

The theme of our December 2016 newsletter is reflection. This is a very important part of all research activities! Reviewing progress over time, and sharing your learning, is important in all organisations but particularly in the charity sector. What are we achieving with our beneficiaries? How can we work differently? What is working well? We are optimistic that 2017 will be a positive year for mental health research, supported by a Department of Health 10 year mental health research strategy. We wish all our supporters the very best for the festive season and hope you enjoy our reflections on 2016!



McPin Methods

First thoughts from the first McPin Methods Workshop

The 30th of November saw the first of what we will hope will be a series of methods workshops. It brought together over 70 researchers to discuss how to integrate 'lived experience expertise in mental health research teams'. The event was massively oversubscribed and if the fact that we had to cut short discussions before we were

physically kicked out of the venue is any guide, it succeeded in its aim of stimulating debate and the sharing of ideas. You can find a small sample of the discussion by looking for #McPinMethods on twitter.

The event was part of a wider week of activity here at McPin looking at how we push forward the discussion on how we involve people with lived experience of mental health problems in research. You can find all the [outputs of the week on our website](#), including a series of personal blogs by our researchers exploring different aspects of their work and practice.

Returning to the workshop: one goal of the afternoon was to develop a sense of what the priorities are in improving how we do Public & Patient Involvement (PPI) and peer research well in mental health. There were a range of issues that emerged from discussions and a huge amount of energy and excitement about tackling them.

The most important point was a very simple one, if involving lived experience in research doesn't make a difference to the research what is the point of doing it?

This stimulated discussions both about how we move beyond a tick box approach to PPI done to satisfy funders' requirements, and how as advocates for involvement we evidence the positive difference it makes.

Power dynamics came up in a number of conversations; sparked by the simple illustration of how people had sat around the table at the first meeting of an advisory group. Researchers and medics on one side, service users on the other. Naturally people will tend to cluster with those they feel comfortable with, but it makes it difficult to break down the traditional hierarchies that can get in the way of free sharing of ideas. More fundamentally, if involvement is to have an impact, researchers have to be willing to cede some power to those they are involving so they can influence the research – and be honest up front (including with themselves) where they can't or won't.

Finally issues of diversity in recruitment came up in a number of forms. One presenter discussed the difficulties of recruiting a group of lived experience advisers for her study who reflected the diversity of the wider population of service users and carers. It was an issue that a number of people in the room were grappling with. The question of who is recruited to become researchers, and especially peer or service user researchers also emerged. We need to do better at ensuring people who may not come from the traditional researcher mould, in either background or approach, are given the opportunities to develop the necessary technical skills but also to offer up different perspectives. This is a question we have been grappling with at McPin, and we wouldn't pretend to have the answers yet.

Ian Bradshaw, Policy Manager



Research in 2016

To mark the end of 2016, we're taking a look back at some of what the McPin team has learned over the past year.

Theories of Change: Facilitating co-production

In 2016 we've been working on a number of projects that have involved developing a Theory of Change, including our evaluation of [Kent County Council's Mental Wellbeing Programme](#), [SLaM's Recovery College](#), the arts-based intervention 'Performing Places', and the SLaM Mental Health Promotion Team's 'Wheel of Wellbeing'. The purpose of a Theory of Change is to establish a clear model for a programme or intervention,

identifying the links between the rationale for setting it up, its implementation and its outcomes. It usually takes the form of a diagram, which is accompanied by a written narrative. A Theory of Change helps a programme clearly articulate its aims and how it intends to achieve these, serves as a decision-making tool for programme activity, and can inform the detail of a subsequent evaluation by making links between activities and outcomes explicit, thus allowing for these to be tracked over time.

In late summer we began a new project for Macmillan Cancer Support, helping their Inclusion Team to co-produce a Theory of Change for their Mental Health and Cancer Taskforce. The Taskforce is an initiative that brings together people affected by cancer and mental health or emotional wellbeing problems, their carers, and professionals and other stakeholders, to find ways to improve outcomes for people with this dual lived experience. However, its initial remit was very broad, as the Inclusion Team wanted to ensure that the specific aims and activity areas were decided on collectively and collaboratively with Taskforce members, and thus commissioned McPin to develop the Theory of Change.

So what did we do? We first carried out interviews drawing on expertise from experience, with members of the Patient and Carer Reference Group who helped to steer the Taskforce. An initial draft of the Theory of Change was developed on the basis of these interviews, and was presented back to this group at a workshop which generated much discussion. A subsequent draft was then presented to professionals working in the field of cancer and mental health and was further refined. Lastly all research participants were invited to feed back on it one final time. The Theory of Change and the accompanying narrative has been well-received by the Taskforce and Macmillan's Inclusion Team, who will be using it in the coming year to help plan and guide their programme of activity moving forward.

