

# newsletter

Autumn 2015

## A personal reflection ...

by Sarah Buckland

This will be my last editorial as Director of the INVOLVE Coordinating Centre as I will be leaving INVOLVE at the end of January 2016 to take early retirement. I am sad to be leaving after 16 years but I have many happy memories of my time with INVOLVE and I am very much looking forward to having some free time at last!

I first became part of INVOLVE (originally called Consumers in NHS Research) in 1999, when the Coordinating Centre was established to support the INVOLVE Group. In 2002 I was appointed Director, taking over from Bec Hanley. Since those early days I have met and worked with so many great and committed people along the way. I would like to thank all of you and especially the current team at the Coordinating Centre and all past and present INVOLVE members for helping to tirelessly continue to push the agenda forward.

There are now so many more members of the public (e.g. patients, carers and service users) who are making a difference to the quality of research, both at a national and local level and across all aspects and types of research. There are also so many more paid staff employed to



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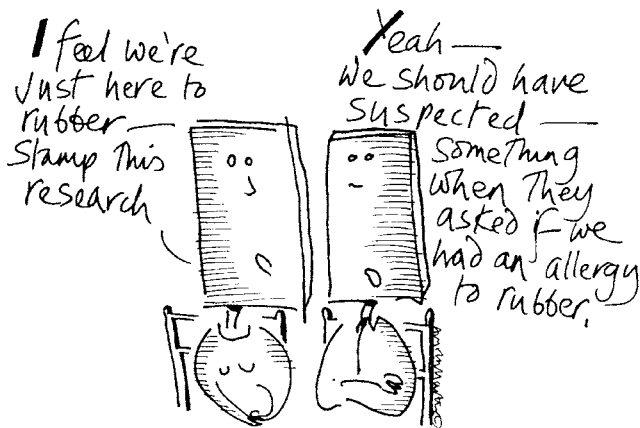
promote and support public involvement across the National Institute for Health Research (NIHR) and beyond than when I first joined INVOLVE. This is backed by a strong commitment from the Department of Health and the NIHR to public involvement. The questions we are asked now are more often about how best to involve the public rather than whether they should be involved.

I am sure, therefore, that public involvement is very much here to stay. However, we must not be complacent as many of the advances and acceptance of the value of public involvement can so easily be lost. Ensuring the support is there for those who wish to get involved is crucial to enable people to continue to influence research and to support and encourage greater diversity.

Some of the language and approaches to involvement have changed. However, the core values and reasons why public involvement is so important to research are the same as they were in the early days. The early cartoons we used at INVOLVE illustrate some of these messages. For example, the importance of public involvement in all stages of the research, helping to ask the right questions, bringing different perspectives and avoiding tokenistic involvement are as important today as they ever were.



When I first started we were based within a charity called the Help for Health Trust and then we moved to be part of the University of Leeds in 2002. In February 2016 the Coordinating Centre will be moving to its new home as part of the Wessex Institute at the University of Southampton. Each move brings a new phase in the life of the Coordinating Centre with new opportunities as well as new challenges. However, the commitment to public involvement continues, and the awarding of the new INVOLVE contract will enable the Coordinating Centre to continue to develop and play its pivotal role in promoting and supporting public involvement across the NIHR. I wish the current Coordinating Centre Team alongside the Wessex Institute and its partners in the Research Design Service every success in continuing to support and advocate for public involvement in research.



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.

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# INVOLVE Coordinating Centre news

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## Important news about the next issue of the INVOLVE newsletter

The Winter issue of the INVOLVE newsletter will be published in electronic format only and sent via email. If you are already on our mailing list and have provided us with a current email address you don't need to do anything – you will automatically receive the next issue. If you are on our mailing list but we don't have a current email address for you, please update your contact details by visiting [www.involve.nihr.ac.uk/about-involve/keep-in-touch/edit-your-preferences/](http://www.involve.nihr.ac.uk/about-involve/keep-in-touch/edit-your-preferences/). If you are not on our mailing list and would like to receive a copy of our next newsletter, please sign up here: [www.involve.nihr.ac.uk/about-involve/keep-in-touch/sign-up-for-mailing-list/](http://www.involve.nihr.ac.uk/about-involve/keep-in-touch/sign-up-for-mailing-list/). If you do not have internet access and would like us to print a copy of the electronic newsletter for you please phone 023 8065 1088 or write to us at: Freepost RTKG-UHJA-HZTJ, INVOLVE, Wessex House, Upper Market Street, Eastleigh, SO50 9FD.

