Public and Patient Perspectives on Non-Traditional Health Data Uses in Cheshire and Merseyside

Exploring Commercial Access, Artificial Intelligence, and Indirect Health Data

Prepared on behalf of the Data into
Action Programme by the Liverpool City
Region Civic Data Cooperative and Civic
Health Innovation Labs
October 2025

Contents

Short Summary

This report summarises public and patient involvement and engagement with the Cheshire and Merseyside (C&M) Data into Action programme on non-traditional health data access and uses. We define non-traditional health data access as access or sharing beyond primary (direct care) and secondary (academic research, planning, and risk stratification) uses.

For this report, this includes health data access for commercial organisations, linking non-NHS data to NHS data (indirect data), and using data to train or test AI systems.

Public attitudes research is consistent, in that most UK residents are wary of unregulated commercial data access and indirect health data usage. Publics are supportive of AI if it's used in health care diagnosis and treatment but sceptical of mental health uses. Concerns include data misuse, privacy breaches, unequal benefits sharing, lack of accountability, and lack of transparency. Nevertheless, there is a political push for greater commercial integration with health data systems, on the one hand for improving both NHS systems and patient care, and on the other for opening a proposed revenue stream for the NHS.

Over the past year, we have supported 91 C & M residents to debate, in detail, their concerns and hopes around non-traditional health data uses. This includes a series of conversation cafés on commercial data access, a large-scale Residents' Assembly, and review of national survey data. In terms of public and patient opinion, we found the following:

- Residents are tentatively supportive of AI, commercial data access, and indirect health data linkage if it is clearly in support of public and community benefit.
- The NHS including organisational and patient-facing arms is highly trusted with health data, but trust drops immediately outside of health contexts.
- Social media and insurance health data access is a clear red line.
- Corporate profit-making and community benefit are seen as opposing goals by residents, nevertheless they want corporations to pay for access to data.
- Residents views on non-health/indirect data usage vary greatly but they want minimal intrusiveness prioritised.

This work represents a continuation of the Data into Action programme's patient and public engagement work. These case studies will be used both to further develop the programme and to further progress the Cheshire and Merseyside Secure Data Environment. This includes the signing of the Liverpool City Region Community Charter on Data and AI, which was formalised on July 3rd, 2025.

Introduction

This report summarises public and patient involvement and engagement with the C & M Data into Action programme on non-traditional health data access and uses. We explore these topics primarily through two case studies of public engagement from 2024 and 2025 conducted in C & M.

This report builds on two key recommendations from 2023-24 on further public engagement with residents. Specifically:

- C & M resident perspectives on sufficient public benefit for commercial access to health data
- The regulation and governance of AI technologies that are built from health data in the Secure Data Environment

As Data into Action continues to develop, there is increased interest in non-traditional data uses both for the advancement of public health benefits and for recompensing the financial costs of the programme. Therefore public engagement on these topics is of immediate priority.

About the Cheshire and Merseyside Data into Action programme

Data into Action uses health and social care information to improve services across C & M. It is a programme of work that sees our NHS, local authorities, the University of Liverpool and other key partners working together to improve health and care for the 2.6 million people in the region.

When people see a GP, go to hospital, or receive care in a care home, information is recorded to help them receive the best possible care. Data into Action uses this information to see what our health and social care services are doing well, to identify how they can improve, and to support them to make positive changes.

Our core areas:

- Improved care: Working together with the local healthcare system to provide better care for patients with complex health needs through prevention, faster diagnosis and improved treatment.
- Advanced analytics: We link and analyse data to identify and support people with complex needs who are at risk of developing health conditions. We use techniques including risk stratification, segmentation, predictive modelling and matching.
- Evidence-based change: We use evidence to evaluate the impact of different healthcare treatments and models of care to support the development of new pathways and interventions.
- Information management: We ensure that your data is safe. We make sure your health and care information is properly protected and adhere to all legal, organisational and ethical obligations.
- Population Health Management Academy: We share the learning and insight that we have gained to equip people with the knowledge, skills, systems and processes to lead transformation for C & M.
- Infrastructure and data assets: We are continually advancing our technical capability by supporting the development of our strategic architecture and associated data.
- Connecting people: We bring together different teams within the C & M Integrated Care System to make the best use of expertise to better support patients.
- Public involvement: We work in partnership with people and communities to improve health and care.

Background

UK residents are worried about data misuse, privacy, and a lack of public benefit in non-traditional uses

We define non-traditional health data access as access beyond primary (direct care) and secondary (academic research, planning, and risk stratification) uses. For this report, this includes health data access for commercial organisations, linking non-NHS data to NHS data (indirect data), and using data to train or test AI systems.

