Your Involvement Matters

December 2016

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

Mae’r ddogfen hon hefyd ar gael yn Gymraeg
PUBLIC INVOLVEMENT NEWS

Welcome to the December issue of ‘Your Involvement Matters’ newsletter, sharing news and stories about public involvement and engagement within health and social care in Wales.

Thank you to all of those who have submitted articles, suggested features and helped develop this issue.

In this edition we’ll be focusing on cancer, with articles on the Wales Cancer Research Centre, National Cancer Research Institute, and ‘Techniquest does Cancer Research’. Regular features include a HealthWise Wales update and a highlight of engagement events that have taken place. You’ll also read on page 7 that the Involving People Network is a decade old!

It has been suggested that the newsletter is a good place to reinforce the definitions of public involvement and engagement. These definitions can be found above, as well as on the Health and Care Research Wales website: www.healthandcareresearch.gov.wales/research-definitions.

We have also updated the website with information on the benefits advice service that we subscribe to. This is provided so that Involving Network members and researchers can access free advice, and can be found here: www.healthandcareresearch.gov.wales/network-member-resources/

The Public Involvement and Engagement function within the Health and Care Research Wales Support Centre held its first three-monthly Operational Working Group (OWG) meeting in August. The group includes two network members as well as representatives from the Health and Care Research Wales infrastructure. Their main role is to oversee the Support Centre’s operational delivery of Public Involvement and Engagement. One of the priorities for the group is to oversee the conduct of a review of the existing services, systems and processes provided through and supporting the Involving People Network.

The first part of the review is a survey, which is underway. By now all stakeholders, including the Involving People Network, have had the opportunity to take part in either an online or paper survey to have their say about how the Involving People Network is supported, as well as provide ideas for the future. The next stage of the review involves a series of workshops, and if you completed the survey you will have been asked to express an interest in participating in one of the three workshops. Workshops will be taking place across Wales in December and January to review the survey results and to develop recommendations that will be presented to Welsh Government.

Public Involvement and Engagement Definitions

**Public involvement in research:** The active involvement of members of the public in research projects and research organisations, for example reviewing information given to patients about research.

**Public engagement in research:** the sharing of information and knowledge about research, for example at a research conference.

Foreword

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Some of you will have attended the Annual Health and Care Research Wales Conference 2016, entitled ‘Research with Impact’ that took place on October 13th. One of three workshops was about the ‘Impact of public involvement on research’. A summary of the conference can be found on page 12.

The Peer Support and Training workshops from this year’s annual meeting have some further outcomes to report. Planning is well underway for the fast approaching Involving People Network Conference, taking place on St David’s Day, Wednesday March 1st 2017, at Cardiff City Stadium. Registration will be opening in December but in the meantime please save the date.

Before the annual meeting we have Christmas and the New Year to celebrate. The team would like to wish all our readers a happy and healthy festive season and to thank you all for your commitment to Public Involvement and Engagement in health and social care research during 2016.

I would like to acknowledge that sadly five Network Members passed away this year. We pay tribute to Margaret Barnard, Sid Kidwell, Annie Mulholland, Ron Woodall, and Ann Yeomans, and their invaluable contributions.

We hope you enjoy this edition. The newsletter belongs to you so please continue to submit articles and suggest features. Our next edition will be out in March 2017.

Barbara

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

In the last newsletter we shared information about two workshops that were held at the Involving People Annual Meeting 2016, “Broadening Horizons”. Here’s an update on what’s happened since.

Identifying Training Needs Workshop

Here’s what you told us you wanted:

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

Amongst all of the training needs, 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.

What we did next:

We discussed the themes that emerged from the workshop with the Health and Care Research Wales Senior Training and Development Manager, and agreed on some actions to address these themes. We’re pleased to report that we are already progressing in some of these areas.

Work is in progress and we have clear actions which align with our operational plan.

