Your Involvement Matters

April 2018

Brought to you by the Health and Care Research Wales Public Involvement and Engagement Team

Mae'r ddogfen hon hefyd ar gael yn Gymraeg
Welcome to the Spring 2018 edition of ‘Your Involvement Matters’. This newsletter features articles about the work of the Centre for Ageing and Dementia Research (CADR).

Many of you will have attended the Involving People Network Annual Meeting on 21 March: ‘Co-production: public voices in action’. For the first time we featured co-produced interactive stands demonstrating models of public involvement from around the infrastructure. Delegates were told about plans for the future to support more diverse and flexible public involvement and the National Standards for Public Involvement pilot phase was launched. Those of you who did not attend can read a network member and researcher’s review on pages 14 and 15.

We are delighted that new members are continuing to join via the online application form and researchers are requesting our support via an online process. We have updated finance and benefits guidance and produced a handbook for researchers to complement the revised ‘First Steps: members of the public and researchers working together’ training. The handbook is available on our website.

You can find out about the peer support project for network members on page 6 and hear about the most recent case study that the team have developed on the next page.

In answer to requests about public involvement training, you can read a summary of training programmes available on page 15.

Thank you to all those who have contributed, we hope this edition is useful and an enjoyable read. If you have any suggestions or questions, you can contact the team by emailing research-involvement@wales.nhs.uk or phoning 02920 230457.

Barbara Moore
Senior Public Involvement and Engagement Manager
Last year, the Public Involvement and Engagement team were asked by the Centre for Trials Research to write a case study on their very positive experience of involving members of the public in the design of their research study.

The CONSCOP study is looking at the role of colonoscopies in the diagnosis of bowel cancer and monitoring. The study aims to analyse innovative ways of doing a colonoscopy and the feasibility of undertaking these procedures.

The case study features trial manager Georgina Gardner providing a background to the study and talking about how the two members of the public made a difference.

Georgina said: “There were things that the clinician hadn’t thought of and us as a trial team, about the effect that would have on the patients, so there were little personal things that did make a difference.”

Involving People Network members Bob McAlister and Jeff Horton were the two patient representatives that were involved. They have shared their personal perspectives on being involved, why they decided to get involved and how public involvement plays a key role in research.

To read the full case study, please visit our website.

You can also watch films of Georgina, Jeff and Bob talking about their experiences and the CONSCOP study on our YouTube channel.

Rosie Hagland
Public Involvement and Engagement Administrator
First Steps Training

Everything we do at Health and Care Research Wales is underpinned by the belief that the people of Wales have a key role to play in improving the quality and relevance of research. We want to create an environment in which all health and social care research that takes place in Wales happens with the public, for the public.

The First Steps training is an interactive course developed for joint audiences:

- Researchers who want to improve their understanding of user/public involvement in research and how it will benefit their research.
- Involving People Network members who want to increase their understanding of user/public involvement in the research process and to expand their research knowledge to help in their role.

The course includes an overview of the research cycle and lay involvement, a discussion of service user roles and responsibilities and practical tips for effective involvement. It was originally designed by Macmillan and has been adapted for our audience in Wales.

Its current format is a half day workshop that is co-facilitated by network members and the Support and Delivery Centre team. The course was due to take place in North Wales last month but was unfortunately postponed due to the snow. Nonetheless, we have since been able to review and reflect on our capacity for delivering this training and we are hoping to develop training for network members to help us provide the course in the future. The new date in North Wales is 14 June 2018 and here is the link for further information: ‘First Steps: members of the public and researchers working together’.

New training resource for researchers

Next steps handbook

The next steps handbook can be found here. It has been developed for researchers including, but not limited to, those who have attended the face-to-face training.

Attendees of the course requested a tool they could use to inform their practice after attending the course. The handbook was developed by the Public Involvement and Engagement team with input from the training team and has been reviewed by the network member facilitators of the course.

Take a look and see what you think. The Public Involvement and Engagement team develop tools, through consultation, to assist researchers. Please email any comments to research-involvement@wales.nhs.uk to help the team continue to improve.
Still involved: New national standards for public involvement arrive

In late November 2017, I attended the ‘Involve at 21’ conference at Church House, Westminster which had the aim of celebrating the progress of public involvement (PI) in research and considering the opportunities ahead.

