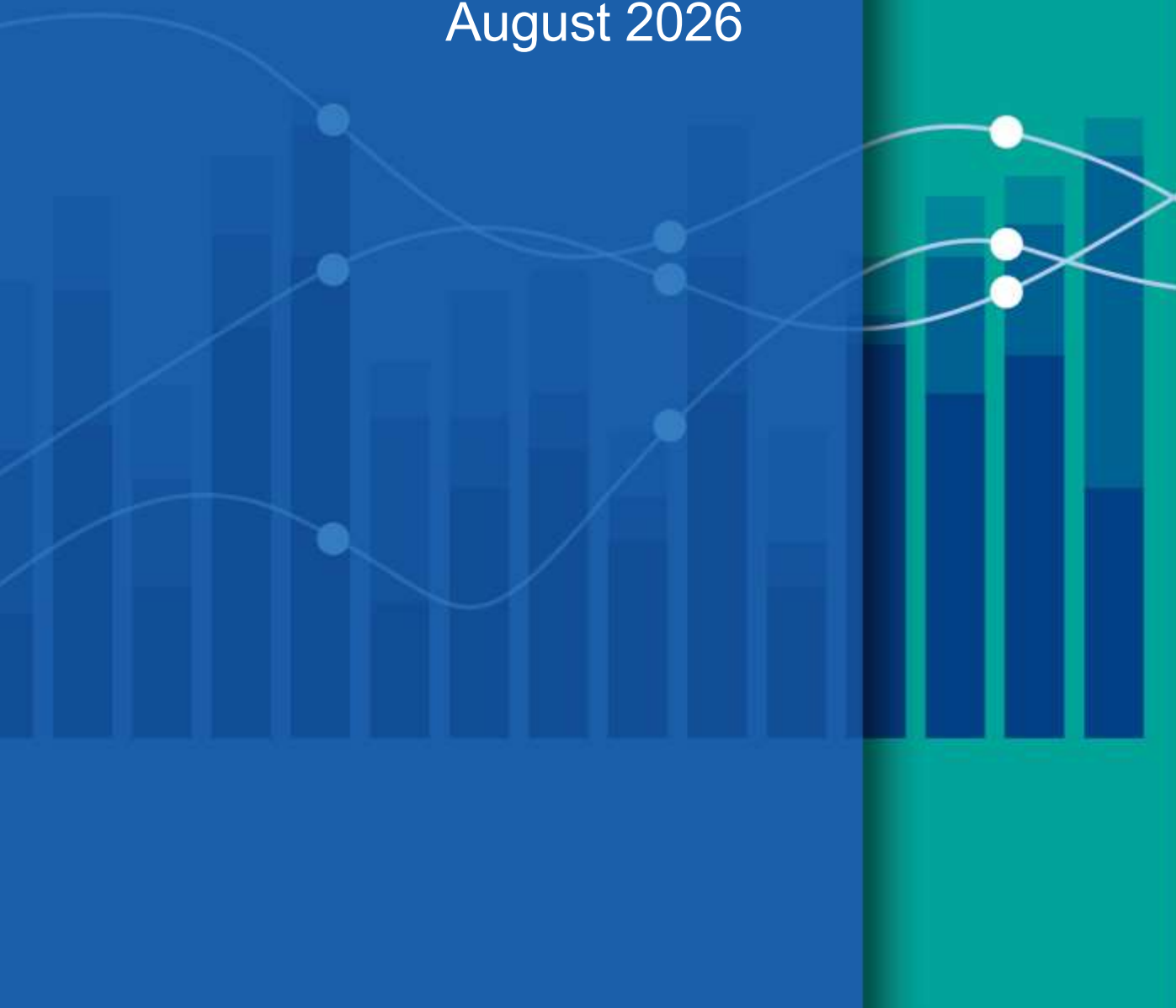


Views on health data and research

August 2026



Contents

Executive Summary	3
Introduction	3
Key Findings	3
Summary of Findings	4
Recommendations	4
1. Increase Transparency and Communication	5
2. Improve Public Understanding of Health Data Research	5
3. Strengthen Confidence in Privacy and Security	5
4. Increase Awareness of Anonymisation	6
5. Be Open About Commercial Access and Public Benefit	6
6. Strengthen Public Involvement and Accountability	6
7. Prioritise Future Engagement Topics	7
Next Steps	7

Executive Summary

Introduction

This report provides an overview of the findings from a survey conducted between June and August 2026 to explore views on the use of health data for research purposes. The survey sought feedback from members of the public, patients and professionals across the Yorkshire and Humber region to better understand awareness, trust and attitudes towards health data being used for research.

A total of 73 individuals participated in the survey. Participants were asked about:

- Awareness of health data use for research
- Levels of trust in organisations using health data
- Attitudes towards different organisations accessing health data
- Factors influencing confidence in health data use
- Emerging topics of interest relating to health data research and governance

Key Findings

The findings demonstrate broad support for the use of health data for research purposes where there is a clear public benefit. Respondents recognised the role of health data in improving healthcare services, supporting medical research and enabling the development of new treatments and therapies.

