

newsletter

Autumn 2014

Welcome

From Una Rennard, Chair of INVOLVE 2014 Conference Planning Group

On behalf of the INVOLVE 2014 Conference Planning Group I'd like to welcome you to this year's conference edition of our newsletter. This newsletter gives you just a taster of the exciting couple of days we have planned at the National Exhibition Centre (NEC) in Birmingham.



This year's conference "Changing Landscapes" is bigger than ever. In an effort to meet the growing demand for places we have moved to the NEC for this year's event. We hope this conference will give people an opportunity to reflect on and explore the changes that are going on in and around public involvement.

As in previous years we have received an unprecedented number of applications to present a huge range of topics in several different ways. As a result we have a packed schedule with lots of variety.

We have also been overwhelmed by the quality and quantity of poster submissions and have tried to ensure a number of opportunities over the two days to view and discuss the posters with presenters.

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In this issue:

Welcome	1
INVOLVE Coordinating Centre news	2
Interesting articles and publications	4
Review tunes into future priorities	5
Learning to listen at Parkinson's UK	6
Involving 'seldom heard' groups in HIV research	7
Using social media for public involvement in research	9
Putting the horse before the cart: an agenda for public engagement	10
Noticeboard	12

INVOLVE National Institute for Health Research

INVOLVE 2014: Changing Landscapes
An opportunity for people interested in public involvement in NHS, public health and social care research to meet, discuss and debate

26 and 27 November 2014
National Exhibition Centre, Birmingham

programme
Conference programme (outline)
DAY 1: Wednesday 26 November 2014
Registration from 18.30am onwards

Home
Programme
Registration Form
Registration Fee
Help with Costs
Venue

If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

INVOLVE Coordinating Centre news

We have also taken the opportunity this year to promote the use of plain English by running a poster competition that will present awards for posters that are clear and easy to understand for a wide audience.

In this newsletter we have four fascinating articles from projects that will be presenting at the conference. We chose these projects as they reflect the scope of the conference and the diversity of the changes we need to embrace and make:

- How listening to patients and responding to their concerns can lead to embracing patient involvement throughout an organisation
- The importance of understanding the characteristics of seldom heard patient groups in order to be able to really involve them in research.
- An innovative and exciting patient led social media activity to connect patients with a rare condition that enabled them to be part of the research agenda both in the UK and the US.
- A thought provoking discussion about putting patients at the heart of the research agenda.

We hope that these and other projects presenting at the conference will lead to stimulating debate and discussion over the two days.

I am also pleased to let you know there will be two pre-conference sessions. These sessions will start at 11.00 am on the first day and will run for up to an hour:

- Practical guide to the INVOLVE conference – for anyone new to the INVOLVE biennial conference or to conferences in general, or who wants to come along and ask questions about the two days.
- International forum – for anyone interested in sharing perspectives on involvement and working internationally.

If you are new to the INVOLVE conference you can find our conference guide on our website (www.involve.nihr.ac.uk/involve2014). It covers a wide range of issues including tips and information on what to expect.

An accessibility report is available on the conference website, with advice on getting to and around the NEC, and the facilities available there www.profbriefings.co.uk/involve2014/involve14accessibility.html

To keep up to date on all the latest conference news visit our website www.involve.nihr.ac.uk/involve2014 or follow us on twitter @NIHRINVOLVE

INVOLVE conference 2014 update

We are delighted that Dr Russell Hamilton, Director of Research and Development, Department of Health will deliver the keynote speech to open the INVOLVE conference on 26 November 2014. Simon Denegri, Chair of INVOLVE and National Institute for Health Research (NIHR) National Director for Public Participation and Engagement will talk about the NIHR 'Breaking Boundaries' review on day two (see Simon's article about the review on page 5 of this newsletter). And for the day two plenary session, we are greatly looking forward to hearing from Tracey Brown, Managing Director of Sense About Science, a charity that equips people to make sense of scientific evidence. Other highlights from the conference will include: the chance to share experiences and vote on the impact of public involvement in research; a 'Question Time' panel responding to your questions about public involvement in research; and Simon Denegri hosting 'The Soapbox', our own version of Speakers' Corner. We will also be presenting some of our recent projects and resources, which are outlined below.

