HDRUK
Health Data Research UK

Health Data Research UK 2024-2028 Patient and Public Involvement and Engagement Strategy :

How we plan to work with patients and the public to improve how data is used for health research

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Abbreviations and Glossary

Alliance	UK Health Data Research Alliance. An independent consortium of over 118 leading healthcare, research and patient organisations, united to establish best practices for the ethical use of UK health data for research at scale.
Collaboration	Working with someone to produce something.
Consensus	A general agreement or majority opinion shared by a group.
Co-production	A highly collaborative approach that seeks to share power amongst people and an organisation to design, manage and deliver research.
Demographic questions	Questions which ask about a person's background, these can include age, gender and education level.
Diversity	Differences between people based on their backgrounds, beliefs and experiences.
Early Career Researchers	Someone who is at the beginning of their research career.
EDI	Equality, Diversity and Inclusion.
Evaluation	A structured way of assessing what has been done and deciding on whether (and at times why) it has been successful or not.
Governance Structures	How power is distributed and decisions are made in an organisation.
HDR UK	Health Data Research UK.
Information Governance	Managing and sharing information in a way which ensures data is treated appropriately, legally and ethically.
Infrastructure	Research infrastructure is the facilities, services, and resources that allow researchers to conduct research. These can include equipment, data, facilities and tools.
Knowledge exchange	A two-way process that involves sharing ideas, skills and expertise.
Knowledge generation	The process of creating new information, awareness, understanding and skills.
Logic map	A structured and visual way of showing key steps required in order to turn a set of resources into activities that are designed to lead to a specific outcome or change.
Large-scale data	A huge amount of data often covering a large proportion of the population in a country.
Macro-level	Something that is large in scale or scope.

Metrics	A measurement.
Multi-stakeholders	A group of individuals and/or organisations often collaborating to address common issues or problems.
Pan-UK Data Governance Steering Group	A sub-group of the Alliance representing organisations which hold data, policymakers and other organisations across the four nations of the UK.
PEDRI	Public Engagement in Data Research Initiative.
PPIE	Patient and Public Involvement and Engagement.
Practitioners	A person who is actively engaged in a profession, such as health or public involvement and engagement.
Reciprocal	Given or done equally by both sides.
Research Data Infrastructure	The facilities, services, and resources that allow data researchers to conduct research. These can include equipment, data, facilities, tools and services.
Research Driver Programmes	Funded research projects or programmes which aim to act as an example to demonstrate whether and how a research question can be answered.
Secure Data Environment or SDE	Secure Data Environments are data storage and access platforms, which uphold the highest standards of privacy and security.
Steering Group	A group of people who makes important decisions about a project or organisation.
Transparency Standards	The Transparency Standards were created by the Pan-UK Data Governance Steering Group and members of the public and include recommendations for enhancing the transparency of research using data.
Theory of Change	A description of how a strategy will lead to change or impact.
Underrepresented communities	Groups of people who are not adequately represented in society.

Health Data Research UK and Patient and Public Involvement and Engagement

Health Data Research UK (HDR UK) is accelerating trustworthy use of health data to enable discoveries that improve people's lives.

HDR UK is the national institute for health data science. We are an independent charity supported by nine of the largest government and charity research funders in the UK.

Our mission is to unite the UK's health data to enable discoveries that improve people's lives.

Our 20-year vision is for large-scale data to benefit every interaction with patients, every clinical trial and every biomedical discovery and to transform public health.

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.

During its first five years, HDR UK earned an excellent reputation as a leader in Patient and Public Involvement and Engagement (PPIE) in health data research. HDR UK has robust governance structures in place, including a Public Advisory Board (PAB) who are actively involved in our work. We have a network called HDR UK Voices with over 200 public members and PPIE practitioners who engage with us regularly, sharing PPIE opportunities and outputs in data science.

Our approach to active involvement of the public in decision-making through our PAB has been highlighted by key decision makers in UK research, including in this case example by UK Research and Innovation (external link). Munisa Hashimi, a member of the HDR UK PAB who was featured in this case example, said:

"The number of times I've seen my small experiences add huge value to a project is the reason why I think members of the public should be involved in research. The more experiences and varied outlooks we can bring, the better the impact."

Notably, the PAB has also been active in co-producing Transparency Standards, which offer guidance on providing information to the public and researchers about data access processes. The PAB were also involved in a related funding call, which contributed towards increased transparency and trustworthy data research.

HDR UK was one of the founding members of the Public Engagement in Data Research Initiative (PEDRI). PEDRI is a sector-wide partnership bringing together organisations that work with data and statistics to produce learnings that can inform policy and practice.

HDR UK is building on these successes through a collaborative approach to improving the UK's data facilities and systems. HDR UK also focuses on delivering innovative research to unlock the power of large-scale data to improve health and care. This document presents HDR UK's PPIE strategy, which will support HDR UK's overall organisational Strategy.

What is health data research?

