Public Involvement and Engagement Working Group: 14th December 2023

Executive summary

The workshop highlighted key considerations regarding the adoption of standards for public involvement and engagement in the context of data science. The advantages of embracing standards are evident, with a focus on enhancing public participation and understanding through improved data literacy and training. Transparency emerges as a cornerstone for building trust and boost confidence in research initiatives, emphasising the need to explain anonymisation processes and safeguards in place to enable data use to b. Early and continuous public involvement is recognised as a crucial factor, with case studies and examples of good practice serving as valuable tools for illustrating effective engagement.

However, concerns about the tokenistic adoption of standards, challenges in measuring success, and ensuring accountability present notable hurdles. Participants express the need for more than just guidelines, calling for the 'institutionalisation' of standards to ensure they are treated seriously and integrated into organisational missions. Addressing concerns about under-represented populations becomes a key theme, stressing the importance of careful consideration, justification, and the added value of such efforts. The discussion underscores that diversity extends beyond ethnic backgrounds.

In conclusion, while the benefits of adopting standards for public involvement and engagement in data science are evident, addressing concerns, sharing best practice and implementing solutions is crucial. The push for institutionalisation, developing crystal marks and CPD opportunities, and engagement plans demonstrates a commitment to ensuring standards become an integral part of organisational practices. The discussion serves as a foundation for a more transparent, inclusive, and effective approach to public involvement and engagement in the dynamic landscape of data science.

Advantages	Challenges	Suggestions
• Enhancing PIE in data science • Data literacy and training • Building trust through transparency	• Adoption of standards • Measuring and ensuring accountability • Engaging with under-represented groups	• Learning from good practice • Institutionalising standards • Developing crystal mark to ensure committment • CPD opportunities

Introduction

This was the inaugural meeting of a new Public Involvement and Engagement working group, convened by the Alliance in partnership with PEDRI (Public Engagement in Data Research Initiative).

The UK Health Data Research Alliance (the 'Alliance') is an independent alliance of leading healthcare and research organisations united to establish best practice for the ethical use of UK health data for research at scale.
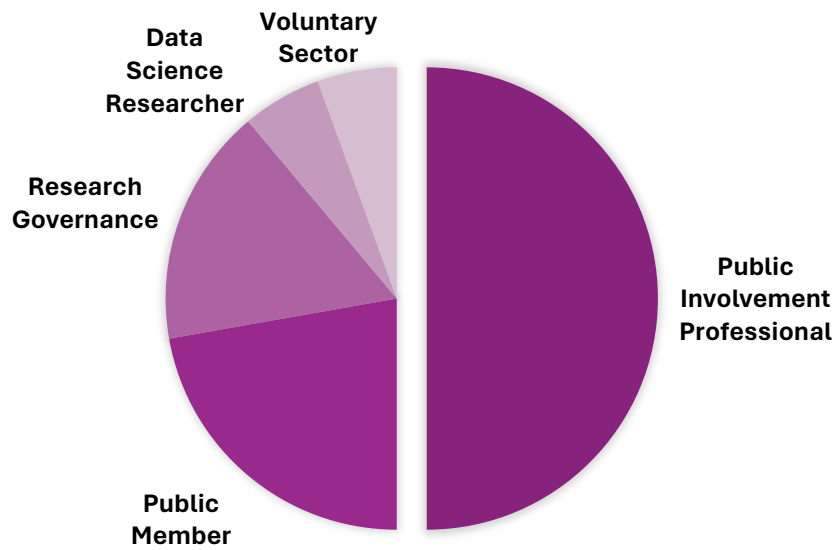
This was the first of a series of events, aiming to provide an opportunity to discuss public involvement and engagement priorities of Alliance members and partner organisations, explore ways to reduce complexities and drive adoption of best practice in public engagement and involvement, and gain insight into PEDRI's strategic objectives.

