

newsletter

Winter 2013-14

Welcome to the Winter 2013-14 issue of the INVOLVE newsletter. The theme of this newsletter is social care research and we feature a range of projects and initiatives illustrating public involvement in this area. We begin with INVOLVE Group member Tina Coldham's insight into participating in a social care research webinar that we ran in collaboration with the NIHR School for Social Care Research.

Webinars: an insider's view

By Tina Coldham

The first time I heard the word 'webinar' I automatically thought it was something to do with spiders. As I'm not a great fan of arachnids, I was relieved to find that a webinar is a sort of seminar held by virtue of the World Wide Web.

My first experience of a webinar was being invited to join one via a link in an email.



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The next INVOLVE conference will be on 26 and 27 November 2014 at the National Exhibition Centre in Birmingham. Turn to page 3 to find out more about sending in your proposals for presenting at the conference.

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.

Through this link I registered for the webinar and I was then told to download a simple application for my iPad to get me in. All rather simple and yet my scepticism kept me wondering whether this would actually work. Nearer to the time of the webinar I received email reminders and at the allotted time I logged in using the unique identification code I was sent on registering. Low and behold, I was taken to the 'app'. It loaded and all of a sudden I was viewing a PowerPoint presentation and listening to the presenter talk this through. The advantage of webinars is that you don't have to travel to them; in fact I was comfortably seated on my sofa with a cuppa. You can come and go without embarrassment as no one can see you. Yet it is possible to take part by voting or asking questions. So a webinar can be interactive too.

When I was invited to take part in a webinar for INVOLVE, at first I didn't realise I would be appearing in it! INVOLVE joined forces with the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) at the London School of Economics (LSE) to hold their first webinar on Friday 13 September 2013. The theme for the day was public involvement in social care research, featuring me as a survivor researcher, Simon Denegri, Chair of INVOLVE and NIHR National Director for Public Participation and Engagement in Research, and Mike Clark, Research Programme Manager of the SSCR. So, we called the webinar 'Get all sides of the story'. We had all prepared PowerPoint presentations to talk to, and I had worked with Helen Hayes, Senior Public Involvement Advisor at INVOLVE, to put together some slides showing critical things to remember when involving people in research. We also showcased some good examples from the 'Turning the pyramid upside down: examples of public involvement in social care research' report (www.involve.nihr.ac.uk/posttypepublication/turning-the-pyramid-upside-down-examples-of-public-involvement-in-social-care-research/).

On the day, Simon, Mike and I took turns presenting to our unseen audience in front of an enormous flat screen TV, which was weird to start with. Even weirder, we could see ourselves as there was a video camera seated on top of the TV, and we could also view our slides. We had the vital technical assistance of the LSE team to move the camera from us to the presentation and back again for those viewing the webinar. INVOLVE staff were ensconced in the corner out of view, taking questions from emails and tweets.



Mike Clark and Simon Denegri at the webinar

Less technical little pieces of paper passed hands and we ended with a discussion on the questions the audience posed. The hour went quickly in the end and the whole event was enjoyable even if a little nerve-racking to begin with.

The webinar I took part in was the first in a series of themed webinars that INVOLVE are producing. A second webinar on the topic of research with black and minority ethnic people using social care services took place on 20 January 2014. If you can't 'attend' the webinars, INVOLVE are adding the presentations to their website for viewing any time, along with all the questions and answers (www.involve.nihr.ac.uk/posttypenews/nihr-school-for-social-care-research-and-involve-webinar-series-2/).

Whilst there is no substitute for face-to-face contact, webinars offer another mode of getting a message across in an accessible format if you can afford and access the kit. They can be part of a portfolio of communications methods that organisations, and indeed user groups, can use to get their message across. All power to the web!

INVOLVE Coordinating Centre news

INVOLVE 2014 conference: call for presentations now open

Closing date for applying to do a presentation: Friday 4 April 2014

The ninth biennial INVOLVE conference is being held at the National Exhibition Centre (NEC) in Birmingham on 26 and 27 November 2014. The conference will bring together people with a common interest in public involvement in NHS, public health and social care research. This includes members of the public, service users, researchers, research commissioners and representatives of voluntary sector organisations.

