Your Involvement Matters

June 2016

Spring has sprung and summer is on its way!
Welcome to the June edition of ‘Your Involvement Matters’ sharing news and stories about public involvement and engagement with health and social care research in Wales.

This newsletter belongs to all of you so please continue to get in touch with us with ideas for features. It has a dedicated section for answers to any questions we have received so please send us any questions you may have.

Have you attended any of the engagement events promoted on the noticeboard of the public page of the website? Would you like to share a summary of the event? Then let us know!

This edition features an update about the Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit.

Ten years of the Involving People Network

We continue to celebrate ten years of the Involving People Network and would like to invite those of you who have been involved with the network for the ten years to help us celebrate and publicise the anniversary by sharing your stories.

You may want to tell us what public involvement in research was like ten years ago, and what has changed and improved and what cause there is to celebrate! If this is you please submit your story in no more than 300 words, with a photograph if possible, to research-involvement@wales.nhs.uk; and we look forward to featuring your stories in future editions.

Launch of HealthWise Wales

The launch of HealthWise Wales took place in February and Network Members continue to be involved in its management. A HealthWise Wales update will be a regular feature in the newsletter, the latest article appears on page 20.

Workshop and website updates

We will be providing an update from the training and peer support workshops that took place at the Annual Meeting (page 4) as well as the results of the website survey (page 14).

Don’t forget your pledge

If you attended the Annual Meeting you may remember the engagement stand with plastic...
PUBLIC INVOLVEMENT NEWS

Please don’t forget your pledge, the dedicated public page of the website will assist you in promoting the Network, with information ranging from what research is, inspiring stories about public involvement to how to join the Network. You can find this and more on the public page of the website (page 14).

Working Groups

Public Involvement and Engagement is one of the 12 functions of the Health and Care Research Wales Support Centre. Working Groups are being created for each function to oversee operational delivery. Membership of the groups will be established over the coming weeks and will include relevant stakeholders.

For the Public Involvement and Engagement Working Group this will include Network Members. The group’s first task will be to advise on a review of the "existing services, systems and processes provided through and supporting the Involving People Network".

We look forward to engaging with all our stakeholders in the review and will provide regular updates for the newsletter on its progress.

Barbara Moore
Senior Public Involvement and Engagement Manager
Involving People Network Annual Meeting Workshops
– what you told us!

On 1st February we held the Involving People Network Annual Meeting 2016 ‘Broadening Horizons’. As part of the programme delegates broke off into interactive workshops to identify training needs and peer support needs. We’re keen to share what you told us at these sessions.

Identifying Training Needs Workshop

The aim of this workshop was to identify and prioritise training needs in public involvement and engagement, and was developed and facilitated with Zoe Hunter, Health and Care Research Wales Training Manager.

Health and Care Research Wales’ vision and aim is for Wales to be internationally recognised for our excellent health and social care research that has a positive impact on the health, wellbeing and prosperity of the people in Wales. In order to achieve this vision and aim we need to ensure public involvement and engagement is central to what we do and visible in all elements of it.

We kept coming back to this when we planned and facilitated the workshop, in order to keep its purpose strongly in mind.

Workshop delegates were from a variety of backgrounds and included Involving People Network Members, researchers and health care professionals. There were quite a number of delegates and everyone sat at circular tables to allow for group discussion. Zoe and I recapped on what public involvement and engagement in research is and isn’t, and we asked everyone on each table to consider what training would be required to support internationally recognised public involvement in health and social care research.
The ideas generated at each table were then pinned to the wall and everyone was asked to take a pen and prioritise five ideas with a tick each.

We ended up with lots of great ideas and lots of ticks!

**Here’s a summary of what you told us:**

- **You told us you want training to develop a basic understanding of health and social care research.**
- **You told us you want training which would help you to understand participation, engagement and involvement in research, including for example how to engage with hard to reach groups.**
- **You told us you want training on research governance and ethics, for example public accountability.**
- **You told us you want training in communication skills.**
- **You told us you want to be trained to train!**

Amongst all of the training you told us that you require you also told us which training principles were important to you, for example accreditation of training, the use of plain English/Welsh and training through a variety of media resources, including patient stories.

