McPin Public Involvement in Research Bulletin

Issue 3: June 2015

This is the third edition of the quarterly McPin Public Involvement in Research bulletin. In these bulletins we provide news about mental health research and advertise any relevant user and carer involvement in research opportunities and events within the McPin Foundation. 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 include in our involvement bulletin or if you would like to be placed on the mailing list to receive future editions of the bulletin then please sign up here. You can email us at contact@mcpin.org or phone 0207 922 7874.

To sign up as a supporter of the McPin Foundation and to receive our organisational newsletter, also produced quarterly and distributed by email, please click here or go to www.mcpin.org
Contents

- **Opportunities**
  - People with recent experience of their first experience of psychosis wanted for new study
  - Service user needed to join the Programme Advisory Group for the Research into Antipsychotic Discontinuation And Reduction (RADAR) study
  - Consultation with people who have experienced peer support
  - Help needed to develop new mental health outcome measure (ReQoL)

- **News**
  - Independent Mental Health Advocate (IMHA) Briefings, reports and films from SCIE and UCLan

- **Articles**
  - The Vice Guide to Mental Health
  - A rough guide to types of scientific evidence

- **Book review**

- **Mental health research in the news**

We welcome submissions of articles for publication in this Bulletin on a voluntary basis. We reserve the right to edit articles that are submitted (in consultation with the contributor) before publication. The views expressed in articles in this bulletin are solely those of the authors and do not necessarily represent the views of the McPin Foundation.
Opportunities

People with recent experience of their first experience of psychosis wanted for new study

Seven people with recent experience of their first episode of psychosis needed to sit on a Lived Experience Advisory Panel (LEAP) for a new and exciting study lasting one year. We hope that the study will eventually lead to a new way of helping some people who have psychosis. People who have recently experienced psychosis and currently use early intervention services or who have had antibody mediated encephalitis are particularly encouraged to apply.

Background

There is some evidence that around 6% of people that present with psychosis have very particular kinds of antibodies in their system. Essentially the body is acting as if it is fighting an infection and psychosis soon follows. Indeed there is a known illness called ‘antibody-mediated encephalitis’ where this is exactly what happens.

People who have these antibodies often have symptoms that are very similar to schizophrenia. So much so in fact that people are often treated in mental health services and given antipsychotic medication.

About the study

A team of researchers from Cambridge and Oxford have received funding for a one year study involving people with psychosis who have the antibodies that causes antibody mediated encephalitis. The study team want to investigate a possible new way of helping people with psychosis that have been tested as having a particular kind of antibody in their system. You can find out more about the research by looking at the study website (www.sinapps.org.uk) or by clicking here.

What would be involved?

Being involved in the study would mean sitting on a Lived Experience Advisory Panel (LEAP) with seven other service users.
You would be asked to help develop information materials for people taking part in the study and suggest ways of dealing with any issues that arise during the course of the study. Payment for attendance at meetings is offered and reasonable travel expenses will be reimbursed. It is likely that the LEAP will meet three times a year in London although we may vary where we hold the meeting. For this reason LEAP members will need to be able to travel to London, Oxford, or Cambridge. Meetings will last around four hours with breaks. Lunch and refreshments will be provided.

To apply to join the LEAP please send an email or letter by July 10th 2015 to Thomas Kabir (email: thomaskabir@mcpin.org, phone 0207 922 7874) with:

- Your contact details (including an email address)
- Your postal address
- Why you are interested in being involved in the study
- Some information about yourself including something about your mental health background
- Any special needs that you have
- It would also be useful to know if you have been involved in research before

If you have any questions then please feel free to contact Thomas Kabir.

You can listen to an interview with Dr Belinda Lennox (one of the researchers on the above study) by clicking here.