There is extensive social research and public engagement that demonstrates the acceptability of health data for secondary uses like research (Cascini et al., 2024; Jones et al., 2022; Kalkman et al., 2022). This includes a series of workshops held last year in C & M that demonstrated consistent support for data sharing for academic research in the region (E. S. Rempel, 2024). However, publics only support data sharing for research that demonstrates clear public benefits to themselves, their communities, or NHS systems. There is also a consistent finding across this research and engagement that publics are sceptical of sharing data with commercial organisations (Aitken et al., 2016; E. S. Rempel, 2024). Adding to this, growing public concerns around the social and economic impacts of AI puts health data access for non-traditional uses firmly in the 'no' column for many (Aitken et al., 2018; Marres et al., 2024; Modhvadia et al., 2025). Before looking at what this means for C & M, we summarise below existing public attitudes research on our three non-traditional health data use cases.

Commercial access to health data may be acceptable under strict conditions and governance

A large-scale UK public deliberation exercise by Ipsos Mori in 2016 found that health data sharing for commercial access could be more acceptable than not under certain conditions (Ipsos MORI et al., 2016). Data sharing with commercial organisations was acceptable if it provided public benefit, had a link to improve health, and had no risk to identifiable information being re-identified. Marketing and insurance companies were not acceptable in any circumstance. However, 1 in 4 participants said they would prefer research not to happen at all if commercial organisations had to have access.They concluded that in addition to these standards being met, clear opt-out mechanisms and significant public communications and engagement would be necessary for commercial health data sharing to move forward (Ipsos MORI et al., 2016). More recently, Tully et al. (2019) conducted a citizen jury in Manchester and York of 36 people to debate commercial use of health data. While opinions varied, more were positive than negative at the end of the jury. They similarly found commercial use of health data would be acceptable if underpinned by public benefit.

Perspectives on indirect health data linkage are highly variable with mixed support

Commercial organisations collect immense amounts of data on individuals as indirect health data (Kostkova et al., 2016; Schneble et al., 2020). Examples include everything from step counts to individual travel patterns to what people buy in the grocery store or search for on the internet. Hirst et al. (2023) surveyed 1,534 UK residents on their willingness to share indirect health data. They found trust in organisations was the largest predictor for willingness to share with the NHS. Loyalty card data was most supported followed by internet history, smart phone data, and then data from wearable tech. Social media data was least supported with 69% saying they would probably not to never want to share this data for health usages. Respondents' level of concern about data being misused or privacy breaches best predicted their willingness to share. The Health Foundation has similarly disaggregated kinds of indirect health data in surveys looking at support for linkage with NHS data and use in AI (Binesmael et al., 2024; Thornton et al., 2024). They found the strongest support for linking data stored in phones, e.g. step counters, which had 48% support. Whereas respondents were not supportive of linking NHS data to information about shopping (64% did not support) or social media (68% did not support). It's important to note that none of these non-traditional data types met a threshold of majority (50%) support (Binesmael et al., 2024). These surveys demonstrate a high amount of variation in public perspectives on indirect health data linkage.

Artificial Intelligence in health may be supported if human interaction is maintained

Public opinion and debate on AI has been at the forefront of media in recent years as large language models like ChatGPT® become increasingly familiar (Marres et al., 2024). The Ada Lovelace Institute and Alan Turing Institute report routinely on public attitudes to data and AI in the UK (Modhvadia et al., 2025). In their most recent 2024 survey wave of 3,513 people, they asked about two healthcare uses of AI: mental health chatbots and diagnosing cancer. They found less than half of people were familiar with either use, 25% and 40% respectively. Whereas 61% of people were familiar with ChatGPT®. Survey respondents were highly supportive of using AI in cancer diagnosis but conversely highly concerned with mental health chatbots. 63% of respondents were fairly or very concerned about this latter use (Modhvadia et al., 2025). Their most frequent concerns include the loss of human interaction and providing misleading advice. Other UK surveys have found strong AI scepticism in health care. In the aforementioned 2024 survey by The Health Foundation, only 2 in 6 respondents thought AI would improve care quality and 1 in 6 thought AI will worsen it (Thornton et al., 2024). This shows a similar pattern to other kinds of data technologies, namely that support for and acceptability of AI depends on how people perceive it's potential to deliver public benefit.

