

Summary Report: PEDRI Roundtable on Project Level Public Involvement and Engagement for TRE/SDE Access.

19 November 2024

Introduction

Public Engagement in Data Research Initiative (PEDRI) is a sector-wide partnership that brings together organisations working with data and statistics to generate insights that can inform policy and practice. The initiative aims to foster collaboration to advance good public involvement and engagement (PIE) practices within data research, to bring the views of the public to policymakers and data holders in a meaningful way.

A roundtable meeting was organised to explore the challenges and potential solutions related to Public Involvement and Engagement in Trusted Research Environments (TREs) and Secure Data Environments (SDEs) at the project level.

Before researchers can access data about the population for secondary data research projects such as health records, census data or education data they must apply to the data provider. This application is reviewed taking into account a number of factors including what public engagement plans the researcher will carry out. PEDRI recently convened a Roundtable meeting to discuss the challenges raised by researchers in relation to carrying out Public Involvement and Engagement (PIE) at the project level for Trusted Research Environments (TRE) and Secure Data Environments (SDE) access.

The group explored current mechanisms and approaches to assess Public Involvement and Engagement (PIE) activities in research within the context of Trusted Research Environments (TREs) and Secure Data Environments (SDEs). Each organisation presented its current approach to incorporating PIE into their approval processes. This provided an opportunity to share insights and explore the strategies others are using in this area.

The second part of the roundtable provided an opportunity to explore the challenges from both public and researcher perspectives, as well as potential solutions. A summary of the key points from the discussion are outlined in this report.

Exploring the challenges

The table below summarises the key points discussed during the session:

| Key area | Key points |
|--------------------------------------|---|
| Researcher Challenges | <ul style="list-style-type: none"> • Junior researchers lack knowledge and expertise in PIE. • Limited time and funding to conduct PIE activities before project development. • Difficulty understanding PIE requirements for different types of projects (e.g., sensitive data, AI). • Challenges in finding relevant public members with lived experience. |
| Public and Patient Challenges | <ul style="list-style-type: none"> • Public and patients struggle with complex research terminology, hindering meaningful involvement. • Lack of standardised PIE induction for public contributors, leading to a feeling of disempowerment. |
| Organisational Challenges | <ul style="list-style-type: none"> • Defining the appropriate level of decision-making power for public contributors. • Insufficient funding and resources for effective PIE. • Ensuring public contributors maintain a lay perspective while acquiring necessary data literacy. • Achieving inclusivity and establishing a feedback loop to maintain public trust. |

Discussion

The discussion at the roundtable emphasised the importance of aligning efforts across various organisations and initiatives to ensure a consistent approach to PIE while avoiding duplication. It was suggested that a collaborative, "consortium of consortia" approach could help achieve this. Clear messaging on the broader benefits of involving the public was highlighted, focusing not only on improving research quality but also on providing learning opportunities for both researchers and public contributors, thereby strengthening mutual relationships. Additionally, the need for consistency in PIE requirements was discussed, along with the importance of making PIE approaches reproducible, so that researchers can benefit from the learning of others.

The group also recognised the need to engage regulators in the consensus-building process, ensuring that PIE is aligned with the regulatory context. Setting clear expectations for PIE, even before funding has been secured, was seen as essential to overcoming challenges. There was a focus on identifying

and involving the right public contributors, especially those with relevant lived experiences or those from underrepresented groups such as children and young people. Ensuring that the feedback loop is completed was also seen as crucial in maintaining public trust, ensuring contributors understand how their involvement impacted the research, not just through the dissemination of findings. The discussion also addressed the nuances of PIE in relation to different types of data, particularly consented versus non-consented data, and emphasised the importance of non-project-level PIE engagement.

Finally, the group acknowledged the different risk appetites in the private and public sectors and the implications of these differences for PIE, stressing the need to consider these factors in future work.

Proposed Solutions

- Establish **citizen juries** to conduct in-depth discussions on public acceptability of data research. This initiative will empower communities, generate critical insights, and ensure that public perspectives are central in shaping research practices, building trust, and increasing transparency.
- **Implement a structured rotation of PIE panel members** every 2-3 years to ensure fresh, diverse perspectives. This will help maintain relevance, avoid stagnation, and bring in new insights that reflect changing public attitudes and concerns.
- Build and share a comprehensive, **accessible repository of PIE insights across the sector**. This knowledge base will be a crucial resource for researchers, enhancing the overall understanding of best practices and enabling more effective, informed public involvement strategies.
- **Develop standardised tools, including decision trees and research proposal templates**, to streamline and guide PIE efforts across the sector. These resources will ensure consistency, simplify the process for researchers, and provide clear frameworks for engaging the public meaningfully.
- **Introduce a standardised PIE induction** program for public contributors, providing them with the knowledge and skills to engage effectively. This training will ensure that public members feel empowered, informed, and equipped to contribute meaningfully to research.
- Collaborate with **charities and voluntary organisations** to recruit appropriate public contributors, particularly those with lived experience. Charities can play a crucial role in identifying diverse, relevant voices and ensuring that the research process is inclusive and reflective of real-world experiences.
- Establish a clear, **unified message** about the importance and value of PIE, consistently communicated to researchers, stakeholders, and the wider public. This messaging will raise awareness, drive engagement, and reinforce the critical role that public involvement plays in shaping high-quality research outcomes.
- Explore the integration of PIE-specific training into **the existing ONS Five Safes framework**. This will ensure that all researchers working with sensitive data are equipped with the

necessary skills and understanding to engage the public effectively, fostering trust and facilitating the ethical use of data in research.

Next steps

- Engage in the NHS Scotland PPIE Event 2025 to continue the conversation and explore new insights. This workshop will serve as a platform to refine existing strategies, uncover emerging issues, and ensure that the progress is both sustainable and impactful.
- Organise follow-up meetings with key stakeholders committed to advancing PIE initiatives. These meetings will focus on tracking progress, addressing challenges, and identifying next steps to ensure continued momentum.
- Establish Task and Finish groups to tackle specific, high-priority activities. These focused groups will drive tangible outcomes, ensuring that action is taken on the most pressing PIE challenges identified during the roundtable, resulting in measurable improvements in public engagement in research.
- Develop a comprehensive consensus paper that consolidates the group’s discussions and presents actionable recommendations

This roundtable marked a pivotal moment in addressing the challenges of PIE in TRE/SDE research, laying the groundwork for concrete actions that will strengthen public trust, enhance engagement, and ensure that data research practices remain inclusive and transparent.

Participating Organisations

| Organisation | Attendee(s) |
|--------------------------|--|
| Roundtable Chair | Samaira Khan |
| Co-chair | Doreen Tembo |
| PEDRI Public Partner | Jan Speechley |
| UK LLC | Robin Flaig Andy Boyd Stela McLachlan Kirsteen Campbell |
| The Francis Crick | Pete Barnsley |
| Smart Data Foundry | Patricia Ruddy Magdalena Getler |
| Use My Data | Dave Chuter Samina Begum |
| BHF Data Science Centre | Rouven Priedon Amy Hodgkinson |
| Research Data Scotland | Katie Oldfield |
| Honest Broker Service NI | Alan Harbison Nicola Armstrong |
| Public Health Scotland | Carole Morris |

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| Health Research Authority NHS | Alison Knight |
| Health Care Research Wales | Peter Gee |
| Arcturis Data | John Latham-Mollart |
| Barts NHS Trust | Francene Clarke-Waldren |
| Cancer Research UK | Matt Howard Murray Ashley-Anne Brown |
| Health Data Research UK | Rachel Brophy |



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