

Public Engagement in Data Research Initiative Governing Board

Date: Wednesday 6th November

Time: 10.00 – 11.30am

Location: Online

Chair: Cassie Smith (HDR UK, BHF DSC & DARE UK)

Attendees:

Cassie Smith (CS)	HDR UK / BHF DSC / DARE UK
Doreen Tembo (DT)	PEDRI / HDR UK
Samaira Khan (SAK)	PEDRI/BHF
Dave Chuter (DAT)	UMD
Larisa Florea (LF)	PEDRI
Paul Manners (PM)	NCCPE
Nicola Perrin (NP)	AMRC
Nicola Hamilton (NH)	UPD
Layla Robinson (LR)	RDS
Melissa Lewis-Brown (MLB)	CR UK
Robin Flaig	UK LLC
Sam McGregor	SDRUK/ESRC
Fergus MacDonald	DARE UK
Anna Woolman (AW)	HDR UK / PEDRI

Apologies:

Sam Haskell	DHSC/NHSE
Emma Gordon	ADR UK
Joe Cuddeford (JC)	SDR UK, ADR UK
Helen Miller-Bakewell	OSR

Alistair Forrest (AF)	DHSC/NHSE
Ceri Steele (CS)	UMD
Amy Weedall (AW)	WG

Secretariat: Sally Boylan (SB)

1. Welcome and Introductions and updates

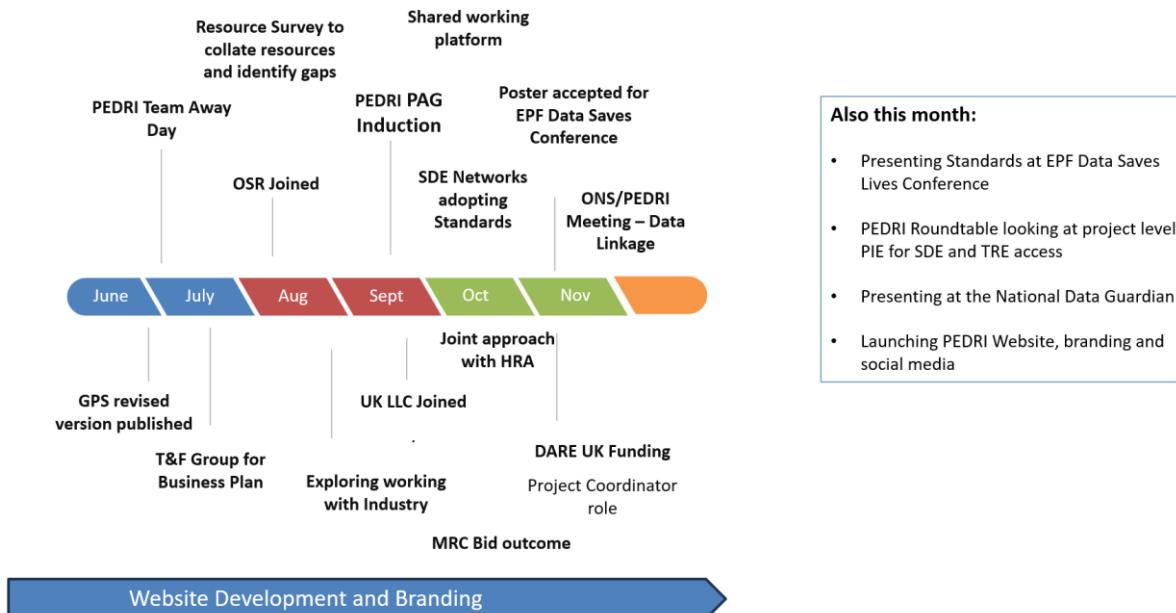
- a) CS welcomed board members to the Governing board and introductions were made.
- b) CS informed the board of a new PEDRI member, UK LLC. The NI Honest Broker Service is a possible new member.
- c) CS informed the board that since the last meeting the PEDRI, Public Advisory Group (PAG) had been set up. It currently has 5 members including representing DARE UK, the Welsh Government, CRUK and BHF DSC. The current focus of the group is PEDRI EDI plans.
- d) CS informed the board that additional PEDRI resource has been funded through DARE UK and recruitment for a part-time Project Coordinator is underway.
- e) CS informed the board of two current funding opportunities for PEDRI: a UKRI interdisciplinary cross-council scheme; and a DARE UK Community Groups funding call. Applications are being prepared for both calls.
- f) The UKRI bid aims to explore and implement methods that effectively engage underrepresented groups in understanding data science, with a particular focus on building trust. The project will address key challenges in promoting EDI and will incorporate arts-based methods, behavioural science, and data literacy programmes to ensure the communication of data science concepts is accessible, engaging, and aligned with the needs of diverse groups.

