PUBLIC INVOLVEMENT IN RESEARCH BULLETIN

Issue 16: June 2019
About

In these bulletins, we advertise involvement opportunities and events within the McPin Foundation. We also advertise opportunities for people to get involved in mental health research with other organisations. From time to time we advertise opportunities for people to take part in studies as participants.

If you have an involvement opportunity you would like to include in our next bulletin, please email us at contact@mcpin.org. If you would like to receive future bulletins direct to your inbox, please sign up here.

We also advertise involvement opportunities on social media, so to be kept up-to-date please do follow us on Twitter and Facebook.

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Involvement Opportunities

Would you like to advertise your involvement opportunity in our quarterly Involvement Bulletin?

Email: contact@mcpin.org including the following information:

- Some background information about your opportunity
- Where the opportunity is taking place
- Payment amount and whether travel expenses are reimbursed
- The deadline to express interest or apply

About

Time to Change are looking for someone with lived experience of mental health to join their Time to Change Senior Management Group. This role involves attending the quarterly meetings of the Senior Management Group, which consists of members from Time to Change, Mind, Rethink Mental Illness and also three other Lived Experience Advisors.

Interested?

For more details and how to apply click here or if you have any questions, please contact Hannah Rawson, h.rawson@time-to-change.org.uk
BECOME A MEMBER OF A RESEARCH ADVISORY PANEL TO IMPROVE PERINATAL MENTAL HEALTH SERVICES FOR ETHNIC MINORITY WOMEN.

Location: East London

Remuneration: Up to £80/meeting

Travel expenses: included, as well as childcare costs

Deadline: 5 PM on 28th of June 2019

About

PAAM is a research project, being funded by the NHS, which is conducting interviews with South Asian and Black women with perinatal mental illnesses in order to improve Perinatal Mental Health Services for ethnic minority women.

They are looking to recruit ethnic minority women who have experience of a mental illness during the perinatal period (pregnancy or up to 1 year after birth) to be a part of a Lived Experience Advisory Panel (LEAP). They will also be recruiting family members/carers/partners of ethnic minority women with perinatal mental illness.

The panel will help the research team by contributing their stories and experience in order to make sure the research being conducted is as appropriate as possible.

Interested?

Email the PAAM Research Co-ordinator Fatima Umar at Fatima.umar3@nhs.net or phone her on 0207540 4380 (ext:2307)

GET INVOLVED WITH A SERIES OF MINI-DOCUMENTARIES ABOUT SMOKING CESSATION

Location: Bath

Remuneration: £100 (PAYE or gift voucher)

Travel expenses: included

Deadline: continually accepting expressions of interest

About

Addiction and Mental Health (AIM) at the University of Bath are co-ordinating a series of five service-user led short films about experiences of quitting smoking while experiencing mental health problems. They are looking for people who were previous smokers, and quit smoking around the time of experiencing a mental health difficulty, to be interviewed for these films.

This project is funded by Cancer Research UK

Interested?

Please contact Gemma Taylor by email G.M.J.Taylor@Bath.ac.uk or on twitter @Bath_AIM
Your Experiences in Research

How did you find out about The McPin Foundation?

I had spent a year in treatment for Anorexia Nervosa as an inpatient in an Oxford Eating Disorders Unit, Cotswold House. Before becoming so unwell that I couldn’t work, I was working in Mental Health and my interests lay predominantly in Psychiatry.

During my discharge transition from Cotswold House, I became a member of Restore, a charity organization that supports people with Mental Health Illness by equipping them with tools and skills in order to reach their own future goals. It was here where I found out about The McPin Foundation. I attended their service user workshop about the implementation of a new Virtual Reality therapy in the NHS. I found the workshop fascinating and it awoke the part of my mind that had been ‘inactive’ for the time I was in treatment. I met Humma, Dan and Thomas who were so welcoming and very fascinating!

This was 13th February 2019 and since then, I am fortunate enough to have been involved in various groups and meetings with McPin.

Did you have to certain degrees/qualifications to get involved with McPin?

Not at all! Whilst I do have qualifications in this area, it is not required for this type of participation with The McPin Foundation.