To keep up to date with conference news visit www.involve.nihr.ac.uk/involve2014/

Payments, reward and recognition for involvement: new and old resources

INVOLVE will shortly be launching a new web page on payment and reward for involvement. This will provide in one place all our INVOLVE publications on payment as well as other relevant materials.

A small group of INVOLVE members has been working with the INVOLVE Coordinating Centre to review and revise the resources we currently produce on payment. Our Payment for involvement guidance will be replaced by:

- new guidance on the principles and good practice when recognising and rewarding members of the public for involvement, with advice on payment and non-payment methods
- a new 'welfare benefits supplement' that will be updated regularly to ensure it offers the latest advice on how payment may affect those receiving state benefits

- examples of how organisations are rewarding or acknowledging members of the public who are actively involved.

The payment and reward web page will also include:

- the existing Involvement cost calculator and
- an updated version of 'Budgeting for involvement', which accompanies the Involvement cost calculator and provides practical advice on budgeting for actively involving the public in research studies.

A discussion session at the INVOLVE conference will explore these resources and discuss issues around the complexity of offering payment for involvement.

www.involve.nihr.ac.uk

A new INVOLVE report: Support for learning and development

A National Institute for Health Research (NIHR)-wide working group, established by INVOLVE following a NIHR-wide stakeholder meeting in 2013, has developed a series of recommendations around learning and development to support involvement in research.

The report also provides principles for learning and development that can help to establish good practice and examples of tools and resources that can help assess learning needs. The report encourages regional and national collaborative approaches to learning and development, working across the NIHR and with partner organisations.

The recommendations from the report will be discussed at the INVOLVE conference, with an opportunity to explore learning and development issues. Copies of the report will also be available at the conference.

www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

New INVOLVE guidance notes: the use of social media for active public involvement in research

As the use of social media in research gains momentum, an INVOLVE advisory group has worked in collaboration with Bec Hanley of TwoCan Associates to explore this area. The group has developed guidance on how different types of social media can be used for public involvement, with examples of how researchers have used media like Twitter, Facebook, interactive websites and blogging to involve the public in research.

This guidance document, which will shortly be available on our website, will be presented at the INVOLVE conference, where there will be the chance to discuss how social media can best be used to actively involve the public.

www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

Consultation: Values, principles and standards for involvement

In 2013 INVOLVE carried out a review of resources, publications and reports that looked at values, principles and standards for public involvement in research.

Following this review an advisory group of researchers, clinicians and members of the public used the information from the review to draft a framework that could be used as a flexible tool to allow learning, sharing and reflection on public involvement in research.

The 2013 review identified six values that were reported as underlying good practice in public involvement:

- respect
- support
- transparency
- responsiveness
- diversity and
- accountability.

The principles provide more detail about these values, explain what each value means in terms of public involvement, and summarise what was found in the review. The principles are then broken down into standards that outline different activities.

We welcome your views on the draft framework. You may respond as an individual or send an organisational response.

For information on how to respond please visit www.involve.nihr.ac.uk/about-involve/current-work/standards-for-public-involvement-in-research/, where you can either respond using SurveyMonkey or email us your views.

You will also be able to hear more about this work at the INVOLVE conference, where we will be presenting the framework in one of the parallel sessions.

