



WELCOME to our summer newsletter. While the heat has been raging outside and political changes are afoot, it seems appropriate that inside the (not always adequately air-conditioned) offices of McPin, we have been thinking about the hot topic of power. In this issue, our Research Director, Vanessa, reflects on power sharing in co-production, an academic researcher experiences a power inversion with our Young People's Advisory Group and Gary, a peer researcher at McPin, reviews a book about the experience of homeless women, one of the most powerless groups in society.

Co-Production Week

It was National Co-Production Week in July, an excuse to celebrate the benefits of co-production and a chance for organisations to share their work and engage in discussions about good practice. McPin took part in a [webinar](#) organised by Professor Martin Webber at the University of York on co-production and research. Vanessa wrote a blog about power sharing (the theme of CoPro Week) in the mental health sector that addressed some tricky questions. Who are the people holding power and how is it distributed? What does power sharing mean in the context of public and patient involvement? How can we distribute power more evenly to realise our goal of doing research where experiential expertise is on a par with academic and practitioner expertise?

How to break down power structures in coproduced research

A blog by Vanessa Pinfold



The theme of Co-Production Week was [sharing power](#), something that is central to the very [definition of co-produced research](#). According to the National Institute for Health Research, “Co-production is about working in equal partnership with people using services, carers, families and citizens. Co-production offers the chance to transform social care and health provision to a model that offers people real choice and control”.

I was first introduced to co-production as a distinct approach for collaboration a few years ago and have not looked back since. It is an approach that we often use at McPin as it is values based and it makes sense – why wouldn't you involve different types of expertise to improve your work? It also has the

potential to dismantle unhelpful hierarchies of established practice, something that is key if you are trying to do something new, interesting and innovative.

This isn't easy, however, especially in research. Hierarchical power structures are everywhere. Take two examples – universities and gold standard evidence.

- Universities are built around power structures that include a promotion ladder for academics to professorship and head of the department roles linked heavily to demonstrating 'research excellence'. People who make it to the top often exude a sense of power. Academics can also be found working in charities or industry but they may be less visible and less valued without the kudos that comes with working at a university on a permanent contract.
- Gold standard evidence refers to approaches – usually randomised controlled trials (RCTs) – that are deemed the 'best' way of evaluating scientific data. They are the top of the hierarchy of study design. This means that RCTs are privileged over other study designs, such as qualitative approaches that are often used in mental health research.

These and other hierarchical structures make doing co-produced research really very difficult. Even with [excellent guidance](#), the practice of building relationships, sharing power and valuing all types of knowledge (whether that's from different types of expertise or different study designs) can be extremely challenging. With all the good will in the world, power structures and professional status can get in the way. I think the hardest part is sharing power and reducing personal influence over the process. This is true for everyone but particularly those with a research status such as “professor” or “doctor” – PhD or medical.

Compromise and careful planning

In my experience, co-production in research is a learning journey for all involved. It requires everyone to give of themselves personally and professionally, often in a different way to usual. I enjoy that but not everyone does, so understanding different preferences is part of the process of building relationships and trust across the entire team. Compromise is needed, as is lots of effort and careful planning. Projects must set up mechanisms to enable shared decision making – so the “project lead” doesn't decide everything! There should also be ways for members of a team to be mentored or trained in new research methods or approaches, be they established academics or people new to research.

The upshot of co-production is that it is not one thing – it has to be different in every context. We must consider the people involved, the topic being researched, the setting for the study, timescale, budget and ... so much more. This is a strength as it's not a fixed framework but something to co-create with others in the team.



I learn from the people I work with on every study how to co-produce research. Here are a few practical things I've found can help reduce power disparities:

- Rotate the roles during meetings – change who chairs each time
- Change how a room is set up to make sure people sit in different places – you don't want all the academics in one cluster, mental health service users and carers in another, practitioners again grouped separately
- Use more group work and have fewer presentations, as this will enable people who don't like speaking in front of a big audience to give their opinions more easily
- Have clear roles for everyone and equalise them as far as possible in terms of how much paid time people have to work on the project and what outputs are expected from everyone
- Provide opportunities for members to develop new skills and share their own expertise. Include a budget for training.
- Try and keep group membership stable with a balance of backgrounds, for example, a group with 3 practitioners, 3 people with experience of mental health issues and 3 researchers (while acknowledging people can have multiple expertise).

It's great to see Co-production Week focusing on the topic of power. I look forward to learning from lots of other examples because although coproducing research it is not easy, it is vital.

Incorporating feedback

Researchers often experience power dynamics when engaging with service users – and in traditional research environments, this usually goes one way. One of the ways McPin is trying to change this is by providing an opportunity for researchers working in the area of young people's mental health to meet and learn from our

Young Person's Advisory Group (YPAG). Miriam Avery, a child and adolescent mental health nurse and researcher, met our YPAG earlier in the year. She has [published a paper on the experience](#) and blogged about her fears of receiving direct feedback from the young people and their impact on her research proposal.

