

Health and Care Research Wales

**‘Discover Your Role
in
Health and Social Care
Research’**

**Public Involvement Action Plan
2025 - 2029**

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Discover Your Role in Health and Social Care Research

Every week, hundreds of people contribute to health and social care research in Wales, which is essential for discovering new treatments and improving services. This research relies on public support, whether through participation in studies or by sharing personal experiences to shape research priorities, design and delivery—known as public involvement.

Many studies already include public involvement, which, when done well, results in research that is more relevant and understandable and provides a better experience for those taking part. Those involved often gain confidence, build positive relationships and friendships and learn new skills. However, poorly conducted involvement, with unclear roles and poor communication can lead to negative experiences.

Health and Care Research Wales is committed to making public involvement an essential part of the health and social care research process, recognising that it is important, expected and possible in all types of health and social care research. We have joined the [‘Shared Commitment to Public Involvement’](#) with other UK organisations as a joint effort to improve the extent and quality of public involvement across the sector so it is consistently excellent. For Health and Care Research Wales, this means ensuring the public has a say in how research is prioritised and funded; how it is designed and conducted; and how its impact is recorded and communicated. Our strategic plan [‘Research Matters’](#) reinforces the importance of public involvement to good research practice, and outlines intention to continue supporting and developing public involvement approaches by building on the work achieved through the original [Discover Your Role in Health and Social Care Research Action Plan](#).

We are proud of the great progress already being made by public contributors, researchers, and others involved in our community. Their efforts have helped improve public involvement in research across Wales and shaped national discussions, such as the UK Standards for Public Involvement and guidance on paying public contributors. However, we know there is still much more to do.

Discover Your Role 1.0

In 2020, Health and Care Research Wales introduced Discover Your Role in Health and Social Care Research, an action plan to boost public involvement in research. It was co-designed with input from the public, researchers and research administrators, focusing on seven key areas for activity, establishing a shared vision for public involvement and practical actions for improving the quality and quantity of public involvement. Over the past four years, public contributors and researchers

have worked together to tackle barriers and develop solutions across all the areas identified for action.

Some key successes include:

Co-design and delivery of the public engagement strategy:

The “Where would we be without research” campaign, which was part of the strategy, was collaboratively developed and delivered with public contributors and researchers, raising awareness about the critical role of research in improving health and social care. In response, there has been a 30% increase of public members to our community, with the total number of public contributors currently at 650.

Storytelling and tracking impact:

Research groups now include involvement stories and evidence of impact in their annual reporting, ensuring public contributions are recognised and celebrated. Over 30 research stories have been developed to promote this impact, with 3459 views to our campaign page.

Public Engagement and Involvement Forum:

Consistently high levels of engagement in our public engagement and involvement forum have provided a platform for sharing best practices, fostering collaboration and driving progress in public involvement.

Developing Discover Your Role 2.0

During early 2024, we used the Public Engagement and Involvement Forum to reflect with researchers and public contributors on what had been achieved as part of implementing the Discover Your Role Action Plan and what still needed attention. Using these engagement sessions, we agreed a process for co-designing the next version of the Discover Your Role Action Plan, including:

1. Learning from Discover Your Role 1.0 to identify ongoing challenges.
2. Engage with a wide range of stakeholders, including those frequently involved and those with less experience.
3. Undertaking a fresh co-design process to build shared agreement on the aspirations and specific actions that should be addressed in a new action plan.
4. Consult with the community on the new draft plan.

We organised a series of community engagement events across Wales, bringing together more than 180 attendees. These events served as a platform for open discussions, collaboration, and idea-sharing, with the goal of identifying practical and

effective solutions to the challenges faced with public involvement. The valuable insights and perspectives gathered during these sessions played a crucial role in shaping the initial draft of our Discover Your Role action plan.

This draft action plan was made available for public consultation between September 2024 and January 2025. During this period, we actively sought feedback from a wide range of stakeholders, including community members, professionals and researchers. The consultation process helped us in refining and strengthening the action plan, leading to the development of a more comprehensive and actionable second version.

Through this co-design process, a clear set of principles emerged that should guide our approach to future of public involvement and engagement in Wales:

- Embedding public involvement as a routine and accepted part of the research cycle.
- Ensuring opportunities for public involvement are accessible, inclusive and straightforward.
- Allocating appropriate resources to support public involvement, alongside comprehensive training available to both researchers and public contributors.
- Enhancing communication and engagement by sharing stories and case studies that highlight the public's vital role in health and social care research.

From this collaborative process, we developed 15 problem statements, which were then prioritised through an online survey involving over 80 public members and researchers. This effort enabled us to narrow our focus to seven key focus areas for the new Discover Your Role Action Plan:

1. Resources

- a. Insufficient funding for involvement activities.
- b. Lack of time allocated for developing public involvement activities.

