

# PEDRI: Findings from our Public Consultation on the Best Practice Draft Standards for the Use of Data for Research and Statistics



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# Executive Summary

This report provides insights into the public consultation on the [draft Best Practice Standards for Public Involvement and Engagement \(PIE\) in data research and statistics](#). Initiated by the Public Engagement in Data Research Initiative (PEDRI), a collaborative effort with stakeholders from the data research field, academia, and the public sector, these standards aim to advance good PIE practices.

Over ten months, the Best Practice Standards Working Group - comprising a diverse range of professionals alongside a member of the public - worked together to define best practices, identify key barriers and facilitators to those, and explore strategies for adoption. This process led to the formulation of seven draft standards addressing **equity, data literacy, effective communication, transparency, mutual benefit, meaningful involvement, and a culture of PIE**.

In June and July 2023, a public consultation on these draft standards was conducted through an online survey. The survey, comprising open and closed questions, aimed to assess the standards' value, relevance, and language. Invitations to participate were disseminated through various channels, including partner networks and social media. The Best Practice Standards Working Group analysed the data by reviewing the survey responses. Individuals and organisations, predominantly from England answered the survey. The survey respondents had diverse roles but were predominantly public and patient members. Researchers, working with varied data types, primarily health data, also responded to the survey. Many respondents held experience in the field, ranging from over a decade to less than a year. The survey findings and respondent characteristics are detailed in the report, providing insights into the background and expertise contributing to the consultation process.

While the draft Best Practice Standards represent a significant step towards advancing PIE practices in data research and statistics, the 139 responses gained from this consultation have provided several valuable suggestions for improvement. The Best Practice Standards Working Group will conduct further consultation to understand how to implement the proposed changes and foster adoptions within the broader research and statistics community, facilitating piloting initiatives and ongoing refinements.

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## List of abbreviations

PEDRI	Public Engagement in Data Research Initiative
PIE	Public involvement and engagement
VCSE	Voluntary Community and Social Enterprise
n.	Number of something, e.g. 'people (n.72)' means 72 people

## Introduction

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

This report summarises the findings from a public consultation conducted to inform good practice in PIE regarding the use of data for research. This consultation was linked to the development of the Best Practice Standards to support people working with the data to conduct meaningful PIE. These standards are an outcome of the PEDRI efforts.

**We are thankful to all the people who took the time to respond to the survey to provide their valuable insights, which will inform the final version of the Best Practice Standards for PIE in data research and statistics.**

# Best Practice Standards Draft

## The development of draft standards

The standards represent a culmination of ten months of collaboration among a group of stakeholders, including: PIE professionals, academics, public members, and representatives from the voluntary community and social enterprise (VCSE) sector and the National Health Service Transformation Directorate. This collaborative effort is also known as Best Practice Standards Working Group.

The development of the draft standards began with working group members reviewing existing and relevant standards, principles, guidance, and strategies related to PIE (see Appendix A). The goal was to pinpoint common themes, which were then discussed in two hybrid workshops with a total of 62 attendees - 25 who joined in person and 37 who joined online. Attendees included members of the public, PIE professionals, representatives from the VCSE and government departments, and both early career and senior researchers. There was representation from all four home nations of the UK.

These workshops aimed to gain a greater understanding of several key aspects:

- Identifying barriers currently faced to embed best practice PIE in data research and proposing strategies to overcome them.
- Defining what constitutes best practice in cross-domain data research or data-specific programmes.
- Exploring the adaptability of existing standards to meet these needs.
- Exploring ways to facilitate and support organisations and research teams to accept and adopt best practice standards.

The insights gained from these workshops informed the creation of seven standards for PIE in data-driven research. Table 1 provides an overview of the draft standards used for consultation, and for a more detailed explanation, refer to the detailed overview in Appendix B.

Table 1. Standards overview

Standard	Definition
<b>1. Equity, diversity, and inclusion</b>	Effective PIE requires equity of representation of different members of the public, irrespective of their background, 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.
<b>2. Data literacy and training</b>	Effective data literacy, training, and supporting members of the public to have the vocabulary, confidence, and understanding.
<b>3. Effective communication</b>	Effective two-way communication and dialogue supports meaningful data research. Enabling all parties to understand one another, and meaningfully contribute to discussions.
<b>4. Proactive transparency</b>	Working openly throughout all PIE activities, to create a comfortable environment for all parties. Project information must be freely accessible for discussions with members of the public.
<b>5. Mutual benefit</b>	PIE activities should enable mutual benefit between all those involved. Researchers should gain new insights/ideas to develop more impactful research informed by public views.
<b>6. Meaningful involvement and engagement</b>	Meaningful PIE should take place at every stage of research with clear objectives. PIE should be focused with clear tasks, purpose, and impact, while avoiding tokenism.
<b>7. Creating a culture of PIE</b>	Creating a culture of PIE in an organisation at every level. Organisation should value PIE and embed it in their institution.



## Public consultation on the draft standards

A public consultation was held from 1 June to 14 July 2023 to gather feedback on the draft standards. This consultation was an online survey facilitated through the SurveyMonkey online platform. The survey included a mixture of open and closed questions designed to assess the value, relevance, and language of each standard, while also seeking feedback on examples provided to support each standard (see Appendix C). The target audience for this consultation was any person in the UK with an interest in PIE activity in data research. Invitations to participate in the survey were shared through PEDRI partners' communication channels, including newsletters, websites, and social media, as well as other networks associated with PIE organisations.

The survey findings were analysed by the Best Practice Standards Working Group, with each response reviewed by at least two assigned reviewers. The following sections provide a detailed account of the responses, and some supporting quotes.

### Survey respondents

#### Organisational distribution

The survey started with introductory questions designed to collect information about the respondents. Of the 139 responses, 15 originated from individuals completing the survey on behalf of groups or organisations, which are detailed in Table 2. The remaining 124 responses were from individual contributors without any specified organisational affiliations.

Table 2. Organisations mentioned in the survey

List of organisations in alphabetic order
<ul style="list-style-type: none"><li>● Beat Kidney Stones</li><li>● Cancer Research UK</li><li>● Innovative Healthcare Delivery Programme (IHDP) x 2</li><li>● Ipsos</li><li>● Lancashire Teaching Hospitals NHS foundation Trust (LANDER Data Science Environment)</li><li>● medConfidential</li><li>● NIHR - Public Partnerships</li><li>● NIHR Blood and Transplant Research Unit in Data Driven Transfusion Practice</li><li>● NICRCF</li><li>● Pelvic Pain Support Network</li><li>● Understanding Patient Data</li><li>● University of Aberdeen</li><li>● University of Liverpool</li><li>● use MY data/</li></ul>

## Geographic distribution

Of the 117 respondents, most specified their location as England (n.100). Wales, Scotland, and Northern Ireland received fewer than 10 responses each. Additionally, there was a response from Italy.

