

3.0 Phase 1: The First WG Meeting

3.1 Introduction

3.1.1. Purpose and Context

The first WG meeting took place following the generation of initial project evidence (see Section 2). The research team designed the session to be both informative and collaborative, reflecting the core principles of effective working group engagement. The primary objective was to share and discuss the evidence generated to date with stakeholder members. In parallel, the session 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 sensitive data could be used in the future. Overall, the event sought not only to support the dissemination and use of project evidence, but also to provide insight into the needs, experiences, and perspectives of WG members in relation to sensitive data and evidence.

3.1.2. Objectives of the meeting

The first WG meeting aimed to:

- Discuss the potential of sensitive data
- Understand stakeholders' current data and evidence use practices
- Present evidence on the WHO, WHAT, WHERE, and WHEN of ADHD among young people in NI.
- Gather stakeholders feedback on the usability, clarity, and presentation of the evidence
- Explore how the evidence may be used in the coming months

3.2 Methods

3.2.1. Procedure

The event was held in the Atrium Suite of the Belfast Campus of UU (room BC-06-321) from 9am to 4pm on Monday 2nd February 2026. Morning refreshments and lunch were provided, and dietary and accessibility needs were canvassed during registration. All WG members received a save-the-date notice in early December, followed by the finalised event agenda in January. All members confirmed their intention to attend; however, two members were unable to attend and instead nominated a colleague to attend on their behalf. Additionally, the public co-chair member was unable to attend on the day.

3.2.2. Presentations & Activities

The first WG meeting was designed to combine presentations with interactive discussion. Three presentations were prepared by academic research team members, focusing on the ethos underpinning the WG, researcher perspectives on the potential of sensitive data evidence, and of course, the evidence generated relating to the WHO, WHAT, WHERE, and WHEN of ADHD among young people in NI. Elizabeth Nelson, an independent public engagement consultant, prepared and delivered a presentation entitled "Bringing data to life: Co-producing the use of data-driven evidence".

A series of facilitated group discussions were also planned for between presentations, providing opportunities to explore stakeholders' current evidence-use practices, their reflections on the evidence presented, and their perspectives on how the evidence might be used between now and the next WG meeting.

3.2.3. Evaluation

Following the event, a Microsoft Teams form was circulated to all WG members. The evaluation sought feedback on: (i) which evidence was usable immediately and why; (ii) what additional evidence would increase usefulness; (iii) whether further analysis could be conducted using the existing data; and (iv) whether any aspects of the day required clarification.

Additional questions focused on the WHO, WHAT, WHERE, and WHEN findings, asking members to rank the most useful evidence within each category and explain their reasoning.

3.3 Results

3.3.1. Attendees

In total, 15 individuals attended, including academic researchers from ADRC-NI and UU, an independent public engagement consultant, and representatives from a range of organisations and sectors, including RCPSYCH, Neurodiversity Spark, Centre for Effective Services, CAMHS, ADDNI, Department of Health, VOYPIC NI, and the Centre for Effective Services.

3.3.2 Current data and evidence use

In the first group discussion, members were asked about their current use of data and evidence.

3.3.2.1. Lack of clear feedback loops between research & practice

Participants from both academic and practice-based backgrounds highlighted a clear lack of feedback loops between research production and practical application. An academic researcher described spending much of their career working on externally funded research projects that require demonstration of impact. To meet these requirements, projects are often designed in partnership with organisations in the relevant space, involving them in shaping the evidence. However, over time, they learned that stakeholders' actual needs and priorities often don't line up with researchers' assumptions.

Concepts academics take for granted – like “tailoring services,” “allocating resources,” or “informing policy” – mean very different things to different organisations. Even when researchers try to listen and respond to what stakeholders say they want, the resulting evidence doesn't always get used in the way researchers expect.

Stakeholder members echoed these experiences, describing how research can feel “done to” organisations rather than conducted collaboratively. In these cases, data are collected, findings written up, outputs shared on a single occasion, and the relationship then ends, with limited opportunity for ongoing dialogue or learning.

