

newsletter

Welcome to this edition of the INVOLVE newsletter, which features a special tribute to Sir Nick Partridge, who is stepping down as Chair of INVOLVE. Nick has been a member of INVOLVE since it was first set up as Consumers in NHS Research, fifteen years ago.

A message of thanks and appreciation

By Professor Dame Sally C Davies, Chief Medical Officer

I would like to take this opportunity to thank Nick for his outstanding contribution as Chair of INVOLVE. He has, since 1999, been a key figure in helping us make sure that public involvement is at the very heart of what we do – that is **real** involvement.

We have both long shared the belief that involvement is key to high quality research and that high quality research is essential to an evidence based health service. In the days before the National Institute for Health Research (NIHR), and as Chief Executive of the Terrence Higgins Trust, Nick had for many years championed public involvement in research. He was a founding member of INVOLVE back in 1996 and has consistently

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Sir Nick Partridge

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.

advocated the need to work with and win over researchers, clinicians and research funders and to create partnerships with patients, the public and the voluntary sector.

Not only has he been a dedicated Chair of INVOLVE but also, once NIHR was established, Nick has worked tirelessly with us, often challenging us as an NIHR programme, to help ensure it has become the organisation it is today.

With Nick's steer, INVOLVE have been instrumental in providing practical support to other NIHR Programmes and NIHR infrastructure. Patients are increasingly involved in our research funding processes, for example, as reviewers of research applications, members of our commissioning boards and in the development of research protocols. As a matter of course, NIHR expects grant applicants to say how they have and will involve the public in their research. Nick has also enthusiastically encouraged us to stress the need for investing in the evidence base to understand better the most effective approaches to public involvement, and to learn from others the difference that it is making to the quality of research.

Finally, I want to pay tribute to Nick's personal qualities. His formidable talents, from which we have greatly benefited, include an impressive ability to identify common ground and shared aspirations. His challenge with charm and his willingness to lead from the front and to take people with him is truly impressive.

Thanks to the Terrence Higgins Trust for sparing so much of Nick's time over the years. I am sure that they share my admiration for what Nick has achieved as Chair of INVOLVE and for the enhanced standing of public involvement in research that he has helped to secure.

Nick will be greatly missed by us all, but I know that he, like me, is reassured by the news that from June 2011, Simon Denegri will be taking over as Chair of INVOLVE.

Thank you Nick.

– Professor Dame Sally C Davies
Chief Medical Officer

Simon Denegri, incoming Chair, comments:

“I feel very privileged to have been asked to succeed Sir Nick Partridge as Chair of INVOLVE. Public involvement is fundamental to us maximising the potential of NHS, public health and social care research in the UK in these challenging and exciting times. The need for INVOLVE has therefore never been greater – in building collaborations, developing and supporting good practice and demonstrating the benefits of an active partnership between researchers and the public. I am looking forward to championing this effort with my colleagues at INVOLVE and across NIHR so that public involvement truly does become the rule and not the exception in research.”

We will be hearing more from Simon in future newsletters.



Simon Denegri - INVOLVE's new Chair

INVOLVE

Coordinating Centre News



What you need to know about payment

Alison Faulkner has been working with us to produce a new introductory guide about payment, which is aimed at members of the public who are thinking about getting involved with research. The guide provides basic general information, suggests some useful 'key tips' and also lists the important questions members of the public should seek the answers to when being offered payment for involvement. We hope the new guide will also be useful to all sorts of research organisations, for example, as part of an induction pack when new people are getting involved. Feedback from some of the people who were involved in developing the guide included:

"I think this is very good and clear – no jargon that I could see!"

– Patsy Staddon, Survivor Researcher

"It looks very useful and I would certainly like to have something like this to give to people who get involved with us."

– Maya Albert, Rethink

This booklet supplements the information about involvement in research in our Public Information Pack. More detailed information about payment issues is available in 'Payment for involvement' (our guide for researchers and research organisations).

The full title of the booklet is 'What you need to know about payment: an introductory guide

for members of the public who are considering active involvement in NHS, public health and social care research.' INVOLVE (2011). It can be downloaded from the publication section of our website or printed copies are available on request (contact us on admin@invo.org.uk or call 02380 651088).