## Roles in data-driven research and statistics

The respondents represented a diverse range of roles in data-driven research and statistics. Out of 109 respondents, the majority identified themselves as public/patient members (n.72). Eighteen individuals classified themselves as researchers, which included: early career researchers (5); mid-career researchers (5); senior researchers (3); and Masters/PhD candidates (3). Seven respondents identified themselves as PIE professionals. The remaining participants classified themselves as: research governance or professional support (n.5); data custodian/controller (n.2); VCSE (n.2); with three individuals identified a specified role and/or affiliation with an organisation (i.e., 'researcher and data processor with lived experience and PPIE role'; 'information governance'; and 'currently working with Queen's University Belfast, and British Heart Foundation').

## Type of data

The types of data respondents worked with varied. The majority of respondents (n.81) worked with health data, while 22 worked with statistics, 17 worked with administrative data, and 11 indicated other data types (i.e., personal/lived experiences, patient pathways, and diverse roles supporting researchers' public involvement and engagement).

## Level of experience in the field of data and statistics

Over half of respondents (n.54 out of n.99) had over a decade of experience in the field of data and statistics. A fifth of respondents (n.20) reported having five to 10 years of experience, while 15 individuals listed experience ranging between three and five years. Finally, five respondents indicated less than a year's experience.

# Findings

## Standard 1: Equity Diversity and Inclusion

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 98 people answered the question. The majority (n.88) considered this standard as being relevant, while 6 found it irrelevant or did not express an opinion. A total of 55 respondents added their comments in the free text box, highlighting challenges faced when selecting multiple options in response to the examples provided (see Appendix C). Although this may have affected the findings, the inclusion of a free-text box enabled respondents to contribute their thoughts on the standards statement and related examples.

### Insights

A free-text box under the first standard was available for respondents to provide their perspectives of the standards as a whole. Many used this space to highlight the need for a stronger **alignment with UK Standards for Public Involvement** to enhance understanding of differences within the context of data use in research and statistics.

*‘An overarching comment for all the Standards- it would be helpful to demonstrate how they relate to the UK Standards for Public Involvement. This could strengthen how they are perceived (contributing to system wide standards, contextualised to the context of the use of data for research and statistics.)’ – Survey Respondent 1*

A significant emphasis is placed on advocating for more **active and inclusive language** within the standards. Many ask for a change from passive to active examples and case studies which demonstrate meaningful involvement and engagement of underrepresented voices rather than merely allowing it.

*‘Overall comment on these examples; they are largely passive [...]. Specific points on this standard: all the examples are relevant, but they don't all illustrate what the standard might look like in practice. [...]. I would also add here something more "active" rather than passive as it comes across, about targeting the most excluded or least heard voices [...] relevant to the type of data driven research and characteristics. Adopting a flexible approach should also not just be to allow*

*anyone to join conversations but to actively participate and make a difference in ways that work for them.’ – Survey Respondent 1*

Moreover, respondents highlight the need for **clearer language** in the provided examples and recommended concise and easily understandable phrasing.

*‘Some of the language used in the examples is longwinded and impenetrable (eg. ‘to join conversations’ - why not ‘talk about’; ‘engaging different demographics....’ - change to something shorter, clearer)’ – Survey Respondent 37*

Respondents reiterate the significance of defining terms like equity, inclusion, and diversity, in addition to involvement and engagement, to ensure **clarity of contexts and interpretation**.

*“‘Equity’, ‘inclusion’, ‘diversity’, ‘involvement’ and ‘engagement’ are all terms used differently by different people and organisations but it is useful to state what you mean in this specific situation.’ – Survey Respondent 2*

They also explain some of the consequences of unclear communication of such meanings.

*‘The policy document states a desire to improve involvement and engagement, suggesting a difference between these activities. Yet the document does little to explain what is meant by the terms and says much more to conventional understandings of engagement than meaningful involvement. Therefore, inclusion and diversity are actioned in conversation, publicity, opinion research, and delegated forms of representation and community recognition. These are but aspects of what it means to build inclusive and diverse organisation-based practices and capacities. It says almost nothing about \*why one should do this, specifically in health data. The document does not acknowledge legacies and debts of injustice embedded in health data research. If there is social justice mission to this work, say so.’ – Survey Respondent 24*

Diversity, particularly beyond gender and ethnicity, garnered considerable attention. Respondents stress the importance of incorporating **voices from less represented** and/or at risk groups, including LGBTQ+ communities, individuals experiencing homelessness or poor health, undocumented migrants, and diverse age groups.

*'I would also add that aiming to be representative of the regional demographics is key. Some areas have greater concentration of Asian communities whilst other have more white European communities. Be conscious of this when developing PPIE and ensure you have the right demographics for your work.'* – Survey Respondent 8

*'Gender and ethnic diversity is not the only dimension in which EDI standards should be upheld. Inclusion of groups such as LGBTQ+ people, people experiencing homelessness, undocumented migrants, and people from different age groups must also be strived for in order for a range of voices to contribute to the research.'* – Survey Respondent 9

*'Ensuring that those who carry a disproportionate burden of poor health are sought out and included. These are often voices that are seldom heard...or not [more] accurately easy to ignore.'* – Survey Respondent 30

Additional suggestions included mitigating bias, understanding the costs and benefits of inclusivity, exploring needs for suitable adaptations, avoiding overrepresentation, and respecting the multifaceted experiences, cultures, and identities within minority communities.

*'Being mindful about your own conscious/unconscious biases (as an individual, team, or organisation) and be proactive in stopping these from influencing your work - Acknowledging that achieving this inclusivity may come at additional financial cost but could yield higher non-financial benefits.'* – Survey Respondent 19

Finally, respondents express strong feelings regarding the value and language used in the fourth example (*Recognising the different skills and knowledge members of the public and subject experts bring*) encouraging some further reflection on its content.

*'The 4th one doesn't make sense'* – Survey Respondent 33

*'I don't understand point 4'* – Survey Respondent 39

*'Point 4 makes no sense.'* – Survey Respondent 8

## Standard 2: Data literacy and training

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 89 respondents answered this question. The majority (n.78) considered the standard relevant, 5 expressing its irrelevance, and 8 having no opinion. A total of 46 respondents added their comments in the free text box provided, informing the following section.