Thanks to those of you who contributed, and please watch this space for information on what we did with what you told us…

**Natalie Simon**

Public Involvement and Engagement Manager
Identifying Peer Support Needs Workshop

The aim of the Peer Support Needs workshop was to identify and prioritise peer support needs in public involvement and engagement in order to meet Health and Care Research Wales aims and vision.

The workshop was facilitated with Barbara Moore, Public Involvement and Engagement Senior Manager. The delegates were members of the Involving People Network, researchers and other stakeholders with an interest in health and social care research.

We gave an overview of what the aims and objectives of the workshop were along with an explanation of what Peer Support is. The delegates were then asked to consider and discuss two questions: What are your peer support needs? What would be useful to help your role?

Delegates were soon in full discussion, whilst at the same time writing notes on what they felt peer support meant to them and how this could be best supported. Once the notes were completed delegates were given five ticks to decide on which they felt were the most important. This again generated a lot of discussion.
Once back at the office we collated all the information provided and have come up with a brief outline of what was suggested:

- You told us you wanted training on how to engage and brief participants on what to expect from being involved.
- You told us that you would like to have local meetings and Peer Leads in local areas to support less experienced network members.
- You told us that you would like tools and strategies to help identify the right people to become involved and to involve people from hard to reach backgrounds.

Watch this space for further details on how we will be developing what you have told us...

Emma Langley
Public Involvement and Engagement Coordinator
Feedback and Opportunities

As you may be aware, we collect feedback on your involvement in opportunities to make sure everything is going well. We’ve received many positive quotes from network members and researchers about their experiences of involvement. Here are just a few:

“We found that using the Involving People Network was an excellent experience which really enabled us to get relevant members of the public involved in the development and governance of our research. The process was easy and well supported whilst the list of applicants was both broad and impressive in individual’s wealth of skills and experiences. I now regularly recommend the Involving People Network to colleagues and would not hesitate to use them again for my own work in the future.”

“My role has developed significantly, I have added a lot of experiences of research to what I had already gained from IP.”

“Public involvement has really helped shape the research for the people it is intended to benefit. I would thoroughly recommend public involvement at all stages in research.”

“As I have expressed previously this involvement, I feel, is very worthwhile. I have gained knowledge and I think I have given knowledge from a patient/service user perspective. SAIL is one of the most interesting projects and since my involvement the consumer panel has moved on and embraced even more areas.”

Since January 2016 we have recruited to sixteen involvement opportunities for a variety of disease areas. One of the opportunities we recruited to was the newly established Systems Immunity Research Faculty based at Cardiff University. The faculty is the first of its kind at the University and will transform the way research and engagement is coordinated.

Professor Paul Morgan, the Director of the Systems Immunity Research Institute explained:

“Our Institute is a newly created research centre at Cardiff University that addresses many of the greatest health challenges of the 21st century. We strive to deliver long-term impacts on science and education and make a real difference in the clinic, and are therefore proud to have a Lay Faculty in place that will help us reach our goals.”

One of the Lay Research Faculty Members, Roy Norris, who is also a member of the Involving People Network stated:

“The issues addressed by the Institute are absolutely relevant for the entire population. I know that I owe my life to research and that people must involve themselves to the best of their abilities in order that research is focused, relevant and explained to the public at large.”

You can read more about the Lay Faculty here: http://www.cardiff.ac.uk/research/systems-immunity/engagement-and-involvement/lay-faculty
Dedicated online area for members of the public

The Health and Care Research Wales website has a new section dedicated to providing information about research for members of the public.

It’s a huge step forward and means that for the first time a range of information for members of the public is available in one place.

You’ll find information on:

- Taking part in a research study, including links to HealthWise Wales
- Information and resources about research, for people who are interested in finding out more about what research does and why it’s important
- Information for members of the public who are interested in using their experience and knowledge to work with researchers to improve research studies
- Resources for existing Involving People Network members

Although this means that the Involving People website will no longer exist as a separate website, the new Public section on the Health and Care Research Wales website will mean it is quicker and easier for members of the public to find information and links related to research in Wales.

Visit the Public section at: www.healthandcareresearch.gov.wales/public to find the information which is available online. You can also read our article on page 14, which reveals how members of the public helped to develop the section.
REAL LIFE RESEARCH STORIES

Getting ENGAGEEd with research

Keeping active - we all know how important it is to our everyday health.

