

PEDRI: Public Involvement and Engagement Best Practice Draft Standards for the use of data for Research and Statistics

29 June 2023

Introduction

The Public Engagement in Data Research Initiative (PEDRI) published draft Standards to guide best practice for involvement and engagement activities in the use of data for research and statistics. The aim of these draft Standards is “to support researchers and [Public Involvement and Engagement] (PIE) professionals to conduct meaningful PIE related to the use of data for research and statistics”.

We note that PEDRI is a sector-wide partnership bringing together organisations who work with data and statistics to generate insights that can inform policy and practice. A key aim is “to establish and drive forward best practice for public involvement and engagement with data research, including the views of the public in a more meaningful way”.

The Secretariat sought the views of Members of use MY data and their direct views have been collated into this summary response.

We noted the invitation to contribute to the document by 30 June 2023.

This response has been submitted directly using the [online web form](#). The contents of our submitted review are also shown in this document, to make it more readily accessible and referenceable to our Members and other readers.

Responses to the questions in the consultation

For each of the Standards in the consultation (shown in blue) we have answered the question, “Please rate the relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics”. We have also included any summary comments.

Standard 1 - Equity, diversity, and inclusion

“Effective PIE requires provision of equity of representation of different members of the public, irrespective of their background and identities. Inclusivity requires actively seeking out diverse voices and proactively adapting engagement approaches to make them accessible. Engagement should seek to break away from solely including the same communities or those familiar with the topic.”

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

A mechanical approach to diversity and inclusion is to be avoided. It is about the data researchers and their institutions being culturally and intrinsically open to the broadest involvement of patients and the public when defining the research question and designing study methods.

The National Institute of Health Research (NIHR) approach is to be commended.

We should note the key problem of resource. Many organisations may be extremely constrained by resource, so may choose to prioritise solely on what is achievable, which is likely to perpetuate lack of equity of representation.

Standard 2 - Data literacy and training

“Data-driven 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.”

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

An accessible information approach needs to underpin general health data understanding. use MY data runs regular Educational Sessions with Members on a wide range of patient data topics. These are highly regarded and proving extremely useful in supporting our Members in widening the scope of their involvement work.

We would encourage PEDRI to look at our Educational Sessions as an exemplar.

Standard 3 - Effective communication

“Data-driven 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.”

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

Public understanding of and confidence in the use of patient data is the key principle. Analytical approaches can obscure understanding. Understanding and trust can be generated from patient and public personal experience of their own health care.

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.”

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

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

*What do we mean by:

Accessible:

- Easily see what data/information is there
- Meta-information i.e., the rules about what is there, how it is held, what are the rules/processes for access etc.
- Must also be clearly available, must be understandable, and adherence to the rules stated (both the legal ones and the self-imposed ones) must be checkable
- There must be a clear statement on what rules are used to check that the data is eligible for inclusion.
- These must be around the sources of the information, what processes are used to validate the information, why data might be excluded (e.g., someone’s opted out, we don’t include children.....)

Assessable:

- Bland ‘PR’ statements tell the audience nothing
- If it’s personal information how you can dispute the content and what processes they would use to check, correct or exclude disputed info

There is a clear need for an ambitious, transparent and inclusive approach to the uses of health data for patient benefit.

Standard 5 - Mutual benefit

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

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

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

The NIHR approach is commended - its whole system incorporates Public Involvement and Engagement (PIE) as methodologically necessary.

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.”

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

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.

Standard 7 - Creating a culture of PIE

“Creating a culture of PIE in an organisation can support a seamless partnership between researchers and the public. 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.”

Relevance of this standard to your role in supporting public involvement and engagement activities in data-driven research and statistics: Very relevant

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.

Additional comments

In conclusion, to note that a common view was that whilst the Standards document may be a useful summary, it does not move the agenda forwards substantially, which several Members found disappointing.

We had several comments that many of the suggestions, such as “this might look like” were very aspirational and “not always grounded in reality”.

Several Members commented that the Standards were really a set of high-level principles, which lacked any real clarity about real-world implementation.

The only independent UK movement of patients, relatives and carers focussed on the use of patient data to save lives and improve outcomes

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

- **use MY data** is a movement of patients, carers and relatives.
- **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.
- **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.
- **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
 - We work to bring a patient voice to all conversations about patient data.
 - We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available [here](#).
 - We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
 - We provide learning resources for patient advocates on patient data issues, including:
 - Hosting events for patients and the public, focussing on patient data topics
 - a library of resources of data security, consent
 - narratives from individuals about the value of collecting and using patient data.
 - We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.
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