HDRUK
Health Data Research UK

# From Standards to Impact: Embedding the Public Engagement in Data Research Initiative Good Practice Standards in Data for Research and Statistics

## Date Issued: 7th July 2025

# Opportunity

The Public Engagement in Data Research Initiative (PEDRI), in collaboration with Health Data Research UK (HDR UK) and Data and Analytics Research Environments UK (DARE UK), are proud to launch a funding opportunity offering awards of up to £15,000 per project. These awards aim to empower organisations to embed the PEDRI Good Practice Standards (see Appendix 3) into their public involvement and engagement work to champion more inclusive, transparent, and impactful data research.

## About the PEDRI Good Practice Standards

PEDRI is a sector-wide partnership of organisations working with data and statistics. The PEDRI Good Practice Standards were co-developed through a rigorous collaborative process involving members of the public, researchers, and Public Involvement and Engagement (PIE) practitioners from academia and the public sector. These Standards provide a practical and values-led framework to guide high-quality public involvement and engagement in data research and statistics. This funding opportunity invites organisations to adopt and apply these Standards in their work—helping to raise the bar for effective public engagement in the data research landscape. Further details on how the Standards were developed can be found in this blog post.

W: https://www.pedri.org.uk/

E: contact@pedri.org.uk

## About Health Data Research UK

Health Data Research UK (HDR UK) is accelerating effective and impactful inclusion of public voices in data research to enable discoveries that improve people's lives.

We are the national institute for health data science. Our vision is for large-scale data to benefit every interaction with patients, every clinical trial and every biomedical discovery, and to transform public health. The UK is in a unique position to realise the potential of health data, thanks to the NHS and its cradle-to-grave records for a population of over 65 million people.

Safe and secure use of this data could improve treatments, deliver better health care and save lives. It could help tackle some of the biggest health challenges worldwide, including cancer, diabetes and cardiovascular disease.

However, access to this data for researchers is often a lengthy, fragmented process, meaning the potential for improving healthcare is far from being realised in full.

We work in partnership with the NHS, industry, charities and universities to realise the potential of the UK's health data in life-changing research. Patients and the public are actively involved in shaping HDR UK's work and ensuring it delivers public benefit.

## HDR UK's values

HDR UK's values guide how we work together within HDR UK and with our partners and other stakeholders:

1. **Transparency**: we will share information, insights and innovations so that we learn faster together.
2. **Optimism**: we believe that we can make things better, that we can do things differently and that we can overcome challenges to create a new and thriving health data ecosystem that benefits patients and the public, the NHS, scientific discovery and industry.
3. **Respect**: we deliver better results when we work in a truly interdisciplinary way. We listen, share and respect a diversity of thought and opinion, perspective and experience. We are inclusive - leveraging and fairly attributing the expertise and capabilities of others.
4. **Courage**: we are leading the way and will be prepared to try new things, take risks, embrace ambiguity and challenge the status quo. We will contribute opinions to shape the future of health data research.
5. **Humility**: we have a lot to learn from others; and aim to be free from pride and arrogance.

## About DARE UK

DARE UK (Data and Analytics Research Environments UK) is a programme funded by UK Research and Innovation (UKRI) to design and deliver a coordinated and trustworthy national infrastructure for sensitive data research.

Data has the power to improve lives, and has been fundamental to the UK's response to the COVID-19 pandemic. It is crucial that the different components of the UK's data research infrastructure work in a joined-up, impactful and trustworthy way, to support research at scale for public benefit. They need to be able to support fast and efficient sharing, linkage and advanced analysis of sensitive data in an ethical and secure manner, whilst maintaining the confidence – and meeting the needs of – researchers, data controllers and the public.

DARE UK has therefore been established to design and deliver a novel and innovative data research infrastructure for the UK, with a specific focus on supporting cross-domain linkage and analysis of sensitive data. The programme is one of a number of initiatives funded by UKRI as part of the Digital Research Infrastructure programme.

W: Home - DARE UK

E: enquiries@dareuk.org.uk

# Call Details

## From Standards to Impact: Embedding the Public Engagement in Data Research Initiative Good Practice Standards in Data for Research and Statistics

## Background

Public Involvement and Engagement (PIE) in research helps improve organisational practices by incorporating the perspectives of people directly affected by the organisation's work. When done well, PIE leads to more relevant research, richer insights, and outcomes that have a long-lasting, positive impact. To support this, the PEDRI Good Practice Standards were developed in partnership with members of the public and professionals from across research, practice and policy. These Standards provide a clear, practical framework to help organisations carry out meaningful and effective PIE in data research and statistics.

The PEDRI Good Practice Standards are designed to be used across a wide range of sectors where public data plays a key role in shaping services, products, and knowledge. This includes healthcare, public services, academia, the private sector, and the voluntary sector. Building on existing guidance, the Standards address the specific challenges of delivering effective public involvement and engagement in the context of large-scale or 'big data' research. They offer a practical pathway toward a holistic, organisation-wide approach to PIE, ensuring public voices are embedded at every stage of data-driven work.

Recognising the budget and time pressures many organisations face, we are offering these grants to support the practical adoption of the PEDRI Good Practice Standards. This funding aims to make it easier for organisations to embed sustainable, effective and meaningful public involvement and engagement into their data research and statistical analysis activities.

## Purpose of this funding opportunity

1. To support organisations and infrastructure programmes in embedding the PEDRI Good Practice Standards into their public involvement and engagement (PIE) activities in data research.
2. To explore and better understand the practical challenges of delivering effective PIE in the context of data research and statistics.
3. To evaluate the application and impact of the PEDRI Good Practice Standards across diverse data sectors and research environments—testing their value and adaptability in real-world settings.
4. To create a community of practice for PIE practitioners using the PEDRI Good Practice Standards.

## Funding Opportunity

Applicants can apply for funds up to the amount of £15,000 (see below for eligible costs). Funded projects must deliver a distinct public involvement and engagement (PIE) activity in data research within a 12-month funding period, starting on 1st November 2025.

We welcome applications from a range of UK-based organisations in varied data and statistics domains (e.g. administrative, financial, health, environmental, social), this call is not limited to existing PEDRI members. Proposed projects should contribute to the development of PIE in a data research organisation or infrastructure programme. While the activity may be part of a larger or ongoing project, applicants must clearly define a standalone component that applies the PEDRI Good Practice Standards from the outset and must involve PIE practitioners or leads.

Proposed projects are encouraged to address all seven PEDRI Good Practice Standards. However, applicants may choose to focus on the specific Standards that are most likely to improve PIE within their organisation. In such cases, the project must address a minimum of three Standards in depth and one of these must be Standard 1 Equality, Diversity and Inclusion

Applicants are expected to engage and involve relevant public members in the development of their proposal, and the delivery and evaluation of their project. Proposals which demonstrate consideration of the long-term sustainability of their proposed activities or initiatives are most likely to be successful.

