

# Young People's Engagement with the West Midlands Secure Data Environment Report of Findings



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# Foreword

The meaningful involvement of children and young people is essential to ensure that the West Midlands Secure Data Environment (SDE) is trusted, inclusive and relevant to future generations.

As future patients, data contributors and decision-makers, young people have a direct interest in how their health information is used, governed and communicated.

Early engagement helps build confidence in data-driven healthcare, supports transparency in public decision-making, and ensures emerging health needs and concerns are understood. This programme was undertaken to listen to young people's views, test understanding of health data use for research, and identify how best to communicate and involve them in the ongoing development and governance of the West Midlands SDE.

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



# 1. 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.

## 1.1. 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.

## 1.2. 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.



## 2. Background and Context

Public involvement has been integral to the development of the West Midlands Secure Data Environment since its initiation.

An extensive programme of patient and public engagement completed in March 2025 engaged over 700 people across the region and embedded public voices within governance structures, including the Public and Patient Advisory Group (PPAG) and the Data Access Committee (DAC).

A key recommendation from this work was to undertake **dedicated engagement with young people**, recognising them as current and future users of health services and contributors of data. This report documents that programme of work and sets out learning to support the SDE's ongoing development.



## 3. Aims and Objectives

The engagement programme aimed to:

01

Explore young people's understanding of health data and secure data environments

02

Understand attitudes to data sharing, consent, trust and governance

03

Capture views on opt-out, charging for access and public involvement in decision-making

04

Identify effective methods for communicating with and engaging young people

05

Inform future youth involvement in SDE governance and engagement.

# 4. Methodology

Taking into consideration the diverse population of the West Midlands and to maximise reach and inclusion a mixed methods approach was adopted.

Activity included:

- A regional programme of **online and in-person engagement sessions**
- A **culmination event** for young people aged 18–25
- A **pilot questionnaire** followed by a simplified **final questionnaire**.

Participants were recruited through a large database of organisations working with young people across all areas of the West Midlands, including schools, colleges, universities, youth forums, charities, faith groups and carers' organisations.

The various methodologies deployed enabled cross-triangulation of both qualitative and quantitative data demonstrating the same recurring themes:



## **Autonomy and choice:**

people should be able to consent, opt out, and know who is using their data.



## **Transparency:**

every organisation with access should be publicly visible, and their reasons clear.



## **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.

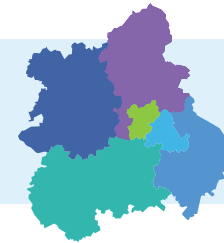
# 5. Reach and Participation



150+ children and young people participated.



Ages ranged from 12 to 26 years.



All areas of the West Midlands were represented.

## 4.1. What is your ethnic group?

The information below details the wide and inclusive response to the pilot and final questionnaires. Full demographics can be found in Appendices H & I.

Any other ethnic group (please specify below):	1	Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic background (please specify below)	1
Asian/Asian British: Any other Asian background (please specify below)	3	Mixed/Multiple ethnic groups: White and Asian	3
Asian/Asian British: Bangladeshi	2	Mixed/Multiple ethnic groups: White and Black Caribbean	1
Asian/Asian British: Chinese	1	Prefer not to say	2
Asian/Asian British: Indian	2	White: Any other White background (please specify below):	4
Asian/Asian British: Pakistani	10	White: English/Welsh/Scottish/Northern Irish/British	22
Black/African/Caribbean/Black British: African	4	White: Irish	2

# 6. Regional Engagement Sessions

## Engagement Events (13 in total) across all regions of the West Midlands.

Engagement events and workshops were delivered with children and young people across all areas of the West Midlands between January and March 2026. In total 13 Sessions were held both online and in person and included youth forums, colleges, youth clubs, carer groups and hospital- based engagement.

Group	Region attendees came from
Meetings organised by invitation sent out to the database x 2 - <b>Online</b>	Black Country x2
<b>Existing Meetings</b>	-
Positive Youth Foundation - <b>Online</b>	Coventry
Boys and girls Teen Club - <b>In person</b>	Coventry
Young Carers Coventry and Warwick - <b>Online</b>	Coventry and Warwick
Telford Youth Forum - <b>In person</b>	Telford
Stoke-on-Trent Youth Club - <b>In person</b>	Staffordshire and Stoke-on-Trent
Telford All Age Autism Hub - <b>In person</b>	Telford
SHAPE Youth Forum - <b>In person</b>	Black Country
Birmingham City College - <b>Online</b>	Birmingham
Birmingham Women and Children Youth Advisory Group - <b>Online</b>	Birmingham
Herefordshire and Worcestershire Youth Board - <b>Online</b>	Herefordshire and Worcestershire
Young person's 18 to 25 years event organised by invitation sent to the database - <b>In person</b>	Birmingham

## 6.1. Key findings

A

### Understanding of Health Data



Young people demonstrated a strong and often sophisticated understanding of health data, recognising its role in improving diagnosis, treatment, prevention and service planning. Many distinguished between different forms of data and emphasised public benefit.

B

### Trust, Security and Transparency



Trust emerged as a dominant theme. Participants stressed that honest, open communication about how data is used, who accesses it and why is essential. Reassurance must include both benefits and risks, alongside safeguards.

C

### Autonomy, Consent and Opt-out



Across all sessions, young people were clear that individuals must have meaningful choice. Opt-out and withdrawal of consent were viewed as fundamental rights, particularly for sensitive data such as mental health information.

D

### Governance and Public Involvement



There was strong support for patient and public involvement in decisions about who can access data. Many young people expressed interest in youth representation within governance structures, provided adequate support and clarity of role.

E

Young people felt that health data and the SDE are not well understood. They favoured communication through:



- Schools, colleges and universities
- Social media platforms
- Peer-to-peer activity
- Creative and interactive approaches.

Please find full details and feedback from all the engagement events at **Appendix A: Engagement sessions, locations and attendance.**

# 7. Young People's Engagement Event (Birmingham)

The final event brought together young people aged 18–25 to reflect on learning and participate in creative workshops.

Participants explored consent, governance and data use before developing video and animation concepts aimed at their peers:

- Young people broadly support data sharing where public benefit is clear
- Trust depends on transparency, security and choice
- Opt-out is seen as essential
- Public involvement strengthens legitimacy and confidence
- Communication must be age appropriate, honest and engaging.

The event demonstrated high levels of engagement, creativity and digital literacy and highlighted the value of co-produced communication.

**How do you feel about sharing your health data via the West Midlands Secure Data Environment?**

**"I feel comfortable sharing my data if it benefits others in the investment of any illness."**

WHERE DOES HEALTH DATA FOR RESEARCH COME FROM?



Should you be able to opt out of having your data shared?

"Yes, patients deserve to have full autonomy of their care as this makes them feel more valued and empowered."

"I think people should never be forced into sharing any very sensitive medical data."

"Yes, however I think the standard should be opt-in. If they don't want data shared, opt out."



Should organisations be charged to access the West Midlands Secure Data Environment?

"Universities shouldn't be charged for research and development. However private companies / pharmaceutical companies should."

"Yes — if private organisations benefit from the data, their benefit should go to the NHS."

"No, because it prevents other charities with less known companies who have genuine goals of helping people to access them."

Should patients and the public have a role in approving who is allowed to access the West Midlands Secure Data Environment?

"Yes, because it is part of their autonomy to approve who should be allowed to access their data such as organisations. The public / society should be able to decide what direction the NHS should improve."

"Yes, it is their own after all, and they should be able to know and control where it goes."

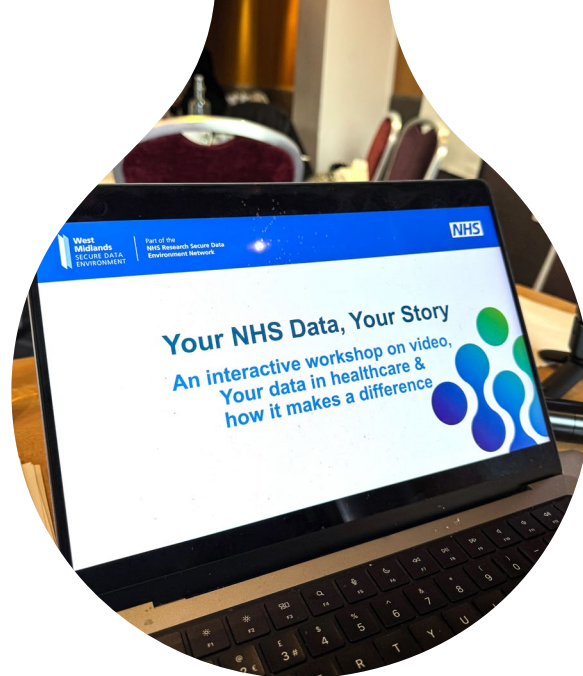


Do you think it is important for the NHS to tell young people about health data for research and the West Midlands Secure Data Environment?

“Yes, to demystify and prevent people from creating conspiracy about data.”

“Yes, because it is important to get the younger generation knowledgeable, since it will affect us and it can be important for many years to come.”

“Yes, prevent panic. And if people understand what’s happening to their data, they are less likely to spread misinformation.”



Please tell us the best ways we can reach as many young people as possible.

“Social media! But in a different, non-boring way. Use young people who do the work to appeal to other young people.”

“Short-form content. Young speakers going to schools. Adverts to attract attention.”

Do you think it is important to have young people’s groups for different ages, e.g. primary school age, secondary school age, university age?

“Extremely important. These individual groups have different experiences and developmental challenges. Having groups of different ages allows us to identify different struggles to inform prevention.”

“Yes, since realistically, similar age groups would relate better than a mixed one. And it will also help with sharing opinions from different age groups.”

“Yes, but there has to be communication between the groups.”

Full findings from this event are provided in **Appendix B: Young people’s engagement event (age 18 to 22 years in Birmingham).**

## 7.1. Summary of evaluation of the event

Feedback from participants was overwhelmingly positive, highlighting the quality of delivery, the welcoming atmosphere, and the value of the content. A smaller number of practical and developmental suggestions were offered, focusing on accessibility, reach, and opportunities for deeper engagement.

### Overall Experience and Delivery

Participants consistently described the event as engaging, well delivered and inspiring. Many comments praised the friendliness and passion of those involved in hosting the event, which created a supportive and motivating environment. Several participants noted that the sessions were easy to understand and thought provoking, even for those with limited prior knowledge of NHS data roles.

There was appreciation for learning about the breadth of career pathways within the NHS beyond traditional clinical roles, with data and digital careers described as eye opening and informative:



**“Really interesting event and it helped inform me about other pathways in data I didn’t know and different pathways you can take.”**



**“I loved how friendly everyone was, you can tell everyone involved in hosting the event was really passionate and I found that inspiring.”**



**“Today was great, impressive and engaging.”**

(Full evaluation report is provided in **Appendix C**).

# 8. Summary of Questionnaire Findings

Two questionnaires (pilot and final) captured views from young people unable to attend engagement sessions. Findings were consistent with themes identified through discussions.

Please see questionnaires and detailed finding in **Appendices D – G**.

## 8.1. Attitudes to Data Sharing

Young people were generally supportive of health data being used for research and service improvement, particularly where benefits to patients and communities were clear.



## 8.2. Conditions for Confidence

Support was conditional on:

- Anonymisation and confidentiality
- Robust security and governance
- Clear explanations of data use
- Meaningful consent and opt-out.



## 8.3. Trust and NHS Leadership

NHS leadership was widely reassuring, though trust depended on transparency, accountability and ongoing engagement.



## 8.4. Charging for Data Access

Views were mixed. Charging was acceptable to some where it supported public benefit, but controversial where it raised concerns about commercialisation or fairness.



## 8.5. Engagement and Involvement

Respondents supported increased youth involvement and suggested education settings, digital platforms and peer-led approaches as effective methods.



# 9. Key Points for Consideration

(All suggested points for consideration at **Appendix J**).

- Young people broadly support data sharing where public benefit is clear
- Trust depends on transparency, security and choice
- Opt-out is seen as essential
- Public involvement strengthens legitimacy and confidence
- Communication must be age appropriate, honest and engaging.



# 10. Key Recommendations

(All recommendations in **Appendix K**).



1. Sustain and expand youth engagement as an ongoing programme
2. Strengthen outreach through schools, colleges and digital platforms
3. Use clear real world examples to demonstrate public benefit
4. Ensure inclusive, accessible delivery
5. Increase interactivity and peer-to-peer approaches.

# 11. Conclusion

This engagement programme demonstrates that children and young people across the West Midlands are engaged, thoughtful and capable contributors to conversations about health data.

Their views affirm the importance of transparency, ethical governance and meaningful involvement in shaping the future of the West Midlands Secure Data Environment.



# Appendices

Appendix A: Summary of engagement sessions, locations and attendance

Appendix B: Young people's engagement event (aged 18 to 22 years in Birmingham)

Appendix C: Evaluation of the event

Appendix D: Pilot questionnaire

Appendix E: Full data analysis for pilot questionnaire

Appendix F: Final questionnaire

Appendix G: Full data analysis for final questionnaire

Appendix H: Pilot questionnaire demographics

Appendix I: Final questionnaire demographics

Appendix J: Points for consideration

Appendix K: Recommendations



# Appendix A: Summary of engagement sessions, locations and attendance

## Across all sessions:

- 150+ children and young people took part
- Ages ranged from 12 to 26 years

The main conversation was around sharing health data and the West Midlands SDE. We also asked young people for their ideas on how to reach as many other young people as possible to tell them about sharing health data for research and hear their views. The next section of this report details what they said:

## Engagement Events

Engagement events and workshops were delivered with children and young people across all areas of the West Midlands between January and March 2026. Sessions were held both online and in person and included youth forums, colleges, youth clubs, carer groups and hospital-based engagement.

## Key Findings

Overall, children and young people demonstrated a strong and thoughtful understanding of health data and its role in improving healthcare. The majority were supportive of health data being used for research and service planning, particularly where it was clearly framed around public benefit, improved treatments and better planning of services. Support for data sharing was strongest when the NHS, universities and charities were involved.

However, this support was not unconditional. Across all sessions, young people were clear that their willingness to share data depended on anonymisation, robust security, transparency and trust. Concerns were consistently raised about data breaches, hacking, misuse of data and lack of clarity about who has access.

Young people were particularly wary of private, commercial, technology and social media companies accessing health data, especially where profit rather than public benefit was perceived to be the primary motive.

A dominant theme throughout the engagement was autonomy. Young people felt strongly that individuals should be informed, respected and given genuine choice about how their data is used. There was overwhelming support for the right to opt out, with many participants stating that having this choice would increase trust and make them more likely to support data sharing in principle. Opt-out was seen as especially important for sensitive data, including mental health information.

Children and young people were also overwhelmingly supportive of public involvement in decision making about who can access health data. Many felt that patients and the public should have a role in approving access requests and expressed interest in the idea of youth representation within governance structures, provided those involved were appropriately informed and supported. Younger participants recognised the need for parental or carer involvement for children while still valuing young people's perspectives.

## Communication and Engagement

A strong and recurring message was that health data, and the Secure Data Environment are not well explained to young people. Participants consistently called for clearer, more honest communication that explains not only the benefits of data use but also the risks and safeguards in place. Messaging that focused solely on reassurance without acknowledging risk was viewed with scepticism and, in some cases, distrust.

