

Public Engagement in Data Research Initiative

Governing Board

Date: Wednesday 1 July 2025

[Link to action log](#)

PEDRI Update on Last Quarter

- Asma Khan joined PEDRI in May as Impact and Evaluation Officer.
- The [PEDRI Good Practice Standards Frontiers Meeting](#) was held at Wellcome on 18 June where we officially launched the Good Practice Standards and [the Pledge](#). We also announced [a new funding call](#) to support small-scale projects that is linked to the Good Practice Standards.
- The Good Practice Standards Working Group are currently working on an evaluation toolkit, the development of which was announced at the Frontiers meeting.
- PEDRI have held two successful webinars so far, linked to the Good Practice Standards. Our first webinar in April had over 400 registrants. We publish a blog after each webinar with reflections on the webinars and links to further resources.
 - o Blog reflecting on webinar 1: [Bringing good practice in public engagement in data research to life](#)
 - o Blog reflecting on Equality Impact Assessment webinar: [Prioritising equity in public engagement in data research](#)
- We received funding for [a CRUK/PEDRI project](#) which looks to scope the development of a national platform to support the involvement of children and young people with lived experience of cancer in data research. We are currently recruiting for a Research Officer for this project. We've had a lot of interest (over 300 CVs received).
- PEDRI had a pre-conference workshop accepted for the ADR UK Conference in September.
- PEDRI held a Theory of Change workshop in May with the Governing Board. The document has been updated based on the discussion in this session. We plan to take this work forward internally with new Impact and Evaluation Officer and potentially come back to the Board for further comment.
- PEDRI attended a Department of Health and Social Care (DHSC) data linking engagement workshop. This workshop brought together partner organisations to discuss data linking public engagement activities. DHSC are capturing this information to develop an evidence base for a literature review.
- In the [Resources Hub](#), we now have a section for resources relating to public consultations. We will work with DHSC to populate.
- PEDRI have developed a stakeholder engagement strategy. Samaira will be in touch requesting any further comments from the Board. The Strategy has had input from Governing Board, Steering Group and Public Advisory Group.

- A blog on the Good Practice Standards will soon be published on the European Patient Forum website.
- PEDRI involvement in workshops/events:
 - o Doreen was involved in the closing plenary session for the [PEOF/EUPATI](#) event in Italy.
 - o Doreen was on a panel at the [Genomics England Research Summit](#). It was a chance to engage the data community, and we had interest in PEDRI membership.
 - o Doreen and Samaira facilitated an EDI workshop at the [Use MY Data Patient Data Day](#) on 24 June. They have been invited to do an educational session on PEDRI with executive members.
 - o Samaira led a public panel at the [UK AI Conference](#) on 23 June. This delved into the importance of public involvement and engagement in AI research. Had a lot of engagement with early career researchers.
 - o Doreen sat on a panel for a [webinar led by the Ada Lovelace Institute, Alan Turing Institute and UKRI-funded programme Public Voices in AI](#), where she discussed public involvement and engagement and public attitudes to AI.
 - o PEDRI had stalls, along with HDR UK, at three science festivals over the past month e.g. [Rochdale Science Extravaganza](#). This is an opportunity to showcase work at PEDRI and talk to public about data. Festivals are an opportunity for partners to get involved. Get in touch with PEDRI team if interested in supporting science festivals.
- Planned expenditure:
 - o PEDRI are in discussions with ESRC and Future Data Services. ESRC have an interest in learning and development and applicability to social sciences. They are investing in PIE. PEDRI has put in bid to get further support. Not yet confirmed.
 - o Why do staffing costs go down from 25/26? The HDR UK budget subsidises a lot of work for PEDRI, and we have some staff on temporary contracts, so costs taper off.
 - o Need to look at support for PEDRI beyond current funding period. Ensure PEDRI are aligning with priorities of other partners.
 - o PEDRI started as a short-term pilot with limited funding, and great to see it expand. Need an element of prioritisation.

Smart Data Research UK Safari

- Mark Gardner (Smart Data Research UK) presented findings from [their recent public dialogue](#) which was held with [ScienceWise](#) and delivered by [Thinks Insight and Strategy](#).
- Next steps for this work are to discuss and review data services; to pilot a public panel; and to develop training for policymakers and government researchers.
- DARE UK, HDR UK, OSR and use MY data offered support for promoting public panel opportunity.
- In the public dialogue, did participants think about use of their data and benefits to them, or was there discussion on benefits to other people? In the dialogue,

participants explored the scales of impact i.e. is it okay to spend money on data that affects a few people in a big way, or the opposite? The participants thought that benefits to a few people is still a useful way to use public money.

