

Public Engagement in Data Research Initiative (PEDRI) Governing Board: Q3 2025 Meeting Minutes

Date: Tuesday 30 September 2025

[Link to action log](#)

Welcome

Team updates:

- The Impact and Evaluation Officer has left PEDRI and the Good Practice Standards Lead will be leaving at the end of October.
- A new Research Officer joined in July to lead the Cancer Research UK/PEDRI project.
- The Learning and Development Lead has reduced their PEDRI time to two days a week.

PEDRI Update on Last Quarter

Events

- PEDRI held a pre-conference workshop at the [ADR UK Conference](#) where we discussed the Good Practice Standards and the associated draft toolkit.
- Samaira presented a lightning talk on the Good Practice Standards at the [UK TRE Community Conference](#).
- PEDRI made two successful abstract submissions for [NCCPE's Engage Summit](#) next year.
- PEDRI will have a poster at the [HDR UK Conference](#) about the findings from our first roundtable exploring PIE in TREs/SDEs.
- PEDRI will be hosting an online roundtable on Equity, Diversity and Inclusion on 24 September. A summary report will be published on our website.
- PEDRI will be co-hosting a roundtable with DARE UK on public involvement and engagement in relation to AI (taking place on 20 September).

Theory of Change

- PEDRI are updating their Theory of Change based on the Board's feedback and will be discussing the updated version with the Steering Group on 9 October.

Good Practice Standards

- PEDRI received twelve eligible applications for the [Good Practice Standards \(GPS\) Funding Call](#), including from industry and social care. Feedback stated that excluding existing staff salaries from scope might look unattractive to some, so PEDRI will explore whether this can be covered in future calls, as well as a focus on non-health sectors.

- PEDRI received supplementary funding from DARE UK to develop a digital version of the Good Practice Standards Toolkit. This toolkit will support planning, delivery and reflection of PIE activities and project, in line with the Standards.

Pledge

- At the Frontiers meeting PEDRI launched [the Pledge](#). So far, 8 organisations and teams have signed up.
- Should PEDRI partners sign up to the Pledge? Clear guidance is needed.

Partnerships

- The UK Data Service has joined as a PEDRI partner.
- PEDRI are currently onboarding Ada Lovelace Institute, UK Biobank, ADR Northern Ireland.

Comms and engagement

- PEDRI's [summer round-up blog](#) summarises the activities they were involved in over the summer.
- Data Saves Lives published [a blog on PEDRI](#) and the Standards on their website.
- PEDRI have had good response to our webinar series, averaging ~200 registrations.
- On 18 November, PEDRI will have their 1-year anniversary of branding and website.

Learning and Development/Resources

- The L&D/Resources workstream has received funding from DARE UK's Community Fund to develop CPD-accredited training modules and a searchable database for PIE groups (connecting researchers with established PIE groups).
- PEDRI are also in discussions with ADR UK about supporting drop-in surgeries for early career researchers on their fellowship scheme. This would also be something worth exploring with UKRI or their councils.

Children and young people project

- PEDRI was involved in a CRUK webinar and talked about the new children and young people project ([read more about the project in this blog](#)).

Planned expenditure for 2026 and future sustainability for PEDRI

- Lower than anticipated ESRC funding has impacted PEDRI's financial position, prompting the Board to explore options for long-term sustainability. While some partners contribute membership fees and in-kind support, this does not provide sufficient stability to reflect PEDRI's cross-sector ambitions. Ongoing discussions will continue with ESRC-funded PEDRI partners, including ADR UK and DARE UK, as DARE UK considers its future contribution in the context of a potential phase three programme.
- The Board reaffirmed the importance of maintaining balanced governance irrespective of funding sources and recognised the value of mixed funding models such as NCCPE's. In light of UKRI's growing emphasis on economic growth, PEDRI should clearly articulate its strategic role and strengthen the core PIE infrastructure, ensuring a clear distinction between involvement and engagement.

Discussions also highlighted the need for greater clarity on cost recovery, asset creation, ownership, and capacity, with PEDRI's focus remaining on coordination and strategic alignment rather than direct delivery of all PIE activities. Clear parameters will be essential should PEDRI adopt a paid service model, alongside a shared understanding of what success and long-term sustainability look like. As technology and AI continue to evolve, PEDRI should play a key role in maintaining coherence across the system, balancing central coordination with locally led engagement to ensure meaningful and lasting impact.

EDI Roundtable

- PEDRI hosted an EDI roundtable on 24 September with presentations from Julian Harrison (Centre for Ethnic Health Research), Jane O'Rourke (Health Research Authority), Katie Oldfield and Sian Robson (Research Data Scotland), and Doreen Tembo.
- Agreed next steps: Continue and improve PEDRI's Resources Hub; Create a "dating service" tool to connect researchers to established PIE groups and community groups; survey PEDRI partners for to explore collaboration priorities. PEDRI will explore hosting a convening session to develop recommendations further.

