

Public Engagement in Data Research Initiative Governing Board

Date: Thursday 2 July 2026

Time: 13.00–14.30

Chair: Cassie Smith (HDR UK, BHF DSC)

Secretariat: Doreen Tembo, Samaira Khan, Katie Porter (PEDRI)

Welcome and key updates

Member introductions

- Adam Bradley has joined the Governing Board as DARE UK's representative.
- Richard Ballerand joined the meeting as use MY data's representative
- Spela Godec joined the meeting as Understanding Patient Data's representative.
- Katie Oldfield joined the meeting as Research Data Scotland's representative.

Team updates

- Basil Udeh has joined the PEDRI team through HDR UK's Black Internship Programme as Ethics and Public Engagement Officer for 12 weeks.
- Katie Porter has been promoted to Programme Manager within the PEDRI team.

PEDRI updates from last quarter

The Board received an update on PEDRI activities undertaken during the previous quarter.

- PEDRI supported a [Data Science for Health Equity webinar on inclusive PIE](#). Two of the project leads awarded PEDRI From Standards to Impact funding presented on their work as part of this Webinar.
- Delivered two successful PEDRI webinars in the last quarter:
 - [Talking data: Deliberative approaches to engagement on complex data issues \(June\)](#)
 - [Data meets creativity: Arts-based approaches to data engagement \(April\)](#)
- Continued to strengthen cross-sector collaboration through participation in Use my Data's National Patient Data Day. This four-way collaboration between Understanding Patient Data, Connected by Data, use MY data and our team also included the webinar "[Collaborating for Impact: Building Capacity for Public Engagement in Health Data](#)," which supported shared learning and strengthened public engagement capacity across the wider health data ecosystem.
- NCCPE Engage Summit: PEDRI had a poster presentation and oral presentation, co-delivered with a public partner.
- DARE UK Community Groups event: Presented on the Good Practice Standards.
- Digital Footprints Conference: Presented on the Good Practice Standards.

- Successful abstract submission to the International Clinical Trials Methodology Conference relating to Young Voices in Cancer Data Research project.
- Published blogs on:
 - [How PEDRI partners are adopting the Good Practice Standards at their organisations](#)
 - [DARE UK 'Making it happen' blog on delivering the AI public dialogue](#)
- Involved in Genomics England workshops on developing public involvement and engagement principles utilising the PEDRI Good Practice Standards
- Met with the Department for Science, Innovation and Technology (DSIT) regarding the National Data Library (NDL), the Good Practice Standards, and how the Standards could support accessibility.
- Delivered a webinar in collaboration with NIHR RSS and the Health Data Science strand of the NIHR Applied Health and Care Research Methodology Incubator.
- Delivered a PEDRI training session at Lancaster University for researchers on public involvement and engagement in data research and statistics, with 19 participants and strong engagement.
- Successful acceptance of three PEDRI abstracts for the IPDLN Conference.

Learning & Development project

The Learning and Development project is funded by DARE UK and runs from October 2025 to October 2026. Key outputs include enhancement of the PEDRI Resources Hub, including a searchable directory and new landing page, and two training modules on PIE in data research and statistics.

Young Voices in Cancer Data Research

An update was provided on the progress of the Young Voices in Cancer Data Research project. Key learnings include:

- Good engagement with children and young people (CYP) and parents/carers.
- Recruitment of young people aged 16 to 19 continues to present challenges.
- Emerging findings indicate:
 - Strong willingness among CYP to contribute.
 - High levels of engagement.
 - A desire for meaningful involvement in research activities.
- Participants expressed a strong interest in co-developing an associated app, which is currently in the scoping phase.

Next steps:

- Work with Centre for Ethnic Health Research to help increase diversity and inclusivity of our CYP from different communities.
- Dissemination of findings through conferences and events. For example, successful abstract for the [International Clinical Trials Methodology Conference](#).
- Exploration of involvement opportunities with additional charities.

PEDRI Forum 2026

- 62 abstracts were received across four thematic areas. The quality of submissions was high. Abstracts were relatively well balanced across the four themes. Submissions were received from across the UK and a couple from overseas.
- Secured speakers for a PEDRI Forum 2026 panel discussion, including Mary De Silva (DHSC), Bernadetta Lacey (DSIT), Emma Gordon (ADR UK), Joe Cuddeford (SDR UK), Caleb Meath (ABPI) and Jan Speechley (Public Partner), focused on building a culture of public involvement and engagement in data research. Confirmed speaker information will be made available via the website.

Ethical PIE in data research and statistics

Doreen Tembo presented ongoing work relating to ethical PIE in data and statistics. The work has emerged through a Health Research Authority (HRA) subgroup focused on ethics. There is growing interest across health and social care research regarding the ethics of PIE.