2. PEDRI Update on Last Quarter

Key updates

SAK provided an update to the board on key PEDRI activities during the last quarter:

PEDRI Quarterly Update



PEDRI

Business Plan Updates

- Separate **strategy** and **operational plan**
 - Updated **audience** to reflect discussions from Away Day and Comms Working Group
 - Importance of **EDI added as key objective** and our approach
 - Focus on **standards**, publishing and adoption, each area of work includes which standard it related to.
 - Success metrics added and measures will be included
 - Large comms campaign on hold until further resource and support is provided
 - Updated **finance section** to reflect partner contributions and spend to date.
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- A recent PEDRI away day focused on prioritising activities contained in the Operational Plan and workstreams using an Impact Framework to support the prioritisation process. This informed the work of the T&F group.
 - The revised Good Practice Standards (GPS) have been published and will form a key part of the PEDRI website launch at the end of November.

- UK Longitudinal Linkage Collaboration (UK LLC) and the Office for Statistical Regulation (OSR) have joined PEDRI.
- A survey was carried out to identify and collate existing resources for inclusion in a Resource Hub on the PEDRI website – over 50 organisations responded to the survey. The survey highlighted a huge gap in non-health related resources and guidance.
- The PEDRI team are exploring working with industry and have had several meetings with IQVIA. IQVIA were represented and spoke at the recent HDR UK PPIE event in Manchester. There is an opportunity to apply the BHF DSC framework and principles for working with industry.
- Several board members highlighted the resource intensive nature of, and risks associated with engaging with industry and the need to be selective. SAK reflected that the PAG had also raised this as a risk.
- The first PAG induction took place in September we now have 6 public members who have joined PEDRI
- The NHS SDE network are using the GPS as benefit metrics to measure progress against PIE activities
- The team has created a shared working platform using Box so that members can work collaboratively and share resources.
- The MRC bid (DRIVE) was unsuccessful but helpful feedback was provided which the team can learn from.
- PEDRI has been approved for a poster on the GPS at the European Patients Forum, Data Saves Lives conference in Brussels in November.
- The team met with the ONS to discuss a communications and engagement campaign in relation to data linkage and non-health data

Business Plan

- Following feedback from the previous board meeting the PEDRI Business Plan has been updated by the Task & Finish (T&F) group and the plan has now been split into two documents: Strategy document and Operational Plan.
- Target audience is now included for each workstream as well as success metrics.
- EDI has been woven across all workstreams. The PAG has been discussing how this can be achieved as well as enhancing diversity of the PAG itself.
- The GPS are now connected to each of the projects and metrics will capture this.
- A Theory of Change (ToC) workshop was suggested by the Steering Group, and this will take place at the next meeting.
- The Communications Campaign has been taken out of the plan pending resources and support. This work will take place on a needs-based approach for now.
- CS thanked SAK for a great summary and for taking on board feedback on the Business Plan
- DT informed the board that discussions on the PEDRI sustainability model have begun, and the team are considering whether it would be more appropriate to move to an annual membership model as opposed to a one-off joining fee model. DT asked the board for their views on this.
- FM asked if DT could please clarify what membership entails and asked whether the minimum fee of £5000 is sufficient in terms of sustainability.
- DT clarified that the membership model takes a tiered approach to membership fees depending on the size of the organisation. Some smaller resource constrained organisations contribute in-kind via staff time being involved in delivery. There are challenges associated with getting the membership fees right and with encouraging larger organisations, who currently pay a lower fee, to contribute more.
- There will be an administrative burden of managing an annual fee model.

- There is the option to have multi-year membership as well as annual membership.
- Overall, the board agreed that moving to an annual or multi-year membership model would be more sustainable.
- A question was asked about PEDRI's vision for expanding its membership.
- DT outlined that the vision is to build a Community of Practice with researchers with a joining fee which would fund capacity building work. The team has been advised to focus on developing good relationships with existing partners rather than seek to expand membership rapidly.
- For those members who are in receipt of external funding for their work, it would be important to ensure that funders are happy for PEDRI membership fees to be paid out of their funding.
- It was noted, however, that engagement with new audiences, such as young people, would likely require PEDRI to seek new partnerships working with organisations who engage with that target audience.

ACTION

The board agreed to revisit the question of sustainability and the membership model at its next meeting in January 2025.

3. Website and Branding Launch

AW shared a presentation with the board on the new PEDRI branding and website development:

Background and plans for launch

- There has been engagement with a wide group of stakeholders on the branding and website development including the Communications Working Group, Website Working Group, Public Contributors, HDR UK Comms team.
- The mosaic brand is intended to be vibrant and to give a sense of connection without being too science focused. It has been integrated into the logo and used in a variety of ways as required.
- The messaging of the brand centres around 4 pillars: Openness, Impact, Collaboration and Integrity.
- Feedback on the branding was extremely positive; the investment of time and effort was well worth it.
- User testing of the new website is taking place w/c 11 November 2024
- The website will go live on the 28 November.
- A communications toolkit is being developed for all PEDRI partners to use post-launch and will be shared with the governing board.
- A rich discussion took place on developing content for the website going forward as well as how board and PEDRI members could contribute to that, avoiding duplication with their own individual communications plans. A medium- longer-term strategy for this is considered important.
- In the medium term, a strategy will be important but in the short term, 2025, approaches will be trialled to see what is most effective. AW outlined that during 2025 an exploratory/iterative approach will be taken via a series of blogs and knowledge sharing webinars delivered in partnership with members.
- AW will prepare a content plan for a number of 'thought pieces' or case studies that members may wish to showcase.
- The GPS would be a key focus for the PEDRI website and the Resources Hub.
- SAK suggested that PEDRI's story and the journey taken to develop the GPS and membership should be told. The PEDRI website offers an opportunity to amplify the work of members.

