

INVOLVE

Promoting public involvement in NHS, public health and social care research

NHS

**National Institute for
Health Research**

newsletter

Welcome to the INVOLVE newsletter. It's going to be an exciting year for public involvement in research. The joint funding call by NIHR Health Service Research Programme and INVOLVE will generate new research (see page two) and the INVOLVE conference in November will be a fantastic opportunity to share knowledge and learning on public involvement in research.

Innovation and impact: share your experience at INVOLVE's 2010 conference!

INVOLVE's 7th Conference will take place on November 16th and 17th 2010 and we're hoping that many of you will respond to our call for presentations. The focus of this conference is innovation and impact, including:

- ways in which the public are involved in research
- understanding the impact of public involvement – how it makes a difference
- providing a platform for research on public involvement in research.

If you have experience to share, let us know!
We will particularly welcome **Continued →**

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**INVOLVE group members L to R:
Richard Baker, Ade Adebajo, Hugh
McLaughlin, Sue Banton**

Winter 2009/10

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.

www.invo.org.uk

presentations that explore:

- how public involvement is being carried out
- the impact of involvement
- ways to illustrate and document evidence of impact of involvement.

We are also interested in presentations that discuss international perspectives, address issues of diversity and accessibility as well as report on new developments, ideas and innovative approaches.

There are five different types of presentations that you can apply for: posters; poster talks; papers; workshops; and other approaches. The closing date for applications is **Monday 12th April 2010**. For further information please visit the Conference website at: www.profbriefings.co.uk/involve2010/involve2010callforpapers.html or contact Professional Briefings, 37 Star Street, Ware, Hertfordshire SG12 7AA.

Special edition journal

The Mental Health and Learning Disabilities Research and Practice journal will be publishing a special edition on service user and carer involvement in mental health or learning disability research, practice and education in October 2010. They are seeking articles illustrating service user and carer involvement in mental health research, learning disability research, mental health or learning disability practice, or education of mental health and learning disability professionals. Also articles which reflect on, or analyse:

- Current or future directions of service user and carer engagement in mental health or learning disability research, practice and education; or
- Dynamics of mental health or learning disability research, practice and education in 2010; or
- The development of outcome measures.

Email Alison Holmes: a.holmes@hud.ac.uk or Dr Virginia Minogue: virginia.minogue1@nhs.net

INVOLVE Coordinating Centre News



Joint funding call

On 25th February 2010 we announced a joint funding call on public involvement in research funded by the National Institute for Health Research (NIHR) through INVOLVE and delivered by the NIHR Health Service Research (HSR) programme managed by NIHR Evaluations, Trials and Studies Coordinating Centre (NETSCC).

The three key aims of the call are to collect evidence on:

- Impact: to increase knowledge and understanding of the impact of public involvement in research
- Evaluation: to identify methods of evaluating public involvement in research
- Implementation: to identify effective ways of involving the public in research.

The call invites outline applications by the closing date of 1.00pm on 6th May 2010. If shortlisted, applicants will then be invited to submit full proposals and will have the opportunity to apply for a small user involvement discretionary grant to enable public involvement in developing the full applications. Applications will be welcomed from a range of organisations including user controlled organisations. For further information, please go to the HSR website: www.hsr.nihr.ac.uk/

This paper has been produced by INVOLVE on behalf of the National Institute for Health Research (NIHR) for the Senior Investigators Conference, November 2009. The document provides examples of how NIHR Senior Investigators have involved the public (e.g. patients, carers, service users) in their research. We selected examples from 31 Senior Investigators to illustrate the wide range of activities and different ways they are involving the public across all stages of the research process.

Senior Investigators are selected by an international panel of judges through open competition and are chosen for the contributions they are making to research. As part of their application to become a Senior Investigator, they are asked how they have involved the public in their research. The information in this paper is taken (with their consent) from the information they provided in their applications. A copy of the paper can be downloaded from the INVOLVE website publications page: www.invo.org.uk/All_Publications.asp

This is a new INVOLVE report outlining how the ten regional Research Design Services plan to promote and support public involvement in research. The document includes information on the lead for Patient and Public Involvement in each of the services as well as the individual approaches to public involvement. It can be downloaded from the Research Design Service page on the INVOLVE website: www.invo.org.uk/RDS1.asp where you can also link to the websites of each service.