The conference call for presentations is now open. The overall theme for the conference is Changing landscapes: Public involvement in research across the changing landscape and how we can influence the direction of change. We are inviting presentations on public involvement in NHS, public health and social care research that will encourage critical thinking, debate and discussion on the following topics areas:

- celebrating range and diversity
- learning and development
- recording and assessing impact
- international perspectives
- future directions.

Presentations may take the form of posters, workshops, papers, performances and other approaches, speed sessions and practical sessions.

For further information and to complete the call for presentations application form, visit www.involve.nihr.ac.uk/involve2014

We have created #INVOLVE2014 on Twitter and will be using this before and during the conference to disseminate information and encourage delegates to debate, discuss and share what's happening. Please tweet @NIHRINVOLVE using the hashtag.

Booking to attend the conference will open in Spring 2014. We will have information about this in our next newsletter.

New INVOLVE publication: Values, principles and standards for public involvement in research

We recently completed a report reviewing work on principles and standards for public involvement in research.

We plan to develop a framework based on the values and summary principles we have identified from the literature, which will include examples of what these principles mean in practice. We welcome comments and feedback on the values and principles we have identified as well as information on other work being undertaken in this area. We also encourage you to reflect on these principles and values and send us examples of whether and how you can apply them in your own work. www.involve.nihr.ac.uk/about-involve/current-work/standards-for-public-involvement-in-research/

NIHR Trainees Coordinating Centre conference

We recently attended the National Institute for Health Research (NIHR) Trainees Coordinating Centre annual conference, where trainee researchers whose work focuses on people and patient-based applied health research gather to showcase their work and take part in learning opportunities. There was great interest in the INVOLVE stand, where our staff answered questions and provided publications. One of the sessions at the conference was a workshop on public involvement run by Bec Hanley and Derek Stewart and supported by our Director, Sarah Buckland, who provided information about INVOLVE and how to access our resources.

INVOLVE information cards

Our information cards highlight some of our key resources for researchers and members of the public. These cards briefly describe each resource and point people to the relevant sections on our website. They are perfect for putting in delegate packs and displaying on information tables or on noticeboards. To order free copies of these A5 cards for your events or to share with colleagues please contact admin@invo.org.uk



Interesting articles and publications

Social care scoping reviews and methods reviews

Over the past couple of years, the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) has published a number of scoping reviews and methods reviews. The five scoping reviews, which systematically evaluate the current literature in a particular area, include one on user controlled research written by Peter Beresford and Suzy Croft. There are currently 14 methods reviews, which aim to help researchers make the best use of the various approaches available. Topics include research governance and ethics, care homes and a new review which examines the Medical Research Council's guidance on developing and evaluating complex interventions and its application to research on palliative and end of life care. The two SSCR/INVOLVE public involvement and participation in adult social care research webinars (see page 1 of this newsletter) were based on these methods reviews.

<http://sscr.nihr.ac.uk/scopingreviews.php>
<http://sscr.nihr.ac.uk/methodsreviews.php>

Can research development bursaries for patient and public involvement have a positive impact on grant applications? A UK-based, small-scale service evaluation

D M Walker and R Pandya-Wood
Health Expectations, doi: 10.1111/hex.12127, epublication ahead of print

This report describes the impact of a pre-funding bursary scheme that aims to support user involvement in the early stages of developing a grant application. Feedback from researchers who received a bursary suggests that the involvement helped to: refine research questions and design; develop dialogue between service users and researchers; identify service users for involvement in the remainder of the project; and create opportunities for researchers to learn about involvement and for service users to learn about research. The authors draw out a series of recommendations for setting up similar schemes.

onlinelibrary.wiley.com/doi/10.1111/hex.12127/abstract

Mental health service user involvement: where have we come from, where are we going?