Interesting articles and publications

Activity and views of service users involved in mental health research: UK survey

S Patterson, J Trite and T Weaver

British Journal of Psychiatry, July 2014, 205 (1), 68-75

This article reports on the findings from a survey of service users involved in mental health research in the UK. The respondents included a range of people, from employed researchers through to volunteer service user representatives. The respondents reported that their involvement had a positive impact on the quality of research. In particular, they had helped identify topics and research questions, and contributed to research design. When involved in data collection, service users highlighted being able to reach 'hard to reach' groups and increasing the quality of information obtained in interviews and focus groups by ensuring participants 'felt understood'. More generally, they felt their presence challenged academics to consider alternate worldviews. The majority of respondents found their involvement to be very positive, providing them with a sense of purpose and belonging, and enhancing their self-respect. However, a small minority felt involvement had a negative impact on their mental health. This was due to the pressure of work, exposure to distressing material or an experience of workplace conflict.

www.ncbi.nlm.nih.gov/pubmed/24723628

Learning from people with long-term conditions: new insights for governance in primary care

F Ross, P Smith, R Byng, S Christian, H Allan, L Price and S Brearley

Health and Social Care in the Community, July 2014, 22 (4), 405-416

The authors report on the findings from a study of the governance of primary care. The aim was to find out how health professionals are managing the complex demands of centrally imposed changes to governance of health care (eg practice based commissioning) at the same time as greater emphasis is being placed on patient and public involvement. The researchers worked with service users at a national and local level and describe the difference that this made.

The service user involvement added value by:

- validating understandings of governance, in particular how governance relates to the individual professional's emotional and practical experience of delivering care to service users;
- keeping the project focused on the issues that matter to service users;
- providing different perspectives that helped to open up discussions about governance at a local level;
- and helping to disseminate the findings locally.

www.ncbi.nlm.nih.gov/pubmed/24612289

Patient involvement in research programming and implementation: A responsive evaluation of the Dialogue Model for research agenda setting

T Abma, C Pittens, M Visse, J Elberse and J Broerse
Health Expectations, May 2014, epublication ahead of print

The Dialogue Model involves multiple stakeholders in identifying and prioritising research questions. It was developed and is now used in the Netherlands. This study followed up nine different agenda-setting projects to see whether there was any subsequent impact on research programmes and funding. Fifty-four different stakeholders including patients, researchers and funding agencies were interviewed, and three focus groups were held to discuss the findings. The study found very limited impact of agenda setting on subsequent research. A wide range of factors had an influence. Firstly, commissioners of agenda-setting projects did not always consider what they wanted to do with the patient priorities, nor did patient involvement continue in the following stages. When researchers were involved in the agenda-setting process, there was a greater chance of the research priorities being adopted. Timing was a problem when priorities were set after deadlines for funding applications. Researchers may also need support and resources to develop new research areas in line with the patients' agenda. These issues need to be considered at the start of agenda-setting projects, to ensure that the exercise is meaningful.

www.ncbi.nlm.nih.gov/pubmed/24889933

Patient and public involvement in research and the Cancer Experiences Collaborative: Benefits and challenges

K Froggatt, N Preston, M Turner and C Kerr
BMJ Supportive & Palliative Care, April 2014

This article reports on the experiences of eight people affected by cancer who were involved in supportive and palliative care research over a period of six years. Their views on the benefits and challenges of involvement were obtained by semi-structured interviews. The main benefits were reported as making a difference to the research and gaining personally from new knowledge, skills, increased confidence and personal support. The challenges included the emotional demands of the work that came from revisiting personal experiences, as well as practical issues, such as demands on people's time and researchers' use of complex, technical language. The service users also stated that they would like a clearer understanding of the long-term impact of their involvement on the projects.
<http://spcare.bmj.com/content/early/2014/04/11/bmjspcare-2013-000548.abstract>

If you have written or know of any articles or publications relevant to public involvement in research that might be of interest to readers, please contact Marisha Palm at the Coordinating Centre with details: mpalm@invo.org.uk

Review tunes into future priorities

By **Simon Denegri**

The National Institute for Health Research (NIHR) 'Breaking Boundaries' review has been the largest exercise of its kind in any country to take the temperature of public involvement. The depth and breadth of the response cannot be ignored.

