



Service Users in Research
Mental Health Research Network



**National Institute for
Health Research**

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Service Users in Research Bulletin

Issue Seventeen: September 2011

This is the seventeenth 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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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.

SUNLOWS Seminars 2011

The service-user consultants attached to the North London Hub of the Mental Health Research Network are organising a series of seminars showcasing some of the most interesting and up-to-date mental health research. The seminars aim to inform service-users and carers in North London, West London, North East London, Central and East London, Essex, Hertfordshire, Berkshire, and Oxfordshire (all regions covered by the Hub) about the latest research being undertaken in mental health. We will provide both professional and service-user perspectives on the following topics:

Friday 30th September 2011 - 2pm to 4.30pm

Personalisation Forum Group

Personalisation means ensuring that people have wider choice in how their needs are met. Members of the personalisation forum group, based in Doncaster, will present on this topic. They are a service user group run by, and for, people with mental health difficulties. They are committed to continue working together to reduce stigma and to promote recovery, independence and social inclusion. They are the winners of the 2010 Great Yorkshire and Humberside care awards in the category of 'Putting People First'.

Friday 28th October 2011- 2pm to 4.30pm

An investigation of the impact of introducing Individual Placement and Support in a mental health catchment area

Speakers: Bryn Lloyd-Evans (UCL), the former study lead researcher (Camden and Islington NHS Foundation Trust), along with David Hindle (service user researcher). Employment rates of people with severe mental health issues are very low and have fallen over the past few decades. Individual Placement and Support (IPS) helps people find and keep jobs. Studies in the USA have shown that IPS is successful in increasing employment, but UK studies suggest possible difficulties in finding people willing to use the scheme. This seminar will discuss the ongoing WISE study, which aims to find out how much difference IPS makes when introduced into an area (Camden), and how to maximise its success. In addition, the seminar will examine the role of service user researchers in the study.

All seminars will be held at the offices of the MHRN North London Hub, Imperial College, The Claybrook Centre, St Dunstan's Road, London W6 8RP. Please email or call Rosie Evans at: r.evans@imperial.ac.uk or 02073861145 to register. Seminars will take about 2 hours with at least 1 hour for discussion. Tea, coffee, and biscuits will be served at 2pm and, for those with excess energy, we will continue the debate and networking afterwards in a local pub or cafe. Further details regarding future seminars will be available soon. The SUNLOWS website (www.sunlows.org.uk) contains information about mental health research being carried out in the North London area and is maintained by people with experience of mental health problems who work with the hub.



National Institute for Health Research

NEW OPPORTUNITY – LAY COMMITTEE MEMBERS NIHR RESEARCH FOR PATIENT BENEFIT PROGRAMME

The National Institute for Health Research Central Commissioning Facility (NIHR CCF) is looking for patient and public representatives (lay members) for the Research for Patient Benefit (RfPB) programme to take a part in the work of the ten regional advisory committees. The committees meet three times a year with individuals from clinical, academic and methodological backgrounds to discuss and decide which applications to the programme should be recommended for funding. Lay members take a full committee role and have the key task of providing the patient and public perspective in the research assessment processes. There are up to three lay members on each committee at present.

Committee experience and some healthcare background are useful. For example, you may be a service user or a carer, been a member of an ethics committee, or have worked with volunteer groups in a health related role. You must also reside in England. If you are interested and would like to know more please contact Liz Scott, Patient and Public Involvement (PPI) Assistant Programme Manager, using the contact details below.

Lay members of the Research for Patient Benefit programme are also invited to take part in an annual PPI workshop where they can update their knowledge of the programme and network with other members and the RfPB programme team from the NIHR CCF.

For further information on the NIHR Research for Patient Benefit programme, please go to the website www.ccf.nihr.ac.uk/rfpb/ppi

If you would like to be considered or would like more information, please contact Liz Scott by email to: liz.scott@nihr-ccf.org.uk .