The PEDRI initiative builds on a sector-wide desire to share learning, best practice, and collaborate on public involvement and engagement (PIE) in data-driven research and statistics. PEDRI was officially launched on 19th October 2022 as a partnership between Administrative Data Research UK (ADR UK), Data and Analytics Research Environments UK (DARE UK), Health Data Research UK (HDR UK), NHS Transformation Directorate (NHS TD), Research Data Scotland, and Office for National Statistics (ONS).

PEDRI has recently received funding from DARE UK and is a formal DARE UK community group. As part of this, PEDRI is forging a strategic partnership with the Alliance. This partnership marks a significant step towards achieving our shared goals in data research and enhancing the impact we can make in our community. The Alliance's wealth of expertise and resources will complement PEDRI's mission and initiatives.

Workshop participation

The workshop was held online over Zoom on the 14th of December 2023. 25 attendees participated in the workshop, with half identifying as Public Involvement and Engagement (PIE) professionals. Public members also participated in the workshop and constituted about a quarter of the attendees. The workshop was recorded for note taking purposes. List of participating organisations can be found in the appendix at the end of this document.
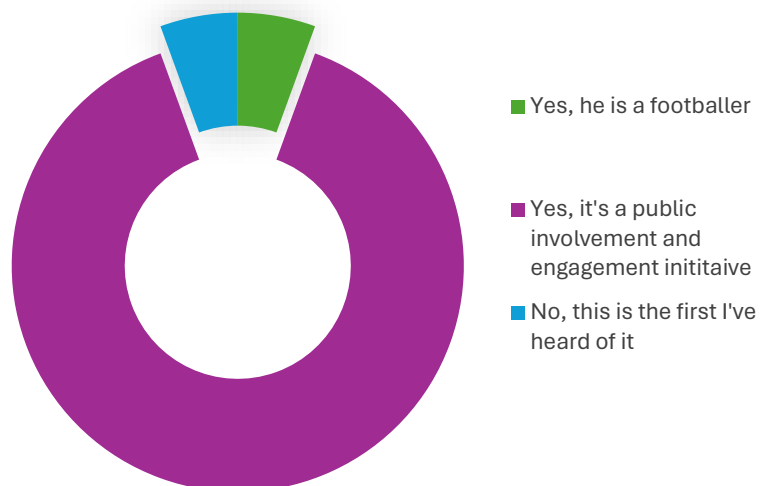

Workshop outputs

There were five outputs from the workshop:

1. Results of polling on PEDRI name
2. Presentations by speakers
3. Feedback about PEDRI Best Practice Standards (draft)
4. Exploration of opportunities for collaboration, learning and development
5. Suggestions from the community on focus areas for future workshops

1. Results of polling

As PEDRI moves into phase two in 2024, and plans are underway to expand its activities we wanted to know if the PEDRI name was recognised amongst those working in the data science ecosystem. The poll was conducted on Zoom during the workshop and attendees were asked to select their answer from a list of three options. Close to 90% of attendees said they had heard of PEDRI and knew it to be a PIE initiative. Only one attendee said they had heard of PEDRI because it is the name of a footballer.

Had you heard about PEDRI before receiving an invitation to this workshop?

- Yes, he is a footballer
- Yes, it's a public involvement and engagement inititaive
- No, this is the first I've heard of it

2. Presentations

The workshop had four presentations by the speakers. The presentations were followed by Q&A sessions. The links to the presentations can be found in the appendix section at the end of this document.

3. Feedback on PEDRI Best Practice Standards

Attendees deliberated on the draft of the PEDRI Best Practice Standards in the breakout rooms. The breakout rooms were recorded and used jam boards to brainstorm ideas. Attendees were provided with the draft of the standards ahead of the workshop. The current PEDRI standards are:

1. Equality Diversity and Inclusion
2. Data Literacy and Training
3. Effective Communication
4. Proactive Transparency
5. Mutual Benefit
6. Meaningful Involvement and Engagement
7. Culture of Public Involvement and Engagement

The feedback was generated around four broad questions relating to the standards:

1. How might adopting the standards enhance public involvement and engagement?
2. What methods or approaches can facilitate this transition?
3. Are there any concerns regarding the adoption of the standards?
4. How might these challenges be addressed or mitigated?