We have received over 500 survey responses and 80 submissions from organisations, held workshop events with patients and the public around the country, and taken evidence from public involvement colleagues across the globe and from charities and industry.

It says everything for the passion and commitment of the public involvement community that so many people have put such significant amounts of time and energy into responding to the review. As Chair of the review I know I speak for my colleagues on the review panel in saying that we are acutely aware of the duty upon us to do justice to your generosity with a report that stands the test of time.

As this newsletter goes to press, the panel will be meeting to discuss its vision of public involvement in 2025 and to finalise our conclusion and recommendations. Our findings will be made public at the INVOLVE conference at the end of November.

It is pretty clear from what people have told us that we have achieved much in public involvement over the last decade. Our international colleagues are envious of the extent to which public involvement is embedded in the NIHR. They regard INVOLVE as a jewel in the crown which they wish they had.

But we all know progress has been inconsistent and patchy. A lot of what goes under the banner of public involvement is tokenistic. We still haven't mastered the way to do it. Too many patients, the public and researchers feel insufficiently supported and empowered to be partners. People are anxious to see greater diversity in our community. Questions over 'quality' and 'impact' are perennial headaches that, unless addressed soon, will seriously undermine how we grow and prosper.

Listening, reading and speaking to the many voices who contributed to the review and understanding where public involvement has made a difference has been a little like tuning in a radio. Some of the signals are stronger than others.

Making research more relevant, improved priority setting, greater accountability, a more transparent research cycle and growing rates of research participation are just some 'wavelengths' where the signal is clearest.

But the signal that is intermittent is the extent to which patients and the public are equal partners in producing new knowledge that will improve health and social care. Making this happen, making it the norm, is the challenge for the future.

Learning to listen at Parkinson's UK

By Claire Stephenson

Public involvement in organisational change

Before Parkinson's UK rebranded in 2010, we asked our members how we were perceived. The results were quite surprising with words like 'disempowering' and 'not representative' used. The steps we took to rectify this were bold, innovative and changed everything about the way we work as an organisation.

For the first time we started talking about meaningful involvement.

We introduced a user involvement team and employed people with Parkinson's to work across each department to support teams to improve the way they involve people in their work. Meaningful involvement was introduced as a team performance measure and recruitment, induction programmes and on-going training now had a strong user involvement focus. This new approach was championed by our Board of Trustees as one of our core values.

We wrote involvement into our organisational five year strategy:

"Everything we do will be informed by the views and experiences of people living with Parkinson's, their families and carers."

As a result our members, volunteers and the patient community found a more supportive, representative and dynamic charity that responds to and reflects their needs and views.

And whilst our vision for research "to find a cure and better treatments for Parkinson's" remained, we focused on working with people with Parkinson's to achieve this:

"We'll ensure our research programme is shaped by and accountable to people with Parkinson's."

"We will develop and support a global network to allow people affected by Parkinson's to be involved in a variety of research activities."

In 2011, the Parkinson's UK Research Support Network (RSN) was born. Its aim: to bring together people driven to help find a cure and better treatments for Parkinson's.

Parkinson's UK Research Support Network

The Parkinson's UK Research Support Network (RSN) is an online network of people interested in Parkinson's research. It's a way to bridge the gap between people affected by Parkinson's and the research community. Instead of passively hearing about Parkinson's research at an event, the RSN mobilises them to take it further, find out more, participate and also get involved in research.

Over 95% of our Research Support Network members are people with Parkinson's, their carers, family members or friends. With over 1,300 members, our RSN affords us an ideal opportunity to gain opinion, insights, case studies, participants and volunteers as well as help people affected by Parkinson's to feel in control as their voice is heard by the research community.

We know that almost 60% of our RSN members are interested in taking part in research and 43% joined to be able to work with the research community to help shape Parkinson's research.