But it also has the potential to make a real difference to those living with Huntington’s disease.

Huntington’s disease is an inherited neurological disease, which over time results in progressive problems with movement, thinking and behaviour, and ultimately, difficulties in undertaking the usual activities of daily living.

Although we know that keeping active can have real benefits, it has been difficult to develop an exercise programme which can be easily maintained, as the day-to-day realities of people living with Huntington’s disease can make it challenging to complete.

Researchers at Cardiff University’s Huntington’s Disease Research and Management clinic, in collaboration with the South East Wales Trials Unit (Centre for Trials Research, Cardiff University), are trying to find a solution to this problem by working with people who have Huntington’s disease, their family members, carers and professionals.

The ENGAGE-HD study, funded by Health and Care Research Wales, has evaluated a home-based activity programme delivered by a
trained physical activity coach, which included a purpose developed exercise DVD and a Physical Activity Workbook.

Astrid Burrell, Involving People Network Member, and Professor Monica Busse, Researcher at Cardiff Huntington’s Disease Centre, talked to us about the public involvement at the heart of this study.

Professor Monica Busse, Researcher

How did you find members of the public to become involved in the research study?

We wanted to capture varied perspectives from people with Huntington’s disease, their family members, carers and professionals.

People with Huntington’s disease and their caregivers (both formal carers and informal carers, i.e. family members) were invited to participate in a series of focus groups, contacted through regional care advisors of the Huntington’s Disease Association of England and Wales (HDA).

The HDA maintain a confidential mailing list of members who have agreed to be contacted in this way.

All correspondence was initiated by the HDA and no personal details were provided to the research team without the consent of the involved individuals.

Additional members of the public were identified via the Wales Huntington’s Disease Involving People Group. [A group of members of the public involved in the work of the

"Involving people in this research has been crucial to the success of the subsequent research study."

Cardiff Huntington’s Disease Research and Management clinic.]

What role have members of the public had?

Eight focus groups were conducted with a total of 56 people.

At the outset, the members of the public shared their experiences of physical activity and discussed aspects of their condition that created barriers for them to exercise.

They also helped us to identify an approach that they considered to meet their needs in terms of supporting them to exercise.

Following this, two members of the Group were closely involved in reviewing and commenting on the ENGAGE-HD physical activity workbook.

We posted hard copies of all the materials to their homes and arranged to phone them to discuss at their convenience. We also provided postal paid return envelopes so that they could send us written copies of their comments.

How did members of the public make a difference to the research study?

Through the focus groups and in depth discussions, the study team were confident that the intervention that was developed would meet the needs of people with Huntington’s disease, and was truly a shared intervention.

Involving people in this research has been crucial to the success of the subsequent research study.
The ethics committee commented on the quality of the study documentation and did not require any amendments, as it was evident that it was truly a shared process.

I also learnt how much it meant to the public to be involved in the project and they considered it to be a rewarding process.

Why do you think public involvement is important?

It is very clear to me that without this consultation process we would not have developed an intervention which was suitable for a follow up research study.

The intervention the study team had initially planned to develop was very different from what we ended up developing and this was as a result of the open discussions and valuable feedback from the public over a six month period.

What advice would you give to researchers who are looking to involve the public in their research?

It is very important to give very clear aims of your work and to develop a shared process for discussing the research.

It is important the patient and public reviewers feel that you listen to them and are willing to act on their advice or input. We often don’t give enough time to public involvement activities.

We should be doing this right from the outset rather than as an after sight or a requirement of a funder or ethics body.

Astrid Burrell, Involving People Network Member

How did you get involved with the research study?

I was already a member of the Wales Huntington’s Disease Involving People Group. Monica Busse was pleased with my work on other studies and we had developed a very good working relationship. She e-mailed me to ask if I would be willing to review the ENGAGE-HD workbook.

What interested you about getting involved?

I was particularly interested in this study regarding physical fitness, as my own husband with Huntington’s disease had managed to stay fit longer than we dared hope, because of his physical fitness, walking and somehow playing golf almost right up to the time he went into care. I knew I could bring a lot of experience to this study.