As a network member tasked with some development work in respect of future public involvement in research, the conference was particularly interesting and relevant for me. You can find out all about the conference here: http://www.profbriefings.co.uk/involve2017/

Throughout the day, although a large amount of content was covered, there was plenty of evidence of public involvement in health and social care research. I was taken aback by the scale and layers of public involvement across England and I did not envy anyone trying to coordinate it.

The display stands also proved very interesting, providing opportunities to have direct ‘worker’ chats on the detail of involvement projects. I myself was there to represent the Public Involvement Standards group to further our consultation on the draft standards. A number of delegates took the opportunity to meet us and discuss the proposals.

There had been 677 written responses to the circulated draft standards and by most measures this was notable, showing the interest in our efforts to give guidance in respect of what should underpin meaningful public involvement. As I have said in a previous newsletter I, as a member of the public, have been a full part of this development.

The standards are currently being launched and you can find full details here: https://sites.google.com/nihr.ac.uk/pi-standards/home.

Whether you are a researcher or member of the Involving People Network, have a read and consider how they measure up to your experience of being involved in research. They mainly relate to basic undertakings and good practice, for example:

• Are your views heard and recorded in Public Involvement meetings? (Standard 2, Indicator 4 of ‘Working Together’)

• Is your availability considered when meeting dates /times are set? (Standard 1, Inclusive Opportunities, Indicator 1.2)

There are six standards and a number of indicators for each. It is important to make sure your involvement meets these standards. There is still time to feed back on their practical fit and ease of use via the network.

Bob McAlister
Member of the Public Involvement Delivery Board
Since holding the peer support workshop at the 2016 Involving People Network Annual Meeting and undertaking training, a meeting has been held with network members to provide feedback and input into the development of the peer support model.

The day was attended by network members, long standing and new, allowing for a broader selection of responses. There were discussions around what peer support is, culminating with an agreement that peer support is used to develop skills, build confidence and increase social networks.

The group also discussed the various models of peer support and the potential advantages and disadvantages within the network. There are three main ways of delivering peer support; one to one, one to many, and group - all of which have good and bad points.

It was suggested that a mixed model could be used for network members, but there was agreement that it should not be forced. It is important people feel comfortable with the person to whom they would be looking for support.

As a result of these discussions, business cards have been developed for network members to share their details with each other and actively provide peer support without pressure. Additionally, network members were encouraged to interact with each other at this year’s Involving People Network Annual Meeting, by giving them space away from the conference to network and share contact details.

Moving forward, it is not necessary to have a rigid peer support system. Instead there is a system in place, managed by network members, that allows them to exchange contact details to share knowledge and experience.
The key priorities at CADR include:

- understanding and reducing the risks for dementia
- developing age friendly communities
- maintaining independence and wellbeing
- providing cost effective health and social care

To complement the diverse research skills in the centre, CADR aims to harness the wisdom, skills and experiences of older people and those affected by dementia and use research to address the priorities of the centre and challenge the dominant negative discourse that can lead to prejudice, stigma and ageism.

Bringing a research project to life can often be a long and complicated journey. Engagement and involvement activities are in place to ensure that the research questions that are important to stakeholders match the expertise of researchers and collaborators at the centre. Although research bids do not always result in funding, the ideas that are produced continue to inform the research teams.

A public involvement and engagement event

In May 2016 CADR co-hosted ‘Loneliness in later life: Research, Engagement & Impact’ with the Wales Institute of Social and Economic Research, Data and Methods (WISERD),
Emerging Researchers in Ageing (British Society of Gerontology) and Ageing Well in Wales.

The event brought together academic researchers, early career researchers, older people, people living with dementia, community project teams, service providers and practitioners to discuss key issues around loneliness and social isolation in later life.

The workshop discussions were used to help with the development of a practical idea for an innovative assessment tool to match social, psychological and service needs to local solutions.

A bid that included additional feedback from older people was submitted to NIHR in 2016, and although unsuccessful now looks as though it will be developed with a commercial partner.

Ideas from this and other consultation events, with older people and people living with dementia, helped to develop another related bid that was submitted to the Medical Research Council in January 2017.