- RDS have spent a lot of time exploring private sector access to public sector data and recently completed public consultation work on this. Report currently being drafted. This PIE work was building on some of the Understanding Value of Data work run by Scottish Government a few years ago with a plan to inputting findings into informing the Private Sector Access Operational Framework.
- One lesson from public dialogue work is not to pack too much in. Underestimated the time for people to understand research and data
- Findings are similar to other public dialogues i.e. public concern with data usage and access linked to big business. There is a [summary of cross-cutting findings from Sciencewise](#).
- The public are generally happy for use of data if it's in the public good and controls are in place.
- A project, led by the Bennett Institute at Cambridge, looks at data through the lens of value, which might provide a way of making sense of these findings. [Access the project summary report](#).

Frontiers meeting

- We had fantastic opening keynotes from Emma Gordon (ADR UK), Ed Humpherson (OSR) and Jan Speechley (PEDRI Public Partner). Jan launched the PEDRI Pledge. There were lightning talks on EDI, AI and Industry. The industry speakers were able to cross-compare their principles with the PEDRI Good Practice Standards. There was also a closing keynote from Andrew Morris (HDR UK).
- A reflective blog will be published in July (Post-meeting note: [Blog now published on website](#)).
- We had around 65 people attend. Received largely positive feedback with some learning for future events. Overall people want more of these types of events going forward - with a hybrid option.
- Need to think about how we engage those who are not already converted (i.e. those who don't see benefit of PIE).
- The next Frontiers Meeting will focus on outputs, for example, projects linked to the Good Practice Standards Funding Call.
- The academic talks and public talk were fantastic. The industry talks felt a lot more high-level, like a sales pitch. If invited to future events, provide more detail on what audience is and help to shape their presentation.
- There was too much content packed into short space of time.
- If extending the timing of events in the future (e.g. to full day), consider the travel and if we would lose people towards end of day. Or put the most important things in the middle of the day. The advantage of these timings was that it was possible to travel to in a day.

GPS Funding Award Launch

- PEDRI, in collaboration with HDR UK and DARE UK, are launching [a funding opportunity](#) offering awards of up to £15,000 per project. These awards aim to empower organisations to embed the PEDRI Good Practice Standards into their public involvement and engagement work to champion more inclusive, transparent, and impactful data research. (Post-meeting note: DARE UK support confirmed).
- With this Funding Call, we want to deal with practical issues in terms of time and resources in PIE work. These projects will also help with improving the Good Practice Standards. For funded projects, we will offer a community of practice to support teams.

Board Member Updates

- Use MY data held their National Patient Data Day in Leeds which was very successful. Exploring whether to make it an annual event.
- Understanding Patient Data are scoping a couple of projects, one of which is a state of the nation report capturing learning from PIE work in data research. They are starting to track public sentiment via quantitative surveys and a social media listening tool.
- For the stakeholder strategy, consider using a different term than “stakeholder”. Some people are using the term 'constituencies' as an alternative. [Read this article for further detail.](#)
- NCCPE are hosting an Engage Conference in April 2026. [Call for contributions now open.](#) It would be good to have PEDRI presence at the conference.
- DARE UK are planning a public dialogue this year. Once completed, can bring it to this group for comment and explore best way forward from recommendations.

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	Open	
6	PEDRI to have interim discussion with DARE UK on planned expenditure and aligning with DARE UK phase 3.	01/07/25	Doreen / Samaira	Open	
7	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	
8	Understanding Patient Data to bring "state of the nation" work to future Governing Board meeting for discussion.	01/07/26	Samaira & Anna	Open	
9	PEDRI and Paul Manners to meet to discuss potential abstracts for the NCCPE Engage Conference.	01/07/26	Doreen / Samaira & Paul	Open	
10	PEDRI to circulate Doodle polls to book in future 2025 meetings.	01/07/25	Katie	Closed	Circulated on 1 July.

Attendees	
Name	Organisation
Emma Gordon	Administrative Data Research UK (ADR UK)
Nicola Perrin	Association of Medical Research Charities (AMRC)

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
Katie Oldfield	Research Data Scotland (RDS)
Mark Gardner	Smart Data Research UK (SDR UK)
Robin Flaig	UK LLC
Anna Steere	Understanding Patient Data
Ceri Steele	Use MY Data (UMD)
Apologies	
Layla Robinson	Research Data Scotland (RDS)
Alex Newberry	Welsh Government
Dave Chuter	Use MY Data (UMD)
Joe Cuddeford	Smart Data Research (SDR UK)
Melissa Lewis-Brown	Cancer Research UK (CRUK)

Next meeting: Tuesday 30 September 2025, 13.00-14.30