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Engaging communities:

Insights from the Healthwatch-led community workshops across the East of England

Abstract
This report summarises the key findings from the 6 regional community workshops held in conjunction with Healthwatch in Summer 2024

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Engaging communities:

Insights from the Healthwatch-led community workshops across the East of England SDE

1. Executive summary and observations

Six regional Healthwatch events took place in June, July and August 2024. They were held in Bedford, Colchester, Hertfordshire, Peterborough and Norfolk (two events). The key objectives of these events were to:

- Gain an understanding of what people from each region understand and believe about current and potential uses of NHS data.
- Uncover the specific concerns and apprehensions individuals have regarding the use of their NHS data, particularly around privacy, security, and misuse.
- Understand people's expectations, hopes, and priorities for research involving their NHS data, focusing on areas where data could drive meaningful healthcare improvements.
- Identify what rules, protections, and safeguards would enhance public trust and make individuals feel more comfortable with their data being used for research purposes.
- Determine the most effective channels and formats for delivering information about the project, including opt-out options, ensuring accessibility and visibility for diverse audiences.

Key findings

The six Healthwatch events were attended by attended by a diverse audience of residents from across the East of England, which included members of the public and a few people with a research background (Norfolk events). These workshops have provided valuable insights into the perceptions and concerns of both researchers and the public regarding data use in healthcare.

i. General findings

The use of data for **direct, individual patient care** is more salient and important to people than its uses in research, as it resonated on a personal level for participants. This made it difficult in some instances to shift discussions toward topics related to research uses of data.

People are eager to see data being used to improve NHS infrastructure, personalised care, treatment and efficiency, reflecting a strong alignment with **healthcare system reform**. Communicating **research outcomes** in simple language is a critical opportunity to engage the public and empower them to make informed decisions about their own health.

People are increasingly more conscious of **their data being collected and used in general** – from information shared on social media to press about data breaches. Safeguarding data, i.e., ensuring **confidentiality** and preventing breaches remains a top priority, with individuals deeply invested in the handling of data integrity.

Attendees generally expressed **scepticism and caution about the SDE** but were not openly hostile. There was evidence of heightened consciousness, and some nervousness, regarding the collection and use of personal data—particularly **health data**—along with concerns about **data quality and equity,** and the accuracy of their own patient record.

The public is increasingly aware of **health inequalities** and the potential for data to exacerbate or address these disparities.

ii. Determining who should access data

There were mixed opinions on the Data Access Committee (DAC) operations and while there were varying views on how a **DAC** should function, there was broad agreement that it must include both relevant **professionals** and patient **(lived experience)** representation to ensure balanced **decision-making** and **co-production**.

iii. Communicating with the public about the SDE

People favoured **integrating information** about the SDE into existing NHS **communication channels**, such as letters, emails, texts, the NHS app, website, and even prescription labels. Communications about the SDE need to be accessible and **presented in multiple formats** to ensure **inclusivity** and understanding **across diverse audiences** to foster informed decision making. Ultimately, few people would choose to **opt-out** of the SDE

Conclusion

The six workshops demonstrated clear, but cautious interest in using data to enhance healthcare, but concerns around privacy, security, and inclusion need to be addressed. A strategy that emphasises transparency, education, and meaningful integration of the use of healthcare data into the NHS system will foster trust and greater engagement with data-driven healthcare improvements such as the SDE.

Introduction

Six regional workshops hosted by Healthwatch about the East of England Secure Data Environment took place in June, July and August 2024. These **one-off public engagement workshops in the community** aimed to gather more feedback about public hopes and concerns and to test the materials that we had developed with our Core Advisory Group for public engagement with the SDE. The insights garnered from these workshops have enabled the SDE team to further develop communication materials and the security and decision making processes for the SDE, while helping to meet the goal for meaningful and diverse involvement of patients and public in how their data will be used. The workshop times and locations are shown in Figure 1.