Helen Kara

Journal of Public Mental Health, volume 12, issue 3, pages 122-135

This article reports on the findings of a knowledge review which looked at the extent and value of mental health service user (MHSU) involvement in research in England. The review found that MHSU involvement has become mainstream and there is clear evidence that it adds value. However, it also identified some gaps in the literature concerning the experiences of non-service-user researchers working with MHSUs and the recognition of the multiple roles that anyone involved in research, including MHSUs and their carers, may play. www.emeraldinsight.com/journals.htm?articleid=17095793&show=abstract

Supporting public involvement in research design and grant development: a case study of a public involvement award scheme managed by a National Institute for Health Research (NIHR) Research Design Service (RDS)

J D Boote, M Twiddy, W Baird, Y Birks, C Clarke and D Beever

Health Expectations, doi: 10.1111/hex.12130, epublication ahead of print

This report describes a funding award scheme to support public involvement in grant development. It includes examples of how awards have contributed to successful grant applications as well as findings from an evaluation of the scheme. The early public involvement in research design helped to: assess the feasibility of data collection processes; inform trial design; improve recruitment and consent processes; improve information for potential participants; agree outcomes and outcome measures; identify ways to involve the public in the conduct of research; and improve lay summaries for the application form. The evaluation of the scheme identified areas for improvement, including making sure members of the public/patients can be rapidly reimbursed for their expenses.

onlinelibrary.wiley.com/doi/10.1111/hex.12130/abstract

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

Optimising adult mental health service configurations across health and social care

As part of the INVOLVE series of examples which highlight public involvement in research funding applications (www.involve.nihr.ac.uk/resource-centre/examples/exploring-public-involvement-in-nihr-research-funding-applications/), Kristina Staley interviewed Jane Hughes, Lecturer in Community Care Research at the Personal Social Services Research Unit (PSSRU), University of Manchester about public involvement in a service evaluation being carried out by the Unit. This article is a summary of that interview¹.

About the project

The National Institute for Health Research School for Social Care Research (SSCR) has commissioned the PSSRU to carry out a service evaluation, the aim of which is to provide local commissioners and providers with evidence to inform the reconfiguration of local mental health services. The focus is on the needs of service users receiving inpatient and community mental health team services.

Patient / carer involvement prior to applying for funding

The project team has been asked to carry out this study by Pennine Care NHS Foundation Trust. The Chair of the Trust's Service User and Carer Mental Health Forum invited the researchers to a Forum meeting to discuss the project. At this meeting the researchers asked for feedback on their outline proposal and also invited further involvement in developing their bid for funding. All Forum members were invited to a consultation meeting to develop the bid and nine of them came to share their experiences of accessing and using local services and to discuss the challenge of disseminating the findings to large numbers of local organisations. The Trust provided a venue and refreshments for the meeting and also paid people's travel expenses. Forum members were asked to give their time free of charge and they were fine to do this as a one-off. They were advised that involvement in the subsequent research would be fully funded.

Impact of the early involvement

The feedback from service users and carers at the consultation meeting shaped the development of the bid, in particular strengthening the user involvement and helping to develop a local dissemination strategy. Originally the plan was to have only a small reference group but the project team subsequently decided to also include a lay panel in order to help reach a wider constituency. The feedback challenged the team to be crystal clear about the role of user involvement in the project and about payment for members of the reference group, not only for attending meetings but also in helping carry out the research. This made them careful to ensure that the user involvement was correctly funded. The researchers were keen that the project's findings would reach the wide range of local organisations with a role in providing care to mental health service users and carers. It was suggested that members of the reference group might take responsibility for this task as they were in touch with lots of organisations.

Continuation of involvement following funding

Forum members have been invited to join the reference group and lay panel and the Forum administrator is helping with recruitment to these. It was very important for the Forum to hear how their involvement had made a difference to the bid as this encouraged them to continue to engage with the project. Working with an existing organisation has been a very useful way forward because they have easy access to service user expertise and a network of people they can contact.