“The YPAG gave me a totally different perspective”

A blog by Miriam Avery



As a child and adolescent mental health nurse, making sure that children and young people's opinions are listened to is something that is really important to me. I recently attended some workshops about patient and public involvement in research (PPI), where I learnt about young persons' advisory groups (or YPAGs, for short). These are groups of young people (unsurprisingly) that can help shape ideas, give feedback, set research priorities or get involved in conducting research itself.

As a newbie researcher, the idea of working with a YPAG appealed to me

and I decided to find out more. I had heard of the McPin Foundation through their recent research priority-setting project '[Right People, Right Questions](#)', and so knew that they were dedicated to involving young people in research in a meaningful way and that they coordinated a YPAG. I emailed to introduce myself and to see if they would be interested in giving some feedback on my research proposal.

Poorly understood symptoms

My proposal was in the very early stages – a vague outline of a qualitative research project which would investigate young people's experiences of healthcare services for medically unexplained symptoms (MUS). MUS is an umbrella term for any poorly understood physical symptoms, from recurrent headaches to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), irritable bowel syndrome (IBS), fibromyalgia and somatic symptom disorder. Often young people have a difficult time accessing the right treatment for these kinds of symptoms and have negative experiences of healthcare services. My aim was to design some research which could help improve matters. Luckily for me, the group's facilitator replied to say that she thought the YPAG would be interested in my project and we began thinking together about what would be important to ask the YPAG and how best to ask it.

On the day of the meeting, I travelled down to London feeling very nervous about presenting my work. Everyone made me feel very welcome and there was time for a bit of a chat and lunch before I was due to speak. After I presented my project and explained important terms and concepts, there were immediately lots of questions and suggestions from the group who were clearly very knowledgeable about both mental and physical health as well as research methods. Many of the group had taken part in and been involved with research before.

Proposal under the microscope

Next the group split into three and I asked them to each focus on a different aspect of the project. Firstly, what did they think of the research question? Did it make sense? Was this an issue important for young people? Secondly, what did they think of the proposed methods? What kinds of approaches did they think would be suitable for younger or older participants? And thirdly, how did they think I could best involve young people throughout the project itself?

The groups had so much to say, it was difficult to keep up at times! But luckily there was someone taking notes which I could refer to after. The experience really helped me consider my ideas (and the way I had presented them) from a totally different perspective. As a result of the group's suggestions, my research question is much more focused and precise. I also now have a lot of ideas for methods to make the research accessible to younger people, for example, story-telling!

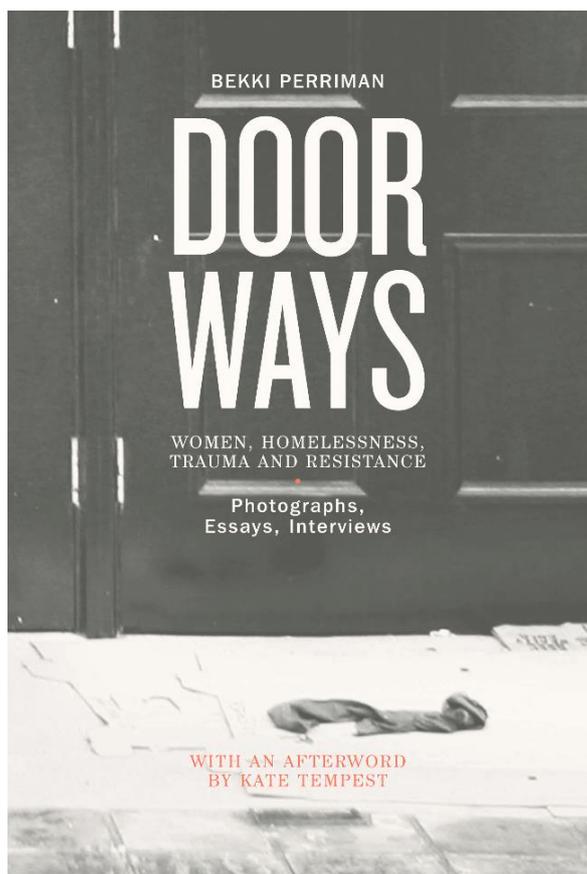
Practical considerations

There were some suggestions that I couldn't take on for practical reasons. For example, I particularly loved a suggestion that young people could be trained to conduct interviews, but after careful consideration I realised that this would only be possible with much more funding than I will have access to. However, this is now something I will keep in mind for future research. What's more, rather than have this be a one-off experience, I have decided to work with a YPAG throughout the project, to give feedback and help develop any materials, such as interview questions.

These are just a few of the ways that my project idea has developed and been improved as a result of my meeting with the YPAG. Overall, it was a really positive experience. I feel like I learnt a lot from the group and now feel more confident to work with a YPAG in the future.

Listening to the most vulnerable

When discussing power dynamics, it is important to amplify voices who are typically silenced or neglected. Gary Coyle, a peer researcher at McPin, reviews 'Doorways: Women, Homelessness, Trauma and Resistance' by Bekki Perriman. Gary writes about the book through the prism of personal experience, emphasising the need for books like Perriman's to give voice to a group of women that are poorly understood and often ignored.



