the use of data creates benefits that are visible, recognised and valued by service providers and the wider public.</b>	Are the benefits tangible and measurable?	Benefits are difficult to define			Benefits are tangible and measurable
	Are the benefits delivered able to be clearly attributed to the use of data?	Benefits not directly attributable.			Benefits clearly attributable
	Are the benefits able to be clearly communicated to the public?	Will need considerable explanation to demonstrate value to the public			Benefits will be immediately recognisable to the wider public
	Is the organisation able, and willing, to defend their use of data in this way if objections were raised?	Maybe not.			Absolutely
		The proposed use of data may not be recognised as delivering public benefits (but may still be justified on different grounds)	Some issues – think about whether there are ways to move answers further to the right	The proposed use of data is likely to be assessed as delivering 'public benefit'	

## Appendix C - Engagement Methodology Options

The text for the methods summarised below has been adapted from Involve's Knowledge Database.<sup>1</sup>

### *Distributed Dialogue*

A distributed dialogue is a decentralised approach to deliberation with the aim of developing dispersed ongoing sets of discussions around a given policy issue. It is based on the idea that complex issues need to involve a range of conversations that happen in different spaces.

The defining feature is that the dialogue events are self-organised by groups of participants, with the aim of engaging a wide range of communities in the discussions. While the overarching policy questions are the same, the groups or individuals organising dialogues enjoy autonomy over who is involved. They work best when there is a strong level of 'scripting' provided for the distributed events – with clear questions, background information and a planning and facilitation toolkit provided. By their very nature however the commissioning body has limited control over the quality of the discussion, the mix of people involved or the neutrality of the organisers/facilitators.

The method works to offset the limitations of more traditional methods; fixed time and place of workshops, limited numbers of participants; high costs of centrally organised events, and the top-down nature of traditional consultation and engagement methods.

The advantage of Distributed Dialogue is that it allows for the participation of a variety of actors, e.g. community activists, who will be able to reach citizens at the local level. Size of local discussions tend to range from 5-50 but have the potential to engage large numbers of people overall.

While distributed dialogues are, by design, open to everyone, there should be strong framing questions to ensure some degree of consistency across different dialogues and clear mechanisms for feeding into decision makers and ensuring outcomes are fed back to all participants.

Costs vary depending on the scope and breadth of the engagement. Central costs are contained and devolved through the involvement of local groups that run their own events.

#### **Pros**

- Ability to engage a large number of stakeholders and lay people in different locations;
- Insights into concerns and aspirations in different localities around the same issues;
- A cost-effective way of enabling large numbers to participate;
  
- Opportunities for continuous engagement integrated into decision-making; and
- Gives a high degree of autonomy and control to citizens.

#### **Cons**

- Can take a long time to organise; not suitable when fast action is needed;
- Encouraging others to run workshop can be resource intensive;
- Limited control of how discussions are framed or facilitated;
- Data collected can be inconsistent or contradictory;
- Difficult to ensure inclusiveness and transparency of local dialogues; and
- It is difficult to ensure inclusiveness and transparency of process.

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<sup>1</sup> <https://www.involve.org.uk/resources/methods>

## *Citizens' Jury*

A Citizens' Jury is a method of deliberation where a small group of people (between 12 and 24), representative of the demographics of a given area, come together to deliberate on an issue (generally one clearly framed question), over the period of 2 to 7 days.

They are relatively inexpensive compared to larger deliberative exercises, such as [Citizens' Summits](#) and [Citizens Assemblies](#). Their small size allows for effective deliberation, while remaining broadly representative and citizens are exposed to a wide range of perspectives.

Citizens' juries are broken into three broad stages. The first stage is dedicated to understanding the process that jurors are about to embark upon. They receive a brief overview of the issue and get comfortable with each other. The next is dedicated to hearing from the 'expert witnesses' aiming to provide a balanced and complete picture of the issue. The final stage provides time for the jurors to have concluding deliberations on the issue and answer the crucial charge question(s). The final decision is reached by either consensus or voting.

All phases are facilitated by a trained facilitator(s) who ensures a level playing field. On the final day a public forum is held where the jurors present their findings and recommendations and explain how they reached their decision. About two to three weeks later a final report is issued and made available to the public.

