WELCOME to our spring newsletter. Inspired by our office move and new neighbours, this edition is all about connecting with others - from talking about mental health issues to visiting an exciting initiative to turn research ideas into reality. Also in this edition, our Research Director reflects on diversity among scientific leaders of mental health research.

**Our news: new office, new friends**

In February we moved offices. In some ways not much has changed as the office provider is the same and the location is barely one tube stop different (Southwark to Borough). As well as having to track down new favourite lunch spots, one of the exciting things is that we have new neighbours. The offices are specifically for charities and third sector organisations so there is plenty of interesting work going on. Our nearest neighbours are Magic Bus who help children in India out of poverty by supporting their education. It has been particularly interesting to connect with the Jo Cox Foundation through an old colleague and find out about the Great Get Together, a celebration of community unity. In an age when it is all too easy to @ an organisation on Twitter, type ‘Please RT’ and consider it outreach, the chance to connect with so many great organisations in person is a useful reminder of the power of actual face time.

Our arrival coincided with Time to Talk Day, an event organised by the Time to Change Campaign which aims to end stigma for people with mental health difficulties. To mark the event, Senior Research Manager, Rose
Thompson, wrote a blog about what people are looking for when they open up about their mental health difficulties.

**The key to talking about mental health? Listening**

At the McPin Foundation, we see high quality research carried out in partnership with people who have mental health difficulties as an important way of tackling stigma. Because this is the focus of our work, we spend a considerable amount of our time talking and thinking about mental health. This is not the case for many people in their day to day lives. This means that for some people it can be difficult to know how to contribute to a conversation about mental health. People may be worried about saying the wrong thing or find it difficult to know how they should respond when someone mentions they have experienced mental distress. For this reason, conversations about mental health can feel like ‘difficult’ conversations to have.

In the last four years, McPin have conducted a number of research studies and evaluations into peer support, including the **Side by Side evaluation**. In this context, peer support refers to situations in which people with mental health difficulties support each other by providing emotional, and sometimes practical, support. Many of the things we have learned through our research with peer supporters can help the rest of us when faced with those sometimes difficult conversations. Peer supporters described how conversations went well when they were based on core values such as feeling safe to talk about emotionally difficult things, and of sharing common experiences with each other. They spoke of relationships in which people concentrated on building a respectful, human connection with each other and in which, most importantly, people felt free to be themselves.

For me, the message from this research that can help those of us feeling a bit nervous about talking about mental distress is this. For someone to be able to open up, to feel respected and to feel heard, someone else needs to be ready and willing to listen. My personal experience with the many wonderful people I have talked to about mental health, both my own and theirs, has taught me this. Frequently, the most valuable thing you can do is to not really talk at all. Frequently, when someone who is experiencing mental health difficulties reaches out to talk, they are not asking for you to have answers and they are not asking for your advice. They are asking to be heard, to feel listened to and to have their experiences respected and understood. So during those difficult conversations, when you are not sure of what to say, instead of talking, listen. **Rose Thompson**

**Whose idea is it anyway? Using research infrastructure to turn people’s ideas into projects**

Connecting with others and working in partnership is a big part of McPin’s ethos. One of the best ways to do this is to visit people on their home turf. In February, our Deputy Research Director, Dan Robotham, went to see an initiative at the University of Cambridge that helps people’s research ideas get off the ground.
The premise of the Patient Led Research Hub in Cambridge is that patients* often understand their needs better than medical professionals, and are in a position to identify what research they think should be done. The hub is dedicated to helping patients develop research ideas, which are then assessed for feasibility and matched to researchers who might be interested in taking them forward, in collaboration with the individual or patient organisation. This provides another way of identifying people’s research priorities, outside of the priority setting partnerships developed through the James Lind Alliance, whose framework we followed to come up with the most pressing unanswered questions for children and young people’s mental health.

To date, much of the hub’s work has focused on kidney disease (for example, patients with Gitelman Syndrome proposing a trial on salt intake), but the hub is open to ideas in other fields. This is an interesting idea - we know that research driven by people with direct experience of the topic being studied is more likely to have real world value and impact.

In the mental health sector, ‘patient-led research’ or ‘service user-led research’ describes research that has been initiated, designed and carried out by people using their lived experience of the topic being studied. People with lived experience are involved at every step of the research process, and in some cases they control, direct and manage the research (sometimes referred to as user-controlled research).

The Patient Led Research Hub at Cambridge may not be ceding this level of control to individuals or patient groups but it is still to be commended for seeking out and acting on people’s ideas. It is all the more striking that it is doing this from within a Clinical Trials Unit – places that are not particularly known for being patient-centred.

For me, this is the important thing: the hub is part of the research ‘infrastructure’ resourced by a major funder, the National Institute for Health Research (NIHR). Anyone who has dipped a toe into clinical and health research funded by the NIHR is likely aware of the large amounts of funding spent on research infrastructure, either in the form of Clinical Research Networks (CRNs), Biomedical Research Centres (BRCs), Applied Research Collaborations (ARCs), Research Design Services (RDS), etc. However, so far, little of this infrastructure and associated money is dedicated to helping patients develop their own research ideas.

