



Welcome to our summer newsletter, the season for showers and sunshine! In this edition we comment on research exploring **risks in pregnancy of taking psychotropic medication**, and summarise research on using **virtual reality to beat paranoia**. We also hear from Gary, a peer researcher at McPin, about why he joined our team. Over the next few months we will be evaluating more wellbeing programmes in Kent, progressing our peer support evaluation, and planning a campaign to raise the profile of mental health research.



### Our news

The past few months have flown by and summer approaches with a number of staff changes at McPin. We look forward to welcoming back Sarah Hamilton (Research Manager) and Naomi Clewett (Senior Researcher) from maternity leave. We also welcome Ian Bradshaw to the team as our new Policy Manager. This is an exciting new position at McPin which will help us engage across the sector to influence mental health research policy

through the appropriate use of research evidence. Do get in touch with Ian directly if you have ideas you would like us to progress linking mental health research and policy agendas.

There are also some goodbyes this month. Huge congratulations to Laura Hemming our Researcher and [mental elf blogger](#) who starts a PhD in October 2016. Laura leaves us to go travelling ahead of her relocation to Manchester. Dr Ben Gray who has produced Cochrane Schizophrenia Collaboration [lay review summaries](#) for the past 5 years, first for Rethink Mental Illness and since September 2015 at McPin, also leaves us. Ben also worked on the [Primrose study](#). This is research looking at the management of cardiovascular risk among people with long term mental health needs. We look forward to the trial results from that study which are due out in 2017. Finally we also say goodbye to Kirsten Morgan who joined our PPI (patient and public involvement) team to help us cover a staff absence and stayed on. She has been writing a talking point paper for us and supported the setup of [research with young people in schools](#). We wish all three the very best moving onto things anew.

Our news also relates to project work. We have many projects to reflect on so it is hard to choose a few and we have been doing some work on our website to help people keep track of our various activities. Do let us know if you have ideas for how we can improve our website – we are keen to do so!

Something that helps bring our team together are events. We were asked to host a consultation event recently for the London Health Board at the GLA (Greater London Authority). It was a very tight commission timewise but the first Friday in June saw 30 people providing their views on how we can improve the mental health of Londoners. We are always inspired by getting people together talking about mental health. There was a strong sense that the time was right for a city wide conversation on mental health. We had a diverse audience, capturing the view of people from: the LGBT+ community; BAME communities; men, women and non-binary gender identity attendees; employed and unemployed individuals; the young and old.

And it looks like the new London mayor – Sadiq Khan – is listening. He has written two blogs on mental health; firstly reflecting on his [manifesto pledge](#) to support mental health services in London, second to support [mental health awareness week](#), themed around relationships, in May. Strong and supportive relationships are important for our mental health, and acknowledgement that loneliness is found across every community in the capital. At the McPin Foundation we are working on a study based in London to tackle loneliness with colleagues at University College London ([@ucl\\_loneliness](#)). We have employed a peer researcher and are supporting a working group of practitioners, experts by experience members and researchers to come up with a 10-week programme for people experiencing problems with depression and anxiety. We can be surrounded by people and feel very alone; combating loneliness in a 24-hour city like London will require innovation and compassion, kindness, time, valuing of community, and more. We hope our work can help – just a little.

As always, if you want to know more about any of our projects, please do get in touch.



## Research in the news

‘Paranoia’. It’s one of those words that retain their stigma despite all the good work of campaigns such as Time to Change. A reason for this might be the way that the word is used so much in everyday life. The term your paranoid can be used as a response to so many statements. “I think that [insert details of situation]’... to which the reply comes “you’re paranoid!”

In a mental health context paranoia is one of the more damaging labels that you can have. It can create a catch-22 situation where anything you say is treated with great suspicion as 'you're paranoid'. Recent research shows that paranoia is pretty common. A 2011 [study](#) shows that 18.6% of the general population report that 'people were against them' with "1.8% reporting potential plots to cause them serious harm".

For a great overview of paranoia and how it is treated please visit: [www.paranoidthoughts.com](http://www.paranoidthoughts.com)

To further complicate matters, helping people with severe paranoia is quite difficult. Paranoid thinking tends to be quite hard to alter. Talking treatments such as [Cognitive Behavioural Therapy \(CBT\)](#), [medication](#), and other approaches such as [mindfulness](#) have all been used with varying degrees of success.