Alternatively you can visit the Naked Scientists website: www.thenakedscientists.com
Service user needed to join the Programme Advisory Group for the Research into Antipsychotic Discontinuation And Reduction (RADAR) study

Introduction

We are looking for a mental health service user to join the Programme Advisory Group for a new and exciting six year study. The study is about the process of discontinuing or reducing antipsychotic medication. The study lead is Dr Joanna Moncrieff from UCL. The research will take place in London and Essex.

What is the Programme Advisory Group?

The function of the Advisory Group is to provide external scrutiny to this NIHR Programme Grant for Applied Health funded research study. The chair of the group is Prof Tom Craig from the Institute of Psychiatry Psychology and Neuroscience (IOPPN). The Programme Advisory Group will meet twice a year in London.

What will be required?

The following will be required of Advisory Group members:

- Attending face to face meetings of the group in London twice a year. Meetings will last between three and four hours (with breaks).
- Reading papers ahead of meetings and with other group members holding the study team to account.
- Constructively raising any concerns that you might have and offering possible solutions.
- Responding to occasional correspondence between meetings of the group by email.

Reimbursement for your time will be offered and all reasonable travel expenses will be covered. Applicants will need to be comfortable in using email and have some experience of sitting on similar groups for other mental health research studies. Some knowledge of mental health research will also be required. Experience of taking anti-psychotic medication is essential. The research will focus on people with a diagnosis of schizophrenia and so we are looking for people with relevant lived experience.

How to apply

To apply please complete the application form and return it to Thomas Kabir (email: thomaskabir@mcpin.org) by 5pm on July 17th 2015.

For more information please contact the study lead Dr Joanna Moncrieff (email: j.moncrieff@ucl.ac.uk).
Consultation with people who have experienced peer support

Do you have experience of peer support for mental health problems? If so, we want to hear from YOU!

We are researching a new national programme of peer support initiatives involving MIND, Bipolar UK, Depression Alliance and local partners. One aim of this research is to identify the core characteristics of peer support, and your views are crucial to making this research meaningful. For more information about this work please click here.

We are collecting people’s views via an online survey, which is open to anyone who has experienced peer support.

This means any form of support between people with lived experience of mental health problems. This can be formal (i.e. a peer support worker or a peer support group) or informal (i.e. between friends, family members, co-workers etc.). The person could have received support, given support, or both.

SURVEY

Please tell us what you think are the most important principles and values of peer support by completing our short online survey. It will only take around 10 minutes.

You can complete the survey here: Peer support survey

The survey will close on: Monday July 13th 2015
REQOL: Are you a person with lived experience of a mental health problem?

ReQoL is a questionnaire that is being developed to help understand feelings and monitor progress of recovery and quality of life for people with different mental health problems. The study is being led by a team of researchers based at the University of Sheffield. The McPin Foundation is one of a number of organisations that are supporting this study.

To help develop the questionnaire further we would like to invite you to fill out the following online questionnaire:

Please click here to complete the questionnaire

It will take around 10 minutes of your time to complete the questionnaire. The ReQoL questionnaire is quite long at the moment and your answers will help us produce a shorter one.

Please visit www.reqol.org.uk for further details regarding the study.

If you do not wish to complete the questionnaire, please feel free to ignore this request. If you have any questions then please feel free to contact Thomas Kabir by email (thomaskabir@mcpin.org) or phone (0207 922 7874).

Your response is very valuable and we thank you for your time. ReQoL is being developed by The University of Sheffield through funding from the Department of Health Policy Research Programme

Thomas Kabir
McPin Public Involvement in Research Manager
Independent Mental Health Advocate (IMHA) Briefings, reports and films from SCIE and UCLan

Being detained in hospital or on being on a Community Treatment Order can be a confusing and distressing experience. An Independent Mental Health Advocate (IMHA) can help by supporting people to get their opinions heard and to make sure that they know their rights under the law. However, research reveals that people with mental health issues don’t always have access to an IMHA. Many people with mental health problems are not getting the independent advice and support which is their statutory right. Service users that need IMHAs the most (for instance, older people, people with learning disabilities and people from BME groups) are the most likely to miss out on having access to one.

