

Informing the Nation: Evidence on Sensitive Data Use

*Insights from The Sensitive Evidence
Tracking Working Group*





Foreword

Sensitive data are gathered whenever people interact with public systems and services. Because these data are routinely collected, longitudinal, and increasingly linkable, they offer enormous potential to deepen our understanding of people's experiences across the life course. They can help us identify who in society is most vulnerable, what those individuals and communities are experiencing, where vulnerabilities are concentrated, and when they emerge.

Across the UK, significant investment has been made in improving access to sensitive data. We now have stronger infrastructure, better data linkage, and increasing sophisticated analytic methods. The assumption is straightforward: better use of data will generate high-quality evidence and lead to better policies, services, and outcomes

But do we actually know that this happens in practice? Who uses the evidence? How is it used? What makes it useful? And what prevents it from making a difference? We know far less about these questions than we do about producing the evidence itself. Addressing this gap was the motivation for establishing the Sensitive Evidence Tracking (SET) Working Group.

The SET Working Group was established to understand how evidence generated from sensitive data is accessed, interpreted, translated, and used by stakeholders across different sectors. To provide a clear focus, we examined attention deficit hyperactivity disorder (ADHD) among young people in Northern Ireland.

This report, however, is not primarily about ADHD. It is about how sectors and organisations concerned with a shared societal issue engage with and use evidence generated from sensitive data. ADHD provides the context through which we can examine the wider journey from data to evidence, and from evidence to action.



Foreword

This report is dedicated to colleagues working with sensitive data across England, Scotland, and Wales. We share our findings from Northern Ireland and invite you to consider how they resonate within your own context. Access to and linkage of sensitive data are not equal across the four UK nations, and differences in infrastructure, governance, capacity, and institutional relationships will inevitably shape how evidence is generated and used. Nevertheless, the central challenge is one we share: ensuring that the evidence produced through sensitive data research reaches the people who need it, is presented in ways they can use, and is capable of contributing to meaningful change. We hope this report encourages further reflection, dialogue, and collaboration across the UK as we work to understand—and strengthen—the path from sensitive data to public benefit.

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1. Background

Sensitive data are collected for administrative, rather than research, purposes whenever people interact with public systems and services, including healthcare, education, employment, justice, and social welfare. These data have become increasingly important for understanding and addressing complex societal issues such as climate change (Ford et al., 2016), mental health (e.g., Hoagwood et al., 2016), migration and immigration (Ernsten et al., 2018; Haan & McDonald, 2018), global pandemics (Chow et al., 2025), and gender inequality (Richards et al., 2022).

Compared with other data sources, these data offer several important advantages: broad population coverage; the inclusion of vulnerable groups who may be underrepresented in research studies; the ability to examine small subgroups and rare events; greater statistical power for advanced analyses; and the capacity to study longitudinal processes, social change, and the effects of policies and programmes over time (Connelly et al., 2016). For these reasons, sensitive data can help identify *who* in society is most vulnerable, *what* those individuals and communities are experiencing, *where* vulnerabilities are concentrated, and *when* they emerge.

Across the UK, substantial investment has been made through initiatives such as DARE UK, ADR UK, and HDR UK to strengthen the UK's sensitive data research ecosystem. Collectively, these initiatives seek to improve secure access to linked data, develop trusted research infrastructure and analytical capability, and enable research that informs policy, improves public services, and delivers public benefit. The potential

value of such investment is considerable: an independent economic evaluation of ADR UK estimated a benefit-cost ratio of 5.05, equivalent to just over £5 in benefits for every £1 spent on the programme (Kendall et al., 2024).

Underlying these initiatives is the expectation that investment in the sensitive data ecosystem will enable researchers to generate world-leading evidence with the potential to transform lives. However, the gap between research and practice is widely established (Dwivedi et al., 2024; Mohajerzad et al., 2021), and research using sensitive data may not be an exception to this. At present, we know relatively little about what happens to this evidence after it is generated. Who uses it, and for what purposes? Why is some evidence used while other evidence is not? What barriers do stakeholders encounter? What works, what does not, and what needs to change for research using sensitive data to achieve meaningful impact?