Non-traditional health data access is controversial in the UK but already happening

Adding to the narrative of both public support and scepticism, health data is already routinely shared with commercial organisations in the UK (Kostkova et al., 2016; Marelli et al., 2021). For example, with technology companies who provide the software that underpins NHS data sharing infrastructure or for commercial research purposes (Marelli et al., 2021). These examples, however, are usually one-off use cases of individual data sharing agreements. Beyond NHS data, as mentioned, commercial organisations already collect immense amounts of health data through smartphones and the internet (Kostkova et al., 2016; Schneble et al., 2020). They sell that data to marketers and insurance companies without needing NHS data access or approvals. Kostkova et al. (2016) describe the immense scale of non-traditional data in healthcare and call for increased training, public involvement, and transparency to address it. Schneble et al. (2020) highlight the risks in the limits of EU GDPR, for example, in regulating these kinds of health data. They point out that indirect and inferred health data (new information being produced from combining two or more data sources) do not fall under the GDPR health data sharing guidelines and therefore have unclear legal ramifications. Marelli et al. (2021) assert that 'big tech' is aware of this leeway and have purposefully moved in to health research as it allows for greater opportunities for high value data access and subsequent profits.

Beyond tech-centric narratives, this kind of non-traditional health data could be immensely useful to health researchers to help to fill gaps in existing administrative data sources like GP records and hospital episode statistics (Kostkova et al., 2016; Schneble et al., 2020). Similarly, commercial organisations are keen to have access to NHS data which can provide reliably standardised health information for training and testing AI systems for health care. Some put the value of selling NHS data at £250 million annually (Kakkad et al., 2024). It is understandable then, that National government sees the sale of NHS data access as a way to address an overburdened health system (Donnelly, 2024). This kind of tech-centric and profit-driven narrative of NHS health data does not go unchallenged. Cheung (2020), for example, calls for a reimagination of the narrative on commercial health data sharing. They state that a common 'trade-off' fallacy exists within the NHS. Specifically, that commercial data sharing must happen to benefit society despite public concern.

"In this scenario, despite public aversion to commercial involvement and fears over ensuring harms, in accepting the social need to improve public health through increased sharing and reuse of their personal data, individuals are tied into accepting any subsequent commercial involvement and financial benefit that may derive from the pursuit of important 'public benefits'."
(Cheung, 2020, p. 9)

In other words, it is easy to colloquially overrule public concerns in the name of public benefits. But more broadly, non-traditional health data sharing and access is already happening, it's just not benefiting the NHS at scale.

What this means for our publics and patients

Public attitudes research is consistent that while many UK residents are wary of unregulated commercial data access, they are supportive of health data projects if they can demonstrate public benefit. It would be reasonable to propose this would also hold true for C & M residents. It is still unlikely that non-traditional health data uses will be wholly uncontroversial amongst local residents. Publics are sceptical for valid reasons. Concerns around misuse, privacy breaches, unequal benefits sharing, lack of accountability, and lack of transparency are key to consider moving forward.

It's also important to be wary of policy and corporate narratives around data and AI solutionism. It’s clear many see non-traditional health data access as a golden goose for an overstretched public health system (Kakkad et al., 2024). However, profits do not erase public concerns (Aitken et al., 2018). Taken together, a key lesson for C & M public and patient engagement moving forward is the need to develop clear guidelines for non-traditional uses.

Specifically, mapping out what accountability, transparency, and acceptable public benefit looks like. Second, to ensure clear red lines around not providing data access to commercial organisations that are unacceptable to publics. And third to not shy away from professional and public engagement on these topics. That includes everything from communication campaigns and to public deliberation. We next turn to discuss two case studies of this kind of public engagement we have completed over the past year.

Case Studies

The aim of this report is to explore common expectations and views of public and patients on non-traditional health data usage in C & M. We explore this through two case studies and a literature review.

Spotlight 1

Conversation Cafés on Commercial and Indirect Health Data

From August 2024 to May 2025, the Liverpool City Region Civic Data Cooperative and NHS Arden & GEM Commissioning Support Unit (CSU) planned a series of public engagements on commercial access to health data on behalf of the Data into Action programme.

What we did and how we did it

Our aim was to explore what residents felt sufficient public benefit looked like to find commercial health data access acceptable. The question was intentionally framed as a fait accompli. In other words, we wanted to ask residents specifically about what their perspectives on commercial access would be if they assumed it was happening. This was due to established evidence from our own and others' public engagement exercises on mixed acceptance for commercial data access. We wanted to push new conversations for C & M residents.

We ran four events comprising six group conversations in a World Café format. A World Café, what we call Conversation Cafés, involves multiple stages of facilitated small group conversations around a central topic with a large group of people. Moderators at each table guided participants through three questions:

- What kinds of commercial or industry uses of data could create the most public benefit?
- What kinds of commercial organisations should have priority over health data access?
- What kinds of non-health data are important to link to health data?

Participants were provided with a briefing on health data prior to getting started including access to health data literacy materials prior to the discussion.

Residents were given sort cards to facilitate each discussion with examples of commercial organisations that may want access to health data and examples of commercial data that could inform health research. See image above as an example.