I wanted to put my past experiences to some use and to play my small part in helping to improve the lives of people with Huntington’s disease.

What activities have you been involved in as part of your role?

I was involved in the focus groups that were conducted to inform the production of the ENGAGE-HD Workbook. I then reviewed the actual ENGAGE-HD Workbook to ensure that everything could be fully understood and easily read by Huntington’s disease participants. In addition, I always proof-read any work with which I am involved and I now have a reputation
for being very thorough! This was of course particularly important when the Workbook was to be printed and published, and proof-reading is something which I love doing, as well as my role as a reviewer.

After reviewing and sending my comments in, Monica and I had telephone communication to clarify various things and we have developed a friendship and a lot of respect for each other.

What have you learned from being in the research study?

Above all, I think I have learned of the dedication and enthusiasm of the team in Cardiff. They are a wonderfully inspiring group of people who go over and above the call of duty to try to improve the lives of Huntington’s disease families. I had never been aware of how much research was going on before I joined the group and I have learned to have great hope for the future.

Why do you think public involvement in research is important?

It is vital that members of the public fully understand any research studies that they are asked to participate in and that they also fully understand the implications. Sometimes researchers may use language that we lay people do not understand and it is important that is clarified.

Despite maybe not having scientific or medical knowledge, sometimes we family members know more about actually living with an illness than a researcher could possibly know, and this information can be useful to researchers planning and evaluating their research. All the researchers I have met have welcomed and respected this input.

Find out more about Astrid, her experience of Huntington’s disease and how she first got involved with the Wales Huntington’s Disease Involving People Group by reading her Research Story.

”I had never been aware of how much research was going on before I joined the group and I have learned to have great hope for the future.”
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/

Network Members help create new public facing online resource

Earlier in the newsletter, we featured an article about the new public-facing section of the Health and Care Research Wales website.

The Public Involvement and Engagement Team worked closely with the Health and Care Research Wales Communications Team during the design and development stage.

What you may not know, is that Network Members have also been a crucial part of its development. Here’s a summary of how their feedback guided content and design of the new online pages.

Involving People Network Survey

At the end of 2015, Network Members were asked to complete a short survey about online public involvement resources. 76% percent or respondents visited the Network Members’ Area on the old Involving People website and 81% said it was important to have a dedicated area online.

We discovered that for most members, their primary source of information is the weekly bulletin sent out by the Public Involvement and Engagement Team and they used the website when needing to access extra information or to refer to guidance.

The feedback in the Survey led to a range of actions when the new Public section of the website was being developed, including:

A dedicated area for Network Members on the new website, with a focus on information that Network Members can refer to as and when they need it.

Reminders to be sent out to Network Members that the dedicated online area and a range of resources are available.
The order and priority of information on the public involvement pages was based on what Network Members had told us was most important.

A Research Stories section was developed, which will feature stories from researchers, members of the public and include examples of real-life public involvement.

Made sure there were links to resources you identified, such as FutureLearn & the EUPATI toolkit.

There were also some great suggestions that need to be discussed with other teams within Health and Care Research Wales:

- Open access to study results
- Possibility of a forum or something similar for Network Members
- Develop new guidance and tips for different types of involvement e.g. reviewing a research protocol
- Transparency about the funding received for research
- Support system between Network Members - a mentorship programme

One piece of feedback through the Survey didn’t directly relate to the website, but led us to set up the ‘your questions answered’ section in the Your Involvement Matters newsletter. Which we will feature when you send us your questions!
Testing period

Once the draft Public section of the Health and Care Research Wales website had been developed, a ‘test’ period was carried out in February to find out how the structure and content worked. Thank you to all the Network Members who got in touch with their feedback.

There were some really positive comments that showed the section was heading in the right direction, including:

“It’s nice and clear, easy to navigate…”

“The colours are nice, the whole home page looks inviting and welcoming.”

“I particularly like the fact that when you have gone to one of the sections, there are very clear links back to all the others.”

“It has excellent links between each section and the patient pages are very informative.”

