Your Involvement Matters

November 2017

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

Foreword

Welcome to the autumn edition of ‘Your Involvement Matters’.

This newsletter is focused on the Public Involvement Delivery Board, so if you were unsure of the role of the Delivery Board or were wondering who the members are and what they are doing then hopefully you will feel more informed and engaged after reading articles by members of the Board.

One responsibility for members of the Board is to represent Wales in the development of UK Standards for Public Involvement. One article by a member will feature this work which is being undertaken in partnership with UK colleagues. Many of you will have taken part in a consultation survey on draft standards over the summer and we look forward to announcing the launch of the final standards.

March 1 seems a long time ago - when we held the 2017 Involving People Network Annual Meeting - but we hope you enjoy reading a report on the day.

As well as the other usual features, you can hear about the progress to date of the formal Involving People Network review. We are however constantly responding to the feedback and developing our processes. Since May we have been using ‘Your Involvement is Extraordinary’ postcards. These are for members of the public we meet at events. They can post them to the team, free of charge, giving us their name and email if they are interested in joining the Involving People Network. The joining form has also been simplified and is now available on the website. We are delighted that members of the public are now applying to join in this way. To assist with submitting expressions of interest for opportunities, we have produced a template to be completed and submitted online. Researchers can now tell us what support they require via an online form, we of course remain contactable be phone and email.

News from the Public Involvement and Engagement team includes introductions from our new members of staff; Rosie Hagland and Rebecca Burns. Rebecca is based in Bangor and we are looking forward to having a member of staff based in another region of Wales.

Thank you to all the contributors to this newsletter, we hope this edition is useful and an enjoyable read. We always welcome suggestions for future features as well as any questions you may have. You can contact the team by emailing research-involvement@wales.nhs.uk or telephoning 02920 230 457.

Barbara Moore
Senior Public Involvement and Engagement Manager
Snapshot of public involvement between May - July 2017

20 members of the public joined the Involving People Network

16 opportunities advertised which resulted in 23 people appointed to public involvement opportunities

Involving People Network

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

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

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

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How public involvement is shaping the research pathway in Wales

A total of 128 people attended the Involving People Annual Meeting on a bright, spring St David’s Day at Cardiff City Stadium. Proceedings were chaired by network members Roy Norris and Sian Jones with an introduction in Welsh delivered by Natalie Simon, Public Involvement and Engagement Manager.

The event started early in order for two promotional films about the importance of public involvement in research to be launched. They were developed by Cardiff University with funding from the Wellcome Trust. They were introduced by Sarah Hatch, Engagement Manager at the School of Medicine, and network member Henry Yeoman. One film targets the public and the other researchers, both of which can be viewed on the Health and Care Research Wales website. The audience were then asked if they thought the films were useful and were invited to vote.

Delegates then met members of the research community by visiting interactive engagement stands and having lunch. Over 20 parts of the infrastructure used various approaches to engage delegates and inform them about their work. Feedback indicated that the interactive stands were very well received among delegates. One delegate said that the best feature of the event was the varied array of stands and that discussions led directly to them getting involved as a lay member of a clinical trial steering group which would not otherwise have happened.

Afternoon proceedings started with Barbara Moore, Senior Public Involvement and Engagement Manager, delivering a short
presentation celebrating the network’s achievements in the last year and the direction of travel. This included celebrating the success of four network members now facilitating the ‘involving the public in the design and conduct of research, building research partnerships’ course. Delegates also heard about the online ‘Introduction to Public Involvement’ training that is now available and the UK partnership which is developing a set of standards to assist the assessment of the quality of public involvement across the UK. Delegates were informed that the review of the Involving People Network had taken place and options will now be considered by Welsh Government. Catherine Poulter, Social Care Research Manager, gave delegates a taste of the public involvement within the social care research sector which is taking place in Wales. Roy Evans, Lay Ethics Committee Chair then treated delegates to a very informative and engaging talk about the vital role of the ethics review process.

Two hours were then dedicated to ‘pitches’. Delegates had earlier been given the opportunity to choose one of a number of pitches where researchers were able to discuss their research or ideas. The format of the pitches was based on the successful Dragons Den that takes place at the annual National Cancer Research Institute conference. Feedback has indicated that the Dragons Den approach was liked though there were some lessons learnt in its organisation which will inform future events.

