DARE UK (Data and Analytics Research Environments UK)

DARE UK Working Group (WG) Charter Template

Name of Proposed WG: PEDRI PIE Standards Evaluation and Adoption Group
Affiliated DARE UK Interest Group (if applicable): 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. *

The proposed Working Group will address the need for a robust, standardised evaluation tool to assess adherence to the PIE Good Practice Standards (GPS) in data-driven research. This aligns with DARE UK's mission to ensure data research is ethical, inclusive, and aligned with public trust by fostering best practices in public involvement and engagement (PIE). The WG will deliver a value adding output: a comprehensive evaluation tool that integrates with existing PIE frameworks, ensuring continuous improvement and practical adoption of the PEDRI GPS. This will help the sensitive data research community measure, refine, and demonstrate high standards in PIE practices, promoting trust and transparency.

By evaluating adherence to the PIE GPS, the proposed tool will ensure that organisations meaningfully involve and engage diverse stakeholders. This is essential as data research increasingly intersects with public concerns, privacy, and societal impact.

The outputs will be highly beneficial for multiple stakeholders. For researchers and practitioners, they provide a structured framework to evaluate and enhance their PIE practices. Organisations will gain tools to align with best practices, enabling accountability and public trust. For the public, these efforts ensure data research reflects their needs and concerns, boosting confidence in its integrity. Key beneficiaries include academic and private researchers, organisations in health, social, and public sectors using TRE's and SDE's and public-led advocacy groups like Use MY Data.

The WG's outputs align closely with DARE UK programme recommendations by enhancing public trust through transparent, public-informed PIE practices and operationalising PEDRI's GPS. They support alignment and collaboration by building on PEDRI's partnerships and engaging senior executives in a webinar to promote sectorwide integration of the standards. Additionally, the WG contributes to improving ethical data research frameworks with a tailored, adaptable evaluation tool, while strengthening monitoring systems by piloting and refining the tool to measure benefits and address gaps in PIE practices effectively.

The WHAT

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

The PEDRI Working Group will deliver several interconnected outputs to advance the implementation and evaluation of the GPS. These outputs are designed to ensure alignment with public and sector needs, support continuous improvement in PIE practices, and also broad adoption of the standards across different organisations.

Development of a GPS Evaluation Tool

The focus of this WG will be a robust evaluation tool to measure and ensure adherence to PEDRI's GPS by organisations and researchers. This tool will:

- **Include clear and detailed evaluation criteria** - the tool will align with GPS guidelines and integrate feedback from stakeholders, ensuring it reflects the needs of diverse users.
- **Offer pre-designed templates for recording and organising information** - standardised templates will facilitate structured assessments, simplifying the process for organisations.
- **Include Scoring Practices:** Clear, actionable scoring mechanisms will guide organisations in evaluating their adherence to the GPS.

The PEDRI PIE Standards Evaluation and Adoption Group will oversee the tool's development, supported by a dedicated staff member who will manage stakeholder consultations, co-develop resources, and conduct iterative testing. The tool will also leverage insights and resources from the DARE UK-funded PEDRI Resource Hub to ensure integration with existing frameworks and avoid duplication.

GPS Funding Call to Encourage Adoption

To drive the adoption of the GPS, PEDRI will introduce a small-scale funding call. This initiative aims to lower barriers for organisations seeking to adopt the standards. Key aspects include:

- Small grants (£500–£1,000) will be provided to organisations to adopt two or more GPS standards. Full adoption is not a prerequisite, ensuring flexibility.
- Funded projects will serve as pilot case studies, capturing innovative examples of GPS implementation. These will be shared to inspire and inform broader adoption.
- A panel comprising the PEDRI Senior Partnerships Manager, PAG members, and the GPS Working Group will manage the call. Funding will prioritise a balance of health and non-health data organisations.

This targeted funding call will help organisations overcome practical challenges in implementing GPS while advancing knowledge-sharing and collaboration. This will be funded by HDR UK but developed and designed by PEDRI PIE Standards Evaluation and Adoption Group.

Executive Frontiers Webinar

To promote widespread adoption of the GPS and ensure senior-level engagement, PEDRI will host a hybrid Executive Frontiers Webinar. The event will feature:

- A Roundtable Discussion with senior directors from diverse sectors will explore the implementation and impact of GPS.
- Clear, actionable recommendations on GPS adoption will be developed and widely disseminated.
- The webinar will provide a platform to highlight successes and address challenges, promoting alignment and collaboration across the sector.

