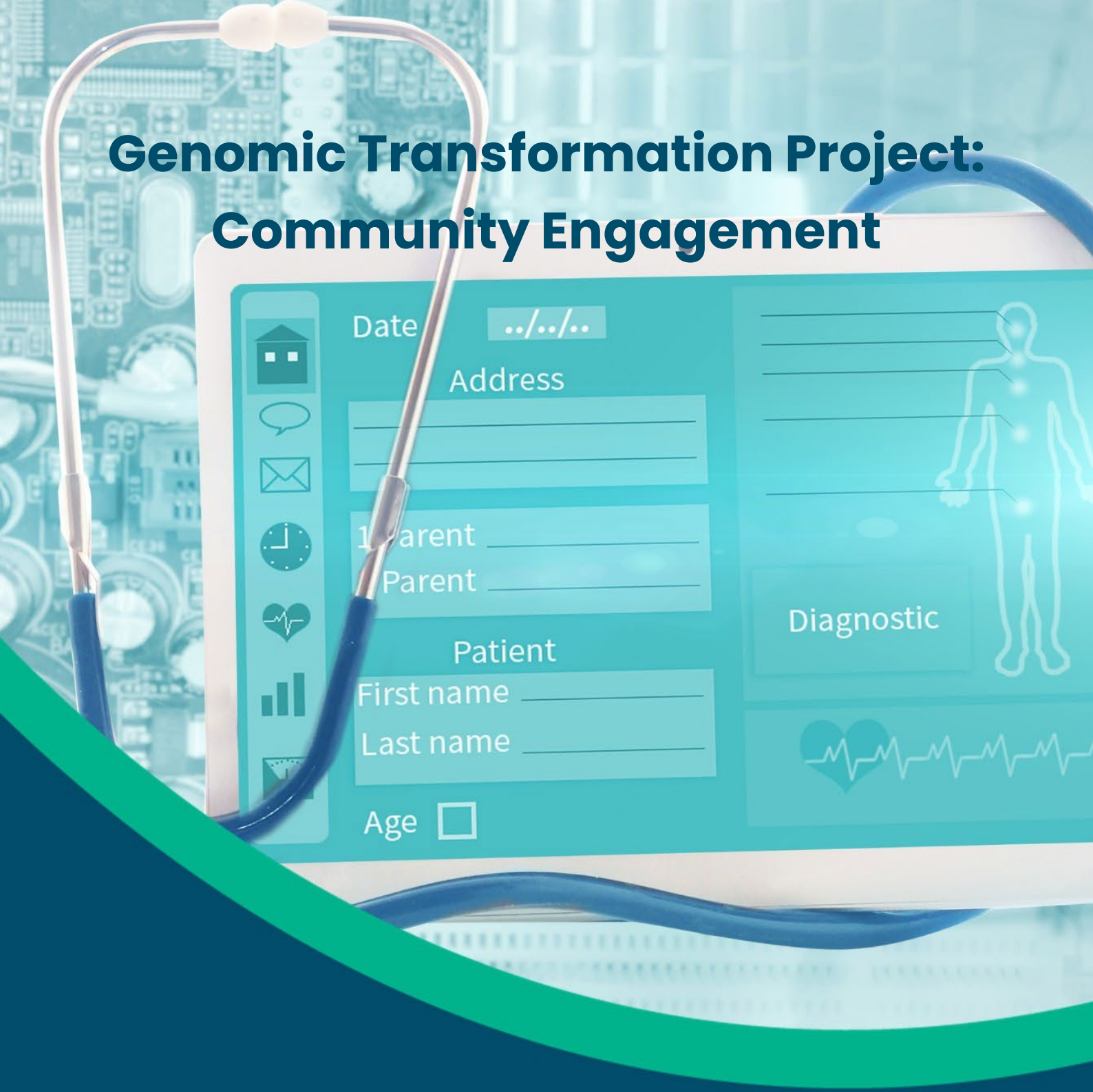
Genomic Transformation Project: Community Engagement



Using Patient Genomic data to support research through the Eastern England Secure Data Environment

May 2026

healthwatch Hertfordshire
healthwatch Essex
healthwatch Leicester and Leicestershire

Eastern England SECURE DATA ENVIRONMENT

healthwatch Norfolk

Contents

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Why we looked at this

Genomic Medicine is the study of how the information contained within a person's DNA influences their health. Advances in genomic science and technology are transforming healthcare by embedding earlier and more accurate diagnosis of conditions, as well as supporting more personalised treatment approaches. By identifying specific genetic variations in patients with inherited and rare diseases and cancers, clinicians can better predict which treatments are most likely to be effective for individual patients. In addition, analysing genomic data across large populations or groups of patients with similar conditions can support new scientific discoveries, helping to improve care and contribute to the development of new medicines.

To support the use of population-level health data for this research, there is an increasing interest in the use of Secure Data Environments (SDEs). An SDE is a highly protected digital platform that allows approved researchers to access sensitive health data securely, without the data leaving the environment. This approach is designed to protect patient confidentiality while enabling valuable research to take place.

Within Eastern England a wider programme of work is underway to develop capability for the Eastern England Secure Data Environment (EE-SDE) to support the use of data from routine Genomic Medicine Service (GMS) tests for research. Currently, researchers can only access genomic GMS data from patients who have provided explicit consent for their data to be stored in the National Genomic Research Library (NGRL). The NGRL contains data from less than 10% of all GMS tests, with the remainder of the data stored at local GMS laboratories and not having explicit consent for use in research. In addition, existing digital systems do not easily support the linkage of genomic data with other types of clinical data at scale. These limitations can restrict the potential for research and slow the development of new insights that could benefit patients.

Given the sensitive nature of genomic data, it is important that any approach to its use in research is acceptable, transparent, and trustworthy. Public understanding of genomics and data use varies, and people may have concerns about privacy, consent and how their data is accessed and used. Ensuring that patients and the public are involved in shaping these approaches is therefore a key part of the programme.

Healthwatch organisations across Eastern England were commissioned to carry out a programme of public engagement to explore people's views on the use of data from routine genomic tests for research within an SDE. This project aimed to gather insight from patients, the public and stakeholders to understand levels of awareness, perceptions of data use, and attitudes towards different approaches to patient choice – opt-out model that is currently used in the EE-SDE for NHS and other health data, versus explicit consent that is currently used for research involving NHS GMS data available in the NGRL. Through a range of engagement activities, including focus groups and deliberative approaches such as a public panel, the project sought to identify key themes, concerns, and expectations.

The findings from this work are intended to inform the ongoing development of the EE-SDE programme, helping to ensure that approaches to the use of genomic data are shaped by public views and are both ethically robust and publicly acceptable.

Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.
We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

We are often asked to look at specific services, and to support programmes like this to understand how the public feels about new developments in healthcare and research.

For this project Healthwatch Norfolk collaborated with other local Healthwatch: Healthwatch Essex; Healthwatch Hertfordshire, and Healthwatch Leicester and Leicestershire.

The EE-SDE is a digital platform that supports secure, controlled access to de-identified NHS patient data for approved research to improve people's health. It is part of a national network of regional NHS secure data environments across England.

Acknowledgements

Whilst this report has been produced by Healthwatch Norfolk, we would like to thank our colleagues at Healthwatch Leicester and Leicestershire, Healthwatch Hertfordshire and Healthwatch Essex, who contributed to the design and delivery of the focus groups and the Public Panel.

These events were considerably enhanced by the involvement of 'subject experts' from the EE-SDE team, who supported the focus groups by explaining complex topics and answering participants' questions. We would also like to thank the wider EE-SDE team for commissioning and supporting this project.

Finally, and most importantly, we would like to thank all the participants who took part in the Focus Groups and the Public Panel and generously shared their time, views, and experiences.

How we did this

A co-production approach

The aim of this project was to gather public and patient views on the use of genomic data for research within an SDE, to help inform the development of the wider SDE programme. The project focused on the routine NHS Genomic Medicine Service tests that are carried out by local GMS laboratories, with test results stored in the electronic patient record, and raw data from machines stored in separate digital systems. The project covered understanding levels of awareness, perceptions of data use, and attitudes towards different approaches to consent.

This work was delivered collaboratively by Healthwatch Norfolk, Healthwatch Leicester and Leicestershire, Healthwatch Hertfordshire and Healthwatch Essex, working with the EE-SDE team. Engagement took place between February and March 2026.

A total of 85 people took part across Eastern England. This was achieved through a combination of focus groups and a one-day Public Panel.

Session design

Early engagement with relevant local and national PPIE panels helped to identify where public uncertainty and interest was focused (more detail on the findings of these earlier sessions is detailed in the Public Panel report). The engagement format was then designed collaboratively with Healthwatch partners and the EE-SDE team, bringing together local insight on what works for community participation, with expertise on the complex topic.

The focus groups and Public Panel were facilitated by Healthwatch staff experienced in public engagement. Facilitators were briefed by EE-SDE staff beforehand and joined by a member of the SDE team on the day, (as an observer) to ensure they could accurately explain key concepts and answer questions.

The Public Panel in particular included a panel of researchers, clinical geneticists, genomics data specialists, and an information governance expert to answer questions.

These experts were given a clear role description emphasising the importance of sharing unbiased information in plain, accessible language as far as possible.