## Eligibility

All proposed projects must:

1. Commence on the 1st of November 2025 (or as close to this date as possible)

2. Be completed within twelve months.

3. Not exceed £15,000 (see Point 6 for examples of eligible costs)

4. Address a minimum of three Standards in depth, one of these must be Standard 1: Equality, Diversity and Inclusion

5. Identify any risks to successful project completion and propose appropriate mitigations

6. The project budget should be limited to eligible costs. These include:
    a. costs of engaging external service-providers (e.g. consultants or temporary staff) to work on specific elements of the funded project (staffing costs are not otherwise eligible)
    b. training, travel or materials required to complete the project
    c. the cost of public involvement (e.g. reimbursement of travel expenses, childcare, PIE payments)

    *Please note this is not an exhaustive list of all possible expenses, please get in touch with the PEDRI team to check whether costs are eligible*

Successful applicants will be expected to:

- Produce an accessible 200-word summary of their project to include on the PEDRI website.
- Complete self-evaluation activities using the Good Practice Standards Evaluation Tool
- Participate in a PIE community of practice to share experiences and learning through monthly online meetings.
- Produce an accessible blog post of 500 words to describe their project, and its impacts and outcomes at the end of their project.

## How to apply

Applicants for funding will need to complete an application form. Please note, this is a light-touch application form and word counts are provided as guidance on maximum limits. There is no explicit expectation or requirement to reach those maximum limits.

Please include the following with your application:

- Project timeline (Gantt chart or similar)
- Statement of Support from your organisation (e.g. Head of Department or Service)
- CV of applicants and any co-applicants

All applications must be submitted by 01/09/2025 at 23:59 BST to procurement@hdruk.ac.uk, with involvement@hdruk.ac.uk in cc and the subject title: From Standards to Impact Funding Call

## Selection criteria

1. The proposed project can feasibly be completed within the 12-month funded period.
2. The proposed project addresses all seven PEDRI Good Practice Standards, or a minimum of three Standards of which one must be Standard 1: Equality, Diversity and Inclusion.
3. There is evidence of involvement of public members (e.g. as collaborators or partners) in the development of the application, and the delivery and evaluation of the proposed project.
4. Evidence of applicants’ ability, or potential, to successfully complete the proposed project.
5. Applicants demonstrate consideration of the longer-term sustainability of the proposed PIE activity within their organisation and evidence of organisational support for this.

Applications will be evaluated on the basis of the Scoring Criteria, as set out in Appendix 1, by a review panel that will include a member of the PEDRI Public Advisory Group, members of the PEDRI Team, and an external expert.

## Clarification Questions

Clarification questions may be submitted to HDR UK by the deadline set out in the timing sections below to procurement@hdruk.ac.uk. A clarification log of all questions and responses will be created and published alongside the call documents in all locations where this Call for Funding has been published by the date set out in the timing sections below.

## Timing

| **Stage of process** | **Date** | **Contact Details** |
|---|---|---|
| Date CFF Issued | 07/07/2025 | |
| Deadline for clarification questions | 01/08/2025<br>23:59 BST/UTC/BST | Procurement@hdruk.ac.uk |
| Clarification log published | 14/08/2025<br>12:00 BST/UTC/BST | |
| Deadline for applications | 01/09/2025<br>23:59 BST | Procurement@hdruk.ac.uk |
| Notification of intent to award | 01/10/2025 | |
| Contract start date | 01/11/2025-01/12/2025 | |
| Contract end date | 31/10/2025 | |

## Non-compliance and Exclusion

HDR UK expressly reserves the right to reject any grant application where it:

- It is received after the stated deadline for submission;
- It does not follow the Application response format and instructions; or
- It is incomplete, where answers to any questions are not provided, or a reasonable explanation is not provided of why any answer to any question has been omitted;

# Appendix 1: Evaluation Criteria

## Compliance Criteria

| **1.0 Compliance Criteria** | | |
|---|---|---|
| 1.1 | Application received on time? | PASS/FAIL |
| 1.2 | Application complete and in the requested format? | PASS/FAIL |
| 1.3 | Applicant meets Eligibility Criteria? | PASS/FAIL |
| 1.4 | Compliance with HDR UK Ethical Assessment Policy | PASS/FAIL |
| **Scoring Criteria:**<br>PASS – Application is compliant, or Applicant has corrected any obvious error in their proposal after clarification.<br>FAIL – Application is not compliant, including any clarification measures. | | |

If the Application is compliant, it can be scored as follows.

## Scoring Criteria and Weighting

| **ITT Selection Criteria Weightings** | |
|---|---|
| **Quality** | **Weighting** |
| 2.1 The project plan demonstrates an awareness of their organisation's needs in relation to Public Involvement and Engagement and identifies how these can be met. Applicants must demonstrate that the project can feasibly be completed within twelve months. Any potential risks to successful project completion should be identified and appropriate mitigation strategies proposed. | 20% |
| 2.2 The Applicant demonstrates a good awareness of the PEDRI Good Practice Standards and focuses on the application of a minimum of three Standards in their project plan (one of which must be Standard 1: Equity, Diversity and Inclusion) | 20% |

| | |
|---|---|
| 2.3 Evidence of involvement of public members in the development of the application, and plans for their ongoing involvement in the project | 20% |
| 2.4 The Applicants' expertise and track record, or potential, to successfully deliver the project | 20% |
| 2.5 Evidence of consideration of longer-term sustainability of the proposed PIE activities and organisational support for this | 20% |

Each criteria is scored from 0-5 in accordance with the score definitions below:

**Score Definition:**

0 - Absent or does not meet the criterion in any respect

1 - Response has significant major shortcomings and clear deficiencies, which on balance outweigh positive aspects that meet some of the criterion requirements

2 - Response has multiple shortcomings and/or deficiencies, which are balanced with the positive aspects that meet some of the criterion requirements

3 - Response has minor shortcomings and/or deficiencies, but on balance these are outweighed by the positive aspects that meet the majority of the criterion requirements

4 - The response meets most aspects of the criterion with only very minor weaknesses

5 - The response meets the criterion in all material respects

# Appendix 2: Terms and Conditions

## Health Data Research UK Terms and Conditions of Funding

These Terms and Conditions of funding (the "Terms and Conditions") relate specifically to funding (the "Grant Award") from Health Data Research UK (company registration number 10887014 and charity number 1194431) ("HDR UK").

