



Service Users in Research

Mental Health Research Network



National Institute for Health Research

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Service Users in Research Bulletin

Issue Seven: October 2010

This is the seventh edition of the bulletin that we send out to members via post or email. In these bulletins we 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. You can also join online at:

<http://www.mhrn.info/pages/join-service-users-in-research-online.html>

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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Who Decides the Definition of a Good Outcome?

Who decides the definition of a 'good outcome'?

Researchers routinely use a variety of standard questionnaires to assess people's mental health, their symptoms, side effects of medication and people's quality of life. The questionnaires are used in studies to gauge the success of new treatments and packages of care, and also in evaluations that may determine future funding of NHS services. But does the concept of success – a 'good outcome' – differ between professionals and people who have experience of mental health problems?

The Mental Health Research Network commissioned a team led by Dr Mike Crawford at Imperial College London to find out what people who use services for mood disorders and psychosis think of questionnaires designed to assess their state-of-being, and whether, in their opinion, they do the job they are supposed to do accurately.

In the world of research, the questionnaires are called 'measures' or 'scales' and are either completed by a professional who interviews an individual, or completed by the individual themselves. They are mostly designed by researchers and aim to measure change or improvement, or set out to give an insight into someone's mental health. But the project showed that a professional's view of what constitutes a 'good outcome' doesn't always tally with the opinion of the individual whose life is being assessed.

Two expert panels of people with experience of mental health problems discussed and analysed a sample of two-dozen questionnaires that are commonly used in research studies, and increasingly by mental health professionals working with people with psychosis and people with mood disorders. The 25 people on the panels were recruited through the Bipolar Organisation, the Mental Health Foundation, the Mental Health Research Network, MIND, Rethink and the Service User Research Enterprise at the Institute of Psychiatry, King's College London. All volunteers had personal experience of mood disorders and/or psychosis.

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Researchers routinely use a variety of standard questionnaires to assess people's mental health, their symptoms, side effects of medication and quality of life. Questionnaires are used in studies to gauge the success of new treatments and packages of care, and also in evaluations that may determine future funding of NHS services. The Mental Health Research Network tasked a team led by Dr Mike Crawford at Imperial College London to find out what people who use services for mood disorders and psychosis think of questionnaires designed to assess their state-of-being, and whether, in their opinion, they do the job they are supposed to do accurately.

This project had a high level of patient involvement throughout; Dr. Diana Rose, a senior lecturer in user-led research worked

closely with Mike Crawford and several organisations including the MHRN, MIND, and Rethink recruited patients for the two expert panels. Two expert panels of people with experience of mental health problems discussed and analysed a sample of two-dozen questionnaires commonly used in research studies, and increasingly by mental health professionals working with people with psychosis and people with mood disorders.

'There is widespread agreement that the development of effective treatments for health-related problems requires active input from people who use services,' said Mike Crawford. 'One of the areas where active service user involvement is essential is in deciding which measures should be used to examine the effectiveness of new treatments. **Funding of health services is often linked to 'outcomes'** – so the choice of what constitutes a good outcome and way of measuring it is important for health services as well as trials and studies. **We believe it is essential that service user views are taken into account when outcome measures are selected,**' he said. **The results of this work showed that some of the most widely used outcome measures are those least valued from a patient point of view.** The Health of the Nation Outcome Scale is an example of such a measure. The results of the project are of potentially huge significance to the NHS and patients. Without user involvement this work could never have taken place.

An English plain English summary of the findings of the project has been produced for the MHRN by a journalist called Jane Smith. A paper reporting the full findings of the study has also been submitted for publication.

This summary is sent alongside this bulletin and is also available to download at:

http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/mhrn_A4_news_who_decides_a_good_outcome.pdf

National Institute of Health Research (NIHR) Comprehensive Spending Review Statement

Every few years the government is obliged to carry out a review of all government spending. This is called a 'comprehensive spending review'. The MHRN is funded through the NIHR. The following statement has been placed on the NIHR website (www.nihr.ac.uk).

"The Government announced the outcome of the [Spending Review on 20 October 2010](#).

The Department of Health, through the NIHR and the DH Policy Research Programme, will increase spending on health research in real-terms over the spending review period. From this, additional funding will be made available so the NIHR can lead the way in pulling basic scientific advances through into benefits for patients and the economy.

The Government also announced that, to complement this increase in health research funding through the NIHR, the budget for the Medical Research Council will be maintained in real terms. Finally, it was announced that the Department of Health, through the NIHR, will provide £220 million of capital funding for the UK Centre for Medical Research and Innovation (UKCMRI).