Another hugely positive outcome following similar workshops including a presentation by a CADR network member describing his lived experience of loneliness has prompted the production of a booklet ‘Making a Difference’ about loneliness which has been distributed widely, including in all branches of Barclays Bank. An animation by Dr Vanessa Burholt and Dr Deborah Morgan at Swansea University was developed, exploring the connection between cognitive impairment and loneliness. The animation suggests ways in which we can support people in wider society who are experiencing loneliness to give them a greater quality of life.

There is common belief that dementia contributes to withdrawal from social interactions and activities.

25% of people who participated in the assessment were identified as lonely.

Social networks and friendships help us to feel happier and healthier.

Making a Difference
A pocket guide to help you deal with loneliness.

Ensuring Wales is a good place to grow older for everyone.
The North Wales Dementia Network

In 2016, a ‘dementia supportive practice community’ was established in North Wales by Dr Catrin Hedd Jones. The project was initially funded through the Economic and Social Research Council (ESRC) Impact Acceleration Award, with additional support from CADR, and many other partners.

The North Wales Dementia Network brings together individuals personally affected by dementia and people working in academia, health, social care and the third sector to share knowledge and discuss new ideas. Members initially used informal art activities to break down traditional barriers.

People living with dementia are integral to the success of the network, they are partners on the steering group, have presented at the series of meetings and conferences and continue to both inspire and challenge others in the network.

Themes discussed at the cross county meetings included: effective signage, ensuring access to support, the latest in research and peer support. Groups on social media have also enabled members to share news and best practice between meetings.

A number of research themes have been put forward and developed in partnership; these include the Friendly Face initiative, a volunteer peer support under the leadership of Teresa Davies and focus groups on bilingual access to dementia support.

The network also made key contributions to the consultation on the first Dementia Action Plan for Wales, hosting meetings where individuals affected by dementia could give feedback.

A conference, ‘Living with dementia in North Wales - we’re in it together’, took place to celebrate the work of the network in January and a national conference was held in Llandudno on 7 March 2018.

The network is testament that people can come together to tackle dementia in partnership irrespective of location, roles or experience.

“ We are in this together. ”

A network member and her partner using art to illustrate how the meeting had brought “sunshine to a frosty situation” although her partner still felt he was “going round in circles".
Keeping people informed

Between CADR’s three centres there is always an abundance of news, publications and calls for contributions and we want to keep people informed about these research activities and their progress.

• The CADR website lets people know about our current and past research, events and publications. It includes a suite of presentations that members of CADR are happy to present to community groups.

CADR supports Join Dementia Research, an easy-to-use service to match up volunteers interested in taking part in dementia research with researchers looking for potential participants.

There are currently 93 research studies open for registration in the UK, spanning prevention and diagnosis, new treatment, or surveys aiming to improve the quality of life for people with dementia and their carers.

Anyone, with or without dementia, over the age of 18 can register as a volunteer or sign-up for someone else as long as they have given their consent.

Sign up today at:
www.joindementiaresearch.nihr.ac.uk

• We host a free public monthly seminar programme, alternating through our centres, and which can be supported by live video links.

• Sign up to our newsletter to find out about upcoming events and opportunities to join research activities and give feedback.

• A lay summary group has recently started to help us to develop better ways of disseminating research findings in more accessible ways.

• We support a variety of dissemination and engagement activities including holding a Q & A session at a dementia relevant film screening (Away From Her) in Cardiff, attending events, and appearing on television and radio to break down barriers around dementia and ageing.
• We work with Ageing Well in Wales (hosted by the Older People’s Commissioner) and other partners to help us identify individuals and organisations who can contribute to our work in a lay capacity and that reflect our diverse population.

• Our annual report has more details and highlights of our research activities, outcomes and impact.

What next?

Over our next two year funding period, we want to make improvements to supporting those who are involved in our work. Based on feedback, we will better target information and invitations based on members’ preferences, interests and skills and support those who are not typically involved in our work to do so. We also have new and developing research areas that will be looking for lay people with an interest in these areas.

New research areas

Work, retirement and ageism

Lead - Associate Professor Martin Hyde

As our workforce continues to age, governments across the world are looking for ways to enable people to remain in work for longer and to retire successfully.

To help stakeholders in Wales understand and respond positively to these challenges and opportunities, this research will look at a range of issues that older workers face such as ageing well in work, age diversity in the workplace, precarious working/gig economy, ageism/age discrimination and retirement planning.