2. Inclusivity

- a. Difficulty in involving under-served groups with limited time and resources.

3. Involvement opportunities – Ongoing support and development for public contributors

- a. Involvement opportunities often request prior experience, excluding newcomers with emphasis on making the process easy for those offering

the opportunities rather than providing inclusive access to public contributors.

- b. Need for more support and skill development opportunities for public contributors, such as chairing meetings, to emphasise the mutual benefit of being involved.

4. Opportunities / Accessibility - Helping shape research

- a. The process for finding and applying for involvement opportunities is repetitive and time consuming.
- b. Difficulty in finding a comprehensive list of available opportunities.

5. Payments

- a. Complicated payment processes that discourage involvement.
- b. Invoices often lack details, making it hard for public contributors to manage finances.

6. Impact

- a. Poor ongoing communication from study teams leaves public contributors unaware of outcomes and misses opportunities to demonstrate impact.
- b. Unclear how research affects Welsh services, and the role of public involvement plays in facilitating good, impactful research.

7. Discover Your Role evaluation

- a. The overall impact of Discover Your Role and working to a collective plan to improve Patient and Public Involvement in Wales. How to monitor and capture this.

Delivering Discover Your Role 2.0

With the insights gathered from our community engagement events and consultation process, we have developed a comprehensive Discover Your Role 2.0 action plan. This plan sets out the key focus areas and activities needed to transform our shared ambitions into meaningful, lasting change. By incorporating diverse perspectives and lived experiences, the plan ensures that public involvement remains a central part of health and social care research in Wales.

Now the consultation phase is complete, we have finalised the action plan with **seven** focus areas and **nine** key actions. Additionally, the plan acknowledges a set

of secondary actions for some focus areas. These are activities that can further support our focus areas but will be undertaken as time and resources allow. We will create a Project Oversight Group to monitor and evaluate Discover Your Role. This group will be responsible for assessing the outcomes and impact of each focus area, providing strategic direction, and ensuring the overall success of Discover Your Role. We will also re-convene the Public Engagement and Involvement Forum every four months. This forum will serve as a key platform for:

- Sharing updates on Discover Your Role activities, ensuring transparency and aid ongoing communication.
- Providing opportunities for the public involvement community to offer further input, helping refine and shape our approach.
- Facilitating the exchange of best practices, allowing stakeholders to learn from each other and build collective expertise.

Beyond Wales, we remain committed to collaborating with our UK partners, sharing our progress, exchanging insights and learning from others' experiences. This includes engagement with initiatives such as [Learning for Involvement](#) which supports continuous learning and the adoption of effective public involvement practices.

To ensure a high standard of public involvement across all focus areas, the [UK Standards for Public Involvement](#) will serve as the guiding framework for this action plan. These standards will shape our approach, ensuring every action aligns with best practices and is evaluated through the lens of inclusivity, transparency and meaningful participation.

Health and Care Research Wales remains committed to fostering a vibrant community of practice, one that encourages ongoing dialogue, facilitates collaboration and promotes the sharing of best practices. Building on the momentum of what we have already achieved, this next phase of Discover Your Role aims to embed public involvement and engagement as a fundamental part of health and social care research across Wales.

Action Plan for Public Involvement and Public Engagement 2025 – 2029

Focus area 1: Resources

Challenges in public involvement activities often stem from constraints in time and resources. When these limitations are not addressed, public involvement may become tokenistic, meaning it lacks depth and does not effectively influence decision-making.

To develop and achieve meaningful public involvement, a creative and collaborative approach is essential. This includes learning from each other, sharing and pooling resources, and advocating for appropriate recognition of the costs associated with public and patient involvement.

To achieve this, we will explore creative strategies and models to improve the use of current resources allocated to public involvement and collect and share information about public involvement teams and existing resources to enhance collaboration and effectiveness.

Actions

| Priority Action | Description | Expected output | Timeframe |
|--|---|-----------------------------------|---------------|
| Create a task and finish group to generate recommendations on implementing sustainable funding models for public involvement | Drawing together Welsh and wider UK expertise (including Public Involvement leads and public contributors) to consider current examples of sustainable funding models for public involvement in university settings (in the first instance) and potential for implementation across Wales | Report with clear recommendations | November 2025 |

Additional actions to strengthen collaboration and resource sharing in public involvement:

1. Create and maintain a database of all public involvement leads in Wales, including those from external organisations. This will facilitate collaboration and resource sharing when funding is limited.
2. Encourage collaboration amongst Health and Care Research Wales funded community: Promote collaboration among funded communities by requiring teams to share resources and information as a condition of membership in our Involvement Alliance.
3. Develop an annual training programme that highlights existing public involvement training, ensuring it is better signposted and communicated for researchers seeking to effectively involve public contributors in their research.

