PEDRI

Public Engagement in Data Research Initiative: Shaping the future of public involvement and engagement in data research

PEDRI

- Founded by ADR UK, HDR UK and ONS
- Sector wide partnership across the data driven research ecosystem
- Focus on health, administrative, statistical data

PEDRI Focus

- Convening collaborations sand partnerships

- Defining and subscribing to best practice while furthering adoption in the sector

- Sharing and creating resources to enable best practice

- Develop strategic approaches to engagement and communications

DARE Community Groups Funding

PEDRI: Public Involvement and Engagement Best Practice Draft Standards for the use of data for Research and Statistics

Work stream 1: Development and adoption of the draft PEDRI Best Practice Standards for the Use of Data for Research and Statistics:

- **Purpose:** Initiated to help data research professionals and organisations to effectively engage with the public.

- **Collaborative Standardisation**: Working together to improve and streamline standards coordinated by PEDRI.

- **Public Consultation Process:** In 2023, inclusive consultation involving public involvement and engagement professionals, academics, and the public refined and amended standards.

- **Report Publication:** Outcome of the public consultation detailing insights and recommendations. Further engagement via 2 or more online workshops

Work stream 2: Community Engagement and Knowledge Sharing focused on PIE in data science

- Organise community activities e.g. at least 3 online meetings

- Focused discussions, topic identification and promote active participation

- Discuss challenges and find possible solutions together with potential of adding to the evidence base around PIE in data intensive research

- Share resources which could be hosted on the new PEDRI Website

- A possible sub-group on health in partnership with UK Health Data Research Alliance ('Alliance')

Work stream 3: Establishing a Central Resource Hub and Improving Transparency and Functionality of the PEDRI Website and Alliance PIE Web Pages

- Redevelop the PEDRI website

- Create a Resource Hub

- Redesign the PPIE Alliance Web Pages

Work stream 4:Planning for national public awareness campaigns

- Inclusive and accommodating methods of engagement and communication

- Cater to the diverse needs of our audience

Findings from our Public Consultation on the Best Practice Draft Standards for the Use of Data for Research and Statistics

Results

- **Work package** 1:
  - Final [report] on public consultation published (April)
  - Two (public and practitioner/academic) formal consultation meetings sought feedback and explored barriers and facilitators to adoption
  - One informal consultation with the NHS England Secure Data Environments (SDE) Network to explore barriers and facilitators to adoption
- **Work package 2**: Three very successful community workshops held (exploring PEDRI standards, partner work outside of health, EDI and impact)
- **Work package 3**:
  - Website rebranding and redevelopment in progress
  - Resources collation and scoping survey
  - Partnership discussions with stakeholders e.g. NIHR
- **Work package 4**: Workshop held to develop plan for engagement and communications campaign (with assistance from [Sciencewise])

PEDRI next steps

1. Refine standards and establish a strategy for dissemination, adoption, monitoring, evaluation and learning

2. Finalise and publish final two PEDRI-Alliance workshop reports and recommendations for future working between PEDRI and the Alliance

3. Continue to collate resources and advising the web developers on the development of the resource Hub.

4. A workshop report will be produced which will then be utilised by the communications working group to develop a strategy and plan for public engagement and communications.

Lessons Learned

- Need for adaptability in project management

- Open two-way communication with funder and stakeholders

- Realistic time scales for partnership initiatives

- Partnership building to avoid duplication

- Low awareness of benefit of Public involvement and engagement outside of health data research (and sometimes within)

Questions?

For enquiries or further involvement opportunities:
contact@pedri.org.uk

Standard	Definition
1. Equity, diversity, and inclusion	Effective PIE requires equity of representation of different members of the public, irrespective of their background, experiences, and identities. Inclusivity requires actively seeking out diverse voices and proactively adapting engagement and involvement approaches to make them accessible. PIE should broaden the public audience to new communities and those less familiar with the topic.
2. Data literacy and training	Effective data literacy, training, and supporting members of the public to have the vocabulary, confidence, and understanding.
3. Effective communication	Effective two-way communication and dialogue supports meaningful data research. Enabling all parties to understand one another, and meaningfully contribute to discussions.
4. Proactive transparency	Working openly throughout all PIE activities, to create a comfortable environment for all parties. Project information must be freely accessible for discussions with members of the public.
5. Mutual benefit	PIE activities should enable mutual benefit between all those involved. Researchers should gain new insights/ideas to develop more impactful research informed by public views.
6. Meaningful involvement and engagement	Meaningful PIE should take place at every stage of research with clear objectives. PIE should be focused with clear tasks, purpose, and impact, while avoiding tokenism.
7. Creating a culture of PIE	Creating a culture of PIE in an organisation at every level. Organisation should value PIE and embed it in their institution.