

Public Engagement in Data Research Initiative Governing Board

Date: Friday 17th January

Chair: Cassie Smith

Welcome and introductions

- The Board welcomed Katie Oldfield who has joined the Board representing RDS.

PEDRI Update on Last Quarter

- PEDRI are in discussion with Clinical Practice Research Datalink (CPRD) about joining as a new partner.
- PEDRI successfully recruited a Project Coordinator who will start on 5th February.
- PEDRI presented a poster on the Good Practice Standards (GPS) at the European 'Data Saves Lives' meeting in Brussels. Led to multiple networking opportunities.
- PEDRI attended both a UKTRE event and a meeting held by the National Data Guardian to talk about the GPS.
- The first PEDRI Public Advisory Group (PAG) meeting was held in December. Discussions focused on EDI and what PEDRI should focus on in this area. The PAG agreed to write a blog on this topic. It's important to consider this in the context of discussions around diversity in data specifically.
- PEDRI have submitted two funding bids since the last meeting to UKRI and DARE UK. The DARE UK bid was successful.
- PEDRI are working with the Department of Health and Social Care on a series of cohort deliberations.
- What is the scope of PEDRI? This needs to be taken into account when promoting the GPS and collaborating with new partners. The current strategy is to prioritise stakeholders in the non-health space as this is a gap. The team would also like to diversify the current focus away from SDE/TRE, if necessary.

1. Good Practice Standards workstream:

- Final version of the GPS is on the website: Our work - PEDRI
- Details of what has changed between the draft and final versions are in the final report which can be found on the website: PEDRI: Findings from our Public Consultation on the Best Practice Draft Standards for the Data for Research and Statistics
- A journal paper submission on the GPS is being developed
- A case study, working with NHS SDE network, on how the standards have been adopted by them in their work is being developed. It might be helpful to include relevant case studies from DARE UK here.
- An evaluation framework is being created for the GPS. DARE UK funding will support this.

2. Learning and Development workstream:

- The results of a survey used to identify PIE resources for data and statistics research are being written up in an internal report. This will be shared with the Governing Board.

- The team are developing a call to action for PEDRI partners to prioritise and contribute to the development of new resources to address the gaps identified by the survey.
- Synopses of existing resources are being created and the team is aiming to upload 10 resources per month to the Resources Hub on the PEDRI website. A 'resource of the month' related to current topics of discussion will be highlighted on the website.

3. **Comms and engagement workstream:**

- A new [PEDRI website](#) and branding have launched. Three blogs on the new branding were shared on the website in November (written by UKLLC, SK and AW). ADRUK is also writing a blog.
- New branded documents and other resources are available on the website.
- A baseline for website traffic has been established based on traffic between November until end December 2024. Going forward the team hopes to use these baseline figures to monitor engagement, potential new collaborations and use of the Resource hub.
- A webinar to promote the GPS is planned for April.
- It may be worth connecting with NCCPE's Head of Communications to collaborate on comms activities (e.g. write and share a feature blog via NCPPE's newsletter and possibly run events for universities).

4. **Roundtable on project level PIE for SDE and TRE access**

- A roundtable meeting on project level PIE for SDE and TRE access took place in November. Paper 1 summarises the discussions that took place.
- UK LLC have written a blog to share their reflections on the discussions at the roundtable.
- RDS and PEDRI submitted a proposal for delivering a workshop as part of the NHS Scotland PIE event in 2025 to build on roundtable discussions.
- A follow-up meeting is planned to explore solutions to the challenges identified. The aim is for the group to develop a consensus paper on challenges and solutions and to develop relevant resources to support solutions. There is a lot of interest from other organisations in supporting this work.
- There seems to be a gap around career progression for PIE professionals. This topic was not raised at the meeting but it would be good to explore and involve DARE UK in this.
- There has been a lot of work on PIE in the SDE/TRE space but the roundtable brought together those who are implementing this and how it intersects with governance. It would be good to capture studies of how people are doing it and recommendations for good PIE. RDS are doing this with their Researcher Access Service.

PEDRI Frontier Meeting

- Paper 2 (PEDRI Strategy Summary) outlined the significant strategic role PEDRI can play in embedding PIE and fostering ethics, transparency and trustworthiness in the data research ecosystem across the UK. It has been suggested that PEDRI showcase its work to funders at a Frontiers meeting. DT asked for thoughts on the paper and about the Frontiers meeting.
- Carrying out high quality PIE is an essential component of a funding call. Funder systems and processes should reflect this. How can PEDRI enable the sector to meet these expectations?
- PEDRI is a small team with huge ambitions. There is a concern about how realistic it is that the team can deliver all the new activities (e.g. setting up a Behavioural Science unit). DT said that the team would look to form a partnership with a university to set up a Behavioural Science unit.
- The National Data Library could be a big opportunity. How can PEDRI add value here?

