



Service Users in Research
Mental Health Research Network



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Health Research**

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Service Users in Research Bulletin

Issue Twenty: December 2011

This is the twentieth edition of the bulletin that we send out to members via post or email. In these bulletins we provide news about mental health research and advertise user involvement opportunities and events in the NIHR Mental Health Research Network (MHRN). We also advertise opportunities for people to get involved in mental health research with other organisations.

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

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Happy Christmas and New Year everyone!

Please note that for events organised by MHRN hubs or local NHS trusts, travel expenses are usually only able to be offered to people living in the area covered by that hub or NHS trust. Please always check beforehand.

Study Title: On Becoming a Service User Researcher: An investigation of the professional identity roles and experiences of service users working in mental health research in the UK.

Participant Information sheet v1.4 30.8.2011

You are being invited to take part in a study looking into the roles people who have used mental health services play in mental health research. **You have not been personally chosen to receive this invitation.** Instead, because there is no way to know which people involved in mental health research have used services we are using electronic 'snowballing' to recruit our sample. We have asked people who receive the information about the study to circulate it through their professional networks so we reach as many people as possible.

You are eligible to complete the questionnaire **if you identify as someone who has used mental health services** including public or private psychiatry or psychology services, community mental health teams or inpatient care **AND are involved in mental health research as other than a participant.**

If this is **not you**, thank you for reading this far. Please forward the email and survey link through your networks as appropriate. If **this is you** and you are interested, please read on to learn more about why the study is being done and by whom and what will happen to the results so you can decide whether you wish to complete the questionnaire.

The study is being conducted because although user involvement in research is widely promoted, little is known about how people with experience using mental health services are involved in research activities. We do not know what roles service users play and how service use influences research activities. Understanding this is important to help in development of best practice models.

The study is being conducted by a team from Imperial College London and the North London Hub of the Mental Health Research Network. It is co-led by a service user researcher (Jenny Trite). The study has been approved by the Fulham Research Ethics Committee (Ref: 11/LO/1480). Dr Tim Weaver is named as the chief investigator.

Taking part involves completion of a questionnaire on line. If you decide to take part you can choose to complete all or some of the questions.

The questionnaire asks about the roles you play in research, the types of activity you undertake and how you experience your involvement. Some questions relate to how much time you spend on research activity and any reimbursement you receive. We also ask about factors that influence your participation in research and whether your involvement in research has influenced your use of services. We ask you to tell us as much as you feel comfortable about your service use but do not ask any details about your mental health. If any identifying information is inadvertently provided, it will be deleted immediately. Completion of the questionnaire will imply your consent to analysis of the information you provide and inclusion of your anonymised responses in any reports of the research.

Your responses are anonymous (unless you choose to provide your name and contact details) and will be treated in strictest confidence. No person outside the research team will have access to any data at individual level.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator (Dr Tim Weaver on t.weaver@imperial.ac.uk). The normal National Health Service complaint mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial College Joint Research Office.

Findings will be available on the North London Hub service user website: SUNLWS www.sunlows.org.uk in due course (anticipated May 2011).

No funding has been sought or received for the conduct of this study.

For further information please contact j.trite@imperial.ac.uk, t.weaver@imperial.ac.uk or susan.patterson@imperial.ac.uk or telephone Sue on 07939 925 104.

On Becoming a Service User Researcher: an investigation of the professional identity roles and experiences of service users working in mental health research in the UK

Dear Colleague,

A team of researchers, co-led by a service user are seeking your support in a study designed to understand the roles service users play in research. This invitation includes a link to a survey questionnaire for people involved in mental health research who have also used mental health services.

If this describes you, please take the time to read the participant information sheet on p3-4 of this Bulletin and follow the link (or copy it to your internet browser) to complete the questionnaire: <https://www.surveymonkey.com/s/DRKNX25>

If not please forward this Bulletin to contacts who might be eligible to participate or able to distribute it further. It is important that we reach as many potential participants as possible. Your assistance with this is much appreciated.

