



Welcome to our Autumn newsletter. We cover this month interest in a link between immunity and depression, research on medication side effects, writing for peer review journals and we hear from Evan about his cycling challenge. Within our sector there is a lot of activity at the moment, including the development of a 10 year strategy for mental health research led by the Department of Health. Here at McPin we are getting ready to launch a new seminar series – integrating lived experience in mental health research teams. Get in touch if you want to know more!



Our news

During the summer the team at McPin have started some exciting new projects working with new partners and old. These have included:

The Judi Meadows Memorial Fund is supporting [a new PhD studentship with Exeter University on GPs and suicide prevention](#). The PhD student, Daisy will be working with Professor Rose McCabe at Exeter University to develop new ways to help GPs spot people at risk

from suicide and how to support them. We have part funded this studentship and are currently fundraising to support a second fellowship.

Evaluating the impact of South London and Maudsley's "[Wheel of Wellbeing](#)". This is alongside our ongoing [evaluation of their Recovery College](#). With world mental health today on 10th October 2016 focused upon [psychological first aid](#), both of these projects have learning to draw upon.

Wellbeing is a growing theme in our work and we have been working over the summer to evaluate Kent's "Healthy Living Centre's", building on our existing work looking at their [wider wellbeing programme](#). There is a commitment across the public sector to build an evidence base for mental health promotion and prevention.

We look forward to seeing the impact of our reporting locally, as evaluations are delivered to support learning and programme improvement.

We have also been helping academic teams with bid preparations for research funding. We are always keen to form new partnerships, developing patient and public involvement plans with university research teams. News coverage of topics we are working on such as antibody mediated psychosis is great to see, raising awareness of mental health research.

Finally we have just been commissioned to help Macmillan Cancer Support's Cancer and Mental Health Taskforce to develop a 'theory of change' for their work. It is great to work outside of our mental health sector joining mental and physical health.

What else? We say a big thank you and farewell to our volunteer Ali and Administrator Annabelle, we wish you well and are grateful for all their hard work. [We also published a new 'Methods Paper'](#) looking at the impact that being survey champions had on the service users who took on that role as part of last year's ['Your Experience in Mind Survey'](#). It demonstrates some ways that involving people with lived experience of mental health problems in such projects can have a positive impact on the participant's wellbeing, as well as improving the quality of the output for the commissioner.

We continue to support the involvement of people with experience of mental illness in studies across the country. Currently highlights include preparations for a major project on young people's mental health, and information materials for people with antibody mediated psychosis.



Research in the news

There is a growing amount of evidence that some mental health problems may be due in part to the brain becoming 'inflamed'. In August BBC Radio 4 broadcast a programme about this titled 'The inflamed Mind'. You can listen to the programme by clicking [here](#). I loved it. It has interviews with some of the key figures in the world of research into the immune system and mental illness.

Pleasingly the radio programme and the accompanying BBC news [article](#) include the perspectives of service users.

But what does 'inflamed' actually mean? I sometimes get knee pain. Usually the advice I get is to do some stretching, take some ibuprofen, and not to exercise for a couple of days. Apparently, the problem is that my knee is inflamed and ibuprofen will help because it's an 'anti'-inflammatory. But coming back to my question. The Oxford English Dictionary provides a few [definitions](#). The most relevant seemed to be 'a morbid process affecting some organ or part of the body, characterized by excessive heat, swelling, pain, and redness'. In the case of my knee, if it's swollen, a bit red, and it hurts, then I am told that it looks a bit inflamed.

Inflammation itself is caused by the body's [immune system](#). The immune system is meant to protect us from infections and other invaders like viruses. But the immune system can over-react or attack healthy cells leading to a whole range of serious diseases from arthritis to lupus.

So what happens when the brain becomes inflamed? Well, some very bad things can happen. To some extent it depends on how the brain becomes inflamed. If it's due to the immune system fighting a viral infection you could get [Encephalitis](#). It's pretty serious. From this, people sometimes develop psychosis and they usually need to be treated in an intensive care unit.

A dysfunctional immune system might cause [psychosis](#) in its own right. Belinda Lennox, from Oxford University is quoted by the BBC health reporter James Gallagher as saying that up to "one in ten" people with psychosis for the first time have antibodies "targeting part of their brain circuitry". Antibodies are a key part of the immune system. They help identify and destroy harmful invaders such as bacteria and virus. These antibodies disrupt the way that cells in the brain communicate with each other and psychosis follows. It's a bit akin to a motorway pile-up going on in your brain. The McPin Foundation is supporting a study called [SINAPPS](#) which is looking into a possible new treatment for these people.