The Involvement Helpline Milton Keynes

If you are involving people in research who are receiving welfare benefits, it is important they are able to access good quality, personalised and confidential advice on how the involvement, any payment offered and the reimbursements of expenses might affect their benefits. The Involvement Helpline, run by Milton Keynes Citizens Advice Bureau, has been set up to help with this. The aim of the helpline is to ensure that people who offer their assistance can make an informed decision as to whether to get involved following a discussion with a specialist caseworker. Researchers and research organisations can now buy individual advice referrals, as required, at the cost of £140 per referral – they call these one-off spot purchases. A typical referral may involve discussion about the type of involvement, proposed payments and any proposed reimbursement of expenses incurred, including the costs of personal assistants and/or facilitators, benefit conditions and any restrictions on earnings. The case worker can also liaise with benefit agencies, with permission, when this is required.

The Helpline annual report 2009-2010 gives examples of how their support and advice has enabled people to take up involvement opportunities without affecting their benefits.

To request a copy or ask for more information, please contact the Involvement Helpline. Email: involvement@mkcab.org.uk Tel: 0800 652 0941.



Do you want to become a member of INVOLVE?

During the summer months we will be advertising for new members to join the INVOLVE working groups. We will be looking for:

- members of the public (for example, service users, patients, carers) actively involved in research and
- people from voluntary sector organisations and health and social care research organisations who have a commitment and ability to promote public involvement in research.

Members participate in our work through four meetings a year and other activities in between meetings. If you are not in full time employment in the public sector, you will be offered a fee for taking part. All members' expenses are covered. We'll be holding information meetings where you can find out more about being a member of INVOLVE and how to apply for a position. More details will be on our website, sent out through our mailing list and advertised through other methods soon. We hope you will be interested in finding out more. Watch this space!



INVOLVE newsletter changes

Unfortunately we are no longer able to routinely send out our newsletter by post. If we have your email address, **we will send you future newsletters by email unless you contact us to ask for a printed copy to be posted to you.** If you do not currently receive information from INVOLVE by email, we will still continue to send you a printed copy. However, please contact Helen Hayes at the Coordinating Centre to update your details and let us know how you would like to continue to receive the newsletter – email mailinglist@invo.org.uk or call 02380 651088. We are working to improve how our newsletter can be read online as part of our website update – this will be in place for our Summer 2011 edition.

Interesting articles and publications

• **Consulting parents about the design of a randomised controlled trial of osteopathy for children with cerebral palsy**

Vanessa Edwards, Katrina Wyatt, Stuart Logan and Nicky Britten.

Health Expectations – published online 18 January 2011

This paper found that the involvement of parents helped design a trial that was acceptable to families and addressed outcomes that mattered to them. Consulting parents about the design of the research led to a trial that achieved excellent recruitment and retention rates.

• **Public involvement in the design and conduct of clinical trials: a review**

Jonathan Boote, Wendy Baird and Anthea Sutton
The International Journal of Interdisciplinary Social Sciences, Volume 5, Number 11, pages 91-111

This study reviewed examples of public involvement in the design and conduct of clinical trials, to synthesise the contributions of the public, as well as the identified tensions and facilitating strategies.

• **Can the impact of public involvement on research be evaluated? A mixed methods study**

Rosemary Barber, Jonathan Boote, Glenys Parry, Cindy Cooper, Philippa Yeeles and Sarah Cook.
Health Expectations – published online 17 February 2011

This study found consensus amongst panellists that it is feasible to evaluate the impact of public involvement on some research processes, outcomes and on key stakeholders. The value of public involvement and the importance of evaluating its impact were endorsed.

• Doing research together: bringing down barriers through the ‘coproduction’ of personality disorder research

Steve Gillard, Kati Turner, Marion Neffgen, Ian Griggs and Alexia Demetriou
Mental Health Review Journal, Volume 15, Issue 4, December 2010

This study looked at the extent to which research teams on two recent projects have ‘coproduced’ knowledge about personality disorder, and considered the potential impact of coproduction on research findings and service delivery. The two qualitative research projects were conducted by teams comprising of conventional academic, clinical, service user and carer researchers.