Table moderators took notes during the discussion which we reviewed for common discussion topics on commercial access to health data and indirect health data. We did not conduct a formal academic analysis of this work, rather we summarise notes below.

Who took part

We held three in-person World Cafés, one in Liverpool, one in Crewe, and one in Chester. Residents were compensated £50 for taking part in the two-hour session. Participants were recruited through flyers at community centres and libraries in the region, emails and newsletters to community groups, and paid and non-paid social media posts. In total 32 residents took part. The Liverpool and Crewe events were open to anyone. The Chester event was specifically held with a Hong Kong Cultural Group. We intentionally recruited a more diverse group of people than previous events, subsequently nearly half (46.9%) of people who took part identified as an ethnicity other than white British. Full demographics are available in Appendix 1.

What people said

Similar to our previous report, the most common resident perspective on sufficient public benefit for health data access focussed on collective benefit for individuals and communities, regardless of the commercial organisation seeking access. Residents drew metaphorical lines in conversation around which organisations they felt were more likely to deliver public benefit. Which organisations were most preferred was directly related to the degree that residents could imagine them prioritising public good. Hypothetical examples like social media companies and insurance companies were perceived to be unlikely to provide any kind of public benefit and therefore less supported. Other examples like pharmaceutical companies and digital or tech providers were perceived as offering a higher likelihood of providing public benefit, due in part to perceptions of a clear line to healthcare and therefore the NHS.

Some residents felt strongly that commercial organisations should not have any access to health data unless they could clearly demonstrate public benefit through transparent future planning for healthcare delivery in the UK. This burden of proof was closely correlated with acceptability for data access. Financial payment to the SDE was not seen as sufficient to demonstrate public benefit but was nevertheless considered important to allowing commercial access.

Residents felt all data projects should focus on having human dignity as a core principle and should improve community well-being instead of exacerbated existing inequalities. They also discussed the importance of holding commercial organisations to a high standard of ethical approval and accountability.

Similarly, residents discussed supporting indirect health data linkage to NHS data if they perceived potential public benefit. Things like water quality were supported because of a strong hypothetical association to public benefit. Opinion varied on things like smart meter readings, daily step counts, and social media posts. Some residents were less supportive of linking surveillance data as this was seen to be intrusive. This includes examples like using CCTV data or phone location data being less supported to link to NHS data. Residents tended to discuss acceptability of data linkage along two key questions: how intrusive is it and how much potential good can it do?

Lessons learned

- Commercial access to health data may be supported similar to academic health data access if it is clearly in the public good and can evidence profits and benefits.
- Social media and insurance companies are red lines for residents.
- Residents are mixed in their views on non-health data usage but want minimal intrusiveness prioritised.

Spotlight 2

Liverpool City Region Residents' Assembly on Data and AI Innovation

In March 2025, 59 residents of the Liverpool City Region debated the direction of data and AI innovation in the region. The assembly's purpose was to build a set of open principles (a Charter) on what beneficial and trustworthy data and AI innovation looks like. The Data into Action programme was one of three convening organisations alongside the Liverpool City Region Combined Authority and the University of Liverpool.

What we did and how we did it

Our aim was to explore what residents felt Residents took part in six sessions and four in-person days split across learning and deliberation held in Liverpool City Centre. This included presentations from experts and stakeholders as well as interactive learning activities, including C & M Data into Action representatives. There were also two online or telephone sessions held for induction and debrief before and after the in-person days. An independent evaluator reviewed all materials and sessions. On the final day residents suggested potential principles for the Charter and ranked their preferred options. After additional resident and stakeholder review, a final charter of 11 principles was developed.

We report on the results from the principle vote and from recordings taken during the Assembly. We analysed the transcriptions for common themes (Braun & Clarke, 2006). The main question of the Assembly was used to guide the thematic analysis. Specifically, what does trustworthy and beneficial data and AI innovation look like for the Liverpool City Region? A detailed methodology is available in the Final Report (E. Rempel et al., 2025).

Who took part

59 residents took part in all four days of the Assembly. They were chosen to represent both the six local authorities and the diversity of the LCR. This included representation across gender, ethnicity, age, location, and knowledge about AI. Sortition Foundation recruited all participants on behalf of the University. A 'postcode lottery' style mail-out included randomised invitations to 21,000 households of which 523 applied to take part. Residents had to normally live in the area and live full or part time at an address that received an invitation. Only one person from a household could be randomly selected after application. Full demographics and recruitment details are also available in the Final Report.

What people said

Residents shared 152 hopes or fears about data and AI throughout the Assembly. They wrote their thoughts on postcards and then shared back through group discussion. Residents' main hope for data and AI technologies was seeing positive change in their community. They were specific that improving healthcare quality and efficiency was a core example of doing good with AI.