## INVOLVE contract update

The University of Southampton has been awarded a four-year contract to deliver the INVOLVE Coordinating Centre, taking account of the Going the Extra Mile report ([www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf](http://www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf)).

Based in the Wessex Institute at the University of Southampton the new contract will start on 1 February 2016. INVOLVE will build on its strong foundations of providing support and expertise whilst evolving the way it delivers its services, through a new partnership with the National Institute for Health Research (NIHR) Research Design Service. Further information is available on the NIHR website: [www.nihr.ac.uk/newsroom/new-involve-contract-awarded-to-the-university-of-southampton/2967](http://www.nihr.ac.uk/newsroom/new-involve-contract-awarded-to-the-university-of-southampton/2967)

The Wessex Institute has published the second of a monthly series of briefings from the INVOLVE Coordinating Centre transition team. The briefings will keep people up to date with progress and information as the new Centre takes shape. They can be viewed on the Wessex Institute website: [www.wiep.southampton.ac.uk/about-us/wessex-institute/involve](http://www.wiep.southampton.ac.uk/about-us/wessex-institute/involve)

## Farewell to Marisha

Marisha Palm left the INVOLVE Coordinating Centre in July to move back to the United States to be close to her family and start work at a university in the North East. It was sad to see her go but we wish her all the best in her new start.

## New INVOLVE publication

A new INVOLVE report 'National Institute for Health Research (NIHR)-wide learning and development for public involvement: working group report and recommendations' documents the activities of a NIHR-wide working group and makes recommendations for improving learning and development for public involvement in research. The recommendations are aimed at the NIHR on a strategic and organisational level, as well as at researchers and research managers supporting public involvement.

The report has been submitted to the Department of Health. Following a response, we will be exploring with others across the NIHR how best to address implementing the recommendations. You can download a copy of the report from the publications page of our website:

[www.involve.nihr.ac.uk/resource-centre/publications-by-involve/](http://www.involve.nihr.ac.uk/resource-centre/publications-by-involve/)

## Over 300 references in our Evidence library – do we have yours?

The INVOLVE Evidence library includes over 300 references and abstracts of reports and articles that cover:

- the impact of public involvement on research
- the nature and extent of public involvement in research, for example mapping public involvement
- reflections on public involvement in research.

Search the online library ([www.involve.nihr.ac.uk/resource-centre/evidence-library/enter-search-the-database/](http://www.involve.nihr.ac.uk/resource-centre/evidence-library/enter-search-the-database/)) or download Evidence bibliography 5 ([www.involve.nihr.ac.uk/wp-content/uploads/2014/11/Bibliography5FinalComplete.pdf](http://www.involve.nihr.ac.uk/wp-content/uploads/2014/11/Bibliography5FinalComplete.pdf)), which contains all of the references in the library up until September 2014.

If you have a document or reference that you would like to be considered for inclusion in the Evidence library, please tell us about it by visiting [www.involve.nihr.ac.uk/resource-centre/evidence-library/submit-a-document-2](http://www.involve.nihr.ac.uk/resource-centre/evidence-library/submit-a-document-2)

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## Interesting articles and publications

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### **Alzheimer's Society: A history of the Research Network (Quality Research in Dementia)**

Barbara Woodward-Carlton and Shirley Nurock, 2015

The authors of this account of the 15-year history of the Alzheimer's Society's Research Network (Quality Research in Dementia) are carers and members of the Network since its inception in 1999. The report presents a record of the Alzheimer's Society research programme, which was set up to give a voice to those affected by dementia, particularly in the areas of research funding and prioritising topics. It charts the progress, expansion and success of the network and highlights some of the key projects funded, as seen through the eyes of the network members themselves and of the research community. The extended report is downloadable from the Society's website.

[www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2765](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2765)

### **Beyond Boundaries**

Charlotte Walker

The Lancet Psychiatry, September 2015, volume 2, number 9, pages 785-786

In this essay, Charlotte Walker writes about her experiences of becoming a service user researcher with the McPin Foundation. Charlotte, along with three other service users, was involved in a qualitative study exploring how women with severe mental illness decide whether to take antipsychotic drugs or mood stabilisers during pregnancy. The service user researchers were all women of childbearing age, taking similar medications for bipolar disorder, schizoaffective disorder, or schizophrenia. They were involved in writing the research protocol, adding to the ethics committee submission, developing an interview schedule, and gathering data by carrying out interviews with participants. The author discusses some of the benefits and challenges of involvement, with particular reference to social media and issues of identity, anonymity and confidentiality.