Young people were clear about how they want to be engaged. Schools, colleges and youth settings were seen as the most effective places to reach large numbers of young people, supported by social media platforms such as TikTok, Instagram and YouTube.

Participants emphasised that content should be short, visual, creative and engaging, and strongly preferred peer to peer communication, with young people creating content for other young people. Animation, art, music and interactive workshops were consistently highlighted as effective approaches, alongside incentives such as certificates, prizes or opportunities that add value to education or careers.

## Conclusions

The findings from this engagement demonstrate that children and young people across the West Midlands are engaged, thoughtful and capable of contributing meaningfully to discussions about health data and digital systems. They broadly support the use of health data for research and service improvement but expect this to be underpinned by transparency, security, public benefit and personal choice.

The engagement provides strong evidence for the continued and expanded involvement of children and young people in the development, governance and communication of the West Midlands Secure Data Environment. It reinforces the importance of sustained, age appropriate and creatively delivered engagement that builds trust, promotes understanding and places young people at the centre of conversations about data that relates to their lives and their future healthcare.

# Appendix B: Young people's engagement event (aged 18 to 22 years in Birmingham)

This engagement event was delivered as a culmination event of the engagement programme. Session 1 of the event, as with previous events, explored young people's understanding of health data for research, secure data environments, involvement and consent. Session 2 included a creative workshop for participants to design their own media messaging.

## Session 1 Key Message Summary

Across the thirteen questions, young people demonstrated a strong and nuanced understanding of health data, secure data environments, and the governance choices that surround them. A handful of themes appeared repeatedly:

- Autonomy and choice; people should be able to consent, opt out, and know who is using their data.
- Transparency: every organisation with access should be publicly visible, and their reasons clear.

- 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.

Young people wanted to be informed and actively involved, particularly in age-specific ways, and saw peer-to-peer communication through social media, schools, colleges and trusted platforms as the most effective way to reach other young people.

Views were more divided on charging organisations and on the mechanics of opting out, but the underlying principle was consistent: health data belongs to the people it comes from, and they should have a meaningful say in how it is used.

Attendees were asked for their views by responding individually with post-it notes to questions displayed on comment walls. Please see responses on the following pages:

## Q1. What is health data and why is it collected?

### Summary of feedback

Young people described health data as information about a person's medical history, conditions, treatments and day-to-day health, gathered from patient interactions, surveys, research studies and routine clinical care. Several responses were notable for their sophistication where participants distinguished between qualitative data (interviews, patient narratives, lived experience of a condition) and quantitative data, and recognised that health data takes many forms.

When asked why it is collected, young people identified multiple purposes: to improve diagnosis and care, to spot patterns and trends, to support research into rare and common illnesses, to inform legislation, and to help plan services so the NHS can provide the right support for patients. There was a clear recognition that health data collection is connected to a wider public benefit.

### Illustrative quotes

**"Health data is something we collect for research - to identify common rare illnesses and to properly diagnose."**

**"Health data can come in various forms such as qualitative, quantitative and lifestyle techniques."**

**"For research purposes and to ensure a holistic approach is being provided to the individuals nationally."**

## Q2. What is a Secure Data Environment?

### Summary of feedback

Young people described a secure data environment as a protected space where health data is contained, anonymised, and only accessed by authorised people for approved purposes. Several participants used vivid metaphors: an "impenetrable walled garden" or simply "a way to keep data safe" that emphasised containment, encryption and strict access control. A recurring point was that data itself should stay inside the environment, with only aggregated results (such as graphs) leaving it.

### Transparency was also part of how young people defined a secure environment:

participants expected anyone wanting access to explain why, and for those reasons to be publicly available. A few responses were more tentative, indicating that clearer, plain-language explanations of what an SDE is would be helpful.

### Illustrative quotes

**"A secure digital environment only accessed by individuals on a need-to-know basis. It is heavily encrypted and secure to ensure maximum patient confidentiality."**

**"An environment in which data is contained within one system, with only graphs being able to leave. Any person trying to look at the anonymised data must be fully transparent for why they want the data."**

### Q3. Where does health data for research come from?

#### Summary of feedback

Young people identified a broad range of sources, with GPs and hospitals most cited. Other sources named included pharmacies, clinics, clinical trials, research laboratories, national research studies, surveys, the census, and the information that health professionals gather during routine interactions. Several participants also specifically mentioned voluntary participation, including data that people have consented to share for research, whether through universities, clinical trials, or dedicated involvement groups.

The responses demonstrated a clear recognition that health data for research ultimately comes from people from the population of the UK and that its purpose is to improve the country's healthcare.

#### Illustrative quotes

**"1) GP Records, 2) Hospital anonymised data, 3) Volunteers."**

**"From you, from individuals – it comes from the population of the UK to help with the UK's healthcare."**

**"Census – data collected that people have consented to use for analysis / find patterns."**

### Q4. Which organisations do you think want to use your health data for research and service planning?

#### Summary of feedback

Young people listed a wide range of organisations. The NHS, universities, charities (including named ones such as Cancer Research and the British Heart Foundation), pharmaceutical companies and the Government were named most often. Other suggestions included the NIHR, local authorities, public health bodies, emergency services (999, 111 and 112), schools and educational services.

Opinions diverged sharply on private-sector access. Some participants felt that access should be tightly restricted, with several explicitly stating that third-party and private healthcare companies "shouldn't have it". Others took a more permissive view, suggesting that private companies could have access, but only for a fee and under full transparency to fund the NHS. A common thread running through both views was that any organisation with access should have clear public-benefit aims.

#### Illustrative quotes

**"1) Pharmaceutical companies, 2) Universities, 3) Charities, 4) NHS, 5) Government."**

**"NHS, University, Charities: for free, but with full transparency. Private corps can access the data with a fee and under full transparency. Would help alleviate and fund the NHS."**

**"It should be restricted to companies that aid society directly and indirectly such as charities and pharmaceutical companies."**

## Q5. How do you feel about sharing your health data via the West Midlands Secure Data Environment?

### Summary of feedback

Young people were broadly positive about sharing their health data, but their willingness was conditional. The key conditions were consent, anonymisation, security, the right to withdraw, and a clear public benefit. Many participants said they would share their data if it meant helping researchers, informing policy, or contributing to better treatments and prevention, but not if there was any risk of misuse or private profit at public expense.

A theme of autonomy ran throughout the responses: participants wanted full control over their own data, the ability to withdraw access at any time, and transparency about how their data is being used. Several respondents said that their confidence in the West Midlands SDE specifically came from the expectation that confidentiality would be properly maintained.

### Illustrative quotes

**"I feel comfortable sharing my data if it benefits others in the investment of any illness."**

**"I'm fine with my data being shared, as long as an enquiry, consent and right to withdraw is present."**

**"I'd be happy to share my data, as long as I have full autonomy and access to my data and can withdraw access at any time."**

## Q6. Should you be able to opt out of having your data shared?

### Summary of feedback

Young people were strongly in favour of being able to opt out. The dominant theme was autonomy – participants felt that patients deserve control over their own data and the choice of whether it is shared. Several noted that having this choice makes patients feel "valued and empowered", and that without it, people would be less comfortable sharing any information at all. Sensitivity was another recurring point, especially for medical data that people may never want shared, particularly in relation to mental health conditions.

A smaller number of participants raised the tension between personal choice and research value. One respondent noted that opt-outs can affect the statistical significance of research, and another argued that people should understand why they might want to stay in, as well as how to opt out. One participant suggested that the default should be opt-in, with a clear, easy route out for anyone who later changes their mind.

### Illustrative quotes

**"Yes, patients deserve to have full autonomy of their care as this makes them feel more valued and empowered."**

**"I think people should never be forced into sharing any very sensitive medical data."**

**"Yes, however I think the standard should be opt-in. If they don't want data shared, opt out."**

## Q7. Should organisations be charged to access the West Midlands Secure Data Environment?

### Summary of feedback

Young people were divided on this question, with many responses taking a nuanced “yes and no” position. A common thread was that organisations with a public or non-profit mission such as universities, charities and the NHS itself should not be charged, because fees would create a barrier to research that benefits the public. Private companies and pharmaceutical firms, on the other hand, were frequently singled out as organisations that should be charged, with several participants arguing that if private companies benefit commercially from publicly generated data, some of that value should return to the NHS.

Concerns were raised about unintended consequences. Some worried that charging could exclude smaller charities or lesser-known organisations with genuine aims or push researchers away from using the SDE at all. Others saw a charging model as a practical way to help fund NHS research, security and patient care.

### Illustrative quotes

**“Universities shouldn’t be charged for research and development. However private companies / pharmaceutical companies should.”**

**“Yes, however I think the standard should be opt-in. If they don’t want data shared, opt out.”**

**“No, because it prevents other charities with less known companies who have genuine goals of helping people to access them.”**

## Q8. Should patients and the public have a role in approving who is allowed to access the West Midlands Secure Data Environment?

### Summary of feedback

Young people were overwhelmingly in favour of patients and the public having a role in approving who can access the SDE. The dominant theme was personal autonomy because the data is about them, they felt they should have a say in who uses it. Many emphasised transparency, participants wanted clear, up-front information about which organisations have access so they could make an informed decision. Several noted that public involvement would bring accountability and help build trust, and that a lack of transparency could fuel rumours, panic and reluctance to share data in the first place.

Several responses introduced nuance. Some felt that patients should be well informed before giving any approval and acknowledged that safeguards would be needed for patients not in a position to give informed consent. Others argued that while public involvement matters, the ultimate trust should rest with the professionals responsible for the data though this was a minority view.

#### Illustrative quotes

**“Yes, because it is part of their autonomy to approve who should be allowed to access their data such as organisations. The public / society should be able to decide what direction the NHS should improve.”**

**“Patients should know exactly who is given access to their data, otherwise it could cause panic or rumours as to what’s happening to their data and that could make less people comfortable with sharing it.”**

**“Yes, it is their own after all, and they should be able to know and control where it goes.”**

### **Q9. Do you think it is important for the NHS to tell young people about health data for research and the West Midlands Secure Data Environment?**

#### Summary of feedback

Young people overwhelmingly said yes. Their reasoning centred on the idea that young people are the future the decisions being made today about data will shape the health system they inherit, so they need to understand what is happening and have a voice in it. Several participants said that being informed would help them feel involved, educated and respected, and would make them more willing to take part.

A strong secondary theme was misinformation and mistrust. Participants argued that without clear, up-front communication, young people would be more likely to create or spread conspiracy theories about data use. Being honest and transparent with young people was seen as the best way to “prevent panic”, demystify the subject, and build long-term trust.

One dissenting voice cautioned that the approach would need to be age-appropriate, particularly for younger age groups.

#### Illustrative quotes

**“Yes, to demystify and prevent people from creating conspiracy about data.”**

**“Yes, because it is important to get the younger generation knowledgeable, since it will affect us and it can be important for many years to come.”**

**“Yes, prevent panic. And if people understand what’s happening to their data, they are less likely to spread misinformation.”**

## Q10. Please tell us the best ways we can reach as many young people as possible.

### Summary of feedback

Social media was by far the most common answer, mentioned in almost every response. Young people named specific platforms such as TikTok, Instagram, LinkedIn, YouTube and Meta, and stressed that content needed to be short, visual and, as several participants put it, “not boring” for it to be read. Several said peer-to-peer communication was essential: young people should hear about the SDE from other young people, including influencers and those already involved in the work.

Beyond social media, schools, colleges and universities were the next biggest theme, seen as places where almost every young person could be reached. Other suggestions included local community events, networking events, campaigns, adverts on TV, radio and in cinemas, animations, and working through family and community networks.

### Illustrative quotes

**“Social media! But in a different, non-boring way. Use young people who do the work to appeal to other young people.”**

**“Short-form content. Young speakers going to schools. Adverts to attract attention.”**

**“Social media, within schools / universities, local events.”**

## Q11. Do you think it is important to have young people’s groups for different ages, e.g. primary school age, secondary school age, university age?

### Summary of feedback

Young people felt strongly that age-specific groups are important. The central argument was that different age groups have genuinely different experiences, developmental stages, concerns and levels of understanding and that these differences are too significant for a single mixed-age group to capture properly. Several participants noted that primary school children, secondary school students and university students would each bring distinct perspectives on health data, and that tailoring engagement by age would make conversations more relevant, accessible and inclusive.

Some responses also pointed out that starting engagement earlier could help build long-term understanding and trust, and that there should still be communication between the different age groups so that insights could be shared across them.

### Illustrative quotes

**“Extremely important. These individual groups have different experiences and developmental challenges. Having groups of different ages allows us to identify different struggles to inform prevention.”**

**“Yes, since realistically, similar age groups would relate better than a mixed one. And it will also help with sharing opinions from different age groups.”**

**“Yes, but there has to be communication between the groups.”**

## Q12. When a young person's involvement group is being created, would you like to be informed?

### Summary of feedback

The response to this question was almost unanimous: yes. Young people said they wanted to know about, and be part of, any involvement group being set up. The reasoning was consistent, that young people bring lived experience and a distinct generational perspective, and their views need to be represented in research and policy decisions that will shape their future care. Several respondents said that policies involving young people should be designed with direct input from people their own age.

Participants also saw involvement groups as an opportunity to learn, to speak up about issues that matter to them, and to feed into the ongoing growth of the SDE itself. Consent and clear communication about what being "involved" actually means were mentioned as essential conditions.

### Illustrative quotes

**"Yes 100%! I believe there are more people wanting to be more involved in their own care."**

**"Yes, policies involving young people should be designed by their own adapted experiences."**

**"Yes, the younger generation through experiences and of course wider opinions, because the situation of the issue in question may have a bearing on them."**

## Q13. Is there anything else you'd like to tell us?

### Summary of feedback

In open responses, young people raised a range of additional considerations. Several encouraged the SDE team directly and thanked them for the work being done. Practical suggestions included conducting background checks on people accessing the data, using platforms like TikTok, Instagram and YouTube rather than email to reach young people, and covering transport costs for engagement sessions so that low-income young people would feel able to attend and be properly represented.

Broader concerns were also raised. One respondent felt that the collection of health data should not overshadow more urgent mental health issues affecting young people and highlighted how sensitive mental health information is. Others emphasised the importance of partnering with young people who would safeguard data and act as advocates for informed, responsible use.

### Illustrative quotes

**"I love what you guys are doing – keep up the great work."**

**"Using other platforms like TikTok, Instagram, YouTube to inform young people – most young people do not mostly engage by emails."**

**"Have these sessions cover people's transport expenses so it will encourage low-income young people to attend, so they are well represented."**

## Session 2 Workshop Activities

The design and content for the second session of the event were gathered from the previous engagement events across the West Midlands. At all the engagement events young people were asked for ideas on how best to communicate and engage with as many young people as possible. As you can see from findings reported of previous meetings many creative ideas and recommendations were suggested. The recommendation for young people talking to young people about health for research and the West Midlands secure data environment had been repeatedly suggested. Suggestions to create an animation and/or video footage for social media and websites, and to cascade throughout schools and colleges was also a recurring theme. Therefore, two workshops were offered in the second session at the event. The first workshop was how to create a video, the second on how to create an animation. Both sessions involved young adults exploring how healthcare data, digital storytelling and public trust connect. The highlight for both sessions was where participants turned complex data privacy ideas into engaging, social-media-ready content and ideas for an animation storyboard for people their own age.