Twelve new resources were launched on 11th March at an event at the House of Lords, by the Social Care Institute for Excellence (SCIE) and the University of Central Lancashire (UCLan). Briefings, reports and films give an overview of the current situation regarding IMHAs and provide everything you need to know to improve access to, and to provide, high-quality IMHA services.

In 2012, UCLan published a review of IMHA services. Entitled ‘The Right to be heard’, the review found variations in the access to, and uptake of, IMHAs. It found that only half of those eligible for an IMHA in England actually had access to one. The Care Quality Commission’s (CQC) 2015 annual report of the Mental Health Act found that 20% of people sectioned in hospital did not have their rights properly explained to them.

The new resources are:

- Briefing: Understanding IMHA for service users
- Easy read version: Understanding IMHA for service users
- Social Care TV film: Understanding IMHA for service users
- Briefing: Understanding IMHA for mental health staff
- Social Care TV film: Understanding IMHA for mental health staff
- Briefing: Commissioning Independent Mental Health Advocacy (IMHA) services in England, 10 Top tips for commissioners
- What does a good IMHA service look like?
- Briefing: Improving equality of access to IMHA
- Report: Improving equality of access to IMHA
- Social Care TV film: Improving equality of access to IMHA
• Improving Access to Independent Mental Health Advocacy for Providers of Mental Health Services
• Report: How to measure the outcomes of IMHA

SCIE’s Chair, Lord Michael Bichard, who is hosted the event said:

“Improving access to IMHA and the quality of IMHA are important and complex issues; issues which no one body can solve by themselves. Advocacy providers, commissioners, regulators, central government, mental health professionals and service users need to work together to ensure that everyone who is eligible for an IMHA gets to see one. Then, when they do access an IMHA, they should receive a high quality service - because everyone has the right to heard.”

The resources have been co-produced with peer researchers and other service users, so that they draw on people’s direct experiences. Users were involved in a number of roles including as advisory group members, writers, film-makers, editors and project lead.

Survivor consultant June Sadd was a peer researcher for the UCLan ‘Right to be Heard’ review. June says:

“I see, in effective advocacy provision, the ‘seeds of empowerment’ for people with mental health and other social care issues. I know from my experiences that access to an IMHA would have been invaluable when I suddenly found myself detained in a mental health unit, in great distress with no understanding of my rights, or what was going on.”

UCLan’s Dr Julie Ridley, Reader in Applied Social Sciences and Co-project Lead, says:

“The latest CQC figures show increased rates of detention and Community Treatment Orders, meaning increased demand for IMHA services. Our research reveals that the reasons qualifying patients are not using IMHA services point to a lack of awareness or understanding of the service, and thus how it can help. Urgent action is required to increase the quality and the accessibility of IMHA provision, and the resources we have produced will help to promote it more widely among service users and mental health professionals.”

Access to an IMHA can ensure people’s rights are respected, can greatly enhance the service user experience and can improve staff / service user relations and support prevention.

• Until 2012, IMHAs were commissioned by Primary Care Trusts. Now responsibility for commissioning IMHAs is with local authorities.
• The project has been commissioned by the Department of Health.

You can find a press release together with links to the resources and videos mentioned in this article by clicking here or by visiting www.scie.org.uk.
I hadn’t heard of Vice until a couple of years ago. Vice is an online media company that operates in over 36 countries according to Wikipedia. Vice has actually been around for a while having been founded in 1994. The vast majority of its articles and videos can be accessed via its website (www.vice.com) and its various YouTube channels.

Vice has something of a reputation for picking up on stories that few others do and for sending its reporters to places that others simply won’t dare. Late last year Vice itself hit the news after it sent reporters to investigate everyday life deep within ISIS controlled territory in Iraq.

Vice has been increasingly reporting on mental health and indirectly mental health research. Their videos and articles on mental health are (in my opinion) some of the most interesting anyone is producing at the moment.