What difference has public involvement made?

The Research Support Network is the only network of its kind focused on Parkinson's research. It gives us the unique position of accessing both a diverse and rich pool of experience of people affected by Parkinson's to help us at different stages of the research cycle.

Examples of the work of our RSN members includes:

- helping us to identify unanswered research questions in the day-to-day care and management of Parkinson's
- advising us on our developing research strategy for 2015-2019
- working with us to decide which research we fund
- working with the Parkinson's UK Brain Bank to decide which projects receive brain tissue
- advising researchers on study design, protocol and recruitment methods
- becoming members of research project steering groups
- helping us to disseminate research by talking about research across our branches and groups nationally.

The Research Support Network has transformed the way we do research. It has inspired us, given us confidence and leverage, helped us attract new members and it has made us more attractive for researchers and funders.

We have also been able to develop our relationship with researchers. Researchers work with our RSN at all stages, and this is not exclusive to research that we fund. Members of our RSN join us at conferences worldwide, including the World Parkinson's Congress and Grand Challenges in Parkinson's. We also have RSN speakers at our upcoming annual researcher conference. It is vital to keep that sense of urgency alive in the research community, and no one can do that better than people affected by this condition.

Finally, the RSN has made a difference to people affected by Parkinson's. In a condition that has taken away their control, our RSN allows them to seize some of it back:

"I wanted to be proactive and to find out as much as possible about available research opportunities; it seemed to be more upbeat and of interest to younger and newly diagnosed people with Parkinson's and I just wanted to be involved and help to find better outcomes for treating Parkinson's. It helps sustain my hope for the future."

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Parkinson's UK Research Support Network Steering Group

Involving 'seldom heard' groups in HIV research

By **Annabelle South** on behalf of the Medical Research Council Clinical Trials Unit (MRC CTU) at University College London (UCL) Patient and Public Involvement (PPI) group*

There is a long-standing tradition of actively involving patients in HIV research. However, there are some groups of people affected by HIV who have not been actively involved. This article explores the experiences of two studies by the Medical Research Council Clinical Trials Unit at University College London (UCL) that have tried to address this.

Ask ALFIE

Adolescents and Adults Living with Perinatal HIV (AALPHI) is a study that follows a group of young people (aged 13-23) who were either infected with HIV when they were babies, or are HIV-negative and live with someone who is HIV-infected. This group is particularly hard to involve because of their age and the intense stigma around HIV. From the outset the study team worked with voluntary organisations that support young people with HIV to:

- pilot the interview with young people
- get young people to comment on the patient information sheet.

A group of HIV-infected young people rebranded the study as 'ALFIE', designing the logo and poster, and making a sock puppet video about the study. A young person is also on the study steering committee, and attends meetings with a mentor, meeting the chair beforehand to discuss how they want to contribute.

What difference has this made?

The input of young people made sure the questions and tests were acceptable and the study materials were appealing and understandable. Voluntary organisations have helped to promote the study to young people.

Lessons learnt

- Involvement has to start at the design stage to ensure acceptability
- Young people are a transient group, so involving a group rather than one or two individuals can provide stability while allowing for change

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- Involving voluntary organisations that support young people affected by HIV is key – they have acted as a bridge between researchers and young people
- Involvement of young people must be on their terms, using the right language and avoiding tokenism
- Offer support and training to young people who are involved, and prepare them for any meetings.