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 Helen Hayes at the Coordinating Centre with details: hhayes@invo.org.uk



An INVOLVE working group meeting

WhyNot!

Trained by Anglia Ruskin University, members of WhyNot! are able to carry out research in a variety of ways. We can carry out literature reviews, develop research methodology and questionnaires, interview people either face to face or by telephone, and write and produce final reports. We live across Essex and come from a wide variety of professional, voluntary and work backgrounds. Previous projects include:

- Lack of uptake by disabled and elderly people for ‘Telecare’ products
- Evaluating the care received by inpatients from the statutory and voluntary sectors when leaving and returning home from hospital
- The value of home delivery service given by volunteers for people unable to visit a library
- The experience/value to older people able to visit a library
- Questioning if ‘Village Agents’ are providing useful information to vulnerable individuals on services available to them.

We are also involved with focus groups who evaluate the courses run by the NHS for carers of vulnerable people.

Supported by Anglia Ruskin University, we are currently involved in a project Scoping older people’s research groups. We would like to contact any research groups similar to ourselves with a view to exploring how they are constituted, the type of activities they are engaged in and sustainability strategies.

If you think you can help us, please send your details to Helen Hayes at the INVOLVE Coordinating Centre Tel: 02380 651088 or email hhayes@invo.org.uk and we will contact you.

Working with patients and members of the public in the Manchester Biomedical Research Centre

By **Marisha Palm and Bella Starling**

The National Institute for Health Research (NIHR) Manchester Biomedical Research Centre (MBRC) is one of the nation's 12 flagship centres, appointed as a specialist centre in genetics and developmental medicine. The MBRC conducts translational research, moving findings from the laboratory into practice. As part of the MBRC, Nowgen has a strong reputation for public programmes, and leads the centre's involvement and engagement strategy.

The MBRC and Nowgen believe that patients and the public should be involved in a variety of ways and at all stages of the work of the MBRC. In 2010, we therefore published our strategy for engaging and involving people with our research entitled 'Working with patients and members of the public'. Formed in the context of an increase in people taking an active role in research, the strategy proposes a range of transparent processes.

Importantly, involvement is seen in its widest context, from information-giving activities and creative ways to stimulate thinking about research, to integrating public opinions into the work of the MBRC, and empowering patients to contribute to decision-making in the MBRC as an organisation. Through all these approaches, MBRC hopes to stimulate an informed and inclusive research environment, create an atmosphere of mutual trust and confidence between the MBRC, patients and members of

the public and ultimately enable the highest quality translational research.

The four main objectives of the MBRC strategy are:

- 1) To consult actively, listen to and involve patients and members of the public
- 2) To inform, educate and stimulate thinking about the work of the MBRC among citizens of today and tomorrow
- 3) To ensure that patients and members of the public are embedded within MBRC decision-making processes
- 4) To place the MBRC at the forefront of involving patients and the public in research.

One of the first steps in the implementation of the strategy was to conduct a mapping activity of existing engagement and involvement activities in the MBRC. Researchers were asked:

- what kinds of involvement work they and their teams had carried out;
- any challenges; and
- what could be done to best support working with patients and members of the public in the MBRC.

Researchers highlighted a huge range and diversity of engagement activities across the MBRC with many examples of good practice. Activities broadly fell into three categories: informing, engaging and involving. The following are just some examples.

Patients as partners

Patients and members of the public are included on MBRC research boards, guidelines groups and governance committees. Patients have also been partners in the preparation of grants, the direction of networks, and the dissemination of resources; and patients have been actively consulted on research design, methodology and

study materials (e.g. cover letters, information sheets). Researchers reported respecting and appreciating the perspectives that patients brought to these situations.

Public consultation and advisory groups

MBRC researchers have held focus groups to get patients' opinions on the direction of research, and public consultations encouraging feedback on projects. Advisory groups have involved patients and the public at early research stages and throughout the research process. Depending on their purpose, some groups advise at the proposal stage and meet to review multiple studies, while others are convened to give advice on a particular project and meet at regular intervals to review the conduct and direction of the project.

