Happy Easter!

YOUNG PEOPLE’S NETWORK BULLETIN

Issue 3: October 2019
Welcome to the third McPin Young People’s bulletin! Here, you’ll find out what’s happening in the world of children and young people’s mental health—especially at McPin. Keep updated with what our Young People’s Advisory Group (YPAG) are up to, who advise and help shape important mental health research projects! Most importantly, you can find out about some of the ways in which you can be directly involved in mental health research. We’ll be releasing these every four months. I hope that you find it interesting! :)

Best Wishes
Rachel
Young People’s Involvement Coordinator at the McPin Foundation

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What have we been up to?

A new team member

Anja Hollowell joined our Public Involvement in research team this year. She attended her first Young People’s Advisory Group meeting in July. Below she describes what it was like!

My first YPAG

On July 3rd, I got to facilitate my first YPAG meeting with Rachel. Being relatively new to McPin and having seen some of the other advisory panels for specific studies (like gameChange and PARTNERS2), I was excited to see how this one works. Unlike our other advisory groups which focus on a particular study, the YPAG advise on a range of different projects.

In this meeting, two researchers came along to give presentations and receive feedback on their research projects. The first, Esther Walton from the University of Bath, talked about epigenetics and mental health. Epigenetics, literally meaning “on” or “above” genetics, is how reversible modifications are made to DNA, which switch genes on or off. Esther talked about how negative events in a young person’s life can cause these epigenetic changes, which can lead to mental health problems later down the line. She asked the group questions about the relationship between biology and mental health – and even asked whether they think exploring this relationship is an appropriate thing to do?

I really enjoyed listening to the responses from the group. It was particularly striking how they talked about the complexities of the emotions that might surround this topic: some people might feel relieved that their mental health problem is genetic and therefore “not their fault” whereas others might feel helpless and unable to change their situation. We also talked about how to communicate such findings in an acceptable, yet effective way for young people.

The second researcher, Ben Perry, presented his research idea about creating a risk calculator for diabetes in young people with mental health problems. In people with psychosis, there is a higher risk of developing diabetes. The current risk calculators that determine this risk are designed for adults but given that the risk increases with age, they hugely underestimate the risk when used for younger people. Ben wanted to make a calculator specifically for young people for this reason but wanted the input of the YPAG to help guide his research.
He asked questions like ‘If you were at risk of developing diabetes or obesity, would you, as a young person, want to know?’ and ‘If you would want to know about this risk, would you be willing to have more ‘invasive’ tests (like a blood test)?’. The young people provided Ben with insight into how they would react to a calculator like this and how this would be perceived if it was used in everyday practice. This included things like how people may care less about their physical health if they are dealing with mental health problems, and advice on how GPs should approach the subject of physical health with young people. Personally, I feel that risk is a difficult concept to deal with – it can feel quite abstract until you see proof of it and we often get lured into that “well it won’t happen to me” way of thinking.

The final thing on the agenda was ‘Right People Right Questions’. This was a project that McPin led, which aimed at identifying the top 10 priority questions that should be answered by research into young people’s mental health. The YPAG were at the core of it all, shaping all decisions made and choosing which ‘themes’ of questions to take forward. In the process of making the list, a number of questions came up that were in fact already answered by research, but the results not widely known. We now want to find a way to involve the YPAG in disseminating the answers to the questions. So, in the meeting we all started working together to categorise the questions so as to make them more manageable. We tried to merge a few questions here and there to break down the long list. There are 84 in total! Even though this was the last thing to do at the end of a long meeting, everyone got stuck into the task. The next step for this will be to combine more questions and start thinking about the ways in which we can spread the word about the answers; there are ideas like podcasts, videos, and artwork on the table - but I’m looking forward to the YPAG’s input and suggestions!

At the end of the session, it was time for feedback. This is where everybody in the room jots down one good thing and one thing that they wanted to change or improve about the YPAG meeting. This was interesting to see because McPin has been doing some work recently around seeing how we can improve our advisory panels. Two of the YPAG came to a meeting in May where we brought together people from different groups to discuss how to improve our groups. It was therefore really great to see that feedback is a standard part of every YPAG meeting. In this meeting, there were a lot of comments about the room being too small, so we’ve already booked a larger one for next time! Someone also said that they didn’t like some of the questions that the researchers were asking. Feedback like this is essential so that we can figure out ways of making meetings more comfortable and useful for everybody involved. It was a very long day and we didn’t have a very large room but nonetheless the YPAG provided some excellent input until the very end of the meeting.

