Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Ariennir gan Llywodraeth Cymru
Funded by Welsh Government

Health and Care Research Wales Public Engagement strategy

A framework for raising awareness, extending reach and achieving impact in health and social care research

2021 - 2024

1 Background

The coronavirus pandemic has catapulted health and social care research to the forefront of the general public's minds. People who had never thought about research before were talking about the development of a vaccine, clinical trials and treatments as a beacon of hope against the deadly virus.

Multiple vaccine trials, conducted across Wales, provided opportunities to share the process of clinical research with the wider public on national TV, radio and in the press. This is an opportunity to capitalise on this momentum; to use the success of the vaccine development and roll out to engage the public further, for people across Wales to see the benefits and importance of all research and ultimately participate and get involved.

This document has been developed in conjunction with feedback and insight from a working committee[i] made up from public involvement and engagement leads from across the Health and Care Research Wales community and members of the general public.

What is public engagement?

Public engagement is defined as "where information and knowledge about research is provided and disseminated"[1].

This strategy hopes to set out ways to achieve truly meaningful public engagement, which will enable a large number of diverse people from Wales to be inspired to find out how they can contribute to impact the lives of their loved ones.

We understand there are many ways in which people can engage with research, and to those not as familiar with research, won't use/understand the sector specific terminology. For ease, see below a few definitions and easy to understand terms and phrases we will use throughout this document.

Terms and phrases	Examples
Public Engagement / finding out more	Clicking on Health and Care Search Wales website, liking and commenting on social channels, attending events, signing up to bulletins
Public Involvement / helping shape	Providing personal experience to help shape research, set research priorities by commenting on patient documents, attending focus groups, working committees etc.
Participation / being part of	Being part of a clinical trial and other types of research studies like questionnaires, observations and focus groups

Engagement is the first step to further action, this isn't a strategy for public involvement or participation however good engagement, in its nature, facilitates action. Clear communication will support the increase in participation and public involvement and will be the catalyst in people phoning up, signing up and clicking to find out more.

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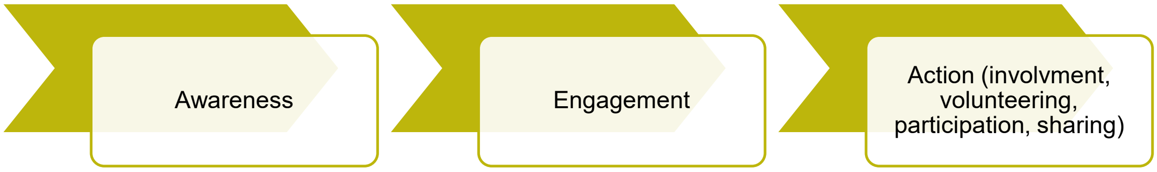
[1] National Institute for Health Research (NIHR)



The research sector is clear on the terminology and definitions of how the general public can engage with research but throughout this document (and in further communications) we want to be as clear, simple and informal as possible - so as not to intimidate or put people off engaging with research across Wales.

This strategy document provides information about the contextual considerations and insights which have helped the working group to develop some of the ideas to help to implement this strategy, along with measures like key performance indicators and evaluation methods.

2 Vision

Health and Care Research Wales is committed to increasing the number and diversity of people who help make research happen, ensuring they know what research is being conducted, how to get involved and take part and most importantly how it impacts people's lives.

This commitment is detailed in the Discover Your Role vision co-created by Welsh Government, Health and Care Research Wales partners and a wide range of stakeholders.

This document will outline the proposed purposeful public engagement strategy for Health and Care Research Wales. Our vision is to have as many people across Wales understand the importance of research and we aim to do this by:

1. Showcasing the value and importance of research by sharing human interest stories to inspire others to find out more, take part and help with research
2. Celebrating the existing research happening in Wales and its impact in improving treatment and care
3. Championing the key players in the health and social care research in Wales to illustrate trust and expertise in research
4. Reaching more research partners from a cross-section of communities across Wales

In a nutshell, the strategy highlights the *impact* of research and will facilitate more people to find out more, help shape and be part of health and social care research in Wales.

3 Audiences

Meaningful engagement, which is the first phase on the journey to public involvement and participation, must be embedded in the NHS, social care and research community. Separate targeted communications are required to ensure there is a flourishing research-focused environment in Wales for the members of the public to be a part of.

All messaging is reflective of feedback from established networks, the public engagement working advisory group and the attendees of the discover your role forums.

The target audience is identified as the general public and all potential patients and service users in Wales. Understanding that this group is too large to effectively communicate with, segmenting and prioritising will help to achieve impact. The strategy will be implemented in phases, allowing time for reflection and refinement.