## Participant Profile

- **Cohort:** 20 participants, primarily university students (aged 19-23)
- **Academic Background:** Majority studying science-based subjects
- **Media Experience:** Mixed – some had previously produced informational videos for organisations (e.g. local police) or for university coursework.

## Insights: Media Consumption & the Importance of “The Hook

Participants agreed that for healthcare messaging to resonate with their age group, content must:

- **Evoke Emotion:** Use authentic personal stories that inspire or motivate action
- **Maintain a Fast Pace:** Quick editing, concise messaging, and strong visuals
- **Reflect Influencer Culture:** Many reported they primarily encounter NHS or health-related content via influencers rather than official NHS channels.

These insights helped shape the creative direction of their video concepts and informed the animation storyboard.

## Conclusion & Impact

The workshop was highly successful. Participants demonstrated enthusiasm, creativity, and an impressive capacity to articulate complex technical concepts through accessible and relatable storytelling.

### Key Observations

- **Critical Thinking:** Use of internal monologue (“thinking bubble”) and rewind techniques showed deep understanding of privacy decision-making
- **Peer-to-Peer Communication:** Students naturally adopted a tone and style that speaks directly to Gen Z audiences
- **High Digital Literacy:** Delivering complete video edits within the workshop timeframe demonstrated excellent technical skills and creativity.

Participants did not shy away from sensitive topics such as data privacy, misconceptions, or public mistrust. Instead, they used these as creative catalysts to provide clarity and reassurance.

## Strategic Takeaways

- **Direct Address Works:** “moral panic to facts” approach is effective for challenging misinformation
- **Inclusivity Matters:** The diverse characters used throughout storyboards reflect an instinctive awareness of representation and health equity
- **Professional Output:** Students developed storyboards featuring audio cues, props, shot lists, and cast roles, demonstrating commitment to the brief.

## Final Verdict

The workshop delivered exceptional value. The participants demonstrated that young adults can effectively shape the narrative around NHS data by combining emotional resonance, speed, and authenticity.



# Appendix C: Evaluation of the event

Following the event, participants were invited to complete a concise evaluation form to provide feedback on the day's proceedings. Of the 20 attendees, 17 submitted their feedback, yielding a strong response rate of 85%. Analysis of the graph below reveals that most sessions received an 'excellent' rating, with a handful marked as 'good'. Notably, none of the respondents selected 'satisfactory' or 'poor', indicating a consistently high level of satisfaction across all aspects of the event. The scoring criteria, ranging from 'excellent' to 'poor', demonstrate that the delivery of the event was well received and met the expectations of participants.

## Participant comments

Feedback from participants was overwhelmingly positive, highlighting the quality of delivery, the welcoming atmosphere, and the value of the content. A smaller number of practical and developmental suggestions were offered, focusing on accessibility, reach, and opportunities for deeper engagement.

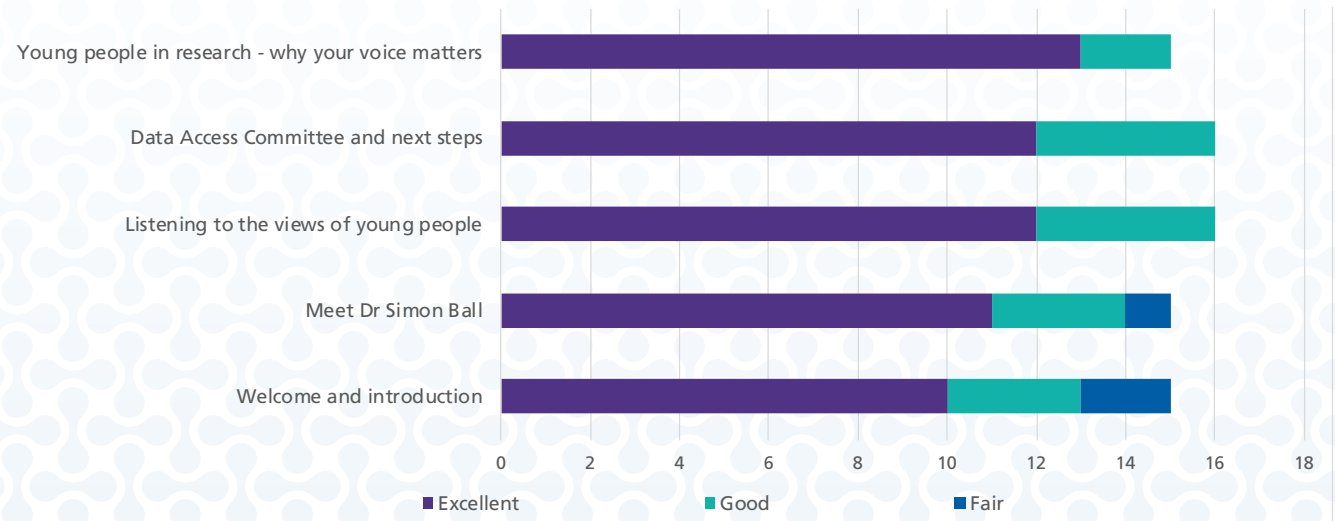
## Overall Experience and Delivery

Participants consistently described the event as engaging, well delivered and inspiring. Many comments praised the friendliness and passion of those involved in hosting the event, which created a supportive and motivating environment.

Several participants noted that the sessions were easy to understand and thought-provoking, even for those with limited prior knowledge of NHS data roles.

There was particular appreciation for learning about the breadth of career pathways within the NHS beyond traditional clinical roles, with data and digital careers described as eye-opening and informative.

### West Midlands SDE young people's event evaluation



### Illustrative quotes:

**"I loved how friendly everyone was, you can tell everyone involved in hosting the event was really passionate and I found that inspiring."**

**"Today was great, impressive and engaging."**

**"Really interesting event and it helped inform me about other pathways in data I didn't know and different pathways you can take."**

## Impact on Awareness and Understanding

Several responses indicated that the event successfully broadened participants' understanding of the NHS, especially the role of data and its impact on health and research. This was seen as an important outcome, particularly for young people considering future study or career options.

Some participants expressed a desire to share what they had learned more widely, suggesting that access to materials such as videos would help spread the message to other young people.

### Illustrative quotes:

**"I didn't think there were other jobs in the NHS other than the standard research and medicine."**

**"Maybe having access to these so that we can spread the information and get more people to know that NHS isn't only about doctors, GP hospitals but also data management and the impact it can have in health."**

## Suggestions for Future Improvement and Expansion

Suggestions for improvement focused primarily on increasing reach, interactivity, and depth. Participants expressed interest in hearing more concrete examples of how health data is used in practice and its impact on diseases, services, and patient outcomes.

There was also strong support for running more sessions, increasing opportunities for peer to peer discussion, and promoting events more widely through schools and local communities.

Overall, these suggestions reflected enthusiasm for further involvement rather than dissatisfaction.

### Illustrative quotes:

**"I would love to hear more about who is using the data and examples of diseases / illnesses that have been cured because of our data being available."**

**"Perhaps more interactive, getting to speak to other peers in the group setting."**

**"Add more sessions to improve involvement... I'd love to attend many more events regarding this."**

## Accessibility and Practical Considerations

A small number of comments highlighted practical issues. These included accessibility needs, such as ensuring speakers can be clearly heard, and logistical considerations such as catering preferences and use of embedded videos to avoid technical issues.

These comments were constructive in nature and framed as suggestions to further improve an already positive experience.

### Illustrative quotes:

**“It would [help if] the speakers spoke a bit louder as I am hard of hearing and it was quite hard to hear at times.”**

**“You can put in the videos in the slides to avoid any technical difficulties.”**

## Summary

In summary, participant feedback demonstrates a high level of satisfaction with the event, particularly its delivery, atmosphere and informative content. The comments reinforce that the event met its aims of engaging young people, increasing understanding of health data and the West Midlands SDE, and inspiring interest in wider NHS roles. Suggestions for improvement were practical and forward-looking, indicating strong appetite for continued and expanded engagement.



# Appendix D: Pilot questionnaire

## NHS listening to the views of young people – West Midlands Secure Data Environment (SDE)

Complete the questionnaire to share your thoughts and to be entered into a prize draw and receive a £20 shopping voucher!

### About you

1. How old are you?

.....

2. How would you feel about researchers using your health information for research through the West Midlands SDE?

.....

3. Why do you feel this way?

.....

4. What do you feel would reassure you and others and help people feel confident to share their health data?

.....

5. Does it make you feel more reassured or not that it is the NHS who are leading and managing the West Midlands SDE?

.....

6. What do you see as benefits or disadvantages in sharing health information?

.....

7. Do you think patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?

8. We will charge other organisations to access health information for research. What are your thoughts/feelings about this?

.....

9. Is it important that people who do not wish to share their health data with the West Midlands SDE are given the option to opt-out?

.....

10. Do you think it is important for young people to hear about the West Midlands SDE? If so, why?

.....

11. Do you have any ideas on how best to involve young people?

.....

12. Would you like to get involved in this project (for example becoming a member of a Youth forum)? If yes, please provide your contact details below.

.....

12a. If you would like to be entered into the prize draw, please provide your email address below: (please note that your email address will only be used to contact you if you win)

.....

## About you

We would like to know a little more about you. The following questions will help us understand more about who has responded to this survey. This will help us to make sure we have listened to as many different people as possible. You can leave this section blank if you want.

13. Which area of the West Midlands do you live in?

.....

14. What is your ethnic group? Choose 1 option that best describes your ethnic group or background.

.....

15. What is your religion or belief?

.....

16. How do you identify?

.....

17. What is your sexual orientation?

.....

18. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (In the last 26 weeks / 6 months.)

.....

19. Do you have any conditions or disabilities that may have an impact on your day-to-day life?

.....

20. Do you provide care for someone? A carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support. (Tick as many as appropriate.)

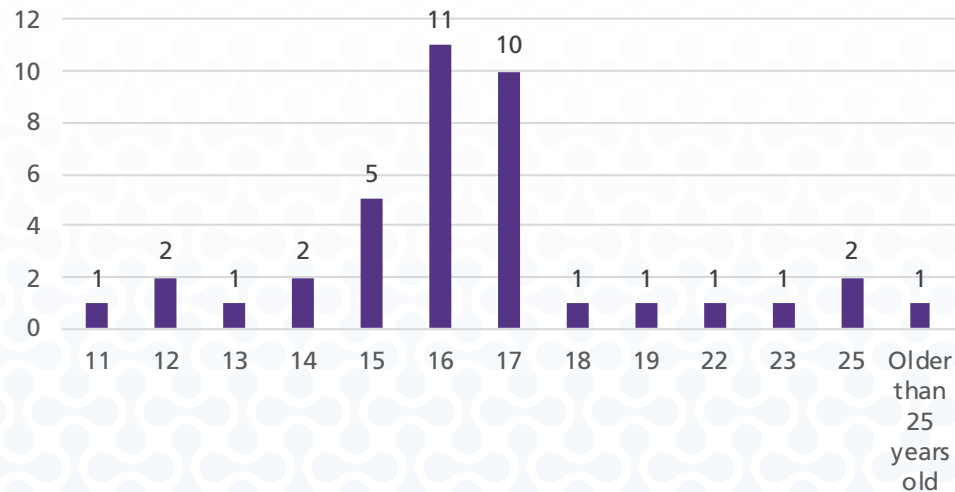
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# Appendix E: Full data analysis for pilot questionnaire

A questionnaire was designed and circulated widely to capture the views of young people we were unable to reach at engagement meetings. Firstly, we piloted the questionnaire and monitored responses. We received 38 responses to the pilot questionnaire and 28 responses to the final one. The final questionnaire was modified asking mainly quantitative questions making it less time consuming to answer to encourage more responses.

## Responses to the pilot questionnaire

### Q1. How old are you?



It was important to make sure that the questionnaire was answered by young people. Therefore, the age range was set as 10 to 25 years. The graph above shows the ages of those responding to the survey.



## Q2. How would you feel about researchers using your health information for research through the West Midlands SDE?

Respondents were asked for their thoughts on their health information being used for research through the West Midlands SDE. 36 responses were received.

Table 1 presents the complete list of themes, sentiments and sub-themes.

**Table 1. How would you feel about researchers using your health information for research through the West Midlands SDE?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Willingness to Share Data	Comfortable sharing health data for research	22	61%
Positive	Value of Health Research	Health research is important and beneficial	7	20%
Neutral	Data Protection & Safeguards	Willing if data is anonymised, kept confidential and secure	8	22%
Neutral	Transparency & Consent	Needs reassurance or clarity about how data is stored and used	6	17%
Negative	Privacy Concerns	Uncomfortable or unwilling to share health information	8	22%
Observation	Public & Societal Benefit	Data sharing benefits society, NHS or future patients	4	11%

Overall, responses to this question were largely positive, with many participants expressing acceptance of their health data being used for research purposes. A substantial proportion of respondents described health research as important and beneficial, particularly in terms of improving healthcare, advancing medical knowledge, and benefiting society or future patients.

However, this support was often conditional. Many respondents emphasised that they would only feel comfortable if their data were anonymised, kept confidential, and securely stored. Clear reassurance that personal identities would not be disclosed appeared to be a key factor in building confidence.

A smaller, but significant, group of respondents expressed discomfort or opposition to data sharing. These concerns were typically framed around privacy, personal control over health information, and uncertainty about how data might be accessed, stored, or used. Some participants reported feeling uneasy specifically because they lacked detailed information about data governance and safeguards.

In summary, while attitudes towards sharing health data for research are predominantly supportive, they are highly dependent on trust, transparency, and strong data protection measures. Clear communication about these safeguards appears critical to maintaining public confidence.

### Q3. Why do you feel this way?

Responses to this question provide important context for the views expressed in Question 2 and highlight several consistent underlying motivations and concerns. 35 responses were received.

Table 2 presents the complete list of themes, sentiments and sub-themes.

**Table 2. Why do you feel this way?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Altruism & Social Contribution	Using my data helps others or the wider community	15	43%
Positive	Value of Health Research	Health data supports medical research and healthcare improvement	11	31%
Positive	Trust in Institutions	Trust that NHS or researchers will protect and use data appropriately	1	3%
Neutral	Transparency & Understanding	Uncertainty due to lack of information about how data is used	6	17%
Neutral	Data Protection & Safeguards	Acceptance depends on anonymity, confidentiality, or data security	1	3%
Negative	Privacy & Personal Boundaries	Personal health information should remain private	5	14%
Negative	Risk & Harm	Concerns about misuse, exploitation, or data being unsafe	3	9%
Observation	Beliefs, Culture & Values	Views influenced by personal, cultural, or religious values	1	3%

Many participants justified their support for data use by pointing to the value of health research. Common reasons included improving healthcare quality, advancing medical understanding, supporting statistics and evidence-based decision-making, and helping others in the community. For some respondents, contributing data was described as “the right thing to do” or a way to have a positive impact beyond themselves.

Altruism and social contribution emerged as strong themes. Several participants expressed satisfaction in knowing their data could help others, improve services, or benefit future generations. Trust also played a significant role: respondents who expressed confidence were often those who stated trust in the NHS or in researchers to handle data appropriately and responsibly.

Conversely, concerns were most rooted in privacy and risk. Participants who were hesitant or opposed frequently cited fears of misuse, commercial exploitation, hacking, or lack of clarity about who would access the data and for what purposes. The vagueness of “research” as a concept was mentioned by some as a reason for uncertainty, with respondents wanting clearer explanations before feeling reassured.