The McPin Foundation has recently started to provide service user input into a programme of research on paranoia called the [Feeling Safe](#) study. The study itself is a trial of a version of CBT that has been tailored specifically for people with 'paranoid persecutory delusions'. The preliminary [results](#) are encouraging. A 'paranoid persecutory delusion' is a strongly held and false belief that someone or something is going to harm you. The research is being led by Daniel Freeman at Oxford University. The McPin Foundation runs a group of five people with lived experience of paranoia that are advising this programme of research. We will additionally be carrying out an evaluation of the Feeling Safe intervention led by a service user researcher.

On May 5<sup>th</sup> an [article](#) appeared on the BBC news website about a new experimental approach for treating paranoid persecutory delusions using virtual reality. I was delighted to see the article featured a video of one of our advisers trying out the approach together with Daniel Freeman and Felicity White from the research team.

One of the scenarios used in the virtual reality approach is being inside an underground tube train. Several computer generated figures move about inside the carriage occasionally moving towards you and making eye contact.

Thirty people who experienced paranoid persecutory delusions were divided into two groups of equal size. Fifteen people were asked to act as they normally would in the computer generated tube train. The other fifteen were asked to make eye contact and stay where they were when the virtual 'passengers' came near them. In other words this group were asked to confront what they might feel to be an uncomfortable and threatening situation. The results are encouraging with people in the 'confront' group reporting significantly lower levels of distress and of being threatened than those who are asked to behave normally.

The research was published in the [British Journal of Psychiatry](#). The Mental Elf produced a [review](#) of the research the day after the BBC article appeared.

I was pleased about this research for so many reasons. First and foremost the approach seems to work. Secondly, the use of virtual reality technology. This is innovative. Thirdly, the research got a lot of attention in the press. The video in the BBC article was at one point the most viewed video on the BBC News website. The American newsmagazine [Newsweek](#) and many of the major UK newspapers produced articles about the study. I hope that this press coverage may do something to address the stigma that still surrounds paranoia.

And finally it was very pleasing to see someone with lived experience of paranoia being featured very prominently in the BBC article and video. His voice and those of the other four members of our advisory group will continue to shape and influence further research into paranoia for years to come.

*Dr Thomas Kabir, Public Involvement in Research Manager*



## Hot off the press

Many women with severe mental illness take psychotropic medication. This can put them in a difficult situation if they become pregnant, or wish to become pregnant, as there are concerns about the possible effects of these medications on unborn children. Until now there has been a lack of evidence about the risks to the unborn child, putting the women and their healthcare professionals in a quandary. How do you weigh up the potential benefit to a woman's mental health of taking medication, against the potential risks of the medication to the unborn child? In short, a decision has to be made with very high stakes, with little or no information to make it.

In March, a team from UCL led by Professor Peterson published the [results](#) of a much needed research project which investigated the risks and benefits of taking psychotropic medication during pregnancy.

The mental health website The Mental Elf recently published a clear and useful [summary](#) of the research study focusing on the risks of psychotropic medication to the unborn child.

Peterson et al. found that there is no increased risk of major congenital malformations for the babies of women taking antipsychotics. However, there is an increased risk of major congenital malformation, neurodevelopmental and behavioural disorders in women taking anticonvulsant mood stabilisers, in particular sodium valproate.

In 2013/2014 I had the privilege of working with researchers at the McPin Foundation and UCL on this project as a member of a Lived Experience Advisory Panel. The panel was made up of myself and three other women with experience of severe mental illness who all had experience of making or considering decisions about using psychotropic medicines in pregnancy. We were also recruited as peer researchers and led on the design of a related qualitative study. Given the lack of evidence about the effects of psychotropic medication on the unborn child, we decided it would be productive to look ourselves at how women make these high stake decisions about use of psychotropic medication during pregnancy.