Tel: 020 8843 8041



*National Institute for
Health Research*

Would you like to get involved with INVOLVE?

We are looking for new members

INVOLVE has a key national role supporting public involvement in NHS, public health and social care research. We are looking for people with an understanding and experience of public involvement in research to join our Working Groups. INVOLVE has around 30 members with a range of skills and backgrounds.

INVOLVE is funded by and is part of the National Institute for Health Research (NIHR).

INVOLVE

Supporting public involvement
in NHS, public health and
social care research

Who are we looking for?

- **Members of the public**, including patients and potential patients, carers, people who use health and social care services, disabled people.
- People from **voluntary sector organisations** which represent people who use health and social services.
- People from **NHS, local authority and research organisations** with commitment and ability to promote public involvement in NHS, public health and social care research.

We value diversity and welcome applications from all sections of the community.

What is involved?

- Participation in four meetings a year, mainly in London.
- Opportunities for undertaking other activities for INVOLVE as agreed.

Your expenses for INVOLVE activities will be covered. If you are appointed as a public member and are not employed full-time in the public sector, you may also claim a committee fee.

How can I find out more?

Look at our website www.invo.org.uk/Membership.asp

This has more information and Frequently Asked Questions which we will update during the application period.

Get a Membership Information and Application Pack

You can download a pack from our website or contact us to have one sent to you:

Tel: 02380 651088 (Text phone: 02380 626239)

Email: membership@invo.org.uk

Attend a Membership Information Meeting

Tuesday 4 October 2011	Bristol
Thursday 13 October 2011	Manchester
Monday 17 October 2011	London

The meetings are an opportunity to meet some current Working Group members, find out more about being a member and get advice on how to apply. Places are limited - **you must book in advance**.

It is not essential to attend one of these meetings to apply for membership. Information provided will also be available on our website.

For more information about the Membership Information Meetings and to apply for a place, please contact Professional Briefings on www.profbriefings.co.uk/involvemim or call 01920 487 672.

The closing date for all applications is **12 noon on Monday 31 October 2011**

If you would like any of this information in a different format please contact us.

www.invo.org.uk

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www.mhrn.info
www.sunlows.org.uk



NHS
**National Institute for
Health Research**

INVOLVEMENT MERGER

NORTH MEETS SOUTH

The North London and the South London & South East Hubs of the NIHR Mental Health Research Network (MHRN) are excited to announce that their Patient and Public Involvement (PPI) activity is merging.

By combining the expertise and experience of both Hubs there will be more opportunities for service users and carers to get involved with research and to meet other members.

Both Hubs will be aiming to:

- organise away days
- host SUnLOWS Seminars
- seek involvement with the FAST-R service
- provide opportunities to sit on advisory panels and attend management committee meetings
- provide opportunities to get involved with research projects.

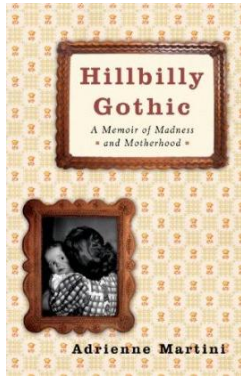
This merge will come into effect immediately but please bear with us during this process. If you have any questions with regards to this, please do not hesitate to contact Stu or Jemma at either hub (details above).

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



**Mental Health
Research Network**

Book Reviews



Hillbilly Gothic - A Memoir of Madness and Motherhood

By Adrienne Martini

Published by Fireside RRP £11.69

ISBN-10: 0743272765

I was recommended this book at the second of an excellent series of lectures, organised by the Mental Health Research Network in the North East. It was a bipolar forum about advances in our understanding and research into this illness and we were lucky to hear many inspiring speakers. Ian Jones, from Cardiff University, whose interest is in perinatal psychiatry, spoke highly of it and since it had a compelling title I had to read it. And it did not disappoint.