Lessons learnt

Holding the meeting on the Forum's premises – on familiar territory – made it feel like coming to an ordinary meeting for them. Jane reflected: "You have to be very clear about what's up for negotiation, the parameters of the consultation. Then you need to be flexible and prepared to sit back and listen to what people are saying so you don't just get what you want to hear. Then you'll hear some things you weren't expecting. We heard interesting things about the link between what people want from a service and their age, which made us think through that in planning the research."

www.nursing.manchester.ac.uk/pssru/research/nihrsscr/projects/adultmentalhealthservices/

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¹ To read the full interview visit www.involve.nihr.ac.uk/wp-content/uploads/2013/10/Example-3-publicinvolvement-in-funding-app2013.pdf

The NIHR School for Social Care Research and user involvement

By Michael Clark and Anji Mehta

With four months to go in its first five-year cycle, the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) has made significant strides in user, carer and practitioner involvement in the adult social care field, not just limited to its own work but in the sector more widely. Its 56 studies all involve users and carers in some form; the School's User, Carer, Practitioner Reference Group are very active in setting and implementing the School's strategies; and user involvement continues to be promoted at all levels.

SSCR was set up by the NIHR in May 2009 with the aim of improving the evidence base for adult social care practice in England. As part of this mission, we emphasised user involvement at all levels of the School's activities in our business plan. Yet we knew that this would not be easily implemented. Different areas of social care research have different histories and developments with regard to wider involvement: mental health, physical disabilities and learning disabilities, for example, are all areas that have significant examples of wider involvement in social care research, which is not necessarily the case with, say, research into the care of older people. And it is not always clear what counts as involvement (versus participation), how to do it effectively, nor how to identify care users at a time when funding changes mean people are funding their own care and, thus, are not easily identifiable.

So what has the School achieved?

Involvement at the organisational level

We set up our User, Carer, Practitioner Reference Group (UCPRG) early in 2009 and it has continued to go from strength to strength. We have included practitioners in the Group as, compared to health care, there is a less-well developed culture and fewer resources to support practitioner-research roles and engagement. The Group engages enthusiastically in all School activities, from advising us on our direction, identifying research priorities, supporting us in setting and implementing research and knowledge exchange strategies, to reviewing proposals and end of project reports. Members from the Group also

contribute their expertise as members of our Advisory Board and our Commissioning Selection Panel, as advisors for specific research projects (both funded by us and by others) and through involvement in our communication activities. One member is now also on the national Social Care Research Ethics Committee, while another is a co-investigator on a recent Economic and Social Research Council (ESRC)/NIHR-funded study on dementia.

The Group is also contributing to the development in social care research of a critical mass of users, carers and practitioners who can be better networked to support each other and be active in research.

Involvement in research studies

Involvement has always been a requirement for our studies, with all research proposals having to set out an appropriate plan for the involvement of users, carers and practitioners, and all plans reviewed by a member of UCPRG. All of our studies involve such members, either through local advisory groups or as members of project teams. Although we are currently drawing together a complete picture across all projects, in 17 projects involvement extends to:

- 20 people with direct experience of using social care services who are involved on advisory groups and/or as researchers
- 16 people who are carers of people who use social care services
- an extensive network of national bodies representing people who use social care services, or carers, such as Age UK, Mental Health Foundation, British Heart Foundation, MIND, Mencap, the Stroke Association, the National Council on Independent Living and Disability Rights UK
- many local organisations representing, and directly working with, social care client groups, such as black and minority ethnic (BME) communities, homeless people, older people, and people experiencing domestic violence
- many representatives of commissioning and providing organisations, including councils, care home providers, and third sector organisations.

The following example highlights one study (among many) and its approach to user involvement. An article about another SSCR-funded study 'Optimising adult mental health service configurations across health and social care' appears on page 5 of this newsletter.