Every day, large amounts of health data are generated by the NHS and other health and care services, and from other sources such as academic research. Some of this data is general information about local or national populations, like the number of babies being born or how many people are admitted to hospital on any given day. Data is also generated from studies about the health of groups of people, from blood or tissue samples, scans and X-rays (imaging data), and even from health and fitness devices.

Data used in health data research is usually de-identified, meaning that names, addresses and other information that directly identifies a person is removed. The data is increasingly stored in a secure virtual space, often called a secure data environment. The secure data environment can only be accessed by authorised researchers. Authorised researchers can analyse the data and obtain results such as in tables or graphs, but the data itself cannot be taken out of the secure data environment (SDE).

Health data research is an exciting and developing area and can make positive changes in health and care for everyone. It combines maths, statistics, and technology to manage and analyse very large amounts of different health data sets, across our health and care systems. It is a way of gathering, analysing and linking information about people and their health, to enable us to make advances in healthcare and ultimately improve healthcare for all.

Watch the video 'Your data could save lives' from the PIONEER Health Data Research Hub (https://www.youtube.com/watch?v=pGz2aff-RIM)

What we mean by Patient and Public Involvement and Engagement

Patient and Public Involvement and Engagement, or PPIE for short, is key to everything we do at HDR UK. Involvement and Engagement are interrelated and sometimes are interchangeably used within in research. At HDR UK we use the terms according to the following definitions:

Involvement
means that activities and research are carried out 'with' or 'by' members of the public or patients, rather than 'to', 'about' or 'for' them. Patients and members of the public (including carers) are actively involved in the development, running and management of research projects or activities.

(This definition is from the National Institute of Health and Care Research)

Engagement
describes the many ways in which the activity and benefits of an organisation or research can be shared with the public. Engagement is a two-way process, involving interaction and listening, with the goal of generating mutual benefit.

(This definition is adapted from the National Coordinating Centre for Public Engagement)

PPIE ranges from sharing research findings in an accessible way for non-specialist audiences to conducting research that involves the public as decision-makers. HDR UK is committed to working with patients, carers, and the public, aiming for co-production wherever this is possible.

How Patient and Public Involvement and Engagement is organised at HDR UK

HDR UK has a PPIE team which is based in the Legal Trust and Ethics Team. The PPIE team works closely with staff in other teams within the organisation, as well as PPIE Leads across all the programmes we deliver or fund. Two PPIE-specific advisory groups inform our work. The Public Advisory Board provides strategic public advice and public input into the delivery of our work. The PPIE Strategy Steering Group (SSG) is a multi-stakeholder group with expertise in engagement, involvement, data science, research, and information governance. We further consult, and share opportunities and findings/results (outputs) with a network called HDR UK Voices which has over 200 public and PPIE practitioners. PPIE Leads from our Research Driver Programmes, Research Data Infrastructure, Regional Networks and former Health Data Research Hubs also meet to share knowledge, skills and time, and support the delivery of the HDR UK PPIE strategy.

The PPIE team coordinates the Public Engagement in Data Research Initiative (PEDRI). PEDRI brings together organisations that work with data and statistics to generate learnings to inform policy and practice. HDR UK also coordinates the UK Health Data Research Alliance ('Alliance'). The Alliance is an independent consortium of over 118 leading healthcare, research and patient organisations, united to establish best practices for the ethical use of UK health data for research at scale. Many Alliance organisations have PPIE leads who we partner with to deliver certain initiatives.

Who this strategy is for

This strategy will guide the work of the PPIE team and other teams in HDR UK. This strategy shows groups outside our organisation how we plan to work with patients and the public over the next four years. Publishing the strategy ensures transparency of our planned work.

Such groups include patients and patient groups, the public (including carers), PPIE practitioners, local and national PPIE networks, data science researchers and technicians, and information governance specialists. They also include health and social care practitioners and organisations, 'data custodians' (organisations who hold patient or public data), data research organisations, charities and voluntary and community sector organisations.

This strategy highlights the opportunities for us to involve these groups, and for them to influence or jointly deliver some of our work.

Our guiding values, principles and standards

We are governed by our organisational values of Transparency, Optimism, Respect, Courage, and Humility. We have signed up to the Shared Commitment to public involvement which champions the adoption and implementation of the UK Standards for Public Involvement. We are also a signatory to the Concordat for Engaging the Public with Research and are committed to embedding the Good Practice Standards for the use of data for research and statistics, published by the Public Engagement in Data Research Initiative. We have compared these guidance and standards, mapping alignment across them. You can read more about this in **Appendix 1**.

How we identified areas for improvement

We spoke to people who work for or with HDR UK, our public and professional advisory groups and boards, and external people working within health data science or PPIE to find out what was working well and what required improvement. Four key areas of challenge currently being experienced within PPIE in data research were identified through these conversations. HDR UK would like to build on its previous good PPIE work by addressing these **four key areas of challenges** over the next four years:

1. **Relevant, inclusive and understandable good practices:** Although there is plenty of advice and information on general PPIE good practices, there's less specific evidence regarding its application in data science. This information is not always easy for researchers, patients, or the public to understand and use.

