



Welcome to the third edition of our newsletter. We have an exciting month coming up with our first ever fundraising event – four people peddling 100 miles for us on 10th August in Ride London, so a huge thank you to them! People tell us they feel it is important to have a charity emphasising the importance of involving people with direct experience of mental health issues in the research process - that has been very good to hear as it is what we are all about at the McPin Foundation and we are looking forward to achieving far more and involving more people in our work. You can help by encouraging people to sign up to receive our newsletter. We really want to grow our supporter numbers to show how many people feel user focused research is vital to achieving quality mental health research.

McPin Foundation Our year in numbers

The McPin Foundation is a mental health research charity. We place those with lived experience at the heart of research. We conduct top quality research, offer consultancy and influence others to recognise the value of lived experience perspectives within research. Find out more about us at www.mcpin.org, contact@mcpin.org, or follow us on twitter @McPinFoundation.

Our participants

In our first year, we gathered data from 2,704 people across England and internationally.



Our reporting

We have been reporting our findings in various ways and to different audiences.

- 3 practical guides for service users, families and professionals.
- 9 written reports for funders and the public.
- 5 peer-reviewed journal articles.
- 15 presentations at conferences and events.

Our social media

We started using Facebook and Twitter to communicate directly with the public and begin to recruit supporters.



Our news

McPin Foundation news July 2014.

The McPin Foundation has been reflecting on its first 12 months and produced an **infographic** to help us summarise our work by painting a picture with numbers. In the future we will turn our attention to the impact of our work – so you have more staff but what have you actually achieved?! One important activity is the setting up of a new project called **PARTNERS2** a study that will develop and test a new

system of primary care-led mental health care for people with schizophrenia or bipolar. We welcome Ruth Sayers to our team who is the dedicated PPI coordinator within this major research project over the next 5 years. If anyone is interested in **getting involved as a lived experience advisor within this study**, and lives near Birmingham, Lancashire or Devon please do get in touch.

We also welcome Vicky Nicholls, an experienced researcher with lived experience of mental distress, to the team this month who joins us to coordinate our research on women's medication decision making during pregnancy when living with severe mental illness. Thanks to a huge effort on social media we recruited 12 women to this user-led project to tell their story and are now working on data analysis and writing up these findings.

Our work is not all about severe mental illness, and we are also busy interviewing vulnerable women about their experiences of the support provided by a charity called [Birth Companions](#). People using this service require support before, during and immediately after birth because they are facing a number of difficulties and issues including immigration and asylum, housing, a history of mental health problems, abuse, and/or substance misuse. This study will finish next year and we are already thinking about how we can build on this work at the McPin foundation because we are doing a number of projects addressing wellbeing among children and families.

Last but not least this month, we are celebrating the success of three members of the original McPin Foundation research team who will all be doing doctorate studies in 2015. Jess Cotney found out this month she has been awarded a PhD place at Sussex University to start January 2015, Daryl Sweet who works with us part time is nearing the end of his first year at the University of Manchester and finally Paulina Szymczynska starts her PhD studies this October at Queen Mary University, London. It shows that the third sector is a good place to develop research experience and expertise, hone ideas for what topic to research as a PhD and develop partnerships with academics. We will be recruiting new staff to join us in the autumn.



Shaping McPin

Launching the McPin Public Involvement in Research Programme.

The mission statement for the McPin Foundation is 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 have been thinking hard about how to do this and we have a way forward. I started work in early May as the McPin Public Involvement in Research Manager. So how do you

‘transform mental health research’?

My first thought was, one step at a time. We are forming a McPin Public Involvement in Research Advisory Group. It will meet for this first time on July 31st. The Group consists of some of the most well-known people with lived experience of mental illness with an interest in research in the country. The Group will help us develop and carry out a programme of public involvement work following on from the [Peer Researchers day](#) that we held here held in June 2013.