This work links to the Ageing Well in Wales commitment to improving labour market outcomes for older workers. It also links to the UK government’s ‘fuller working lives’ agenda and builds upon the global drive, spearheaded by the World Health Organisation to combat ageism.

To deliver on our goals we aim to carry out the following:

• Build stakeholder-led research development groups

• Establish a network of employers in Wales who are committed to improving labour market outcomes for older people and/or tackling age discrimination

• Connect with other organisations and networks in the UK and internationally who are addressing similar issues

• Identify programmes that deliver improved labour market outcomes for older workers and/or reduce negative age stereotyping

• Organise and participate in workshops, seminars and conferences in order to develop projects to improve labour market outcomes and tackle age discrimination

• Mentor early career researchers and PhD students
A Social Care Innovation Lab – ‘Seeking Serendipity’

Leads: Diane Seddon, Steven Baker, Fiona Verity

Members of CADR, in collaboration with the Alternative Futures Organisation are developing a Social Care Innovation Lab (#SCIL) that provides unique opportunities for individuals to develop research and practice development ideas.

Acting as a connecting hub, #SCIL is a new organisation of people, with a broad range of academic and practice-based experiences, working together because of their shared interest in making a positive difference in the complex field of social care.

The ethos of the Lab is underpinned by Warren Weaver’s work which suggests that we should “stop thinking of science in terms of its spectacular successes in solving problems of simplicity” and focus on the complex social situations that people experience, finding real solutions to some of the most important problems faced by so many.

Appreciating complexity can lead to serendipitous results that cut through the noise of traditional research straight to what matters, including collaborations that focus on improving care and support for older people and their carers and creating the right environment for new ideas to emerge.

It is hoped that the Innovations Lab will not only promote research development activity and build capacity but, in the future, also facilitate knowledge exchange.

There were opportunities to hear more about the Lab at the Involving People Network Annual

Meeting in March 2018, when Diane Seddon and Steve Baker were exploring with delegates how best to engage with the general public and involve them in the Labs work going forward.

If you are interested in being involved in this exciting new world please get in touch with Diane Seddon d.seddon@bangor.ac.uk

Public involvement and engagement is core to CADR’s work and we want to encourage older people, people living with dementia and their families and carers to become actively involved in CADR at all levels.

If you would like to get involved in any of the areas mentioned in this article please contact the researcher leading the area you are interested in or for more general enquiries contact cadr@swansea.ac.uk
Involving People Network Annual Meeting 2018
Involving People Network

The Involving People Network brings together members of the public from across Wales who are interested in working with researchers to improve treatments and care.

If you’d like to join the Involving People Network, please contact the Public Involvement and Engagement Team, phone 02920 230457 or email research-involvement@wales.nhs.uk

For more information visit www.healthandcareresearch.gov.wales/involving-people-network/

Involving People Network Annual Meeting

I was both surprised and delighted to be asked to contribute to the Task and Finish group for this year’s Involving People Network Annual Meeting. From a researcher’s perspective I was not sure what my contribution would be or how it would fit in with the ideas the network members had for their annual conference. However working alongside them proved to be a really enjoyable experience, resulting in some fantastic ideas for a conference based around co-production. It also highlighted that ultimately, we are all working towards the same goal, to make a difference. Co-producing the conference in this way helped reinforce this.

The buzz in the room on the morning of the event demonstrated how working together can achieve great things. The quality of the presentations was extremely high and emphasised the importance of working together at all stages of the research process, bringing expertise from all areas to enhance the quality and relevance of the work we do. This was illustrated beautifully by Dr Christine Dobbs and Alex Drummond, who spoke about how public involvement was woven throughout the Trans* Ageing and Care Project. The With Music in Mind choir, which itself was developed as a result of a research project, represented a fitting finale to a fantastic co-produced conference. I can’t wait for next year.

Deborah Morgan
Researcher
Swansea University

The Involving People Network Annual Meeting in March was an upbeat and positive event packed with good practice on public and patient involvement in health and care research in Wales.

