



Research News

Summer 2009 | Issue 2

CONTENTS

**Service Users in Research ...
Launched** [page 1](#)

Launch Event at the Wellcome Trust
by Thomas Kabir [page 2](#)

**The MHRN National Scientific
Conference** by Pippa Brown [page 3](#)

**What are the proper roles of service
users in mental health research?**
by Peter Tyrer [page 4](#)

Jargon Busters [page 4](#)

**News from the MHRN Heart of
England Hub** by Jackie Smart [page 5](#)

Introducing Sue Collinson
by Sue Collinson [page 6](#)

Book Review by Diana Rose [page 6](#)

**Service Users in Research:
Interesting Things** [page 7](#)

Membership Form [page 8](#)



Tim Loughton MP, Co-Chair of the All Party Parliamentary Group on Mental Health, speaking at the launch of the new MHRN DVD 'One in Four' at the House of Commons on 19th June 2009

Service Users in Research ... **Launched**

Service Users in Research was successfully launched at an event held at the Wellcome Trust in London on 24th March. You can read about the launch on p2. Since the launch we have been very busy. Together with FACTOR (the carer arm of the MHRN) we organised a gathering for service users and carers at the annual MHRN scientific conference. The gathering was very well attended by roughly sixty service users and carers. This was far more than expected and indeed the room was absolutely at capacity. An account of the conference is given on p3 from Pippa Brown.

The MHRN has produced a DVD on how service users and carers can get involved in the work of the MHRN. The DVD can be downloaded (legally!) at www.joosetv.com/mhrn. The DVD was launched at the House of Commons' on 19th June and a full account of the launch will be included in the next issue of Research News.

The Service Users in Research Committee has met twice. The Committee links up service user involvement in MHRN research at a local level with activity at a national level. The Committee consists of over twenty service users from

all the MHRN hubs together with representatives from areas of the country not covered by one of our hubs.

The MHRN East Anglia Hub held a research day together with the Cambridgeshire and Peterborough NHS Trust on 24th May in Norwich and the MHRN Heart of England Hub held a research day at the University of Birmingham on 1st June. Jackie Smart, the new Service User and Carer Development Officer of the Heart of England Hub writes about the research day on p5.

Service Users in Research has commissioned two service users to write plain English or 'lay' summaries of research projects that the MHRN supports. These lay summaries will begin to appear on the MHRN website over the coming weeks. Service Users in Research is also working towards establishing a national 'people bank' of service users that can review the patient material (consent forms, and patient information sheets etc) for researchers that wish to have their research supported by the MHRN at a later date. A summary of some of the other work that Service Users in Research is undertaking can be found on page 7.

Service Users in Research has got off to a good start; but we want to do more and to do that we need people to join us. Membership is open to all (not just service users) and you can join by filling out the membership form on page 8 and returning it to the Freepost address.

Service Users in Research: Launch Event at the Wellcome Trust

by Thomas Kabir



The panel discussion at the Service Users in Research launch event. The panel consisted of Diana Rose, Thomas Kabir, Sue Collinson, George Szumukler, and Jo Evans

Service Users in Research was launched at the Wellcome Trust in London on 24th March. The event was well attended by a wide range of service users, researchers and others from across the country. In the morning Thomas Kabir, the Service Users in Research Coordinator, gave an introduction to Service Users in Research. In his talk Thomas said that one of the most powerful ways to change the mental health system is through research. The talk finished with the message that only one thing is for certain - that if service users and others do not get involved in mental health research then things will not change. The director of the MHRN, Til Wykes then gave a talk introducing the MHRN and its work.

Jo Evans from the Service User Research Enterprise (SURE) at the Institute of Psychiatry talked about their work on developing a new measure of service user perceptions of inpatient care. The new measure (called VOICE) was generated almost entirely from the perspective of service users.

SURE largely consists of service users and is one of the largest sources of service user generated research in Europe. Its director,

Diana Rose, will be a member of the new Service Users in Research Advisory Board.

