McPin Public Involvement in Research Bulletin

Issue 10: October 2017

This is the tenth edition of the quarterly McPin Public Involvement in Research bulletin. In these bulletins we provide news about mental health research and advertise any relevant user and carer involvement in research opportunities and events within the McPin Foundation. We also advertise opportunities for people to get involved in mental health research with other organisations. From time to time we advertise opportunities for people to take part in studies as participants.

If anyone has anything that they would like to include in our involvement bulletin or if you would like to be placed on the mailing list to receive future editions of the bulletin then please sign up here. You can email us at contact@mcpin.org or phone 0207 922 7874.

To sign up as a supporter of the McPin Foundation and to receive our organisational newsletter, also produced quarterly and distributed by email, please click here or go to www.mcpin.org
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We welcome submissions of articles for publication in this bulletin on a voluntary basis. We reserve the right to edit articles that are submitted (in consultation with the contributor) before publication. The views expressed in articles in this bulletin are solely those of the authors and do not necessarily represent the views of the McPin Foundation.
Finding the right people to ask the right questions: new survey on young people’s mental health

What do we really know about young people’s mental health? We know it’s a big issue. Around 1 in 10 young people experience problems with their mental health. Around 75% of people with a mental health problem start developing it before the age of 18. Only 1 in 4 young people actually get the help they need after being referred to services.

Despite this the gaps in our understanding of young people’s mental health are huge. One young person I spoke to likened it to listening to a nearly blank record with a few seconds of sound here and there.

We don’t have a good idea of why young people experience mental health problems. Worse we don’t have a good idea of what really helps young people when they do.

This needs to change. We need more investment in services for young people. We need to promote emotional wellbeing and good mental health is schools, and elsewhere. We need to better understand the impact of physical health problems on mental health. Research is part of the answer. And we need your help to shape future research otherwise we will continue to be blundering in the dark.
Research that will truly address what’s most important to young people. We need the **right people** to ask the **right questions** about young people’s mental health. We need you to submit questions and ask people in your networks to do so as well!

The McPin Foundation together with others have launched a national survey entitled ‘Right People, Right Questions,’ giving people interested in young people’s mental health, either personally or professionally, the chance to submit their questions to us in order to shape future research. We are specifically looking at questions relating to young people aged 11-25.

To find out more about the project and to complete the short survey please go to: www.mcpin.org/youngpeopleMHQ.

The result of the survey will be a list of the pressing questions about young people’s mental health, which will be shared with researchers so that future research targets these priorities. To use the record analogy, if the blanks in our knowledge really are so great then prioritising what we look at is a very important first step. There simply isn’t enough money available to fund all the research that needs to happen all at once.

The project follows a way of working that was developed by the **James Lind Alliance**, which brings together service users, parents, guardians, clinicians, and researchers to produce a survey and then prioritise the resulting questions the public have about young people’s mental health. The end result will be a list of research questions around which researchers together with service users and others can design individual studies, and can help shape research funders’ strategies for the future. These questions are topics research funders like the NIHR and MRC will look to fund.

Our project is overseen by a steering group made up of young people, parent’s researchers, clinicians, and funders.
We also have a Young People’s Advisory Group who have fed into every aspect of the project. Together with Inkwell Arts the group have specifically helped develop a video about the project. Please do take a look!

Whilst the project is led by the McPin Foundation we have been lucky to have received funding support from range of organisations including MQ, The Charlie Waller Memorial Trust, The Matthew Elvidge Trust, and Mental Health Research UK. As well as this we have the support of a much wider range of organisations. See p5 of the project protocol.

But for this project to succeed we need you to get involved. Please fill in the survey if you have an interest in young people’s mental health. Encourage anyone you know who has a question or questions about young people’s mental health to respond too. Help us to find the right people to ask the right questions about young people’s mental health.

If you have an enquiry about the survey or the project, email Lauren Evans, Project Co-ordinator (laurenevans@mcpin.org).

Follow us on Twitter, Facebook and Instagram using @youngpeopleMHQ or join the conversation using #youngpeopleMHQ
What do you want to know about young people’s mental health?

Right People, Right Questions are collecting your unanswered young people’s mental health questions for researchers to answer.

