



Welcome to our first newsletter of 2015. Spring is in the air and we are on a recruitment drive for staff, which will help us deliver new projects and our first organisation strategy that our trustees signed off earlier this month. We also need your help. Calling all cyclists! We have charity places for the Prudential RideLondon-Surrey event on Sunday 2nd August 2015 – only 100 miles, through iconic city roads and countryside! Get in touch if you fancy a challenge contact@mcpin.org

Our news



As we approach the end of our **second year** at the McPin Foundation, it's a good time to reflect on our progress in the last year and the new, exciting work we have planned. Our research work centres on **five themes**: Children, Young People and Families; Improving mental health support; Wellbeing and Connectedness; Inclusion and combating stigma; and Collaborating with people with

lived experience. The last area touches all of the work that we do. We have on-going projects in each of these themes, and if you'd like to find out more about them, please do visit our [website](#).

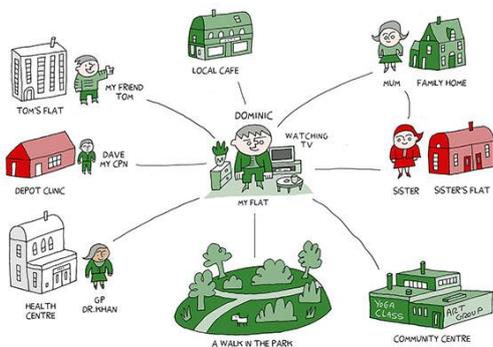
A key milestone this year has been setting up our **Public Involvement in Research programme**, its advisory group and various projects including [partners2](#). We have started pieces of work which we continue to develop like our online involvement in research forum. This will enable people interested in mental health research to communicate with each other easily. More on progress with the forum over the summer.

Reflecting on this past year, we are also coming to the end of a few major research projects this month, so look out for the reports of our findings later this year. This includes the evaluation of [Time to Change's](#)

[work](#) to change attitudes among school children; the final year of our large survey of discrimination experiences among people who use mental health services ([Viewpoint Survey](#)) and our user-led evaluation of the [IAPT for Severe Mental Illness](#) pilots, commissioned by NHS England.

So what next? We are starting a new and exciting evaluation in April to look at the impact of peer support for people living with a mental health problem. We will be working with St George's, University of London in South West London to evaluate one of the largest programmes of peer support across England so far. The [peer support programme](#) is being set-up by Mind, Bipolar UK and the Depression Alliance, and is funded by the Big Lottery. It will provide a great opportunity to learn about the value of peer support – how does it work and for whom? It will also include working with peer researchers and others to look at the principles and values of peer support, and considering from commissioners how it fits with plans for mental health commissioning intentions going forwards. The project will take place over two years.

This work is one of a growing number of projects that we are delivering to improve the mental health of communities everywhere. To help us to deliver all this work, we are also growing. We are **about to recruit two new researchers, a new Public Involvement in Research co-ordinator and a new administrator**. We are also going to have more opportunities for people to influence our work in lots of different ways, from working as a peer researcher on a specific project, to sitting on a Lived Experience Advisory Panel. A great way to find out about these opportunities is to sign up to our new Public Involvement in Research bulletin. The first edition came out in January and it lets you know about opportunities to get involved, not just with us, but also with other research organisations. Please **sign up for the involvement bulletin [here](#)**, and you will receive it by email.



Shaping McPin

We have reached a birthday milestone and created a [strategy](#) for the organisation: that feels like a real achievement and significant changes are planned in order to deliver our vision for transforming mental health research. Our [strategy](#) is modest, but focused, centred on our key concern to put expertise by lived experience at the heart of mental health research. Over the past two years we have delivered a lot of projects to various funders including the National Institute of

Health Research (NIHR) and set up a public involvement in research programme led by Thomas Kabir. In 2015 we are particularly keen to develop our staffing team, and support opportunities to bring people together to discuss new research ideas, and current challenges in mental health research.

Recently we held a consultation session for an academic team developing ideas for a research proposal – these are always **inspiring sessions** and highly valued by both those talking and those listening. Keeping careful note of changes made as a result of public consultations on research ideas is crucial for considering impact of the expert by experience voice. I particularly enjoy the opportunity to meet new people, extending the invitation of service user and carer involvement far and wide. We want to do more of this.