Before lunch an interactive voting session was held. The audience was given five questions to answer. Every person in the audience had a handset through which they could give their preferred response to the question being asked. The first question was, 'Do you think that it is a good idea to [actively] involve service users in research funded by drug companies'. Roughly 80% of the audience gave the 'yes' response. The audience was asked: 'Do you think that mental health research influences government policy to any significant degree?' Around 65% of the audience responded 'yes' to this question. About 80% of the audience thought that the quality of mental health research would be much improved if service users were actively involved in its design.

During lunch everyone took full advantage of the Wellcome Trust's excellent food. As well as food we had two therapists offering massages and reflexology which were well received.

After being suitably fed and relaxed everyone returned for the afternoon session of the meeting.

In the afternoon Liz Pitt and Christine Barrowclough from University of Manchester received the annual MHRN award for the best service user involvement in a portfolio study. The study for which the award was made was entitled 'Recovery-focussed self-help therapy for psychosis: an evaluation of different modes of delivery and patient preferences'. Liz Pitt has written an article on this study in the first issue of Research News entitled 'Involving service users in Recovery Programme Research'.

The MHRN is one of several clinical research networks funded by the NIHR. There are a number of other networks focused on topics such as cancer and diabetes. The body which oversees all of these networks (including the MHRN) is called the NIHR CRN CC (<http://www.ukcrn.org.uk>). Derek Stewart, the Associate Director for Public and Patient Involvement, gave an overview of public and patient involvement across the various NIHR-funded networks.

Steve Gillard from St George's, University of London, then gave a presentation asking the question, 'Does more service user involvement in research always mean good involvement?' The talk generated a lot of good discussion and it became clear that involving people in research is valuable but needs a lot of careful thought if it is to be done properly.

At the end of the day a panel discussion was held. The panel consisted of many of the people who had spoken throughout the day. The panel took questions from the audience and a good discussion of a range of issues was had.

The MHRN National Scientific Conference

by Pippa Brown

An informal pre-conference gathering was held for service users and carers in the Gallery of the East Midlands Conference Centre. This provided an opportunity to meet each other, to become familiar with the conference schedule, and to engage in debate about the issues and challenges face by service users and carers in research. The gathering, organised by Dr Thomas Kabir and Dr Geraldine Mason, coordinators for Service Users in Research and FACTOR, respectively, was full to capacity; a mark both of the growing involvement of service users and carers in research and of recognition from the wider mew, with a keynote address from Clair Chilvers followed by a welcome reception in the Banqueting Suite. The conference programme ahead was varied and there was much to appeal to everyone, with sessions in both medical and social science.

The conference provided a fantastic opportunity to listen to scientists and researchers at the top of their fields. Those present were able to gain a greater appreciation of how research informs treatments and interventions and of the importance of engaging in good research to ensure that the best and safest interventions are made available. Additionally, the conference highlighted the need to conduct good quality research to secure much needed funding within the mental health system. Prior medical or scientific knowledge was needed for a full understanding and appreciation of presentations in some of the medically orientated sessions. However most speakers provided relevant background information and explained the rationale for their studies in a way which facilitated active engagement.

On the second day of the conference, Dr Rufus May, a clinical psychologist at Bradford District Care Trust, gave a presentation on true collaboration. He invited the audience to think about how experts by experience and professionals can



Clair Chilvers (Chair of the Nottinghamshire Healthcare NHS Trust) giving the keynote address at the MHRN Scientific Conference. Clair Chilvers has also agreed to sit on the Service Users in Research Advisory Board

truly work together. The presentation was impressive, in part because, through 'lived experience', Dr Rufus May impressive presentation imparted some of the tremendous wisdom and understanding of the needs of those experiencing mental illness which he has acquired through 'lived experience'; and it challenged the established roles of professional and service user, raising the question of what it is to be an expert. Collaboration certainly seems like a sensible approach and hopefully one that will increasingly be practiced within the mental health system. Listening to a professional with 'lived experience' was powerful. I felt a little more at ease with my own experiences and much more hopeful that my own and others' experiences of mental distress could be utilised in effective ways.