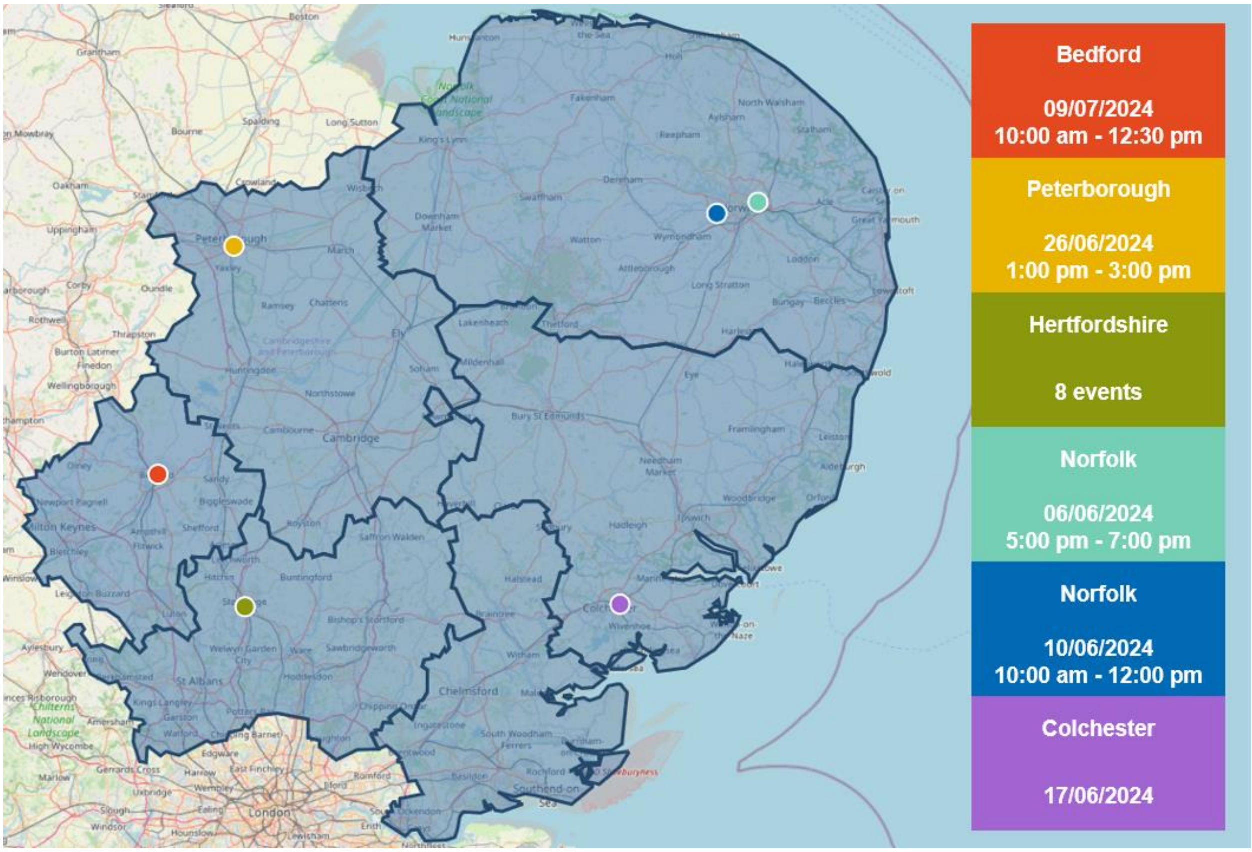

Figure 1: Map depicting workshop locations

The key goals of these events were to understand:

- what people in each group and region already know and think about the uses of NHS data.

- what their specific concerns are about the uses of their NHS data.
- their hopes and priorities for research using their NHS data.
- what rules, protections or other measures might make them feel more comfortable having their data used for research.
- the best place(s) to put information about this project and how to opt out, so that people similar to them could find it.

2. Detailed findings

iv. Findings which confirmed existing feedback

Baseline understanding

The majority of participants across workshops already had some awareness that their NHS data was used for additional purposes beyond their individual care, including health research. However, as found previously, there were different levels of awareness of the types and scale of research that could be done without their explicit permission/consent.

