

DARE UK (Data and Analytics Research Environments UK)

DARE UK Working Group (WG) Charter Template

Name of Proposed WG: *Sensitive Evidence Tracking (SET) Working Group*

Affiliated DARE UK Interest Group (if applicable): *n/a*

The WHY

Sensitive data offers enormous potential to generate critical insights into the *who, what, where, when, why, and how* of pressing societal challenges. Recognising this, UK-wide sensitive data initiatives like DARE UK, ADR UK, and HDR UK have invested in secure and robust infrastructures to enable the responsible use of public data for public good. These initiatives are grounded in a shared assumption that the generation of high-quality evidence using sensitive data will lead to more effective policy, practice, service provision and resource allocation. However, to our knowledge, no study to date has investigated if or how, stakeholders involved in sensitive data research apply the evidence generated from their projects to better understand their target populations, or to improve operational effectiveness. We believe this represents a significant gap in the broader sensitive data infrastructure. Without this insight, there is a risk that evidence is unusable, inaccessible, or misaligned with user needs, meaning that efforts to streamline secure data use may not produce its intended impact.

To address this gap, this proof-of-principle Sensitive Evidence Tracking (SET) Working Group, comprising academic researchers, a large and diverse group of stakeholders from public, and Voluntary, Community, and Social Enterprise (VCSE) sector organisations, and a public contributor, aim to explore how stakeholders, united by a shared focus on a common population/societal issue, consume, translate, and utilise administrative data research findings to deliver meaningful change/impact. The WG aims to co-develop and disseminate two summary reports detailing the key insights of cross-sectoral evidence translation and application and any identified knowledge/skills gaps or needs relating to evidence use. They will be supplemented by an audio roadmap ensuring project discussions and findings reach the widest possible audience. All outputs will be curated on a project webpage.

The population/societal issue that this proof-of-principle WG will focus on is ADHD among young people in Northern Ireland (NI), a locally relevant issue with wide relevance across the UK. It's early life emergence and significant life course implications demand the attention of multiple organisations across multiple sectors, each likely to engage with evidence in different ways and for different purposes. The WG's academic researchers will provide its stakeholders members with administrative data findings pertaining to ADHD in NI and will then track how this evidence is used. Based on these insights, along with those generated from a public involvement and engagement (PIE) event and a UK-wide cross-sectoral event, the WG aims to co-develop and disseminate the two summary reports and accompanying audio roadmaps that can be adapted for different target populations or societal issues.

The WG will directly support DARE UK's programme recommendation of Demonstrating Trustworthiness. Public benefit is the foundation for the WG's formation, with the WG's overall aim being to provide a comprehensive insight into what works, what doesn't, and what, if anything, needs to change to ensure that evidence derived from sensitive data is translated into measurable public benefit. By documenting whether and how stakeholder members translate and apply sensitive data evidence through summary reports and audio roadmaps, the WG will promote transparency regarding both the intended and actual outcomes and

impacts of its use. The WG will provide members of the public with the opportunity to comment on and help shape its outputs through the NI Public Data Panel (NIPDP) and its public contributor.

The summary reports and audio roadmaps will serve multiple audiences. Researchers will gain valuable insights into how different stakeholders across sectors consume, translate, and apply research findings, supporting them in developing sensitive data research projects that more directly align with the needs of its intended consumers. For the public, they will build trust by demonstrating the sensitive data community's proactive efforts to addressing any potential risks to delivering on public benefit. Finally, national initiatives like DARE UK, ADRUK, and HDR UK will have tangible evidence on how sensitive data research evidence is currently used by its intended consumers and current knowledge/skills needs or gaps relating to evidence needs. This will enable them to identify and address any of these potential needs or gaps in the sensitive data ecosystem and ultimately, inform their future strategic directions.

The WHAT

The WG will co-produce two summary reports, each supplemented by an audio roadmap. These will be curated on the project webpage to ensure transparency and broad dissemination. A detailed description of these outputs, and the key project milestones underpinning their development, is provided below.

Summary Report and Audio Roadmap 1

The WG will co-produce the first summary report and accompanying audio roadmap based on five key project milestones:

- **Pre-project:** Academic researcher members will analyse linked Census (2011/2021) and Enhanced Prescribing Database data to generate outputs describing the *who* (*demographic & household profiling*), *what* (*education, employment, health outcomes*), *where* (*geographical distribution*), and *when* (*longitudinal prescribing trends and trajectories*) of ADHD among NI youths.
- **WG meeting 1:** All WG members will be introduced, and the cleared administrative data research findings generated prior to the group's commencement will be presented for review and discussion. Stakeholder members will then engage with the evidence independently for four months which will support understanding of how different stakeholders typically interact with and apply sensitive data evidence. During this time, the academic researchers and public contributor will conduct a scoping exercise to identify examples of how sensitive data evidence has been translated and applied in other sensitive data studies.
- **WG meeting 2:** After the first four-month period, the WG will reconvene to review if, how, when, and why stakeholders used the evidence shared at the start of the project. This review will include discussion of: (i) similarities and differences in evidence translation and application across stakeholders, (ii) identification of 'blind spots' and knowledge/skills gaps in data use, (iii) broader needs around evidence translation/application; and (iv) public contributor views based on lived experience. The group will also review findings from the scoping exercise to inform discussion and support stakeholders in considering how the evidence may be applied in their own contexts. Following this meeting, stakeholders will enter a second four-month evidence use period, during which the academic researchers and public contributor will begin co-developing the first summary report and accompanying audio roadmap.
- **WG meeting 3:** After the second four-month period, the WG will reconvene to review any changes in evidence use. This review will include reflection on whether and how the scoping evidence contributed to those changes.