[www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(15\)00393-4/fulltext](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(15)00393-4/fulltext)

### **Service user involvement in research**

Fenella Lemonsky

The Lancet Psychiatry, September 2015, volume 2, number 9, page 780

The author of this short correspondence piece is a service user researcher, who writes about her strong commitment to mental health service user involvement in clinical research. She discusses the importance of a clear structure and good practice guidance in order for involvement to be successful. She also covers issues of payment, training and support, and tokenism.

[www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(15\)00365-X/fulltext](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(15)00365-X/fulltext)

### **Co-production and participation: paying people who receive benefits**

Social Care Institute for Excellence (SCIE), At a glance 50, August 2015

The Social Care Institute for Excellence (SCIE) has launched an updated version of its guide on payments to service users and carers on benefits. The updated guide covers the important changes in benefits rules since April 2014 that mean it is easier for people who use services and carers to be paid for taking part in co-production/ participation activities. The changes allow payments by a wider range of organisations, including research bodies and education establishments. The guide also covers people receiving Universal Credit.

[www.scie.org.uk/publications/ataglance/ataglance50.asp](http://www.scie.org.uk/publications/ataglance/ataglance50.asp)

### **Mental Health Wales: the research issue**

Hafal, summer 2015

Hafal (meaning 'equal') is a leading mental health charity in Wales for people with serious and enduring mental illness. The summer issue of Hafal's Mental Health Wales journal was a research special, featuring articles about involving service users and their families in mental health research in Wales.

[www.hafal.org/wp-content/uploads/2015/05/Summer-15-1.pdf](http://www.hafal.org/wp-content/uploads/2015/05/Summer-15-1.pdf)

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 Paula Davis at the Coordinating Centre with details: [pdavis@invo.org.uk](mailto:pdavis@invo.org.uk)

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# Micro-enterprises in social care: a co-research study

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**By Adrian Murray, Gareth Welford  
and Kerry Allen**

Hello, we are Adrian Murray, Gareth Welford and Kerry Allen. We were all researchers in a national study led by the University of Birmingham. We will tell you about our study and share some thoughts.

**Kerry:** I am a researcher and lecturer at the University of Birmingham. Our study explored the contribution of very small social care providers (micro-enterprises) within adult social care. We found micro-enterprises can deliver more personalised, innovative and valued support for a similar or lower cost than larger providers.

For detailed findings see [www.birmingham.ac.uk/research/activity/micro-enterprises/index.aspx](http://www.birmingham.ac.uk/research/activity/micro-enterprises/index.aspx)

Seventeen co-researchers designed the research, led peer interviews, analysed data and told local and national audiences about the findings. The co-researchers were older people, people with autism, learning disabilities or mental health problems, and carers.

**Adrian:** I am a 28-year-old with autism who was involved in the research. I trained over a number of days and interviewed service users about how they found their care. I also fed back to the University on how it was to be a co-researcher and to the local council about our findings. Our aim was to find if micro-enterprises offered better value than larger services.

**Gareth:** I became involved with the research while I was volunteering at the Oldham Disability Information Point. I first found out about the study through Community Catalysts (a social enterprise interested in communities and social change), then I met Kerry Allen, who would train us and lead the research project in Oldham. As co-researchers we had used services or had some experience with micro-enterprises. We interviewed service users with questions that we created in the group training.

## What did we learn from being part of a co-research team?

**Adrian:** We needed to forward think and adapt to different situations while conducting the interviews and presentations. It was important to be able to communicate with people in different ways. It would be helpful to make even more use of signs or pictures to ensure everyone can be included.

**Gareth:** It was a great idea to get service users to interview other service users as it builds self-confidence for both parties. Sometimes our questions had to be re-phrased so that people understood what we were asking. I found that communication could be a problem, especially if people had speech impediments, therefore patience was needed.

**Kerry:** Benefits of the co-research approach were:

- **Insights into local service contexts.** Local researchers were able to offer new experience-based perspectives about local services and political contexts. The research teams developed a richer understanding of their localities by listening to co-researchers.
- **Lasting local impact.** Local co-research approaches have the added benefit of generating local interest and knowledge in aspects of health and social care that can live on beyond the research timeframe.

