Welcome to the first edition of ‘Your Involvement Matters’, sharing news and stories about public involvement in, and engagement with, research in Wales. You can find out a bit more about how the newsletter name came about on page 8.

We want this newsletter to belong to everyone, so if you have an idea for a news item, article or topic you’d like to see featured, please get in touch!

A message from Barbara Moore
Senior Public Involvement and Engagement Manager

What’s on the horizon in 2016?
Last year we saw some important changes in health and social care research in Wales, especially in terms of the role the public will play going forward.

Since the launch of Health and Care Research Wales in May, there has been an emphasis on the public being at the heart of research in Wales.

It’s exciting to see actions developing from this ambition - here are some of the activities the Public Involvement and Engagement Team are excited about for 2016.

10 years of the Involving People Network
In 2016, we’ll be celebrating 10 years of the Involving People Network, which was set up to provide a way for members of the public to connect with researchers and work together on research studies.

This year we’ll be reflecting on the Network’s achievements, but also looking forward to its continued development as a vital part of Health and Care Research Wales’ ambitions for public involvement in research. Read more about the Network on page 10.

HealthWise Wales
This is an exciting new study that the population of Wales will be invited to take part in, making a difference to the future health of their family, friends and communities.

Members of the public, especially Involving People Network members, have been involved in the development of the study which launches to the public at the end of February. Read more about HealthWise Wales on page 17.

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Online Public pages

New online presence for the public
The new public section of the Health and Care Research Wales website brings together, for the first time, a range of information and resources for the public.

The new pages will make it easier for people to learn more about research, to find out how to take part in research and to access opportunities to influence research taking place in Wales.

The section has been tested during February and will be finalised in March. We’ll have an update in the next edition of ‘Your Involvement Matters’.

Public Delivery Board
The establishment of the Board shows the commitment from Welsh Government to ensure that members of the public are involved in decision making at all levels. It is responsible for overseeing public involvement and engagement in health and social care research in Wales and held its first meeting last year.

There are seven members of the public on the Board, including the Chair, and we’re excited to see the impact of their work over the next few years. Find out more on the Health and Care Research Wales website.

Reviewing public involvement and engagement services and support
A major piece of work this year will be making sure the Public Involvement and Engagement Team can contribute to the Government’s aim to increase the number of people involved in health and social care research, and to ensure that the involvement is meaningful.

We also need to ensure we are providing appropriate advice and support to the health and social care research and development community in Wales.

Over the coming months, the Team will be reviewing existing services and support. There will be a series of surveys, questionnaires, interviews and workshops which many of you will have an opportunity to contribute to, with recommendations of the review being presented to Welsh Government.

It’s going to be an exciting and busy year, and we look forward to working with you all along the way!
Your Public Involvement and Engagement Team

Ever wondered what the Public Involvement and Engagement Team get up to on a daily basis? In December, we kept a diary of our activity to give you a brief insight into our roles.

Advice and guidance
We are regularly contacted by professionals across Wales who either need our services or want advice.

In December, this ranged from Welsh Government and Health Board colleagues seeking advice, to PhD students and researchers who we worked with to develop adverts for their public involvement opportunities.

Strategic work
We met with Welsh Government colleagues to start planning a review of the public involvement and engagement services we provide.

Networking
We had requests to meet with two of the Health and Care Research Wales Research Centres to discuss and agree on specific pieces of work.

We also had meetings with colleagues in England and third sector colleagues in Wales. Natalie travelled to London to attend the NCRI consumer forum, of which she is a member. It gives us a great opportunity to promote the public involvement and engagement services and support we offer.

We also accepted invitations to present at three conferences over the next few months.

Communicating
We invited one of the researchers who had involved service user assistants in their work to share their experience with us and develop an article.

We submitted an abstract about the public involvement and engagement service in Wales to the UK R&D Forum, for their conference in May.

Communicating with Involving People Network members is an important part of our role. We sent out five weekly bulletins, the December edition of our newsletter and asked members to give feedback about online services.

Involving People Network support
During December, we supported 25 Network members to take part in opportunities at seven different meetings, this included a scientific steering group, research development groups and a Health Board risk review meeting.

It was a quiet month in terms of advertising new research opportunities, with expressions of interest being collected for just one opportunity.

However, supporting Network members with their expenses and payment for time is a major part of our monthly work and, in December, 64 finance claims were processed.

Working with Support Centre Teams
The Team were part of the Working Group developing the Public section of the Health and Care Research Wales website and we were invited to give our comments on the designs.

Another key piece of activity was working with colleagues from other teams in the Support Centre to plan the Involving People Network Annual Meeting.