A small number of responses highlighted personal, cultural, or religious values as influencing attitudes, illustrating that views on data sharing are not solely technical but may also be shaped by identity and personal beliefs.

Overall, this question demonstrates that attitudes towards data sharing are shaped by a balance between perceived public benefit and perceived personal risk, with trust, transparency, and respect for personal values acting as key mediators.

## Q4. What do you feel would reassure you and others and help people feel confident to share their health data?

Respondents were asked to share what would reassure them and make them feel confident in sharing their health data. 36 responses were received.

Table 3 presents the complete list of themes, sentiments and sub-themes.

**Table 3. What do you feel would reassure you and others and help people feel confident to share their health data?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Neutral	Uncertainty	Unsure what would reassure me	4	11%
Negative	Discomfort	Still uncomfortable	1	3%
Observation	Transparency & Communication	Clear explanations about how data is used, stored, and shared would increase confidence (e.g. who can access the data)	18	50%
Observation	Data Protection & Privacy	Confidence depends on data being anonymised and kept confidential (e.g. minimise risk of discrimination)	12	33%
Observation	Security & Governance	Robust security measures and safeguards are essential	6	17%
Observation	Engagement & Education	Workshops, schools, or engagement activities would help increase reassurance (e.g. surveys, rewards etc.)	6	17%
Observation	Trust in Institutions	Trust in professionals or reputable organisations increases confidence (e.g. data not used commercially)	5	14%
Observation	Autonomy & Consent	Having choice, consent, or the ability to withdraw increases trust	3	8%

## Summary of views

Young people consistently identified transparency as central to feeling reassured. Many emphasised the importance of understanding:

- How their data would be used.
- Who would access it.
- How it would be stored and protected.
- What benefits would result from its use.

Anonymity and confidentiality were repeatedly highlighted as non-negotiable conditions. For many, reassurance was directly tied to assurances that personal identities would not be exposed and that data could not be misused or sold.

Strong security and governance measures were also seen as critical. Respondents referred to fears of data leaks, hacking, and misuse, and some suggested formal protections such as contracts, penalties, or enforceable promises as reassurance mechanisms.

A significant number of young people emphasised the importance of choice and control, including the ability to opt in or out, decide when data is shared, and withdraw consent. This reflects a clear expectation that participation should be voluntary and reversible.

Finally, young people highlighted the value of education and engagement, particularly through schools, workshops, and discussions with trusted professionals. These were seen as ways to normalise data use, address concerns, and build understanding over time.

A smaller group expressed uncertainty or discomfort regardless of safeguards, indicating that reassurance will not be universal and that some individuals may choose not to participate even with robust protections in place.

## Q5. Does it make you feel more reassured or not that it is the NHS who are leading and managing the West Midlands SDE?

Respondents were asked whether knowing that the NHS are leading and managing the West Midlands SDE makes them feel more reassured. 36 responses were received.

Table 4 presents the complete list of themes, sentiments and sub-themes.

**Table 4. Does it make you feel more reassured or not that it is the NHS who are leading and managing the West Midlands SDE?**

Sentiment	Main theme	Code (sub-theme)	Count	%
Positive	Institutional Trust	NHS leadership is reassuring (e.g. it is a trusted organisation)	25	70%
Positive	Reassurance & Confidence	NHS involvement increases confidence in appropriate data use (e.g. would not trust private organisations)	12	34%
Neutral	Indifference or Uncertainty	NHS involvement does not change reassurance	5	14%
Neutral / Conditional	Conditional Confidence	Reassuring but more information and safeguards are needed	3	8%
Negative	Institutional Scepticism	Concerns remain despite NHS leadership	4	11%

## Summary of views

Most young people reported feeling more reassured knowing that the NHS leads and manages the West Midlands SDE. The NHS was commonly described as:

- trusted,
- publicly accountable,
- professional,
- and motivated by patient care rather than profit.

For these respondents, NHS involvement increased confidence that health data would be handled responsibly and used for appropriate purposes.

However, reassurance was often qualified. Some young people felt that NHS leadership was reassuring only if it was accompanied by:

- clear governance,
- transparency about who within the NHS accesses data,
- and strong oversight arrangements.

A smaller group expressed neutral or mixed views, stating that NHS involvement made little difference to how they felt, or that reassurance depended on additional information.

A minority expressed scepticism, citing concerns about the size and complexity of the NHS, previous controversies, or a general mistrust of large institutions.

## Q6. What do you see as benefits or disadvantages in sharing health information?

Respondents were asked what they perceive as benefits or disadvantages in sharing health information. 35 responses were received.

Table 5 presents the complete list of themes, sentiments and sub-themes.

**Table 5. What do you see as benefits or disadvantages in sharing health information?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Research & Healthcare Improvement	Sharing data helps improve research and healthcare outcomes	23	66%
Positive	Social & Public Benefit	Sharing data benefits society or communities	17	49%
Neutral / Conditional	Conditions & Safeguards	Benefits outweigh risks only if safeguards exist	3	9%
Neutral	Uncertainty	Uncertain about benefits or disadvantages	3	9%
Negative	Privacy & Data Misuse	Risk of privacy breaches or misuse of data	17	49%
Negative	Personal Control & Comfort	Sharing data can feel uncomfortable or like loss of control ( e.g. especially if there is lack of information on how the data is stored/ used)	12	34%
Negative	Research	Waste of time if nothing is achieved by research	1	3%

## Summary of views

Many young people identified clear benefits of sharing health data, particularly:

- improving medical research,
- supporting better diagnosis and treatment,
- identifying patterns in health and illness,
- and improving services for communities and future generations.

These benefits were often framed in terms of societal gain, rather than individual advantage.

At the same time, respondents frequently highlighted risks and disadvantages, most notably:

- privacy breaches,
- hacking or leaks,
- misuse of data,
- commercial exploitation,
- and loss of personal control over sensitive information.

For some, health data was described as inherently personal or sensitive, making the idea of sharing uncomfortable regardless of potential benefits.

Many responses reflected a conditional position, where benefits were accepted only if strong safeguards, confidentiality, and responsible use could be guaranteed.

A smaller group expressed uncertainty, stating they were unsure about the benefits or disadvantages, while a minority felt that the risks outweighed any potential gains.

## Q7. Do you think patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?

In question 7, respondents were asked whether patients and public representatives should have a role in approving who is allowed to access the information stored in the West Midlands SDE for research projects. 36 responses were received.

Table 6 presents the complete list of themes, sentiments and sub-themes.

**Table 6. Do you think patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Public & Patient Involvement	Patients and public should have a role in approving access	32	89%
Positive	Consent & Personal Control	People should have a say over who accesses their data	8	22%
Positive	Trust & Accountability	Public involvement would increase trust, transparency and confidence	4	11%
Neutral / Conditional	Conditions & Safeguards	Involvement is appropriate only with clear rules, limits, or safeguards	5	14%
Neutral	Institutional Oversight	The NHS should retain responsibility or final oversight	2	6%
Neutral	Uncertainty	Unsure, mixed views, or no strong opinion	1	3%
Negative	Opposition	Patients/public should not have a role in approving access	1	3%

## Summary of views

Young people expressed strong overall support for patients and public representatives having a role in approving access to the West Midlands Secure Data Environment for research purposes. Most responses were clearly affirmative, often stated simply as “yes” or “definitely,” indicating broad instinctive support for public involvement in access decisions.

A significant number of young people linked public involvement to greater trust, transparency, and confidence in how health data is managed. Some respondents felt reassured knowing that people who understand lived experience, rather than only organisations or researchers, would have a voice in deciding who can access sensitive health information. Involvement was felt necessary to ensure decisions are made in the public interest, rather than for unclear or inappropriate purposes.

Closely related to this was a strong emphasis on personal control and consent. Many young people explicitly stated that, because the data belongs to patients, individuals should have some say over who accesses it and how it is used. This reflects a consistent theme across the wider survey that autonomy and respect for personal data are critical to public confidence.

While support was widespread, it was often conditional rather than unconditional. Several respondents stressed that the management of the SDE should operate within clear limits, rules and safeguards. Young people commonly emphasised that only necessary or appropriate people should be allowed access, and that approval processes should be accompanied by clear criteria, policies, or agreements. Some also highlighted the importance of confidentiality and minimising unnecessary data sharing.

A smaller number of respondents felt that institutional oversight, by the NHS, should remain central. In these cases, public involvement was seen as complementary to, rather than replacing, the NHS responsibility and governance.

Only a very small minority expressed opposition or scepticism, suggesting that patients or the public should not be involved, or expressing discomfort with the idea in principle. A small group of respondents also expressed uncertainty or mixed views, often framed as concern that public involvement could be difficult to manage or “get out of hand” if not well structured.

## Q8. We will charge other organisations to access health information for research. What are your thoughts/feelings about this?

Respondents were asked if they think that organisations and researchers should be charged to access health information. 36 responses were received.

Table 7 presents the complete list of themes, sentiments and sub-themes.

**Table 7. We will charge other organisations to access health information for research. What are your thoughts/feelings about this?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Public Benefit & Value	Income should generate public or NHS benefit	11	31%
Positive	Individual Rights	Consent and individual choice are essential	6	17%
Positive	Value of Data	Perceived value or worth of health data (e.g. people should understand why there is a charge, high charges)	5	14%
Neutral	Uncertainty	Do not mind/unsure/okay	10	28%
Neutral	Financial Governance	Views on charging to cover costs versus profit-making	4	11%

Sentiment	Main theme	Code (sub-theme)	No.	%
Neutral	Safeguards & Ethics	Strong ethical safeguards are required	4	11%
Negative	Commercialisation & Ethics	Concerns about commercialisation or selling of data (e.g. data should be used to improve research)	11	31%
Negative	Personal Impact	Personal discomfort or emotional reaction (e.g. do not agree)	7	19%
Negative	Scope of Sharing	Limits on how widely data should be shared	4	11%
Negative	Fairness & Access	Concerns about fairness or access for organisations	3	8%
Negative	Trust & Confidence	Impact on trust or confidence in data use	1	3%

Young people expressed mixed and often cautious views about charging organisations to access health information for research purposes. While some respondents were broadly accepting of charges in principle, support was usually conditional, with clear expectations around ethics, transparency, and use of income.

A prominent concern related to commercialisation and ethics. Many young people reacted negatively to the idea of data being “sold” or used for financial gain, describing it as data harvesting or inappropriate commercial exploitation. This often-triggered feelings of discomfort, unease, or distrust, particularly where respondents were unsure how organisations might use the data once accessed.

At the same time, several respondents felt that charging could be acceptable if it strictly covered costs associated with processing, transferring, and securing data. In these cases, young people drew a clear distinction between cost-recovery and profit-making, with profit-driven use viewed far less favourably. Where charges were seen as reasonable, respondents often wanted reassurance that income would support the NHS, patients, or public benefit, such as reinvestment in services or research.

Consent and individual choice emerged as another important theme. Many young people stated that charging would only be acceptable if patients were aware, had approved the arrangement, and retained control over how their data was used. Transparency about who is paying, why, and for what purpose was seen as essential to maintaining confidence.

Concerns about fairness and access were also raised. Some responses suggested that high charges could restrict access for organisations working towards beneficial research, while others questioned whether charging was necessary at all if the work was in the public interest. A small number of respondents felt that data access should remain available to those within the NHS or be available freely for medical research.

## Q9. Is it important that people who do not wish to share their health data with the West Midlands SDE are given the option to opt-out?

Respondents were asked whether it is important that people who do not wish to share their health data with the West Midlands SDE are given the option to opt-out. 36 responses were received.

Table 8 presents the complete list of themes, sentiments and sub-themes.

**Table 8. Is it important that people who do not wish to share their health data with the West Midlands SDE are given the option to opt-out?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Autonomy & Choice	People have the right to choose whether their health data is used	36	100%
Positive	Consent & Ethics	Informed consent and voluntary participation are essential	10	28%
Positive	Trust & Confidence	Offering opt-out increases trust and confidence	3	8%
Negative	Privacy & Confidentiality	Concerns about privacy and confidentiality	3	8%
Negative	Risk & Misuse	Fear of misuse, leaks, or data being exploited	2	6%
Observation	Respect for Individual Views	Respecting personal beliefs and comfort levels	6	17%

Young people expressed agreement unanimously that individuals must have the option to opt out of sharing their health data with the West Midlands SDE. Responses were overwhelmingly positive and often expressed strongly, indicating that opt-out is viewed as a fundamental requirement rather than an optional feature.

A dominant theme was personal choice and autonomy. Many young people stated that health data belongs to the individual, and that people should be free to decide whether they wish to contribute. Opt-out was widely framed as a matter of respecting personal boundaries, values, and comfort levels, particularly because health information is seen as sensitive and deeply personal.

Privacy and confidentiality were also a concern. Many young people stated that opting out is essential to protect privacy and prevent unwanted sharing, misuse, or leaks of personal information. Some responses suggested that without a clear opt-out option, trust in the system would be undermined, particularly if people felt their wishes were not respected.

Several respondents explicitly linked opt-out to trust and confidence. Providing a genuine choice was seen to reassure people, demonstrate transparency, and show respect for patients. In some cases, young people suggested that offering an opt-out might increase willingness to participate among those who feel reassured by having control.

## Q10. Do you think it is important for young people to hear about the West Midlands SDE? If so, why?

Respondents were then asked whether it is important for young people to hear about the West Midlands SDE and why. 36 responses were received.

Table 9 presents the complete list of themes, sentiments and sub-themes.

**Table 9. Do you think it is important for young people to hear about the West Midlands SDE? If so, why?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Knowledge & Awareness	Yes, young people should be informed about how data is used	33	92%
Positive	Informed Decision-Making	Information is essential and enables informed choices	9	25%
Positive	Rights & Ownership	Health data belongs to individuals and they have rights over it	5	14%
Neutral	Trust & Transparency	Transparency is important and improves trust in data use	6	17%
Neutral / Negative	Uncertainty or Lack of Awareness	Low awareness or confusion about the SDE (e.g. unsure, N/A)	2	6%
Negative	General	Informing young people is not necessary	1	3%

Young people largely agreed that it is important for them to hear about the West Midlands SDE, with most respondents stressing the value of awareness and understanding from an early age. Informing young people was seen as essential to enabling them to make informed choices about their health data.

A key theme was knowledge and transparency. Many young people said that understanding how their data is used, where it goes, and why it matters helps reduce uncertainty and confusion. Several respondents noted that lack of awareness could lead to fear, mistrust, or people opting out automatically in the future because they do not understand the purpose or benefits of data sharing.

Closely linked to this was the importance of choice and agency. Young people emphasised that because the data belongs to them, they deserve to be informed and involved in decisions about its use. Awareness was also associated with building trust, particularly when young people know their data is being handled safely and responsibly.

### Q11. Do you have any ideas on how best to involve young people?

In the next question, respondents were asked if they had any ideas on how to best involve young people in the future. 34 responses were received.

Table 10 presents the complete list of themes, sentiments and sub-themes.

