On the campaign trail

By Simon Denegri

I have always approached what we are doing in public involvement as a campaign. A movement that’s focused on changing for good the way health research is done.

It takes time to build a head of steam behind any campaign. The month of May saw the National Institute for Health Research (NIHR) run ‘OK to ask’ for the third year running. Each year it seems the campaign is challenged in a different way – this time we had the small matter of a General Election to navigate.

But this was our best yet. Over 100 NHS Trusts took part. Locally and regionally the campaign fizzed with energy. From the ubiquitous stands in hospital reception areas to research buses, mock trials with chocolate and even Ken Dodd giving it his endorsement on Merseyside.

We remain the only country in the world to run a national campaign of this sort aimed at raising awareness and increasing the public’s participation in clinical research. I know some grumble about this campaign and its focus. But actually it has everything to do with involvement.

When I go around the country, I see ‘OK to ask’ bringing together patients, researchers, clinicians, nurses and others in an emboldened community where mutual trust is growing. It’s this ethos that must be at the heart of what we are doing in public involvement.

INVOLVE’s leadership of public involvement is a campaign on a much bigger canvas, more ambitious, challenging and complex, even if the essential message is a simple one: the world of research works better when it involves the public.

On the day that the General Election was called, the independent review group looking at public involvement across the NIHR, which I have been chairing for the last year, published its report and recommendations. Continued>>
‘Going the extra mile’ (www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf) sets out a new vision of wanting to see our citizens and their communities more actively involved in public involvement than ever before. It calls for public involvement to be seen as important in science as ‘accurate measurement’. It puts forward six common objectives that all NIHR organisations – national and local – should be working towards:

- Opportunities to engage and become involved in research are visible and seized by the public
- The experience of patients, service users and carers is a fundamental and valued source of knowledge
- Public involvement is a required part of high quality research conducted by researchers and their institutions
- Public involvement is locally driven and relevant whilst strategically consistent with the NIHR’s goals
- Evidence of what works is accessible so that others can put it into practice
- The NIHR has maintained its global presence and influence for working in partnership with the public.

The report also urges all those committed to public involvement to think about its impact in terms of its reach into an ever more diverse population, the degree to which it has made research more relevant to patient and carer needs and, finally, how it is adding to the quality of the research by refining or improving the way it is done.

We expect the Chief Medical Officer (CMO) and Director General of R&D, Professor Dame Sally Davies, to respond to the report later this year. That will be the trigger for us to begin its implementation.

Next year the NIHR celebrates its 10th birthday. But it will be 20 years since INVOLVE was established. That may sound a long time but it’s a relatively short one for a campaign that is about changing the culture of a health research system that has been established over many centuries.

Nonetheless, in those two decades we have pioneered thinking and practice and become the recognised leader internationally. ‘Going the extra mile’ is about maintaining this momentum by ensuring our purpose is clear, and that we are better organised and more effective than ever before in working towards it.

That the Department of Health has announced it will be supporting and funding INVOLVE for a further five years is a sign that they see it as a vital champion of the work needed to realise this vision.

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The Patient Research Ambassador Initiative

By Roger Steel

It is right that patients using local NHS services should have much better information about and access to health research and more opportunity to take part or be otherwise involved. To do this we need to embed a better patient-centred research culture in the NHS.

One of the effective ways to engage both patients and NHS care staff to achieve this is through patients, carers and lay people who have experienced health research themselves. As ‘Patient Research Ambassadors’ (PRAs) bringing the patient perspective to bear in their local NHS care organisations, they can help ensure people using care services have the best opportunities and choices about taking part in research studies.

The idea of PRAs is not completely new. What is new is making this kind of activity the norm rather than the exception. After all the right to expect your doctor, consultant or nurse to tell you about research that may be relevant to a clinical condition is embedded in the NHS Constitution and NHS Choices Framework. But we know this does not happen as often as it should.

The Patient Research Ambassador Initiative (PRAI) aims to promote the role of PRAs in local NHS services. It provides a resource for the research community to take action. By ‘research community’ we mean everyone involved with research: from nurses to patients, from carers to study coordinators and from family members to NHS Trust Boards.