Interesting articles and publications

- **Public involvement at the design stage of primary health research: A narrative review of case examples**

Jonathan Boote, Wendy Baird, Claire Beecroft
Health Policy (2009)

A review of published examples of public involvement in research design which identified several papers. In press – available online.

- **A critical assessment of the development of patient and public involvement in the UK Clinical Research Collaboration: Lessons Learned**

TwoCan Associates November 2009

The aim of the assessment was primarily to draw out lessons learned for people who have a responsibility for taking forward Patient and Public Involvement within a research organisation. A full report and executive summary are available to download from the UK Clinical Research Collaboration website:

www.ukcrc.org/publication/reports/

- **Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis**

Irene Tuffrey-Wijne and Gary Butler

Health Expectations – published September 8th 2009 – online.

Examines the potential contribution of people with learning difficulties to data analysis in qualitative research. The report is a reflection on one research experience. **Continued →**

• Keeping Service User Involvement in Research Honest

Hugh McLaughlin

British Journal of Social Work – published online June 2009.

Service user research has increasingly become a significant development on the research landscape. This article seeks to critically examine this development and to identify ways in which service user research can retain its honesty and avoid the twin dangers of either becoming a tokenistic exercise or being seen as a panacea. In particular the article highlights issues concerning our conceptions of service users, recognising both the benefits and costs of service user involvement in research and begins to open up discussions about the contribution of service user research to knowledge development. The article also argues that we need to subject such research to the same standards of scrutiny and critique we would apply to other research approaches if service user research involvement in research is going to develop further.

If you have written or know of any publications or articles 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

Deadline for contributions for our next newsletter: **26th March 2010**

If you have any questions on contributing to the newsletter, please contact Sarah Buckland Tel: 02380 65 1088 Email: sbuckland@invo.org.uk

Involvement Portfolio for service users and carers

By the NHS R&D Forum Service User and Carer Working Group

Many people using health and social care services are involved in a range of involvement and voluntary activities such as membership of committees, consultation, evaluation, research, teaching and training. Much of this involvement goes unrecognised although the participants are gaining valuable skills and experience as well as contributing their experience and expertise. It is vitally important that the skills and experience gained through involvement and voluntary activity are recorded and recognised as it can help with applications to undertake new activities, voluntary work, for educational or vocational courses, or to find employment. It is important that records of experience and evidence of each of the involvement activities taken part in are kept. This might be to just keep a personal record or might be supporting evidence for applications to do something new.

The Involvement Portfolio has been developed by the NHS R&D Forum Service User and Carer Working Group. It is a tool for those using health and social care services who are involved in voluntary or involvement activities such as consultation, committee membership, research and development, to record and provide evidence of their activities. Its use is voluntary and it is up to the individual how they use the portfolio, what they record and how they choose to use it in demonstrating their skills and expertise. In the portfolio, the portfolio holder has the opportunity to record their involvement and participation experiences including those gained

through voluntary activity or life experience such as being a carer or a parent, and any employment experience. A record of training events and experience of leading or facilitating training can also be maintained. There are sections of the portfolio for recording involvement and experience including taking part in committees, consultation events, NHS or social care research and development, or curriculum development for educational courses. The portfolio holder can record the type and level of involvement, the skills learnt, and any qualifications gained. There is also space to record feedback from others that you worked with.

Often people want to write their own personal reflections on their experience and there is a section to record those thoughts. Individuals may want to remove their own reflections from the portfolio if choosing to share it with prospective colleagues or employers. Finally, professionals or other people may wish to provide a reference or testimonial about involvement. There is a space for their contact details at the end of the portfolio.