HDR UK is funded by the Medical Research Council (being part of United Kingdom Research and Innovation) (MRC), National Institute for Health Research (NIHR), the British Heart Foundation (BHF), Cancer Research UK (CRUK), Economic and Social Research Council (being part of United Kingdom Research and Innovation) (ESRC), Engineering and Physical Sciences Research Council (being part of United Kingdom Research and Innovation) (EPSRC), Health and Social Care Research and Development Division (Welsh Government) (HCRW), Scottish Ministers Acting Through Their Chief Scientist Office of the Scottish Government Health and Social Care Directorates (CSO Scotland), Health and Social Care Research and Development Division, Public Health Agency (Northern Ireland) (HSC PHA NI) (together the "Funders"). These Terms and Conditions reflect the Funders' requirements.

Acceptance of a Grant Award constitutes acceptance of both these Terms and Conditions and any additional Terms and Conditions in the Grant Award agreement. These conditions also apply to activities subcontracted to third parties, collaborators or sub-awardees. These Terms and Conditions cannot be waived or varied without the consent of HDR UK. Compliance with these Terms and Conditions is a condition of funding.

Compliance with these Terms and Conditions is a condition of funding. Any obligations and responsibilities expressed in these Terms and Conditions to be obligations or responsibilities of one of more parties/persons shall be assumed by each such party/person on a several basis.

### Data Protection

Provided in accordance with applicable data protection laws (including the Data Protection Act 2018, the Privacy and Electronic and Communications (EC Directive) Regulations 2003 and the retained EU law version of the *General Data Protection Regulation ((EU) 2016/679)* as it forms part of the law of England and Wales, Scotland and Northern Ireland by virtue of section 3 of the European Union (Withdrawal) Act 2018 and as amended by Schedule 1 to the *Data Protection, Privacy and Electronic Communications (Amendments etc) (EU Exit) Regulations 2019 (SI 2019/419)* ("UK GDPR"), in each case as amended or replaced from time to time and together the "Data Protection Legislation"):

- HDR UK will use information provided by the Lead Organisation for processing funding proposals, the award of any consequential funding, and for the payment, maintenance and review of the funding and may share the information with Funders. This may include but is not limited to:
    - Registration of proposals
    - Operation of processing, funding and management information systems
    - Preparation of material for use by peer reviewers and peer review panels
    - Administration, investigation and review of funding proposals
    - Sharing proposal information on a strictly confidential basis with other funding

  - organisations to seek contributions to the funding of proposals
  - Statistical analysis in relation to the evaluation of research and the study of trends
  - Policy and strategy studies

- To meet HDR UK's accountability obligations to the Funders and to disseminate information on research and training programmes, details of budget/awards, and research and training will be made publicly available e.g. on one or more of the HDR UK's or any of the Funders' websites, and/or other publicly available databases, including the Gateway to Research, in reports and documents (e.g. annual reports, council/board papers, portfolio's etc), and through responses by the relevant Funders to parliamentary business (e.g. parliamentary questions, inquiries, debates etc). Disclosable information would include:
  - general overview information on budget and research/training programmes/projects;
  - the names of investigators;
  - the dates associated with the Grant Award(s);
  - a description of research/training programmes/projects (e.g. project summary/abstract, and impact summary information).

During and after completion of the Grant Award, HDR UK or its Funders, may contact named Principal Investigators concerning funding opportunities or events, or for the purposes of evaluation.

**Freedom of Information Act and Environmental Information Regulations**

Attention is drawn to the provisions of the Freedom of Information Act 2000 ("FOIA") and the Environmental Information Regulations 2004 ("EIRs"), and their equivalents in Scotland where applicable, which apply to a number of HDR UK's Funders including the MRC, EPSRC, ESRC, NIHR, HCRW, CSO (Scotland), and PHA (but not BHF and CRUK). The relevant Funders have an obligation to respond to valid requests for information relating to these Terms and Conditions and may be required to disclose information in relation to HDR UK funding. In some cases, such Funders may consult with the Lead Organisation before disclosure, but they are under no obligation to do so. Where such Funders do consult, they will do so as soon as is reasonably practicable and shall take account of any representations made in respect of that information by the Lead Organisation as part of reaching their own, unfettered, independent decision on disclosure of the requested information.

In some cases, a Lead Organisation may be directly responsible for complying with requests made under the FOIA and the EIR; in such cases HDR UK accepts no responsibility for any failure by the Lead Organisation to comply with its own obligations in this regard. To the extent that any request for information under the FOIA or the EIRs is received by a Lead Organisation which includes information relating to HDR UK, any of the Funders or these Terms and Conditions, the Lead Organisation receiving the request shall promptly notify HDR UK as soon as reasonably practicable and in any event within 5 Business Days and shall take account of any representations made in respect of that information by HDR UK or any of the Funders as part of reaching its own, unfettered, independent decision on disclosure of the requested information

**The following conditions of funding are the responsibilities of the Lead Organisation RO a Principal Investigator; where any of the following conditions are expressed to be responsibilities of the Principal Investigator, the Lead Organisation will procure that the Principal Investigator is made aware of and complies with his/her responsibilities hereunder:**

**Governance**

It is the responsibility of the Lead Organisation and Lead Organisation Principal Investigator (or other person where responsibility has been delegated) to ensure that the research at the Lead Organisation is organised and undertaken within a framework of best practice that recognises the various factors that may influence or impact on a research project. Particular requirements are to ensure that all necessary permissions are obtained before the research begins, and that there is clarity of role and responsibility among the research team and with any collaborators. HDR UK expects the research it funds to be conducted in accordance with the highest standards of research integrity and research methodology.

- The Lead Organisation and Lead Organisation Principal Investigator are responsible for meeting HDR UK's expectations for good research practice at the Lead Organisation as set out in the MRC's 'Good research practice: Principles and guidelines (2012) and any subsequent amendments (see https://www.ukri.org/publications/principles-and-guidelines-for-good-research-practice/); and any other policy set by HDR UK from time to time and notified to the Lead Organisation.
- The Lead Organisation Principal Investigator must be aware of which activities come primarily under the responsibility of the Lead Organisation and which come primarily under the responsibility of HDR UK, and ensure that the Lead Organisation Principal Investigators are also aware.
- The Lead Organisation and the Lead Organisation Principal Investigator are responsible for ensuring that HDR UK expectations for management, finance, accountability, branding and translation are met in relation to the Lead Organisation. There must be regular communication with HDR UK
- The Lead Organisation and Lead Organisation Principal Investigator must ensure that the research at the Lead Organisation supported by the funding complies with all relevant legislation and Government regulation, including that introduced while work is in progress. This requirement includes approval or licence from any regulatory body that may be required before the research can commence.
- The Lead Organisation and the Lead Organisation Principal Investigator are expected to adopt the principles of the 2016 Concordat on Open Research Data (see **UKRI-020920-ConcordatonOpenResearchData.pdf**).
- The Lead Organisation must comply with the HDR UK Attribution policy (**https://www.hdruk.org/about-us/policies/hdr-uk-attribution-policy/**), the Open Access Policy (**https://www.hdruk.org/about-us/policies/open-access-statement/**) and the HDR UK Development Principles (**https://www.hdruk.org/about-us/policies/development-principles/**).