2. **Two-way open communication and shared learning:** Many professionals working in data have limited awareness and knowledge about involving the public in data science, and the public do not always trust how data is secured and used. There is not enough conversation with the public, and their views are sometimes not included.

3. **Effective engagement and diversity:** HDR UK has limited reach and relatability with the general public and underrepresented communities.

4. **Coordination:** HDR UK works in a complex field, where many organisations involve the public - but not in a coordinated way. This lack of coordination can make messages, projects and procedures sometimes overwhelming or confusing for the public to understand.

We developed our draft HDR UK PPIE strategy which outlined our vision mission and goals which aim to address these challenge areas. We had further conversations with our staff, public members and advisory groups and external people working within health data science to refine the draft strategy.

Public Consultation

We worked with an organisation called Stand and ran a public consultation on our draft HDR UK PPIE Strategy from 4 March to 21 April 2024. We invited patients, carers, the public, and anyone from across the UK to give their views on our draft strategy. During this time, we offered various ways to provide input, including a survey, online workshops, focus group discussions and telephone interviews.

The full public consultation report and easy-to-read summary are available on our website. There was a consensus that the draft strategy was a welcome commitment to delivering PPIE. Our approach to involvement of the public in the development of the strategy was welcomed. Respondents were generally in agreement that the strategy included necessary key aspects. The commitment to a four-year timeframe was also viewed positively. Amendments to the goals and objectives were suggested.

Areas for improvement were suggested, and an overview of key recommendations are listed below:

1. Ensure the strategy document is accessible and relatable.
2. Provide more detailed information on the delivery of the strategy, including case studies to add context, and add specific targets.
3. Ensure equal partnership with the public in decision-making.
4. Develop clear plans to reach and include a diverse range of voices, especially those who do not usually engage with research.
5. Be clear on which good practice standards HDR UK will follow.
6. Ensure that underrepresented voices are engaged and involved effectively. HDR UK should work with organisations which already have links and experience in working with underrepresented communities.
7. Maintain transparency in HDR UKs work. Launch a communication campaign to raise awareness, trust and transparency. The campaign should explain health data research and showcase positive case studies of the benefits of sharing health data for research purposes.

The recommendations from the consultation helped us to refine our proposed approach to addressing the four key challenges identified and detailed in the previous section. We involved our Public Advisory Board, PPIE Strategy Steering Group, and HDR UK-wide PPIE Leads in the finalisation of the strategy and our work plan. Finally, we held two engagement events, one for professionals and one for public members who were involved in the consultation process. We explored their thoughts on these final goals, objectives and activities. A summary of the outputs from the engagements as well as actions we took to address feedback is available in **Appendix 2.** This final strategy document was reviewed by three members of our Public Advisory Group.

Our PPIE Mission and Vision

Our mission is to establish good practices in patient and public involvement and engagement, which can improve research, innovation, transparency, public trust and confidence within our organisation and the wider health data research sector.

Our Vision is that all health data research will deliver benefits to diverse people, research and innovation by listening to the needs and concerns of patients and carers, and by enabling shared decision-making throughout the research process.

Our priorities, goals and actions

Our main priority over the next four years will be to ensure that we integrate good PPIE practices based on our values, principles and standards as outlined in this strategy. We will work to facilitate and promote the adoption of good practices to organisations we work in partnership with.

We will be focusing on addressing the **four key areas of challenge** which have been identified through our consultation processes.

1. **Relevant, inclusive and understandable good practices:** Contributing to PPIE knowledge generation and exchange, dissemination, adoption, learning and development within health data research. These activities will be targeted at both the public and the research communities.

2. **Two-way open communication and shared learning:** Sharing resources and providing learning and development opportunities to researchers focusing on the benefits of PPIE, and how to do PPIE in health data research. We will use engaging methods to communicate the information governance and technological safeguards which contribute towards making health data secure, as well as the benefits which come from using health data for research. We will actively listen to the public and respond to their needs, concerns and interests.

3. **Effective engagement and diversity:** Working with organisations which have good relationships with the general public and underrepresented groups to appropriately and effectively engage and involve them in our work.

4. **Coordination:** Improving coordination of PPIE within health data research partnerships, working with the Shared Commitment to public involvement, Public Engagement in Data Research Initiative, UK Health Data Research Alliance and other organisations working within health data science.

Table 1
Our Goals and Objectives between 2024 and 2028

Goal 1:

Good PPIE practices and decision-making

▶ Ensure that we collaborate with a diverse group of patients, carers, the public (with varied lived experience), researchers, patient and public involvement and engagement (PPIE) professionals and health practitioners, when decisions are made.