The study, approved by the Fulham Research Ethics Committee (Ref: 11/LO/1480), is being conducted by researchers from Imperial College London with support from the North London Hub of the Mental Health Research Network. The study is co-led by a service user researcher and is overseen by a working group of service users.

All responses to the survey are anonymous and will be treated with the strictest confidence. **We do not ask for any identifying information.**

If you would like further information please feel free to contact us.

Sue Patterson: susan.patterson@imperial.ac.uk

Tim Weaver: t.weaver@imperial.ac.uk (Chief Investigator)

Jenny Trite: j.trite@imperial.ac.uk (Chair Service User Working Group).

Many thanks

Sue Patterson, on Behalf of the team



Mental Health
Research Network

SUNLWS

PSYCHIATRIC MEDICATION ?

Your Questions Answered

Why it is prescribed? What is the right dose and how do I get it? Why don't some patients take it? What does it feel like? How do carers feel about it being given to their loved ones? Do you want to know research evidence from a variety of professional and service-user perspectives?

This is a FREE event for mental health service-users (including carers) who are interested in research undertaken by the Mental Health Research Network in London, the South East, and Oxfordshire.

**Please contact Stu Morris for a place at this event:
slsehub@kcl.ac.uk or Tel: 020 7848 5015**

There are limited places so book now to avoid disappointment!

www.sunlows.org.uk

SUNLWS Tries to make the whole subject of research user friendly.



**National Institute for
Health Research**

Speakers to include:

- Prof Peter Tyrer
- Prof Lewis Wolpert
- Dr Joanna Moncrieff
- Prof Hugh Middleton
- Isabel Clarke



**4th January 2012
Kings College London
Waterloo Campus
Franklin Wilkins Building**

The Mental Health Research Network is part of the National Institute for Health Research and supports studies in England.

East Midlands & South Yorkshire MHRN Hub Annual Research Meeting

RESEARCH INTO PRACTICE THROUGH THE MENTAL HEALTH RESEARCH NETWORK

Friday 9th March 2012
(9am – 4.30pm)

The Nottingham Belfry Hotel, Mellors Way, Nottingham. NG8
6PY.
(Just off M1, Junction 26)



Confirmed Speakers:

Professor Graham Thornicroft, Institute of Psychiatry
Professor Jenny Shaw, Offender Health Research Network
Professor Mike Cooke, Nottinghamshire Healthcare NHS Trust
Professor Richard Morriss, University of Nottingham
Professor Nav Kapur, University of Manchester
Professor Glenys Parry, University of Sheffield
Professor Tim Kendall, Sheffield Health & Social Care
Dr Mike Harris, Nottinghamshire Healthcare NHS Trust
Dr Ronnie Browne, Lincolnshire Partnership NHS Foundation Trust
Keith Waters, Derbyshire Healthcare NHS Foundation Trust

If you would like any further information, or to secure a place at the conference, please contact:

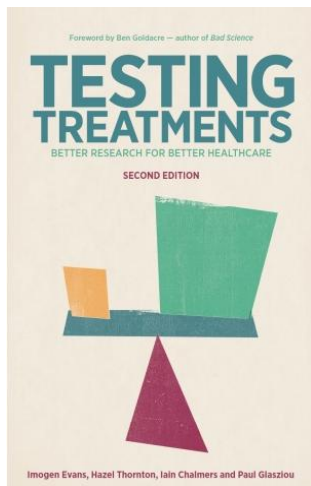
Joanne Greenwood

Institute of Mental Health, Sir Colin Campbell Building, Triumph Road, Nottingham NG7 2TU

 joanne.greenwood@nottshc.nhs.uk  0115 82 31282

Book Reviewer Wanted

Would anyone like to review these books for the January edition of the Bulletin?