We had our monthly Team meeting, which gives us the opportunity to share information and plan for the months ahead, and with Christmas approaching the office held a Christmas jumper day to raise money for charity.
February saw our first Involving People Network Annual Meeting as part of Health and Care Research Wales. It was an inspiring day with over 100 Network members, researchers and other professionals joining us from across Wales.

Many thanks to Geoff Tanner and Henry Yeomans, Involving People Network members, who did a fantastic job of chairing the day and keeping us all to time!

And thank you to all who attended for making the day a success. For those of you who were unable to be there, please read on.

Our first ever interactive session

It’s always our hope that the Annual Meeting will inspire delegates and bring together people who are passionate about research, and our first interactive networking session really made this happen.

Eight Health and Care Research Wales funded organisations took up the challenge to inspire delegates with a range of interactive stands. From creating a bead bracelet based on gene sequences to labelling parts of the body – there was plenty going on for everyone to get involved in.

It was great to see people network, share ideas and learn a bit more about research taking place around Wales. Congratulations to Wales Gene Park who were voted the most engaging stand by delegates.

Opening remarks and presentations

As always, we’re grateful to all our presenters for giving their time to be part of the event!

Our opening remarks were given by Professor Jonathan Bisson, Director of Health and Care Research Wales.

Professor Bisson spoke about the pivotal role the Involving People Network has within Health and Care Research Wales to ensure that public involvement and engagement is central to what we do and visible in all elements of it.

Meet the Public Involvement and Engagement Team and colleagues

The Team provided an overview of their roles, the achievements of the Involving People Network over the past 10 years, and discussed plans for the future.

They were then joined on stage by Angela Martin, Welsh Government, and Andrew Rix, Chair of the Health and Care Research Wales Public Delivery Board.

EDDY – a public involvement case study

Julia Townsend, Researcher, and Stephen Thomas, Involving People Network Member, shared their experience of public involvement in the EDDY study.

Palliative and End of Life Care Priority Setting Partnership

Dr Sabine Best, Head of Research, Marie Curie, discussed a survey carried out with James Lind Alliance to identify research priorities for palliative and end of life care, how the top ten priorities were identified from the results and what’s happened since.

Sabine kindly acknowledged the contributions made by the Involving People Network to this work.
Research Champions
Lee Eynon, National Centre for Mental Health, and Laura Gernie, Research Champion, provided an uplifting end to the event. The presentation highlighted the importance of members of the public not only taking part in research but also championing it.

Presentations from the event can be found on the Health and Care Research Wales website.

Workshops
The Annual Meeting wouldn’t be complete without our workshop sessions, which always provide an opportunity to share ideas on a set topic. This year there were two workshops, one focussed on prioritising training for public involvement in research and the second on prioritising peer support for public involvement in research.

Lots of fantastic ideas were collected and these will be shared through the public involvement and engagement newsletter in a few months’ time. We’ll also keep you up to date on how we use these ideas to inform our future plans.

Newsletter competition
Congratulations to Candida Lovell-Smith who suggested the winning name for our public involvement and engagement newsletter - ‘Your Involvement Matters’. Network members were asked to suggest ideas and three names were shortlisted by the Annual Meeting Task and Finish Group, with delegates at the event voting on the one they liked best.

Results from our interactive session
Thank you to everyone who left messages to share with other delegates. We haven’t got room to print them all, but here are a few!

Why does research matter to everyone?
Research matters to everyone because we are all citizens with a stake in society, and the best research which produces evidence with real potential to improve the health and care of patients can only happen with all of our involvement.

Angela Watkins, PRIME Centre Wales

Why is public involvement in research important?
Sometimes you have to stand in someone else’s shoes to know what it is really like, my voice gives you, the researchers, that opportunity and hopefully together we can make a difference, something we all want.

Malachy O Donnell
Involving People Network Member

Pledges to promote
We asked delegates how many people they pledge to promote the Involving People Network to this year:

- 6 delegates pledged to tell 1-2 people
- 23 delegates pledged to tell 3-5 people
- 19 delegates pledged to tell 6-10 people

Research priorities
Colleagues in Welsh Government set a question for delegates - which area should be a research priority?

- Prevention - 42 votes
- Diagnosis / treatment - 15 votes
- Cure - 11 votes

Why did you join the Involving People Network?
Since joining in 2010, I have been privileged to work with and meet some amazing people that I wouldn’t necessarily have met in my working life. I feel passionate about research and my role as lay representative.

Sian C. Jones
Involving People Network Member

Why does research matter to everyone?...
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.

Members have a wide range of interest areas from cancer, mental health and diabetes, to ageing and emergency care.