The event will be recorded and distributed to ensure its insights reach a broader audience. It will emphasise how GPS can enhance transparency, equity, and public trust in data research.

The WG will explore the feasibility of an accreditation system, possibly introducing a "kite mark" certification to encourage adherence to GPS and enhance credibility. This will involve consulting stakeholders to create a practical accreditation framework and developing a detailed plan, led by a project officer, to define the criteria, processes, and implementation roadmap. The accreditation will serve as a clear indicator of commitment to PIE best practices, strengthening trust and accountability in data research.

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?

This Working Group is well-positioned to advance the PIE GPS due to the unique expertise, diverse perspectives, and extensive experience of its members. All members have been actively involved in the development of the standards and represent PEDRI partner organisations that are committed to adopting them. This strong foundation, combined with the working group's communications and planning expertise, will be essential for the successful development and execution of our initiatives.

We will collaborate closely with PEDRI partners through quarterly steering group meetings to gather input on our plans and leverage their wider networks to amplify engagement across all areas of work. This approach will not only support broader adoption of the standards but also ensure that we reach all four nations where possible. Furthermore, by working directly with our PAG we will seek valuable advice on design, implementation, and engagement to ensure the initiative reflects public needs and concerns. Close collaboration with PEDRI members such as Use MY Data and Understanding Patient Data will support our outreach efforts with an aim to drive meaningful engagement.

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?

We will work with UK TRE, COP SDE networks to enhance our efforts of uptake as well as working with PEDRI partners.

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

The group will convene monthly, utilising the workplan/Gantt chart as a reference point to assess our advancement. During these monthly meetings, a standard agenda will be followed to evaluate progress across all facets of our work. Additionally, these sessions will offer a collaborative platform to address any concerns or challenges, fostering collective discussions for finding solutions.

In the interim between meetings, we will employ project management tools such as Monday.com to monitor and track progress across all work areas. This includes task assignment when necessary and diligent follow-up on pending actions.

(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).
(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.

-

Development of the GPS Evaluation Tool:

- **Feb - June:** Design and development of the evaluation tool, followed by stakeholder consultation and pilot testing. The tool will be refined based on feedback.
- **Jun - Jul**: Final refinement and creation of dissemination plans for the tool.

Frontiers Hybrid Webinar

- **Mar - Jul:** Planning and co-development of the webinar agenda with PEDRI partners, including the identification of key speakers.
- **Sept/Oct:** Delivery of the webinar, followed by post-webinar evaluation and recommendations dissemination.

GPS Funding Call

- **Feb - Jul:** Design and development of the funding call, including assessment of applications, final shortlisting, and awarding grants to selected organisations.
- **Aug - Jan:** Monitoring of funded groups, reviewing case studies/reports, and evaluating the impact of the funding call.

PIE Activities

- **Feb - Jan:** Continuous public advisory group consultations and online involvement to ensure public involvement is central to the process.

Adoption of PEDRI GPS

- **Feb - Jan:** Collect feedback on GPS adoption from NHS SDE Network and other partners. Monitor the adoption progress and explore accreditation systems for the GPS.

The working group's outputs are directly aligned with the needs of researchers, health and public sector organisations, and public-led groups. The development of the GPS evaluation tool and funding call provides practical resources to support the immediate adoption of PIE best practices, encouraging early implementation within the timeframe. The Frontiers Hybrid Webinar will facilitate stakeholder engagement and promote collaboration on the PIE GPS, while ongoing PAG and stakeholder reviews ensure the outputs remain relevant. The exploration of an accreditation system will formalise adherence to the standards, enhancing credibility and trust. Collaboration with PEDRI partners and public representatives will ensure widespread adoption, including integration within NHS SDE Networks and targeting all four nations.

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

FIRST NAME	LAST NAME	EMAIL	(Co-)Chair / Member
Doreen	Tembo	doreen.tembo@hdruk.ac.uk	(Co-)Chair
Samaira	Khan	samaira.khan@hdruk.ac.uk	(Co-)Chair
Shayda	Kashef	Shayda.Kashef@esrc.ukri.org	(Co-)Chair
Jan	Speechley	jand3406@hotmail.co.uk	(Co-)Chair
Matt	Howard-Murray	Matt.HowardMurray@cancer.org.uk	(Co-)Chair
Neha	Okhandiar	neha.okhandiar@researchdata.scot	(Co-)Chair
Katie	Oldfield	katie.oldfield@researchdata.scot	(Co-)Chair

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.