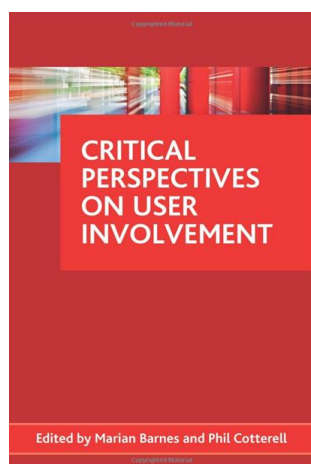


Testing Treatments: Better Research for Better Healthcare

By Imogen Evans, Hazel Thornton, Iain Chalmers, and Paul Glasziou

Published by Pinter & Martin Ltd (RRP £9.99)

ISBN: 1905177488



Critical Perspectives on User Involvement

Edited by Marian Barnes and Phil Cotterell

Published by Policy Press (RRP £26.99)

ISBN: 1847427502

If you would like to review these (or other) book for us then please let us know. The book needs to be on a mental health topic (ideally vaguely related to research, mental health services etc). If you do have any ideas of a book that you would like to review for the Bulletin then please let us know. If you write a review for us, we will buy the book for you, and we will give you a £25 Amazon voucher as a token of our appreciation. Please email mhrnppi@kcl.ac.uk if you have any suggestions.

The Spectrum Centre – Lancaster University: ‘Factors helpful to functioning in Bipolar Disorder: A Qualitative Study’.

The Spectrum Centre at Lancaster University is dedicated to research into Bipolar Disorder and associated conditions. We are developing a range of psychological approaches to help people with various aspects of Bipolar Disorder and conducting research into the psychology of Bipolar Disorder. We are currently recruiting participants to the following study: ‘Factors helpful to functioning in Bipolar Disorder: A Qualitative Study’.

Because of the specific focus of the study we are looking for people who are currently in full-time employment or the full-time equivalent of work/study/caring role. Participation in the study would involve answering some questions about mood/symptoms/other experiences, some brief questionnaires and an exploratory interview about factors which you think have helped you to function well with bipolar disorder.

These interviews are designed to be conducted by telephone but if you live in the North West there is the option of face-to-face interviews if you would prefer. If you are interested in finding out more about the study then please contact Kirsty Stevenson-Turner (Service User Researcher) on 01524 592569 or k.stevenson@lancaster.ac.uk or Alison Beck (Senior Research Associate) on 01524 93171 or a.beck@lancaster.ac.uk

Mental Health Research in the News

The strange and curious history of lobotomy



Its 75 years since the first lobotomy was performed in the US. Lobotomies came to be seen as something of a ‘miracle cure’ in the US and it wasn’t long before the operation was performed in the UK. At the peak of its popularity it is estimated that around 1000 lobotomies a year were performed here in the UK.

It has been said that roughly a third of people that had a lobotomy reported some improvement. For others the results were quite disastrous.

One of the most famous people to have a lobotomy was Rosemary Kennedy, the sister of President John F Kennedy.

After the operation Rosemary Kennedy was left with an ‘infantile mentality — staring blankly

at walls for hours. Her speech became unintelligible'. The BBC has put a really good article about the history of the lobotomy on their website.



You can access the article by clicking [here](#). There was a fascinating programme on Radio 4 recently entitled 'The Lobotomists' which really goes into the history of the operation and those that carried them out. The programme is still available on BBC iPlayer and can be listened to by clicking [here](#)

The Wellcome Trust has produced a short, but informative article about lobotomies (and brain surgery for mental health problems) which you can access by clicking [here](#)

Self-harm practiced by one in 12 adolescents, study reveals

“One in 12 adolescents self-harm but most will stop in early adulthood, according to a study of the scale of the problem and the reasons why young people want to hurt themselves”. This is the conclusion of a study that was recently published in the Lancet. The Guardian newspaper ran an article about the findings of the study which can be accessed by clicking [here](#)

You can read the abstract of the original Lancet article by clicking [here](#). The Lancet has also produced quite an interesting podcast about the research. You can download the podcast by clicking [here](#)

313 Drugs in Development for Mental illness in the US in 2010

As the title suggests the pharmaceutical sector were developing around 313 medicines in 2010 for the treatment of mental illness. Frankly, I was surprised by this. I had thought that the figure would be rather lower.