Focus area 2: Inclusivity

Effectively involving and engaging under-served communities in public involvement requires time, effort, and a well-structured approach. We use the term "under-served" as defined by [NIHR INCLUDE](#), which has carefully researched the most appropriate terminology and its meaning. Without a clear strategy for involvement, these groups may be unintentionally excluded, leading to a lack of diverse perspectives in research and decision-making.

Additionally, building trust and strong connections with under-served communities takes time and consistency, which can be hindered by tight research deadlines. A lack of specialised training on inclusive practices and the need for tailored support further complicates efforts to engage these groups meaningfully. Without the right tools, strategies, and training, research risks missing valuable insights from communities that are often most affected by the issues being studied.

To address this, we will develop and implement sustainable plans, toolkits, and training to involve under-served groups in research through targeted outreach, community partnerships, and support from the Equality, Diversity and Inclusion (EDI) Advisory Group, ensuring meaningful and consistent involvement and representation.

Actions:

| Priority action | Description | Expected output | Timeframe |
|---|--|-------------------|----------------|
| Develop and pilot funding scheme within Enabling Involvement Fund | Use the EIF and Health and Care Research Wales public involvement support to provide financial and practical | Launch pilot call | September 2025 |

| | | | |
|---|--|--|----------------|
| (EIF) to facilitate public involvement support for matching researchers and under-served communities | resources, assisting researchers in designing and delivering involvement activities with under-served communities in Wales | | |
| Form a working group, including members of our EDI advisory group, to co-create training/ toolkit to support researchers to consider issues and engage inclusively for involvement in studies | Identify ways to involve under-served communities in research, create best practice guides, and establish a structured approach for meaningful involvement. Build on allyship guidance and incorporate insights from joint work with NIHR into a Health and Care Research Wales document. Collaborate with the EDI advisory group and community organisations to deliver inclusive, relevant training. | Develop toolkit. launch inclusivity training | September 2026 |

Additional actions to support inclusive involvement:

- Continue community outreach plan by the Health and Care Research Wales public involvement team to engage under-served groups, including clear messaging guidelines, and an inclusive framework for planning and evaluating events and measuring value

Focus area 3: Ongoing support and learning for public contributors

Requiring prior experience for public involvement opportunities creates a barrier for newer members, limiting the diversity of perspectives in research and decision-making. Without accessible entry points, many people who could offer valuable insights are excluded. Additionally, there is a need to provide public members with more chances to develop their own skills, to ensure meaningful involvement and ensure that all voices are heard. Involvement opportunities are often focused on how researchers can benefit from the time and lived experiences of public contributors, but the current system does not always provide enough opportunities for skill-building, which can make it harder for public contributors to engage in research and decision-making. To address this, we should focus on creating and expanding learning opportunities and mentorship that support public contributors in building the skills they want to benefit themselves from being part of involvement activities.

Actions:

| Priority action | Description | Expected output | Timeframe |
|--|--|---|------------|
| Develop an annual training programme offering learning and development opportunities to support public contributors in shaping research. This training will be optional. | <p>Review and update the current support system for public members to map available activities and resources and establish an improved learning framework for public involvement.</p> <p>Develop a plan to improve training and mentorship focusing on development for public contributors and promoting continuous development. Insights from other organisations and funded community initiatives will be incorporated to share valuable resources and best practices.</p> | <p>A structured training calendar covering key topics relevant to public contributors.</p> <p>Delivery of six training workshops, seminars, and online modules, per year.</p> | March 2026 |

Focus area 4: Accessible opportunities – helping shape research

The current process for getting involved in research is often repetitive and takes a lot of time, which may cause frustration for those interested. It's often hard to find a complete list of available Health and Care Research Wales opportunities, making it difficult for people to know how to get involved. As a result, potential public contributors may feel overwhelmed or discouraged, leading to lower engagement and a less diverse range of voices in research. Simplifying the process, removing unnecessary barriers, and improving access to opportunities are essential steps in increasing meaningful public involvement.

To address these issues, we will streamline the application process to save time and reduce repetition. We'll also create a clear, accessible list of opportunities, making it easier for people to find and support research involvement.