Working with young people

MBRC researchers regularly host students in their labs, visit schools and take part in 'Meet the Scientist' events at Manchester Science Festival. A youth forum website is currently in preparation for young adults who are interested in clinical trials research and MBRC researchers have taken part in Teachers' TV programmes bringing contemporary genomics into the classroom. In addition, Nowgen holds 'hands-on' molecular genetics workshops with MBRC researchers for A-level students. Over 1,000 students attend these practical workshops every year.

Challenges and next steps

Sometimes however, effective engagement and involvement can be difficult. MBRC researchers identified seven challenges to their work in this area: practicalities, lack of funding, lack of communication or awareness, a feeling that involvement activities aren't always valued, concerns about 'tokenism', difficulties in finding

people to involve, and uncertainties about how to engage or how to present complex and technical research. To address these, researchers suggested methods of support that would help them to meaningfully involve patients and the public, including opportunities for sharing good practice, peer-to-peer advice, facilitation and training courses.

Following the mapping activity, a day for sharing good practice was recently held for researchers and research support staff at the MBRC. Over the next 12 months, the MBRC and Nowgen will create a sustainable network for sharing good practice, run training for patients and researchers, support innovative public and schools events, and develop engagement 'toolkits'.

We are also excited to be holding a pan-BRC conference on engagement and involvement, with a focus on young people, in October 2011. Watch this space!

'Working with patients and members of the public' and further details of MBRC's involvement work are available at:

www.manchesterbrc.org/CubeCore/.uploads/Documents/MBRCPPIStrategyJune2010.pdf and www.nowgen.org.uk

For a hard copy of the mapping report, or if you would like to get involved in the work of the MBRC, please contact Marisha Palm –

Tel: 0161 276 3215

Email: marisha.palm@cmft.nhs.uk

Marisha Palm PhD is Research & Evaluation Officer at Nowgen. Bella Starling PhD is Director of Public Programmes at Nowgen.

Reflections on a user led research project at Bristol Mind

By Rosie Davies

The research aimed to explore how both statutory and voluntary sector services could best work to promote effective access to, and engagement with, services for people with serious mental health problems who get labelled as being 'hard to engage'. The primary focus was on the perceptions and needs of people using services and of those who had gone out of contact with them, but it also gathered information from carers/supporters and staff. There was also a focus on people from black and minority ethnic groups, including Gypsies and Travellers.

This project came about as a result of a successful funding application for a research grant to the Big Lottery Fund. Over £290,000 was awarded to Bristol Mind, a user-focused charity. In 2003/4, when the funding application was being written, Bristol Mind had a User Focused Monitoring (UFM) project. UFM is a way of evaluating and researching mental health services by the people who have had experience of using them.

The funding application was put together by a team of people including the UFM Coordinator, who had used mental health services; a development consultant and academic from the South West Development Centre (which at the time was called the Care Services Improvement Partnership South West); a Bristol Mind trustee who was both a university based academic researcher and a mental health service user; the Research and Development Director of the

Avon and Wiltshire Mental Health Partnership NHS Trust (which delivered all statutory mental health services in the area and which sponsored the research); an academic psychiatrist from the University of Bristol; and the Director of Bristol Mind. This team of people (apart from the UFM Coordinator) supported the project from the funding application right through to completion of the project. The strength and continuity of support from this team was an important factor in the success of the project.

The application to the Big Lottery Fund for a research grant required a lot of detailed information and the study had clear aims and research methods described in the application. When the funding application was successful, the team advertised for a researcher to lead the study. I was the person appointed, a mental health service user who had previously been involved in user-led research and worked for a short time as a research assistant at a local university.

It was a big jump to go from being a research assistant to being described on forms as the Chief Investigator! I had not previously run a research project of this scale but was responsible for all aspects of the three year project. Two other service user researchers were subsequently appointed. Two members of the team gave me supervision and the whole team met regularly as a Steering Group and gave me informal advice on request. I was also supported by independent external supervision which was invaluable. We received tailored training at various stages of the research project.