Professor Dame Sally Davies, Director General for R&D at the Department of Health said:

"This is a great settlement. The Government has again confirmed its support for health research in the strongest way possible - by increasing the budget for NIHR above and beyond the rate of inflation for the next four years. This is an explicit recognition of the key role played by health research in driving improvements in the health of the population and in the economic growth of our country. It is also a ringing endorsement of the place that NIHR now occupies in the landscape of the UK - thanks to the hard work of all of you. Now we look forward to the challenge of pulling through basic science into benefits for patients."

20 October 2010"

Service User Research Job Opportunity

Researchers at the University of Sheffield are seeking to recruit a Service User Researcher to work part time on a research project studying ways of improving NHS care for people with longer-term depression. For more information please see the IQuESTS website:

<http://clahrc-sy.nihr.ac.uk/theme-iquests-introduction.html>

Self-management
of longer-term
depression



Do you have experience of using mental health services?

Researchers from the University of Sheffield are carrying out research to find out how to improve the way the NHS helps people with longer term depression in South Yorkshire.


We are looking for a Service User Researcher to join our existing research team to contribute to the ongoing implementation of the project. The post holder will be primarily involved in research which aims to explore service users' experience of self-management in long-term depression.

The service user will be appointed to work for approximately 52 days (it is expected that the majority of the work will take place in the initial 6-8 months) and will be paid an hourly rate.

Interested? Email Anna Thake at a.thake@sheffield.ac.uk or phone her on 0114 222 6387 to find out more.

Sheffield Health and Social Care
NHS Foundation Trust


The University
Of
Sheffield



A job description and person specification for this position has been sent alongside this bulletin. **The deadline for completed applications is November 30th 2010.**

Understanding Bipolar Disorder Report

Spectrum Centre for Mental Health Research, Lancaster University

A tendency to extreme moods can have significant benefits as well as sometimes leading to problems, says a report published by the British Psychological Society's Division of Clinical Psychology.

The report, **Understanding Bipolar Disorder**, is the result of an in-depth review of recent research undertaken by a team of leading university academics and clinical psychologists, led by Professor Steven Jones of the Spectrum Centre for Mental Health Research at Lancaster University.

- ❖ Between one and two percent of the population have a diagnosis of bipolar disorder. This diagnosis is made when someone experiences periods of extreme mood (highs and lows).
- ❖ Biases in previous research had led to an exaggerated emphasis on the difficulties at the expense of the potential positive aspects, such as increased creativity. The report suggests that some people's experiences are more extreme forms of the mood variation we all experience, can result from life experiences rather than always only brain chemistry, and it is not always helpful to think of them as an 'illness'.
- ❖ In addition to this, much of the research in bipolar is on people in mental health services and so is very biased since it does not take into account those people who have positive outcomes.
- ❖ A psychological perspective is lacking in many people's experience of mental health care for bipolar disorder with the default therapy model being biological and based on medication. What is lacking is a shared psychological understanding of individual experiences.

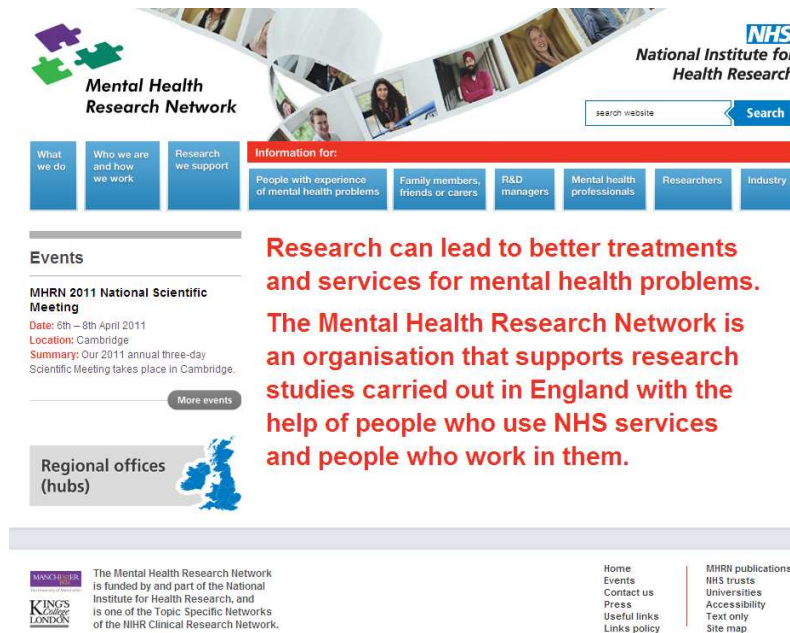
Professor Richard Bentall, Professor of Clinical Psychology at the University of Bangor, says:

"This is a timely and clearly written report, which very neatly summarises our current understanding of bipolar disorder in a way that is authoritative, but very accessible to service users, carers and the general public. It will do much to promote a better understanding of a condition that can cause a great deal of distress and disability to sufferers and their families."