**Research Ethics**

The Lead Organisation is responsible for ensuring that ethical issues relating to the funded work are identified and brought to the attention of the relevant approval or regulatory body. Approval to undertake the research must be granted before any work requiring approval begins. Ethical issues should be interpreted broadly and may encompass, among other things, relevant codes of practice, the involvement of human participants, tissue or data in research, the use of animals, research that may result in damage to the environment and the use of sensitive economic, social or personal data and managing the risks of research misuse (e.g. bioterrorism). Policies and guidance relating to good research practice and research integrity can be found at https://www.ukri.org/who-we-are/mrc/our-policies-and-standards/ and https://www.ukri.org/councils/mrc/guidance-for-applicants/policies-and-guidance-for-researchers/)

**Medical and Health Research**

The Lead Organisation is responsible for managing and monitoring the conduct of medical and health research of the Lead Organisation in a manner consistent with the Department of Health's Research Governance Framework for Health and Social Care (or equivalent). There must be effective and verifiable systems in place for managing research quality, progress and the safety and well-being of patients and other research participants. These systems must promote and maintain the relevant codes of practice and all relevant statutory review, authorisation and reporting requirements.

Research of the Lead Organisation involving human participants (including healthy volunteers and staff) or data within the social sciences that falls outside the Department of Health's Research Governance Framework must meet the provisions and guidelines of the ESRC's Research Ethics Framework. While this research may involve patients, NHS staff or organisations, it is defined as research that poses no clinical risk or harm to those who are the subjects of research. Any research involving NHS patients is automatically covered by the Research Governance Framework. The Lead Organisation and appointed Chief Investigator (with the Lead Organisation Principal Investigator taking procedural responsibility to ensure processes are followed) must ensure that appropriate arrangements are in place for independent ethics review of such research that meets research ethics committee standards.

Significant developments must be assessed as the research proceeds, especially those that affect safety and well-being of research participants, which should be reported to the appropriate authorities and to HDR UK The Lead Organisation and Lead Organisation Principal Investigator must take appropriate and timely action when significant problems are identified. This may include temporarily suspending or terminating the research.

The Lead Organisation is responsible for managing and monitoring statutory requirements, for example, in relation to legislation on clinical trials, use of human organs, tissues and data.

Guidance from the MRC on the conduct of medical research, and by ESRC on the conduct of social science research, provided on behalf of the Funders, must be observed.

The Lead Organisation and Lead Organisation Principal Investigator must ensure that the requirements of the Employing Organisation under the UK Policy Framework for Health and Social Care Research (see https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/ ) are met for research of the Lead Organisation involving NHS patients, their organs, tissues or data, and that the necessary arrangements are in place with partner organisations. Where the Lead Organisation accepts the responsibilities of a Sponsor (as defined in the Governance Framework), the I Lead Organisation must also ensure that the requirements for Sponsors are met by it.

When research involves clinical trials, award holders must act in accordance with MRC policy on UK clinical trials regulations (see www.mrc.ac.uk/research/policies-and-guidance-for-researchers/clinical-research-governance/clinical-trials-regulations/) in relation to ethical, sponsorship, reporting, monitoring and publication requirements.

The Lead Organisation must abide by UK Code of Practice for the use of Human Stem Cell lines and must deposit a sample of any newly derived primary human embryonic stem cell lines in the UK Stem Cell Bank.

**Use of Animals in Research**

The Lead Organisation is expected to:

- Adopt the principles of the 3Rs (Replacement, Reduction and Refinement, see www.nc3rs.org.uk/the-3rs).
- Abide by the core principles set out in the cross-funder guidance 'Responsibility in the use of animals in bioscience research: Expectations of the major research councils and charitable funding bodies' (see Responsibility in the use of animals in bioscience research – UKRI).
- Abide by the core principles set out in the Concordat on openness on animal research (UAR; see Concordat on Openness on Animal Research in the UK | Openness in animal research (concordatopenness.org.uk)

Wherever possible, Lead Organisation researchers must adopt procedures and techniques that avoid the use of animals. Where this is not possible, the research should be designed so that:

- The least sentient species with the appropriate physiology is used.
- The number of animals used is the minimum sufficient to provide adequate statistical power to answer the question posed.
- The severity of procedures performed on animals is kept to a minimum. Experiments should be kept as short as possible. Appropriate anaesthesia, analgesia and humane end points should be used to minimise any pain and suffering.

The provisions of the Animals (Scientific Procedures) Act 1986 must be observed. The entirety of the Grant Award is awarded on the absolute condition that no work which is controlled by the Act will begin until the necessary licenses have been obtained from the Home Office. Any recommendations arising from peer review processes with regards to animal use must be followed.

When animals are purchased from commercial suppliers, UK suppliers should be used wherever possible to minimise the risk of suffering during transport.

All research involving non-human primates must comply with the NC3Rs Guidelines 'Primate accommodation, care and use' (see www.nc3rs.org.uk/non-human-primate-accommodation-care-and-use).

Researchers should ensure that they report animal-based studies in accordance with the ARRIVE guidelines (www.nc3rs.org.uk/ARRIVE) as far as possible, taking into account the specific editorial policies of the journal concerned.

The Lead Organisation is expected to contact FESA to highlight mouse strains engineered, or characterised using the Grant Award, and are encouraged to deposit these strains with the archive.

Any new procedure likely to replace the use of animals in research or testing, reduce the numbers used or refine animal use must be reported to HDR UK and disseminated through the usual channels to all those who might make use of it.

**Data assets**

The Lead Organisation must comply with the Data Protection Legislation in relation to the use and sharing of data assets.

The Lead Organisation must comply with the MRC policy on research data sharing (**https://www.ukri.org/publications/mrc-data-sharing-policy/**) and the MRC policy on sharing of research data from population and patient studies (**https://www.ukri.org/publications/mrc-guidance-on-sharing-research-data-from-population-and-patient-studies/**).

**Health and Safety**

The Lead Organisation is responsible for ensuring that a safe working environment is provided for all individuals associated with a Lead Organisation co-ordinated by it. Its approach and policy on health and safety matters must meet all regulatory and legislative requirements and be consistent with best practice recommended by the Health & Safety Executive.

Appropriate care must be taken where Site staff are working off-site. The Lead Organisation must satisfy itself that all reasonable health and safety factors are addressed.

HDR UK reserves the right to require the Lead Organisation to undertake a safety risk assessment in individual cases where health and safety is an issue, and to monitor and audit the actual arrangements made.

**Misconduct and Conflicts of Interest**

The Lead Organisation must assume full responsibility for staff funded from the Grant Award and, in consequence, accept all duties owed to and responsibilities for these staff, including, without limitation, their Terms and Conditions of employment and their training and supervision, arising from the employer/employee relationship.

