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

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Content

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Introducing PEDRI

The Public Engagement in Data Research Initiative (PEDRI) is a sector-wide partnership bringing together organisations who work with data and statistics to generate insights that can inform policy and practice. The goal is to collaborate on establishing and driving forward best practice for public involvement and engagement with data research, to bring the views of the public to policymakers and data holders in a more meaningful way.

A key aim of the 'Public Engagement in Data Research Initiative' (PEDRI) is to establish and drive forward best practice for public involvement and engagement with data research, including the views of the public in a more meaningful way. To support this work PEDRI has created these draft standards to guide best practice for involvement and engagement activities in the use of data for research and statistics. **The aim of these draft standards is to support researchers and PIE professionals to conduct meaningful PIE related to the use of data for research and statistics**. These draft standards are intended for everyone involved in conducting, building infrastructure, or supporting public involvement and engagement activities.

What we are addressing

Public sector data contains confidential information about people. Those working with public data understand why this data is collected, how it is stored, who has access to it, how and why it is used, and the likely outcomes of its usage. This process can be complex and is not well known by members of the public. It is therefore important that we, who work within the data and statistics community, conduct ourselves with the highest levels of transparency and professionalism and ethical standards to maximise public benefit from the use of public data. We must utilise data for research and statistics in the name of all of those who have provided their data. We must also understand and include the public voice in the work we do. However, the challenges to effectively include the public perspectives are varied and diverse.

Guide to this document

The draft standards follow this introduction to this document and our intentions. At the end of this document there is information on those involved in drafting these standards and the method used, in addition to how to find out more about PEDRI and how to get involved.

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Your feedback

This is a public consultation; we want to hear your views on the draft standards. Everyone is invited to take part, whether you are a member of the public who rarely interacts with data research, researchers, or data custodians. Once you read the draft standards, we hope you can complete the following form to capture your feedback in this survey.

https://www.surveymonkey.co.uk/r/RZJWQF8

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Draft Standards

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.

This might look like:

- Adopting a flexible approach to allow anyone, regardless of their background and identity, to join conversations about how their data is being or is planned to be used.

- Collaborating with charities and representatives of underrepresented groups to ensure inclusive and accessible approaches to PIE activities.

- Gathering diverse views by engaging different demographics and those unfamiliar or sceptical about the topic.

- Recognising the different skills and knowledge members of the public and subject experts bring.

- Recognising that while diversity and inclusion may not always lead to consensus, they are still valuable by enriching PIE activities.

2 – Data literacy and training

Data research and statistics often involves complex topics. Understanding 'non-expert' public perspectives can be extremely valuable, but occasionally some level of understanding may be needed to conduct effective PIE. Effective data literacy, training, and support enables members of the public to have the vocabulary, confidence, and understanding, which can empower them in their role as a contributor. Before beginning any engagement activity, it is important to assess baseline knowledge to determine if training requirements or support should be provided.

This might look like:

- Engaging with members of the public to understand what they already know and what they would like to learn about the topic.

- Supporting members of the public to have a baseline knowledge and understanding of the research to meaningfully contribute.

- Providing effective training that is delivered based on good teaching standards.

- Prioritising time and resources for public members to gain confidence in data literacy.

- Grounding discussions about data in real life use cases, relevant to those involved.

- Emphasising the perspectives and knowledge of public members and the critical thinking they bring.

- Creating and sharing informational resources for members of the public to interact with, whether or not they are involved in specific PIE activities.

3 – Effective communication

Data research and statistics often include complex terminology and abstract concepts. Effective two-way communication and dialogue is key to having meaningful conversations with the public about the use of data research and statistics. This can enable all parties to fully understand one another, and meaningfully contribute to discussions.

This might look like:

- Ensuring discussions are engaging, relevant, and tangible for members of the public.

- Listening, acknowledging, and responding to public views and concerns.

- Ensuring language is accessible to a wide audience with the use of jargon free and accessible language.

- Broadening accessibility using a variety of mediums, such as large text documents, videos, images, and diagrams.

- Anticipating the likelihood of difficult conversations and addressing these as they arise.

- Acknowledging that consensus may not be achievable and providing open and positive mechanisms for differing views and exchange of ideas.

4 – Proactive transparency

Proactive transparency means that information is freely available, accessible, and subject to wider discussions with members of the public. Working openly in accessible formats, throughout all engagement and involvement activities, and being open to discussions with the public are essential in demonstrating trustworthiness. Working in this way helps create a comfortable environment for all parties to effectively contribute to discussions.

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This might look like:

- Making members of the public aware of the entire research process, timelines, and how decisions are made.

- Meeting public expectations of transparent ways of working through a two-way conversation, including time for questions and answers.