Network members have access to:

- the latest opportunities to get involved in research in Wales
- a wide range of training
- support with expenses and payment for time
- regular newsletters and bulletins
- support and guidance

Join the Involving People Network

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/

New version of the Code of Conduct

Over the next few weeks, Network members will receive a copy of the revised Involving People Network Code of Conduct in the post.

It has been updated to be fit for purpose for the Health and Care Research Wales Involving People Network, and to remove references to NISCHR CRC in the previous version, which no longer exists.

Please sign this document and return it to the Public Involvement and Engagement Team promptly, using the stamped addressed envelope provided.

Congratulations to our Building Research Partnerships facilitators

Congratulations to Alan Meudell, Sian Jones and Jacqui McCarthy who were awarded certificates of achievement for successfully completing their training to become facilitators of the Building Research Partnerships training day.

Ann Yeomans

Ann died peacefully on 14 February 2016, following a relatively short period of illness in hospital.

Since joining the Involving People Network in January 2011, Ann has contributed to a large number of research groups across Health and Care Research Wales.

A previous career in Higher Education provided Ann with a good knowledge of health and social care research and this knowledge, combined with an enthusiasm for service user involvement in research drove a clear passion in Ann.

As a sufferer of Ankylosing Spondylitis since the age of 19, and with diabetes, Ann was able to share her experience as a service user to influence research and champion several pieces of work.

Ann was a bright and energetic character, a strong but warm lady who was well respected and very much liked by the Public Involvement and Engagement Team, colleagues and Network members. Our thoughts are with Ann’s family, including her husband, Henry, also a member of the Involving People Network.

Alwyn Rowlands

Alwyn was a valued, longstanding member of the Network, having joined in January 2009. Alwyn’s strong commitment to public involvement in research was demonstrated through his active work as a member, contributing to numerous research groups across Health and Care Research Wales over the years. Alwyn was a proud Welshman and worked tirelessly to support the promotion of the Welsh language in research planning and conduct.

A strong advocate and champion, Alwyn volunteered with a number of charities and support groups across a range of health and social care areas. For example, Alwyn volunteered with the Stroke Association, sharing his experience as a stroke survivor. Before Alwyn retired as a result of his stroke, he was a police officer, serving in North Wales Police.

Alwyn was a true gentleman with many qualities including a warm nature and a good sense of humour. Alwyn was very well known and liked by the Public Involvement and Engagement Team, fellow Network members and colleagues across Health and Care Research Wales. Thoughts are with Alwyn’s family.
Your Questions Answered

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.

Who has access to submitted expressions of interest?

Network members submit expressions of interest for each research opportunity they are interested in being involved in.

Access to expressions of interest submitted by Network members is secure, restricted and dealt with confidentially by the Public Involvement and Engagement Team.

We adhere to the data protection act and to NHS records management policy.

Once expressions of interest have been reviewed by the Team, they are sent onto the researcher / opportunity Lead.

This process is always explained in our research opportunity adverts.

What happened to Wales Epilepsy Research Network and the other Registered Research Groups in the new infrastructure?

Some of the topics and themes covered by the NISCHR Registered Research Groups became part of the Health and Care Research Wales Research Centres and Units.

The five Centres are: Wales Cancer Research Centre; National Centre for Mental Health; Centre for Ageing and Dementia Research; PRIME Centre Wales (the Wales Centre for Primary and Emergency Care Research); and the National Centre for Population Health and Wellbeing Research.

The three Units are: Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit; Wales Kidney Research Unit; and the Diabetes Research Unit Cymru.

Epilepsy research is now carried out as part of the BRAIN Unit. Find out more about the Centres and Units on the Health and Care Research Wales website.

However, those topics which are not covered by the Centres and Units will be championed by Specialty Leads who are currently being recruited by Health and Care Research Wales.

Researcher interview: Rhiannon Phillips

Rhiannon Phillips is one of a group of researchers from Cardiff University, Swansea University, and Public Health Wales, who have an interest in supporting mothers to breastfeed.

In 2013, they responded to a funding call question from the National Institute for Health Research - can you use a peer support model to help mothers maintain breastfeeding?

The idea behind the peer support model is that mothers who have already got experience of breastfeeding provide support to other mothers, on the basis that you develop a better connection if you are talking to someone who has actually been through a similar experience to yourself.

The Research Team knew there was a huge variety of peer support for breastfeeding going on.

They wanted to get a better understanding of what was already happening, to think about how those programmes work, and to work out what it is about one mother helping another mother that can make that support effective.