This report provides an overview of the current state of psychological knowledge about why some people tend to experience periods of extreme mood and what can help. By publishing this report it is hoped that it will increase access to psychological treatments, challenge the idea that service users must always accept one particular (usually biological) view of their problem, provide a resource for front-line workers and service users and influence the thinking of commissioners, managers and opinion formers.

"I hope that this report will prove to be a useful resource for people with experience of bipolar disorder, clinicians, academics and service managers. It aims to provide accessible information on the range and variety of bipolar experiences and on the importance of developing services which offer a genuine choice of recovery focussed interventions for people who have such experiences" Steve Jones.

Understanding Bipolar Disorder can be downloaded from the British Psychological Society's website www.bps.org.uk/dcp without charge until **31 October 2010** or after that www.understandingbipolar.co.uk .



The MHRN website has been completely re-launched and updated. Please do visit it at www.mhrn.info and let us know what you think. The tab entitled 'people with experience of mental health problems' under the red bar on the front page of the website is the part of the website where all the information about Service Users in Research is placed.

These pages also contain the personal accounts of two people that have got involved in the MHRN.

You can now also join Service Users in Research online by filling out a form at:

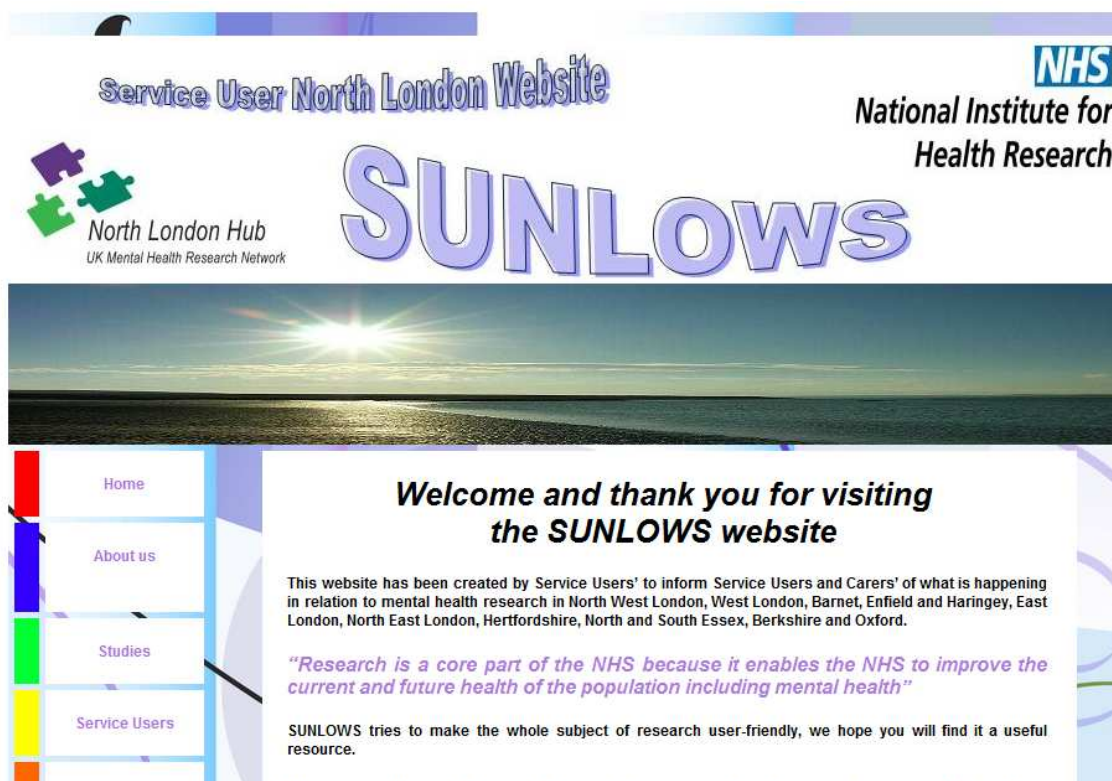
<http://www.mhrn.info/pages/join-service-users-in-research-online.html>



All of the publications that the MHRN produces (including copies of past Bulletins) are also available on the website at:

<http://www.mhrn.info/pages/publications.html>

Re-launched SUNLOWS Website



www.sunlows.org.uk

The SUNLOWS website was originally constructed by service users from the area covered by the MHRNs North London hub. The website has recently been completely revised and the result is impressive.

The website aims to let people know "what is happening in relation to mental health research in North West London, West London, Barnet, Enfield and Haringey, East London, North East London, Hertfordshire, North and South Essex, Berkshire and Oxford". The new website has a completely up to date 'news and event's page, plain English information on local research studies, and lots of information about how to get involved in the North London hub and the MHRN.

