

Health and Care Research Wales

'Discover Your Role in Health and Social Care Research'

Summary of feedback to date and upcoming events, in partnership with Swansea University and PRIME Centre Wales

1. Health and Care Research Wales published the '*Discover Your Role in Health and Social Care Research*' ambitions document in September 2019, outlining a draft of our vision for the public engagement and public involvement agenda as part of the new Health and Care Research Wales strategy period (2020-2025).
2. We have been seeking feedback from a wide range of stakeholders on the vision and content of the document, including individual feedback (via emails/meetings), an online survey, and three open-invitation community of practice events that have involved a deeper exploration of each of the four themes outlined in the '*Discover Your Role*' document.
3. This document provides a summary of the feedback we have received to date, and will be used to:
 - Consider any changes/revisions to the '*Discover Your Role*' vision document before publication of a final version;
 - Inform the development of a 'map' of activities and actions that will contribute to turning the vision into reality. The next community of practice events in Bangor University on **12th February** and Swansea University on **25th February** will play a key role in shaping the development of this map and providing feedback and suggestions on the key themes that have emerged to date. Registration for these events is at <https://www.healthandcareresearch.gov.wales/discover-your-role-consultation/>
4. This document is split into 3 sections:
 - i. A summary of the current public involvement/engagement landscape to date, based on the perspectives shared by those attending the community of practice events;
 - ii. Consensus on the key achievements that the community would like to see delivered by the end of the next strategy period (the 5 year vision);
 - iii. The key areas for development identified, as a synthesis of the individual comments provided via the community of practice and online survey.

i. Where we are currently for public involvement and engagement across Health and Care Research Wales
5. Consensus is that:
 - Understanding and acceptance of the role of public involvement in health and social care research has improved significantly in the last 5 years.
 - Whilst there have been improvements, public involvement is still far from a routine part of the research process.
 - There are resources available to facilitate and support public involvement activity, but it is apparent that awareness of these resources, and access to support, is not utilised as much as it could be.

- Most of the information collected about public involvement activity is quantitative, which can be useful but has limited value in determining whether the involvement has been meaningful in terms of impact on the study and its outcomes.
- There are plenty of good examples and case studies on public involvement activity, but Health and Care Research Wales does not routinely or consistently collate them or use them to support the involvement and engagement agenda in a wider sense
- It has been reported that there continue to be administrative barriers to undertaking public involvement activity, particularly tied to reimbursement for time of public members via universities.
- Infrastructure groups and individual research projects are generally pro-active on research engagement activities, but there is not an agreed rationale for how best a system-wide Health and Care Research Wales public engagement strategy can be delivered and add value. The recent 'Let's Talk Research' pilot events and HealthWise Wales activity can provide some key learning on this area of work.

ii. Five Year Vision for Public Involvement and Public Engagement

6. Consensus is that in 5 years:
 - There will be a research culture where public involvement is an accepted, routine part of the research cycle and embedded across the research system
 - 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 made available to support effective public involvement and there will be comprehensive training and support available for both researchers and public members
 - We will use stories and evidence on the importance of research, research involvement, and the vital role that the public can play (through participation and involvement), to communicate more effectively with the public on how they can take part in health and social care research

iii. Key areas for public involvement and engagement development

7. The points below provide a condensed and summarised version of the key areas for development that have been raised from the feedback process.
8. The list is not presented in any specific order and whilst many of the comments have been provided in response to the four themes (Engaged, Empowered, Embedded, Evidenced), they are not grouped against these themes as many of the areas for development have connections to multiple themes.
9. Areas for development to achieve the vision for public involvement and engagement include:
 - Be clear and transparent on how public involvement is reflected in Health and Care Research Wales' own processes and review regularly

- Improving the feedback loop between researchers and those involved to understand, value and learn from the experience and impact of involvement
- Greater recognition and support for public involvement in research in leadership and senior roles
- Adopt the UK Standards for Public Involvement as the model of practice for involvement activity across Health and Care Research Wales, its governance and what it funds.
- Provision of training and resources to support public involvement in the research we fund; for example a GCP-style framework with introductory and refresher courses.
- A single portal of standardised support, with a clear way of accessing information around what public involvement or engagement opportunities are available to apply to
- Research should as accessible as possible - cutting the jargon and encouraging lay summaries when it comes to dissemination.
- Less silo working and better join-up of those doing public involvement so the whole system can learn and benefit from positive involvement activities
- Tackling the administrative barriers that undermine the ability to do public involvement effectively (particularly in terms of reimbursement of public members time)
- Ensuring that public involvement is planned and resourced appropriately and that it begins as early as possible in the research cycle
- Provide clear definitions of public involvement, public engagement and participation and how they can all be valued and interlink, whilst also having distinct functions
- Support researchers to consider how opportunities can be open and inclusive, and how connections, where appropriate, can be made to better represent disadvantaged communities and seldom-heard groups
- Develop peer support models within the Health and Care Research Wales system to drive culture change and create a space to discuss, improve and adopt good practice by working together, in addition to supporting those less familiar/confident with public involvement.
- Provide clarity and consistency on the performance management information that is requested relating to public involvement, ensuring its value and use is reflected proportionally with the ensuing reporting burden and providing an opportunity for reflection on lessons learned This will also give a clearer picture of the real costs and financial and staff resource required to deliver effective PI, which will in turn inform future sustainability and raise awareness among those not already engaged.
- Package up the information we collect through this process to promote the value and importance of public involvement in a more engaging and effective way, using case studies and testimonials.
- Be clear on the purpose of a public engagement strategy and recognise that a one-size fits all approach is unlikely to be effective. Ensure effort is allocated towards targeting the ‘unconverted’ and seldom-heard/neglected communities and groups, not just those who are already engaged. This could take the shape of mini-workshops/roadshows or awards to highlight excellent practice in public involvement.
- Change the narrative around public involvement so that it is less about a specialist, niche subject and more a core, common part of how good, ethical research is designed and delivered