"Mine's the same as everyone else's. Hope that everything works well together as a system when it comes to the NHS, children services, mental health. It's just good for our region, that's my hope." -Table 8, Day 3

Residents had general worries about AI leading to job losses and damaging the environment through things like overusing water. But they were equally hopeful that if used wisely AI could lead to a reduction in inequality and benefits for future generations. They held clear concerns around bad actors and data misuse, for example scammers and hackers. They worried some organisations would not prioritise data privacy and security.

"My fear is that the data collected could be hacked and or the data is used by unethical organisations." – Table 8, Day 3

Residents told us addressing power and who controls AI will be essential to trustworthiness. They saw current data and AI use as reinforcing existing power imbalances. In other words, residents do not want data and AI to be used solely for corporate profit-making. Some residents described corporations making money as the opposite of benefiting local people. They fear that when profits are prioritised, communities lose out. They don't see corporations as accountable to creating positive change in community.

"And the Third Point I wrote, civil versus corporate interests. I think when you touched on that, sorry, that like companies are prioritising profits over public wellbeing, that's definitely a big issue." - Table 4, Day 3

Residents also discussed the unknowable future of AI. They were worried about AI leading to a loss of human skills and social connection. They hoped their concerns around AI could be addressed if core ethical principles were followed and corporations were held accountable.

"I think the long-term benefits could be huge, like 10/15/20 years down the line. It could minimise discrimination and close the gap between socioeconomic inequalities." – Table 6, Day 4

We asked residents specifically about four case studies of data and AI usage that included health care data linkage to non-health data. This included examples in mental health, children's services, fire safety, and education.

We also asked residents to design their own ideas for how AI could be used in public services. Healthcare was the second most prioritised area for AI tied with waste collection. Overall we found:

- Residents want data and AI technologies to address real, lived problems. They want technology to prevent people from falling through the cracks of services, particularly in health care.
- Residents are supportive of the kinds of data and AI projects happening in the region but are concerned about data accuracy, invasiveness, and whether change will happen.
- Two areas residents prioritise in health care include improving existing service quality and improving service accessibility.

On the final two days of the Assembly, residents proposed and voted on the contents of a Community Charter on Data and AI. The 11 Charter principles include ideas about beneficial data use, communication on AI, privacy and security, and external oversight. After several rounds of feedback, the Charter was finalised and launched on July 3rd, 2025. It was signed by NHS Cheshire and Merseyside alongside the University of Liverpool and the Liverpool City Region Combined Authority. Full results from the Assembly and the Charter Principles are available in the Final Report.

Lessons learned

- Residents are supportive of AI and non-health data linkage if it is clearly in support of public and community benefit.
- Corporate profit-making and community benefit are seen as opposing goals by residents.
- Residents have provided a clear set of rules and guidelines they want to be followed to support AI and data access both between public services like the NHS and with corporations.

Spotlight 3

Survey evidence on the role of trust in non-traditional data usage

A common theme throughout both the Assembly and Conversation [SP1] Cafés is that some organisations are most trustworthy than others. To round out this discussion we summarise national surveys that explore this theme in more detail. Unfortunately, for the purposes of this report these surveys are not disaggregated by region. Regardless, they provide recent snapshots of UK resident perspectives on trusted organisations. We look at three national surveys below.
[SP1]Should we stick with "Conversation Cafés" like elsewhere in the report?

Department for Science, Innovation, and Technology's Public Attitudes to Data and AI Tracker

First, the Department for Science, Innovation, and Technology's 2024 Public Attitudes to Data and AI Tracker of 4,947 people (Responsible Technology Adoption Unit, 2024). Consistent with previous waves, UK residents rank the NHS as the most trusted organisation in relation to data. Taken across all questions on trust, social media companies and government are least trusted. Looking specifically at whether respondents trust organisations to use their data to benefit society they order organisations as follows: NHS (72%), academics/universities (64%), pharmaceutical companies (62%), banks (50%), government (46%), utilities providers (44%), big tech (42%), and social media companies (30%). In this case, government does slightly better but still falls 26 percentage points below the NHS. As well, there is evidently significant overlap between social media and big tech, and it is unclear how respondents differentiate these.

Given these wide gaps in trust, the authors report in their additional conjoint analyses, "comfort with data sharing is less about whether data is anonymous or identifiable, and more about who is collecting or using the data" (Responsible Technology Adoption Unit, 2024, p. n.p.)

