DARE UK

Public involvement and engagement (PIE) guidelines for DARE UK funded projects and initiatives

A playbook for PIE planning, delivery, evaluation and reporting

Updated on 31 July 2024

UK Research and Innovation

HDRuk
Health Data Research UK

ADRuk
Data-driven change

Public involvement and engagement (PIE) guidelines for DARE UK funded projects and initiatives

A playbook for PIE monitoring, evaluation, learning and reporting

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.

Prior to this effort, DARE UK conducted a public dialogue at the start of Phase 1. This dialogue was instrumental in understanding the public's vision of a joined-up national data research infrastructure. The insights gained from this exercise formed a foundation for the DARE UK programme and its future projects and initiatives, ensuring that the public's expectations and perspectives are not just considered but actively incorporated into programme decisions and outputs.

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 in Phase 1 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 ran from February to October 2023. It was made up of five Driver Projects, each of which played a leading role in informing the design of a UK-wide secure and interoperable network of TREs.

All the projects funded by DARE UK have integrated Public Involvement and Engagement (PIE) throughout, with each team implementing PIE activities using diverse methods tailored to their projects. This diversity of approaches, coupled with DARE UK's dedication to PIE excellence, has necessitated the development of a universal reference document for PIE planning, delivery, and reporting.

This document has been further revised to incorporate learnings and recommendations from the PIE evaluations conducted after the delivery of the DARE UK Phase 1 funded projects (see the Driver Projects PIE evaluation report and Sprint Exemplar Projects PIE report). Additionally, discussions at an in-person PIE strategy development workshop conducted with members of the public provided further guidance in revising this document.

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, contribute to all activities and are involved in decision-making. One of the seven key outputs from the DARE UK 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* workstream in Phase 1 to embed Public Involvement and Engagement (PIE) in all aspects of the programme. DARE UK

appointed members of the public to its decision-making boards, organised a series of online and in-person public events and workshops and created other opportunities for public input, such as requests for comment and surveys.

DARE UK shares its commitment to PIE with all programme partners and collaborators, including funded and commissioned projects and aims to deepen this commitment in Phase 2 of the programme by strengthening its PIE strategy through community-led initiatives, consistent public dialogues and strategic partnerships.

The recently launched DARE UK community groups initiative has further strengthened DARE UK's PIE commitment, broadening the opportunity to interface with members of the public through DARE UK interest groups and working groups and the wider communities of practice. DARE UK community groups are required to involve the public in their activities as group co-chairs or public contributors.

3. Rationale

PIE is an integral part of the DARE UK programme delivery strategy because DARE UK aims to improve sensitive data research for the benefit of the public. Therefore, it is crucial for all DARE UK-funded projects to follow PIE principles and best practices. Clear guidelines should be established to ensure that DARE UK-funded projects and initiatives align with the programme's PIE commitments. These guidelines will act as a framework for planning, executing, and documenting PIE activities in a methodical and comprehensive manner. Adhering to these guidelines when designing, conducting, evaluating, and reporting PIE activities will ensure that the PIE efforts of DARE UK-funded projects and initiatives are meaningful, impactful, and aligned with DARE UK's overall programme objectives.

4. Reference standards

The guidelines provided in this document are drawn from the recommendations of three PIE reference standards adopted by UK organisations and initiatives to implement and evaluate their PIE activities in a data and research context. DARE UK-funded projects and initiatives are required to align their PIE strategies with these standards, ensuring that their activities and outputs are consistent with the established principles and methodologies.

4.1. Public Engagement in Data Research Initiative (PEDRI) Good Practice Standards

PEDRI is a sector-wide partnership bringing together organisations that work with data and statistics to generate insights that can inform policy and practice. PEDRI has created seven draft standards to guide good practices in public involvement and engagement. 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. DARE UK is one of the founding members of PEDRI.

The seven draft PEDRI Good Practice Standards include:

1. **Equity, diversity, and inclusion**: Effective PIE requires equity of representation of different members of the public, irrespective of their backgrounds, 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**: Data research and statistics often involve complex topics. Understanding general 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 enable members of the public to have the vocabulary, confidence, and understanding which can empower them in their role as contributors. Before beginning any engagement activity, it is important to assess baseline knowledge to determine if training requirements or support should be provided.
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.
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 is essential in demonstrating trustworthiness. Working in this way helps create a comfortable environment for all parties to contribute effectively to discussions.
5. **Mutual benefit**: PIE activities should adopt an ongoing dialogue-based approach to enable mutual benefit between all those involved. This allows researchers to gain new insights and ideas to develop more impactful research informed by public views.
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 on clear tasks, purpose, and impact while avoiding tokenism.
7. **Creating a culture of PIE**: Creating a culture of PIE in an organisation can support a seamless partnership between researchers and PIE professionals. The value and necessity of PIE should be recognised and embedded throughout every organisation at every level. Time and other resources should be dedicated to supporting the role of involvement and engagement in projects.