I don’t want to say that the articles and videos that Vice produces are perfect. They are not. Some of the articles are personal opinions. Other articles suffer from being a little too opinionated. But for all this, it is willingness of Vice to engage with topics that others simply wouldn’t touch that impresses me the most.

Recently Vice pulled together all of its articles and videos about mental health into a collection called ‘The Vice Guide to Mental Health’. You can access the guide by clicking here or by visiting www.vice.com

The guide itself covers some pretty interesting topics. Everything from female hormones and mental health to ‘This Is what developing acute schizophrenia feels like’ is covered.

The guide is constantly growing as more and more articles are added. Some of the most recent additions include ‘When Are We Going to Stop Marginalising Black and Minority Ethnic Mental Health Patients?’, and ‘Prisons Are Acting as De Facto Mental Health Facilities for Indigenous Australians’.
Vice has even ventured into the area of ancient history. In May Vice released an article by Johannes Niederhauser entitled ‘Can the Long History of ‘Madness’ Help in Our Understanding of Mental Health Today?’ The article itself is based around an interview with Andrew Scull about his new book entitled ‘Madness in Civilization: The Cultural History of Insanity’. As well as documenting how mental health has been understood since ancient times the book and article point out that ‘madness’ actually has a history of being viewed in more positive terms then we would expect.

If anyone would like to review Andrew Scull’s book for this Bulletin then please let me know!

And from ancient history to the present day in late June Vice reported on a new video game that is designed to help people understand what it’s like to suffer from psychosis. It’s not what you would expect. On the face of it the game doesn’t look too different from a lot of other role playing games on the market. But don’t be fooled. The subject matter is anything but conventional.

The game revolves around a female Celtic warrior called Senua. Senua is left traumatised after a Viking invasion and experiences hearing distressing voices around her. The game isn’t out until next year but it sounds like it could be a very innovative way of helping people to understand mental health.

By Thomas Kabir

A Rough Guide to Types of Scientific Evidence

In the last issue of the Bulletin we included an article entitled ‘how can you tell if research is any good?’ We included a poster entitled ‘a rough guide to spotting bad science’ from a group called Compound Interest (www.compoundchem.com).

Well the good people at Compound Interest have done it again and produced a poster entitled ‘a rough guide to types of scientific evidence’. You can find a full copy of the poster on the next page. If you would like to download a full copy of the poster then please click here.
A Rough Guide to TYPES OF SCIENTIFIC EVIDENCE

Being able to evaluate the evidence behind a claim is important, but scientific evidence comes in a variety of forms. Here, the different types of scientific evidence are ranked and described, particularly those relevant to health and medicinal claims.

1. **ANECDOOTAL & EXPERT OPINIONS**
   - Anecdotal evidence is a person’s own personal experience or view, not necessarily representative of typical experiences. An expert’s stand-alone opinion, or that given in a written news article, are both considered weak forms of evidence without scientific studies to back them up.

2. **ANIMAL & CELL STUDIES** *(experimental)*
   - Animal research can be useful, and can predict effects also seen in humans. However, observed effects can also differ, so subsequent human trials are required before a particular effect can be said to be seen in humans. Tests on isolated cells can also produce different results to those in the body.

3. **CASE REPORTS & CASE SERIES** *(observational)*
   - A case report is a written record on a particular subject. Though low on the hierarchy of evidence, they can aid detection of new diseases, or side effects of treatments. A case series is similar, but tracks multiple subjects. Both types of study cannot prove causation, only correlation.

4. **CASE-CONTROL STUDIES** *(observational)*
   - Case control studies are retrospective, involving two groups of subjects, one with a particular condition or symptom, and one without. They then track back to determine an attribute or exposure that could have caused this. Again, these studies show correlation, but it is hard to prove causation.

5. **COHORT STUDIES** *(observational)*
   - A cohort study is similar to a case-control study. It involves selection of a group of people sharing a certain characteristic or treatment (e.g. exposure to a chemical), and compares them over time to a group of people who do not have this characteristic or treatment, noting any difference in outcome.