Several members noted limited insight into whether findings are subsequently used or lead to system-level change. One member reflected that while individual practitioners may adapt their work based on evidence, it “doesn't really feed back into the system”.

3.4.2.2. Funding pressures and reactive evidence use

Several members discussed using data and evidence in a largely reactive manner. Evidence was often mobilised to meet funder requirements, justify existing services, or support business cases, funding bids, or reports produced under time pressure. A member noted that many projects are designed after funding criteria have been established, meaning that evidence is shaped to fit predefined outputs rather than organisational needs. Overall, members reported that data and evidence can be episodic, occurring at key pressure points such as policy reviews, rather than being embedded into routine decision-making. This reactive pattern was commonly linked to limited organisational capacity. Members highlighted constraints in time, staffing, and analytical resources, which restricted their ability to engage consistently and strategically with data. In this context, evidence use became closely tied to sustainability.

Some members described the need to continually “re-invent” themselves in funding applications in order to sustain services. This process was characterised as exhausting and resource-intensive.

This reinforces the importance of having access to relevant, up-to-date evidence to demonstrate need, make the case for expanded provision, educate beneficiary populations, and advocate for policy change.

However, this experience was not universal. Some members described how data and evidence are embedded across strategic planning, service design, and prioritisation processes in their organisation. In these cases, the primary challenge was not the absence of evidence but translating complex findings into accessible and usable formats for practice.

3.4.2.3. Accessibility

Accessibility emerged as a central theme, with members highlighting difficulties in navigating the administrative data landscape in NI, including uncertainty about what data sources exist and how to access them. An academic member described the development of a web-based roadmap to support researcher accreditation and access to sensitive data. It was agreed that this resource would be shared with members after the event.

In a similar vein, members discussed structural and governance barriers, particularly the impact of departmental siloes. Members noted that accessing and linking evidence across different IT systems and government departments can take several years, limiting the timeliness and utility of evidence for decision-making.

Several members noted limited insight into whether findings are subsequently used or lead to system-level change. For example, one member reflected that while individual practitioners may adapt their work based on evidence, that it “doesn’t really feed back into the system”.

Members also noted that research outputs are often written primarily for academic reviewers rather than end users. One member commented that “the language we write in is almost like a legal document”, making engagement difficult for those unfamiliar with academic conventions. Paywalls restricting access to publicly funded research were also highlighted, alongside challenges faced by frontline staff and communities in accessing and interpreting data.

3.4.2.4. The “WHO, WHAT, WHERE, WHEN” approach resonates

Members strongly endorsed the operational usefulness of the WHO, WHAT, WHERE, and WHEN framework. It was seen to align well with how organisations think about targeting services, identifying pressure points, and communicating needs to decision-makers.

However, members emphasised that the framework represents a starting point rather than a comprehensive account, and that additional contextual and explanatory information is often required to support interpretation.

Specifically, consideration of the “WHY” was viewed as essential. One member suggested that the WHO, WHAT, WHERE, and WHEN should collectively convey the WHY, while acknowledging that there will be times when the data cannot tell the full story. Another member highlighted the importance of combining “stats and stories”, noting that integrating quantitative evidence with lived experience would significantly strengthen the overall impact of evidence.

3.4.2.5. The Danish administrative data model makes sense

Members reflected on international examples of administrative data infrastructure, including Denmark, where the use of a unique personal identification number enables routine linkage of data across governmental and other sectors. Participants noted that a similarly streamlined and integrated system would offer considerable benefits in the NI context, particularly for those working on the frontline who require timely, linked, and comprehensive information to inform service planning and delivery.

At the same time, members acknowledged the substantial progress made through UK-wide initiatives such as ADR UK, DARE UK, and HDR UK in strengthening secure data access and linkage capabilities. The discussion highlighted a shared interest in continuing to develop and enhance integrated administrative data systems in ways that support responsible, ethical, and impactful research and practice.



3.4.3. Reflections on the presented evidence

In the afternoon session, a member of the research team presented evidence on the WHO, WHAT, WHERE, and WHEN of ADHD among young people in NI. Members were then invited to reflect on the understandability and usefulness of the evidence, as well as on alternative ways it could have been presented. As the discussion moved flexibly across topics rather than following a linear structure, the key themes are summarised below.

