



Welcome to the seventh edition of our newsletter. We compile this with a great sense of change in the air. NHS England's five year forward review for what mental health services should look like will be out soon, and we have 1000's of people on the move to Europe fleeing war and conflict. A huge driver for mental health problems is poverty and trauma. In this edition we feature mental health research priorities for Europe from the ROAMER study, world suicide prevention day and our report into people's experiences of #IAPTSMI in six demonstration sites. Thank you for helping us to [#transformMHresearch](#).



MCPin
Foundation

NHS
England



A Service User
Evaluation
of the IAPT for SMI
Demonstration Sites

Our news

Assessing psychological treatment services – findings from our user focused evaluation

This month marks an important milestone in our project evaluating an NHS England funded programme known as IAPT for SMI, as the reports on our findings have been launched, both a [full report](#) and [summary](#) – the culmination of 10

months' intensive work here at McPin!

'IAPT for SMI' is an extension of Improving Access to Psychological Therapies (IAPT), a national programme which aims to allow more people with mental health difficulties to access talking therapies. In 2011, the government made a commitment to expand this programme to people with 'severe mental illness' (SMI), including psychosis, bipolar disorder and personality disorders. NHS England identified six demonstration sites which, building on existing provision of psychological treatments in these sites, have been piloting IAPT for SMI services since 2012. NHS England has been evaluating whether these IAPT for SMI services are effective in a number of ways. While it is important to know about the clinical results for people receiving talking therapies, it is also essential to understand people's experiences of using them – which is why the McPin Foundation was commissioned to find out about the experiences of people accessing talking therapies in these sites. We wanted to understand what they felt helped or didn't help them, and what they liked or didn't like about using IAPT for SMI services. We also wanted to hear from people who had been referred to the service, but had not gone on to receive talking therapy, so that we could understand why they didn't feel it was suitable for them, or what prevented them from accessing it.

We invited people who had used (or been referred to) IAPT for SMI services to complete a survey questionnaire about their experience. We then invited 61 of the survey respondents with a range of experiences to take part in an interview with the researchers. The interviews allowed us to ask more detail about their views and feelings about the therapy, or about why they did not end up receiving therapy.

The reports on our findings come at the same time as [information](#) from the mental health task force is published based on a survey of 20,000 people. This survey asked people how they would like things to be different in mental health services by 2020. The number one change people said they would like to see is improvements in [access](#) – followed by choice of treatments, prevention and quality of provision. Our evaluation of the IAPT for SMI pilot supports these findings – and also suggests how to achieve improvements in this area.

Overall, our research found that people were very positive about their experiences of the therapy – although some aspects of the service were experienced more negatively than others, notably waiting times, but also the process of exiting from the service. We made a number of recommendations including:

Access

- Simplification of the referral process
- Reduction in waiting times and provision of clear information about waiting times from outset
- Good communication, information and support from IAPT services and others during the waiting period

Choice:

- Clear information about what to expect from therapy and choices on offer
- Flexibility and accommodation of individual needs

Central to our evaluation methodology was the involvement of 'peer' researchers with lived experience of mental health problems. The research team consisted of three peer researchers based in different parts of the country who worked closely alongside researchers at the McPin Foundation during all the different phases of the project - the design of the research materials, data collection, analysis of the data, and

reporting. They were also able to liaise directly with the demonstration sites in their respective localities, to support them with promoting and distributing the survey and, at a later stage, disseminating the evaluation findings. Crucially, all of the interviews were carried out by the peer researchers on the team, as the shared experience helped build rapport with interview participants. This collaborative approach ensured that the evaluation really prioritised the views of people who have used mental health services.

This month has seen not only the publication of the final reports, but also the presentation of the research findings at two conferences. Earlier this month, Julie Billsborough and Lisa Couperthwaite, who worked on the project, presented the evaluation findings at the Lancashire Care demonstration site, and in a couple of weeks, Vanessa Pinfold will be speaking at the IAPT for SMI networking National Conference in Birmingham.

It's not quite over yet, though, as we have also been working on an in depth analysis of the interview data and are planning to write it up as a peer review publication – allowing us to address some of the key research findings in more detail – watch this space!

