McPin Public Involvement in Research Bulletin

Issue 2: March 2015

This is the second 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 be 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
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*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

McPin Public Involvement in Research coordinator

We are recruiting a **Public Involvement in Research coordinator** who will support our user-led programme including providing lived experience expertise within an NIHR study called PARTNERS2 coordinating advisory panels. We need a motivated and skilled team player, with experience of involving people with mental health problems in research, to join a team of experienced public involvement in research experts and mental health researchers to deliver engagement programmes with McPin Foundation supporters.

The post is full time (37.5 hours Monday – Friday) based at our offices in central London – Southwark.

**The closing date for applications is 7th April, 9pm.**

We will be interviewing week beginning 13th April 2015.

Interested? Please read the job summary: [PliR coordinator Job Description March 2015](#)

To apply please complete an application form: [McPin-application-form- PliR coordinator March 2015](#) and [Equal-opportunities-monitoring-form-PliR coordinator](#)
Are you an experienced mental health trainer with expertise in bipolar or schizophrenia?

The PARTNERS2 research study, funded by the NIHR programme grant for health, is looking for an experienced mental health trainer to work immediately with the team to develop a training manual and deliver training to front line mental health staff. The trainer must have personal experience of schizophrenia, bipolar or psychosis and draw on these experiences in their work.

What is PARTNERS2?

PARTNERS2 aims to help primary care and community based mental health services work more closely together. We think this could be achieved by developing a system of collaborative care based in GP surgeries where many adult service users are seen regularly by an experienced mental health worker who acts both as overall co-ordinator or care partner (supporting individuals to access other services and activities) and therapist. This person would see the person regularly, help them help themselves and facilitate recovery in the broadest sense and, where required, call on the talents of other parts of the health service, particularly secondary mental health care and voluntary/community organisations. This is a simple idea - but we need to work through all the details carefully by testing things out and then set up a pilot trial to see if it makes a difference to the care provided and try out the use of a range of outcome measures.

At the end of the five year Programme, we will know if collaborative care for people with schizophrenia and bipolar disorder in England is likely to work, based on the views of all the people involved in setting it up and using it, how well people are feeling in themselves, the quality of their lives, how many feel they are more recovered, and what the system costs to run. More information is available at: http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PCCS/partners2/index.aspx

You can find out more about the service user and carer involvement in PARTNERS2 by clicking here: http://mcpin.org/wp-content/uploads/Our-PPI-plan.pdf

Tender specification

We are looking to appoint a trainer to work for up to 4 months (April – July 2015). The whole project has a well developed programme of involvement for service users and carers and we want to make sure this is incorporated into the training of staff. This short project involves:

- Working with researchers on the PARTNERS2 team to write a training manual. This manual draws on a year of research into recovery, collaborative care and service user / care experiences of current care pathways for people with schizophrenia and bipolar.
• Working with researchers on the PARTNERS2 team to **develop a 2-day training programme** for mental health staff in collaborative care. The staff will be drawn from the three pilot areas – Devon, Birmingham and Lancashire.

• Working with researchers on the PARTNERS2 team to **deliver the 2-day training programme on collaborative care** as part of a training team that will include Academic GPs and/or psychiatrists (who are experts in collaborative care), PARTNERS2 lead researchers developing the intervention and other people as required. The role within the training team will be to specifically to draw on personal experiences of mental health problems alongside training expertise.

PARTNERS2 is based in Devon, Birmingham and Lancashire. The lead for the development of the training is in Exeter and thus the trainer needs to be able to travel easily to Exeter for face to face meetings.

The budget for the work is £300 per day (including VAT). We estimate that over the 4 months this will require up to 15 days. The maximum cost of this contract will be £4,500 including travel expenses.

Interested? Please contact:

Vanessa: Vanessa.pinfold@mcpin.org or Ruth: R.C.Gweman-Jones@exeter.ac.uk

To apply: please send your CV, including two referees and covering letter explaining why you are suitable and why you are interested in this work to either Ruth or Vanessa by 7th April 2015. We will short list from CVs and invite people to interview in order to commission this work.
Interested in contributing to health research?

