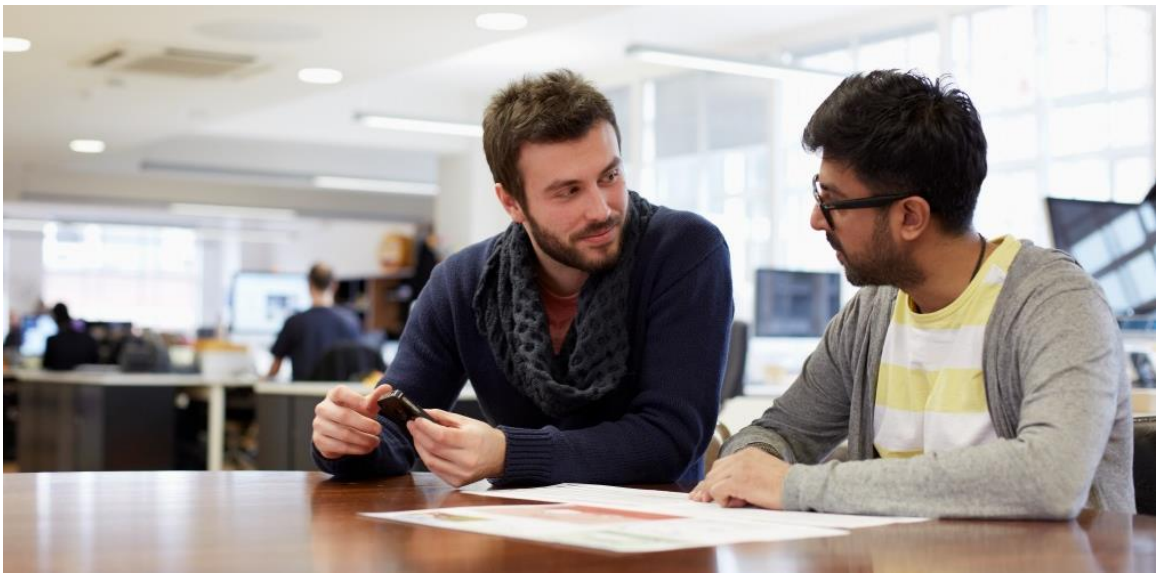
McPin Foundation

Transforming mental health research

T: 020 7922 7877 E: contact@mcpin.org www.mcpin.org



Welcome to the sixth edition of our newsletter. Summer is on the way – hopefully – and we wanted to share our news with our supporters, update on new opportunities to get involved with us and reflect on some research in the news. What does a new UK government mean for mental health research? There is a task force set up to generate a "five year forward view" and produce an all age national strategy for mental health in the autumn. And yes 'research' gets a mention in the scope of the task force which is a positive step forward for us in the research community. In this edition we look at mindfulness, experiences of crisis care services and a new area of work for us – the mental health sciences.

## Our News

This month we started work on an exciting new project; an evaluation of a national **Peer Support programme**. It is led by Mind, Bipolar UK and Depression Alliance, funded by the Big Lottery, and aims to promote peer support and develop local peer support projects in communities across England. Building an evidence base for peer support is one of the

programme's objectives. This is really important because there are still many unanswered questions about mental health peer support. Here are a few:

*What are the principles and values that underpin different models of peer support?*

*Who benefits from peer support and who doesn't?*

*Is peer support cost effective?*

We hope to address some of these questions during the project over the next 2 years, and will be doing this in collaboration with some very knowledgeable and experienced people; our evaluation partners and study lead at St Georges University of London as well as the London School of Economics.

Our evaluation team is taking a 'coproduction' approach, which means peer voices (from people with experience of mental health problems) are working alongside others to deliver the study. This way of working is different to how an academically or clinically led mental health evaluation might usually be done. We believe this approach places powerful knowledge, grounded in lived experience, within the evaluation as a key asset to draw upon alongside expertise in research methodology, statistical analysis and economic assessment. Many of us have personal experience of mental health problems, and will be supported to actively use our lived experience during the project. This personal voice is already evident in the commitment and passion of our team members, and we hope that this connects with other parts of the Peer Support programme over the course of the study. We look forward to welcoming three new peer support evaluators to the team shortly from our study sites in Blackpool, Suffolk and London.