Agnes Hann, Senior Researcher, The McPin Foundation



Research in the news

Marking world suicide prevention day

On the 10th September 2015, across the globe, people came together to mark the 13th annual [World Suicide Prevention Day](#). This saw reports of [candlelight vigils](#) in the UK, [flash-mobs](#) in India, the [release of balloons](#) across America, and in Ireland, famous landmarks were [lit up in orange](#). It is exactly this kind of global solidarity that the International Association for

Suicide Prevention (IASP) wants to promote; according to latest figures over [800,000 people](#) die by suicide across the world each year, so it is crucial that countries work together to share strategies for suicide prevention.

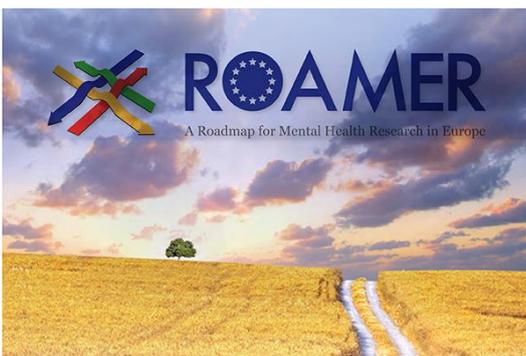
This year's World Suicide Prevention Day also marked the two year anniversary of the launch of '[Preventing Suicide in England](#)', England's cross-government suicide prevention strategy, which aims to both reduce the suicide rate and improve the support available to those affected by suicide. This was the first time that support for people who have been bereaved by suicide was addressed in UK policy- something our Trustee, [Amy Meadows](#), has also been trying to improve (just last week she launched [Help is at Hand](#)- a new resource to support people after someone has taken their own life). However, since the global financial crisis in 2008, suicide rates within the UK have been rising, with 4, 513 people dying by suicide during 2013 - an increase of around 5% on the previous year. This is a saddening, but perhaps not unsurprising statistic, given that there is [strong evidence](#) for a link between economic recession, unemployment rates and suicide. This summer, suicide statistics [hit the headlines](#), with the launch of the [Annual Report](#) from the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness, which cites a 73% increase in the numbers of men aged 45-54 taking their own lives since 2006. We know that men are [over three times more likely](#) to die by suicide than women, and it seems that middle aged men are particularly at risk.

So what can we do to address this issue? Alongside the development of specialist support, England's suicide prevention strategy identifies research as a key area for action. Research is essential for the development of effective approaches to suicide prevention, but we need to make sure our studies make a meaningful contribution. Whilst completing my PhD (into self-harm within inpatient services), I was surprised to find that the vast majority of research in this area was focused on identifying 'risk factors' for suicide, whilst very few studies investigated *how* we can support people who are suicidal. Studies investigating risk factors often claim to have identified characteristics which can help us to predict whether or not someone will take their own life (see [here](#) for an example from recent news reports). Whilst this research is valuable, simply using these types of 'indicators' to predict risk is not the only approach to suicide prevention, and can be unreliable. We need more studies which help us to develop a better understanding of what approaches work in suicide prevention, and what families, friends and our local communities can do to help people who are feeling suicidal access support, re-connect with life and start to feel more positive about living.

This year's theme for World Suicide Prevention Day, '[Preventing Suicide: Reaching Out and Saving Lives](#)', considered the importance of social connections. The [widespread stigma](#) associated suicide means it can be very difficult for people, [particularly men](#), experiencing suicidal feelings to speak out. Recently, a number of powerful social media campaigns such as [project semi-colon](#), and [#RUOK?](#) have been doing their part to encourage people to start conversations about these issues, both online, and within their local communities, but we still need research evidence to help us determine the impact of these types of interventions.

Suicides are preventable, but it is clear that more research is needed to make this possible. We also need to understand how we can best support people who have lost someone to suicide. A number of us at McPin have some expertise in this area- through both personal and professional experience, and we have been thinking about how we can address these issues in our future projects, so if you have any ideas please do get in touch.

Karen James, Research Manager, The McPin Foundation.



Hot off the press

Mental health research priorities for Europe

There seems to be a lot of conversations at the moment about priorities for mental health research. What should funders fund to improve the lives of individuals and communities with regard to mental health? Where are the promising breakthroughs? How can we gain parity for mental health research funding alongside other health areas? How can we

ensure generated knowledge and evidence translates quickly into changes in frontline practice?

There are two important questions. How much money should be invested in mental health research? And what should it be spent on?

How much money should be invested in mental health research?

