



UK Standards for Public Involvement in Research

Standards to help the public be part of research



About this booklet



This booklet is for people and organisations that do research.



Research is when people want to find out more about something or test a new idea.

For example, people may want to test a new medicine to see how it works.

This booklet is about helping **the public** to be part of research.

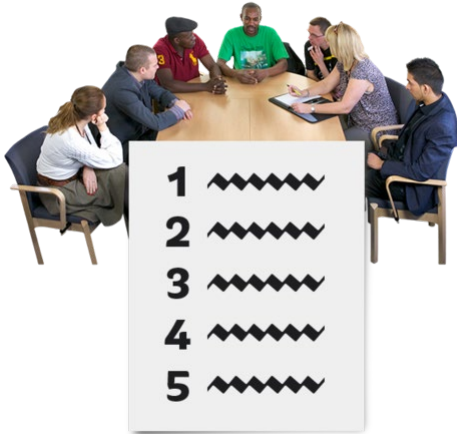
The public can be anyone, like:

- people who use health and care services
- family and carers
- organisations that speak up for people, families and carers





The public can help make research much better.



The public can be part of research in many ways.

For example, they may want to:

- do research
- help make plans or information about the research



This booklet has some **standards** to help the public be part of research.

Standards are a list of things to do or think about.

They help people know how to do something in the right way.



The standards will help people know the best way for the public to be part of research.



People can use the standards to think about:

- how the standards can work for their research
- how the public are taking part in research
- what needs to change



Many people in Scotland, Wales, Northern Ireland and England helped make the standards.



There are **6** standards in this booklet.

They start on the next page.

The standards



Making sure lots of people can help do research

This is about making sure lots of different people can be part of research.

How to make this standard work

To make this standard work the research organisation or project should:



- Make sure the public can take part in research early on so they can help plan the research.
- Solve any problems that could stop the public taking part.



For example, this could mean:

- asking people when they want to have meetings
- paying people back straight away for travel costs

The research organisation or project should also:

- Tell people about research and that they can take part.

Tell people in different ways so that the right people can find out.

For example, tell people using Facebook or information with easy words.



- Tell people how they can take part in research.

Use different ways to do this, like the internet, local papers and local health services.

Make this fair for everyone.



- Make sure there are different ways for people to take part in research.

And make sure they can take part in a way that is right for them.





Making sure everyone doing the research works well together

This is about working together in a good way, sharing ideas and knowing what everyone has to do.

How to make this standard work

To make this standard work the research organisation or project should:

- Write down and share why they want the public to be part of their research and how this will help.
- Make sure members of the public can help make plans about how the public will take part in the research.



The research organisation or project should also:

- Make sure members of the public doing the research understand what will happen and what everyone has to do.

This may change over time.

Make sure members of the public doing the research are happy with what they do and how things are going.

Keep checking this.



- Make sure members of the public can share ideas and help make decisions about the research.



Making sure the public has the right support, information and skills to be part of the research

How to make this standard work

To make this standard work the research organisation or project should:



- Make sure there is enough money to support the public to take part.

- Make sure they find out what support the public needs to take part and give it to them.

For example, someone may need support to understand information, feel safe or speak in meetings.



- Make sure there is someone doing the research that the public can speak to if they need information or support.



The research organisation or project should also:

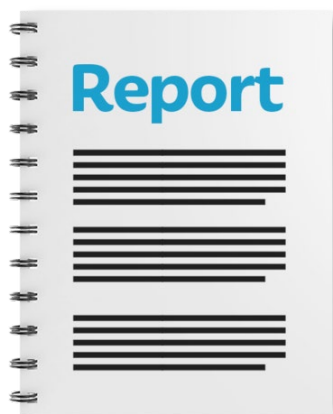


- Make sure members of the public doing the research can learn what they need to learn for the research. Everyone should work together to:
 - decide what people doing the research need to learn
 - check how well this is working



- Make sure the research project or organisation keeps learning about how to work with the public on research.

- Everyone should work together to:
 - look at how the public are taking part in research



- change things if they need to
- share what they have learned



Giving people clear and easy information about the research

How to make this standard work

To make this standard work the research organisation or project should:

- Make a plan about how to give people clear information about the research and how to take part.
- Make sure the research project or organisation gives people information in different ways if it needs to.



For example, in easy words and pictures, by email or in different languages.

The research organisation or project should also:



- Ask the public how they feel about being part of the research.
Make sure the research project or organisation solves any problems with this.



- Make sure the research project or organisation:
 - shares what it has learned and what it has done to make things better
 - keeps people up to date with how the research is going



Looking at how it has worked for the public to be part of research.

Sharing what the research project or organisation finds out. This will help make research better.

How to make this standard work

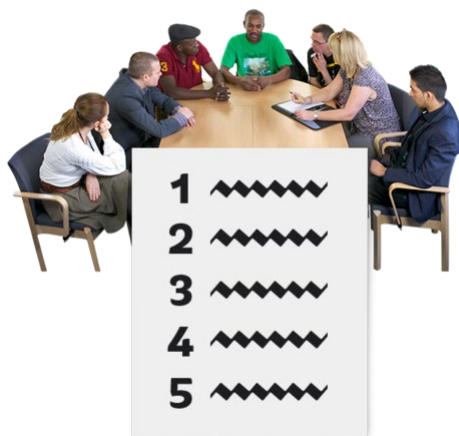
To make this standard work the research organisation or project should:

- Make sure the public can have a say in how well it has worked for the public to be part of the research.

And how to find out how well it has worked.

- Say at the start how they want the public to be part of the research and what they want to happen.

Make sure members of the public doing the research have a say about this.



The research organisation or project should also:

- Keep the right information to show how the public takes part in research. Use this information to see:

- how it has worked for the public to take part in research

- what needs to change

- Write reports about the public taking part in the research and how it has worked.

Make sure the project or organisation learns from what it finds out and uses it for future research.





Making sure members of the public doing research can help make decisions about the research.

How to make this standard work

To make this standard work the research organisation or project should:

- Make sure members of the public doing the research:
 - are listened to
 - can have a say in big decisions about the research from the start
- Make sure they have good plans about how the public can be part of research.

Make sure members of the public doing the research can help:

 - make the plans
 - check how the plans are working and change them
 - share the plans





The research organisation or project should also:

- Make sure everyone doing the research knows who is in charge of making sure the public can take part.



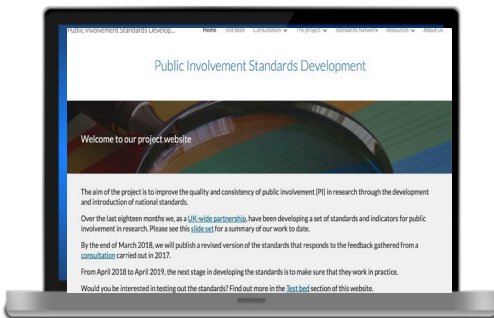
- Make sure there is enough money, people and other things they need for the public to take part.

Make sure members of the public doing the research have a say in how money and other things are used.



- Make sure people's personal information is kept private and safe

This is the end of the standards.



For more information about the standards please go to this website: <https://sites.google.com/nih.ac.uk/pi-standards/home>

These are the organisations working together on the standards:

NIHR | National Institute for Health Research



HSC Public Health Agency