PROUD

PROUD is an HIV prevention study for gay men at high risk of HIV. It is investigating what impact taking a drug called Truvada (which can reduce the risk of HIV infection) has on gay men's sexual and risk behaviour, as well as HIV and sexually transmitted infections (STIs). This approach is called pre-exposure prophylaxis (PrEP) – taking a drug before exposure to the virus, to reduce the chance of becoming infected if exposed to it. This group has not traditionally been involved in research as they are not 'patients', and there is some stigma in the gay community around the use of PrEP. The researchers have involved the community in a variety of ways:

- The **Community Engagement Group** was formed at an early stage, and consists of voluntary organisations that support people living with HIV, and represent gay men and other men who have sex with men, and transsexual women. It advises the trial team on recruitment, communication, media activities and patient and public involvement (PPI) strategies.
- The **Trial Steering Committee** has three community representatives, one of whom is the joint chair.
- The **Independent Data Monitoring Committee** has a community representative as a member.
- **Participant involvement meetings** have been held (via teleconferences and face-to-face meetings) to get the views of some trial participants on study procedures and future trial priorities. These meetings were facilitated by community representatives, and were advertised by clinics and on the study website.

What difference has this made?

The Community Engagement Group helped to shape the whole trial from a very early stage. They provided advice about the acceptability of the study design and also advised on a change in the eligibility criteria.

Recruitment to the trial was initially slower than expected. The Community Engagement Group met to discuss this, and as a result HIV charities released a joint statement outlining their position on PrEP. This resulted in considerable media coverage. The Terrence Higgins Trust also used GRINDR (a gay social networking app) to raise awareness of PrEP. This boosted recruitment.

Participant involvement meetings have helped to inform the development of a larger trial application, changes to the data collection tools, new recruitment materials, and identify the need for additional participant support such as social media platforms.

Lessons learnt

- Understanding your target audience is crucial for prevention trials
- Involve as many people as possible as early as possible, and keep the involvement dynamic
- Talking to participants and community groups may help to identify why there are problems with recruitment or retention, and how they may be addressed
- Community groups often have better channels of communication with potential participants than researchers do
- Researchers need to be politically aware, especially if they are doing research in an area that is potentially contentious
- Participants are keen to be involved and are well positioned to advise on ways to improve study conduct and help prioritise future research.

Conclusions

There is no 'one size fits all' way to involve 'seldom heard' groups. Study teams must consider the needs and preferences of their target groups, and design the involvement approach around that. Doing so can result in involvement that has a real impact on the research.

Further information

*With thanks to those involved in patient and public involvement for the AALPHI and PROUD studies.

To find out more about patient and public involvement in the MRC CTU at UCL, visit www.ctu.mrc.ac.uk/our_research/patient_and_public_involvement/

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SCAD survivors

Using social media for public involvement in research

By Rebecca Pritchard

Spontaneous coronary artery dissection (SCAD) is a rare type of heart attack in young, healthy people. Usually, when a person has a heart attack, one of the blood vessels that provide blood to the heart muscle is blocked, often by fatty deposits in the blood vessel. In SCAD, a flap of the blood vessel lining comes loose and blocks the blood vessel, which causes a heart attack. We don't know why this happens.

As SCAD is a rare condition, survivors can feel isolated and concerned about the future. Getting information, even from the medical profession, is tough because so little is known about the illness. Patients with this condition often turn to the internet to find out about their illness. Over the last few years, as more people use Facebook and Twitter, people who have had this type of heart attack have started to find and connect with each other. Rebecca Breslin, a SCAD survivor, set up a Facebook group that enabled more survivors to get in touch with each other, to offer and find mutual support. The self-titled SCADsters (a contraction of 'SCAD sisters' brought about as a few men with SCAD got in touch) are from all over the UK, USA and Europe. Without this Facebook group they would struggle to communicate with each other, and they are using it to raise their questions, voice their concerns, share their experiences and ultimately find a voice with which to demand a response to the situation.

Some people in the group discovered the work of the Mayo Clinic in the USA and signed up to their research remotely. Around the same time, Dr David Adlam of the NIHR Leicester Cardiovascular Biomedical Research Unit at Glenfield Hospital wrote an article about the existing research into the condition. SCADsters found his article online, shared it with the Facebook group and quickly realised there was potential for a UK based research project.