Evidence is slowly [emerging](#) that the brain becoming inflamed may have a role to play in depression as well. Carmine Pariante of Kings College London is quoted in the programme as saying that "nearly 30% to 40% of depressed patients have high levels of inflammation and in these people we think it is part of the causal process".

Within the world of research there is a lot of excitement about all of this. This is reflected in the title of the BBC news article ('depression: A revolution in treatment?'). The excitement seems to be for two reasons. Firstly, there is a clear indication about what might be contributing to someone's depression or psychosis (inflammation of the brain). Little is really known about the exact causes of mental illness. Anything that throws light on the causes of mental illness is exciting.

And secondly, there are approaches that are already in use to treat inflammation. Could these approaches help people with mental illness? One approach is anti-inflammatory medications. In the SINAPPS study it's a procedure called IVIG together with a drug called rituximab. It's too early to say if any of these approaches will work. But at the very least identifying people with mental health problems suffering from inflammation might help doctors and others to tailor more personalised treatments for them. This was one of the conclusions from a recent [paper](#) from Carmine Pariante's [research group](#).

Three things struck me when I listened to the Radio 4 programme. First of all is the connection between physical and mental health. The two are connected. Perhaps they should be treated as such instead of NHS services being broadly separated along 'physical' and 'mental' health lines with GP's being left bridging the gap. Secondly, the amount of excitement within the research community. A 2015 Lancet Psychiatry [article](#) makes an interesting point. This is not the first time that a possible physical cause of mental illness has caused excitement: "Early in the 20th century, there was great excitement when general paresis of the insane was shown to be due to syphilis and curable with penicillin,

inspiring hope that similar organic causes might be found for other types of mental illness". Why is the physical basis of mental health so exciting? Indeed this is the main focus of the last few minutes of the radio programme.

And lastly, that there are already treatments that are used in a physical health context that might help people with mental health problems. The SINAPPS study is due to start soon. I'll let you know how we get on...

Dr Thomas Kabir, Public Involvement in Research Manager



Hot off the press

Medication side effects are a burning issue for many service users and carers. Yet research to date has failed to accurately reflect the prevalence of the adverse events and effects resulting from long term psychiatric medication use. This is a particularly urgent issue for people diagnosed with Bipolar, as influential guidelines on its management, including those of the [National Institute for Health and Care Excellence \(NICE\)](#) and the [British Association for Psychopharmacology](#), advocate the

long term use of medications. This article provides an overview of a recent study looking at the long term physical impacts of medications used to treat Bipolar.

It is thought that approximately 1-2% of the population will develop Bipolar at some point in their lives. Of those who seek treatment, the majority are offered medications such as Lithium, which are often prescribed long term in what is known as 'maintenance treatment'.

The effectiveness of these medications continues to be a focus of research. [Systematic reviews](#) and meta-analyses to date suggest that some medications are generally more effective than a placebo drug in reducing the severity of symptoms associated with a Bipolar diagnosis. The exact mechanism by which these drugs work is still unknown.

In contrast to the evidence on the efficacy of existing medications in reducing the burden of some symptoms, there is only limited information on the prevalence of adverse events and effects resulting from their long term use. This presents those seeking treatment with a conundrum. What are the risks of taking psychiatric medication long term and how can these be balanced against the potential benefits?

At present there is very little for people to go on. All of the possible side effects are described on a medication's accompanying leaflet, but there is currently no way of determining prior to consumption whether a specific individual will experience adverse effects. As with many other psychotropic medications, people who wish to explore it as a treatment option for Bipolar must embark on a journey of trial and error.

For those who experience fast relief and few or no adverse effects, medication can be a life changing treatment. For others, the search for a medication that works can take months or years, and can include debilitating adverse effects along with any withdrawal symptoms as they try different drugs. Even for people who find a medication that is therapeutic, the lack of information relating to the long term impacts on physical and mental health can make it difficult for them to be confident in taking medication for a prolonged period.

I was therefore pleased that a new study led by Joseph F. Hayes based at University College London has been published in the PLOS Medicine, which looks into the adverse effects of the long term use of medications commonly prescribed for Bipolar ('[Adverse Renal, Endocrine, Hepatic, and Metabolic Events during Maintenance Mood Stabilizer Treatment for Bipolar: A Population-Based Cohort Study](#)').