As a result of the initiative there is now a steadily increasing number of examples of PRAs being hosted by NHS Trusts. Some Trusts have two or three people, whilst others start with one. The future looks bright as we now have the momentum to achieve much more across the country. In the long run we see PRAs as the future patient leaders for research in the NHS. For more information see http://bit.ly/PRAIwebsite

Contact: Roger Steel, Project Lead
Email: roger.steel@nihr.ac.uk
Telephone: 0113 343 0441
INVOLVE Coordinating Centre news

INVOLVE contract
The invitation to tender for the INVOLVE contract was issued in February with a closing date for applications of 22 April 2015. The new contract is due to start on 1 February 2016.

New INVOLVE report – Taking stock: INVOLVE Coordinating Centre

New INVOLVE publication: Public involvement in research applications to NRES
In February we published a follow-up report of a joint INVOLVE and Health Research Authority (HRA) project to provide baseline data on public involvement in applications to the National Research Ethics Service (NRES). This report compares 2010 and 2012 responses to the public involvement question in the ethics application form.

In the report non-commercial (e.g. National Institute for Health Research (NIHR), medical research charities) and commercial (e.g. pharmaceutical companies) are analysed separately to more accurately reflect the different patterns of responses to the public involvement question by type of funder.

You can download the report from the publications page of our website: www.involve.nihr.ac.uk/posttypepublication/public-involvement-in-research-applications-to-the-national-research-ethics-service-comparative-analysis-of-2010-and-2012-data/

Exploring the impact of public involvement: new examples
We are continuing to develop the impact examples area of our website and have recently added five examples of public involvement in studies funded by the National Institute for Health Research (NIHR) Evaluation, Trials and Studies Programmes:

- Preventing depressive relapse in NHS Practice through mindfulness-based cognitive therapy (MBCT)
- Transitions to palliative care for older people in acute hospitals
- Evaluating Acupuncture and Standard care for pregnant women with Back pain (EASE Back): a feasibility study and pilot randomised trial
- Health-Related Quality of Life in two treatment pathways for primary open angle glaucoma and ocular hypertension: a randomised controlled trial of initial selective laser trabeculoplasty versus conventional medical therapy
- Outreach programmes for health improvement of Traveller communities: a synthesis of evidence.

You can download the examples from: www.involve.nihr.ac.uk/resource-centre/examples/examples-of-public-involvement-in-studies-funded-by-nihr-evaluation-trials-and-studies-programmes/

INVOLVE at the EULAR 2015 Congress
We were excited to attend the European League Against Rheumatism (EULAR) Congress in Rome on 10-12 June 2015. INVOLVE Group member Carol Rhodes and Helen Hayes from the Coordinating Centre contributed to the conference with a poster presentation giving an insight into membership of INVOLVE from the patient and organisational perspective.

More information about EULAR conference is available at www.eular.org/

People in Research
The People in Research website continues to facilitate the sharing of information about opportunities for public involvement in research. During 2014-15, 83 new opportunities were submitted and more than 8,300 visits to the site were recorded.

The website enables researchers to register and publicise their research opportunities for members of the public to get involved. While members of the public can search the database of opportunities to find out about research activities they can get involved in, and sign up to receive email alerts when a new opportunity is posted.

To find out more visit www.peopleinresearch.org
Interesting articles and publications

We’ve recently added the following references to our Evidence library and Putting it into practice database. To find out more about the libraries and view more references visit www.involve.nihr.ac.uk/resource-centre/

Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions
Sarah Knowles, Ryan Combs, Sue Kirk, Mary Griffiths, Neesha Patel and Caroline Sanders
Health and Social Care in the Community, February 2015, epublication ahead of print

This study aimed to explore what carers of people with long-term conditions think about their role, whether they struggle to identify themselves as ‘carers’ and whether they access support. The study was designed collaboratively with a carer who identified the need for this research and who is a co-author. A steering group of people with lived experience of caring were also consulted on written materials, recruitment strategies and interview questions.


