



Public views on organisations  
accessing health data

# Findings from our Festival of Data engagement activity



# Introduction

In February 2026, the Data into Action programme took part in the Festival of Data at ACC Liverpool. The event brought together families and members of the public to explore how data is used in society through interactive activities, exhibitions and talks.

As part of the event, the Data into Action team ran a short public engagement activity to explore how people feel about different kinds of organisations accessing health data for research and innovation.

Participants were invited to step into the role of a decision-maker and consider whether they would approve different requests to use health data.

The Festival of Data was hosted by the Civic Data Cooperative at the University of Liverpool. It was held at ACC Liverpool from 5 to 7 February 2026 and had over 400 families registered to take part.

Beyond the Data into Action exercise, which ran on 7 February, the festival included interactive data art exhibitions, short talks, face-painting, virtual reality experiences, and data games. The festival marked the end of the Civic Data Cooperative's ambitious 5-year programme of work around data stewardship and innovation.



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# What we did

Visitors to the Data into Action stand were invited to take part in a short interactive activity about how health data might be used for research.

The exercise was designed to explore attributes important to Cheshire and Merseyside residents in balancing profit and benefit in the approval of secondary health data sharing. Secondary health data sharing means sharing health data for purposes secondary to why it was originally collected. This could include using it to carry out research or for planning and improving health and care services.

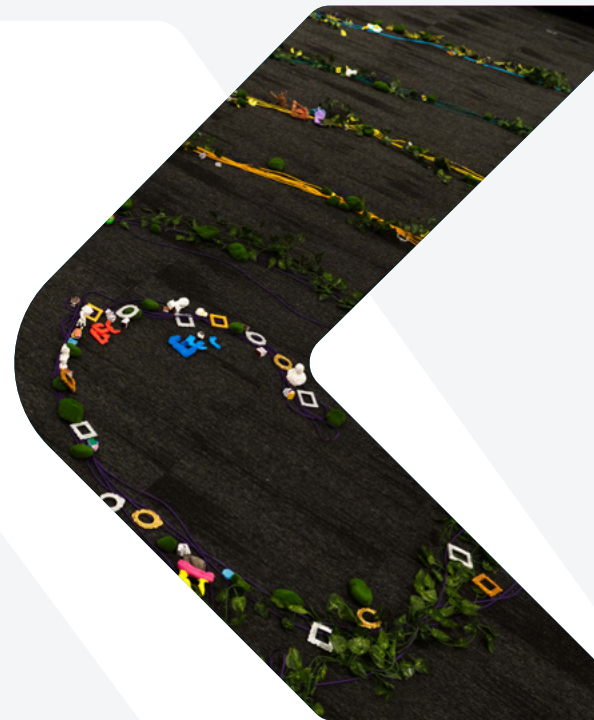
Participants were asked to imagine they were members of the Cheshire and Merseyside Data Access and Asset Group (DAAG). This group reviews requests to access data within the Secure Data Environment and considers whether projects should be approved.

## How this topic was chosen

This engagement activity was shaped with the help of the Data into Action Patient and Public Advisory Group (PPAG). The PPAG is a group of local residents who work with the programme to provide independent public advice and challenge.

In earlier work exploring public views on the use of health data, the PPAG helped identify commercial access to health data and the sharing of benefits as a priority topic for further public engagement.

Members of the PPAG also helped co-design the Festival of Data activity. Their input helped ensure the exercise asked meaningful questions and reflected issues that matter to the public.



# How the activity worked

Participants created a scenario by randomly selecting cards describing different aspects of a data access request. Each scenario included:

- An organisation requesting access (for example a university research group, a pharmaceutical company, an insurance company, an AI start-up or a health technology company)
- The type of health data involved (for example hospital care data, GP records, social care data, community services data or mental health services data)
- The purpose of the data use (for example improving patient care, research or commercial product development)
- The type of benefit offered to the community.

Examples of community benefits included:

- direct improvements to patient care locally
- publishing results openly with a plain-English report
- reinvesting money into the local NHS
- reducing health inequalities
- or providing no additional community benefit beyond paying to use the system.

Participants were then asked two questions:

1. If you were a member of the Data Access and Asset Group, how likely would you be to approve this request?  
(1 = highly unlikely, 10 = highly likely)



2. Thinking about benefits to the community, how acceptable does this project feel?  
(1 = not at all acceptable, 10 = completely acceptable)



# What we heard

**16 people participated. The mean answer to Q1 was 5.25 with a range from 1 to 10. The mean answer to Q2 was 7 with a range of 1 to 10.**



Although this activity involved a small number of participants, some patterns emerged.

## Paying to use the system alone was not enough

Projects that offered no additional community benefit beyond paying to access the Secure Data Environment received very low scores.

This suggests that participants expected something more than financial payment alone when organisations request access to health data.

## Reinvestment in the local NHS did not guarantee approval

Projects that included financial reinvestment into the local NHS were often seen as acceptable in principle. However, participants indicated that reinvestment alone would not usually be sufficient to justify approving the request.

This suggests that financial return may be one factor people consider, but they also expect clear public benefit from how the data will be used.

## Improving patient care locally received the strongest support

Projects that included a direct commitment to improving patient care locally received the highest approval scores.

Participants appeared more comfortable approving requests where there was a clear and tangible benefit to patients or services.

## Transparency mattered

Participants responded positively when organisations committed to publishing results openly and providing a plain-English summary of findings.

This suggests that transparency and accountability play an important role in acceptability.

# What we heard

Participants also shared comments about why they chose their ratings.

Two emerging themes came up:

## People wanted more information

Some participants said they would have rated projects more positively if they had more information about:

- how the data would be protected
- how organisations would be monitored
- how the public benefit would be delivered.



## Concerns about privacy and profit remained important

Even though the activity explained that data would be accessed securely, participants still raised concerns about:

- data protection
- privacy
- organisations making profit from health data.

These themes are consistent with feedback from previous public engagement work in Cheshire and Merseyside.



# What this means

This activity involved a small number of participants and was designed as a quick engagement exercise at a public event. The results should therefore be seen as directional insights rather than representative findings.

However, the results echo themes from earlier engagement work carried out as part of the Data into Action programme.

In particular:

- People appear to care more about **why health data** is used than **who is using it**
- Clear and meaningful **public benefit** is important when deciding whether data access feels acceptable
- **Transparency and accountability** help demonstrate trustworthiness in how data is used.



# What happens next

This activity helped us test a new way of asking people about how benefits from health data use should be shared.

We will use what we learned to:

- continue working with our Patient and Public Advisory Group (PPAG) to explore what “public value” should mean when organisations request access to health data
- design future public engagement activities on this topic

We will continue to seek input from local residents, patients, carers, and community groups to help guide how health data is used to support research and improve health and care.



## Find out more

If you would like to learn more about the Data into Action programme and how health data is used to support research and improve health and care in Cheshire and Merseyside, visit [dataintoaction.cheshireandmerseyside.nhs.uk](https://dataintoaction.cheshireandmerseyside.nhs.uk)

You can also find out more about:

- the role of the Secure Data Environment (SDE)
- opportunities to get involved in public engagement activities
- how to join our Patient and Public Advisory Group (PPAG).

Stay  
positive