### Insights

The majority of respondents who provided additional comments emphasised the significance of this standard, acknowledging the diverse range of numeracy skills and understanding of statistics within the public. While some members of the public may be confident in their knowledge of data and statistics, others may **feel intimidated** due to their lived experiences, for example such as those they may have had in an educational setting. As such, strong support for accessible and inclusive training emerged.

*'It's important to recognise that members of the public have widely varying numeracy skills and understanding of statistics. Some have degrees in maths or statistical subjects, but many others are actually scared of numbers after having a bad experience of maths at school. It is important that no-one is unintentionally excluded by their poor understanding of statistics, so I fully support this standard and the provision of training for the public, as long as it recognises people have many different starting points.'* – Survey Respondent 2

Some respondents highlight the benefits of **training** for both the public and researchers, with some sharing personal experiences underscoring its impact within PIE.

*'Having just returned from a week's residency at a workshop as a PPI member, if I had no knowledge about such things I wouldn't have been able to take part. patients/public don't have to become scientists/researchers but it is really difficult if they don't understand the terminology used and what they mean in practice. it is equally as important to assess PPI contributors' knowledge and experience before patronisingly putting everyone through the same sheep dip process.'* – Survey Respondent 20

Despite the overarching support for training, some respondents caution against its **potential drawbacks**. Structured training might inadvertently intimidate people from

engaging in PIE activities, suggesting that empowerment should go hand-in-hand with training to encourage self-advocacy.

*'I think the onus is on the research team to enable people to be their own advocates and listen to their voices. Training may help people feel confident in their interactions but equally it may scare off those who are unwilling or unable or scared to engage, thus marginalising some voices.'* – Survey Respondent 24

Moreover, respondents flag practical barriers to providing training, including time constraints and the **challenge** of gauging individuals' levels of understanding without creating feelings of being tested or undervalued.

*'Very interesting to see this. I feel its an excellent idea, my only concern is that the time needed could feel a barrier. And that it could feel patronising if not handled well.'* – Survey Respondent 12

*'Training must be fairly remunerated at NIHR payment rates. People won't want to be 'tested' so might be tough to gauge levels of understanding.'* – Survey Respondent 19

Some suggest an alternative solution of using available resources to **assess baseline knowledge**, maintaining a library of accessible materials, and recognising the impact of pre-existing opinions. This underscores the need to be prepared to face challenges and be flexible in PIE strategies.

*'it is important to assess baseline knowledge and explain at multiple different levels to account for the fact that even among the public, people have varying levels of engagement and understanding. - while we can take steps to train and educate, it doesn't necessarily mean that people will respond to PPIE work with what the team has taught them in mind, rather than their pre-existing opinion'. – Survey Respondent 33*

Despite widespread support for the standards, a few respondents raise concerns about the implied **hierarchy** associated with the term 'non-expert', suggesting a potential undervaluing of the public's experiential knowledge compared to academic expertise. There is advocacy for a fundamental shift in approach, respecting the diverse experiences and expertise held by the public and providing opportunities for learning and support aligned with the public's interests and needs rather than imposing predetermined information or agendas onto them.



*'There is a major issue with how this is framed - use of the phrase 'non-expert' immediately implies a hierarchy of knowledge [...] I would like to see the emphasis on gaining an understanding of the experiences and expertise of the public.'* – Survey Respondent 11

## Standard 3: Effective communication

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 88 survey respondents answered the question. The majority (n.81) acknowledged the relevance of this standard. Only 2 respondents indicated its irrelevance, while 7 expressed no opinion. A total of 44 respondents added their comments in the free text box, informing the next section.

### Insights

The feedback received from survey respondents highlights **the importance of communication** for meaningful PIE. One respondent emphasises the tendency of the scientific community and statisticians to overlook communication and the potential divisiveness caused by language, particularly within social media and scientific circles. They warn against allowing such divisions, as it could deter PIE.

*'We need to accept that disagreements do occur and can be exacerbated by language used. We shouldn't fall into the trap of allowing this to happen in PPIE as it can be divisive and ultimately off putting to some people.'* – Survey Respondent 33

**Establishing a platform** that fosters open, constructive, and respectful discussions is strongly advocated. This platform should encourage the expression of diverse perspectives while openly addressing areas of consensus and acknowledging situations where consensus may not be reached.

*'start with develop[ing] mutually acceptable ways to constructively and respectfully surface and debate differing views and ideas, and be clear and transparent about where consensus is able to be achieved and not and why'* – Survey Respondent 1

Additionally, the necessity of using **multiple languages**, recognising communication barriers (e.g., digital exclusion), clarifying the extent of involvement, and managing expectations on related outcomes are all relevant to effective communication. Ideally, the two-way conversation that underpins the value of this standard is initiated at the outset rather than being considered along the way.

*‘- Consider using multiple languages if your work relates to people whose primary language is not English. This may not be possible in all circumstances, but it's important to look at your target population. [...] - Consider the mechanisms being used for communication [...] - where possible, be open and clear about what you are seeking the public's input and how you will be incorporating their views to manage expectations regarding what changes will be adopted, and be clear about the process for doing so [...] - the two way conversation should be initiated from the beginning of a project rather than a last-minute add on at the end as a tick box.’ – Survey Respondent 16*

Respondents stress the importance of **avoiding technical language**, providing clear and concise explanations, and maintaining an accessible format that accommodates varying communication needs. Others include ideas creating a glossary of terms, avoiding acronyms, and using visual aids such as videos and images.

*‘A glossary of terminology might be helpful together with the avoidance of acronyms.’ – Survey Respondent 7*

*‘Use of technology, graphics and video will all support PIE understanding - along with clear glossary of terms and lay summaries.’ – Survey Respondent 14*

Investigating individual **communication preferences** can help to ensure diverse needs are met effectively and engagement is inclusive.

*‘I would also add in identify individuals preferences to how they prefer to receive the information and how best they like to communication back. For example, a person with neuro-diversity may require adaptation to effectively engage with a group dynamic. If this are [sic] identified upfront then you can ensure that the individual's needs are accommodated and met.’ – Survey Respondent 32*

A **balance** needs to be struck between keeping discussions on data engaging without compromising on technical relevance. Some respondents warn against dismissing necessary technical details, acknowledging that not all aspects of data might be inherently stimulating but are nonetheless crucial.

*‘Some aspects of data are necessarily dry - I think it is unreasonable to expect all discussions to be engaging, but it is important that they are relevant. This standard could be 'over-applied' by researchers in deciding that the 'boring' aspects of data won't be engaging or the 'technical' aspects of data won't be 'relevant' - ultimately reducing the amount of involvement that takes place’. – Survey Respondent 43*

Finally, it was advised to consider how the current version of the standard relates to **facilitation** and make the examples provided more data specific.

