



WELCOME to our winter newsletter. In this edition, we reveal the Top 10 priorities for young people’s mental health research, as decided by those who know best, young people and those that support them. We take a look at what our Community Navigator study taught us about how to reduce loneliness. As we approach the end of the year, we reflect on what we have achieved and what we have to look forward to. A big thank you to everyone who has worked alongside us and supported our mission this year.

The Top 10 priorities for young people’s mental health research

Parental attitudes, suicide and support while on waiting lists: the questions children and young people want answered about their mental health...



The [Right People, Right Questions](#) project set out to identify gaps in research on children and young people’s mental health, as identified by children and young people, parents, teachers, mental health and social work professionals, and researchers. The output is a list of the Top 10 most important questions about treatments and services not conclusively answered by research. The hope is that this list will be used by researchers, funders and policymakers to shape research on young people’s mental health over the next three years.

We revealed the questions at an event in Parliament at the end of November. Since then, staff and members of our Young People's Advisory Group have been reflecting on the importance of the questions. Here are a few edited extracts.

Question 5: What interventions are effective in supporting young people on Child and Adolescent Mental Health Services (CAMHS) waiting lists, to prevent further deterioration of their mental health?

“Waiting lists are a fact of life. But it is also a fact that while you wait for treatment to begin, your mental health could be steadily deteriorating. When we reviewed the evidence for the RPRQ project, we were surprised to find that research has little to say about how to help people while they are waiting.

My suspicion is that the NHS and research funders find this a difficult matter. The topic seems to be taboo. Nobody wants to be seen to be offering an approach that may be seen as second best to the treatment and help that people are actually waiting for. But, in the meantime, people suffer.

We know that helping people on waiting lists is not easy. But there is the real possibility that if people are not helped or supported in the right way they might get worse. On the other hand, encouraging people to do something in preparation for a treatment might not be a bad thing. It could give people a kind of head start. What's more, there is always the possibility that someone may not find the treatment or approach that they have been waiting for useful anyway. In such a case, it could even be that something they tried while on a waiting list could be of more use!

One thing is for sure: more needs to be done. Let's break the taboo surrounding research to help people on waiting lists”.

Thomas Kabir, Project Lead for Right People, Right Questions at McPin

[Let's break the taboo and find out what helps young people on waiting lists](#)

Question 7: Which interventions are effective at supporting suicidal young people?”

“Following recent media coverage of student suicides, many universities have publicly stated that they are taking student mental health extremely seriously. Yet, myself, like many other students, question whether this is actually happening or being done in the most effective way.

Take the University of Bristol's recent announcement that they are allowing academic tutors the freedom to contact the guardians of students they feel are at risk. This came after the suicide of a 19-year-old first-year English student. After his death, it became apparent that he had been missing seminars and lectures, yet at the time, none of his tutors questioned his declining performance. Bristol's opt-in scheme is innovative and welcome, but the tragedy that precipitated its introduction encapsulates the complete failure of the student support networks that currently exist.

For a start, what is supposed to happen when the guardian is informed? Presumably they are supposed to take the matter into their own hands and sort out some non-university-based support. The bigger picture question is, why let it get to this stage in the first place? Why can't universities think of more sustainable ways to tackle the rising rates of student mental ill health?”

Lucy Power, member of the Young People's Advisory Group

[Universities need to find ways to prevent students reaching crisis point](#)

Question 8: How do family relationships, parental attitudes to mental health, and parenting style affect the treatment outcomes of children and young people with mental health problems (both positively and negatively)?

“When I look at my daughters, one niggling thought is what effect my everyday parenting decisions have had on them. Is this just me? I doubt it - the inclusion of this question in the RPRQ list suggests that people are hungry to know more.

Kathy Greenwood is a professor of Clinical Psychology and a McPin collaborator. She thinks that parents likely play a hugely important role: “Most young people tell us that parents are critical in the help-seeking process. Different parents often have different views on mental health and treatments. How parents interact and cope while supporting their child can be a further critical factor”.

In other words, this is a really important but complex area. I don't think that lots of expensive research is the only response required. Common sense has a very important place in our parental approach. But having a greater understanding of how we, as parents, affect our children's mental health and having access to more information on the best ways to support them would be very useful. I know it would help me sleep easier at night”.

Vanessa Pinfold, Co-founder and Research Director at McPin

[Why we shouldn't be scared to talk about how parents impact children's mental health](#)

Question 9: What are the most effective self-help and self-management resources, approaches or techniques available for children and young people with mental health issues?

“In the RPRQ workshop, where the 25 questions rated most important by the public were prioritised, the squeeze on mental health services was at the forefront of everyone's minds. The room was divided about what, if any, role self-help and self-management techniques should play to ease the strain. Some people argued that putting too much emphasis on these approaches reduces the responsibility on services to support children and young people, unfairly shifting that burden onto the young people themselves.