Go to: bit.ly/YP_MHQ
People needed to help the TYPPEX study (Tailoring evidence-based cognitive behavioural therapy for People with common mental disorder including Psychotic Experiences)

Introduction

The McPin Foundation (www.mcpin.org) are looking for ten people to form an advisory group that will advise and help develop a new study. The aim of this study is to develop a new talking therapy that can be delivered in Improving Access to Psychological Therapies (IAPT) services (sometimes called psychological wellbeing services).

Specifically, we will be developing a talking therapy that better fulfils the needs of people who experience more severe forms of common mental health conditions such as depression, anxiety, or trauma.

Do you:

- Have experience of using IAPT/ psychological wellbeing services?
- Feel that your problems were too severe to be addressed by IAPT services?
- Live within easy reach of London or Cambridge?

Then we would love to hear from you. The research study is led by Professors Peter Jones and Jesus Perez from the University of Cambridge.

How can you get involved?

Where? The group will meet in London or Cambridge.

£50 payment for attending each meeting will be offered. Appropriate training as well as lunch and refreshments will be provided. Travel expenses up to an average of £40 per person will be offered.

When? We hope to hold the first meeting of the group in November or early December 2017. The group will meet roughly four times a year throughout the course of the study.

Interested in becoming a member of the group? Please contact Thomas Kabir by email thomaskabir@mcpin.org or telephone 0207 922 7874 by Friday October 13th 2017.
People needed to form a new panel looking at research on the role of the immune system and mental health

Seven people with an interest in the role of the immune system and mental health are needed to sit on a Lived Experience Advisory Panel (LEAP). The LEAP will primarily provide advice to a study called SINAPPS. We hope that the study will eventually lead to a new way of helping some people who have psychosis. The group will additionally provide help and advice to other researchers looking at the role of the immune system in other mental health problems such as depression.

People who have experience of having treatment for autoimmune diseases such as arthritis and lupus are also very welcome to apply.

Background

There is a growing body of evidence showing that inflammation and the immune system has a significant role to play in mental health. You can listen a BBC radio programme entitled ‘The inflamed Mind’ about all of this by clicking here. The strongest evidence that we have at the moment is for psychosis and depression. Around 11% of people with psychosis for the first time have very particular kinds of antibodies in their system. Essentially the body is acting as if it is fighting an infection and psychosis soon follows. Carmine Pariante of Kings College London is quoted as saying that “nearly 30% to 40% of depressed patients have high levels of inflammation and in these people we think it is part of the causal process”. Research into other issues such as the immune system and stress is underway.

To read more about the immune system and mental health please click here.

About the SINAPPS study

A team of researchers from Cambridge and Oxford have received funding for a four year study involving people with psychosis who have the antibodies that causes a condition known as antibody mediated encephalitis. The study team want to investigate a possible new way of helping people with psychosis that have been tested as having a particular kind of antibody in their system. You can find out more about the research by looking at the study website (www.sinapps.org.uk) or by clicking here.
Who are we looking for?

We are looking for people with recent experience of:

- Depression
- Psychosis
- Autoimmune (or inflammatory diseases) such as Lupus or Arthritis

Applicants will need to:

- Be within easy reach of London, Oxford, or Cambridge
- Communicate over email
- Contribute to a range of medically orientated research studies

The vast majority of research being conducted into the role of the immune system and mental health is quite medical. Possible treatments being studied often involves people taking anti-inflammatory medications used for physical health problems. The research considered by the LEAP will therefore most likely be quite medical in nature.

Payment for attendance at meetings is offered and reasonable travel expenses will be reimbursed.

It is likely that the LEAP will meet three times a year in London although we may vary where we hold the meeting. For this reason LEAP members will need to be able to travel to London, Oxford, or Cambridge. Meetings will last around four hours with breaks. Lunch and refreshments will be provided.

Interested in becoming a member of the group? Please contact Thomas Kabir by email thomaskabir@mcpin.org or telephone 0207 922 7874 by Friday October 27th 2017 with:

- Your contact details (including an email address)
- Your postal address
- Why you are interested in being involved in the study
- Some information about yourself including something about your mental health background or if you have experience of an autoimmune/inflammatory disease
- Any special needs that you have
- It would also be useful to know if you have been involved in research before

If you have any questions then please feel free to contact Thomas Kabir.
Transitioning between Child & Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services

Kate Massey-Chase is a researcher at the University of Exeter. Kate is designing a drama project to support young people who are going through the transition from child to adult mental health services. She has some surveys that take about 10 minutes that will help with this project. The answers will be used anonymously (there is more information at the start of each questionnaire). As you can see from below, Kate is looking for people to participate who have been service users, parents/carers of young people and professional who work in children’s and/or adult’s mental health.