The final presentation was about the public involvement within a study looking at the family attitudes, actions, decisions and experiences following implementation of deemed consent and the Human Transplantation Act in Wales. This was co-presented by Leah McLaughlin from the School of Social Sciences Bangor University and Maria Mesa, a member of Women Connect First.

The event closed with a prize being presented for the most interactive stand and an exclusive preview of a public-facing animated film about research which was consequently launched in May for International Clinical Trials day. Congratulations must go to the winners, Wales Gene Park!

Feedback indicated that some delegates felt there were too many researchers and not enough network members in attendance. This is something the Health and Care Research Wales Support Centre is addressing and ideas and feedback from the public is welcomed. Get in touch by sending us an email.
A message from our new starters

Rosie Hagland
Public Involvement and Engagement Administrator

“I applied for this role because of the opportunities and potential within the Public Involvement and Engagement team and Support Centre as a whole and I have not been disappointed! As well as building on my administrative skills, the nature of the work appealed to me – being part of a team that strives to improve health and care research matters a lot to me. I’m delighted to have been given this opportunity and my first few months have been brilliant; I feel like I’ve arrived at a very exciting time, I’ve learned lots already and I’m looking forward to immersing myself further in the role whilst helping to make a positive difference to public involvement!”
Feedback

We regularly ask researchers and members of the Involving People Network for feedback. Here are just two of the comments we’ve received in recent months.

“The network member was wonderful. This was potentially quite a challenging opportunity to be involved with as it involved high level managers in the Health Board and Welsh Government. However, due to the person’s previous experience, she was very capable and offered very useful insight. I have always been very happy with the support received from Involving People and with the people involved. It is especially good how it is possible to turn adverts around quite quickly in time for the deadline and be able to re-advertise and amend as appropriate to the needs of the project. I have also appreciated being able to talk briefly on the phone to check over a query with a member of staff. The support available for developmental work is fantastic.”

- Researcher May 2017

“It was really just a one off piece of work, but we exchanged emails when needed and I did feel that my input was valued both by the Trial Manager and the Chief Investigator, both of whom I know personally from earlier involvement. I’ve learned a lot about the new test being devised, (which always interests me) I have felt that my input has been appreciated and I have been kept informed of the bid’s progress through the funding stages.”

- Network Member June 2017
HealthWise Wales Update

We now have almost 13,000 participants! The study is gathering momentum as our support from the NHS and the general public increases toward this important and ambitious project.

57-year-old Sue Cowburn has signed up to HealthWise Wales, our flagship Welsh study aiming to better understand the health and wellbeing of the nation, to develop better treatments for a range of conditions. People aged 16 and over and living in Wales are being asked to take 10 minutes to complete an online questions as part of HealthWise Wales.

It is the first study in Wales to build a picture of future health needs. It collates detailed health and wellbeing information from people of all ages and backgrounds.

This information will then be used to plan future health services and invite people to take part in further relevant health research on specific conditions and their management and treatment.

A mother of two, Sue worked for 14 years as a sister and nurse tutor at Guy’s Hospital in London before leaving to have a family in 1992. During her time as a nurse, Sue saw many cases of renal problems and saw first-hand how research initiatives such as HealthWise Wales could benefit the NHS.

She said: “I first heard about HealthWise Wales and thought it was a great resource and a way to get people thinking about their health.

“My background is in renal care, which is something that’s grown close to my heart over the years. I would love people to realise the importance of this area of their health as kidney problems can be the result of heart disease, high blood pressure and diabetes. The more cases of diabetes there are, the more renal problems we’ll see, so it’s something to consider when looking to the future of the country’s healthcare.

“This is why I believe HealthWise Wales is such a good idea, as I can see how the research would benefit the NHS in terms of finding new treatments and in planning for the future, improving on current practices and making the health service more efficient.

“I’ve always been passionate about healthcare,
as I come from a family of GPs and was surrounded by people from the medical profession while growing up. My mother also has type 1 diabetes, and understanding the impact that has and how to deal with it has been a big help to her.