- CRUK has a data webinar series and there was one on PPIE recently. CRUK would be happy to run a jointly branded webinar with PEDRI which could centre around a call to action to adopt the GPS.
- The board agreed that it would be helpful if members could draft blogs on why they chose to become PEDRI members, how they have adopted the GPS and how they are implementing them.
- Is there a budget for ongoing maintenance and development of the website? Having a budget for this will be important. It is also important to plan and prioritise content creation to manage expectations.

PEDRI LinkedIn Page

- A PEDRI LinkedIn page has been set up. Several social media options were considered but given the nature of PEDRI's target audience (professional organisations), LinkedIn was deemed most appropriate.
- All board members were encouraged to 'follow' PEDRI. AW has already followed PEDRI members using the account.

ACTION

- AW to contact Board members to explore blog and webinar ideas for 2025

4. Launching PEDRI Standards

- The board had a very rich discussion about launching the PEDRI GPS and how directive PEDRI should be about adopting them. Should PEDRI have a 'harder edge' and hold to account those who do not adopt the standards, benchmarking against them like a Crystal mark?
- Should PEDRI use the carrot or stick approach? Shining a light on good practice could be a good initial approach. It could also be helpful to highlight the negative impacts of not adopting the GPS as well as how organisations themselves have changed as a result of adopting the GPS.
- CS reflected that perhaps as PEDRI evolves a more directive approach could be taken.
- DT agreed that a staged approach is being taken, with pushing for adoption of the GPS in the first instance and measuring against them later in the journey (e.g. Athena Swan).
- Many of the ideas generated through the discussion about the website could support launch of the GPS (member blogs etc).
- DT informed the board that a summit of key leaders is being planned (which will have board member representation) to discuss adoption of the GPS.
- SAK informed the board that a paper is being written on development of the GPS.

ACTION: SAK to summarise discussions to Standards Working Group for consideration.

5. PEDRI Phase 2 – Key Priorities for next 12 months

SAK summarised the priorities for the coming 12 months:

Learning and Development

- The Learning and Development working group are considering the Resource Hub and the needs of the community, being careful to avoid duplication.
- The majority of the resources highlighted in the survey are health related so there needs to be a focus on identifying non-health related resources with partners. There is opportunity here to explore this with non-health partners.
- The results of the survey will be written up in a report and a call to action will be developed in the new year

Communications

- The team wants to develop a series of webinars to enhance visibility of PEDRI – this will require the team to understand the audience and develop an appropriate communication and engagement plan.
- The monthly bulletin will be reviewed and updated.

Culture of Public Involvement and Engagement

- The PAG has been set up and the group is very interested to be involved in delivery too.

ACTION

- SAK will share the 12-month priorities. Gantt charts will be added for each workstream over time.

6. Update from ABPI Roundtable

NH gave an update from the ABPI roundtable:

- The meeting aimed to identify who's doing what in the health data space. They are pulling together a proposal for UPD to have a convening role in this space.

UPD/PEDRI collaboration

- They are keen to collaborate with PEDRI on a pilot which would test approaches to collaboration in a particular sector.
- SAK highlighted that they would reach out to BMJ regarding a paper on UDP/PEDRI collaboration.
- DT highlighted that improved cohesion in the sector is a recommendation of the Sudlow Review so the approach to collaboration could take place in this context.

ACTION: SK to keep board updated on progress

7. Board Member Updates

- Smart Data Research UK have just completed a series of Public Dialogues. An 'evidence safari' took place to go through the learnings from the dialogues. Much of the learning is not specific to SDR and could be more generally applicable to research. In light of this, it would be good to explore cross-cutting issues as potential future focus areas for PEDRI.
- Has anyone heard anything about PPIE being included in the Data Save Lives consultation? No information was forthcoming on this but important to keep a watching brief.
- A report is now available on the CASE/National Centre for Social Research PPIE principles and resources. High degrees of mistrust amongst the public around how data is used was a significant finding in the report.

- The first pilot phase of the citizen panel design project is underway, and the first panel meeting has taken place. The project is developing materials to support explanation of TREs to the public. Members of UKLLC and public members of underrepresented groups are included in the project. UPD's 'What Worked?' project could be complementary to this work.

ACTION

- The board agreed it would be helpful to have a board session on the outputs from SDR UK's 'safari'

Next Meeting: Friday 17th January 2024 at 10.30am

8. AoB

None.