- **Public Involvement and Engagement (PIE) event:** The WG will meet with the NI Public Data Panel (NIPDP) to discuss the key learnings from tracking evidence use over the two four-month periods and invite members to explore their views on how their data is being used across sectors.

Planned outputs

- **'Tracking Multi-Sectoral Uses of Sensitive Data Evidence' Summary report:** A high-level report outlining the key insights of evidence translation and application across stakeholders from different sectors. It will also include findings from the PIE event and identify any knowledge/skills gaps or needs relating to evidence use.
- **'Tracking Multi-Sectoral Uses of Sensitive Data Evidence' Audio guide/roadmap:** An audio roadmap that presents the key discussions and findings that informed the first summary report in a detailed and alternative format.

Summary Report 2 and recorded overview

This WG will co-develop the second summary report and recorded overview based on one key project milestone:

- **UK-wide KE event:** The WG will host a KE event with UK-based organisations that mirror the WG's stakeholder members, during which the first summary report and audio roadmap will be presented. The event will facilitate discussion on: (i) the relevance of findings to other UK regions, (ii) UK-wide practices in the use of sensitive data evidence, and (iii) evidence translation needs across UK communities.

Planned Outputs:

- **"Informing the Nation: Evidence on Sensitive Data Use" Summary Report:** A high-level report outlining the key insights of evidence translation and application across stakeholders from different sectors UK-wide. It will identify any knowledge/skills gaps or needs relating to evidence use across the UK.
- **"Informing the Nation: Evidence on Sensitive Data Use" Audio Guide/Roadmap:** An audio roadmap that presents the key discussions and findings that informed the second summary report in a detailed and alternative format.

The WHO

This WG includes academic researchers, stakeholders from public and VCSE sector organisations, and a public contributor with lived experience of ADHD.

The WG's academic researcher chairs are:

- **Dr Enya Redican**, Research Associate at ADRC-NI
- **Jamie Murphy**, Deputy Director of ADRC-NI
- **Professor Mark Shevlin**, Professor of Psychology, Ulster University
- **Professor Una O'Connor Bones**, Deputy Director of UNESCO Centre, School of Education, Ulster University

Collectively, they bring expertise in collaborating with government, non-government, and third-sector organisations to use sensitive data to investigate topics such as mental health, special educational needs, and learning disability. Their work also includes contributing to capacity building and sharing their knowledge, such as developing [a roadmap](#) for data access and accreditation in NI, delivering research methods and statistics training, and conducting government advisory work. Within the WG, they will be

responsible for coordinating the WG's activities, conducting the scoping exercise, facilitating group and event discussions, and developing initial drafts of all outputs.

The WG's stakeholder members are:

- **Dr Holly Greer***: Consultant Psychiatrist for CAMHS Intellectual Disability service and Regional Deaf CAMH service. Chair of the Child and Adolescent Faculty, NI Royal College of Psychiatrists (RCPSYCH).
- **Professor April Hargreaves***: Director of Research at Neurodiversity SPARK, leading projects investigating the lived experiences of those with ADHD and autism and applying participatory and community-based methods to inform inclusive policy and practice. Programme Director at ICEP Europe and Co-Director of the Stigma and Mental Health Ireland Laboratory.
- **Dr Siona Hurley**: Consultant Child & Adolescent Psychiatrist in a Neurodevelopmental Service within Community Paediatrics. Vice Chair of the Child & Adolescent Faculty of RCPSYCH NI and the NI Representative for Child & Adolescent Psychiatry Surveillance System.
- **Gerard O'Hanlon**: Regional Coordinator for the Children's Emotional Health and Wellbeing Framework in the Strategic Planning and Performance Group in the Department of Health. Responsible for paediatric ASD and ADHD services.
- **Dr Grant Chai**: Specialist Clinical Psychologist for CAMHS, supporting therapeutic work with children with ADHD through a new healthcare pathway.
- **Dr Joanne Ilsley**: Consultant Lead Clinical Psychologist for Specialist CAMHS, Children's Early Intervention Services and Paediatric Autism Services. She is currently developing a Specialist Assessment and Intervention Pathway for ADHD and a neurodevelopmental pathway within Child Health and Emotional Wellbeing.
- **Dr Alison Montgomery**: Senior Project Specialist for The Centre for Effective Services, working with individuals/teams in VCSE sector organisations to support them through research, evaluation, knowledge, and evidence translation. She will be accompanied by a colleague from the CES.
- **Emily Salters**: Dedicated ADHD Practitioner working at ADD-NI. Passionate about supporting young people in the criminal justice system and committed to education, early intervention, and advocacy.
- **Sarah Salters**: Chief Executive of ADD-NI, drawing on social work background and specialist training to lead ADD-NI's trauma-informed approach. She champions young voices through the ADD-NI Youth Committee, delivers cross-sector ADHD training, and has secured major programme funding.
- **Iain Black & Brenda Kilpatrick**: Area manager and engagement development worker, respectively, for Voice of Young People in Care (VOYPIC), providing advocacy and participation programmes for youths in care.
- **Elizabeth Nelson**: Engagement and involvement expert specialising in bringing people and communities into conversations and decision-making about how their data is used. Co-Director of the NIPDP with extensive experiencing designing and implementing co-production and participatory initiatives with diverse groups (e.g., communities, policymakers).