The National Institute for Health Research (NIHR) needs people with everyday experience of having or caring for someone with a mental health problem to comment on research proposals. **In particular we need more reviewers who are parents of children with mental health problems and young people (aged 16 and over).**

As a public reviewer for the NIHR, Evaluation, Trials and Studies (NETS) programmes, you could be invited to read a research proposal or commissioning brief related to your own ‘lived experience’ and answer some key questions. Your comments would go on to inform the funding board or panel in making a funding decision. Each review is a stand-alone task, which is sent to you to do in your own time, to an agreed deadline. We do offer payment for reviews undertaken by public reviewers.

The NIHR funds health research that produces evidence for health professionals, policy makers and patients, so they can make informed decisions. And we know that research that reflects the needs and views of the public is more likely to produce results that can be used to improve health and social care.

**To express an interest** in being a public reviewer for research proposals please email us on [netspublic@southampton.ac.uk](mailto:netspublic@southampton.ac.uk) or call a member of our team on 02380 599302.

Other ways of helping to shape health research include:

- Suggesting a research topic
- Becoming a public member of a panel or board.

**To find out more:** Visit [www.nets.nihr.ac.uk/ppi](http://www.nets.nihr.ac.uk/ppi)
We are seeking to employ a researcher who is interested in using their own lived experience of mental health problems in their work (as a peer researcher) in this important evaluation of the national mental health charity Mind’s new Big Lottery funded programme of peer support. The post-holder will be a key member of the team from the Population Health Research Institute at SGUL, working alongside researchers from the McPin Foundation and the Mental Health Foundation. The evaluation will comprise a number of strands determining the effectiveness of new peer support interventions, developing a change model and establishing the principles underlying peer support, and exploring the commissioning of peer support services in mental health. The post-holder will undertake literature review and scoping work at the outset of the project, coordinate data collection through an online ‘peer support diary’ in Mind peer support projects across England, and will provide additional support to qualitative components of the evaluation. The team at SGUL has a strong track record in supporting researchers to use their lived experiences of mental health problems in their work.

It is essential that applicants have experience of the development and conduct of quantitative or qualitative research in a mental health setting as well as experience of using personal lived experience of mental health problems in a research capacity.

Further details: download the job description [here](#)
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
Are you a member of the public involved in the work of the National Institute for Health Research (NIHR)?

Would you like more information on how payment of fees and expenses for being involved in research might affect your state benefits?

Contact our new, free, confidential advice service run by Bedford Citizens Advice Bureau, launched 29 January 2015.

Who can use the Benefits Advice Service?

If you are a member of the public involved in an NIHR organisation, or in a research project funded by the NIHR, you can use the service. There are different ways you might be involved, such as in reviewing research funding applications, as a member of an NIHR board or panel, or working with an NIHR funded research team or study.

What does the Benefits Advice Service offer?

The service is free and confidential. Specially trained staff with knowledge on how payment for involvement might affect state benefits will be able to give you personal advice.

The service:

- provides advice based on the benefits you are receiving, to help you decide if and how you want to get involved in research or receive payment for your involvement
- provides supports you should you need it to make contact with the Department for Work and Pensions, or other benefits agencies about your involvement work.

How can I contact the Benefits Advice Service?

Contact INVOLVE by email benefits@invo.org.uk or phone 02380 651088. Tell us the name of the NIHR organisation you are involved with, or the name of the NIHR programme funding the research project you are involved with. We do not need to know anything about your benefit situation.

We will give you an email address (or telephone number) so that you can contact the Benefits Advice Service directly. We will also give you a code. Please give this code to the service when you contact them.
The service prefers that the first contact is by email if possible. The service will then arrange a time to call you. If you do not know if the organisation you are involved with is part of the NIHR, please contact the person who asked you to get involved. They should be able to advise you further.

Please note:

The service is not able to give advice on tax or National Insurance queries or for benefits enquiries relating to payment for participating in research (for example, for taking part as a subject of a clinical trial or research study).

Articles

The Nocebo effect

In the last edition of the Bulletin I had an article about some research into the Placebo effect and antipsychotics. The Placebo effect is reasonably well known. But I wonder how many people have heard of the Nocebo effect? I had never heard of it until I listened to a Radio 4 programme entitled 'The Placebo Problem'.

I later found a rather provocatively titled article on the same topic on BBC website entitled ‘The contagious thought that could kill you’.