Our staff team is changing and we are really pleased that Karen James will start as our Research Manager (maternity cover) post from 1st April. Karen is just completing her PhD and has been working with us recently on our wellbeing research, developing this from a research idea to a therapeutic approach that could be used in a new model of care. Just touching on wellbeing networks, we saw the publication of our research report in February - all 300 pages. There are summaries as well and you can access them on the [NIHR health service and](#)

[delivery research programme site](#) . [Our briefing papers](#) describe this work. As part of our team developments we will be looking for an operations manager to join us later in the year to help us with all the significant functions that a charity needs including communications and fundraising. We don't do much fundraising except through the [Prudential RideLondon event](#) which this year is on Sunday 2nd August. Please do spread the word if you know anyone who likes cycling. We need people to ride for Mental Health Research! It is 100 miles through iconic city roads and countryside. More information is available, so please do email us at contact@mcpin.org.

Collaboration is a theme in our work and vision for how to improve the quality of mental health research. One way in which we collaborate with others is through the [Alliance of Mental health research funders](#). With the general election in May 2015 we need to clearly articulate why research matters and why mental health research matters. This is often not well articulated and we are keen to work with others with ideas to raise awareness of how evidence informed practice – based upon research and evaluation activities - can improve the wellbeing of communities everywhere.



Research in the news

“Medicine is not only a science; it is also an art. It does not consist of compounding pills and plasters; it deals with the very processes of life, which must be understood before they may be guided.” Paracelsus

With the next general election in less than two months' time, mental health and wellbeing issues have recently become a political talking point with several parties promising to [“bring mental health out of the shadows”](#). This attention is much needed given the [estimated 8%, or £600 million, cuts to mental health over the course of this parliament](#). As a result, politicians and commissioners alike are looking for ways to do ‘more for less’.

One approach that has been a recent talking point in the news is that of ‘social prescription’, which one [news article](#) suggests could save the NHS in excess of half a billion pounds. Social prescription can be defined as [“a mechanism for linking patients with non-medical sources of support within the community”](#). The most common examples prescribed to people with an array of health conditions are: [exercise on prescription](#), [prescription for learning](#) and [arts on prescription](#). However, these are only a small number of potential schemes that may fall under the remit of social prescription which can range from [fishing clubs](#) to [knitting groups](#) and include initiatives such as The Royal Society of Arts’ [‘Social Mirror’ project](#) which aims to [demonstrate how GPs can help spread healthy behaviour amongst isolated populations](#).

[As well as media attention, this approach has also begun to gather political attention](#). For instance, the independent task force behind [‘the mentally healthy society’](#) recently recommended that GPs should regularly use social prescribing. Moreover, earlier this month, [Vince Cable spoke of his personal experience with social prescription within his family](#), describing how his mother grappled with postnatal depression for a year in hospital, but purports her recovery began only when she was given the opportunity to attend an adult education course. He explains:

“She’d never had a proper formal education. She started going to these classes and learned about art and history and things she’d never studied before. It gave some focus to her life and perhaps it kind of stabilised her mentally and she started leading a normal life. The mental illness problems went away. She attributed it to the fact that she had had these educational opportunities later in life.”

These claims for social prescribing suggest that it could have a real, positive impact on the lives of people with a mental health problem, so we wondered what the published research literature had to say.

There is [some evidence](#) to show that social prescription leads to a wide range of benefits for those with mental health problems, including: increased awareness of skills, activities and behaviours that improve and protect mental wellbeing; increased levels of social contact and social support among marginalised and isolated groups; and reduced levels of inappropriate prescribing of antidepressants. However, there is, as yet, no concrete evidence to support media claims that social prescription will lead to significant cost savings; the most relevant [economic evaluation](#) of primary care referral to non-medical, voluntary sector activities showed that the costs actually increased in the short to medium term.

However, the evidence remains limited due to a paucity of research examining social prescription and its impacts. This is partly due to the challenging nature of researching such a complex, person-focused intervention. Whilst the media showcases an array of positive case studies of social prescription, there are still several questions that remain unanswered. Research must untangle which prescriptions work best for whom and why; and which specific aspects of the prescription result in the greatest benefits.

Janet Brandling and William House explain this challenge in their [blog](#) for the British Journal of General Practice:

"The multiplicity of options is one of the key challenges. The idea is simple but the reality is complex. How can busy GPs and others in primary care know what is available? How is it done? You can't write it on an NHS prescription. What is the evidence that it works? Which patients might benefit? Is it yet another unwanted role to be foisted onto GPs, or a welcome path away from the medicalization of society?"