A Citizens' Jury can be used on different policy issues and it's particularly effective on value-laden and controversial questions, where knowledge is contested and there might be important ethical and social repercussions.

### **Pros**

- Direct citizen input;
- Impartial and objective decisions;
- Interrogation of issues and experts/evidence;
- Extended deliberation and highly focused discussion;
- Low costs for depth of deliberation; and
- Highly specified outcome delivered through a verdict.

### **Cons**

- Specificity of the issue/decision;
- Top-down framing of the question;
- Questions about who determines the criteria for the jurors' final decision; and
- Cost can appear high for the number of participants.

## *Citizens' Panel*

A Citizens' Panel aims to be a representative, consultative body of local residents. They are typically used by statutory agencies, particularly local authorities and their partners, to identify local priorities and to consult service users and non-users on specific issues.

Participants are generally recruited through random sampling of the electoral roll or postcode address file. Postal recruitment tends to be a popular approach given its wide reach and relatively low cost. However, a number are recruited by other means to ensure recruitment of socially excluded and hard to reach groups.

Citizens' Panels range in size from a few hundred to several thousand people. Participants are invited to a rolling programme of research and consultation. This typically involves regular surveys and, where appropriate, further in-depth research tools, such as focus groups and workshops. Not all members will be invited to take part in all Panel activities.

Larger panels can allow the identification of sub-groups of Panel members who can be surveyed or consulted about issues specific to their needs or interests.

Costs vary depending on the size of the Panel, the methods in which the members are consulted, the frequency of consultation and how often membership is renewed. In some cases, incentives are given to encourage participation in a Panel; for example, a prize draw.

Effort is required to keep the Panel database up to date, recruit new participants, and to run and analyse the consultations. Feedback on the outcome of consultation needs to be produced and spread among the participants (often through a newsletter) and among the wider public (often through local or new media).

Planning a sensible programme of research and consultation is important to ensure that a variety of topics and research methods are employed, and that activities are spaced out throughout the year.

### **Pros**

- Can be sponsored and used by a partnership of local agencies;
- Allows you to target specific groups if large enough;
- Allows surveys or other research to be done at short notice;
- Helps assess local service needs and identify priorities;
- Can determine appropriateness of developments within the area; and
- Can track local sentiments over time.

### **Cons**

- Needs considerable staff support to establish and maintain;
- Can exclude non-native speakers;
- Responses to surveys often reduce over time, particularly among young people; and
- Can exclude certain residents not comfortable participating in this way.

## Appendix D – Positive & Negative Features of the Methodology

Method	Positives	Negatives
<i>Citizens' Jury</i>	<ul style="list-style-type: none"> <li>• Straightforward/do-able (with expert facilitation).</li> <li>• Very easily tailorable/focus</li> <li>• Can be quite sophisticated in the info.</li> <li>• A recognised “brand” &amp; concept that has wider legitimacy [courts] – limited number but if were established for each project [this could help numbers].</li> </ul>	<ul style="list-style-type: none"> <li>• Small number of jurors means it is hard to ensure participants representative of wider communities.</li> </ul>
<i>Citizens' Panel</i>	<ul style="list-style-type: none"> <li>• Sometimes already exist and can be used in partnership.</li> </ul>	<ul style="list-style-type: none"> <li>• Need very “good” question construction.</li> <li>• Results could be less reliable.</li> <li>• Less nuanced.</li> <li>• Requires ongoing skills internally.</li> <li>• Limited depth of info.</li> </ul>
<i>Distributed Dialogue</i>	<ul style="list-style-type: none"> <li>• Emphasis on dialogue.</li> <li>• Gives away a bit of control – potential to build trust.</li> <li>• When goes well/multiple can feel grassroots/diverse/rich.</li> <li>• Potential for honest, reflective &amp; ongoing discussion.</li> </ul>	<ul style="list-style-type: none"> <li>• Question of lack of control may make results less robust.</li> <li>• Risk that if it doesn't take off/low uptake then lots of energy needs to go in to getting people involved.</li> <li>• Worry about handing over to different groups to summarise – creating different narratives.</li> </ul>