McPin Public Involvement in Research Bulletin

Issue 4: October 2015

This is the fourth 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
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. The McPin Foundation is a registered charity 1117336. Find out more about us at www.mcpin.org.
Opportunities

Service users and carers needed to join and advisory groups for Research into Antipsychotic Discontinuation And Reduction (RADAR) study

Introduction

We are looking for six people to join a Public and Patient Involvement (PPI) group supporting the RADAR study. This group will meet regularly at first and then less frequently over the course of the 6 year study which is all about the process of discontinuing or reducing antipsychotic medication. The study lead is Dr Joanna Moncrieff from University College London (UCL). The research will take place in London and Essex. It is funded by the National Institute for Health Research (NIHR).

What is the RADAR PPI group?

The function of the PPI group is to help the research team deliver a high quality research study by providing expert input based upon lived experience in the role of a mental health service user or carer. For this study members need to:

- Have experience of taking anti-psychotic medication or supporting a relative or close friend who lives with psychosis in the role of informal carer.
- Have an interest in mental health research and particularly randomised control trial (RCT) methods of research. A key role will be providing advice on the delivery of a multi-site RCT.
- Live near London as all the RADAR PPI group meetings will be in London and there is a limited travel budget. Also need to be able to travel independently to meetings.
- Be comfortable reading meeting papers and preparing comments prior to sessions. Able to comment on documents using track change function in Microsoft Word. Be able to use email to communicate.
What will be required of members?

The following will be required of RADAR PPI Group members:

- Attending face to face meetings – once a month at the start of the study (Jan-March 2016) – in London. Meetings will last between three and four hours (with a break).
- In the first year of the study, helping to develop Research Ethics Committee (REC) materials, commenting on the discontinuation protocol to support the development of intervention content and a manual.
- Attending face to face meetings of the group in London twice a year over the course of the study. We ask for a 2 year commitment to join the group. The study will last 6 years.
- Reading papers ahead of meetings and with other group members providing expertise to support the study team decision making. Not all suggestions from the PPI group will be able to be taken forward. The opinions of members of the wider study team will often need be sought.
- Constructively raising any concerns that you might have and offering possible solutions.
- Responding to occasional correspondence between meetings of the group.

Payment for this work will be offered and all reasonable travel expenses will be reimbursed. The rate of pay is £60 per meeting. This includes preparation and meeting time.

Applicants will need to be comfortable in using email and have some experience of sitting on advisory groups. Some knowledge of mental health research will also be required. Experience of taking anti-psychotic medication, or supporting someone on medication, is essential. The research will focus on people with a diagnosis of schizophrenia thus we are looking for people with similar experiences.

How to apply

To apply please complete the application form and return it to Annabelle Davies (email: annabelledavies@mcpin.org) by 5pm on Friday 13th November 2015.
New mental health and cancer taskforce

Have you had cancer and found that the experience impacted on your emotional and mental health? Or perhaps you had pre-existing mental health problems and then developed cancer as well? Have you cared for someone who experienced both cancer and mental health problems?

We are holding an engagement event with people affected by both cancer and mental health problems, on Saturday 5th December, to get a sense of the issues people feel are important.

People with both cancer and mental health problems can face disadvantage, inequality and discrimination. It can be hard to get the care and support you need. Macmillan Cancer Support is setting up this mental health and cancer taskforce to look at the issues faced by people with this dual lived experience. Those involved will help shape our work nationally to improve outcomes for people with cancer. We want people affected by cancer and mental health problems to participate in and be central to the work of the taskforce.

The event will be structured and interactive, but led by the views and input of those attending. Lunch and refreshments will be provided free, plus reasonable travel costs will be paid in advance or reimbursed. The venue is fully accessible.

Where: 3 minutes’ walk from Euston Station, London, NW1

When: Saturday 5th December, 10.30am-3pm

Maximum number of places: 29 people

To express interest in participating, please email research.learning@macmillan.org.uk, telling us a bit about yourself and why you would like to attend; if you are not online, please phone Anna on 020 7091 2056 to leave a message and we will call you back. You will be called back between 2nd November and the event, and asked a bit about yourself and what your experience has been before you are offered a place, as we want to ensure that we get a good mix of people in the room in terms of ethnicities, ages, gender, types of cancer and mental health problem, and the area you come from. If you are not available on the 5th of December or are not offered a place, there will be other ways you can get involved in the taskforce in the future, so do get in touch to register your interest.
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.