We already have some good ideas about the work that needs to be done, informed partly by a session we held a year ago (link to report). We will be looking at ways of connecting groups and people from across the country. Our first step in this will be to develop a directory of mental health service user and carer researcher groups. We will be launching a small scheme for a year offering a limited number of bursaries to help fund service user and carer involvement in studies at a very early stage. This is important as there is a severe lack of financial support for people trying to arrange service user and carer involvement in studies before an application for funding is made.

We want to develop a series of case studies that will highlight new ways that service users and carers can get involved in research. To start we will focus on areas of mental health research in which public involvement is relatively under supported.

In terms of influencing the research agenda the McPin Foundation is talking to different academic teams and working with other charities to influence how research is carried out, and what gets funded. A good example is our support of the [Depression: asking the right questions](#) initiative. The project will bring together service users, carers and researchers to produce a ranked list of unanswered research questions relating to depression. These initiatives typically lead to several substantial pieces of research being funded.

So have we ‘transformed mental health research’? Not quite yet, but we are making a start. For more information please email thomaskabir@mcpin.org



Research in the news

Improving wellbeing for everyone – and the challenges for research.

Wellbeing is currently a buzzword in the world of public health. In July [CentreForum](#) released a [report](#) on happiness and wellbeing which recommended that a focus on wellbeing be embedded across Governmental and community work, and that subjective wellbeing should be used to evaluate and allocate health resources. We welcome this emphasis at McPin Foundation, where we’re passionate about conducting user-focused research that improves wellbeing and mental health. We recently completed a research study mapping [Community Health Networks](#) by exploring the connections people with severe mental illness had to people, places and activities and assessed each contact’s impact on wellbeing. The very start of the study involved some consultations to think about which term to use to cover everything that impacts on mental and physical health. We found that the term ‘wellbeing’ was understood implicitly by most of the people with mental health problems who took part as incorporating a wide-ranging and holistic sense of wellness, happiness, and how you feel your life is going. From that point on the study was focused on wellbeing rather than health; so we have been thinking about how to evaluate wellbeing for a while.

One of the attractions of the concept of ‘wellbeing’ in mental health research and practice is that it’s quite a positive idea which doesn’t have the negative connotations of more medical and stigmatised terms like mental health problem or mental illness; this attractiveness may be behind a growth in popularity in recent years for wellbeing programmes, such as [wellbeing at work](#) and the [5 ways to wellbeing project](#). However, there is still the question of what exactly wellbeing means or *subjective* wellbeing as called for in the Centre Forum report. If we’re going to help improve wellbeing, we need to measure it accurately and consistently. There are some conceptual and methodological problems, with no fixed consensus on what wellbeing actually means or the most reliable way to measure it. Many studies use the term, but the way that they measure it differs from one study to the next, making comparison difficult - and definitions often overlap with other terms such as quality of life and life satisfaction. This is not a new problem – we have seen the same in work seeking to ‘measure’ social inclusion or exclusion.

A few weeks ago in June, I attended a symposium to debate the issues involved in researching wellbeing at the University of Manchester. The interdisciplinary event included speakers from the fields of politics, business, public policy, psychology, nursing and economics. It was great to see researchers from so many different backgrounds interested in wellbeing but it was also apparent that this multidisciplinary interest could be both a strength and a weakness in wellbeing research.

On the one hand, multiple perspectives no doubt help provide a richer understanding of any topic and despite the differences in background, there was a general agreement that improving wellbeing for everyone, rather than just focusing on the absence of illness, was something that we should be striving for in society. The ethical view that people should be supported to live satisfying and full lives was apparent in the majority of perspectives offered and I thought it echoed the recovery approach found in mental secondary mental health services: the sense that recovery is not necessarily the absence of mental illness, but a process of living life to the fullest regardless of the effects of mental ill-health.