Remember that no amount of qualifications, exams, book reading and studying can equip another with the personal experiences of your own Mental Health Illness! It is these experiences that McPin aims to champion and put at the forefront of research.

Describe your most recent experience with The McPin Foundation and what have you gained from this experience?

On the 21st May I attended a meeting held at McPin’s office in London. The meeting aimed to identify where improvements can be made to Lived Experience Advisory Panels (LEAPs), and to explore alternative ways of involving people. LEAPs are one of the major ways that McPin involve people who had lived experience of Mental Health Illness in their research.

At this meeting there were staff from McPin, members of LEAPs and the Young People’s Advisory Group (YPAG), peer researchers, and study representatives. During this meeting we heard about recent and on-going research projects. We discussed what works and what requires some adjustments and why, and how we could collectively share positive experiences in order to better support LEAPs that have come up against unpredictable challenges.

Last year, McPin used feedback from LEAP members to produce an information sheet for all LEAP members, which, in my experience, has incredibly useful.

About the Author

Hannah-Louise Toomey has been involved in the gameChange study service user workshops as well as the Feeling Safe Patient Advisory Group (PAG). This month, she will be joining our newly formed LEAP for a new study looking at virtual reality treatment for obsessive compulsive disorder (OCD).
What are your plans for the future?

My experience with McPin, in conjunction with the support I have received from local Mental Health organizations in Oxford, has given me the motivation to pursue my dreams of working in Mental Health. Being part of the McPin’s gameChange project has given me a new outlook and perspective on how I would like to use my own experiences to help others. Their belief in me has helped me to believe in myself and apply for a Masters in Occupational Therapy at Oxford Brookes University. I have recently been awarded a place at Oxford Brookes for September 2019 and I plan to continue my involvement with McPin throughout this time.

Would you recommend similar opportunities that McPin have offered you, to others?

100% YES! If anything, being a part of workshops, research projects and developmental meetings has given me a space to feel seen, valued and heard. And this in turn has given me the confidence to use my knowledge and experience to embark on a life that I would like to lead, to the best of my ability.

Would you like to contribute to ‘Your Experiences in Research’?

We invite people with lived experience of mental health problems to either:

- Write a short article (no more than 300 words) by hand or on the computer (we can transcribe handwritten pieces into computerised text for you if required)
- Produce a drawing or piece of art by hand or computer

The content must be on the topic of mental health research or your experience of involvement in mental health research, for example working on a lived experience advisory panel or patient advisory group.

We would love to see some of your creative flair and hope that the brief we have provided may give you some ideas. It is completely optional if you would like us to include your name with your work in the bulletin, or if you would like it to be anonymous.

If you would like to produce some content or have any questions, please contact Anja Hollowell by email: anjahollowell@mcpin.org, or phone 020 7922 7871.

We will be happy to discuss what you plan to produce and if you would like it to be anonymous. We can also arrange for how you would like to send us your content (either by email or post). A £20 Amazon voucher will be offered to you as a thank you for your contribution.
What is this research?

People experiencing obsessive compulsive disorder (OCD) struggle with obsessive and persistent thoughts. This leads them to perform compulsions to relieve the anxious feelings associated with these thoughts. One of the more common forms of OCD involves carrying out repeated physical compulsions. For example, repeatedly checking that a door has been locked correctly, repeating an action until it ‘feels right’ (such as turning a switch on and off), or repeating an action in order to prevent harm to yourself or others.

Breaking free from these compulsions can be very difficult for people experiencing OCD. The compulsions keep the OCD cycle going because they tend to reinforce the obsessive thoughts and feelings. As well as this, performing compulsions can be very time-consuming and can prevent people from doing the things that they want to do. It can lead to great distress and avoidance of many activities.

One possible way to help people with OCD may be technologies, such as virtual reality (VR). It could be used as a form of therapy to help gently expose people with OCD to their fears and worries, and help them to reduce compulsions. VR therapy involves wearing a headset and exploring a computer-generated environment. A virtual coach will guide users through their thoughts, feelings and responses in situations that people with repeated action OCD find difficult.