“It’s important to me that as many people as possible sign up to the initiative. There’s so much information out there, but people need to take the time to absorb that knowledge and apply it to their own lives. I think that awareness of your own health can lead to a better quality of life, and will also help the NHS to save money and resources in the future.”

Those who register at www.healthwisewales.gov.wales will be contacted every six months to complete questions about their health, lifestyle and wellbeing, so researchers can track changes in health, study how to prevent the onset of ill-health and treat and manage a range of health conditions. In addition, participants will also be contacted about new research studies they can take part in if they wish to do so.

To find out more and to complete the study, visit www.healthwisewales.gov.wales, or call the HealthWise Wales team on 0800 9 172 172/ 02920 768 090 between 08:00 and 19:00, Monday to Friday.

“I trained to be a champion two years ago after being involved in the National Population Survey focus group in 2015. The National Population Survey was one of the titles used when the concept of the HealthWise Wales project was being developed.

“I received training with others who were going to be championing HealthWise Wales as promoters of the National Survey. Once I completed training I then put myself forward to attend various public events. In a previous life I used to recruit and promote volunteering, asking people to participate in the study to me was a dream come true.

“I really enjoy interacting with people from all walks of life; learning about where they came from, how long in some cases had they lived in Wales and whether they were confident to use a computer in order to participate in the study; if they weren’t confident we complete a consent to contact form. I enjoyed talking to people about why we were completing a mapping exercise in Wales on people’s health.”

- Sian Jones
Public member, Public Involvement Delivery Board
Health and Care Research Wales has made a clear commitment to ensuring members of the public of Wales have opportunities to be participants in research, to engage with research, and to be actively involved in all relevant aspects of the research process. Through continuing to work towards and to expand these principles we will ensure that we deliver on our vision for all health and social care research in Wales to be conducted with the public and for the public.

One of the major challenges over the last few months has been scrutinising and reviewing key elements of the Health and Care Research Wales research infrastructure, including all our research Centres and Units. I am pleased to be able to report that members of the public were involved at all stages in this process, from commenting on the specific public involvement activities of research groups through to being active members of the review panels. The valuable contributions that were made by members of the public during this process has reiterated to me the importance of ensuring that we provide opportunities for the public to contribute as equal partners to the decisions we make about the commissioning, design, delivery and evaluation of public services and the use of public funding.

Linked to this is the development of the new National Standards for Public Involvement. These are a very welcome development, and I am very pleased that members of the Public Involvement Delivery Board, alongside Welsh Government public involvement policy leads, have been actively involved in shaping and developing the Standards with UK colleagues. The Standards will provide a clear benchmark to which the Health and Care Research Wales research infrastructure can be related. They will drive improvement in public involvement by providing greater clarity for research teams to see what is expected of them. They will also enable Health and Care Research Wales to form a much clearer picture of how we are performing in public involvement – both across Wales and in contrast to the rest of the UK.

We have used the draft National Standards as the basis for determining the winner of our new Health and Care Research Wales Public Involvement Achievement Award, which was announced at this year’s Health and Care Research Wales Conference.

Public Involvement is supported across Wales through the Public Involvement and Engagement team at the Health and Care Research Wales Support Centre, who continue to do an outstanding job in managing the Involving People Network. The Network, which provides opportunities for the public to get involved in research and supports them to do so, has undergone a review this year to ensure it is optimally configured, supporting and rewarding participants appropriately whilst continuing to provide excellent value for money. The Network is not just a way for the...
public to be involved in research. It is also a critical resource for health and social care researchers across Wales, enabling researchers to improve their work through accessing the lived experience of members of the public and ensuring that their insight is reflected in the research they conduct.

All of our activity at Health and Care Research Wales will continue to be overseen by the Public Involvement Delivery Board, and I am very pleased to welcome our new Chair, Barbara Harrington. Barbara has already had an impact even in the short time she has been in this role. For example, Barbara has refocused the role of the Board and made improvements to the way that the public work with HealthWise Wales. Barbara has recruited four new members to the Board, two from the third sector and two from the public, which will further expand the experience and expertise the Board provides. The commitment of all members of the Board to improving health and social care research in Wales is extremely valuable to us at Health and Care Research Wales and never fails to impress me.