Issues we faced were:

- **The 'small world' of local social services.** There was a strong chance of service users with shared characteristics either already knowing each other or of their paths crossing in the future. This complicates the extent to which anonymity can be protected. In this context it becomes critical for researchers to understand and uphold confidentiality.
- **Paying co-researchers.** Payment was offered to co-researchers. We identified co-researchers receiving benefits and tried to understand when payment might endanger those benefits. We found it really difficult to get accurate information about permitted earnings, which created anxieties for everyone involved. Advice from the Citizens Advice Bureau (CAB) suggested that each person's situation differed and they needed one-to-one guidance, but that guidance wasn't always available locally. In at least one case a co-researcher couldn't find enough information about their benefits situation and so decided not to get paid at all.

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Members of the research team

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## ‘Who’ you involve makes a difference – the added-value of patient involvement

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By Kristina Staley, Joanne Ashcroft, Lisa Doughty, Roger Oliver and George Szmukler\*

One of the frequently asked questions about involvement is ‘Who should I involve?’ A recent evaluation of the involvement of the FAST-R Panel in mental health research has helped answer this question in the context of reviewing written research materials. At one level, any lay person could be involved because their input would help make the information clear and easy to understand. However, our findings suggest the gold standard would be to involve patients with relevant experience because their knowledge and expertise will also make the information relevant to participants.

The Feasibility and Support to Timely recruitment for Research (FAST-R) Panel was originally set up by the National Institute for Health Research (NIHR) Mental Health Research Network in 2011. The Panel is made up of patients and carers with experience of mental health problems. They all receive training in reviewing research documents, similar to the training provided to the lay members of research ethics committees (RECs). Researchers working in mental health can submit protocols, patient information sheets, publicity material and questionnaires to the Panel, who then provide feedback within seven days. Each set of documents is reviewed by two or three Panel members in a face-to-face meeting with the Panel’s facilitator. Their collective comments are then sent in writing to the researcher. This takes place before the REC review, with the aim of speeding up the regulatory process, improving the quality of the written information and generally improving the feasibility and design of studies.

The Panel has been evaluated internally by asking the researchers who have used the service for their views. All the researchers thought the Panel’s comments ‘very good’ (86%) or ‘good’ (14%). We recently carried out a more in-depth assessment to find out precisely how they are making a difference, by analysing the comments

### What difference has this involvement made?

**Kerry:** Our independent evaluation suggests benefits for the co-researchers and for the research, but also explores the complexity of implementing co-research. These findings contain more detailed learning for those undertaking similar projects or co-producing services. For the full evaluation see [www.birmingham.ac.uk/research/activity/micro-enterprises](http://www.birmingham.ac.uk/research/activity/micro-enterprises)

**Adrian:** People were more honest when approached by us, than say, if they were being asked by the local council. It was enjoyable to input into a piece of work where your views were valued and listened to. I would enjoy doing it again and maybe in future find permanent work doing this sort of thing.

**Gareth:** I feel that I have gained new social skills, friends, and a new-found confidence. I feel this has been a great opportunity and experience, and would recommend it to others. I was only able to participate because I had a flexible personal assistant who could take me to different research meeting and events; for that I am thankful.

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made by the Panel on a total of 155 documents from 85 studies, during the period July 2011 – January 2015. An article detailing our findings will soon be published in the Journal of Mental Health and Social Inclusion.

We found that the Panel's comments fell into three broad categories relating to the quality of the written information, ethical issues and recruitment. For example, Panel members made numerous suggestions as to how to rewrite the information in plain English. They raised many ethical concerns, for example asking whether support would be available for people who became distressed and suggesting that the right to withdraw from a study be explained more clearly. They also challenged researchers' assumptions about recruitment targets when reviewing research protocols.

In addition, within each of these categories, the Panel made many comments that were informed by their unique experience as a patient or carer, picking up details that anyone lacking this perspective might miss. For example, in a study of schizophrenia that required participants to undergo a MRI scan, they commented that it wouldn't be sufficient to explain that music would be played through headphones during the scan – a person experiencing paranoia would need to know precisely which piece of music would be playing in advance. In studies where they were concerned about the welfare of people with mental health problems, they were also able to identify solutions that patients and carers would find acceptable. For example, in a study recruiting participants from a secure unit, they suggested involving an ex-service user to talk to the in-patients to avoid people feeling intimidated into taking part. Based on the experience of some of our team (KS and GS, who between them have over 15 years' experience as REC members), these comments were unlikely to be made by members of the general public or clinicians.