Service user’s questionnaire

https://socialsciences.exeter.ac.uk/limesurvey/index.php/712363/lang-en

Parents/carers of young people who have been through this transition:

https://socialsciences.exeter.ac.uk/limesurvey/index.php/685842/lang-en

Professionals

https://socialsciences.exeter.ac.uk/limesurvey/index.php/647952/lang-en

If you have any questions, please contact Kate at km532@exeter.ac.uk
Postgraduate Opportunities

Bournemouth University

PhD Studentship: Development and validation of a novel smartphone application for the assessment of acute and chronic stress, allowing the investigation of eating behaviours in association with stress during everyday life.

Closing date: 5pm, Wednesday 18 October 2017.

Project description: This project aims firstly to develop and validate a novel smartphone application for the assessment of both acute and chronic stress during everyday life. Secondly, the project will utilise this application to investigate associations between stress and eating behaviour. The work will be undertaken over a three year period in a series of studies, based on: reviewing existing measures of stress; development and validation of a smartphone application; and the investigation of eating behaviours in relation to acute and chronic stress.

Eligibility: Studentship candidates must demonstrate outstanding academic potential with preferably a 1st class honours degree and/or a Master’s degree with distinction.

Some computing or programming skills and experience are desirable, but not essential.

Funding: £14,000 maintenance grant per annum

Lead Supervisor name: Professor Katherine Appleton

For further information click here or email pgradmissions@bournemouth.ac.uk
Oxford Brookes University

Faculty of Health and Life Sciences

PhD Studentship: Three year full time Oxford Brookes University PhD Research Studentship, funded by the Elizabeth Casson Trust (Part time considered following discussion)

Start date: 22nd January 2018 (possibility of September 2017 enrolment)

Closing date: 29th October 2017

Project description: The recently established Research Centre within the Oxford Institute for Nursing, Midwifery and Allied Health Research (OxINMAHR) is currently exploring research themes that range from improving mental health and wellbeing management in people with long-term conditions to the development of therapeutic interventions for the ageing population. Projects are being delivered through close relationships between the Centre and its partners: OxINMAHR, Oxford Health (OH), Oxford University Hospitals (OUH) and Higher Education England Thames Valley (HEETV).

For this studentship, the successful candidate will join the Centre for an exciting opportunity within a new PhD programme. Funded by the Elizabeth Casson Trust, the Elizabeth Casson PhD award aims to develop and promote the evidence base of occupational therapy in order to increase the understanding of the efficacy and unique contribution of occupational therapists to those people with occupational needs within the UK. We invite applications for projects which pursue research in line with this aim. Projects that also align with the evolving UK care agenda are encouraged. Any successful applicant will be subject to a DBS search once they enrol.

Eligibility: UK/EU Applicants who have qualified from a World Federation of Occupational Therapists approved programme

Entry requirement is a Master’s degree which has included research training and a research project. In exceptional cases, applicants who have a good honours degree (or equivalent) may apply for direct registration to PhD if they have appropriate research or professional experience at postgraduate level which has resulted in published work, written reports or other appropriate evidence of accomplishment.

Funding: £14,553 per annum (pro rata for academic year 2017/18) plus fees and reasonable project costs

Director of Studies: Professor. Helen Dawes (Elizabeth Casson Trust Chair)

For further information on the project please click here or e-mail Professor Helen Dawes hdawes@brookes.ac.uk
UCL Institute of Neurology

Wellcome Centre for Human Neuroimaging

PhD Studentship: Metacognition and Decision-Making Capacity In Health and Neuropsychiatric Disorders

Starting date: 1st January 2018 and the contract is for 36 months. In exceptional cases, the start date may be delayed.

Closing date: 30th October 2017

Project description: In England the legal test for decision-making capacity (DMC) includes a requirement that a person is able to “use or weigh” information as part of the decision-making process. This is especially relevant to mental health but is a focus of controversy as it is hard to operationalise and quantify, and does not readily map onto basic psychological functions. The studentship will develop tools to understand DMC through the lens of experimental paradigms in cognitive psychology and neuroscience.