- The suggestion to accredit the GPS with a Kitemark is key. Has PEDRI considered providing a Kitemark assessment as a paid for service? DT highlighted that PEDRI are looking to learn from the Athena Swan scheme as a model for this. DARE UK funding will support a feasibility study for Kitemarking, how could it work and what others are doing.
- A Kitemark has to be something very tangible before an assessment service could be offered. From a PIE perspective it is important that the Kitemark is externally benchmarked, well established and trusted before it is promoted.
- PEDRI is occupying a unique space, offering a forum for speaking with one voice and presenting a coherent message whilst empowering partners to elevate their own efforts.
- There is a need for PEDRI to demonstrate their ability to deliver before seeking out further funding opportunities. It is important to maintain a focus on PEDRI's USP. It would be helpful to understand how decisions on priorities are made.
- OSR has a voluntary application scheme for its Code of Practice so organisations can choose to adopt the principles. HM-B offered to discuss this approach in more detail and flagged that OSR's legal team has indicated that a legal basis is required for a Kitemark.
- A fellowship scheme would be a huge endeavour, but there are existing initiatives which PEDRI could offer to partner with (e.g. OSR has put itself forward as potential partner for Centre UB Early Career Researcher fellowship scheme).
- Timing is key to discussions with funders. External factors/events may drive the timing of discussions with funders (e.g. The National Data Library).
- It is important to talk to the right people in funding organisations; we need to speak to those who look after data portfolios.
- General consensus amongst the Board was agreement that PEDRI needs to outline a clear set of activities/priorities before applying for further funding especially as funders might not want to explore models just for data research.

PEDRI Forward Look 2025

- PEDRI Theory of Change: The team will consider the 'quality vs quantity' discussion at the Away Day on 10th February. It was agreed that a separate session is needed to develop the Theory of Change with the Governing Board
- DARE UK Funding: An Impact Specialist will be recruited to develop an evaluation tool/framework for the GPS. They will coordinate workshops for development of the evaluation tool and will also develop the funding call for adoption of the standards.

<p>Action: SK to circulate a Doodle Poll to assess availability for a Theory of Change session.</p>
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Board Member Updates

- A priority for OSR in 2025 is refreshing the Code of Practice for statistics. A public consultation is currently running outlining OSR's proposals for how OSR includes users and the public in its work (*consultation closed 14 Feb*).
- A report on enabling data sharing for statistics research, which sets out a high-level brief statement on what government needs to focus on to further data sharing, is now available.
- CRUK held its first data driven conference last year and is now thinking about the next one which will be in Edinburgh on 25-27 Feb 2026. They welcome PEDRI involvement either as a stand holder or a speaker. A data driven research PIE network in will be launched in March 2025.

- Last summer the Welsh Government delivered a public dialogue on contacting people about research opportunities with the [National Centre for Social Research](#). Funds are available to do more work related to this in partnership with HRA and focussing on who can access data and for what purposes. DT expressed interest in following up on this piece of work as HDR UK is currently having a debate on the issue of ‘re-contacting’.
- ADR UK has published a report on a piece of work commissioned to evaluate the Integrated Data Programme. The report validates ADR’s model of working with government to open up access to administrative data for research and looked at whether ADR UK is building trustworthiness in what it does with the public.
- A Pan-UK Information Governance Frontiers meeting took place at HDR UK on the 15th January. Standards to support the Five Safes framework were considered. There was great enthusiasm for adoption of the standards.
- Nicola Hamilton has now left Understanding Patient Data.

Attendees	
Name	Organisation
Emma Gordon	Administrative Data Research UK (ADR UK)
Nicola Perrin	Association of Medical Research Charities (AMRC)
Melissa Lewis-Brown	Cancer Research UK (CRUK)
Fergus McDonald	Data and Analytics Research Environments (DARE UK)
Cassie Smith	Health Data Research UK (HDR UK) & British Heart Foundation - Data Science Centre (BHF-DSC)
Paul Manners	National Co-ordinating Centre for Public Engagement (NCCPE)
Helen Miller-Bakewell	Office for Statistics Regulation (OSR)
Doreen Tembo	PEDRI & HDR UK Alliance
Larisa Florea	PEDRI
Samaira Khan	PEDRI & BHF-DSC
Sally Boylan	PEDRI
Katie Oldfield	Research Data Scotland (RDS)
Joe Cuddeford	Smart Data Research (SDR UK)
Ceri Steele	Use MY Data (UMD)
Alex Newberry	Welsh Government
Apologies	
Layla Robinson	RDS
Robin Flaig	UK LLC

Next meeting: Wednesday 2nd April