Service user involvement in social work research: Learning from an adoption research project
Jeanette Cossar and Elsbeth Neil
British Journal of Social Work, 2015, 45 (1), 225-240

This article reports on the impact of service user involvement in a project that aimed to map, cost and evaluate services provided to the families of children adopted from care. The project included two advisory groups, one with the adoptive parents and one with the birth relatives. This report focuses on the birth relative group, whose input made a difference to many stages of the research. They helped to: develop the recruitment strategy; design the interview schedules, information sheets, consent forms and assessment measures; analyse the data, developing alternative interpretations of qualitative interview data that more accurately reflected their experiences; identify ways to improve practice that were specific, concrete and rooted in service user needs; and disseminate the findings at the launch conference. The service user consultants described the benefits of their involvement as: meeting people with similar experiences; feeling valued and important; and being able to channel their anger into something constructive.

http://bjsw.oxfordjournals.org/content/45/1/225

Co-research with older people: Perspectives on impact
Rosemary Littlechild, Denise Tanner, and Kelly Hall
Qualitative Social Work, January 2015, 14(1), 18-35

This article reports on an evaluation of the involvement of older people with dementia and older people from a black and ethnic minority group as co-researchers in a study of service users’ experiences of moving between different types of care. The study involved interviewing older service users and carers and reporting the findings to practitioners. The co-researchers were involved at all stages, from design through to dissemination. Evaluation interviews were undertaken by an academic who was not involved in the project. The co-researchers made a difference to the nature and quality of these interviews, which encouraged interviewees to share their experiences. All stakeholders agreed that the co-researchers’ involvement was particularly helpful at the stage of feeding back the findings to service providers and managers.

The authors also reflect on recent criticisms of involvement in research and concerns that it might reinforce existing power imbalances. They comment that a partnership approach in itself is not a problem, but the quality of the process is crucial. They conclude that it is important that the evaluation of involvement includes all parties.

http://qsw.sagepub.com/content/14/1/18

A little more conversation please? Qualitative study of researchers’ and patients’ interview accounts of training for patient and public involvement in clinical trials
Louise Dudley, Carrol Gamble, Alison Allam, Philip Bell, Deborah Buck, Heather Goodare, Bec Hanley, Jennifer Preston, Alison Walker, Paula Williamson and Bridget Young
Trials, April 2015, 16, 190

The aim of this study was to explore researchers’ and patient and public involvement (PPI) contributors’ views on training for PPI in clinical trials, in order to inform the design of training for both parties. Interviews were carried out with researchers and PPI contributors working on clinical trials.
The study found little support for training PPI contributors and widespread concern that such training might lead to contributors losing their patient perspective. The authors comment that training could focus on how to maintain a patient perspective while being involved. Researchers commented that it was more important to find the ‘right’ contributor who already has the relevant skills and experience for a given role, which raises concerns about how to achieve diversity amongst PPI contributors. The authors suggest that it is important to think about the different ways in which PPI contributors can get involved in clinical trials and they recommend using more than one approach.

Although some people questioned what training in PPI for researchers would cover, there was more support for this training overall. The authors suggest that as some PPI contributors are not clear about their role, training that helps both researchers and PPI contributors to learn about ‘how to do PPI’ would be beneficial.

Members of the public
For people considering active involvement, there are often some initial questions that arise when payment is offered for their time, skills and expertise. Clear information from researchers and organisations should advise:

- how much is being offered, and for which activities
- whether tax and National Insurance will be deducted before payment is made
- that payments might affect any welfare benefits that an individual receives
- how to claim payment, and who to contact if there is a problem.

‘What you need to know about payment’ offers more information about what members of the public might expect when offered paid involvement opportunities: www.involve.nihr.ac.uk/posttypepublication/what-you-need-to-know-about-payment/

For welfare benefits guidance, it is strongly recommended that individuals seek expert, personalised advice at the earliest opportunity. The complexities of benefits regulations mean that broad advice is rarely possible, as much depends on knowing the latest regulations and how they relate to an individual’s personal circumstances.

Some benefits have conditions, such as weekly earnings limits that restrict what someone can learn. Other benefits conditions require that permission be sought from Jobcentre Plus before paid activity is undertaken. Expert advice can help to prevent individuals from being unnecessarily penalised.

Continued>>
Benefits advice service for involvement
The Benefits Advice Service offers free, confidential personal advice and support (anonymously, if necessary) on how payment of fees and expenses for public involvement might affect an individual in receipt of state benefits and the best ways to prevent problems arising www.involve.nihr.ac.uk/resource-centre/benefits-advice-service/

The National Institute for Health Research (NIHR) in partnership with others is offering a service that covers advice on payment of fees and expenses for public involvement in health or social care research, service design or service delivery. The service is being provided by Bedford Citizens Advice Bureau, initially as a pilot for one year from January 2015.