On the other hand, it was also obvious that many of the speakers meant different things when they spoke about wellbeing, and measured it in different ways which often seemed to clash. I heard it was a state of being or behaving physically or mentally well, or of being in work without absence due to illness. I heard it was about a wide range of factors such as quality of family and friend relationships, job satisfaction, autonomy, self-confidence and hope for the future. For some it was a catch-all term to include physical and mental wellness but others felt strongly wellbeing is distinct from physical or mental health. The CentreForum’s report includes ‘mental wellbeing’

suggesting there are various other sub-types on offer too. It's not always clear if wellbeing is seen as the *outcome* of healthier minds, relationships and societies, or a *factor* that leads to these. The presence of so many definitions will be a problem for tracking wellbeing over time and is something to remember when reading about new research that claims something is good for your wellbeing!

It seems that we still have some way to go before there is agreement on how to conceptualise and measure wellbeing. It's also important to recognize that different things may be important to people's wellbeing - for example some might value their career most highly, others their family. This was echoed in our Community Health Networks findings – people value a very wide range of activities, hobbies, community resources and relationships to support and maintain their personal wellbeing.

Perhaps therefore one specific definition is not possible or desirable; it may be preferable to think of wellbeing in ways that are specific to different groups of people. For example, last year a [conceptual framework for wellbeing for people with psychosis](#) was published. This is useful because it outlines some issues that are specific to those who experience psychosis such as the impact of medication and mental health services on wellbeing. But everyone has mental health and the vast majority of factors outlined in this framework – such as relationships, activities, self-worth and empowerment - can apply to anyone, so wouldn't it be better if we thought of wellbeing in terms of the whole population? We will be taking an active interest in discussions of wellbeing; will it become an enduring term like "poverty" within social research or pass us by like the "big society". I hope to contribute to thinking and writing on wellbeing through my PhD study research and would be interested in anyone who wanted to get in touch to discuss.



Hot off the press

Personalisation and mental health – new research report launched.

A research project commissioned by Mind, the mental health charity has just [reported its findings](#). It was carried out by a team of researchers from the University of Central Lancashire (UCLAN) as part of a programme of work on personalisation in mental health funded by the Department of Health. Using qualitative research methods involving 49 participants it asked important questions:

- What do service users, family members, commissioners, mental health service providers and policy experts...
 - think about personalisation as a concept and its relevance for mental health service users?
 - know about personal budgets and how aware of them are they?
 - believe are the factors affecting the uptake of personal budgets in social care?
- What are people's personal experiences of personal budgets?
- Do we need more research on personal budgets in mental health?
- What recommendations need implementing to improve current practices?

The report was particularly timely for the McPin Foundation research team because we have also recently finished work on [personal budgets in mental health](#). We were very interested to see if the findings overlapped and how.

Our study worked with similar stakeholder populations – service users, families and practitioners – and used qualitative research methods including some longitudinal interviewing to assess the impact of personal budgets over time with people managing complex and enduring mental health problems. Overall, we interviewed 166 people from four local authority areas. Our findings are strikingly similar to the UCLAN research group and we concur with many of the observations they have made about both the use of, and barriers to, personalisation in mental health care. The lack of use of personal budgets for prevention work in mental health is a missed opportunity, and an area we would like to address in future work such as making personal budgets available to people on discharge from secondary to primary care services.

Our emphasis in recommendations was different. The UCLAN report focuses on changing the systems of care within which the practices of personal budgets must operate: improve staff work loads and low morale; increase the emphasis on early intervention and prevention within care pathways; improve information sharing between services; remove inequity and lack of transparency over access to personal budgets. We agree – major barriers to the implementation of personal budgets are interface challenges between health and social care systems underpinned by a different values base and operational culture, practitioner workloads and low prioritisation of social recovery, the belief that personal budgets are someone else’s responsibility and poor training or awareness in the potential of personal budgets to achieve real change in people’s lives.

Our study took a different approach to the findings. We used the experiences we heard about to develop practical guides for service users, families and practitioners to attempt to address some of the barriers to the effective use of personal budgets that both pieces of research have highlighted. The guides support individuals to better use personal budgets to support recovery and promote choice and control for people with mental health problems over their care packages.