People were aware of the idea that they had a patient record, and able to suggest different types of data that their records would contain, and that this would vary depending on what health conditions and treatments people had had. In discussing what "secure" data means, most groups talked about the protections data needed from people trying to access or steal it, as well as legal safeguards and confidentiality. Most participants had a good understanding of research from their prior engagement with organisations focused on making research opportunities more inclusive, and were generally aware of the benefits that research can bring in terms of better health.

Only some of the workshop participants were aware that de-identified NHS data can be used without consent. Consistent with previous public involvement work, different people respond to this information differently, with it being a source of concern and dismay to some, and a 'common sense' use of data to others – with the consistent caveat that this could only be appropriate with robust de-identification of the data.

Some participants were aware of existing opt outs, particularly if they had a background in health or research. However, few people were able to articulate what the different opt outs applied to or how they function. Few people felt that the available opt outs gave them the options that they desired, or that information about them was accessible and understandable.

Concerns

The most common concern expressed was a fear of the data being compromised/leaked and sold to unknown parties. Some individuals were worried that their data could be made public following a breach, and other people able to see or misuse their private information. Participants in several groups said data security was a key consideration for opting out.

Some participants also raised concerns about the data being used by private companies and governments from other countries (Russia was cited as the specific example), where those seeking access to data might be motivated by commercial or political gain, rather than an interest in improving health. Participants wanted to know who is benefitting from how the data is used. Others wanted reassurances about researcher credentials to ensure that the right person was accessing their data.

There was concern about possible re-identification, particularly for people with less common conditions or complex cases due to the small numbers of such patients, balanced by some concern that such people could be unnecessarily excluded from research due to concerns about privacy. Generally, people were reassured by the knowledge that their data would be adequately anonymised, but some had questions about how the process of removal of identifying information worked, and about how robust it was to deliberate or accidental attempts to identify people.

People were also aware that disproportionate opting out could affect the “credibility” and accuracy of the research due to the incompleteness of the datasets, and in turn, the equity of the research if many similar people opted out.

Attitudes

Across the workshops, participants agreed that the SDE is an improved way to access data for research compared with the current methods of sharing data with researchers. There was general agreement that where the SDE is accessed for valid reasons there is a lot of potential for valuable learning. Many participants felt that it is important to involve patients in research to ensure that it is informed by lived experience, and to build credibility with the public that the data are being used for purposes aligned with patient priorities.

Participants felt that robust de-identification is a key element of research “safety” and that a project is only ‘safe’ if there is a benefit to patients and, conversely, it will not be used to discriminate (especially against groups which are already under-served). They also felt that using the data to improve NHS systems is an acceptable “benefit”.

The need for researchers to gain and retain trust was apparent, with participants stating that researchers can't be associated with "dodgy" people and that they should demonstrate that their motivations are ethical and do not have ulterior (e.g. political) motives.

Recommendations

Across the workshops there were mixed findings about exactly how the Data Access Committee (DAC) should function, and who should be on it. However, there was unanimous support for public representation on the DAC, and that they should have equal decision-making power to the professionals represented on the committee. It was also agreed that the DAC should include a mix of expert professionals (in research, data science, governance, ethics and law), but less consensus on whether the professionals should represent broad professional backgrounds or have expertise directly relevant to each project.

Consistent with recommendations made by the Core Group, most workshop participants felt that it was acceptable and efficient to 'pre-review' each application to determine whether it could be done, before sending feasible applications for a 'full review' by the whole DAC to make the final decision about whether the project should go ahead.