Experimental work will begin in healthy volunteers before moving on to populations with different conditions such as dementia, brain injury, mood disorders and psychosis. We will apply the same paradigms (adjusted for difficulty) to enable comparison between healthy and clinical groups. The work will quantify disorder-related deficits in decision-making and metacognition, and seek to link such deficits to the legal framework surrounding DMC.

Funding: UK/EU tuition fees and a generous tax-free stipend at Wellcome Trust rates

Eligibility: Applicants should have an Honours Degree (minimum 2:1) in experimental psychology, neuroscience or a related field, previous experience working with human participants in an experimental or clinical setting, and familiarity with computational and statistical methods (ideally in MATLAB and/or R).

Contact details: Kamlyn Ramkissoon k.ramkissoon@ucl.ac.uk by 30th October 2017. Shortlisted candidates will be interviewed in November.

Further information: please click here. Informal enquiries are welcome to Dr Stephen Fleming (email: stephen.fleming@ucl.ac.uk).
Why should patients and the public bother with Public and Patient Involvement (PPI)?

Public and patient involvement (PPI) in research is defined by INVOLVE, the national NHS advisory group which supports public involvement in research, as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”. In recent years, the use of PPI in research has grown significantly as a result of a shift in approaches to health care from that of a paternalistic nature to one of shared decision-making and person-centred care. Major funders such as the National Institute of Health Research (NIHR) now make it a requirement for there to be active involvement of public and patients in studies they fund.

The benefits of PPI in research are not straightforward to determine. Research is ongoing, with current evidence pointing to PPI having a range of positive impacts on research. However, “much of the evidence base concerning impact remains weak and needs significant enhancement in the next decade”.

The mechanisms through which PPI impacts upon research are not yet clearly understood, and there is a continuing debate as to how to measure the impact of PPI, or even whether its impact should be measured. Much of the discussion so far has been dominated by professionals.

A recently published paper claims to be the first UK-based in-depth exploration of the views of service users and carers who are actively involved in research (hereafter known as PPI contributors).

The paper explores a number of issues, including whether PPI contributors believe PPI impact on health research should be assessed, and if so, how it should be carried out. It also examines the personal views of PPI contributors about their perceived impact on research in order to further our understanding of the “mechanisms” behind PPI in research. The latter findings particularly resonated with me, both as a PPI contributor and as someone who works with the Public Involvement in Research team at the McPin Foundation, and will be the focus of this article.

Methods:

38 participants who were PPI contributors were interviewed and then key themes from their responses were extracted.
Key findings

<table>
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<tr>
<th>Perceived role</th>
<th>Proposed mechanism of impact</th>
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<tr>
<td>The expert in lived experience</td>
<td>Through their lived experience of a condition, PPI contributors are able to consider the</td>
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<td></td>
<td>acceptability and feasibility of research proposals for the target population</td>
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<td>The creative outsider</td>
<td>PPI contributors bring a fresh perspective from outside the research system, and can help to</td>
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<td></td>
<td>solve problems by thinking ‘outside the box’</td>
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<td>The free challenger</td>
<td>PPI contributors are able to challenge researchers without fear of consequences</td>
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<td>The bridger</td>
<td>PPI contributors bridge the communication gap between researchers and patients or the public,</td>
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<td>making research more relevant and accessible</td>
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<tr>
<td>The motivator</td>
<td>PPI contributors increase researchers’ motivation/enthusiasm, for example by emphasizing how the</td>
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<tr>
<td></td>
<td>research will benefit people.</td>
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<tr>
<td>The passive presence</td>
<td>PPI contributors can change the way that professionals think just by being present at meetings</td>
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Adapted from Crocker et al (2017), page 523 - 524

The table above summarises the roles (or “mechanisms”) which PPI contributors believe they play in health research. The researchers emphasise that the roles set out are not clear cut and may overlap, and that an individual PPI contributor may embody different roles at different times in the course of a project.

To put my PPI contributor hat on: what I liked most about the paper was the inclusion of illustrative quotes from contributors of from each of these identified roles in response to an important question: **Why should we spend our time getting involved with health research?** I don’t think I am in a minority when I say that I don’t often get a chance to talk to other PPI contributors about why they came to the research meeting this morning. It was interesting to see in their own words what my fellow PPI contributors thought of their own impact on research, making the paper an insightful and comforting read.

There was one part of the paper which particularly struck a chord with me. In addition to the 6 roles identified above, there was the PPI participant who did not know what impact their PPI contributions had on research. For a long time, I was also that person.
All I knew was that if I proofread a few things, or if I shared my experiences of x or y or z, I’d get a free lunch and reimbursement for my time.

