OpenSAFELY

OpenSAFELY Service – Public Engagement Workshops
Report of Findings and Feedback

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Executive Summary

A series of online workshops with members of the public has taken place between December 2024 and January 2025 to help shape the future of OpenSAFELY: a platform for analysing large, sensitive datasets, safely and securely. The objectives we set out to achieve involved understanding public perceptions, identifying what topics and conditions/safeguards are important to people, learning about preferred patient and public involvement and engagement (PPIE) approaches, and to increase awareness of OpenSAFELY.

Around 90 people participated in the workshops which has provided us with important feedback and insights from patients and the public. The workshops involved a presentation on OpenSAFELY and how it works followed by time for questions, a Mentimeter interactive survey to find out about the audience's perspectives, and then into a breakout session for a discussion. This report is formed of two parts: the findings and insights and an evaluation all of which lead to 15 recommendations for the PPIE Team, Bennett Institute for Applied Data Science, and NHS England.

The main purpose of the presentation and time for questions was to provide participants with information about OpenSAFELY to enable them to enter the later discussions. The questions are however useful for all OpenSAFELY interest-holders, as it offers a view into the level of understanding and areas of interest about electronic health record research from the public.

The areas in which participants said would increase trust and confidence in sharing their health data for research and planning included:

- Communications, awareness and visibility to build trust and confidence
- Conditions and safeguards for data security and privacy
- Research purpose, outcomes, and impact for public benefit
- Meaningful and recurring PPIE and co-production
- Opt-out, opt-in and ongoing choice
- Data completeness, quality, and accuracy
- Governance, ethics, and oversight

The feedback forms, sent to participants after the events, provide us with a wealth of information to understand the audience we reached and insights as to how we can tailor PPIE future activities and improve content and delivery. Overall, the average rating of the event was 4.49 out of 5 stars. We reached people from a range of identities and backgrounds, however there are some voices missing from this round of workshops, including those aged 18-24 and 75 and older. While each of the nine categories of region in England were represented, most people joined from Greater London and only one person joined from Yorkshire and the Humber.

Building on these activities and insights, a plan for ongoing PPIE will be developed through discussion with the Digital Critical Friends (OpenSAFELY Public Advisory Group), PPIE Team, NHS England, OpenSAFELY interest-holders, and this feedback from the public workshops.

We will ensure that our approach to PPIE is responsive to social and policy changes and supports our commitment to continuously understand people's perspectives.

The complete set of recommendations, drawn from the feedback and insights from workshop attendees, is shown below.

Recommendations for the Bennett Institute and NHS England

Recommendation	1	The Bennett Institute and NHS England to develop public-facing material to be available in different formats and use the representative question set to inform a communications and PPIE plan.
Recommendation	3	The Bennett Institute and NHS England to create a communication strategy and plan for OpenSAFELY that is shaped by patients and the public to determine the messages to ensure content is understandable by the general public.
Recommendation	8	The Bennett Institute to work with NHS England to ensure the public voice to be heard in the development of and contribution to the decision making/approval of applications made to the service.
Recommendation	10	NHS England and the Bennett Institute to continue to engage with the public to continually understand levels of trust and sentiment towards an OpenSAFELY model.

Recommendations for the Bennett Institute

Recommendation	4	Bennett Institute to introduce a feedback and engagement mechanism on the website for people to connect and ask questions.
Recommendation	7	Bennett Institute to explore what a public-friendly online space showing ongoing studies, their stage, preliminary findings, final outputs, and impact would look like. This could include: ● Public-friendly explanatory content on electronic health record research and intended public benefit. ● Build in a requirement that researchers share a summary of results and study impact.
Recommendation	12	The Bennett Institute to add details about the ability to opt-out onto the OpenSAFELY website.

Recommendations for the OpenSAFELY PPIE Team (includes Bennett Institute, public contributors, consultants and NHSE)

Recommendation	2	PPIE Team to design public involvement activities to include more people who are uncomfortable with sharing their data.

Recommendation	5	PPIE Team to continue involving the public to inform the development of policies or governance practices relating to uses of data in health research, such as data security and privacy conditions and safeguards.
Recommendation	6	PPIE Team to share feedback and findings that it isn't widely known that electronic health records are used in health research and planning to NHS England and Department of Health and Social Care and into the knowledge and insights base around the other public engagement on data activities and programmes.
Recommendation	11	PPIE Team to report feelings about opt-out and dissatisfaction with knowledge about opt-out to NHS England and the Department of Health and Social Care into the knowledge and insights base around the other public engagement on data activities and programmes.
Recommendation	13	PPIE Team with support from Bennett Institute and NHS England to communicate findings about data completeness, quality, and accuracy in OpenSAFELY to external interest-holders and connect into other insights gathering and public engagement exercises.
Recommendation	14	PPIE Team to use feedback survey findings to inform the planning for the second wave of workshops, including: ● Targeted workshops to reach those who are less represented (including low-trust groups as shown from Mentimeter) ● Adapt the feedback survey to ensure that questions on demographics are inclusive of a broader range of options for people to identify with and select. ● Tailor the presentation to a general audience and test this with public reviewers before the workshop.
Recommendation	15	PPIE Team to explore how a "Critical Friends of OpenSAFELY" Network can be established to involve and engage people who have consented to future contact.

Complete table of recommendations, in order

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Recommendation	8	The Bennett Institute to work with NHS England to ensure the public voice to be heard in the development of and contribution to the decision making/approval of applications made to the service.
Recommendation	9	Bennett Institute to create a "Public Involvement" space on the OpenSAFELY website to house information about OpenSAFELY PPI, such as the role of the Digital Critical Friends, upcoming opportunities, links to other initiatives and groups, and a forum for ideas.
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1. Introduction

OpenSAFELY is a platform for analysing large, sensitive datasets, safely and securely. It was built to solve one of the biggest problems in medical science: overcoming the inherent tension between the needs of researchers who want to use health data for science, and the needs of patients, who expect their personal information to be kept secret and secure. OpenSAFELY was built by a collaboration led by the Bennett Institute for Applied Data Science at the University of Oxford. The platform is funded by NHS England who handles all information governance, permissions, and additional data sources. On behalf of NHS England, the OpenSAFELY service provides a platform for the secure analysis of full GP records of the entire population of England to approved users (e.g. NHS analysts and researchers) since the pandemic in 2020 - for health service audits, evaluations, and COVID-19-related research. It has recently received substantial new funding from NHS England and the Wellcome Trust[1].

