

# 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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UK Research  
and Innovation



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

### A Playbook for PIE Monitoring, Evaluation, Learning and Reporting

#### 1. Background

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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, as well as 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

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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

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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 project 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 impactful and aligned with DARE UK'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

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### 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

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Based on the two reference standards above, DARE UK recommends adopting the outline below to report PIE activities. Project teams should provide clear and detailed answers to all questions and consider the same when 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 strategy 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 robust, measurable, and impact-driven way.*

- Did you develop a PIE strategy? Was the public involved in the development of your strategy?
- Did you assemble a PIE team or appoint a PIE Lead?
- Was the public part of your project governance, participating actively in decision-making processes throughout project delivery?
- What methods did you adopt to conduct your PIE activities (e.g., surveys, meetings, focus group interviews, workshops, public events, etc.)?
- Did you commission a third-party agency or consultant to support the delivery of some or all aspects of your PIE strategy?
- What specific steps or decisions did you take to make your PIE activities inclusive, accessible and collaborative?
- How did you ensure a mix of experience in data-driven research from newcomers to members of the public with previous experience?
- How did you communicate and promote your PIE activities and outcomes?
- What clear feedback mechanism did you establish to support possible PIE assessments before delivery, midway through, and after the project?
- What is the demographic spread of your public participants? (e.g., countries of origin, residence/locality, ethnicity, age, education, income bracket, etc.)
- How did you arrive at your choice of public participants, and why them?
- How did you translate complex information into public-friendly messages?
- How did you communicate with your participants during and outside your core PIE activities? (i.e., channels and frequency)
- Did you offer any incentives for participation? What were they, and how were they offered?

## Activities and Timelines

*Explain the schedule of activities you conducted to deliver your PIE strategy.*

- What activities did you conduct to deliver your PIE strategy?
- How were these activities scheduled? (i.e., Were they scheduled along the programme delivery cadence, or were they standalone activities scheduled independently?)



## 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 monitor your PIE promotion, and how would you rate participation?
- How did you measure the impact of these activities?
- How did you collect feedback directly from your public participants, and what does this feedback tell you?
- Did you plan for a possible independent PIE evaluation at the end of your project delivery?

## 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 did you identify when delivering your PIE?
- 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 strategy and its implications for your project and the DARE UK programme.*

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

## Other Questions

*Answer these additional questions to further enrich your PIE assessment.*

- Did your public participants have prior experience in contributing to data science projects?
- Why did members of the public accept the invitation to participate? What did they think they could contribute? Were they pleased they did so?
- To what extent were public participants interested in and committed to your project? How many sessions did they attend? How many stayed until the end, and how many dropped out?
- Was there a noticeable difference in the level of interest and quality of engagement between public participants involved in your project governance versus project activities?
- Was the information you provided to public participants easy to understand or difficult? What worked well to make it comprehensible, and what should be avoided in the future?
- What did participants think about the value/risks of linking data across sectors as proposed by DARE UK? How did they weigh the pros and cons of privacy risks versus research outcomes?
- How did participants rate the value of their involvement? Did they feel listened to? Did they feel they made a difference? Did project team leads feel public participants made a difference?
- What can other similar projects learn from the experience of public involvement and engagement in your project, including positive and negative examples?
- What would you do differently in the future?

## 6. Data Gathering and Reporting Templates

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Project teams are advised to download and use this [Excel worksheet](#) to document their PIE outcomes and this [DARE UK 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

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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.