Broad Objective 1

▶ We will embed PPIE good practices into how the organisation is managed and how we deliver our work. We will accomplish this through our activities detailed in 1.1 to 1.4

1.1	**Improve collaborative/co-produced decision making**	• Conduct an annual evaluation of how our work with the Public Advisory Board and Strategy Steering Group could be improved and act on recommendations. • Increase collaboration and co-production with our Public Advisory Board and Strategy Steering Group, further involving them in PPIE and the wider organisation's strategy, delivery monitoring and evaluation plans.
1.2	**Develop and implement strategies to enhance the diversity of our Public Advisory Board**	• Conduct a diversity audit of our current Public Advisory Board members to establish a baseline (or initial measure of diversity) • Engage with voluntary, community, and social enterprise organisations, collaborating with them to co-create a robust 2024-2025 recruitment strategy aimed at developing plans to actively engage, recruit, develop and support members from underrepresented groups.
1.3	**Strengthen internal institute-wide PPIE communications and collaborations**	Increase shared learning, collaboration and joint working within the HDR UK PPIE Leads Groups (covering our Research Driver Programmes, Research Data Infrastructure, Regional Networks and other initiatives, e.g. British Heart Foundation Data Science Centre and former Health Data Research Hubs).
1.4	**Develop and promote good practice**	Collaborate with the Public Advisory Board in creating and delivering good practice guidance and training materials for HDR UK researchers, targeting early career researchers and researchers interested in health data research.

Goal 2:

Public interests influence our work

▶ Strengthen our public engagement, including unengaged and under-served communities, ensuring that their needs, interests and concerns are understood and influence our work.

Broad Objective 2

▶ We will work with our Public Advisory Board, HDR UK Voices members, researchers and health practitioners to collaboratively develop engaging communications and activities, which encourage feedback from patients and the public (including carers). We will accomplish this through our activities detailed in 2.1 to 2.6

2.1	**Monitoring, evaluation and learning related to equality diversity and inclusion**	• Create standardised evaluation forms for public engagement activity which include demographic questions where appropriate, and other questions on diversity, ensuring language is in line with current best practice. • When developing projects, events and programmes, relevant equality diversity and inclusion guidance such as the Diversity & Inclusion at Conferences and Events (DICE) Charter and Equality, Diversity and Inclusion in Science and Health (EDIS) inclusive conferences and events should be used.
2.2	**Continuing to improve on how we involve the public in our engagement activities**	• Conduct an annual evaluation of how our communication and work with HDR UK Voices could be improved and act on recommendations. • Continue to involve HDR UK Voices in our public engagement activities, ensuring content is relevant and accessible to the those taking part.
2.3	**Increasing diversity of membership of HDR UK Voices**	• Conduct a diversity audit of the current HDR UK Voices members to establish a baseline (or initial measure of diversity). • Engage with voluntary, community, and social enterprise organisations, collaborating with them to co-create a robust 2024-2025 recruitment strategy aimed at developing plans to actively engage, recruit, develop and support members from underrepresented groups.
2.4	**Engaging new communities**	• Carry out a review of which communities are underrepresented and unengaged in data to confirm communities and locations that will be our primary focus over the next four-years. • Create a community engagement programme which is responsive to the needs of the communities we need to serve better. The programme will involve collaborative working with voluntary and community sector organisations.

2.5	**Diversifying our public engagement activities**	Expand public engagement activity HDR UK is involved with beyond science festivals (e.g. cultural events, artist collaborations, etc.), matching activities to the interests of the communities we aim to serve.
2.6	**Encouraging feedback from members of the public**	Collect feedback in different ways to make sure everyone has the opportunity to feedback (e.g. social media polls or chats, citizen-driven data research, and feedback from HDR UK Voices members).

Goal 3:

Trustworthiness and Confidence

▶ Use effective inclusive approaches to demonstrate trustworthiness and promote confidence in the ethical use and re-use of health data for research and innovation among diverse UK communities.

Broad Objective 3

▶ We will involve the public in developing best practice guidelines for health data information governance and technology processes and activities. We will also engage with the public to raise awareness and enhance understanding of, as well as gain support for, health data research across the UK. We will accomplish this through our activities detailed in 3.1 to 3.7

3.1	**Enhancing transparency and accessibility**	• Develop and share engaging, clear, accessible, and inclusive materials focused on information governance and good practice standards. We will focus on involving and engaging the public in the work carried out with the HDR UK Legal Trust and Ethics Team, other teams in the wider HDR UK Institute, the UK Health Data Research Alliance and its Pan UK Data Governance Steering Group. • We will actively help the public to understand and get involved in data governance process in the research we fund or are involved in.
3.2	**Integrating public involvement into technological developments**	We will actively help the public to get involved in ensuring that technological updates to the Health Data Research Innovation Gateway are accessible to the public.

