



**Survey  
deadline extended  
to midnight  
Sunday 21 April**

Public consultation

# Draft Patient and Public Involvement and Engagement (PPIE) Strategy 2024-2028

This public consultation will run from 4 March until 12 April 2024



**HDRUK**

Health Data Research UK

**How is your health data  
improving lives?**

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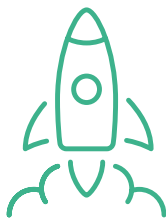
Your views are important to us  
and will help us shape our work.

If you need this document in another language or another format such as large print or audio, please call 0191 535 5881 or email [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk)

## Who we are

Health Data Research UK (HDR UK) is the UK's national institute for health data science. It is an independent registered charity, funded by 10 major funders.

Health data research is a way of gathering, analysing, and linking information about people and their health to improve health and care for all.



### **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 and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health.**

We will deliver our mission through partnerships with patients and the public.

We have appointed Stand, expert involvement practitioners, to support us in conducting the consultation process on our draft Patient and Public Involvement and Engagement (PPIE) Strategy for 2024-2028 and who will carry out independent analysis of the feedback received.

## Why your feedback is important

Your feedback is so important in making sure we understand how patients, the public and communities want to be engaged and involved in our work, and that this is reflected in our PPIE strategy. Involving and engaging communities in ways that suit them will ensure that our work together is more meaningful and produces the best outcomes.



## About our draft PPIE strategy

We started working on our draft PPIE strategy in 2023. PPIE is key to everything we do at HDR UK.

The words involvement and engagement are interrelated and are sometimes used interchangeably. At HDR UK we use them according to the following definitions:

### **Involvement**

Health data-related activities or research carried out 'with' or 'by' patients, carers and the public.

### **Engagement**

Health data-related activities dedicated to sharing information and research outcomes with patients, carers and the public.

Our draft PPIE strategy sets out how we will involve and engage with people during the next four years. It has been developed with input from:

**Internal teams** which are central to the delivery of the strategy (for example, communications, information governance, training, research programmes and infrastructure) and groups such as our:

- ▷ [Public Advisory Board](#)
- ▷ Strategy Steering Group
- ▷ [Senior Leadership Team](#)
- ▷ Strategy Integration Group
- ▷ HDR UK PPIE Leads Group
- ▷ One Institute PPIE Leads Group

Key **external stakeholders** identified through a stakeholder mapping exercise. These included:

- ▷ Funders
- ▷ Research charities
- ▷ Advocacy groups
- ▷ Public bodies
- ▷ User-led organisations
- ▷ HDR UK's Voices network

The feedback from these diverse groups has refined the **goals** and **objectives** outlined in our draft PPIE strategy. It has also enabled us to explore potential **activities** and **partnership working** opportunities.



## About this consultation

Now, we want to share our draft PPIE strategy more widely to ensure our identified goals and objectives are the ones we should be focusing on.

We also want to make sure everything is included.

This document includes a **summary of our draft strategy**. We recognise this is a preliminary version, and we are committed to refining it based on your feedback. We will ensure it effectively includes patient and public perspectives, leading to greater benefit for all.

We encourage you to review the draft strategy carefully and share your thoughts with us. On page 12 you will find more information about the ways you can have your say.

## Who this consultation is for

### **Our draft PPIE strategy for 2024-2028 is aimed at:**

- ▷ Patients and carers
- ▷ The public
- ▷ PPIE specialists
- ▷ Data science researchers and technicians
- ▷ Information governance specialists
- ▷ Health and social care practitioners and organisations
- ▷ Data custodians (organisations which hold patient or public data)
- ▷ Data research organisations
- ▷ Voluntary and community sector
- ▷ Patient and community groups

We are looking for feedback on our draft PPIE strategy from all these audiences.



