

Young People's Engagement with the West Midlands Secure Data Environment Executive Summary



Background



The West Midlands Secure Data Environment is part of a national NHS programme that allows researchers to analyse health and social care information without it leaving the secure environment, making it much safer.



Researchers will use it to find new medicines and treatments – faster and more efficiently than ever before.

The role of a Secure Data Environment is to provide a trusted NHS-run setting where approved researchers can securely access and analyse de-identified health and social care data to support research and innovation. By allowing data to be used within a protected environment rather than shared more widely, it helps safeguard privacy while enabling work that can improve services, develop new treatments and technologies, and deliver better outcomes for patients and communities across the region.

The West Midlands Secure Data Environment will give authorised, trained researchers the ability to analyse the health and social care information from our region. They will use it to find ways to improve care for everyone.

The West Midlands Secure Data Environment (SDE) covers six integrated care systems (ICSs):

- Shropshire, Telford and Wrekin ICS.
- Staffordshire and Stoke-on-Trent ICS
- Black Country ICS
- Birmingham and Solihull ICS
- Coventry and Warwickshire ICS.



Total population **6.2 million** and **848 health and social care partner organisations**. An ICS is the partnership of these organisations in your local area.



Patient and public involvement and engagement is fundamental to the West Midlands SDE because public trust, transparency and accountability are essential to the safe and responsible use of health and care data for research. From the outset, involvement has been hardwired into the programme, with engagement helping to shape communications, governance and decision-making.

This has included wide-reaching conversations with communities across the region, dedicated roles for public contributors through the Patient and Public Advisory Group and the Data Access Committee, and direct public representation within key programme workstreams. Embedding involvement in this way helps ensure that the West Midlands SDE is informed by lived experience, reflects public expectations, and remains focused on delivering clear public benefit.

“Hearing directly from young people is essential if we are to build a Secure Data Environment that is trusted, inclusive and responsive to the expectations of future generations.”

Dr Simon Ball, West Midlands SDE Senior Responsible Officer



Executive Summary



More than **150 children and young people aged 12-26** engaged.

12 regional engagement sessions delivered online and in person.



One **young people's engagement event in Birmingham** (aged 18-25).



Two questionnaires (pilot 38 responses and final 28 responses) captured a total of 66 additional views.



Main themes included:

- **Autonomy and choice;** people should be able to consent, opt out, and know who is using their data
- **Transparency;** strong data protection, meaningful choice, and trust in those managing the data
- **Trust;** without open communication, young people believed rumours and mistrust would follow
- **Public benefit;** data use is welcomed when it is visibly in the public interest, but not when private organisations benefit without giving back
- **NHS leadership;** is reassuring for most but must be underpinned by clear governance and communication to maintain confidence
- 11 points for consideration are detailed in the full report
- Five recommendations are detailed in the full report.

Headline findings

- Young people are **broadly supportive** of health data being used for research and service improvement
- Support is **conditional on transparency, security, meaningful choice and public benefit**
- **Opt-out** is seen as ethically essential and trust-building
- **NHS leadership** is reassuring but must be accompanied by clear governance and communication
- There is strong support for **patient and public involvement**, including youth representation
- Views on **charging organisations for access** are mixed and highly sensitive.
- Young people are clear about **how and where they want to be engaged**, favouring education settings, peer-to-peer approaches and digital platforms.

Five recommendations are presented to inform ongoing engagement, governance and communication activity.

The following report is concise and provides a clear overview of the engagement findings. The full detailed analysis is contained in the appendices.

If you would like this information in an alternative format, (for instance, braille, audio, easy read or your spoken language) please email WMSDE@uhb.nhs.uk

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