**Table 10. Do you have any ideas on how best to involve young people?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Neutral	General	Uncertainty or lack of ideas on how to engage	5	15%
Observation	Active Participation	Young people want opportunities to participate and have a voice (e.g. face to face engagement, youth councils, provide certificates, incentives, encouragement, leaflets, volunteering)	21	62%
Observation	Location	Engage with young people in their environments (e.g. schools, colleges, universities, youth groups, hospitals)	15	44%
Observation	Digital Communication	Digital and social media are effective engagement tools (e.g. ads, posts)	11	32%

Young people offered a wide range of practical and constructive ideas for how to involve their peers, with strong emphasis on education-based and digital approaches. Schools and colleges were frequently identified as key settings, with suggestions including assemblies, workshops, PSHE (Personal, Social, Health, and Economic) lessons, classroom activities, and partnerships with educational institutions.

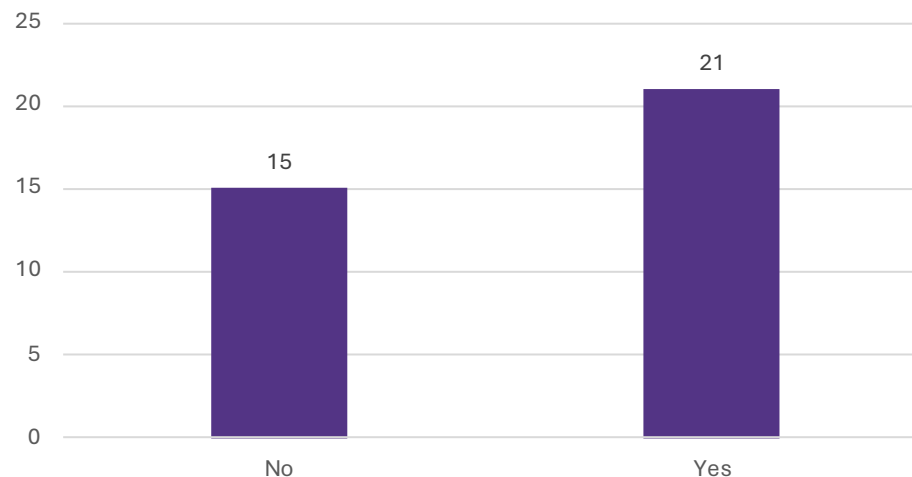
Digital communication was another dominant theme. Social media platforms, short videos, online content, and interactive campaigns were seen as effective and accessible ways to reach young people. Respondents highlighted the importance of making information engaging, relatable, and easy to understand, rather than overly technical.

Many young people also stressed the value of active participation and voice. Suggestions included youth panels, youth councils, volunteering opportunities, feedback forums, workshops, and opportunities to take part in discussions or decision-making. Involving young people directly was suggested to ensure their views are genuinely heard and to build trust and confidence.

Incentives and engagement tactics, such as certificates, rewards, competitions, or recognition for participation, were mentioned by some respondents as ways to encourage interest. Others emphasised the importance of making involvement fun, inclusive, and non-embarrassing, particularly for those who may feel uncomfortable discussing health topics.

A smaller number of respondents said they were unsure how to involve young people or had no ideas, highlighting the need for clear, accessible engagement strategies.

## Q12. Would you like to get involved in this project?



The majority (21) of young people who responded to this question said they would like to get involved further in this project and left their contact details.

# Appendix F: Final questionnaire

## NHS listening to the views of young people – West Midlands Secure Data Environment (SDE)

Complete the questionnaire to share your thoughts and to be entered into a prize draw and receive a £20 shopping voucher!

### About you

1. How old are you?

2) To what extent do you agree with researchers using your health information for research through the West Midlands SDE?

3. Please explain why do you feel this way and how we can help you and others to feel more confident to share their health data.

4. To what extent do you agree that you feel more reassured that the NHS is leading and managing the West Midlands SDE?

5. What do you think are the benefits or disadvantages of sharing health information?

6. To what extent do you agree that patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?

7. To what extent do you agree that organisations should pay to access health information for research?

8. Please tell us why you think this.

9. To what extent do you agree that people are given the option to opt-out if they do not wish to share their health data with the West Midlands SDE?

10. To what extent do you agree it is important for young people to understand the work of the West Midlands SDE? (For example, who it is and what it does).

11. Please tell us why you think this.

12. Do you have any ideas on how best to involve young people?

13) Would you like to get involved in this project (for example becoming a member of a Youth forum)? If yes, please provide your contact details below.

.....

13a) If you would like to be entered into the prize draw, please provide your email address below: (please note that your email address will only be used to contact you if you win)

.....

## About you

We would like to know a little more about you. The following questions will help us understand more about who has responded to this survey. This will help us to make sure we have listened to as many different people as possible. You can leave this section blank if you want.

14. Which area of the West Midlands do you live in?

.....

15. What is your ethnic group? Choose 1 option that best describes your ethnic group or background.

.....

16. What is your religion or belief?

.....

17. How do you identify?

.....

18. What is your sexual orientation?

.....

19. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (In the last 26 weeks / 6 months.)

.....

20. Do you have any conditions or disabilities that may have an impact on your day-to-day life?

.....

21. Do you provide care for someone? A carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support. (Tick as many as appropriate.)

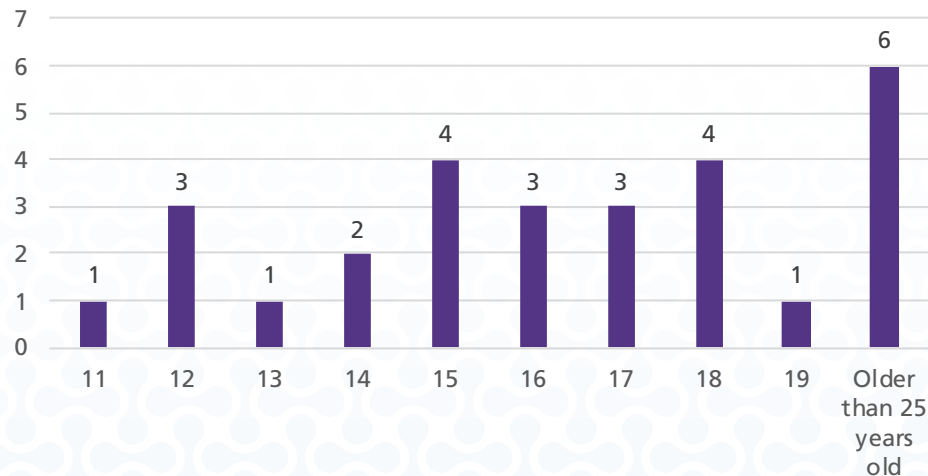
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# Appendix G: Full data analysis for final questionnaire

## Responses to the final questionnaire

It was important to make sure that the questionnaire was answered by young people. Therefore, an age range was set as 10 to 25 years. The graph above shows the age range of those responding to the survey.

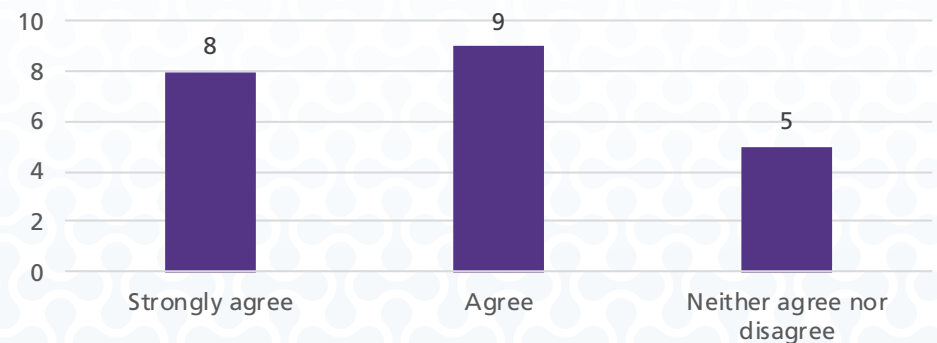
### Q1. How old are you?



It was important to make sure that the questionnaire was answered by young people. Therefore, an age range was set as 10 to 25 years. The graph above shows the age range of those responding to the survey.

### Q2. To what extent do you agree with researchers using your health information for research through the West Midlands SDE?

Most respondents (17) agreed with the researchers using their health data for research through the West Midlands SDE. There were no respondents who disagreed to any extent.



### Q3. Please explain why you feel this way and how we can help you and others to feel more confident to share their health data.

Respondents were asked to elaborate on question 2 and share why they feel this way and how we can help them and others to feel more confident to share their health data. 20 responses were received.

Table 11 presents the complete list of themes, sentiments and sub-themes.

**Table 11. Please explain why you feel this way and how we can help you and others to feel more confident to share their health data.**

Sentiment	Main theme	Code (sub-theme)	Count	%
Positive	Value of Health Research	Health data supports medical research and healthcare improvement	13	65%
Positive	Altruism & Social Contribution	Using my data helps others or the wider community	6	30%
Positive	Trust in Institutions	Trust that NHS or researchers will protect and use data appropriately	3	15%
Neutral	Transparency & Understanding	Uncertainty due to lack of information about how data is used	2	10%
Neutral	Communication	Communication and transparency is important (e.g. seeing clear examples of benefit would increase confidence and trust)	2	10%
Neutral	Uncertainty	Do not mind/unsure/okay	1	5%

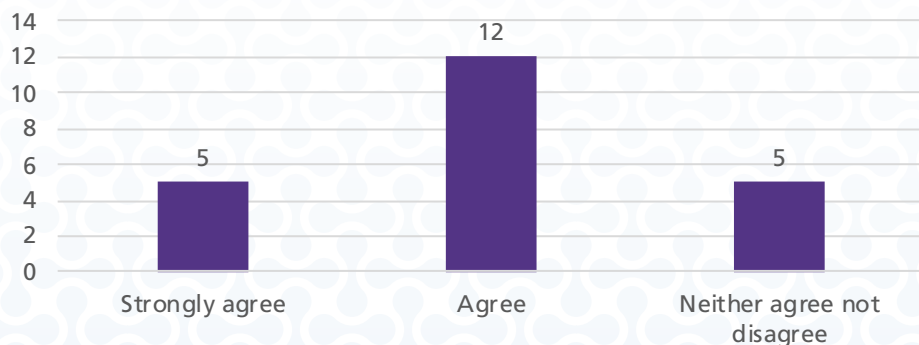
Sentiment	Main theme	Code (sub-theme)	Count	%
Neutral	Data Protection & Safeguards	Acceptance depends on anonymity, confidentiality, or data security	1	5%
Neutral	Personal experience & relevance	Personal or lived experience shapes support for data use	1	5%
Negative	Privacy & Personal Boundaries	Personal health information should remain private (e.g. patient consent is vital)	4	20%
Negative	Risk & Harm	Concerns about misuse, exploitation, or data being unsafe	2	10%
Observation	Beliefs, Culture & Values	Views influenced by personal, cultural, or religious values/beliefs	1	5%

Young people expressed strong overall support for the use of health information for research through the West Midlands Secure Data Environment. Many respondents emphasised the value of health research, particularly its role in improving treatments, supporting earlier diagnosis, and advancing understanding of disease at population level. For these individuals, data sharing was viewed as a necessary and positive contributor to better healthcare outcomes.

However, this support was often conditional rather than unconditional. A recurring theme was the need for data protection and safeguards, with respondents frequently stating that they would only feel comfortable if data was anonymised, confidential, and handled securely. Several participants expressed concern about not knowing who has access to their information or how it is being used, indicating that uncertainty and lack of clarity can undermine confidence even where attitudes towards research are broadly positive.

There was also a clear emphasis on transparency and consent. Many young people indicated that confidence in data sharing would increase if organisations clearly explained how data is used, who benefits, and how risks are mitigated. A smaller number of respondents expressed unease or reluctance about sharing health information at all, primarily driven by fears of misuse or loss of control.

#### Q4. To what extent do you agree that you feel more reassured that the NHS is leading and managing the West Midlands SDE?



Most respondents agreed that they felt more reassured that the NHS is leading and managing the West Midlands SDE (17 respondents). There were 5 respondents who neither agreed nor disagreed. The response to this question is encouraging as it tells us that most respondents do trust the NHS to lead, however, it also may indicate there is still the need to continue to build public trust as 23% neither agree nor disagree that to have the NHS leading and managing the West Midlands SDE is reassuring.

#### Q5. What do you think are the benefits or disadvantages of sharing health information?

Respondents were asked their thoughts on what the benefits or disadvantages of sharing health information are. 20 responses were received.

Table 12 presents the complete list of themes, sentiments and sub-themes.

**Table 12. What do you think are the benefits or disadvantages of sharing health information?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Social & Public Benefit	Sharing data benefits society or communities	13	65%
Positive	Research & Healthcare Improvement	Sharing data helps improve research and healthcare outcomes	12	60%
Neutral / Conditional	Conditions & Safeguards	Benefits outweigh risks only if safeguards exist	1	5%
Neutral	Uncertainty	Uncertain about benefits or disadvantages	1	5%
Negative	Privacy & Data Misuse	Risk of privacy breaches or misuse of data	7	35%
Negative	Personal Control & Comfort	Sharing data can feel uncomfortable or like loss of control	3	15%

## Summary of responses

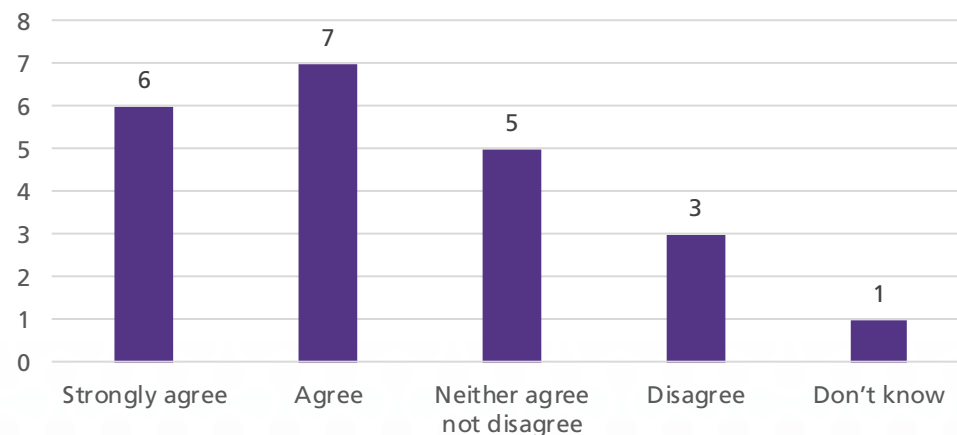
Young people identified a range of clear benefits associated with sharing health information, particularly in relation to research and healthcare improvement. Many respondents highlighted that data sharing can support better diagnosis, improve treatment pathways, reduce inequalities in care, and help the health system make more informed decisions. Several responses also stressed the **social and public benefit**, noting that shared data can help others, support the NHS, and contribute to better outcomes for future patients.

At the same time, respondents were very aware of potential risks and disadvantages, most notably around privacy, data misuse, and security breaches. Concerns about personal data being leaked, misused, or accessed inappropriately were common, and often framed as the key tradeoff against the benefits of sharing.

Some young people also expressed concerns about personal comfort and control, stating that health information can feel sensitive and that individuals may feel uneasy if they do not fully understand or control how their data is used. Some responses indicated that benefits only outweigh risks if appropriate safeguards are in place, reinforcing the importance of strong governance and reassurance.