Good Practice Standards

- PEDRI has been developing a Good Practice Standards Toolkit to support the practical application and ongoing reflection of the Standards in PIE activities and projects. The toolkit could provide a clear audit trail for funders and ethics bodies.
- PEDRI have held around 18 consultations with people and groups who reflect the intended audience for the toolkit and have recently published a consultation survey for further feedback (closes 20 October). A consultation report will be shared with partners.
- Next steps are to test the toolkit with PEDRI-funded applicants, create a digital version of the toolkit, and link up with the L&D/Resources Working Group to create bitesize videos to support adoption of the Standards.

Board Member Updates

- DARE UK:
 - o DARE UK is starting to think about Phase 3 and what role PEDRI plays in this.
 - o DARE UK is also delivering a pilot public dialogue on AI with a view to potentially a wider dialogue in 2026 (UK-wide).
 - o DARE UK's Research Exemplars Call is now open. It will be interesting to see the PIE plans received. The GPS toolkit could be utilised in evaluating PIE.
- OSR:
 - o OSR will soon be posting their Code for Statistics, which directly mentions PIE.
 - o Helen recently published [a blog for OSR](#) about her reflections on the ADR UK Conference.
- SDR UK is exploring how to get researchers to think more about research outputs that are of direct interest to the public and see the public as an end user earlier in

the chain. If Board members would like to get involved in any work in this space, reach out to Joe.

- useMYdata's National Patient Data Day was a success and they are looking to build on this again for next year.
- UK LLC's Citizen Panel Project is now completed. A [protocol paper](#) has already been published, and UK LLC is keen to report on the results and lessons learned. This project was cofounded by ESRC and MRC.

Action Log

Action Item #	Action	Date reported	Assigned to	Status	Resolution / Comments
1	PEDRI to arrange the publication of the Governing Board meeting minutes on the PEDRI website.	2/4/25	Katie	Closed	Minutes now on website: Governing Board Meeting Minutes - PEDRI
2	PEDRI to share the agenda for the Frontiers meeting on 18 June with the Governing Board for comments.	2/4/25	Katie	Closed	
3	PEDRI to add the Cancer Research UK Cancer Data Patient and Public Community opportunity to the next bimonthly bulletin.	2/4/25	Katie	Closed	Added to April PEDRI Bulletin.
4	PEDRI to explore partnering with Ada Lovelace Institute and inviting them to be involved in our work (e.g. Frontier meeting AI presentation).	2/4/25	Doreen / Samaira	Closed	Invited to Frontiers meeting. Doreen spoke at Ada Lovelace panel session on 26 June.
5	Item for future meeting on planned expenditure (what's planned for beyond 26/27?)	01/07/25	Samaira	Closed	On agenda
6	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	Open	
7	Mark Gardner to contact Ceri Steele about doing an	01/07/26	Mark Gardner	Open	

	educational session on the public dialogue work for Use MY data.				
8	Understanding Patient Data to bring "state of the nation" work to future Governing Board meeting for discussion.	01/07/26	Samaira & Anna	Closed	UPD item at December meeting
9	PEDRI and Paul Manners to meet to discuss potential abstracts for the NCCPE Engage Conference.	01/07/25	Doreen / Samaira & Paul	Closed	Two abstracts accepted for Engage Conference
10	PEDRI to circulate Doodle polls to book in future 2025 meetings.	01/07/25	Katie	Closed	Circulated on 1 July.
11	To agree whether PEDRI partners will need to actively sign up to the Pledge	30/09/25	PEDRI delivery team	Open	
12	PEDRI to circulate GPS toolkit for comment by email for any comments	30/09/25	Katie	Open	To circulate with minutes

Attendees	
Name	Organisation
Melissa Lewis-Brown	Cancer Research UK (CRUK)
Fergus McDonald	Data and Analytics Research Environments (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)
Helen Miller-Bakewell	Office for Statistics Regulation (OSR)
Doreen Tembo	PEDRI & HDR UK Alliance
Samaira Khan	PEDRI & BHF-DSC
Katie Porter	PEDRI & DARE UK
Joe Cuddeford	Smart Data Research (SDR UK) / ESRC

Alex Newberry	Welsh Government
Robin Flaig	UK LLC
Charlie Wilkinson	Understanding Patient Data
Dave Chuter	Use MY Data (UMD)
Apologies	
Emma Gordon	Administrative Data Research UK (ADR UK)
Nicola Perrin	Association of Medical Research Charities (AMRC)
Layla Robinson	Research Data Scotland (RDS)
Anna Steere	Understanding Patient Data

Next meeting: Thursday 8 January, 11.00-12.30