*‘This one is a tricky one. I feel that some of the principles fit under standard one, as they are more related to accessibility (rather than communications), especially the use of mediums. Others seem much more linked to facilitation, which isn't a category on its own. I still think these are important, but I would potentially reframe this as communication and facilitation. I also think you could tighten some of these points to be more specific about data.’ – Survey Respondent 37*

## Standard 4: Proactive transparency

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 85 survey respondents answered this question. The majority (n.81) recognised the relevance of this standard. Only 1 respondent indicated its irrelevance, while 4 did not express an opinion. A total of 40 respondents added their comments in the free text box, informing the following section.

### Insights

Feedback for this standard includes a distinct emphasis on fostering collaborative environments, defining expectations, and highlighting transparency as a **joint responsibility** from the outset. This approach could perhaps encourage a shift in attitudes, mitigating potential power imbalances.

*'I would probably reframe number 2 in that it is important from the outset to codevelop expectations of transparency (what it actually means) in working together and shared responsibilities for achieving it also acting upon input and being honest when there are barriers to transparency which mean input cannot be acted on important to be clear which decision can be influenced which not and why.'* – Survey Respondent 1

*'I think it is about changing attitudes - it's important for researchers not to try to control or withhold information for reasons of power.'* – Survey Respondent 2

While survey respondents support transparency, a notable concern is the **potential for overwhelming the public** with excessive information. To address this issue, suggestions include the provision of summaries and easily accessible materials, potentially supplemented by contact details for further clarification. Furthermore, respondents emphasise the importance of enhancing online platforms to ensure user-friendly web pages.

*'Challenges of creating too much material and overwhelming people. Summaries may be better. Some of this work could be contact details should people want further information. Perhaps the standard could consider how to make materials more accessible on websites/search engines etc. as part of the issue is finding the information.'* – Survey Respondent 5

**Oversight and accountability** within this standard are also flagged, with respondents underscoring the necessity of involving the public in decision-making processes. They advocate for creating an environment where decisions are collaboratively shaped with the public input rather than being communicated to them after the fact.

*'This document lacks teeth when it comes to oversight and accountability - There is little mention of bringing the public into decision making organs and having them observe how decisions are made (not just told how they are made). Public oversight helps foster better behaviour from decision makers.'* – Survey Respondent 6

The **essence** of proactive transparency is understood as an integral part of organisational culture rather than a standalone task. According to some, this culture should embody principles of accessibility, understandability, relevance, and proactivity in sharing both positive and negative outcomes in a timely way.

*‘Transparency is not a task in itself, but rather a culture which needs to be embedded and adopted throughout an organisation or programme. Transparency should underpin everything and is essential if the trust and support of patients and the public is to be maintained and developed. Transparency means operating in such a way that it is easy for others to see what actions are performed. In a nutshell – say what you do, do what you say. Our guiding principles for transparency: accessible – easy access to information; understandable – the right language for the audience; relevant – addresses audience concerns; useable – in a form that meets the audience needs; assessable – is checkable/provides sufficient detail; being as pro-active with ‘bad news’ as with ‘good news’; being timely with communication’. – Survey Respondent 14*

Some survey respondents highlight the need for a more comprehensive **commitment to transparency**, particularly concerning academic publications in open-source journals. They stress the frequent absence of this aspect, making the public feel excluded or perceive that they have been taken advantage of.

*‘I’d add to this that Research Papers should be made available to PPIE contributors, as many are published in Non-Open Source publications. This can make the PPIE community feel excluded from the whole process or worse: used!!!’ – Survey Respondent 32*

Finally, some raise concerns about the **terminology used** to articulate this standard, with some defining 'proactive transparency' ambiguous and not aligned with the commitment to ensure accessibility.

*‘Proactive transparency is an awful term (fortunately then explained) that completely lacks, in my view, your stated standard intentions to be jargon-free and accessible.’ – Survey Respondent 31*

## Standard 5: Mutual benefits

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 87 survey respondents answered this question. The majority (n.78) acknowledged the relevance of this standard. Only 2 respondents indicated its irrelevance, while 9 did not express an opinion. Additional insights provided by 39

respondents sharing their views in the free text box can be found in the following section.

## Insights

While recognising certain repetitions within the standards, there is a consensus on the role of 'mutual benefit' within PIE. Several survey respondents highlight the need to **align expectations** between researchers and the public involved in PIE activities. Additionally, some recommend proactive preparation to address scenarios where these expectations are not fulfilled.

*'Feels like an overlap between some of these standards - setting mutual expectations and understanding reasons for involvement is important - final one is pretty vague - agreeing frequency of communication and what to do when things aren't delivering mutual benefit is also important here.'* – Survey Respondent 1

Several concerns regard the **ambiguity** present in the language used, especially regarding the definition of 'mutual benefit' and the lack of discussions surrounding potential risks involved.

*'Would define what you mean by mutual benefit, it's a bit of a buzz word.'* – Survey Respondent 6

*'There is nothing here about potential risks for them - benefits should not be discussed without counter risks, especially in research!'* – Survey Respondent 7

While some respondents express concerns that offering **monetary compensation** for participation in PIE activities might introduce bias, most feedback received points to its importance in maintaining equity among all involved parties and validating the expertise that the public contributes. Nonetheless, respondents flag the need to ensure clarity in payment expectations. This includes recognising the financial challenges people might face when receiving compensation and acknowledging the diverse circumstances affecting those participating in PIE initiatives.

*'Important. also vital for organisations/researchers to appreciate the many difficulties PPI contributors can have in getting paid despite published policies on remuneration for such work. systems are rarely able to cope for those like me who are self-employed but won't be employees then can't issue P60s for my tax return yet don't have other ways of paying as I don't want 'shopping vouchers' for work even if that may be appropriate for one off engagement focus groups. many assume I get paid, yet I rarely do - somehow, I'm expected to live on fresh air - as assumptions that all PPIE contributors are retired, on a pension, well off or on benefits as policies go into great detail about ensuring the tokenistic payment may impact benefits when not all patients/survivors are on such state benefits. it's one thing to consider the heterogeneity of the conditions but patients' working/financial/social considerations differ too!' – Survey Respondent 18*

Some respondents note the need to be considerate of those who might be unable to accept monetary compensation due to their benefit status, emphasising the equal value of their contributions.