You can contact the service if you are:
- a member of the public involved with a NIHR organisation or a NIHR-funded research project www.involve.nihr.ac.uk/resource-centre/benefits-advice-service/benefits-advice-service-for-involvement-for-members-of-the-public/
- a member of staff within a NIHR organisation or research project supporting members of the public to get involved www.involve.nihr.ac.uk/resource-centre/benefits-advice-service/benefits-advice-service-for-involvement-for-nihr-organisations/

Involving children and young people
Many of the above issues also apply when involving children and young people, but there are some additional considerations that should be taken into account when planning these activities. These include:
- ensuring that levels and methods of payment are age-appropriate, providing a choice where suitable
- covering expenses, which may include those of any parent or carer who needs to accompany the child or young person
- being aware of legal restrictions on the times and amount of hours that young people aged under 16 can undertake as paid activity
- being aware that young people aged over 16 may be working and / or in receipt of benefits.

Research organisations
In research organisations, Finance or Human Resources departments will be involved in developing the payment processes. This can be challenging for those departments that do not have experience or knowledge of public involvement in research, and solutions are often based on processes used for staff, or for visiting academics and clinicians.

Some of the issues that organisations and researchers address include:
- should they deduct income tax and National Insurance before payment is made?
- should they advise the public that it is their responsibility to declare payments for tax and National Insurance purposes?
- does employment law apply, and are contracts required?

Institutions often seek local advice to tackle these issues (for example from local tax offices) and determine their own method of processing payments. It is helpful if the processes have some flexibility built into them, allowing people to choose not to be paid, or to ask for less than the amount offered.

Payment and reimbursement policies
With the variety of approaches and processes adopted, there is an increased need for organisations to offer clear information to the public. Payment policies help members of the public when considering whether to become involved and whether to accept payment.

These do not need to be long or complex documents, but should be developed in consultation with the host institution’s Finance and Human Resources departments, and in consultation with members of the public.

For guidance on what to include in a payments policy, please see: www.involve.nihr.ac.uk/resource-centre/payment/developing-a-policy-for-payment-and-recognition/

Resources
INVOLVE has launched a new web page that gathers payment and budgeting resources in one place: www.involve.nihr.ac.uk/resource-centre/payment/

We will continue to develop and update this information.

Sharing practical information, such as payment policies, template letters or details of where to get expert advice, helps others to tackle similar issues. If you would like to share what you use via the INVOLVE website, please contact Martin Lodemore at the Coordinating Centre: mlodemore@invo.org.uk
Dramatic approach to patient and public involvement

By Sophie Petit-Zeman

The Diorama Arts Studio isn’t what you’d think of as a hotbed of patient and public involvement (PPI). But in April, as spring sunshine brightened the more usual gloom of that corner of London, the venue saw the first meeting of an advisory group for a project with potential to revolutionise PPI.

Supported by the final year of a Wellcome Trust Strategic Award and the National Institute for Health Research (NIHR) Oxford Biomedical Research Centre (BRC) (http://oxfordbrc.nihr.ac.uk/blog/when-one-curtain-closes/) the project will be masterminded by Theatre of Debate (TOD), an independent company taking forward the last 25 years work of Y Touring (www.theatreofdebate.co.uk/).

TOD will use live performance, film and digital technology to engage mainly young audiences in informed debate around PPI and social and ethical dilemmas that it raises. Y Touring previously tackled subjects including animals in medical research (‘Every Breath’) and clinical trials (‘Starfish’ www.telegraph.co.uk/technology/4641850/Medical-ethics-meets-kitchen-sink-drama.html) and built an exceptional track record of uniting those with very different views to agree – not on the ‘answer’ to the central debate but on a play that paints a balanced picture. TOD, and Y Touring before, never try to teach people what to think, but do a compelling job of making them want to think about the topic under the microscope.

At first glance, PPI may be less divisive than other subjects tackled, but one of the first hurdles in setting up this advisory group was to persuade PPI sceptics to speak frankly. Anyone who works in PPI knows they exist – in droves – but with NIHR and other funders mandating PPI in research bids, it can be hard for those who feel negative about it to speak openly.

At first meeting, we heard from Lester Firkins about being asked to join a group of carers to discuss CJD (the ‘human’ form of ‘mad cow disease’) research priorities, after his son died from the condition. He said, “This was back in 2001 and yet we were being consulted. If it was right to do when an illness was in the public gaze, surely it’s right always?”