In conclusion, coming back to the question of who to involve in reviewing research documents, the answer might then depend on how you are thinking about the task and the purpose of this involvement. If the purpose is thought to be about making technical information clear, then it would be appropriate to involve anyone with a lay perspective. It might even be argued that a science journalist would be the best person for the job.

However, if the purpose of involvement is also recognised to be about making the information relevant to the target audience and making the research process acceptable to participants, then it becomes essential to involve patients and carers with relevant experience. The interests and concerns of a specific group of patients are likely to be different to those of the general public, researchers and clinicians. On this basis, we conclude it would be valuable to consider how patient involvement could be usefully integrated into our current system of ethical review.

### **\*The authors**

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Roger Oliver, FAST-R Panel member  
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For further information about the FAST-R Panel email: [FAST-R@kcl.ac.uk](mailto:FAST-R@kcl.ac.uk)

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## Working with the diverse autism community to make the biggest impact

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### **By Rebecca Sterry**

Autistica is the UK's leading autism research charity. We are committed to funding research that will make a real difference to people affected by autism. Families and individuals with autism are involved in everything that we do.

We ask the community for their research priorities. Last year, Autistica celebrated its 10th anniversary. We launched an ambitious five year research strategy ([www.autistica.org.uk/research-strategy-2015-2020/](http://www.autistica.org.uk/research-strategy-2015-2020/)), which followed on from our One in a Hundred report ([www.autistica.org.uk/wp-content/uploads/2014/10/One-in-a-Hundred-Autisticas-Report.pdf](http://www.autistica.org.uk/wp-content/uploads/2014/10/One-in-a-Hundred-Autisticas-Report.pdf)), a consultation with 1,000 families to find out where their concerns and priorities lay in the field of autism. This led to us identifying three key areas in which to direct our efforts over the next five years: ageing with autism, early diagnosis and intervention, and mental health.

**Continued>>**

The consultation combined face-to-face focus groups and telephone interviews to provide in-depth insight, and large online surveys, with parents of children with autism and adults with autism themselves. A significant proportion of those who responded were contacted via the Autism Spectrum Database (ASD-UK – see below for details) and we also partnered with other national autism charities who circulated the survey amongst their own networks. The enthusiasm of families to be involved in research came across extremely strongly (almost 90% wanted to take part themselves) and this has made us more determined than ever to involve families in every step of the research process.

One of the issues stalling progress in autism research is small study sizes. As a result, we fund ASD-UK ([www.autistica.org.uk/research/investing-in-the-research-community/autism-spectrum-database-uk/](http://www.autistica.org.uk/research/investing-in-the-research-community/autism-spectrum-database-uk/)), a national database of individuals and families with autism, which can be used by any research organisation, and we have also founded a brain tissue bank ([www.brainbankforautism.org.uk/index.php](http://www.brainbankforautism.org.uk/index.php)). We will also be seeking to fund a research gateway to direct families to studies and databases looking for research volunteers, provide information on current and past trials in plain English, and provide information on the value of autism research and why taking part can be beneficial on a personal level.

Following on from the One in a Hundred report we decided to embark upon a larger scale initiative to set research priorities, one recognised by UK research funders, a James Lind Alliance (JLA) Priority Setting Partnership (PSP) ([www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-priority-setting-partnerships](http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-priority-setting-partnerships)) Autism: Top 10 Research Priorities ([www.autistica.org.uk/research/top10/](http://www.autistica.org.uk/research/top10/)). This is an independent, transparent and collaborative project, led by Autistica in partnership with a coalition of interested parties, bringing together individuals with autism, carers and clinicians to identify their research priorities for autism. When we launched the PSP, the first stage asked people to submit their top three questions for research. We received 3,331 questions and a good range of responses; 23% of respondents were individuals on the autism spectrum, 52% were family members and caregivers and 25% were clinicians and professionals. We expect to have a long list of research priorities ready for voting on in early 2016, and will publish the final top 10 list of unanswered questions in April 2016.

**Individuals with autism and family members play an important part in our staffing, boards and committees.** We are committed to taking an innovative approach to engagement and involvement and use those with professional expertise and personal connections to bring fresh perspectives and skills beyond our core team. Individuals with autism also provide strategic advice, and take part in our peer review and comment on applications. Each of the projects we fund has a steering group with parents, carers and individuals as members to provide regular feedback on project design. We are funding a post for a person with autism to work with our ageing research team in Newcastle to advise on how best to engage those challenged by communication.