Mood stabilisers and antipsychotics can cause a wide variety of adverse effects. This study focused on the negative impacts of the four most commonly prescribed medications for Bipolar: Lithium, Valproate, Olanzapine and Quetiapine. It looked at adverse impact on the kidneys; hormone glands such as the thyroid; the liver; and metabolism, particularly in relation to weight gain and associated hypertension/diabetes. Although Olanzapine and Quetiapine are relatively newer drugs, Lithium was first approved for 'manic disorders' back in 1970. Data was collected from The Health Improvement Network (THIN); a UK primary care database that contains anonymised patient information. In total, 7,000 individuals' records were analysed for incidence of adverse effects. All study participants had a diagnosis of Bipolar and were taking one of the above mentioned medications.

The research concluded that, taken over the long term (up to 17 years), individuals prescribed lithium were significantly more likely than other participants to experience a deterioration in kidney function, known as Chronic Kidney Disease (CKD), as well as being more likely to develop thyroid problems. In many people, CKD does not result in any noticeable symptoms, but individuals are at significantly higher risk of developing both heart disease and stroke. Thyroid problems can cause a range of symptoms including weight gain/loss, fatigue, depression and hair loss.

Compared to people taking Lithium, individuals prescribed the antipsychotic Olanzapine had the highest rate of weight gain and new onset hypertension. Incidences of significant weight gain were also higher for individuals prescribed Quetiapine and Valproate. Significant weight gain can be one of the most distressing adverse effects of psychiatric medication. It can lead to problems such as cardiovascular disease and diabetes but also can affect people's self-esteem and body image, which can have a negative impact on their mental wellbeing.

A key strength of the study is its large sample size and long follow up period. Most studies into the effectiveness of these medications do record incidences of adverse effects such as weight gain, but over a far shorter period of time (6-12 months). Given that many individuals take medications for longer periods and some adverse effects only become apparent after prolonged use, it is essential for research in this area to reflect the current prescribing practices.

However, I couldn't help but feel a little underwhelmed by the study's results. Although it is a welcome addition to an under-researched area, the Lithium related incidence of CKD and thyroid issues are already acknowledged in treatment guidelines that specify routine monitoring of individuals' kidney and thyroid function. Furthermore, the weight gain associated with Olanzapine is also pretty well [established](#). On an anecdotal basis, I have rarely met a person who is taking or has taken Olanzapine and not bemoaned the impact of the drug on their weight. Therefore, for me, the concluding remark, '[g]iven the need to balance an array of risks and benefits, an individualised and collaborative approach to treatment choice is likely to be most appropriate,' sums up the crux of the issue. For many people who take psychiatric medication long term, they know what the benefits and adverse effects of their medication are because they experience them day in day out. Yet, with ever shorter appointment times and the tendency of mental health professionals to focus on 'symptom reduction', it can be difficult for people to find the space to address a complex and subjective question: 'overall, is medication the best option for me?'

Understanding how individuals currently go about answering this question and how services can best support people to feel confident in their choice could provide the foundation for a personalised and holistic approach to treatment. [Some small steps have already been taken to give us a better understanding of how pregnant women go about making decisions regarding psychotropic medication](#). A similar exploration of decision making processes relating to psychiatric medication use by the wider population is long overdue.

Megan Rees, PlIR Coordinator



Feature

A new special edition reporting findings from the Viewpoint survey was published in July. It includes a paper on our [qualitative research into mental health discrimination experiences](#) which was co-authored with four peer researchers. We reflect on the importance of experts by experience being named as authors, and why they are so often absent from peer reviewed journal articles.

Research is not done for its own sake. Research is meant to be talked about. It should become part of ‘what is known’ about a subject, used by practitioners, policy makers, commissioners and all of us. People with lived experience of mental health problems need to be heard at this stage – indeed, their voice should be as loud as anyone’s. But this voice is often not present in some of the important places where research is discussed. In particular, in research journals.

Research journals are only one way of getting research findings out into the wider world, but they are an important one. The idea of ‘peer review’ is central to this. Anyone can do research and make claims about what they’ve found. To check that these claims are credible and trustworthy, research published in journals is carefully reviewed by experts in the subject. They look at how the research was done, whether it takes into account what is already known, and whether it reports what it found fairly and accurately. This system is not perfect, but it helps us to speak with confidence when we say there is evidence for something. So, when policy makers and other researchers look at what is already known about a topic they often focus on ‘peer reviewed’ research. And yet the people who are shaping this evidence with their lived experience are often not visible in this literature.