Personally, it felt like a very productive meeting and I felt positive about the impact that the YPAG can have on current mental health issues simply by applying their lived experience as young people.

The next YPAG meeting will take on October 12th. You’ll hear all about it in our next edition!
Designing a mental health audio tour for the National Gallery

Outside of our core YPAG meetings, we facilitate various other opportunities for our Young People’s Network. These opportunities are advertised regularly through our mailing list. We have recently been working with Dr Helen Fisher from Kings College London and the National Gallery team to design a brand new mental health-themed audio tour. Eight members of our network signed up to attend a series of different workshops whereby we developed materials and a script to be used for the audio tour. Below, one of our young people describe their experiences of the project:

When I was given the opportunity of being a part of creating the National Gallery’s mental health audio tour, I took it with open arms. To use my experiences of mental health to help raise awareness is exactly why I became a part of the YPAG in the first place. With the first meeting came extreme anxiety and nerves as I did not know what to expect and this was deepened by my lack of art knowledge. Everyone in the group was so welcoming and despite the first meeting being very art based, I began to feel a lot more comfortable. As the meetings went on we undertook a variety of tasks; discussing the paintings, mapping the tour and sharing our own experiences. All were enjoyable and it was very interesting to listen to everyone’s individual perspectives. The overall experience is one that enriched my own knowledge of both mental health and art, and should result in awareness being raised for others too. It has been an honour to work on such a worthwhile project with so many wonderful people and I cannot wait to see the impact the final audio tour will have.

By Niamh Elam, YPAG member.

Look out for the finalised mental health-themed audio tour - launching on World Mental Health Day on 10th October 2019 at the National Gallery, London!
What else has been happening?

Improving McPin advisory groups

We’ve been busy collecting feedback from some of our advisory groups at McPin. Two of our YPAG members attended a larger meeting at the McPin Foundation in May, where the whole team and members from other groups came along to reflect on how things are going. On the day, the two YPAG members shared what they like about YPAG, as well as what they would like to see improved. One of the key things that they said was that, after researchers come to meetings, they would like to be kept in the loop with how their impact has made a difference to the project. Here’s how we’ve tried to improve this:

- Created a YPAG impact log – documenting key changes made to research projects a direct result of the input of the YPAG
- Put together a Young People’s Request form – any researchers seeking involvement from our network must complete the form and explicitly state how they will keep the young people informed about their project
- Speaking with coordinators from other young people’s groups to share learning
- Putting together resources for improving the way that we run meetings, including ways to help people to feel able to contribute

Other meetings

Our Young People’s Network have been involved in plenty other young people’s projects outside of our core YPAG meetings. Here’s a snippet of what else we’ve been up to throughout the past few months...
Here’s your chance to have your voice heard. We’re looking for young people aged 13-24 to write about a mental health topic of their choice. It can be related to personal experiences if you like. We’ll offer you a £20.00 Amazon voucher as a thank you!

What we’re after:

- An article between 600-1000 words about a mental health topic related to children and young people
- The article should mention mental health research, e.g. would you like to see more research done in this area? Is there some research that’s been in the news related to this area?
- Article must be suitable and appropriate for a young audience

Interested? Contact Rachel: racheltemple@mcpin.org
Your Say

What it’s like to live with psychosis and why I’m a VR therapy convert

This edition is written by Leo, 15 from our Young People’s Network. He shares his personal experiences of psychosis and post-traumatic stress disorder (PTSD) and how they have shaped his opinions about different forms of therapy, including virtual reality (VR).