- You told us you wanted training to develop a basic understanding of health and social care. We looked into this and found that the Health and Care Research Wales Training Programme already offers “An Introduction to Research Methodology” course. We agreed that this course could be better promoted to you, so we’ll be looking into this.

- After you told us you wanted training on research governance and ethics, we found that the training programme already offers a “Good Clinical Practice (GCP)” course, which covers governance and ethics. We agreed this course could be better promoted to individuals who are actively involved in research, so we’ll be looking into this.

- You told us you want to be trained to train. We’re already starting to do this. For example we supported network members to become facilitators and we’re submitting a paper on the process we went through.
Identifying Peer Support Needs Workshop

Here’s what you told us you wanted:

• Training on how to engage and brief participants on what to expect from being involved

• Local meetings and Peer Leads in local areas to support less experienced network members

• Tools and strategies to help identify the right people to become involved and to involve people from hard to reach backgrounds

What we did next:

We discussed the workshop findings and set about developing a report and recommendations for a peer support model for public involvement in Wales. The Public Involvement and Engagement Operational Working Group agreed the following recommendations:

• For the Public Involvement and Engagement Team to work with Stakeholders to develop a robust peer support mechanism. To enable this to be carried out, Emma Langley was supported to attend a two-day training course about developing and managing a peer support system, with the National Council for Voluntary Organisations (NCVO). Emma will now work with the rest of the Public Involvement and Engagement Team to develop a pilot model for face-to-face peer support for network members.

• In August 2016, discussions with the Senior Training and Development Manager took place to start considering an appropriate mechanism for researchers to access peer support whilst attending training days.

And we’ll tell you more in the next newsletter!

Natalie Simon
Public Involvement and Engagement Manager

Emma Langley
Public Involvement and Engagement Coordinator
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.

Researcher

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 (The Secure Anonymised Information Linkage Databank), is one of the most interesting projects and since my involvement the consumer panel has moved on and embraced even more areas.

Network member

PUBLIC INVOLVEMENT NEWS

40
opportunities advertised

Team stats

Network members:

85% of network members rated their overall experience of being involved in a particular opportunity as very good or good

89% of network members felt they had a shared understanding with the research team about their role

85% of network members felt the role matched their expectations

Researchers:

88% of researchers were very satisfied with the support provided by the Public Involvement and Engagement Team

100% of researchers rated the overall experience of involving the public as very good

40 opportunities advertised

“...”

“...”

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Researcher

40 opportunities advertised
Involving People Network: 10 year Anniversary!

The Involving People Network was established 10 years ago.

This is how we looked then:

Read what longstanding Involving People Network member Harold Toone has to say:

As a member of Involving People I have been able to realise my dream of helping to improve the way healthcare is delivered to people here and around the world. During my time with Involving People I have been involved in research projects in various disciplines, my main one being cancer. Alongside this I have been associated with professionals dealing with arthritis, older people’s health and wellbeing, LGBT (lesbian, gay, bisexual, trans) issues with an emphasis on transgender issues, as well as mental ill-health, and also new surgical procedures dealing with abdominal hernias. Working alongside the professionals has given me an insight and working knowledge of how research is formulated, designed and carried out and have been treated with great respect by all I have had the pleasure of working with. Today's research is tomorrow's benefit to millions and I would urge anyone with an interest in any or all fields of health and wellbeing to get involved.

Best wishes,
Harold
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.healthandcarereresearch.gov.wales/involving-people-network/

Network member profile – Julie Hepburn

When I retired in 2013 I wanted to get involved in some work contributing to the community but wasn’t sure what was available. I had always been interested in medicine and health, having studied Physiology and worked in the NHS for three years, but my latest 25 years of employment had been in University careers work finishing as Deputy Director, which, at first, didn’t seem to me to be particularly relevant.