So how are we going to be evaluating peer support? Much of the project is guided by the funder Mind on behalf of Bipolar UK and Depression Alliance. They have asked us to look at:

*What impact does the programme have on the people that it is meant to help?*

*What are the most important principles that are true for all peer support, even if the support looks very different (in a group, one-to-one, online etc)?*

*How are the programme and the different projects working to improve things for the people who engage with the peer support?*

*Is peer support 'good value for money'?*

*Has the programme influenced mental health commissioners' views about whether they should pay for more peer support projects in the future?*

We have already started with our application for ethics submitted and our first consultation event to look at principles and values in peer support complete. This was a great event held on 11th of June with a great bunch of people who had a lot to say about peer support. We started the day with almost 40 different principles and values, but by the end of the event, had agreed on 11 that people thought were the most important. We take these to Leeds at the end of June and it will be interesting to see whether the same or different discussions are held.

But there is a lot to do and you can help too. Are you interested in peer support? Want to share your views? Please do complete out online consultation **here**.

We are going to be in touch with lots of people over the next 2 years, and we really look forward to working with colleagues at St Georges and London School of Economics. We are going to learn a lot as a team in this project – we hope others will benefit from this evaluation journey too.

## Shaping McPin

**A new area of work for the McPin Foundation – mental health sciences**

"Thomas – you need to look at a protein structure from lots of different points of view to understand how it works". This was some of the most valuable advice I ever got when I was doing my PhD. I was studying how proteins stick to one another to form complexes at UCL in London. Proteins are 'nature's robots'. They do everything from fighting infections to carrying oxygen around the body. At the time I was a bit fixated on looking at protein structures that had been discovered using one particular technique.

How proteins work depends a lot on their shape. Proteins are a bit like keys. If the shape of a key is out by even a little then it may not work. To understand the shape of a protein you need to use a number of different techniques and to quite literally look at its structure from a number of different angles.

I actually believe that the same **principle** is true for mental health. Mental health is complicated. It's **very** complicated. I don't think that many people would disagree with that. And to make progress in truly understanding and treating mental health problems we will need to use a number of different approaches.

At the McPin Foundation we are beginning to work in areas that we have not worked in before. The aim of this is to look at mental health problems from a variety of different perspectives. We hope that this will lead to greater understanding, and ultimately better ways of treating mental health problems.

**New Studies!**

So what are we going to be doing? Firstly, we will be working with a team from the Institute of Psychiatry, Psychology, and Neuroscience on developing a new version of cognitive bias modification for psychosis. Cognitive bias modification has received quite a lot of attention in recent years and a multitude of self-help smartphone apps based on this approach have been developed. But, as highlighted by recent Mental Elf reviews, there is a pressing need to carry out further

research to assess how well it really works. We will be providing public and patient involvement into the study.

Secondly, we are currently working with researchers from Cambridge and Oxford on a possible new way of understanding and treating some people with psychosis. There is evidence that around 6% of people that present to services with psychosis have very particular kinds of antibodies in their system. 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. 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. Crudely put, the end aim of the study is to see if someone gets better when you target the antibodies. You can find out more about the research by looking at the study website (www.sinapps.org.uk) or by clicking here. We are currently looking for people to join the Lived Experience Advisory Panel for this study. For more details please see the opportunities section of this newsletter.

The third study that we are working on together with researchers from University College London is a study comparing an antidepressant called Sertraline with cognitive behavioural therapy for people with generalised anxiety disorder. Again we are organising patient and public involvement through a Clinical Advisory Group made up of three people who manage anxiety problems.

These studies collectively fall into a new area of work here at the McPin Foundation that we call 'mental health sciences'. This area of work complements our more socially orientated research well. Needless to say, we will put the lived experience of people with mental health problems at the heart of our work in the field of mental health sciences. This is a new and exciting venture for us. We hope it will take us one step further towards our mission to 'transform mental health research'.

## Research in the news

Over the past couple of months, **mindfulness** has been making headlines again. This is partly due to a new study, published in the Lancet that suggests that the practice is 'as effective as pills for treating recurrent depression'.

It is fair to say that for some years now, there has been a lot of hype surrounding mindfulness – a type of therapy that draws on aspects of ancient Buddhist practices and is aimed at 'increasing people's awareness of themselves, their emotions and the environment around them, through meditation, yoga and breathing'. Perhaps predictably, there has also been a backlash – with critics urging us to 'be mindful' of what some have dubbed 'McMindfulness', often suspicious of its increasing commodification and positioning as a panacea for all ills.