Your input is important and if you are happy to help with our research, we invite you to complete the following online questionnaire:

Please click here to complete the questionnaire or go to https://goo.gl/F14Cc4

It will take around 10 minutes of your time. The questionnaire is longer than usual and your answers will help us produce a shorter one. This questionnaire will be followed up by one further questionnaire in approximately 3 months’ time.

When you are filling the questionnaire, please provide your email address so that we can contact you with the follow-up questionnaire, should you choose to complete it. This is a crucial part of the study. Please note that the research team will not be able to identify who you are. The email address you provide will ONLY be used by our research team at The University of Sheffield to email out the follow-up questionnaire when it is due. Your email address will be kept securely and we will treat any information you provide us with in strict confidence. When the study is complete details of your email address will be destroyed.

For further details regarding the study, please click here

If you do not wish to complete the questionnaire, you do not have to do anything else.

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
Have you worked or volunteered on an early intervention in psychosis program or project as a peer? Interested in sharing your experiences and perceptions of challenges and needs?

In consultation with early intervention peer staff & peer leaders, researchers at Stanford have developed a survey concerning peers’ and young people’s experiences, challenges and perceived priorities in early intervention in psychosis (EIP) programs, nationally and internationally. We invite participation from peers with any experience of EIP-related work (including planning, policy, peer support, evaluation and/or research).

**What:** We have developed an online survey for peers that includes both open-ended and close-ended questions about their experiences. The survey should take about 30 minutes to complete.

**Who:** Peers with experience working or volunteering on an early intervention in psychosis project or service.

**Reimbursement:** There is no reimbursement for participation.

Direct Link: [https://stanforduniversity.qualtrics.com/SE/?SID=SV_6hRZ3VlaFvwPzkF](https://stanforduniversity.qualtrics.com/SE/?SID=SV_6hRZ3VlaFvwPzkF)

Sign up or find out more: Nev Jones PhD nevjones@stanford.edu or (773) 639-8360

[www.voicesoutside.org](http://www.voicesoutside.org)
**Article**

**Talking Point: Randomised Control Trials (RCTs) - the straitjacket of mental health research?**

On Thursday 8th October 2015 at Jerwood Space in Southwark we held our first public event to launch our Talking Point paper series. This was an important night for the McPin team as part of our mission to transform mental health research (#transformMHresearch). Our first paper looked at the role of Randomised Control Trials in mental health research, authored by Alison Faulkner, survivor researcher and trainer. Alison’s report was titled “Randomised control trials – the straightjacket of mental health research?” You can read the paper here. We live tweeted from the event and had a very active contribution from both those in attendance and those following the tweets, including academics, peer researchers, service users and health and social care professionals. Read the #RCTDebate twitter discussion here.

**What are our talking point papers?**

They give people with lived experience the opportunity to discuss and debate under-discussed or particularly difficult issues in mental health research. We hope that these papers, and the discussion around them, will aid us in our mission to ‘transform mental health research’. The funding for the Talking Point papers is from the McPin Foundation but the views expressed in the papers are the author’s own.

**What did others say on the night?**

We are in the process of collating comments generated from our discussion. These will be published in due course. Professor Sonia Johnston explained the use of RCTs and her experience of them within a career that has used mix methods and various naturalistic, observational and qualitative studies alongside RCTs to build an evidence base for effective supports in mental health. Her presentation is available here: In defence of clinical trials (up to a point!). Amy Price subsequently wrote a review of the paper which can be viewed on the Mental Elf website.

**What will happen next?**

We’re going to summarise the discussion around RCTs in booklet which will be available later in the year. You can read the discussion on twitter by searching the hashtag #RCTDebate – and please feel free to continue to use it to share your views. You can also get in touch with us at contact@mcpin.org.
The Other Side of Silence: A Psychiatrist’s Memoir of Depression

By Linda Gask

ISBN: 1849537542

A few months ago I was on a conference telephone call with colleagues for a research project I am working on. The team is dispersed. Linda lives in Scotland, other members of the team are based around Birmingham, across Devon and Lancashire and I am in London. Conference calling is a good way of keeping a research team together. Linda mentioned she was coming down to London to do a photo shoot for her book. The Times were planning a feature piece for September. I was intrigued – what’s the book about?