This is a very engaging personal account of how Adrienne Martini experienced postpartum depression. She does have the advantage of being a talented freelance writer and teacher and this makes it a page turner. She has a wry/black sense of humour and quick wit and points out many insights a reader will relate to and empathise with.

I enjoyed Full Blown by David Lovelace, which was also similar in its lively immediate style and family history of bipolar through three generations and how you come to terms with your own mental health and your family at the same time quite a challenge.

Martini's challenge did not come until she became a mother, which is a big enough challenge and upheaval in itself, aside from the depression. What is encouraging for the reader is how she meets the challenge, comes through it and then at the end of the book, casually mentions she is having her second child. The power and strength of human spirit again shines through from the darkness of deepest depression. I am glad she wrote the book. It was a brave and courageous task not always welcomed by friends and family it is not always easy to be honest about depression and suicide, when family members feel you should flush it all away and not dig up your dirt to share with everyone but by doing this, it reduces stigma and shows we are all human and importantly helps others in the same situation it is a role model and gives hope to others, who are cruelly told it would be better if they did not have children. This happened to Kay Redfield Jamison too, in her wonderful memoir, An Unquiet Mind. Also World Health Organisation say it is more like one in three people, not four who will experience mental health problems.

This book sends out a positive message that we are strong and can do many amazing things but we do need the right support and understanding to do this.

I particularly enjoyed section describing her feelings on the acute ward and how she climbed out of depression, her talks with her psychiatrist and how she describes her family, mother, grandparents and brother. I also liked her interactions with others on the acute ward who claimed not to be brain broke and evoked sympathy and compassion towards them.

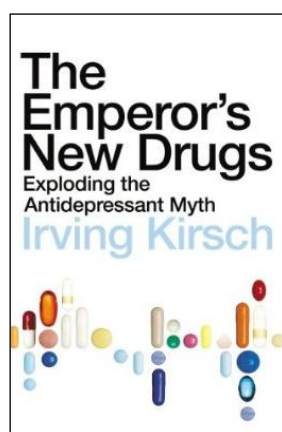
I admire her openness and generosity. This cannot have been easy. BUT she achieved what she set out to do: come clean in sharing her story and in so doing helps and

supports anyone in a similar position, and their partners, family and carers, with the birth of a new baby quite a trial in any circumstance.

The final message is uplifting and positive, saying you must meet the mountains on your own terms and shows you CAN climb them, but probably not on your own and although she now has two healthy children must live with the fear they might too suffer what she has, in their turn, BUT at least with their combined experience and insight they know they can cope with it as she did we are lucky our knowledge and treatment has greatly advanced from the time even of our parents generation and grandparents.

And new research and cleaner medicines, and better talking therapies provide us with the tools to climb the mountain. We have to thank Adrienne Martini for helping us on the journey.

Book review by Caroline Kemp (carer and lay researcher)



The Emperor's New Drugs – Exploding the Antidepressant Myth

By Irving Kirsch

Published by The Bodley Head, London (RRP £11.99)
ISBN: 978-1-847-92083-6

“How did antidepressant drugs gain their reputation as a magic bullet for depression? And why has it taken so long for the story to become public?” So tantalisingly starts the marketing information on the back cover of the book.

The book lays out its stall in chapter one where evidence is provided to suggest that the effect of antidepressants is one of Placebo effect rather than anything else. Evidence from trials shows that even those using a Placebo can significantly improve. It is suggested that the ‘small’ difference between that improvement compared to those using antidepressants within clinical trials is due to those using antidepressants experiencing side effects, thereby having an enhanced Placebo effect, as they have ‘broken blind’.

Subsequent chapters go on to suggest that the claimed positive benefits of antidepressants in trials are ‘exaggerated’, by means such as not reporting trials where positive benefits do not exist, reporting more than once those where positive benefits do or bundling together good and bad results to give a ‘distorted’ view of the benefits of antidepressants.