The conference dinner took place that evening at the Royal suite of the Crown Plaza Hotel during which we were delightfully serenaded by a member of staff from the MHRN! The following day saw the final day of the programme, comprising a number of excellent presentations and a final speech summarising the conference and looking to the future of mental health research.

Pippa Brown is a member of the Service Users in Research Committee and attended the MHRN Scientific Conference.

What are the proper roles of service users in mental health research?

by Peter Tyrer



One of the shining lights of the Mental Health Research Network since its formation 6 years ago has been the placement of service users at the forefront of its endeavours. All research studies accepted by the Network have to address the concerns and welfare of service users and carers and to do this in a way that does much more than paying lip service to an important aspect of research which has often been neglected. What we all would like to see is many examples of service users being involved early in the development of research studies, helping to hone and improve them, and then ensuring that they are rolled out to the NHS with high ethical standards, transparent information for potential participants, and successful outcomes in terms of recruitment and retention.

The service user representatives of the North London Hub are of great value to us and listed below are some of the current activities they are currently engaged in:

- Providing a PPI overview for funding proposals
- Writing lay summaries for our SUNLOWS website, as well as maintaining and updating the site regularly
- Providing feedback on patient/carer information sheets
- Looking at possible barriers to recruitment when necessary
- Representation on the Service Users in Research Advisory Committee
- Training
- Organising and sending out invites to relevant hub events
- Inclusion on interview panels
- Joint collaboration in formulation of research proposals where possible
- Making of a promotional DVD

Another very important aspect of development along the service user pathway is social inclusion, and in our context this is research hub inclusion. The service user representatives in our hub do not

have a special office headed 'Service User Office' or euphemistic acronym for this, but are inextricably linked with the workers in the main hub offices.

Research inclusion means equipoise; or, in other words, an equal balance between users and researchers with clear responsibilities for each. One thing I have learnt from all my experiences in my position as what is now called a 'clinical academic', a researcher who also sees patients, is that the closer you can come to dealing with patients in all forms of contact as ordinary human beings, the more successful you are in overcoming the experiences of patienthood and achieving full integration into society. At the Annual Meeting of the MHRN in Nottingham I upset service users and others attending the meeting by singing a rather silly song about one of my former patients who exaggerated his disorder. I am very sorry for any offence caused and apologise unreservedly to those who were troubled by this. In my work with service users I always ask myself if I am respecting them as equally as I do all the other people I meet in society. I think I usually do, but in this case I may have fallen short.

Peter Tyrer is the lead of the North London MHRN Hub

Jargon Busters

jargon, *n.*¹

1570 *LEVINS Manip.* 163/42 Iargon, rime, j

3. Unintelligible or meaningless talk c

1340-70 *Alex. & Dind.* 462 Swiche wordus Iargon. 1658 *BRAMHALL Consecr. Bps.* iii 4 all meer jargon and insignificant non-sence About sights seen in the city. 1876 *FAWCET*

There are eight definitions of the word 'jargon' in the Oxford English Dictionary. The third definition, 'Unintelligible or meaningless talk or writing; nonsense, gibberish', seems to be the most widely used. The medical and scientific world is replete with acronyms and jargon. We have listed some of the most useful Jargon busters available online together in one place and these can be found at www.mhrn.

info. The jargon busters give plain English meanings of acronyms and terms used in the NHS and mental health research.

News from the MHRN Heart of England Hub

by Jackie Smart

I am really pleased to be given the opportunity to introduce myself to the Network.

In April I was appointed the Service User Development Officer for the Heart of England Hub. Prior to my appointment I had been involved in a number of events in connection with 'refreshing' the HoE network and identifying the needs of our colleagues both from the service user movement and the research community.

Three events have now taken place and the energy and desire to be involved and collaborate with each other has been captured on all occasions. The key I believe to its success has been the joint working between the team members of the hub and our service user colleagues in establishing how to take each event forward and the rationale behind the ideas for each workshop held. Some excellent ideas came out of these small and intimate meetings and the relationship between all those involved has flourished.

