

DARE UK



Public Involvement and Engagement (PIE) Guidelines for DARE UK Projects

A Playbook for PIE Monitoring, Evaluation, Learning
and Reporting

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1. Background

The DARE UK (Data and Analytics Research Environments UK) programme aims to create a secure federated network of trusted research environments (TREs) operating within a common best practice framework to facilitate faster and more efficient access to sensitive data research in the public good. DARE UK's collaborative programme delivery model led the programme to seek technical guidance from key experts in the UK data and research landscape to explore innovative ways to actualise its vision.

With funding from UK Research and Innovation (UKRI), the UK's largest public funder of data and research innovation, DARE UK commissioned two project portfolios to lead fact-finding missions to inform the direction of the programme. The first portfolio, which ran from January to August 2022, was made up of nine Sprint Exemplar Projects commissioned to uncover and test early thinking in the development of a joined-up and trustworthy national data research infrastructure. The second portfolio of projects, which will run from February to October 2023, is made up of five Driver Projects, which will play a leading role in informing the design of what will be a UK-wide secure and interoperable network of TREs.

Based on the outcomes and learnings from these projects, and interactions with data and research stakeholders across the UK, DARE UK will implement other interventions throughout the programme life cycle to achieve its mission.

2. DARE UK's Commitment to Public Involvement and Engagement

DARE UK is committed to meaningfully involving the public in all aspects of the programme to ensure that the public, who are central to the programme's vision, have sight of all activities and are involved in decision-making. One of the seven key outputs from the [DARE UK Initial Phase 1 Recommendations](#) report was the need to proactively and consistently practice transparency to build trust and foster public participation. Based on this recommendation, DARE UK established the *Demonstrating Trustworthiness* work stream to embed Public Involvement and Engagement (PIE) in all aspects of the programme. Notably, DARE UK has appointed members of the public to its decision-making boards, organised a series of public events and workshops, and created other opportunities for public input, such as requests for comment and surveys. Plans are underway to expand the programme feedback environment further through community-led groups – *Interest Groups*, *Working Groups* and *Communities of Practice*. DARE UK shares its PIE commitment with all programme partners and collaborators, including funded and commissioned projects.

3. Rationale

To ensure that DARE UK projects are aligned with the programme's PIE commitments, it is critical to establish clear guidelines to inform the strategy and implementation of their PIE deliverables. These guidelines will provide the necessary framework for executing and documenting PIE activities in a methodical and comprehensive manner.

The implementation of these guidelines will facilitate the design, conduct, evaluation, and reporting of PIE activities, ensuring that they are aligned with the programme's overall objectives.

The guidelines provided in this document are drawn from the recommendations of two reference standards widely adopted by UK-based projects and programmes to implement and evaluate their patient and public involvement and engagement activities in a data and research context.

4. Reference Standards

4.1. UK Standards for Public Involvement

The [UK Standards for Public Involvement](#) were designed to improve the quality and consistency of public involvement in research. Developed over three years by a UK-wide partnership, the standards are a description of what good public involvement looks like and encourage approaches and behaviours that are the hallmark of good public involvement, such as flexibility, sharing and learning and respect for each other. The standards are for everyone doing health or social care research and have been tested by over 40 individuals, groups, and organisations during a year-long pilot programme. They provide guidance and reassurance for users working towards achieving their own best practice.

4.1.1. The Six UK Standards for Public Involvement

1. **Inclusive Opportunities** – Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
2. **Working Together** – Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
3. **Support and Learning** – Offer and promote support and learning that builds confidence and skills for public involvement in research.
4. **Communications** – Use plain language for well-timed and relevant communications as part of involvement plans and activities.
5. **Impact** – Seek improvement by identifying and sharing the difference that public involvement makes to research.
6. **Governance** – Involve the public in research management, regulation, leadership and decision-making.