The advice and constructive criticism that the Board gives to Health and Care Research Wales will ensure that we continue to provide and expand opportunities for members of the public to be involved in and have a say on how health and social care research is prioritised, funded, developed, designed and delivered. We remain fully committed to the co-production of health and social care research, ensuring that the public of Wales are equal partners with researchers in the creation of new knowledge and have a strong and meaningful voice in health and social care research activity.
What is the Public Involvement Delivery Board, what are they doing and how could they develop?

**Membership**

- Independent Chair
- Director, Health and Care Research Wales
- Head of Research Engagement, Health and Care Research Wales Welsh Government
- Public Involvement and Engagement Lead, Health and Care Research Wales Welsh Government
- HealthWise Wales representative
- Public Involvement and Engagement Senior Manager, Health and Care Research Wales Support Centre
- 3rd Sector Health Representative
- 3rd Sector Social Care Representative
- Public members (x 6)

The Public Involvement Delivery Board was set up in 2015 by Health and Care Research Wales in line with its strategic priority to facilitate and enable wider public involvement, engagement and participation in research. The Board was initially chaired by Andrew Rix and comprised six public members, two representatives of the third sector, and senior staff from Health and Care Research Wales. The functions of the Board specified by Health and Care Research Wales were to:

- Individually and collectively support effective public involvement and promote the benefits of public involvement in research;
- Build relationships within the research community and model a partnership approach to delivering better research;
- Support and challenge Welsh Government and the research community to deliver better research through effective public involvement;
- Advise on strategic direction of public involvement in research and research engagement activities in Wales;
- Consider and provide feedback on current and planned research involvement and engagement activity across the Health and Care Research Wales infrastructure;
- Further develop policy and practice in public involvement and engagement in order to guide the work of Health and Care Research Wales, including the continuous development and promotion of principles and standards of public involvement in health and social care research.

Like any new board, we have taken some time to find our feet and develop as a team. We have had some changes in membership; I became the new chair earlier this year and we have recently recruited two new public members and two new third sector representatives.

The Board has been working hard in recent months to develop a clear focus and plan of activity and we now feel we are on our way. Our overarching aim is to drive improvements in public involvement and engagement in health and social care research with the aim of improving the quality, relevance and impact of research undertaken for the benefit of the people of Wales.
We have been involved in the development of the standards of public involvement and are keen to work closely with the research infrastructure and support them in adopting and implementing the new standards.

The Board has a key role to play in the oversight of HealthWise Wales and we have been working closely with the project team to develop a coherent and integrated approach to public involvement in this major initiative conceived to work ‘with the public, for the public’.

More recently we have started working with the communications team to ensure that the public are involved in all public facing communications about health and social care research and every opportunity is taken to promote the value of public involvement and engagement.

We know that, thanks to the commitment and dedication of Involving People Network members and the support and inclusive approach of researchers who recognise the value of public involvement, there are already lots of good examples out there that demonstrate the positive difference involving the public can make. To this end we introduced a new award that recognises achievement in public involvement which was presented at the Health and Care Research Wales conference in October.

The Board meets four times per year and progresses specific pieces of work as required through task and finish groups. Whilst we are ambitious in our aspirations for public involvement in Wales, it’s important to remember that the Board is purely advisory.

We can only achieve change through building relationships, influence and persuasion, promotion of good practice and the support of all those working in the research infrastructure.

We do feel we are making progress but there are a number of areas where we have yet to make real inroads. We are very keen to widen the diversity of public contributors – we want to see more young people and people from a wider range of backgrounds and communities becoming actively involved. We positively encouraged applications from these groups to fill the recent vacancies on our Board. We want to increase opportunities for the public to influence the research agenda and are at the early stages of reviewing how this has worked elsewhere and what an appropriate system would be for us to engage with the wider population of Wales to determine research priorities.

We are clear about what we want to achieve and next year we will review and report on our progress. As the founder members reach the end of their three-year term of office, we will make recommendations to Health and Care Research Wales regarding the future of the Board and its potential role in helping make Wales a world-class model of public involvement in research.

