DARE UK (Data and Analytics Research Environments UK)

DARE UK Working Group (WG) Charter Template

Name of Proposed WG: *PEDRI Learning and Development Working Group*
Affiliated DARE UK Interest Group (if applicable): *The Public Engagement in Data Research Initiative (PEDRI)*

The WHY

Introduction: [A brief articulation of what tractable challenge(s) or issue(s) the WG will address, how this WG is aligned with the DARE UK mission, and what this WG would deliver as a value-adding output or deliverable to the sensitive data research community]

(1) What is the research case? Why will the output(s) be useful and for whom?
(2) Which specific DARE UK programmes recommendations is this WG's output(s) supporting to address and how so? If none, please explain why this is the case. *

Public engagement is crucial to ensuring ethical and safe data use for the benefit of society. At PEDRI, Public Engagement in Data Research Initiative, we have outlined clear standards for good practice with public engagement in data research. However, the data and statistics community are still missing the key tools, resources and guidance needed to embed these standards in practice. The PEDRI Learning and Development Working Group aims to provide the data research community with the knowledge and skills they need to carry out effective public engagement. PEDRI has started to improve navigation to existing resources on public engagement in data research through the establishment of the PEDRI resource hub, but challenges still remain.

DARE UK programme recommendations highlight the need for greater consistency in transparent communication about sensitive data use and emphasises the importance of embedding public involvement and engagement (PIE) throughout the sensitive data research lifecycle to demonstrate trustworthiness. However, researchers often lack the training and confidence to communicate about complex data topics in accessible and sensitive ways, while public contributors are frequently engaged too late in the research cycle to shape meaningful outcomes.

To address these challenges, the PEDRI Learning and Development Working Group will deliver two core outputs. Firstly, the co-development of an online series of learning modules focused on strengthening the capacity of data researchers and data professionals to engage public members effectively. This will support more consistent and transparent communication around data use, while also establishing good practice for public engagement early in the data research lifecycle. The second output will build on PEDRI's existing digital resource hub by developing a dedicated focus on public attitudes toward data use. This strand of work is distinct from the hub's broader collection of tools and guidance. It aims to reduce duplication of effort across the sector by collating, synthesising, and signposting to existing evidence and insight on public views. This will enable data professionals, researchers, and PIE specialists to better understand the context in which they are working and make informed, evidence-based choices about how to approach public engagement. By offering practical pathways through existing knowledge, this output directly addresses a frequently cited barrier in the data and statistics community: the difficulty in accessing relevant insight to

shape effective and meaningful engagement strategies. As part of this second output, a searchable database of public groups and networks will be developed. This will make it easier for PIE professionals, researchers, and data professionals to identify and connect with relevant communities, enabling more targeted and meaningful engagement around specific data topics. By expanding the functionality of the existing hub in this way, PEDRI aims to remove a key barrier often cited in the data and statistics community, the difficulty of finding and engaging with public audiences.

The WHAT

(3) A reasonably detailed description of the intended output(s) that will be delivered through this WG.

Output 1: Online learning modules on public engagement in data research

To design and deliver a series of online, CPD-accredited learning modules to build capacity among data researchers and data professionals in meaningful, inclusive public engagement with data research.

The module content will cover three core themes:

1. Introduction to PEDRI Good Practice Standards for Public Engagement
   - Offering practical guidance to support the embedding of the PEDRI Good Practice Standards different scenarios with case studies from PEDRI partners
   - Including how to apply the standards to both health and non-health contexts, working closely with ADR (Administrative Data Research) UK and Office for National Statistics (ONS) to identify relevant examples
2. Communicating the use of sensitive data in clear, engaging ways with a trauma-informed approach
   - Exploring two-way communication techniques that support understanding and transparency about sensitive data use
   - As well as developing co-creation and facilitation skills that support inclusive, empathetic and compassionate approaches to sensitive topics of discussion
3. Tracking impact and evaluating successful public engagement in data research
   - Supporting learners to evaluate engagement activities against the PEDRI Good Practice Standards using PEDRI's newly developed evaluation framework
   - Providing tools to track and communicate PIE impact meaningfully, encouraging continuous learning practices

Co-developing this content with working group members, PEDRI partners and the PEDRI Public Advisory Group (PAG) will ensure modules are grounded in real life case studies of good practice and brought to life through interactive quizzes, visuals and expert contribution.