Materials development

Session materials were developed collaboratively to ensure plain-language explanations of complex topics. Researchers and clinical geneticists were also involved, contributing case study examples of research that could be enabled through the SDE to bring the topic to life in both focus groups and the Public Panel.

Draft focus group materials were then iterated based on:

- Feedback from patient representatives, to ensure the framing was fair and understandable.
- Input from peer Patient and Public Involvement and Engagement (PPIE) professionals at other SDEs, drawing on experience from similar engagement topics.
- Comments from other Healthwatch organisations, ensuring inclusivity and practicality for delivery.

Iteration and adaptation to what participants actually needed

Following the first focus groups, we explicitly reflected on points of curiosity, confusion, and concern, and then updated the session structure and explanations to address what participants signaled mattered most. This ensured later sessions did not repeat avoidable misunderstandings, and that the engagement remained participant-led in practice.

Focus group learning was also treated as a live design input for the Public Panel, informing the scope of the questions asked, case study selection, the balance of context provided, and the structure for Q&A with experts. The Panel therefore built directly on earlier public priorities and uncertainties.

Participant diversity

We sought to include a broad range of participants to ensure a diversity of perspectives. This included people from different geographic areas, including both urban and rural communities, as well as a range of ages, ethnicities, and genders. The

project also included participants with lived experience of relevant health conditions, alongside members of the wider public.
This approach enabled us to capture both informed perspectives from those with direct experience of genomic testing, as well as wider public views.

Focus groups

In total, nine focus groups were conducted between 23 February and 11 March 2026. These included a mix of face to face and online sessions to support accessibility and participation. While most sessions were delivered in a traditional group format, one session consisted of a series of individual interviews with four participants who were unable to attend a group session. For consistency, this has been included as the ninth focus group within this report.

Considerable efforts were made by the four Healthwatch organisations to recruit participants to these focus groups. For each group there was an agreed 'cohort focus'. These included:

- People with experience of cancer as a patient or carer
- People with experience of rare diseases and genetic testing
- Women from BAME backgrounds / minority faiths with lived experience of genomic testing
- People involved in genomic trials / testing
- 'Lay people' with a general interest

Participants were recruited through a variety of social media and digital channels (Facebook; Instagram; LinkedIn; X formerly known as Twitter) as well as Healthwatch networks and partner organisations' websites. Posters and flyers were also developed and distributed to community venues and used at Healthwatch engagement events.

Further information on the 'cohort focus' and the methods used to recruit participants to the focus groups can be found in Appendix 5 in this report.

Each session was facilitated by Healthwatch staff using a structured discussion guide to ensure consistency across all groups. Participants were provided with information about genomics, the SDE and the purpose of the project to support informed discussion. Sessions were designed to encourage open and honest conversation, allowing participants to explore their views, raise questions and discuss any concerns.

Public Panel

A one-day Public Panel was held on 11 March 2026 to explore the topic in more depth. The Public Panel sought to answer four questions:

1. What safeguards would need to be in place for you to feel confident about genomic data being used for research within the Eastern England SDE?
2. Is it acceptable for information from clinical reports of routine genomic tests (the summary results shared with your doctor) to be used for health research within the Eastern England SDE, in the same way as other NHS data (such as blood tests or prescribing information), using the current opt-out model?
3. What model should be used to give people a choice about how raw data from routine genomic tests (large files containing all of a person's DNA) is used for health research within the Eastern England SDE – asking everyone for explicit consent, or including everyone automatically with the option to opt out?
4. Do your views about the acceptability of using genomic data for research within the Eastern England SDE change if the research involves smaller groups of people where it may be easier to identify individuals, such as in rare disease research?

This provided an opportunity for participants to engage in more detailed discussions, consider different perspectives, and reflect on the use of genomic data for research in a deliberative setting.

Recruitment to the Public Panel was carried out with expressions of interest sought, and then a selection criterion applied. Details of this can be found in Appendix 1.

Participants' involvement and consent

All participants were provided with clear information about the purpose of the project, how their views would be used, and how their data would be stored and handled. Informed consent was obtained from all participants prior to taking part.
Participants were assured that their contributions would be anonymised, and that no identifiable information would be included in the final report. They were also informed of their right to withdraw their participation at any point prior to the publication of findings. All data were handled in accordance with relevant data protection legislation, (including the 2018 Data Protection Act and EU General Data Protection Regulations)

and Healthwatch policies and will be securely deleted in line with data retention requirements (e.g.: personal data should not be kept for longer than is necessary for the purpose for which it is collected.)

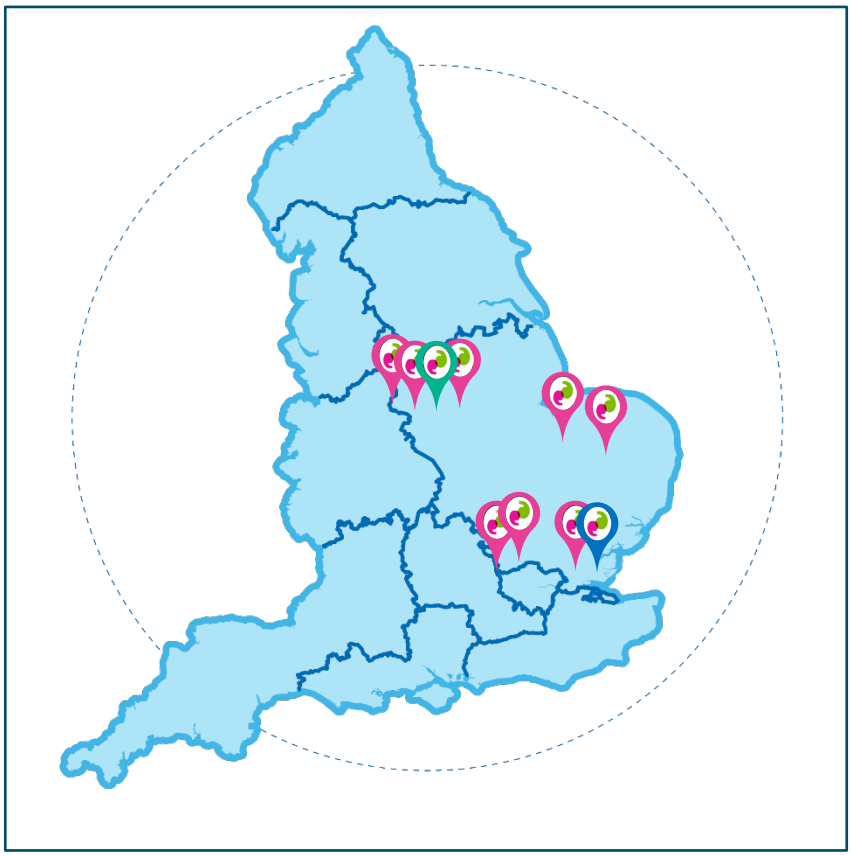
Limitations

This research provides valuable insight into public and patient views on the use of genomic data for research. However, there are some limitations to consider when interpreting the findings.

Firstly, while efforts were made to include a diverse range of participants, the sample is not fully representative of the wider population. Participation was voluntary, and it is possible that those who chose to take part may have had a greater interest in health research or data use than the general public.

Secondly, genomics and the use of health data for research are complex topics, and levels of prior knowledge varied among participants. Although information was provided during the sessions to support understanding, together with some pre-reading material, participants' views may have been influenced by how information was presented or by the time available to fully consider the issues.

Finally, as the research was conducted through focus groups and a Public Panel, findings are based on self-reported views and discussions at a specific point in time. While this approach provides rich qualitative insight, it may not capture the full range of perspectives across all communities.



Eight focus groups with different communities, to understand different perspectives

Four interviews with members of the public, unable to attend focus groups

A full-day Public Panel, to develop recommendations through informed deliberation

Figure 1 Map showing the locations where engagement events took place.

What we found out and what this means

In the Focus Groups and the Public Panel, we identified a number of key themes. These were:

- Public Understanding of genomic data and its use
- Genomic Research and its potential benefits
- Navigating Genomic sensitivity
- Security and Trust in the genomic data pathway
- Transparency and Communication

This section is therefore organised around these themes. They are summarised below.

Details of the feedback and views of participants can then be seen in the following pages.

Public Understanding of genomic data and its use

We looked at how the public understood genomic data. Whilst the language and terms used might differ, a number of participants were familiar with the use of genomic tests for clinical care. This came from direct 'lived experience' or through family members. Few had knowledge of the use of genomic tests in research.

Public awareness of the EE-SDE was low. Many participants were not familiar with the concept, highlighting the importance of building visibility and understanding from the outset. Without this, there is a risk that the use of genomic data may be perceived as lacking transparency, which could undermine trust.

Genomic Research and its potential benefits

Throughout all nine of the focus groups and the Public Panel we heard that research using data from genomic tests was seen to have real potential benefits. For this reason, the use of genomic data for research within the EE- SDE was broadly supported by the participants.

Overall, participants were broadly supportive of the use of genomic data for research within the EE-SDE. However, this support was consistently conditional on several key factors, including strong data security, transparency, clear communication, and meaningful opportunities for choice and control.

Many participants described this as a balance between achieving potential benefits and addressing concerns and risks. Where these conditions were met, participants viewed the use of genomic data as acceptable and in the public interest.