**Barbara Harrington**
- Independent Chair, Public Involvement Delivery Board
Since July last year I have been going the extra miles to London with Barbara Moore of the Support Centre and Angela Martin of Welsh Government to work on the Public Involvement Standards. Through the course of this update I will give you the background to the work, details of the forming content and what I see as the improvements that will happen when the Standards are available.

Public involvement in health and care research has been successfully happening across the Health and Care Research Wales infrastructure and beyond for many years, so some may question why we need standards.

A similar question had been considered by the National Institute for Health Research (NIHR) in England which resulted in the landmark March 2015 Report, ‘Going the Extra Mile’.

It states:

"Every day patients and the public go the extra mile to help make UK research happen. They help decide research priorities, shape its design and spread the word about its importance to fellow citizens. The public have already made a huge difference to NHS research and the work of the NIHR. We must match their commitment with an equal resolve to involve voices from all parts of the community in all that we do."

However, it was felt that consistency was needed for the public and for those researchers already working with the public. Also for anyone new to involving the public then it was believed some form of framework would be useful.

The report recommends that the NIHR should: “commission the development of a set of values, principles and standards for public involvement. These must be co-produced with the public and other partners. They should be framed in such a way, and with a clear set of self-assessment criteria, so that organisations across the NIHR see their adoption as integral to their continuous improvement in public involvement."
Although the report referred to matters in England, the need to develop Standards was also recognised in Wales. Even more broadly the working group that has since been formed also has members from Northern Ireland and Scotland, who are at various stages of maturity in their public involvement in research. So we have ‘un-devolved’ on this occasion to ensure that no worthwhile development is missed. So we were to seek to develop standards that assisted with consistency of public involvement and continuous improvement. Although the joint working is at this time in respect of health research, from my own experience to date the work will be transferable and of value to social care research.

As a project it has involved many meetings, some of which have taken place in Cardiff. These have involved discussions, more discussions and the preparation of draft work for consideration by the public, the researchers and by the commissioners of research. Very importantly - as the public member for Wales I have been allowed a ‘full say’. There has been no polite tokenism around my presence and I am pretty sure that the public members of the group from England would be of the same opinion.

As the finalised standards are circulated, it is envisaged that public involvers could populate the work with their own examples of what works for them in terms of achieving the standards. Whilst the actual standards and indicators are prescriptive, the underpinning examples are more flexible and offer scope for ‘bespoking’.

To avoid the usual criticism that this work has taken place in isolation of the real research world, the key headlines of the working group meetings have been publicised as we progressed, having already made the work and intentions of the group as known as possible. Also, the draft standards document has been widely circulated in the form of a contributory survey which you will have seen through IPN publicity. I would hope many of you took part in the survey - commenting on and scoring the work whilst giving your ideas and opinions. Some Centres and Units were represented at a dedicated consultation event at the Support Centre in July of this year.

Personally, I think the new Standards will not be an obstacle for most who are already committed to public involvement in health (and care) research as you will just have a more detailed reckoner for that which you are already doing. Conversely, if you are new to public involvement as a researcher or a member of the public it will give you information on what you should be expecting and contributing. Importantly the indicator inputs are for the research commissioners, the research team and the public members - everyone being expected to know and play their part in team research.

As ever, the challenge we will need to rise to in Wales is to ensure the Public Involvement Standards are made widely available along with any interpretation guidance and support that will be required to ensure they are successfully adopted and implemented. For more information on the present position of the development of Public Involvement Standards please visit the working group website https://sites.google.com/nihr.ac.uk/pi-standards/standards-network

Bob McAlister –
Public member,
Public Involvement Delivery Board
Public Involvement Delivery Board

Being involved in grant applications

It is, for some, the holy grail of research partner involvement that they should be part of the research process from establishment of priorities right through to the dissemination of the results of studies. Very few research organisations or research partners arrive at this point. However, more and more researchers are involving members of the public as co-applicants in grant bids. In recent years I have been involved in this way on some 12 occasions.

One of the most interesting of these was with the Marie Curie Palliative Care Research Centre for a study entitled: ‘Supporting People Bereaved throughout Advanced Illness: A Systematic Review of the Evidence and Development of a Core Outcome Set for Bereavement Research in Palliative Care’. The lay summary, developed together with the project's research partners (me included) reads:

‘Organisations which provide palliative and end of life care have an important role to play in providing bereavement support to the loved ones of patients, but there are limitations in the research evidence available which is needed to improve how such support is provided. This project has two main objectives and stages.