Since its launch in November 2008, the Involvement Portfolio has been warmly welcomed as a tool to record involvement and participation activity. It has been taken up by several service user and carer groups involved in research and other activities, and promoted by a number of health and social care organisations. An example of how it is being used in the North West includes its use as part of an induction pack for Healthy Community volunteers and participants. If you would like a copy of the Portfolio or more information about it, please visit the website: www.rdforum.nhs.uk/docs/involvement.doc or contact: Dr Virginia Minogue (R&D Forum service user and carer working group facilitator) at Virginia.minogue1@nhs.net

Involving service users in prioritising research projects

By Andy Gibson, Institute of Health Services Research, Peninsula Medical School, University of Exeter

The Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC for short) is a new collaboration of universities and NHS organisations in the South West of England. It aims to deliver high-quality health research that improves medical practice. An important part of this work is ensuring that the research we carry out addresses the needs and priorities of patients and carers, and results in beneficial new treatments and services. We are therefore developing the involvement of service users and carers throughout our research process.

One way that service users, carers and members of the public are involved is in helping PenCLAHRC to prioritise ideas for research projects. PenCLAHRC receives these ideas from local clinicians, academics and lay people and then prioritises them on a six monthly basis. We worked with Rachel Purtell of Folk.us (Folk.us is an organisation based in Exeter, funded by the Department of Health, which brings the world of research and researching to people who use health or social care services across Devon) to develop a process designed to give lay people the opportunity to influence the PenCLAHRC prioritisation process and research agenda.

We initially sent an open invitation letter to local organisations that we knew already had some user involvement, e.g. Folk.us, **Continued →**

the local Stroke Research Network, and community groups. This letter invited people to an initial meeting where we explained what PenCLAHRC is and the criteria that PenCLAHRC uses to judge research ideas. Six service users attended this meeting. They were people with experience of a wide range of conditions, both patients and carers. In addition Rachel Purtell and I attended the meeting (I am the Research Fellow in Patient and Public Involvement with PenCLAHRC).

We then held a second meeting where the twelve research projects in the prioritisation process were discussed in detail. The group's thoughts and comments about each project were written down. The group then chose two people to represent the group's views at the PenCLAHRC prioritisation panel meeting. This panel includes academics, clinicians and representatives from the local NHS. At the panel the strengths and weaknesses of each project were discussed. The two service users present actively participated in these debates. The projects were prioritised using a simple voting system, with the project receiving the most votes being ranked first and so on. We were pleased when one of the projects that had begun life as an idea from a service user was prioritised (PenCLAHRC is currently working with this person to developing the idea into a full research proposal).

Afterwards we held a meeting with the group to review the process. People generally felt that it had gone well. Those who attended the prioritisation panel said that they felt their views had been listened to. The group also made some suggestions for improvement which formed the basis of a report to PenCLAHRC. People at this meeting also reported that they were very excited by the idea of getting involved in

PenCLAHRC at an early stage and being able to help shape its development. Most of them are now members of the Peninsula Public Involvement Group (PenPIG). They will be advising PenCLAHRC on the future development of Patient and Public Involvement.

For more information, contact: Andy Gibson, Research Fellow in Patient and Public Involvement, Institute of Health Services Research, Peninsula Medical School, St Luke's Campus, University of Exeter EX1 2LU Email: andy.gibson@pms.ac.uk Tel: 01392 262913 Fax: 01392 262926

We make a good double act

By Jane Paterson and Mary Reed

Jane Paterson, who cares for her husband who has had a stroke, has been an active member of a research team undertaking a qualitative systematic literature review and meta-analysis examining stroke survivors' long term needs. The findings of the review were presented by Jane, another carer, and a stroke survivor, to five 'user' focus groups for validation and feedback, and to local Primary Care Trusts. The users were supported by Mary Reed, researcher, who joins Jane in reflecting back on the project and why their working relationship seemed to work so well.

Mary: So Jane, when I first contacted you, what made you want to get involved in this project?

Jane: I wanted to get involved because I was feeling so frustrated that the stroke rehabilitation services were not providing the range and continuity of support that my husband so desperately needed, or that I needed as his carer. We were both trapped by his mobility and

communication problems and there seemed no way out. As soon as I met you and joined this project I felt that I was talking to people who understood and were working to bring about change, people who felt as passionately about the need for change as I did.

M: When you first got involved, the project was in danger of falling down the 'user involvement as tokenism' trap by having you just turn up every three months for a steering group meeting.

