

Public Engagement in Data Research Initiative (PEDRI) Governing Board: Meeting Minutes

Date: Thursday 8 January 2026

[Link to action log](#)

Welcome

The Chair welcomed two new members: Steven McEachern (UK Data Service) and Vahe Nafilyan (ONS).

PEDRI Update on Last Quarter

Samaira presented updates on progress across the PEDRI workstreams and events over the last quarter (Oct-Dec 2025).

Collaboration & partnerships

- New partner: UK Data Service joined.
- Roundtable on EDI in Data Research and Statistics: [Summary report published.](#)
- Roundtable on strengthening PIE with AI in data research: Held on 20 November in York with 34 attendees. Summary report to be published at end of January.
- Roundtable for PIE for project level TRE/SDE access: Second roundtable planned for 26 January. [More information on the first roundtable held in 2024.](#)
- Abstracts accepted for conferences: Abstracts accepted for [NHS Scotland PPI Event](#), and [NCCPE Engage Summit](#).
- Presentations: Presented on PEDRI at a SDR Investments meeting and in a [TREvolution](#) Collaboration Café.
- Advice sessions: In conversation with [NIHR Research Support Services](#) to explore potential offer of advice sessions on PIE in data research and statistics.
- Strategic event planning: Exploring synergies with Understanding Patient Data, useMYdata and Connected by Data.
- Children and Young people project (PEDRI and Cancer Research UK): Ethics approval achieved and have recruited two young people to the advisory group.

Communications & engagement

- Webinars: Completed 2025 webinar series with sessions on [co-production in data research](#), [effectively engaging minority ethnic communities](#), and [creating a culture of PIE](#). Currently planning for 2026 series. Topic ideas for this series include AI, engaging children and young people, and arts-based engagement approaches (not an exhaustive list). Members were asked to contact the PEDRI team if they have ideas for other webinar topics.

Good Practice Standards

- GPS Toolkit: The Toolkit went to the Board for final sign-off before publication. The aim is to publish the Toolkit on an interactive webpage by April 2026. The Toolkit will be reviewed regularly, and user feedback will be captured via forms and from the community of practice for GPS funded projects.
- GPS funded projects: Projects kicked off on 1 November. The first monthly community of practice meeting was held with leads in December.

Learning & development

- Training (DARE UK funded): Development of the CPD-accredited training modules has started. Focus groups are being held this month to consult on potential content.
- Improving the Resources Hub (DARE UK Funded): This project focuses on building a new searchable directory to support connecting researchers with PIE groups, and improving the functionality of the [Resources Hub](#), which includes adding public attitudes reports.

Culture of PIE

- Pledge: Co-designed a [new infographic](#) to support the Pledge. All partners are encouraged to [sign-up to the Pledge](#).
- PAG: Plan to recruit more public members this year.

Kitemarking for GPS

Maham Zaman has been leading a scoping review to explore what kitemarking for the GPS could look like and any potential challenges with doing this. Recommendations from this review will be shared with the Governing Board and Steering Group to agree next steps.

The Governing Board highlighted important considerations such as the associated logistical and financial implications with being an accreditor, potential changes in relationship dynamics with others in the sector, and practicalities such as the validity of PEDRI as a kitemarking organisation. Changing to an accrediting body and policing a kitemark system would be a significant undertaking, PEDRI would need to consider whether this is the appropriate way forward as this work progresses.

Understanding Patient Data: Programme Plans

Anna Steere (Head of Understanding Patient Data (UPD)) gave an overview of upcoming programme plans and their public sentiment tracking work.

Upcoming plans included PIE community research; developing a practical tool to guide proportionality in public engagement; deep dive on refugees and asylum seekers needs around the use of health data; case studies/explainer resource on population health management; and creating a new audience-led website. UPD also look to have a greater convening role via a Health Data Compass.

UPD are experimentally using Kantar to support public sentiment tracking work. With this they can track media coverage and public debate on social media relating to specific topics. This can help to surface issues and guide decisions. They are currently exploring a range of topics such as single patient data, American tech giants, and digital ID. UPD plan to run a Kantar survey up to four times a year. If Governing Board members have a subject they would like to test, reach out to UPD.

Board members welcomed this work and were keen to see related outputs. The Board had a question on how these findings are acted upon and discussed the need for improving communications with the public on data research. Key points raised include:

- The need to proactively highlight positive, evidence-based stories in data research to counteract the negative. The NHSE/DHSC Health Data Public Panel have expressed a need for this.
- PEDRI needs to work as a collective to learn about misinformation being shared with the public and collectively decide on how to respond to it in a proportionate way. The PEDRI Comms and Engagement Working Group will start to look at a potential communication campaign addressing this for the next financial year (pending funding).
- In terms of countering negative sentiment, PEDRI should identify areas which are suitable to respond to. For other areas, PEDRI may need to support other teams in how they respond.