We have enjoyed delivering this work and have learnt a great deal. Theory of Change is a useful framework to engage in using a co-production approach, although reaching a consensus can be challenging. Our solution was to understand the differences in opinion and attempt to make sure diverse voices were heard and represented in the final model.

Evaluating Innovation: Our work with Kent County Council's Mental Wellbeing Programme

The end of 2016 marks the end of our mixed methods [evaluation of Kent County Council's \(KCC\) Mental Wellbeing Programme](#), on which we have been working since November 2014. The public health team at Kent County Council commissioned a series of projects and services to improve wellbeing amongst the local population – some were targeted at specific vulnerable groups, such as people with moderate mental health problems, people at risk of isolation, young people, and professionals working in a range of roles – and others at the general public. The Programme was one of the first of its kind among local authorities to put the promotion of positive mental health

and the prevention of mental illness and at its core. It was unusual in terms of both the level of investment in service provision, but also in evaluation. The commissioners were keen to learn how well the programmes had achieved the goal of improving wellbeing.

Measurement is important in mental health, and often we are drawn to standardised assessment instruments. The Kent programme used the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) as a key measure across a number of their projects. We have also used this in other projects, and like many research measures, it is imperfect. In Kent, we



demonstrated the positive impact the interventions were having on wellbeing through the increase in WEMWBS scores. These findings were reinforced with qualitative insights, based on interview and observational data, into the mechanisms that bring about improvements for people participating in the projects. We found this combination of approaches very valuable in drawing conclusions and helping to explain how results may have been achieved. The Kent Mental Wellbeing Programme was found to improve personal wellbeing for individuals, and also achieve community level change. It was an innovative and experimental 'pilot' in public mental health commissioning, with the diversity and the flexibility of the individual projects commissioned crucial to the success of the Programme as a whole. The robustness of the evaluation has led to a number of the projects being recommissioned by KCC over the long-term, and to securing additional funding. We really enjoyed working on it and meeting the committed and inspiring people delivering the projects.

More Meaningful Co-production: The Community Navigator Study

This year, we have been busy developing our work on coproduction - an approach that brings people with different expertise together to co-design solutions. McPin have been involved in setting up a working group, including people with lived experience of mental health problems, clinicians and academics for the Community Navigator Study, which we are working on in partnership with University College London. Due to how successfully the working group provided input to the study, its remit expanded, with members of the working group with lived experience sitting on the interview panel for the Community Navigator roles and helping to co-deliver some of the training for Community Navigators. Not only did this give people additional opportunities to shape the study, but it also allowed the opportunity for personal development.

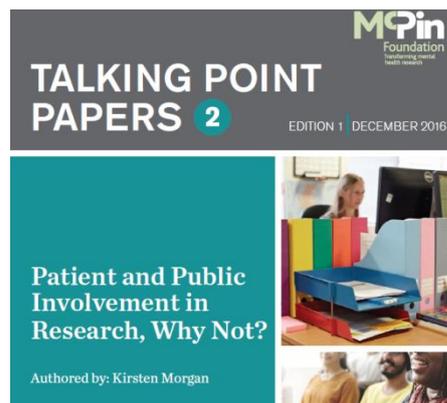
There are, of course, still ways that we can improve how we do co-production. For instance, we received feedback from working group members that more needed to be done to ensure that information is accessible. This means providing clear explanations of terms used and avoiding jargon altogether where possible, as well as giving people time to process the information. Saying this, feedback was generally very positive and demonstrated the benefits of meaningful coproduction.

In 2017, we aim to further develop the ways that we do coproduction and our understanding of what it means to do coproduction well. One of the areas that we have already identified is how to increase the diversity of participation in co-produced research. The discussions we had at our first methods workshop – integrating lived experience expertise into mental health research teams – were very informative and will help us with this goal.

Dr Agnes Hann, Senior Researcher, and Johanna Frerichs, Researcher

Reflections on Patient and Public involvement (PPI) at McPin

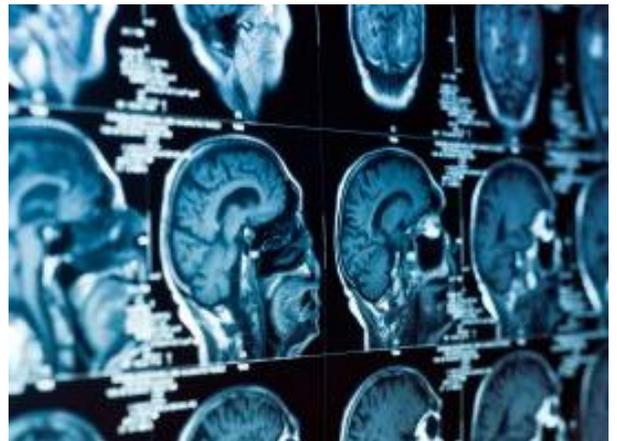
This year has seen the expansion of our mental health science theme of work. We have engaged with scientists developing new treatments and testing them in research studies. Are these treatments that patients want? What are the ethical considerations of developing the treatment? How can we improve the recruitment and engagement of research participants in the study? These questions are all something public advisors can help researchers think about and plan strategies to address issues that can arise. We are keen to more of this public advisory work – so do get in touch if we might be able to help you.