Simon Denegri, Chair of INVOLVE, reflected that “PPI is messy, people are messy, but given my own family experiences and campaigning background, I’m passionate about helping people break open the system, make it listen to them.”

Louise Locock shared her findings from Healthtalkonline interviews with folk who have done PPI (www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics) and some early findings from her interviews with researchers about their reactions – good and bad – to PPI.

Even in this initial meeting of the advisory group it became clear that alongside some who disagree with the basic principle of PPI, more subtle tensions bubble away. Debate unfolded about payment: some ‘PPI-ers’ feel that paying patients for their time ensures their involvement is fair, equal to those who are employees; another said paying people traditionally considered volunteers “just feels wrong in my guts”.

Alongside this debate, we chatted about whether (and how) to gather the evidence that PPI ‘works’ – makes research better for patients – or whether, as one leading light in evidence based medicine was quoted as saying, “some things just don’t need evidence”.

Continued>>
Playwright Judith Johnson (www.rlf.org.uk/fellowships/judith-johnson/) will now pick her way through this and more. For those old enough to remember Grange Hill rest assured: between this, writing three plays for the prestigious National Theatre Connections and much else besides, her credentials in creating compelling drama are impeccable.

At the end of the meeting, Judith enticingly asked us, “If you had to write this play, what would you focus on?” Suggestions included the importance (and challenges) of PPI in research with children; conveying uncertainty; why much research focuses on drugs rather than more subtle issues of quality of life; and how to do good PPI when one person’s view about what matters differs radically from another’s.

Nigel Townsend, TOD’s Director said, “We need to engage audiences in informed debate about our futures, the world we want to live in and the role science and the arts have in achieving that. We’re so excited to launch Theatre of Debate doing just this.”

Commentators such as The Observer’s Robin McKie have written of Townsend’s past work that it “…raises key ethical questions without giving glib answers – important in preparing us for the future”. While a teacher at a school that saw Y Touring’s play about genomics wrote “I would recommend Dayglo because it’s a truly original way of bringing cutting edge science into schools. Our Year 11s were really engaged with the event, some were tweeting it that same evening.”

Judith’s PPI play will tour schools nationwide in Spring 2016, with up to 2,000 youngsters seeing – and debating about it – each week. After TOD leaves the school, online resources support students and teachers to continue conversations around the subject. The advisory group will help ensure accuracy of all associated material as well as the play itself, and a filmed performance will be screened at Picturehouse cinemas during National Science and Engineering Week.

It will be a fascinating journey for PPI.
Contact: Sophie Petit-Zeman, Director of Patient Involvement, National Institute for Health Research (NIHR) Oxford Biomedical Research Centre (BRC) and Unit; Scientific Adviser to Theatre of Debate
Email: sophie.petit-zeman@ouh.nhs.uk
Telephone: 01732 751524

Public members on Trial Steering Committees: interview study points way forward on guidance

By Heidi Surridge

Members of the public have the opportunity to get involved with all stages of health research. One of the ways a member of the public can get involved is by becoming a public member of a group of people called the Trial Steering Committee (TSC). Clinical trials and similar studies usually have TSCs. TSCs oversee the work of the study by meeting to discuss how the study is going and any problems that have arisen. They don’t actually do the research; they monitor the progress of the study. As well as members of the public, doctors, other health professionals and academics make up the group.

Here at one of the National Institute for Health Research’s (NIHR) funding centres we fund and manage NHS research. We wanted to find out what members of the public do on TSCs, how useful they feel they can be to the group and what the experience is like for them. We also wanted to ask the Chairs of these groups what they felt about having public members, how useful they are and how they contribute to the work of the committees.

We selected a small sample of public members and Chairs involved in these groups to take part in a telephone interview. The interview questions were put together with help from a patient and public involvement (PPI) advisory group at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). Nine public members and seven Chairs of TSCs took part.

The findings revealed:
1. Most Chairs and all public contributors felt that the TSC was the right place for a public member as it:
   ■ provides a fresh viewpoint away from research and the clinical world
   ■ provides the viewpoint of someone who could imagine what it would be like to take part in the study
   ■ includes someone who could benefit from the results of the research.
2. Public contributors were involved in one or more of the following activities:

- making decisions about the importance of the research
- devising ways of measuring success of the study (outcome measures)
- reviewing study documents (protocol)
- developing and reviewing patient documents
- inputting into ways of recruiting people to the study
- reviewing study questionnaires, tests and so on.