Addressing these questions is especially important for sensitive data research where public funding, public data, public trust, social license, and public value of the data remain important conditions of access and linkage (Greenhalgh et al., 2016; Paprica et al., 2019). In the absence of such understanding, there is a risk that research conducted using sensitive data will be misaligned with the needs of those best placed to interpret and apply the evidence. These include policymakers, service providers, public bodies, practitioners, voluntary and community social enterprise (VCSE) organisations, funders, and advocates.



Many of these stakeholders work directly with affected populations, have first-hand insight into the challenges they face, and are well positioned to use evidence to inform meaningful change. The importance of engaging with evidence users is increasingly recognised. For example, a recent study argued with *“VCSEs should be at the centre of research endeavours because they are uniquely placed to identify critical evidence gaps and to realise the full potential of research findings through improved resource allocation and ability to tailor and target services”* (Spikol et al., 2026, p.2). While this observation relates specifically to VCSEs, it reflects a broader principle: research is more likely to generate meaningful impact when it is informed by the needs, priorities, and experiences of those responsible for translating evidence into policy and practice.

Overall, this gap in knowledge – how sensitive data evidence travels across and within sectors to make meaningful change – was the motivation for the establishment of the Sensitive Evidence Tracking (SET) Working Group. The SET Working Group was established as a proof-of-principle project, bringing together a diverse group of stakeholders from public sector and voluntary, community and social enterprise (VCSE) organisations, alongside a public contributor. The Working Group aims to explore how stakeholders, united by a shared focus on a common population or societal issue, access, interpret, translate, and use evidence generated from sensitive data to support meaningful change.

To make this task manageable, we focused on a specific case study: Attention Deficit Hyperactivity Disorder (ADHD) among children and young people in Northern Ireland. ADHD was selected because it is a neurodevelopmental condition with implications across the life course (French et al., 2024). As a result, it is relevant to multiple sectors and organisations, each of which may engage with data and evidence for different purposes and in different ways. Using ADHD as a case study therefore provides a practical lens through which to examine how stakeholders across sectors engage with sensitive data evidence more broadly. We believe the insights generated through this work may also be relevant to a wider range of societal issues and challenges.

2.SET’s approach

2.1. Aim of the Working Group

The Working Group had several key aims including to understand:

- 1.How different stakeholders consume, interpret, and use administrative data evidence.
- 2.The most effective dissemination strategies, formats, and mediums for their needs.
- 3.Existing knowledge and skills gaps related to data use
- 4.What support is needed for evidence translation and application
- 5.Perspectives on data interpretation and application informed by lived experience



2.2. The Structure of the Group

The SET Working Group brought together academics, representatives from public sector and VCSE organisations, and a public contributor. Collectively, members represented organisations including Health and Social Care, the Royal College of Psychiatrists, the Department of Health, ADD-NI, the Voice of Young People in Care, Neurodiversity SPARK, and the Centre for Effective Services. The Working Group also benefited from the perspective of a public contributor with lived experience of ADHD.

2.3. Methodology

The core focus of the WG is to provide stakeholders with sensitive data describing ADHD in Northern Ireland and track how this evidence is interpreted, translated, and used across sectors and organisations. To facilitate this, the Working Group had several key phases. Before the Working Group activities could commence, academic members first needed to generate evidence for our stakeholder members.

Specifically, **Phase 1A** focused on generating evidence on the WHO, WHAT, WHERE, and WHEN of ADHD medication prescribing among young people in Northern Ireland. We linked data from the Northern Ireland Longitudinal Study (NILS) and the Northern Ireland Enhanced Prescribing Data (EPD). The NILS is a 28% sample of the Northern Ireland population (O'Reilly et al., 2012). Analyses for this project focused on NILS members aged 6 to 20 years who were enumerated at the 2011 Census.

These individuals were linked to Census 2021 data, the Northern Ireland Enhanced Prescribing Data (EPD), Land and Property Services valuation data, and General Register Office (GRO) data. The EPD contains information on all medications dispensed in community pharmacies across Northern Ireland and referred to the Business Services Organisation (BSO) for reimbursement (Bradley et al., 2012). Land and Property Services valuation data provide information on property values, while GRO data contain information on deaths and emigrations in NI.