We found that most of the women said that their healthcare professionals were not able to provide sufficient information about the effects of psychotropic medication during pregnancy for an informed decision to be made. This led women to seek to obtain information on their own initiative, principally from the internet. However, this was unsatisfactory as online information can be contradictory and unclear. This meant that the women had to depend on past experience and common sense to make decisions. The women had to take a gamble with their own health or the health of their unborn child. To read more click [here](#).

We also found that agency or lack of agency was an important feature in each woman's story. We observed significant variation in the way decisions were reached and were able to classify them as predominately mother-led, predominately practitioner-led, or collaboratively reached. The way decisions were reached was affected by features such as the woman's sense of self-identity, her experiences of mental health problems, and characteristics of the service provided and support offered. We are still working on a publication that will explore these themes in more detail.

Working on the study was exhilarating, challenging, and stimulating. Positives were the sheer pleasure of being taken out of my normal life periodically and being trained in research skills by senior researchers. Other positives were being valued and treated as if my views mattered after going through a dehumanising psychiatric system. Challenges including learning about statistics after a 5am start to get to the McPin offices, and facing up to the fact

that my brain doesn't work as well as it did before the onset of schizophrenia. Thinking on my feet was a particular challenge.

Regarding the interviews, the experience of interviewing the women was incredibly moving and the interviews have stayed with me for the two years that have passed since they were conducted. One woman I interviewed previously lost a child through stillbirth. She was so profoundly affected by the experience that she developed grief induced psychosis. With her most recent pregnancy she was determined not to do anything that might jeopardise her unborn child. This informed her choice not to take psychotropic medication during pregnancy, against medical advice. At the time of interview mother and child were both well.

Another interview was equally moving. The woman came off medication after being given the option by her treatment team. She subsequently had a psychotic episode and lost custody of her child. Listening to the woman share her story was emotional. However, there was something cathartic about the interview in that it gave the woman space to take stock and tell her story. I felt honoured to bear witness to her, and to the other women we interviewed.

Thinking ahead, there is a lot of scope to develop this work. The study into decision making was quite small as only twelve women were interviewed. My hope is that a larger qualitative study might be conducted, perhaps one that has a greater geographical spread and diversity of participants. Several case studies were written up from the existing study data. If a larger study was embarked upon, it would be good to produce a bank of case studies about decision-making and consequences for women taking psychotropic medication who are, or wish to become, pregnant. This is a format that can accommodate quite complex information in a style that is easily accessible to women and their families, who are considering similar, difficult decisions.

I would also like to see healthcare professionals involved in future qualitative work in order to understand their experiences and what the challenges are as they see it. Do they feel able to supply good support and information, or are they frustrated by the situation? How do they envisage an ideal process for supporting women and their families in making these decisions? It would also be useful to find out how families participate in the decision-making process and whether the dominance of a traditional doctor-patient model of medical interaction has the effect of excluding other family members from participating. Finally, I would like to see interviews with women who have chosen not to have children due to their mental illness or medication.

*Harminder Kaur, Peer Researcher*



## Feature

In March this year I took on an exciting opportunity: working with The McPin Foundation as a Peer Project Assistant on a pilot scheme entitled '[My Story, Our Future](#)'. We will be exploring the stories of people who have themselves used or supported others accessing Early Intervention for Psychosis (EIP) services. Over the next few months we will be carrying out recorded interviews, gathering qualitative data and using this to inspire original and collaborative creative work.

McPin has a policy of utilising people with first-hand experience of dealing with psychiatric problems, as a key part of their research team. This demonstrates in real life the wise saying 'there's no teacher like experience'. With too many professionals focusing only on their text book theories, it is good to 'level the playing field' by giving employment to people who have been through and know the system. When suffering from depression, 'I felt like I

was the only person in the world feeling so much pain. I know that isolation can be psychologically crippling. Listening to people's stories, as others did for me, and giving back to the community are important.

Having met people with mental health experiences similar, and different to my own, I have a broad outlook on psychiatry, psychology and society. A person living with a mental illness has to make sense of what has happened and this can take many years. I could go on about my own experience of mental health services, but in a nutshell, they have helped me through the pain, to move on with my life. Due to government cuts, the help that I received is now not available to some people.