The first event held in September 2008 was titled 'Influencing Mental Health In Research: A commitment to Genuine User Involvement'. Stories of good practice were relayed to the audience and workshops focused on questions concerning the nature of research, engagement with interested parties from local perspective, and perceived barriers to involvement. The second workshop held in December 2008 was titled 'Developing Systems and Structures for Involving Services Users in Research'. On this occasion it was felt we should deal with the issue surrounding 'barriers' and how we could overcome them.

My first role as a development officer was to assist with the co-ordination of the third event, held on 1st June 2009, titled 'Developing Research Ideas'. We were keen to identify



One of the workshops held at the Developing Research Ideas event held at Birmingham University on 1st June 2009

the skills mix and gaps (levels of participation) of our service users and carers and borrowed the idea from our Hub colleagues in the South London and South East Hub and Thomas Kabir who had used a similar way of capturing this evidence at the Scientific Mental Health Event held in Nottingham.

From this one small 'borrowed' idea we are in a position to identify what gaps we have locally and where we should be concentrating our efforts to ensure that we provide or source training and support to the right people, in the right places, at the right times. From the snapshot it became evident we are still lacking service user involvement in Level 4 (Multiple Project, Advanced) and Level 5 (Employment). This visual element assisted with the discussions held in the workshops and enabled us to identify the research interests of those attending and some of the ways in which we can facilitate various levels of involvement.'

Pockets of research interests were exchanged with a commitment from those in attendance to continue to communicate with each other with offers to assist each other where possible at all levels. All in attendance were asked to complete

the register of interest form to capture this.

What has been the result of this? I shall shortly be forwarding my findings to the coordinators of Service Users in Research and FACTOR so they can get an overall picture of what is taking place within our region. I have received emails from those in attendance reiterating their desire to be involved and highlighting their field of interest and requests for service users to be involved in teaching seminars.

A database is now being compiled in line with that of the Mental Health Research Network so that information captured can be forwarded seamlessly.

I have only been here for just over two months, but I have learned the importance of open communication and sharing of information in overcoming the hurdles that face us. I am always happy to share my knowledge and skills with the research network and not just keep it local.

Jacqueline Smart
Service User Development Officer
Heart of England Hub

jacqueline.smart@bsmhft.nhs.uk

Introducing Sue Collinson

by **Sue Collinson**

Sue Collinson is the new Chair of the external Service Users in Research Advisory Board. The advisory board will scrutinise and inform the work of Service Users in Research from an external perspective.

I am incredibly pleased to have been invited to become Chair of the Advisory Board. I hope that the next few years will be both productive and constructive, in terms of helping to enhance the role of service users as researchers.

My own background is in higher education, though with the onset of my mental illness, ten years ago, this became somewhat derailed. After quite a long period of going in and out of hospital and getting on to a therapeutic regime which suited me, I struggled to get back into university work, so I would probably now describe myself as a lapsed academic. At present, I work four days a week as a case worker in the Department of Respiratory Medicine at Homerton University Hospital, and

the practical, commonsense nature of this work seems to suit me, as I have now managed to hold this post for three years.

I have had experience as a service user researcher, which was interesting and at times quite challenging. Overall, I enjoyed this experience, and found it very rewarding. Indirectly, it led me to feel able to apply for my current, case worker post. However, there were also some uncomfortable moments; so I feel that I will be able to bring to the Chair's role the experience of both the positives and the negatives of being a service user researcher. I have recently agreed to participate in another large study, and I will be interested to find out how much has changed, in terms of recruitment, support and training, since I first became a service user researcher. I have had experience of being a service user representative on the steering group of large, multi-site studies and again, since the first time I did this, the process of engaging service users at this level has become much more thoughtful.

The first challenge for both myself and the Associate Director, Professor George Szmukler, is to put together



Dr Sue Collinson, Chair of the Service Users in Research Advisory Board

a lively and committed multi-disciplinary board membership. We are hoping to attract people from a range of backgrounds, and with a wide variety of expertise. First and foremost, however, we would like them to have experience of being a service user.

