



Welcome to our spring newsletter that celebrates our **3rd Birthday!** Thank you for supporting us and helping us champion expert by experience roles within mental health research. We have come a long way in 3 years but as the **Mental health taskforce report** points out – there is still much more progress required to ensure mental health is improved in communities everywhere. We cover in this edition **work and mental health**, and how progress towards the goal of employment must not be overlooked. We present our findings from an evaluation of the **Crisis Care Concordat** and also feature a piece from our **first ever Marathon runner Helen**, on why she is running for mental health research this April. Earlier this month we advertised a full time peer researcher role to join our team, receiving 43 applications and we interviewed 8 people. It was a tough job appointing just one person. This drives us forward to create more opportunities for people to use their lived experience in mental health research, seeking funding to enable us to do so.

# Crisis Care Concordat

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## Mental Health

### Our news

Earlier this year, The Mcpin Foundation completed its brief evaluation (click [here](#) to read the summary and [here](#) to read the full report) of the local implementation of the national [Crisis Care Concordat](#). The underlying approach of the Concordat was to improve partnership and multi-agency working; recognising the range of statutory and non-statutory agencies involved in crisis care, the role of family and friends, and working to ensure that crisis support is as effective as possible. Through interviews,

observations, an analysis of local area action plans and two surveys with service users and carers, we were able to begin to identify what had worked well and where there was still further work to do, as well as making a number of recommendations.

“I really enjoyed working on this project. Talking to people involved there seemed to be a real commitment to achieve change despite the difficulties that professional cultures or system barriers might pose. It did feel to me as an evaluator that people were trying hard to make the concordat an opportunity to fix some long standing problems” Susanne Gibson.

It was clear that the Concordat had been successful in encouraging local areas to develop partnership working across a range of areas, incorporating prevention and recovery into conversations and plans as well as the delivery of urgent care to people experiencing or at risk of a crisis. One particular area of success was the [reduction of the use of police cells](#) as a Place of Safety for people experiencing a mental health crisis by more than 50%. Further, we were pleased to discover from our [survey](#) that there had been some significant improvements in service users’ experiences of crisis care in the twelve months between November 2014 and November 2016. While this is from a relatively small sample, and we can’t say whether it’s the result of the concordat directly, it is nevertheless an encouraging result.

However, not all of the experiences reported by our survey respondents were positive, and it was also acknowledged in the interviews with key stakeholders in local areas and with members of the national steering group that there was still a great deal of work to do to ensure that care for those in a mental health crisis is given parity of esteem with care in a physical health crisis. One of the concerns expressed both in the interviews and by our survey respondents was how far the momentum of the Concordat would be maintained into the future.

“I feel that on paper the recommendations are very positive and beneficial but have serious concerns and doubts about its implementation, due to cuts and lack of funding.” (Survey Respondent)

While this is a very real concern, two recently commissioned reports may help with this momentum, picking up on a number of areas identified for further improvement.

[‘Old Problems, New Solutions: Improving Acute Psychiatric Care for Adults in England’](#) is the report from the independent Commission on Acute Adult Psychiatric Care, set up by the Royal College of Psychiatrists in January 2015. Responding to the twin problems of inadequate access to acute psychiatric care and provision of care and treatment in the community, it makes a number of recommendations. These include ensuring that people who are acutely ill do not have to travel long distances for care, and that there is a maximum four-hour wait for admission or acceptance of home-based treatment following assessment. Working in partnership to share information and resources, and to find innovative ways to deliver services is also emphasised, as is the importance of co-production not only in receiving care but also in service design, provision, monitoring and governance. In line with the

Concordat evaluation, the report also stresses the need for good quality data to improve services and ensure accountability.