Case study: Service users as advisors in a research project on the needs of homeless women

This study, led by Dr Emma Williamson at the University of Bristol, aimed to identify homeless women's experiences of the wider support system over time. The study followed homeless women over a period of two years to explore their experiences and needs. Recognising the potential difficulties in recruiting homeless women into the study (such as retaining contact over a sustained period, avoiding adding additional burdens on the women, and the need to balance the researchers' needs and the potential emotional vulnerability of the women), the study recruited four previously homeless women who were now in stable accommodation to act as advisors to the study. Three of these women had been involved in an earlier study by the project team, and had been willing to engage further.

The advisors were given confidence-building sessions and background training in research methods and ethics. They were actively involved in the design and methodology of the research, and were able to provide insights for recruitment purposes.

The project team has drawn together key learning from the involvement of these women as advisors in the project. They stressed the importance of building trust between the advisors and the researchers involved in the study and treating them as full members of the team, for example being transparent in decision-making discussions and fully enabling them to be part of project meetings without appearing to alienate anyone, and noting the need for clarity in all aspects of the study. The study concluded that the involvement of service users in the design and methods of the research project greatly improved the research tools and procedures.

For further information see www.bristol.ac.uk/sps/research/projects/current/RK7228/index.html



Angie Carmichael, user member of UCPRG, on Selection Panel considering research proposals to SSCR. Photo © SSCR

Developing methods of involvement and participation

The School has commissioned a number of methods reviews, several now completed, some of which focus on promoting an inclusive view of social care research (see page 4 of this newsletter).

User involvement takes effort, time and resourcing on the part of all parties involved to ensure it is done appropriately for each project, and without being tokenistic. We commissioned a review on user controlled research from Peter Beresford to explore some of the issues around user involvement in research. Within the School we are keen to support users and carers to develop their skills to play more of a leading role in social care research. We have also actively tried to promote the submission of user-led/controlled project proposals.

Next steps

We hope to move forward with user involved and controlled research in our next five-year cycle from May 2014. We are particularly keen to explore and apply innovative ways to bring the full range of people who use adult social care services into discussions about research. There is still relatively little involvement of some groups, such as people with dementia or adults with severe intellectual disabilities, for example. We would like to see more research that is led by service users and carers. We hope to work with INVOLVE and others to invest in structures to support this, and welcome further suggestions from users and carers. We also welcome suggestions for research priorities or topics. Please contact us via email or telephone as below.

Contact: **Michael Clark and Anji Mehta**

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SCIE: Talking and walking co-production

By Michael Turner and Pamela Holmes

“What we need to be doing is shouting from the rooftops about how good co-production is, what we can do, what we can achieve together and actually try and make sure that those lessons are learnt,” says Andrea Sutcliffe, former Chief Executive of the Social Care Institute for Excellence (SCIE) and now Care Quality Commission (CQC) Chief Inspector of Adult Social Care, in SCIE’s new film ‘Have we got co-production news for you?’ (www.scie.org.uk/socialcaretv/video-player.asp?v=havewegotcoproductionnewsforyou2)

SCIE is shouting the co-production message from the rooftops with a major new National Institute for Health and Care Excellence (NICE) accredited (www.nice.org.uk/accreditation) guide ‘Co-production in social care: what it is and how to do it’ (www.scie.org.uk/publications/guides/guide51/). This new guide is, in itself, an example of co-production. The guide looks at what co-production is by examining the importance of definitions and principles along with the policy context and issues around the potential costs and benefits of co-production. It then takes readers through the steps needed to put co-production into action with a jigsaw model of change management. This organises the actions needed for co-production around four key areas/pieces of the jigsaw: culture, structure, practice and review. The guide is informed and illustrated by 10 practice examples which cover a range of social care settings, some of which overlap with health care, including a clinical commissioning group. But SCIE has never been about just ‘talking the talk’ and is ‘walking the walk’ with its own practice on co-production.

An independent review of SCIE’s participation work completed in 2010 pointed the way to improving the impact of work with people who use services and carers, through a co-production approach. This led to the development of a new strategy which began with the recruitment of a person who uses services to SCIE’s board and who would also chair a new Co-production Network. Tina Coldham, a mental health service user and survivor researcher (and member of INVOLVE) was appointed to this role.