In addition to contributing to the research design and application and running the study, people who had used mental health services contributed to the project in other ways. Service users, including someone using assertive outreach

services, were members of an advisory group, as were a member from the Gypsy and Traveller communities and a service user involvement worker from the local mental health trust. The advisory group also included members of staff from assertive outreach teams and from the voluntary sector. Pilot interviews were conducted to make sure that service user experiences shaped the interview topic guide.

We were very successful in recruiting people to the study, despite the explicit focus on people who were 'hard to engage'. Thirty-two people using assertive outreach services and voluntary outreach services were recruited. Voluntary outreach services were mainly for the homeless and people with drug and alcohol problems.

Fifteen people were recruited who had gone out of contact with mental health services; they were recruited mainly in response to adverts in local magazines and from service user led groups. The study wanted to recruit people from the Gypsy and Traveller communities but no one was recruited initially. The recruitment approach was adapted so that we visited sites with a member of the community and were introduced to people who might be interested. Using this strategy, nine people were recruited. Eleven other service user participants (mainly using assertive outreach) were from black and minority ethnic groups. Carers and staff were also successfully recruited.

All study participants (apart from staff) were offered £10 as a thank you for taking part plus expenses. Interviews took place at times and locations convenient to participants, often in people's homes. We usually interviewed in pairs supported by a safety policy. Offering payment encouraged some people to take part in the project; it was valued by many participants, who were poor and on benefits, particularly by people

using outreach services for the homeless. All participants knew that we had used mental health services and this helped us build rapport, openness and trust. Participants were sometimes surprised to hear that I had been detained under the Mental Health Act a number of times; this information appeared to challenge stereotypes of people with serious mental health problems. Being based in an independent user focused organisation gave people confidence that the research was independent from services.

From a personal perspective as lead researcher, running this project was a big challenge and I often felt out of my depth. It was only my second full-time paid job after being ill and out of work for some time and I had an episode of illness, which included being detained in hospital, early in the project. Managing illness among the user researchers was a challenge when the project timetable did not allow for delays. It was a real privilege to speak to so many people who were willing to share their experiences with us. I hope that we have done them justice.

The project was called 'Effective Involvement in Mental Health Services. Assertive outreach and the voluntary sector.' The study took place in Bath and North East Somerset, Bristol, North Somerset and South Gloucestershire from 2005-2008.

Study reports are available from Bristol Mind's website:

www.bristolmind.org.uk/training-research/effective-involvement-project

For more information, please contact Rosie Davies –

Email: Rosemary3.Davies@uwe.ac.uk

Tel: 0117 328 8796 (shared line)

New NIHR Research for Patient Benefit (RfPB) Programme website

The RfPB Programme has a new website, designed to match the main National Institute for Health Research (NIHR) website, reflecting its position within the NIHR family. The pages – at www.rfpb.nihr.ac.uk – have been completely redesigned, and contain lots of new information about the programme.

There is a whole section just for patient and public involvement (PPI) within RfPB, which reflects the fact that active service user participation is embedded in all aspects of the programme. For example, each application submitted to RfPB is not only reviewed by academic and clinical peers but also by members of the public, who sit on our regional committees and provide lay review. On these new PPI pages, there is information for researchers and for patients and members of the public. The section entitled 'How to get involved' provides information about being a lay reviewer and about sitting on the Regional Advisory Committees. There is also information for researchers, providing links to the Research Design Service and other resources that help researchers address PPI in their applications.

In addition, visitors to the site will soon be able to read the abstracts from all the funded projects, and, in the next few months, the first final reports from funded RfPB projects will also be available. The final reports will not only summarise the research outputs and the resulting patient benefit, but will also contain information about PPI in the funded projects, providing good examples of how PPI has benefited RfPB research.

The redesigned site, with its depth of information, will be a great resource for all involved in research and for those interested in learning about or getting involved in the RfPB programme. The website will regularly be updated with additional resources and hints and tips, so feedback is always welcome from visitors to the site. For further information, please see: www.rfpb.nihr.ac.uk

Launch of North West People in Research (NWPiR) Forum

The North West People in Research (NWPiR) Forum is a new organisation that aims to support patient and public involvement (PPI) and public engagement (PE) in health research. The Forum is jointly sponsored by NHS North West and the Research Design Service NW, and works across Cumbria, Lancashire, Greater Manchester, Merseyside and Cheshire.