It is reassuring that both pieces of research have similar findings and this emphasises that these are common and important issues for social care and for people with mental health problems. We hope that by taking both of these studies with their different lessons for practitioners and local authorities, real improvements can be made to the experience of people with mental health problems. We will be in touch with the UCLAN group to see if we can join forces to combine our data findings which will make for a stronger basis for change.



Opportunities

Take part in research as advisors or participants in focus groups.

We are currently recruiting to some new research advisory groups. One study working with researchers at University College London (UCL) on an NIHR HTA funded study, which needs a group of three people to form a “Clinical Advisory Group” for research into anxiety that will assess the impact of drug treatment versus Cognitive Behaviour Therapy (CBT) within a Randomised Control Trial. We are

looking for people who have experience of managing anxiety using either or both medication and CBT who live in London. The second study is [PARTNERS2](#) and we are recruiting people with experience of schizophrenia or bipolar, and/or who have a keen interest in mental health research and mental health service design, to form three [Lived Experience Advisory Panels](#) (LEAPs). We will be convening these groups in Birmingham, Lancashire and Devon. Anyone interested in either opportunity please email contact@mcpin.org

Finally, we will be running some focus groups in Birmingham and Lancashire in September with researchers at the University of Birmingham for people with schizophrenia or bipolar about how health issues affect people’s lives and the goals that they set for themselves in order to see which “outcomes” are most important to achieve with the support of mental health and primary care services. This work is also part of PARTNERS2. Interested in taking part or know someone who might be please email contact@mcpin.org and more information is available.

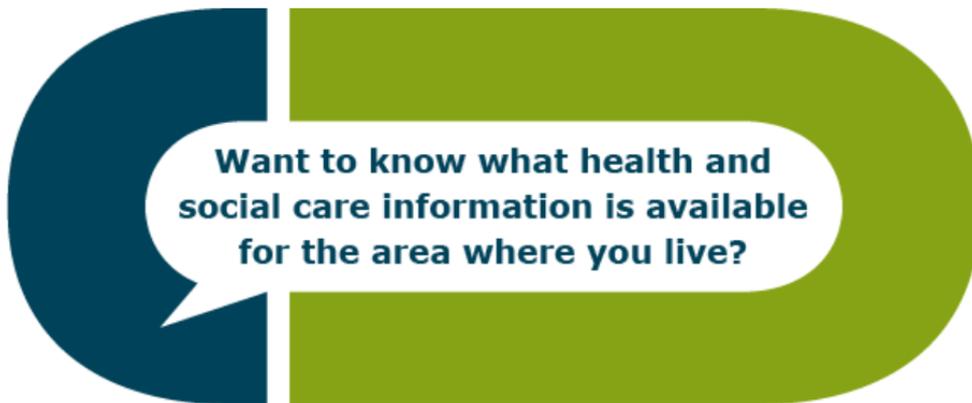
Thank you

We want to say a huge thank you to the four guys taking part in Ride London for the McPin Foundation which is a 100 mile bike ride from London into the Surrey hills and back to finish on the Mall in central London on Sunday 10th August. This is our very first fundraising event and if anyone would like to sponsor them, they and we would be very grateful. Click on their names to see their fundraising page: [Thomas](#),



Mark, Nick, John. If you want to join us to cheer them on we will be having stations along the route and we can let you know where we will be if you get in touch – shouting loudly for mental health research! In addition, our research manager Sarah Hamilton is going to be walking 100km of the Thames path in 24 hours on 13th September (is that feasible we ask – apparently so). Again, if you would like to show your support for her please visit Sarah’s fundraising page [here](#).

The final thank you is to our amazing volunteer Emily who is doing a fantastic job supporting us through the summer with a mountain of data entry and transcription work, as well as other tasks. We will be sad to see her leave us!



Then take a look at a new website **MHDNIN** from Public Health England.