[‘The Five Year Forward View for Mental Health’](#), a report from the independent Mental Health Taskforce, commissioned by NHS England also made recommendations for achieving parity of esteem between physical and mental health not only for adults but also children and young people. It is widely recognised that mental health care, including crisis care for children and young people has been a ‘Cinderella service’ even within mental health services, for example with particular concerns over the lack of [locally available inpatient services](#). Although this lack of provision was addressed to some extent through the Concordat, with all local area action plans including actions to improve provision, it is clear that this is an area that requires considerable additional resources and attention; something that again was acknowledged in our interviews. It might also require radically different ways of responding, and systems that allow different solutions to emerge. In line with the report of the Taskforce, our evaluation recommends that the lack of parity in services for children and young people is addressed, including looking at ways to move beyond a model that expands existing adult services to one that takes into account the specific needs of children and young people who are experiencing a crisis. At the heart of this approach would be the voice of young people. We encourage far more co-production in research and service development with young people, their parents and front line practitioners whose expertise is needed for solutions to emerge. It is clear that care for people experiencing a mental health crisis still requires improvement and it is essential that the good work begun by the Concordat is continued. But how? McPin Foundation is looking for opportunities to work with existing and new partners, especially those involved in research that seeks innovative solutions to transform the experiences of people in crisis. Do you have ideas of research you would like to see delivered in the area of crisis care? Do get in touch.



## Research in the news

As the [recent report](#) from the Mental Health Taskforce points out, only 43% of people with mental health problems are in work, compared with 65% of people with other health conditions, and 74% of people in the general population. The figures are far lower for people with severe mental illness – for example, [the employment rate for people with schizophrenia is around 8%](#).

The current programme of welfare reforms are aimed at moving working age people off benefits and into paid employment. For anyone relying on Employment Support Allowance, the main benefit for people who are unemployed due to a physical or mental health condition, this can mean undergoing a reassessment of their eligibility. The Work Capability Assessment (WCA) or ‘fit-for-work’ test has attracted a lot of attention in the press, much of it negative. First, there are claims that there has been a failure to adequately assess the impact of mental health on ability to work, and although changes have been made to respond to these criticisms, it appears that there are still question marks over [whether the tests are fit for purpose](#). Second, the impact of the test itself has the potential to cause deterioration in mental health. While much of the evidence to support this has been [anecdotal](#) in a [recently published research study](#) that also attracted attention from the [press](#), Barr et al (2015) found a link between the WCA and rises in suicide rates, self-reported mental health problems and antidepressant prescribing rates. That is, where a higher percentage of the population in a local area were subject to the WCA process, there was a greater increase in these three mental health outcomes. Although the study

controlled for variables that might have had an impact on the findings, such as deprivation and long-term mental health trends, it was not able to make a direct link between the people undergoing the WCA and those experiencing the adverse mental health outcomes. Nevertheless, the authors believe that the study provides sufficient evidence for a policy rethink.

Yet many people who have a mental health problem do want to find and stay in employment, and workplaces and back-to-work programmes need [to understand and respond to the impact of mental health problems and the kinds of support that are genuinely helpful](#).

One evidence-based approach to supporting people with long-term mental health needs to get into work and stay in work is the [Individual Placement and Support \(IPS\) model](#). The IPS model is based on the idea that not only is it possible for most people with a long term mental health needs to work, but that work itself is therapeutic. The model provides support aimed at rapidly finding paid, competitive employment, and continuing to support the individual once they are in work. It is also based on integrating employment support with clinical support. Developed and shown to be successful in the United States, it is increasingly being used in the UK. While to date the success rates have not matched those in the US – and it is suggested that there are some important differences between the two contexts to explain this – work to implement and evaluate the model continues. We are interested in this model because of our own work in this area. We are fortunate enough to be working with the Centre for Mental Health, Trust for London and the DWP on a project called “[100 People into Employment](#)”, evaluating a pilot programme based on the IPS model, aiming to support people with schizophrenia or psychosis into employment. As part of this project, we are undertaking a longitudinal study, interviewing people with schizophrenia or bipolar disorder about their experiences of being supported to find and stay in work. Through this project we hope to develop an understanding not just of the ways in which the IPS model can be adapted, but more broadly of the journey into work for people with long term mental health needs; to understand more about what it is like, what is most helpful, and to celebrate their successes.

There are multiple facets to the relationship between work and mental health and supporting people at whatever stage of their journey requires joined up thinking. This is something the McPin Foundation wants to continue to engage with and understand. Tell us what you think are the important areas for research.



## Hot off the press

Researchers at Kings College London have just produced an interesting paper, published Feb 2016. It is available [online](#), and can be easily accessed. It looks at the ease of reading participant information sheets over a 10 year period – June 2003 to October 2013. Why is this interesting? We think it is an important piece of research and it is something the McPin Foundation has been getting more involved with of late. We have been helping study teams write plain English ‘lay’

summaries of their research ideas. We have been trying to make information sheets more accessible to people they would like to recruit as participants in their studies.