The NWPiR Forum recently held three launch events, engaging almost 120 researchers, patients and members of the public in venues in Liverpool, Preston and Manchester. The events in January and February included an introduction to the Forum followed by workshop sessions on PPI and PE and a brief concluding session on how to join the Forum and what it will offer. Good practice across the North West was highlighted, with active researchers, representatives from the Comprehensive Research Network, Medicines for Children Research Network, Primary Care Research Network, Mental Health Research Network and Biomedical Research Centre all invited to share their experiences.

The launch events also included a workshop

that asked people to think about the barriers to PPI/PE and how the Forum could help to address these. Common themes were collated in order to inform the development of the Forum and to help members of the Executive Committee decide on what activities to prioritise.

Barriers to PPI/PE included fear and scepticism; language (jargon, acronyms) and culture; lack of time, funding and training; difficulty identifying and accessing patients and members of the public to involve; and the challenge of ensuring that patients and the public remain interested and engaged over time.

People who attended the launch felt that the Forum could help by raising awareness of PPI/PE in research and showcasing good practice, and by providing opportunities for mentoring and training. They also felt that the Forum should work to support information sharing across the region and to facilitate links between patients and the public and researchers.

Despite limited budgets for advertising the launch events, the numbers in attendance show that there is significant interest in PPI/PE across the research community and amongst the wider public in the North West. Evaluation of the events found that people appreciated the opportunity to network and hear about PPI and PE being carried out in their communities.

Based on the success of the launch events and the positive feedback from those in attendance, the NWPIR Forum plans to run further local good practice sharing events in the future. Join the Forum and be the first to be informed of these events!

If you would like any more information about the launch events, or if you are not already a member of the NWPIR Forum and would like

to join, please contact Marisha Palm –
Tel: 07554 413269
Email: marisha.palm@northwest.nhs.uk

The Forum welcomes interested people living or working in the North West to join us; local organisations may also join as Corporate Members.

New website – Involving London in research

Involving London is a new website designed to enable patients and the public in London find out how they can get involved in health and social care research and to get up-to-date information on current research opportunities. The website aims to bring patients and the public together, to work with researchers who are looking for people to get involved in research studies across the capital.

Launched in March 2011, Involving London was set up by Patient Public Involvement Lead and Managers from various NHS Trusts, Research Networks/centres and Support Services. Each organisation will use the website to promote research opportunities, in specific disease groups, research groups or local areas. Involving London has features on the latest news and events as well as other useful online resources all available at the click of a button:

www.involvinglondon.co.uk

Deadline for contributions for our next newsletter: **4th July 2011**

If you have any questions on contributing to the newsletter, please contact Helen Hayes Tel: 02380 651088 Email: hhayes@invo.org.uk

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 article on our noticeboard please contact the Coordinating Centre.

Two new publications from the National Children's Bureau (NCB) on involving children and young people

• **Young people in research: How to involve us. Guidance for researchers from the PEAR young people's public health group.**

PEAR stands for Public health, Education, Awareness, Research. It was an NCB Research Centre project supporting young people's involvement in public health research. The project ran from 2008-2010, supported by the Wellcome Trust. The young people felt it was important to develop guidelines on how to support young people to get involved in the planning and process of research and to give their perspective on how they would like to be involved. The guidance can be downloaded from the PEAR website:

www.ncb.org.uk/pear/home.aspx

• **Guidelines for Research with Children and Young People**

By Catherine Shaw, Louca-Mai Brady and Ciara Davey

These guidelines have been produced for researchers who are thinking about involving children and young people in their research project, whether as participants or in a more active role. Available at the NCB website:

www.ncb.org.uk/pdf/Web%20guidelines%20CYP.pdf

Involving People in Research

The University of Western Australia's School of Population Health and the Telethon Institute for Child Health Research have developed a strong, sustainable consumer and community participation programme. You'll find their new series of short fact sheets for researchers at the website:

www.involvingpeopleinresearch.org

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INVOLVE is a national advisory body funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development. If you would like to receive a copy of the newsletter or find out more about INVOLVE please do contact us.

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