The Ada Lovelace Institute and Alan Turing Institute's Public Attitudes to AI Survey

In their most recent 2024 survey wave of 3,513 people, they found that only about 1 in 4 (27%) respondents agreed that their views or values are represented in AI decision-making. And they found that 83% of respondents were "concerned by the idea of public sector bodies sharing data about them with private companies to train AI systems" (Modhvadia et al., 2025, p. 51). Modhvadia et al. (2025) highlight the importance of this finding given NHS data access plans with the commercial sector. It is unclear, however, given the high general trust in the NHS if respondents interpreted public sector bodies to include government alone.

The Health Foundation's 2024 Surveys on Data and AI

Third, The Health Foundation also reports on public attitudes to health technology, data, and AI (Binesmael et al., 2024; Thornton et al., 2024). The results of these surveys are more mixed than previous examples. In a 2024 survey of 7,201 people, authors disaggregated components of the NHS to compare high versus low trust within the health sector. GP practices (68%), local hospitals/clinics (66%), and national NHS organisations (61%) had the greatest level of 'high trust' with health data. Whereas again national and local government are ranked lowest, each only had 33% of respondents reporting high trust. Health technology (38%), pharmaceutical (43%), and software companies (40%) again rank lower but still higher than government.

Lessons learned

- The NHS including organisational and patient-facing arms is highly trusted with health data, but trust drops immediately outside of health contexts.
- Public bodies, like the NHS and local or national government, hold highly variable trust amongst UK publics, with governments often ranking much lower than healthcare.
- Social media health data access is a clear red line for UK publics.

Summing it all up

Over the past year of public engagement, we have supported 91 C & M residents to debate, in detail, non-traditional data uses both for healthcare and public services. This includes a series of Conversation Cafés on commercial data access and a large-scale Residents' Assembly. In sum, we found residents' tentatively supportive of commercial access to health data and artificial intelligence if strict guidelines and principles would be followed. This includes ensuring that NHS Cheshire and Merseyside holds commercial organisations accountable for good practice.

In terms of public and patient opinion, we found the following:

- Residents are supportive of AI, commercial access to health data, and indirect health data linkage if it is clearly in support of public and community benefit.
- The NHS including organisational and patient-facing arms is highly trusted with health data, but trust drops immediately outside of health contexts.
- Social media and insurance health data access is a clear red line.
- Corporate profit-making and community benefit are seen as opposing goals by residents, nevertheless residents want corporations to pay for access to data.
- Residents views on non-health/indirect data usage vary greatly but they want minimal intrusiveness prioritised.

The findings around mixed views on indirect health data and the red lines on social media companies are consistent with previous research on public attitudes to non-traditional health data uses (Binesmael et al., 2024; Hirst et al., 2023). The tentative support for commercial access to health data, given clear guidelines, is also echoed in similar work (Ipsos MORI et al., 2016). Our work to define those clear guidelines is novel. If fully enacted, the Community Charter would be the first of its kind designed by public and patients and signed by all core public service organisations in a region. The Liverpool City Region Community Charter on Data and AI is a step forward in ensuring public and patient voice in data and AI practice in healthcare. You can see a representation of the charter in the political banner above.

This work represents a continuation of the Data into Action programme's Patient and Public Engagement work. These case studies will be used both to further develop the programme and to further progress the Cheshire and Merseyside Secure Data Environment.

Recommendations for further public engagement

In addition to enacting the Charter, we initially drafted the following topics for further public participation and practice:

- Developing a profit and benefit-sharing model for commercial data access that aligns to public preferences.
- Creating a clear definition of social media and insurance companies to align to public preferences on who should not have access to health data.
- Debate on what access to sensitive data means for academic and commercial organisations – what is supported and not supported.
- Exploration of the perspectives of young people and children on data sharing and non-traditional health data uses.

Patient and Public Advisory Group (PPAG) Feedback

The Data into Action PPAG discussed the above recommendations and considered how they should be prioritised for future public engagement on non-traditional health data use.

The group discussed each of the recommendations in turn and gave the following feedback collated by Arden & GEM CSU.

Recommendation 1 (profit and benefit-sharing model for commercial data access)

- The wording of the recommendation could be simplified.
- Profit and benefit could be separated and engaged on separately.
- If we talk about "products", we need to explain what this means.
- A matrix could set out for the different parties and types of benefit/profit; RAG ratings could be applied to see whether there is a fair balance of benefits.

Recommendation 2 (defining social media and insurance companies)

- Engaging on recommendation 1 would help with this. This could potentially be included as part of recommendation 1 engagement.
- The public should consider the positives and negatives of each organisation rather than the definition of the type of organisation.
- Ethical conduct matters more than organisational type – but ethics aren't fixed or universally agreed.

Recommendation 3 (access to sensitive data for academic and commercial organisations):

- Engagement should ask the public about the purpose and the consequences of access to sensitive data.
- It was noted that the picture is complex as private companies could fund academic research.
- Academia and commercial should be separated out.
- "Commercial organisations" is a broad term.
- What "access" looks like needs to be explained carefully to the public during engagement.
- Levels of sensitivity should be explored.