Given that one of the objectives of the Working Group was to understand the most effective dissemination strategies, we prepared presentation of the evidence in numerous ways. Data linkage was performed by the Northern Ireland Statistics and Research Agency (NISRA) Research Support Unit (RSU). Data were de-identified and pseudonymised prior to release to the research team. Participant consent was not required for this study.

In **Phase 1B**, we hosted our first Working Group meeting. This meeting aimed to share and discuss the evidence with stakeholder members. The session also aimed to develop a clearer understanding of stakeholders' current data and evidence use practices, their perceptions of existing evidence dissemination approaches, and their views on how the evidence could be used in the future. After this meeting, members had three months to engage with and use the evidence.



3. Key findings

In **Phase 2**, we hosted our second Working Group meeting. The aim of this meeting was to explore stakeholder engagement with the evidence thus far, including its relevance, whether they had shared it within or beyond their organisations, what had prevented or enabled use, and what new evidence would make the findings more useful. After this meeting, members had another three months to engage with and use the evidence. We also hosted an event with the Northern Ireland Public Data Panel (NIPDP) to discuss our learnings and explore the panel's views on cross-sector use of their data.

The final phase of the project (**Phase 3**) involved developing resources to share the Working Group's findings with colleagues across the UK sensitive data community. Alongside this report, we produced an accompanying audio presentation that summarises the project's rationale, approach, and key findings. We encourage readers to use the report and audio guide together. The project is ongoing and will conclude with a final Working Group meeting on 17 August 2026. This meeting will provide an opportunity to reflect on the findings, identify priorities for future research, and consider how the lessons learned can inform future sensitive data initiatives.

2.4. The ADHD evidence

The evidence addressed four questions commonly asked of sensitive data:

- Who is affected?
- What are their characteristics and experiences?
- Where are patterns and inequalities observed?
- When do these patterns emerge across the life course?

3.1. General use of data & evidence

All stakeholder members engaged with and used data and evidence in some form. However, there was no single consistently used model of evidence use. Instead, the discussion revealed a set of recurring opportunities and challenges.

- **Feedback loops:** One of the strongest messages from the Working Group was that researchers and stakeholders often have different priorities. Researchers are typically focused on producing rigorous, publishable evidence, whereas stakeholders require timely, practical information that supports decision-making within organisational and policy constraints. Consequently, research questions and stakeholder needs do not always align. Participants emphasised the importance of establishing stronger feedback mechanisms throughout the research process so that evidence is shaped by real-world information needs while remaining methodologically robust. They also noted that demonstrating impact beyond individual organisations remains challenging, particularly where evidence contributes to long-term or indirect changes.
- **Reactive evidence use:** Many organisations use evidence reactively rather than proactively. Evidence is frequently gathered to support funding applications, respond to consultations, prepare reports, or satisfy other requirements. Opportunities to use evidence strategically—before decisions are made—were perceived to be much less common. This suggests that the timing of evidence production is as important as its quality.



- **Accessibility of sensitive data:** Many reported that the wider sensitive data landscape remains difficult to navigate, particularly outside academia. They reported uncertainty about what data exists, who can access them, and how evidence generated from linked sensitive data might support their work. Within government, organisational silos were also perceived to limit opportunities for sharing evidence across departments. Similarly, research outputs were often described as overly technical, reducing their accessibility for practitioners, policymakers, and third-sector organisations. These discussions reinforced the importance of communicating research findings in ways that are tailored to different audiences.
- **Using evidence effectively:** The Working Group found that the “Who, What, Where and When” framework provided an effective starting point for communicating complex findings. However, members also emphasised that statistics alone are rarely sufficient. Quantitative evidence is often strengthened by lived experience, qualitative insights, and contextual understanding that help explain why observed patterns exist and their implications.
- **Learning from elsewhere:** Members reflected on international examples of evidence use, particularly the Danish model. The Danish model was viewed positively because it appeared to support more timely evidence generation, clearer prioritisation, and stronger integration between research and decision-making.