Chapter 4 is an important one as it gives evidence challenging the prevailing ‘wisdom’, regarding depression being caused by chemical imbalance. I found this chapter particularly challenging to read, as it does get rather technical, but ultimately I suppose such a chapter is necessary, as if the theory can be shown to be incorrect, then it supports other evidence within the book.

The author then takes two chapters to examine what the Placebo effect is and how it works. This is done by looking both at history and how it has been studied within

clinical trials. The final chapter then looks at alternatives to antidepressants, highlighting therapeutic interventions (notably CBT) and exercise as two. It should however not go un-noted that the author is a psychotherapist.

Overall I found the book interesting and challenging. It contains a great amount of references to clinical trials and research. Whilst a lot of the evidence is presented in a convincing fashion, I find myself wondering whether the fact that trials/studies understandably look at groups of individuals rather than different treatments on the same individuals makes it impossible to draw firm conclusions. Still this book represents an important contribution to the debate over antidepressants in treating depression. Given the potentially harmful side effects that can sometimes be experienced from antidepressants it is important to continue the search for the 'truth'.

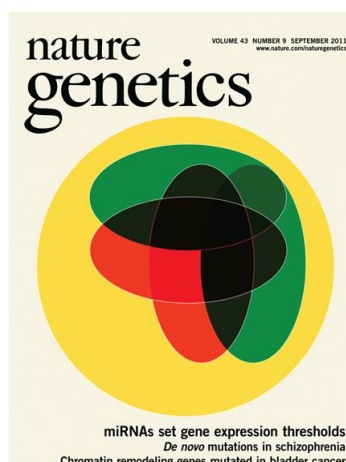
Book review by David Hindle (Service User Researcher)

Would you like to review a book for us?

If you would like to review a 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 mhrnpipi@kcl.ac.uk if you have any suggestions.

Mental Health Research in the News

Scientists make schizophrenia breakthrough



"A report in the journal Nature Genetics showed that "fresh mutations" in DNA are involved in at least half of schizophrenia cases, when there is no family history of the illness"

The BBC reported on this research recently. Click [here](#) for the full article.

You can read the abstract of the original research article by clicking [here](#). The research article itself is quite technical but the BBC article does quite a good job in summarising the findings of the research in a non-technical way.

Psychiatrists failing to adequately monitor patients for metabolic side-effects of prescribed drugs

“New research from the University of Leicester demonstrates that psychiatrists are not offering adequate checks for metabolic complications that are common in patients with mental ill health - especially those prescribed antipsychotic medication”

The research is actually based on the results of 48 studies that had previously been carried out. The research indicates that less than half of people on antipsychotic medications are given weight, cholesterol, or glucose checks.

Click [here](#) for the full article. You can read the abstract of the original research article by clicking [here](#)



A third of Europeans are suffering from a mental disorder in any one year

This is a screenshot of a news article from the Guardian website. The URL 'guardian.co.uk' is at the top. Navigation links for 'News', 'Sport', 'Comment', 'Culture', 'Business', 'Money', and 'Life & style' are visible. The article title is 'A third of Europeans are suffering from a mental disorder in any one year'. A sub-headline reads: 'Research finds 164m people have problems such as depression and anxiety with men more likely to become alcohol-dependent'. The author is Sarah Boseley, health editor, and the article was published in The Guardian on Monday 5 September 2011. Below the text is a photograph of a woman sitting on a bed, resting her head on her hand in a distressed pose. A caption below the photo states: 'Depression among women is a growing problem, the new European research identified. The problem has doubled since the 1970s. Photograph: Getty Images'. At the bottom of the screenshot, a line of text reads: 'More than a third of the population of Europe suffer from some sort of a'.