“Safer on the streets than at home”: women's stories of homelessness

A review by Gary Coyle

Reading outside one's comfort zone is one of the most effective ways to increase knowledge. [Doorways: Women, Homelessness, Trauma and Resistance](#) by [Bekki Perriman](#) is certainly outside most people's 'comfort zone'.

'Doorways' gives essential insight into an increasing population of women that are living on the streets and the kind of abuse and blame they experience. The title is borrowed from a project that Bekki Perriman started called 'The Doorways Project', which is a touring sound installation that aims to give voice to women experiencing homelessness. She continues the theme of giving voice to people's experience through the book, which is made up of a series of personal accounts of women who have experienced homelessness.

The personal nature of the book made a strong impression on me. Throughout the author includes photographs of the doorways she slept in when she herself was made homeless. It

was frequent that caretakers or porters would move her on, police pushing people out without any advice as to where they should go.

Weekly, I make a commute to work that involves a short walk from London Bridge to Borough. Each time I pass, five or more homeless people begging on the street. I don't have enough money to help them all but each time I remind myself that anyone is a few steps of misfortune away from the same situation. In fact, this was my situation. However, I was lucky that this was only for a short time 30 years ago when it was much easier to get a place at a hostel.

'Doorways' demonstrates that everyone has a story. The personal accounts give a humanising insight into some of the many individuals who are living rough on our streets. This is not a choice, more of a lack of options. This is especially true in our contemporary world, in which I still find it hard to understand how a country as wealthy as the UK, has so many people who are homeless.

The book shares insight into the daily grind of their situation and the ever-present threat. Some women settle in small groups to support each other from people who are looking to exchange money for sex and other kinds of abuse. The abuse and bullying that some had experienced at home simply follows them onto the streets. The sad reality though is that for some women this is a better option: one woman's account said she felt safer on the streets than she did at home having experienced domestic violence. Although there is a strong sense of community and loyalty amongst the homeless, people who are desperate will take desperate actions and some will steal from people in the same situation. Maslow's Hierarchy of Needs shows that without the basic provision of housing, running water and food, it is near impossible to move forward to a fulfilling relationship and a satisfying career.

On the night of the book launch some of the women included in the anthology read extracts from the book. The emotion and pain they had suffered was still raw in their voices. While some women manage to survive the experience, there are an alarming number that don't. On the small stage was a large collection of candles in the shape of the feminist symbol representing about 140 homeless women who had died on the streets last year.

Whose problem is this? Who is responsible for this situation? Is it the government's problem? Nobody seems to want to take ownership of the situation and society's inability to meet the needs of people.

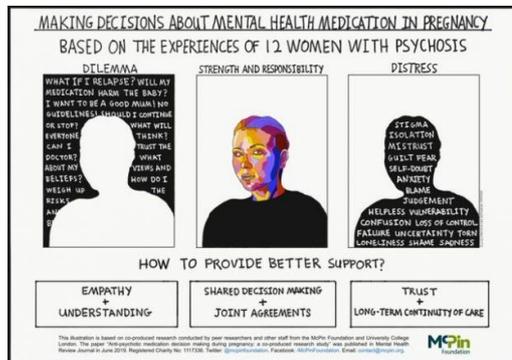
Removing shame

At the end of the book is a poem written by poet and singer Kate Tempest. The poem explores how commuters respond to people begging on the tube. People keep their eyes on their phone as if the fellow person doesn't exist. Shame should not be placed on the person in need, but more on our society's negligence. The number of times I have heard the mantra 'Oh – I won't give them money because they will probably spend it on drugs!' is upsettingly frequent. It is wrong to assume that all homeless people are drug users, and even if they are, there are complex reasons why people will fall into patterns of abuse. From my experience working in a charity for the homeless and as a peer researcher in mental health, I have seen the multiple traumas that often bring people into this kind of situation.

Humans are extremely resourceful – I really do know that myself! And so do these women! But this should not be a story of personal triumph despite the odds – this needs to be a collective effort to address an increasing issue. This book is essential reading, giving loud and impactful accounts of people who are systematically silenced. If you care, I urge you to read this book.

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:



Decisions about pregnancy and medication

We recently published a paper looking at how women with a mental health condition decide whether to continue [taking medication while pregnant](#). By shining a light on this difficult dilemma, we hope that healthcare providers will be able to better support women. We are asking people to pass an [illustration](#) with suggestions and the main messages from the research to their GP, psychiatrist or other appropriate person. If you are a teacher of healthcare professionals, you may wish to use it as a teaching aid.



Blog for us

Would you like to write about an issue related to mental health or mental health research for our [blog](#)? We welcome guest writers who are able to draw on their personal experience to engage a wide audience. Guest blogs are between 500 and 700 words. Please email contact@mcpin.org with an outline of what you would like to write about.



Get in touch:

W: www.mcpin.org

E: contact@mcpin.org

T: 020 7922 7877

Follow us:

