



Discover Your Role in Health and Social Care Research



Get in touch:

Research-involvement@wales.nhs.uk

02920 230 457

www.healthandcareresearch@wales.nhs.uk

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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 support and contributions of the public. This can be through **participation** 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**.

Health and Care Research Wales believe that meaningful public involvement is important for undertaking good, safe and ethical research and should be a routine and normal part of the research process.

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.

We also believe that the more people 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. This increase in awareness can only be achieved by successful engagement activities to publicise the benefits of health research to the population of Wales.

Health and Care Research Wales has a mission to support and develop excellent research which has a positive impact on the health, wellbeing and prosperity of the people in Wales.

To support this mission, excellent public involvement and engagement is necessary, and it is our intention to:

- improve the ways in which public involvement is embedded throughout the health and social care research landscape in Wales, and
- enhance the ways in which public engagement can promote the vital contribution that the public make to health and social care research, and offer inclusive, open opportunities to take part in research, welcoming of many different perspectives.

To understand how this can be achieved, Health and Care Research Wales has worked with researchers, research managers and members of the public to collectively agree the vision and practical actions that should form our approach to public involvement and public engagement as part of the new strategy period (2020-2024).

Whilst much of the work that forms this action plan was developed prior to Covid-19, The impact of the pandemic has had an enormous effect on society-at-large, and the management and response to Covid-19 is likely to be with us for a long time. This has already re-shaped how we interact with each other as individuals and groups, with significant implications for public involvement and public engagement in research. Adapting to new working practices will be an important feature in the work that is proposed in this action plan.

Creating a shared plan for improving public involvement and public engagement in health and social care research

This document brings together the outputs of a co-designed approach, including reflections on the current experiences of those doing research involvement and engagement; the shared aspirations for where we would like to be in four years; and the activities required to get us there.

While the research and processes funded and managed by Health and Care Research Wales will be our main sphere of influence, meaningful public involvement and engagement is relevant for all health and social care research taking place in Wales, and we would strongly recommend that researchers funded from external sources should also follow the recommendations for good practice which will arise from this plan.

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.

Health and Care Research Wales has supported the development, testing and launch of the [UK Standards for Public Involvement in Research](#). These Standards are designed to improve the quality and consistency of public involvement, and will be a key resource to support the delivery of our ambitions for public involvement and public engagement in health and social care research in Wales.

Reflections on current public involvement and public engagement in health and social care research

In developing our co-designed approach, information has been gathered through events and surveys that provide a picture of what people feel about current public involvement and public engagement activities in Wales. The consensus view is that:

- Understanding and acceptance of the role of public involvement in the research community has improved significantly in the last five years;
- Whilst there have been improvements, meaningful public involvement is still far from a routine part of the research process;
- Resources are available to facilitate public involvement activity, but awareness of these resources and support is not widespread in the research community;

- Most of the information collected about the impact of public involvement is quantitative, which can be useful but has limited value in determining whether the involvement has been meaningful or not;
- There are plenty of good examples and case studies on public involvement approaches, but they are not routinely or consistently captured and shared, which undermines the value they have to support the public involvement and public engagement agenda;
- There continue to be some administrative barriers to undertaking effective public involvement activity, particularly linked to timely reimbursement for time of public members via some universities;
- Funded research groups and individual research projects are generally pro-active on public engagement activities for their own research, but there is not yet an agreed approach for how best to effectively deliver a broader public engagement strategy which can add value.

A vision for the role of public involvement and public engagement in the future

Through the discussions that have helped shape this plan, consensus has emerged on the aspirations for the future and how public involvement and public engagement should be reflected in the research environment in Wales by the end of the Health and Care Research Wales strategy period 2020-2024.

These ambitions are that:

- There will be a research culture where public involvement is an accepted, routine part of the research cycle, embedded across the research system in Wales;
- Opportunities for the public to be involved in research will be simple to access and as open and inclusive as possible;
- Appropriate level of resources will be available to support effective public involvement and there will be comprehensive training and support available for both researchers and public members; and
- Effective communication and engagement with the public can be improved by publishing stories and case studies illustrating the vital role they can play in health and social care research through participation and involvement.

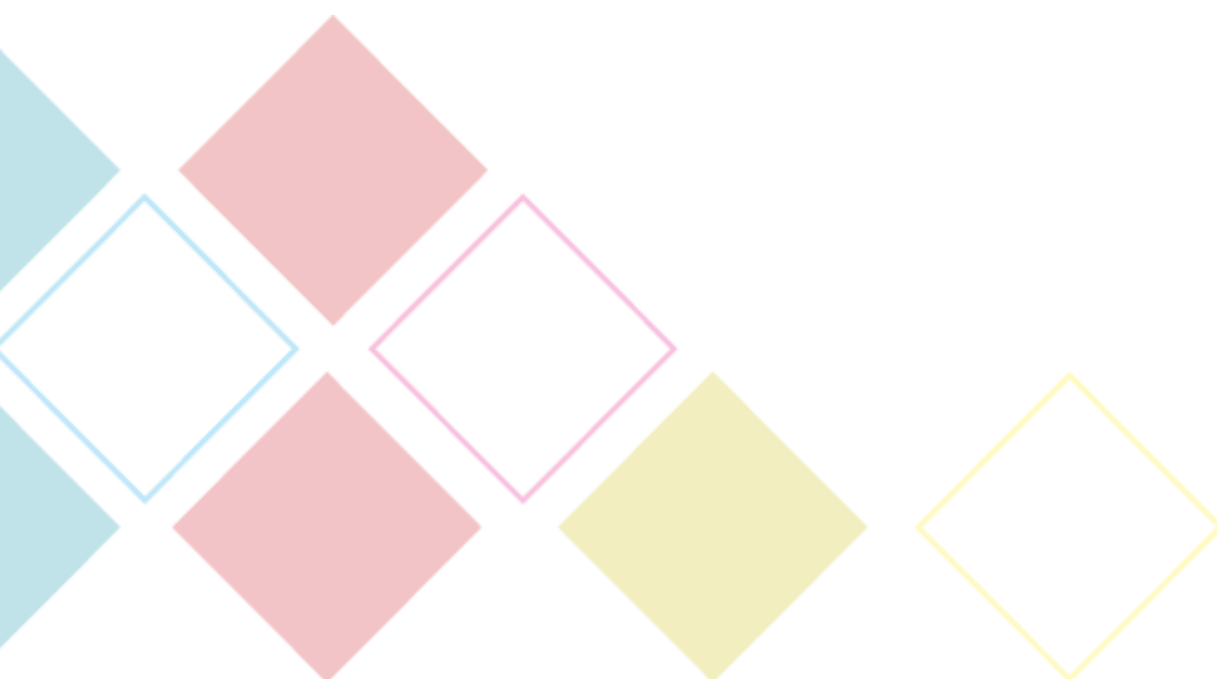
Making the ambitions a reality

This plan highlights the areas of focus and the activities to be addressed if we are going to make these shared ambitions a reality. For some activities it is already clear how the actions will be undertaken and who will be involved. For other activities, further dialogue will be required to work out what the practical steps and implications for delivering the activities are.

The development of this plan has been based on public members, researchers and policy makers collaborating and sharing ideas to agree what needs to be done, and the implementation should also reflect this collective approach. The plan is intended to be a

living document that can be updated as new activities may emerge from the initial actions and new information is revealed about the value of public involvement and public engagement.

Health and Care Research Wales intends to maintain the community of practice model, evolving into a regularly convened forum for discussion on public involvement and public engagement, and a place to share good practice.



Action Plan for Public Involvement and Public Engagement 2020-2024

Focus Area 1:

Create a more coherent network for public involvement discussions, peer support and sharing good practice.

Actions:

1.1 Create a forum for regular discussion on public involvement and sharing good practice

- Health and Care Research Wales will develop a proposal for new forum, working with existing groups, and establish the forum with consideration of how to balance face-to-face events with virtual methods of engagement.

1.2 Pilot model for 'seminars' on public involvement, with evidenced examples and 'top tips'

- Health and Care Research Wales will develop a specification and invite and assess expressions of interest for groups wishing to deliver a public involvement seminar series. The proposal will be assessed to help consider the value and impact of the work.
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Focus Area 2:

Ensuring public involvement is promoted and supported at senior levels across Health and Care Research Wales.

Actions:

2.1 Set expectations around the roles of researchers to promote public involvement

- Health and Care Research Wales to provide some guidance on the expectations and ways in which researchers can be leading by example for the role of public involvement in the research process and culture.
- Health and Care Research Wales will work with colleagues across the research community to explore the practicalities and implications of how public involvement responsibilities can be included in job roles.

2.2 Ensure there is appropriate public member representation on high level governance of Health and Care Research Wales

- Welsh Government officials will include appropriate public representation as part of revised high-level governance arrangements for Health and Care Research Wales.

2.3 Make connections into undergraduate and postgraduate education to promote the value of research and public involvement as a key aspect of training

- Health and Care Research Wales to undertake a survey to understand how research aspects are currently included in university courses/curriculum and how prominent public involvement features as part of existing materials.
 - Health and Care Research Wales to work to promote examples of practice where public involvement has been successfully incorporated into the curriculum.
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Focus Area 3:

Develop a purposeful public engagement strategy for Health and Care Research Wales.

Actions:

3.1 Create and implement a coherent strategy for raising public awareness on the importance of health and social care research

- Health and Care Research Wales Support and Delivery Centre will lead on the development of a public engagement strategy. This will include the development of a refined set of messages on the value of health and social care research, including articulating the importance (and difference) of both participation and involvement. It will also balance public engagement events with 'out-reach' activities that offers an inclusive approach via national and local organisations and community groups.
 - Health and Care Research Wales to consider the opportunities to develop a partnership with 'Be Part of Research' initiative, including a UK wide publicly accessible search tool for health and social care research studies currently 'live'.
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Focus Area 4:

Be transparent about how public involvement is reflected in Health and Care Research Wales own processes.

Actions:

4.1 Conduct an audit of Health and Care Research Wales processes against the UK

- Welsh Government to undertake assessment of current processes against the UK Standards for Public Involvement.

4.2 Standards for Public Involvement to identify areas for further improvement

- Welsh Government to consider how use of UK Standards for Public Involvement should be appropriately incorporated into expectations and conditions of Health and Care Research Wales.
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Focus Area 5:

Tackle administrative barriers to effective public involvement.

Actions:

5.1 Clarify arrangements and expectations for the use of public involvement resources and payment policies.

- Health and Care Research Wales to set up a time-limited working group involving colleagues who are having difficulties implementing reimbursement for time for public members, and those who have found ways to manage this issue, to identify a solution that can be adopted across all relevant organisations.
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Focus Area 6:

Provide effective training, resources and support to researchers, research managers & administrators to enable them to do public involvement well.

Actions:

6.1 Review the current ‘package’ of public involvement support and ensure it is fit-for-purpose

- Health and Care Research Wales Support and Delivery Centre to review the current support and resources available for Public Involvement, assessing any gaps or opportunities to enhance delivery.

- Health and Care Research Wales Support and Delivery Centre to take a more pro-active approach to promoting the available resources and engaging with researchers and research managers/administrators to support their use.
- Health and Care Research Wales Support and Delivery Centre to develop a 'infographic' or similar highlighting how public involvement can play a role at all stages of the research process. There may be an opportunity to link this development to showcase stories and case studies as examples of the value of public involvement.

6.2 Consider accreditation of public involvement training, based on the UK Standards for Public Involvement, to support its uptake by researchers.

- Health and Care Research Wales Support and Delivery Centre to develop online training package around the UK Standards for Public Involvement.
- Health and Care Research Wales to consider how the training packages available to support public involvement can be accredited, and what practicalities and implications there are to setting expectations for undertaking and refreshing training

Focus Area 7:

Collect useful information to demonstrate the value of public involvement to research

Actions:

7.1 Review and revise reporting requirements for Health and Care Research Wales funded projects and groups, to include a qualitative element.

- Health and Care Research Wales will work to incorporate appropriate public involvement reporting as part of the new monitoring framework for the research groups that are funded by Health and Care Research Wales Research.
- Health and Care Research Wales infrastructure groups to reflect annually on how activities are being undertaken with consideration of the UK Standards for Public Involvement as an 'audit' or self-assessment exercise.

7.2 Develop a template to consistently capture public involvement stories and case studies.

- Health and Care Research Wales will work to incorporate appropriate public involvement reporting as part of the new monitoring framework, based on consistent narrative model around 'who was involved', 'what did they do', and 'what difference did it make'.
- Health and Care Research Wales will explore opportunities to showcase stories and studies to promote the value of public involvement.

7.3 Introduce support and guidance for feedback to public members, and ways for public members to give their insights on their experiences of being involved.

- Health and Care Research Wales will scope whether there is existing Wales, UK or international guidance on providing feedback to public members who have been involved, and how this can be adopted and promoted within Wales.

7.4 Create a framework to evaluate the difference that this action plan and co-design approach has made to public involvement and public engagement in Wales.

- Health and Care Research Wales will use the regular public involvement forum to work collectively on an evaluation plan, considering the difference that is expected and how this might be measure.