It is about the story of Linda Gask – psychiatrist, academic and person living with depression. “The Other Side of Silence” is compelling reading – well I think so! It is both a memoir and a book to educate others about what it feels like to live with depression. Linda sent me an early copy and I dipped into the chapters – on “fear”, “loss”, “love”, “grief” and “loneliness”. It is really well written. I mean that – I found it engaging, thought provoking and so interesting for ‘telling it how it is’. The text is broken with reflections from seeing patients over the years (some detailed changed of course) or details about her own treatment and state of mind in the past. It is, however, mostly prose outlining very personal reflections on her life exploring many emotions and explanations for why she felt the way she did and coping strategies she found along the way. The message is clear: “I’ve survived and come through it, and I know others can too”.

But within this strong message is also a journey of pain and darkness:

“In the last decade I have experienced a relapse of my depression every couple of years or so. I have now taken one antidepressant or another continuously for more than 20 years. I have experienced some side effects, but I can usually tolerate them. My periods of low mood, which have from time to time been more severe, necessitating a change in my treatment, have almost always been triggered by life events related to my work. My skin is still too thin and I am easily wounded, and I still live my life in a state of perpetual fear of
being discovered to be a fraud. I am frequently anxious. Day-to-day life can still be a struggle. Yet, despite experiencing depression, I have achieved a great deal…”

I really did feel like I was getting to know Linda which was very odd because up until that point all I knew of her was her eminent reputation as an academic, and a glimpse of the person through being in meetings together. I knew she was straight talking and intelligent, decisive, hugely experienced in delivering large scale research studies and developing new ways of doing things in mental health care, was personable, friendly, loved cats and I had a sense always wore mainly black clothes. As I started reading ‘The Other Side of Silence’ I had a feeling that clothing choices were going to become particularly relevant.

What I was to learn and you will also if you read the ‘The Other Side of Silence,’ is how it felt to pass through ordinary stages of life through a lens of living with depression – and why. Leaving home, getting married, changing jobs, death of a parent, establishing and ending significant relationships. A key theme in the book is Linda’s fear of failing – her exams, being the doctor her patients need, and as a daughter, sister and wife. Depression and anxiety envelop her through every life stage, and looking back she tries to explain why. I hope that this book feels like a massive achievement. Being able to read about a person I very vaguely “know” through a beautifully crafted book that really does humanise what it is to live with a mental illness, was a privilege. I am not sure what I will say to Linda when I next see her – I think a hug is probably the first part of the communication. I really feel books like ‘The Other Side of Silence’ help demystify mental health. When I was doing my PhD research, I befriended a person to ‘give back’ into a community I was studying and to understand psychosis better through having a relationship with someone who could tell me far more than reading research papers. The second best thing was reading autobiographical books. I always recommend such books to new staff as a “way in” to understanding mental health and mental illness. We now have another book on the shelf to help us open up conversations about “madness”.

My interest in Linda’s book also stems from insights we might learn about the role of lived experience in mental health research. This is what the McPin Foundation is developing as a particular strategy for helping to improve mental health research. What did Linda Gask, the psychiatrist, academic and person living with depression, make of her contribution to research? We did not learn that much about her research career from the book to be honest, so I asked if we might explore that in a Q&A dialogue. We spoke for 10 minutes about these issues and you can listen to our discussion by clicking here.

Book review by Vanessa Pinfold, Research Director, the McPin Foundation
Madness in Civilization: A Cultural History of Insanity, from the Bible to Freud, from the Madhouse to Modern Medicine
By Andrew Scull

ISBN: 0691166153

Scull has written a beautifully illustrated book that should be commended for its clear and accessible writing style. It is an ambitious text that spans nearly 3000 years and numerous societies including ancient Israelite, Greek and Roman cultures, Imperial China, the UK, France, Germany, America and Japan. The book is divided into twelve chapters which cover a broad range of topics from madness in the ancient world; a history of 'madhouses' and 'mad doctors'; the birth of the modern asylum; the development of psychoanalysis; and the origins of contemporary psychiatry.

Amongst other things, Madness in Civilization explores the divergent ways different cultures at distinct historical junctures have received and understood mental illness. Scull outlines how in the ancient world a spiritual cause was often ascribed to madness. In ancient Israel, the Hebrews looked to punishment from God, to possession by evil spirits, and also to divine inspiration that could cause a person to prophesise. Greek physicians put forward the idea that an imbalance of the four basic elements namely, blood, phlegm, yellow bile and black bile that made up a person could cause madness. In contrast in Imperial China, actions in a past life, destiny, ghosts, possessions by demons and ruptures in the cosmic world were as likely to be appealed to as reasons for madness as internal problems in the body.