I find my experiences of Post-Traumatic Stress Disorder (PTSD) and psychosis very hard to talk about. Some people describe psychosis as feeling as if they are watching a movie that is their life. Others say it’s simply the most troubling loss of self you can experience. It’s like your worst enemy is inside your head. Psychosis isn’t fun because your mind plays tricks on you and this can be terrifying. Having PTSD on top of this makes everything twice as scary. PTSD to me felt like I was randomly and repeatedly being dragged into a looping nightmare behind my eyes, constantly being sent back in time to relive the worst moment of my life. It was a stomach churning feeling, a feeling you could only feel if you were falling backwards off a cliff. I spent more time back in that hell than I did in my real life. After I came back from my flashbacks I would forget who I was due to the confusing effects of psychosis and start breaking down into floods or intense anger, fear and sadness.

These two conditions are often seen as being on the more severe end of the mental health spectrum but this doesn’t mean that they are particularly rare. In the survey, 3.7% of men and 5.1% of women screened positive for PTSD. Women aged 16-24 were most likely to screen positive (12.6%). Ages 55-64 was the only category where men were more likely to screen positive than women. The ‘Adult Psychiatric Morbidity Survey 2014’, published in September 2016, includes a chapter on psychosis. It includes an estimated prevalence of psychotic disorder in the last year in England of 0.7% of adults aged 16 and over.

During my episodes of psychosis, I used marijuana as a self-medication for staying calm during the daily struggles I had in my life. One day, things took a turn for the worst when I consumed a high dose of very strong marijuana. It caused me to feel that I was living in a simulation - and always had been. I sat trembling on a step outside a church completely paralysed with fear. It was the most traumatic day of my life. I felt an insane feeling of dread, hopelessness and loneliness as though, at that moment, I was the only person in the universe alive and everyone else was there to kill me. My life was just a game to get information from me. This is how scary psychosis can be. I’m not exaggerating when I say I’ve been to hell and back, but along the journey I found my way to Cognitive Behavioural Therapy (CBT). This is a talking therapy which focuses on treating your thoughts, feelings and behaviours as one big cycle. The only way to break the cycle is to work on changing your beliefs and reactions to your feelings, and vice versa.
My clinicians told me what I was experiencing was just a bad trip caused by an overdose of strong drugs, which in turn was causing an overload of anxiety. I didn’t believe it at the time because of how strong my beliefs were. In my mind when they told me it was all in my head I thought they were trying to cover up the ultimate truth about reality that I thought I had been shown. And yet, every time I had a good day, every time I looked into my girlfriend’s eyes, I suddenly saw the simulation of reality again. I would repeat to myself daily “This isn’t me. The real me is stuck back there.” It was absolutely terrifying.

**My journey to recovery**

After a long and painful year of CBT, I started to see signs of recovery. Fewer flashbacks, less frequent panicked episodes and slowly coming to terms with the idea that my delusions were not as real as I once thought. After my therapy ended, I felt a sense of peace - as if the past year had all been a bad dream. I want to thank Liz my CBT therapist for getting me through the hardest year of my life. You are the reason I didn’t give up.

I have always been interested in virtual reality and one experience that stands out as a turning point in my recovery was getting involved in the gameChange project. The project has involved designing and testing a virtual reality therapy to help people with paranoia. In particular, it aims to help people with experiences of psychosis by helping them practice the social situations that they find scary in a safe virtual environment, hopefully giving them confidence to do the same in the real world. When my therapist first told me about the project, I questioned how this would all work but after working with the team and trying out their VR software, I gave the therapy a go. When I took off the headset I felt more confident with speaking to people and using eye contact in social situations, I felt as if I had conquered a fear. I know in my heart for a fact that if I had found gameChange earlier my recovery process would have taken half the time it did. I can report that I am a convert – it truly showed me the possibilities of using virtual reality for therapy.

Throughout my year of being unwell I was helped by so many people. Each put in as much as they could to get me back on the right track. After my recovery, I wanted to give something back. Inspired by gameChange, I am currently learning how to develop virtual reality games and programs to help people with mental health.

So what is my message for others? When I was going through my episodes, I thought there was no hope for me. No future. I thought I would end up either homeless or dead. At times, I was on the verge of giving up. Now I know that just because you have issues with your mental health, it doesn’t mean it’s over for you. Keep pushing. Take everything you can out of your experience and never give up.