J: I do get very irritated about tokenism and sitting on a committee simply so that the patient/carer involvement box can be ticked, but because I feel so strongly about the cause I am not in awe of committees of professionals. I have nothing to lose by being outspoken and perhaps people will even listen. This project was different, however, because we were always made to feel that we had an essential contribution to make and were encouraged to become involved in some of the academic aspects of the project as well. I really enjoyed learning how to deal with qualitative research, for instance. It was interesting and intellectually challenging and was just what I needed at the time because being a carer is not only a very lonely occupation but also intensely boring! I needed some intellectual stimulus.

M: For me the real eureka moment was when we were working together in the focus groups. The understanding and compassion you conveyed made participants feel instantly safe and valued and enabled them to open up to you. Your insight was also invaluable when it came to the analysis and presentation of the focus group data.

J: Interviewing the focus groups of stroke survivors was unforgettably moving. I had been driven to fight for change by my own experience but the life stories that confronted me were so illuminating that I really felt these people's pain. I came away feeling even more desperately that

something must be done to overcome their sense of abandonment, and provide support to enable them to live rewarding lives in their communities.

M: Finally, there were the feedback events to local Primary Care Trusts. We presented a shared vision for support for stroke survivors in the community. You spoke about your own experiences and the evidence from the focus groups. This was presented to enraptured audiences and at our last presentation you received a spontaneous round of applause. I think we got our message across even when our presentation times were limited!

J: I wasn't well prepared for the first meeting, so wrote out a statement for the second which I read out and this seemed very stilted. It wasn't until the third meeting that I felt able to use my notes as a prop but to speak from the heart. We had a generous and receptive audience and I just hope we had some influence on their planning for the rehabilitation element of the Stroke Care Pathway.

M: The academic work formed the body of this project and you were able to breathe life into it.

J: I have really enjoyed working with you and I know you feel as passionately as I do about stroke survivors' needs. Although we were working together on a project that involved so much sadness in people's lives, you helped me to remain positive with your enthusiasm and vision. I just wish the project could continue.

This was a National Institute of Health Research (NIHR) 'Research for Patient Benefit' funded project, based at the University of Bath. The full title was: 'Supporting Stroke Survivors long term needs; A meta-analysis of qualitative literature' For further information please contact: Mary Reed, Stroke Project coordinator, University of Bath Email: mpxmr@bath.ac.uk

Towards inclusive living: a record of a research journey

By Christine Hutchinson, Eunice Bell, Mick Bond, Lindsay Carter, Paul Mitchell, Phil Moore, Alistair White: members of the Towards Inclusive Living Research Group.

Our journey started in 2006 when there was a planned move from an old hospital building to new purpose built premises. At this time a Listening Event was held to capture patient views about issues that were relevant to them in respect of the culture of the new hospital (Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry). One of the sessions during that day was on research. Some ideas were suggested and those who were interested in taking them forward met again during the autumn of 2006. This group of people, comprised of service users, carers, and voluntary sector partners was facilitated by a health care professional from Walkergate Park and an academic from Northumbria University. The group has met monthly ever since. Our original idea was: 'How do we ensure that people with disability maintain and develop integration with communities and explore possibilities that are available – focusing on what people can do?'

We were interested in looking at issues of participation in treatment and how we felt about that. This led to discussions about notions of inclusion and led to a new focus for our study, now called: 'Towards Inclusive Living: A case study of inclusive practice in Neuro-Rehabilitation /Neuro-Psychiatry Services using a collaborative action research approach.' We developed the ideas into a fully articulated application which was ultimately funded by the Long Term

Neurological Conditions Policy Research Programme under the National Institute for Health Research.

Getting from the first idea to the final questions has been lengthy and necessitated much discussion and debate. Everyone had different knowledge and skills that they brought to the table. We then began the process of working together to find a clear focus for our research that we all thought was important enough to commit a considerable amount of time to and held the possibility of improving practice. The discussions were about the difference between integration and inclusion, what we meant by the NHS 'community' and the way that we would go about doing the research.