I understand the controversy. But I've learned that recovery comes from the individual. So then the question becomes: When things are tough and we feel like we're on fire, how do we help ourselves? Self-management won't work for everyone but it might help some people who have not yet reached crisis point and who are receptive to it. In my view, one overlooked tool is self-help books. I've gained most of my tools from books. There are some books that talk about the author's experiences of a mental health condition, while others specialise in therapy itself. It's essentially therapy without the therapist.

A while ago, a therapist recommended a CBT-based book for my OCD while she supported me with social anxiety. It's difficult to compare two conditions which manifest so differently but I can honestly say that the tools I've acquired for OCD have been life-changing. And all from a book. Yet, I can't say the same for social anxiety because it still interferes with my life a lot. This may be because I waited so long to be treated for the latter, but dealt immediately with the former. Self-help is readily available. Mental health services often aren't.”

Rachel Temple, Young People's Coordinator at McPin

[Therapy without the therapist: what role should self-help play?](#)

View the Top 10 questions [here](#) and the press release [here](#).

What does it take to be a 'Community Navigator'?



How do you reduce loneliness? This is a question that we have been thinking about a lot over the last two years, while working on the Community Navigators project. This was a research study led by University College London to develop a new programme to support people with complex depression and anxiety address feelings of loneliness. Key features of the programme included:

- Up to ten sessions with a Community Navigator, who was specifically recruited to this new salaried role, supervised within a secondary mental health service and who followed a manualised person-centred programme
- The option of attending up to 3 group sessions with others enrolled on the programme for a social gathering where information about useful resources in their local community was shared.

Before we describe what we learned, we can go back to September 2016 and see what two members of our working group, Anjie and Jackie, had to say about our plans and their hopes for the research. [They wrote:](#)

Reducing loneliness – how do you do that then? Hopefully through recruiting the right Community Navigators! Here we reflect on how involving experts by experience in a recruitment exercise can add value and hopefully contribute to a successful research study. We are experts by experience (people who use their lived experience of mental health to inform and contribute, in this case, to a research project) on the working group of a study involving [the McPin Foundation](#) and [University College London](#). The [study](#) is looking to see whether support from a Community Navigator can help to increase a person's social connections in their community and reduce feelings of loneliness. It is focused on people with persistent anxiety or depression.

When the research team were looking for people with lived experience to be involved in the recruitment interviews for the Community Navigators, we thought, count us in! During episodes of poor mental health, we experienced how loneliness and isolation can impact on recovery, and how important it is to reconnect and reengage. This meant we knew what a huge difference a Community Navigator could make, if the right candidates were chosen.

Presenting the results

In early December, we presented the findings of our work at the launch event of the new [Loneliness and Mental Health Research Network](#). Two members of our working group, Bev and Nick, were co-chairs of the event. We described how our small research study had created a programme that most people liked and felt was helpful to them. Although the study was about demonstrating how such a programme might work and was not intended to show whether it was effective or not, there were indications that it had a positive effect on people's levels of depression and loneliness. However, our data also showed that addressing loneliness is no easy matter and people sometimes felt challenged by the programme. Significant efforts were put in by participants and their Navigators to make progress towards goals set by individuals themselves.

In our presentations, we emphasised the importance of the Navigator skills and qualities, such as a positive outlook, empathy and kindness, patience and resilience. Questions from the audience picked up on these vital skills and wanted to know more about them. Could the Navigators have been volunteers? We explained no, not in our opinion. We feel that this is a distinct professional role which requires a considerable skill set, and that it is also important that supervision is available. We feel we were very fortunate that the 'right' candidates applied to work as Navigators in our programme. Their commitment to the issue of addressing loneliness among people with depression and anxiety is evident in their continued support of the research team's work, including attending events such as the Loneliness Network launch!

The project has been a hugely enjoyable experience for us at McPin because of the co-production aspect of the research. We can't thank the members of the working group enough for all they have taught us – whether they are clinicians, experts by experience or researchers, some of whom were wearing several 'hats' or identities at the same time. We hope that we can take the energy and learning forward into a larger research study in 2019. The next steps are to share the knowledge generated by this study and to seek support for a project that works in more places, and can reach out to more people under the care of mental health services experiencing loneliness.

A [summary of the findings](#) is available on the funder's website, as is a [shorter news article](#). To keep up to date with the project and the Loneliness network, follow [@ucl_loneliness](#)

Our achievements this year

The year seems to have raced away with us! We have been busy in 2018 and I've selected a few highlights to share with you.

As covered in more detail elsewhere in the newsletter, at the end of November we launched [Right People, Right Questions](#) in Parliament. This event was the culmination of two years of work that resulted in a list of most



important, unanswered questions that young people and their supporters want researchers to answer about their mental health. Hosted by Charles Walker MP, the launch saw members of our Young People's Advisory Group and network speak passionately about why each of the Top 10 research priorities had been selected. Now we've got the priorities we need to push for researchers to develop quality studies and funders to resource them. You can help us by promoting the Top 10 questions and discussing the topics. None have straight-forward answers.