One reason for this (among many others) is that the things requested of me seemed so mundane that I did not understand how they would be of use to researchers. This would lead to me doubting myself: Am I just talking gibberish or are my comments actually useful? Several contributors noted that it would be helpful if researchers provided feedback on their contributions in order to improve their future participations and increase their motivation to stay involved. I concur.

To quote my favourite research academic, Professor Pawson would argue that researchers need to tell me your theory and I’ll tell you mine. In other words, there needs to be open dialogue between researchers about what they want in order for participants to provide relevant answers.

If I now put on my PPI worker hat on, the point regarding more feedback being needed from researchers is a clear and concrete suggestion as to how PPI contributions could be improved. In addition, the different identified roles of PPI contributors also puts into words the exact mechanisms through which PPI may impact upon research. For me, the benefit of this is that it provides a better understanding and appreciation of the value of PPI in a research environment.

The authors argue that their findings could help researchers recruit PPI contributors with the specific role(s) that would be beneficial for their project. However, if this becomes a reality, I question how this would work in practice and the implications for PPI recruitment. Are we going to start prioritising PPI contributors with certain types of experiences and personalities over another? How do you recruit for a “creative outsider”?

Overall, this paper provides a mostly positive view of the impact of PPI. It may strengthen the views of supporters of PPI in research but will be unlikely to persuade sceptics. The authors admit there is likely to be bias in their findings, with PPI contributors having to rely on recall of past experiences and, given their involvement in the process, may be reluctant to speak critically about it. Another noted weakness is that the provided accounts of PPI are mostly positive, with little probing of the potential negative impacts. I’ve alluded to some of the negative impacts of PPI in my personal experiences. If it were able to provide a more balanced view, then perhaps it would be a more credible paper for PPI sceptics.

If one day there was indeed a paper which examined the negative impacts of PPI from the perspective of PPI contributors, critics and onlookers should not however focus on the
“weaknesses” of PPI, but rather on how we (researchers and participants) can mitigate them. PPI is a relationship-based process and so the onus lies on both the researchers and the participants to solve the issues that arise.

A similar conclusion is drawn elsewhere in a McPin Foundation Talking Point paper. You cannot blame poor PPI contributions if your project has not been made easy to understand, or if only a token effort to involve the public and patients has been made. It is for this reason that the debate surrounding PPI must focus on and involve both researchers and PPI contributors.

Article by Nhung

Reference


Thoughts on service user and survivor led research following the Asylum: Action and Reaction conference

The first issue of Asylum Magazine was launched in the spring of 1986. Since then, the collective has been publishing issues on the theme of democratic psychiatry, centring the voices of service users and survivors, as well as mental health professionals. To celebrate over 30 years of publication, the collective ran Asylum: Action and Reaction, a full day conference held at Manchester University. Topics covered ranged broadly from critical psychiatry, to service user and survivor led mental health research, to creative responses to psychiatry.

Given McPin’s commitment to centring lived experience in mental health research, I was particularly interested to attend the break out session on survivor-led research.

The session had been introduced earlier in the day by Diana Rose, who spoke about ways of interacting with what she termed ‘privileged spaces of knowledge generation’ as a survivor/service user.

This is a difficult question that often comes up in grassroots movements and activist circles: should you keep yourself completely separate from a dominant oppressive system, or
should you work within it to improve it? On the one hand, working within the system makes you complicit in its failures; on the other, doing so gives you access to resources that have the potential to create much bigger change and improve more lives in the process.

So, in the case of mental health research, engaging with psychiatric institutions and funders, even though those institutions might have historically done great harm, is important work, which has the power to create positive change through the increased inclusion of survivor and service user perspectives.

The survivor-led research break-out session began with a talk about the ‘Mad People’s History and Identity’ course, which is run at Queen Margaret’s University, Scotland. The key entrance criterion for the course is self-defining as having lived experience of mental health issues. Its students and teachers are valued as experts by experience. In order to help to secure funding to continue running this ground-breaking course, participants evaluated their course using a technique called community based participatory action research. This research technique is about taking patient and public involvement in research a step further: members of a community affected by an issue work together to design and then carry out research into that issue within their own community, with the aim of taking practical steps to create social change.

