



Public Engagement in Data Research Initiative Governing Board

Date: Thursday 9 April 2026, 11:00 – 12:30

Welcome

Cassie Smith welcomed Board members and provided key updates, including:

- New PEDRI partners: [Smart Data Foundry](#) and [Understanding Society \(The UK Household Longitudinal Study\)](#).
- Work is ongoing to simplify PEDRI's Theory of Change which was signed off by the Governing Board earlier this year.
- Continuing to develop PEDRI's financial sustainability plans in collaboration with ADR UK.

PEDRI updates from last quarter

Samaira Khan presented updates on progress across the PEDRI workstreams and events over the last quarter (January–March 2026).

Collaboration & partnerships

- A second roundtable on strengthening public involvement and engagement (PIE) in TREs/SDEs was held in January. Further engagement with researchers and data scientists on this topic needed so a survey has been circulated targeted at this audience.
- [Published report](#) on the PEDRI-DARE UK roundtable on strengthening PIE with AI-driven research.
- The PEDRI team hosted a workshop at [CRUK's Data-driven Cancer Research Conference](#) to help prioritise content for PIE training modules and also had a poster on the '[Young voices in cancer data research](#)' project.
- Collaborating with [Data Science for Health Equity](#) on an [online event](#) on 14 April focused on data diversity and inclusive PIE.
- Presentation to the [PIER HSC R&D group](#), which included a discussion on the absence of Northern Ireland representation within PEDRI partnership. Noted as largely related to capacity constraints within Northern Ireland organisations.
- An intern will be joining the PEDRI team in June under the Black Internship Programme.
- Research Data Scotland hosted the PEDRI Steering Group Away Day in March.

Communications & engagement

- Three abstracts accepted for IPDLN Conference.
- Participated in Love Data Week (February), showcasing roles across the data sector and resulted in a spike in LinkedIn engagement.
- Delivery of the first PEDRI webinar on 26 March ([Young people involvement in data research](#)), with the next scheduled for 22 April ([Data meets creativity](#)).

Good Practice Standards

- The GPS Toolkit has been finalised and is in the process of being published on the PEDRI website.
- The '[From Standards to Impact](#)' Community of Practice (CoP) continues to meet monthly, providing a forum for shared learning.

Learning & development

- Focus groups were held in January to help shape training modules for the data community. 95 individuals expressed an interest in contributing, including information governance specialists, technicians, data scientists, and public involvement and engagement professionals. This work is being co-led with public partners.

Culture of PIE

- Exploratory work on kitemarking is ending. Key recommendations will be shared in due course.
- The [PEDRI Forum](#), themed around creating a culture of PIE, will take place at the Wellcome Trust on 22 September 2026. A Planning Committee has been convened, abstract themes agreed, and proposed speakers identified.

Take the Lead programme

The [Take the Lead community grants](#) launched in September 2025. Achievements include nearly 500 applications, with 70% of applicants new to health data research, and 26 communities funded, supported through co-funding from SDR UK, BHF Data Science Centre, and CR UK.

The next phase will increase grant amounts to £3,000 and introduce work with "connectors" to build health literacy and leadership skills. The programme is seeking additional funders, with a target of £167,000 to enable a September 2026 launch. Interested partners were advised to contact Doreen Tembo or Anna Woolman.

- The Board discussed advertising strategies, particularly for rural communities, and the need for improved reach across all four UK nations.
- It was noted that an understanding of applications from Wales in more detail would be beneficial. Doreen Tembo to feed this back to Anna Woolman.
- An externally funded evaluation is being commissioned to assess the impact of the first funding round.
- The Board noted unintended but positive connections emerging between communities and researchers.

Objectives and Key Results for 2026-2027

Samaira presented PEDRI's draft objectives and key results (OKRs) for April 2026-March 2027 for the Board's feedback. The Board confirmed their support for the relevant OKRs across the following workstreams: Communications and engagement; Culture of PIE; Learning and development; Collaboration and partnerships.

Good Practice Standards

- Need better understanding about which types of organisations are adopting the GPS. The GPS Working Group have developed a Monitoring, Evaluation and Learning (MEL) framework for the GPS Toolkit to support continuous learning.

PIE in AI

- The Board supported a practical, incremental approach to expanding the GPS rather than revising it in a similar way to [OSR's Codes of Practice for Statistics](#).
- Emphasis on building public trust in AI through tailored communication.
- Question raised on engagement with Sciencewise who have experience in facilitating public dialogues on AI.
- DataLoch (University of Edinburgh) have experienced issues relating to AI use in TREs. There was a recommendation for DARE UK to connect with their team.

