



WELCOME to our summer newsletter. In this edition, we look at research on maternal mental health, the importance of involving young people in research and how new virtual reality technologies could be used to support people who experience psychosis. We also highlight current opportunities for getting involved with us. Lastly GDPR impacted a lot of charities including us – we are now building our supporter base again if you know people who might like to read our newsletter – please send them the [sign up link](#).

Involving young people in research - why it matters



RESEARCH INTO YOUNG PEOPLE'S MENTAL HEALTH

This week we released our second [Right People, Right Questions](#) national survey looking at the top ten questions people think are most important for researchers to answer about young people's mental health. Rachel Temple

reflects on the importance of making sure the views of young people are heard and on how McPin is making sure young people help shape this research project.

In today's society, everyone knows someone, who knows *someone* that experiences mental health difficulties. Given that [three in four mental health problems are established during childhood](#), it's possible that 'someone' is a young person.

We are starting to see an emphasis on young people's mental health: [The increase of mental health referrals in schools](#). [The benefits of counselling in school settings](#). It makes sense that we would approach the problem as early as possible. You certainly wouldn't wait for an infection to spread before treating it.

Projects like '[Right People, Right Questions](#)' are important because they address the needs of young people. It asks those aged 11-25, as well as parents, carers, teachers and mental health professionals, what our mental health priorities should be. What should we research about children and young people's mental health? Where is change needed the most? We offer young people a voice in this project. The results will reflect what *they* think needs to change.

Having worked in a young people's mental health inpatient unit, as well as experiencing mental health difficulties myself, this project feels somewhat personal. I have seen why change is needed so desperately. [Suicide is the biggest cause of death for young people in the UK](#). Facts like this cannot simply be brushed under the carpet- it's everyone's responsibility to act.

As researchers, it can be easy to assume that we are mirroring the best interests of young people, despite not explicitly involving them in our work.

As a support worker for young people on a mental health inpatient unit, it was easy to make this assumption as well. I quickly learned that young people are not always included in decisions surrounding their own care. They might wake up to learn that they are no longer visiting a relative that they'd been excited to see. Or, they might be considered 'too unsettled' to attend therapy, despite repeatedly requesting it. Experiences like these would result in resentment towards services and further problems along the road. The 'we know best' approach remains very much intact within children's services, and it's a real problem. It drives a wedge between the young people and the service that seeks to support them. Ultimately, this can lead to an increased time spent within that service- a slower rate of recovery.

If my experiences have taught me anything, it's that no one wants to be 'told' which treatment plan they will receive. This seems obvious. Young people need to be directly involved with decisions made about them.

The same issue applies to research. We can't possibly make discoveries that have real impact without listening to, and collaborating with the people who will be affected by those decisions. In other words, if we are researching young people, then we need to work with young people!

The way in which we involve young people needs to be meaningful. It needs to extend beyond meeting attendance. It needs to be more than tokenism.

We have embraced this message throughout our project Right People, Right Questions. We don't just involve our Young People's Advisory Group (YPAG). We work *alongside* them. They shape the decisions that we make, from social media content, to creating and analysing research questions. Their input is not restricted to merely ticking the right boxes. It stretches to key aspects of this work and makes a noticeable difference, which is essentially what meaningful involvement is all about.

Within the mental health world, young people are starting to be more involved in decisions made about them. Efforts are being made to balance the scales, so that voices are not just being heard- they are being listened to. The outcome of our project will contribute to this, and I hope that people seize the opportunity to be a part of it!

The Right People, Right Questions national survey about young people's mental health is now live. To take part, please click [this link](#). The survey asks you which top ten questions you think are most important for researchers to

answer. It will only take fifteen minutes to complete. The survey will be closing in three weeks so don't miss out on your opportunity to help reshape children and young people's mental health!

Virtual Reality and psychosis

By Dan Robotham



Many people find social situations difficult. This includes people with psychosis. Virtual Reality (VR) may be able to help some overcome this, and the immersive worlds created by VR technology are now convincing enough (and affordable enough) to be used in psychology therapy. Find out how VR is being used within a new research programme for people with psychosis.

Virtual Reality (VR) has been around for decades, but the immersive worlds created by VR technology are now convincing enough (and affordable enough) to be used in [psychological therapy](#). VR environments have already helped people with phobias, forming part of an [exposure therapy](#) programme. People can experience virtual simulations of things that they might be frightened of to confront in real life (e.g., heights or spiders).

The National Institute for Health Research (NIHR) sees the potential of using VR in the NHS, [awarding](#) the 2017 Invention for Innovation (I4I) funding to a team led by Professor Daniel Freeman at the University of Oxford. The programme, operating in five sites across England, will develop, demonstrate and test VR therapy to help people who experience psychosis and who may find social situations difficult.