# A summary of our draft PPIE strategy

## Our PPIE mission

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

## Our PPIE vision

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

## Our challenges

- ▶ We work in a complicated field where various organisations involve the public, but they don't coordinate effectively. This lack of coordination can sometimes make messages, projects, and procedures confusing for the public to understand.
- ▶ Although there's plenty of information on general PPIE best practices, there's less specific evidence regarding its application in data science. Also, this information isn't always easy for researchers, patients, or the public to understand and use.
- ▶ People don't know much about involving the public in data science (PPIE), and they don't always trust how data is secured and used. This is because there isn't enough conversation with the public, and their perspectives aren't included enough in the field.
- ▶ We have limited reach and relatability with the public and underrepresented communities.

## Our goals and objectives

We have identified **four interrelated goals** to address our four challenge areas and guide our strategy.

### Goal 1

We will ensure that patients, the public, researchers, PPIE professionals and practitioners will be our partners in decision-making.

#### Objective

We will embed PPIE good practices into the organisation's governance and delivery structure, using appropriate guidance and evidence to inform decision-making.

### Goal 2

We will ensure the needs and interests of the public are understood and embedded in our work.

#### Objective

We will scope, develop, and assess platforms and forums that unite patients, the public and pre-established groups and networks, encouraging the collection of a diverse range of voices.

## Goal 3

We will ensure trust and confidence in the use and re-use of health data for research and innovation are promoted among diverse UK communities.

### Objectives

We will design, deliver, and evaluate public engagement activities aimed at raising awareness, enhancing understanding, and gaining support of health data research across the UK.

We will integrate PPIE into information governance and technology developments to ensure clear communication of data research processes and promote involvement in related activities.

## Goal 4

We will establish partnerships with local, national, and international organisations to continually advance PPIE in research and innovation.

### Objectives

We will promote collaborations for strategic and operational support to existing PPIE initiatives, such as PEDRI, the Alliance and [HDR Global](#).

We will identify opportunities for collaboration on cross-sector initiatives led by other stakeholders (for example, NHS England, Department of Health and Social Care, and industry).

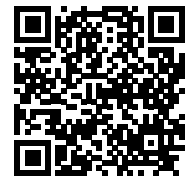
# How to have your say

**Our consultation runs from Monday 4 March until Friday 12 April.** There are multiple ways you can have your say and influence the final version of our PPIE strategy for 2024-2028.



## Survey

Our short online survey takes 10 minutes to complete. You can [access the survey through this link](#) or by scanning the QR code. The closing date for responses is **Friday 12 April**.



Individuals will not be identifiable, but we may attribute quotes to an organisation.



## Focus groups

We are working in partnership with 15 community groups across the country to run focus groups aimed at gaining feedback from underrepresented groups.



## One-to-one interviews

To make sure we gain meaningful feedback from our partners and key stakeholders, we are carrying out a series of short one-to-one interviews. If you are a partner of HDR UK and would be interested in providing your views in this way, please email [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk).



## Online events

Four online events are being held to capture feedback from stakeholders, including patients and the public, across the UK. If you are a partner of HDR UK and would be interested in taking part in this way, please email [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk).

Date	Time
Tuesday 12 March	6pm-7.30pm
Wednesday 13 March	10am-11.30am
Tuesday 26 March	12noon-1.30pm
Saturday 6 April	10am-11.30am



### Direct feedback

If you would prefer to provide feedback directly to our team, please email [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk) or call 0191 535 5881.

## Equality assessment

We have conducted an equality impact review to identify groups and communities which may be underrepresented and inclined to opt out of data use and re-use. These groups are integral to our consultation process, and we will engage with them by targeting relevant voluntary and community sector organisations. By doing so, we aim to provide everyone with the opportunity to provide feedback, ensuring inclusivity and broadening the scope of voices heard through this consultation.



## What happens next

The consultation runs for six weeks, starting 4 March and ending 12 April 2024.

Feedback will then be independently analysed and key themes will be drawn out so that we can refine, finalise and publish the strategy.

All those who have taken the time to engage with us during the consultation period will be kept updated through our [website](#) where we will publish the independent consultation analysis report and the report of how we have changed our draft PPIE strategy as a result of feedback received during this consultation.



Your views are important to us  
and will help us shape our work.

**Health Data Research UK**

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