When OpenSAFELY was included in the Citizens' Juries commissioned by the National Data Guardian in Collaboration with NHSX and Citizens Juries inc. in 2020, the juries supported the continuation of an OpenSAFELY data initiative beyond the pandemic[2]. The Department of Health and Social Care and NHS England leading on the establishment of a legal basis for OpenSAFELY for non-COVID-19 research have requested that there is demonstrable ongoing patient and public support.

To take this request forward, in collaboration with the OpenSAFELY Public Advisory Group (the OpenSAFELY Digital Critical Friends (DCFs)), a series of online workshops were co-designed and delivered to focus on the post-COVID existence of OpenSAFELY.

The aim was to engage in discussions with a diverse group of approximately 100-120 contributors from across England, being explicit about prioritising input from underserved communities and individuals who are often underrepresented in health research. The workshops were to be advertised publicly, via Eventbrite but also via specific recruitment channels, and designed to appeal to as many different groups of people as possible. It should be noted that the exercise was not intended to create a representative sample of the general public as this would be a duplication in efforts with the national public engagement on data programme[3].

The workshop objectives were to:

1. Understand public perceptions and feelings about OpenSAFELY, a platform for securely analysing electronic health records to support public health and research.

[1] Major investment to transform mental health treatment research and further develop secure NHS data platform (2025) https://www.phc.ox.ac.uk/news/researchers-17m-wellcome-award-mental-health-data-research?ref=image

[2] Citizens' Juries on Health Data Sharing in a Pandemic (2021) https://www.arc-gm.nihr.ac.uk/projects/Citizens-Juries-on-Health-Data-Sharing-in-a-Pandemic

[3] National public engagement on the use of health and care data https://transform.england.nhs.uk/key-tools-and-info/data-saves-lives/national-public-engagement-on-the-use-of-health-data/

2. Identify the types of data and public interest protection measures and boundaries the public community deems necessary.
3. Discover the questions and topics participants find most significant and wish to see addressed by OpenSAFELY.
4. Learn about the preferred methods and approaches for patient and public involvement and engagement (PPIE) that would make OpenSAFELY more inclusive and reflective of diverse community needs.
5. Increase awareness and understanding of OpenSAFELY and its role in advancing public health through secure and responsible data use.

Seeking feedback to meet these objectives will guide efforts to adapt and improve OpenSAFELY, ensuring it not only continues to meet the scientific and health objectives but also aligns with public expectations and ethical standards. The workshop exercise is part of a commitment alongside that of NHS England's to ongoing and recurring PPIE and to continuously understand people's perspectives and public sentiment around data sharing initiatives. This work will feed into the knowledge and insights base around the other public engagement on data activities and programmes.

This report is formed of two parts: the findings and insights and an evaluation of this first wave of workshops. The appendices are in an accompanying pack. The report will be shared with the NHS England OpenSAFELY Steering Group, OpenSAFELY Oversight Group, other external interest-holders, and made publicly available on the Bennett Institute website. The recommendations will inform a public involvement plan for the NHS England OpenSAFELY service which is created and delivered collaboratively alongside NHS England.

2. Approach: What did we do and how did we do it?

Design and methodology

The first outline of the plan was supported by the NHS England OpenSAFELY Steering Group in 2023/2024. Owing to general elections and staffing, the planning of the events resumed in Autumn 2024 when the PPIE Lead (Freddie Longfoot) joined the Bennett Institute for Applied Data Science. As some time had passed, it was important that the plan was revisited and this was done collaboratively with the DCFs through a Task and Finish approach, led by the PPIE Lead with support from John Kellas (Consultant, This Equals) and Andy Gibson (Associate Professor, UWE) who together form the Bennett Institute's *PPIE Team*.

The previously agreed objectives were deemed to still be relevant, and so time was spent designing how the workshops would run and the open questions to be asked. It was agreed that the purpose of the workshops was to gather insights and capture feedback, and as such were not designed to be deliberative to reach a consensus and would not involve polling (other than Mentimeter questions on personal attitudes) or producing statistically significant research.

An annotated agenda and facilitator briefing pack were written and shared with the delivery team.

Delivery Team

All of the workshops were attended by Freddie Longfoot and John Kellas. Facilitation was by Freddie Longfoot (who was also Compere at each workshop), John Kellas, and Andy Gibson. DCFs were invited to attend as independent co-Facilitators/observers and a rota was arranged where there were three DCFs at each session. The presentation was delivered by a member of the Bennett Institute for Applied Data Science Senior Leadership Team - either Pete Stokes (Director of Platform Development) or Ben Goldacre (Director of the Bennett Institute).

Audience

The plan was to reach a diverse audience, including those from underserved communities, to encourage different perspectives. The workshops were promoted through Clinical Research Networks (CRN) (now Research Delivery Networks), NHS-led Patient and Public Involvement and Engagement (PPIE) groups, Research Engagement Networks and Health Champions networks, NIHR People in Research, and social media. Bookings were made through Eventbrite and there was a capacity of 20 bookings per workshop. This was to ensure that there was a suitable amount of people per workshop to enable a rich discussion.

People were offered reimbursement for their participation at a rate of £50 in line with NIHR standard guidelines. People were offered this as either a bank transfer or choice of retail voucher.

Observers from within the Bennett Institute were also invited to attend. This was to provide an insight into the public perception of OpenSAFELY to people who work on and with the platform.

Delivery Format and Structure

The six workshops were held online on Zoom. They were held at different times of day and days of the week, including an evening and weekend session, through December 2024 and January 2025. This was to accommodate different schedules by offering choice to enable participants to attend at a time which was most convenient for them.