[MQ landscape analysis](#) published April 2015, built on previous work by the Medical Research Council (MRC) Review of Mental Health Research 2010 to highlight how much is spent on mental health research and what areas are targeted. The [UK health research analysis 2014 from UK Clinical Research Collaboration \(UKCRC\)](#) has also just been published, providing 10 years of data revealing percentage spend on mental health increasing from 4.3% in 2004/2005, 5.5% in 2009/2010 to 5.77% in 2014 but this lags behind figures documenting the scale of the health problem. The gap in 2014 was 13.66%. [MQ landscape analysis](#) shows how the UK invests about £115 million per year in mental health research but that works out as £9.75 per affected person whilst in cancer the equivalent figure is £1571 per person. In terms of public giving, for every £1 spent by government, the public gives 0.3p to mental health and £2.75 to cancer research. All these analyses are imperfect and you can identify issues with how things are categorised or organisations that have been left out, but the picture is pretty clear. Mental health research is underfunded. We have less than we need and funding comes mainly from the government and a few large trusts.

What should be the funding target? Well if we align to [Disability Adjusted Life Years \(DALYs\)](#) as shown in the [UKCRC 2014 report](#), 13.66% of research spend would need a £258.99 million investment compared to the current £109.4 million - so quite a lot more.

What should we be spending research funding on?

This is a very important question and a difficult one to answer. Who should decide? Currently, the most democratic approaches are based on consensus methods – asking stakeholders to work together to decide; service users, families, clinicians, researchers, and policy makers. Great in theory, but institutions with budgets to allocate research funding make the final decisions. These exercises are only really feeding information in. And all organisations and people within them are biased, with strong preferences for areas of research or types of research. The challenge remains ensuring investment is spread across the prevention – service delivery - treatment – cause pathway.

Currently there is much activity around priority setting.

Firstly, there are two priority setting exercises focused on bipolar and depression, run by the [James Lind Alliance](#): we will soon learn what 10 priorities are identified for each.

Secondly, the [NHS England Mental Health Taskforce – the five year forward view](#) will report autumn 2015 with a vision for mental health to 2020, linked to the Comprehensive Spending Review from the HM Treasury; it is working on research recommendations jointly with the Department of Health.

Thirdly, ROAMER which stands for Roadmap for Mental Health Research in Europe, and was funded by the European Union has published its [findings](#) and is promoting them.

It was with great interest that we read a viewpoint paper in the Lancet Psychiatry by the ROAMER team led by Professor Til Wykes. What were Europe's mental health research priorities building on three years of consultation? Would current European pressures that can impact on mental health including economic crises and migration with thousands fleeing war and trauma seeking sanctuary be relevant within these recommendations? [Published last week](#), this open access paper (meaning anyone can read it, you just need to register with the journal) outlines the recommendations made by a European team of researchers who have been mapping current mental health research across Europe, identifying gaps and then seeking consensus on priority areas. They came up with a list of 20 priorities, generated by 486 scientific experts and 245 stakeholder organisations across Europe. You might well ask how they decided on these priorities.

- Did each country have to agree?

- Did they have to build on established research that showed “progress”?
- Did they consider timely impact on frontline practice and individual quality of life for mental health service users?
- Did they have to be relevant for every mental health problem to go onto the list?

These were questions we thought of, but many would have their own check list of how to decide if something was ‘priority’ enough. The ROAMER team did too. ROAMER participants rated 151 priority areas on a ten-point scale for:

- Relevance (likelihood that advance will result in effective intervention to improve mental health)
- Feasibility (likelihood that the advance can be achieved)

The exercise was the most inclusive and comprehensive priority setting process ever delivered in mental health research. Building on European Science it has developed six priority areas that are very broad but actionable, and supported by high level service user input into their development.

The first one is around the theme of early intervention – [Preventing mental disorders, promoting mental health and focusing on young people](#)

The second is on understanding the development of mental health problems and causal mechanisms, including comorbidity [having more than one health problem].

The third area is about research infrastructure – building collaborative networks, sharing databases, running multidisciplinary training programmes. [Research is a complicated endeavour and it often requires a myriad of ‘support’ from different organisations such as the Clinical Research Network for it to succeed. The support necessary to make sure that research happens is called ‘infrastructure’]

Fourth, is to develop and implement better interventions using new scientific and technological advances for mental health and well-being.

Fifth, reduce stigma and empower service users and carers in decisions about mental health research.

Lastly, establish research into health and social care systems that can address quality of care taking into account local approaches.