Within and across workshops, however, there was less consensus about how to balance both efficient decision making and in-depth review of each application with meaningful, representative and supportive public representation on each committee. Again consistent with our core group, some participants prioritised having a greater number of public representatives in a separate committee who could review each application and make recommendations/request additional information on each project. People in support of this model tended to argue that this would allow a greater representation of different groups and conditions, and that people might feel more comfortable expressing questions or concerns in this format. However, other participants prioritised equity, visibility and transparency of decision making by the professional DAC members and felt that the public members should not be on a separate committee, even if this meant reducing the number of public representatives present at each DAC meetings (to avoid the DAC becoming overly large, and thus reducing efficiency and thoroughness of review). Models and approaches used by other groups (such as at Genomics England) were discussed, and there was general agreement that there are advantages and limitations to all models. Given the diversity of opinion and lack of a clear preferred option, participants in several workshops agreed that a way forward might be to test one option out, with review after several meetings or at a milestone, in consultation with our Core public group and the public members on the DAC committee.

Participants were clear that DAC materials should be presented in an accessible format and language (and researchers need to ensure this at the application stage). They also felt that the committee should prioritise reviewing applications which have a stronger likelihood to have an impact on public health.

As an NHS-backed project, there was a general expectation that people would receive information about the SDE and uses of their data from NHS sources, including via GPs as they are usually first port of call for members of the public to engage with the NHS. However, participants were also very clear that members of the public need different and multiple ways/channels to find out about the SDE and the opportunity to voice any questions, concerns or other feedback, that accommodate different demographics and via avenues where they are likely to see the information – e.g. in local news/TV. It was also important that the information about the SDE should be available in multiple formats, such as different languages and animations, video, EasyRead etc. The participants encouraged a focus on the positive impact of SDE research projects in public comms.

The use of interpreters and/or translated formats can also help engaging with people who are not native English speakers. From this there is an opportunity to engage with community leaders and community health champions who can help disseminate information about the SDE.

Communications materials should contain clear information about the security measures used to keep data safe, the anonymisation methods used to keep data confidential and the processes by which researchers and organisations are checked and trained in appropriate and safe uses of NHS data.

Materials should also contain clear information about the options for opting out of the SDE, and what uses of their data those opt outs would apply to. It was felt that carefully worded information about the risks of opting should be provided along with information about how to opt out, and how to opt in again. Similar to findings on general communications, there should be different options for people to opt out through (eg phone, email, website). Some workshop participants also mentioned that there should be optional spaces in opt out materials for people to be able to explain their reasoning if they chose to do so – though it should be made clear that no explanation was required and that opt out information should be accompanied by information that it was possible to opt back in again at any time.

v. Novel findings

Baseline understanding

Confusion/lack of understanding about how the NHS works was a key 'novel' finding from the workshops. Across several workshops it was observed that participants struggled to engage with discussions about research uses of NHS data without first discussing their own experiences of the NHS for their own care – both positive and negative. It was expected that many workshop participants would want to focus some discussion on such experiences, and the facilitator notes and packs included information that this was to be expected. However, it was interesting to note that some of the scepticism and frustration about the SDE was related to a sense of disbelief that the SDE could overcome problems of bringing together health data from lots of people for research when '*my GP can't even see my hospital records*' or '*my hospital consultant doesn't even know my medical history*' and some frustration that equivalent amounts of time, effort and funding weren't being used to address the problems outlined above. In addition to the completely understandable frustration that the participants expressed on these points, it has highlighted that information resources about the SDE need to also contain some information about how data is normally used by different health organisations to support individual care, and that different parts of the health system cannot always access information held about the same patient in other parts of the system. Some participants were aware of local or regional projects such as the various 'Shared care record' projects in some ICBs, but many participants did not realise that sharing information within the NHS is currently so complex. Some participants' early support for the SDE was erroneously tied to a belief that the SDE could help their GP access their hospital record or vice versa, and some workshops and discussions came with a sense of dismay or disappointment that the SDE wouldn't do more to improve their individual care.

Despite a sense of disbelief that the SDE could achieve what it was set out to do (eg make it easier to bring together de-identified health records from across the East of England for research), some workshop participants were concerned that the SDE could be used to do things that are much more complex or wider than the health system, either at an individual or community level. For example, linking information from different sources about them to certify a person's ability to perform certain tasks (e.g. driver's license renewal), to test their eligibility for benefits or to support better planning for housing. There were also concerns about data being used to delay, withdraw, or under-deliver care because of an individual's lifestyle choices, or local funding priorities not being aligned with that person's personal needs. A few attendees mentioned that data can be used in service planning – specifically, funding allocation, and whether the SDE could be used to support planning that might result in reduced services in low use areas.