The two-hour workshops started with an informative expert presentation (an introduction to OpenSAFELY and how it works), followed by time for questions. In the later four of the six sessions, the OpenSAFELY explainer animation was played at the beginning following feedback from the first two sessions. There was an interactive Mentimeter (a web-based tool for interactive presentations, polls, and surveys), followed by facilitated breakout sessions.

The workshops enabled a space between public contributors and specialists on a level playing field with neutral facilitators supporting the discussion through a carefully designed approach. The approach involved a variety of tools and delivery styles to provide people with different mechanisms to engage (e.g. raise hand to speak, use of chat function, email contact afterwards). Notes were taken by the facilitators and shared back with all participants using the Mural web-based platform. Participants were given the opportunity to clarify and sense-check the notes and reply with any corrections.

3. Part 1: Findings and Insights Report

Questions and Clarifications Asked

The first half of the workshop involved a presentation on OpenSAFELY and how it works. Space for questions and clarifications was prioritised. Below is a selection of direct questions or concerns people posed. These covered a range of topics specific to OpenSAFELY and some topics that are applicable to the health data research ecosystem more broadly. Appendix 1 shows the full set of questions asked and comments made.

People and access

- “Can scientists, research students, charities, pharmaceutical and insurance companies access the data and do they pay equal amounts to use it? Just wondering if you have lower rates for charities and patient groups doing research”
- “If you don't agree with a company's ethos or the type of research do you have a say on if they can access your anonymised data”
- “Do researchers have to do refresher training?”

How OpenSAFELY works

- “How do you know that the fake patient data is representative of real patients so that it can be used to write useful code?”
- “How does OpenSAFELY handle potential biases in the health data it processes”
- “Are there any further controls to prevent (or route out) fraudulent users from entering into the secure platform?”
- “So am I correct in saying that OpenSAFELY is a digital platform that's administered by various organisations, not an organisation in itself?”
- “Who owns OpenSAFELY?”

Area and data source

- “Anything similar in Wales or any plans to expand Open Safely to Wales?”
- “Are there any plans to expand the remit of this platform to other parts of the UK? What kind of barriers are there to doing that?”
- “Are private diagnosis and health treatments or surgery included. For example my autism diagnosis and knee surgery were done privately.”
- “The data that OpenSAFELY sees - is it anything on your record? Or only codes? For e.g., could a researcher use an LLM/AI to verify diagnoses based on recorded symptoms/test results held in a record?”

Public involvement

- “Do you have a data access committee with members of the public on it like other data access committees do?”
- “How much patient input is there into the selection of projects, and are there any patient-led projects?”

- “Do applicants to use data on your system require PPIE involvement as a requisite to access? If not, why not?”

Opt-out, choice, and consent

- “Does the nationwide opt-out of the use of patient data also work here?”
- “How am I informed of the ability to opt-out?”
- “Are everyone's records included by default?”

Data security

- “Is data in a stable place?”
- “How is data protected from hackers?”
- “data flow and data storage. Is trust outsourced?”

Outcome and impact

- “As a patient do we have right to know where is data used and what is outcome of it? (*sic*)”
- “Do the researchers write plain English summaries of the research and newsletters for members of the public?”
- “As patient, but as researcher and clinical also, how I can *(sic)* trust results? There’s a XAI/XIAI framework to share with all “actors” of a Health Record?”

Research ecosystem

- “Does this mean there would be fewer clinical trials with this”
- “What is the difference between OS and HDR UK?”

Communications

- “Who owns the Comms campaign for it (/OpenSAFELY Platform / service etc.)”

Other links, comments, and resources were also shared in the chat, including:

- NIHR guidance and support modules for inclusive research
- 2024 Edelman Trust Barometer
- https://www.pulsetoday.co.uk/news/technology/gp-practices-thwart-nhs-england-attempts-to-prevent-removal-of-gp-connect/
- “The platform looks very positive and very secure”
- “It does feel quite secure and I like that the open code prevents hackers or bad actors doing harm”
- “With non-COVID topics, it's important that this includes physical and mental health”
- “Transparency about what it's being used for and how it has helped patients and their families Improvements that have been made to healthcare. Even research that shows that a drug or treatment does not work is valid research. Suggested a newsletter”

- “After today's session I am less likely to trust OpenSAFELY - Too much hearing of the researchers opinion - You have to let the people feel safe. Keeping bias out of the conversations”
- “There are lots of different secure data environments and it's getting very complex. I'm involved with the setting up of the East of England Secure data environment.”
- “I often feel with health research there is a disconnect between doing the research and then seeing any actual benefits for everyone rather than just a few. If nothing feels like it has changed and improved in the NHS, then I feel a bit disheartened about the research and sharing my data”

Reflections and recommendation:

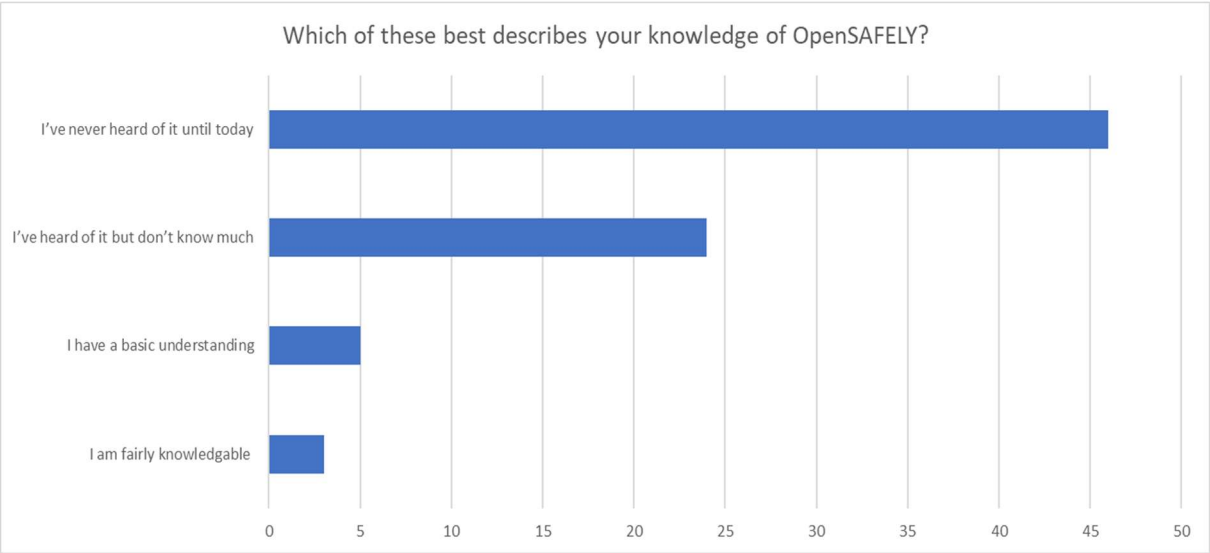
The main purpose of the presentation and time for questions was to provide participants with information about OpenSAFELY to enable them to enter the later discussions. The questions are however useful for all OpenSAFELY interest-holders, as it offers a view into the level of understanding and areas of interest about electronic health record research from the public. These questions and comments can inform building a communications plan with the goal of ensuring that the general public know what OpenSAFELY is and understand how it works from the materials created.