These modules will be initially piloted with a small cohort of researchers and data professionals to test content and delivery. Feedback gathered during this pilot will inform refinements before the modules are made freely available. By developing these modules in a flexible online format, the output will support continuous professional development in the sector beyond the funded project period, directly addressing recognised gaps in researcher confidence and capability in engaging the public around the use of sensitive data.

Output 2: Enhancing PEDRI's Resource Hub

To enhance PEDRI's existing resource hub to better meet the needs of data researchers, data professionals and PIE professionals and encourage the embedding of public involvement and engagement at the earliest stages of the data research lifecycle. This extension will consist of a curated, interactive suite of tools and materials aimed at overcoming common barriers to early engagement.

A central feature will be a searchable directory of existing public involvement groups, beginning with PEDRI partner organisations to identify existing groups and expanding to include disease-specific and data-focused networks. This will help researchers identify and connect with relevant public contributors during the early design of projects, particularly at the point of research question generation.

To complement this, we will enhance the searchability function of the existing tools and guidance page to highlight public insights and attitudes on data research topics drawing from previous consultations, deliberations and public dialogues. This will allow researchers, data and PIE professionals to explore public perspectives on key themes, helping reduce duplication of engagement efforts and grounding new projects in existing public priorities.

By integrating these components into PEDRI's website, which already has an established engaged audience, the resource hub expansion will help ensure that public voices actively shape data research from the outset.

The WHO

(4) Why is this WG and its proposed members the right group to tackle this?
(5) Which communities will be involved and what relevant skills/knowledge/experience do they have?

PEDRI unites different UK organisations working with data and statistics to improve how we all work with the public. This offers a unique opportunity for collaboration as PEDRI partners and PEDRI PAG bring together a variety of expertise and perspectives on public engagement within health and non-health data contexts. Core PEDRI team members Doreen, Samaira, Ester and Amy offer invaluable insights into public involvement and engagement best practices and understand the needs of the community after working within this space for 2 years. Co-chair Amy is the current Learning and Development Lead at PEDRI and has a background in developing training, toolkits and guidance to support professionals to carry out effective involvement and engagement. She has also led on the development and maintenance of the existing PEDRI resource hub. Co-chair Samaira is the current Partnerships and Operational Lead for PEDRI as she oversees all PEDRI workstreams she provides crucial leadership for this working group.

Public involvement and engagement will be embedded throughout this work. Working group member Jan, co-chairs PEDRI's PAG and provides a vital public perspective, as well as having already contributed substantially to the development of the existing PEDRI resource hub. We will also work with our wider PEDRI public partners and external public representatives to seek valuable advice on the design and implementation of our training course and resource hub to ensure they reflect public needs.

Working with partners from Health Data Research UK (HDR UK), Cancer Research UK, Understanding Patient Data and ADR UK will provide both a health and non-health data point of view. Matt, Simon and Rosie have already been actively contributing to the PEDRI Learning and Development workstream, supporting the ongoing review of resources being continuously added to the resource hub. Rosie links to the HDR UK capacity team who have established HDR UK Futures, an online learning platform which has been used internationally. Charlie and Laura will ensure alignment with two key partners, Understanding Patient Data and ADR UK, identifying new opportunities for collaboration. We will also work with our partners at the ONS to ensure that relevant statistical data case studies and examples are integrated into this work.

The HOW and WHEN

(6) What related initiatives/groups/work – not represented through this WG or related IG membership – will the group engage with? Are there other adjacent or relevant WGs this group will coordinate and/or collaborate with?

PEDRI Good Practice Standard Working Group, PEDRI Communication and Engagement Working Group, Big Data for Complex Disease Programme, British Heart Foundation Data Science Centre, Use my Data, ONS and Office for Statistics Regulation (OSR).

(7) Describe how often the group will meet and sustain progress between meetings?

The PEDRI Learning and Development Working Group will meet monthly throughout the 12-month project, on a consistent day, providing regular opportunities for collective input, decision-making and review of progress. Key milestones in the project plan will be linked to meet dates to ensure collaborative decision making.

Each meeting will:

- Be supported by a clear agenda, circulated one week in advance
- Include standing items to review progress against milestones and delivery timelines
- Be recorded, with assigned actions and deadlines noted to ensure accountability

Between meetings:

- Activity will be tracked through shared tools such as Monday.com or Trello to track tasks, timelines and deliverables
- A shared drive will be used to keep key documents both for reference and co-development
- Tasks will be assigned to group members such as reviewing draft materials

(8) A high-level work plan describing intermediate milestones and output(s) that will be developed during the WG's work, and the overall timeframe (max. 12 months) for the WG to deliver the proposed output(s).