Some participants observed that if data could be linked better across services, it would have cost saving implications and lead to better care (an example from one participant was needing to have the same blood test performed by 3 different services), but when informed that there are projects (such as the NHS Federated Data Platform) that are looking at how better to do this, concerns about privacy, data security and the intentions of data service providers resurfaced. Throughout the workshops, participants moved back and forth between frustration that data weren't being better used for theirs and others care and concern about increasing usage of data by different players in the health care system and for different reasons. Participants generally did not easily grasp the distinctions between different types of data use in different parts of the NHS ecosystem as they see the NHS as a single health system.

Several workshop groups discussed the potential for data and research to improve the wellbeing of communities and to address health inequalities, for example, to gain a better understanding of diabetes in specific communities or to "build a bigger picture" of population health – e.g. the spread of contagious diseases and how they affect people differently based on age or gender. Projects that used the SDE to support research that specifically aimed to reduce inequalities in care in the East of England were felt to be a positive use of the SDE. However, there were some concerns about 'culture' motivating opting out – due to mistrust about how their data would be used, or lack of accessible information (e.g. in their own language) to support making an informed choice was also raised.

Concerns

Discussions around data quality came up independently across several workshops, with a few participants suggesting that the key words "relevant", "accurate" and "clean" needed to be attached to the word "data". In several workshops, people recounted their own experiences or concerns about the accuracy of their own health records – either that they were missing important information, or that information about their symptoms and diagnoses had been inaccurately recorded. At least some participants were conscious of how large numbers of people from similar groups opting out could negatively affect the quantity and quality of data available, thus further exacerbating health inequalities.

"Unsafe conclusions" as a result of research (e.g., abortion) was another worry and concern that if data are mismanaged, they could be used to exploit vulnerable people – e.g., private pharmaceutical companies trying to sell weight loss medication. Participants queried whether policies or laws could be changed in a way that affected the security of the data.

In addition to measures to protect data from external misuse, some participants had concerns about what would happen if someone from within the SDE team handling the data intentionally or negligently mishandled or misused it, and how the SDE would keep up to date with security in light of the ever-evolving security challenges.

There was also anxiety about how the DAC would make decisions, whether any panel members could have a conflict of interest, and what happens if the panel is split in how they feel about a specific project.

Some participants from the Hertfordshire workshop shared anecdotal evidence of their own personal concerns at lack of effectiveness of some health professionals in sharing medical records. These participants stressed how not sharing medical records can be detrimental to patient care. The SDE was difficult for participants to conceptualise (due in part to their learning disabilities) which made it harder for them to understand how the information would be held digitally and not in a filing cabinet for example. Participants could not understand how data would be kept safe without physical measures such as locks and bolts.

Attitudes

Participants felt that for projects to be worthwhile, the public needs to be informed about their outcomes – not just for transparency but because it helps people make decisions about their own health (such as risks). There was variation in the level of enthusiasm/optimism for the outcomes of SDE-based research, which could be related to general scepticism about the motives of data use for research or to wider feelings about the state of the NHS (or a combination of these), further underscoring the need for transparency and sharing of findings from SDE research.

People across workshops generally felt positively about the cardiovascular disease (CVD) use case, and found it a useful and encouraging illustration of the potential power of the SD. Several workshops also favoured research that can benefit people from groups who are disproportionately affected by certain conditions, i.e., promoting health equity. They went on to say research can help us understand co-morbidities and develop a more 'holistic' understanding of illnesses and therefore treatment. There was also general support for projects with longer term benefits or that focused on prevention.

The vast majority of group members said that the workshop had not changed their attitudes towards the use of their data, but encouragingly none of the participants across workshops said that they would wish to opt out of the SDE personally. However, they did note that people who have previously fallen victim to misuse of their data or also scams may be more likely to opt out.

