



Transforming mental health research

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The McPin Foundation exists to transform mental health research by putting the lived experience of people affected by mental health problems at the heart of research methods and the research agenda. We are delighted to launch our new e-newsletter which aims to bring you all McPin's latest activities, comment on important developments in mental health research and share useful resources.



## Our news

Over the last six months the McPin team have been completing a research study on the use of personal budgets by people with mental health problems...

### **Personalisation: Evaluating Outcomes, Practice and Lived Experience of People using Mental Health Services**

#### **1. What was this research?**

The PEOPLE study was a three year project funded by the Big Lottery Fund and led by Rethink Mental Illness and the McPin Foundation, in partnership with the University of Birmingham and King's College London.

The aims of the PEOPLE study were to:

- Develop an understanding of how personalisation is shaping the lives of people with severe mental illness (SMI)
- Understand the role of carers and family members in assisting people with SMI to negotiate challenges and opportunities offered by personalisation.
- Understand how organisations and care staff are adapting to support people with SMI, within personalised models of health and social care

The project has been guided throughout by a group of people with lived experience of mental health problems and with an interest in personalisation. This Lived Experience Advisory Panel has helped us to put together our data collection tools, to recruit people to the study, to gather local intelligence and to analyse our data.

*"I'm proud of my personal involvement with the People Study and I know that I have learnt such a lot from the process and from everyone involved in the study. I have found it to be very rewarding and the journey has been an interesting one. I'm really fascinated by research processes and have a healthy respect for the amount of work that goes into putting together innovative research."* Shirley Dean, All Together Positive

## **2. Why is this research important?**

Personal budgets are being rolled out across the country with various degrees of success. The People Study focused on the impact of personalisation for people with a severe mental illness (SMI), a group which has received less attention than others in the implementation and evaluation of Personal Budgets and personalised care. People using mental health services can benefit from a greater choice and control over the support they receive from local authorities. Personalisation enables care co-ordinators to work with their clients in a person-centred way and allows the clients to have a lead role in support planning.

We used the findings from our research to develop three practical resources providing guidance to people who might be receiving or considering receiving a personal budget, their family members and mental health professionals.

*"The PEOPLE study was important and timely as it was the first to focus on people with severe mental health problems and the challenges in making sure that the positives of personalisation reach them too. It is ground breaking in making sure that research findings are relevant to people's lives and professional practice – rather than being the type of research that just sits on a shelf – or in the inbox. Lastly the study has been one of the first to involve groups of people with mental health problems from the start and their views and experiences have helped shape the study and its outputs."* Professor Jill Manthorpe, King's College London

## **3. What did we do?**

The project used a longitudinal case study approach based in four local authorities. The research was carried out over two main phases.

In the first phase, we used a combination of observation and interviews with 58 key stakeholders, including representatives from the local authorities, the mental health trusts and third sector organisations. This phase explored the main challenges and facilitators to implementation of Personalisation for severe mental illness.

Phase two consisted of in-depth interviews with three groups: people using mental health services, family members and care staff.

- We interviewed 54 service users up to three times over the course of a year to provide a longitudinal perspective. All service user participants had either received, were in the process for receiving, or had been declined Personal Budgets or Direct Payments.
- We interviewed 20 family members and informal carers about their experiences of supporting someone with severe mental illness who received a Personal Budget.
- We interviewed 30 key workers about their experiences of and views on Personal Budgets for their clients.

*"Interviewing different groups of people with a stake in personalisation allowed us to build a thorough understanding of the key issues and complexities from various perspectives. Being able to follow our participants' journeys through longitudinal interviews was extremely rewarding and provided a unique perspective on individual experiences."* – Paulina Szymczynska

## **4. What is the current status of the project?**

We have completed the research and produced practical guides for key stakeholders. We are currently preparing a final report to the funder and we are writing with academic papers presenting the findings.

## **5. What next?**

We will present our findings to different audiences, including people using services, their families and practitioners through presentations, reports, blog posts and peer-reviewed papers.

## **6. Who do I contact for more information?**

You can contact the team via [contact@mcpin.org](mailto:contact@mcpin.org)



## Research in the news

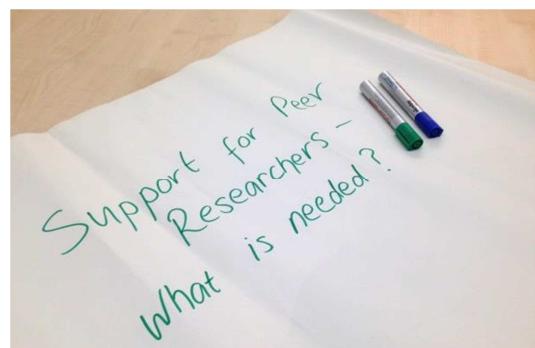
### Does involving people with mental health problems, families and other stakeholder groups in research make a difference?

There is increasing interest in the impact of Public and Patient Involvement (PPI) in the design and delivery of research. At the McPin Foundation we have recently completed a study funded by the NIHR Health Services and Research Delivery programme (more on that another time) and within two weeks we had been asked by the funder to report on how clinical research networks supported us – the MHRN (Mental Health Research Network) and PCRN (Primary Care Research Network) – and what had been the impact of PPI in our study. We were really pleased to be asked! An article which evidences the impact of PPI in mental health research was published recently in the British Journal of Psychiatry. Ennis and Wykes (2013) look at how service user involvement in mental health research across 374 studies on the MHRN portfolio changed over time – 2004 to 2013 – and its impact on factors such as study recruitment. They had three main findings:

- Service user involvement has increased over time in research that was supported by the MHRN
- Level of service user involvement varies and was highest in studies funded by charities and not for profit organisations, studies that investigated developmental disorders, personality disorders or social interventions.
- Recruitment success – judged as recruiting 90% of planned sample – was highest in complex interventions, studies without follow-up, and studies with highest levels of service user involvement.

