



Service Users in Research
Mental Health Research Network



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Health Research**

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Service Users in Research Bulletin

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This is the fourth bulletin that we send out to members via post or email. In these bulletins we will provide news about user involvement in the NIHR Mental Health Research Network (MHRN) and advertise opportunities for people to get involved in the MHRN and mental health research generally.

If anyone has anything that they would like to be in the bulletin or if you would like to join Service Users in Research then please let us know. You can email us at: mhrnppi@kcl.ac.uk.

To Join Service Users in Research please fill out the membership form which is sent out alongside this email.

These bulletins are additionally placed online at www.mhrn.info



We are on Facebook! To find the Service Users in Research page type in 'Service Users in Research' in the search box at www.facebook.com

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Service Users in Research News

Service Users in Research is the national service user involvement arm of the Mental Health Research Network (MHRN). Since the last bulletin was issued in February we have been very busy. Our webpage's have been completely updated at <http://www.mhrn.info/index/ppi/SUR.html>. An update on the work so far of Service Users in Research has been placed on the website in the section entitled 'meetings and events' and a workplan is available giving full details of the work that we will be undertaking over the next year or so.

2010 MHRN PPI Conference

In March the MHRN held its first annual Public and Patient Involvement conference at Goodenough College in Central London. The event was very well attended and we had over one hundred and sixty people who attended from all over the country.

In the morning Thomas Kabir the coordinator of Service Users in Research spoke about user involvement and Geraldine Mason spoke about the work of FACTOR, the MHRNs involvement arm for carers.



Grant Lewison of Evalumetrics speaking at the 2010 MHRN PPI Conference

The MHRN commissioned a report into the way that the BBC reports on mental health research and Grant Lewison from Evalumetrics presented the results. At the conference Grant Lewison said that the report showed that "compared with the number of people who have a diagnosis of Alzheimer's is over-reported by the BBC and research into depression is under-reported".

Prof. Stefan Priebe from Queen Mary, University of London gave a presentation on his research study entitled 'financial incentives to take medication: ethical and practical issues'. Stefan Priebe's talk stimulated a good deal of debate amongst the delegates.

The study and indeed the principal of paying people to take medication have proved to be quite controversial. The study has been reported by the BBC quite extensively (for example see: <http://news.bbc.co.uk/1/hi/health/8290295.stm>). In the afternoon the conference split into service user and carer themes. The feedback that was received from those that attended was positive.



Stefan Priebe of Queen Mary, University of London, speaking at the 2010 MHRN PPI Conference

A full report on the 2010 MHRN PPI conference together with the presentations of all the speakers has now been placed on the MHRN website at: <http://www.mhrn.info/index/ppi/SUR/meetings-events.html>.

MHRN Scientific Conference

The MHRN held its national scientific conference in Bristol between the 19th and 21st of April. The conference was organised by the MHRN's West Hub. At the conference prizes were given to individuals from each hub that had made an outstanding contribution to the network. A number of people who were service users or carers won prizes this year. The MHRN West Hub User and Carer Steering group organised a workshop entitled 'Perspectives on Service User Involvement in Research'. During the workshop a number of users and academics from research projects from across the country talked about their experiences of working together. An interactive session was held and a report by the West Hub User and Carer Development worker on the session will be made available.

Bridge to Recovery
Findings of A Service User Led Research Project Carried Out By The Leeds Researchers

Questions Addressed In The 'Bridge To Recovery' Project:

- How successful can practice, what role does being part to practice have in the process of recovery from mental health difficulties?
- What activities are available which work for people with mental health problems?
- What are the barriers to engaging in activities and what factors people engage?
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Activities Available In Leeds For People With Mental Health Difficulties

People who took part in the study reported being involved in many activities, showing that within the west area there are many activities available. These include exercise groups, activities, social activities, practical activities, education, leisure and work related activities.

Barriers To Accessing Activities

There are a number of barriers that prevent people from accessing activities, including activities, the most common being mental health difficulties and a lack of confidence and motivation. On a practical level, cost, lack of information and transport issues are also potential barriers.

What Helps People With Mental Health Difficulties Access Activities?

We found that support given to people was an important factor for the people who reported consistently good or what had improved/continued to access activities. Support can be provided in a number of ways: encouragement, information and being there. Support can be provided in a number of ways: encouragement, information and being there. Support can be provided in a number of ways: encouragement, information and being there.

Experiences Of Being Involved In Activities

People have had many positive experiences of being involved in activities. Activities have been shown to help in their recovery from mental health problems. In terms of recovery, activities can help in a number of ways: recovery, information and being there. Support can be provided in a number of ways: encouragement, information and being there.

Points To Take Away

- There are many activities available in Leeds for people with mental health difficulties and engaging in activities can be beneficial to their recovery.
- Support which does not require a receipt of illness is important.
- Encouragement, information and being there are important factors in helping people with mental health difficulties access activities.
- The report should be considered as a starting point for further research and service user led research projects.
- Choice of activity is important; for maximum benefits the activity should please worthwhile to the person accessing it.

For more information about this study or a copy of the report please contact:
Sarah Hardy
Clinical Studies Officer
West Yorkshire Mental Health & B&C Consortium
20 May's House, 20 May's Road, Leeds LS17 7LQ
Tel: 0113 2623287 or 0113 2623288
www.wyhmhrcdconsortium.nhs.uk

A poster competition was held and this year out of over fifty posters the top prize went to a poster on a service user led research project entitled 'Bridge to Recovery' by Sarah Hardy. The research project itself was supported by the West Yorkshire Mental Health Consortium.

'Bridge to Recovery' poster by Sarah Hardy and the West Yorkshire Mental Health Consortium. This poster that won first prize for the best poster at the 2010 MHRN Scientific Conference.