Some people were generally fearful about their data being mis(used) but those same people already share their data all the time with shopping sites, social media, etc – and don't give it the same level of thought. Participants pointed out that younger people are "used" to sharing their data (e.g. on social media) so likely to be less concerned about this compared to older people.

Recommendations (Novel findings)

Some participants were interested in specific details about how the SDE protects data security and privacy, for example what the physical arrangements are for accessing the SDE. e.g., whether the researchers would need to be in an NHS or university building, or could they log in from their garden and using their own WiFi connection and how the SDE can control or prevent data being shared with third party organisation. This suggests a need for some public-facing materials that go into greater detail about the technical details that help keep data secure and private.

Several participants spoke of the need for researchers to receive rigorous training, clearly demonstrate the need of their research project, and prove their adherence to clear confidentiality measures. Participants from Essex mentioned that access to data should be time-limited, even after all appropriate approvals. This suggests that details of the researcher accreditation process might be useful to make publicly available, potentially linked through Frequently Asked Questions or similar. There also suggestions that researchers should be asked or recommended to complete an Equality Impact Assessment (EqIA) before applying to use the SDE to demonstrate that the research is equitable and what the benefits are to participants.

Several workshops recommended that continued in-person events to promote/raise awareness of the SDE were important, particularly for some groups who may have further questions or be less likely to engage with other materials. This included events similar to the workshops themselves, presence at local/community and/or health events or in community spaces such as libraries and supermarkets. Similarly, some discussions focussed around creating an environment where research use of data is seen as 'normal' in the future – so considering working with schools and young people to broaden awareness and 'NHS literacy' more generally.

Most workshops included at least some discussion of the relevant laws and policies around data access, consent and/or how data is used more widely across the NHS, for example around consent (or lack thereof), the opt out options and how data does (or doesn't) normally flow between NHS and health organisations. Few participants had full knowledge of how these aspects of the NHS worked, which impacted the ability to be able to discuss the need for and function of the SDE as well as people's attitudes to and trust of data use for purposes beyond their care. Public-facing materials and communications need to reflect these variations in background knowledge, and, where possible, include information that places the SDE in the wider context of people's understanding of the NHS and data use.

3. Summary of overall findings

Concerns about data privacy and security – in common with our wider engagement work, these remain the most cited concerns about data use. Most people are reassured by knowing that their data are de-personalised, and that the SDE has been independently tested against vulnerability to hacking. Some people prefer further details about how de-personalisation of data works in practice and/or specific use cases (such as rare disease, or sensitive diagnoses) or about specific security measures.

Trust and transparency - Transparency and clear information about who would be accessing data, for what purpose and what their findings were are essential for building and maintaining trust. Many people could see the potential benefits of data research in the SDE, but there is skepticism about both the motives of researchers (particularly commercial ones) and the likelihood of benefits being realised. People want to be able to easily access information about who is applying for and accessing data, and they want enough information to be able to understand whether their own data is being included in the opt out.

Low overall awareness about data use in the NHS – People try to relate their understanding of the SDE to their wider knowledge and experience of the NHS and are frequently not aware of the different rules related to research use of NHS data compared with how their data are used to support their own care. Furthermore, people's attitudes towards and expectations of the SDE are firmly rooted in their own experiences of the NHS, healthcare and wider life. It can be challenging to meaningfully engage people on how the SDE will work without providing background information about how it relates to the wider NHS system and some people simply do not have the patience, energy or interest needed to build up that understanding – it simply feels too complex to deal with on top of the rest of their lives. Similarly, managing people's expectations of positive outcomes and how the SDE will help improve their individual experiences of the NHS (particularly where that experience relates to poor or inefficient use of their data for individual care, or where their data has been breached) will be an ongoing challenge.