On a personal level, I have children who persist in presenting me with grandchildren, and a loving husband who has been a wonderful carer, with whom I share a perverse passion for Bob Dylan and baroque opera.

This is Survivor Research - Book Review*

by **Diana Rose**

'This is Survivor Research' marks the coming of age of service user research in mental health. Survivor research in mental health can be traced back to two programmes of work in Non Governmental Organisations (NGOs) – Strategies for Living at the Mental Health Foundation, and User-Focused Monitoring at the Sainsbury Centre for Mental Health. These were established in 1996, the same year that INVOLVE was founded as Consumers in NHS Research. 'This is Survivor Research' demonstrates the huge progress

that has been made since then and the lively nature of the field. The book brings together a wide range of contributions spanning step-by-step advice on how to get started in service user research through to accounts of specific projects, descriptions of personal experiences of research, both positive and negative, as well as more theoretical and philosophical pieces.

We have also included a chapter where we reflect on what brought us to survivor research and you will find that this shows the very different histories that the contributors have. 'This is Survivor Research' is aimed

at a broad audience including mental health service users who want to get started in research, seasoned service user researchers, students, academics and policy makers. The book should also be of interest to consumer researchers and their collaborators in other parts of the health and social care arena as one model of how to develop and progress consumer research in the NHS, social care and public health as well as in the wider research community.

ISBN 978 1 906254 14 8
Published: 2009 PCCS Books

Service Users in Research Interesting Things

Payments and the Involvement Helpline

The MHRN offers payment to service users who get involved in our work. One long-standing problem that many organisations, such as the MHRN face is making payments to people who are on welfare benefits. The rules on receiving payments for people on benefits are very complicated. There are quite complicated rules on what can be classified as a legitimate expense.

INVOLVE is a body which promotes public and patient involvement in the NHS and public health research (www.invo.org.uk). INVOLVE recently commissioned Judy Scott, a well known benefits consultant who has written policies for various national organisations to produce a short guide on how to avoid problems with the benefits agencies when making payments to people on benefits. This document is called 'Payment for involvement in research: helpful benefit rules and systems for avoiding benefit problems' and is available online at http://www.invo.org.uk/All_Publications.asp.

The MHRN has commissioned a comprehensive payments policy. The policy will be a substantial document and will be based on the payments policy document that the National Institute of Mental Health of England (NIMHE) used. The policy will enable the MHRN to help service users and carers who may be on benefits receive payments in a safe way. The policy will be publically available and will be regularly updated.

The MHRN has commissioned a specialist Citizens Advice Bureau service called the Involvement Helpline to help service users and carers who get involved in the MHRN's activities on an ongoing basis deal with any problems that they may have with receiving payments. You can find out more about the helpline at: http://www.mkweb.co.uk/Citizens_Advice/ under the 'benefits advice for social care agencies' section.

The NIHR Research Design Service and RDInfo

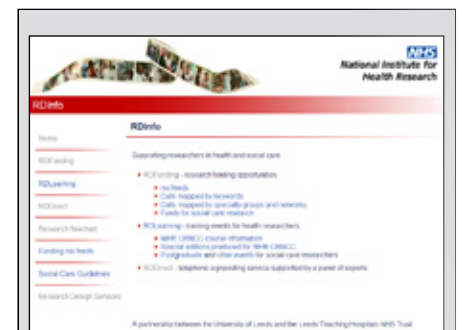
The National Institute of Health Research (NIHR) is the government body that funds the MHRN. As well as funding the MHRN the NIHR funds several other networks which range from supporting research into diabetes to research into medicines for children. You can find out more about NIHR funded bodies at: <http://www.nihr.ac.uk>.

Two of the newest NIHR bodies are the NIHR Research Design Services and NIHR RDInfo.

The NIHR Research Design Services can 'help researchers develop and design high quality research proposals for submission to national, peer-reviewed funding competitions for applied health or social care research.' There are ten Research Design Services across the country. Most of the local Research Design Services are now operational or are just opening. The London Research Design Service was launched on 14th July at City Hall, London. You can find details of

your local Research Design Service at: <http://www.rdinfo.org.uk/RDS/Default.asp>.