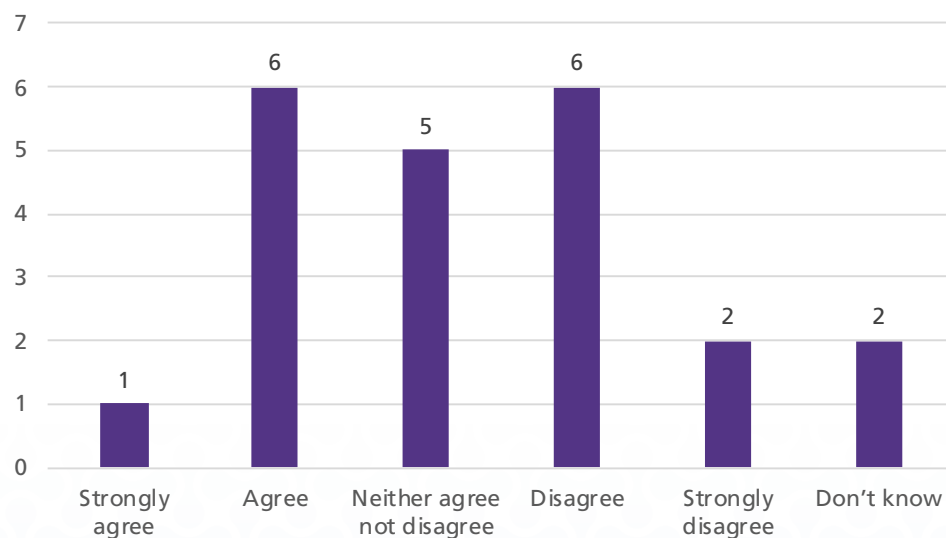
A smaller group expressed uncertainty, reflecting either a lack of knowledge about data sharing or uncertainty about how to weigh benefits against risks.

## Q6. To what extent do you agree that patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?



Most people agreed or strongly agreed that patient and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research (13 people). However, the remaining number of respondents (40.9%) may indicate there is still a need to continue to engage and communicate with young people on access approval.

## Q7. To what extent do you agree that organisations should pay to access health information for research?



Respondents who agree or disagree with organisations paying to access health information for research is almost the same, with one additional respondent strongly agreeing. However, as we consider other responses (don't know and neither agree nor disagree) along with those who disagree there is the suggestion that people need to understand more about the reasons for paying to access data as a strong consideration for the West Midlands SDE.

## Q8. Please tell us why you think this

Respondents were asked to elaborate on why organisations should or should not be charged to access health information for research. 18 responses were received.

Table 13 presents the complete list of themes, sentiments and sub-themes.

**Table 13. Please tell us why you think this**

Sentiment	Main theme	Code (sub-theme)	No.	%
Positive	Public Benefit & Value	Income should generate public or NHS benefit (e.g. better funding for NHS, payment to patients who share their data)	5	28%
Positive	Value of Data	There is value and worth in health data	4	22%
Neutral	Safeguards & Ethics	Strong ethical safeguards are required (e.g. ensuring legitimate or high-quality research)	6	33%
Negative	Commercialisation & Ethics	Concerns about commercialisation or selling of data (e.g. data should be used to improve research)	10	56%
Negative	Fairness & Access	Concerns about fairness or access for organisations	7	39%
Observation	Individual Rights	Consent and individual choice are essential	3	17%

## Summary of responses

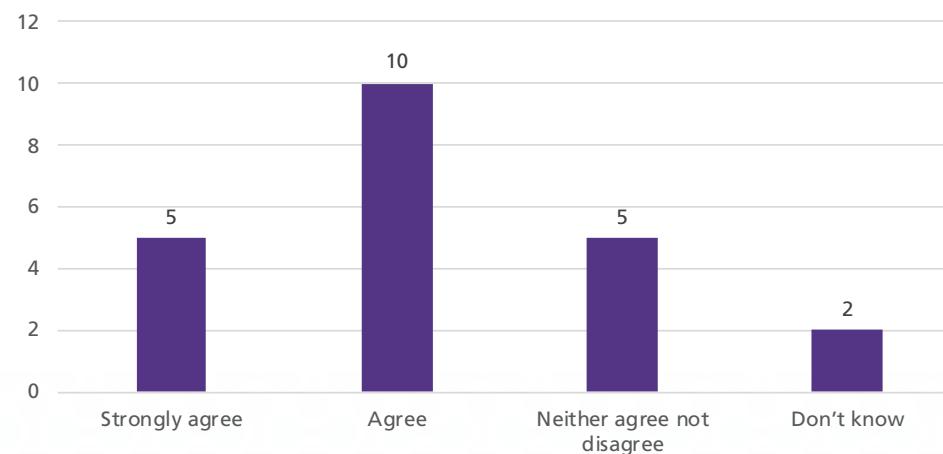
Young people expressed mixed and nuanced views about whether organisations should pay to access health information for research. There was no clear consensus, with opinions shaped by ethical, practical, and fairness-based considerations rather than simple approval or opposition.

A prominent concern related to commercialisation and ethics. The majority of respondents were uncomfortable with the idea of health data being sold or used for profit, particularly where individuals whose data is accessed do not directly benefit. These concerns were closely linked to fairness and access, with some young people worried that charging could restrict access for smaller organisations or limit beneficial research.

At the same time, some respondents felt that fees could be acceptable under certain conditions, particularly if income is used to support the NHS, improve services, or strengthen healthcare systems. Others viewed charging as a potential way to ensure legitimate, high-quality research, suggesting that fees or checks could act as safeguards against misuse or low-quality research activity.

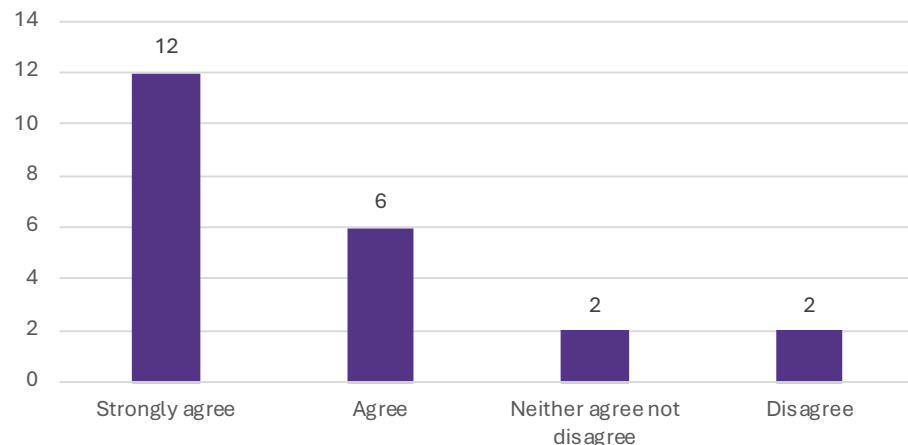
There was also recognition that the health system faces capacity and resource pressures, with some respondents framing payment to support sustainability or ensure appropriate staffing and infrastructure. However, trust remained a central issue, with respondents emphasising that payment should not undermine transparency, consent, or public confidence.

## Q9. To what extent do you agree that people are given the option to opt-out if they do not wish to share their health data with the West Midlands SDE?



15 respondents agree to some extent that people are given the option to opt out if they do not wish to share their health data. No one said they did not agree with having the option to opt out although 7 respondents seem unsure.

## Q10. To what extent do you agree it is important for young people to understand the work of the West Midlands SDE?



## Q11. Please tell us why you think this.

Respondents were asked to share their thoughts on why they agree (or disagree) that it is important for young people to understand the work of the West Midlands SDE. 19 responses were received.

Table 14 presents the complete list of themes, sentiments and sub-themes.

**Table 14. Please tell us why you think this**

Sentiment	Main theme	Code (sub-theme)	Count	%
Positive	Knowledge & Awareness	Yes, young people should be informed about how data is used	16	84%
Positive	Rights & Ownership	Health data belongs to individuals and they have rights over it (e.g. keep the opt-out simple)	4	21%
Positive	Informed Decision-Making	Information is essential and enables informed choices	1	5%
Neutral	Uncertainty or Lack of Awareness	Low awareness or confusion about the SDE (e.g. unsure, N/A)	3	16%
Neutral	Trust & Transparency	Transparency is important and improves trust ( e.g. in the NHS, in data use, countering misinformation and improving public understanding)	2	11%
Negative	Knowledge & Awareness	Informing young people is not necessary	1	5%

## Summary of responses

Young people expressed strong support for involvement and representation in decisions relating to health data use. Many respondents emphasised that because health information is personal, young people should have a voice in how data is accessed, governed, and used for research.

Key themes included the importance of trust, transparency, and consent. Respondents indicated that involvement would help build confidence in data systems, ensure decisions reflect lived experience, and reassure individuals that their interests are prioritised. Some young people felt that engagement would also improve understanding of how data is used and why it matters, reducing fear or misunderstanding.

There was also recognition that involvement should be meaningful and structured, rather than symbolic. Respondents highlighted the importance of clarity about roles, limits on access, and continued oversight, often seeing public involvement as complementary to – rather than replacing – NHS responsibility.

A smaller number of responses expressed uncertainty or cautious views, often linked to concerns about practicality or how involvement would work in practice.

Overall, young people support greater involvement in health data governance to enhance trust, accountability, and public confidence, provided it is well-defined and responsibly implemented.

## Q12. Do you have any ideas on how best to involve young people?

Respondents were then asked to share their ideas on how we can get other young people involved. 18 responses were received.

Table 15 presents the complete list of themes, sentiments and sub-themes.

**Table 15. Do you have any ideas on how best to involve young people?**

Sentiment	Main theme	Code (sub-theme)	No.	%
Neutral	General	Uncertainty or lack of ideas on how to engage	5	28%
Observation	Location	Engage with young people in their environments (e.g. Schools, colleges, universities, youth groups, hospitals, direct outreach by professionals)	10	56%
Observation	Active Participation and Engagement	Young people want opportunities to participate and have a voice (e.g. face to face engagement, youth councils, provide certificates, incentives, encouragement, leaflets, volunteering, peer-led engagement and co-creation)	6	33%
Observation	Digital Communication	Digital and social media are effective engagement tools (e.g. ads, posts)	2	11%

Young people provided clear, practical, and actionable suggestions for how they could be more effectively involved, with a strong preference for meeting young people where they already are rather than relying on passive or adult-led communication.

A dominant theme was the importance of engaging young people in familiar physical settings, particularly schools, colleges, universities, youth groups, and healthcare environments. Many respondents felt that direct, in-person engagement – such as school visits, workshops, talks, and outreach by professionals – would be more effective than relying solely on written information. This approach was seen as more trustworthy, relatable, and likely to reach a wider range of young people.

Digital communication was also highlighted as a key route for engagement. Respondents frequently suggested social media platforms, short videos, and digital advertising as effective ways to capture attention, particularly when content is short, visual, and youth-friendly. Several responses emphasised that digital content should be relatable and not overly formal, with some suggesting platforms such as TikTok and Instagram as particularly suitable.

Many young people expressed a desire for active participation rather than passive involvement. Suggestions included youth councils, focus groups, workshops, volunteering opportunities, peer-led activity, and co-creation of content. Respondents indicated that young people are more likely to engage when they feel their voices are genuinely valued and when they can contribute ideas, feedback, or creative input. Incentives such as certificates, prizes, or vouchers were also mentioned as ways to encourage participation, particularly for those who may be less initially motivated.

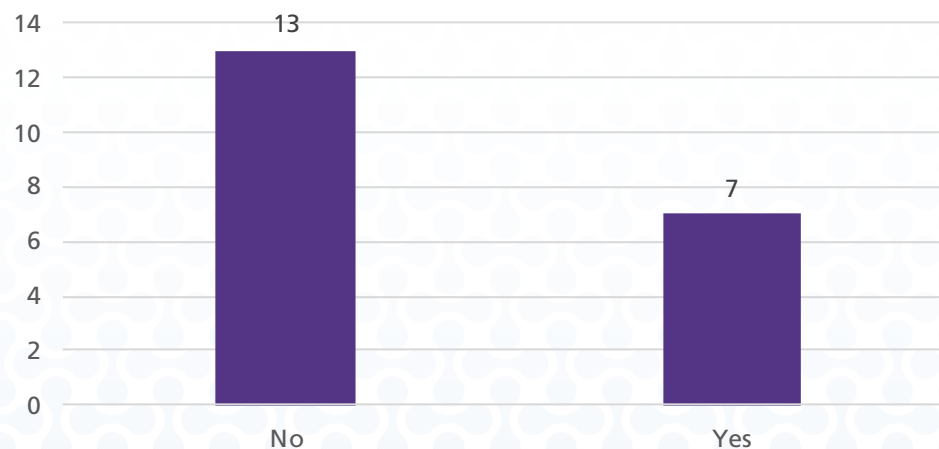
A smaller number of responses reflected uncertainty or lack of ideas, with some young people stating “no” or indicating that they were unsure how engagement should work. This suggests that not all young people feel confident imagining engagement opportunities without clear prompts or examples.

Overall, young people favour multichannel engagement approaches that combine:

- in-person outreach in trusted environments,
- digital and social media communication,
- and meaningful opportunities for participation and co-creation.

These findings suggest that engagement strategies will be most effective when they are visible, interactive, and tailored to young people’s everyday settings and communication habits, rather than relying on one-way information sharing alone.

### Q13. Would you like to get involved in this project?

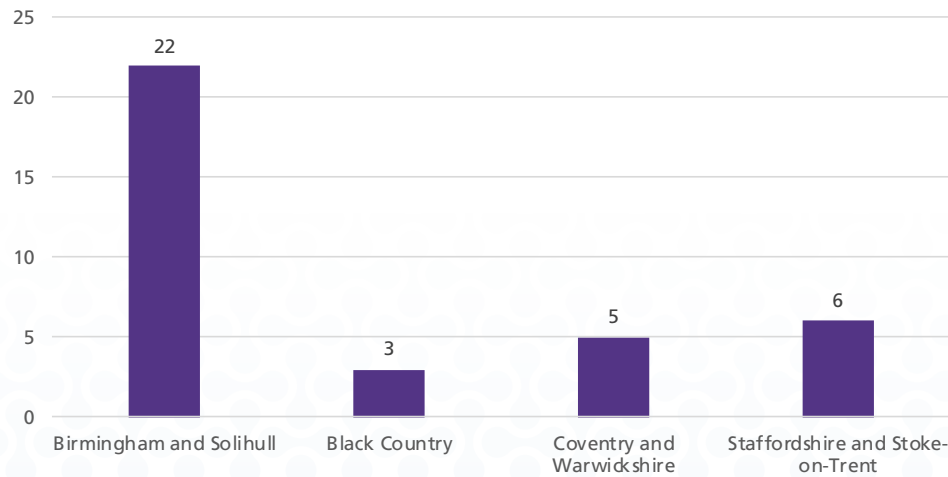


Seven (7) young people who responded to this question said they would like to get involved in this project and left their contact details.