3.4.3.1. Evidence as a starting point

Similar to previous discussions, members consistently described the WHO, WHAT, WHERE, and WHEN evidence as a good starting point rather than a definitive account. The evidence was valued for its ability to identify patterns, inequities, and gaps in service provision, and for generating further questions to guide future analysis and engagement. As one member highlighted “what questions come out of this are more valuable than the answers”. However, it was also noted that there was information missing from the evidence that undermined its practical utility, including the absence of the “why”.

3.4.2 Absence of the “why”

Members repeatedly emphasised that while the evidence described observable patterns, it did not explain the underlying reasons for these patterns. For example, although the evidence showed that girls tend to receive ADHD medication later than boys – suggesting potential underdiagnosis in early development among girls – it did not explain why this occurs.

Members suggested that this may reflect factors such as service failure, gender bias, or broader structural issues. Members of the research team acknowledged these limitations, noting that while administrative data are effective at identifying patterns and associations, they can be limited in their ability to explain the background story. Members stressed that without explicitly acknowledging these potential explanations, findings could reinforce stigma, mislead policymakers, or obscure structural factors.

Similarly, members raised concerns about the potential for evidence to be misinterpreted or misused. In particular, findings indicating that young people prescribed ADHD medication are more likely to experience poorer health, education, and employment outcomes were seen as being vulnerable to being read as implying causation. Members emphasized that these outcomes more likely reflect systemic failures and structural barriers rather than individual incapacity. As one member noted with respect to the employment outcome findings, “it’s not that people with ADHD can’t work – it’s that the environment isn’t built for them”.

Similarly, members noted how they needed the findings situated within the realities of local service provision. For example, while prescription counts were highest in the Belfast Trust area, members noted that the Belfast Trust no longer assesses young people over the age of twelve. Members indicated that failure to acknowledge such contextual factors could undermine confidence in findings.

Several participants emphasised that incomplete or poorly contextualised evidence risks being dismissed in its entirety, with uncertainty about one element undermining trust in the wider body of findings. Overall, discussions highlighted the importance of anticipating misinterpretation and of pairing statistical findings with clear explanatory and local context.

3.4.3.3. Different audiences need different stories

In a similar vein, members highlighted that the evidence does not have a single audience. While population-level evidence was viewed as particularly useful for funders and policymakers, participants cautioned that presenting the same information to families or young people without careful framing could be distressing or stigmatising. This highlighted the need to tailor outputs to different audiences, with attention to tone, context, and purpose. At the same time, members noted that making trusted, population-level data available can have positive effects, including reducing reliance on untrustworthy information sources and reframing individual struggles as systemic rather than personal failure.

3.4.3.3. Limits of the data

Members identified clear limitations in the available data. In particular, the absence of diagnostic data in NI was highlighted as a key constraint. Members of the research team explained that diagnostic data are not currently available, meaning that receipt of ADHD medication must be used as a proxy for the presence of ADHD.

Members suggested that this approach is likely to capture more severe cases while omitting individuals who are undiagnosed or who do not receive pharmacological treatment.

One member suggested that estimates from other countries regarding the overlap between diagnosis and medication receipt could be incorporated into outputs to provide additional context. Again, participants emphasised that all limitations should be clearly stated to avoid unsafe or misleading conclusions.

3.4.3.5. Alternative ways of presenting the evidence

While some members were satisfied with the presentation of findings, others indicated that tables, charts, and graphs alone were insufficient. Members expressed a need for explanatory text, comparative context, and guidance on how to interpret statistical outputs. One participant suggested that presenting the data separately from the researchers' interpretation could support transparency and enable users to engage with the evidence from different perspectives.

3.4.4. Predicting the future

Following discussions about the evidence, the focus of discussion next moved onto how participants think they might use the evidence over the subsequent three months. While participants acknowledged that this was a short timeframe in which to expect measurable impact, several potential uses were identified.