4.2. 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.

4.2.1. The six UK Standards for Public Involvement

1. **Inclusive Opportunities** – Offer accessible public involvement opportunities that reach people and groups according to research needs.
2. **Working Together** – Work together in a way that values all contributions and 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.

4.3.   Guidance for Reporting Involvement of Patients and the Public (GRIPP2)

GRIPP2 is 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, particularly for the data gathering and reporting templates.

5. Guidelines

Based on the PIE standards, concepts, and resources above and the PIE evaluations conducted by the DARE UK Delivery Team, this section offers guidelines for planning, delivering, and evaluating PIE activities. DARE UK-funded projects and initiatives should thoroughly assess their PIE strategy against the recommendations outlined in this section where it makes sense to do so.

5.1.   Recruitment

5.1.1.   Equity, diversity and inclusion

DARE UK-funded projects and initiatives should make deliberate efforts to conduct an open and equitable public recruitment process that ensures a diverse range of people can participate in their decision-making panels, delivery teams and project activities. Public participants should actively seek to include individuals from all four UK devolved nations, as well as people from various backgrounds, identities and life stages in the UK, such as different countries of origin, residence, ethnicity, age, education, career level and income brackets, among others. There should also be a mix of people who have been involved in PIE activities and those who have not.

5.1.2.   Third-party recruitment

Recruitment of public participants may be carried out directly by the project team or through a third-party agency or collaborator commissioned by the project team or provided by the DARE UK programme. Where a third party recruits public participants on behalf of the project, the above considerations for equity, diversity, and inclusion should be upheld. At the point of recruitment, whether directly or through an agency, participants should be given a clear project brief, including what is expected of public participants as well as what they should expect. Public participants should also be informed of the possibility of a post-project evaluation, which may involve getting back in touch with them. To facilitate this, public members should be asked to provide their contact information (i.e., an email address) and consent to be reached if they are willing to participate in the evaluation.

5.1.3.   Incentives

As part of a public member recruitment process, DARE UK-funded projects and initiatives may notify members of the public of incentives to be offered to them for participating in their activities. Where this is done, the incentives should be equitable and fully accounted for in reports. DARE UK may also offer incentives to public participants of funded projects and initiatives as part of a programme-led evaluation or

other exercise to support the delivery of the project or initiative. Where this is done, such incentives will be provided in line with the [HDR UK PPIE Honoraria and Expenses Policy](#).

5.2. Delivery

5.2.1. Activity planning and delivery

DARE UK projects and initiatives are required to appoint a dedicated PIE Lead to oversee PIE planning and delivery as part of the project delivery team. In addition to the PIE Lead, project teams should appoint members of the public to participate in appropriate project delivery meetings, strategic proceedings, decision-making forums and project delivery activities to ensure public input throughout the project. PIE activities must be fully integrated into all aspects of the project plan, highlighting time points where PIE insights can shape the next stages of project development. It is also essential to provide a summary of how public data will be used in the project and identify existing PIE work in specific project focus areas before commissioning further work. Most importantly, project PIE activities should serve a meaningful purpose and not be tokenistic.

5.2.2. Communications and engagement

To effectively communicate project plans and outcomes to the public, it is important to create a simple and memorable project title and brand identity that can be easily recognised by a public or non-technical audience. This can be achieved by creating a simple logo design using the project title or acronym and a combination of colours (less is more – it's best to keep it simple!). Utilise a variety of content formats such as posters, infographics, photos, videos, animations and text-based content across different channels like a Medium blog, website, flyers, and social media to provide clear, simple, and consistent messages about the project and any complex information.

Project teams are encouraged to prepare and deliver simple presentations on project activities, including PIE activities, at public webinars and events, encouraging questions and discussions. Additionally, whenever possible, project teams should collaboratively engage with the public across their projects and conduct regular cross-project public webinars to showcase the PIE work that projects have been doing and how they align. The DARE UK programme will provide support to project teams in amplifying project activities and outputs, including PIE outcomes and insights, whenever possible.

5.2.3. Feedback

After each PIE activity, project teams should gather feedback from participants to assess the impact of the activity and the quality of the participants' experience. This involves evaluating understanding, changes in knowledge and trust, and the accessibility and engagement levels of content and interactions. It's important for teams to understand the actions or changes made by the public because of their participation and ensure that participants feel their contributions are meaningful.