But what does the existing research – and especially the Lancet study – tell us about the effectiveness of mindfulness-based interventions? The study consisted of a randomised control trial involving 424 individuals drawn from 95 general practices in the South West of England. All were receiving maintenance antidepressants at the point of being recruited to the trial, and all had had three or more previous major depressive episodes. Half of the group received a mindfulness-based cognitive therapy (MBCT) class and were supported to taper or discontinue antidepressant treatment, while the other half continued with their medications. Both groups of people were followed up over a 24 month period. The study found that 'both treatments were associated with enduring positive outcomes in terms of relapse or recurrence, residual depressive symptoms, and quality of life'.

These findings add to a growing body of research spanning over a decade that suggests that MBCT is effective in helping people with ongoing problems with depression. This is not 'new news' – MBCT has been recommended by the National Institute of Clinical Excellence as a treatment for recurrent depression since 2005, and it is endorsed in the Chief Medical Officer's report. And yet depression remains not only the most common mental illness, but also one of the most tenacious. The increased use of maintenance antidepressants as a way of preventing relapse has failed to improve longer-term outcomes for those most at risk – who often find that the medications lose their effect over time, or may be associated with unpleasant side effects. Alternative evidenced-based therapies such as MBCT are not widely available, with only a handful of CCGs offering it in their area. In this context, the Lancet study, which is the first definitive trial that compares an MBCT approach with maintenance antidepressant treatment, makes a powerful case for the overhaul of existing treatments and services for people with depression.

So far, so good. But what about mindfulness for the masses? Mindfulness for those who get stressed at work (isn't that everyone?) Mindfulness that can 'boost your career and help you get a job'? Mindfulness to help high-achieving young people cope with pressures at school?
What do we make of the poster for a mindfulness course on the wall of the kitchen of our serviced office space? Well – one of my colleagues is trying it out. And, as a team, we're thinking about a mindfulness workshop for our annual 'wellbeing day' later this year.

A quick scan of news articles during the weeks following the publication of the study – as well as my own network of friends, acquaintances, colleagues suggests that there is far more public and professional interest in mindfulness as a wellbeing promotion mechanism than as a form of evidence-based treatment for a diagnosed mental health condition. In many ways, this is good news reflecting a shift in mental health practice and policy, which is increasingly focused on prevention and early intervention, and not just mental health treatment.

This shift towards 'keeping people well' is something that we have observed in the context of our evaluation of Kent County Council Public Health's Mental Wellbeing Programme. Most of the innovative interventions we are looking at are aimed at improving the wellbeing of the general population through everyday activities, while others target particular sub-groups who are deemed as 'high-risk'. The mechanisms through which they operate are proving to be effective at promoting

wellbeing – but not as a treatment for people with more severe or long-term mental health conditions, who tend to be referred or signposted towards specialist mental health services.

These learnings parallel some of the common criticisms levelled at mindfulness – can it really be everything at once? A simple activity that anybody can integrate into their day-to-day routine to enhance their wellbeing, and also a treatment for a specific mental health condition? This is, in turn, complicated by the fact that 'wellbeing' is increasingly becoming a jargon term, a catch-all that can mean many different things, depending on the individual and context in question. In mindfulness' defence, it is likely that popular and media discourses are prone to oversimplify and overlook key differences in the way in which it is delivered – including distinguishing between MBCT and mindfulness-based stress reduction (MBSR), and 'clinical' and 'adapted' versions of both.

But the question remains: how can mindfulness work to promote wellbeing and prevent mental illness at a population level? How should mindfulness-based approaches be delivered? Is it really good for everyone? Or is it more (or less) effective in certain contexts (e.g. in the workplace), or with certain groups? There is some evidence that under certain circumstances, mindfulness can have unequivocally negative outcomes, or that you can have 'too much of a good thing'. These critics caution against the idealisation of mindfulness as 'natural' and therefore free of side-effects. Some of the more radical critiques of mindfulness suggest that it promotes an inward-looking, depoliticised sense of self that rejects critical engagement and social change in favour of self-improvement, thereby encouraging and enabling oppressive agendas and structures of power and inequality.

There is a clear need, then, for further research into the effectiveness of mindfulness, especially in the context of mental health and wellbeing promotion, prevention and early intervention. Future research should aim to address some of the accusations outlined above by paying close attention to the way in which these kinds of interventions influence, and are shaped by, broader discourses about mental health and the way in which mental health services are structured and funded. This is particularly important given that mindfulness, and wellbeing programmes more generally, are often framed in terms of long-term cost-effectiveness – a vision which may not match up with reality.