Rhiannon spoke to us about the study and how members of the public have been involved in its development.
So those were the sorts of issues we’ve been working out with mothers who are breastfeeding, health professionals, and mums who are already working as breastfeeding peer-supporters.

We’re running this study in three different sites; in Cardiff, Cwm Taf and in Blackpool. We’ve got peer supporters working in each site who we’ve trained, and we’re providing regular supervision. They are now working out with local services going to see mums.

So what we will do next is to go and talk to mums who took part in the project and their peer supporters, and find out how that went. We are mapping out how many people have actually taken the service up, how often they see their peer supporters, and whether they found it useful.

We are also looking at the best ways to actually measure breastfeeding, for example, by phoning mothers to ask them or by using information that’s routinely collected by midwives and health visitors.

So at this stage, we’re looking at whether it’s possible to provide and evaluate this type of service. We are not at the stage of looking at whether it actually worked or not in terms of changing breastfeeding rates just yet, but that’s our next step….

What would you say is the main reason you have been involving people in your work, in this particular design stage of the programme?

We’ve done a lot of stakeholder engagement to actually design the programme - finding out what people want, what they are going to find helpful, what the style of communication and ethos of the programme should be, how it should be delivered.

We’ve been running interviews, focus groups, stakeholder workshops, and of course we’ve got Siân [Involving People Network Member] who is our public representative co-applicant for this project.

I think when mums have got a new baby they’ve got an awful lot of things going on. So without actually engaging with mothers and talking to them about the proposed programme, we would run into real problems.

What can happen with research is that you go and design an intervention, go out and test it and its effective, but then nobody uses it. And that might be because it’s too expensive, that it’s too complicated to integrate with local services, or that it’s not pushing the right buttons for the people who are using it.

So by actually getting this bit right early on, talking to the people who will actually use the service, we are designing it with that in mind. It gives you a much better chance of success in the end, and of actually making a difference to people.

So has the public involvement made a difference?

It’s completely changed the design of the intervention really, to make sure it fits well with people’s needs. We’ve designed this breastfeeding peer-support programme with mothers rather than for mothers.

Involving the public in this project has given us that understanding of the complexity of the context, you know, you understand more about the whole person. It’s not just about the breastfeeding, it’s about the situation that mothers are in at that stage of their lives, and the society around them.

What was really interesting was how much the mums and health professionals we talked to emphasised the importance of kindness, warmth, and not being judgemental when working with mothers with young babies - these were the features they wanted in their peer supporters.

One of the other things that was really influenced was how we give information to mothers. We are working in deprived areas in this project, so it was really important to us that we were communicating in a way that was very clear and accessible, so again our patient and public involvement helped us there….

And I think that’s helped us with the level of engagement that we’ve had with the project - we’ve been able to explain things in a way that actually makes sense to people.

Tell us a little about your public representative on the study.

We came to Involving People [now the Public Involvement and Engagement Team] to recruit somebody to be co-applicant for the trial.

Siân Regan joined our project at the early stages when we were still designing the study and bidding for funding. She is now involved with the management of the research project, and comes to our Study Management Groups.
Your Involvement Matters

REAL LIFE RESEARCH STORIES

There is absolutely no point in us running research that nobody then finds out about, sat in a report on somebody’s shelf looking pretty - that’s no use to anybody.

Siân has also helped to present in some of the stakeholder workshops, talking to stakeholders about what she does, because she’s also a peer supporter herself now, so that’s been fantastic.

Siân’s linked in with a whole network of mothers and peer supporters, she’ll often gather views for us from other people.

One of the things she’s helped us with is working out how we recruit peer supporters for our study, and Siân has helped us with communication with mums and peer-supporters through social networking sites and things like that.

What have you learned through the process of involving people in your research?

I’d say it’s gone far beyond our expectations really.

We wanted to involve mothers, service users, and other peer supporters right from the beginning, but I don’t think we’d appreciated how much of a team effort it would be. That’s been a really nice surprise, because it’s not just been somebody contributing the odd bit in a meeting or commenting on the odd document. It’s actually been much more integrated and involved, and we’ve had a lot of engagement.

What I would say is that it’s really important to get that involvement early, right from the point when you are starting to think about your research question and your design.

If your patients and members of the public can’t see the benefit of your research, then you really have to question whether it’s worth doing, if you see what I mean. At the end of the day, they are the people that we are working for really.

Patient and public involvement input is also really useful towards the end of a project, to help make sense of what we’ve found and plan the next steps. We’re looking to hold another stakeholder group towards the end of the study to say, right, this is what we found, what do you think? How should we let people know about this?

There is absolutely no point in us running research that nobody then finds out about, sat in a report on somebody’s shelf looking pretty - that’s no use to anybody.