Representatives from the Department of Health and ADHD NI indicated that the evidence could be used to support funding arguments. Participants from VCSE sector organisations highlighted its potential for demonstrating inequities in ADHD treatment by gender, age, and geography.

Representatives from professional bodies identified potential applications in service redesign and advocacy for adult ADHD services. Education sector participants noted its relevance for discussions on education system reform, while community organisations emphasised its value for empowering members through timely access to trusted evidence.

Participants from CAMHS highlighted potential use in informing ADHD care pathways. Some participants reported that they were not yet in a position to identify specific applications but anticipated that further reflection and discussion would clarify future use.

3.4.5. Post-event evaluation

Four members across three sectors completed the post-event evaluation form. The responses from these forms are provided below.

3.4.5.1. Usability of evidence in the here and now

Members were asked to tell us what evidence they believed was usable for them right now, and the reason for that.

Members noted the most useful evidence as being:

- Having NI-specific evidence, including demographic of people needing support

- The profile of young people with ADHD and the range of educational, health, and social outcomes for this group
- Higher prescribing rates for other medications in the ADHD group
- Prescribing data per trust
- Later diagnosis in females

With respect to the reasons for such evidence being most valuable, members noted:

- Support funding applications and identify risk factors
- Providing contextual information for student teachers and teacher practitioner, reinforcing the idea that “education does not take place in a vacuum”.
- Provides an evidence base that could be used to inform planning to improve outcomes at school level such as the transition from primary to post-primary, transition post-16, and options for alternative educational pathways.
- Early identification and treatment
- Later diagnosis in females supports the need for age-inclusive services to prevent discrimination.

3.4.5.2. Additional evidence needs

Members were asked “if additional evidence were to be added, what would it be, and how would it be used and how would it make the findings more useful?”. Responses included:

- Mortality rates, including risk of death by misadventure
- Connection between female health conditions

- Supplementary narratives that describe the lived experience of CYP with ADHD to draw out the impact of circumstances and contexts.

3.4.5.2. Additional evidence needs

Members were asked “*Before our next meeting, is there any additional evidence or analysis you’d like us to produce using the existing data?*”. Responses included:

- Tailoring the trust areas to account for differing ages in diagnostic services
- One member noted that while not feasible within scope of the study, they’d like to see interrogate Department of Education data on this group at primary and post-primary relative to the wider Special Educational Needs (SEN) pupil population and other factors.
- Linking deprivation data to better contextualise findings.

3.4.5.3. Further clarification

Members were asked if they required further clarification on any of the content from the day. All members reported no clarification was required, with one member noting “the entire day was hugely informative and accessibly presented, with analysis of data and its implications very clearly explained to the group”.

3.4.5.5. Ranking of evidence

WHO

Members were asked to rank the findings from each of the four W’s in terms of their degree of relevance (see Figure 3.1). Three of four members (75%) reported that the higher likelihood of ADHD medication use among families with fewer material resources was most relevant.

This was considered important because it situates ADHD within a whole-person framework, identifies a priority group for early identification and treatment to improve life-course outcomes, and provides clear evidence of inequalities. One member (25%) reported that the higher likelihood of ADHD among children aged 6–10 years at baseline was most relevant, as it highlights the importance of early assessment, diagnosis, and intervention.

WHAT

Two members (50%) reported that the higher likelihood of lower or alternative education qualifications among those who received ADHD medication was most relevant (see Figure 3.2). Reasons for this included that the evidence demonstrates the need for early support, the identification of effective educational supports, and the expansion of opportunities for further study or employment, with potential knock-on benefits for health, and social and emotional well-being.

One member (25%) reported that the higher likelihood of economic inactivity and fewer working hours was most relevant, as it identifies an important area for further research. In particular, comparing economic outcomes for individuals with ADHD who receive medication with those who do not may help support the case for increased resources for ADHD services.

A further member (25%) reported that the higher likelihood of multiple health conditions and psychotropic medication use among those receiving ADHD medication was most relevant, as this highlights the need for early identification and diagnosis to prevent adverse outcomes.