Advantages of adoption of standards

1. **Enhancing public involvement and engagement in data science:**
   - Adoption of standards will improve public involvement and engagement and provide an easy checklist for PIE professionals.

2. **Importance of data literacy and training:**
   - Acknowledgement of the critical role of data literacy in public engagement.
   - Need for training to empower the public to interpret media reports and access information from trustworthy sources.
3. **Building trust through transparency:**
   - Transparency around how data is collected and used is important for earning building trust.
   - Explaining anonymisation processes, data access processes and safeguards to ensure privacy is crucial to make the public more comfortable and aware.
4. **Transparency as a pillar for engagement:**
   - Transparency as a crucial element for effective communication and patient engagement.
   - Potential of adoption of standards and improved communication about use of standards can boost confidence in research initiatives.

Challenges

1. Adoption of standards:

- Considerations about standards being tokenistic or not properly followed through.
- There is a need for meaningful adoption and potential consequences for lack of adherence.

2. Measuring and ensuring accountability:

- Measuring adoption of standards and ensuring accountability can be challenging.
- Exploration of mechanisms to encourage and enforce adherence, including potential "sticks" alongside "carrots" will be helpful.

3. Addressing concerns on under-represented populations:

- There is a need for careful consideration and justification when seeking information on under-represented populations.
- Emphasising the importance of adding value to both the population and researchers in such endeavours.
- Understanding Equality Diversity and Inclusion beyond ethnicity to ensure better inclusivity.

"...adopting the standards would really give a huge boost to transparency, and from transparency you have at least the opportunity to try and build confidence".

"...things need to be a bit more official than just yet another activity on the sidelines"

Suggestions to improve adoption of standards

1. Amplifying examples of good practice:

- There is a need for case studies to illustrate what "good" looks like in terms of public involvement and engagement.
- Efforts should be made to spotlight exemplar organisations to showcase best practices.
- There is a need for better sharing best practice and avoid duplication of efforts.

2. Institutionalisation of standards:

- Participants advocated for the 'institutionalisation' and embedding in of standards in organisational practice to ensure they are taken seriously.
- There is a need for official commitments and organisational buy-in to make standards a central part of practice.
- Recognised standards should be embedded in organisational practice.

3. Developing crystal mark, CPD opportunities and engagement plans:

- Consideration of Continuous Professional Development (CPD) opportunities to integrate standards into professional training for everyone working in the data science field, including PIE professionals.
- Increase awareness and adoption of standards across the sector.
- Standards accreditations or crystal marks could be considered to incentivise adoption.

4. Collaborating for improvement:

- Collaboration and sharing of knowledge and strategies among organisations to improve standards is key.
- Recognition of the need for organised strategies and capacity-building within organisations.

"Crystal marks have been used to demonstrate how well or not organisations are meeting standards, so that's something that PEDRI could explore."

4. Exploration of opportunities for collaboration, learning and development

- PEDRI and Understanding Patient Data's work on public deliberation can benefit from collaboration.
- Health Data Research UK Wales/Swansea University are in the initial phase of a project that is looking at refining what co production means for research and creating a checklist. They plan on engaging the PIE community in a DELPHI style process in early 2024.

- The Alliance would like to engage with organisations that have engaged with ethnic minorities in data science for its Diversity in Data project. Find more information about the project here: https://ukhealthdata.org/projects/diversity-in-data/
- Research Data Scotland (RDS) funded 8 projects this year, two of which focussed on engaging with groups that aren't represented in data research. One was ethnic minorities in Aberdeen and the other was people with a history of drug usage in Dundee. RDS is going to organise an event in February to showcase these projects. Find more information here: https://www.researchdata.scot/our-work/shaping-our-services/public-engagement/public-engagement-fund/
- UK TRE Community - open to all working within or with TREs across the UK meet a few times a year online and in person. They also discuss issues around governance and the role of PIE in their meetings. Find more information here: https://www.uktre.org/en/latest/index.html
- Exploring platforms to bring together PIE leads across organisations and public members to facilitate learning and development.
- Engaging with PIE professionals working internationally to understand best practice globally in data science research.

