



Easy
Read

Research Survey: Resources for involving the public in data research

What we found out



HDRUK
Health Data Research UK

 **ADRU**
Data-driven change

NHS
England

 **Research
Data
Scotland**

 **Office for
National Statistics**

DARE UK



**CANCER
RESEARCH
UK**



**British Heart Foundation
Data Science Centre**

Led by Health Data Research UK

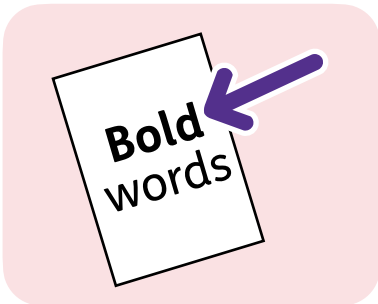
Easy Read



This is an Easy Read version of some hard information. It may not include all of the information but will tell you about the important parts.



This Easy Read information uses easier words and pictures. You may still want help to read it.



Some words are in **bold** - this means the writing is thicker and darker.



These are words that some people will find hard. When you see a bold word, we will explain it in the next sentence.



Blue and underlined words show links to websites and email addresses. You can click on these links on a computer.

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Introduction



We are a small group which is part of PEDRI - this stands for Public Engagement in Data Research Initiative.

PEDRI is an organisation that finds the best ways for **researchers** and the public to work together.



Researchers are people who look into something, to find out new information about it.



We used a survey to find out how people involved in research can work together better.



This Easy Read information will tell you:

- About our survey.



- What information we found out from our survey.

About the survey

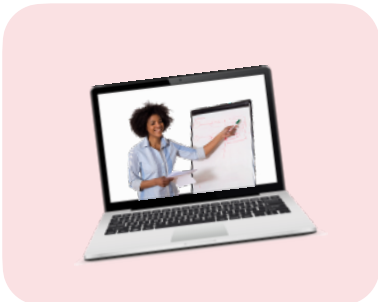
What we wanted to find out



We wanted to know if everyone involved in **data** research has the **resources** they need to be able to work with members of the public.



Data is information like facts or numbers that can be collected to help find out about something.



Resources might include guides, videos, and presentations.

These resources can be used to help everyone involved in research:



- Understand the research they are taking part in.



- Be more involved in the research they are taking part in.

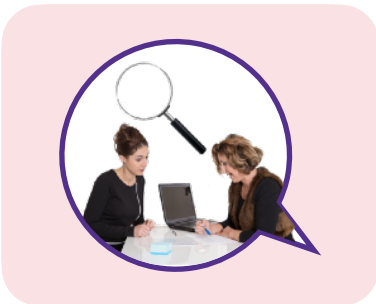
Why is this important?



Working with the public helps to improve services that everyone uses. These services include education and healthcare.



It is important researchers and the public have the resources to work together.



When researchers work with the public, it is important that they tell the public:

- What they are looking into.

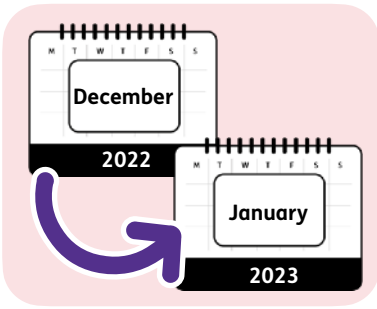


- Why what they are looking into is important.



- How being involved in the research could help them.

What we did



We shared an online survey in December 2022. The survey ended in January 2023.

People who could fill in the survey included:



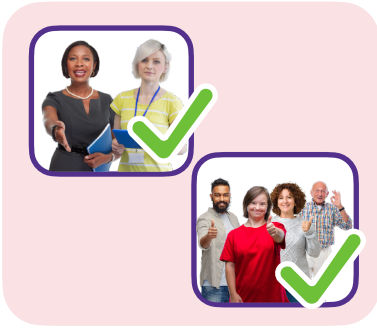
- Researchers.



- Professionals who work with the public.



- Members of the public.



Some questions were just for researchers and professionals who work with the public.

Some questions were just for members of the public.



123 people filled in the survey.



Everyone who filled in the survey was asked how they were involved in research.

What we found out



Most of the people who filled in the survey said they wanted lots of different kinds of resources.



Most people said they did not always know what resources were available to them.

What members of the public said

Members of the public said:



- They wanted clear resources that do not use **jargon** and are easy to understand.

Jargon means complicated words that are hard to understand.



- Resources should be **accessible** to everyone.

Accessible means it is easy to use and suitable for people with different needs.

Members of the public also said:



- Resources should be available in different formats.



- They used the internet to find out more information if they wanted it.



- They liked it when presentations explained research in a way that let them ask questions and be involved.

What researchers and professionals said

Researchers and professionals said:



- There are not enough resources for their work with members of the public.



- Finding resources that do not use jargon is hard.



- They would like to find a way of speaking about the work they do that suits both them and members of the public.



- Sometimes they made their own resources.



- They liked to use videos and resources that have already been made to help the public understand their work.

What we did next



We have looked at all the information we found out from the survey.

We have used this information to decide what to do next.



We have made **recommendations** about how things can be better for everyone involved in research.

Recommendations are ideas that will help fix a problem or issue.

Our recommendations



1. There should be a website that tells people how to find resources.



2. Resources should be correct, up to date, and available in lots of different formats.



3. Researchers and professionals should try to:
 - Reduce the amount of jargon in resources.
 - Use plain language.



4. Researchers and professionals should use the same plain language in all resources made for the public.



5. The public should be more involved in choosing resources that help them take part in data research.

Find out more



You can read the full report about our survey and what we found out here:

www.hdruk.ac.uk/wp-content/uploads/2023/04/Resource-Survey-Report-Final.pdf



You can also look at the PEDRI website for more information: www.pedri.org.uk

This Easy Read information has been produced by easy-read-online.co.uk