There was also feedback on areas you didn’t think were working as well, which helped improve the final online version, for example:

• Finalised a noticeboard to share events, external news.
• Made sure the difference between each section linked to from the public home page was clearer and the text was amended.
• We’ll be adding a voice over to the ‘Research Matters’ short video in the Why Research Matters’ section. We’ve also amended some of the wording within the video.
• You reminded us that not everyone is confident using computers – text has been added to the landing page inviting people to call if they’d prefer to speak to someone.
• A ‘Getting involved’ resource is being developed, which will have more information about how people can get involved at different points during the research cycle.
• Plan to develop new range of photos for the website, within budget limits.
• Positive messages have been highlighted within the Public section, to really show people they can make a difference.

The Working Group

Finally, we’d like to say a big thank you to Julie Hepburn and Carol Cleary, who were part of the working group overseeing the project. Their honest and constructive feedback about the design and content of the website was essential and really helped achieve key deadlines.
Network Member profile - Allan Barham

After working for 35 years in a variety of management support roles in the steel industry it was important for me to find new intellectually challenging interests when I retired.

Despite having no medical background I thought that the developing field of public/patient involvement looked promising. I joined (and now Chair) the Editorial Board – a committee of lay volunteers that is tasked with vetting and approving all new Patient Information Leaflets used in Abertawe Bro Morgannwg University Health Board.

Later, I learnt of the existence of the Involving People Network and became a member. With my experience of reviewing patient information I was able to contribute to a number of opportunities concerned with trial participants’ briefing papers, questionnaires and websites, sometimes at very short notice and to tight deadlines.

It was through the Network that I also first made contact with Wales Cancer Trials Unit and was invited to sit as a lay research partner on a number of Trial Management Groups. I had myself been treated for cancer in my forties so was able to get into the mind-set of potential participants when reviewing trial material.

For me the best involvements are those which allow me to act in the role of ‘Critical Friend’ or even occasionally as ‘Devil’s Advocate’. Without being obstructive, I like to feel free to ask questions about ‘Who?’, ‘What?’, ‘Where?’, ‘When?’ and ‘How?’.

I also find that I can sometimes give new insights by challenging researchers’ preconceptions; for example, the common mistake of using participants’ level of formal education as a surrogate for socio/economic classification, which is manifestly unsound for cohorts comprising older patients.

I have made use of Involving People Network Training Courses and Annual Meetings to improve my knowledge base and to meet like-minded members. Long may it continue!

News specific to the Network

Some highlights of network activities since the last edition:

We held our Annual Meeting
Zoe Grey announced as new Director of INVOLVE

We sent out rebranded Code of Conducts
Public involvement toolkit launched by European Patients’ Academy
It’s important to us that we keep Network members up to date with the latest opportunities, news, events and guidance.

We have a number of different ways of doing this and here’s a reminder of how we’ll keep you up to date:

**Weekly bulletin**

Providing information about the latest opportunities to get involved in research, as well as news of events and training.

**Your Involvement Matters**

The regular newsletter gives us an opportunity to give you more detailed information about public involvement in Wales and for you to read real life research stories.

**Online Network members’ area**

You’ll find guidance and information relevant to all Network members.

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Tribute

It is with sadness that we share the news with you that Margaret Barnard has passed away.

Margaret has been a valued member of the Network since 2013, she suffered from Chronic Obstructive Airways Disease (COAD) and we often used a quote from her describing the value of public involvement in relation to living with a chronic condition: ‘Working for the good of others living with the same, or similar, condition as you, is a very positive thing to do’.

She contributed to a NICE review of Chronic Obstructive Pulmonary Disease (COPD) and a Welsh Oxygen Procurement review as well as sharing the patient’s perspective of living with her condition with student physiotherapists.

She helped us to develop a case study about her involvement with the PACE study and we were delighted when Margaret and her husband agreed to attend the INVOLVE conference in 2014 where Margaret co-presented at a speed session.

Our thoughts are with her family and friends.
HealthWise Wales is a major new study which involves people across Wales. Colleagues from the HealthWise Wales Team have provided the following update.

**Ambitious Welsh health research project launches**

*HealthWise Wales needs you to sign up!*

An ambitious project, designed to better understand the health of people living in Wales, has now launched. Led by Cardiff University and funded by Welsh Government, HealthWise Wales is a confidential research study, which aims to develop an in-depth knowledge of the health of the nation — the information gained will be used to help the NHS plan for the future.

