Engagement Findings Report – Somerset Linked Data Platform

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Purpose

This report summarises public engagement findings relating to the use of health and care data across Somerset. It draws on engagement activity originally undertaken to inform the Somerset Linked Data Platform (SLDP). Although the SLDP project will not proceed, the insights gathered remain highly relevant and will inform future work on health and care data use, analytics, population health management, and system integration.

The report provides an evidence-based overview of what people told us, how feedback was gathered and analysed, and how this insight should inform future communications and engagement approaches.

Contents

1. Executive summary

NHS Somerset undertook extensive public engagement between September 2025 and March 2026 to understand public views on how health and care data is used beyond direct care. Engagement included surveys, community events, focus groups, and digital communications, reaching over 360 residents across Somerset.

Overall, the findings show conditional public support for the use of health and care data, particularly where the purpose and public benefit are clearly explained. Trust is highest when the NHS is seen to lead and govern data use, when data is used to support prevention and care, and when people understand their choices. However, confidence is fragile and heavily influenced by concerns about security, transparency, commercial involvement, and lack of clarity about opt-out options.

These insights highlight the importance of clear, honest and proactive communication for any future data initiatives, with particular emphasis on explaining how data is used, where identifiable data is required, how risks are managed, and how people can exercise choice.

2. Purpose and aims

The engagement aimed to:

- Understand public awareness and confidence in the use of health and care data beyond direct care
- Explore attitudes to data being linked across NHS and other public services
- Identify what reassures or concerns people about data security, governance and oversight
- Assess awareness and understanding of opt-out choices
- Generate insight to inform future communications and engagement on data use

Engagement involved residents of Somerset, with a particular focus on people who regularly interact with health and care services.

3. Context

The engagement activity was originally undertaken to inform the Somerset Linked Data Platform (SLDP), a proposed system to enable population-level analysis of health and care data. While the SLDP will not proceed, future data platforms and analytical work remain a core requirement for population health management and integrated care.

The findings in this report therefore provide system-wide insight relevant to any future initiative involving the use, linkage or analysis of health and care data.

4. Methodology

Engagement activity

Engagement took place between September 2025 and March 2026 and included:

- Two phases of a public survey:
    - Phase 1 led by Healthwatch Somerset
    - Phase 2 reopened and promoted directly by NHS Somerset
- Community engagement and drop-in events (51 events across Somerset)
- Focus groups (3)
- Social media campaigns (organic and paid)
- Printed and digital communications

Survey data

- Combined valid survey responses: 360+
- Surveys were completed online and on paper
- Respondents consented to anonymous sharing of responses

Respondent profile (summary)

- Majority aged 50+
- Predominantly White British
- High proportion of respondents with long-term conditions or disabilities
- Significant number of carers and veterans

Analysis approach

AI was used to support organisation and summarisation of survey and qualitative data. Human review ensured themes accurately reflected the evidence and that minority and dissenting views were retained.

5. Key themes

Theme 1: Awareness of health and care data use varies

Summary
Most respondents were aware that the NHS uses data beyond direct care, but a persistent minority were not.

Evidence

- Around 75–80% aware
- 20–25% unaware or unsure (across both survey phases)

Representativeness
Findings reflect a population with high NHS contact; awareness may be lower in the wider population.

Recommendation
Future communications should not assume baseline knowledge and should clearly explain why and how data is used.

Theme 2: Support for data use is conditional on understanding purpose

Summary
Comfort levels increased when people understood the purpose and benefits of data use.

Evidence

- Over 80% expressed comfort with NHS data use in later survey phase
- Earlier survey responses showed higher discomfort, suggesting messaging influences confidence

Recommendation
Lead communications with clear purpose and benefit, using real-world examples.

Theme 3: Confusion around anonymisation and identification undermines trust

Summary
Many respondents struggled to understand how data could be “non-identifiable” yet still used to offer individual support.

Evidence

- Recurrent comments across survey free-text and focus groups
- This issue featured strongly even among those otherwise supportive

Recommendation
Be explicit and honest about when identifiable data is used, why it is needed, and what legal safeguards apply.

Theme 4: Data security concerns are widespread and deeply felt

Summary
Confidence in data security was lower than confidence in data use itself.

Evidence

- Approx. 60–65% felt sure their data would be protected
- 30–35% unsure or very unsure
- Frequent references to hacking, NHS breaches and cyber risk

Recommendation
Move beyond reassurance to transparent explanations of governance, audits, controls and accountability.

Theme 5: Strong opposition to commercial or overseas access to data

Summary
Concerns about private or overseas companies accessing data were one of the strongest emotional themes.

Evidence

- Repeated references to commercial misuse
- Specific concern about large technology companies, even symbolically

Recommendation
Address commercial concerns directly and transparently, including who is involved and who is not.

Theme 6: Awareness of opt-out exists, but understanding is low

Summary
Most people know they *can* opt out, but few know *how*.

Evidence

- 60–70% aware of opt-out
- Only 25–30% know how to opt out
- Many asked directly for this information

Recommendation
Future initiatives must include proactive opt-out communications, not passive signposting.

Theme 7: How people are contacted matters as much as why

Summary
Scenario-based responses showed higher acceptance when contact was led by trusted NHS routes and clearly explained.

Evidence

- Greater discomfort with “cold contact”, especially about mental health
- Strong preference for GP or known services as first contact

Recommendation
Design data-enabled interventions around trust, sensitivity and informed contact.

6. Next steps

These findings will be used to:

- Inform future communications strategies on health and care data use
- Shape standard messaging on:
    - Purpose
    - Data flows
    - Identifiable vs anonymised data
    - Governance and oversight
    - Opt-out choices
- Support “You said, we did” feedback for future engagement
- Provide baseline insight for any future data platform work

NHS Somerset – Statement on the use of AI technology

This report was produced with the support of AI technology to assist in organising and summarising large volumes of public feedback, in line with the NHS Somerset Engagement Team’s AI Verification Framework. AI was used solely to support data organisation and thematic analysis and did not replace human judgement or decision-making. All data was fully anonymised and all outputs were reviewed, checked and approved by the NHS Somerset Engagement and Insight Team, which retains full responsibility for the report’s content and conclusions.

If you identify any errors or omissions, please contact Jacquie Silcox - Engagement Officer at **somicb.engagement@nhs.net** so corrections can be made.