Meaningful public input into decision making about data – one area that remains unresolved is the practicalities of public involvement in decision making about individual data projects – particularly how to balance having a good number of public representatives for each data decision, while ensuring that they were adequately supported and trained, felt truly heard and while not having the overall committee become so cumbersome as to not be able to make decisions efficiently. There is broad agreement around things like transparency, training and the need for broad representation of lived experience – but disagreement about exactly how to put that into practice on a decision-making committee, while still having a committee that can efficiently and consistently make decisions. We had many very constructive conversations about the pros and cons of different models of DAC (particularly around separate, larger public committee vs smaller number of public contributors on a single committee), showing that people highly value transparency, and meaningful, equitable decision-making power of the public members of the committee. There was a general acceptance that one model would need to be selected to be able to move forward, but that it might adapt over time for practical or other reasons. Regular review, in conjunction with the public members on the committee and the SDE public advisory group was recommended.

4. Conclusions

These events showed that in general the public are supportive of research using de-personalised NHS data. Attendees' understanding of health data and research varied based on their backgrounds. Those with learning disabilities found the SDE concept complex to understand highlighting the need for clearer communication and inclusivity in presenting the SDE to audiences.

Data privacy and security remain the key concerns across the workshops, in keeping with our wider public engagement activities. There was a heightened awareness of data breaches, particularly with third-party access, AI risks, and potential misuse for commercial or governmental exploitation. Ensuring data accuracy, security, and confidentiality was a top priority.

Despite concerns, many participants saw the value of using health data to improve NHS services, treatment pathways, and community well-being. Research on mental health, aging-related conditions, cardiovascular diseases, and cancer was seen as crucial. Attendees appreciated the potential of data to address health inequalities and improve care efficiency.

While participants expressed uncertainty and caution about the SDE, they were not entirely opposed to it. They favoured integrating the SDE into familiar NHS communication channels for better accessibility and understanding. Participants supported the idea of time-limited data access to ensure ethical use, and many wanted transparency in how data is shared and used in research to build public trust. Some were concerned about potential conflicts of interest in decision-making bodies like the Data Access Committee (DAC).

Clear and simple communication about research outcomes was emphasised as essential to inform and empower the public. The importance of engaging people with accessible information to foster informed decision-making was frequently highlighted. Many participants acknowledged the potential negative impact of opting out on data quality and health inequalities, though they understood why some people, especially those affected by past data misuse, might choose to do so.

Overall, the views reflected cautious optimism about the SDE, recognising both its potential benefits and challenges, particularly in ensuring trust, security, and ethical use of health data.

5. Response

Key takeaways and actions from the regional events and other public engagement activities as relate to communications are:

Finding	Response
Desire for communications that come to them AND further resources that can quickly and easily be found by people wanting further information	We will work with local, regional and national NHS bodies to encourage information about data uses, including the SDE, to form part of routine communications with patients AND develop a range of materials/leaflets/resources that will be available at healthcare locations and through trusted community and other organisations.
Desire/expectation that information will be available in places where they receive NHS healthcare and from trusted NHS professionals. There is a general expectation that people will receive information *from* the NHS as this is an NHS programme using NHS data.	
Desire for repetition/ongoing communications that support transparency and support transition to NHS data use as part of wider public awareness	Ongoing plan of communications beyond early promotion activity has been developed, communications will remain part of the core function of the SDE team.
	We will plan responsive communications to tie into ongoing news, events and other relevant activities to keep SDE activity visible and relate it to the wider NHS and national affairs
Desire to be able to understand whether/when *their* data is being used – e.g., enough information provided about each project to understand whether it is relevant to them as an individual	We have developed and are piloting a Data Access Register that will be publicly accessible on our website. Items to be included in the register have been selected to provide provide enough information about each SDE project to help people understand whether their data may have contributed to that research.