An information sheet is very important in the conduct of research delivered to high ethical standards. Having an easy to understand information sheet is essential so that people can give ‘informed consent’. In this context, informed consent means having enough information to make a well thought out decision about whether you want to take part in a research study or not. An information sheet contains information such as:



- Why are you asking me?
- What do I have to do?
- Will I or other people benefit?
- Will any harm be done to me?
- Who will know I took part?
- How will my responses be stored and used?
- Will my responses be confidential?

There is guidance on how to write an information sheet from bodies such as the [Health Research Authority \(HRA\)](#) and how to specifically write [using plain English](#). But it isn't easy and many research teams insert legal text, at the request of their own organisations, which is extremely hard to provide jargon free.

So what did the researchers Liam Ennis and Til Wykes find? Having looked at 522 unique information sheets from studies within the National Institute of Health Research (NIHR) mental health portfolio data base they found some long and very complicated text.

- For device intervention or pharmacological studies the average word count was 3000 – that is likely to run to 7 pages of text. The most complicated section of text in these sheets was graded “very difficult”. This needs to be seen in context. Many organisations insist that researchers use long and legalistic templates to base their information sheets on and legal departments of funders often include page upon page of text in an attempt to protect them from any possible legal action.
- Studies that were working in the area of intellectual disability or dementia had information sheets that were easier to read. However the reading age grade was still 13-14 years (the UK national reading age).
- Information sheets were shortest in studies based on observation. These did not need to explain complicated interventions or the process of randomisation.
- One factor that seemed to reduce the length of information sheets was the involvement of patients in study design and delivery. They found as patient involvement increased in a study, the length of the sheet fell by about 150 words per level. However, patient involvement did not impact on readability.
- They found that over time information sheets were getting longer in terms of word count.
  - In 2003, across all studies average word count was 1333 and by 2013 it was 1714.
- They were not getting more complicated over time, but as already stated their readability as rated by reading age and a score known as the Flesch Index was high – average reading age 15-16 years and most complicated sections within the information sheet was measured as average age 18-19 years.
- Ease of reading did not contribute to recruitment success in the studies assessed. Two factors that did influence recruitment. The first was level of patient involvement; the higher the involvement the better the recruitment to target. The second was intervention type, with pharmacological or device studies less likely to recruit to time and target than other study designs.

What do we learn from this research? Firstly, it confirms our concerns at the McPin Foundation that often participant information sheets are overly complicated and hard to understand. Do people know what they are consenting to do? The data suggests that ease of reading information sheets does not impact on recruitment, but it may introduce bias into research samples. Are those with the stamina to read long information sheets more likely to enter studies than other people who might struggle to understand complex information? We know when your mental health is challenged, for many people concentrating and reading anything is difficult.

Secondly, the study reinforces the importance of involving patients in the design and delivery of studies as collaborators. More can be done to improve the use of plain English within information sheets, but it does seem that

involving experts by experience keeps the lengths of these vital recruitment tools in check and helps ensure studies recruit to target. Writing in this way is a skill to be nurtured and developed, and we encourage the training of more service users and carers mental health research writers.

What else can we do to improve information sheets? Ennis and Wykes' article suggests using a glossary to help make language more accessible and they provide a really helpful appendix to show how complicated text can be simplified and word length reduced without sacrificing meaning. We need informed research participants, who know exactly what is being asked of them, and for how long, so that retention within studies is high. The quality of a study is diminished if you lose lots of people during the course of the research, and thus have lots of missing data when you come to your analysis.

We have also started to think of ways of making information sheets better.

Two of the studies we are currently working on are producing a one page summary of the full information sheet as an easy read version. This gives people a choice. You can read the full version by yourself or you can read a summary and ask the research team to help you understand the full information sheet prior to giving informed consent. Having someone help you go through the full information sheet can make the whole process feel less daunting, and you can ask questions more easily. What is very important is the informed consent process can only take place after the full information sheet has been read and time provided for the person to make a decision over participation to prevent coercion.

Another idea we are progressing is to create an audio recording of the information sheet, or a video version. This would help people who find reading hard. The patient information sheet could be delivered in another format.