Recommendation	1	The Bennett Institute and NHS England to develop public-facing material to be available in different formats and use the representative question set to inform a communications and PPIE plan.

Mentimeter Interactive Survey

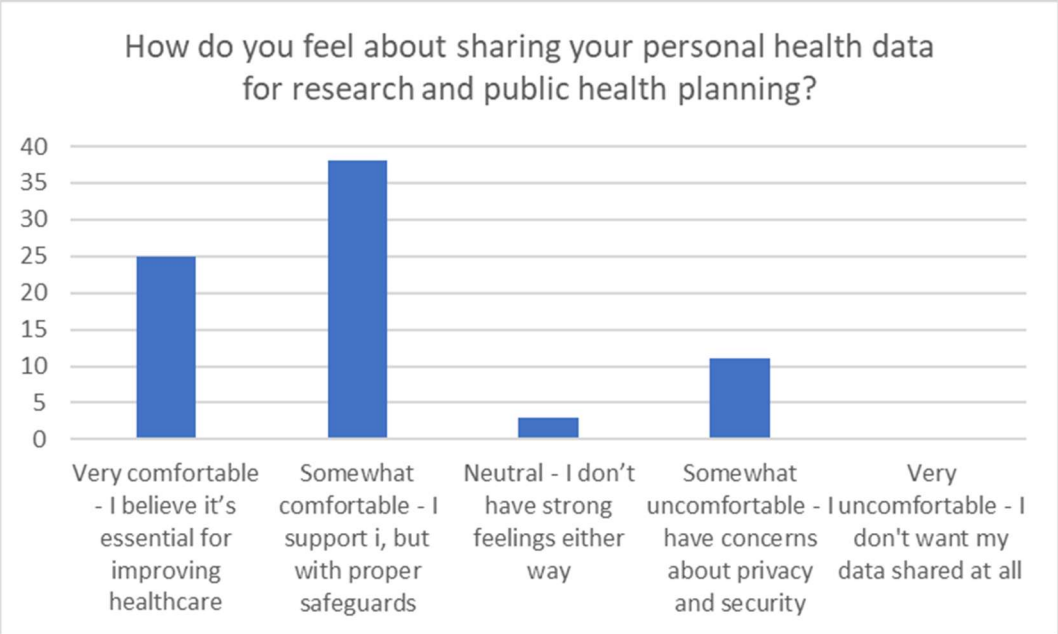
Over the course of the six workshops, 76 participants were able to connect to the Mentimeter interactive survey. Not everyone who attended was able to connect to Mentimeter. The survey involved four questions:

1. **Which of these best describes your knowledge of OpenSAFELY?**



2. **What stands out to you about OpenSAFELY?** (shown as a combined word cloud - individual session results are in Appendix 2)

3. **How do you feel about sharing your personal health data for research and public health planning?**



4. **What is most important to you when it comes to how your health data is used?** (in the first four sessions, this was asked as a multiple choice question. In the later two sessions, this was asked as a free text response)

Item	Count
Data privacy and security	31
Improved health outcomes	20
Transparency and public oversight	16
Ethical use of data	13
Trust in the institutions using the data	12
Fair and equal access to healthcare	12

Reflections and recommendation:

The main purpose of the Mentimeter survey was to initiate the discussion with an engaging question and interactivity and determine the existing knowledge/perspectives of the attendees. Some participants elaborated on their responses in the subsequent discussions. These insights can inform the communications plan and future public involvement activities to reach a greater diversity of attitudes towards data sharing.

Recommendation	2	PPIE Team to design public involvement activities to include more people who are uncomfortable with sharing their data.

Breakout Discussion Room Feedback and Findings

The breakout room discussion was focused on the following:

OpenSAFELY has been used to analyse health data for conditions like COVID-19, but in 2025 it could be applied to many other health issues.

- What would make you feel more confident sharing your health data for research?
- Imagine you were in charge of OpenSAFELY: What would you change or implement?

Notes from each of the six workshop discussion rooms have been compiled together and shown below. The following section details the insights derived supported by anonymised quotes (shown using quotation marks) from workshop participants to illustrate findings.

The full data can be in Appendix 3.

Communications, awareness and visibility to build trust and confidence

- **People want to know about OpenSAFELY**. Many individuals had never heard of OpenSAFELY before, and said that they would feel more confident sharing their health data if they knew more about ways in which it is processed and used.
- **Accessible communications** in different formats (including online and offline) and languages to be accessible to a range of people were suggested.
- **Newsletter or "progress updates"**: People suggested regular communications about OpenSAFELY and ongoing or completed research.
- **Show who is behind OpenSAFELY, including NHS England**. Knowing the individuals and organisations involved (and their ethos) on an easy-to-find website. Emphasise that this is an NHS programme to reassure people about who commissions and directs the NHS OpenSAFELY Data Analytics Service (GP data).
- **Public outreach and engagement through GP surgeries & community organisations.** People would trust and learn more if OpenSAFELY were promoted via healthcare touchpoints or people they knew (e.g. posters, leaflets, short videos in waiting areas, or via Healthwatch).
- **Plain-English information should be available** that addresses repeated questions and concerns (opt-out, privacy, data usage, safety processes).