*'Being mindful of what people can accept in terms of monetary means i.e. those on benefits and ensuring people who can't accept contribution is as valuable as those who can.' – Survey Respondent 9*

Regarding **ways of working**, many respondents advocate a dialogue-based approach to facilitate understanding of needs, encourage collaboration, and potentially offer practical support during PIE initiatives.

*'A dialogue-based approach allows a mutual spontaneity, so that researchers and the public inform each other in both intentional and unintentional ways.' – Survey Respondent 13*

*'A discussion should be held with participants to understand if there is anything in particular that could be provided to them that would assist them. This could be connection or new skills or support that might help them access opportunities.' – Survey Respondent 25*

*'I would add allowing members of the public to co-chair or lead discussions and dialogue.' – Survey Respondent 2*

One respondent noted the importance of applying **co-production principles**, whenever feasible, to ensure that everyone involved can make significant contributions to the project.

*'I'd also add that, if possible, PPIE engagement should follow the principles of Co-Production to maximise the contribution of all parties in any given project.'* – Survey Respondent 30

Finally, some respondents suggest reviewing the **language used** within these standards to avoid sounding patronising and to ensure clarity about the value of public members' contributions.

*'I would recommend revisiting some of the language used in the examples as it is currently it is coming across very paternalistic and is not reflective of the sentiment of the Standard item, I believe you are trying to portray. for example, 'why they have been chosen to be engaged with/involved in the research'. I hope what you actually mean is being clear to the members of public what value their contribution will add to the research process and why it is important to embed their lived experience of the research topic currently being studied to ensure the research output/outcome is fit for purpose.'* – Survey Respondent 28

## Standard 6: Meaningful involvement and engagement

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 86 survey respondents answered this question. The majority (n.81) considered this standard as being relevant. Only 2 respondents indicated its irrelevance, while 5 did not express an opinion. Additional details on the comments received from 42 respondents in the free text box provided can be found in the following section.

### Insights

There is consensus that achieving mutual benefit is dependent upon ensuring meaningful involvement where appropriate individuals, with relevant experiences, are engaged for the right reasons. **Clarity regarding objectives, purpose, and outcomes** is vital for everyone involved to comprehend their roles and contributions.



*'I wonder whether this and mutual benefit are part of the same thing - mutual benefit is achieved when the involvement is meaningful because the right people with right experience are involved for the right reasons, and everyone is clear why they're doing it and why and what they're trying to achieve and why.'* – Survey Respondent 1

A prevalent theme highlights the significance of the public role in determining meaningful PIE practices. Respondents stress the importance of **collaboratively formulating plans** from the outset, continually monitoring progress, and making necessary adjustments based on real-time feedback.

*'Members of the public are the only ones who can decide whether PIE is meaningful. They should be involved from the outset in planning activities and there should be a feedback loop built into the plans to ensure they can report back on their actual experiences.'* – Survey Respondent 2

**Being open to changes** as research progresses is also considered integral to this standard. While acknowledging the changes that may arise from ongoing assessment of experiences, respondents also emphasise the need for adaptability in plans based on new insights gained throughout the research process.

*'Can be difficult to commit to a plan at the start as process might develop and plan may no longer be suitable. Involving the public with steering groups etc allows for this flexibility.'* – Survey Respondent 11

Further considerations include the fair assessment of public contributions in parallel with professional expertise, ensuring adequate funding and resources to support PIE activities, advocating for language sensitivity and cultural relevance, and clarifying the tangible impact of PIE on research findings.

*'It's important to create an equal value of PIE vs professional input - equal project partners and included throughout, always welcome.'* – Survey Respondent 12

*'Unless time and other resources are dedicated to supporting the role of involvement and engagement in projects, the Standards are meaningless. Appropriate language and design - as to understanding and to cultural sensitivity - are essential to successfully promote the Standards and allow them to reach the intended audiences of the research community and the public.'* – Survey Respondent 14

Frustration with tick-box exercises, rigid planning, and the need to balance objectives with valuable unplanned interactions or conversations emerged. There are also reservations about emphasising evaluation without a standardised evaluation tool.

*'This is missing the essential 'Working with public contributors to understand what meaningful involvement and outcomes looks like to them'. Planning PPI is useful and beneficial - but doing so too rigidly or insisting that plans are adhered to (or researchers interpreting the standard this way) is likely to reduce the impact of PPI rather than improving it. Similarly, it's easy to become obsessed with objectives (particularly SMART ones), losing activities and conversations that would have been beneficial but were not undertaken or recorded as they were not part of the objectives. Finally, emphasising 'evaluation' without providing an agreed tool or measure with which to evaluate unreasonable - record impact, yes, share outcomes and lessons, absolutely - but please do not suggest that 'evaluation' is essential without providing an agreed standard by which the evaluation should take place'. – Survey Respondent 41*

## Standard 7: Creating a culture of PIE

### Relevance and examples

Respondents were asked to tell us how appropriate or inappropriate they found this standard, and 93 survey respondents addressed this question. The majority (n.85) acknowledged the relevance of this standard. 4 respondents indicated its irrelevance, while 45 did not express an opinion. Additionally, insights from the comments received by 34 respondents can be found in the next section.

### Insights

Survey respondents took this opportunity to highlight the importance of understanding and appreciating the benefits of PIE for effective cultural change. In particular, it draws attention to the need for researchers, often deeply embedded in academic expert culture, to **acknowledge and value PIE** to ensure research outcomes remain relevant and implementable in real-world contexts.

*'Understanding and valuing the benefits is also important to changing cultures.' – Survey Respondent 1*

*'This is essential and more difficult than it sounds, as researchers are usually steeped in expert culture.' – Survey Respondent 2*

Respondents share a sentiment about the need to **champion PIE at all levels** within organisations. Rather than viewing PIE as a mere task, it is a values-based approach integral to problem-solving processes. Establishing a consensus on the value and necessity of PIE at all levels is key.

*‘Way too many check boxes that are basically all highly relevant but don't add to the process. When researching something that will lead to public policy it is a vital part of the research to understand if the policy will be workable and for that you need to understand public attitudes and behaviours or you risk your research being pointless as it will not produce an outcome, or policy that is implementable. PPIE is already a vital component of good research practice.’ – Survey Respondent 4*

Moreover, survey respondents highlight the importance of **senior decision-makers' oversight and public accountability** to prevent power vacuums and ensure ethical behaviour.

*‘Here needs more about patient oversight of senior decision makers and accountability to the public. No power vacuums that lead to corruption and unethical behaviour.’ – Survey Respondent 5*

The comments also discussed the need for **building sustainable infrastructure** and providing continuous support for PIE beyond the duration of individual projects. Long-term investments in infrastructure and capacity building are crucial.