The Lead Organisation is required to have in place procedures for governing good research practice, and for investigating and reporting unacceptable research conduct, that meet the requirements set out in the Concordat to Support Research Integrity (2012)

**www.universitiesuk.ac.uk/highereducation/Pages/Theconcordattosupportresearchintegrity.aspx** and the Research Councils' Code of Conduct and Policy on the Governance of Good Research Conduct (2013) **https://www.ukri.org/councils/esrc/guidance-for-applicants/research-ethics-guidance/our-policy-and-guidelines-for-good-research-conduct/uct – UKRI** and any subsequent amendments.

The Lead Organisation must inform HDR UK immediately of any issues or circumstances that arise that might result in a reputational risk to HDR UK and its Funders (including, without limitation, investigations of alleged scientific misconduct, breach of conditions of research ethics approval, breaches of data security or data protection legislation, infringements of licences relating to the use of animals in research, or infringements of Health and Safety regulations, fraudulent activity or acts of bribery).

The Lead Organisation must ensure that potential conflicts of interest in research are declared by all research staff funded by the Grant Award and subsequently managed in a timely manner in accordance with the Lead Organisation's policy on managing conflicts of interest. Guidance on providing declarations of interest can be found at **https://www.ukri.org/councils/stfc/guidance-for-applicants/what-to-include-in-your-proposal/applicant-declarations-of-interest/– UKRI**

**Lead Organisation Principal Investigator and Project Staff**

The Lead Organisation and Principal Investigator are expected to adopt the principles, standards and good practice for the management of research staff in the Lead Organisation, as set out in the 2008 Concordat to Support the Career Development of Researchers (see Home - The Concordat to Support the Career Development of Researchers (researcherdevelopmentconcordat.ac.uk)), and subsequent amendments. The Lead Organisation, together with the Principal Investigator, must provide an environment in which research staff are selected and treated on the basis of their merits, abilities and potential. The Lead Organisation must ensure that reliable systems and processes are in place so that the principles of the Concordat are embedded into practice within the Lead Organisation. The Lead Organisation must ensure compliance with all relevant legislation and Government regulation, including any subsequent amendments introduced while work is in progress and in particular compliance with the terms of the Equality Act 2010.

It is not permissible for the Principal Investigator to be changed without approval from HDR UK

The Lead Organisation will ensure that Lead Organisation employees and other persons engaged in research funded by the Grant Award of the Lead Organisation will operate to the highest standards of conduct.

The Lead Organisation is responsible for ensuring all clinicians supported by HDR UK funding at the Lead Organisation are aware they are individually responsible for maintaining appropriate professional indemnity insurance. This should be with a professional defence organisation for any activities not covered by NHS indemnity arrangements or by additional provision made by the research organisation. HDR UK will not meet the costs of such cover.

**Finance**

*Use of Funds*

Subject to the following conditions, funds may be used, without reference to HDR UK, in such a manner as to best carry out the funded work. Funds cannot be used to meet the costs of an activity that will fall beyond the actual end date of the Grant Award, e.g. when travel falls after the end of the Grant Award, the costs cannot be charged to the Grant Award even if the tickets, etc. can be purchased in advance. Funds should be deployed with due consideration to value for money across all activities. All travel claims should evidence value for money as the primary consideration. Consequently, these should only include travel by standard class by train and economy class by air for flights.

The Lead Organisation and Principal Investigator must ensure proper financial management of HDR UK funding and accountability for the use of public and charitable funds. The Lead Organisation should have a dedicated cost centre within the Lead Organisation for the Grant Award. These obligations apply whether the research activities are carried out within the Lead Organisation or other research organisations eg by a collaborator, subcontractor or other third party. The Lead Organisation must maintain auditable accounts relating to the Grant Award in order to demonstrate how resources made available from all sources have been used, mapping them onto research and training activities, and type of spend.

HDR UK and its Funders reserve the right to inspect the records and financial procedures of the Lead Organisation, or to appoint any other body or individual for the purpose of such inspection, at any time upon giving reasonable notice. The Lead Organisation must, if required by HDR UK, provide a statement of account for the Grant Award, that is independently examined by an auditor who is a member of a recognised professional body, certifying that the expenditure has been incurred in accordance with these Terms and Conditions.

HDR UK reserves the right to make adjustments to the payment profile during the lifetime of the award, should there be a business need. Any such change would, so far as reasonably practicable, be discussed with the Institute RO in advance. The change would be accompanied by explanatory notification and a revision of the remaining payment schedule.

*Starting Procedures and Payments*

The funding for the Grant Award will be set out in the Grant Award agreement and will be profiled over the funding period and an expected payment schedule will be provided. The start of the work must not be earlier than the date of the Grant Award agreement itself.

Until further notice, Payment of the Grant Award will be made quarterly in arrears subject to an invoice accompanied by an expenditure and contributions statement and quoting the award reference. A template expenditure statement will be provided. Failure to submit them in a timely manner may result in delayed payments or subsequent payments not being met.

The final payment will be held by HDR UK and will be released as part of the end of the Grant Award reconciliation.

Any significant underspend against the expected profile will be discussed with the Lead Organisation. If there is no good justification for the underspend, together with plans for how the money will be spent, then HDR UK has the right to reduce the award total value and amend the expected payment profile.

*Other funding streams*

The Lead Organisation is allowed to apply for additional funding from any suitable source on behalf of the Lead Organisation for the applicable project. The Institute RO may not request funding for resources already provided by HDR UK. It is the responsibility of the Lead Organisation Principal Investigator to inform the HDR UK of any such applications.

When seeking additional funding, partnership opportunities, or in-kind support, the Lead Organisation and the Lead Organisation Principal Investigator are expected to consider whether the source or intended use of such funding has the potential to bring into question HDR UK's reputation, impartiality (for example if the funder has a direct financial interest in one research outcome rather than another) or where the terms of an award would introduce restrictions (for example on publication). In such cases justification should be provided to HDR UK by the Lead Organisation Principal Investigator, and HDR UK reserves the right to request the Lead Organisation not to approach or continue negotiations with particular funders or to decline awards.

*Extensions and Supplements*

No extensions or supplements will be made to the awards. Costs of Parental Leave and Sickness Absence during the original period of the Grant Award can be claimed from the award, in proportion to the percentage of that person's time allocated to the funded work. The Lead Organisation is responsible for any liability for costs of Parental Leave and Sick Leave pay for staff supported by the Grant Award outside the original period of the Grant Award.

*Procurement, Estates & Assets*

The procurement of equipment, consumables and services, including maintenance, must comply with all relevant national and EU legislation and the Lead Organisations' own financial policy and procedures. For all equipment and services where the contract value is more than £25,000, excluding VAT, professionally qualified procurement staff must be consulted before the procurement process begins, and, where appropriate, at the market research stage, and must approve the order/contract before it is placed with a supplier.

