

## Public Engagement in Data Research Initiative Governing Board

**Date:** Wednesday 2nd April

**Chair:** Cassie Smith

### Welcome and introductions

- The Board welcomed Rachel Brophy who joined the meeting as a guest speaker and Katie Porter who has joined the Board as part of the secretariat.

### PEDRI Update on Last Quarter

- PEDRI successfully recruited an Impact and Evaluation Officer who will be starting in April.
- On 8 May we are hosting a Theory of Change workshop with the Governing Board. We will also be consulting with the Public Advisory Group. A visually appealing version will be made available on the PEDRI website.
- Two new PEDRI blogs have been published:
  - [Introducing the PEDRI Good Practice Standards](#)
  - [Creating PEDRI's Public Advisory Group](#)
- A downloadable version of the standards is now available on the PEDRI website: [Good Practice Standards](#).
- The proposal PEDRI submitted to the Cancer Research UK Data Research Fund was successful. This project has a focus on engaging children and young people in cancer data research.
- PEDRI are exploring publishing the Governing Board minutes with the Communications Lead.
- PEDRI met with DARE UK and the Department of Health and Social Care (DHSC) to discuss potential overlap in our public engagement work. PEDRI suggested hosting a roundtable to explore. DHSC are hosting a roundtable at the end of April to discuss this further and PEDRI will be supporting this.
- At the PEDRI Steering Group meeting, the Group discussed decision-making processes. It was agreed that strategic decisions will be made by the Governing Board and operational decisions with the Steering Group.
- PEDRI will host a follow-up meeting to the roundtable on public involvement in trusted research environments and secure data environments that was hosted towards the end of last year. A task-and-finish group will be setup to explore public involvement and engagement for secondary data use at project level. Discussions will focus on solutions to the challenges raised in the roundtable.
- PEDRI are applying to more funding opportunities, both bilateral funding as well as funding for different calls.
- PEDRI will be in touch with members soon in relation to their annual contributions for this year.
- At the Frontiers Event on 18 June, PEDRI will launch the Good Practice Standards Funding Award.
- In addition to the planned Equity, Diversity and Inclusion (EDI) Roundtable in September 2025, PEDRI also plan to setup a task-and-finish group specific to EDI.

- PEDRI will develop a Community of Practice. This would be for people who want to engage with PEDRI but do not fit into our current membership model (researchers, community organisations).
- PEDRI's L&D Group are exploring public advocacy training which focuses on engaging underrepresented groups to work with early career researchers around how data is used. It is a way to grow our public community.
- PEDRI are hosting a series of webinars this year relating the Good Practice Standards. The Governing Board were asked for speaker suggestions.
- UKLLC are currently exploring how to include an assessment of EDI as part of an application. Not all data research applications that come in can be diverse due to the conditions etc. that the researchers are looking at. How do we help researchers address that? Could explore this in EDI webinar.
- For the EDI webinar, Faye Scott who led the development of the [NIHR Race Equality Framework](#) is a good speaker.
- For the webinar on two-way communication, the British Science Association have just published a series of essays about community engaged research. One of these is around [community engagement with data](#), led by Louise Marryat at Dundee University with various partners, who could be a possible speaker.
- Another project for this webinar is one led by Queens Community and Place at Queens University Belfast about [building a data gateway for a community in central Belfast](#).
- On 17 June, there is a [patient engagement event at University College London](#). It may be good for PEDRI to have a stall at this event.
- National Patient Data Day is on 24 June. Hosted by use MY data and PEDRI is a sponsor.
- Cancer Research UK has recently launched their [Cancer Data Patient and Public Community](#).