Any cynicism around the new National Standards system as being a bit bland was easily dispelled with a proficient presentation by Jon Bisson and colleagues. The system requires each Standard to build to the next one, rather than standing alone. Test Bed pilot sites using Before and After assessments also ensure the new Standards are a dynamic means to encourage continued quality.
In this section we'll be sharing questions that we have received from Involving People Network members, where the answers may be of interest to the network as a whole.

**What training is available?**

Our extensive training programme provides high-quality, needs-driven training delivered across Wales by our team of expert facilitators. The training is open to researchers, health and social care professionals, or other research team members employed by the NHS or within a university. Members of the Involving People Network can access our training courses free of charge.

The available training covers the following subject areas:

- Communication skills in research
- Good Clinical Practice in research
- Informed consent and essential documents
- Public involvement in research
- Research methods
- Research study set up

Find out more about our training courses and how you can sign up.

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**Your Questions Answered**

Improvement in patient and public involvement in health and care research. The initiative being comparable across the UK’s 4 nations is a further advantage.

In other plenary sessions, the opportunity to put faces and voices to the Involving People Network and Co-production teams was useful. Presentations on ongoing public involvement in research were encouraging, with promises of more where they came from.

Most of the stands rose to the challenge of being interactive and kept participants busy in the breaks. The memorable ones for me were the Exercise for All therapy bicycle, ingredients for a good public involvement soup (the PRIME SUPER group) and the 23 chromosomes game (Wales Gene Park).

The layout of the venue was exemplary, with the plenary area conveniently alongside the stands and refreshment areas. The screens half way back in the sitting area were a thoughtful addition for a sense of involvement for those sitting further back, or not wanting to push themselves to the front.

Last but not least, there was a good balance between academics and public/patients working together in ‘mutual respect’. This was not only in numbers but also in qualitative contributions to conference sessions. It was appropriate that the last word should be had (in song) by the public participation singing group With Music in Mind leading the gathering in Hen Wlad Fy Nhadau.
HealthWise Wales and public and patient involvement

HealthWise Wales is a research study, led by Cardiff University and backed by the Welsh Government, which will help NHS Wales plan for the future. They are asking people aged over 16 who are living in Wales, or accessing healthcare in Wales, to answer questions about their health and wellbeing so they can contribute to research on the prevention and treatment of conditions such as coronary heart disease, diabetes, cancer, mental health and dementia.

Public and Patient Involvement (PPI) Representatives

HealthWise Wales aims to create a partnership between researchers and the public as equal contributors. It was conceived and is managed with the public, for the public and greatly values the views of the PPI representatives. The public members take part in the Executive Management meetings, promoting the project at events and two PPI reps, Jeff Horton and Helen Gerrard, attend the monthly Project Team meetings. They contribute their ideas to the project planning and ensure the work will be relevant and understood by the public. Both representatives support HealthWise Wales, not only by attending the meetings, but also by reviewing all public facing promotional materials and checking the research questionnaires. Jeff and Helen have also been involved in the production of the new television adverts which aired in February. This helps to ensure messages are pitched effectively to members of the public.

Medical students

 Twice a year medical students join the HealthWise Wales Cardiff University research team to undertake a practical project. The student selected component (SSC) of the medical degree at Cardiff University is an opportunity for students to develop innovative research in topics of their choice in collaboration with a number of clinical and academic experts based in Cardiff. HealthWise Wales introduces students to population research and working with the public.

• In December 2017, a group of five second year students spent a week with the HealthWise Wales team. The task for this group was to: Investigate how HealthWise Wales has been used by a researcher

• Prepare a piece utilising the 10,000 cohort analysis to effectively disseminate the early results from HealthWise Wales to members of the public in a manner that is likely to engage the public.

The student group were asked to test their messaging on members of the public prior to finalising.

The group presented their findings to members of the HealthWise Wales Team, and HealthWise Wales Champions (public representatives). The HealthWise Wales Champions were positive in their feedback to the students, and
felt the summarised information was targeted appropriately.

The messages produced by the students will now be used by HealthWise Wales in their newsletter and in future public relations campaigns. Their five key findings are shown in this diagram:

If you are over 16 and living in Wales we need your help. To join, or find out more, please visit: www.healthwisewales.gov.wales or phone 0800 9 172 172 08:00-18:00 Monday-Friday.
My name is Radha Nair-Roberts. I am 41 years old and I have Secondary Progressive Multiple Sclerosis. Though I was first diagnosed at the age of 21, the illness didn’t immediately affect me seriously – I’ve been able to travel, study for several postgraduate degrees at university, work as a scientist, marry and start a family.