Within the WG, the stakeholder co-chairs/members will be responsible for attending all WG meetings, contributing to discussions on evidence translation and application, and co-producing and reviewing all outputs. *These stakeholder members will act as co-chairs.

A **public contributor** with lived experience will also act as co-chair and will be recruited prior to the commencement of the WG. Their role will be to support coordination of the WG's activities, complete the scoping exercise alongside academic members, help facilitate group and event discussions and contribute their lived experiences to these discussions, and support co-production of initial drafts of all outputs.

The HOW and WHEN

Three full WG meetings will be held with all members, as outlined above. All WG meetings will be facilitated by the chairs/co-chairs and recorded and transcribed to inform outputs. To ensure regular communication throughout the project lifespan, virtual meetings will be held monthly among chairs and co-chairs, a discussion board will be maintained on Microsoft Teams, and all documents will be stored within a shared team folder on Microsoft Teams. A selection of WG members will represent the group at PIE and KE events and between meetings and events, smaller task teams will work on developing project outputs.

The overall timeframe of the project is the 20th of October 2025 to 19th October 2026.

20th October 2025 to 31st August 2026

The first summary report and audio roadmap will be co-developed, completed, and curated on the project webpage by 14th August 2026. The key milestones that will facilitate this summary report and audio roadmap are:

- **WG Meeting 1:** 20th October 2025
- **Evidence Tracking Period 1:** 3rd November 2025 - 2nd March 2026
- **Scoping Exercise:** 3rd November 2025 - 2nd March 2026
- **WG Meeting 2:** 3rd March 2026
- **Evidence Tracking Period 2:** 9th March - 8th July 2026
- **Co-development of Summary Report 1 and Audio Guide/Roadmap Begins:** 9th March - 8th July 2026
- **WG Meeting 3:** 9th July 2026
- **NIPDP event:** July 2026

1st September 2025 to 19th October 2026

The second summary report and audio roadmap will be developed, completed, and curated on the project webpage by 14th October 2026. The key milestones that will facilitate this summary report and audio roadmap are:

- **KE event with UK-based organisations:** 7th September 2026
- **Co-development of Summary Report 1 and Audio Guide/Roadmap Begins:** 7th September 2026

The outputs of this WG are intended for use by researchers, stakeholders, the public, and initiatives such as DARE UK, HDR UK, and ADR UK. Each summary report and audio roadmap will be made publicly available immediately upon completion by being uploaded onto the project webpage and will be shared widely through social media and WG members' networks (e.g., ADRC-NI/UK, HSC, RCPSYCH, CAMHS, Neurodiversity Spark, ADDNI, CES). Dissemination at KE and PIE events will support active engagement with the summary reports and audio roadmaps and will shape subsequent outputs.

Potential members:

FIRST NAME	LAST NAME	EMAIL	(Co-)Chair / Member
Enya	Redican	e.redican@ulster.ac.uk	Chair
Jamie	Murphy	ja.murphy@ulster.ac.uk	Chair
Mark	Shevlin	m.shevlin@ulster.ac.uk	Chair
Una	O'Connor Bones	ub.oconnor@ulster.ac.uk	Chair
April	Hargreaves	april@neurodiversityspark.com	Co-chair
Holly	Greer	Holly.Greer@northerntrust.hscni.net	Co-chair
Gerard	Hanlon	Gerard.O'Hanlon@hscni.net	Member
Siona	Hurley	siona.hurley@belfasttrust.hscni.net	Member
Joanne	Illesley	joanne.illesley@northerntrust.hscni.net	Member

Grant	Chai	Grant.Chai@northerntrust.hscni.net	Member
Alison	Montgomery	amontgomery@effectiveservices.org	Member
Sarah	Salters	info@addni.org	Member
Emily	Salters	info@addni.org	Member
Elizabeth	Nelson	ebienelson@gmail.com	Member
Iain	Black	Iain.Black@voypic.org	Member
Brenda	Kilpatrick	brenda.kilpatrick@voypic.org	Member

***Public contributor will be recruited as co-chair prior to WG commencement.**

** Note, please do not hesitate to point out gaps in the current DARE UK set of strategic themes and/or recommendations that the programme should consider as it continues to evolve these. Community feedback and input is welcomed.*