Navigating Genomic Sensitivity

Many participants described genomic data as particularly sensitive, compared to other kinds of health data because it is unique to them but can also reveal information about family members. Participants were introduced to the differences between the genomic test results data used to produce clinical reports, and the 'raw sequencing data' from which test results are derived, but which contain more extensive genomic information and are stored in the laboratories undertaking those tests. The latter were seen as more sensitive and personal, presenting greater challenges and the need to consider whether this affected the way in which they could be included within research.

Security and Trust in the Genomic Data Pathway

Participants expressed concern about ways in which data would be held securely and the risks of data breaches and misuse, together with that of personal identification. The subject matter experts who attended the focus groups and the Public Panel were able to explain many of the existing and proposed mechanisms for addressing these risks and this gave some reassurance, but the view remained that having a very clear and robust set of safeguards was absolutely essential.

Transparency and Communication

Above all participants placed a great emphasis on the need for transparency and on improving communications. This was both to provide assurance that the arrangements in place fully addressed the concerns expressed, and to build confidence and trust in the whole programme of using genomic data for health research.

Improving public understanding is therefore critical to maintaining confidence as the EE-SDE expands to include genomic data. This includes not only awareness of genomics, but also clarity about how data is used in practice, what choices people have, and how to opt out if they wish.

Conclusions

In the Public Panel the overall conclusion was that both clinical report data and raw sequencing data, could be used for health research, under the current opt-out model, where data is included unless people choose to opt out.'

However, there was a clear distinction drawn between the two levels of data. The Panel felt more comfortable with clinical report data, as they saw it as similar to other health information already used in research. Raw sequencing data was seen as more sensitive and personal. However, this did not lead to opposition. Instead, people felt that this type of data needs more careful consideration and further discussion about how it is used and protected.

Particular attention should be given to explaining the use of 'raw' genomic data if used and the safeguards in place when working with smaller or potentially identifiable groups. This was because the public felt that this data was more sensitive, and smaller groups were more at risk of being identified.

Feedback from the focus groups would suggest that people with lived experience of genetic disease tended to be the most supportive of their full data being used for research and the least concerned about the risks of re-identification.

The potential benefits that could come from this research were seen as substantial and there was a notable enthusiasm to work with those responsible to ensure that these were realised.

Taken together, these findings indicate that public support for the use of genomic data exists but must be actively maintained. This will require clear communication, robust safeguards, transparency, and ongoing public engagement as the EE-SDE programme develops.

Public Understanding of genomic data and its use

Current understanding

Most people indicated that they had heard of 'genomic testing.' While many had heard of the concept, the terminology was not always familiar, 'genomic testing' was not necessarily a phrase used by most participants. They often referred to 'DNA testing' or 'genetic testing.'

'The majority of participants had heard of genomic testing, but 'not the finer details.' ***(Norfolk 1 focus group)***

'While most participants had heard of genomic testing, they did not have an in-depth knowledge or understanding of it.' ***(Norfolk 2 focus group)***

After exploring participants' initial understanding, it became clear that many concepts around genomics were unfamiliar and required further explanation. Once explained, participants were better able to understand and relate to the concept.

'Most participants had heard of DNA testing, though many were not familiar with the term "genomic testing" specifically. When the facilitator clarified that genomic testing involved DNA, more participants recognised the concept and made links to things like ancestry testing or cancer-related screening' ***(Leicester and Leicestershire 1 focus group)***

'Several participants expressed that the concepts became clearer only after the workshop explanations.' ***(Leicester and Leicestershire 2 focus group)***

Experience of genomic testing

When exploring participants' experiences, it became clear that many had some knowledge of genomic testing, either through their own direct experience, or through family members, even when they were using different words to describe this.

"I had a test following cancer treatment to identify any markers and to see what could be passed to my children." (Leicester and Leicestershire 2 focus group participant)

"I don't personally, but a family member had it for cancer treatment, and they were told it could help guide the best treatment options." (Leicester and Leicestershire 3 focus group participant)

Many of the focus group participants had shared their experience with genetic testing and/or rare diseases when introducing themselves at the beginning of the group. They demonstrated baseline understanding of genetic testing as many of them had experience of it or were keen to have a genetic test in order to understand their condition. ***(Essex 1 focus group)***

Respondents all had experience of cancer in some way, as a patient or carer, and some of them had experienced genomic testing because of that. One respondent had a family history of cystic fibrosis so had also had genomic testing themselves. ***(Hertfordshire 1 focus group)***

Some respondents knew of family or friends who had experience of genomic testing, most commonly for genetic conditions or pre-dispositions. One respondent had been part of the 100,000 genomes project and had had genetic screening for cancer which she was able to share with family members for their information ***(Hertfordshire 2 focus group)***

Several people in the group had either personally undergone genomic or related genetic testing or knew someone who had. Their experiences varied, ranging from large national research programmes to private or charity-led initiatives. ***(Leicester and Leicestershire 2 focus group)***

Several participants reported direct or indirect exposure to genomic testing, particularly within the context of cancer care. A participant shared, ***"I don't personally, but a family member had it for cancer treatment, and they were told it could help guide the best treatment options.".***
(Leicester and Leicestershire 3 focus group)

In a few cases this appeared to be linked to research:

'One participant had taken part in genomic testing, and her data had been used by the University of Cambridge.' ***(Norfolk 1 focus group)***

'One participant had previously taken part in a genomic research project.'
(Norfolk 2 focus group)

However, for most participants, experience was directly linked to the treatment of an individual or to advice and counselling regarding a genetic condition, including:

- Genetic testing for rare eye disease (FEVR)
- Cancer-related genetic testing (e.g., BRCA gene testing)
- Family screening following cancer diagnoses
- Genetic counselling processes
- Situations where test results shaped monitoring or treatment plans ***(Leicester and Leicestershire 1 focus group)***

Genomic Research and its potential benefits

Throughout all nine of the focus groups and the Public Panel there was a clear recognition of the potential benefits of genomic research.

"It's exciting for the future." (Norfolk 1 focus group participant – female 70s)

"Having more data to look at or compare for a research project is probably a good thing." (Hertfordshire 2 focus group participant – female 50s)

'Participants recognised the potential for genomic research to improve treatments for conditions like cancer and rare diseases, support medical breakthroughs and benefit future generations.' (Public Panel)

"Personalised treatment for cancer is already being done. It is much more personalised than it used to be, and this can only make it better." (Norfolk 1 focus group participant – female 70s)

There was a strong sense that such research would benefit both current and future generations.

"Eventually I see them doing lots of DNA tests for potential diseases as soon as someone is pregnant." (Norfolk 1 focus group participant – female 70s)

'The participants consistently expressed that using genomic data for research particularly in areas such as cancer, rare diseases and early diagnosis offered substantial potential benefits for future generations'
(Leicester and Leicestershire 1 focus group)

'A few participants shared emotional examples of cancer detected too late, arguing strongly that genomic data could have:

- *Identified risks earlier*
- *Saved lives*

These participants were highly supportive of genomic research as a result.'
(Leicester and Leicestershire 2 focus group)

"Organisations are doing their best to come up with cures and treatments, and we need to support them as much as possible"
(Hertfordshire 2 focus group participant – female 70s)

There was a particular recognition of the potential benefits of research to support underrepresented groups and those with rare conditions.

'Participants viewed the sickle cell research project positively, supporting it because of its potential to help an underrepresented patient group and advance medical understanding' ***(Leicester and Leicestershire 2 focus group)***

'Some of our participants had lived experience of rare diseases and could see the benefits for themselves, the families and society'
(Leicester and Leicestershire 3 focus group)

One participant reflected on his friends and peers who lived with the effects of sickle cell anaemia and felt that this project would be highly beneficial to them:

"They're very interested and they wouldn't give a hoot about it being [a small sample size] probably they're desperate to get it solved. So, and I think that's the general, the general view. Anyone who's getting involved in this is generally wanting a solution and not if not for themselves"
(Essex 2 focus group participant – male 80s)

Many focus group participants described this as a balance between achieving potential benefits and addressing concerns and risks. They were clear that they saw the benefits outweighing the risks and concerns.

'The benefits outweigh the risks – participants were largely supportive of genomic data being included in the SDE and aligned with other health data. They recognised that individuals and families – especially those living with rare diseases – would likely always welcome additional research that may benefit themselves, those that they care for, and others affected by similar conditions.'
(Essex 2 focus group)

"The health benefits of genomic research within the SDE for current and future generations outweigh the majority of any associated data risks, provided the appropriate security and access checks and balances are established and maintained.' (Norfolk 1 focus group participant)

"The benefits are so great that it really wouldn't worry me so much that people could identify me. But I understand that people would be concerned, but for me personally, I wouldn't be."
(Hertfordshire 2 focus group participant – female 70s)

The key message of support was summed up by one participant:

"Ultimately, it's important that research is being done. For me there's so much good that could come out of researchers having access to data, our DNA data, that I think it's got to be the way forward with so many cure and pharmaceutical products and things like that." (Hertfordshire 2 focus group participant – female 60s)

Navigating genomic sensitivity

Many participants described genomic data as particularly sensitive, compared to other kinds of health data because it is unique to them but can also reveal information about family members.