Unfortunately 2015 saw a major relapse in my neurodegenerative condition and since then I’ve experienced a progressive deterioration in my mobility. I can no longer do many of the things I once enjoyed or walk unassisted. To do normal everyday activities, I need to use a powered wheelchair.

Obviously the sudden deterioration in my condition came as a huge shock. My ability to do many mundane activities, which I’d taken for granted all my life, vanished. My family life changed forever too, as I could no longer physically care for my young children or participate in their activities in the same way. I had no choice but to give up my job as a stem cell neurobiologist. I found myself spending more time at home with no real purpose and no intellectual connections with the community around me, beyond medical appointments and needs assessments from local government.

Faced with pain and immobility, a sense of being worthless inevitably led to depression. I craved intellectual stimulation, a sense of purpose and a chance to work with like-minded people again. Thankfully an opportunity to join the Involving People Network came up by chance, and has since given me all these things I yearned for, and more.
As a member of the Network, I have had an opportunity to learn about cutting edge medical research to help improve care and service provision for people in society suffering from illness, like myself. Better still, by signing up for research opportunities (advertised in the weekly bulletins), I’ve become a member of a number of patient and public involvement panels. This means I get to attend meetings with actual researchers and health care professionals involved in medical research. I have been able to use my expertise and research skills to help steer research projects and service design.

Far from being excluded as simply a “patient” or “member of the public”, I have truly felt that my voice and my experiences as a patient are valued and can make a difference. I’ve had a chance to get out of the house and meet new people, fellow patients and professionals alike. One of my greatest Involving People Network experiences has been helping in the design and organisation of this year’s annual meeting (Co-production: public voices in action).

**Exercise for All Wales (EfA Wales)**

I have also started my own community association – Exercise for All Wales (EfA Wales) to tackle issues with access to genuinely inclusive fitness in the community. Venues for community exercise are not always accessible and there is a lack of staff trained to help the disabled to exercise. Exercise and fitness are very important to people suffering long term mobility impairment, both physically and mentally.

As grass-root advocates for disabled exercise we have been able to raise our voices; EfA Wales have so far submitted evidence to the Welsh parliamentary review of Health & Social Care, presented at several conferences (including an interactive exhibition at this year’s Involving People Network Annual Meeting) and met with health care professionals in government, such as the Deputy Chief Medical Officer for Wales. We are also collaborating with Better, the company running Cardiff’s leisure centres, to improve their disabled facilities.

Achieving real change is challenging, so our work continues. It will not end until there is true equality of opportunity to access exercise for the long-term disabled.

**Dr Radha Nair-Roberts**

Network Member
Research engagement events - a snapshot of the last six months

Ageing Well in Wales
Celebrating Communities event with the Centre for Ageing and Dementia Research
16 January 2018

A celebration of some of the fantastic work taking place in Welsh towns, villages and cities to make them good places to grow older, as well as an opportunity to share knowledge and develop new ideas on how together we can make Wales a nation of age friendly and dementia supportive communities.

Wales Cancer Research Centre
Tackling Cancer Together
25 November 2017

Members of the Wales Cancer Partnership met to highlight and raise awareness of the excellent cancer research happening in Wales. Activities included interactive stalls, a lab-themed escape room, talks about cancer research, prevention, early diagnosis, treatment and support, and a virtual reality lab tour.

NIHR INVOLVE at 21
28 November 2017

Bringing together people with a passion in public involvement in health, public health and social care research, the conference celebrated the progress of public involvement in research and considered the opportunities ahead. The day was also an opportunity to hear about the development of the Public Involvement Standards for Research.

Wales School for Social Care Research
Second Annual Conference
14 February 2018

‘The Time is right’: Strengthening links between social care research and practice. Exploring the dynamic connections between social care research and practice and how links can be strengthened in ways that create positive impact.

Don’t forget to keep an eye on our online noticeboard which we regularly update to keep you up to date with all the latest news, events and opportunities across the research network.
Public involvement statistics: a snapshot
August 2017 – January 2018

34 new network members

23 researcher requests for public involvement

53 network members were recruited to take part in opportunities