3.3	**Facilitating training and public engagement**	Provide relevant training and facilitate researchers to co-deliver public engagement and science communication and activities.
3.4	**Facilitating PPIE knowledge sharing**	Trial 'share, talk, learn' discussion series, where internal and external speakers share learnings from their PPIE work.
3.5	**Disseminating good PPIE practices**	• Produce an annual report detailing learning from our activities each year. • Deliver a biennial (two-yearly) hybrid meeting focused on sharing and celebrating PPIE activity in health data research.
3.6	**Communicating the benefits of health data research**	• Create digital communications prioritising stories which showcase the people behind the research, to help the relatability and accessibility of health data research. • Ensure equality diversity and inclusion considerations when developing content, including ensuring there is a balance of people from different backgrounds and perspectives being showcased.
3.7	**Expanding our partners in public engagement and communications**	Find and try out successful engagement and communication activities involving people such as frontline healthcare professionals, research ambassadors, advocacy or campaign groups, and social and media influencers.

Goal 4:

Coordination and partnerships

▶ Advance Patient and Public Involvement and Engagement in research and innovation at the local, regional, national and international levels

Broad Objective 4

▶ We will actively share learning and work in partnership with existing data research organisations as well as those we are yet to engage. We will progress good practices within and outside of the organisation through our activities detailed in 4.1 to 4.2

4.1	**Identifying and engaging organisations working within data research**	Further explore who our stakeholders are and create a plan to communicate, engage and develop good working relationships with them.
4.2	**Continuing to improve on how we involve the public in our engagement activities**	We will collaborate closely and share our learnings with colleagues from the following initiatives: • Shared Commitment to public involvement: The Health Research Authority, the National Institute for Health and Care Research and a host of organisations across the UK have been working together to bring about changes which will drive up standards in health and social care research. Together we have signed up to the Shared Commitment to public involvement group. We will support the work of the Shared Commitment group and ensure that at least two of our Public Advisory Board members are involved in their activities. • Public Engagement in Data Research Initiative (PEDRI): PEDRI is a sector-wide partnership bringing together organisations that work with data and statistics to generate insights that can inform policy and practice. The goal is to collaborate on establishing and driving forward best practices for public involvement and engagement with data research, to bring the views of the public to policymakers and data holders in a more meaningful way. We will continue to host and provide a secretariat for PEDRI and be actively involved in leading its workstreams. We will also ensure that at least two public members from the Public Advisory Board or HDR UK Voices are involved in PEDRI's work. • UK Health Data Research Alliance: The Alliance unites leading healthcare and research organisations in establishing best practice for the ethical use of UK health data for research at scale. We will continue to support the Alliance to involve public members in their work, and to encourage the adoption of PPIE best practices amongst Alliance members.

4.2	**Continuing to improve on how we involve the public in our engagement activities**	• NHS Research Secure Data Environment Network: The NHS Research SDE Network aims to deliver an England-wide system of SDEs that provides safer and faster access to different types of NHS data by 2025. In improving access to NHS data, the SDE Network will enable world-class research to prevent, diagnose, and treat our biggest healthcare challenges. This will improve patient care, support innovation and help us sustain the NHS in the future. HDR UK will continue to work with the Network to further adopt PPIE good practices, as well as support efforts related to monitoring, evaluation and learning. • We will actively work with HDR Global, our International team and our International Advisory Board to share learning with international organisations and initiatives focused on health data research.

Governance, resources and our delivery approach

Governance: The delivery of the PPIE strategy will be overseen by our Public Advisory Board and the HDR UK Senior Leadership Team. Advice will also be sought from professionals working within PPIE and health data research who make up our PPIE Strategy Steering Group.

Resources: The delivery of this strategy will be led by a small PPIE Team of six, including Senior Leadership Team member Cassie Smith, Director of Legal Trust and Ethics; and Doreen Tembo, Head of Public Involvement and Engagement. The PPIE team will work closely with other teams within HDR UK (e.g. Communications, Information Governance, Technology, Training) and the PPIE leads in the wider HDR UK community (made up of funded research and infrastructure programmes). We will also work with consultants and contractors as necessary. We will work very closely with colleagues in PEDRI and the UK Health Data Research Alliance to deliver on our ambitious projects, to further good practice across the whole data for research and statistics sector.

Delivery approach: Activities to drive existing PPIE initiatives forward, as well as emerging new work to support the wider organisation have been taking place since HDR UK's inception. We have been continuously improving our work based on feedback from the PPIE strategy consultation process and advice from the Public Advisory Board. We have also carried out work to support the future delivery of this strategy alongside its development. Activities within this strategy, as well as any unanticipated activities, will be prioritised based on the advice of the Public Advisory Board and the needs of the wider organisation, sector and public. The Public Advisory Board and the HDR UK Voices Network will be actively involved in delivering our activities.

How we will measure success

We will develop, a Theory of Change or a description of how our strategy will lead to change. Measurable objectives and key results will be included in the delivery plans. We will co-create an evaluation framework with our Public Advisory Board and PPIE Strategy Steering Group members. The framework will be informed by our guiding values, principles and standards as set out in our strategy. Annual work plans for each objective will be developed. The PPIE team will monitor, evaluate and learn from ongoing activity and report on this to the Public Advisory Board and the HDR UK Senior Leadership. An annual report will be made available on our website and shared with stakeholders.