Sometimes people challenge us about recruiting a group of patient advisors, feeling we will engage the usual suspects with advisors lacking diversity of experience and opinion, or worried the advisory group will end up being tokenistic – their advice not taken on board by a busy research team “set in their ways”. There is an ongoing debate about how much research knowledge advisors need, alongside their lay knowledge and experience of the topic being researched, to work with research teams effectively. Unsurprisingly, maybe, our response is that it depends. We are actively thinking about all these issues, and this is a key development this year at McPin with the publication of [our ideas](#) on this topic. We will do more development work next year on different approaches to PPI.

Immunology and psychosis

This is a topic attracting attention. BBC Radio 4 aired a programme in August entitled ‘[The Inflamed Mind](#)’. The research is based at Oxford and Cambridge Universities and we are a partner in the [study](#). Members of the PPI group have developed a website and written an information booklet to help people decide if they want to take part in the study as research participants. A PPI group member was on the BBC2 Victoria Derbyshire programme on December 8th to talk about her experiences. The programme is still available on the [BBC iPlayer](#). The footage begins at 1hr 46 minutes into the start of the programme. A BBC news [article](#) was released on the same day.



Cognitive modification behavioural therapy for psychosis

In this [study](#) we asked people with experience of psychosis to write vignettes for the researchers to use in the study. Lots of them. We were also asked to help recruit for the trial – the original planned recruitment strategy was struggling to generate the number of people needed to take part. So the McPin Foundation went out and about – giving talks and speaking with people in the community to gauge interest. We know that it is a good strategy to go out and meet people, rather than wait for them to respond to an advert or letter from the university to ‘get involved’ in our study.

Discontinuation of anti-psychotic medication – trial led by researchers at UCL

This is a really interesting [study](#) (called RADAR) and we have a brilliant PPI group providing advice to the research team. They have written scripts and recorded some videos to support researchers talking with clinical teams about the study. One issue that is emerging in a number of studies is how we communicate with people about the randomisation process. In a trial, which has two conditions within it being tested, people have a 50:50 chance of being in the control condition (sometimes that is treatment as usual) or the new treatment group. Explaining that people might not get the chance to discontinue medication in the RADAR study is very important as the team do not want to lose people after recruitment because they do not like the group to which they are allocated randomly. Other studies use a technique called participant preference allocation – hoping 50% will choose group A and 50% will choose group B. At the McPin Foundation we are interested in the wording being used to communicate with potential participants and have reviewed a few studies to look for examples.

Next year we will be setting up another PPI group for research into recovery, led by Professor Mike Slade from Nottingham. More news on that study in 2017!

Thomas Kabir, PPI Manager

Influencing Policy in 2016

Mental health policy and research in 2016 – a glass half full?

At McPin we know that research and evidence are vital to improving the lives of people affected by mental health problems. But research does not take place in a vacuum. Decisions about what questions are seen as relevant, and what research (and how much) is funded are driven by people and how they respond to events in the outside world such as Brexit. Evidence does not change people's lives unless it has an impact on policy and practice.



As we reach the end of the year I wanted to think about whether 2016 had been a glass half full or glass half empty year for mental health policy. I think it just tips into the half full camp, if only because it appears that the challenges we face in improving mental health in England are starting to get wider attention.

For mental health policy watchers the big event of the year came in February with the launch of [NHS England's Five Year Forward View for Mental Health](#), prepared by an independent taskforce chaired by Paul Farmer of Mind. Although the report highlighted the many shocking inequalities that people affected by mental health problems face, and the distance we still have to travel to achieve 'parity of esteem', the taskforce's report at least set out an ambitious agenda for reform against which we can hold the NHS and the Government to account. It also highlighted the need for a more holistic view of mental health, taking into account issues such as employment and housing that are vital for wellbeing, and the links between mental and physical health.

Most important, from a McPin point of view, was the recommendation that the Department of Health (DH) produce a new 10 year strategy for mental health research. The Taskforce highlighted the lack of investment in research, and the gaps in the evidence base underpinning many existing treatments. Since the summer we have been working hard with DH on that strategy, successfully arguing that expertise from experience should be included around the table in the working groups they have created. The proof of the pudding will of course be in the eating, with the final strategy emerging in the spring next year.