Practical ideas from participants:

- **Communication and marketing strategy**
    - "Marketing and communication strategy to raise awareness of OS"
    - "Information and resources in different languages and accessible formats"
    - "Bringing this platform to life, needs more promotions and information on what's happening with our data to the wider population"
- **Inclusive public and community engagement and feedback**

- “Introduce a feedback mechanism” "That would be useful - then we can ask lots more questions..... maybe a website with an FAQ section"
- “I would prioritise increasing community engagement to ensure the platform better represents the needs of underserved and diverse groups, particularly those from cultural, racial, and neurodivergent backgrounds. This would include actively seeking input from these communities on how their health data is used in research, ensuring that the platform is responsive to their concerns and priorities. Furthermore, I would introduce accessible feedback mechanisms so that users could share concerns, ensuring that the platform evolves to meet the needs of the public.”

Reflections and recommendations:

From this feedback it is clear there is value in creating and improving materials about OpenSAFELY so that they are more accessible to a general public audience. People wanted to know about OpenSAFELY and its features in a way that is understood, and leaned towards the benefit of trusted voices in communities to support the engagement as well as having feedback mechanisms to share views on OpenSAFELY.

Recommendation	3	The Bennett Institute and NHS England to create a communication strategy and plan for OpenSAFELY that is shaped by patients and the public to determine the messages to ensure content is understandable by the general public.
Recommendation	4	The Bennett Institute to introduce a feedback and engagement mechanism on the website for people to connect and ask questions.

Conditions and safeguards for data security and privacy

- **Data security measures**: People wanted to know there were robust safeguards to ensure data was safe from hacking or a breach, and how the data is safe (inc. within GP system suppliers).
- **More transparency about data flows**, and about specifically what data is held / shared and used.
- **Where there are rare or unique patient groups**, there were some concerns about small populations or unusual medication potentially being re-identifiable.
- **Detailed explanation of “the five safes”**: People appreciate simplified, plain-English explanations of how Secure Data Environments work, and how this would inform choice to opt-out.
- **People wanted to know who can access the data** (pharma, insurance companies, etc.) and on what terms (e.g. a charging structure).
- **Output checking:** Put another layer of supervision in the output checking (check the check).

Practical ideas from participants:

- None

Reflections and recommendation:

When described and explained in the session, people generally found OpenSAFELY's features sufficient. The conditions of data access seemed very sensible and reassuring to participants. The suggestions were to build on or strengthen these, and explain how these features work to a general audience (see also *section 3.3.1*). Specific topics on access and usage could benefit from focused deliberative sessions with the public. There should be disambiguation with other Secure Data Environments (SDEs) and their features.

Recommendation	5	PPIE Team to continue involving the public to inform the development of policies or governance practices relating to uses of data in health research, such as data security and privacy conditions and safeguards.

Research purpose, outcomes, and impact for public benefit

- **Explain Electronic Health Record (EHR) research and how data is used.** Simply knowing how EHR are being used for research and planning will increase confidence.
- **Show what the data contributed to** as people want updates on how their data is actually used and how findings are acted upon. Some worry about purely commercial interests or government research that is never published.
- **Plain-English summaries** to share methods and results in a non-technical, accessible way (including easy-read versions, newsletters, or short videos) were suggested.
- **Ensuring research is for public benefit** and knowing that data is being used to effectively determine need, address deprivation and inequalities.
- **Demonstrating impact beyond papers**, and showing real-world changes in health policy or service delivery.
- **Knowing who the researchers are and which organisations are involved,** including what makes a trusted researcher, research/researcher inclusivity, and knowledge about researchers - and assurance that researchers undertake anti bias researcher training will increase confidence.

Practical ideas from participants:

- **A public-friendly space showing ongoing studies, their stage, preliminary findings, final outputs, and impact**
    - "Privacy protection and a transparency about regular updates on the research findings or maybe an outcome of what my data contributed to".
    - "What if there was a gradual start where a small number of small studies were selected to start with and those were shared with the public so we can see it live - if we got fed back the progress it would be good"
    - "Sharing outcomes and positive stories - ensure there are easy-read versions and co-create these with members of the public"
- "KPI's to prove that OS helping the public"

- "Prioritise / support research that 1) links with more rich data - and 2) that joins with live patient involvement"

Reflections and recommendations:

Participants generally felt there should be a raised awareness about how electronic health records were used in health research and planning and its benefits as this information isn't widely known. Generally people were supportive of this providing that there is clear public benefit, and what the data has contributed to is shown. These topics should be covered in the communications plan.

Recommendation	6	PPIE Team to share feedback and findings that it isn't widely known that electronic health records are used in health research and planning to NHS England and Department of Health and Social Care and into the knowledge and insights base around the other public engagement on data activities and programmes.
Recommendation	7	The Bennett Institute to explore what a public-friendly online space showing ongoing studies, their stage, preliminary findings, final outputs, and impact would look like. This could include: • Public-friendly explanatory content on electronic health record research and intended public benefit. • Build in a requirement that researchers share a summary of results and study impact.

Meaningful and recurring Patient and Public Involvement (PPI) and co-production

- **Invite research ideas that are patient-led or patient-informed**. People want a role in shaping research priorities and project approvals.
- **Public involvement in governance.** Having lay members or patient representatives in the governance structure and data access committees builds trust.
- **Independent Citizens' Juries or trust audits**. People supported re-running or expanding exercises like Citizen Juries to gauge ongoing trust and shape future policies.
- **Ensuring diversity** of PPIE activities so that they include underserved or minority communities, and reach people with long-term health conditions as well as the general public.
- **Different languages and accessible formats** to ensure information is suitable for those with lower literacy or for those who are visually/hearing impaired (also mentioned in section 3.3.1).