So, in the case of the course, participants interviewed each other about their experiences in order to evaluate the course, with the practical outcome of providing proof of the course’s success, which could be used to secure more funding to further develop and share service
user and survivor knowledges. A participant spoke to us about how being interviewed by someone she knew and trusted, who was also involved with the course, made a huge difference to how comfortable she felt being interviewed.

The shared experience of both interviewer and interviewee having participated in the course reduced the power imbalance between them, and ensured that those evaluating the success of the course had strong, experience-based knowledge of their subject.

This kind of knowledge generation is quite different from that of traditional research methodologies. There is a historical assumption that objectivity requires distance from the topic of research. The basic idea is that by not being personally involved in something, you have a more neutral, unbiased stance. Whilst this understanding of objectivity might seem logical, its implication is that those who have in-depth understanding of their own experiences of mental health problems are dismissed as unreliable, whilst those who do not share those experiences are in a position of power to make decisions on their behalf.

As I was thinking about the differences between how experiential and removed, ‘objective’ knowledges are valued, my mind was drawn to a current project with which McPin is involved called Mental Health and Justice. One of the big questions the project is asking is, how does one make an objective decision about whether an individual has the capacity to make their own decisions, or take responsibility for their actions? In the context of the politically hot topic of the Mental Health Act, is detaining someone against their consent based on fear for their safety, or that of those around them, ever acceptable, and if so, who should have the power to make that decision, and how do they make it? These are very difficult questions, and the project is approaching them using survivor/service user led research, to ensure that the knowledge of those with personal experience of mental distress, and those who have experienced (re)traumatisation at the hands of a legal system aiming to protect them, has an impact on the outcome of the research project.

Whilst my day at the Asylum conference was full of complex and emotive subject matters, I left Manchester feeling invigorated. Despite the difficulty of addressing the huge systemic barriers those of us with experience of mental health problems face, I had spent a day learning about various person-centred and trauma informed approaches to thinking about and reimagining mental health and care. I am hopeful for the possibilities for change contained in survivor knowledges, and grateful to Asylum for their ongoing work to platform the voices of service users and survivors. You can find out more about Asylum magazine here.

Article by Megan Dalton

Book reviewers wanted!

If you would like to review a book for us then please let us know. The book needs to be on a mental health topic (ideally vaguely related to research, mental health services, and so on) and be reasonably priced. If you write a review for us, we will buy the book for you, and we will give you a £20 gift voucher as a token of our appreciation. Please email thomaskabir@mcpin.org if you have any suggestions.
The mental health research charity MQ has launched Open Mind, a new series of podcasts that will be talking to a wide range of individuals about their lived experience of mental health and also the researchers trying to gain a better understanding of the topic.

In the first three episodes, they will be looking at the following issues: Could problems with our immune system cause depression? Could an algorithm end the trial-and-error approach to mental health treatment? And the reality of life with social anxiety and the app that could help.

The podcasts are available free to listen to or download via iTunes (Apple) or Podbean (Android). You can listen to the podcasts online (for example on a PC) by clicking here.

**Mental Health Research in the News**

**Sensitive hearing and mental health**

On the 20th August the *Daily Telegraph* reported on new research, led by UCL and Durham University, which is looking into hearing and mental health.

It is known that a significant percent (up to 15%) of the population have sensitive hearing, which can cause people to hear imaginary voices. These individuals are sometimes called ‘voice hearers’. And researchers have found that people who experience ‘auditory verbal hallucinations’ may have an increased risk of developing mental health problems.

The researchers studied people with this ability, and using MRI scans were able to show that they could pick out meaning in sounds more often and much quicker than a group with ‘normal’ hearing. The article noted how the researchers believe that ‘the brains of people who hear voices are particularly tuned to meaning in sounds’.

And although this was a comparatively small study, they hope that their research may lead to new treatments for mental health problems where auditory hallucinations are an issue.

The study was published in the journal *Brain* and further details of the work can be found in an article on the UCL research website.
Self-help therapy: the way forward?

On 23rd August the *Guardian* carried an interesting article by Mark Brown on a study that looked at the effectiveness of CBT through self-help versus CBT conducted by a therapist. The researchers conducted a meta-analysis (review of several studies) that found that there appeared to be little difference between the two approaches in terms of treatment results.

The author noted that these findings will please people who believe that individuals should take more responsibility for their health, and look after themselves, such as the present government.