Thank you

We would like to sincerely thank all the people, too numerous to individually mention, who gave their time and shared their knowledge to support the development of this strategy. We would like to especially thank the sub-group of the Public Advisory Board, who closely collaborated with the HDR UK PPIE Team and Stand throughout the strategy development process.

Contact

Please contact us if you would like to be involved in our work by emailing **involvement@hdruk.ac.uk**

Appendix 1: Comparing the PEDRI Good Practice Standards with Other Guidance

The PEDRI Good Practice Standards, and the Concordat for Engaging the Public all aim to encourage public involvement and/or engagement in research. While they share some similarities (see Table 1), they differ in structure, target audience, level of detail, and research field (see Table 2). Despite these differences, they can be integrated into a comprehensive framework that encourages inclusive, transparent, and mutually beneficial public involvement and engagement (see Table 3).

Key similarities across the documents

Commitment to Public Involvement/Engagement: A central theme across all three documents is the strong emphasis on public involvement and/or engagement as an essential element of research which achieves impact. Whether through the provision of principles, reflective questions, or strategic frameworks, each document underscores the importance of the public in enhancing the impact, relevance, and inclusivity of research activities.

Focus on Inclusivity and Equity: PEDRI Good Practice Standards and UK Standards for Public Involvement directly focus on inclusivity as a core principle. These documents aim to tackle barriers that challenge diverse participation in research, ensuring that underrepresented groups have the opportunity to contribute. While the Concordat for Engaging the Public does not explicitly focus on equity as a standalone principle, its strategic principles align closely with values of fairness and inclusivity, emphasising the need for research organisations to promote these values at an institutional level.

Encouragement of Two-Way Communication: All three documents advocate for a dynamic, two-way communication model between researchers and the public. This approach to involvement/engagement is reflected in the emphasis on dialogue, transparency, and collaboration. The documents agree that engagement should involve informing the public and listening to and incorporating their perspectives, encouraging an environment of mutual understanding and respect.

Impact: All three documents emphasise the importance of measuring and understanding the impact of public involvement and engagement. The PEDRI Good Practice Standards focus on the benefits of transparency, mutual benefit, and effective engagement. The UK Standards for Public Involvement highlight the importance of identifying improvements and benefits from both the public and research perspectives. Similarly, the Concordat for Engaging the Public with Research underscores the need for monitoring and reporting engagement activities and their outcomes, offering a framework for impact evaluation that ensures accountability and maximises the benefits of public involvement.

Table 1.

Key similarities	PEDRI Good Practice Standards	UK Standards for Public Involvement	Concordat for Engaging the Public with Research
Commitment to Public Involvement/ Engagement	Yes, focuses on public involvement and engagement	Yes, focuses on public involvement	Yes, focuses on public involvement and engagement
Focus on Inclusivity and Equity	Yes, equity and inclusion as a standard	Yes, discusses inclusive opportunities	Yes, Implicit in broader strategic principles
Two-Way Communication	Yes, emphasises reciprocal dialogue	Yes, encourages mutual understanding and collaboration	Yes, advocates for open, reciprocal engagement
Focus on impact	Yes, by focusing on benefits of transparency, mutual benefit, and effective engagement	Yes, as it helps identify improvements and benefits from both perspectives (public included)	Yes, highlighting the need for monitoring and reporting activities and their outcomes, while also providing a framework for evaluation

Key differences across the documents

Structure: The structure of each document varies significantly. The PEDRI Good Practice Standards are organised around seven key themes, each with detailed steps for achieving specific goals. The UK Standards for Public Involvement organise their content into categories accompanied by reflective questions aimed at encouraging self-assessment of practices. Finally, the Concordat for Engaging the Public, adopts a strategic, high-level approach, presenting principles with actionable points for research organisations to adopt at the institutional level.

Level of Detail: The PEDRI God Practice Standards offer detailed, step-by-step guidance, making it highly practical for PIE practitioners looking for clear instructions on how to implement involvement and engagement strategies. The UK Standards for Public Involvement offer a balanced approach, providing practical guidance alongside reflective questions that allow practitioners to evaluate and adjust public involvement practices. In contrast, the Concordat for Engaging the Public operates at a more abstract level, focusing on macro-level strategic changes within research organisations, rather than individual-level practices.

Primary Target Audience: The intended audiences for the documents vary, which influences their structure and content. The PEDRI God Practice Standards are aimed primarily at researchers, public involvement and engagement practitioners, and research organisations. The UK Standards for Public Involvement target public involvement practitioners. Meanwhile, the Concordat for Engaging the Public is directed at Researchers, institutional leaders, and policymakers, encouraging them to create an organisational framework for public engagement.