Financial sustainability and transition of PEDRI to a delivery-focused model

PEDRI has built strong foundations and is now exploring what phase 3 will look like. One aim for PEDRI in 2028 and beyond is to position itself as the national delivery organisation for PIE in data research and statistics. Phase 3 will include three major transitions:

- From partnership-building to sector-wide delivery, supporting organisations to implement standards, tools and training at scale.
- From early funder dependence to a diversified, resilient financial model, ensuring long-term sustainability.
- From influencing culture to driving measurable change, delivering sector-wide improvements in trustworthiness, transparency and public participation.

Board members discussed the future of PEDRI and diversification of funding:

- Consider what a thriving research and innovation system needs to be effectively managed. There is a compelling argument for funders to PEDRI as it is a platform to ensure quality of PIE and trustworthiness of what data research organisations do. This is a long-term strategic need. HDR UK could support this argument by explaining why PEDRI is so important for the wider data infrastructure landscape.
- Moving to a delivery organisation is key for the next phase of PEDRI. The children and young people project is a good example of PEDRI doing this already.
- There is a need to think about how researchers will use PEDRI for services in the future. But need to be careful about deskilling the research community by doing

PIE for them; instead, PEDRI should support the development of core skills to do PIE.

PEDRI Conference Autumn 2026

PEDRI is planning to host a one-day conference in Autumn 2026 (possible date: 22 September). This was discussed at the last Steering Group meeting and suggestions included providing a collaborative space to design solutions to tackle challenges in PIE, public members as co-speakers/co-chairs, and “speed data-ing” to connect researchers and organisations.

The Board highlighted suggestions for conference format and discussed sponsorship.

- Sponsorship costs could cover public members to attend for free and to support teams to have a public speaker in sessions.
- As there are many conferences already throughout the year, PEDRI could instead utilise what already exists to meet with the relevant audiences.

Board member updates

- DARE UK: The AI public dialogue pilot is complete. Findings from this will feed into larger 2026 UK-wide public dialogue. If any organisations are interested in collaborating, reach out to Fergus McDonald or Lizzie Waind.

Action Log

Full action log can be [accessed on Box](#). Actions which have been acted upon since September’s meeting or remain open are outlined in the following table.

Action Item #	Action	Date reported	Assigned to	Status	Resolution / Comments
1	PEDRI to have interim discussion with DARE UK on planned expenditure and aligning with DARE UK phase 3.	01/07/25 Repeated on 30/09/25	Doreen / Samaira	Closed	Doreen and Fergus have met to discuss.
2	Mark Gardner to contact Ceri Steele about doing an educational session on the public dialogue work for Use MY data.	01/07/26	Mark Gardner	Open	
3	To agree whether PEDRI partners will need to actively sign up to the Pledge	30/09/25	PEDRI delivery team	Closed	All partners expected to sign up to the PEDRI Pledge.

4	PEDRI to circulate GPS toolkit for comment by email for any comments	30/09/25	Katie	Closed	Circulated with agenda for meeting discussion.
5	Doreen to meet with Paul Manners to discuss further the PEDRI business plan and financial sustainability strategy.	08/01/26	Doreen and Paul	Open	

Attendees	
Name	Organisation
Emma Gordon	Administrative Data Research UK (ADR UK)
Nicola Perrin	Association of Medical Research Charities (AMRC)
Matt Howard-Murray	Cancer Research UK (CRUK)
Fergus McDonald	DARE UK (Data and Analytics Research Environments)
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)
Helen Miller-Bakewell	Office for Statistics Regulation (OSR)
Doreen Tembo	PEDRI & HDR UK Alliance
Samaira Khan	PEDRI & BHF-DSC
Katie Porter	PEDRI & DARE UK
Layla Robinson	Research Data Scotland (RDS)
Mark Gardener	Smart Data Research (SDR UK)
Alex Newberry	Welsh Government
Steven McEachern	UK Data Service
Robin Flaig	UK LLC
Anna Steere	Understanding Patient Data (UPD)
Charlie Wilkinson	Understanding Patient Data (UPD)

Ceri Steele	Use MY Data (UMD)
Apologies	
Joe Cuddeford	Smart Data Research (SDR UK)

Next meeting: Thursday 2 April 2026, 13.00-14.30