However, Brown highlighted how there was greater variability in the data related to self-help CBT and its success. This highlights often harder to define variables, such as whether an individual is ready to engage with CBT or their particular circumstances. He argues that this is where a therapist can be helpful because they may identify potential stumbling blocks and suggest an alternative approach. Brown points out that the ‘therapeutic relationship’ therefore brings additional benefits. But that the current government is less keen on this approach. And maintains that any discussions on the merits of these two approaches should not be reduced to ‘an either/or proposition’.

He concludes that as a country we should therefore make sure that ‘self-help is never the only help on offer’. I concur with that, and although self-help therapy undoubtedly has a role to play, if people are struggling to find their way, they should always have access to a helping hand.

Has the concept of schizophrenia reached the end of the line?

On 4th September the *Independent* carried an interesting article on schizophrenia and its usefulness as a diagnostic label.

In the article, the author showed how the idea of schizophrenia as a ‘distinct disease’ had been ‘fatally undermined’ over the last few years. And that even psychiatry, a field that had traditionally been a strong proponent of the definition, was now beginning to turn its back on the concept.

In recent years, it has been recognised that psychosis, just like autism, has varying degrees of severity. In other words, it is on a ‘continuum’, with schizophrenia at the more extreme end.

Some people are now calling for the term ‘schizophrenia’ to be abandoned all together, because more research and a greater understanding of the subject has shown that there are many different ways an individual can come to experience the symptoms of psychosis, including problems such as hallucinations and disorganised thinking. For example, genetic makeup, cannabis use, trauma in childhood, viral infections when young, immune
responses and inflammation, as well as many other factors are all known to increase the risk of developing problems.

**Insomnia and mental health**

In other research news, the *Guardian* (and *Daily Express*) reported on a new study that looked at the link between insomnia and mental health. In the past, insomnia and lack of sleep have traditionally been seen as a symptom of mental health problems.

This UK wide collaborative study, which was led by a team from Oxford University, looked at students with insomnia who were enrolled through online surveys, with some then being offered CBT to tackle the condition. The data suggests that insomnia, as well as being recognised as a symptom, is also an important risk factor for mental health problems. With for example, students offered CBT to tackle their insomnia not only seeing improvements in their sleep, but also experiencing less anxiety and depression, as well as a reduction in psychotic symptoms.

The report highlighted that other scientists interested in the field of sleep had broadly welcomed the findings, although they recommended caution, since the study involved self-reporting and had a high dropout rate, all of which could have affected the results.

But the *Guardian* reported that one of the authors, Daniel Freeman, suggested that one of the main benefits of their work is that it may make it easier for students to seek help for their problems, since difficulty sleeping does not carry the same level of stigma as that attached to mental health.

The research was published in the journal *Lancet Psychiatry*.

**Cuts to children’s mental health services, having an impact**

In research news from the University of Cambridge, the authors of a study published earlier in the year, which found that young people who had accessed community mental health services were less likely to suffer problems with clinical depression in their later teenage years, have written a further article in the *Journal of Public Mental Health*, which looked at the policy implications of their work. The researchers who wrote the article were from the department of psychiatry.

In the report on the University of Cambridge research news website, one of the lead authors, Sharon Neufeld, stated that their earlier work had been based on data from before (pre-2010) the recent cuts in mental health services, and that these were likely to have reduced access and had a knock on effect.
For example, the web report noted that ‘the number of young people attending A&E due to a psychiatric condition had doubled by 2014/2015, compared with 2010/2011’. Neufeld argued that it is therefore imperative that such services be restored. And with child and adolescent mental health services offering preventative strategies, it seems totally short sighted in an age of cost efficiencies, to reduce funding for services that help save money in the long term. To read the research news article in full, please click here.

High level of mental health problems amongst UK young people

In related news, the Daily Telegraph (and The Guardian), reported on new research highlighting the high levels of mental health problems found amongst young people in the UK. The study, conducted by researchers from UCL and Liverpool University was based on data collected from the Millennium Cohort study, which is following more than 10,000 teenagers. The research based on survey data, found that young women (14 year olds) in particular were reporting high levels of ‘depressive symptoms’ (24%), and amongst boys this was also significant (9%).

The news report noted that the study also raised other issues, with for example, the findings showing that parents were far more likely to be worried about their sons mental health and often missed their daughters problems, yet this was not matched by what the young people were themselves reporting. The article spoke to a number of mental health charities about the study, with organisations such as the National Children’s Bureau (NCB) that helped fund the research, and Young Minds, highlighting their concerns about the findings.