**We work collaboratively** with related organisations in other ways too. We work closely with the National Autistic Society ([www.autism.org.uk](http://www.autism.org.uk)) and are a member of Autism Alliance UK ([www.autism-alliance.org.uk](http://www.autism-alliance.org.uk)) – an umbrella group bringing together the largest group of national and regional autism service charities nationwide. Both organisations help us to reach out to members of the community who have not previously been aware of or involved in research. As a member of the Association of Medical Research Charities (AMRC) we can link up with other related research charities, such as those dealing with disability, epilepsy and mental health to spread subject-specific information among their own stakeholders. We also sit on the Advisory Committee of the



All Party Parliamentary Group on Autism ([www.appga.org.uk](http://www.appga.org.uk)), ensuring that our research-focused voice is heard in policy discussions.

### **We share good quality information and make autism research more accessible.**

We have a regularly updated website ([www.autistica.org.uk](http://www.autistica.org.uk)), with weekly blog posts and send regular e-news updates in family-friendly language as well as a monthly researcher-specific newsletter. These include general autism information and news as well as our own research projects and signpost useful resources and organisations. We also have active Facebook and Twitter accounts where we share breaking news and encourage discussion.

### **If you are interested in hearing more about Autistica's activities please get in touch. You can sign up to our newsletter online.**

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## NIHR Dissemination Centre

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By **Alison Ford**

### **About the Dissemination Centre**

One of the newest parts of the National Institute for Health Research (NIHR) has some interesting ways of using patients' experience and insight. The new NIHR Dissemination Centre ([www.dc.nihr.ac.uk](http://www.dc.nihr.ac.uk)) has been set up to make health research evidence easier to reach for those who need it.

### **What is a Signal?**

Each week we publish three or four new 'Signals' – short summaries of health research that has appeared recently in peer-reviewed journals. Abstracts of research are turned into Signals by specialist writers based at Bazian ([www.bazian.com](http://www.bazian.com)), our partners in the Centre. Signals are then published on the Dissemination Centre's portal 'Discover' (<https://discover.dc.nihr.ac.uk/portal/home>). This is a free, open access site and is fully searchable. You can sign up on our website ([www.dc.nihr.ac.uk/email-sign-up](http://www.dc.nihr.ac.uk/email-sign-up)) to receive a monthly

update of all Signals that we publish or you can choose to receive Signals in particular categories.

The Dissemination Centre editorial team includes clinicians and research specialists. But this team needs the insight of patients, carers, health professionals and academics to help them decide which abstracts will make the most useful Signals. Each week we ask a group of these people to read and 'rate' research abstracts in their area of interest. They also write a short piece of advice about why we should – or should not – get the abstract written up.

Jennifer Bostock is an experienced NIHR public contributor who has been 'rating' for the Dissemination Centre since this summer: "As an experienced reviewer I have found the new task of rating abstracts for the Dissemination Centre a fresh challenge. This is a quick task but one that enables me to bring together my experience of health issues and my interest in research evidence to support the work of a valuable initiative. I look forward to NIHR Signals becoming a routine place for NHS decision-makers to go to look for research evidence."

We welcome everyone to visit our website and sign up as a rater; raters make an invaluable contribution. Public raters are offered an honorarium of £5 for each rating they complete. Sign up by completing a short form, giving us your profile details. You can find more information on our website: [www.dc.nihr.ac.uk/get-involved](http://www.dc.nihr.ac.uk/get-involved)

The Dissemination Centre also relies upon the contribution of a wide range of experts to provide 'critical friend' advice on how we develop our research summaries. This external advisory group has helped us refine the format of the Signals and has also advised on our other products: Highlights and Themed Reviews.

### **What is a Highlight?**

Highlights are short digests of up to six NIHR-funded research studies or systematic reviews. The Highlight is developed in discussion with key stakeholders and is presented in different formats for varying audiences. A Highlight includes clear guidance for readers on how they can follow-up or implement the findings of the research. The first Highlight is about obesity in men and will be published in mid-November.

**Continued>>**

## What is a Themed Review?

Themed Reviews are more extensive reviews of 'the state of the evidence' on a key health or social care issue. They are developed with a steering group of professional and patient/carer experts and will give decision-makers of all kinds the research evidence they need to shape the delivery of services. The first Themed Review is on end of life care and will be published at the beginning of December.