Rebecca Breslin, the Facebook group administrator, happened to have Dave Adlam as her consultant cardiologist (heart doctor) and was able to speak to him in the clinic about the unanswered questions of the SCAD survivors, the research project at the Mayo Clinic and the idea voiced on the Facebook group of a UK based research project.

Dr David Adlam: "We are excited by this developing partnership between the Leicester Cardiovascular Biomedical Research Unit (BRU) and the Mayo Clinic to advance our understanding of this condition. This research programme has been driven by patients who have this condition but for years have been frustrated by a lack of meaningful research into SCAD resulting in a dearth of information on effective treatment and prognosis. The UK SCAD patients have been directly involved in setting up this programme and will be key to its continuing success."

On 4 July 2013, a group of UK patients who had experienced a SCAD came to the Leicester Cardiovascular BRU to share their experiences of the condition, raise their unanswered questions and discuss research plans. They also heard about a website about the condition being

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developed by our in-house Informatics Team, which is now live at <http://scad.lcbru.le.ac.uk/>. This website enables survivors to express an interest in taking part in research projects, share their stories, provide information about the condition and access peer support. Colleagues from the Mayo Clinic also spoke about their research, and the questions that had arisen there. Together the research team and the SCAD survivors put together a very broad research project that would work towards answering their questions. A subsequent bid for British Heart Foundation funds was successful and ethical review completed for the SCAD Research Project.

Rebecca Breslin: "When I first started researching SCAD after my heart attack in March 2012, there were far more questions than answers. It was a frightening time. However, there was hope. The Mayo Clinic had just started some research and the American non-profit SCAD Research, Inc. had recently formed to raise awareness of SCAD and fund the research. To now have the Leicester Cardiovascular BRU on board is an amazing step forward in the research programme and our quest for answers."

The SCAD patients are integral to the research project as we, a unified patient and researcher team, begin the most challenging aspect of the research: getting people to take part. Usually we find people with an illness to take part in research through their doctor but SCAD is so rare that every doctor signed up to the project would probably only be able to invite one or two people to take part. For this project we are asking patients to come to us through a website where they can express their interest in taking part. The people who will be raising awareness about this website, the research and the opportunity to take part will be the patients from the Facebook group themselves, as they are the best connected to existing SCAD patients and most likely to hear about any new SCAD patients. Doctors will also be made aware of the research and the website through their professional body, the British Cardiovascular Intervention Society, and can also advise SCAD patients how they can take part.

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Putting the horse before the cart: an agenda for public engagement

By Kath Maguire

Swapping roles from that of a patient/carer involvement activist to become an associate research fellow for public engagement, I was only too aware of the challenge. From where I had been standing the public engagement horse had always looked as if it was being dragged, often reluctantly, behind the research cart.

The importance and magnitude of this challenge was brought home to me recently when we, at the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South West Peninsula (PenCLAHRC), ran a workshop with our public involvement group on the NIHR 'Breaking Boundaries' review [an article about the review appears on page 5 of this newsletter]. Overwhelmingly, people identified the main barrier to patient and public involvement as arising from a general lack of awareness that it takes place or how people could go about getting involved. This seems to indicate that there is an important piece of work to be done, not only engaging people with research, but also engaging research with people.

Until recently, public engagement has been seen as following research rather than preceding involvement. It has been about telling people what research does rather than asking them what it should be doing. The INVOLVE website makes a clear distinction between engagement and involvement. Instead of the active involvement of patients and members of the public in research projects and organisations, engagement is defined as where information and knowledge about research is provided and disseminated to them. This reflects the way public engagement in science has traditionally been framed. It is an agenda that has focused, almost exclusively, on informing the public in the hope of getting them to engage with the importance and value of academic research.

There is a good reason for this. In a democracy, public science can only be sustained if it has the support of the public, a public motivated to value and to pay for it. This truth has been disseminated



PenCLAHRC public engagement event

widely across the scientific community, though perhaps some were a little slow to catch on. I am not claiming this as the only motivation for public engagement activities but it is a very strong driver, especially at institutional and strategic levels. Research institutes and universities want us to understand why they are worth funding.