The MHRN makes an award each year to research project that it has adopted over the last year with the best level of user and carer involvement. This year the award went to Toby Brandon of Northumbria University for his study looking at care coordination pathways for people who use mental health services in North Tyneside.

Useful Information

What people can earn whilst on Benefits

The benefits system is complicated. It's very complicated. It is often hard to know what service users, carers, and others, can earn for carrying out work whilst on benefits. To

help service users, researchers, and others find out what people can and cannot earn whilst on benefits.

The MHRN has produced two comprehensive documents on involvement work and benefits which should answer most commonly asked questions. These documents can be downloaded from:

<http://www.mhrn.info/index/ppi/SUR/Payment-information.html>

These documents are fully up to date and were written by Judy Scott a well known benefits consultant that has written the MHRN model payment policy for users and carers. These documents are now some of the most comprehensive, freely available, sources of information on the benefits rules relating to doing involvement work in the country. The documents will be kept updated on an annual basis.

Action on Postpartum Psychosis (APP)



Postpartum psychosis is a term that covers a group of mental illnesses with the sudden onset of psychotic symptoms following childbirth. A network has been formed called Action on Postpartum Psychosis whose aims are:

- To provide up to date research information to women who have experienced PP and their families.
- To facilitate research into all aspects of postpartum psychosis.
- To increase awareness of postpartum psychosis – its symptoms, management and impact – among health professionals and the general public.

APP produces regular newsletters which can be downloaded from their website. The website of the network together with details on how to join can be found at:

<http://www.app-network.org/>

The January 2010 edition of their newsletter can be downloaded at <http://www.app-network.org/wp-content/uploads/2010/02/appnewsletter201>

Involvement Opportunities

GAP Study

Some researchers based at the Institute of Psychiatry in South London are looking for two to three service users with experience of psychosis to get involved **as advisors** to a study entitled GAP (Genetics and Psychotic illness).



The GAP research team at the Institute of Psychiatry

Travel expenses will be paid in addition to small participation fee. Those interested would need to live within easy reach of London.

If you would like to get involved in the project then please contact Thomas Kabir by emailing:

Thomas.kabir@kcl.ac.uk

The text below just explains a little more about what the GAP study is all about:

“In our research project we are interested in identifying what the main risk factors that predispose to psychosis are.

In particular, we want to know whether there are any genes that increase the risk of developing a psychotic disorder, either alone or by interacting with environmental factors such as stress, cannabis, and infections. Part of the reason why some people become ill may lay in genetic differences between people, in the same way that we are different in the colour of our eyes, hair etc. To achieve this, we will compare the genetic make-up of people with a diagnosis of psychosis with the make-up of people with similar characteristics but no history of mental health problems.

We also aim to establish whether some genes might influence the course of the illness and response to medication. Some patients experience an improvement of their psychiatric symptoms when they are treated with medications, whereas others do not do so well and/or experience severe side-effects. Therefore we aim to look at how genes can influence individual differences in response to drug treatment so that we may be able to choose better drugs for each person”

You can find out more about the GAP study at:

<http://www.iop.kcl.ac.uk/departments/?locator=912>

MHRN Anxiety Clinical Research Group

The MHRN funds groups of researchers, users, and carers, to produce research proposals and then to apply to potential funders. These groups are called clinical research groups (or CRGs).

The Anxiety Clinical Research Group is a small group of GPs and academics from three cities (Bristol, London and Manchester) with an interest in anxiety and primary care. They believe that this area is under-researched, and so have been granted funding for two years, during which they are to come up with research proposals for this area.

So far the group has had meetings where they have talked generally about ideas for research and come up with a few thoughts to pursue. They are keen to have some

service user input to discussions and have some funding to cover time and travel expenses.

The role would involve coming to three two-hour meetings in London. It might in addition involve some email correspondence/ discussion. Discussions are fairly fast paced, so the person would need to be ready for this, although, of course, it's always okay to ask for explanations as we go along.

Payment will be made to users to take part in the group together with reasonable travel/subsistence payments. If you are interested please contact Thomas Kabir at Thomas.kabir@kcl.ac.uk saying a little about yourself and saying what made you interested in taking part in the Anxiety CRG.

Improving the Lives of Patients: Significant Developments in Schizophrenia Care

Mental Health Retrosight Delphi Survey

We are carrying out an international research project that will assess the translation of mental health and schizophrenia research into clinical application and community practice. The aim of the project is to better understand the origins of knowledge in mental health care and to improve the translation of research into treatments and medical practice.

As part of this project, we would like to invite stakeholders to help identify key advances in schizophrenia care. These findings will enable us to select case-studies for this project. The aim is not to come up with a definitive list of advances but to help us shortlist those considered most relevant to practice and the research study. All responses will be treated as confidential and will not be published individually. A link to an online questionnaire can be found here:

<https://spreadsheets.google.com/viewform?formkey=dFExek1xUIVRMXVDOTI1UFRncm9sMGc6MQ>

It will take approximately five minutes to complete.

The project is part of a collaborative initiative, SOS for Mental Health, which is led by the Graham Boeckh Foundation and RAND Europe and supported by several international public and not-for-profit partners, including the US National Institutes of Mental Health, the Canadian Institutes of Health Research and the National Institutes for Health Research in England.

We would be grateful if you could respond by April 27th

Thank you for your help.
Steve Wooding
RAND Europe

www.rand.org/randeuropa

Events

MDF Annual Conference, Beating Bipolar 5th June 2010, Birmingham

The Manic Depression Fellowship (MDF) is holding its annual conference on the 5th of June in Birmingham. The conference is entitled 'Beating Bipolar'. The registration fee for this event is £20 for members of the MDF and £40 for non members. A full programme for the conference can be found online at: <http://www.mdf.org.uk/>