

Discover your role in health and social care research

Every week, hundreds of people help make health and social care research happen in Wales. Good quality research is essential to help us find new treatments and ways to improve health and care services.

This research is not possible without the help of the public. This can be by taking part in individual research studies. It can also be through people sharing their time and personal experiences to help inform the priorities, design, delivery and implementation of research, so that it is more relevant to people's needs. This is known as **public involvement** in research.

For people to be able to take part in research, we need to tell them that research is happening and how important their participation and involvement is. What we do to tell people about research is called **public engagement**.

Many research groups and studies already include ways for members of the public to be involved in some or all parts of the research process. When it is done well, public involvement can lead to research that really matters to people, is well run and makes a difference to people's lives. People who are involved in research in a meaningful way tell us it can help them feel more confident, because it helps everyone understand how important their contribution is.

However, there are still some problems with public involvement becoming a normal part of the research process. When it is done badly, public involvement can be a negative experience for everyone involved, particularly when it is poorly thought through, roles are unclear or just paying lip service to involving the public.

Health and Care Research Wales wants to make sure that future research is developed as a joint venture between the public, researchers and people working in health and care. We believe that meaningful public involvement is important to good, safe and ethical conduct of research and should be a routine and normal part of the research process.

Below we set out our ambitions to make public involvement and engagement a much bigger part of health and social care research in Wales. This will mean changing the way we do things and some of the systems we have in place. We developed the ambitions with help from members of the public, researchers and other people involved with how health and social care research is designed and carried out.

Our ambitions for public engagement and involvement in health and social care research are based on the following:

- **Engaged:** more people are aware of research and understand how important it is.
- **Empowered:** people feel empowered and able to take part and be involved in research.
- **Embedded:** public engagement and involvement used as normal practice in all Health and Care Research Wales activity.
- **Evidenced:** we can show the value and impact of public involvement.

Health and Care Research Wales is going to coordinate the work to make the ambitions happen. These changes will not happen overnight and to be successful it will require commitment and work from many of the organisations and people that are part of making health and care research happen in Wales.

Health and Care Research Wales will support a **community of practice** so that everyone involved with this project can work together on what needs to be done.

A community of practice is a way of working by forming a group of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly. We hope to use this approach to work together to decide what needs to be done.

This community of practice will also help to check on the progress being made to turn the ambitions into a reality.

The ambitions

Engaged

Many people generally understand how important research is for health and care, but fewer know what happens in research, or how to take part or get involved.

The more people who are aware of and understand the value of health and social care research, the more likely they will want to contribute to health and social care research. This might mean participating in research studies, suggesting priorities for future research, sharing their personal experiences with researchers to help inform and design how a study will be conducted, or promoting the role and value of research in our health and care system.

By doing more public engagement activities around research, we hope that public participation and involvement in health and social care research can be seen in the same way that other activities such as blood donation or volunteering are recognised and celebrated.

We want members of the public to be able to find out about the research that is of most interest to them. We hope that our support can lead to more people having the opportunity to take part in research and becoming involved in as many parts of the research process as they wish to.

Empowered

We want to make sure that we involve a diverse range of people in research to ensure that research is relevant to everyone and provides better health outcomes for all.

Taking part and being involved in health and social care research should be as easy and straightforward as possible. Opportunities for the public to contribute should be open and inclusive, welcoming many different perspectives. People should feel confident to ask about participation and involvement in health and social care research.

Members of the public should feel valued for their contribution and have opportunity to know about the findings of the research they have been involved in.

It is also important to share realistic expectations of what is possible. Not every research study will be suitable for everyone to take part in. How the public might be involved will also vary between research studies.

Embedded

Involving the public should be a routine part of the research process. This includes the prioritisation, funding, design, development, delivery and implementation of research.

Making research involvement a common part of the culture of undertaking research requires changes to how people work together and how systems are set up. It is important that the organisations that fund and sponsor research set clear expectations of how public engagement and involvement activities should be included in the research they support, ensure that it is resourced effectively and ensure the planned activities go ahead.

Researchers should make use of the [UK Standards for Public Involvement in Research](#) as a tool to help decide how and when to involve the public involvement in their plans.

Embedding meaningful public involvement will depend on sharing learning, highlighting good practice and celebrating success. Training and guidance will be needed for both researchers and members of the public.

Evidenced

We need to assess the impact of public involvement in research so that we can share good practice and demonstrate how it makes a difference.

We need to make sure that our monitoring and reporting processes looks at the difference that has been made by involving the public, rather than just describing what happened. Understanding the difference it has made will help us highlight the benefits of involving the public. An important part of this is understanding what the experience was like for the people involved.

As well as learning from what we do in Wales, we will look at what is happening in other countries, along with working with colleagues and organisations based in England, Scotland and Northern Ireland.

Working together to achieve our ambitions

Health and Care Research Wales is seeking views on the ambitions we have set out, and how they can be achieved as part of developing, undertaking and promoting health and social care research in Wales. We will be doing this in two ways:

1. Consulting with a wide range of individuals and groups, using a short questionnaire to get feedback; and
2. Establishing a community of practice, offering an open invitation for groups and individuals interested in this work to attend a series of events that will help create the plan for actions and activities to make the ambitions a reality.

The survey for feedback can be found here: [Discover your role in health and care research survey](#)

The survey will be open until **27 November 2019**.

We will be reviewing responses submitted via the survey on an ongoing basis throughout the consultation period, and will be feeding in ideas and suggestions from survey responses into the discussion at community of practice events. We therefore encourage people to respond to the survey at the earliest opportunity, and we are happy to receive multiple responses from individuals/groups throughout the consultation period.

Colleagues from Health and Care Research Wales will be meeting with groups and individuals about the ambitions during the consultation period, in addition to hosting a series of community of practice open events.

The community of practice events will be held during October, November and December 2019. More information on the exact date, timing and agenda for the events will be available on the [Health and Care Research Wales website](#).

If you would like to contact Health and Care Research Wales about this consultation, or to register your interest to receive more information about the community of practice events, please email DiscoverYourRole@gov.wales.