6. **RANDOMISED CONTROLLED TRIALS** *(experimental)*
   - Subjects are randomly assigned to a test group, which receives the treatment, or a control group, which commonly receives a placebo. In ‘blind’ trials, participants do not know which group they are in; in ‘double blind’ trials, the experimenters do not know either. Blinding trials help remove bias.

7. **SYSTEMATIC REVIEW**
   - Systematic reviews draw on multiple randomised controlled trials to draw their conclusions, and also take into consideration the quality of the studies included. Reviews can help mitigate bias in individual studies and give us a more complete picture, making them the best form of evidence.

Note that in certain cases, some of these types of evidence may not be possible to procure, for ethical or other reasons.
I have a diagnosis of schizophrenia, which I have long since rejected because it did not reflect the reality of my life – it made no sense to continue to believe in it. However, I am still affected by that label. I have always held the medical profession in high regard, to the point where I believed for years that psychiatrists knew something about me that I did not, that I was fundamentally flawed, and now it is hard to reverse that thinking.

I have taken renewed courage though, since reading this book, written by a mental health professional who tells me and others like me that accepting psychiatric diagnosis should be a choice. ‘A Straight Talking Introduction to Psychiatric Diagnosis’ is a short, concise work which combines scholarship with humanity and compassion. It provides a unique resource for those of us who have been harmed by the workings of psychiatry and want to prevent future harm to others. The author, a consultant clinical psychologist, acknowledges the fact that, ‘Mental distress is very real’ but, as she says ‘Psychiatric diagnosis is not a valid or evidence-based way of understanding the difficulties and distress that people experience’.

Challenging the veracity of psychiatric diagnosis might sound shocking, but Johnstone makes her argument in a clear and balanced manner. Psychiatrists, as she points out, would have us believe that their pronouncements are based on firm science, but this is never the case, because there are no medical tests to ascertain the existence or absence of any sort of ‘mental illness’. Rather, diagnosis is made by observation of symptoms alone – often without even listening to the story of the patient; without even asking what has happened to bring him or her to the point of emotional collapse. And, as Johnstone states, ‘Not all human suffering is best understood as a disease process’. She goes on, ‘We need to acknowledge people’s suffering and lack of control in many areas of their lives, while at the same time building on their strengths so that they can, with the right support, move towards recovery’.
In order to understand the importance of the debate about the validity of psychiatric diagnoses, it is necessary to comprehend the scale of the damage such labels can do to the individual. As the mental health system stands, such diagnoses are often required in order to access services and benefits – I certainly used mine for such purposes for a number of years.

However, what seems compassionate at the outset becomes a trap. The lifelong stigma of a diagnosis of schizophrenia, for example, is a terrible thing to inflict on a person. Less severe diagnoses can be equally harmful. It is important to understand that psychiatric labels do not help psychiatrists to decide the appropriate treatment for patients in the same way that medical diagnoses help doctors to do. Psychiatric medications are not tailored to individual conditions and even psychiatrists do not claim that these drugs cure the ‘diseases’ they are intended to treat, they only mask the symptoms. As Johnstone points out, ‘There are many powerful vested interests in preserving the diagnostic system, not least the pharmaceutical companies whose influence is felt in every area of mental health work’.

The author does not simply criticise the current status quo, she suggests alternatives. She writes about the use of psychological formulations, which are made in a collaborative manner with the patient, addressing the question of ‘What happened to you?’ rather than the more judgemental ‘What is wrong with you?’ She suggests next steps for service users who want to explore alternatives to diagnosis, providing guidance for those who wish to write their recovery story and play a part in their own healing. In my case, Johnstone’s book preaches to the converted but it has the potential to make a difference to the lives of many people. It deserves a wide audience and I sincerely hope that it will gain one.

Book review by Louise Gillett, author of ‘Surviving Schizophrenia: a Memoir’ and its sequel ‘Surfacing’

Book reviewers wanted!