The study hopes to recruit 260,000 people aged 16 and older over a five-year period.

Professor Shantini Paranjothy, from Cardiff University’s School of Medicine, said:

> HealthWise Wales is a unique opportunity that builds on a strong tradition of population health research in Wales. This large-scale project will use modern technology to engage people in research and provide opportunities to contribute to the design and conduct of research studies.

If you’re over 16 and live in Wales, you can help us better understand the health of the nation. Young or old, fit or unwell you will be contacted every six months to get an ongoing understanding of your health. This is about people sharing their knowledge to improve health and care in Wales.

We are calling on people to register now for HealthWise Wales to inform the future by helping today.

HealthWise Wales will engage with members of the public by holding roadshow events across Wales to encourage people to sign up to the research, alongside TV adverts and social media activity.
BRAIN – Innovation through collaboration

The Brain Repair And Intracranial Neurotherapeutics (BRAIN) Unit is a research organisation working to develop new therapies for brain diseases. Our work focuses on neurological and neurodegenerative conditions such as Huntington’s disease, epilepsy, Parkinson’s disease and multiple sclerosis. BRAIN is funded by Welsh Government through Health and Care Research Wales and is based at Cardiff and Swansea University and Cardiff and Vale University Health Board.

BRAIN held its launch event on the 21st March at the Life Sciences Hub in Cardiff Bay. We invited speakers from the Welsh Government, Welsh Universities and the NHS to talk about the excellent research and support infrastructure being developed and implemented throughout Wales for patients with neurological diseases.

Over 70 people attended the launch and took part in interactive research sessions showcasing the range of research which is currently being undertaken within BRAIN. This includes developing novel therapies for brain repair, using advanced imaging to develop more accurate models of clinical cell and drug delivery to the brain and implementing clinical databases and developing wearable technologies (for example, watches and smartphones) to monitor the real clinical and social impact of neurological and neurodegenerative diseases.
The day ended with a talk from BRAIN’s director, Professor Liam Gray, telling the audience about a new state-of-the-art Renishaw surgical robot the University Hospital Wales will be receiving in May. It will enable the highly accurate and safe delivery of drugs and cell therapies to the human brain. This robot is only the second of its kind in the UK.

BRAIN believes that active involvement from members of the public leads to research which is more relevant and more reliable. We have formed a new involving people group called BRAIN Involve to bring together patients, carers and academics to shape cutting-edge research into neurological and neurodegenerative diseases.

BRAIN Involve is not about taking part in research but about using your experiences to help inform and develop research ideas and projects that are relevant to you. If you would like to play a role in informing the research being undertaken in BRAIN please contact us in one of the following ways:

Freepost BRAIN UNIT

(Please note, to write to us for free please use the exact text above, BRAIN UNIT must always appear in uppercase and you do not need to put a stamp on the envelope.)

Tel: +44 (0)29 2068 8608

Email: brainunit@cardiff.ac.uk
Research Engagement

Research engagement is considered to be when information and knowledge about research is provided and shared, for example at a conference or at an open day. Engagement and an understanding of health and social care research is vital in order to be publically involved in the process when research is carried out with and by members of the public.

Health and social care research engagement opportunities and events can be found on the noticeboard of the Public page of the website so please visit the noticeboard to hear about seminars, conferences and events you may want to attend.

The noticeboard will also be promoting external involvement opportunities as well as studies looking for participants or surveys that members of the public are invited to take part in.

If you know of an engagement opportunity that we have not featured on the noticeboard please contact us.

Some highlights so far include:

♦ Rare Disease parliamentary reception held in Wales
♦ Opportunities with NIHR Evaluation, Trials & Studies Co-ordinating Centre
♦ Public Q&A with NICE’s Chief Executive
♦ UK policy forum for Health & Social Care research – public consultation
♦ Wales Cancer Research Centre & Cancer Research UK engagement event
♦ Centre for Ageing and Dementia Research Annual Conference
♦ Wales Neurological Alliance Conference ‘From the lab to the living room: the benefits of co-production in research into neurological conditions’
♦ Cancer Research UK review of Centres & Experimental Cancer Medicine Centres strategies
♦ James Lind Alliance – non-alcohol related liver and gallbladder partnership survey