



**HDRUK**  
Health Data Research UK

Public consultation

Survey  
deadline extended  
to midnight  
Sunday 21 April

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

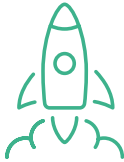
This public consultation will run from 4 March until 12 April 2024



# About us

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

To establish good practices in patient and public involvement and engagement, improving transparency and trust in health data research.



## Our 20-year vision

All health data research benefits from diverse perspectives, enabling shared decision-making and innovation.

**Our Challenges:** Coordination among organisations, lack of specific evidence in data science PPIE, limited public engagement, and reach.

We have now launched a public consultation to gather views on our draft Public and Patient Engagement Strategy 2024-2028.

## Why your feedback is important

We want to share our draft PPIE strategy 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.

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.

All feedback will be analysed independently. We will refine our strategy, and publish updates on our website.

# Our Goals and Objectives

## 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).

# Have your say



## Complete the survey at:

<https://www.smartsurvey.co.uk/s/HDRUKPPIEStrategy/>  
or via the QR code



## Join an online discussion:

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

Visit the website [www.hdruk.ac.uk](http://www.hdruk.ac.uk) or call 0191 535 5881 to book your place.

## Contact us via social media:

 [@HDR\\_UK](https://twitter.com/HDR_UK)

## Write, email or call us at:

Write to us:  
240 Blackfriars Road,  
London  
SE1 8NW

Email: [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk)  
Telephone: 0191 535 5881

If you need this booklet or our PPIE Strategy in another language or format such as large print or audio, please email [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk)

**hdruk.ac.uk**