One area of concern I have is the breadth of Scull's study. He is right to acknowledge that, '[w]e run enormous risks of misconstruing history when we project contemporary diagnostic categories and psychiatric understandings back on the past' (p.15). Whilst Scull talks of 'madness' and 'insanity' in the title of the book he does not attempt to define what he means by these terms in the text. On one level this is understandable as different societies formulate ‘madness’ in different ways at different times and exploring this is in many ways the point of the project. However, on another level it is frustrating, as the figure of the ‘lunatic’ the ‘raving’ or the ‘violently mad’ person is at times lost in a discussion of ‘melancholie’, nervous disorders, and ‘The English Malady’, a fashionable disorder amongst the rich and the cultivated. What is already a marginalised phenomenon is thus in a way re-
marginalised: the book becomes less a history of madness and more a history of mental illness.

Because the scope of Scull’s overview is so vast it is perhaps inevitable that the book is less clearly focused than it might be, scanning across the meanings of madness and mental illness in vastly different cultural contexts, looking at representations of madness in art and literature, presenting histories of the asylum, of psychoanalysis and of psychiatry. However I greatly enjoyed this book, particularly the last chapter, ‘A Psychiatric Revolution?’ which contextualises the advent of psychotropic medications and the closure of the major asylums; and I would recommend Scull’s study to anyone interested in a very broad overview of the cultural history of mental illness.

Book review by Harminder Kaur

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

Recent publications

The past few months have seen a number of interesting articles relating to service user involvement published, including notable achievements by the McPin team.

These include success for one of our PARTNERS2 Lancashire Lived Experience Advisory Panel members, Lindsey Cree, whose article entitled, Carers experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services, was published in the August edition of Biomed Central Psychiatry. Herself a carer this study led by Lindsey has developed the understanding of the potential role of carers within the care planning process within mental health services, along with the facilitators and barriers to achieving optimal involvement. The full-text article is available here.
Also published in the September edition of *The Lancet Psychiatry* an article by Charlotte Walker who works as a peer researcher for McPin. Charlotte’s article, *Beyond Boundaries*, explores her personal experience of conducting interviews as part of a qualitative study run in partnership with University College London exploring how women with severe mental illness decide whether to take antipsychotic drugs or mood stabilisers during pregnancy. Here, Charlotte considers the power dynamic in qualitative interviews, and how social media demands the renegotiation of more traditional notions of boundaries in research.

‘*In the era of social media, interviews are not necessarily controlled by the interviewer but are a fluid exchange of ascribed power, experiential expertise, and potentially unbalanced online knowledge of one another.*’

In same edition of *The Lancet Psychiatry*, Fenella Lemonsky, writes about mental health service user involvement in clinical research. In her article entitled ‘service user involvement in research’ Fenella writes that:

“It is time for clinical researchers who have no clear commitment to service user involvement to change their outdated attitudes, especially now that service user researchers are very much part of academe”. Fenella covers other issues in her article such as how to properly pay and reward service users who get involved in research.

The full-text of the article is available here.


Joanna highlights the increasing importance of experiential wisdom derived from the expert knowledge of services users and carers in all aspects of UK mental health practice, research and education.

To find out more about Joanna Fox and her research please click here.
And elsewhere in the news

Mindfulness

Earlier this month The Guardian reported on a new mindfulness study that plans to track the effects of meditation on 7000 teenagers. The £6.4m study from Oxford University and University College London plans to recruit children aged 11-16 from 76 secondary schools as part of the seven-year study, in what the researchers claim to be ‘largest trial of its kind ever conducted and it would test some of the increasingly ambitious claims about the power of mindfulness meditation to tackle illnesses such as depression and anxiety’

The research is timely, as today saw the launch of the latest report by the Mindfulness All-Party Parliamentary Group (MAPPPG), based on evidence presented to the all-party group of the UK parliament. The ‘landmark’ British report, Mindful Nation UK, is the first policy document of its kind, and lays out recommendations for the provision of mindfulness interventions across many public policy areas including, education, health, the workplace, and the criminal justice system.

However, adverse reactions to Mindfulness have been reported including rare cases of de-personalisation. Ahead of the launch, Jon Kabat-Zinn - the founding father of Mindfulness-Based Cognitive Therapy – emphasised the ‘huge health potential’ of mindfulness – ‘but Mindfulness is no panacea’. Jon Kabat-Zinn began teaching his Mindfulness Based Stress Reduction Course (MBSR) at the University of Massachusetts Medical Centre in the late 1970s.