First, we review the research evidence on services which support people who have lost loved ones throughout terminal illnesses such as cancer. In doing so this review will consider:

• What kinds of bereavement support have been provided and to whom (eg spouses, people with learning difficulties)

• The key features of these services (e.g. what support is given, when and where)

• How well these services meet the needs of different groups of people

• How these studies assess how well the service is working and the tools or 'outcome measures' that they use to do this

• How much these services cost to provide and how much they potentially save the NHS in terms of other healthcare costs.

To carry out this review in a robust manner, a 'systematic review' methodology will be followed. This means that specialist databases will be searched and decisions on which studies to include will be made using agreed criteria. The quality of these studies will be assessed and findings will be presented as themes which emerge across the different studies. Where possible, the results of statistical studies will be combined and compared. This review will help improve services by identifying what type of support works best for different groups of people, and how such support might be improved. Gaps in the evidence base will be identified with recommendations for further research.

The second objective and stage of the project is to develop an agreed set of assessment criteria known as a 'core outcome set'. To do this, the information that we collect on outcomes and outcome measures in the systematic review will be collated, discussed by a group of experts and used to construct a survey designed to
reach consensus on this set of core outcomes. The expert panel and survey participants will include policy makers, academics, health and social care professionals, and people with bereavement experiences. The development of a core outcome set will improve the quality and usefulness of future research. The resource will also be designed to be useful for assessing and responding to the needs of bereaved individuals in clinical practice.

The study was, for me, exciting in three ways:

- The extent and quality of the research partner input through not only active participation in the study management group and the traditional commentary on documentation but also acting as facilitators at consensus meetings and supporting networking by identifying and recruiting key stakeholders.

- Having research partners as both co-applicants and researchers by the side of fulfilling the more traditional role described above.

- We embedded, within the study from its beginning, a mechanism to evaluate the impact of its research partners on its shaping and conduct. This was done by agreeing objectives for them right at the beginning of the study and recording progress against them. Alongside two other projects this forms part of a trialling of impact measurement for the Wales Cancer Research Centre.

The first two of these 'sources of excitement' had their origins in the long time commitment of the staff of the Marie Curie Palliative Care Research Centre to 'proper' involvement of the public in their research, often in innovative ways. The last owes its existence to a desire of all of us involved in the Wales Cancer Research Centre to find a way of measuring the value added to research by the inputs of research partners. This aspect of its work is led by one of its theme research partners.

The study is still running and we all look forward to the publication of its results, in all their aspects, in 2018.

Jim Fitzgibbon – Public member, Public Involvement Delivery Board
What experiences do public members of the Public Involvement Delivery Board have to help them fulfil their role?

You may, or may not, have heard of the Public Involvement Delivery Board before reading this newsletter, or maybe wondered who we are and what we do?

We had a wide range of experience between us, we didn’t all join the Board with extensive public involvement experience, but increased our involvement as we went along. For anyone wanting to become a member in future, a passionate interest in health and social care research and a willingness to become involved and work hard is more important than an extensive CV. We will be looking to increase the diversity of members, so what follows next is not necessarily a shopping list for future membership!

We are all active members of the Involving People Network with a range of roles related to health and social care research. Between us, we cover membership of a number of trial management and steering groups for clinical trials and social research projects, membership of strategic bodies and management boards, roles as research partners, training associates, advocates, and membership of funding allocation boards, charities and user groups.

This covers roles in Wales, but some of us also work for UK bodies like the National Institute of Health Research (NIHR), various charities as well as INVOLVE and NICE.

We cover quite a wide range of sectors, though we don’t and can’t have personal experience in all health and social care sectors, and this spread might be something to bear in mind for future membership. Currently we work in groups working in the fields of cancer (including prevention, treatment and palliative care), social care (including elderly abuse, care and support, looked after children and dementia), diabetes, limb amputation, primary and emergency care, NHS whistleblowing, biomarker development, surgical techniques, data management and national standards for public involvement and public health.