Not surprisingly given the state of the Government finances, discussions have focussed on how we get the most out of the existing money, rather than arguing for more public money. However, we have been arguing that there is more Government could do to support charities like McPin and our colleagues in the Alliance of Mental Health Research Funders to raise money from the public and to provide strategic leadership themselves.

The main political shock of the year, in the UK at least, was the Brexit vote in June. [As I wrote at the time, this raises many questions for mental health research](#), both financially if, as predicted, the economy slows, and from the disruption to the pan European funding, collaborations and workforce that is a strength of our current research economy in the UK.

Determined to be glass half full there was one chink of light from the fallout of Brexit: a new Prime Minister who was explicit that mental health would be one of her priorities – raising it repeatedly in her speeches before and after she entered No. 10.

Away from Westminster the strongest theme in mental health policy in 2016 has continued to be children and young people. The most shocking statistic I saw this year (in a crowded field) came from our friends at the Centre for Mental Health. [They found that on average there is a 10 year gap between a child first experiencing mental health difficulties and receiving any help from the NHS](#). A decade. At least there now seems to be a growing consensus that this is unacceptable.

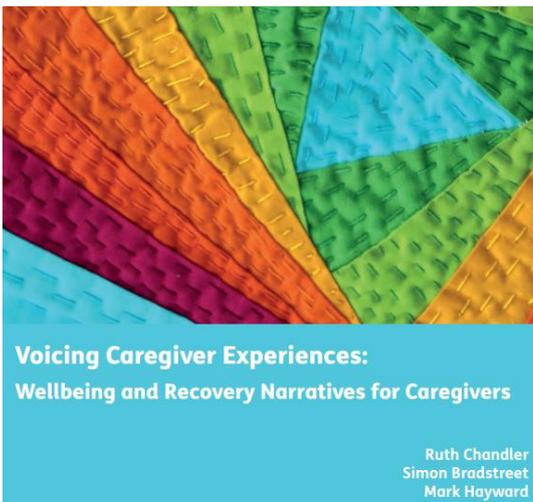
Overcoming the many challenges children and young people's mental health faces is not just a question of more resources. We still know far too little about how to best help children and young people who develop mental health

problems, let alone how to prevent them in the first place. We need sustained investment and commitment to research that addresses the issues that matter most to young people, their parents, and the professionals that support them. [That is why are collaborating with the James Lind Alliance to launch a priority setting partnership next year.](#) This will bring together the view of leading researchers, policy makers, parents and most importantly young people themselves to develop a list of the most important research priorities in children and young people's mental health.

Finally 2016 has seen a growing movement towards local action on mental health. This time last year New York City launched their [Thrive NYC programme](#) of action the city would take locally to improve mental health and wellbeing. Following the election of Sadiq Khan in May, the Mayor of London's office has been moving apace to draw up a London version that should be launched in spring 2017. We brought together a group of service users in May to inject some expertise from experience into their early thinking. We are now working with the working group looking at mental health and employment, making sure the evidence for what works and the voices of people with mental health problems are represented at the table.

So it has been a busy year, with a lot to build upon in 2017. We will continue to use our own research and patient involvement programmes to influence policymakers, and continue to make the case for high quality mental health research.

Ian Bradshaw, Policy Manager



Remembering Ruth

We were all saddened to hear about the passing of Ruth Chandler on 6th December. Ruth was the service user and carer involvement coordinator in research and development at Sussex Partnership NHS Foundation Trust. Ruth was a highly valued friend to many in the mental health user movement. At McPin she delivered research skills training to experts from experience, worked on studies with us, and was writing a Talking Point paper for us. Ruth was very talented and her work will endure. We will be considering how best to celebrate her life and work appropriately next year. In the meantime we express our condolences to Ruth's family and all who knew her.

Opportunities

We are looking for eight people with personal experience of mental health problems to join a London based Service User Advisory Group (SUAG) for a new study entitled 'Mental Health and Justice'. This is a great opportunity to be involved in a unique and exciting study about understanding what legal and other support people with mental health problems need to lead full and independent lives. If you're interested and want to find out more please read [here](#).

You can read the full advert for the study [here](#), and download an application form [here](#).





Blooming Monday

The third Monday of January has become known as “Blue Monday”, the most depressing day of the year. This is, of course, rubbish. So on 16 January 2017 we at McPin will be supporting our friends at MHRUK in their bid to turn Blue Monday into Blooming Monday, by making our office as colourful as possible and raising some money for mental health research in the process. You can find out [more and how to join in with Blooming Monday on MHRUK’s website](#).



You can get in touch at contact@mcpin.org

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