Recommendation 4 (engaging children and young people)

- Engaging with young people would be beneficial as they offer different perspectives.
- It would be important to define what age groups it is realistic to engage with.
- It is important to engage with young people approaching adulthood.

Ranking recommendations

PPAG members were asked to rank the recommendations for future engagement from the highest priority to the lowest priority. The results (counted post-meeting) were:

- Profit and benefit-sharing model development (highest priority)
- Exploring young people's perspectives
- Debating sensitive data access
- Defining social media and insurance companies (lowest priority)

Final recommendations for further engagement

- C & M resident preferences for profit models for commercial access to health data and how that varies by type of commercial organisation
- Perspectives of young people and children on health data access and artificial intelligence in healthcare
- Views among residents on the definition and levels of sensitive health data access for different secondary use cases

Authorship and Statement of Work

Sophie Powers and Rachel Newton from Arden & GEM CSU and Midlands and Lancashire CSU recruited for and ran the Conversation Cafés alongside Emily Rempel. They also run and report on the Data into Action Patient and Public Advisory Group. The Residents' Assembly was completed by the Civic Data Cooperative. This report was authored by Emily Rempel from the Civic Data Cooperative at the University of Liverpool. Opinions expressed are those of the author.

Suggested citation:
Rempel, E. (2025). Public And Patient Perspectives on Non-Traditional Health Data Access in Cheshire and Merseyside. University of Liverpool.

Acknowledgements

Thank you to the residents and partners who made this work possible. This includes the Data into Action PPAG; Liverpool City Region Civic Data Cooperative; North-West Coast Health Innovation; Lancashire and South Cumbria NHS Foundation Trust; Cheshire and Merseyside Integrated Care Board; and the Arden & GEM and Midlands and Lancashire CSU engagement team.

References

Aitken, M., de St. Jorre, J., Pagliari, C., Jepson, R., & Cunningham-Burley, S. (2016). Public responses to the sharing and linkage of health data for research purposes: A systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics, 17(1), 73. https://doi.org/10.1186/s12910-016-0153-x

Aitken, M., Porteous, C., Creamer, E., & Cunningham-Burley, S. (2018). Who benefits and how? Public expectations of public benefits from data-intensive health research. Big Data & Society, 5(2), 205395171881672. https://doi.org/10.1177/2053951718816724f

Binesmael, A., Thornton, N., Horton, T., & Hardie, T. (2024). How does the public feel about health technologies and data? The Health Foundation. https://www.health.org.uk/reports-and-analysis/analysis/how-does-the-public-feel-about-health-technologies-and-data

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Cascini, F., Pantovic, A., Al-Ajlouni, Y. A., Puleo, V., De Maio, L., & Ricciardi, W. (2024). Health data sharing attitudes towards primary and secondary use of data: A systematic review. eClinicalMedicine, 71, 102551. https://doi.org/10.1016/j.eclinm.2024.102551

Cheung, S. (2020). Disambiguating the benefits and risks from public health data in the digital economy. Big Data & Society, 7(1), 2053951720933924. https://doi.org/10.1177/2053951720933924

Donnelly, L. (2024, March 19). Labour vows to save NHS by sharing data from GP records. The Telegraph. https://www.telegraph.co.uk/politics/2024/03/19/labour-vows-to-save-nhs-by-sharing-data-from-gp-records/

Hirst, Y., Stoffel, S. T., Brewer, H. R., Timotijevic, L., Raats, M. M., & Flanagan, J. M. (2023). Understanding Public Attitudes and Willingness to Share Commercial Data for Health Research: Survey Study in the United Kingdom. JMIR Public Health and Surveillance, 9(1), e40814. https://doi.org/10.2196/40814

Ipsos MORI, Castell, S., & Evans, H. (2016). The One-Way Mirror: Public attitudes to commercial access to health data.

Jones, L. A., Nelder, J. R., Fryer, J. M., Alsop, P. H., Geary, M. R., Prince, M., & Cardinal, R. N. (2022). Public opinion on sharing data from health services for clinical and research purposes without explicit consent: An anonymous online survey in the UK. BMJ Open, 12(4), e057579. https://doi.org/10.1136/bmjopen-2021-057579

Kakkad, J., Mökander, J., Naylor, N., Paling, S., Refsum, C., Rebolledo, I., Salem, E., & Smith, T. (2024). A New National Purpose: Harnessing Data for Health. Tony Blaire Institute for Global Change. https://institute.global/insights/politics-and-governance/a-new-national-purpose-harnessing-data-for-health