November was a little hectic because as well as the parliamentary launch, we [co-hosted an evening of forum theatre](#) with the [THIS Institute](#). Staying true to our co-production values, this is a type of theatre where the audience is asked to influence and act in the performance. The Menagerie Theatre Company worked closely with a number of people from one of our working groups to develop the script and provide a realistic sense of what it is like to live with anxiety and depression. On the day itself, we had a very enjoyable night at the Bridewell Theatre near Fleet Street in London. When we began, we didn't really know what to expect but we wanted to get out of our comfort zone as a key aspect of transforming mental health research is challenging ourselves. Working with non-traditional media encourages us to reflect on what types of evidence we need and how to produce useful evidence to change practice, thus bringing us closer to our goal of improving mental health in communities everywhere. The play allowed us to do just that, unpicking how to improve primary care in the NHS by testing out solutions generated by the audience. We hope that this can be the start of further artistic collaborations.



Our staff, peer advisors and others who work with us are vital to the McPin Foundation and the work we do. We were very sad to say goodbye to Johanna Frerichs and Lauren Evans but are pleased they are moving on in their careers, and are taking forward peer research methods, patient and public involvement and user-focused research into their new organisations. We have been recruiting new advisors for Lived Experience Advisory Panels, with two new studies starting this year. Next year we will create more peer researcher roles within an evaluation of women-led peer support.

Survivor research is a crucial part of mental health research. In the summer, we hosted the launch of a paper by [Jasna Russo, on how experiential knowledge can contribute to research surrounding psychiatric drugs](#), as part of our Talking Point series. In June, team member Jennie Parker and I wrote a [Mental Elf blog](#) reflecting on a review paper about the factors that influence service user experiences of diagnosis. We added in some personal reflections which was a little bit of innovation within the blogging process. If you aren't familiar with Mental Elf, do take a look as it's an excellent source of the latest research findings in an accessible format.

One surprising invitation came from the Department of Health, to attend the Global Ministerial Summit on World Mental Health Day. Dr Thomas Kabir, our Public Involvement in Research Manager, was invited to co-chair a workshop charged with producing recommendations for ministers. The event focused on trauma, lived experience leadership and international collaboration. This blog summarises the [recommendations and our reflections](#).

Of course, we wouldn't have anything to launch or draw on at events without the substantive work of our teams. We are currently involved in different studies, with a variety of roles. Here are a few highlights –

- A prominent piece of work has been adapting a values framework and developing quality assurance principles for peer support that focuses on [peri-natal mental health](#). The project is in collaboration with Mind and we've had fantastic engagement from people up and down the country at our consultation events.
- [Game Change](#) is another project requiring expert input from people with personal experience, this time of psychosis. Led by [Professor Daniel Freeman](#) at the University of Oxford, the project is developing a virtual reality programme to help people with psychosis cope in anxiety-provoking situations. McPin has two roles - ensuring expertise by experience guides the research at every step and hosting consultation workshops to design the intervention. Later in the project, peer research methods will be used as part of the evaluation.
- People with psychosis are also the focus of our work on the [Life Stories project](#). This aims to understand people's life trajectories before they made contact with early intervention services so we can identify new ways of supporting people. The team completed data collection in the summer and are now in the process of writing up the results.
- The [PARTNERS2 trial](#) got underway, exploring how people with bipolar and schizophrenia could be better supported within primary care. In May, the patient and public involvement work within PARTNERS2 was awarded [joint first place](#) at the NIHR Service User Involvement Awards.
- We continue to develop our training of [peer evaluators](#) and in May, delivered sessions to MacMillan Cancer Care volunteers working at hospices in London. The aim of the training was to provide the volunteers with an understanding of co-production research methods for them to use when evaluating their services.
- We are currently evaluating [Open Space](#) in libraries, a voluntary-sector led, financial services and mental health project operating in each of the four nations, as well as a [peer coaching service](#) developed by a London NHS Trust, delivered within primary care.

As you can see, work is very varied. I could go on but I will not. In 2019, we hope to deliver impactful work that can make a real difference. We want to work with others to expand the sector, and ensure more studies use peer research methods. Do get in touch with your ideas. We are grateful to everyone for their support.

Get Involved

We are currently recruiting for new members of McPin's Peer Review Panel and Young People's Advisory Group (YPAG). Find more information, including details on how to apply, [here](#).

Aged 13-24 and interested in mental health? Then become part of our [Young People's Network](#) to keep up-to-date on the latest news and opportunities in young people's mental health research.

Are you a keen cyclist? Do you want to raise money for vital mental health research? Then why not join the McPin Foundation RideLondon team. Find out more [here](#).

Our latest [Involvement Bulletin](#) came out last month. It contains all the latest opportunities to get involved in research, post-graduate opportunities and more.

A message from Words that Carry on – Lindsay's Fund, hosted by McPin

We are looking for help deciding what research to fund in the area of personality disorder and autism. Please complete our short survey: <https://www.surveymonkey.co.uk/r/WTCO>

It has been designed by the family and friends of Lindsay Riddoch. You can find out more about us on our website. We are grateful to everyone for their help and support. Fiona, Robyn, Elena and Jessie.



Get in touch:

W: www.mcpin.org

E: contact@mcpin.org

T: 020 7922 7877

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