The process of doing this, of listening to others, debating and then finding a clear focus, has been lengthy but necessary. We all learnt a lot from the process itself and felt that once the application was complete the group would like to record their experiences of being part of this research process. We had the minutes of the meetings but we also chose to either record our thoughts in written form or talk through our experiences with a group member who recorded it for us. Some of the key learning outcomes from working together, what we thought was important about going through this process, are listed below:

- Learning about ourselves, we acquired insights into our own prejudices and assumptions. Some group members found this uncomfortable and painful but very important. We were being challenged through the social model of disability to examine attitudes.
- Learning to recognise the power of language to discriminate.
- Learning from the collective wisdom of people from diverse backgrounds and life experiences.

- Learning about research methodologies and getting the question right was challenging but important because the words we chose had to clearly and unambiguously convey the purpose of our research.

Some members of the group felt the discussions were a reminder that our views were of secondary importance or validity to those in the group with first hand disability experience.

What worked well? The commitment from group members despite a range of competing demands. An appreciation for the skill of the facilitator's guidance in building trust and openness.

What would have helped us? Provision of secretarial support to undertake administrative tasks.

Summary: Throughout the process of preparing the research application the group was tenacious in its belief of wanting to make a difference to the experience of service users when using the NHS. This conviction shaped our discussion about the question we developed and the research methods we have used. Learning to trust and respect each other and work collaboratively with people from diverse backgrounds enriched discussion and enabled our assumptions about inclusion, integration and disability to be challenged. New understandings, ideas and solutions were constructed. The development of discipline and rigour helped us to overcome set-backs as we engaged with the research process.

Our experience of working together has been challenging yet energising and currently we are working on the process of data gathering as well as finding ways of analysing our material. We hope to write further articles documenting our research journey.

Acknowledgement: The members of the Towards Inclusive Living Research Group wish to acknowledge the support and encouragement received from Dr Tina Cook and Ms Helen Atkin in writing this article. For further information, please contact: Dr Tina Cook, Northumbria University Email: tina.cook@northumbria.ac.uk

Patient and Public Involvement in Research module

The University of Hertfordshire is one of seven universities in England to offer a part-time modular masters degree programme in Clinical Research for Nursing, Midwifery, Health Visiting and Allied Health Professions. It is jointly funded and supported by the National Institute of Health Research (NIHR) and Chief Nursing Officer (CNO).

The programme includes a module on Patient and Public Involvement in Research, which we are opening up to members of the wider community if there is sufficient interest. Individuals who undertake the module would join the nursing and allied health professional students on the course but would not be required to undertake any assessment.

The module will be held over two two-day blocks: 25/26th May 2010 and 8/9th June 2010. The cost for this module is £330.00.

If you are interested and would like to find out more about the module, please contact:
Dr Diane Thompson, Senior Research Fellow/
Lead Public Involvement in Research, Centre for Research in Primary and Community Care, University of Hertfordshire.
Email: d.1.thompson@herts.ac.uk
Tel: 07989 678943

The First All Wales Service User and Carer Led Research Group: part of the Mental Health Research Network-Cymru (MHRN-C)

By Darryl Turner and Christine Wilson

During the earlier part of 2008 a number of people who attended Interlink, (a local voluntary organisation for people in receipt of mental health services) were offered the opportunity to take part in a short programme of empowerment and research training at the University of Glamorgan. The training programme was designed in collaboration with Christine Wilson from the University of Glamorgan, Elle McBride, Participation Officer with the local Borough Council, and Polly Kitzinger from Interlink.

Darryl explains: “At first not everyone attending the training really knew what to expect. Few, if any of us were very confident in ourselves but the empowerment training facilitated by Christine Wilson helped to build our confidence and opened up our minds to the endless possibilities of what we could achieve as a lay research group. Much of the early empowerment training involved the use of creative writing, storytelling, poetry and video diaries. This helped us talk about our experiences of mental illness. This really was breaking new ground for us and some members of the group were amazed because we found it so enjoyable to compose poetry, which is something we previously had never thought we were capable of achieving. With each meeting our confidence grew and we became closer as a group and this helped us to get over any initial embarrassment. We quickly

learnt that we could really put a lot of our own thoughts and experiences into the creative work. This boosted our confidence even more and helped everyone to bond and work together as a group.”

After the initial training, the group chose a name – The SURE Group – and created their own free hosted website which continues to grow as a valuable resource for the group. Darryl helped the group to populate the website with different stories, images, documents and videos about the group.