"It's our data. It's our DNA."
(Leicester and Leicestershire 1 focus group participant)

For one group, data was particularly sensitive because:

'Unlike general medical records, genomic data was viewed as:

- *Deeply personal*
- *Relating to family as well as self*
- *Impossible to fully anonymise (especially in small datasets)'*

(Leicester and Leicestershire 1 focus group)

As a result, it was felt in another group that:

"Genomic testing is more intrusive than healthcare testing, like x-ray. Scans and tests are your current composition, whereas genomics are your potential."
(Leicester and Leicestershire 2 focus group participant)

Participants also recognised that it could reveal information about family members, which adds an additional layer of complexity. This created additional ethical considerations, particularly around re-identification and family impact. Participants were generally open to data use for research but expected stronger protections due to this sensitivity.

'Some women emphasised that genetic information impacts children and relatives, making data sharing decisions feel weightier and more emotionally complex' ***(Leicester and Leicestershire 1 focus group)***

In other groups consisting of people with direct or indirect 'lived experience' of cancer or rare diseases they did not see the need to distinguish between genomic data and NHS data and saw the alignment as important.

In one group:

> *'participants felt that genomic data should be treated similarly to NHS data, and didn't have any concerns with them being linked'*
> ***(Hertfordshire 1 focus group)***

In another group the same view was expressed:

"It makes sense to me to do that. I don't have any particular hang-up about that. You know, really. If it seems to me almost essential to do that." (Essex 2 focus group participant – male 80s)

Raw Genomic data

In the Public Panel a group specifically looked at how raw data from routine genomic tests could be used in health research within the SDE.

Raw genomic data generated by DNA sequencing machines, was seen as more sensitive than that in clinical reports, which contain only specific disease-relevant DNA changes. A 'raw data file,' consisting of a person's full or partial DNA sequence, is stored by the laboratory in specialist digital systems, rather than being included in an electronic patient record accessed by clinicians. This data can only be analysed by specialist software and interpreted by specialised NHS or research scientists.

Public Panel participants raised a number of concerns about the nature of raw data:

Raw data is a wider issue. It's massive versus clinical reports. Could GPs access it? Who else would have access? (Public Panel participant)

'Wider and bigger scale.' (Public Panel participant)

'In what scenario would researchers need to look at the whole genome.' (Public Panel participant)

‘Would it allow researchers to look at specific ethnic groups?’ (Public Panel participant)

All of these responses indicated that within this group raw data was seen as ‘fundamentally different and higher risk.”

Within the Public Panel as a whole, raw sequencing data was seen as ‘more sensitive and personal.

This greater sensitivity led to the conclusion that:

‘People felt that this type of data needs more careful consideration and further discussion about how it is used and protected.’ ***(Public Panel)***

Security and Trust in the Genomic data pathway

A key theme emerging from the focus group discussions was participants' concern about security and trust in the genomic data pathway.

Participants' concerns centred on:

- The risk of data breaches and the misuse of data
- The risk of personal identification
- A lack of trust in some organisations and people accessing the data

They were also clear that they wanted 'trusted sources' to be used when patients were contacted to participate in further research and that this contact should be handled sensitively.

The risk of data breaches and the misuse of data

Participants expressed concern about the potential for data breaches. These concerns came from a combination of what people had read and heard about, often in the media.

"There's so much around about data protection and hacking. It's difficult because we don't understand it. There's probably a minuscule chance of that happening, but we hear so much about people being compromised and hackers getting into your bank accounts and other things. This is another part of you that is held somewhere and people might get access to." (Norfolk 2 focus group participant)

"Are there any risks of this information being used adversely? Eg: if data is hacked and people are targeted." (Public Panel participant)

"There will always be loopholes on the data protection" (Public Panel participant)

In one group, participants alluded to examples of previous data breaches they had heard about in terms of cyber security, scams and hacking. They also shared examples of more local data breaches where physical information had been misplaced, or mislaid or digital data had been shared in a public arena.

*'Some women described NHS data systems as **"shambolic",** citing anecdotal experiences and media reports of breaches. This was an unexpectedly forceful concern voiced by several attendees. **(Leicester and Leicestershire 1 focus group)***

'The group agreed that while reassurances as to the level of cyber security were needed, it was difficult to completely mitigate against incidents of hacking or unauthorised access to data held on digital platforms.'
(Norfolk 2 focus group)

'Data security- participants highlighted possible public reticence about data being made available in the SDE due to high profile data scandals and breaches.'
(Essex 2 focus group)

The risk of personal identification

The risk of personal identification for people from small groups was raised in the focus groups and the Public Panel. The risk was that although dealing with anonymised data, it might be possible for a researcher to identify an individual, especially if the analysis was conducted on a small group e.g., people with a rare condition.

Participants were clear that this should not be a barrier to research involving small groups because they had a rare disease.

*'People with a rare condition must not miss out on potential research and benefits.' **(Public Panel)***

Some people did not believe that the risks changed.

*'It doesn't change irrespective of group size.' **(Public Panel)***

Others felt that the benefits outweighed the risks.

'Some participants had some lived experience of having people impacted by rare diseases. So, this personal experience made them feel strongly that the benefits outweighed the risks. *People felt that this type of data needs more careful consideration and further discussion about how it is used and protected.'* ***(Public Panel)***

One suggestion mentioned in the focus groups and Public Panel was that a larger database be created by combining data sets across regions or even beyond.

'Participants understood that sickle cell is rare locally, so combining data sets across regions or countries increases the usefulness of the research and is justified '(Leicester and Leicestershire 2 focus group)

"I think probably the way that the steps that you have to handle it.....were probably the right ones actually...So then I think either having a certain cut off where we say that this is too small a group that we have to blunt the research or kind of round it up, as you were saying, or kind of combine it with another SDE." (Essex 1 focus group participant – female 30s)

The second risk was where the focus groups discussed a case study in which following the initial analysis of genomic data, patients would then be re-identified in order to be invited to participate in a research study.

Many groups felt that it was acceptable but wanted to be clear about the conditions under which this should happen.

'Participants expressed that it could be acceptable if done securely...' ***(Norfolk 1 focus group)***

A lack of trust in some organisations and people

Participants had clear views on who should have access to the data, and how it should be managed.

'There were clearly a number of organisations that participants did not necessarily trust with their genomic data. In one group some participants expressed strong distrust in Industry; Politicians; Tech companies; Insurance; Employment; Marketing and Police!' ***(Leicester and Leicestershire 1 Focus group)***

'In another group Trust in the NHS and public institutions was high, but trust in commercial or unknown organisations was significantly lower.'
(Leicester and Leicestershire 2 focus group)

Using a trusted source

The issue of who was the most trusted source then extended to the question of where contact should come from.

'Contact should come from a trusted professional…. Research invitations should never appear to come from unknown or commercial organisations.'

If researchers need to re-identify patients for recruitment into studies most participants said that they would only feel comfortable if contact came from: Their GP, hospital, or another local trusted NHS service' ***(Leicester and Leicestershire 1 focus group)***

'Participants clearly preferred being contacted by their clinical team, or a recognisable organisation, rather than by researchers directly.'
(Leicester and Leicestershire 2 focus group)

Contact handled sensitively

It was also identified that contact for further research participation needed to be handled in a sensitive fashion

'Unfamiliar phone calls or letters were viewed with suspicion because of scams.' ***(Leicester and Leicestershire 2 focus group)***

Participants felt that patients should be asked whether they would prefer communication through e mail, post, or other methods.' ***(Leicester and Leicestershire 3 focus group)***

'Participants wanted any communication inviting them to take part in further research to be approached with care and worded clearly.' ***(Leicester and Leicestershire 1 focus group)***

"If someone is contacted later about research, could it not be hugely distressing to get that letter? If they have struggled to get over their original cancer and then get a letter about something else"

"Contact does have to be handled on a very individual basis, so it doesn't build up hope" (Norfolk 2 focus group participant – female 70s)

Assurance in the system and processes

Participants sought assurance that their genomic data would be securely stored, protected from breaches, and handled in a way that safeguarded their identity throughout the research process.

Some reassurance was provided by the 'subject matter experts' attending the focus groups which increased confidence. They were able to provide information on arrangements in place within the EE-SDE, designed to safeguard people and their data from these risks.

Importantly, concerns about security did not lead to rejection of data use but reinforced that robust safeguards are a condition of acceptability.

There were aspects of the existing arrangements that gave confidence to the participants. For example,

*'Despite concerns over re-identification, participants showed a strong level of trust in the SDE's security measures, including the de-identification process, the trusted intermediary role of NHS Trusts and the use of 'ethical penetration testing' to maintain security. Although there were concerns about data sharing more generally, the details of the SDE security measures were felt to be strong and robust.' **(Leicester and Leicestershire 3 focus group)***

Many participants asked the subject matter experts questions about data security in the EE-SDE. These covered topics such as:

- Where the data was stored
- Whether it would be accessible to international researchers as well as researchers based in the UK
- Whether the information would be accessible to other organisations such as the police and insurance companies
- How the anonymisation process works
- Whether people's family members would be identifiable via genomic data
- How the process of bringing together data from different sources works, how data is transferred to the SDE, and who manages the transfer.
- Who sits on the Data Access Committee
- The risk of data leaks

The responses to these questions provided considerable assurance that many of the concerns expressed by participants were already being addressed by the SDE.

Transparency and Communication

Awareness of the current 'opt out' arrangements and use of data in research.

One of the challenges for participants was that many of them were unaware of the current arrangements for NHS organisations making data available to researchers through the SDE. They were informed that this was done based on individual hospitals initially agreeing to share data through the EE-SDE.

However, there was a lack of awareness of how individual patients could opt out of this happening to their NHS data in general.