But it’s not all just about our public involvement experiences. Other experiences are just as valid for being a member of the Board, such as patient experience, carer experience, voluntary work experience and previous work experience. I say ‘previous’ because many of us are retired or semi-retired, which means that we have the time to devote to public involvement, but it is also a concern for the diversity of our group in the future. Our work backgrounds are also varied, covering education, social services, the NHS, finance, police service, housing management and self-employment.

Being a member of the Board requires a responsible approach, but we also operate in a very friendly atmosphere and enjoy each other’s company. I think it’s a case of the more you put into it, the more rewarding it is, so if the role sounds attractive to you, do consider putting in an application for any future vacancies.

Julie Hepburn – Public member, Public Involvement Delivery Board
The Public Involvement Achievement Award 2017

The Public Involvement Achievement Award was one of the prizes given at the Health and Care Research Wales annual conference on Thursday 5 October 2017. It is the first time that an award has specifically recognised and helped to celebrate the excellent public involvement across the Health and Care Research Wales infrastructure.

A broad range of public involvement case studies were eligible for nomination. Judges were keen to see examples of involving the public in the governance of the organisation and in research prioritisation as well as in particular studies where the public are involved in research conduct, delivery, dissemination, impact generation or indeed details of the grant application itself. Judges were impressed with how the research team were able to demonstrate how public involvement had made a positive impact both on the research and on the public members themselves.

As we approach the two year mark of the Board’s existence it has long been apparent that some very effective public involvement in research is already happening and that has been driven from within the different parts of the infrastructure. A key challenge is to capture detail of the work that is ongoing and to ensure that any transferable good practice is made known so that it may assist others across the Health and Care Research Wales infrastructure and beyond.

Only one entry was chosen to receive the prize but the real winner was overall public involvement. This represents a real ‘win win’. It is hoped that the award will continue to be given annually, after full regard is given to feedback on this year’s process.

Bob McAlister – Public member, Public Involvement Delivery Board
New members of the Public Involvement Delivery Board

Following interviews from a high quality field of applicants, we are pleased to welcome Warren Fauvel and Sarah Peddle to the Public Involvement Delivery Board.

Warren Fauvel

“As an entrepreneur I'm passionate about improving healthcare in Wales and around the world. I applied to join the Board based on my personal interest in research as a driver for change in health. I'm hoping my career in technology will provide insights to enable Health and Care Research Wales to improve the organisation’s engagement. I look forward to learning from my new colleagues as I gain experience of driving public involvement in research.”

Sarah Peddle

“I joined the Involving People Network and a pilot project, Population Advice for Research Committee (PARC), with Swansea University as I have always had an interest in this area. A large part of my career has been spent in local government, working with data and information and working at a senior management level for over nine years. Membership of these groups affords me an opportunity for my (public) involvement in health and care research and I have undergone training and taken up opportunities to contribute to research studies.

“I have amassed a great deal of skills, knowledge and experience throughout my career, and I am really excited about taking up this role, as it will allow me to apply my skills whilst contributing to an area of interest to me, with the ultimate aim of benefitting wider society. I have two young children, which coupled with a chronic health condition, has prompted me to take some time out from full time working, but provided me with the capacity and opportunity to fulfil this role.”
Involving People Network review update

A survey was developed to seek stakeholders’ feedback on the current services and to gather ideas and suggestions to revise the service. The Research Design and Conduct Service assisted the development of the anonymous online survey with paper copies available, workshops were developed for delegates who had completed the survey to further explore the comments received and telephone interviews were held with those unable to attend a workshop.

The survey was piloted in September 2016 and was open for four weeks during October and November 2016. 201 responses were received, 33% from network members, and 66.7% other stakeholders.

Following the survey a number of options and recommendations were presented to Welsh Government.

Summary of results

Recruitment to the network

Responders were generally supportive of current promotion but comments suggested ideas to increase and diversify the network. There was also support for the current joining process, but a new model of membership was suggested with different flexible levels of commitment.

Selection for opportunities

There was strong support for current process, suggestions included exploration of how to streamline the process and how to ensure researchers take a more prominent role and articulate what is to be expected of the network member.

Provision of induction and training

Continuing with current provision scored well.