This is a problem because it means that people who bring their lived experience to studies have less chance to influence the wider debate, to write about what they think is important to them, and to have their contribution recognised. It may limit career opportunities for new peer researchers, since a publication record is important in developing research careers. It may also mean that the contribution of experts by experience throughout the study is less prominent than it should be and does less to promote the benefits of involvement to other researchers.

Our experience in the Viewpoint survey and other studies highlights some of the challenges that may prevent peer researchers from getting involved in writing up research for journals. The process itself raises practical challenges. Writing journal papers often continues after funding has ended. While this may not be a problem for people in permanent research positions, for those who are employed on a particular project it can be harder to stay involved at this stage.

The process is also often a long one. The time between completing a project and seeing a paper in print may take more than a year. Over this time, there are often changes to the paper in response to reviewers’ comments. If a paper is rejected by one journal, it may be completely re-written to meet the requirements of another. At each stage, the wider team may feel more and more distant from the paper and have less opportunity to spend time on it.

In the Viewpoint survey the interviews were conducted by four people with lived experience of mental health problems, and the analysis was carried out as a group which included the interviewers and colleagues from the McPin Foundation. However, writing as a team was more difficult. Journals have a particular style and structure which can feel unfamiliar and restrictive to people who have not written in this way before. In general (though with some exceptions in particular fields of study, such as ethnography) this style does not lend itself to personal reflection or being explicit about researchers’ personal experiences.

Finally, writing is often a very personal thing. While a group may all contribute to the findings, it normally falls to one person to find the words. Writing as a committee is never an easy process, either for the person doing most of the writing, or for those who are changing it.

So, how can experts by experience be involved more at the writing stage? First, by recognising that writing for peer review publication is a skill that needs to be developed. All new researchers learn to write for journals by doing it, usually with guidance from senior colleagues. It is important that those who bring their lived experience to studies also have these development opportunities so that they become more visible and more influential in published research.

Second, this stage of the research needs to be properly resourced so that those who are not in a full-time research role can continue to work on the writing after the project itself is completed. And finally, journal editors and reviewers need to recognise the important contribution brought by people with lived experience and allow their perspective to be given appropriate prominence in their journals.

Sarah Hamilton, Research Manager



Opportunities

NIHR Challenge Awards – help us decide how mental health research is funded

Are you or do you care for a mental health service user?

Are you interested in helping decide how the NHS funds mental health research?

Are you enthusiastic with good communication skills?

If so we need YOU to apply to become a PPI member of our selection panel

The National Institute for Health Research (NIHR) is the research arm of the NHS. Its invention for innovation (i4i) programme provides funding to support the development of innovative healthcare technologies for patient benefit.

In January 2017 we will be inviting applicants to submit project proposals for our Challenge Awards. These awards aim to fund innovative technologies with potential to influence the patient care pathway and improve outcomes, in this case for those experiencing mental health problems.

We are seeking patient and public involvement panel members with the above experience to join our selection panel to help decide which projects will be awarded funding.

To receive an information pack and application form please email i4i@nihr.ac.uk. Completed application forms should be received by Monday, January 2nd, 2017.

Measuring user and carer involvement in physical health care planning

The University of Manchester are undertaking a research study exploring mental health service users and carers experiences of the care planning process, and would like people who have had, or cared for someone who has had a UK mental health care plan. They are looking in particular at the quality of physical health information within the

care plan as this was something that was raised as an issue for the service users and carers they work with. It is a fairly short survey which can be completed online [here](#).

For more information please see the attached flyer [here](#).

Bipolar research – what outcomes matter most to you?

Do you have a current diagnosis of bipolar? Are you a family member or carer of someone with a diagnosis of bipolar? If so, the Partners2 research team would like you to take part in a project to help shape how mental health research is carried out. Would you like to help make sure that future research involving people with bipolar investigate the things that matter most to you? Have your say!

For more information please see the attached flyer [here](#).



Thank you

We would like to say a huge thank you to Sarah, Evan, Martin, Mark and Vanessa for taking part in Ride London this July to raise funds for McPin. The five cycled 100 miles through Surrey and London to raise a fantastic total of £4,132.06. A special thank you to Evan, who has written about his experience of taking part in the event. His blog explores the positive impact that cycling and exercise have had for his own mental health. You can read his blog below.