What is clear is that there is a demand for these questions to be answered. [In polls commissioned by Nesta in 2013](#) for their report "[More than Medicine](#)" they found that out of 1,000 GPs surveyed, four out of five thought that social prescriptions should be available from their surgeries, whilst 59% of the 2,000 members of the public surveyed said that they would like their GP to offer social prescriptions. For this to occur there must be a wider base of evidence which may give GPs, as well as the general public, the confidence to engage in these schemes. As [one news article](#) put it "If social prescribing is to be more widely and systematically adopted it needs to be seen to work. It needs to demonstrate it can reduce queues in GP surgeries and A&E and relieve hard-pressed mental health services and social care."

So what are we doing at the McPin Foundation to explore social prescribing?

Currently, we are evaluating the [Kent Six Ways to Wellbeing Project](#) which includes multiple Kent County Council funded initiatives. Several of these are relevant to the notion of social prescription, including library wellbeing hubs to promote self-help books, creative arts programmes to enhance the wellbeing of 11-19 year olds and a primary care link worker program which aims to link primary care professionals with the voluntary sector. [We will be monitoring these programs](#) in terms of their impact on people's wellbeing, using a standard scale – the Warwick-Edinburgh Mental Wellbeing Scale – and mapping mechanisms for change in each project to unpick how these impacts have been achieved. Through this work, we hope to contribute in a small way to the evaluation of projects that could be part of a social prescription.

So what's next for social prescription? As outlined, there is a clear case for further research into social prescription, to see whether the reality lives up to the promising claims made in recent news reports. This research needs to grapple with the challenge of providing good evidence without reducing social prescription to a 'one-size-fits-all' intervention, recognising that social prescription is most effective when it is truly person-centred. This year is the anniversary marking 15 years since a UK government first declared the intention to create a 'patient centred NHS' and this commitment must be reflected in any innovations to improve mental health support.

What is your experience of social prescribing? How can we help to build the evidence base around social prescribing? If you have suggestions, please do get in touch.



Hot off the press

A crucial factor in making a piece of research successful or not is **participant engagement**. Do people want to take part and can you keep them engaged for follow-up if that is required? But very little research has been carried out of participant experiences of what's involved in "taking part in research" and why people do. So we were pleased to read about a qualitative research study that is addressing this

very issue by talking to participants in the PRODIGY trial which is a study of the prevention of long term social disability among young people with emerging mental health needs. The authors – **Notley et al 2014** – have published their findings in the British Journal of Psychiatry. The full reference is:

Notley *et al.*, (2014), Participant views on involvement in a trial of social recovery cognitive-behavioural therapy. The British Journal of Psychiatry, 1–6. doi: 10.1192/bjp.bp.114.146472

The PRODIGY qualitative study aimed to: (a) explore individual experiences of participating in the trial and initial views of therapy; and (b) explore perceived benefits of taking part in research versus ethical concerns and potential risks. The experiences of the thirteen people interviewed centred on key themes of acceptability, disclosure, practicalities, altruism and engagement. People were interviewed in both "arms" of the study – those receiving the new treatment (6 people) and those in the control group (7 people). What did they learn?

In terms of **practicalities**, they found it was essential for participants that researchers take a practical and measured approach to helping people participate. Twelve of the participants reported that they appreciated flexibility in research appointments, in time, location and also in being able to split the assessments in sessions that suited them in terms of length of time and content. Those interviewed said that flexibility and a person-centred approach showed empathy on the part of the researchers and this was valued. Three people said they would have liked more information about the length of assessments. People were also extremely open and **accepting** of research procedures and measures. Three people even identified some of the research tasks as fun.

Closely linked to the theme of **acceptability** was the theme of **disclosure** - disclosing personal and sometimes sensitive information to researchers - and what facilitates this process. The actual disclosure dialogue was discussed as being a useful and therapeutic process in its own right. Ten of the thirteen people interviewed felt the positive disclosure experience was the result of the researcher being supportive, non-judgemental and empathetic. Some expressed surprise at the extent of their disclosure and how natural that was, reflected as a 'positive surprise'.

Seven people spoke at length of their keenness to be involved in research, for **altruistic reasons**, and there was an understanding and willingness to be involved as part of 'helping others' regardless of whether they received treatment or not. This was important with reference to randomisation, which was mainly well understood and accepted, though recommendations relating to this emerged as not all did. There was also concern that **engagement** in the study may be too demanding for people who were unwell and vulnerable, and who were socially isolated. Encouragingly, several people spoke of engagement with the research processes. This engagement with the trial was experienced as a positive

step and potentially had additional benefits through the data collection process, providing information that helped people make changes in their lives.

Overall the feedback was that involvement in research was a positive experience.