Equipment purchased from the Grant Award is primarily for use on the work for which the Grant Award was awarded and belongs to the Lead Organisation.

Where there is spare capacity in the use of the equipment, HDR UK expects this to be made available to other users. Priority should be given to research supported by HDR UK, HDR UK-funded students, any of the Funders, UKRI, and to UKRI-funded students. To facilitate this, equipment should be registered on the equipment.data.ac.uk database.

*Sanctions*

HDR UK reserves the right to impose financial and other sanctions (including withholding of payments) where they identify areas of non-compliance with the Terms and Conditions of the, these Terms and Conditions, or the Grant Award agreement.

*Transfer of a Grant*

It is not possible for the Grant Award to be transferred to another organisation without prior written permission of HDR UK. The Lead Organisation must consult with HDR UK if it is proposed to change the Grant Holder, for example, following retirement or resignation. In such cases HDR UK may consider termination of the award.

*End of Grant Reconciliation*

The Lead Organisation is accountable for funds dispersed and must complete and return an End of Grant Award Reconciliation form, documenting spend on the project, within one month of the end date of a Grant Award. The final quarterly payment will be withheld until the Grant Award reconciliation has been completed and agreed. Any balance will be released/clawed back. The reconciliation will be final.

**Monitoring, Reporting and Evaluation**

HDR UK requires the Lead Organisation research to be well-defined and to be fully costed and represented this way consistently, in returns to HDR UK and Researchfish.

HDR UK will provide the Lead Organisation with reporting templates. HDR UK reserves the right to make adjustments to its reporting templates should there be a business or regulatory need to do so. Any such change would be accompanied by explanatory information.

HDR UK captures data related to the outputs, outcomes and impacts of the research it funds via Researchfish. It is the responsibility of the Principal Investigator to ensure that all requests for submission of this data are met in a timely manner – research organisations must support their staff in the submission of this data. Data will be required annually throughout the duration of the funding, and for several years after the award has finished.

HDR UK may also require a separate final report on the conduct and outcome of the project. If so, it must be submitted by the Lead Organisation within one month of the end of the Grant Award, on the form provided.

While it is the responsibility of the Principal Investigator to manage the research at the Lead Organisation, HDR UK reserves the right to call for periodic information on progress and/or to visit the Lead Organisation. HDR UK may request Lead Organisation staff attend meetings to exchange information and

ideas with others undertaking research in the same or similar fields; the I Lead Organisation must allow compliance with these requests.

HDR UK must be consulted in the event of any significant change in the proposed research funded by the Grant Award, including failure to gain access to research facilities and services, or to gain ethical committee approval for the research, particularly those which make it unlikely that the objectives of the research can be achieved. The Principal Investigator is responsible for notifying HDR UK of changes to the research funded by the Grant Award (***N.B. this notification must be provided in the quarter the programme has changed (i.e. started, updated or terminated).***

### *Exploitation and Impact*

It is the responsibility of the Lead Organisation and the Principal Investigator to make every reasonable effort to ensure that the intellectual assets arising in the course of the research funded by the Grant Award, whether protected by intellectual property rights or not, are used effectively to the benefit of society and the economy, and to promote health data science research. Research outcomes must be disseminated to both research and more widespread audiences in a timely manner - for example to inform potential users and beneficiaries of the research.

### *Disclosure and Inspection*

HDR UK reserves the right to have reasonable access to inspect the records and financial procedures associated with the Grant Award or to appoint any other body or individual for the purpose of such inspection. This includes expenditure by third parties. HDR UK shall be entitled to request and/or have access to any financial records and reports that are deemed appropriate to demonstrate the regularity and propriety of expenditure, including but not limited to:

- Annual report & accounts
- External audit management letter
- ISA260 – Communication with those charged with governance
- Related internal audit reports
- That required licenses, approvals, permissions and consent are in place, or were in place when the activity occurred.

The Lead Organisation must report to HDR UK:

- Any investigations (and their outcomes) into research misconduct associated with the Grant Award at the stage that it is decided to undertake an informal inquiry; and

on request provide information on:

- Its management of research integrity and ethics as described at https://www.ukri.org/what-we-offer/supporting-healthy-research-and-innovation-culture/research-integrity/
- Details of any retractions or withdrawal of submissions/publications
- Any allegations, proven or not, of any cases of fraud.

The Lead Organisation must, if required by HDR UK, provide a statement of account for the Grant Award, independently examined by an auditor who is a member of a recognised professional body, certifying that the expenditure has been incurred in accordance with these Terms and Conditions.

**Communications and Branding**

The public announcement of the Grant Award will be managed by HDR UK and is under embargo until notified by HDR UK. All promotional work relating to the Grant Award (e.g. press releases, exhibitions, events, etc.) will be drafted in consultation with HDR UK, supported by the Lead Organisation. The Lead Organisation is expected to co-ordinate local announcements in line with the national communications and will contribute content (in the form of quotes and material for a case study) to support this.

HDR UK brand identity (e.g. name, logo, etc.) must be preserved in all communications and publicity relating to the Project. The Funders' brand identities as Funders will be utilised alongside "Health Data Research UK" (e.g. name, logo, etc.), in accordance with the HDR UK Brand and Communication Policy (**https://www.hdruk.ac.uk/wp-content/uploads/2019/10/HDRUK-Brand-Guidelines.pdf**) and the HDR UK Attribution Policy (https://www.hdruk.ac.uk/about-us/policies/hdr-uk-attribution-policy/).

In any online or printed materials (including procurement, press releases, poster, exhibition materials, PowerPoint presentations, digital and social media) related to activities funded by the Grant Award the Organisations must make reference to the HDR UK funding. Logos and other materials will be provided to the Lead Organisation to ensure appropriate representation of the HDR UK brand. Agreement on appropriate attribution should be agreed in advance by contacting **enquiries@hdruk.ac.uk**.

All outcomes and achievements should be communicated to HDR UK's Communications Team (**enquiries@hdruk.ac.uk**) before publication.

Award holders must inform HDR UK at **enquiries@hdruk.ac.uk** as soon as a paper presenting outcomes funded by the Grant Award is accepted for publication. HDR UK must be notified at least five working days in advance of any publicity arising from work funded by the Grant Award, and any press releases referencing HDR UK must be approved by HDR UK before it is released to the media.
Funded organisations may be required by HDR UK to participate in communications activities e.g. blog posts and case studies.

It is the responsibility of the Lead Organisation and the Principal Investigator to communicate the research to the public at both local and national level, and to raise awareness of the role of science and research in any related issues of public interest.

**Public Engagement, Publication and Acknowledgement of Support**

HDR UK expects all publications to be deposited at the earliest opportunity, and certainly within six months of publication, in Europe PubMed Central (europepmc.org/). This applies both during and after the period of funding.