The focus of the first phase is to:

- Target the general public – to increase knowledge and awareness of the impact of research to encourage those to take part when approached or seek out ways to help
- Communicate with non-research staff in NHS and social care – highlighting the importance of research within day-to-day care/treatment
- Equip researchers, research leaders and specialty leads – to act as ambassadors and champion engagement in research internally to other members of staff and externally to potential patients are service users

Public engagement takes a variety of forms so as not to exclude any groups. Equality Diversity and Inclusion (EDI) is embedded in all engagement to ensure underserved groups and those who haven't traditionally engaged with research are reached. In addition, research participants collectively must be as reflective of the Welsh population as possible.

Work needs to be conducted to identify the research partners we need to communicate with, to ensure our research is as diverse and inclusive as possible - making a meaningful difference to a cross section of communities across Wales.

This will be achieved through several scoping exercises, statistics and data from Stats Wales, stakeholder database development, insights and building on existing relationships built within our working group. Work (coproduced with members of our research community) will also be conducted to reach out to key groups we have not engaged with before, to raise awareness of the impact of research and inspire them on the next stages of how they can shape, find out more or be part of research.

We aim for the majority of content we produce to be as accessible as possible to those of all abilities and where possible, translated into native languages.

4 Insights

A YouGov survey, carried out on behalf of Health and Care Research Wales, asked 1,000 respondents a range of questions on their understanding of coronavirus research - especially research in the UK - and the role it had played in overcoming the pandemic.

The survey found:

- 91% of people in Wales think health research in the UK has been important during the COVID-19 pandemic
- 34% are now more likely to take part in health research because of the pandemic
- 86% feel the UK has played a significant role in finding COVID-19 treatments
- 87% are proud of the UK researchers and NHS staff who identified some of the first effective treatments and vaccines
- 91% feel grateful to the people who have taken part in the research for vaccines, tests and treatments
- 78% are keen for health research to be part of routine care offered by the NHS

However, the majority of people who responded didn't know local NHS hospitals in Wales offered opportunities to take part in COVID-19 health research (60%) or health research unrelated to COVID-19 (71%). We will also look to track these stats in relation to social care research in upcoming surveys and existing insights.

From our work existing networks, relationships and the public engagement advisory group, the current blockages to engagement, as highlighted from lived experience, are time constraints, lack of recognition to those who have invested their time and feeling intimidated by jargon or a complicated and lengthy journey to get started. This has helped to shape the strategy in terms of how we support people to get involved with research, taking these barriers into account.

5 Implementation

Taking the insight into consideration, we've developed five key strategic pillars to ensure we expand the reach of engagement in health and social care research and combat the barriers to engagement. These include:

1. Multi-platform public awareness campaign
2. Building meaningful relationships
3. Aligning with UK strategies
4. Developing easy to understand, standardised Wales wide key messages
5. Equipping researchers, senior leaders, public involvement leads, principle investigators, support and delivery staff to act as advocates and ambassadors championing the importance and impact of research from within their sectors

1. Multi-platform public awareness campaign

As seen in the insights from the YouGov survey, the majority of people who responded did not know local NHS hospitals in Wales offered opportunities to take part in COVID-19 health research (60%) or health research unrelated to COVID-19 (71%).

Awareness is vital.

To start the conversation and encourage the general public to become engaged in health and social care research we must raise its profile. In order to do this, a multi-platform public awareness campaign is required. The communications will be assertive to cut through the vast amount of media noise and will include as many real-life human-interest stories as possible, creating emotive and relatable content. The aim is to educate, inspire and motivate.

To reiterate the call to action in every element whether that be digitally, at events or through the press, the campaign will be packaged under one overarching theme, which is:

Where would we be without research?

Health and social care research saves lives, to find out more visit
www.healthandcareresearchwales.org/withoutresearch

Ble fydden ni heb ymchwil?

Mae ymchwil iechyd a gofal cymdeithasol yn achub bywydau; i gael gwybod mwy, ewch
www. www.healthandcareresearchwales.org/bydhebymchwil

This overarching campaign line provides us with flexibility to emotionally resonate with the general public. By changing the last word of the campaign line, we can focus our content to speak to different audiences. E.g. Where would we be without… participants, diabetes research, COVID-vaccine etc.

The line works to show the shocking impact of a world without research, as research tends to be something people don't even think about, as it tends to happen in the background to ensure people receive the best evidence-based care and treatments.

The multi-platform approach will allow the campaign to reach a variety of target audiences and provide a drip-feed effect to the general public as repetition helps permeate the message.

The methods will include:

- Communication packs for health boards and social care staff
- Internal staff focused events
- Content targeted at NHS/care sites
- Dedicated microsite for the general public
- Explainer videos
- Events, webinars, out-reach activities
- Media relations sharing human-interest stories highlighting the impact of research
- Engaging social media content including polls, infographics, quote cards, video clips
- Non-digital collateral including posters, z-cards, out of home advertising
- A podcast series where each episode will delve into where we would be without research with a list of guest speakers
- Education packs for schools
- Thought leadership pieces championing specialty leads, positioning them as the voice of Welsh research

2. Building meaningful relationships

Engagement wouldn't be possible without relationships. To ensure truly meaningful and diverse engagement, relationships must be made within a range of communities, using existing groups and networks where people feel most comfortable.