4 Responses

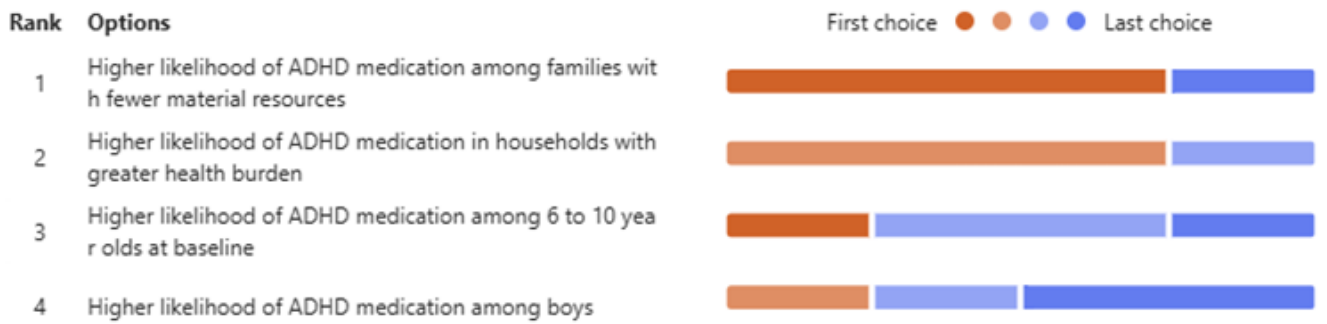


Figure 3.1. Ranking of the WHO evidence

4 Responses

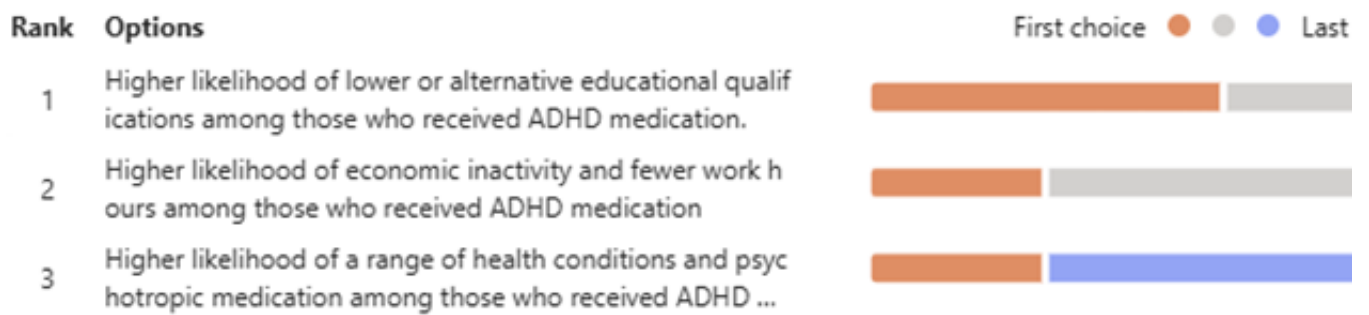


Figure 3.2. Ranking of the WHAT evidence

4 Responses

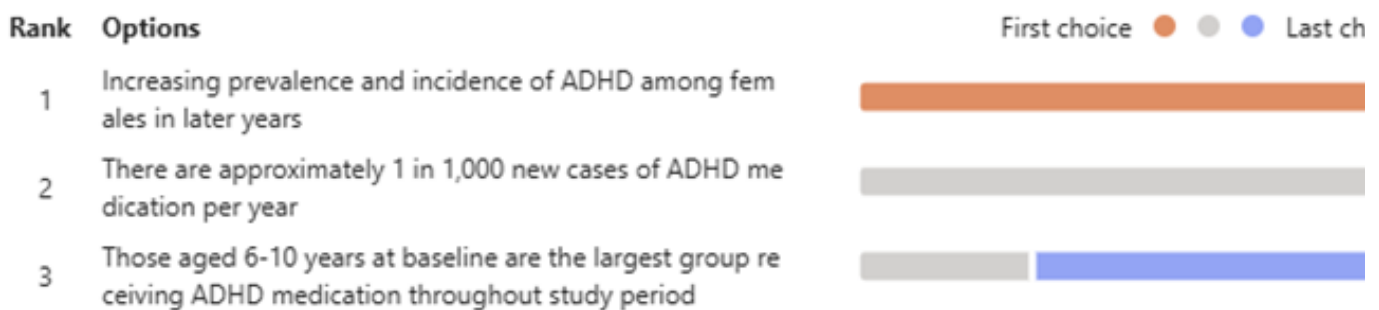


Figure 3.3. Ranking of the WHEN evidence

4 Responses



Figure 3.4. Ranking of the WHEN evidence

WHEN

As shown in Figure 3.3, all members (100%) reported that the increasing prevalence and incidence of ADHD among females in later years was most relevant because it (i) supports what is observed in practice, despite the absence of Northern Ireland (NI)-specific evidence; (ii) emphasises the importance of early-life assessment; (iii) underscores that females are less likely to be identified due to differences in presentation; (iv) identifies females as a hidden cohort whose educational, social, and emotional outcomes may have been compromised during their school years, with potential long-term impacts on wider life choices; and (v) identifies discriminatory practices against woman and girls which could help support advocacy efforts for improved services.

WHERE

Two members (50%) reported the annual rates per 100,000 across Health and Social Care Trusts as being most relevant, while the remainder (50%) highlighted the counts by Health and Social Care Trusts to be most relevant (see Figure 3.4). The former was deemed most relevant due to yielding more informed insights into the demographic landscape of ADHD in NI, while the latter was deemed to identify areas of need and support pleas for more equitable services.

3.5. Discussion

3.5.1. General Discussion

The first WG meeting aimed to support the dissemination and responsible use of sensitive data evidence on ADHD among young people in NI, while also generating insight into the current data landscape and the experiences, needs, and priorities of stakeholder members.

Overall, the meeting facilitated meaningful dialogue between academic researchers and stakeholders and confirmed that data and evidence are embedded, in different ways, across organisational practice. Members described using evidence to sustain investment, meet funder and departmental requirements, advocate for beneficiary populations, redesign services, and support others in evidence use. However, discussions also highlighted structural and cultural factors that constrain the use and impact of sensitive data evidence.