Research field: The PEDRI Good Practice Standards focus on data research; The UK Standards for Public Involvement health and social care research; and the Concordat for Engaging the Public across general research and the higher education sector.

Table 2.

Key similarities	PEDRI Good Practice Standards	UK Standards for Public Involvement	Concordat for Engaging the Public with Research
Structure	Organised around 7 standards with detailed steps	6 Categories with reflective questions	Structured around strategic principles and actionable points
Level of Detail	High: provides specific actions and steps	Moderate: balances guidance with self-reflection	Low: high-level strategic framework
Primary target audience	Public involvement and engagement practitioners and research organisations	Public involvement practitioners	Researchers, institutional leaders, and policymakers
Research field	Data research (including health and non-health data)	Health and social care research	General research and higher education sectors

Integration

Each PEDRI Good Practice Standard aligns with specific categories from the UK Standards for Public Involvement and principles from the Concordat for Engaging the Public. Table 3 offers a breakdown of potential integrations.

Table 3.

PEDRI Good Practice Standards	UK Standards for Public Involvement	Concordat for Engaging the Public with Research
1. Equity, Diversity, and Inclusion	Inclusive Opportunities, Governance	Strategic Commitment
2. Data Literacy and Training	Support and Learning	Skills, Support, and Opportunities
3. Two-Way Communication	Communications, Working Together	Skills, Support, and Opportunities
4. Transparency	Governance, Communications	Implementation and Impact
5. Mutual Benefit	Working Together, Impact	Strategic Commitment
6. Effective Involvement and Engagement	Working Together, Governance	Reward and Recognition
7. Creating a Culture of Involvement and Engagement	Governance, Communications	Strategic Commitment, Implementation and Impact

Appendix 2: Post public consultation engagement, involvement and outcomes

Feedback by group	Action
Public Advisory Board, 11th July 2024	
Need for focused shorter objectives which should be measurable (have a metric) and aligned closely to the goal	Shorter objectives have been created and metrics developed for the delivery plan
Clarity on where recommendations came from and what we will be prioritising and why. Explaining what work we are already doing	This has been made clearer in the final strategy document and the delivery plan will outline which work has been completed
Include 'co-production' and lived experience in the language	This has been made clearer in the final strategy document
Include something around the need to involve people to scrutinise data governance processes	This has been made clearer in the final strategy document
Show how PAB/Voices etc. will be involved in proposed projects and activities and add SMART objectives	This has been made clearer in the final strategy document and metrics developed for the delivery plan
Limit scope/don't do too much to manage resources available to deliver activity	Scope has been limited to supporting the wider work of institute while working with partners to effect sector wide change
Focus on telling positive stories, equality, diversity and inclusion, un-engaged groups, accessibility, sustainable engagement and partnering with organisations and people who can reach under-represented groups.	These elements have been retained as part of the strategy
HDR UK PPIE Leads, 24th July 2024	
Differentiate Mission and Vision a little more	No changes were made to honour changes suggested during the public consultation.
Create a logic map/theory of change	A theory of change will be developed to aid delivery and monitoring evaluation and learning
Improve communication and coordination across HDR UK (including for festivals and outreach work). Focus on sharing resources (financial, human and learning and development)	This aspect has been included in the strategy and delivery plan and governs our delivery approach for activities
Focus on addressing health inequalities, poverty, underserved/underrepresented groups	These elements have been retained as part of the strategy

Consider the impact of language barriers	This aspect will be incorporated into our work and dissemination practices
Consider accessibility issues (e.g. our branding and the effect on people who are visually impaired)	This aspect will be incorporated into our work and dissemination practices. Work to improve the accessibility of our branding will be led by the communications team and will take place throughout 2025
Collaborate with clinicians and others already working with underserved groups	These elements have been retained as part of the strategy
Focus less on HDR UK and more on people's journeys and mutual learning	This approach will continue to govern the delivery approach for activities
Create case studies like those used by Nesta (a Charity which focuses on innovation for social good)	Our science and PPIE communication approaches will be innovative and will build in learning from others who exemplify best practices in communication and engagement.
PPIE Strategy Steering Group, 30th July and 14th August 2024	
Provide clear definitions of involvement and engagement	This has been made clearer in the final strategy document
Reference to budget and other resources available	A section on resources has been added to the strategy. The delivery plan will attach available budget for each activity
Utilise values-based approach to engagement and its evaluation	This is now included as part of the strategy and evaluation approach
Ensure PPIE strategy is linked to HDR UK strategy	This has been made clearer in the final strategy document
Be clear about strategic support and leadership	This has been made clearer in the final strategy document
Create a clear and measurable delivery plan from the outset	A delivery plan with associated metrics will be published in the spring of 2025
Accountability and transparent governance structure responsible for PPIE should be made clear and assessment carried out on the impact of power dynamics in decision making	This has been made clearer in the final strategy document. We have also emphasised that we will seek to co-produce our work wherever this is possible to minimise the impact of power dynamics
Use available teams and infrastructure to deliver strategy	This approach has been made clearer in the final strategy document
Focus on the 'not interested'/inactive audience and develop solutions for engaging and involving them	This approach will continue to govern the delivery approach for activities
Focus on health data literacy before focusing on storytelling to raise awareness	This approach will continue to govern the delivery approach for activities