Practical ideas from participants:

- **Public involvement in decision making**
    - "Project application process to have public involvement"

    - “The application process involving members of the public - however it is important that there is diversity in this involvement and that the voices of communities are reflected”
    - “Focus groups and discussion based on the research question at the application stage”
- **Dedicated “Ideas for Research” Page**
    - "As a starting point, maybe you could add an "Ideas for research" section to your website for anyone to suggest research topics / questions- with a caveat that, although the suggestions can be shared with academia for consideration, no guarantees can be given that the research can be carried out (e.g. because of funding issues)."... "If possible to have a ‘vote’ feature, even better."
- **Sharing information about OpenSAFELY Patient and Public Involvement (PPI)**
    - “Make the PPI policy transparency (sic). (I) Would like to know how PPI involved. Simple image.”
    - “Workshop delivery to include research impact and seeking knowledge and needs beforehand”
- **Re-run Citizens’ Juries or other public consultations to gauge trust**
    - “Carry out a trust audit (or somehow ask members of the public if they trust/support OpenSAFELY and other types of Secure Data Environment / Trusted Research Environment e.g. re-run the Citizens Juries)”

Reflections and recommendations:

Participants shared a number of examples of where there could be public involvement in the design, delivery, and monitoring of OpenSAFELY and associated research. Some of these examples are in scope of OpenSAFELY operations to explore, whereas others would need to be independently organised for integrity (e.g the Citizen Juries).

Recommendation	8	The Bennett Institute to work with NHS England to ensure the public voice to be heard in the development of and contribution to the decision making/approval of applications made to the service.
Recommendation	9	The Bennett Institute to create a “Public Involvement” space on the OpenSAFELY website to house information about OpenSAFELY PPI, such as the role of the Digital Critical Friends, upcoming opportunities, links to other initiatives and groups, and a forum for ideas.
Recommendation	10	NHS England and the Bennett Institute to continue to engage with the public to continually understand levels of trust and sentiment towards an OpenSAFELY model.

Opt-out, opt-in and ongoing choice

- **Better communication about the Type 1 and national data opt-out** was suggested. People tended not to be aware of this or do not recall how or when they were informed.
- **Future changes in policy** and communication about this in relation to opting out. There was some concern that if the data-sharing model changes (e.g., sold to third parties), then prior "consent" might no longer apply. People want reassurance that if terms change, they can withdraw or reconsider consent.
- **Granular consent**: Some would like to indicate specific health areas or purposes they approve (or disapprove) for data use.
- **Children's data and mental capacity** and opt-outs. Clarify how data from minors and those lacking capacity is handled responsibly and ethically.

Practical ideas from participants:

- **Better communication about the ability to opt-out**:
    - "More information on opt-out policy should be available on website"
    - "Better communications about the opt-out policy"
- **Consent: having the option to say what my data should be used for**
    - "Higher commitment to communicating any policy changes about who data is shared with so I could change whether I give consent or not. There is an information gap currently"

Reflections and recommendation:

While the workshops were focused on OpenSAFELY, the discussions covered wider system issues on opt-out and across the groups people raised the importance of widespread awareness and transparency around the opt-out.

Recommendation	11	PPIE Team to report feelings about opt-out and dissatisfaction with knowledge about opt-out to NHS England and the Department of Health and Social Care into the knowledge and insights base around the other public engagement on data activities and programmes.
Recommendation	12	The Bennett Institute to add details about the ability to opt-out onto the OpenSAFELY website.

Data completeness, quality, and accuracy

- **Accuracy of data entry** is important as there were concerns that if clinical coding is poor (e.g., mis-coded diagnoses, missing comorbidities), it undermines research quality.
- **Bias and representativeness**: People wanted to know that research using OpenSAFELY acknowledges and addresses potential bias (such as opt-out bias or incomplete coding of certain conditions).

- **Having the ability to correct personal records** as some worry about personal harm if inaccurate data were ever leaked, so they want opportunities to check or correct their records.
- **Having knowledge of the diversity of dataset and linkages** and how it is inclusive of the majority of the population will increase confidence.

Practical ideas from participants:

- "Reassurance about data accuracy, and opportunity to check health records for accuracy, and change if not accurate"
- "Work with GPs/clinical coders to improve data accuracy."

Reflections and recommendation:

People would feel more confident in sharing their data for health research and planning if they had greater confidence in the accuracy of the underlying data.

Recommendation	13	PPIE Team with support from Bennett Institute and NHS England to communicate findings about data completeness, quality, and accuracy in OpenSAFELY to external interest-holders and connect into other insights gathering and public engagement exercises.

Governance, ethics, and oversight

- **Project vetting** and visibility of how proposals are assessed, who is on the panel, and whether there's a requirement for public/patient involvement (see section 3.3.4)
- **Quality control** of the peer reviewers
- **Ethical oversight**: People want reassurance that each project is ethically and methodologically sound.
- **Publishing all results** for transparency (see section 3.3.3).

Practical ideas from participants:

- **Provide information about governance and ownership**
    - "Images of the icons of companies and groups involved and links to the NHS"
    - "Data Protection Act - do you adhere to this? This needs to be shown / referenced"
- "Assurance of ethics board to review proposal"

Reflections and recommendation:

When described and explained in the session, people generally found OpenSAFELY's features sufficient. Increased peer review of findings was important to participants and was felt to be part of standard practice, however the suggestions were to build on or strengthen these, and explain how these features work to a general audience. Specific

topics on access and usage warrant focused deliberative sessions with the external interest-holders including the public and professionals.

Feedback addressed by **recommendation 5.**

4. Part 2: Evaluation Report

After each workshop, participants were asked to fill out a feedback survey. The purpose of this form is to collect anonymous information about the type of people who take part in our involvement events. This will help us design and deliver more inclusive events in the future.

The survey received 90 responses, and 90 people have claimed reimbursement for their time in a combination of bank transfer and vouchers (totalling £4,500). Some people informed us beforehand that they were no longer able to attend and there were some drop-outs on the day.