Although differences in governance and infrastructure mean that international models cannot be simply replicated, participants felt that they were valuable lessons that could inform future developments across the UK.

- **Progress across the UK:** Stakeholders acknowledged the significant progress that has been made through UK-wide investment in sensitive data infrastructure. Initiatives such as DARE UK, ADR UK, and HDR UK have significantly improved opportunities to generate robust evidence using linked sensitive data.

3.2. Reflections on the ADHD evidence

As stakeholders reflected on the ADHD findings presented to the Working Group, discussions moved beyond the specific results to consider what makes sensitive data evidence useful, how it should be interpreted, and where its limitations lie. Collectively, these reflections highlighted several important considerations for future research.

- **Evidence is a starting point:** Members viewed the evidence as providing an important starting point. By identifying who is affected, what they are experiencing, where inequalities exist, and when key patterns emerge, the evidence provided an overview of the population that many organisations had not previously had access to.



Stakeholders described these findings as helping to identify service gaps, highlight potential inequalities, and identify further questions. Rather than providing definitive answers, the evidence encouraged organisations to consider what additional information was required and where further research should be directed. In this way, participants viewed descriptive sensitive data evidence as the beginning of the evidence journey rather than its endpoint.

- **Understanding “why” requires more than sensitive data:** Although stakeholders valued the descriptive findings, they highlighted that the “why” was missing. While linked data can identify patterns and associations, it cannot fully explain why those patterns exist or how they are experienced by individuals and families. Participants therefore emphasised the importance of combining quantitative findings with other forms of evidence, including qualitative research, lived experience, and professional expertise. Without this wider context, there is a risk that findings may be misunderstood or interpreted in overly simplistic ways. Administrative data can demonstrate what is happening, but understanding why often requires evidence generated through different approaches.
- **Different audiences require different forms of communication:** The Working Group also recognised that evidence is rarely communicated to a single audience. Researchers, policymakers, practitioners, service providers, and voluntary organisations all engage with evidence for different purposes.

Consequently, participants highlighted the importance of tailoring research outputs to meet the needs of different audiences. Technical reports remain important for academic transparency, but they are often inaccessible to non-specialist users. Effective communication was seen not simply as dissemination, but as an essential part of enabling evidence use.

- **Communicating the limitations of the evidence:** Stakeholders also stressed the importance of being transparent about the strengths and limitations of sensitive data. Discussions highlighted a number of gaps within the Northern Ireland sensitive data landscape that inevitably shape what researchers are able to examine. In this project, ADHD was inferred through prescribing information rather than diagnostic information. Therefore, the Working Group reflected on what sensitive data currently doesn’t afford in Northern Ireland and what needs to happen for this to change.
- **The importance of locally generated evidence:** One of the strongest messages emerging from the Working Group was the value of locally generated – or “home-grown” – evidence. Participants described Northern Ireland-specific findings as being particularly persuasive because they reflect local populations, services, and policy contexts rather than relying on evidence generated elsewhere in the UK.



3.3. Projected vs. actual evidence use

At the end of the first meeting, members were asked how they expected to use the evidence over the following three months, prior to the second Working Group meeting.

Expected uses of the evidence included:

- service design;
- advocacy for adult ADHD services
- education system reform;
- empowerment of people with ADHD;
- development of care pathways;
- demonstration of inequalities; and
- support for funding arguments.

Three months later, we reconvened with stakeholder members for the second Working Group meeting. Given that evidence translation is rarely immediate, and that three months represents a relatively short period in which to observe meaningful change, we had modest expectations regarding the extent to which the evidence would already have been used. One member reported how the evidence had been used to support funding and research proposals. For most other members, however, its immediate value lay in generating ideas rather than directly informing decisions.

Members described how the “Who, What, Where, When” findings provided a useful starting point from which to identify further questions and areas for investigation. For example, because the descriptive findings could identify patterns but not fully explain the “how” or “why” behind them, members suggested that they could provide the basis for a doctoral research project designed to explore key findings in greater depth.

A central theme therefore emerged: generating evidence on the who, what, where, and when may not necessarily provide all the answers, but it can help identify the next questions that need to be asked.