A recent blog from the University of Oxford Mindfulness Centre (OMC) emphasises the importance of taking the ‘long view’ on mindfulness and mindfulness-based cognitive therapy. In the long view, what will support sustainable development of this field? That any mindfulness-based intervention must: be clear about its intentions, aims and context; be ‘mindful of the evidence base’, and that the science be reported responsibly; there must be leadership around training standards and best practice in the teaching of mindfulness; the importance of learning through practice, training and science. ‘This work is invitational, empirical, participatory and democratic’.

Depersonalisation disorder: the condition you've never heard of that affects millions

The Guardian produced an interesting article on ‘depersonalisation disorder’. Depersonalisation disorder, or DPD, is characterised by persistent or recurrent experiences of feeling detached from one’s surroundings, mental processes or body.
Individuals may report feeling as if they are in a dream, or watching themselves in a movie. The disorder is thought to be largely under-recognised and misunderstood by many, including health professionals.

Brain game ‘improves lives of schizophrenia patients’

The BBC reports on a new, computer-based ‘brain-training' game, designed to improve the lives of people living with schizophrenia. The iPad game, developed and tested by researchers at the University of Cambridge, claims to improve episodic memory – our memory of specific events, situations and experiences - and daily functioning in schizophrenia. Click here to read the original research paper.

Elsewhere, the BBC reports on a study by The Nuffield Trust that reveals ‘striking’ disparity in emergency care use for people with mental ill health. People with mental ill health had almost five times more emergency hospital admissions last year compared to people without; yet the vast majority of these emergency admissions were not explicitly to support mental health needs, and a proportion of them were potentially preventable.

And finally, The Guardian Datablog asks ‘In which countries does mental health have the most impact?’ Using a measure called a DALY (Disability Adjusted Life Years). The World Health Organisation describes a DALY as ‘The sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability’.

Using the DALY measure Estonia comes out as the most affected country in the world with the West African country Burkina Faso the least.

The Mental Elf (www.nationalelfservice.net/elf/mental)

The Mental Elf seems to get busier by the day! New blog entries are appearing almost every day. The growing list of people that review papers for the Mental Elf could well be responsible for this. We are delighted that Laura Hemming (a Researcher with the McPin Foundation) has recently been accepted by the Mental Elf as a blogger!
‘No proof that 85% of mental health apps accredited by the NHS actually work’

One of the most thought provoking offerings from the Mental Elf is about mental health apps. More specifically those apps that are accredited by the NHS. These apps are listed online in the NHS ‘mental health apps library’. Most of these apps (14 out of a total of 27) are aimed at helping people suffering from depression and anxiety.

The article focuses on a British Medical Journal paper by Leigh and Flatt entitled ‘App-based psychological interventions: friend or foe?’

One of the take home messages of the paper and the Mental Elf review was that:

“just 4/14 are able to provide any tangible evidence of outcomes, as reported by real-world users, to substantiate their claims, while just 2/14 make use of NHS-validated performance measures”.

In other words there isn’t good evidence for most of the mental health apps that they actually work. This is surprising as the NHS in recent years has been very focused on only doing something if there is evidence that it works. This is generally known as ‘evidence based medicine’. Please do read the original paper and the Mental Elf review to find out more.

Other highlights include:

**Antidepressant meta-analyses: big business and bias**

Click [here](#) to read the article.

**The scars of modern slavery: trafficked people with severe mental illness.**

Click [here](#) to read the article.

**Postnatal depression: is it a unique mental health difficulty, or part of a trajectory of depression across the life-span?**

Click [here](#) to read the article.
Easy ways to support the McPin Foundation this Christmas

1. Buy our Christmas cards and help promote McPin by sending them to your family, friends and colleagues!

This year we partnered up with Core Arts – A mental health creative day centre in Hackney, and ran a competition for one of their members to design the artwork for our 2015 Christmas card. The winning entry by Ben Gooch is shown above. The cards (148 x 148mm) and envelopes will be sold in packs of 10 and will cost £4.50 per pack (free postage)! If you would like to enquire or place an order please email annabelledavies@mcpin.org.

2. Shop online using the portal Easyfundraising – charities of your choice get a percentage of what you spend online. You can nominate any charity or group – we’d love it if some of our supporters could support us this way. For more information please click here. Most importantly, it does not cost you a penny. The retailers you purchase from make donations to us based on what you spend with them.