Re-launched People in Research Website

People in Research
Opportunities for public involvement in clinical research

INVOLVE NHS National Institute for Health Research

Home Find out about involvement Get involved Find people to involve About this site

Text size: A | A | A Print this page

Find out about involvement
For members of the public who would like to find out more about public involvement in research.
Popular topics
1. [What is public involvement?](#)
2. [What can I do?](#)
3. [This is my first time getting involved](#)
[Find out about involvement](#) contains further information.

Get involved
Database of Opportunities for members of the public to get involved in research.
Latest opportunities
• [NIHR Call for members of panels and committees](#)
Programme Grants for Applied Research Panel Members & Research for Patient Benefit Committee Members
• [Mental Health Research Network](#)
Opportunities for mental health service users to be involved in research projects.

Find people to involve
For researchers who want to find members of the public to get involved in their research work.
You can advertise your public involvement opportunity to members of the public on this site.
There are three simple steps:
1. [Login](#) (or [register](#) for free)
2. [Read our guidelines](#)
3. Complete [this form](#) to post your advertisement

Accessibility Terms of Use and Privacy Feedback

Designed and managed by Minervation

INVOLVE (www.invo.org.uk) have re-launched the People in Research website. The website is designed to be something of a central place where people can find out about how to get involved in medical research and advertise involvement opportunities. Some of the latest opportunities advertised on the website include an NIHR call for lay members for RfPB panels and members for NIHR Programme Grants for Applied Research panels. The MHRN South London and South East hub also has opportunities advertised on the website.

<http://www.peopleinresearch.org/>

Mental Health in the News

Stress Levels 'leading to more time off work':

<http://www.bbc.co.uk/news/business-11617292>

Not depressed, just sad, lonely or unhappy:

<http://www.bbc.co.uk/news/magazine-11431720>

Rewriting the rulebook on mental illness:

"Defining what is, and what isn't, mental illness is actually quite a hard thing to do ..."
You can read more about the way that mental disorders are being reclassified in the following article:

http://www.bbc.co.uk/blogs/today/tomfeilden/2010/07/rewriting_the_rulebook_on_ment.html

The article also has a podcast of Til Wykes (Professor of Clinical Psychology at Kings College London) speaking on the topic.

Patient/ Public Members sought for Research Capability Programme Pilot Health Research Support Service

The National Institute for Health Research (NIHR) Research Capability Programme (RCP) is establishing a Health Research Support Service (HRSS) to enable research to achieve its full potential as a “core” activity for healthcare alongside other uses of NHS data that lead to improvements in the quality and safety of care. Initially it will test this capability through the Pilot HRSS.

The Pilot HRSS is establishing a PPI Co-ordination Group to promote public participation in health research from a local, regional and national lay perspective.

Lay members will be required to:

- Attend monthly meetings
- Read meeting papers in advance
- Contribute to discussions
- Provide feedback on documents
- Assist the Pilot HRSS in understanding the perspectives of patients and the public
- Consider ways in which wider patient and public involvement can be achieved
- Maintain confidentiality where appropriate
- Declare any conflict of interest where appropriate
- Identify any personal needs for training or support

Additional Considerations:

Some travel may be required to attend meetings and to undertake training
Lay members are appointed on the basis of their ability to provide knowledge and expertise that will be valuable in assisting the Pilot HRSS to deliver its key objectives.
Appointment is made on an individual basis and not as representatives of a particular group or organisation.

Role Requirements/Person Specification

Experience of health services, or research as a patient, carer or advocate, or as a representative of patients and carers.
The ability to listen to others, summarise issues, and express views objectively with a constructive purpose and strategic overview.
Understand the role of health and social care research as a core part of the patient journey
Have a working knowledge of data protection law with regard to patient confidentiality.

Re-imburement

An honorarium will be paid according to the NIHR payment and re-imburement rates for PPI.
All out of pocket expenses will be covered according to Department of Health policy.

For an information pack please contact Paul Tavares, Programme Support Officer
Telephone: 0207 210 6881
Email: paul.tavares@dh.gsi.gov.uk

Address: Research Capability Programme
Room A202
Richmond House
79, Whitehall
London SW1A 2NS

Closing date for application is Friday November 5th 2010.



South London & South East Hub
Mental Health Research Network

Exciting Involvement Opportunities

We would like to hear from you if you can answer yes to any of the following

- Have you experienced a mental health problem now or in the past?
- Are you a current or former user of mental health services?
- Do you think it is important to research new treatments and therapies for mental health problems?
- Do you live in South London or the South East of England?

We support mental health research projects in South London and the South East. We are hoping to increase the amount of research conducted in this area, in addition we are hoping to recruit people who have experience of mental health problems and of using mental health services who are interested in getting involved.

If you would like more information on what we do or how you can get involved in local mental research projects then please get in touch.

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