On retirement, I was diagnosed with bowel cancer, but after surgery and treatment I found that I had relevant experience for being a lay member involved in cancer research. I discovered Involving People through signing up to do research protocol reviews through the National Institute of Health Research and finding a link to Involving People on their website. Early on I attended the Annual General Meeting, where I met a lot of friendly faces and learned a lot about the organisation – it’s a really good first step if you are starting out at that time of year (February or March). Since then I have signed up for a wide range of opportunities from being a member of Trial Management Groups and Steering Committees in cancer research, to giving feedback on website design, becoming a lay member on the Health and Care Research Wales Public Delivery Board, and helping to plan the HealthWise Wales study.

My activities have ranged from giving feedback on documentation for research projects, e.g. patient information sheets, to giving a patient perspective at multidisciplinary research team meetings. Perhaps surprisingly, I have found that my previous work experience, although not health related, has given me very useful generic skills which help me in these activities.

I feel that my input has been valued by the research groups, and I do feel that I have had a positive input on the way the research is being carried out. All the group members have been very welcoming and encouraging and I would advise anyone interested to just go ahead and apply today!

Thanks Julie for submitting your profile and allowing us to share it. And congratulations on having your perspective of involvement in clinical research management published in the UK Clinical Research Collaboration’s newsletter, “The Exchange”.

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Your Questions Answered

In this section we respond to your questions, where the answer might be helpful for all members of the Involving People Network.

How do I know who is paying me and administering my expenses for a public involvement opportunity?

The involvement opportunity advert will contain this information, within the section “What support is available”. We recommend you save or keep a copy of this advert for your reference.

As an Involving People Network member do I represent the Involving People Network when I am taking part in an opportunity?

In a word - no! Neither are you expected to represent the public. The team provides support to enable Involving People Network members to competently and confidently present a public perspective to health and social care research. Your perspective is yours and yours alone. Obviously we expect members to be advocates of public involvement in research, to understand the core aims and vision of Health and Care Research Wales and to abide by the Code of Conduct, but for your voice to be of value it has to be yours.

News specific to the Network:
some highlights since the last newsletter

• We completed the rebranding of the Involving People Network Code of Conduct
• We delivered a face-to-face Involving People Network Induction day
• The Involving People Annual Meeting 2017 Task and Finish Group was established
Protect tomorrow by helping today

The five year Health and Care Research Wales study has been open to recruitment for over a year now. During the summer you may have visited one of the Wales-wide roadshows to promote joining this study, or spotted the TV adverts.

HealthWise Wales is a chance for everyone who is over 16 in Wales, those who are fit and well or those who are not. The study would like 260,000 of us to share our knowledge and experience to improve health and social care in Wales.

In signing up to HealthWise Wales you will have the chance to help shape the health and wellbeing of future generations in Wales. You will be contacted every six months to answer questions and you may be signposted to other opportunities. As with any study, once you have signed up the choice to continue is yours.

Members of the Involving People Network continue to be involved and engaged in the development and conduct of the study.

Sign up to take part in Wales’ largest health study now!

www.healthwisewales.gov.wales
healthwisewales@cardiff.ac.uk
0800 9 172 172
@HealthWiseWales
Wales Cancer Research Centre Patient Public Involvement and Engagement Advisory Group

The Vision for Patient Public Involvement and Engagement

When the Wales Cancer Research Centre was established in April 2015, one of its founding principles was that members of the public should be involved in its governance structures at all levels, including its most senior Executive Committee.

In addition, it was decided that two members of the public (Research Partners) would be attached to each of the Centre’s four principal areas of work (its Themes), offering advice and support to the Theme Leads on patient and public involvement.

Perhaps most significantly, public and patient involvement was to be led jointly by a member of the public (its Lead Research Partner) and a senior academic researcher, supported by an Advisory Group as a critical friend.

The title ‘Research Partner’ has been deliberately chosen for our ‘members of the public’, to emphasise the mutuality of the relationship between all parties in the research process. We’ve drafted something others would call a ‘code of conduct’ for Research Partners and researchers to support their relationship.

However, it might more properly be described as a set of mutual expectations around training, support and mentoring, an approach which, we hope, will benefit research and ultimately the health and wellbeing of the people of Wales.