Feedback Survey - Demographic Information

From the post-event forms (n=90), we know that:

- The majority of participants heard about the workshops through NIHR People in Research, then through word of mouth, email or social media. Few people had heard of the opportunity through their Research Delivery Network.
- There was a mix of the reasons people chose to register for the event, with the most popular reason being to learn about OpenSAFELY. This was closely followed by people wanting to share their views on OpenSAFELY and contribute feedback. People also wanted to share their views on public involvement.
- Overall, the average rating of the event was 4.49 out of 5 stars.
- 61% of participants were female, 36% were male, and others preferred to self-describe or not to say.
- There was a good spread of age ranges represented across the six sessions, with the exception of people aged 75 and older who weren't represented. The least represented age group was 18-24.
- There was a good range of ethnicities represented across the six sessions, with the White group being the most represented (31), followed by Asian or Asian British (25), Black, African, Caribbean or Black British (17), and Mixed (14).
- 51% of people did not have any long-term health condition and 44% did. 5% preferred not to say.
- Each of the nine categories of region in England were represented. Most people joined from Greater London (34) and only one person joined from Yorkshire and the Humber.
- The majority of people had a Bachelors Degree (42) or Masters Degree (25) and 5 with a Doctorate. There was one person with no formal education, 7 high school, and 4 with vocational training.
- Most people's current occupational status was working (51). 10 people were retired, 6 were students, 2 looking after home or family, 6 unable to work, and 3 unemployed.

All data can be viewed in Appendix 4.

Respondents were also asked to consent to sharing their email address for future communications about involvement activities organised by the Bennett Institute. 88 selected "Yes".

Feedback Survey - Qualitative Feedback

The feedback included:

- **85 points** about what people liked about the workshop.
- **30 points** about what people didn't like or would change.

This indicates much more positive feedback, with fewer suggestions for improvement. All feedback is included in Appendix 5.

When asked what they liked about the event, people commented on the following and example quotes are shown below:

Structure and organisation

- "Well structured - informative speakers"
- "Very well spaced and timed and the right amount of information - many of these events try to cram too much in"
- "I like how the session was organized and how everyone where give opportunities to contribute to the discussion"

Informative content

- "I learnt alot about opensafely. How it's already impacting in the public domain. Beening able to lend my voice and sharing my opinion. Very interesting and do much was covered".
- "Very informative, well planned out and I was kept engaged throughout"
- "Clear information and feedback to questions asked"

Engagement and interactivity

- "Chance to learn about opensafely and its benefits, as well as the chance to share my views about how it is used and how it could be more widespread. I liked that the event was multimedia, mix of presentations, videos, big and small group discussions and visual slides."
- "I like the presentation, it has an engaging content, and how the facilitator managed the event"
- "I like the interactive features like the polls and Q&A and using the chats function."

Transparency and accessibility

- "The comfortability of engaging in a way that's convenient for people and the knowledge about data privacy"
- "Fair and transparency in treating participants with respect and dignity"
- "It was very inclusive, accessible with good time given to discuss and debate key points of learning."

Professionalism and atmosphere

- “I like the coordination of the session, the hosts were friendly and it was a safe place to learn.”
- “Inclusive, I felt that I could use chat without being judged”
- “I like the slides that were presented, it was very impactful and I like how the host explain the informations on it and the session was a safe place for everyone to contribute and participate.”
- “It was very opened and expressive and felt ease when speaking to each other participants.”

Impact

- “Well organized and the staff involved were very approachable and informative. It felt like a genuine opportunity to hear the voice of patients.”
- “I like the conversations about OpenSAFELY and the zoom meeting was a safe place for people to share their perspectives in a comfortable and flexible way”
- “One of the better public involvements I have been involved in!”

When asked about what they didn’t like or would change, people said the following:

Time allocation

- “Needed to be longer for more discussion”
- “It was just a shame that the session wasn’t longer. :)”
- “Maybe a longer session, as so much to go through.”

Presentation and technical content delivery

- “There was too much information in short presentation. This information was not easy to understand for non-academics and professionals.”
- “Initial presentation and background information (briefing) was very complex and was very difficult to understand even for me who has worked with OpenSAFELY for the past few years. If I heard this information for the 1st time than I would have switched off and not allow my personal data to be used. I would recommend this initial briefing (presentation) is much simplified and slowed in the delivery of information. Less information is better than too much information”
- “It was too technical and required prior knowledge to obtain full understanding, that was fine for me and my programming background, but not for others.”
- I think the PowerPoint slides should have been kept up for the duration of the meeting to ensure it flowed better and people could continue reading

Accessibility and preparation

- “Receiving the slides before to share an overview and purpose/expectations”
- “Do not use things like mural my computer will not let me”
- “I didn't like that some people had their cameras switched off/some technical issue prevented them to switch them on, so I couldn't see their faces”

Breakout rooms and discussion

- "Too many attendees so difficult to effectively contribute"
- "In the breakout rooms and the host seemed to ignore some of the more challenging with peoples concerns and only focused on the positive feedback."
- "Discussion and feedback was too unstructured, breakout groups were too big so not a chance for everyone to share"

Content and format suggestions

- "What I would change: include anonymised case studies of how opensafely has benefited researchers, GPs, other community groups that have used it, perhaps doing a little interview with such a person or community? Again this would help give more context and inspire more confidence in it"
- "may be more interaction through other strategies"
- "Being careful to shape conversation around things OPEN safely can do/change and not wider research terms like sharing data. Open safely is just the software. I also think you need to ensure the people conducting focus groups with people understand the general public and how to speak to them. Researchers didn't."
- "There was too much time taken to respond to the technical questions, coding and stuff beyond my understanding. Would be better to respond to some of these individually"
- "Assurance of ethics board to review proposal"

Reflections and recommendations:

The feedback forms provide us with a wealth of information to understand the audience we reached and insights as to how we can tailor PPIE future activities and improve content and delivery. We reached people from a range of identities and backgrounds, however there are some voices missing from this round of workshops. The majority of people who joined heard about the event through NIHR People in Research. While this is a good channel for promoting the workshops and was a planned choice, the audience of these workshops perhaps do not reflect a more general public audience which needs to be considered in future PPIE.

Recommendation	14	PPIE Team to use feedback survey findings to inform the planning for the second wave of workshops, including: ● Targeted workshops to reach those who are less represented (including low-trust groups as shown from Mentimeter) ● Adapt the feedback survey to ensure that questions on demographics are inclusive of a broader range of options for people to identify with and select. ● Tailor the presentation to a general audience and test this with public reviewers before the workshop.
Recommendation	15	PPIE Team to explore how a "Critical Friends of OpenSAFELY" Network can be established to involve and engage people who have consented to future contact.