A recurring theme was the absence of clear and sustained feedback loops between research production and practice. Members described limited opportunities for ongoing dialogue once outputs are delivered, pointing to the need for more reciprocal and enduring engagement. Aligning evidence generation more closely with organisational realities – and ensuring that learning extends beyond individual project lifecycles – emerged as a clear priority.

Members also identified limitations within the sensitive data landscape in NI. Some members reported uncertainty regarding what administrative data sources exist and how they can be accessed, underscoring the need for greater cross-sector awareness and professional capacity-building in navigating administrative data systems.

Government and departmental siloes were also described as significant barriers to linking and mobilising evidence in a timely way. These structural challenges, alongside staffing and resourcing constraints, restrict the ability of organisations to move from reactive to strategic and embedded evidence use.

Discussions also highlighted challenges specific to the NI context. In the absence of locally comparable data, practitioners often rely on evidence from England or Scotland despite substantial contextual differences. This reliance risks overlooking NI's distinct sociopolitical and service landscape, highlighting the importance of strengthening locally relevant sensitive data infrastructure and interpretation.

Building on this, it was highlighted that Denmark's administrative data infrastructure would be highly valuable in the NI context. While significant progress has been made in improving secure data access and linkage across NI and the wider UK through initiatives such as ADR-UK, DARE UK, and HDR UK, political, legal, and governance barriers continue to make sensitive data access an arduous, time-consuming, or in some cases, unfeasible process (Moorthie et al., 2022; Morris et al., 2018).

A key insight from these discussions was that by articulating stakeholders' unmet data needs can help the administrative data community to strengthen their case for enhanced access to sensitive data in NI.

Accessibility emerged as another central issue. Members emphasised that research outputs are often written primarily for academic audiences, limiting their usability for practitioners, frontline staff, and communities.