**References:**


If you have been affected by this article, please visit our sources of support page. What do you think about a social media detox? Do we all need one? Share your thoughts on our Twitter or Facebook page!
Get Involved!

Young people’s involvement in mental health research is so important, especially if we want research to be good quality and focusing on what matters the most. Here, we’ll share the latest opportunities to get involved in mental health research. Know about an opportunity for young people? Get in touch!

Become a Young People’s Advisory Group Member at the McPin Foundation

What’s the project?
We are looking for 1 person aged 13-24 with experience of mental health problems and an interest in mental health research to join our YPAG. The group will meet regularly as part different projects related to children and young people’s mental health. We are particularly interested in male applicants, and/or applicants aged below 18.

What’s the opportunity?
As a member of our YPAG, you’d be a key voice of our Young People’s Network. Drawing from your lived experience as a young person with mental health problems, you’d get to help shape and advise on a range of different projects, including our Right People, Right Questions project and a project about creating a risk calculator for young people with psychosis for diabetes and obesity.

What’s required of me?
• Be aged 13-24 with lived experience of mental health problems
• Attend 4 meetings per year and communicate via email
• Live within a reasonable travel distance of London

What will be provided?
• £80 payment per meeting (this includes any prep work required of you before meetings)
• Lunch and refreshments plus reasonable travel expenses reimbursed

I’m interested! Who do I contact?
You can read more about the opportunity on our website by clicking here
The closing date for this opportunity is Friday 4th October, 5PM
Emerging Minds: Kick-off meetings

What’s the Project?
Emerging Minds is a mental health research network funded by UK Research and Innovation. Our vision is to see the number of children and young people who experience mental health problems halved within 20 years.
To do this, we are working with many different researchers and professionals as well as young people themselves to focus on mental health promotion, prevention and early treatment for children and young people.
We have 4 key research challenges that need to be addressed in this work. These challenges build on the questions prioritised by The McPin Foundation’s Right People Right Questions project. They have been further shaped by young people, families, practitioners and with support from our partners: Young Minds and the Centre for Mental Health.

What’s the opportunity?
Emerging Minds are looking for young people in different nations and regions of the UK to take part in ‘kick off’ meetings at different locations in October and November 2019:
Wednesday 16th of October (afternoon) – Glasgow School of Art
Wednesday 23rd of October (morning) – Swansea university
Thursday 21st of November (morning) – University of Nottingham
Wednesday 27th of November (afternoon) – Queen’s University Belfast.
The purpose of these meetings is share our 4 agreed research challenges with people and to encourage them to consider developing research project ideas to address these challenges. During the meeting, you will have the opportunity to suggest ideas for how researchers and other professionals might be able to involve young people in the design and delivery of their research projects. You will also have the chance to suggest ideas or give feedback on some of the developing research project ideas that are already being put together.

What’s required of me?
- Be aged 16-25
- Be available on the morning or afternoon of the kick off meeting in your area.
- Be based in the region or nation of the meeting so that you can travel easily to the meeting venue.
- Reading a short brief about the project prior to coming to the workshop (this will be sent to you)
- Take part in group activities and discussions at the design workshop, particularly encouraging other participants to consider how they will involve young people in the design and delivery of their research projects.

What will be provided?
- Lunch and refreshments
- Reasonable travel expenses reimbursed
- Payment of £75 for your time

I’m interested! Who do I contact?
If you would like to apply, please contact Rachel (racheltemple@mcpin.org) providing your name, age, address, followed by a brief explanation as to why you would like to be involved. If you have previously contacted us about an opportunity and have given us permission to securely store your details, you will not need to provide them again. For more information about the project, you can get in touch with Emily from Emerging Minds: Emily.lloyd@psych.ox.ac.uk

When’s the deadline to apply? Please apply by Friday 4th October, 9am.
Participation opportunity: Interviews about experiences in inpatient mental health units

What’s the Project?
The aim of this study is to ask young people aged 18-25 and their caregivers about their beliefs regarding the reasons for their past admissions (or non-admissions) to, and discharges from inpatient child & adolescent mental health services (CAMHS).

Understanding the beliefs of young people using mental health services and their caregivers regarding CAMHS inpatient admissions criteria are essential. These beliefs are likely to shape how young people view themselves and their difficulties and how they respond to treatment.