The trouble with that concept of engagement is that it is not particularly engaging. The provision of information and knowledge to (or at) the public frames them as a passive audience, spectators rather than players. In fields like health research, where patients and the public are the subjects of the information and knowledge being disseminated, this is particularly problematic. It can be experienced as alienating and disempowering. Unless engagement provides people with opportunities to contribute, to interrogate, and to become involved in research there is a danger of research being experienced as disengaged with them, and therefore irrelevant. Engagement needs to be a two-way process.

In a world where we are bombarded with information, much of which we filter out as unhelpful, public engagement has to do better than provide the public with even more information. It has to create openings through which people can contribute to and benefit from research. Researchers need to be able to engage with members of the public rather than doing engagement at them. Genuine engagement has to involve listening and enabling as well as informing.

Fortunately, and thanks to the work and commitment of many people, engagement is becoming more engaged with the public. The National Co-ordinating Centre for Public Engagement works to support universities in “sharing our knowledge, resources and skills with the public, and to listening to and learning from the expertise and insight of the different communities with which we engage”. This is a much more mutual

picture of engagement, framing the public as co-creators of human understanding rather than as either research subjects or information consumers. Engagement of this kind requires a redefinition of the relationship between the public and science. It also suggests that we need to get better at connecting engagement, involvement and participation in research, making it easier for people to move between them, engaging on their own terms.

This movement of the boundaries has already been recognised by the NIHR. In April 2014 Simon Denegri wrote in the strategy document “Promoting a ‘research active’ nation”: “In time... the NIHR would anticipate integrating our public involvement, engagement and participation plans and their delivery into one strategy.” So it is a good time to open up the debate: what is engagement for? how can research become more engaging? how can engagement support and motivate involvement?

It is time to put the horse where it belongs, in front of the cart.

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We are always interested to hear about your experiences of active public involvement in research, whether you are a member of the public, a researcher or from a research organisation.

If you would like to contribute an article, news item or event notice for our newsletter please contact Paula Davis.

Tel: **023 8065 1088**

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noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in research and development. If you would like to put an item on our noticeboard please contact the Coordinating Centre.

Patient and public involvement on healthtalk.org

healthtalk.org (www.healthtalk.org) contains rigorously researched information for patients, carers, and health professionals about patients' experiences of health and illness conditions. The research is conducted by researchers at the University of Oxford. Funded by the National Institute for Health Research (NIHR) Biomedical Research Centre (<http://oxfordbrc.nihr.ac.uk/>), a new section has been launched on the site about patient and public involvement (www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics). It contains interviews with 37 patients and members of the public about their experiences of getting involved in health or medical research.

The project was overseen by a panel of patients, public members, health professionals and academics. After analysis, 22 reports were written on the key findings including how people became involved, why they stayed involved, and debates around payment and capturing the difference involvement makes. All the main points are illustrated by video or audio clips from the interviews, ensuring the patient/public voice is always present. In addition to creating this freely available online resource, other outputs will include several academic publications co-authored by the researchers (www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/credits) and public members. The next stage of this project is to find out about involvement from the researchers' point of view. It will go live on healthtalk.org next year.

Dr Anne-Marie Boylan, University of Oxford

Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.

North West London Hospital NHS Trust Patient Research Forum

North West London Hospital NHS Trust has a well-established Patient Research Forum. Thirty members provide support to researchers for their research applications, working closely with and guiding researchers throughout the process. The group has been actively involved in service and quality improvement projects in the Trust and won first prize for a poster in the Trust's Annual Research Awards. The group is now planning a project to be conducted in the community in North West London. The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and Academic Health Science Network will be working closely with R&D as this model is being seen as excellent practice.

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If you would like to receive a copy of the newsletter or find out more about INVOLVE please do contact us.