To explore the possibility of using VR to help people with OCD, the McPin Foundation are working with Oxford VR to design an approach that is suitable, effective and appropriate for people with these experiences. This project aims to develop the therapy to the point that its effectiveness can be tested in a research study.

Why is this research important?

Currently people with OCD will be referred to IAPT services for psychological therapy. But it is not clear if IAPT services fully meet the needs of people with OCD. Having VR therapy could mean that therapy is more accessible and people acquire the skills they need as early as possible. As well as this, VR offers the chance for people to try reducing their compulsions in a safe environment. Having tested out their fears, the tools that they acquire in the virtual reality world could then be applied to reality.

How are McPin and people with lived experience of mental health difficulties involved in this research?

The McPin Foundation are facilitating the service user involvement for this study in the form of user-development workshops and a Lived Experience Advisory Panel (LEAP). McPin will ensure that people with lived experience of OCD have their voices heard during the VR design process, as well as supporting them to advise and shape the rest of the project. Some of the McPin staff who are supporting this project will draw from their own experiences of OCD to offer input and expertise.

What is the current status of the project?

Recruitment for the Lived Experience Advisory Panel (LEAP) and workshops has now closed. The first LEAP meeting will be taking place in June 2019. Members of our LEAP will also be carrying out user testing of the VR itself.

Who do I contact for more information?

For more information about the project please contact Rachel Temple via email: racheltemple@mcpin.org
The McPin Communications team is growing!

In June, we welcomed two new comms interns – Kathryn Watson and Cassandre Greenberg. The team now includes people with different skills and past experiences including medical training, fine art and journalism. Our mission this year is to explore different ways of telling McPin’s story – both in terms of shouting about the amazing projects we are involved in and communicating why mental health research and public involvement matter.

LEAP meeting

McPin hosted a meeting on 21st May all about reflecting on our experiences of Lived Experience Advisory Panels (LEAPs) and how we can improve them. We had LEAP and Young Peoples Advisory Group (YPAG) members present, along with study representatives. The day ended with discussions about how we move forward with the reflections we had made and areas that need prioritisation. Watch this space for what we have planned.

Lets Talk Mental Health

Humma Andleep, a researcher at McPin and Katy Pickles from our YPAG have taken part in the ‘Let’s talk mental health’ video series, led by Louise Arseneault. Humma talks to Professor Peter Fonagy, about how their own experiences of mental health have influenced their careers. Katy Pickles interviewed Lord Professor Richard Layard who is looking into factors that influence happiness.

For more information, click here

Featured Blog: Imposter syndrome and Public Involvement: How to make it easier to speak up

Rachel Temple, a lived experience researcher and public involvement officer at McPin, writes about her experiences of imposter syndrome and social anxiety. Drawing from this, she discusses how we can make others with similar difficulties feel more comfortable during meetings, so that they feel able to have their voices heard.

Read the blog here
Mental Health in the News

Transgender no longer recognised as a disorder by WHO

New changes to the World Health Organisation’s global manual of diagnoses, the International Classification of Diseases (ICD-11), mean transgender health issues will no longer be classified as a disorder. This move is one step in the aim to reduce stigma in this area; Graeme Reid from Human Rights Watch, says that this change “will have a liberating effect on transgender people worldwide”.

Members of the UN are now responsible for putting these changes into practice by 2022.

Read more on the BBC here and from Human Rights Watch here

Scotland’s Youth Commission on Mental Health: embed mental health in the curriculum

Findings from Scotland's Youth Commission on Mental Health call for mental health to be put in the school curriculum. The youth commission involves a group of 23 young people with experiences of mental health who have engaged with other members of their communities and various organisations, and made recommendations based on their findings. The commission also made other recommendations such as Mental Health First Aid training being a requirement for organisations working with young people, and a reduction in the waiting time for child and adolescent mental health services.