Feedback can be collected through surveys, interviews, discussions, and workshops. After each PIE effort, maintaining a feedback loop to inform participants about how their feedback has been used and the impact it has made will demonstrate the value of their participation and encourage future involvement. At the end of the project, teams should gather overall feedback from the public on the project's delivery and outputs, paying particular attention to PIE.

5.2.4. Collaboration

PIE Leads of DARE UK-funded projects may be invited to join a group to facilitate collaboration and alignment on PIE efforts across projects. This group will meet regularly to identify areas of collaboration,

collectively showcase examples of innovative PIE practices in their projects and share examples of good PIE practices. Project teams and their PIE leads can share PIE resources to support their PIE deliverables where feasible. DARE UK-funded projects and initiatives may be asked to collaborate with existing public panels and networks to deliver on the PIE outputs.

5.2.5. Risk management

DARE UK-funded projects and initiatives should identify potential threats in terms of public perception and develop strategies to mitigate them. For instance, project teams should consider what concerns the public may have regarding their work and proactively address these concerns to create and sustain a positive atmosphere for public dialogue.

5.3. Monitoring, evaluation and learning

Monitoring, evaluation, and learning are essential in delivering PIE efforts to ensure that PIE activities are achieving their intended impacts. DARE UK-funded projects and initiatives must establish PIE monitoring and evaluation key performance indicators (KPIs) at the beginning of their project and continuously collect KPI data throughout PIE activities. Project teams should clearly define what they want to measure and why and link these KPIs to the established reporting timelines and requirements. Project teams should include processes and documentation to track and record demographics, as well as engagement information about public participation, and document instances of best practices, sharing them in collaborative learning sessions. Project teams should maintain a PIE learning register to document events and decisions that did not go to plan and the recommended steps to address them in the future. DARE UK may evaluate the delivery of funded projects, including an assessment of PIE activities and outcomes. This may be done directly by the Programme Delivery Team or a third-party agency. However, projects are welcome to conduct a self-evaluation of their deliverables, which can support other evaluation efforts by the programme.

5.3.1. Data gathering and reporting templates

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.

5.4. Reporting

Delivery teams should plan to provide clear and detailed answers to **all** questions below in their reports. Project teams should co-develop their reports with the DARE UK delivery team summary reports (including PIE-specific reports), adequately capturing self-evaluation outcomes and documenting lessons learned. DARE UK recommends adopting the outline below to report on PIE activities based on the three reference standards and guidelines above:

1. 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 delivering your project?

2. 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?

3. Approach

Elaborate on the strategy and key considerations for delivering 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.)?
- What specific steps or decisions did you take to make your PIE activities inclusive, accessible and collaborative? How did you translate complex information into public-friendly messages?
- 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?
- Did you commission a third-party agency or consultant to support the delivery of some or all aspects of your PIE strategy? If so, what were they, and how were they delivered?
- How did you arrive at your choice of public participants, and why them?
- 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 ensure a mix of experience in data-driven research from newcomers to members of the public with previous experience?
- What clear feedback mechanism did you establish to support possible PIE assessments before delivery, midway through, and after the project?
- How did you communicate with your participants during and outside your core PIE activities? (i.e., channels and frequency)
- How did you promote your PIE activities and outcomes?
- Did you offer any incentives for participation? What were they, and how were they offered?

4. Activities and timelines

Explain the schedule and frequency 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?)

5. 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?
- 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 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?
- Did you plan for a possible independent PIE evaluation at the end of your project delivery?

6. 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 can other similar projects learn from the experience of public involvement and engagement in your project, including positive and negative examples?
- What key considerations will be crucial for future PIE activities in a similar context?
- What would you do differently in the future?

7. Discussion, recommendations and next steps

Provide deeper insights and an evaluation of your PIE strategy, its implications, and recommendations for future projects and the DARE UK programme.

- What is your overall assessment of the PIE component of your project? Was it meaningful and impactful in delivering your project objectives?
- 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 those involved in your project activities?
- What are the implications for the project and the DARE UK programme?
- What are your recommendations?
- What are your next steps?
- What other developments were worthy of note?

6. Conclusion

The guidelines outlined above will help DARE UK-funded projects and initiatives in formulating their PIE strategy comprehensively by capturing the full scope of activities and impact and emphasising key developments and recommendations. Effective PIE planning, delivery, evaluation and reporting are crucial to the DARE UK programme, and these measures will enable the programme team to cohesively document PIE across all funded projects and initiatives throughout the programme lifecycle and how they have fed into the delivery of the programme vision.