Advisory Group

The Group’s core membership comprises of its five Research Partners, supplemented by a member of the Health and Care Research Wales Public Involvement and Engagement Team and the Chair of INVOLVE (England). They receive reports from a range of researchers, managers, and administrators, who attend the Group meetings as necessary.

To date the Group has, for example, approved the Wales Cancer Research Centre’s Implementation Plan for Patient and Public Involvement and Engagement (PPI&E), and received the results of the initial audit of PPI&E practice in the organisation.

This audit is being used to produce action plans for each of the four Themes. Their implementation will be overseen by the Theme Research Partners, referred to earlier.

In a year's time, the audit will be repeated and its results reported to the Group. We hope we will see improvement over the life of the Wales Cancer Research Centre. The Centre's most ambitious aim is to measure the impact that the involvement of Research Partners has on the quality of its research.

Next Steps

The members of the Advisory Group, alongside four other Research Partners, are eager to take
on their roles in relation to the four Themes. After induction meetings they are now picking up and starting to ‘run’ with their action plans.

How they interact with the Theme Leads for Patient and Public Involvement will be crucial to building on the results of the audit referred to above. To support them in their roles we are currently writing Standard Operating Procedures (SOPs) and developing a scheme to help assess the impact that Research Partners are achieving in their roles. We are also working in partnership with the former Involving People Team to produce a ‘toolkit’ to support researchers new to engaging with the public.

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Thanks to Jim Fitzgibbon, Lead Research Partner Coordinator at Wales Cancer Research Centre and Involving People Network member, who wrote the above piece. And well done Jim on your recent marathon, where you raised money with your wife, Erica, for the charity Prostate Cancer UK!

Research with Impact: Health and Care Research Wales conference

Health and Care Research Wales held its annual conference in October with more than 300 delegates filling the SWALEC Stadium in Cardiff, along with a myriad of partner exhibition stands and guest speakers.

Researchers, academics, scientists, members of the public, Welsh Government and clinical staff from across Wales attended the event which, this year, focused on ‘research with impact’.

The event was hosted by Health and Care Research Wales director Professor Jonathan Bisson and our keynote speakers Dr Frank Atherton, Chief Medical Officer for Wales and Rebecca Evans AM, Minister for Social Services and Public Health, welcomed everyone to the day and spoke passionately about the impact the newly formed Health and Care Research Wales has already made on the research landscape in Wales.

The guest speakers spoke with enthusiasm and hope about the future of research in Wales and the difference it is making for patients across Wales and beyond.
Guest speakers

- Professor Steve Jones, Emeritus Professor of Human Genetics, University College London
- Professor Jenny Kitzinger, Director of Research: Impact and Engagement, Cardiff University
- André Tomlin, National Elf Service
- Professor Malcolm Mason, Professor of Cancer Studies, Cardiff University

Workshops were also held for participants to delve into the meaning of ‘research with impact’ and consider the impact of public involvement on research, policy and on practice.

Awards

Photography

A competition was launched prior to the conference to celebrate research in Wales. Contributors were asked to send in images of anything they associate with research in Wales, whether that meant people, young, old, indoors, outdoors, medical, non-medical, laboratories, technology – wherever and however research takes place.

There were more than 40 entries, and a huge mix of informative, creative and inspiring images based on the theme of Research in Wales.

This was judged by Professor Jon Bisson, Faye Chamberlain (professional photographer and artist in residence of the Football Association of Wales) and a member of the Health and Care Research Wales communications team.

There were four categories, the judges decided upon a special mention for artistic merit and there was an overall ‘photo of the year’. The category winners were:

Up close: Wendy Scrase (BCUHB) with “Handling Age Well”
Having an impact: Grace McCutchan, (PhD student funded by Tenovus Cancer Care) with “Seeing my cells”

Connecting: Barbara Moore, Health and Care Research Wales with “Research improving all our tomorrows”

Everyone’s different: Lewis Waggett, (BCUHB) with “Why we do research”

Special mention for artistic merit: Michele Davies (BCUHB) with “A spoonful of medicine”

Photo of the year: Lewis Waggett, (BCUHB) with “Why we do research”

Each winner was awarded with a canvas print of their entry and an engraved trophy to take home.