Pamela Holmes and Michael Turner

SCIE then approached a range of organisations run by people who use services and carers and organisations representing equalities groups to form the membership of the Network. The members of the Co-production Network are involved in all aspects of SCIE’s work including recruitment panels and project advisory groups, as well as the equality, diversity and human rights forum, and reviewing SCIE’s new resources. The membership meets in full twice a year to give input into SCIE’s strategic direction and work programme.

“We make no claim to having everything perfect,” says Tina. “But we do have a set of principles that sets out how we are implanting co-production at SCIE; and we’re embedding this with new policy and practice and support to staff to develop new ways of working.”

One of the important early steps in the development of SCIE’s co-production strategy was the agreement of a definition of co-production, and it is one that the new co-production guide recommends to other organisations. For SCIE co-production means working as equal partners in all aspects of its work. This is the first point in SCIE’s co-production charter (www.scie.org.uk/coproductionnetwork/files/charter.pdf) which outlines a set of principles to support a whole systems approach to co-production.

A recent SCIE project on end of life care ‘Dying well at home: the case for integrated working’ (www.scie.org.uk/publications/guides/guide48/) gives an example of how co-production is working at SCIE. A Project Advisory Group (PAG) of carers, people who use services, commissioners and providers met twice to support the development of the guide. Of those attending in a professional capacity, many had also been or were currently carers themselves; the chair of the PAG was an

ex-carer as well as an academic with an interest in end of life care issues. The PAG reviewed the way the guide was produced and written, making sure the recommendations and content reflected real-life experiences and practice.

SCIE also brought together another group of carers, some of who were recently bereaved. They generously agreed to take part in a facilitated workshop that extended the co-production opportunity to a wider field. Both the PAG members and workshop participants were asked for examples of good practice in services they had received themselves, or which they had heard about through friends or contacts. The Social Care TV films that support the guide were also produced with input at all stages from an older person who had experience of film production.

Links

SCIE co-production pages:

www.scie.org.uk/coproductionnetwork/index.asp

SCIE end of life care pages:

www.scie.org.uk/endoflifecare

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Merging worlds – the importance of support roles for patient and public involvement (PPI)

By Carol Rhodes

The recent drive to include patients in all areas of health and social care has created an increase in patient and public involvement (PPI) jobs across the country. These include a diverse range of roles, paid and voluntary, part-time and full time, spread across charities, health organisations, research networks and universities. Some have been filled by researchers and health service managers, who have a keen interest in PPI, as a percentage of their full time roles. Others have been filled by patients with no research background but lots of patient expertise and a range of other organisational skills. The common theme that links them all is their desire to get the patient voice heard within health and social

care services and research, and to develop ways of sharing good practice across the country. In this article I talk about my role in facilitating the Research User Group at the Arthritis Research UK Primary Care Centre, Keele University.

It is now accepted that PPI is an important part of the research process, and evidence of meaningful involvement of patients and the public is required by funders and ethics committees. However, bringing together researchers and the general public requires coordination and a good support system. At the Arthritis Research UK Primary Care Centre there was early recognition of the important role of PPI in research. Funding and an organisational structure for PPI were developed in partnership with the Primary Care Musculoskeletal Consortium Board, and a Research User Group was formed in 2006. We now have a group of 60 members involved in 57 projects.

Initially the Research User Group was involved in research across conditions seen in general practice such as fibromyalgia, shoulder, back and leg pain and osteoarthritis in the hands, hips, knees and feet. Now, as the Arthritis Research UK Primary Care Centre has grown and gained UK Clinical Research Collaboration Clinical Trials Unit (UKCRC CTU) status, it has moved into new areas of research. These include arthritic conditions such as polymyalgia and gout, and other long term conditions treated by general practitioners such as myalgic encephalomyelitis (ME), chronic fatigue syndrome and mental health conditions such as depression and self harm. Our Research User Group has also had to grow to incorporate new members who have the experience of living with these conditions.