Actions:

| Priority action | Description | Expected output | Timeframe |
|--|--|---|---------------|
| The Health and Care Research Wales public involvement team to undertake review of current involvement opportunities process and implement changes to simplify arrangements. | <p>Review opportunities to identify the need for prior experience and streamline the application process by simplifying forms, reducing the complexity, introducing auto-fill options and only asking for essential information.</p> <p>Create a clear, accessible list of opportunities, making it easier for people to find.</p> <p>Seek input from public involvement leads and public contributors to ensure proposed changes are appropriate before implementation.</p> | More accessible, efficient and simplified application forms | December 2025 |
| Share targeted opportunities with public contributors based on their specific health and social care interests, sharing relevant opportunities with those who have expressed interest in those topics. | Introduce a new researcher request form to specify health topics. Collect areas of interest from public contributors and develop an automated process to match new opportunities with those who have expressed interest, ensuring a more tailored approach rather than a blanket one. | Customised emails to public contributors, inviting them to apply for research opportunities | March 2026 |

Additional actions to support improving the accessibility of Health and Care Research Wales involvement opportunities:

1. Provide training sessions and an explainer video to guide applicants through the process of applying for involvement opportunities.

Focus area 5: Payments and administrative barriers

We recognise that navigating payments while complying with HM Revenue and Customs (HMRC) and Department for Work and Pensions (DWP) is complicated, creating administrative barriers that hinder meaningful public involvement in research. To help, we offer support for public contributors to access citizen and benefits advice, though this service is only available to those receiving benefits.

These complex payment processes can be time-consuming and difficult for both researchers and public contributors to manage, potentially leading to frustration and confusion. These challenges can discourage involvement, especially among those who may find the processes difficult to navigate. While we are actively working with our UK colleagues to find solutions, it is important to note that Health and Care Research Wales cannot resolve this alone.

Actions:

| Priority action | Description | Expected output | Timeframe |
|---|---|---|---------------|
| Create and deliver training for public and finance leads on timely payments for public contributors and the distinctions between public involvement and employment. | In collaboration with UK colleagues, design, develop, and deliver training sessions for public involvement leads and organisations finance leads to highlight the importance of timely payments for public contributors and to clearly explain the differences between public involvement and employment. | Share easy to read payments documents. Developed materials for delivering training (slides, guidance, case studies). | December 2026 |

Additional actions to support addressing the payment barriers for paying public contributors

1. Develop a clearer strategy for working with universities, collaborating with finance leaders through the involvement alliance group to overcome payment barriers for public contributors.

Focus area 6: Impact

Public contributors play a crucial role in making research more relevant to those affected by the conditions being studied or using the services being researched. Their involvement ensures that the research addresses real-world concerns and has a higher chance of producing impactful results. However, without clear updates from researchers, they may feel disconnected and question their contributions' value, reducing future engagement.

To help demonstrate the impact of public involvement we propose establishing robust communication channels between study teams and public contributors to ensure ongoing engagement and clear updates on study outcomes and how their involvement has or has not influenced the research.

Actions:

| Priority action | Description | Expected output | Timeframe |
|--|---|---|---|
| Defining requirements and mechanisms to ensure ongoing engagement from study teams are communicated to public contributors at key points through development and delivery of research. | Develop and maintain a detailed guide and database to track and document the impact of public involvement in research, both to the study and individuals themselves. Additionally, define and clarify what is considered involvement impact activities. | Case studies Guidance documents and best practices Impact reports Clear guidance on ways public contributors shape and influence research. | Introducing/ consulting on the requirements June 2025 - reporting on impact summer 2026 in line with annual reports |

Additional activities to support assessment of involvement impact:

1. Building on the reporting processes established in the initial Discover Your Role, we will establish a mandatory system to capture and share the impact of research and public involvement, showcasing examples through outreach and engagement to highlight the value of public contributions in driving meaningful outcomes.

Focus area 7: Discover Your Role evaluation

The purpose of developing the Discover Your Role action plan is to create collaboration and collective action to improve the extent and quality of public involvement across the sector so that it is consistently excellent. Without a clear understanding of how the activities proposed are specifically creating outcomes that are changing public involvement, it becomes difficult to measure the success and effectiveness. When the outcomes and impact isn't clearly defined or tracked, it becomes challenging to show how public involvement contributes to meaningful change. This uncertainty may reduce support for public involvement efforts and make it harder to secure resources or commitment to future projects.

We propose implementing an evaluation framework to assess the effectiveness and impact of the Discover Your Role initiative. This framework will include developing specific evaluation criteria to define outcomes, measure success and determine impact. This will ensure ongoing oversight and provide valuable feedback and demonstrate the value of public involvement in research.

Actions:

| Priority action | Description | Expected output | Timeframe |
|---|---|--|----------------|
| Establish a Project Oversight Group to evaluating the impact and effectiveness of Discover Your Role 2.0. | Implement a evaluation framework to assess the Discover Your Role initiative's effectiveness and impact. Develop specific evaluation criteria to measure success and determine the initiative's impact. Ensure ongoing oversight through regular assessments. Provide valuable feedback to improve the initiative. | Comprehensive evaluation framework Defined evaluation criteria Actionable feedback and recommendations | September 2025 |