3. Public contributors had usually been involved in other research activities before sitting on a TSC. This meant that Chairs often felt the public members were experienced and therefore did not need training. People were invited to become members of the TSC usually because they were known to the research team. They were either already involved in other studies, were charity staff, patient support group members or a patient of one of the doctors. Aside from practicalities of meeting times, location and so on, the public members did not receive any written or verbal guidance on the expectations of their role except “to put forward the lay person’s, the patient’s views”.

4. When asked what helped public members to contribute, Chairs and public members suggested the following:

- giving time to explain the study, group members’ roles and responsibilities
- helping the public member to build a relationship with the group
- having a Chair with a commitment to public involvement
- good chairing, where a public member is included, involved and encouraged, therefore creating a friendly environment
- considering having more than one public member for a range of views and support.

5. The following were felt to hinder public members from contributing:

- Complicated studies and words used in health research. The more technical and complex the problems raised at the TSC the harder it was for the public member to take part.
- If you involve public members without training or experience you risk being ‘tokenistic’. The study would not benefit from the public viewpoint.
- Public contributors coming to the TSC with a personal issue or grudge. It’s not the right place to make a complaint.
- Public members seeking help through involvement or finding involvement a strain.
- Meetings held on the phone could make it difficult for the public member to speak up and take part.

Some of the issues raised by this small project apply to other areas of patient involvement. The Chair should ensure that the public members are clear on what they are getting involved in, their role and responsibilities. They should receive training if necessary. It could be argued that public contributors need to be more experienced for this TSC role. Is there then a need for a career ladder of public involvement? Who should provide the training?

As funders of NHS research we will be taking steps to ensure there will be some good practice public membership guidance. Guidance needs to be developed for both professional Chairs and public members of TSCs. We also suggest the development of role descriptions and clear methods of recruitment to prevent coercion and overuse of some public contributors. It would also enable equal opportunity and prevent members of the public using the TSC as a source of help or an outlet for negative experiences.

Contact: Heidi Surridge, Programme Manager, PPI, NETSCC
Email: H.R.Surridge@soton.ac.uk
Diversity in public involvement

By Paula Wray

A ‘whole systems’ approach to public involvement has been adopted by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East Midlands. This approach includes the establishment of an East Midlands Centre for Black and Minority Ethnic Health (EMCBMEH) and a Patient and Public Partners’ Council. These initiatives complement each other by increasing awareness of research and facilitating wider participation and involvement.

The Partners’ Council is a ‘critical friend’ to the CLAHRC and has a fundamental role in observing and supporting funded projects. It acts both as a resource for research teams and as a monitoring body, ensuring that each project has stakeholder involvement to provide support throughout the process and the potential to improve patient outcomes. The Partners’ Council comprises a small group of individuals who represent the region’s counties, bringing their extensive knowledge and contacts from the community, voluntary and charity sectors and Healthwatch, and experience as parents, carers and patients with lived experience of both mental and physical health conditions. This brings knowledge and experience to the CLAHRC and helps its reach into communities.

Recruitment to the Partners’ Council was initially through known local community contacts and assets. This has enabled us to recruit a very diverse group of individuals; however, as the CLAHRC project portfolio changes so will the membership. For example there are now several projects looking at issues relating to children and young people so their voices will need to be added. It has been said that public involvement has not always been taken seriously and has simply been a tick box exercise. We have put structures and systems in place, which are reviewed and refined according to need, to ensure that this is not the case.

Members of the group:
- have oversight of all projects and reports
- are represented at and report to both executive and governance boards.

They make practical and achievable recommendations to improve the public involvement where appropriate including:
- being a mentor for a study team
- providing peer support for public representatives on teams
- acting as a bridge to enable wider perspectives to be included in the project without individuals having to self identify or join a forum they would not be comfortable in.

If concerns are raised around any project this can be escalated through the boards and the Scientific Committee. Public involvement is an essential criterion for CLAHRC EM funding, which potentially can be withdrawn if the public involvement is not adequate.

When they joined, some individuals had been members of the previous CLAHRC and others had no knowledge of research. Training and development has, therefore, been an important element for both individuals and the group as a whole. We funded five members to attend the INVOLVE conference, enabling them to contribute in workshops and presentations. Several members have completed their Lay Assessor training and subsequently completed a number of assignments.