Will anything change? The authors acknowledge that their priorities are similar to those of the past 10 years. But drivers for change include the increase in cost of mental health problems and better infrastructure to progress with [genome-wide studies](#) and next generation sequencing, alongside a policy agenda for personalised care. The paper talks about European researchers being resourced to address some of the biggest social challenges that mental health problems present, and achieving this within 5-10 years. The McPin Foundation would be keen to ensure that a multi-disciplinary emphasis extends beyond psychiatry and psychology, ensuring that other areas of mental health contribute to research agendas. The McPin Foundation would be keen to see the development of nursing research, social work research, mental health systems research, as well as cultural studies, mad studies, survivor research, health geography and public health. This means not just which topics to fund, but also invest in how we carry out research, extend and improve our methodological approaches. We champion experts by experience in order to [#transformMHresearch](#) and will continue to ask how user led priorities can best be set and implemented to influence funding bodies, governments, charities and the public.

The ROAMER team are keen for everyone to join in the debate about mental health research priorities.
@TilWykes @ROAMERproject #ROAMERpaper #MentalHealth

Vanessa Pinfold, Research Director, The McPin Foundation.



Opportunities

London Marathon 2016

We're looking for a runner to take part in the Virgin Money London Marathon on the 24th April 2016 and raise money to help transform mental health research! If you are a keen long distance runner, have been personally affected by mental health problems, and have a passion to see people's mental health improved in communities everywhere then we'd love you to apply!

Please download and complete our marathon runners application form [here](#) and return to contact@mcpin.org before the 30th of October 2015, to be in with a chance of securing a charity place with McPin. Please note: there is only one space, and demand is high, so we will choose who is successful based on the strength of your application, as well as a commitment to raise a minimum sponsorship of £1,000, so please be as detailed as possible in your application.

Understanding Depression survey now underway

The second stage of the Depression: Asking the Right Questions project is now underway. In 2014 over 3,000 people responded to the original survey asking what questions about depression people would like research to address. Over 10,000 questions were submitted and it was decided to split these into two categories, treating depression, and understanding depression.

The survey for people to 'rank' questions (from highest to least important) in the understanding depression category is now underway. To complete the survey please click [here](#). The survey will close on September 30th 2015. You can find out more about the project at: www.depressionarq.org.

Peer-led survey on the experiences of peers in early intervention in psychosis settings

Nev Jones (a peer researcher from Stanford University in America) is conducting an international peer-led survey aimed at understanding and bringing to the forefront the experiences of peers/service users who work or volunteer in early intervention in psychosis settings or related initiatives (e.g. an early intervention planning or advisory council). Target participants include peer support specialists, peer youth workers and so on, as well as individuals involved in early intervention research, program development, policy or evaluation.

To complete the survey please click [here](#). To find out more about the project please visit their website [here](#).

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

In March we invited you to help develop a new mental health outcome measure. We now invite you to help develop the measure even further.

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. The questionnaire is longer than usual and your answers will help us produce a shorter one. This questionnaire will be followed up by one further questionnaire in approximately 3 months time.

Please visit www.regol.org.uk for further details regarding the study. If you have any questions then please feel free to contact Thomas Kabir by email at thomaskabir@mcpin.org or phone (0207 922 7874). Your response is very valuable and we thank you for your time. ReQoL is being developed by The University of Sheffield through funding from the Department of Health Policy Research Programme

Lived Experience Advisory Panels (LEAPs)

Over the next 2 months we will start recruiting to two LEAPs for research studies about psychosis funded by the NIHR (National Institute of Health Research). The first is a study delivering support to carers, with relatives who are under the treatment of Early Intervention in Psychosis services. It is based in Lancashire and London, and the lead investigator is a Professor of psychology – Fiona Lobban.

The second study is led by Dr Joanna Moncrieff, and will develop and deliver a research trial to look at strategies to support discontinuation of medication for people with psychosis. We will be recruiting service users living in or around London to oversee this study.

If you would like to know more about these studies and might be interested in getting involved, do get in touch: thomaskabir@mcpin.org.



Thank you

This month we would like to say a huge thank you to all of our 24 **Your Experience in Mind Survey Champions** who worked with us to complete an evaluation of several Local Minds around the UK for the second year running, and helped us achieve a fantastic 1,449 responses— nearly 50% more than our target of 1,000! To find out more information about the project please click [here](#).



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