What’s the opportunity?
Taking part in an interview to share your experiences of inpatient CAMHS admissions and discharges and to offer your opinion regarding changes that need to be made to these processes. The information you provide will be fed back to relevant organisations (such as the Royal College of Psychiatrists) and has the potential to influence the way in which professional guidance on admissions and discharge criteria is written.

What’s required of me?
• Be aged 18-25 years with experience of CAMHS inpatient services
• Take part in an interview (phone-based or skype if you are not based in Cardiff) about these experiences

What will be provided?
• A copy of the interview questions before the interview (if you wish)
• Details of your responses will be sent to you to check that you are happy with them to be used in the research
• Sources of support will be provided at the end of the email

I’m interested! Who do I contact?
If you are interested in taking part, or would like more information, please contact Rhiannon Lane by email (Lanerc1@cardiff.ac.uk) or by phone (07947814347).

What’s the deadline to apply?
Please apply by the end of October 2019.
Participation opportunity: How can future research answer the questions that matter to you?

What’s the Project?
The Adolescent Mental Health Data Platform (ADP) uses ‘big data’ to answer questions about young peoples mental health. The ADP is working with Self-Harm Research UK (SHARE UK) on the Big Data and Mental Health survey. This is a study to hear young people’s ideas on how self-harm and mental health research can be directed, in order to answer the questions that matter the most to young people.

The results of this survey will be used to shape future research at both the ADP and SHARE UK.

What’s the opportunity?
This is an online survey which asks about which mental health topics are important to you, as well as how you feel about different kinds of personal information being used for research. Examples of personal data are health and social media records.

By filling out the survey, you will be helping researchers to study mental health topics that are important to you. This will help research to ask the right questions, so that we can make discoveries that are more meaningful and change the future for people struggling with mental health. We can also use your results to improve young people’s mental health support services.

What’s required of me?
Be aged 16-24
Ten minutes of your time to fill out the survey
Answer questions about how you feel about how your personal information is looked after and the types of organisations that might have access to it (universities, government or private companies).

There is a question which asks about your experiences of self-harm. This question is asked because we are interested in hearing the views of people who have experience of self-harm, and people who do not. You do not have to answer this question!

What will be provided?
The survey can be completed online. More information about the survey will be provided by following the link below. If you have any questions, just email shareuk@swansea.ac.uk

I’m interested! Who do I contact?
You can take part online at https://www.surveymonkey.co.uk/r/2s3ymx5

If you would prefer to answer questions by email or you have any further questions simply email shareuk@swansea.ac.uk
On Edge: Living in an age of anxiety

What is this event?
Science Gallery London have a new exhibition consisting of a series of events which will explore creative and positive responses to different ways in which people experience anxiety. To do this it will draw from mental health research from the Institute of Psychiatry, Psychology & Neuroscience (IoPPN) at King’s College London as well as the different perceptions of artists, scientists, young people and those with personal experience of anxiety.

When & where is this event?
The exhibition began on 19th September and will be running until 19th January 2020 at Science Gallery London, Great Maze Pond, London, SE1 9GU.

I’m interested! How can I find out more?
You can read more about this exhibition and events programme by visiting the website here: https://london.sciencegallery.com/seasons/on-edge/

4 Young Minds: Mind Over Matter

What is this event?
Opportunity to join the youth panel where there will be discussions about issues such as mental health, social media and youth violence. There will also be plenty of networking and audience discussions so attendance as a guest is also encouraged. If additional spaces are available on the day, youth panellists will also be selected from the audience.

When & where is this event?
The event takes place on Saturday 12th October, at Ambassadors Hotel Bloomsbury: 12 Upper Woburn Pl, Bloomsbury, London WC1H 0HX

What will be provided?
Light refreshments plus giveaways/raffle

I’m interested! How can I find out more?
Please contact Denise: Denise.Brown@4youngminds.com

What’s the deadline to apply?
Sunday 6th October – Youth Panel deadline
The next edition will be released in July. Got any questions or thoughts? Make sure you get in touch.

You are free to Subscribe or Unsubscribe to our network at any time (contact Rachel)

#YPBulletin