"But not many people know how to opt out and not many people, people might not be bothered to do that. If it's quite hidden how you do that, then that could be problematic." (Essex 1 focus group participant – female 50s)

'Several women were unclear about:

- *Whether they had already consented*
- *How to opt out*

Leicester and Leicestershire 1 focus group)

'People were surprised that:

- *They were already opted into data sharing unless they opted out*

The opt-out route is not widely publicised.'

(Leicester and Leicestershire 2 focus group)

"How well known is that opt-out option known?" (Essex 1 focus group participant – female 20s)

'There was a lot of confusion and surprise that data is already shared by the NHS on an opt-out basis and participants were not clear on what this involved.'
(Hertfordshire 2 focus group)

One group identified a lack of awareness of existing data sharing arrangements as a key theme. However, this issue was not seen as specific to genomic data. Participants emphasised that consent is important for all types of health data and did not strongly distinguish between genomic data and other NHS data in this context.

'A lack of awareness about existing non-consent-based data sharing arrangements (i.e., that hospitals currently share NHS (but not genomic) data with the Secure Data Environment without explicit consent.)'

'Participants indicated that consent to data share is always important and didn't distinguish much between genomic data and NHS data.'
(Hertfordshire 2 focus group)

This lack of knowledge came through in the public panel discussions as well.

'It was also emphasised that many people are not aware of how their general health data is used, including its storage, sharing, and potential applications in research." ***(Public Panel)***

People see choice as important

Some focus group and public panel participants discussed the issues of patient and public choice in the use of genomic data for research. A common theme was the need to have a clear process for people being able to exercise a choice over whether their data was used, and an opportunity to 'consent.'

In the focus groups, views were mixed as to how this should be done. Focus group participants were informed about the current national data opt-out model and a number recognised that this may need to be the model used.

The benefits of using an opt-out model were that it was a practical option to ensure that sufficient data is available for research.

In particular it enabled a much more representative data set of the whole population to be compiled and used. By contrast, an opt-in model would require the consent from large numbers of people, requiring significant resources.

Those that supported the opt out model did so on the basis that people needed to be informed about how they could opt out.

'There is a strong belief that patients should have a clear choice about whether or not their data is used, with a preference for opt-out models, but with clear and accessible communication channels for patients to make informed decisions. Communication and choice were emphasised throughout the discussions.'
(Leicester and Leicestershire 3 focus group)

'Participants discussed their thoughts around the opt-out model of the Secure Data Environment. While they recognized the benefit of an opt-out model meaning that more data could be available for researchers, they were also concerned that many people may not know their data was being included and may not be aware of how to opt out. In particular, they emphasised that they would like to be informed if their data was used by an SDE research project.'
(Essex 1 focus group)

"Transparency and consent are important. Knowing what is happening goes a long way to reassure you." (Norfolk 1 focus group participant – male 50s)

Furthermore, participants highlighted that the opt-out model could work, but only if the public had a better understanding of how the system works and what it means for their privacy and rights.

One group suggested that:

> *'The opt-out system should be more visible.*
> *The NHS App should highlight data-sharing options more clearly' **(Leicester and Leicestershire 2 focus group)***

Whilst choice was seen as important for all the focus groups, for two of them explicit consent was preferred.

> *'The issue of consent came through strongly, and participants tended towards preferring there to be a method to gain consent from people before their data was shared to the SDE.' **(Hertfordshire 1 focus group)***
>
> *'Some participants still felt that where possible, it would be better to gain explicit consent for people if their data is being used as part of research, especially for a small-scale study like the example'. **(Hertfordshire 2 focus group)***

Whilst the Public Panel discussed potential differences in how small groups might be treated, they did not see the system of consent as one of these.

The Public Panel addressed the issues of consent both in relation to clinical report data, and 'raw sequencing data.'

With clinical report data '*views on consent evolved during discussion.*'

Views were 'mixed at the start of the discussion but:

> *'As the discussion developed and particularly as participants shared personal experiences of living with or caring for people with rare diseases, understanding of the potential benefits of genomic research increased. This appeared to strengthen support for the use of data where there is a clear public benefit.'* ***(Public Panel)***

This seems to link to the many expressions of support that were found in the focus groups from people with direct or indirect experience of genomic testing.

By the end of the session there was broad support for clinical report data being used under the opt out model.

The same debate between an 'opt out' and an 'opt in' model occurred in the Public Panel group looking at 'raw data.'

> 'In this group 'views on raw sequencing data were more divided. Most participants in the room were broadly comfortable with its use under an opt-out approach, but a small number of participants, particularly those attending online, felt an opt-in model would be more appropriate." Overall, this group did not reach a firm consensus.' (Public panel)

The difficulty that the group found was being able to articulate what an opt-in approach would involve in practice.

There was no 'shared view.' In particular participants in this group 'highlighted that raw sequencing data is different and more sensitive than clinical report data and agreed that this area would benefit from further deliberation and public engagement.'

The overall conclusion was that:

The people who took part in the Public Panel were 'broadly comfortable with genomic data from NHS tests being used for research within an SDE. This included both clinical report data and raw sequencing data, under the current opt-out model, where data is included unless people choose to opt out.' ***(Public Panel)***

There was however a clear distinction between clinical report and raw sequencing data.

'Most participants felt more comfortable with clinical report data, as they saw it as similar to other health information already used in research. Raw sequencing data was seen as more sensitive and personal. However, this did not lead to opposition. Instead, people felt that this type of data needs more careful consideration and further discussion about how it is used and protected.' ***(Public Panel)***

People want clear and consistent communications

All the focus groups and the Public Panel placed a great emphasis on the need for improving communications.

This was for two reasons. Firstly, to provide assurance that the arrangements put in place addressed the concerns raised by them.

'Prioritising transparency, comprehensive patient information and robust consent processes were central to the group's recommendations, as these measures would address the majority of their concerns.' ***(Norfolk 1 focus group)***

Secondly, in order to build confidence and trust.

'Ideally participants said that they would like to be told if their data is being used in research and what the outcomes were. The Panel felt that this could demonstrate the benefits of genomic research to people and encourage people to further support such research in the future.' ***(Public Panel)***

From the Public Panel we heard that information should be:

- *Clear and easy to understand (plain English)*
- *Available in different formats*
- *Reaching a wide range of diverse communities*

(Public Panel)

It should be consistent and ongoing with people given options on the format in which this is provided.

People wanted to know:

- *How their data is used*
- *Who can access it*
- *What difference it is making*

There were a number of suggestions as to how there could be a strong public communications campaign; from national to local approaches, using a variety of different (social) media and video as well as written communications. ***(Public Panel)***

Overall, there was a wide range of needs to address communications about genomics and the use of genomic data:

"Need to inform the public better about genomics." (Public Panel participant)

"We should be informed from school age – how to contribute to future research and help" (Public Panel participant)

About the research that has, and will be, developed using the EE-SDE:

"The group agreed that the public would like to see what research has been developed through the SDE use." ***(Public Panel)***

About how data is being used:

"We should always be kept in the loop and updated on exactly how and where our data is being used." (Public Panel participant)

'Participants wanted to be informed about their data being included in the SDE, which projects their data was being used in, what the risks of their data being included were, and how to opt-out' ***(Essex 1 focus group)***

About the systems of choice and consent:

"Clear explanations and clarifications are needed, as well as choice and consent." (Public Panel participant)

*'Participants felt that where possible, it would be preferable to tell or ask people that their data is being used – via targeted communication to the relevant patient groups so they know about the option to opt-out.' **(Hertfordshire 1 focus group)***

About the processes and systems in place within the EE-SDE

*'Existing data sharing agreements are not well known about, and an opt-out system is only valid if there are sufficient, reliable and widespread communication campaigns.' **(Hertfordshire 2 focus group)***

Recommendations

Based on the evidence from the focus groups and Public Panel, including the recognition of the potential benefits, the EE-SDE can include genomic data to be available for research. This is on the basis that the following recommendations are addressed.

1. Improve public awareness
    - Review and refine communications about the EE-SDE to ensure that it is clear and accessible
    - Create specific communications about genomics, genomic data, and its use for research within the EE-SDE.
    - Increase visibility of current data sharing practices

2. Strengthen transparency
    - Clearly explain how data is used, who can access it, and for what purpose

3. Enhance awareness about patient and public choice
    - Ensure opt-out mechanisms are visible, simple, and widely understood

4. Maintain robust data security
    - Clearly demonstrate safeguards and governance processes
    - Address public concerns about breaches and misuse

5. Use trusted communication channels
    - Ensure contact comes from NHS organisations or recognised trusted bodies

6. Address the sensitivity of genomic data
    - Recognise the additional ethical considerations, including family impact
    - Reiterate the appropriate safeguards in place for small or identifiable groups

7. Continue public engagement
    - Establish arrangements to involve patients and the public in ongoing design and governance
    - Regularly review public attitudes as the programme develops

Appendices

Appendix 1- Demographics of Public Panel participants

Panel members were selected based on age, ethnicity, geography, lived experience and gender. This approach aimed to avoid over-representation from any single group.