*‘If this is about institutional culture, then investment into ongoing (foundational) infrastructure and capacity for PIE should be included here to prevent short term projects or transient activities, instead favouring consistent talent retention, reliable gateways to access research or researchers and ongoing dialogue with communities.’ – Survey Respondent 9*

Additionally, respondents express a need for improved **evaluation methods** and establishing evidence of PIE impact. This evidence serves to substantiate the significance of PIE, particularly in contexts that prioritise evidence-led approaches.

*‘An additional point would be that evaluation of the impact of Public Involvement and Engagement (PIE) can be difficult and time consuming. In an area which is so “evidence-led”, some will feel that PIE may be an imposition that is not explicitly evidence-based. More could be done to establish and highlight the evidence base where it exists, and to seek to generate new evidence of PIE impact where it is lacking.’ – Survey Respondent 12*

Respondents advocate **collaboration across sectors and communities**, expanding the PIE culture beyond organisational boundaries. Suggestions include identifying a senior champion dedicated to PIE to foster more effective practices and support PIE professionals.

*‘Consider PIE culture across sectors and communities rather than ‘just’ within organisations. Often we work on similar content / concepts and could achieve more working together than we can separately. - To the point about “active encouragement and accountability from senior leaders for PIE”, I would suggest identifying one individual at senior level to champion this. Whilst the organisation as a whole should encourage PIE, if something is the job of everyone it can become the job of no one. So, having one person at senior level who “sponsors” PIE even though it’s not their day job, it’s easier for PIE professionals or those incorporating PIE to know who is responsible.’ – Survey Respondent 14*

Respondents also stress **inclusivity and adaptability**, highlighting the importance of accommodating diverse PIE activities’, participants’ needs, and circumstances. Using various methods and ensuring reasonable adjustments for comfort and accessibility needs emerged as a vital aspect of successful PIE.

*‘Important aspect also recognising that many may still have health concerns so what may take a fit and well person x amount of time to do something may require adjustment for others. on the other hand, patients have often been able to take part in online activities whereas previous in person events/sessions may have been too much of a travel/physical burden. try and use varied methods and ensure reasonable adjustments made for in person events without embarrassing the patient concerned.’ – Survey Respondent 18*

There were concerns regarding the risk of treating PIE as a **tick-box exercise** or imposing pre-defined approaches. Instead, survey respondents emphasise the need for genuine recognition of contributions and outcomes arising from PIE activities, in addition to openness towards more innovative practices.

*'The idea of PIE 'professionals' smacks of regimenting what should be spontaneous and innovative contributions from other people, I have noticed this in some sessions, where PPI contributions are either ignored or bent to fit the required or expected outcome of the consultation, as though the consultation is just to tick the box.'* – Survey Respondent 23

Lastly, respondents acknowledge the **challenges** in achieving this standard. These include power struggles, the absence of unified leadership, and the need for systemic changes beyond individual projects. The realisation that embedding PIE throughout the research process necessitates concerted efforts, dedicated resources, accountability, and a paradigm shift across all organisational levels.

*'I think the goal of this 'standard' is excellent - but it depends a bit on how you intend these standards to be used and applied. PPIE absolutely should be embedded throughout an organisation, but this is often far outside the control of individual data projects and PPIE professionals - many of which, in my experience, sit across organisations and institutions, and for which there is no single, accountable 'senior leader'. As a 'standard' this one sits outside of individual projects and is really an important ideal for the entire field of PPI. As a PPI professional, I'd love to see more accountability for seniors, more resourcing and it would be wonderful to have someone/something finally acknowledge the skill set that PPI practitioners bring - but unless high level funders and regulators force this to happen, and, crucially, fund this to happen, this 'standard' is likely to alienate and disappoint PPI professionals and public contributors alike. I do think this 'standard' should be expressed as a goal, desire or requirement in an open letter or communications from major funders - I do not think this belongs as a 'standard' for use to assess PPI plans for individual projects.'* – Survey Respondent 35

## Further thoughts and considerations

### Additional PIE elements to include in the standards

Survey participants were asked to consider if there were any areas, or elements of public involvement and engagement that were not included, but the document would benefit from. A total of 41 survey respondents shared their insights to enhance the initial draft of the standards. Notably, there was a recurring emphasis on differentiating between the Best Practice Standards and the UK Standards for Public Involvement. Participants felt it would help to clarify terminology used, with particular reference to the terms such as *involvement* and *engagement*, offering practical

recommendations to empower public members, and avoiding being repetitive from one standard to another. Some respondents highlighted the absence of reference to key elements, like co-production, impact assessment, and research governance within PIE practices, advocating for their integration into the current version of the standards. Additionally, an eighth standard – *Systems of Accountability* – was proposed to facilitate mechanisms supporting public contributors in high-level decision-making processes.

Regarding contextual factors affecting PIE practices, respondents stressed the importance of the organisational commitment to PIE in order to ensure the adequate allocation of resources, including time, infrastructure, and well-trained staff. Further feedback focused on creating safe spaces for public contributions; encouraging a 'buddy system' to boost confidence levels; maintaining consistent terminology through a library of resources; transitioning from conventional PIE to citizen science approaches; and addressing technical and governance challenges unique to the data and statistics fields. Additional suggestions included clarifying the purposes of PIE activities from the outset and embracing diverse voices within the public, urging greater involvement of carers, people living with mental health conditions, and representatives from various ethnic backgrounds.

A prevalent theme across the responses received was the importance of developing a *living document* that continually adapts to PIE changing needs and expectations.

### Usability of standards

Participants were asked to share if they felt these standards would be usable in their role and 94 people responded. Of these, three-fifths of respondents (n.58) responded yes - they felt the standards would be usable. A fifth of respondents (n.18) said they did not think the standards would be usable, and the same proportion (n.18) said they were unsure.

### Language and style of standards

Participants were asked to consider if the language and style of the standards were appropriate for the intended audiences, and 82 individuals responded. Six out of ten people (n.49) said yes, they felt the language was appropriate. Only seven respondents felt the language was not appropriate and a third (n.26) said they were unsure. Notably, 31 participants provided additional comments in the free text box provided, contributing to the insights revealed in the following section.

The analysis of survey responses reveals a diverse range of opinions on the language, accessibility, and overall presentation of the standards. Respondents expressed concerns about the corporate tone in some sections and observed the content leaning more towards academic audiences than the general public. Many

suggested revisiting the language for inclusivity and clarity, pointing out that jargon and complex wording might hinder understanding, particularly for those new to PIE terminology. There was a prevalent call to define terms like 'involvement' and 'engagement' within each standard to eliminate ambiguity.