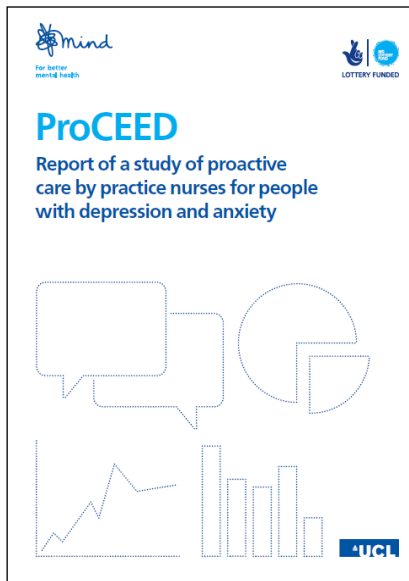
“Research finds 164m people have problems such as depression with men more likely to become alcohol dependant”. This quote is from a very good article that has been placed on the Guardian website. You can read the article in full by clicking [here](#). The abstract and a summary of the original research paper can be read online by clicking [here](#). The research was reported on by both Nature and New Scientist but it was not reported on as much as I would have liked by the mainstream press.

The most commonly quoted statistic in mental health is perhaps that one in four people will suffer from some form of mental health problem at some point in their life. The research that is reported on in this article is remarkable as it implies that around **a third** of Europeans suffer from a mental health problem **in any one year**. In other words far more people (in Europe at least) suffer from mental health problems at any given time than was previously thought.

The research further revealed that only 30-52% of people in Europe with a mental health problem have **any** contact with a health professional and only 8-17% of people are in contact with a specialist (someone like a psychiatrist, or a psychologist). It gets even worse than this. Only 2-9% of people "receive minimally adequate treatment" according to one of the authors of the original research paper that the Guardian reported on.

The research was carried out by an organization called the European College of Neuropsychopharmacology. I had never heard of them before but the research is good. They put out a press release about the paper which can be read by clicking [here](#).

Findings of MHRN Supported Research



In this section we report the findings of MHRN supported research. The MHRN supports hundreds of research studies from all over England. We are keen to make the findings of mental health research as widely known as possible and this Bulletin is one way that we will be doing our part.

The ProCEED Study

The first MHRN supported study that we report the findings of is called ProCEED. Mind has put out an excellent press release about the study which is reproduced below. The full report of the study can be downloaded freely [here](#). Fenella Lemonsky, one of the service user consultants with the MHRN's North London's hub worked on the study analyzing data from

the interviews that were carried out as part of the study.

The press release is reproduced below with kind permission from Mind.

New study finds increased role for practice nurses in treating depression has mutual benefits

Mind, in association with the Royal College of Nursing, today (31 August) releases new findings that show structured contact with practice nurses can help people with chronic and recurrent depression in their recovery.

The three-year [ProCEED intervention study](#) conducted on behalf of the mental health charity by University College London, with funding from Big Lottery Fund, found evidence that enhanced nurse-led care can have significant mutual benefits for nurses and patients.

The report coincides with the launch of a new [training pack](#) on depression aimed at practice nurses.

Depression is one of the most common illnesses in the UK, affecting one in six people at some stage in their lives and accounting for a quarter of GP visits. Despite this, practice nurses receive limited or no training and many feel ill-prepared to discuss depression.

Proactive care is routinely provided by practice nurses for physical chronic conditions such as asthma or diabetes but is not always offered for depression, with nurses often feeling apprehensive about broaching the subject with patients.

The ProCEED intervention study ¹ involved nurses from 42 general practices across the UK being trained to offer proactive, enhanced levels of care, in the form of ten appointments over two years, to patients experiencing severe and recurrent depression.

Sessions addressed satisfaction with current treatments and social factors such as isolation, housing and employment.

Key findings of the study included:

- nurses had improved confidence and skills when empowered to manage patients with depression.
- patients experienced significant improvements in social functioning after receiving regular sessions with practice nurses, reporting increased confidence and self esteem.
- there were small improvements reported in the severity of depression experienced by patients when compared to a control group.
- patients attending all ten sessions were likely to experience significant improvements in both symptoms and social functioning.
- many patients felt that ongoing proactive care should be provided by a practice nurse rather than a GP.
- Proactive care was shown to be potentially cost effective in achieving positive changes in severity of depression and improving the patient's ability to play a fuller role in society.