# Appendix H: Pilot questionnaire demographics

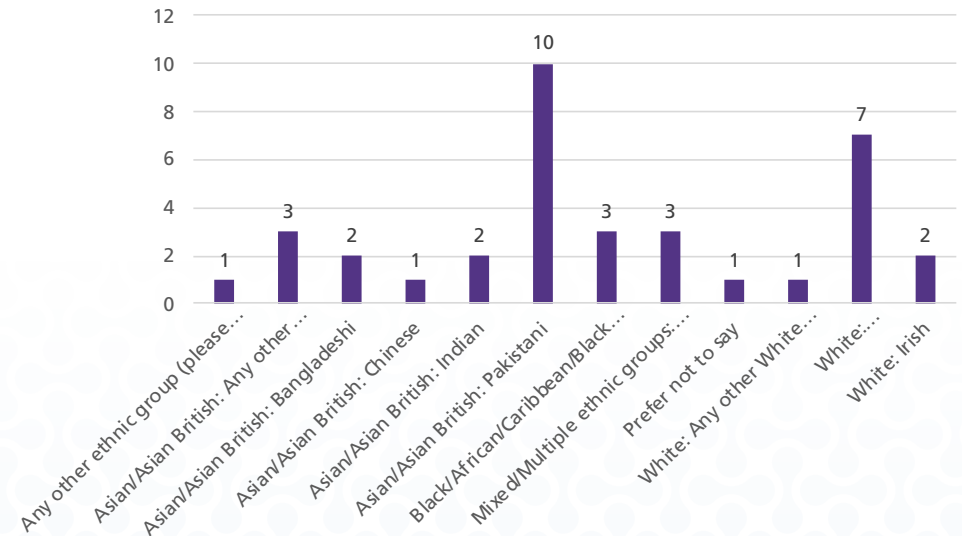
## About you section

### Q13. Which area of the West Midlands do you live in?



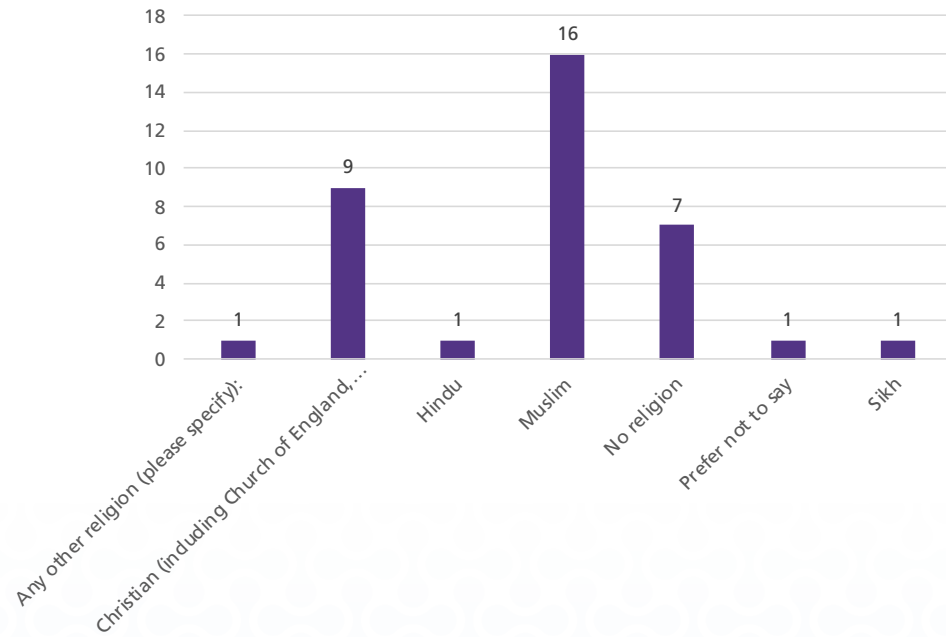
Respondents lived in 4 regions out of the 6 regions in the West Midlands. No responses were received from the Shropshire, Telford and Wrekin and Herefordshire and Worcestershire. This could indicate targeted engagement in these areas may be useful for future engagement.

### Q14. What is your ethnic group?

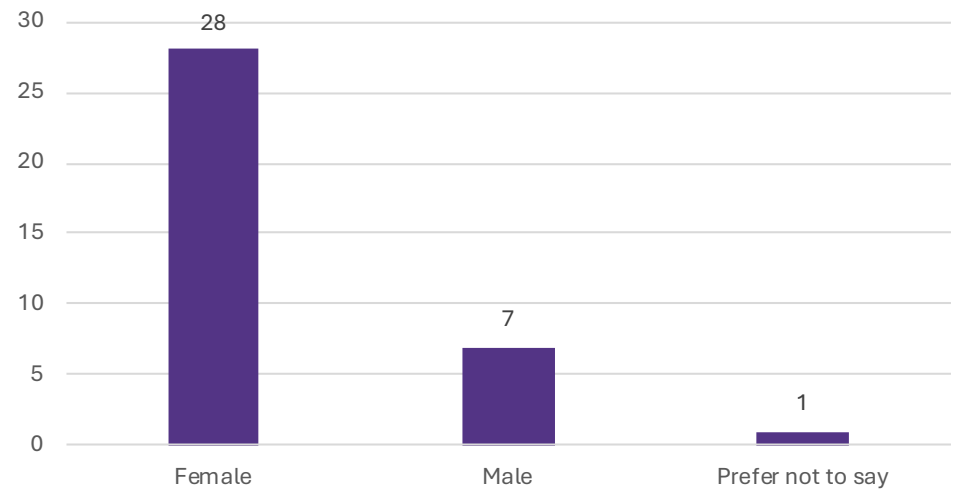


Asian/Asian British: Pakistani was the ethnic group who most respondents to this question (10) identified with. Responses were received across all the ethnic groups listed.

### Q15. What is your religion or belief?

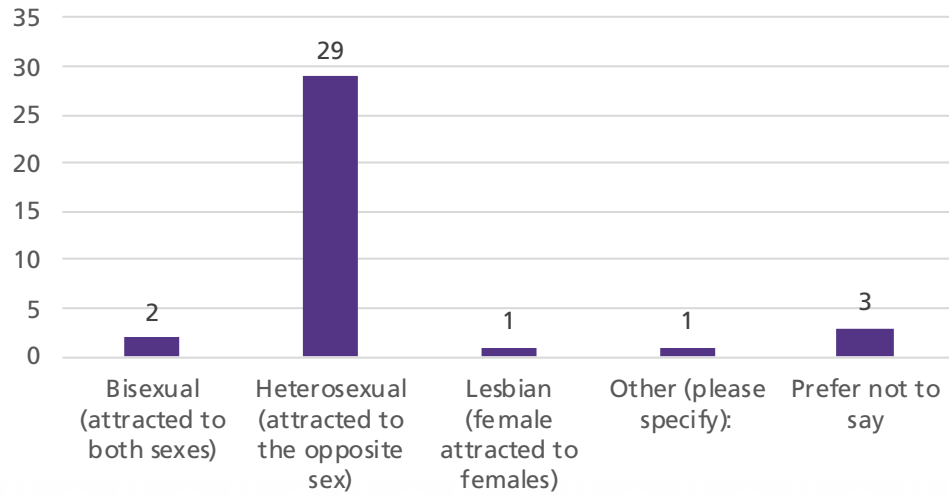


### Q16. How do you identify

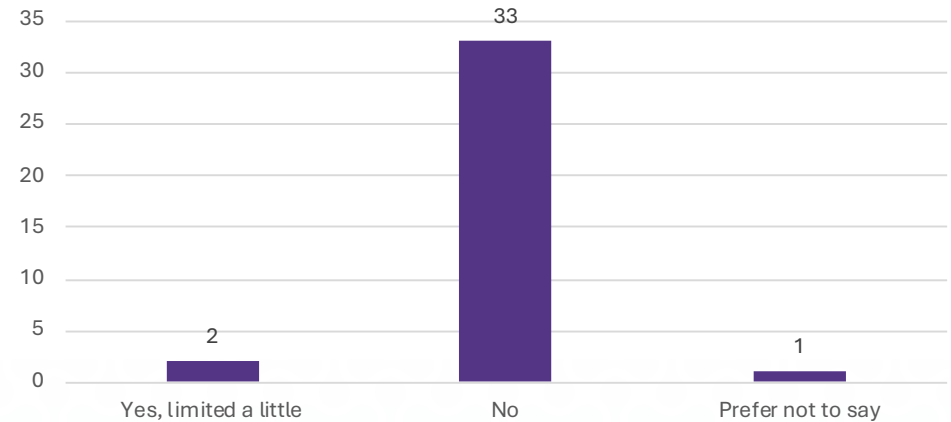


The largest group of respondents were female. This may indicate that questionnaire is not the best engagement method for young men and/or targeted engagement with young men should be planned for future engagement

### Q17. What is your sexual orientation?

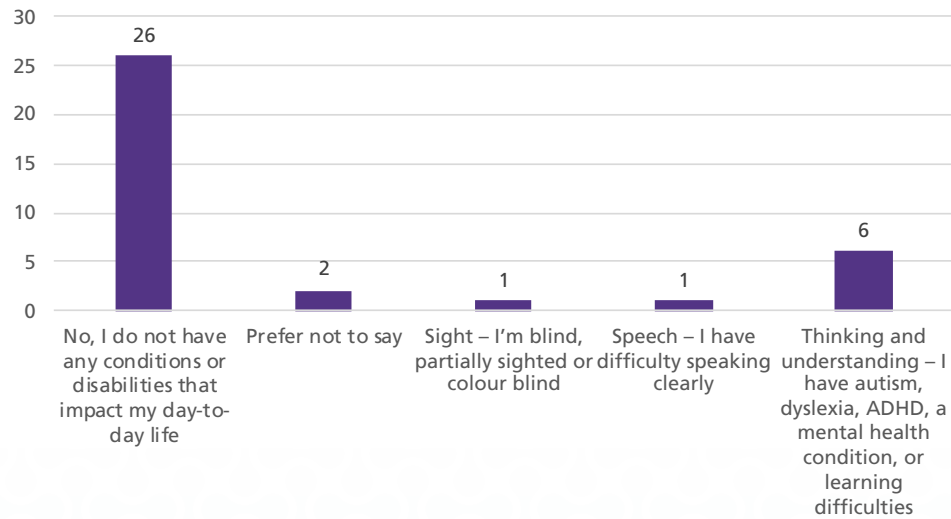


### Q18. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?



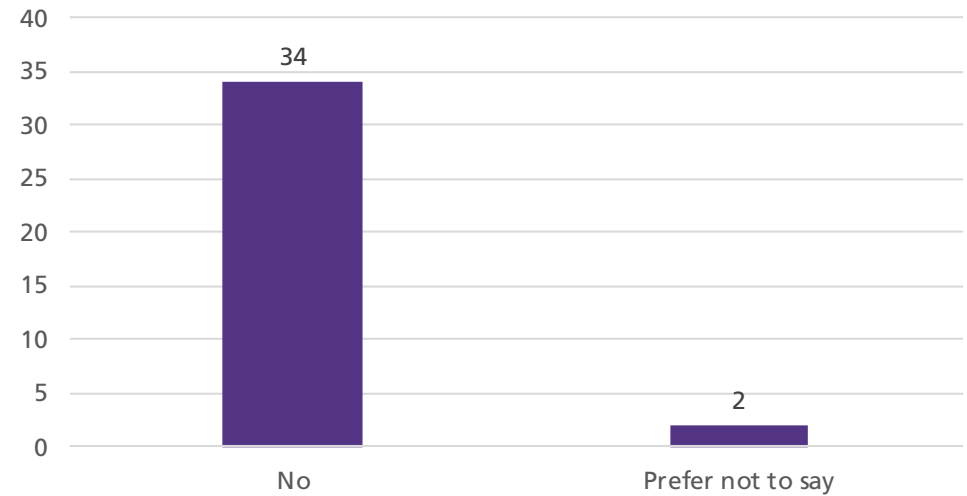
The largest group of respondents tell us they are not limited in their day-to-day activities. This may indicate that future engagement is targeted at more people with health problems or disability. This can be achieved by engaging with disease specific/disability groups.

### Q19. Do you have any conditions or disabilities that may have an impact on your day-to-day life?



This graph tells us that some respondents have difficulty with thinking and understanding and a list of conditions are mentioned. This information could be used when planning further young person engagement. Other responses tell of sight impairment and speech impairment, engaging and listening to more groups attended by those with such impairment could assist in the development of the West Midlands SDE.

### Q20. Do you provide care for someone?

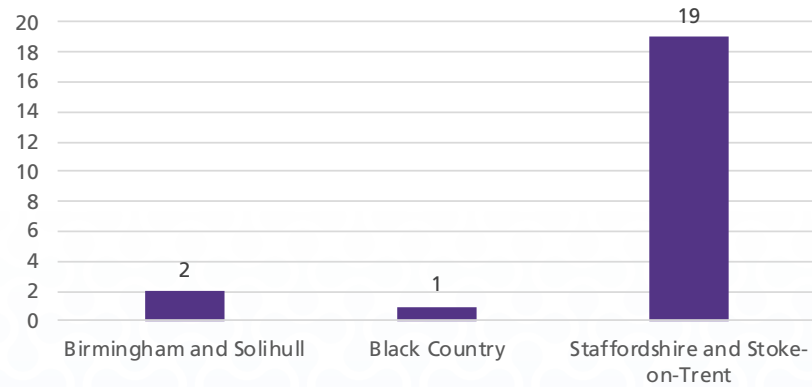


Two people preferred not to say in response to this answer. During this engagement period the engagement team attended the Warwickshire and Coventry Youth forum. The questionnaire link was sent out to hundreds of young carers. The response to the questionnaire may suggest this is not an ideal method to gather views from this group of young people and further attendance at more young person's carer forums would be useful.

# Appendix I: Final questionnaire demographics

## About you

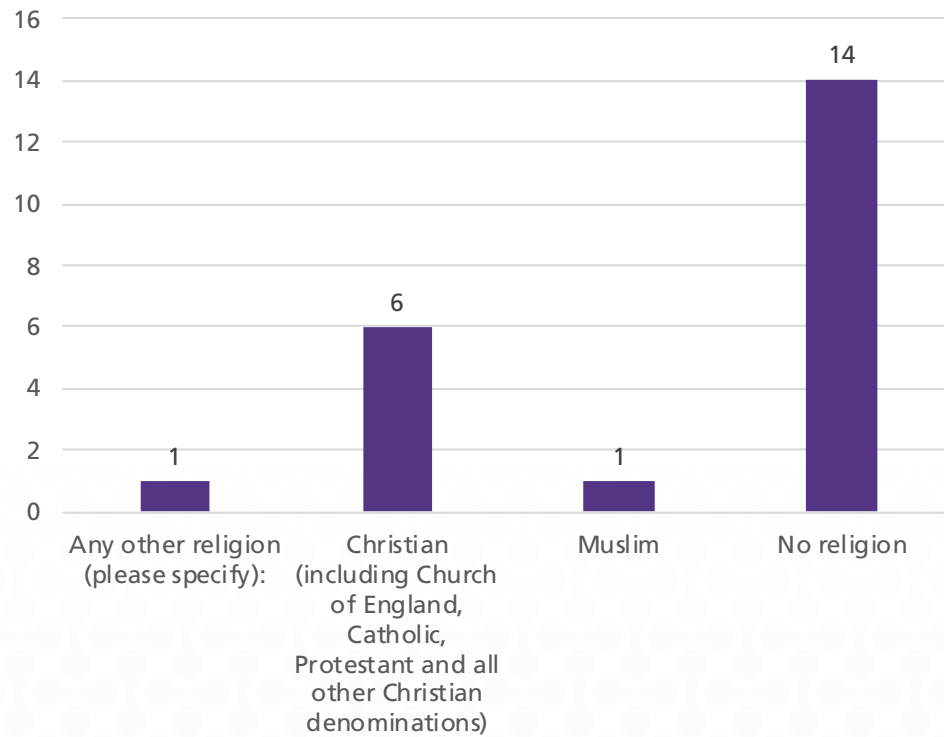
### Q14. Which area of the West Midlands to you live in?