	We have also shared these findings with national consultations on standards for Data Access Registers
Privacy is a key concern	All communications related to the SDE will be clear that researchers do not have access to personally identifiable information
	Some materials/resources will be developed to provide more detailed information that describes how de-personalisation/de-identification is assured within the SDE
Selling of data/commercial use is a common concern	Materials and content about the SDE will explain that commercial data users are subject to the same stringent requirements about public benefit, training and transparency as academic or non-commercial researchers
	Once a pricing structure has been determined, we will make information about how charges for access are calculated available on the website
Concern about data breaches is also very common	We will produce some detailed information about how data are kept secure in the SDE for people who wish to know more as well providing information about the steps that would be taken in the event of a breach
'Put to good use' – many people link their approval/acquiescence to their data being used for public good	The application for accessing data makes it clear that updates on findings will be a condition of data access. The data access register will include a section on findings/public benefit
Accuracy of their own patient record is a common concern	We will have a FAQ that provides people with information about how they can check

	what data are held about them, and what measures are available to respond to inaccuracies
Awareness and understanding of the systems and function of the Opt out systems are low	All materials about the SDE will contain information about the options for opting out, and links to further information about how the National Data Opt Out functions

Key takeaways from the regional events and other public engagement activities as relate to the Data Access Committee (DAC) and decision making about data are:

Finding	Response
The public expect broad public representation on the DAC	50% of the 'core' members of the DAC will be comprised of public members (in practice this will be minimum 4 public members each meeting)
Some projects may benefit from specific experience from public or professional members	A larger pool of public members will be trained to sit on the DAC, allowing spread of workload and the ability to include a wider range of specific lived expertise. Similarly, further professional members may be co-opted where the core members (including public members) deem it necessary
DAC meetings could become burdensome for public members if they are too frequent, limiting the diversity of people who might otherwise be willing to serve	Trained DAC members will be able to choose to be part of the regular 'pool' of public members or to be a 'specialist' member who is only invited to reviews on specific topics of their interest
Some decisions, such as whether a project is technically possible or denial of projects that are clearly illegal, unethical or impossible, could take place prior to decisions by the full DAC to increase efficiency and prevent wasted time	All applications will be reviewed by the DAC team on receipt to check that the application is complete, that the required data are available through the SDE and for any projects that are clearly unethical or illegal
Materials about and for the DAC need to be accessible to all members of the committee	Public advisory group members from the SDE will be involved in drafting and reviewing training and other materials for DAC members.

	Accessibility and inclusion will be specific focuses of a 6-month review after the DAC has been active for 6 months, or after the public members determine is a suitable time point for review
Transparency around decision making is important	Approved projects will be published in the Data access register that will be available to the public.
	Minutes from the meetings will be retained to support internal review and audit

Appendix 1: Demographic characteristics of workshop attendees

Table 1: Gender of workshop participants

Gender	Totals
Male	38
Female	45
Non-binary	2
Total	85

Table 2: Participant age groups

Age bracket	Number	Percentage
<18	0	0%
18-25	2	2.35%
25-35	12	14.11%
35-45	20	23.53%
45-55	15	17.65%
55-65	10	11.76%
65-75	15	17.65%
>75	7	8.23%
Prefer not to say	4	4.70%
Total	85	100%

Table 3: Participant ethnicities

Ethnicity	Count
Arab	0
Asian or Asian British	8
Black, Black British, Caribbean or African	10
White: British/Northern Irish/Welsh/Scottish	57
White: Gypsy, Traveler or Roma	0
Any other White background	6
Mixed or multiple ethnic groups: White and other ethnic background	3
Mixed or multiple ethnic groups: any other mixed or multiple ethnic background	0
Unknown / Prefer not to say	1

Table 4: Sexual orientation of workshop participants

Sexual orientation	
Self-identify as LGBTQ+	10
Do not self-identify as LGBTQ+	64
Unknown / Prefer not to say	11
Total	85

Table 5: Participants affected by cardiovascular disease

Affected by CVD	
Yes, personally experienced	7
Yes, at higher risk for medical reasons	13
Yes, at higher risk for demographic reasons	6
Yes, experienced by close friend/family	22
No	39
Unknown / Prefer not to say	10

Table 6: Participant religious beliefs

Religion	
Buddhist	1
Christian	39
Hindu	1
Jewish	0
Muslim	4
Sikh	0
No religion	24
Other religion	0
Unknown / Prefer not to say	4
Total	85