## Hot off the press

Crisis Care Concordat
Mental Health

The Crisis Care Concordat was launched in February 2014 with the aim of improving the quality and availability of help and support for people experiencing a mental health crisis; support before reaching crisis point, urgent access to safe, respectful and effective care in an emergency, and support for recovery and the prevention of future crises. While the Concordat has been agreed at national level, the emphasis is on implementation locally, with all those agencies

involved in crisis care – the NHS, local authorities, agencies within the criminal justice system – working together to meet the needs of mental health service users.
Twenty-five national bodies have signed up to the Concordat, including the Care Quality Commission (CQC). To support its commitment to the concordat, the CQC has undertaken a review of crisis care. The report on the findings – Right Here, Right Now was published earlier this month and makes for interesting and informative reading. Click here for the summary version.
The headline finding is a mixed picture. The report explains: "There are clear variations in the help, care and support available to people in crisis and that a person's experience depends not only on where they live, but what part of the system they come into contact with".

First, the good news. Many people reported good experiences of seeking help in a crisis. More than half of the respondents to the CQC survey had experienced a caring and empathic response from GPs, ambulance staff and police, with volunteers and charities being given the most positive evaluation. The CQC also found examples of innovative practice, particularly around multi-agency working which lies at the heart of the Concordat mission. For example, street triage schemes have been piloted in a number of areas, with mental health nurses accompanying police officers to incidents involving people who are believed to need urgent mental health support. This helps to ensure that the most appropriate help is accessed, and early indications are that the schemes have led to a substantial reduction in the use of section 136 of the Mental Health Act.

However, the experience of receiving care in A&E departments and from specialist mental health services was far less positive than contact with other agencies, with less than half of people giving a positive response to statements including 'I felt I received the help I needed in a timely way' and 'I felt my concerns were taken seriously and listened to.' Crisis Resolution Home Treatment Teams seem to be struggling to provide the frequency and consistency of support that is required. It is also speculated that the number of people re-attending A&E for a mental health condition, as well as the numbers presenting at A&E with self-harm injuries, may indicate a lack of multi-agency working and problems in the wider system.

Another problematic area highlighted in the report is the inequality in provision for children under 16, for example in the absence of out-of-hours services for children. Indeed, lack of parity is a theme running through the report, with one of the key messages being a need for equality and fairness in provision, against the current picture of considerable variation in the quality and availability of care. Depending on where you live, what time of day or night it is, and which agency you turn to for help, you may receive very different experiences of care.

There are some limitations with the CQC review, acknowledged in the report. These include needing better data and more data to record BME experiences and experiences of people with disabilities. The review covers 2011-2014, and therefore doesn't capture the work that has already and continues to be put into practice by those signed up to the Concordat.

At the McPin Foundation we are evaluating the local implementation of the Crisis Care Concordat. This includes an evaluation of the impact of the crisis care concordat in four areas; London, the Wirral, Gloucestershire, and Cambridgeshire. And like the CQC, we also want to ensure that the voices of those who have experienced a mental health crisis or have cared for someone in crisis are

heard. Our initial survey received 552 responses, we will be repeating this again in 2015. We will also ensure we communicate to all our supporters through our newsletter the findings of this evaluation. Will the crisis care concordat lead to better multi-agency working locally?

## 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 are needed to sit on a Lived Experience Advisory Panel (LEAP) for a new and exciting study. 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 medicated encephalitis are particularly encouraged to apply.

For more information please click here. The deadline for expressions of interest is July 10th. For more information please contact Thomas Kabir (email: thomaskabir@mcpin.org, phone 0207 922 7874)

**ReQol**

We invite you to help **develop a new mental health outcome measure**. 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

For more information about ReQoL please click here

**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.

We have already held two consultation events in recent weeks in London and Leeds, and are now inviting people to share their thoughts and experiences in an online consultation. If you would like to contribute please click here , and complete by Monday 13th July.

## Thank you

We work with lots of different people to keep the charity progressing towards its **vision for improved mental health research.** This includes staff, volunteers, advisory group members, peer review panel, people fundraising for us by taking part in Ride London, peer researchers and freelance consultants. We value each and every one of you. You help us deliver a range of projects by providing your expertise. An example is our work for Mind, surveying people who use Local Mind Associations. You can read our first methods briefing paper **here**, where we reflect on how we worked with Mind Champions to increase participation in the project.

**We're excited to have another 4 riders taking part in Ride London on 2nd August, and they need your support.**

One of our riders Matt would love your donations. Click **here** to donate now!