More engaging branding, creative methods and more platforms for engagement (e.g. Instagram)	The PPIE Team will collaborate with the Communications Team who will deliver more engaging branding and diversify their engagement methods and platforms
Consider translation into other languages	This will be considered especially for printed engagement materials which cannot be automatically translated like online material
Look beyond the usual EDI (protected characteristics) when assessing diversity	This approach will continue to govern the delivery approach for activities (e.g. consideration where practical of socioeconomic status, geographic location, language proficiency, educational background, neurodiversity, family structure, political views, and lived experiences)
Working in partnership with other organisations in mutually beneficial ways	This approach will continue to govern the delivery approach for activities
Focus on AI	The PPIE Team approach will be aligned with the focus of the organisation's strategy on AI
Training focused on all audiences (e.g. media training)	This approach will continue to govern the delivery approach for activities
Focus on producing 'inclusive knowledge' (where people can access and transform information into knowledge and understanding) as opposed to only disseminating	This approach, particularly co-production with our Voices network will continue to govern the delivery approach for our engagement and communication activities
Provide clear definitions of involvement and engagement	This has been made clearer in the final strategy document
Reference to budget and other resources available	A resource section has been added into the final strategy document. Budgets will be allocated to activities in the annual delivery plans.
Utilise values-based approach to engagement and its evaluation	This has been made clearer in the final strategy document
Ensure PPIE strategy is linked to HDR UK strategy	This has been made clearer in the final strategy document
Be clear about strategic support and leadership	This has been made clearer in the final strategy document
Clear and measurable delivery plan from the outset	We have clarified that annual delivery plans have been guiding our progression of business as usual and new activities while this strategy has been developed. We have also clarified that we have been continually improving our work based on feedback from the consultation.

Stakeholder dissemination and engagement event with Professional members, 17 September 2024	
Encouragement to use more engaging and innovative engagement methods	This approach will continue to govern the delivery approach for activities
Use existing networks	This approach will continue to govern the delivery approach for activities
Seek further advice on how to implement micro-grants to voluntary and community sector organisations	This approach will continue to govern the delivery approach for activities
Assess whether the plan is deliverable with the available resources	Our approach to this has been made clearer in the final strategy document
Stakeholder dissemination and engagement event with public members, 18 September 2024	
Small editorial comments	All editorial comments including suggested word changes have been actioned (with a few exceptions as noted below)
Explain why 'good practice' and not 'best practice' is used.	We are using 'good' as we recognise that work is ongoing to determine the impact of context on good practice-based PPIE within data research. We therefore cannot call the practices 'best practice' which implies a method or technique widely recognised as the most effective and superior option in a given situation.
Use 'staff' instead of 'professionals' (Goal 1)	We have stuck with 'professionals' as opposed to staff to avoid confusion in understanding as the Goal is not aimed at internal staff but the wider PPIE Professionals community.
Use 'drives our work' instead of influence (Goal 2)	This change has been made
Use 'effective' inclusive approaches.	This change has been mad
Consider focusing on improved health outcomes instead of demonstrating trustworthiness (Goal 3). Focus on building trust instead of demonstrating trustworthiness.	The focus on 'trustworthiness' has been maintained as we must build trustworthy systems and demonstrate this to increase trust amongst the public. We will focus on showcasing the impact of our work (e.g. health outcomes in our engagement work)
Clearly outline how objectives will be delivered and measured.	A delivery plan will be published in the Spring of 2025
Simplify language in objectives and use an easy-to-read guide. Consider publishing in different languages. Provide clarity around what accessible formats will be used to disseminate.	Language has been simplified, and an easy-to-read version will be produced in English. Material will be translated for in-person events with specific language needs.

Use underserved instead of underrepresented to move the onus from the community to the researchers. However, be clear about both the importance of diversity and representativeness	These points have been taken on board.
Develop culturally tailored engagement approaches for different communities.	This approach will continue to govern the delivery approach for activities
Outline how we will work with partners doing similar work and consider working with patient organisations (with large membership) in addition to Voluntary and Community Sector Organisations. Work with public members to engage and disseminate more widely	These points have been taken on board and will be integrated in our delivery plan
Ensure ongoing, transparent communication about data use, governance and research	We will continue to ensure this going forward
Spell out acronyms or include a glossary	This approach will continue to govern the delivery approach for activities
Make public contributors aware of how their input has shaped the strategy and make them aware of when the strategy has been published.	This will be addressed as part of the strategy document. The strategy document will be shared widely, and people who were involved in the consultation will be notified of its publication