After the training the group were invited by the Clinical Research Collaboration-Cymru (CRC-C) to run a workshop at one of their research conferences in Bridgend. The workshop aimed to help researchers understand what it was like for service users to become involved in research and the benefits of receiving empowerment and research training. The group used a novel engagement technique adapted by Christine to suit the workshop aim. This was the first ‘Living Library’ event in Wales, and only the second to be held in the UK. The SURE group members became ‘living books’ and the researchers were able to borrow a living book for a few short sessions to learn more about the experiences of the individual group members. This approach helped to engage the researchers and made the whole process more enjoyable for the ‘living books’. The researchers were all quite surprised when the tables were literally turned on them and they were invited to become the living books. This gave them an opportunity to explain some of the issues facing health and social care researchers.

With Polly’s help, the group held their own service user and carer led conference at the Glamorgan Business Centre in March 2009. At the conference, the group hosted **Continued →**

another Living Library and also piloted a questionnaire on the thorny subject of 'how to reward and recognise the contributions made by service users.' Further conference appearances followed, including an event in London in May 2009 where the preliminary findings from the pilot research were presented. The group plan to publish a full report on the findings this year.

At the beginning of 2009, Hafal – a leading Welsh charity for people with serious mental illness – and their carers approached members of the SURE group to discuss the possibility of collaborative working. With the support of Christine Wilson, her colleague Dr Anne Fothergill and John Abbott from Hafal, a proposal was submitted to the Executive Board of the Mental Health Research Network-Cymru (MHRN-C) with the idea of forming the First All Wales Mental Health Research Group.

Funding for the proposal was successful and the group has now formed their own Executive Committee with all the major positions held by service users. The support and funding from the MHRN-C will provide the group with more training in research methods. It will also help the group to formulate their own research proposals and undertake their own research. They would also like to offer other service users across Wales the opportunity to take part in the empowerment and research training they were initially provided with.

Darryl says: "Being involved in the group has helped make a big difference to my life and I now have lots more confidence as well as a new group of friends who are some of the nicest people I've ever met. The group recently had a special away day where amongst other things group roles and responsibilities were decided upon. It was a very intensive day but it was also very worthwhile. We were made to feel very

special and we were well supported by the academics in the group. I have to say it is an absolute honour to have a position on the group's Executive Committee. We are aiming to write our first proposal for research funding by March 2010 which we are all very excited about. New members are always welcome as we hope our group will continue to grow and go from strength to strength in the future."

For further information, or to discuss opportunities to get involved with the group, please contact:

Darryl Turner, Exec Communications Officer and Health and Social Care Consumer, c/o University of Glamorgan, Glyntaf Campus, Pontypridd CF37 4BE.

Email: mhrn.group@yahoo.co.uk

Website: www.sure-group.freehosting.net/

or Christine Wilson, University of Glamorgan

Email: cawilson@glam.ac.uk



Polly Kitzinger addressing delegates at the conference organised and led by service users and carers at the Glamorgan Business Centre

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in R&D. If you would like to put an article on our notice board please contact the Coordinating Centre.

Handbook of service user involvement in nursing and healthcare research

We are writing a handbook to help nurses and healthcare researchers to understand service user's expectations about involvement, the types of contributions they can make, and the impact their involvement is likely to have. If you are a service user, carer, representative of a service user led organisation, experienced service user representative or an academic service user researcher and would like to contribute to the book please contact us. We will work with you to develop a short case study (about 500 words) of your experiences of involvement. We cannot offer payment but your name will appear in the book.

Elizabeth.m.smith@kcl.ac.uk

Tel: 02078483201

National Nursing Research Unit.

Public involvement in research in the South West – results

You are warmly invited to come and hear the results of a collaborative scoping study on public involvement in health and social care research in the South West. Areas of potential coordination and collaboration between organisations and researchers will be discussed with the aim of creating an action plan. The event will take place on Monday 26th April 2010 between 10.30am and 2.30pm at the

University of the West of England, Bristol.

It is open to anyone interested in public involvement in research – members of the public, researchers and managers. For more information or to reserve a place, please contact Rosie Davies.

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INVOLVE is a national advisory body funded by the National Institute for Health Research to promote and 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 contact us.

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.