5. Suggestions for future meetings

1	Best ways to demonstrate the impacts of PPI on research and building on the input/insights.
2	Discussing approaches where the nature of research being undertaken may limit the ability to be co-productive throughout a research cycle, for example in technical data analysis.
3	Exploring international perspectives and practices and opportunities for collaboration.
4	Talks by PEDRI partners like the ONS on how they intend to embed best practice standards and become exemplar organisations.
5	Exploring methods to explain impact and benefits of data sharing with the wider public and engender trust and confidence in the process.
6	Data legislation and information governance.
7	Commercialisation and it's impact on public involvement in data research.
8	Reaching underrepresented groups in data research

Conclusion and next steps

While the benefits of adopting standards for public involvement and engagement in data science are evident, addressing concerns, sharing best practice and implementing solutions is crucial. The push for institutionalisation, developing crystal marks and CPD opportunities, and engagement plans demonstrates a commitment to ensuring standards become an integral part of organisational practices. The discussion serves as a foundation for a more transparent, inclusive, and effective approach to public involvement and engagement in the dynamic landscape of data science.
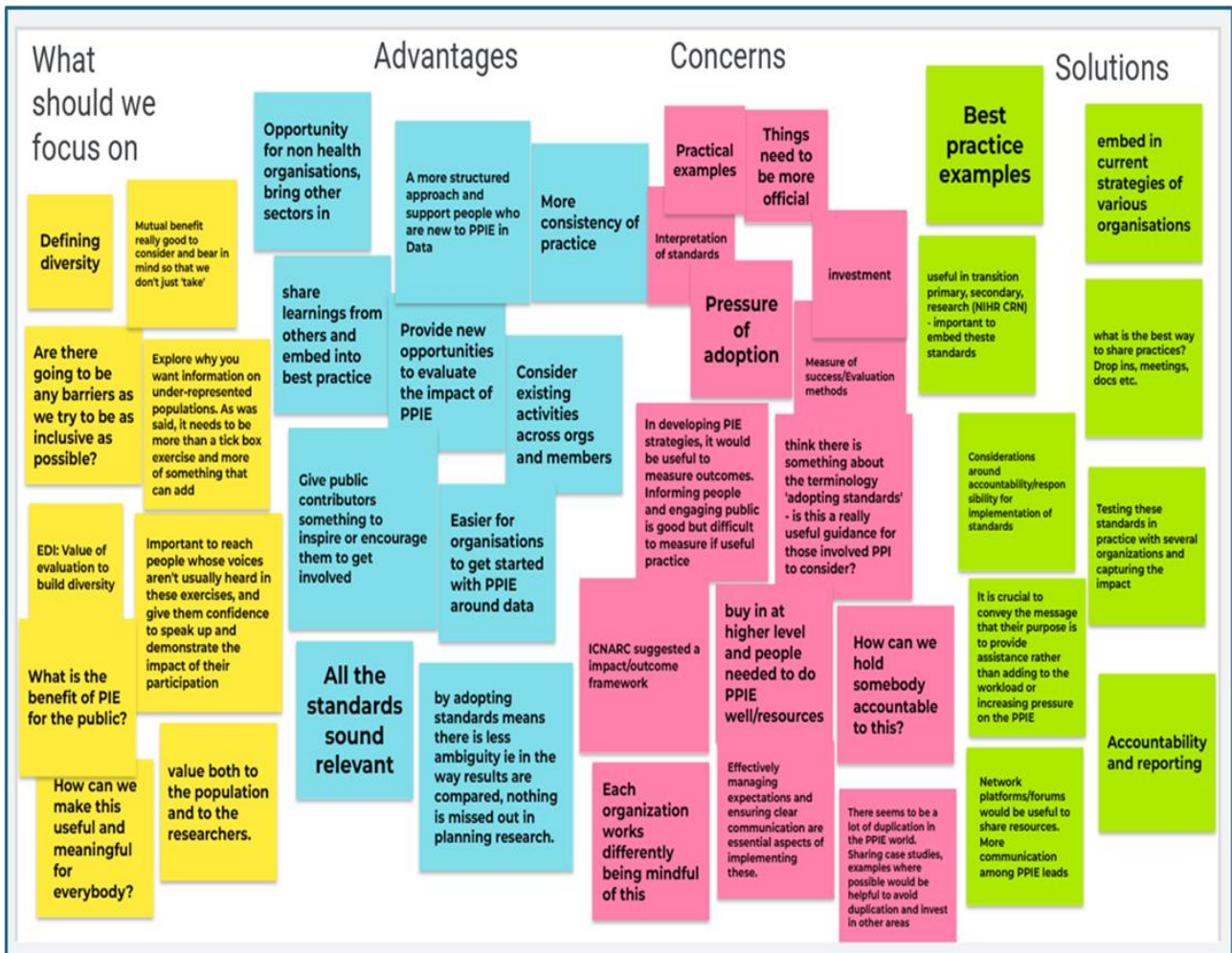
This workshop was only the first of a series to explore strategies to improve awareness of best practice for public involvement and engagement, share knowledge and reduce duplication of efforts. The long-term goal is to encourage collaboration and alignment among organisations in the Alliance and across sectors and to improve meaningful public involvement in data research. The next two workshops are scheduled for:

8th February 2024: 13:30-15:00

14th March 2024: 13:30-15:00

Appendix

Jam-board

Agenda

Chairs: Doreen Tembo (HDR UK) and Paola Quattroni (Alliance)

Time	Item	Lead and Slides
1:30 pm (5 min)	**Welcome and introductions**	**Paola Quattroni**
1.35pm (10 min)	**Public Engagement in Data Research Initiative: Introduction and Overview of Best Practice Standards**	**Doreen Tembo Ester Bellavia**
1:45 (30 min)	**Breakout room: Deliberation around PEDRI's Best Practice Standards**	
	Break (5 minutes)	
2:20 (20 min)	**Spotlighting Alliance Member: Understanding Patient Data**	**Paola Quattroni Nicola Hamilton**
2:40 (15 min)	**Open Forum: Collaborating and Knowledge Sharing**	
2:55 (5 min)	**Wrap-up and thanks**	**Doreen Tembo Paola Quattroni**

Presentations

Doreen Tembo: https://ukhealthdata.org/wp-content/uploads/2024/01/Doreen-Tembo-PEDRI-Overview.pdf

Paola Quattroni: https://ukhealthdata.org/wp-content/uploads/2024/01/Paola-Quattroni-Overview-of-the-Alliance-.pdf

Ester Bellavia: https://ukhealthdata.org/wp-content/uploads/2024/01/Ester-Bellavia-PEDRI-draft-standards.pdf

Nicola Hamilton: https://ukhealthdata.org/wp-content/uploads/2024/01/Nicola-Hamilton-Understanding-Patient-Data.pdf

Participating organisations and hubs

- Clinical Practice Research Datalink
- Understanding Patient Data
- Cancer Research UK
- Use MY Data
- Office for Statistics Regulation
- Health Data Research UK Wales
- Data and Analytics Research Environment UK
- Intensive Care National Audit & Research Centre
- NIHR Clinical Research Network (CRNCC)
- Swansea University
- Health Data Research UK Public Advisory Board
- Health Data Research UK Social and Environmental Determinants of Health Driver Programme
- Research Data Scotland
- Administrative Data Research, Wales
- INSIGHT Health Data Research Hub

Contact us

Email: contact@pedri.org.uk