Mind's Chief Executive Paul Farmer said:

There is clearly an unmet need in offering people with depression ongoing holistic consultation in primary care. Practice nurses are on the front line so are well placed to provide this kind of advice and support. Nurses are already offering enhanced care packages to patients for physical conditions and with the right training and support could be equipped to do the same for depression. There must be a parity of esteem in how mental and physical health problems are addressed in primary care settings.

One of the most encouraging findings of this study was the positive impact the experience had on the lives of participants. It's time for more collaborative working on mental health. It's been shown to be potentially cost effective and has achieved great results for all involved. The Mind and Royal College of Nursing new training pack is a great starting point and will hopefully become essential reading for practice nurses.

Royal College of Nursing Chief Executive & General Secretary Dr Peter Carter said:

General practice nurses play a huge role in managing the care of patients with long term physical conditions. However their potential for improving the quality of life for patients with depression has never been realised across the board. We are delighted to support this new initiative and hope that nurses will be encouraged to use this excellent training pack to enhance their skills, knowledge and confidence in the management of depression.

Depression is a co-existing factor in many long term conditions and this new approach will see a more holistic approach to treatment for the benefit for patients and clients.

Research nurse Kate O'Brien who took part in the study said:

Caring for patients with depression is challenging and, consequently, extremely rewarding. I found that I needed to develop new skills to enable me to feel that I could be of benefit to my patients. The most important thing was listening, really listening to pick up what patients were trying to tell you. This often meant identifying what they weren't saying and finding a way of allowing them to talk comfortably.

If I am checking notes for any reason and the person is someone I have worked with on ProCEED it is such a positive feeling to see that they have not needed to restart their

antidepressants or that they have only had a couple of GP consultations in the last year. It reinforces the impression of making a difference.

Comment from a patient who participated in the study:

I have huge faith in my doctor if I go with a medical problem that's fine but I think depression isn't an acute medical problem. I think it's more something that you need to have time with somebody. And the time to me is more important than the prescription. That time to me (with the nurse) was worth 100 prescriptions.

ENDS

1. ProCEED (Pro-active Care and its Evaluation for Enduring Depression) intervention study: 558 people were recruited to participate in this study, with 282 in the intervention group and 276 in the control group.
www.mind.org.uk/proceed

Notes to Editors

- To request copies of the ProCEED report and training pack please email media@mind.org.uk
- **Mind** is the leading mental health charity in England and Wales. We work to create a better life for everyone with experience of mental distress.
www.mind.org.uk
- For more information, interviews and a range of case studies please contact Mind media office on T: 020 8522 1743 M: 07850 788514 E: media@mind.org.uk ISDN line available: 020 8221 0817.
- Please note that Mind is not an acronym and should be set in title case.
- **The Royal College of Nursing (RCN)** is the voice of nursing across the UK and is the largest professional union of nursing staff in the world. The RCN promotes the interest of nurses and patients on a wide range of issues and helps shape healthcare policy by working closely with the UK Government and other national and international institutions, trade unions, professional bodies and voluntary organisations
- For further information or interviews please contact the RCN Media Office on 0207 647 3633, press.office@rcn.org.uk or visit <http://www.rcn.org.uk/newsevents/media>
- The **Big Lottery Fund (BIG)**, the largest distributor of National Lottery good cause funding, is responsible for giving out 46% of the money raised for good causes by the National Lottery.
- BIG is committed to bringing real improvements to communities and the lives of people most in need and has been rolling out grants to health, education, environment and charitable causes across the UK since June 2004. The Fund was formally established by Parliament on 1 December 2006.
- Since the National Lottery began in 1994, 28p from every pound spent by the public has gone to good causes. As a result, over £26 billion has now been raised and more than 330,000 grants awarded across arts, sport, heritage, charities, health, education and the environment.