Ride London - Evan's blog

When I feel the black dog sniffing around I've learned to hit the gym. I suppose I've always dealt with depression, though generally it's nothing too serious. I went through one period of doing every intensive aerobic session I could find at the YMCA in Montreal. And while some people eat when they're anxious, I lose my appetite and get thin.

Mental health issues run in my family: depression on my father's side, and anxiety on my mother's. There are good attributes too! But I seem to have an excess of feeling in general, and it tends towards melancholy and worry. My great-grandmother was noted for her somewhat negative view of things. Someone once pointed out the beautiful flowers growing in her garden and she responded: "They'll soon be covered in snow." It was July.

Lately I've taken up cycling, something I loved when I was 16, but other than commuting and doing spin classes I let it go. It just didn't seem compatible with living in the city I suppose. Now that I'm living near Epping Forest, the lanes of Essex are handy, and everyone is doing it. Last year I upgraded from my 1987 steel Bianchi and went carbon fibre. Wow! When the offer arose to take up a place in Ride London and raise money for McPin it was just the sort of challenge I needed. I started training quite seriously.

It's not the only serious training I've done since those early cycling days. I've run intermittently, including a few half-marathons, and this past year I've done circuit training twice a week and some swimming too. But cycling is my first choice. A lot of people assume that doing many hours of cycling would give you a lot of time to think, which, for someone who tends towards melancholy and anxiety, isn't always the best thing, but actually I find it makes my mind quiet.

Along the way I've discovered that meditation also helps me to deal with my mental health. Putting myself into a very calm state, not too far away from sleep, and then giving myself some positive thoughts has been very helpful. And I can usually do this for about 15 minutes at a time. When I'm really good I do it every day. When I feel fine I forget.

But cycling has the same effect. While cycling my brain just shuts off and I don't seem to think. Partly it's because I like to go fast. And to do that I seem to put all my focus on breathing, not crashing and pushing myself hard enough to go as fast as possible, but not so hard that I explode, or don't make it back home. With training I've been able to do this for longer and longer.

At first, only about an hour. Then an hour and a half. Then a few hours. Ride London was 5 hours. One minute under, actually! Ride London had the added benefit of a very real potential of crashing into other cyclists, so really my brain was completely occupied; there wasn't a moment that my brain could stray out, just complete focus. I suppose that for me is the answer. When I'm in the zone I'm ok. And when my body is almost exploding in exertion I'm really in the zone!

Ride London was great for a few other reasons. Happily it was beautiful weather. A bit chilly at 5:30 when I rode over to the start, and waited around for my 6:15 start time. But when the sun came up it was splendid. There's always one moment on my long cycles when I feel deliriously happy. I look up, see the sun, or some nice scenery, and I'm cycling fast and not yet in agony, and I think, this is perfect, this is bliss. I remember those thoughts in Richmond Park. No cars, just cyclists all moving in the same direction, a light breeze in our direction too, and beautiful sunshine.

That mood lasted until the first hill at mile 60-something. Then some pain set in! I'd detached myself from a couple of riders in the club I'd recently joined, with whom I'd been riding. They just weren't going to go as fast as I wanted, and at that point I pressed on. The last 30 miles were intense. The closer we got to the finish, the more I realised I'd get in under 5 hours, if I could just keep pushing. The muscles were screaming. I attached myself to someone going just a bit faster than I could and hung on. The last 10 miles were really hard. I just kept pushing. Seeing Trafalgar Square was joyous, though pushing down the mall, I had nothing left.

Seeing all those people, happy, doing something important to them, for a variety of reasons, was great. I felt good about raising money for mental health research, and being upfront to my friends and colleagues that mental health is something that people can talk about. I know exercise doesn't help everyone, and there are a variety of medical opinions out there regarding the efficacy of exercise as a way to improve mental health. But I do know it works for me. The endorphin high is great, as is the exhaustion that puts me right to sleep at night, along with all the feelings that I have when I'm in great shape. It makes me feel strong and in control. And I suppose I can admit to a little vanity with regards to my body too! Cycling makes me look good and feel good. Since Ride London I've been doing club rides. In particular, the Saturday fast rides have really made me push myself further. I've set myself some new goals and I've got some real momentum. I don't think that black dog is going to catch me, and if I see him, I'm just going to pedal faster!

Evan Champion, McPin Rider 2016

If you want to challenge yourself like Evan and raise money for life saving research McPin is looking for riders for next year's Ride London, please [get in touch!](#)



If you're interested please do get in touch at contact@mcpin.org

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