### SafeGUARD Principles

- Rachel Brophy (Head of Information and Research Governance, HDR UK) gave a presentation on the SafeGUARD Principles.
- GUARDS are the overarching principles-based governance framework. safeGUARDS drive the alignment and awareness of existing standards and initiatives.
- A public consultation has been held with HDR UK's Public Advisory Board and HDR UK Voices. The findings from this consultation will be shared widely in a soon-to-be published report.
- The Governing Board were asked for questions and comments.
- What is the relationship between this work and PEDRI's Good Practice Standards? There needs to be further work on how we join them up, potentially linking the Standards to particular areas of GUARDS. The safeGUARDS bring together a lot of different resources and public engagement is only one of the aspects being looked at.
- PEDRI received a lot of questions around the overlap between the Good Practice Standards and the UK Standards for Public Involvement. We mapped the overlap across these so that researchers can see how these meet different criteria. This could be included in this work.
- NCCPE published a [review of various public involvement principles](#) last year, linked to the People's Principles project they helped CaSE to run. This might be a useful companion to this work.

- It is interesting that you mention “public benefit” as NHS England have changed to using “public good”. There is a difference between the two. Is this something that has been explored? There are ongoing discussions on issues with terminology and how certain terms may be received.

### PEDRI Frontiers meeting – 18th June 2025

- This will be a 3.5-hour event to officially launch PEDRI’s Good Practice Standards and a way to encourage others to use them in their own work. At this event we will:
  - o Launch the Good Practice Standards Funding Call
  - o PEDRI Pledge
  - o Visionary keynotes
  - o Presentations around EDI, AI and Industry.
- The Governing Board were asked for suggestions for speakers and their thoughts on the agenda. It was agreed that members will review outside of the meeting.

### PEDRI Stakeholder Engagement Strategy

- Samaira presented the draft stakeholder engagement strategy for comment.
- For the stakeholder list, it might be worth adding Research Funders.
- The primary focus in the objectives is “public engagement”. Public involvement is equally if not more important for some partners. Add “involvement” to the wording used in the objectives.
- It was mentioned the Steering Group were keen for the benefits to be emphasised in the strategy. Are these benefits of PEDRI or benefits of the membership? Be clear that it is both.
- There are multiple platforms and initiatives, and we do not want to silos of different organisations. We need to make sure that we are linking together.
- The Board agreed that the Strategy looked fantastic and well-thought through.

### AOB

- Cancer Research UK are hosting an upcoming funders roundtable on ethics and public involvement.
- Cancer Research UK are thinking about their approach to AI going forward and will be holding a series of roundtables all underpinned by public involvement and engagement.
- HDR UK are in the process of developing AI strategy. OSR are also thinking about AI and how they use it.
- The Ada Lovelace Institute recently published a [report providing insights on AI and public good](#). ESRC funded this work.
- It might be useful to invite someone from the Ada Lovelace Institute to one of these meetings. Also to explore them as a potential partner.
- There is a need for definitions when we talk about AI and highlight where there are higher and lower risks involved. Perhaps this could be explored by PEDRI via a roundtable.
- Cancer Research UK are developing new guidance for committees and researchers for proposals looking at AI and machine learning.
- A link was shared to the [European Commission’s AI for Public Good page](#).
- At the British Heart Foundation Data Science Centre, there is a project looking at involving the public in the development of an AI model.
- The Governing Board were asked to send any item suggestions for future meetings to PEDRI.

## 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	Open	
2	PEDRI to share the agenda for the Frontiers meeting on 18 June with the Governing Board for comments.	2/4/25	Katie	Open	
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 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	Open	

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)
Andy Boyd	Health Data Research UK (HDR UK)
Cassie Smith	Health Data Research UK (HDR UK) & British Heart Foundation - Data Science Centre (BHF-DSC)

Rachel Brophy (Guest)	Health Data Research UK (HDR UK)
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
Layla Robinson	Research Data Scotland (RDS)
Joe Cuddeford	Smart Data Research (SDR UK)
Robin Flaig	UK LLC
Dave Chuter	Use MY Data (UMD)
Apologies	
Fergus McDonald	Data and Analytics Research Environments (DARE UK)
Alex Newberry	Welsh Government

**Next meeting:** Tuesday 1st July at 1pm

**Theory of change workshop:** Thursday 8th May at 10am