RDInfo is a new service that has a telephone helpline which can provide professional advice to researchers with any level of expertise on the design of a research project, possible sources of funding, and more. The website of this service is called RDSDirect (<http://www.rddirect.org.uk/>). The RDS also maintains a service called RDSLearing (<http://www.rdlearning.org.uk/>) which gives details of various courses and training opportunities. The RDS even maintains a blog and a database of organisations that provide funding for healthcare research at (<http://www.rdfunding.org.uk/>).



The RDInfo Website:
www.rdinfo.org.uk

Contact

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Join Service Users in Research by filling in this form

If you would like to have this form in larger type, please contact *Service Users in Research* on 020 7848 0644 or email *Thomas.Kabir@kcl.ac.uk*

Your contact details

1. Name
2. Address
3. Telephone
- May we leave a message on this number?
 Yes No
4. Email address
- We will usually contact you by email.
 Please tick here if you do NOT want to be contacted by email.
5. If you are a representative of an organisation, please tell us the name of the organisation:

More about you

Answering this question will help us make sure we are reaching people with experience of mental health problems from all cultural backgrounds.

1. I would describe myself as:

- | | | |
|--|--|--|
| White British <input type="checkbox"/> | Asian British <input type="checkbox"/> | Mixed – White/Asian <input type="checkbox"/> |
| White Irish <input type="checkbox"/> | Asian Indian <input type="checkbox"/> | |
| White other background (please specify) <input type="checkbox"/> | Asian Pakistani <input type="checkbox"/> | Mixed – other background (please specify) <input type="checkbox"/> |
| | Asian Bangladeshi <input type="checkbox"/> | |
| | Asian other background (please specify) <input type="checkbox"/> | |
| Black British <input type="checkbox"/> | | Other group (please specify) <input type="checkbox"/> |
| Black Caribbean <input type="checkbox"/> | | |
| Black African <input type="checkbox"/> | Chinese <input type="checkbox"/> | I prefer not to answer this question <input type="checkbox"/> |
| Black other background (please specify) <input type="checkbox"/> | Mixed – White/Black Caribbean <input type="checkbox"/> | |
| | Mixed – White/Black African <input type="checkbox"/> | |
| | | |

2. Are you: Male Female

3. How old are you?

- | | | |
|-----------------------------------|--------------------------------|--------------------------------|
| Under 18 <input type="checkbox"/> | 35–44 <input type="checkbox"/> | 65–74 <input type="checkbox"/> |
| 18–24 <input type="checkbox"/> | 45–54 <input type="checkbox"/> | 75+ <input type="checkbox"/> |
| 25–34 <input type="checkbox"/> | 55–64 <input type="checkbox"/> | |

4. Do you have a disability? Yes No

If yes, please describe your disability.

I prefer not to say

Your background

It is useful for us to have some information about your background. Please tick all the boxes that apply.

- I am a user or former user of mental health services.
- I am a carer or friend of someone with a mental health problem.
- I am a mental health or healthcare professional.
- Other. Please specify.....

About research

1. Have you had any experience of taking part in mental health research as a participant? Yes No
2. Have you had any experience of taking part in mental health research in any other way? Yes No
3. Are there any areas of mental health research you are particularly interested in or you think mental health researchers should prioritise?

How did you hear about Service Users in Research?

Data Protection (confidentiality)

All the information that you give to Service Users in Research will remain confidential and will not be passed on to anyone else (including other service users) without your permission. If you are interested in attending training courses and hearing about other MHRN events, you need to give us permission to pass on your contact details. Please tick ONE of the boxes:

- I am happy for Service Users in Research to pass on my contact details to other MHRN staff.
- Service Users in Research must get my permission to pass on my contact details to other MHRN staff.

Signed

Please send the completed form to:

Freepost Plus RSAY-JJZB-BSLG
 MHRN Service Users in Research
 PO77
 Institute of Psychiatry
 16 De Crespigny Park
 London SE5 8AF



Service Users in Research
 Mental Health Research Network