This is an important contribution to the research literature exploring impact of PPI. We have written a blog which you can read on this article too.

Case studies are another important source of information looking at the impact of PPI in research. You can find examples at INVOLVE extending across all areas of health which is important. We can learn a great deal from other research areas on how to innovatively engage with the beneficiaries of research. This was emphasised at the PenCLAHRC conference which we attended earlier this month and is summarised in our blog. The MHRN also has case study examples listed on their web site and annually award one study a prize for its PPI contribution. Last year this was PRIMROSE who donated their prize to the McPin Foundation, we are extremely grateful to them for their generosity and support of our work. We are keen to encourage debate on the impact of PPI. Do get in touch with your views by emailing contact@mcpin.org.



## Shaping McPin

### Peer mental health research – where next for McPin Foundation?

**By Emma Harding, McPin Trustee**

The McPin Foundation held an inaugural service user event on Thursday 20th June. Twenty-eight peer research experts attended and gave their hugely valuable time and energy to a round of debates that will set the scene for our next acts. I was thrilled to be asked to chair the day and am still full of enthusiasm some months later. We first outlined

our aims for McPin's role in the mental health research sector:

- Take our lead from people with their own experience of emotional / mental health issues
- Conduct, fund and bid for research opportunities
- Campaign to increase the presence of researchers with lived experience in the research community and on mental health related research projects
- Train and support more service user researchers to take on different roles influencing all aspects of research commissioning, delivery and dissemination

But we needed to know what the priorities of the people at the heart of the matter were so we asked and were well and truly told. My blog reflects on the day further. The result is a report which we will publish by the end of the year – it's currently with those who attended to ensure accuracy and balance of topics discussed – and the launch of a new programme of work.

The foundation will fund a peer research programme coordinated by a programme manager whom we will be recruiting early in the New Year. This is central to our mission to raise the profile of user focused mental health research, building collaborations, creating more lived experience research expertise and ensuring the research evidence base is accessible and embedded in practice in order to improve the lives of everyone effected by mental health issues.



## Opportunities

We are recruiting people to join a new peer research review panel supported by the McPin Foundation. We are looking for people with experience of mental health problems who are also interested in research. You may be a carer or family member and / or a mental health service user. The closing date for applications is 16th December 2013. Interested? Read on for information on the role and how to apply.

### About the McPin Foundation

We exist to transform mental health research by putting the lived experience of people affected by mental health problems at the heart of research methods and the research agenda.

We work in three main ways:

- We conduct user focused mental health research. Running our own projects, or working as part of a collaborative team, we undertake expert consultancy and innovative research using a range of methods to involve people with lived experience of mental health problems.
- We build the capacity of others to conduct user focused mental health research. We do this by sharing knowledge and skills about research methods, networking with others delivering user focused mental health research, by providing funding and by training and employing peer researchers to carry out research among people affected by mental health problems.
- We seek to influence methods, practice, and decision making in mental health research. By sharing innovation and good practice and raising awareness, we seek to ensure that the views of people with lived experience of mental health problems become central to research methods and the research agenda.

### About the panel

We want to create a panel of people with lived experience of mental health problems to review and comment on our work. Members of the panel will receive training and meet up around twice a year. The panel will be asked to look at our project proposals and information we produce for study participants. The panel's feedback will help us to improve our work and make it as accessible and useful as possible.

Panel members will be expected to:

- Review research proposals, application forms, project documentation (information sheets, consent forms, etc.) and any other materials submitted to the panel
- Write constructive critiques including lived experience perspective which will be provided to researchers
- Provide suggestions for possible improvements
- Attend training sessions held twice a year

Majority of work will be carried out virtually, using e-mail communication. Peer reviewers will benefit from face-to-face training relevant to their role and interests.

Please note that reviewer workload will vary depending on demand but it is likely to be approximately 20-30 hours annually. The role will be remunerated, however it should not be relied on as a primary source of income. The rate of pay would be £11.23 per hour which is the same as the McPin researcher grade.

If you would like to apply to join the review panel please download an Expression of interest application form and return it to us by 16th December 2013 using email to [contact@mcpin.org](mailto:contact@mcpin.org)

## Thank you

Thank you to everyone who has supported us in our first 8 months. A particular mention to Mark Whittaker for providing us with amazing art work for our Seasonal cards. We know it is a little early for New Year greetings but it's taken us a while to get our first newsletter ready to circulate so we are sending an early seasonal message to all our supporters. We hope you have a restful and enjoyable festive period and best wishes for 2014.



Whilst we are thinking about the festive season, and organising gifts, if you have not already signed up to [easyfundraising.co.uk](http://easyfundraising.co.uk) we recommend this as a really good way of supporting any number of causes at no extra cost to yourselves when you shop online. McPin Foundation is listed on [easyfundraising.co.uk](http://easyfundraising.co.uk) and you are likely to find other organisations that are important to you as well.

Lastly, we would like to take this opportunity to thank you for signing up to this newsletter and showing our cause is something important as it is crucial in helping us create a strong "voice" for user focused mental health research. Please do pass on the newsletter to others who might be interested in signing up to support user focused mental health research.



Write these and send to [contact@mcpin.org](mailto:contact@mcpin.org)

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