

# Have your say on Health Data Research UK's draft plans



**Your views are important and will help us plan our work.  
You can tell us what you think from 4 March until 12 April 2024.**

**This is an EasyRead version of Public consultation on  
Health Data Research UK's Draft Patient and  
Public Involvement and Engagement Strategy 2024-2028.**

**If you need this plan in a different way telephone 0191 535 5881  
or email [hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk)**



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# Who we are



We are Health Data Research UK (HDR UK).



We want to make sure health and care is better for everyone. Health data research looks at information about people's health.



In the next 20 years we want to put together all the UK's health data to help find out things that make people's lives and health better.

2024  2028



We will do this by working with people who look at data, the public and carers.



We have asked Stand to look at what you say and help us with our plan.

## Why what you say is important



What you say is important to us to make sure we know how people want to work with us.



By working with us in the way people want will make sure our work has the best results.

## About our draft plans for working with people



People can be patients, carers and the public.



We began writing our plans for working with people in 2023.



These plans show what we will do and how we will involve people in our work.



This means work that is carried out **with** people or **by** people.



These plans are about the engagement of people in our work.



This means telling people about our work.



These plans tell you how we will involve and engage with people over the next 4 years.



They have been written by groups who work with us.



These groups looked at what we want to do and how we will do it.

# Why we want to hear from you



We want to hear from you to make sure the ways we plan to involve and engage with people are ok.



We want you to read our plans and tell us what you think.

## Who we want to hear from



We want to hear from lots of people.



We want to hear from:



- The public.



- People that work with data.



- People that work in health and social care.



- Voluntary groups and charities.



# Our draft plans for working with people in short



We want to make sure we listen to what people say about our plans.



We think all health data research will be even better by engaging and involving people in research.

## What makes it hard:



- Lots of other groups involve people but not in a joined up way. This makes it hard for people to know what is going on.



- There is not much information about engaging and involving people in data science.



- We do not always tell people how to get involved and people do not always trust how their data is used.



- People often do not know who we are and we cannot always get in touch with them.

## What we want to do and how we will do it



We want people to work with us to make our plan.



We will listen to the best way to work with people.



We want to make sure that what is important to the public is in our work.



We will do this by making sure we hear from lots of different people.



We want to make sure people are okay with using data to make lives and health better.



We will do this by telling them about health data research and how they can join in.

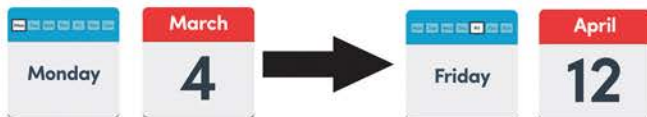


We will work with other groups to make sure working with people in research gets better.



We will do this by working with other groups and finding new groups to work with.

## How you can tell us what you think



You can tell us what you think from Monday 4 March until Friday 12 April 2024.



**Online Survey.**

[HDR UK PPIE strategy consultation survey \(smartsurvey.co.uk\)](https://smartsurvey.co.uk)



**QR code.**

Scan for survey.



We will not know who you are but we may use what you say in our report and say what group you are from.



**Group meeting.**

We are working with 15 groups across the UK to hear what people think.



**Interviews.**

If you are a partner of HDR UK and would like to tell us what you think email

[hdukstrategy@wearestand.co.uk](mailto:hdukstrategy@wearestand.co.uk)



## Online meeting.

If you are a partner of HDR UK and would like to come to an online meeting email

[hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk)

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



Email us what you think at

[hdrukstrategy@wearestand.co.uk](mailto:hdrukstrategy@wearestand.co.uk)



## Phone

0191 535 5881

# How we make sure we hear from everyone



By working with voluntary groups, we will make sure that everyone who wants to can tell us what they think.

## What happens next

# stand.

Stand will tell us what people say.



This will let us write the final report.



Our final report will be on our website.



This EasyRead document was made by The Twisting Ducks EasyRead service. It was written with and checked by people with learning disabilities. For more information:

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