As stated in the UK research clinical strategy, Saving and Improving Lives: The Future of UK Clinical Research Delivery, to do this sustainably, we need to ensure support is available where it is most needed, including primary and community settings, so we can deliver research 'where people are' and actively engage with underserved communities.

Whether that's tapping into faith groups, third sector or even sports groups, all engagement must use tried and tested platforms to engage with those who have may never thought about health and social care research.

The aim is then to educate, inspire and motivate those to get involved.

3. Aligning with UK strategies

The pandemic and vaccine trials has also confirmed the strength of the four-nation approach and Health and Care Research Wales is fully committed to playing its part in delivering a world-leading UK clinical research system.

As a partner in delivering several UK wide strategies Wales will work collaboratively with all stakeholders to improve the health and well-being of the population. This vision and plan are aligned to ‘A Healthier Wales’ strategy, whereby individuals are at the heart of transformation and modernisation of health and care services, and where research is embedded in high quality care.

As we develop our initiatives, we will ensure that we continue to work in partnership with other UK nations. This means that our work will complement UK wide activity to provide consistency and a similar experience for people with lived experience in all parts of the UK.

All public engagement activity will consider the Social Care Wales Strategy and the UK Standards for Public Involvement as one of the next steps. In addition, some of the work will naturally align to other initiatives, for example development of Be Part of Research, where people can find research studies to take part in; and the implementation of the Make it Public transparency strategy, which aims to ensure information about research is readily available and that those involved in research get feedback.

4. Developing easy to understand, standardised Wales wide key messages

Drawing from the national approach, one of the challenges with public engagement has been the varying levels of engagement across the Health and Care Research Wales funded community, NHS and social care organisations, researchers and academics. To encourage as much engagement as possible, it’s clear a set of Wales-wide key messages and agreed terminology should be used when we meet the public to ensure consistency.

The key messages we will use and be at the heart of all work are:

- Research is designed to improve lives
- Research has played a vital role in developing treatments against COVID-19
- Health and social care research will impact us all at some point
- The role of participation and public involvement in research is crucial to drive improvements in health and social care

Along with a set of agreed messages, is the understanding of language. Terminology is very important in the research sector but can cause confusion when speaking to the general public with little or no experience of research.

Use of jargon has put people off from any engagement with research. The language used to speak to the research naive public audience will reflect that of the Health and Care Research website and avoid specific variations of *involvement* and *participation* and use phrases such as*: find out*, *take part* and *help shape research*. Even the term *public engagement* will be used sparingly and language will be informal, accessible, emotive and thought provoking.

5. Equipping researchers, senior leaders, PI leads, support and delivery staff

Specific activity targeted to NHS R&D departments, researchers and social care practitioners is paramount. As stated above, we need to ensure the research infrastructure across Wales has consistent communication messages.

All key stakeholders will be briefed and our insight work will ensure the messages and objectives are well received.

Health and Care Research Wales contractual, governance documents, guidance documents and all Public Involvement Training across Wales will be updated to help increase the recognition and feedback to public contributors about the research study they were involved in.

Toolkits and templates will also be developed to help public involvement leads, researchers and staff with this vital piece of work, bad experiences of engagement will hinder its growth and a key element of getting involved is to be proud and part of the life-changing impact of the research.

6 Evaluation of key activity

This strategy will cover the next three years' work and we will look to review and reflect on a 12-monthly basis.

We must measure this by comparing to the results of the You Gov survey, which we will look to repeat in three years' time and add social care questions, the membership of the public involvement community, social media engagement, anecdotal feedback, results of participant surveys (PRES), event attendance, visits to the public section of the Health and Care Research Wales website and the increase in researchers embedding meaningful public involvement across their studies.

We will track the success of the strategy against the below key performance indicators.

Increase of people in Health and Care Research Wales PI involvement community by 10% in 12 months

Increase the relevance and diversity, (reflective of Wales) of people in Health and Care Research Wales PI involvement community in 12 months

Increase Welsh hits to Be Part of Research website by 10% in next 12 months

Track the number of assets being downloaded, engagement on social media, hits to public facing microsite

10% increase in the number of people likely to take part in health research because of the pandemic in YouGov survey

Qualitative feedback, anecdotable comments, tangible impact on patients/ service users, new ways of working/ treatments etc.

For further information or if you have any questions please contact Hannah.Bertie@nhs.wales.uk

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[i] Members of the working committee included:

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- Adele Battaglia Public member
- Karen Harrington Public member
- Cait Myers, Campaigns and Engagement Manager, Health and Care Research Wales
- Rebecca Burns, Public Involvement Manager, Health and Care Research Wales
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