Not so long ago, it was government policy to give enough financial and social support to people with disabilities who needed it. Many of the day centres have closed down due to funding cuts and people are being assessed to have their benefits withdrawn. Providing housing and enough money to survive works to some extent. But cutting the money and social infrastructures which support people with disabilities is attacking the most vulnerable people in society.

My academic studies have also made me more aware of the social inequalities and deprivation people and communities have to live with. The language and practice of psychiatry are inaccessible to some.

During the past three years I have been a voluntary worker supporting people with mental health issues, through facilitating creative writing workshops. My position with McPin is my first step towards full time paid employment in many years. An exciting and optimistic time for me, working for a worthwhile cause. The people at McPin have made me very welcome and there is a strong sense of team spirit.

### **What I hope to get from my work with McPin?**

By working on the EIP Life Stories study, I hope I will be able to listen to people's accounts of how mental health has affected their lives and help identify strengths and weaknesses in the care they have received. Talking is a great therapy denied to some. Recording these personal and often sensitive explanations can be of great value to the person being interviewed and I hope the process will feed back to help to improve future services.

I would also like this project to help tackle the stigma attached to mental health. Many people are misunderstood by the psychiatric services and I want to help them to get their message across to people who can make a difference.

Finally, at a personal level, I hope to gain experience and learn new skills to use in the future, getting into a routine of working and eventually move on to full-time employment.

*Gary Coyle, Peer Project Assistant*



## **Opportunities**

### **Keeping Control Research Study – Participants now being sought for interview**

Middlesex University London are looking for people aged 18 years and over for a user-led study exploring people's experiences of being victimised because of their mental distress/mental health difficulties. They want your help to make recommendations for adult safeguarding and how systems such as the police can

respond better to people with mental health difficulties.

If you are interested in being interviewed please download, complete and return the recruitment form [here](#).

The information you give on this form will remain strictly confidential but it will help the study team to monitor and plan their research interviews so they include people from a wide range of backgrounds.

**The recruitment deadline has been extended to 4 July 2016.** If you have any questions about the research please email: [keepingcontrol@mdx.ac.uk](mailto:keepingcontrol@mdx.ac.uk) or phone Alison Faulkner on **07729301379**.

Further information on the project is available [here](#).

### **Macmillan Co-design Event for 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 or supported someone who experienced both cancer and mental health problems?

Macmillan are holding a co-design and partnership event for people affected by both cancer and mental health problems to come together with Macmillan staff and healthcare professionals to better define the problems faced by people with this dual lived experience and to co-design solutions to these problems.

The event will be on **Wednesday 20th July** near Euston Station in London, from **10am – 4pm**. Reasonable UK-wide travel can be booked in advance or reimbursed afterwards.

The event will be structured and interactive, but led by the views and input of those attending. Lunch and refreshments will be provided. The venue is fully accessible.

To express interest in participating, please contact Macmillan by emailing [research.learning@macmillan.org.uk](mailto:research.learning@macmillan.org.uk), telling them a bit about yourself and why you would like to attend. If you do not have access to email, please phone **Anna** on **020 7091 2056** and leave a message and they will call you back.

### **National Institute for Health Research PPI webpages redevelopment Advisory Group**

Are you interested in improving the information on patient and public involvement on the National Institute for Health Research (NIHR) webpage? The NIHR PPI team are looking for people who are interested in health and social care research, but do not have a clinical, academic (at Doctoral levels) or social care background to help improve the information provided on patient and public involvement on the NIHR webpage.

You would be responsible for reviewing and commenting on website materials and participating in teleconferences and/or focus groups in London. For more information about the opportunity and how to apply please click [here](#).



### **Thank you**

We would like to say a huge thank you in advance to the five people taking part in **Ride London** this year and raising funds for a **PhD studentship** that will focus on suicide research. Ride London is a 100 mile bike ride through London to Surrey and back finishing on the Mall, taking place on **Sunday 31<sup>st</sup> July**. This year we also have our Research Director Vanessa taking on the challenge! And it is a challenge. If you would like to sponsor them they would be very grateful. You can see their fundraising page by

clicking on their names: [Sarah](#), [Evan](#), [Martin](#), [Mark](#) and [Vanessa](#).



Get in touch for more details

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