3.4. Barriers to evidence use

While the gap between projected and actual evidence use might initially appear disappointing, we interpreted it positively. It demonstrated early engagement with the evidence and, importantly, provided an opportunity to explore why anticipated uses had not yet translated into practice. Some of the key barriers discussed included:

- **The unconventional nature of the Working Group:** Academic members reflected that the Working Group model differed from conventional research practice. Researchers do not routinely share emerging findings with multi-sector stakeholders prior to peer review. Given the project timeline, however, early sharing of findings was necessary to enable the group to explore how evidence might be interpreted and used in practice. Members noted that the non-peer-reviewed status of the findings may have limited their wider dissemination beyond the Working Group.
- **Lack of clear routes into decision making:** Members stressed that strong evidence is unlikely to achieve impact without a clear route into decision-making. Evidence uptake depends on access to the right policy contacts, the presence of an appropriate policy window, an influential advocate, and sufficient resources or funding to act on the findings.



- **Need for context, explanation, and lived experience:** Although sensitive data can reveal important patterns and inequalities, additional qualitative evidence, lived experience, stakeholder engagement, and cross-sector insight may be needed to understand the “how” and “why” behind the findings.
- **Limited time and resources:** Many organisations are already working at or beyond capacity. Even where evidence is relevant and valuable, stakeholders may not have the time, capacity, or resources required to interpret it, translate it into actionable insights, and embed it within routine practice.

4. Key takeaways

The SET Working Group demonstrated that generating evidence is only one part of the research process. Equally important is how evidence is communicated, interpreted, and used beyond the research environment. Our experience highlights several factors to consider when designing future sensitive data research for public benefit.

- **Data quality:** High-quality evidence depends on access to sufficiently comprehensive and representative data. Continued investment in improving data availability and linkage remains essential.
- **Type of evidence:** Descriptive evidence addressing the “Who, What, Where, and When” is an important starting point, but stakeholders also need evidence explaining underlying causes and potential solutions.
- **Evidence dissemination:** Research evidence should be communicated in formats suited to different audiences. Alongside academic publications, policy briefs, presentations, visual summaries, and accessible reports may be more useful for many evidence users.
- **Collaboration:** Meaningful engagement with stakeholders should begin early in the research process rather than after findings have been produced. Co-producing research questions and maintaining ongoing dialogue can help ensure that evidence addresses real-world needs.
- **Organisational evidence culture:** Different organisations use evidence in different ways and under different constraints. Understanding these cultures is essential if researchers are to maximise the likelihood that evidence will be used effectively.
- **Expectations of impact:** Evidence translation is rarely immediate. Meaningful impact often develops incrementally through relationship building, idea generation, and continued engagement rather than immediate policy change.
- **Barriers to evidence use:** Time, resources, organisational structures, communication, and access to decision-makers can affect whether evidence is translated into practice. These barriers should be considered during research planning, not after findings are generated.



- **Capturing evidence use:** Developing practical approaches for documenting evidence use beyond individual projects represents an important opportunity for future work.

5. Reflections for the UK Sensitive Data Community

The findings presented in this report arise from a single proof-of-principle project focused on ADHD among children and young people in Northern Ireland. Although the context is specific, many of the issues raised are likely to resonate more broadly across the UK sensitive data community.

This report is therefore not intended to provide definitive answers about evidence translation. Instead, it seeks to encourage reflection on how research generated from sensitive data is currently used and how its impact might be strengthened.

As colleagues working across different organisations and sectors, we invite you to consider the following questions within your own context:

- How is evidence generated from sensitive data currently used within your organisation?
- What factors enable – or prevent – that evidence from influencing policy, practice, or service delivery?
- Who should be responsible for ensuring that research achieves impact: researchers, stakeholders, funders, or wider system?
- How should impact be defined and measured within sensitive data research?
- What opportunities exist to strengthen collaboration between researchers and evidence users throughout the research process?

These questions have no single answer. However, we hope to encourage continued dialogue across the UK sensitive data community and contribute to a growing understanding of how evidence generated from sensitive data can deliver public benefit.

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