## Public involvement in the Dissemination Centre

The Dissemination Centre's advisory group is co-chaired by patient and experienced public contributor Richard Stephens who says: "I am pleased to be co-chairing this advisory group, supporting the development of new ways to summarise research outputs to reach patients, their clinicians and health service commissioners."

Another equally enthusiastic public member of the advisory group is Tony Sargeant: "I enjoy the challenge of being part of the 'critical friends' advisory group to the new NIHR Dissemination Centre. Patients make important decisions about their own health and care, and those of their families, every day. They, like clinicians, need to be well informed about what health research is telling us. In all my discussions about the evidence summaries that the Dissemination Centre produces, I ensure that they keep patients in mind as a key audience and strive to present their summaries in a way that works for patients."

You can follow the Dissemination Centre on Twitter @NIHR\_DC for tweets about Signals, Highlights and Themed Reviews. For any query about our work, please contact [disseminationcentre@soton.ac.uk](mailto:disseminationcentre@soton.ac.uk)

Contact: **Alison Ford, Head of Engagement, NIHR Dissemination Centre**

Email: [A.R.Ford@southampton.ac.uk](mailto:A.R.Ford@southampton.ac.uk)

Tel: **023 8059 7435**

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](mailto:pdavis@invo.org.uk)

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## What's happening across the National Institute for Health Research (NIHR)?

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### Making progress: Sharing ideas, successes and challenges

This year for the first time, the National Institute for Health Research (NIHR) Central Commissioning Facility (CCF [www.nihr.ac.uk/about/central-commissioning-facility.htm](http://www.nihr.ac.uk/about/central-commissioning-facility.htm)) has compiled and published the patient and public involvement and engagement (PPIE) sections of annual progress reports provided by 93 NIHR-funded initiatives (Research Centres, Units, Facilities and so on).

These reports briefly summarise progress being made in delivering PPIE strategies and include a wide range of examples of involvement and engagement activities and descriptions of how PPIE is making a difference.

Making the reports publicly available supports and promotes openness, transparency, the sharing of knowledge, learning and good practice across the NIHR and beyond.

Initial feedback on the reports has been positive. For example:

"I have found [the reports] very interesting. They not only let me know about the progress of patient and public involvement (PPI) in these areas with quite good growth but keep me in touch with research. I was impressed with 'open events' and also the way that children and young adults have also been included in PPI."

**Michael Osborne, NIHR public contributor**

"We have found the ability to understand how other organisations add value by delivering PPI activity very helpful in delivering [our] own PPI strategy."

**Liz Ralph, NIHR Sheffield Clinical Research Facility**

You can download the reports from the NIHR website: [www.nihr.ac.uk/get-involved/ccf-ppie-reports.htm](http://www.nihr.ac.uk/get-involved/ccf-ppie-reports.htm) and CCF can also provide paper copies of the reports to members of the public, on request. Please contact Louise Worswick by email: [louise.worswick@nihr.ac.uk](mailto:louise.worswick@nihr.ac.uk) or telephone 020 8843 7115.

## Patient and Public Involvement and Engagement in Horizon Scanning

By Kathryn Miles and Ali Cook

### Who are we?

The Horizon Scanning Research & Intelligence Centre (HSRIC) is funded by the National Institute for Health Research (NIHR) ([www.nihr.ac.uk](http://www.nihr.ac.uk)). At HSRIC we are looking for important health technologies that may become available on the NHS in the next few years. These health technologies include new drugs, medical devices and tests. When we find these technologies we write reports on them for groups that make health policies and decisions within the NHS, and for those that fund research. More information about who we are is available at [www.hsrc.nihr.ac.uk](http://www.hsrc.nihr.ac.uk).

Since 2013 we have been working to increase the involvement and engagement of patients and the public with what we do. You can download our activity report for 2012-14 from <http://tinyurl.com/qgm78km>. Looking forward, we have a document that details how we plan to work with patients and the public in 2015-2016: <http://tinyurl.com/pxk9xt6>.

### Case studies of getting involved

The example case studies below demonstrate the breadth of patient involvement and engagement at HSRIC. In all of these examples hearing the patient voice was a positive experience. Their additional perspective was invaluable and had a directive impact, enhancing HSRIC's work.