Magazine name

Another competition awarded on the day was naming the brand new bi-annual magazine featuring news and features about health and social care research in Wales. The lucky winner was Lisa Seale, Senior R&D manager from Hywel Dda University Health Board and the winning name… @ResearchWales.

Best interactive stand

Voting took place throughout the day to choose the winner of the ‘best interactive stand’ at the event. The BRAIN unit, manned by research manager Dr Laura Bunting received the most votes and was crowned overall best stand. Laura and the team asked guests to unleash their creative side and set up canvas paintings to decorate for displaying at the BRAIN unit in Cardiff.
“Dragons’ Den”

This year’s National Cancer Research Institute (NCRI) Conference (November), once again featured the NCRI Consumer Forum’s “Dragons’ Den” session. Now in its fifth year, the Dragons’ Den offers researchers the opportunity to meet with small groups of knowledgeable consumers who are already involved in research, as well as other consumers (patients or carers) who are attending the Conference. Researchers are welcome to present new ideas, to discuss problems with studies already running, to seek endorsements for funding, to disseminate findings to patients or to talk about how to create effective consumer involvement in their work.

The session offers practical on-the-spot advice for those who want to engage some consumers to offer long-term support, or just want to talk through an idea at the back of their mind.

And the Dragons are the friendliest Dragons possible, because they are all patients or carers who are experienced in cancer research. They include NCRI Consumer Forum members who sit on Clinical Studies Groups and other NCRI initiatives, members of the Independent Cancer Patients’ Voice (ICPV), consumers who sit on funding committees, consumers funded by Cancer Research UK, Macmillan, Tenovus or other charities, or those who work with CTUs or other institutions.

The session is also open to any Conference attendee who wish to take part, for example, researchers who may have someone in their family affected by cancer, or who simply wish to see some consumer involvement in action.

Thanks to Richard Stephens, Chair of the NCRI Consumer Forum Steering Group, for this piece which describes an interesting involvement in research methodology.
RESEARCH ENGAGEMENT

Research Engagement

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

The notice board 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 notice board please contact us.

Some highlights between April and October are listed below:

- Various events on International Clinical Trials day, including an event to explain Early Phase Trials (Cancer Research UK and WCRC), exploring how breast cancer runs in families (Wales Gene Park)
- Centre for Ageing and Dementia Research (CADR) events, including “Loneliness in Later Life: Research, Engagement & Impact”; “Tourism Moments, the Sensory Self and Dementia”
- Promotion of new briefing and guidance on public involvement and ethical review (Health Research Authority and INVOLVE)
- Tenovus Cancer Care “Genome data privacy debate”
- Promotion of the Prioritising Recruitment in Randomised Trials – PRioRiTy Survey (James Lind Alliance & Health Research Board)
- Promotion of NIHRs Dissemination Centre Website
- Wales Kidney Research Unit “Meet the Team” event

Admiral and Techniquest After Hours Does Cancer Research!

On 29 September there was quite a lot going on in Cardiff Bay. Queuing in traffic going into Cardiff just before 5pm on Western Avenue my husband and I were perplexed … shouldn’t everyone be going home?

Well, actually, everyone in the know was heading towards two very special events: Wales’ Olympic and Paralympic athletes attended a ceremony celebrating their success in Rio, and Admiral were welcoming scientists and non-scientists to Techniquest After Hours Does Cancer Research.

The doors opened at 6.30 and queues soon formed to get in. Over 400 people wanted to find out about research and new discoveries. It was an event aimed at adults so we hadn’t had to borrow our neighbour’s children as we usually do for Harry Potter films and similar occasions.

