Public attitudes to Clinical trials re-identification

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This briefing note summarises consolidated insights on public attitudes towards the de-identification and re-identification of patient data within NHS Secure Data Environments.

It draws specifically from engagement work undertaken by the Wessex Secure Data Environment, including the recommendations of the Wessex Public Panel on NHS Data and findings from the Wessex Seldom-Heard Groups engagement. This work directly tackled the issue of clinical trials. It also includes insights from national deliberative dialogues and stakeholder engagement initiatives led by NHS England: the NHSE National Engagement on Data Cohort 1 (final report) and Cohort 2 (draft report).

The insights gathered here reflect a robust sample and diverse range of perspectives, ensuring comprehensive understanding of public expectations and concerns about patient data handling. As a further caution, insights from these studies require a degree of cross-reference and interpretation in order to understand their specific relevance to clinical trials discovery. We are not aware of a specific and detailed piece of dedicated PPIE work solely on this topic and a precautionary approach should therefore be taken.

Overview

Public engagement consistently shows that when individuals fully explore the potential benefits of patient re-identification – such as identifying candidates for clinical trials or delivering timely emergency care – they often conclude it can be acceptable, provided very clear public benefits are demonstrated.

But some caution is required. Without the time to consider the topic in detail, there is a great deal more uncertainty, concern, and opposition among the wider public. This is especially the case in marginalised groups or those with a history of poor or traumatic experiences with the NHS or public services more broadly.

Where there is acceptance, as articulated by the Wessex Public Panel on NHS Data, this is conditional on re-identification occurring only via patients' own clinical care teams, who (it is strongly implied) understand the research and its potential benefits and carefully consider patient circumstances before contact.

Participants from NHSE national engagements emphasise that strict safeguards, transparent processes, and independent audits are crucial for public trust. This must be the established, widely understood, and supported backdrop against which conversations about clinical trials discovery happen. We draw the inference that the public also expects clear senior oversight –

ideally NHS and clinically-linked – to manage the re-identification process within the SDE, distinctly separated from researchers themselves.

Additional, stringent safeguards are necessary for vulnerable or underrepresented groups, who have heightened sensitivity around potential misuse of their data.

Specific insights

1. **Re-identification must be rare and justified by public benefit**

   The Wessex Public Panel on NHS Data concluded that re-identification should only occur in rare cases where there is a clear, direct public or patient benefit – such as clinical trial opportunities or urgent care – and must involve oversight by the patient's clinical care team. This position was reached after participants had time to explore specific use cases and benefits in detail.

2. **Trust depends on robust privacy and security**

   Both National Cohort 1 and 2 studies identified the need for more clinical trials but did not address the process of discovering them. Their findings illustrate the importance of establishing in the public consciousness that SDE data security and privacy is robust before publicly discussing re-identification.

   The NHSE National Engagement on Data Cohort 1 Final Report showed strong opposition to any risk of data re-identification. Participants insisted that research data should be anonymised or pseudonymised to prevent re-identification. They were concerned about being contacted unexpectedly without consent, even for population health management purposes.

   Similarly, the NHSE National Engagement on Data Cohort 2 Draft Report says that public trust is highly contingent upon robust measures being in place to prevent the re-identification of patient data, with explicit reassurance required around safeguards and processes.

3. **Re-identification requires transparency, accountability and sanctions**

   Both national and regional public engagement reports stress the need for transparency in how data is managed, with audit trails, clear decision-making processes – and significant enforceable sanctions for misuse. Participants want visible consequences for negligent or inappropriate re-identification.

4. **Seldom-heard groups have heightened privacy concerns**

   The Wessex SDE Seldom-Heard Groups engagement established that groups with experiences of marginalisation or discrimination, including ethnic minorities, domestic abuse survivors, and individuals with justice system interactions, have heightened sensitivity and concerns regarding re-identification. They emphasised rigorous data protection practices to

avoid serious personal repercussions from any breach. A quote from the NHSE Cohort 2 draft report further illustrates this point:

"I think there are some really murky details [when it comes to secondary uses of GP patient record data]. For example, deanonymisation when it comes to piecing together data. Like if you're the only patient in your area who is trans and has a specific long term health condition, you could search that and maybe that person has discussed their condition online or something."

Transgender person, workshop

5. **Clear public benefit is essential to public support**

   The Wessex Public Panel emphasised that re-identification is only acceptable when there is a clear and measurable public or patient benefit – such as improving health outcomes or reducing inequalities. This aligns with national findings showing higher comfort levels when the benefits are concrete and well communicated.

6. **Public reluctance to involve GPs in re-identification for research**

   The NHSE Cohort 2 draft report shows that participants support moving decisions about data use away from individual GPs towards independent, expert-led bodies (e.g. similar to DACs). While GP representation is valued, the public sees GPs' primary role as delivering care – not managing research access or contacting patients. Any such involvement must be justified by strong public benefit.

7. **Third-party access heightens sensitivity around re-identification**

   The public has heightened concerns about research involving by non-NHS organisations. Participants were concerned about organisations putting profit ahead of patient care, contrasting this with the motivations they expect of the NHS. This will be amplified in cases where re-identification is occurring. The NHSE Cohort 1 deliberation showed concerns about even anonymised data being shared with third parties outside of the NHS. They called for strict controls, transparency, and guarantees that any access serves the public good – not commercial gain.