Trust was identified as a key factor influencing support for health data use. Respondents expressed the greatest confidence in NHS organisations, reflecting trust in established governance, accountability and oversight arrangements. Support reduced when non-NHS organisations were involved, particularly where concerns existed regarding commercial interests and potential financial gain.

Concerns relating to privacy, security and the potential misuse of information remain consistent with previous public engagement activity undertaken across the Yorkshire and Humber region. Respondents frequently highlighted the importance of strong safeguards, secure systems and robust governance arrangements.

Anonymisation was viewed as one of the most important safeguards influencing public confidence. Nearly four in five respondents reported that the removal of identifiable information positively influenced their views about health data being used for research.

Respondents also identified the importance of transparency. Many indicated that they wanted clear information regarding:

- Who can access health data
- Why health data is being used
- What safeguards are in place
- How research benefits patients and the public

Although awareness of health data research was relatively high, many respondents indicated that they were not fully informed about how health data is accessed, governed and protected. This suggests that further communication and engagement activities are required to improve understanding across different audiences.

Public involvement also remained an important theme. Respondents highlighted the value of ensuring that public contributors continue to influence decisions regarding how health data is used, accessed and governed.

Artificial Intelligence (AI) emerged as an area where respondents would welcome additional information, engagement and discussion. Respondents identified a need for greater understanding of how AI may be used within health research and the safeguards that support its responsible application.

Summary of Findings

The survey demonstrates continued support for health data being used for research when there is a clear public benefit and appropriate safeguards are in place. Respondents recognised the potential for health data research to improve patient care, support innovation and contribute to future healthcare improvements.

Support for health data use was closely linked to trust, transparency and confidence in governance arrangements. Respondents repeatedly sought reassurance regarding privacy, security and accountability, while expressing a desire for greater visibility of the processes used to manage and protect health data.

The findings suggest that continued public engagement, transparent communications and visible governance arrangements will be important to maintaining public confidence in the use of health data for research purposes.

Recommendations

The findings from this survey provide a strong foundation for strengthening public understanding of health data research and maintaining confidence in how health data is used across the Yorkshire and Humber region. While support for health data

research remains high, confidence continues to be dependent upon assurance that information is used securely, responsibly and for public benefit.

1. Increase Transparency and Communication

Respondents consistently highlighted the importance of understanding how health data is accessed, used and governed. Improving transparency will help strengthen public confidence and trust.

The programme should:

- Publish accessible information about approved research projects.
- Clearly explain who can access health data and under what conditions.
- Share examples demonstrating how health data contributes to improvements in healthcare, treatments and research outcomes.
- Regularly communicate how decisions regarding data access are made.

2. Improve Public Understanding of Health Data Research

Although many respondents were aware of health data research, understanding of governance arrangements and data flows was more limited.

The programme should:

- Develop plain English resources explaining health data research.
- Produce visual and interactive materials that explain key concepts.
- Continue engagement activities with communities across Yorkshire and Humber.
- Provide opportunities for participants to ask questions and discuss concerns.

3. Strengthen Confidence in Privacy and Security

Privacy and security remain the most frequently cited concerns associated with health data use.

The programme should:

- Clearly explain how health data is protected within Secure Data Environments.

- Increase visibility of governance, oversight and security arrangements.
- Communicate how risks are identified, managed and monitored.
- Share examples of the safeguards that protect data throughout the research process.

4. Increase Awareness of Anonymisation

Anonymisation was identified as one of the strongest drivers of confidence in health data use.

The programme should:

- Continue to promote clear explanations of anonymisation processes.
- Use examples and visual resources to demonstrate how identifiable information is protected.
- Explain how anonymisation operates alongside other security and governance safeguards.

5. Be Open About Commercial Access and Public Benefit

Respondents expressed lower levels of confidence when non-NHS organisations were involved in research activities.

The programme should:

- Clearly explain when and why non-NHS organisations may access health data.
- Demonstrate the public benefit associated with projects involving commercial or non-NHS partners.
- Address concerns relating to commercial gain openly and transparently.
- Communicate the governance processes that determine whether access is granted.

6. Strengthen Public Involvement and Accountability

Respondents highlighted the importance of ongoing public involvement in decisions relating to health data use.

The programme should:

- Continue to involve patients and members of the public in governance and decision-making processes.

- Demonstrate how public feedback has influenced programme development and decision-making.
- Promote opportunities for involvement across Yorkshire and Humber.
- Continue supporting mechanisms that enable public contributors to influence future priorities.

7. Prioritise Future Engagement Topics

The survey identified several areas where respondents would welcome additional information and discussion.

Future engagement activities should prioritise:

- Data security and cyber security
- Commercial access to health data
- Governance and oversight arrangements
- Artificial Intelligence (AI)
- The communication of research findings and public benefit outcomes

Next Steps

These findings should be used to inform future public involvement and engagement activity across the Yorkshire and Humber Secure Data Environment programme. Particular focus should be placed on increasing understanding of how health data is used for research, strengthening awareness of safeguards and ensuring that public contributors continue to play a meaningful role in programme governance and decision-making.

The findings should also inform future communications, public-facing resources and engagement campaigns, supporting a consistent regional approach to building trust and confidence in the use of health data for research. Continued monitoring and engagement will help assess changes in awareness, understanding and trust over time.