Our collective challenge is to reduce the average reading age of all mental health study information sheets to 13-14 years, the UK national average. We need to reduce their length and find a way that Ethics Committees, and research organisations, can balance their legal and ethical duties. People must have access to information to make an informed decision, but the length and complexity of information sheets should not be a barrier to engagement in research. Such barriers reinforce the problem that research study participants are not like "real world" people, and study findings that do not transition well from the research clinic to front line service delivery.

We tested this blog in terms of readability. The target is a score of 60 or more to meet the national average reading age standard of 'plain English'. We achieved a Flesch score of 54.8 which is in the fairly difficult to read band. We have more work to do improving the accessibility of our blog pieces.



## Opportunities

### **Service user or carer needed to join Cognitive Bias Modification for Paranoia (CBM-pa) study steering group.**

We are looking for a service user or carer living in London to join the steering group for the Cognitive Bias Modification for Paranoia (CBM-pa) study. The study is about seeing if a new approach called cognitive bias modification can help people suffering from paranoia.

You can find out more about the study here: <http://bryonycrane.wix.com/cbm-pa>.

To apply please complete the application form [here](#) and return it to Thomas Kabir ([thomaskabir@mcpin.org](mailto:thomaskabir@mcpin.org)) **by 5pm on Friday 15<sup>th</sup> April 2016.**

### **Opportunity to help develop an evaluation framework**

The McPin Foundation is partnering with the National Suicide Prevention Alliance and Suicide Bereavement Support Partnership for a Public Health England funded project to improve support for people bereaved by suicide. If you have received support following a bereavement due to suicide (for example, individual counselling or attending a group), you might be able to help us. We need to speak with people who have experience of services supporting people bereaved after suicide to help us develop an evaluation framework. We need to know how people would like surveys to be administered and feedback captured to communicate the impact that services have on peoples' lives. Interested in helping us? Please do get in touch by emailing [susannegibson@mcpin.org](mailto:susannegibson@mcpin.org) or call 0207 9227876.

### **Community Navigators Research Study – Mental health service users wanted to join our working group**

A new research study we are working on in partnership with UCL is looking for up to 5 people with personal experience of mental health problems to advise on developing and testing a programme of support for mental health service users which aims to increase people's community connections and reduce loneliness. To find out more click [here](#).

### **Two PhD studentship opportunities at The University of Worcester**

The University of Worcester is offering two PhD studentship opportunities in the area of adult mental health with a focus on student suicide prevention. To find out more click [here](#).

### **Mosaic Clubhouse Research Volunteer**

Mosaic Clubhouse is an integrated community and resource centre providing personalised support for people with long term mental health needs. An exciting voluntary research opportunity is available for a Psychology/Social Science Msc or DPsych student. They are looking for a committed, diligent and highly organised research student to participate in a research study looking at their outcomes and impact, working with people in Mental Health Recovery. To find out more click [here](#). **The deadline is Friday 15th April at 5pm.**

### **Which research questions about Bipolar are most important?**

If you have Bipolar or someone close to you does, you now have the opportunity to help prioritise questions that you think should be addressed by research.

In September 2014 the first Bipolar partnership survey was launched and received thousands of responses. Your participation in the second Bipolar survey will help prioritise what you believe are the most important top ten research questions.

Effective research can help improve care and treatment: please click [here](#) to complete the survey. The survey will close on **Friday 15<sup>th</sup> April.**

## Prudential RideLondon-Surrey100

We're still building our team of cyclists for the Prudential RideLondon-Surrey100 cycle ride, on Sunday 31st July 2016! Are you a keen cyclist? Have you been personally affected by mental health problems? Do you have a passion to see people's mental health improved in communities everywhere? If yes, then please join our team and help us raise money to transform mental health research!

Please download and complete our riders application form [here](#) and return to [contact@mcpin.org](mailto:contact@mcpin.org) NOW!



## Thank you

This year we recruited our first ever London Marathon runner, Helen. She will be running alongside her husband Rob and her friend Sion who are all raising money for McPin. Helen has written an inspiring blog which you can read [here](#) to find out more about why she's chosen to run for mental health research. So far they have raised an amazing **£5,000!** We would like to say a huge thank you to Helen, Rob and Sion for their efforts and especially to Helen for writing her blog.

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