

Public Engagement in Data Research Initiative Governing Board

Date: Monday 10th June

Time: 1.30pm – 3.30pm

Location: Online

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

Attendees:

Casie 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
Amy Weedall (AW)	WG
Joe Cuddeford (JC)	SDR UK, ADR UK
Paul Manners (PM)	NCCPE
Ceri Steele (CS)	UMD
Nicola Perrin (NP)	AMRC
Nicola Hamilton (NH)	UPD
Layla Robinson (LR)	RDS
Paola Quattroni (PQ)	Alliance
Melissa Lewis-Brown (MLB)	CR UK
Alistair Forrest (AF)	DHSC/NHSE

Apologies:

Sam Haskell	DHSC/NHSE
Emma Gordon	ADR UK

Secretariat: Scarlett Courtney (SC)

1. Welcome and Introductions

- a) CS welcomed board members to the inaugural Governing board and introductions were made

2. PEDRI Rationale and Key Achievements

- a) DT presented a summary of the key achievements from Phase 1.
- b) PEDRI do not currently have a direct partnership with NHIR, although are liaising with the Deputy Director for Centre for Engagement and Dissemination. While the PEDRI Standards differ from NIHR standards, there is a shared commitment to map commonalities to prevent burden and to reduce duplication within the sector. NHIR are connected informally through HDR UK and Health Care Research Wales, but it was acknowledged this could be formalised and establishing a partnership would be a priority going forward.
- c) There was no formal evaluation of stakeholder perceptions conducted for phase one. Workshops were held with a focus on the standards and PEDRI's role in advocating these. PEDRI have been officially encouraged by the perception of stakeholders in valuing these Standards, specifically by the Office for Statistics Regulation.
- d) An external company completed an evaluation of the Young Families Campaign, as part of phase one, which highlighted useful learning on engaging with certain demographics. A key take away was that a 'Call to Action' was needed to answer the 'so what' questions and this will become part of Phase 2.

ACTION – DT to share learnings from Young Families Campaign evaluation

- e) No further formal evaluations have been planned for Phase 1. DT noted that although useful, this would need to be balanced against available resources.

ACTION - DT to discuss the feasibility of further formal evaluations with the PEDRI Steering Group.

3. PEDRI Phase 2

- a) SAK gave a brief presentation of the PEDRI business plan for Phase 2 which will build and enhance the work achieved in Phase 1 which affirmed the need of collective working. Lessons learned through consultations and workshops have determined PEDRI's vision, mission and objectives going forward.
- b) Phase 1 has highlighted knowledge gaps and context related challenges with the public having little knowledge of how data is being used. There is also a scepticism from the public around data. It is important to work collaboratively and use resources efficiently to avoid duplication and waste within the system.
- c) The Good Practise Standards have highlighted the importance of developing transparent and accountable policies in governance processes, as well as tackling ethical issues around consent anonymisation and data storage.
- d) The Phase 2 strategic objectives have been built from the learning found in Phase 1 and are as follows:
 - Collaboration and partnerships
 - Good Public involvement in engagement practises
 - Culture of public Involvement
 - Two-way engagement and communication
 - Learning and development.

e) The PEDRI coordinating team are as follows:

Doreen Tembo	Strategic lead
Samaira Khan	Senior Manager and Operational lead
Ester Bellavia	Good Practice lead
Jan Speechley	Public partner involved across all workstreams
Sue Mohanty	PPIE officer
Anna Woolman	Comms and Engagement lead
Amy Hodgkinson	Learning and Development Lead

- **Business Plan**

- a) The Board congratulated the work and developments achieved in phase one.
- b) While Young families were the focus of the Phase 1 campaign, phase 2 will prioritise what partners would like to focus on while building on the learning and outcomes from the phase 1 campaign. A prioritisation exercise was carried out with the steering group, hosted by an external facilitator, but was unable to progress due to capacity limitations. DT acknowledged that a measured approach is needed in terms of how we engage with partners going forward.
- c) The number of members in the group has grown since Phase 1. It was suggested PEDRI prioritise partners whom they would like to engage with, to create meaningful connections and avoid rushing partnerships.
- d) There may be potential challenges with the CR UK partnership if PEDRI were to continue with a Young Families campaign as CR UK are already involved in significant work within this space.
- e) As PEDRI is a partnership initiative, it is hugely important to have a governance structure that can support and bring together everyone's input however, the governance structure should not be over-laboured and an awareness of the capacity limitations in key. It was agreed that strong communication between all groups within the governance structure was needed, with the opportunity for board members to attend workstream groups & events when appropriate.
- f) There is an opportunity for PEDRI to increase the visibility of other groups and highlight and promote work already covered. It was noted PEDRI can add value in combining and balancing work on health and non-health data. Further engagement with the commercial sector and non-health organisations was suggested along with determining if PEDRI standards are applicable in non-health settings.
- g) A discussion was had on the need to refine the current business plan and focus on what PEDRI's distinctive contribution could be. The current plan is ambitious and PEDRI do not have the resources or capacity to engage with everything listed. The Steering group and PEDRI away day will prioritise and review the business plan before being presented at the next Governing board meeting.
- h) A discussion was had on refining audiences and whether this should be the public, professional organisations or a combination of both.

4. Board Priorities

- a) To assist with prioritisation, a theory of change was suggested, both locally but also collaboratively with external organisations. This would help to determine how partners are working within the data space and to clarify what the distinctive contributions of different organisations.
- b) Key priorities were outlined as follows:

- To ensure the governance structure does not encroach on resource and capacity.
- Prioritising landscape review and community building, particularly outside of health.
- Reviewing which activities sit within PEDRI and potentially prioritising the standards development over the implementation of public dialogue campaigns.
- Strengthening the EDI aspects.
- To identify and promote PEDRI's USP.

5. Board Membership

- a) Governing board meetings will be held quarterly for a duration of an hour and a half, with papers shared in advance.

6. AoB

- a) Feedback from today's meeting will be fed back to the Steering group and also the upcoming PEDRI away day on 1st July. Once the framework has been built upon, and the plan adjusted, it will be circulated prior to the next Governing Board for comment and approval.
- b) SAK thanked board members for their input and feedback.