The data was put together by the Pharmaceutical Research and Manufacturers of America (PhRMA) association (<http://www.phrma.org/>). The report revealed that in 2010 around 90 drugs were in development for the treatment of dementias, 71 for depression, and 54 for schizophrenia. PhRMA has produced quite an accessible report on what the pharmaceutical sector in the US was up to in 2010 regarding drug development for mental illness.

The report can be downloaded [here](#).

As a little aside, it's been reported that one in ten people in the US took “at least one mental health drug in 2010”. You can read this article by clicking [here](#)





Mental Health
Research Network



National Institute for
Health Research

MHRN 2012 National Scientific Meeting Birmingham, UK



25-27 April 2012



Bookings open early
December with Early Bird Rate.
Register your interest now at
heartofenglandhub@bsmhft.nhs.uk



VIEWPOINT is a National Survey of Mental Health Service User's experiences of stigma and discrimination.

In five different areas of England, over 500 people in 2008 and 1000 people in 2009 took part in a telephone interview during which they were asked about their experiences in the 12 months prior to interview.

There were 3 main sections of the interview, asking about experiences of:

Negative discrimination – instances where participants felt that they had been treated unfairly by others because of their mental health diagnosis.

Anticipated discrimination – instances in which participants had stopped themselves from doing something because they feared discrimination.

Positive discrimination – instances in which participants felt they had been treated more favourably because of their mental illness.

Why we did this study

In 2009, a national campaign called Time to Change was launched to try and improve the public's attitude and behaviour towards people with a mental health problem. One of the main aims of the campaign was to reduce discrimination and unfair treatment towards people with a mental health diagnosis.

To find out whether the campaign is working, we are carrying out large surveys asking about people's experiences.

Results

In 2008, only 9 people in every 100 had not experienced discrimination in any of the areas of their lives that we asked about. In 2009, there was a slight improvement with 13 people in 100 saying that they had not experienced discrimination. The five most common areas in which people had experienced discrimination in 2009 were:

- Nearly half of people asked said that they had felt shunned by others (48%);
- Nearly half said that they had been treated unfairly by friends (47%)
- 4 out of every 10 people said that had been treated unfairly by their family (40%)
- Nearly 1 in 3 people had felt disrespected by mental health staff (32%)
- Nearly 1 in 4 people had been treated unfairly in relation to their physical health (24%)

In 2008, 43 in 100 people said they had experienced discrimination in their social lives – in 2009 this fell to 25 in 100.

- In 2008, 31 in 100 people said they had experienced discrimination in dating – in 2009 this fell to 18 in 100

- In 2008, 53 in 100 people said they had experienced discrimination from their friends – in 2009 this fell to 39 in 100
- In 2008, 24 in 100 people said that had experienced discrimination in finding a job – in 2009 in 100.

In 2008, nearly eight out of ten people who took part felt they had to hide their mental health diagnosis from other people. In 2009 this had dropped slightly, but still 73 in 100 people felt that they had to hide their diagnosis. More positively, the number of people who stopped themselves from applying for a job fell from about 65 in 100 to about 45 in 100. Just over 8 in out of 10 people asked in 2009 said they had experienced some kind of better treatment from others because of their mental health diagnosis.

What do these results mean?

The 2009 survey shows that people are still experiencing discrimination very often in their day-to-day lives. The most common sources of unfair treatment are family, friends and mental health professionals. Despite discrimination still being very common, the survey suggests that things might be improving.

What now?

We will continue to ask people about their experiences of discrimination over the next few years. This will help us to see whether these improvements continue and findings from this study will help us learn how to best improve this.

If you would like to get involved in the Time to Change campaign, visit the website at <http://www.time-to-change.org.uk>

**Fiona Stanton is a Clinical Studies Officer with the MHRN's North East hub. This article was originally published in the MHRN North East hub's newsletter and is reproduced here by kind permission.*