4.2. GRIPP2

[GRIPP2](#), which stands for Guidance for Reporting Involvement of Patients and the Public, represents the inaugural international guidance on patient and public involvement (PPI) reporting, rooted in evidence-based and consensus-informed methodologies. GRIPP2 has [long-form](#) and [short-form](#) versions, and the primary objective of both versions is to enhance the quality, transparency, and consistency of PPI research practices on a global scale. By basing PPI practices on the best evidence available, GRIPP2 aims to strengthen the PPI evidence base, thus facilitating the integration of PPI into research initiatives. The GRIPP2 short form was considered for this document.

5. DARE UK Guidelines for PIE Reporting

Based on the two reference standards above, DARE UK recommends adopting the outline below for reporting PIE activities. Project teams should provide clear and detailed answers to all questions and consider the same in developing and implementing their PIE strategy and corresponding activities.

Background

Summarise the project and its relevance to DARE UK's mission, highlighting the role of PIE in achieving success.

- What is the project about?
- How does it fit into the DARE UK programme?
- Why is PIE important in the delivery process?

Aim

Describe the purpose of the PIE activities in achieving the project's goal(s) and objective(s) and supporting DARE UK's PIE commitment.

- What does your PIE intervention seek to achieve, and how will it influence your project outcomes and the wider DARE UK programme?

Approach

Elaborate on the strategy and key considerations taken to deliver the activities in a way that is robust, measurable and impact-driven.

- Did you develop a PIE strategy and establish a PIE team as part of your project delivery strategy? Was the public involved in the development of your strategy and other decision-making processes?
- What method was adopted for your PIE activities? (e.g., surveys, focus group interviews, workshops, public events, etc.)
- What specific steps or decisions did you take to make your PIE activities inclusive, accessible and collaborative?
- How did you promote your PIE activities?
- How did you arrive at your choice of audience, and why them?
- What is the demographic spread of your audience? (e.g., countries of origin, residence/locality, ethnicity, age, education, income bracket, etc.)
- How did you translate complex information into public-friendly messages?
- How did you communicate with your audience during and outside your core PIE activities? (i.e., channels and frequency)
- Did you offer any incentives for participation? What were they, and how?

Activities and Timelines

Explain the schedule of activities you conducted in your PIE process.

- What activities were conducted in your PIE process?
- How were these activities scheduled?

Monitoring and Evaluation

Describe how you documented, tracked, and assessed your PIE approaches and outcomes.

- What key performance indicators did you establish to track your PIE activities?
- How did you monitor these activities, and over what periods?
- How did you measure the impact of these activities?
- How did you monitor your PIE promotion, and how would you rate participation?
- How did you collect feedback directly from your audience, and what does this feedback tell you?

Reflections and Lessons Learned

Review your PIE activities and highlight key learnings and considerations for future practice.

- How were your PIE activities received?
- What key implementation successes and challenges arose from your PIE delivery process?
- What key learnings are important to consider in your project delivery strategy?
- What key considerations will be crucial for future PIE activities in a similar context?

Discussion and Recommendations

Provide a general evaluation of your PIE activities and implications on your project and the DARE UK programme.

- What is your overall assessment of the PIE process?
- What other developments are worthy of note?
- What are the implications for the project and the DARE UK programme?
- What are your recommendations?
- What are your next steps?

6. Data Gathering and Reporting Templates

Project teams are advised to download and use this [Microsoft Excel worksheet](#) to document their PIE outcomes and this [Microsoft Word template](#) to develop their PIE reports based on the outcomes documented. Other supporting documents may be hyperlinked within these documents for further reference.

7. Conclusion

The guidelines outlined above aim to aid the DARE UK programme in formulating its PIE objectives comprehensively by emphasising key developments and recommendations and capturing the full scope of activities and impact. Effective PIE delivery, monitoring, evaluation, reporting and learning are crucial to the DARE UK programme, particularly under its *Demonstrating Trustworthiness* work stream. These measures will enable the programme team to cohesively document public involvement and engagement across all projects and throughout the programme lifecycle.