

# DARE UK (Data and Analytics Research Environments UK)

## DARE UK Interest Group (IG) Charter Template

Name of proposed Interest Group: *PEDRI (Public Engagement and Data Research Initiative)*

### The WHY

**Introduction:** [A brief articulation of what broad-based challenge(s) or issue(s) the IG will address, how this IG is aligned with the DARE UK mission, and how this IG would be a value-added contribution to the sensitive data research community]

PEDRI has set significant objectives within the domain of data intensive research. Our goals encompass ensuring sector wide best practices in public engagement and involvement in data intensive research, establishing a supportive community program, creating a central resource hub, and conducting national awareness campaigns to educate the public. These initiatives align with DARE UK's mission, which centres on building trust between the public and the data research community. Through these pursuits, PEDRI will make a valuable contribution to the sensitive data research community and the wider data intensive research community by enhancing transparency, expanding inclusivity, and promoting adoption of best practices. This, in turn, cultivates a stronger sense of trust and confidence in the field of data intensive research, a key challenge in this domain. Another challenge in this field is providing support for patient and public involvement professionals. A support network and resource hub will serve as a point of assistance for professionals to collaborate, find solutions to challenges, and avoid duplicating efforts or reinventing the wheel.

**User scenario(s) or use case(s) the IG wishes to address:** [what triggered the desire for this IG in the first place]

### The WHAT

**Objectives:** [Set of focus areas for discussion linked to the driving user scenario(s)/use case(s) above, articulate how this group is different from other such groups inside or outside of the DARE UK programme, which specific strategic theme within the [DARE UK programmes recommendations](#) (see page 19) is this IG primarily aligned with. \*]

PEDRI's core objectives align with several of DARE's recommendations, notably the aspect of 'demonstrating trustworthiness.' PEDRI is committed to being a driving force in fulfilling these objectives and contributing to building trust with the public. While Public Involvement and Engagement (PIE) has been explored to some extent, to our knowledge, there is currently no predominant group dedicated to PIE specifically in the realm of data-related matters. PEDRI's core objectives have acted as a compelling incentive for individuals and organisations to join our initiative. The fundamental need for a community focused on identifying solutions for PIE in the context of data research serves as the driving impetus behind PEDRI's mission. As PEDRI encompasses health and non-health data, We believe that PEDRI will not duplicate work of existing groups such as useMYdata or Understanding Patient Data, instead it will encourage cross-organisational coordination and communication using our existing connections within the Alliance and other partners. The Alliance will serve PEDRI as a vehicle to reach out to existing groups, with the aim is to drive alignment, encourage sharing of resources and signposting to best practice. The PEDRI sub-group will facilitate this by bringing together health data organisations.

**Outcomes:** [What does this IG intend to achieve including outputs that may lead to WG topics, any initial ideas on outputs that could be delivered through WGs spawned under this IG]

1. **Development and Adoption of PEDRI Standards:** PEDRI seeks to finalise Best Practice Standards (BPS) for Public Involvement and Engagement in Data Research and Statistics. The outcome of this effort could lead to potential Working Group topics related to the implementation and adherence to these standards, as well as monitoring their impact on data research practices.
2. **Community Engagement and Knowledge Sharing:** PEDRI plans to establish a community program and promote knowledge sharing within the sector. This could give rise to WG or sub-group discussions on community engagement strategies, effective knowledge-sharing practices, and methods to enhance inclusivity and transparency in data research.
3. **Central Resource Hub and Website Enhancement:** PEDRI intends to create a central resource hub and improve the functionality of its website. Subsequently, WGs may support the Website re-design and explore topics related to the maintenance and expansion of this resource hub, ensuring it remains up-to-date and useful for researchers and professionals.
4. **National Public Awareness Campaigns:** The IG aims to plan national awareness campaigns. A WG would work on developing a plan which considers public awareness strategies and effective communication methods for campaigns on public perceptions of data research. The WG will also actively link into and work with other actors involved in Campaigns (e.g., Department of Health and Social Care, NHS England, and the Sub-national Secure Data Environments)

These initial ideas for outputs and potential WG topics demonstrate how PEDRI's efforts could lead to the development of specific initiatives and discussions that contribute to the sensitive data research community and the broader data intensive research ecosystem.

### The HOW

**Participation/Collaboration:** [Which communities will be involved, and what relevant skills/knowledge/experience should they have, are there other adjacent or relevant IGs/WGs this group will coordinate and/or collaborate with]

**Mechanism:** [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.

**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	samira.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.*