Concerns have been identified about potentially unethical engagement practices and insufficient use of trauma-informed approaches. The project aims to explore what ethical PIE should look like within data research and statistics.

Board comments

Members highlighted several areas for further consideration:

- Engagement with [Nuffield Council on Bioethics](#) may be beneficial.
- Ethics remains a complex area. UK LLC faces challenges regarding publication of PIE work without ethics approval. Robin would like to be involved in this work.
- Existing ethics guidance from the University of Edinburgh may provide useful insights.
- Sophie Staniszewska was identified as a key stakeholder to consult.
- The scope of the project was questioned regarding whether it should be limited to pre-funding engagement activities. This was identified as key area by the Steering Group, however, is not definite. The scope can be adjusted.
- The Board highlighted that the project needs to avoid creating tension between encouraging ethical practice and reinforcing the principle that formal ethics approval is not generally required for PIE activities.
- The HRA group do not want PIE to go through formal ethics, but instead a ethically informed approach is needed that avoids unnecessary bureaucracy whilst still ensuring appropriate scrutiny.
- It was highlighted that the project should look at high- and low-level risk PIE and include guidance for higher-risk activities and safeguarding requirements.

The Board supported further development of the work and ongoing stakeholder engagement.

Kitemarking for Good Practice Standards

Maham Zaman provided an update on the scoping review exploring whether a kitemarking approach could support implementation of the Good Practice Standards.

- The aim of this review is to see whether kitemarking would support effective implementation of the Standards and provide assurance regarding quality and trustworthiness.
- Stakeholder interviews were conducted to gather insights from partners and organisations.
- Limited support was identified for a formal certification model. Concerns were raised regarding whether certification would support meaningful cultural change in PIE.
- Lessons from comparators suggested the importance of flexibility and minimising administrative burden.

Board comments

Members noted that:

- Introducing entry costs or additional burdens could discourage the behaviours that PEDRI seeks to promote.
- Greater focus may be needed on supporting funders and institutions to adopt the Standards and influence review panels and researchers.
- Existing mechanisms, including the PEDRI Pledge, may already provide an appropriate foundation for encouraging adoption.
- Approaches that support reflection, self-assessment and continuous improvement may be preferable to a binary accreditation model

Members were invited to provide any additional feedback directly to Maham.

Board member updates

Update from Understanding Patient Data on sentiment tracking work (Spela Godec)

Spela Godec provided an update on the UK Patient Data Sentiment Tracker (Wave 3, May 2026). Key findings included:

- Ongoing concern among the public regarding the “wrong people” accessing data.
- Higher awareness of data use was associated with higher rates of opt-out across demographic groups.
- Lower awareness did not correspond with increased opt-out rates.
- A public dashboard is expected to be launched on the UPD website in autumn 2026.

Update from use MY data

- National Patient Data Day was successful and had a lot of engagement across the online events. Recordings:
 - [The Health Data Research Service: what does £600m of Government and Wellcome Trust money get you?](#)

- [How can the NHS benefit from patient data and not be ripped off?](#)
- A webinar on the Single Patient Record is scheduled for 30 September 2026.

Action Log

Actions which have been acted upon since April's meeting or remain open are outlined in the following table.

Action Item #	Action	Date reported	Assigned to	Status	Resolution / Comments
1	Save the date for the PEDRI Forum to be circulated.	9/4/26	Katie Porter	Closed	Circulated with minutes.
2	Samaira to send Paul Manners more information on training content for the modules.	2/7/26	Samaira Khan	Open	
3	Spela Godec to share presentation slides with the Board.	2/7/26	Spela Godec & Katie Porter	Closed	Circulated with minutes.

Attendees	
Name	Organisation
Emma Gordon	Administrative Data Research UK (ADR UK)
Adam Bradley	DARE UK (Data and Analytics Research Environments)
Emily Jefferson	DARE UK
Cassie Smith (Chair)	Health Data Research UK (HDR UK) & British Heart Foundation - Data Science Centre (BHF-DSC)
Paul Manners	National Co-ordinating Centre for Public Engagement (NCCPE)
Vahe Nafilyan	Office for National Statistics (ONS)
Doreen Tembo	PEDRI & HDR UK
Samaira Khan	PEDRI
Katie Porter	PEDRI
Katie Oldfield	Research Data Scotland
Joe Cuddeford	Smart Data Research UK
Steven McEachern	UK Data Service
Robin Flaig	UK LLC
Spela Godec	Understanding Patient Data (UPD)
Richard Ballerand	Use MY Data (UMD)

Alex Newberry	Welsh Government
Apologies	
Emma Gordon	Administrative Data Research UK (ADR UK)
Gail Rankin	Office for Statistics Regulation (OSR)
Layla Robinson	Research Data Scotland
Anna Steere	Understanding Patient Data (UPD)

Next meeting: Wednesday 30 September, 11.00-12.30