Category		Target	Expressions of Interest	Confirmed Panel members
Age	18-24	3+	7	1
	25-49	7+	43	9
	50-64	4+	17	6
	65-79			8
Ethnicity	Arab			2
	Asian/ Asian British: Indian	4+	22	4
	Asian/ Asian British: Pakistani			1
	Black/ Black British: African	3+	17	3
	Black/ Black British: Caribbean			2
	White: Any other White Background			3
	White: British/ English/ Northern Irish/ Scottish/ Welsh			9
Geography	East Midlands	7+	54	18
	East of England	7+	14	6
Lived experience	Lay population (no lived experience with genomic testing)	5+	38	11
	Lived experience (rare disease) *Patient, loved one or carer*	4+	3	3
	Lived experience (cancer) *Patient, survivor, loved one or carer*	4+	25	10
Gender	Male	7+	18	8
	Female	7+	47	15
	Non-binary		2	1
Total		Up to 20	c68	24

Appendix 2- Demographics of Focus Group participants

Category		Focus Group members
Age	18-24	1
	25-49	26
	50-64	15
	65+	21
Total		63
Ethnicity	Asian/ Asian British: Bangladeshi	2
	Asian/ Asian British: Indian	8
	Asian/ Asian British: Pakistani	4
	Black/ Black British: African	1
	Black/ Black British: Caribbean	1
	White: Any other White Background	2
	White: British/ English/ Northern Irish/ Scottish/ Welsh	44
Gender	Male	15
	Female	49
	Prefer not to say	5
Total		69

Appendix 3 - Focus Group Venues, Dates, Reference, and Numbers of participants

Location	Date	Number of participants
Healthwatch Hertfordshire – Online (Hertfordshire 1)	23rd February 2026 1pm – 3pm	6
Bob Champion Research and Education Building, Norwich (Norfolk 1)	25th February 2026 10.30am – 12.30pm	10
Healthwatch Essex – Online (Essex 1)	25th February, 2026	10
Healthwatch Essex – Online (Essex 2)	Various times 27th February – 11th March 2026	4
Sheringham Community Centre, Norfolk (Norfolk 2)	2nd March 2026 2pm – 4pm	4
Healthwatch Hertfordshire – Online (Hertfordshire 2)	3rd March 2026 11am – 1pm	6
Masjid At-Taqwa, Leicester (Leicester and Leicestershire 1)	4th March 2026 10.30am – 12.30pm	12
Ashby Community Hub, Swadlincote (Leicester and Leicestershire 2)	5th March 2026 10am – 12pm	13
Voluntary Action Leicestershire, Leicester (Leicester and Leicestershire 3)	6th March 2026 10am – 12pm	6
TOTAL		71

Appendix 4 – Public Panel Venue, Date, and Numbers of participants

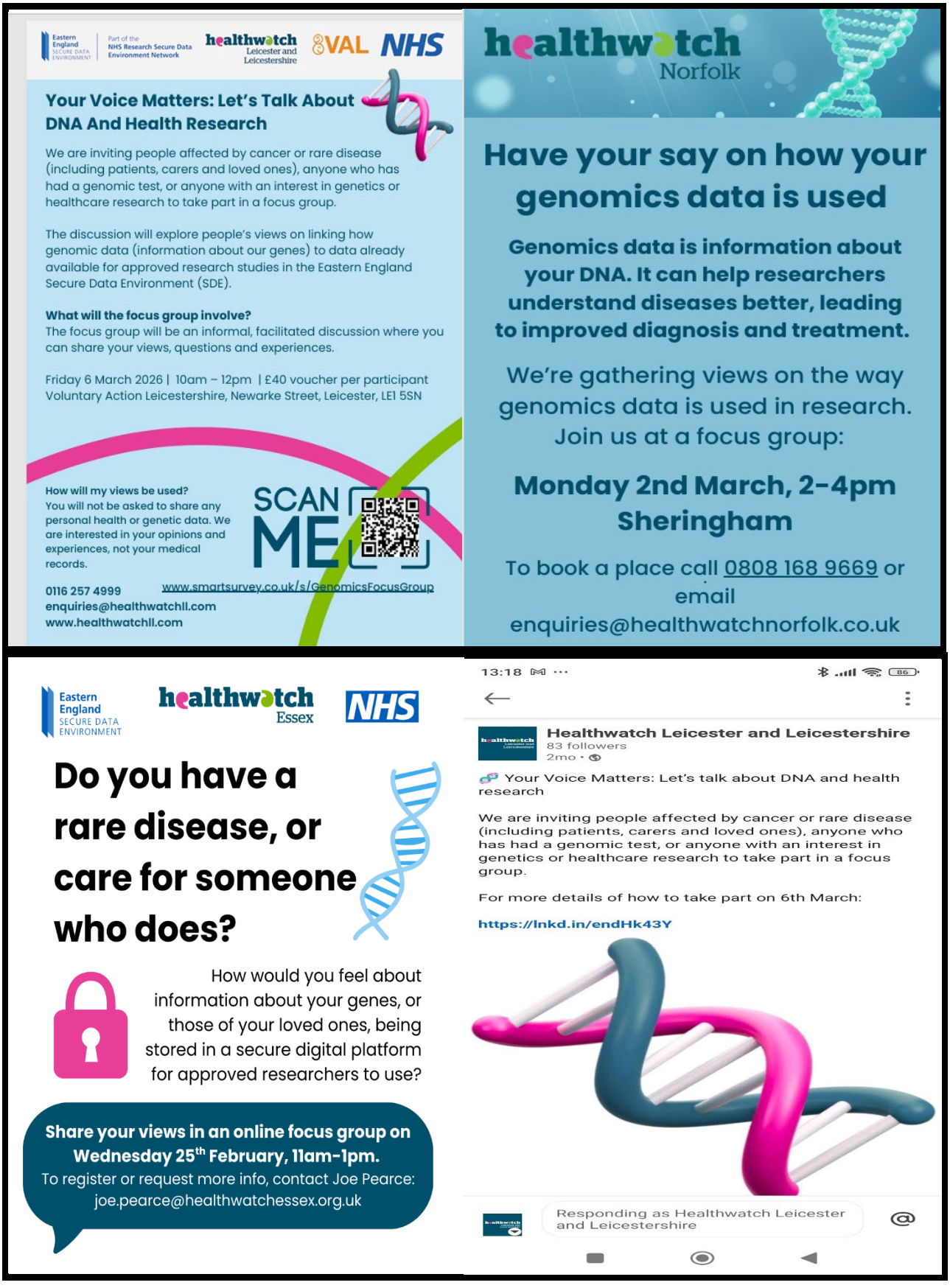
Location	Date	Number of participants
Voluntary Action Leicestershire, Leicester (Public Panel)	11th March 2026 10am – 4pm	24

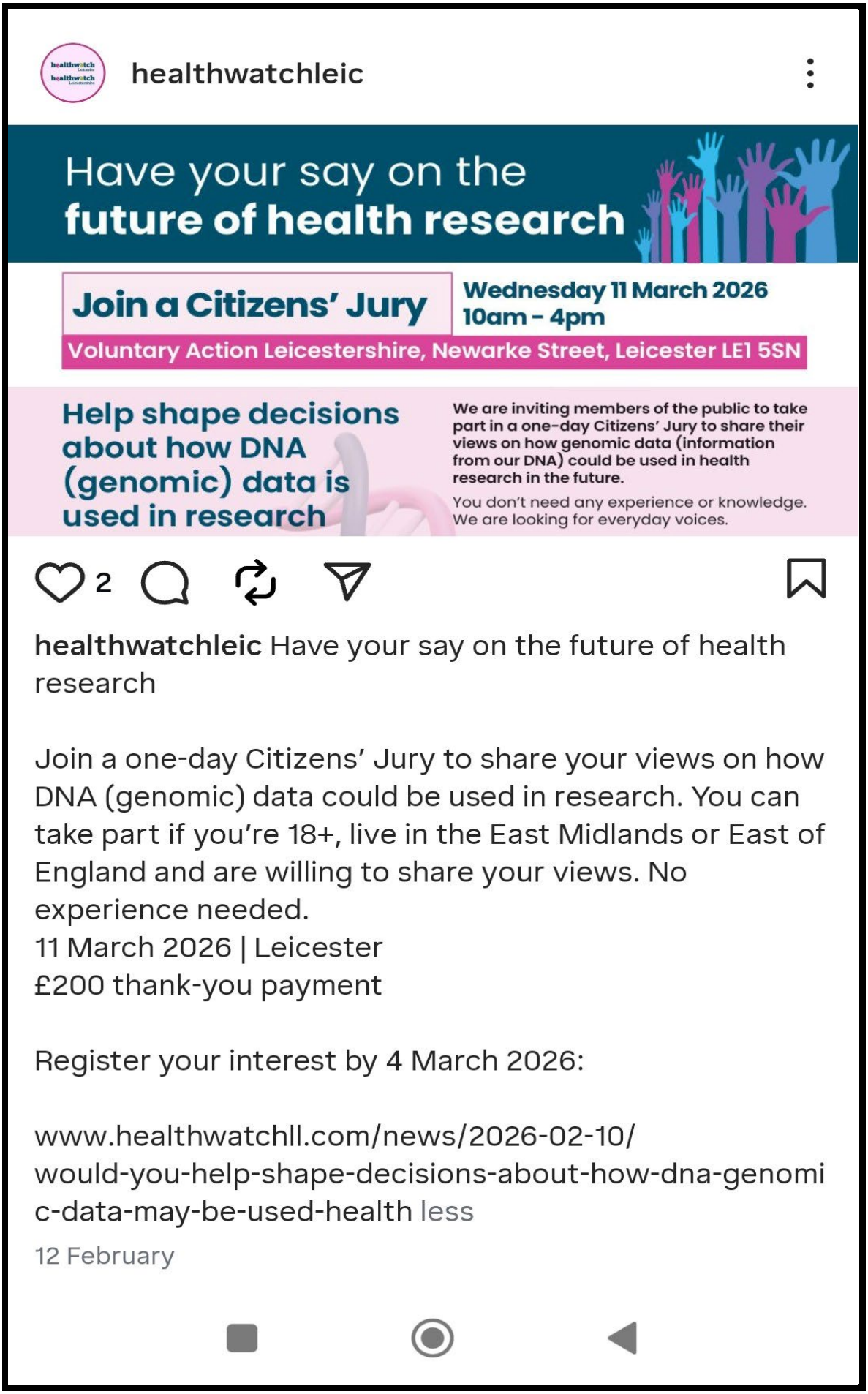
Appendix 5 – Focus Group Venues, Cohort Focus, and Recruitment Approach.