Phase 1: Scoping (October – November 2025)

Key activities:

- **Output 1:** Begin dialogue with data researchers and data professionals to identify learning requirements
- **Output 2:** Scope existing PIE networks and groups through PEDRI partners and the wider community
- **Output 2:** Conduct a desk-based review of existing public consultations, deliberations and dialogues (both health and non-health). Collect existing reports and outputs from PEDRI partners
- Begin discussions with web developers for enhancement of resource hub and development of online modules

Milestones:

- **Output 1:** Define learning objectives for online modules and finalise three core topics
- **Output 2:** Compile list of PPIE networks and public opinion resources
- Draft structure for extended hub and online modules within website functionality

Phase 2: Planning (December 2025 – February 2026)

Key activities:

- **Output 1:** Begin dialogue with PEDRI partners, PEDRI PAG and wider public audiences to co-develop content for modules

- **Output 1:** Scope for case studies of good practice and subject matter experts from PEDRI partners and wider community
- **Output 1:** Explore CPD accreditation
- **Output 2:** Identify core themes for categorising public attitudes and insight materials
- **Output 2:** Define PIE network directory structure (e.g., region, topic, group remit, contact status)

Milestones:

- **Output 1:** Co-create storyboards for each module
- **Output 1:** Identify case studies to support module content
- **Output 2:** Develop tagging system by applying emerging themes to public insight reports
- **Output 2:** Determine with web developers the technical feasibility for resource hub enhancements

Phase 3: Development (March – May 2026)

Key activities:

- **Output 1:** Draft written content for each module in plain language
- **Output 1:** Identify infographics, diagrams and visual aids to support written content
- **Output 1:** Draft and record voiceover/video scripts
- **Output 1:** Create quizzes or interactive checks for each module
- **Output 2:** Developers build backend structure for resource hub enhancement features

Milestones:

- **Output 1:** Module content is built with Articulate Rise
- **Output 2:** Upload and tag public insight reports and resources onto hub
- **Output 2:** Populate searchable database with verified PIE group entries from partners

Phase 4: User Testing (June – August 2026)

Key activities:

- **Output 1:** Test online modules with 6-10 researchers and gather feedback
- **Output 2:** Conduct user testing on enhanced resource hub with PEDRI partners and PEDRI PAG

Milestones:

- **Output 1:** Make improvements to modules, focusing on navigation, clarity and accessibility
- **Output 1:** Submit materials for CPD accreditation
- **Output 2:** Make improvements to website layout, tags and functionality

Phase 5: Launch (September 2026)

- **Output 1:** Officially launch online learning modules on Reach 360, with signposting information on the PEDRI website
- **Output 2:** Officially launch enhanced hub on PEDRI website
- Promote outputs through PEDRI bulletin, PEDRI partner networks and social media

(9) Do the output(s) have potential for adoption by the target beneficiaries articulated in (1)? What is the adoption or implementation plan for WG member organisations? Such adoption or implementation should start before the WG timeframe is complete.

Output 1 will produce a set of free and publicly available CPD accredited online training modules, specific to supporting good practice in public engagement with data research. This, alongside the enhanced resource hub in output 2 will support communication and engagement capabilities of PIE professionals, data researchers and data professionals.

Collaboration with working group member organisations, PEDRI partners and public contributors will ensure wider engagement with the training courses and expanded resource hub. We will work with PEDRI's Communications and Engagement Working Group to support dissemination of both outputs across different platforms (e.g. social media, blogs, webinars).

<u>Potential members:</u> [Including a minimum of two proposed chairs and all members who have expressed interest]

FIRST NAME	LAST NAME	EMAIL	(Co-)Chair / Member
Amy	Hodgkinson	Amy.hodgkinson@hdruk.ac.uk	Co-chair
Samaira	Khan	Samaira.Khan@hdruk.ac.uk	Co-chair
Doreen	Tembo	Doreen.Tembo@hdruk.ac.uk	Member
Ester	Bellavia	Ester.Bellavia@hdruk.ac.uk	Member
Rosie	Wakeham	Rosie.Wakeham@hdruk.ac.uk	Member
Jan	Speechley	Jand3406@hotmail.co.uk	Member
Simon	Jobson	Simon.Jobson@hdruk.ac.uk	Member
Matt	Howard-Murray	Matt.HowardMurray@cancer.org.uk	Co-chair
Charlie	Wilkinson	charlie.wilkinson@understandingpatientdata.org.uk	Member
Laura	Mulvey	Laura.Mulvey@esrc.ukri.org	Member

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.