So first of all what is a ‘Nocebo’? A Nocebo is something that has harmful effects in humans. Just about any medication that you will ever take could therefore be classed as a Nocebo. As well as having positive effects almost every medication has negative effects too. Let’s take ibuprofen as an example. Ibuprofen may well help with aches and pains but it also attacks the lining of your stomach, it can cause nausea and vomiting, and so on.

So what is the Nocebo effect? Loosely speaking it is the harm caused by taking a Nocebo. But it’s a bit more than that. Let’s go back to the example of taking ibuprofen. If you were told by someone that ibuprofen will help you but it also has harmful side effects there is some evidence that you won’t do as well as someone who isn’t told of the harmful effects of the Nocebo (ibuprofen) in the first place. In other words, the expectation of a
negative effect seems to do real harm on top of the actual negative effects of the Nocebo itself.

The Nocebo effect has been described as the ‘twin sister’ of the Placebo effect. The Nocebo effect seems to be just as real as the Placebo effect and it’s arguably even less well studied and understood. In a 2014 mini review of the Placebo and Nocebo effects Ivan Požgain and others state that “regarding psychiatry, the placebo effect has a substantial role in most of psychiatric conditions including depression, anxiety, addictions, and contrary to what may have been expected, schizophrenia. Likewise, the Nocebo effect is not to be neglected as the studies are being conducted to identify the factors causing it so it could be prevented”. Very interesting …

*Thomas Kabir*

**How can you tell if research is any good?**

There’s a lot of research going on around the world. But how do you tell if it’s any good? All research has its limitations. Whether it’s only having a tiny number of participants in a study and then saying that the findings apply to everyone, or simply drawing the wrong conclusions from your data, all research has its strength and weaknesses. Mental health research is certainly no exception!

So how do you assess the strengths and weaknesses of a research study? Well it’s not easy and lots of people have been trying to work out good ways of doing this for a very long time. Assessing the strengths and weaknesses of a research study is generally known as ‘**critical appraisal**’. Critical appraisal is fast becoming a field of study in its own right.

So where do you start? Well, this is a massive topic so all I can do in this article is perhaps to just make some suggestions. Everyone has their own way and I don’t want to say that there is any single ‘right’ or ‘wrong’ of working out what the strengths and weaknesses of a research study are.

So here is a suggested step by step process that I hope might be useful…

**Step 1: get hold of the research in the first place.** Most of the time research is published in journals or magazines. The Mental Health Research Network put together a [guide](#) to finding and reading research publications which is very helpful.
A real problem here is research that has not been published. It’s going to be hard if not impossible to appraise research if you can’t get hold of it. To further complicate matters, there are some indications to suggest that research that shows positive findings are more likely to be published than those with negative findings.

Step 2: understand the research. This is a massive. For starters research is full of jargon. INVOLVE have produced a very useful jargon buster which should help here. It’s also important to understand the ways that the research has been carried out. There are many, many, ways of designing and carrying out a research study. Gill Grimshaw from Warwick University has put together an excellent Research Methodology Guide which should help.

Another useful resource is a book called Testing Treatments and its associated website, Testing Treatments interactive (www.testingtreatments.org). As the title of the book and website suggests the main focus of the book is treatments. The aims of the website are stated as being to help you:

‘1. Learn more about why it is important to test treatments carefully
2. Recognise reliable research
3. Understand what you can do to help make sure that research is more likely to be relevant to you and others’

For our purposes it’s the second point that is most relevant. Chapters 6 (fair tests of treatments) through to chapter 10 (research – the good, the bad, an unnecessary) of the Testing Treatments book are possibly the ones that are most valuable. You can download the entire book for free by clicking here.

Step 3: appraise the research (aka what are the strengths and weaknesses of the research?)

There are different options here:

a) You can rely on someone else to appraise the research for you. The Mental Elf has a large team of people that do exactly this. If you see something in the news and want to know if it’s been reported on accurately the NHS Choices has an excellent Behind the Headlines section on its website. One of the great things about the NHS Choices ‘Behind
the Headlines’ section is that it also appraises the quality of the research reported on in the press.

b) You can appraise the quality of the research either by yourself or working together with others

c) A combination of a) and b)

Let’s assume that you decide to follow option b) and you appraise the research yourself. My favourite way of getting started is to work my way through a checklist.

There are lots of different checklists out there. There are even ones for looking at the quality of service user and carer involvement in a study.