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, and so on) and be reasonably priced. If you write a review for us, we will buy the book for you, and we will give you a £20 gift voucher as a token of our appreciation. Please email thomaskabir@mcpin.org if you have any suggestions.
Mental health research in the news

Care Quality Commission report on mental health crisis care

Earlier this month the Care Quality Commission released its report on mental health crisis care. The report caused quite a stir and it was widely reported on. The BBC produced an article entitled ‘Mental health crisis care ‘struggling to cope’. The Guardian ran a piece on the report entitled ‘A&E staff attitudes to patients in mental health crisis ‘often shocking’.

This report is directly relevant to our evaluation of the mental health Crisis Care Concordat. The Concordat itself is “a national agreement between services and agencies involved in the care and support of people in crisis. It sets out how organisations will work together better to make sure that people get the help they need when they are having a mental health crisis”.

The report itself is quite long. But to its credit the CQC have produced an EasyRead version and a very readable summary document is available. The CQC even produced its own hashtag (#mhcrisiscare) so that people could discuss the report in Twitter.

Some of the headline findings of the report are that “The quality of care experienced by a person in crisis varied depending on where they lived and when they sought help”. “Many people have experienced problems in accessing help at the time they need it and in getting the right help when they have a mental health crisis”. And that “across the country local services are developing innovative approaches to the challenge of providing a high-quality response to people in crisis. More can be achieved where these innovations work in partnership and services are integrated around the needs of the person in crisis”.

And elsewhere in the news

The BBC produced an intriguing article about the ‘glass delusion’. “The "glass delusion" is an extraordinary psychiatric phenomenon in which people believe themselves to be made of glass and thus liable to shatter. It peaked centuries ago but there are still isolated cases today”.

“More than one in three new fathers are concerned about their mental health” according to research carried out by the National Childbirth Trust.

And finally from The Guardian: “new study claims to find genetic link between creativity and mental illness”. Click here to read the original research paper.
The Mental Elf (www.nationalelservice.net/elf/mental)

The Mental Elf has been busier than ever! One of the latest reviews is entitled; ‘do you need more psychotherapy to get better? New study suggests no relationship between number of sessions and improvement’.

This is a review by Sarah Knowles on a paper in the British Journal of Psychiatry entitled ‘Effect of duration of psychological therapy on recovery and improvement rates: evidence from UK routine practice’ by Stiles et al. The authors of the paper and Knowles point out that previous research shows that how well you do is not related to how many sessions of therapy you get. The authors of the paper looked at 26,430 people who had received a psychological therapy in the UK and compared how long they had treatment with how well they did as measured by a questionnaire called CORE-OM. CORE-OM consists of 34 questions split into four domains; wellbeing, symptoms, functioning, and risk. Its used as a “generic measure of psychological distress”.

According to Stiles et al “Rates of RCSI [reliable and clinically significant improvement] and reliable improvement and mean pre- and post-treatment changes were similar at all tested treatment durations. Patients seen in different service sectors showed modest variations around this pattern and reliable improvement and mean pre- and post-treatment changes were similar at all tested treatment durations. Patients seen in different service sectors showed modest variations around this pattern”.

One of the take home messages from the paper and the review by Knowles is that psychological therapies are not like drugs where there are set doses that should be given. Knowles puts it like this “rather than requiring a prescribed number of sessions, patients and therapists can work responsively, with the ‘right’ number of sessions being right for the individual rather than something we can quantify across the board”.

Other highlights include:

**Psychotic experiences: how common are they and how can we predict their onset, course and consequences?**

Click [here](#) to read the article

**Sleep disruption during and after pregnancy may be associated with postpartum mental illness**

Click [here](#) to read the article

Thank you for reading our Public Involvement in Research bulletin! Please do send in suggestions for articles or news to include. It was produced by McPin Foundation, registered charity 1117336. Find out more about us at [www.mcpin.org](http://www.mcpin.org)