“Being part of the Partners’ Council has opened up a whole new world for me. It’s been a steep learning curve but with the support and encouragement from colleagues I have grown in confidence. This has enabled me to gain new skills, for example as a Lay Assessor, and I have already helped develop and refine a number of research proposals. It’s been so satisfying to utilise the extensive network of voluntary groups I am involved in to help shape and inform research.”

Colleen Ewart
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 please contact Paula Davis.

Tel: 023 8065 1088
Email: pdavis@invo.org.uk

One of our members, Fred Higton, describes himself as ‘a chemist by background and a cartoonist by inclination’. He has drawn many cartoons for study teams to use and the ‘Hats’ cartoon (above) to depict our Partners’ Council. During his speech at our Annual Conference, Fred described the Partners’ Council as the ‘Guardians of the CLAHRC’. I fully endorse this view and feel that within our organisation public involvement is seen as a valuable contributor and partner rather than an obligation.

The underrepresentation of ethnic minorities in research limits their ability to benefit equally from new interventions or services. Therefore it is our responsibility to increase involvement of underrepresented communities to ensure that we work as inclusively as possible. The EMCBMEH is bringing together and coordinating the region’s expertise, knowledge and capacity, developing a centralised resource to support individuals and organisations undertaking research and healthcare delivery in partnership with communities. The Centre aims to be an effective and sustainable foundation to reduce health inequalities in the East Midlands.

The Centre works with communities to facilitate the dissemination of health information, and provides the tools for the communities to raise their own priorities and empower themselves to improve health literacy and access to interventions.

The Centre is building trust between minority communities and the research world, with community facilitators being integral to the delivery of commissioned projects. Over 13 health information events have been well attended (over 350 community members) and well received with many more requested.

These initiatives are supporting partnership development with marginalised groups and individuals as the foundations to reduce health inequalities and ultimately achieve equity. We only have one chance to get this right and the multiple perspectives, raising practical, ethical and moral issues along with pragmatic solutions, will ensure that we do get it right.

For further information visit www.clahrc-em.nihr.ac.uk

Contact: Paula Wray or Naina Patel
Email: paw30@le.ac.uk (Paula)
or np89@le.ac.uk (Naina)
Twitter: @EMCBMEH

‘Hats’ cartoon designed by Fred Higton
Involving People is now part of Health and Care Research Wales

Involving People has been part of the National Institute for Social Care and Health Research (NISCHR) Clinical Research Centre since 2010. On 14 May 2015, the services and functions funded by NISCHR were rebranded Health and Care Research Wales (www.healthandcareresearch.gov.wales/). The Involving People Network will continue to exist and will now be known as the ‘Health and Care Research Wales Involving People Network’. If you have queries or want to find out more about public involvement in Wales, please contact Natalie Simon, Public Involvement Team Lead: Natalie.simon@wales.nhs.uk

What should research on HCAIs investigate?

Everyone with an interest in reducing healthcare associated infections (HCAIs) is being urged to take part in a national survey. The survey is part of a priority setting partnership that aims to identify the most important unanswered research questions about HCAIs. The James Lind Alliance Priority Setting Partnership for HCAIs is a collaboration between patients, clinicians and academics. There are a number of different prevention, identification and treatment options for HCAIs and it is important that we try to understand which of these are effective and make a difference to those affected.

The survey is open until 30 September 2015 and can be found at http://goo.gl/forms/ngqQC79cmC. A paper version can be downloaded on the project website at https://sites.google.com/site/jlapsphcai/home or you can request one by emailing k.gurusamy@ucl.ac.uk

Service user and carer involvement in social work education – where are we now?

Submissions are invited for a special edition of ‘Social work education: the international journal’ that will focus on the topic of service user and carer involvement in social work education. In subtitling the themed edition with the question ‘Where are we now?’ the editors are looking to present a critical overview of the contribution that carers and service users make to important aspects of social work knowledge in their engagement with social work students. Papers should clearly evidence the current range and diversity of ‘involvement’ in social work education. A leaflet provides further information on the kind of papers the editors are looking for: www.involve.nihr.ac.uk/wp-content/uploads/2015/07/Social-work-education-flyer-2015.pdf

Closing date for submissions: 16 October 2015

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.