If it succeeds, the Patient Led Research Hub could be a model for other universities and medical institutions interesting in doing more of this. Being integrated into the research infrastructure makes success likely. For one, being part of Clinical Trials Unit means that it has access to specialists who can help turn a patient idea into a researchable question and project plan. It’s location at Addenbooke’s Hospital, a site so large it feels more like a town than a hospital, connects it to many different patient communities (including people with rare conditions). It’s affiliation with one of the world’s most famous universities means there are a pool of ‘world leading’ clinicians and academics to draw on to co-create new project ideas.

What impressed me most about the hub was how simple it all is. Considering the amount of money the NIHR spends on infrastructure, I’m surprised this approach isn’t already more widespread. Even at this relatively early stage, you can see patient ideas coming through the hub’s portfolio (especially in kidney research). You can tell
that these ideas were generated by patients because they relate to everyday life and everyday problems - reducing chronic pain, limiting the side-effects of medication, simply drinking more water to slow kidney cysts. These are the sorts of ‘unfashionable’ ideas that are unlikely to generate high-tech partnerships or valuable intellectual property, but they have the potential to actually help people with these conditions. I am interested in following what happens at the hub and seeing what emerges. Dan Robotham

* I use the term ‘patients’ because this is more commonly used in a general health context. At the McPin Foundation we tend to use the term service users, or better still, people.

**Spotlight: Women in science**

How does the mental health sector shape up in terms of representation among its scientific leaders? On gender, anecdotally, it looks to be doing ok but this is just one aspect we need to consider, says our Research Director, Vanessa Pinfold.

I recently attended the launch of LancetWomen, an event to mark the publication of a special edition of The Lancet journal “Advancing women in science, medicine and global health”. It was a thought-provoking day, not least because it was hosted in one of the many buildings around London that speaks to ‘male power’ of time past – the old General Medical Centre HQ near Regents Park that is now the Hallam Conference Centre.

The opening speaker was the inspirational Caroline Criado Perez (@CCriadoPerez) who successfully campaigned to have a woman on a bank note – Jane Austin is now on the £5 note – and the first female statue in Parliament Square with Millicent Fawcett unveiled in 2018. Yes, it took until 2018 for one of 12 statues in the square to be female. Caroline’s current campaign and book exposes the absence of female-focused design and the problem of the gender-data gap in areas like car safety, where a male default is the standard for test dummies.

Her talk was a fitting opening to a day of discussions that ranged from addressing inequalities of opportunity for women scientists in different countries, to how funders have a role to play in tackling the gender-gap including who sits on funding committees and who is asked to peer review protocols, to how to shift the culture of influencing or networking away from outside of usual office hours.

Prior to attending LancetWomen, I did a tally of projects I have worked on to see what the gender balance is. Currently, I am working on studies led by 11 men, 10 women and two with joint leaders. In the last few years, I have experienced a similar balance of 6 men, 4 women and 1 with a joint leader. I admit, the near balanced score card did surprise me – is mental health doing better than other disciplines? This might be the case in terms of gender but it is certainly not elsewhere. For example, the sector has too few academics from BAME communities in leadership positions. I can only think of a small number of people and this includes a few professors who will be retiring soon. This is really concerning given the complexity of mental health and how this requires diversity of experiences and thinking. One take-home message from the event is that we need a wider lens on equality in science than gender alone. Little was spoken about intersectionality with disability, sexuality, ethnicity and religion as well as considering gender and transgender.

At McPin, we emphasise the importance of ‘expertise by experience’ and mostly this refers to experience of mental health issues. But we all have lots of different life experiences to draw upon, and I have found, in
particular, that experiences of motherhood have helped me in my work. I have actively drawn upon these experiences in several projects including our Birth Companions study and our pregnancy and medication work. Does my gender influence the organisation I lead? Does it impact on the research we prioritise? I don’t think so in any strategic way but it might do subconsciously. What I do know is that after LancetWomen, I am more aware of how important the conversation around gender bias is, the importance of male champions, and how small changes can make a huge difference. Vanessa Pinfold

Get Involved!

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

Are you up for a challenge? McPin has a handful of places left for Ride London 2019 and we would love for you to join our team! In 2018 we raised thousands of pounds to support life-changing mental health research, and had great fun doing it. This year, with your help we hope to raise even more. You can find out more and download an application form here.

Sign up to our Young People’s Network We want to involve young people in research that has the potential to affect them, so it reflects their true priorities and concerns. If you are aged 13-24, find out how you can get involved here.

Health data in research workshop Are you a service user interested in how clinical data such as patient notes is used in research? We have a few places at a workshop exploring this issue in London on 30th April to fill. More details here.

Join our team We currently have several roles to fill and we will be posting more over the next few weeks. There are a range of roles available, in our London office and around the country. Keep checking our vacancies webpage for more information.

Thank you

Thank you to everyone who told us what research they’d like to see into personality disorder and autism. The survey, sent out on behalf of Words that Carry On, received over 350 responses. We are currently analysing the data to help WTCO make a decision about what research to fund.