The article noted how young people are under increasing pressure, with bullying, social media and exam worries being some of the issues that were highlighted. And that schools, children’s services and the NHS all have an important role to play in helping to identify and support young people with mental health problems.

Gut flora and mental health, BBC three report

In other news, the BBC reported on new research that is looking into gut flora and their potential role in mental health.

The article from the Health and Well-being section of the BBC three website noted how researchers from University College Cork have been studying mice with low levels of gut microbes, and found that they have high levels of ‘depressive and anxious behaviour’.

The report stated that it is believed gut flora can influence molecules in particular parts of the brain, the amygdala and pre-frontal cortex, which are thought to play a key role in a number of mental health conditions. Although the article suggested that readers should exercise caution, due to the rise of ‘fad diets’ in recent years, it still said that the findings were interesting. Because while the importance of diet on mental well-being was ‘nothing new’, researchers were beginning to
pay greater attention to the role of the gut, because advances in technology had made it easier to study the bacteria and their genetics.

The article concluded, by noting how we are only just beginning to understand the role of the gut in mental health, and that many mysteries remain.

The Mental Elf (www.nationalelfservice.net/elf/mental)

The Mental Elf has again been busy finding and reviewing new research. Over the following pages we pick out some of the highlights …

The Genetics of Depression

The Mental Elf reports on new research looking into the genetics of major depressive disorder (MDD). Although extensive work has already been carried out in this area, including using approaches such as genome wide association studies (GWAS), it has had varying degrees of success.

However, the Mental Elf reported that this new research was the largest to date. Here the researchers looked at trying to identify risk and protective factors.

Reassuringly, the results broadly match the findings of earlier studies that identified potential biological mechanisms, and show that this approach is still useful, even when analysing larger and more complex data. The study highlighted how GWAS could also be used to identify the potential effects of environmental factors, when this data was included.

The reviewer, Marcus Munafo, concluded that this new study ‘reinforces the view’ that using GWAS on larger data sets, researchers are likely to gain an even greater understanding of the underlying mechanisms involved in depression.

Physical Activity and Sedentary Behaviour, in People with Depression

Mental Elf also reports on research, which again suggests that one of the reasons why people with Major Depressive Disorder (MDD) have a lower life expectancy than the general population, is that they are at greater risk of developing cardiovascular and metabolic diseases.
The research that was based on a ‘systematic review’ of 24 studies that looked at physical activity and sedentary behaviour in individuals with depression, found that ‘people with MDD engage in low levels of physical activity’. And that people with MDD were ‘50% less likely to meet the recommended physical activity (PA) guidelines’.

However, Tayla McCloud (the Mental Elf reviewer) noted that the study showed that people with MDD ‘are not engaging in levels of physical activity far lower than those in the general population’. But that ‘it just may be that those with a mental illness stand to gain the most from rectifying this’.

This research again highlights the importance of encouraging professionals to focus on the physical, as well as cognitive aspects of mental health problems.

To read an abstract of the original paper, please click here.

Greater user participation in mental health, brings challenges

The Mental Elf also reported on new research, which has looked at the impact that greater user participation has had on the practitioner / patient relationship in mental health care. The study’s findings showed that this often ‘brings challenges’ and that the power relations between the two groups played a key role in this.

The researchers studied the discourse (language / talk) that occurred between users and practitioners. Here they showed how complex interactions take place between service users and practitioners when negotiating co-produced care. To read an abstract of the original article, please click here.

Other Mental Elf highlights include:

Preventing anxiety disorders in young people at risk
Click here to read the article

Predictors of adherence to digital interventions for psychosis
Click here to read the article

People with severe mental illness die younger and things are getting worse
Click here to read the article
Access to Psychological Therapies report, update

In our last Bulletin, we reported on the publication of the Access to Psychological Therapies: Considerations for Policy and Practice Report by researchers at the University of Edinburgh, funded by the Wellcome Trust, who asked readers to help fill out their survey.

We are pleased to announce that the full report is now publically available, and can be accessed online here.

Thank you for reading our Public Involvement in Research bulletin! Please do send in suggestions for articles or news to include to thomaskabir@mcpin.org. It was produced by McPin Foundation, registered charity 1117336. Find out more about us at www.mcpin.org