The Lead Organisation and the Principal Investigator are expected to adopt the principles, standards and good practice for public engagement with research set out in the 2010 Concordat for Engaging the Public with Research (see **Concordat for engaging the public with research – UKRI**). The Lead Organisation must ensure that the Lead Organisation provides an environment in which public engagement is valued, recognised and supported. It must ensure that reliable systems and processes are in place so that the principles of the Concordat are embedded into practice within the Lead Organisation.

The results of Lead Organisation research arising from the Grant Award are expected to be published in accordance with normal academic practice and in compliance with the UKRI Open Access Policy (https://www.ukri.org/publications/ukri-open-access-policy/). The Principal Investigator is expected to comply with requirements to encourage and support Lead Organisation staff in this. All researchers will acknowledge the support of HDR UK and its Funders in all communications, including manuscripts submitted for publication, posters at conferences and other presentations. The form of words to use in publications is as follows:

*"This work was supported by Health Data Research UK (insert award reference where relevant), which is funded by the Medical Research Council (UKRI), the National Institute for Health Research, the British Heart Foundation, Cancer Research UK, the Economic and Social Research Council (UKRI), the Engineering and Physical Sciences Research Council (UKRI), Health and Care Research Wales, Chief Scientist Office of the Scottish Government Health and Social Care Directorates, and Health and Social Care Research and Development Division (Public Health Agency, Northern Ireland)."*

The Lead Organisation is expected to adopt the principles of Concordat on Open Research data (or equivalent). If the product of research is code then it should be published in accordance with HDR UK's Attribution Policy **https://www.hdruk.ac.uk/about-us/policies/hdr-uk-attribution-policy/**).

**Disclaimer**

HDR UK accepts no liability, financial or otherwise, for expenditure or liability arising from the funded work, except as set out in these Terms and Conditions, or otherwise agreed in writing.
Where studies are carried out in an NHS Trust, the Trust has a duty of care to its patients. HDR UK does not accept liability for any failure in the Trust's duty of care, or any negligence on the part of its employees.

HDR UK reserves the right to terminate the Grant Award at any time, subject to reasonable notice and to any payment that may be necessary to cover outstanding and unavoidable commitments. HDR UK reserve the right to amend the payment profile at their discretion. The Lead Organisation will be advised, in advance, of any such a change. Changes to payment profiles may affect the overall value of the Grant Award.

If a Grant Award is terminated or reduced in value, no liability for payment or redundancy or any other compensatory payment for the dismissal of staff funded by the Grant Award will be accepted.

Nothing in this section seeks to limit or exclude the liability of HDR UK where such limitation or exclusion is prohibited by law.

**Status**

These Terms and Conditions will be governed by the laws of England and Wales; all matters relating to the Terms and Conditions will be subject to the exclusive jurisdiction of the courts of England and Wales.

If any provision of these Terms and Conditions is found by a court or other legitimate body to be illegal, invalid or unreasonable, it will not affect the remaining Terms and Conditions which will continue in force.

These Terms and Conditions, together with any additional conditions set out in the Grant Award Agreement; contain the whole agreement between HDR UK and the Lead Organisation in relation to the stated research Grant Award. HDR UK and the Lead Organisation do not intend that any of these Terms and Conditions should be enforceable by any third party.

**Version Control**

HDR UK reserves the right to amend these Terms and Conditions. The most recent version of the Terms and Conditions will apply.

HDRUK
Health Data Research UK

# Appendix 3: PEDRI Good Practice Standards

## 1. Equity, Diversity, and Inclusion

Equity, Diversity, and Inclusion (EDI) refers to the fair and balanced inclusion of people with different backgrounds, experiences, and identities in research projects or initiatives involving data about people and communities. This standard supports an environment where anyone, including underrepresented and underserved groups, can participate in Public Involvement and Engagement (PIE) activities and inform change.

This could be achieved by:

- Adopting a jargon-free, flexible, and creative approach to talking about data, to help ensure anyone can participate without being excluded by methods used or inaccessible information.
- Developing targeted and adaptable PIE plans, which incorporate equality impact assessments and follow relevant guidance to address the specific needs of different people, groups or communities.
- Collaborating with a variety of groups and organisations to build and maintain relationships with underrepresented and underserved communities, ensuring their voices are heard.
- Seeking contributions from a broad range of public members, including those who may be unfamiliar or have questions or concerns about the topic at hand.
- Celebrating and embracing the unique skills, knowledge, and real-world experiences that members of the public bring.
- Reimbursing costs associated with taking part in PIE activities to help ensure everyone has access to the tools, support, and opportunities to participate.
- Working with others to find solutions to funding challenges or areas where there is a lack of EDI knowledge.

## 2. Data literacy and training

The ability to read, understand, and communicate data—known as data literacy—empowers people to engage in data research and statistics, which can often be complex and challenging to navigate. By embedding training in PIE activities, it is possible to better understand the unique aspects of research projects or initiatives involving data about people and communities, contributing to a more informed and inclusive community.

This could be achieved by:

- Exploring what public members already know and what they wish to learn about the topic at hand, while managing expectations.

- Personally seeking data training and offering it to public members, ensuring that these opportunities are tailored to individual needs and the specific context of the research project or initiative.
- Defining commonly used terms, such as anonymisation, de-identification, data access processes, and privacy safeguards, to support public participation in conversations about data.
- Ensuring public members have the time and support necessary to build their confidence in understanding data, where needed.
- Providing real-world examples in discussions with the public about data to make them more relatable.
- Sharing any training materials developed for PIE activities widely, so that they are available and accessible to all those interested.

### 3. Two-way communication

Data research and statistics often includes complex terms and abstract information. As such, two-way communication is essential to promote an active exchange of information between parties, allowing both to share and receive insights. This approach can help all parties to better understand each other's views and contribute effectively to the conversation.

This could be achieved by:

- Increasing awareness of how data is used in people's daily lives.
- Ensuring conversations are engaging, culturally sensitive, and relatable for members of the public from all educational backgrounds.
- Listening, acknowledging, and responding to public views and concerns, demonstrating their opinions are valued.
- Investigating communication preferences of various audiences to meet diverse needs, including non-native English speakers, neurodivergent people, or people living with disabilities.
- Using jargon-free language, limiting or avoiding the use of abbreviations where possible, and unpacking abstract information by co-creating summaries and glossaries.
- Increasing accessibility by using a range of channels of communication and formats, such as large print documents, videos, images, and diagrams, to invite feedback and ensure clarity.
- Being mindful of reading age when developing materials for PIE activities, encouraging understanding and open dialogue.
- Acknowledging the barrier of digital exclusion, seeking ways to overcome it where possible.