Paywalls and technical language further constrain engagement, particularly where publicly funded research is concerned. These barriers not only limit democratic access to evidence but also risk weakening trust in data systems more broadly.

Members broadly agreed that the 'WHO, WHAT, WHERE, and WHEN' provides a useful organising structure for sensitive data evidence, particularly for targeting services and communicating need. However, it was recognised as a starting point rather than a complete account. Therefore, more widespread adoption of such a framework may help bridge aspects of the gap between research and practice.

Following presentation of the WHO, WHAT, WHERE, and WHEN of ADHD among young people in NI (see Section 2), stakeholder members engaged actively with both the evidence itself and its presentation.

The research team deliberately presented the findings in a simplified format to enable stakeholders to articulate their needs. While the evidence has widely regarded as valuable for informing practice, advocacy, and further enquiry, members emphasised the absence of the "Why".

Although the four Ws provided a clear descriptive account, they did not explain the broader structural, service-related, and contextual factors underpinning observed patterns. In the absence of explicit contextualisation, stakeholders cautioned that findings could be misinterpreted, potentially misleading policymakers, causing unnecessary concern among affected populations, or reinforcing deficit-based narratives.

Discussions made clear that users require not only clarity on what the evidence shows, but also guidance on what it means. While no single preferred dissemination format emerged, members consistently valued a combination of visual outputs, explanatory narrative, comparative context, and interpretive guidance.

The discussion also reinforced the value of co-production. While researchers are best placed to generate and analyse administrative data, representatives across sectors are best positioned to contextualise the findings. For example, academic researchers were unaware that young people over the age of twelve are not currently assessed for ADHD within the Belfast Trust area, a critical contextual factor that is essential for interpreting prescription patterns. Such exchanges underscore the importance of positioning collaborators as equal partners in sensitive data research processes.

Finally, stakeholder members identified several potential uses of the evidence over the subsequent three months. These included supporting funding applications, informing service redesign, advocating for policy or strategic change, and empowering young people and families through access to trusted information. Although measurable impact within this timeframe may be ambitious, observing how stakeholders engage with and mobilise the evidence will provide valuable insight into its practical utility.

3.5.2. Post-event evaluation

Despite only obtaining responses from four of the attendees, the post-event evaluation provided detailed insights into their perspectives on the evidence and future evidence needs. Overall, these insights underscored the importance and implications of providing the WHO, WHAT, WHERE, and WHEN of ADHD among young people in NI to our stakeholder members, while also identifying areas for future direction such as exploring the role of area-level deprivation in explaining prescribing patterns.

These insights will help inform data analyses for the next WG meeting.

3.5.3. Next steps

The first WG meeting demonstrated both the potential and the limitations of sensitive data in the NI context. While stakeholders clearly value robust population-level evidence, its impact depends on accessibility, contextualisation, and sustained collaboration. The meeting reinforced that responsible data use is not simply a technical challenge, but a relational and governance challenge.

Future WG activity will therefore focus not only on generating further evidence, but on strengthening the conditions under which that evidence can be meaningfully and ethically mobilised.

3.5.4. Conclusions

The first WG meeting demonstrated both the potential and the limitations of sensitive data in the NI context.

While stakeholders clearly value robust population-level evidence, its impact depends on accessibility, contextualisation, and sustained collaboration. The meeting reinforced that responsible data use is not simply a technical challenge, but a relational and governance challenge. Future WG activity will therefore focus not only on generating further evidence, but on strengthening the conditions under which that evidence can be meaningfully and ethically mobilised.

3.6. References

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3.7. Acknowledgements

The help provided by the staff of the Northern Ireland Longitudinal Study (NILS/NIMS) and the NILS Research Support Unit is acknowledged. The NILS is funded by the Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) and NISRA. The NILS-RSU is funded by the ESRC and the Northern Ireland Government. The authors alone are responsible for the interpretation of the data and any views or opinions presented are solely those of the author and do not necessarily represent those of NISRA/NILS.

The Honest Broker Service data has been supplied for the sole purpose of this project.