A comprehensive research programme such as this requires expertise from different types of organisations, working in different fields, to achieve a common goal. The clinical trial itself is only one bit of a much larger picture. The McPin Foundation has been part of this collaboration from the beginning, alongside the [Helen Hamlyn Centre for Design](#) (Royal College of Arts) and [Mindtech](#) (University of Nottingham). McPin has two main tasks; (1) to help embed the expertise of people who experience psychosis into the design and development of the VR scenarios, and (2) to find out how acceptable VR therapy will be to potential beneficiaries, and barriers to implementing it as part of the NHS. This will involve qualitative research work, conducted with expertise from people who have used mental health services.

We are looking forward to working with the Helen Hamlyn Centre, a team which specialises in 'inclusive design' and 'user experience' (UX). They aim to develop products *with* people rather than *for* them. There are obvious parallels to Patient and Public Involvement (PPI), and this project provides an opportunity to bring these two ways of working together. We are also looking forward to working with Mindtech, improving our knowledge about how new services and therapies can be implemented.

Major research funders now [recognise](#) the importance of the context that surrounds a clinical trial. This increases the potential for individuals to inform research with their personal experiences (the new INVOLVE [guidance](#) outlines ways people can do this). People's experiences are relevant in the design and development of therapies,

or in understanding the barriers that people face when trying out new therapies and technologies. Research programmes like this are good news for McPin, as we try to find new and innovative methods for involving people in research.

You can find out more information about our involvement with the project, [here](#).

Maternal mental health peer support

By Andreja Mesaric



The NHS has recently announced it will be committing an extra £1.6million to help mothers with mental health issues during or after pregnancy. With maternal mental health problems affecting up to a fifth of all women, research has shown that peer support can help mums receive the emotional and practical support needed during this time. Andreja Mesaric discusses working with new mums on developing quality assurance principles specific to maternal mental health peer support.

Pregnancy and transition to motherhood can be a vulnerable time for women's mental health. Perinatal mental health problems affect up to a fifth of all women. Although postnatal depression is most common and most well-known, women can be affected by a range of other mental health issues around the time of pregnancy and birth, including anxiety, obsessive-compulsive disorder, birth trauma and post-partum psychosis. These can affect women who have a history of mental health problems as well as women who had never struggled with their mental health before. Lack of social support and isolation can have a particularly negative effect on the mental health of pregnant women and new mothers.

There are several things that make the experience of mental health difficulties during this period of a woman's life distinct. They can affect the mother's ability to care for the baby and can lead to insecure attachment. This can impact on the child's development and mental health in childhood as well as later on in life. Standard mental health advice for mild to moderate depression and anxiety, such as getting a good night's sleep and regular exercise simply are not feasible when caring for a baby. With more severe problems, use of medication is not always straightforward as women have to consider the impact of the medication on the foetus when pregnant and the baby if breastfeeding.

Women also face additional barriers to accessing support for their mental health during this time. Many do not share that they are struggling because they worry about being perceived as bad mothers. Some fear their babies will be taken away if they admit to becoming unwell. The baby's sleeping patterns and lack of childcare can get in the way of attending scheduled appointments. Provision of specialist perinatal mental health services across the UK is uneven, and not all women needing hospital admission can get a place in a specialist mother and baby unit. GPs, midwives and health visitors often lack knowledge and awareness of perinatal mental health issues and do

not always refer women on to appropriate support. We know this first hand from research we did with mothers a few years ago exploring decision making around anti-psychotic [medication use in pregnancy](#).

Access to peer support from other mums who have gone through similar experiences provides women with a safe space where they can be heard and receive emotional and practical support without judgement. It can help to normalise their experiences and gives them hope that they too can get better. The Maternal Mental Health Alliance and Comic Relief have commissioned the McPin Foundation and Mind to develop quality assurance principles specific to maternal mental health peer support. We are building on our previous work with Mind on the [Side by Side](#) project, where we explored peer support values and principles. Our work on maternal mental health peer support has attracted a lot of interest on Twitter and at our first consultation event. This has reassured us of the importance of this work.

The resulting principles will aim to assure the quality and consistency of online and face to face peer support in perinatal mental health. We hope they will serve as a useful resource for peer support projects in ensuring that peer support promotes positive mental health outcomes, is safe for women and babies, and is accessible to all. They will also aim to provide guidance for how to respond when things do go wrong or become challenging.

Over the next four months we will be continuing our consultation events where we will co-design the principles with women with lived experience of perinatal mental health problems, those involved in running peer support, health professionals, and others with an interest in the topic. These co-design events will be planned and led by Lived Experience Facilitators, who will also be facilitating focus groups with women who have used maternal mental health peer support. If this is a topic close to your heart you can keep an eye out for updates on our [website](#). Our London event in July is now fully booked but we will be advertising details of our final event in September soon.

Get Involved!

We need your help to make sure that mental health research has meaningful impact in the lives of those directly affected by mental health problems. Here's how you can get involved:

Blog for us! Have you been an advisor or co-producer of a mental health research study? Would you like to let people know how the involvement of people directly affected by mental health problems makes a difference or what it's like to be involved in mental health research? Then please consider being a guest blogger. If you are interested, please email contact@mcpin.org.



Do you like shopping online and are passionate about life-changing mental health research? Then sign up use **Easy Fundraising** when shopping online and select the McPin Foundation as your charity of choice.



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