This paper was of particular interest to us at the McPin Foundation because we are about to embark on a qualitative study ourselves to look at people's decision making processes when being invited to take part in a mental health research trial. We will be carrying out a service user led qualitative research study using the PRIMROSE project as our case study. It has been developed by the PRIMROSE Lived Experience Advisory Panel (LEAP- a group of 30 service users and carers) and will be carried out by two service user researchers supported by the LEAP coordinator (Ben Gray) and staff within the McPin Foundation.

We will explore approaches to deciding whether or not to take part in a randomized control study by interviewing 20 people who would fit the "criteria" for the PRIMROSE study that is working with people with severe mental illness at risk of cardio-vascular disease. It is only by directly exploring decision making that we might come to a better understanding of how to approach recruitment in future research trials. The project builds on best practice principles for PPI and for co- production. We will report findings in early 2016.

Another important piece of work to mention is a discussion paper the McPin Foundation has commissioned on the limitations of RCTs. That will be out in the next few months. It is important to critically assess current research methods to drive up the quality of work undertaken across the sector. Critical assessment of our own studies, as well as our views of other work is something we actively encourage. That's the best way to learn so do get in touch with your views on engagement and recruitment issues in mental health research studies.

Ben Gray, Senior Peer Researcher, McPin Foundation.



Opportunities

We list here some current involvement opportunities and job vacancies. We are more than happy to advertise for others so do let us know if we can be of help.

REQOL:

Are you a person with lived experience of a mental health problem?

We invite you to help develop a new mental health outcome measure (ReQoL)

ReQoL is a questionnaire that is being developed to help understand feelings and monitor progress of recovery and quality of life for people with different mental health problems. The study is being led by a team of researchers based at the University of Sheffield. The McPin Foundation is one of a number of organisations that are supporting this study.

To help develop the questionnaire further we would like to invite you to fill out the following online questionnaire:

Please click [here](#) to complete the questionnaire

It will take around 10 minutes of your time to complete. The ReQoL questionnaire is quite long at the moment and your answers will help us produce a shorter one.

Please visit www.regol.org.uk for further details regarding the study.

If you do not wish to complete the questionnaire, please feel free to ignore this request. If you have any questions then please feel free to contact Thomas Kabir by email (thomaskabir@mcpin.org) or phone (0207 922 7874).

Your response is very valuable and we thank you for your time.

Thomas Kabir, McPin Public Involvement in Research Manager

ReQoL is being developed by The University of Sheffield through funding from the Department of Health Policy Research Programme

Would you like to be a reviewer for the National Institute for Health Research NETS programme?

The National Institute for Health Research (NIHR) needs people with everyday experience of having or caring for someone with a mental health problem to comment on research proposals. In particular they need more reviewers who are parents of children with mental health problems and young people (aged 16 and over).

As a public reviewer for the NIHR, Evaluation, Trials and Studies (NETS) programmes, you could be invited to read a research proposal or commissioning brief related to your own 'lived experience' and answer some key questions. Your comments would go on to inform the funding board or panel in making a funding decision.

Each review is a stand-alone task, which is sent to you to do in your own time, to an agreed deadline. They do offer payment for reviews undertaken by public reviewers.

The NIHR funds health research that produces evidence for health professionals, policy makers and patients, so they can make informed decisions. And we know that research that reflects the needs and views of the public is more likely to produce results that can be used to improve health and social care.

To express an interest in being a public reviewer for research proposals please email netpublic@southampton.ac.uk or call a member of our team on **02380 599302**.

Other ways of helping to shape health research include:

- Suggesting a research topic
- Becoming a public member of a panel or board.

To find out more: Visit www.nets.nihr.ac.uk/ppi

Job vacancies at the McPin Foundation:

We are currently recruiting for 3 positions within the McPin Foundation team, including a researcher for a peer support evaluation, a senior researcher to lead on two key studies, and a Public Involvement in Research co-ordinator. Go to our [Vacancies](#) page for information about all of these and details of how to apply.

Job vacancies at St George's, University of London:

A project partner is currently recruiting a peer researcher to work on a new study. It will be working alongside us on the evaluation of peer support. Take a look at the job advert [here](#).

Thank you

As we approach the end of the year in terms of our reporting cycle to the Charity Commission we would like to take this opportunity to thank everyone who has been involved in any capacity across all our projects; study participants, advisors, lived experience advisory group members, volunteers, peer researchers and our trustees. We value your contribution enormously.

As we move forward this year our aim is to increase our reach and collaborate with more people with lived experience in various capacities, especially within our Public Involvement in Research programme so please do keep an eye out for opportunities to get involved.



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