Location (and reference)	Cohort Focus	Recruitment Approach
Healthwatch Hertfordshire – Online	People with experience of cancer as a patient or carer	**Contacted** Local NHS; County Council; VCSE organisations; several town / parish councils **Methods used** included social media on Twitter; Facebook; Reddit; Linked In; and Instagram.
Healthwatch Hertfordshire – Online	Lay people / general interest (no experience)	
Healthwatch Norfolk - Bob Champion Research and Education Building, Norwich	Digitally excluded and rural populations	**Contacted** community groups; people attending an engagement event; and the Norfolk and Norwich Hospitals volunteers' group **Methods used** included posters / flyers on social media and handed out at engagement events.
Healthwatch Norfolk - Sheringham Community Centre, Norfolk	Digitally excluded and rural populations	
Healthwatch Essex – Online	Experience of rare diseases and genetic testing including patients, carers, and family members	**Contacted** people through Healthwatch Essex collaborative Essex forum; HW Essex Carers Voices; and a number of organisations that support people with rare or genetic conditions. **Methods used** were social media channels including Facebook groups for low-income areas. Produced posters in community spaces in deprived / low socio-economic status areas.
Healthwatch Essex – Online	Experience of rare diseases including patients, carers, and family members	

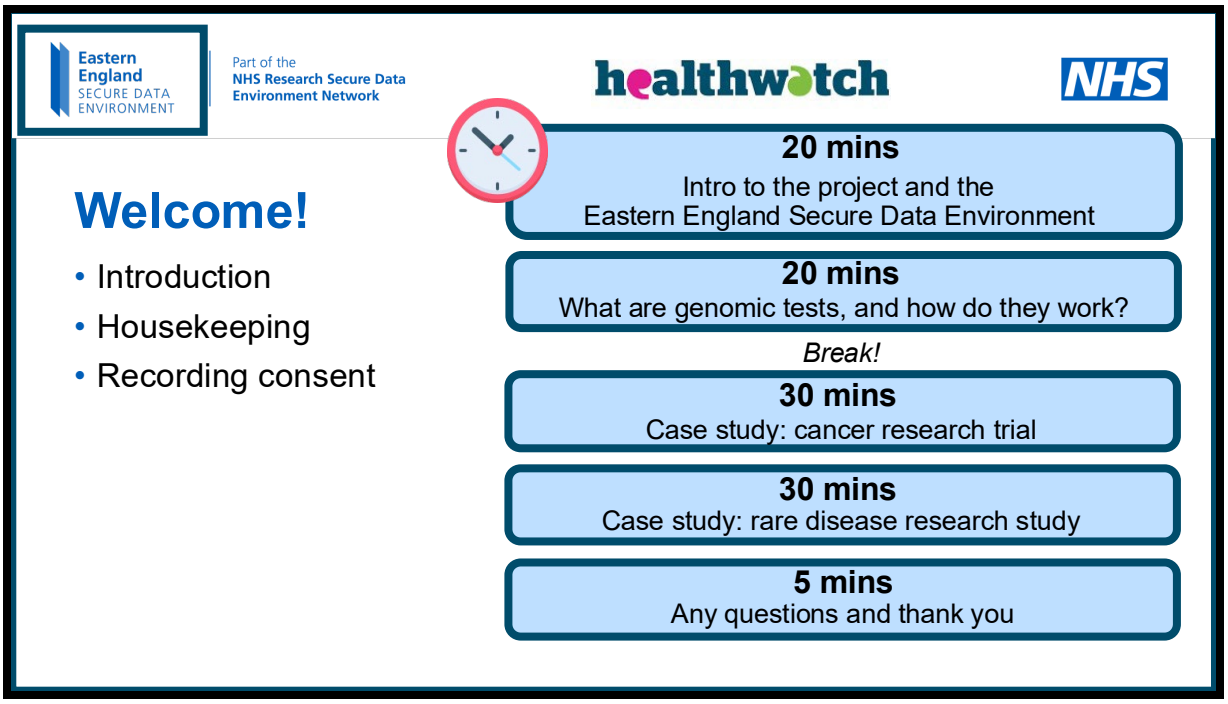
Healthwatch Leicester and Leicestershire - Masjid At-Taqwa, Leicester	Women from BAME backgrounds / minority faiths with lived experience of genomic testing	**Contacted** At-Taqwa Women's Cancer support group in Leicester, a support network for Muslim women living with and beyond cancer, to ensure inclusion of perspectives from minority communities. **Method used** was to liaise directly with group lead.
Healthwatch Leicester and Leicestershire - Ashby Community Hub, Swadlincote	People who've been involved in genomics trials / research	**Contacted** Cancer Active Recovery Support, an established community group based in a rural area to recruit participants with direct experience of genomics related research. **Method used** was to liaise directly with group lead.
Healthwatch Leicester and Leicestershire - Voluntary Action Leicestershire, Leicester	Lay Population	**Contacted** local VCSE and community groups and digital networks. **Methods used** included posters / flyers.

Appendix 6 – Examples of Communications materials used




healthwatchleic
Have your say on the
future of health research
Join a Citizens' Jury
Wednesday 11 March 2026
10am - 4pm
Voluntary Action Leicestershire, Newarke Street, Leicester LE1 5SN
Help shape decisions about how DNA (genomic) data is used in research
We are inviting members of the public to take part in a one-day Citizens' Jury to share their views on how genomic data (information from our DNA) could be used in health research in the future.
You don't need any experience or knowledge. We are looking for everyday voices.
2
healthwatchleic Have your say on the future of health research
Join a one-day Citizens' Jury to share your views on how DNA (genomic) data could be used in research. You can take part if you're 18+, live in the East Midlands or East of England and are willing to share your views. No experience needed.
11 March 2026 | Leicester
£200 thank-you payment
Register your interest by 4 March 2026:
www.healthwatchll.com/news/2026-02-10/would-you-help-shape-decisions-about-how-dna-genomic-data-may-be-used-health less
12 February

Appendix 7 – Focus Group agenda



Appendix 8 – Public Panel Agenda

9.30am - 10.00am	Registration
10.00am - 10.15am	Welcome and Introductions
10.15am - 10.30am	Aims of the day
10.30am - 11am	Expert session 1: The Secure Data Environment (SDE)
11am - 11.30am	Expert Session 2: Genomic Data for Research
11.30am – 12pm	Expert Session 3: Case Study Researcher Perspectives
12pm - 12.45pm	LUNCH
12.45pm - 3pm	Deliberation on safeguards, risks, and benefits
3pm – 3.45pm	Forming conclusions and recommendations
3.45pm - 4pm	Final remarks and closing

Appendix 9 – Patient Information Sheet and Consent Form

Eastern England Secure Data Environment
Genomic Transformation Project
Focus Group

Part 1: Participant Information Sheet

About Healthwatch [insert]

Healthwatch [insert] is the independent organisation that listens to people who use health and social care services in [insert]. We collect people's views and experiences and use them to help improve health and social care services. We share what people tell us with the organisations that pay for and provide care.

About the Eastern England Secure Data Environment Transformation Project

The Eastern England Secure Data Environment (SDE) is a secure digital platform that allows approved researchers to safely access and use health information for research aimed at improving public health and patient care.

When you visit a GP or hospital, information is recorded about your health and the care you receive. Only healthcare professionals directly involved in your care can see your full patient record.

Some of the information from NHS health records is also made available for research through the SDE. Before any data is used for research, it is 'de-identified'. This means that personal details which could identify you, such as your name, date of birth, address, or NHS number are removed.

Researchers use this de-identified information to:

- learn more about diseases
- improve diagnosis and treatment
- improve public health and patient outcomes.

The SDE is delivered by a number of organisations and is led by Cambridge University Hospitals NHS Foundation Trust. The SDE is also considering whether genomic data may be included in the future.

Genetic testing looks at a small number of specific genes in a person's DNA, to help doctors understand more about a particular condition or answer a focused health question.

Genomic testing is a broader type of genetic testing that looks at much more of a person's DNA than a standard genetic testing. It is similar to reading most of a book

rather than just a few pages. This can help doctors diagnose certain conditions and decide on the best treatments.

Using de-identified genomic information together with other health data can help researchers learn more about rare diseases and cancers and help develop better treatments in the future.

You can find more information about the Eastern England Secure Data Environment here: https://www.eoe-securedataenvironment.nhs.uk/index.html.

About your participation

We would like to hear your views about the use of genomic data in research through the Eastern England SDE. Your views will help inform decisions about whether and how this type of data may be used in the future.

You must be aged 18 years or over to take part. We are particularly interested to hear from:

- people affected by cancer or rare diseases, including patients, carers and loved ones
- people who have had a genomic or genetic test
- people with an interest in genomics/genetics or healthcare research [edit according to your specific cohort focus].

What taking part involves

- You will take part in a group discussion with other participants.
- The conversation will last about two hours.
- A trained facilitator from Healthwatch [insert] will guide the discussion.
- A professional will be there to help answer any questions you have about the SDE and genomic data.
- There are no right or wrong answers. We are interested in hearing your honest views and experiences.

With your permission the discussion will be audio recorded. This helps us accurately capture what is said. The recording will only be used for this project.

About you

We aim to hear from a wide range of people in our communities. To help us understand who has taken part, you will be asked some optional questions about your age, gender, your work situation and ethnicity. This helps us see whether participants from different backgrounds have different views. **You do not have to answer any of these questions if you do not want to.**

How your information will be used

We are required by law to protect your information. Your personal details will be kept confidential and will not be shared outside of Healthwatch [insert], unless there is a concern about serious harm to you or others. Audio recordings and notes will be stored securely and will be deleted once the project is completed.

We will produce a report to share what we have learned. When this report is published, you will **not** be identified in any reports or publications and we will take great care to ensure that nothing you say can be used to identify you.

Any information that you give will be stored in accordance with our Privacy Policy which can be viewed online here: [insert link to your policy] or obtained by contacting us via the contact details below.

Your choice to take part

Taking part in this project is entirely voluntary. You do not have to take part, and you can change your mind at any time.

During the focus group session, you can:

- stop taking part at any time
- take a break without giving a reason
- choose not to answer any question.

You can withdraw from the project up until the report has been written. After this point, it may not be possible to remove your contribution because the information will have been combined with other people's views.

Thank you for your time

You will receive a £40 [/£30 for online attendance] voucher as a thank you for your time and participation at the end of the conversation.

Accessibility and support

We want everyone to feel welcome and able to take part. Reasonable adjustments can be provided to support your participation. This may include help with:

- travel arrangements
- accessibility or mobility needs
- information in alternative formats.

Please get in touch via the contact details below if you require any reasonable adjustments.

If you are affected by anything you discuss in the focus group, our project facilitator can signpost you to relevant support services at your request.

If you want to raise concerns about the way you have been approached or treated during this project, you should get in touch with our project facilitator. Should you wish to complain about your research experience, you can contact Healthwatch [Insert] CEO via their contact details here:

Further details

If you have any questions or would like more information, please contact [insert names, phone number and email address].

Part 2: Consent Form

Please initial each box to show that you agree.

Please initial each box

1. I have read and understood the information about this project and I have had the opportunity to ask questions.	☐
2. I agree to take part in the focus group.	☐
3. I give my permission for the discussion to be audio recorded.	☐
4. I understand that my personal details will be kept confidential and will not be shared outside Healthwatch [insert] unless there is a concern about serious harm to myself or others.	☐
5. I understand that what I say may be used in future reports, publications, articles or presentations by Healthwatch and that I will not be identified.	☐
6. I understand the possible risks and benefits of taking part, if any.	☐
7. I understand that taking part in the focus group is voluntary and that I can withdraw my participation at any time before the report is published.	☐

_____ _____ _____

Name of participant Signature Date

_____ _____ _____

Name of Healthwatch staff Signature Date

Appendix 10 – Lessons learned

This appendix summarises our reflections on ways of working and how this public engagement project was designed. It highlights what worked well, the challenges encountered, and the practical lessons that we and others may find helpful for similar engagements with the public on complex topics in future.

1. Inputs and Enablers

What Supported Effective Delivery

Several foundational inputs enabled the project to be delivered effectively within a constrained timeframe.

- Embedded expertise:
  The presence of a knowledgeable and well-informed representative from the Eastern England Secure Data Environment (EE-SDE) team at every engagement event was a critical enabling factor. This ensured participants could receive timely, authoritative responses to technical and operational questions, enhancing clarity, confidence, and credibility throughout the process.
- Engagement with regional and national stakeholders and experts
  Development of the materials we ended up using in the focus groups and Public Panel was greatly helped by effective relationships and early engagement with some key stakeholders. The Education & Training Lead from the NHS East Genomic Medicine Service provided us with baseline materials about genomics and genomic testing. PPIE & Communications Strategy Lead from Cambridge University Hospitals (CUH) facilitated an early session with CUH PPI focus group to test early versions of slides, practice our presentation and framing of the questions, and get initial insights into public views and concerns. An informal discussion with Genomic England Participant Panel members provided us with unique perspectives from patients with lived experience of genomic testing and research involvement. Finally, engagement and sharing of our Public Panel plans and materials with other sub-national SDEs helped us further refine our materials and questions through their constructive and honest feedback, and we re-purposed one of the other SDE's use cases from their own patient engagement materials.

- Strong partnership working:
  Early and sustained collaboration across project partners—including all Healthwatch organisations—supported rapid mobilisation and coordinated delivery. Shared digital infrastructure, particularly a central SharePoint workspace, enabled effective information management, version control, and collective oversight. Partners' openness in sharing experience and learning strengthened consistency and quality across engagement activities.
- Established engagement foundations:
  The project benefited from alignment with previous public engagement on health data and data sharing. This reduced the need to start from first principles and allowed facilitators and participants to build upon existing understanding and prior discussion.

2. Process and Delivery

How the Engagement Was Delivered

- Responsive and adaptive delivery:
  The project incorporated an iterative approach to delivery. Insights from early focus groups were used to refine presentation materials, clarify framing, and sharpen discussion questions for subsequent sessions. This reflexive process demonstrably improved clarity and participant engagement as the project progressed.
- High levels of participant interest:
  The topic of genomic data use generated greater interest than anticipated. Attendance levels were strong, and many participants expressed a desire to remain involved in future conversations. Existing volunteer networks were particularly engaged, reflecting the issue's perceived relevance and importance.

3. Outputs and Immediate Effects

What the Project Achieved

- Delivery of multiple engagement sessions within a limited timeframe
- Meaningful public discussion of a technically complex and unfamiliar topic
- Generation of qualitative insights to inform governance and decision-making around genomic data use
- Identification of priority areas for further engagement and communication

4. Constraints and Limitations

What Limited the Project's Reach or Depth

Time constraints:
Extremely tight timelines for recruitment and delivery restricted the ability to engage more specific or under-represented groups. Relationship-based engagement with community organisations—often essential for trust-building—was curtailed, and some promising connections could not be developed further due to competing schedules and fixed deadlines.

- **Scope limitations:**
  The restricted timeframe also constrained methodological choice. More deliberative formats, such as Citizens' Juries, were explored but deemed unfeasible within the available time and resources.
- **Participant preparedness:**
  Participants were asked to engage with a complex and unfamiliar subject. While engagement during sessions was strong, limited pre-event information meant some participants did not feel fully prepared in advance. Short session formats compounded this issue, as significant time was required to introduce the SDE concept and address foundational questions before progressing to deeper discussion.

5. Risks and Emerging Issues

New Challenges Identified

The project highlighted emerging risks relevant to public engagement practice more broadly:

- **Fraudulent or inauthentic participation:**
  Concerns arose around recruitment fraud, particularly in contexts where participant payment was advertised.
- **Lack of operational guidance:**
  There is currently limited practical guidance on how to identify and manage automated or inauthentic ("bot") responses within qualitative research, presenting challenges for maintaining trust and robustness in engagement processes.

6. Learning and Recommendations for Future Engagement

What Should Inform Future Practice

Drawing together the findings above, several clear lessons emerge:

- **Resource early partnership working.**
  Engaging delivery partners from the outset, investing in shared systems, and considering mechanisms such as pass-through funding i.e., funding that we distribute to partner organisations can strengthen recruitment, promotion, and shared ownership while reducing delivery pressure.
- **Allow sufficient time for community engagement.**
  Longer lead-in periods—potentially six months—are essential when working with specialised, small, or under-represented audiences, enabling trust-building and more meaningful participation.
- **Design recruitment with preparedness in mind.**
  Advance screening calls can confirm commitment, identify inauthentic (fraudulent) participants, introduce complex topics, and reduce drop-out. Where possible, tiered engagement models (e.g., introductory focus groups prior to deliberative panels) support higher-quality discussion.
- **Invest in clear pre-event materials.**
  Accessible, well-designed preparatory information is essential for technical topics, enabling more efficient and confident participation. Also consider multiple formats where appropriate.
- **Learn from trusted partners**
  Engage early with key stakeholders and partners who are prepared to share own experience and expertise. Bring them along the journey and invest time to cultivate relationships going forward.
- **Early Engagement with Genetic Counsellors**
  Engage early with genetic counsellors as this would have added significant value to the design of this work. Their direct experience with patients would have helped shape the framing of questions and provided deeper insight into patient perspectives and concerns regarding the use of genomic data.
- **Build in opportunities for iteration.**
  Even limited scope to reflect and refine materials between sessions can significantly improve engagement quality.

- Address emerging engagement risks explicitly.
  Clear guidance on preventing and responding to recruitment fraud, managing incentives, and identifying inauthentic participation would strengthen the integrity and credibility of future engagement activity.

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