While a database of patients could provide the names of PPI members so that requests from researchers could be sent to the right patient, a lot of the success and growth of our group is due to the individualised support they receive. Support is offered by myself and my colleague, Adele Higginbottom, in paid roles, helping with the administration and support of our group.

Administration forms a large part of the role. Our experience tells us that it's the simple things that make the most difference to patients: accessible reserved parking; refreshment breaks; rooms pre-booked on the ground floor with access to disabled toilets; lay summaries prepared by researchers and sent out well in advance – these are just some of the basics that patients should be able to expect as standard good practice.

Our paid PPI support roles are highly regarded – “the oil that keeps the wheels turning” – supporting lay members alongside the fast-paced, deadline driven world of research.

In addition to administrative tasks, and in order to match the correct patient expertise to a project, you need to know your group. Many members are happy to share what conditions they have, what medication they take, if they are retired or still working (whether paid or voluntary), their hobbies, their family status, or whether they live alone. All of this personal information has to be managed according to good practice guidelines. Our members experience the ups and downs of life just as we all do, including life threatening illnesses, caring for sick grandchildren or elderly parents, and the loss of a user group member. All of these changing circumstances have to be managed with thoughtfulness and kindness. As any PPI facilitator will know, there is a very important emotional-support role to be offered to members and you, yourself sometimes need a listening ear as you support those in your group going through their changing circumstances.

The role is not without its little challenges. Things do go wrong and mistakes are made but next time the refreshments don't turn up, or the parking isn't reserved, or the printer refuses to print your documents, take a breath and just go with it.

Because for every meeting like this there will be another where you are completely inspired by the strength of the human spirit. The people who have travelled alone on the bus to attend a meeting in a building they have never been in before, who are willing to tell their story and then listen to the researchers' ideas for a project, a project they passionately want to be involved in, just because at last someone cares enough to do research into the treatment of this condition that they have struggled with for years – these are the moments to treasure, the moments that make you walk out with your head held high and remember why you love your job!

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You've done the research – now what?

By members of SUCPRDG¹

Introduction

Members of the Service User and Carer Partnership Research Development Group (SUCPRDG), sponsored by the Mental Health Research Network Cymru (MHRNC) and Involving People, facilitated a workshop at the INVOLVE 2012 conference to discuss and debate ways of disseminating research conducted by service users and their supporters.

During the workshop delegates moved between three different themed areas:

1. dissemination and social media
2. dissemination and journals dedicated specifically to service user research
3. other methods of dissemination.

They were asked to address two questions under each theme:

- a. How could service users/carers/members of the public be more involved in research dissemination?
- b. How could research dissemination be better achieved?

The workshop was very well attended and lively discussion ensued. Delegates' ideas were debated and refined at each work station as the discussions progressed. During the last part of the workshop everyone present discussed the ideas generated and these were ranked in importance for future research by the group.

1. Social media

Delegates felt that utilising social media to disseminate research findings creates an open dialogue, with increased accessibility, but were concerned that research could lose its human element. The need for ongoing moderation was discussed, and the possibility that information may be misinterpreted necessitated clear and unambiguous dissemination via social media. Delegates felt that research should be published via all available means, including Facebook, Twitter, radio, phone apps and blogs. Other suggestions included online forums where findings could be discussed, and dedicated websites where people could study the outcomes of research. Filming research findings for those who cannot, or prefer not to, read Twitter and other similar media gathered a lot of interest. It was recognised that not everyone can use social media, and issues were raised regarding the possible negative influence of open access on those who may be vulnerable to stigmatisation and discrimination.