I like using the ones that are produced by the Critical Appraisal Skills Programme (CASP), www.casp-uk.net.

If you would like to have a look at some others then Cardiff University maintains a nice list of critical appraisal checklists. There are eight different checklists on the CASP website to choose from. There are different checklists for different study designs (qualitative research, systematic reviews, and randomised controlled trials, etc.).

The CASP website has a very helpful description of different study designs. This helps enormously when deciding what checklist to use. Each checklist consists of a number of questions that are designed to help you appraise the research. The checklist are “designed to be used as educational tools as part of a workshop setting”. I think that these checklists can be used individually or in a group setting but this is a personal view. Along with working your way through a checklist I like using a great poster entitled ‘a rough guide to spotting bad science’. It was produced by a group known as Compound Interest (www.compoundchem.com). The poster is in itself a kind of checklist. It picks out some of the most common flaws to look for in a research study. I’ve reproduced the poster on the next page and you can download a copy by clicking here.
After working my way through a checklist or two you should have some idea of the likely strengths and weakness of the research that you are looking at. For examples of real appraisals have a look at the Mental Elf website (www.thementalelf.net). In a short article such as this all that I can do is to scratch the surface of this huge topic. But I hope that it is helpful.

Thomas Kabir
Book reviewers needed!

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

'Skunk-like cannabis' increases risk of psychosis, study suggests

A study from Kings College London suggests that smoking ‘skunk like cannabis’ is associated with a “24% of all new cases of psychosis”. [That is new cases of psychosis in South London …]

The study is based on data from 780 people from South London between 2005 and 2011. The paper was published in The Lancet Psychiatry.

You can read the full paper by clicking here.

The lead author of the paper, Marti Di Forti said in a press release that “Compared with those who had never tried cannabis, users of high potency ‘skunk-like’ cannabis had a threefold increase in risk of psychosis,” “The risk to those who use every day was even higher; a fivefold increase compared to people who never use”.

As you might imagine the research got quite a lot of attention in the press. The BBC reported on the research as did the Telegraph, and The Guardian. The reaction to the research was interesting. A researcher called Suzi Gage subsequently wrote a very articulate article looking at the research and the ways that it was reported on in the press.
Suzi Gage points out that “there’s lots of consistent evidence associating cannabis use with psychosis and schizophrenia, but as the saying goes, correlation isn’t causation”. Her article is in effect a critical appraisal of the research and Gage goes on to describe the limitations and weaknesses of the study. The Mental Elf very recently appraised the study as well and you can read the review by clicking here.

‘Mental health budgets cut by 8%, according to new research’

According to the BBC and Community Care “Mental health trusts in England have had their budgets cut by more than 8% in real terms over the course of this parliament, according to new research”. You can watch the BBC News report by clicking here.

Mind and a number of other organisations commented on the research.

The Mental Elf (www.thementalelf.net)

Recent Mental Elf highlights include:

Helping people with depression return to work

Click here to read the article. This is an appraisal of a Cochrane review entitled ‘Interventions to improve return to work in depressed people’.

You can read the orginal full review here. The Mental Elf summary of the findings of the Cochrane review was as follows:

There was inconsistent evidence regarding antidepressants. There was some evidence that psychological therapies could help. Looking at psychological therapies combined with antidepressents “there was high quality evidence that a telephone outreach management program can be effective in reducing sick leave compared to care-as-usual”. And “There was low quality evidence that exercise was more effective than relaxing in sickness absence reduction”. And finally, “There was moderate evidence that a work-directed intervention plus a clinical intervention reduced sick days when compared to clinical intervention alone or a work intervention alone”.

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Coproduction of quality standards for youth mental health in primary care

Click here to read the article

Cognitive bias modification for anxiety and depression: is practice based on sound evidence?

Click here to read the article

Mindfulness based group therapy for common mental health disorders

Click here to read the article

Peer support workers in mental health: Is the NHS ready for this?

Click here to read the article. This is an appraisal of a study entitled ‘New ways of working in mental health services: a qualitative, comparative case study assessing and informing the emergence of new peer worker roles in mental health services in England’. The research was carried out by Steve Gillard and others at St Georges, University of London. You can read the full report of this research by clicking here.

I won’t try and summarise the findings here. They are quite complicated and hard to summarise in a few sentences. Have a look at the Mental Elf article and the report and then decide for yourself!

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