- In 2014 we arranged for members of a local patient group to come to our offices and tell us what they thought of our previous website. Thanks to their input we made changes to our new website that we hope make it easier for members of the public to find the information they are looking for.
- In 2014 we wrote a brief report on a new drug for a condition called alpha-mannosidosis (<http://tinyurl.com/oyrq632>). As this is a rare condition, we sent an early report to the UK charity that supports people with this condition so they could comment.
- In 2015 we published a report about a new type of medical device called a closed-loop artificial pancreas (<http://tinyurl.com/ox4e2gt>) that is being developed for people with type 1 diabetes. We asked members of the public with type 1 diabetes to comment on the benefits they think this new technology might bring.

- In 2015 we identified a technology called Reza Band® to treat acid reflux (where stomach acid rises back up into the mouth). The Reza Band® applies pressure to the neck to stop this happening at night while patients are asleep. We contacted two key charities who support people with this condition to ask their view on whether they thought we should investigate this technology further. As a direct result of their comments we wrote a report on Reza Band® (<http://tinyurl.com/nmu3jtr>), which is available on our website.

### How do I get involved?

If you would like to tell us about a new health technology that is not yet available to patients in the UK please visit our suggest a topic page: [www.hsrc.nihr.ac.uk/suggest-a-topic](http://www.hsrc.nihr.ac.uk/suggest-a-topic)

If you would like to learn more about getting involved in our work please contact us by email: [nihrhsrc@contacts.bham.ac.uk](mailto:nihrhsrc@contacts.bham.ac.uk) or telephone: 0121 414 7831.

### Ninth Annual NIHR Trainees Meeting

The National Institute for Health Research (NIHR) Trainees Coordinating Centre (TCC) is holding its ninth annual national trainee meeting for NIHR-funded trainees. The theme of the meeting, which is taking place in Leeds on 24-25 November 2015, is 'Making a difference – evidence to impact'.

The event allows trainees to present posters of their work, to network and meet other trainees, to share experiences, take part in workshops and learn more about the NIHR. Trainees are asked to write their posters in plain English and a panel, including members of the public, will assess the posters on how easy they are to read and understand. One of the workshops will focus on the impact of public involvement.

Patient and public involvement in the work of TCC falls into three areas:

- Patient and public involvement in research projects carried out by NIHR trainees
- Patient and public involvement in NIHR TCC's review and award processes
- Patient and public involvement learning and support for NIHR trainees.

If you would like to know more about public involvement in the work of TCC visit [www.nihr.ac.uk/get-involved/public-involvement-at-tcc.htm](http://www.nihr.ac.uk/get-involved/public-involvement-at-tcc.htm)

# noticeboard

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

## Professor Dame Sally C Davies response to 'Going the Extra Mile'

Professor Dame Sally C Davies has responded to 'Going the Extra Mile' (<http://tinyurl.com/qz8v1an>), the report from the Breaking Boundaries Review Panel, which she commissioned in March 2014 to provide an independent review of public involvement in research in the NIHR. Having reviewed the report's recommendations, Dame Sally has agreed that the National Institute for Health Research (NIHR) should take them forward, working in partnership with the NIHR community. The work will be led by Simon Denegri, the NIHR's National Director for Patients and the Public in Research, with support provided by the INVOLVE Coordinating Centre. The full response is available on the NIHR website: <http://tinyurl.com/ns9q7hr>

## Patient Research Ambassador Initiative update

The Patient Research Ambassador Initiative (PRAI) aims to promote the role of Patient Research Ambassadors (people who promote health research from a patient point of view) in local NHS services. The PRAI has developed a new online 'learning signpost', which provides support and guidance for Ambassadors who are new to their role and information for those who would like to learn more about the Initiative: <http://tinyurl.com/otfxoqj>

The PRAI hosted a tweet chat in September, where contributors asked questions about what it means to be an Ambassador, provided feedback and offered advice. You can view the discussions at #PRAtalk (<https://twitter.com/hashtag/pratalk>).

## Geoff Aitchison

We were sad to learn of the death of Geoff Aitchison. Geoff and his wife Margaret were founder members of the Warwick Diabetes Research and Education User Group (WDREUG), which Geoff chaired. He worked with Warwick Medical School for 13 years and was a

champion for patient and public involvement (PPI) in diabetes research. Through his work with WDREUG he became involved in Emergency Care PPI at Warwick and also with INVOLVE, where he was invited to give talks and participate in developing resources. The models for involving people with diabetes in research that Geoff was involved in developing and disseminating are now commonplace across most areas of healthcare research. He will be very fondly remembered and our thoughts are with Margaret at this sad time.

**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.

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INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

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