2. Dedicated journal

Examining the issues surrounding the possibility of a journal specifically dedicated to service user research, participants highlighted the practical constraints involved: who would print such a journal and how would costs be met? In addition, delegates considered how research findings might be captured, together with questions concerning what to do about unsuccessful submissions. Ideas centred around the consideration of format and style, ensuring a journal of this kind would be appropriate and meaningful for all service users rather than to an editorial board, and verifying that reports of research findings are honest. Other suggestions included a research register that could include all service user research or a dedicated service user research portfolio with a public interface. These could include brief summaries of all research projects with a contact address for anyone wanting more information.

3. Other methods

General ideas about the dissemination of service user research were considered with delegates suggesting face-to-face meetings between researchers and research participants, with the latter being asked how they wish to be given the results. Other ideas included providing presentations, facilitating workshops and conducting seminars at meetings of service user groups, conferences and events. A newsletter could be created for active participants in research. Some delegates felt dissemination could be better achieved using charity websites and National Institute for Health Research (NIHR) web pages with links to NHS trusts.

A digital TV channel devoted to research findings was also suggested, along with training on research dissemination for interested parties. Funding for dissemination was an issue which ran through all work stations. There were many questions about costs and budgets for dissemination and participants felt strongly that user involvement in funding bodies would help ensure that there is dedicated funding for this purpose. Delegates felt that funders should enquire about patient and public involvement (PPI) and dissemination at the outset, and should make suitably targeted dissemination a condition of any funding. Another suggestion included pharmacological companies funding dissemination, recognising that these should be balanced accounts and not biased. Making journal subscriptions more affordable was another popular idea.

Conclusion

This workshop demonstrated a lively interest among service users and the public concerning dissemination of research. Funding is an ongoing problem that can be overcome by ingenuity and effort.

Since the workshop the SUCPRDG has established a research writing group to ensure that service users and carers have more ownership of, and engagement with, the research writing process, including deciding how best to disseminate their work. Group members have also been involved individually in various dissemination activities, including the publication of an iBook as a new way of disseminating research findings.

The SUCPRDG would be delighted to receive other ideas and observations concerning dissemination, particularly those related to service user led research.

www.mhrc.org/serviceuserandcarerprdg.htm

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¹ Dr. Penny Llewellyn, Amanda Wells, Karen Morgan, Bethan Mair Edwards, Alan Meudell, Bridie Evans, Brian Mitchell and Christine Wilson.

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

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

Tel: **023 8065 1088**

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Deadline for contributions for our next newsletter: **17 March 2014**



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.

Preparing for patient and public involvement in research: training for researchers workshop

On 28 February 2014, the University of Salford is holding a full-day workshop on public involvement in research for researchers and research active staff. The facilitator is Dr Tracey Williamson (Research Fellow Public Engagement/ User Involvement in Research) and she will be accompanied by Elaine Jones (Lay Researcher). The objectives of the day are to:

- identify good practice principles for successful public involvement in research
- understand the application of involvement principles in research design
- appreciate how to strengthen public involvement aspects of funding applications
- consider the impact of involvement – its ‘measurement’ and how to maximise it
- explore the realities of public involvement – challenges, benefits and difficulties.

For details of costs and other information and to book a place see www.salford.ac.uk/spd/course_details?courseid=PREPARwiCD&coursename=course%20Details

Round 3 of the NIHR New Media Competition

The National Institute for Health Research (NIHR) has launched Round 3 of their New Media Competition. For the first time they are including two categories: one for researchers and one for patients and the public involved in NIHR research. The competition allows researchers, patients and members of the public involved in research to communicate their research, enthuse audiences, get creative and win prizes. The competition closes at midnight on **30 March 2014**.

For more information and guidance on how to enter see www.nihrtcc.nhs.uk/NIHRNewMediaCompetition/

Update: The Public Involvement Impact Assessment Framework

The INVOLVE Autumn 2013 newsletter included an article introducing the Public Involvement Impact Assessment Framework (PiiAF), which has been produced to help researchers assess the impact of public involvement in their research.

Since its launch, the PiiAF website has been improved and is now easier to navigate. It includes a summary of the research on which development of the PiiAF was based as well as a new guidance document.

www.piiaf.org.uk/

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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