All the usual exhibits were available so my husband was soon happy swinging a magnet at a large crane and drawing with a pen attached to a pendulum. I did hear him slip into “teacher mode” once or twice, though. We spent some time in the planetarium and had a drink at the bar.
I then headed for the stand with a large selection of shoes. It was actually all about the shoelaces and the aglets which are the plastic bits on the ends. The aglets stop the laces from unravelling. If they unravel and become frayed they can get tangled with the lace from another shoe and trip you up. That is what happens with “bits” of genes and it causes all sorts of medical conditions. I had heard this in a lecture at the NCRI Conference but my brain had struggled to process all the unfamiliar terms. Seeing it in such a practical way was much easier to grasp.

Nick and I both tried to hook a duck at the NHS Wales stand and discussed tailored treatment for cancer.

The Cancer Research UK stall had an activity to pick out viruses from a box healthy cells – harder than it sounds. I managed to quickly pick out the one patient for whom a tailored treatment would work at the next stand and so did not see the full effect when usually lots of little plastic patients are laid in their circles of “treating the cancer but harming the healthy cells” or “not treating the cancer and harming the healthy cells” before you find one who responds without too much damage.

The Wales Gene Park stall had a box of coloured beads. You choose a slip of paper with a code on it, find the beads which match your code and string them to make a bracelet. I had done that before and ended up being told I had the DNA of a banana. I didn’t fall for that trick again! I share most of my DNA with a chimpanzee, thank you very much.

We didn’t have time to attend the talks on Understanding Cancer Research with Professor Andy Sewell about Cancer Immunology or Dr Richard Adams on clinical research for cancer treatment but I am told they were excellent.

I had previously taken part in a “lab” session for non-scientists extracting DNA from strawberries and was delighted to see an interactive session Genes in a Bottle. This is a way of really catching the imagination and making science accessible. The Escape from the Lab group game was also fun and informative, whilst developing your problem solving skills.

Upstairs HealthWise Wales and Tenovus had stalls along with the Wales Cancer Research Centre. The European Cancer Stem Cell Research Institute and CRUK Cardiff were also present. The Wales Cancer Partnership wanted to “bring together cancer organisations to enable better patient care and increase research success in Wales.” I think they succeeded.

Gillian Thomas

Wales Cancer Research Centre Theme Research Partner and Involving People Network member
The Wales Cancer Research Centre – Battling Cancer at Green Man Festival

This summer we took the Centre and its research out to the public at Green Man Festival.

The festival has a special place in its heart for research, reserving a field at the event to showcase science. The field is known as Einstein’s Garden, and it was here that we presented a few elements of our research through a series of fun activities.

We invited festival-goers to join us in our Celtic fortress to make battle with cancer the Welsh way. Young and old alike joined us to learn more about the disease and how we are tackling it, taking up arms beside us.

We explained cancer immunology through presenting guests with two black balloons. One represented a healthy cell, the other represented a cancer cell. From the outside, the ‘cells’ look the same; the only difference is that the cancer cell has a piece of metal in it. When presented with a T-cell (part of the body’s immune system) in the form of a sword with a magnet attached to it, guests were able to ‘see’ deeper into the cell to identify and destroy the cancer cell.

We also allowed guests to explore their own genes by finding out whether they are a supertaster. Each participant was given a strip of paper, covered in a bitter tasting chemical, which can only be tasted by around 75% of people. Those that can taste the chemical have a gene that dates back to Neanderthals. The results spark an interesting debate about how our genes differ and how understanding them better can guide us to target therapies more effectively in cancer patients.

Our stall was decorated with a large tree of life. We invited visitors to add to the tree throughout the weekend, each adding a decorated leaf to its branches with personal messages of hope. Other activities explained what targeted therapy is, what the symptoms of cancer are and revealed some common misconceptions about the disease.

We were in good company at the festival, working beside our friends at Tenovus. They had set up a mobile lab that allowed the public to see their own check cells under a microscope.

Over the weekend we engaged with 600 people, and despite the rain, a good time was had by all.

Jodie Bond
Communications & Engagement Officer, WCRC