5. Reflections and Learning

A summary of the reflections from the DCF and PPIE Team are shown in the table below. The complete set of feedback is in Appendix 6.

What went well?	● Good attendance and a good mix of demographics, experience, and knowledge. ● Participants were very engaged and there were lots of questions and topics discussed. ● Well-facilitated discussions and the focus was maintained. ● Regular co-design and feedback sessions with the DCFs allowed for learning in realtime to adapt and improve following sessions.
What could we do better?	● Have a better geographic and age spread. ● Provide more links to information for people to access in their own time. ● Slow the pace of the presentation and technical content.
What could we do next time?	● Factor in dropouts and increase the event capacity to maximise reach. ● Ensure the presentations are pitched at the right level for the audience, and consider how the audience makeup can impact engagement. The presentations would benefit from being shared/practiced with a test audience. ● Ensure the promotional material fully explains the session aims.

6. Summary of Recommendations

The complete set of recommendations from all of the report sections is below, with responsibility for each recommendation shown.

Recommendations for the Bennett Institute and NHS England

Recommendation	1	The Bennett Institute and NHS England to develop public-facing material to be available in different formats and use the representative question set to inform a communications and PPIE plan.
Recommendation	3	The Bennett Institute and NHS England to create a communication strategy and plan for OpenSAFELY that is shaped by patients and the public to determine the messages to ensure content is understandable by the general public.
Recommendation	8	The Bennett Institute to work with NHS England to ensure the public voice to be heard in the development of and contribution to the decision making/approval of applications made to the service.
Recommendation	10	NHS England and the Bennett Institute to continue to engage with the public to continually understand levels of trust and sentiment towards an OpenSAFELY model.

Recommendations for the Bennett Institute

Recommendation	4	Bennett Institute to introduce a feedback and engagement mechanism on the website for people to connect and ask questions.
Recommendation	7	Bennett Institute to explore what a public-friendly online space showing ongoing studies, their stage, preliminary findings, final outputs, and impact would look like. This could include: ● Public-friendly explanatory content on electronic health record research and intended public benefit. ● Build in a requirement that researchers share a summary of results and study impact.
Recommendation	12	The Bennett Institute to add details about the ability to opt-out onto the OpenSAFELY website.

Recommendations for the OpenSAFELY PPIE Team (includes Bennett Institute, public contributors, consultants and NHSE)

Recommendation	2	PPIE Team to design public involvement activities to include more people who are uncomfortable with sharing their data.
Recommendation	5	PPIE Team to continue involving the public to inform the development of policies or governance practices relating to uses of data in health research, such as data security and privacy conditions and safeguards.

Recommendation	6	PPIE Team to share feedback and findings that it isn't widely known that electronic health records are used in health research and planning to NHS England and Department of Health and Social Care and into the knowledge and insights base around the other public engagement on data activities and programmes.
Recommendation	11	PPIE Team to report feelings about opt-out and dissatisfaction with knowledge about opt-out to NHS England and the Department of Health and Social Care into the knowledge and insights base around the other public engagement on data activities and programmes.
Recommendation	13	PPIE Team, with support from Bennett Institute and NHS England, to communicate findings about data completeness, quality, and accuracy in OpenSAFELY to external interest-holders and connect into other insights gathering and public engagement exercises.
Recommendation	14	PPIE Team to use feedback survey findings to inform the planning for the second wave of workshops, including: ● Targeted workshops to reach those who are less represented (including low-trust groups as shown from Mentimeter) ● Adapt the feedback survey to ensure that questions on demographics are inclusive of a broader range of options for people to identify with and select. ● Tailor the presentation to a general audience and test this with public reviewers before the workshop.
Recommendation	15	PPIE Team to explore how a "Critical Friends of OpenSAFELY" Network can be established to involve and engage people who have consented to future contact.

7. Conclusion and What's Next

The first wave of public involvement workshops have provided us with important feedback and insights from patients and the public into the future of OpenSAFELY. The objectives we set out to achieve involved understanding public perceptions, identifying what topics and conditions/safeguards are important to people, learning about preferred PPIE approaches, and to increase awareness of OpenSAFELY. We met these objectives by gathering feedback on each of these from the range of activities in each of the workshops and by doing so we entered a valuable dialogue with interest-holders which we plan to sustain.

Taking into account the questions asked alongside the discussion room points from participants provides us with an understanding of public perceptions and an idea of what will aid people's understanding of OpenSAFELY and in turn increase confidence through a greater understanding of what OpenSAFELY is and how it works. It is clear from the questions, discussion, and feedback that the pitch and accessibility of the information about OpenSAFELY is not suitable for a general public audience. Indeed, clear communications about all aspects of OpenSAFELY and the wider health data research ecosystem (such as opt-out choices) were a common theme. This provides a focus for the communications and engagement aspects of the PPIE plan.

When described and explained in the session, people generally found OpenSAFELY's features sufficient. The conditions/safeguards of data access seemed very sensible and reassuring to participants. There are topics to be explored in greater detail with the public, such as public involvement in governance. There are also practical suggestions which we can take forward, such as improvements to communications such as a newsletter and building on the engaged cohort and establishing a network.

The feedback form has shown us that we reached a diverse range of audiences, however we could be doing more to hear from younger people (aged 18-24) and older people (74+) and more active promotion and delivery of workshops to audiences in the North East and Yorkshire. The Mentimeter also showed that most people were comfortable or had neutral feelings towards sharing their data. Fewer participants said they were uncomfortable sharing their data and nobody said they were very uncomfortable. While not all participants were able to connect to Mentimeter and submit a response, there would be value in designing future workshops to reach more people who are very uncomfortable with sharing their data for health research and planning.

The findings and recommendations throughout this report can be used to shape the future of OpenSAFELY. As such, a plan for ongoing PPIE will be developed through discussion with the DCFs, PPIE Team, OpenSAFELY interest-holders, and this feedback from the public workshops.