Aim: to review the existing service systems and processes supporting the Involving People Network

Suggestions also addressed provision for researchers and called for a more dynamic approach and the development of bespoke training packages for those who might not engage with conventional models.

Financial support

67% of respondents felt the current process should be kept but there were suggestions for the offer of payment for time being hourly rates, for time banking or the use of vouchers. A theme emerged relating to the ethos of volunteering and ideas around a model of offer of payment to reflect a sliding scale of involvement.

It was agreed that reasonable costs incurred should always be reimbursed.

Feedback

The feedback being reviewed related to the support provided by the Public Involvement and Engagement team and continuing this feedback mechanism was seen as a good idea. There were however comments suggesting a scope for more monitoring to address issues for all opportunities not only those receiving support from the team.

What next?

The report was discussed and commented on by the Public Involvement Delivery Board in August 2017. The implementation plan following response from Welsh Government is to be led from the Support Centre and possibly a change management group established to oversee the plan.

The outcome of the survey and the plan of action will be to be shared, especially with those who took part.
Research Engagement - A snapshot of the last six months

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.

As part of our Public Involvement and Engagement weekly bulletins we feature many research engagement events and opportunities taking place all over the UK, and here are the ones we have facilitated and promoted in the last six months.

Don’t forget to keep an eye on our online noticeboard which we regularly update to keep you up to date with all the latest news, events and opportunities across the research network.

Involving People Network Annual Meeting
1 March 2017
An opportunity for network members, researchers and other individuals who have an interest in public involvement to meet and share experiences. It also allows the Public Involvement and Engagement team to celebrate the achievements and developments of public and patient involvement over the past year.

International Clinical Trials Day
20 April 2017
The Public Involvement and Engagement team took part in a Tweetchat about #WhyWeDoResearch

Celebration of a publication ‘Hitting the Spot’
The main author is a network member who was supported to write the article by the training and Public Involvement and Engagement teams in the Health and Care Research Wales Support Centre.

Wales Gene Park Event
Living with Genetic Conditions
25 April 2017
An educational session with questions and answers and talks from a genetic counsellor or other health professionals specialising in genetics and someone affected by a genetic condition; giving insight into the impact a genetic condition can have on an individual or family.

CADR Event
Two sides of Research: Working Together
30 March 2017
A public event for CADR to promote their work and encourage engagement for those who have an interest in dementia, including a presentation from Barbara Moore and an Involving People Network member.

CADR Event
Dining with Dementia in Mind
21 June 2017
Highlighting the importance of the dining experience for residents in long-term care, with a focus on dementia.
Involving People Network news

Wales Gene Park Event
Genetics and Genomics for the 3rd Generation (3G) Conference
21 June 2017
Discovering more about the fascinating field of DNA, genetics and genomics and how it affects our everyday lives.

A report on the UK’s contribution to medical progress across the EU
Identifying some of the main ways in which UK research contributes to medical progress, it highlights the benefit this has delivered for EU science, and ultimately how this has improved the health of patients across the EU. The report can be found on the Cancer Research UK website.

Swansea BRACE Charity Conference
11 July 2017
Raising funds to support dementia research on the theme of ‘What the community and research can do for dementia?’

Health and Care Research Wales Conference
5 October 2017
This year’s theme was ‘inequalities in health and social care’. The day featured awards for the best interactive exhibition stand voted by delegates and the winners of the Health and Care Research Wales Photography Competition, Impact Award and Public Involvement Achievement Award were announced.

Your Questions Answered

“How can I as an individual give a public view? Surely this will only be my view which may be very different to someone else’s?”

You as an individual can only give your public perspective (your own take or view), this can be of particular value to research teams if you have experience of a condition but in some cases the value is in the lay perspective - does something make sense to a lay audience?

If you are asked to give a public perspective broader than just your own then it should be made very clear that you are expected to do this as well as how it is to be achieved. An example of this could be that you are asked to gather the views of a disease support group that you are a member of. Although this will give the perspective of a wider group it should always be acknowledged there are limitations and this will never represent the public but it does provide a broader public perspective than one individual’s.

Public involvement is one element of the research agenda which will help ensure that research is undertaken with the public and for the public to ultimately improve all our lives and the care we receive.