The feedback received emphasised the importance of providing tangible examples, case studies, and practical illustrations to enhance understanding. Some respondents felt that the language occasionally presented a power dynamic that could be perceived as paternalistic, contrary to the aim of fostering collaboration among all parties involved. Additionally, there were calls for a more inclusive approach, moving away from language that creates an 'us vs them' barrier, and instead recognises the expertise and contributions of all participants.

Additionally, survey respondents stressed the importance of regular revisions, openness to feedback, and a commitment to embracing a wider range of perspectives and language considerations as crucial aspects for improving the standards.

### Final thoughts and comments

Respondents were provided the opportunity to share any final thoughts and comments they may have on the draft standards, and 46 survey respondents answered this question. Several respondents commended the initiative's potential impact on organisational culture and improved PIE practices and considered the document a *great start*. However, many also expressed concerns about the presence of vague and, at times, repetitive examples referred to in the standards. Some also pointed out the lack of clear guidance on where to access relevant tools or resources for implementation, communicating perceptions of being overly aspirational without practical grounding. Suggestions for improvement included concrete examples of good and poor practices, considerations for more succinct and inclusive language, and a clearer distinction between involvement and engagement activities. Respondents also emphasised the need for further review by members of the public, effective communication strategies for dissemination, engagement with PIE professionals and researchers, and clarity around the audience and intended use of these standards.

## Conclusions

This report presents the findings of the public consultation on the draft Best Practice Standards, which was conducted between June and July 2023. These standards were developed as part of the PEDRI initiative to advance PIE practice in data research and statistics.

A total of 139 responses were received to an online survey, which included a series of suggestions for improvement. A summary of findings according to standards is offered below.

1. **Equity, diversity, and inclusion:** Respondents stressed the importance of inclusive language, clearer definitions, and increased representation of marginalised groups such as LGBTQ+ communities, individuals experiencing homelessness, and those facing health challenges. Addressing biases, understanding the costs and benefits of inclusivity, and respecting diverse cultural identities were also highlighted.
2. **Data literacy and training:** Accessibility and inclusivity in training were emphasised to bridge gaps in numeracy skills and statistics understanding. Respondents cautioned against intimidating training methods and advocated for empowerment alongside training to foster self-advocacy.
3. **Effective communication:** Open, respectful discussions and clear, concise language were deemed vital. Respondents encouraged understanding individual communication preferences and maintaining a balance between engaging discussions and technical relevance.
4. **Proactive transparency:** A proactive approach to transparency was considered essential, focusing on accessibility, comprehensibility, and timeliness in sharing information. However, respondents called for a different name for the standard and a more comprehensive commitment to transparency, including support for academic publications open to the public.
5. **Mutual benefits:** Respondents valued this standard and acknowledged the importance of compensating public contributions, setting clear payment expectations, and acknowledging diverse circumstances affecting involvement.
6. **Meaningful involvement and engagement:** Clarity, collaboration, and adaptability were highlighted as crucial factors. Ongoing feedback, fair assessment of contributions, and adequate resources to support PIE activities were considered essential for meaningful engagement.
7. **Creating a culture of PIE:** Organisational buy-in, senior leadership support, sustainable infrastructure, and continuous evaluation were suggested to ensure effective cultural change. Genuine recognition and inclusivity across all organisational levels were also emphasised.



As part of the survey, additional questions were posed to investigate various aspects, including the relevance of the document to the respondents' roles, clarity of language, and any missing information or additional comments. A number of suggestions were received, a summary of which is included below:

- Clearly differentiate between Best Practice Standards and UK Standards for Public Involvement.
- Incorporate practical recommendations into the definition of standards, avoiding repetition.
- Consider integrating elements such as co-production, impact assessment, and research governance, alongside developing a standard focused on accountability.
- Emphasise the importance of organisational commitment to PIE and resource allocation, including time, infrastructure, and well-trained staff to ensure good practice.
- Explore further the implementation of the standards, as they may benefit from additional refinement and clarification.
- Review the language used to ensure inclusivity and clarity.
- Investigate the possibility of regular revisions of the standards and remain open to feedback.

The feedback received through the survey highlights that although the draft standards represent progress in advancing PIE practices in data research and statistics, there is room for improvement. Considering these findings, a prudent step would be transitioning from 'Best Practice' to 'Good Practice' Standards and conducting further consultations to explore potential changes to the standards and investigate adoption while maintaining an ongoing dialogue with the broader research and statistics community to ensure ongoing refinement.

## Appendix A: List of resources

- [ADR UK Public Engagement Strategy](#)
- [Cancer Research UK - Patient Involvement Toolkit for Researchers](#)
- [DARE UK - People want trustworthy researchers to have better access to their data. But only if they're told about it](#)
- [Genomics England - The Participant Panel](#)
- [HDR UK Comms, Engagement, and Involvement Strategy 2020/23](#)
- [HDR UK Involvement and Engagement Guiding Principles](#)
- [Health Foundation Scoping Study - Engaging Communities for Health Improvement](#)
- [Healthwatch: Public Engagement in Health - Literature Review](#)
- [HRA New Best Practice Principles for Public Involvement](#)
- [IJPDS: Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research](#)
- [Involve and NIHR: Public Involvement in Research - Values and Principles Framework](#)
- [King's Fund - How Does the Health and Care System Hear from People and Communities?](#)
- [National Coordinating Centre for Public Engagement](#)
- [NHS Confed - Integration and Innovation in Action](#)
- [NHS England - Guide to Engaging with Communities](#)
- [NHS Statutory Guidance - Patient and Public Participation in Commissioning Health and Care](#)
- [NHSX Involving People and Communities in Digital Services](#)
- [Nesta - Principles for Public Engagement](#)
- [NIHR East Midlands - Approach to PPIE](#)
- [Oxford University - Public Engagement with Research Strategic Plan](#)
- [Sense about Science: Public Engagement - A Practical Guide](#)
- [Shaping Our Lives.org - Tickboxes and Tokenism - Service User Involvement Report](#)
- [SAIL Databank - Public Involvement and Engagement](#)
- [UK Standards for Public Involvement](#)
- [UKRI - Concordant for Engaging the Public with Research](#)

- [UKRI - Guidance on Engaging the Public with Your Research](#)
- [Uni of Bath - Public Engagement with Research](#)
- [Wellcome - How We Engage the Public](#)

# Appendix B: Best Practice Standards Draft

## Standard 1: Equity, diversity, and inclusion

Effective Public Involvement and Engagement (PIE) requires equity of representation of different members of the public, irrespective of their background, 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.