- Making all research materials up-to-date, available, and shared in accessible ways.

- Defining and communicating the purpose of research and any engagement activity to participants and members of the public.

- Having timely follow-up conversations with participants after involvement activity to give feedback on the impact of their involvement and next steps.

- Openly sharing research outcomes once they become available.

5 – Mutual benefit

PIE activities should adopt an ongoing dialogue-based approach to enable a mutual benefit between all those involved. This allows researchers to gain new insights and ideas to develop more impactful research informed by public views.

This might look like:

- Clearly communicating the benefits of being involved in PIE activities, their expected outcomes, and impact.

- Clarifying expectations on PIE and agreeing ways of working.

- Acknowledging public members for their contributions by offering them monetary or other agreed means.

- Helping members of the public to have a clear understanding of why they have been chosen to be engaged with / involved in the research.

- Setting realistic expectations for involvement and engagement processes and ensuring ongoing evaluation by all involved in the process.

- Promoting effective knowledge exchange among all involved in the process, fuelled by listening and responding.

6 – Meaningful involvement and engagement

PIE should be undertaken with clear objectives and meaningful ways to incorporate PIE findings into wider project activities. Meaningful PIE should take place at every stage of research, from planning to dissemination. PIE should be focused with clear tasks, purpose, and impact, while avoiding tokenism.

This might look like:

- Developing a comprehensive PIE plan from the beginning of study development.

- Setting clear objectives for PIE activities, including how PIE input will be incorporated into wider study activities.

- Appropriately resourcing staff time and budget for PIE activities.

- Promoting meaningful PIE activities throughout the research cycle.

- Committing to continually improving how members of the public are involved and engaged.

- Evaluating the impact of PIE activities, sharing outcomes and lessons learned.

7 – Creating a culture of PIE

Creating a culture of PIE in an organisation can support a seamless partnership between researchers and PIE professionals. Throughout every organisation, at every level, the value and necessity of PIE should be recognised and embedded. Time and other resources should be dedicated to supporting the role of involvement and engagement in projects.

This might look like:

- Embedding PIE throughout the research cycle.

- Active encouragement and accountability from senior leaders for PIE.

- Acknowledging the time and contribution made by members of the public.

- Acknowledging the expertise of PIE professionals as skilled practitioners whose expertise is built up through experience and training.

- Resourcing involvement and engagement activities, throughout the entirety of a project, with appropriate staff, funding, and other resources.

- Providing ongoing training for researchers and PIE professionals.

- Sharing and exchanging knowledge of how to conduct effective PIE with other researchers and engagement professionals, particularly those early in their careers.

- Working to continually improve approaches to PIE.

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Who drafted these standards?

The draft standards in this document have been developed by the PEDRI Best Practice Draft Standard working group. The working group has members whose affiliation are: Public members, NHS TD, ADR UK, HDR UK, and Cancer Research UK.

How can I find out more about PEDRI?

For more information please email: contact@pedri.org.uk or sign up to our news bulletin here.

Methods used to draft the standards

The PEDRI team, in close collaboration with the NHS Transformation Directorate, have followed a systematic process to develop these draft standards. A working group of PEDRI members including public involvement and engagement professionals, academics, public members, and representatives from the third sector was established to develop these draft standards.

The working group members reviewed and analysed 29 different standards / principles / guidance / strategies that related to public involvement and engagement to identify common themes. These themes and a wider discussion were presented to community members in two workshops with 62 attendees (25 in-person and 37 online). Attendees at both events included members of the public, public involvement & engagement professionals, representatives from the third sector, governmental representatives, early career researchers, and established researchers. There was representation from all four home nations of the UK   .

The workshops aimed to help us to:

- Understand barriers people are currently facing to embed best practice in public involvement and engagement in data research, and what can be done to overcome them.

- Understand what best practice looks like in cross-domain data research / data-specific programmes and if / how existing standards can be adapted to suit this need.

Understand how we can enable and support organisations and research teams to adopt best practice standards.

Challenges and limitations of these draft standards

The PEDRI members have worked systematically to produce these draft standards reflecting on existing principles and incorporating the wider community views and requirements. A solution to all possible challenges a researcher or PIE professional might face is beyond the scope of this document. Instead, we have created a set of draft standards and guidance, with an attempt to balance generalisability and specificity in a practical way.

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These draft standards are a starting point for further discussion. We realise that some of these draft standards may sound similar or overlap. This is because they are not meant to stand alone, but feed into each other. We are launching this consultation to continue the discussion with members of the public, researchers, and public involvement and engagement professionals. Together, we hope to create a resource to better support the data and statistics community to work with the public. Following this consultation, the findings will be shared with PIE community and public.

To get involved please email contact@pedri.org.uk