- Anticipating the likelihood of uncomfortable conversations and planning for trained facilitators to address them, or to signpost to relevant information and support.
- Providing varied opportunities for the open and constructive exchange of views and ideas.
- Recognising that consensus may not always be possible but ensuring that all perspectives are heard and considered.

### 4. Transparency

Transparency refers to an approach to PIE that involves making information freely available and easily accessible while fostering a safe space for open and honest conversations with the public. This approach can help create an inclusive environment, allowing all parties to contribute comfortably and effectively to discussions.

This could be achieved by:

- Being open and clear throughout the research project or initiative, including the public in decision-making around planning, partnerships, access to data, PIE activities, budget, and timelines.
- Clarifying the purpose of PIE activities at all times, highlighting the value and purpose of public participation.
- Encouraging a dialogue that meets public expectations for transparency, allowing enough time for questions and answers.
- Providing up-to-date research materials in accessible formats, including summaries and user-friendly channels of communication.
- Ensuring timely follow-up with people involved in PIE activities to share their impact and outline the next steps.
- Sharing all outcomes of the research project or initiative (including successes and lessons learned) with those involved in PIE activities.
- Recognising public members' contributions and inviting them to assist in broader communication of information where possible.

### 5. Mutual benefit

To maximise the benefits of PIE activities, it is important to adopt an ongoing, dialogue-based approach that encourages benefits for all parties involved, including public members, professionals, and the wider population. This approach can help achieve valuable insights and ideas that generate impactful research informed by public views.

This could be achieved by:

- Explaining to public members why they have been invited to participate in PIE activities.

- Highlighting the broader benefits of the research project or initiative and clarifying what the public would gain by participating and contributing to PIE activities.
- Setting realistic expectations for PIE together, agreeing on ways of working, and preparing to navigate any disagreements that may arise.
- Acknowledging the contributions of public members by offering payments and or other agreed forms of appreciation.
- Ensuring ongoing evaluation of the PIE impact on all parties involved, while providing updates on any changes made and the rationale behind them.
- Promoting knowledge exchange among all parties involved, ensuring that dialogue is driven by active listening and responsive behaviour.

## 6. Effective involvement and engagement

PIE practices should be led by clear objectives, purpose, outcomes, and a strategy for integrating public input into the project. What constitutes 'effective' PIE may vary depending on the specific context of involvement and engagement, but it ultimately rests on the genuine intention for collaboration. This approach can help ensure that PIE plans and the projects they support are informed by and shaped through public input.

This could be achieved by:

- Collaboratively developing PIE plans, using shared decision-making approaches, such as co-creation, co-development, and co-production.
- Setting realistic objectives for PIE activities, including how public input will be integrated into the relevant projects.
- Creating an environment where everyone feels able to contribute throughout the project.
- Continually monitoring PIE progress and public’s needs, making necessary adjustments based on real-time feedback.
- Ensuring adequate time and budget is allocated to PIE activities, as insufficient resources can limit the achievements of desired results.
- Evaluating the impact of PIE activities by agreeing on indicators of success and clarifying the characteristics that make PIE effective in each specific context.
- Capturing lessons learned and sharing strategies for promoting positive change.

## 7. Creating a culture of involvement and engagement

Creating a culture of involvement and engagement in an organisation means embedding PIE at every level, ensuring adequate resources and ongoing support while also encouraging an environment where public members’ contributions are valued and integrated throughout research projects or initiatives. This approach can support a seamless partnership between the data research community, PIE professionals, and the public.

This could be achieved by:

- Championing PIE at all organisational levels, recognising the added value of public members' contributions to strategic thinking and forward planning.
- Promoting senior leaders' accountability and commitment to adequately resource PIE, ensuring they actively support and take responsibility for the success of PIE efforts.
- Resourcing PIE throughout the entirety of a research project or initiative, ensuring adequate funding, staff, training, and other relevant resources that are necessary to align to good practice standards.
- Promoting the value of PIE across the data research and statistics community to ensure outcomes remain relevant and can be implemented in real-world contexts.
- Offering ongoing and updated PIE training extended to the wider data research and statistics community, beyond just PIE professionals.
- Embedding PIE throughout any research project or initiative, while being mindful of the differences across the four nations, and always prioritising public benefit.
- Sharing and exchanging knowledge on good practices, especially with those new to PIE.
- Continually improving approaches to PIE, including evaluation methods and evidence of impact.

## Glossary

- **Anonymisation:** Anonymisation is the process of changing personal identifiers (i.e., address, name) in some way - such as being removed or replaced - so that the data cannot be traced back to the individual. This process allows data to be shared and used safely while preserving the privacy of people included in the data.
- **Data access processes**: Data access processes refer to procedures and criteria used to grant access to data held by organisations (known as data custodians), such as research institutions, the National Health Service, Police, Education authorities, and others. These processes ensure the data is used ethically, securely, and in ways that benefit the public, while following the law and rules.
- **De-identification**: De-identification is the process of removing personal information from data, creating 'de-identified data'. While this data no longer contains details that directly identify a person, it can still be linked to identifiable information. This differs from anonymised data, which cannot be linked back to an individual.
- **Equity:** Equity means promoting fairness and justice by ensuring that everyone has access to the same opportunities and resources, taking into account their unique needs and circumstances.
- **Engagement:** A series of activities aimed at creating a continuous conversation with the public about data and research, based on listening and responding. Example: A researcher attending science festivals to raise public awareness of a specific topic through hands-on activities.
- **Facilitators:** A facilitator is someone who helps to guide a meeting or discussion, making sure it runs smoothly, everyone gets a chance to share their thoughts, and the goals of the activity are achieved.
- **Good Practice Standards**: A set of standards to support professionals in the data and statistics community to adequately involve and engage the public in the governance and conduct of data-related initiatives and research projects.
- **Involvement**: Including members of the public in shaping, guiding, and making decisions about research or projects. Their input is valued throughout the process, ensuring the work reflects diverse perspectives and priorities.
- **Privacy safeguards**: Privacy safeguards refer to measures designed to protect people's personal information and ensure that data is handled in a way that maintains confidentiality, security, and trust.
- **Public:** This term can cover a broad range of people, including the general public, patients, and professionals working across different sectors.
- **Research initiative**: A research initiative is a broader effort designed to tackle a problem or explore a significant topic. It often includes multiple activities, projects, or collaborations working together to drive innovation, develop solutions, or advance knowledge.
- **Research project:** A research project is a smaller, focused task within a research initiative. It often involves asking questions, collecting information, testing ideas, and looking for answers step by step.
- **Underrepresented:** Underrepresented refers to specific groups, populations, or communities who are not often included as research participants or public contributors in research. This means their perspectives, needs, or concerns may not be represented in research.

- **Underserved:** Underserved refers to specific groups, populations, or communities that face limited access to resources, services, or support due to barriers like social, economic, or systemic factors.