This might look like:

- Adopting a flexible approach to allow anyone, regardless of their background and identity, to join conversations about how their data is being or is planned to be used.
- Collaborating with charities and representatives of underrepresented groups to ensure inclusive and accessible approaches to PIE activities.
- Gathering diverse views by engaging different demographics and those unfamiliar or sceptical about the topic.
- Recognising the different skills and knowledge members of the public and subject experts bring.
- Recognising that while diversity and inclusion may not always lead to consensus, they are still valuable by enriching PIE activities.

## Standard 2: Data literacy and training

Data research and statistics often involves complex topics. Understanding 'non-expert' 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 enables members of the public to have the vocabulary, confidence, and understanding, which can empower them in their role as a contributor. Before beginning any engagement activity, it is important to assess baseline knowledge to determine if training requirements or support should be provided.

This might look like:

- Engaging with members of the public to understand what they already know and what they would like to learn about the topic.
- Supporting members of the public to have a baseline knowledge and understanding of the research to meaningfully contribute.

- Providing effective training that is delivered based on good teaching standards.
- Prioritising time and resources for public members to gain confidence in data literacy.
- Grounding discussions about data in real life use cases, relevant to those involved.
- Emphasising the perspectives and knowledge of public members and the critical thinking they bring.
- Creating and sharing informational resources for members of the public to interact with, whether or not they are involved in specific PIE activities.

### Standard 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.

This might look like:

- Ensuring discussions are engaging, relevant, and tangible for members of the public.
- Listening, acknowledging, and responding to public views and concerns.
- Ensuring language is accessible to a wide audience with the use of jargon free and accessible language.
- Broadening accessibility using a variety of mediums, such as large text documents, videos, images, and diagrams.
- Anticipating the likelihood of difficult conversations and addressing these as they arise.
- Acknowledging that consensus may not be achievable and providing open and positive mechanisms for differing views and exchange of ideas.

### Standard 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 are essential in demonstrating trustworthiness. Working in this way helps create a comfortable environment for all parties to effectively contribute to discussions.

This might look like:

- Making members of the public aware of the entire research process, timelines, and how decisions are made.
- Meeting public expectations of transparent ways of working through a two-way conversation, including time for questions and answers.
- Making all research materials up-to-date, available, and shared in accessible ways.
- Defining and communicating the purpose of research and any engagement activity to participants and members of the public.
- Having timely follow-up conversations with participants after involvement activity to give feedback on the impact of their involvement and next steps.
- Openly sharing research outcomes once they become available.

## Standard 5: Mutual benefit

PIE activities should adopt an ongoing dialogue-based approach to enable a mutual benefit between all those involved. This allows researchers to gain new insights and ideas to develop more impactful research informed by public views.

This might look like:

- Clearly communicating the benefits of being involved in PIE activities, their expected outcomes, and impact.
- Clarifying expectations on PIE and agreeing ways of working.
- Acknowledging public members for their contributions by offering them monetary or other agreed means.
- Helping members of the public to have a clear understanding of why they have been chosen to be engaged with/involved in the research.
- Setting realistic expectations for involvement and engagement processes and ensuring ongoing evaluation by all involved in the process.
- Promoting effective knowledge exchange among all involved in the process, fuelled by listening and responding.

## Standard 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 with clear tasks, purpose, and impact, while avoiding tokenism.

This might look like:

- Developing a comprehensive PIE plan from the beginning of study development.
- Setting clear objectives for PIE activities, including how PIE input will be incorporated into wider study activities.
- Appropriately resourcing staff time and budget for PIE activities.
- Promoting meaningful PIE activities throughout the research cycle.
- Committing to continually improving how members of the public are involved and engaged.
- Evaluating the impact of PIE activities, sharing outcomes and lessons learned.

## Standard 7: Creating a culture of PIE

Creating a culture of PIE in an organisation can support a seamless partnership between researchers and PIE professionals. Throughout every organisation, at every level, the value and necessity of PIE should be recognised and embedded. Time and other resources should be dedicated to supporting the role of involvement and engagement in projects.

This might look like:

- Embedding PIE throughout the research cycle.
- Active encouragement and accountability from senior leaders for PIE.
- Acknowledging the time and contribution made by members of the public.
- Acknowledging the expertise of PIE professionals as skilled practitioners whose expertise is built up through experience and training.
- Resourcing involvement and engagement activities, throughout the entirety of a project, with appropriate staff, funding, and other resources.
- Providing ongoing training for researchers and PIE professionals.
- Sharing and exchanging knowledge of how to conduct effective PIE with other researchers and engagement professionals, particularly those early in their careers.
- Working to continually improve approaches to PIE.

# Appendix C: Best Practice Standards Public Consultation Survey

## Introductory questions

1. Are you completing this survey as an individual or on behalf of an organisation/group
2. What is the organisation/group name you are answering this survey on behalf of?
3. Where do you live in the UK?
  - England
  - Northern Ireland
  - Scotland
  - Wales
  - Other (please specify)
4. What main role do you have in data-driven research and statistics?
  - Public/Patient member
  - Researcher
  - Public involvement and engagement professional
  - Data custodian/controller
  - Third sector/Voluntary Community Social Enterprise
  - Research governance or professional support
  - Other (please specify)
5. What type of researcher would you describe yourself as?
  - Masters/PhD candidate
  - Early career researcher
  - Mid-career researcher
  - Senior researcher
  - Other (please specify)
6. What type of data do you work with?
  - Administrative data, e.g. Housing, Education, policing data etc
  - Health
  - Statistics
  - Other (please specify)



7. How long have you been in this industry?

- Less than one year
- 1-2 years
- 3-5 years
- 5-10 years
- 10+ years

## Questions for each standard

8. Please rate the appropriateness of this standard to support public involvement and engagement activities in data-driven research and statistics.

- Very appropriate
- Appropriate
- Neither appropriate or not appropriate
- Not appropriate
- Highly inappropriate

9. If you would like to comment on this standard, please add your thoughts and suggestions below? *Please describe your thoughts on standard below (200 words)*

## Additional questions

10. Are there any areas of or elements of public involvement and engagement that are not included but this document would benefit from?

11. Do you feel these standards would be usable in your role? *Please expand on your in answer in the free text box*

- Yes
- No
- Unsure

12. These standards are intended for all those involved in conducting or supporting data-driven research and statistics. Is the language and style of these standards appropriate for the audiences? *Please expand on your in answer in the free text box*

- Yes
- No
- Unsure

13. Finally, could you please give any other thoughts or comments on these draft standards?

To get involved please email: [info@pedri.org.uk](mailto:info@pedri.org.uk)