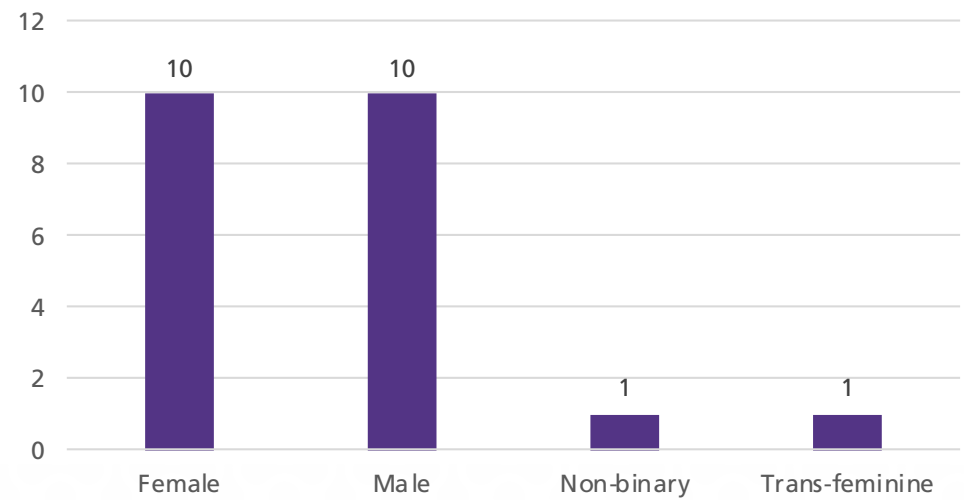
### Q15. What is your ethnic group?



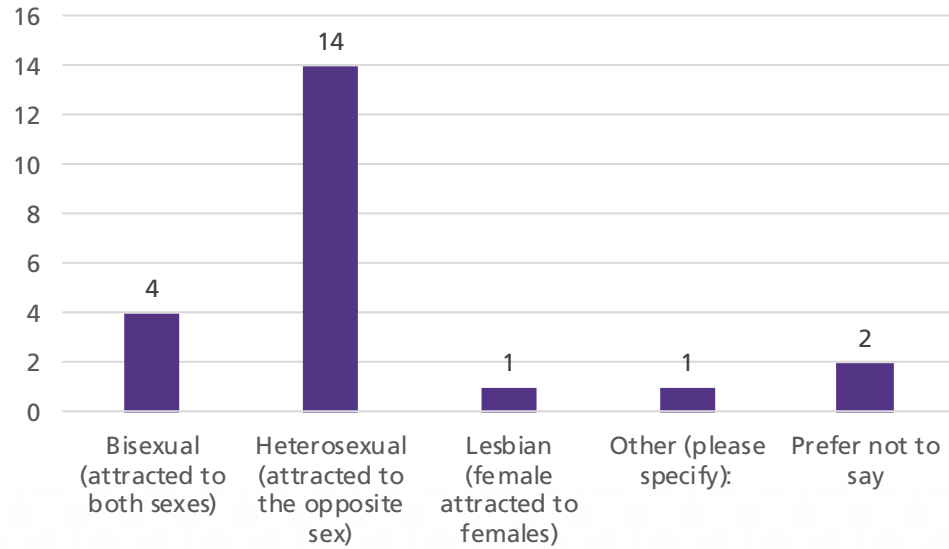
## Q16. What is your religion or belief?



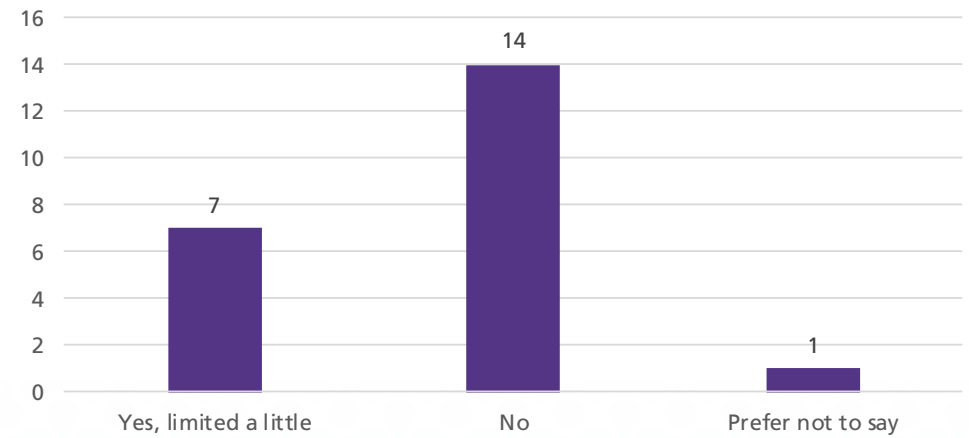
## Q17. How do you identify?



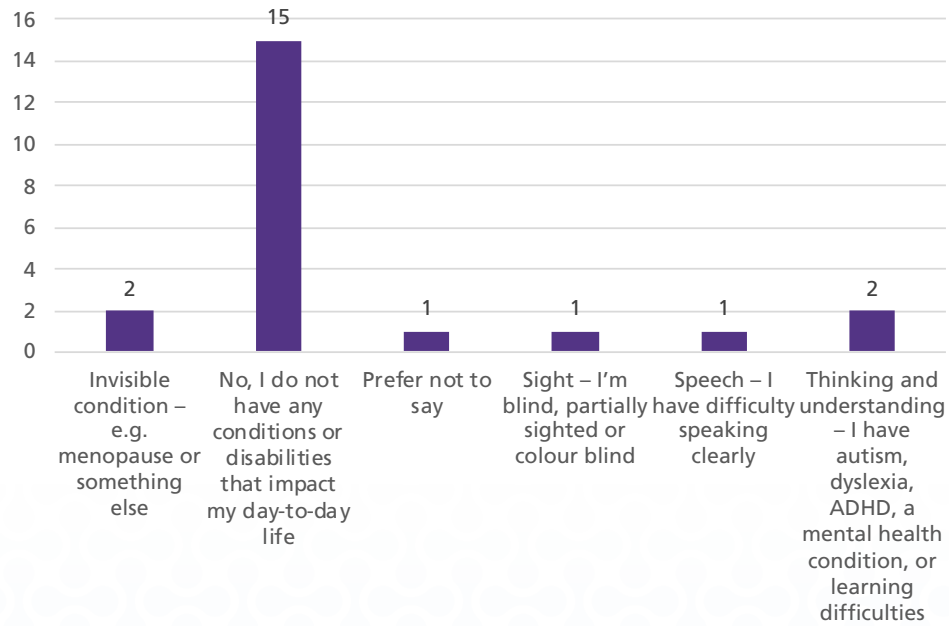
### Q18. What is your sexual orientation



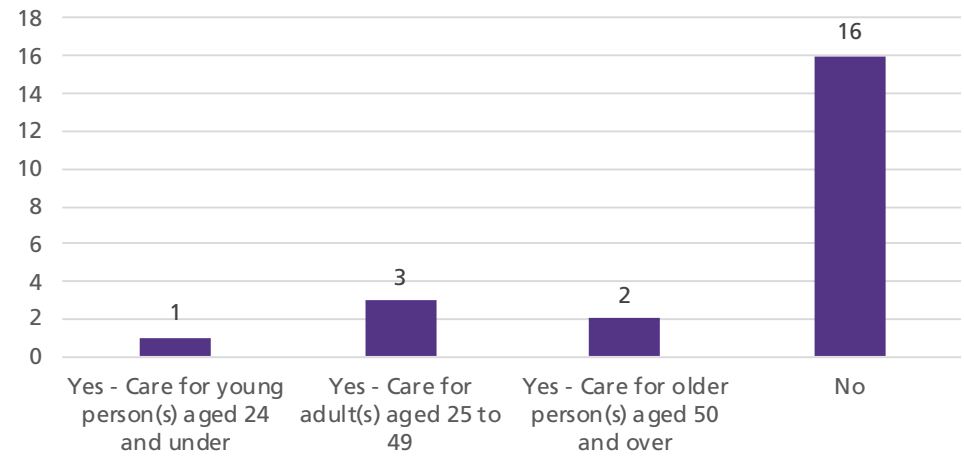
### Q19. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?



## Q20. Do you have any conditions or disabilities?



## Q21. Do you provide care for someone?



# Appendix J: Points for consideration

- The feedback from the regional engagement events demonstrates that children and young people across the West Midlands are engaged, thoughtful and capable of contributing meaningfully to discussions about health data and digital systems. They broadly support the use of health data for research and service improvement but expect this to be underpinned by transparency, security, public benefit and personal choice.
- The engagement provides strong evidence for the continued and expanded involvement of children and young people in the development, governance and communication of the West Midlands Secure Data Environment. It reinforces the importance of sustained, age appropriate and creatively delivered engagement that builds trust, promotes understanding and places young people at the centre of conversations about data that relates to their lives and their future healthcare.
- Participant feedback from Young Person's event in Birmingham demonstrates a high level of satisfaction with the event, particularly its delivery, atmosphere and informative content. The comments reinforce that the event met its aims of engaging young people, increasing understanding of health data and the West Midlands SDE, and inspiring interest in wider NHS roles. Suggestions for improvement were practical and forward-looking, indicating strong appetite for continued and expanded engagement. The details of this event and the evaluation report (please find at [Appendix B](#)) will be useful to inform future young people engagement events.
- Feedback from respondents in both the pilot and final questionnaires shows that young people are broadly supportive of health data being used for research and service improvement, particularly where there is clear public benefit. However, their support is conditional on transparency, strong data protection, meaningful choice, and trust in those managing the data. Views were shaped by how confident participants felt about who would use the data, how it would be safeguarded, and whether its use would lead to genuine public benefit. NHS leadership provides a strong foundation for trust, but clear communication and explanation, and ongoing engagement remain critical to maintaining public confidence. Young people frequently stated that they would only feel reassured if their data could not be traced back to them and if it was kept secure. Closely linked to this were concerns about data security, including fears of hacking, leaks, misuse, or discrimination, and requests for robust safeguards and protections.
- Many respondents highlighted the importance of choice and consent, including the ability to decide when data is shared and to withdraw consent at any point. This reflects a desire for personal control rather than blanket data use.

- Some young people felt reassurance would increase through engagement and communication, such as workshops in schools, one-to-one discussion, or opportunities to ask questions and be listened to. A smaller number of respondents expressed uncertainty or discomfort regardless of reassurance measures, indicating that for some individuals, sharing health data may remain a concern even with safeguards in place. Overall, confidence in data sharing among young people depends on transparent communication, strong protections, and respect for personal choice.
- Young people support patient and public involvement in SDE access decisions, especially where it enhances trust, respects consent and operates alongside clear safeguards and NHS oversight. This indicates that visible public involvement may strengthen confidence in data governance, provided it is well-defined and responsibly implemented.
- Overall, young people are not categorically opposed to charging for access to data held in the West Midlands SDE, but acceptance is highly conditional, depending on fairness, ethics, safeguards, and clear public benefit. Charging for access to health data is not rejected outright, but it is highly sensitive.

Transparency about how money is used, and reassurance that patient interests come first are required assurances. Without these assurances, concerns were expressed around charging risks undermining trust and confidence in data sharing initiatives. Acceptance depends on clear ethical safeguards, and avoidance of commercial exploitation.

- Overall, young people strongly believe that opt-out is ethically necessary, trust-building, and central to respecting individual rights. Lack of an opt-out option would risk discomfort, disengagement, and loss of confidence in health data initiatives.
- Some respondents highlighted wider benefits of early communication, including raising awareness across generations, supporting education about data protection in the context of emerging technologies (such as AI), and helping young people form their own beliefs and values around data use. A small number of responses expressed uncertainty or lack of awareness, reinforcing the point that information about the SDE is not yet widely understood. Young people believe that communicating about the West Midlands SDE is important, necessary, and empowering, enabling informed decision-making, trust, and constructive engagement with health data initiatives.

- When thinking about how best to involve young people, they suggest multichannel, inclusive approaches that combine education, digital communication, and meaningful participation, with a strong preference for being involved in ways that are engaging, transparent, and respectful.

# Appendix K: Recommendations

## Alignment of Participant Feedback with Recommendations

Feedback from participants strongly supports the recommendations arising from this engagement programme. Comments reinforce the importance of continued youth engagement, transparent communication about health data use, and the expansion of accessible, youth focused approaches. Participant suggestions also provide practical insight into how future activity could be strengthened.

### Recommendation 1: Continue and Expand Youth Engagement Activity

Participant feedback demonstrates strong appetite for ongoing and expanded engagement opportunities. Many young people expressed enthusiasm for attending further events and highlighted the value of learning about NHS data, careers and research that they had not previously been aware of. Comments indicate that engagement activity is not only informative but also motivating and confidence-building.

Several participants explicitly asked for more sessions and broader reach, reinforcing the recommendation to embed youth engagement as a sustained programme rather than one-off activity.

### Recommendation 2: Improve Visibility and Reach Through Schools, Colleges and Digital Channels

Feedback demonstrates that young people want information about health data and the SDE to reach them through settings they already trust and access, particularly schools, colleges and wider community networks. Participants also highlighted the importance of being able to share content with peers, suggesting that materials such as animations should be reusable beyond the event itself.

This directly supports the recommendation to strengthen outreach through education settings and to create shareable digital content to widen reach.

### Recommendation 3: Increase Transparency by Using Real-World Examples of Data Use and Impact

Participants showed strong interest in understanding who uses health data and what difference it makes. Requests for concrete examples of research outcomes and service improvements reinforce earlier themes around transparency, public benefit, and trust.

This feedback supports the recommendation that future engagement should include clear, relatable examples of how health data is used in practice and the tangible benefits that arise from this.

## **Recommendation 4: Prioritise Accessibility and Inclusive Delivery**

While feedback was overwhelmingly positive, a small number of respondents highlighted accessibility considerations, particularly around hearing speakers clearly. These comments underline the importance of inclusive design and delivery, ensuring that all young people can fully participate regardless of individual needs.

This aligns with the broader recommendation to ensure engagement activity is accessible, inclusive and responsive to participant needs.

## **Recommendation 5: Build in Greater Interactivity and Peer-to-Peer Discussion**

Some participants suggested that future sessions could include more interactive elements and structured opportunities to talk with peers. This supports earlier evidence that young people value peer-to-peer learning and discussion when engaging with complex topics such as health data.

This feedback strengthens the recommendation to design future engagement with interactive formats that encourage dialogue and shared learning.

Ideas created at the Young Person's engagement workshop to generate the creation of a co-produced animation. This would include the suggestion of peer-to-peer engagement and could be generated into a full campaign for further youth engagement.

### **Summary**

Overall, participant feedback strongly validates the programme's direction and recommendations. Young people reported high levels of engagement, inspiration and learning, while their suggestions provide clear, practical guidance for strengthening future activity. The feedback demonstrates both satisfaction with the current approach and enthusiasm for continued involvement, reinforcing the case for sustained, transparent and inclusive youth engagement within the West Midlands Secure Data Environment.

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](mailto:WMSDE@uhb.nhs.uk)

[westmidlandssde.nhs.uk](http://westmidlandssde.nhs.uk)