Read more on the BBC here or from the Scottish Association for Mental Health (SAMH) here

Researchers in New Zealand establishing YPAG to set priorities

Researchers in Auckland are building on the McPin Young Peoples Advisory Group (YPAG) research priorities to set priorities for mental health in New Zealand. A satellite Cochrane review has been set up to explore Children’s and Young People’s mental health. Over the next two years, they will involve young people in priority setting activities in an effort to co-produce the review questions.

The process is starting with an online survey for young people and those supporting young people’s mental health which will identify the areas that need to be investigated or focussed on.

Read more about it here or follow @Cochrane_CCMD for updates.
Health experts call for emphasis on prevention in mental health

With the rising incidence of mental health problems and new innovations being made in treatment methods, experts have started to ask the question about what is the most effective way to approach mental health care. They say that with more pressure put on health services, the focus should be on prevention more than treatment.

Research shows that the risk factors for mental health problems start to take effect early. With more knowledge about risk factors comes more opportunity for prevention.

Read more from The Guardian here

Mental Elf spotlight: Antidepressant withdrawal: slower and lower tapering of SSRIs

Stopping taking antidepressants can have some side effects similar to the symptoms they are trying to treat, especially if medication is reduced too quickly or after taking them for an extended period of time. A blog written by Master’s students at UCL talks about recent research by Horowitz and Taylor (2019) that investigated ways of reducing the withdrawal symptoms from coming off antidepressants.

Read more on the Mental Elf blog here

ENMESH conference in Lisbon

On 6-8th June 2019, the ENMESH conference was held in Lisbon, Portugal. ENMESH, or the European Network for Mental Health Service Evaluation, is a “network of active researchers in the field of Mental Health Service Research and Evaluation”. Three staff members of McPin attended; Vanessa Pinfold, Dan Robotham and Andreja Mesaric. The theme of the conference was ‘complexity’ in mental health systems, we presented examples from our work on young people's mental health research priorities, co-producing research, peer support, and evaluations of complex community services.

Keep an eye out on the McPin website for a blog coming soon...
Research studies looking for participants

HAVE YOU HAD PERSONAL EXPERIENCE OF SELF-HARM OR OF CARING OR SUPPORTING A PERSON WHO SELF-HARMS?

UK-wide
Voluntary

The University of Manchester are investigating what helps and does not help people receive mental health assessments and access psychological therapies after they present to hospital with self-harm. They are looking for people with personal experiences of:

- Self-harm (self-injury or self-poisoning with or without suicidal intent)
- Mental health services and/or psychological therapies following self-harm (accessing and/or receiving)
- Caring or supporting a person with self-harm

Interested?

Please contact Leah Quinlivan: leah.quinlivan@manchester.ac.uk, phone: 0161 2750727.
For more information, click here

RESEARCH PARTICIPANTS NEEDED FOR CARDIOPHITNESS: EXPLORING THE OVERLAP BETWEEN PHYSICAL HEALTH AND MENTAL HEALTH

Phone/ in-person in Leicester
£10 gift voucher; Care professionals will be offered a £10 gift voucher if they take part in their own time (not within work time)

Researchers at the Aston University want to find out what views, experiences and perspectives are for care provided for physical health problems (such as heart disease or diabetes and related) in those who have been given a diagnosis of a severe mental illness. Examples include schizophrenia, schizoaffective disorder, bipolar disorder and non-organic psychosis.

They are looking for people with the following backgrounds to take part:

- Service users/individuals with lived experience who have been given a diagnosis of a severe mental illness (schizophrenia, schizoaffective disorder, bipolar disorder and non-organic psychosis) - particularly individuals from BAME backgrounds
- Carers of individuals who have been given a diagnosis of a severe mental illness
- Care professionals - particularly GPs, practice nurses
- Pharmacists and pharmacy technicians - particularly from primary care - working in community pharmacies and GP practices

Interested?

Please contact Dolly Sud: sudd@aston.ac.uk. For more information click here
Our new and developing projects

In 2017-18, we were involved in developing proposals to secure funding and start new research projects.

We raised £400,000 in project grants.

We developed and sought funding for 43 projects.

We secured funding for 20 projects and have started 13 of them already.

We worked on a total of 38 projects last year. Of these projects, 24 projects had researchers on the team with lived experience of mental health.