Board member updates

Updates from useMYdata (Dave Chuter)

- Funding has been extended by CRUK for next four years.
- National Patient Data Day will take place on 24 June, with activities running from 1-24 June.
- useMYdata remains keen to support HDRS work and ensure public voice is involved. Recently met with CEO in April to move forward these discussions.
- Dave Chuter has stepped down as Interim Chair; recruitment for a new Chair is underway.

Updates from Understanding Patient Data (Charlie Wilkinson)

- Wave 2 of the public sentiment tracker has been completed. This will not be published publicly but can be shared with the Board.
- An invite-only event at the Wellcome on the European Health Data Space will take place in May to bring together UK experts with international counterparts to discuss areas of interest and potential coalition lobby. [Webinars unpacking the European Health Data Space](#) taking place on 23 April and 12 May.
- Report on how media and communications influence public attitudes to health data will be published in May/June.
- A system-wide evaluation of PIE in health data is underway, which will involve mapping and qualitative research with PIE community to understand their needs, challenges and opportunities to increase impact at sector-level.
- A State of the Nation report including analysis of public attitudes and expectations relative to UK health data policy ambitions will be launching in July.
- The Health Data Compass will launch in September 2026 as part of new UPD website.

Updates from ADR UK (Emma Gordon)

- A new Public Engagement Manager will join ADR UK this month.
- ADR UK is piloting new collaborative engagement models with public experts.
- The ADR UK Ambassadors programme is expanding to include select individuals with lived experience. They will be announced in coming weeks.
- ADR UK will participate in Pint of Science events in May to promote positive narrative of using administrative data for research.
- ADR UK public panel has recently been refreshed with their first meeting in March.
- Work continues to support upcoming DARE UK dialogue and align training offers with PEDRI Learning and Development.
- Season 2 of the [ADR UK podcast](#) has launched.

Updates from CR UK (Melissa Lewis-Brown)

- Renewed funding for useMYdata and encourage other organisations to support.
- Strong public involvement at the CRUK Data-Driven Cancer Research Conference in February.
- Ongoing work to embed PIE as a cross-cutting enabler in new strategy.
- Changes to CRUK's Data Advisory Board membership with a founding member stepping down. Recruitment announcement coming soon.

Updates from AMRC (Nicola Perrin)

- AMRC has [published a briefing](#) on the charity perspective on HDRS.

Updates across the landscape (Doreen Tembo)

- DHSC have withdrawn funding for several contracts, including the NIHR Maximising Impact and Public Partnerships Programme and the CHAIN Network. There has been disquiet in perceived disinvestment in PIE in health research.
- Upcoming roundtable on engagement with HDRS at Wellcome. Representatives from HDR UK, PEDRI and UPD will be in attendance.
- Completed [Census 2031 Topic Consultation](#), ONS was inviting the public and organisations to help decide what information should be collected in the next census.
- The PEDRI team are in discussions with Connected by Data as their business winds down to see how the team can support them as there is an overlap in remit.
- Growing national focus on public involvement in AI, synthetic data and linked data, including work by Connected by Data and the UK Synthetic Data Community Group.
- Increased attention on commercial access to data, including planned HDR UK work, PAN-UK discussions, and a [journal article by DATAMIND](#) on principles for commercial access to mental health data. PEDRI are providing funding to DATAMIND to make findings publicly accessible, via the 'From Standards to Impact' funding award.

Action Log

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

Action Item #	Action	Date reported	Assigned to	Status	Resolution / Comments
1	Doreen to meet with Paul Manners to discuss further the PEDRI business plan and financial sustainability strategy.	08/01/26	Doreen and Paul	Closed	PEDRI team met with Paul Manners to discuss future sustainability.
2	Doreen to talk to Anna Woolman about gathering a better understanding on the	9/4/26	Doreen Tembo	Closed	Completed, Anna will contact Alex Newberry

	spread of applications from Wales to share with Alex Newberry.				
3	Save the date for the PEDRI Forum to be circulated.	9/4/26	Katie Porter	Open	To circulate with minutes. A calendar hold has already been sent to Board members.

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)
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)
Gail Rankin	Office for Statistics Regulation (OSR)
Doreen Tembo	PEDRI & HDR UK
Samaira Khan	PEDRI
Katie Porter	PEDRI
Mark Gardener	Smart Data Research UK
Jo Webb	UK Data Service
Robin Flaig	UK LLC

Charlie Wilkinson	Understanding Patient Data (UPD)
Dave Chuter	Use MY Data (UMD)
Alex Newberry	Welsh Government
Apologies	
Layla Robinson	Research Data Scotland
Steven McEachern	UK Data Service
Anna Steere	Understanding Patient Data (UPD)

Next meeting: Thursday 2 July 2026, 13.00-14.30