So we have to work out how to get those findings out there, and working with patients and members of the public to find the best ways of doing this is crucial.

A final thought

People have a mixed bag of experiences of breastfeeding. To some people it’s really easy, enjoyable, and straightforward, but for other mums it’s actually really difficult and challenging. There’s a real will there amongst mums to share their knowledge and experience, and help other mums.

So it’s been a lovely project in that sense - so much enthusiasm and passion. It’s felt like a real team effort.

It hasn’t felt at all like it’s researchers telling other people what they want, it feels very much like it’s been co-created between us all.

“HealthWise Wales is a major new study that will involve people across Wales. Colleagues from the HealthWise Wales Team have provided the following update.

Unique research project shaping the future of healthcare in Wales

Key project team members from HealthWise Wales gathered at Cardiff City Stadium on Monday 1 February for an event hosted by Health and Care Research Wales. The team discussed how Wales is leading the way with the provision of this unique research project and delivered a progress update to the participants signed up so far.

The morning was opened by Andrew Rix, Chair of the Public Delivery Board, who addressed the importance of prudent healthcare.

He expressed how the future of healthcare is shifting toward prevention and a focus on a “better understanding of health issues to determine effective treatments for diseases affecting thousands, such as diabetes and cancer.”

Dr. Shantini Paranjothy, Scientific Lead, reinforced the public health challenges that Wales is facing.

“We know that there are not just biological reasons for ill-health but also environmental factors too. We can research how these factors interact to better understand how and where we can act to improve health outcomes.”

The project has exceeded recruitment targets for the pilot phase with 580 participants already signed up. These participants can look forward to receiving a questionnaire regarding diet in March 2016.

The audience then heard from Dr. Fiona Lugg and Julia Townson who spoke on the importance of the public’s involvement and how their opinions and help will shape the progress of the project.

“We have listened to those in our focus groups and actioned on these issues. One issue that surfaced is we need to be more transparent in our rigorous process of data safety and total confidentiality. We take this seriously and protecting our participants’ data is our key focus.”

A preview of the national media campaign due to launch in February was also shared with participants. This campaign will mark the start of the drive to encourage people to be part of this unique and exciting nationwide project and to sign up and complete a ten minute questionnaire about their lifestyle and health. Taking part in this research will help the NHS to plan for the future.

For more information and to join, visit the HealthWise Wales website www.gov.wales/healthwisewales

HealthWise Wales website

Doeth am lechyd
Cymru
HealthWise Wales

www.gov.wales/healthwisewales
Many thanks to Richard Stephens, NCRI Consumer Lead, who provides an insight into the work of the National Cancer Research Institute Consumer Forum.

“The National Cancer Research Institute (NCRI) Consumer Forum is a group of between 75-100 patients, carers and others affected by cancer (collectively known as ‘consumers’) who participate in various ways across all aspects of NCRI’s work.

NCRI involves consumers on every board, committee and workstream, and the NCRI Consumer Lead is a consumer rather than an Involvement professional.

The word ‘consumer’ was chosen in 2002 to indicate that all cancer research should have patients and carers as the intended beneficiaries.

The forum aims to foster a vibrant and collaborative community to work with NCRI as partners in cancer research; exchanging knowledge and expertise in a coordinated way.

Recruitment is to specific roles within NCRI, most commonly to be one of two consumers sitting on a Clinical Studies Group, managing the UK portfolio of trials in a particular cancer.

Those recruited are required to have some previous experience of involvement or participation in research, and we then provide two days of consumer-led Induction Training.

Further training opportunities are offered during the remainder of consumers’ time with NCRI, and when people finish serving on one group, NCRI is keen for them to remain within the Consumer Forum, but to go on and develop roles as consumers elsewhere, for example, for one of the NCRI Partners such as Cancer Research UK or Tenovus Cancer Care.

The Forum also produces its own work. Four posters have been produced looking at patients’ awareness of and willingness to be approached about research opportunities, as shown by the 60,000 or more responses to the annual National Cancer Patient Experience Survey.

The Forum works with Astra Zeneca to look at ways of supporting patients who choose to participate in early phase drug trials, and has designed its own Toolkit for Consumers sitting on academic committees.

The Forum also hosts a Dragons’ Den at the annual NCRI Conference, which is so successful that people have been turned away for four successive years.

The Den is for researchers to bring their ideas or challenges to small groups of consumers, friendly but critical Dragons who offer advice or possible solutions, with many remaining involved with that piece of research for some time afterwards.”

For more information about the NCRI Consumer Forum, please see www.ncri.org.uk/resources/ncri-consumer-forum/