Kalkman, S., van Delden, J., Banerjee, A., Tyl, B., Mostert, M., & van Thiel, G. (2022). Patients' and public views and attitudes towards the sharing of health data for research: A narrative review of the empirical evidence. Journal of Medical Ethics, 48(1), 3–13. https://doi.org/10.1136/medethics-2019-105651

Kostkova, P., Brewer, H., de Lusignan, S., Fottrell, E., Goldacre, B., Hart, G., Koczan, P., Knight, P., Marsolier, C., McKendry, R. A., Ross, E., Sasse, A., Sullivan, R., Chaytor, S., Stevenson, O., Velho, R., & Tooke, J. (2016). Who Owns the Data? Open Data for Healthcare. Frontiers in Public Health, 4. https://doi.org/10.3389/fpubh.2016.00007

Marelli, L., Testa, G., & Van Hoyweghen, I. (2021). Big Tech platforms in health research: Re-purposing big data governance in light of the General Data Protection Regulation's research exemption. Big Data & Society, 8(1), 20539517211018783. https://doi.org/10.1177/20539517211018783

Marres, N., Castelle, M., Gobbo, B., Poletti, C., & Tripp, J. (2024). AI as super-controversy: Eliciting AI and society controversies with an extended expert community in the UK. Big Data & Society, 11(2), 20539517241255103. https://doi.org/10.1177/20539517241255103

Modhvadia, R., Sippy, T., Field Reid, O., & Margetts, H. (2025). How Do People Feel About AI? Ada Lovelace Institute and The Alan Turing Institute. https://attitudestoai.uk/

Rempel, E., Leeming, G., Reed, G., Murphy, C., McCloskey, E., & Buchan, I. (2025). The Liverpool City Region Residents' Assembly on Data and Artificial Intelligence Innovation Final Report. University of Liverpool Repository. https://doi.org/10.17638/03193485

Rempel, E. S. (2024). Public and Patient Engagement: The Use of Administrative Health Data for Research. University of Liverpool. https://dataintoaction.cheshireandmerseyside.nhs.uk/media/vknp3xtz/the-use-of-administrative-health-data-for-research.pdf

Responsible Technology Adoption Unit. (2024). Public attitudes to data and AI: Tracker survey (Wave 4) report. Department for Science, Innovation and Technology and the UK Government. https://www.gov.uk/government/publications/public-attitudes-to-data-and-ai-tracker-survey-wave-4/public-attitudes-to-data-and-ai-tracker-survey-wave-4-report

Schneble, C. O., Elger, B. S., & Shaw, D. M. (2020). All Our Data Will Be Health Data One Day: The Need for Universal Data Protection and Comprehensive Consent. Journal of Medical Internet Research, 22(5), e16879. https://doi.org/10.2196/16879

Thornton, N., Binesmael, A., Horton, T., & Hardie, T. (2024). AI in health care: What do the public and NHS staff think? The Health Foundation. https://www.health.org.uk/reports-and-analysis/analysis/ai-in-health-care-what-do-the-public-and-nhs-staff-think

Tully, M. P., Hassan, L., Oswald, M., & Ainsworth, J. (2019). Commercial use of health data—A public "trial" by citizens' jury. Learning Health Systems, 3(4), e10200. https://doi.org/10.1002/lrh2.10200

Appendix 1: Demographics

Table 1: Self-Reported Participant Demographic Characteristics of Three C & M Conversation Cafés, n=32

Demographic		Count (n)	Percentage (%)
Ethnicity*			
	White: English / Welsh / Scottish / Northern Irish / British	17	53.1
	White: Other	1	3.1
	Asian / Asian British: Hong Konger	5	15.6
	Black / African / Caribbean / Black British: African	1	3.1
	Asian / Asian British: Chinese	6	18.8
	Mixed/multiple ethnic groups: any other Mixed/Multiple ethnic background	2	6.3
English as a First Language			
	Yes	20	62.5
	No	12	37.5
Health Problem or Disability that limits day-to-day activities lasting or expected to last at least 12 months			
	Yes	10	31.3
	No	19	59.4
	Somewhat	3	9.4
Carer			
	Yes	14	43.8
	No	8	25
	Not answered	10	31.3
Gender			
	Female	23	71.9
	Male	9	28.1
	Trans man	0	0
	Trans woman	0	0
Age			
	16-34	4	12.5
	35-59	19	59.4
	60+	9	28.1
Employment Status			
	Unemployed (eligible for state benefits)	3	9.4
	Unemployed (not eligible for state benefits)	6	18.8
	Employed (part-time)	8	25
	Employed (full-time)	7	21.9
	Retired	8	25

*Only ethnicities with at least n=1 reported

Data
Into
Action

civic
data
coop