McPin Public Involvement in Research Bulletin

Issue 5: March 2016

This is the fifth 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.

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
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.
Opportunities

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

Introduction

We are looking for a service user or carer to join the steering group for the Cognitive Bias Modification for Paranoia (CBM-pa) study. You can find out more about the study here: http://bryonycrane.wix.com/cbm-pa.

The steering group meets every six to eight weeks in south London. The study is about seeing if a new approach called cognitive bias modification can help people suffering from paranoia. The study lead is Dr Jenny Yiend from the Institute of Psychiatry, Psychology, and Neuroscience (IOPPN). The research is funded by the National Institute for Health Research (NIHR).

What is the CBM-Pa steering group?

The steering group consists of researchers and four service users. The role of the group is to oversee and assist the study as a whole. In general terms this means helping to ensure that the study is carried out to the highest possible standard and that it reaches a successful completion.

Issues that service user members have specifically considered are, the study recruitment documents, putting together a study website, producing scenarios that will be used in the study, and advising on where best to hold sessions for study participants.

What will be required?

The following will be needed:

- Attending face to face meetings of the study steering group every 6-8 weeks in Denmark Hill, London. Applicants will need to live in London. The study is due to end in 2017. Around twelve people attend each meeting. Steering group members are very friendly and meetings are fairly informal
• Reading papers ahead of meetings and with other group members providing expertise to support the wider study
• Constructively raising any concerns that you might have and offering possible solutions.
• Responding to occasional correspondence between meetings of the group

Payment for this work will be offered and all reasonable travel expenses within London will be reimbursed. The rate of pay is £50 per meeting. This includes preparation and meeting time.

Applicants will need to be comfortable in using email. Some knowledge of mental health research would be helpful (although not essential). Experience of paranoia or of caring for someone with paranoia is essential.

How to apply

To apply please complete the application form and return it to Thomas Kabir (thomaskabir@mcpin.org) by 5pm on Friday 15th April 2016.

Diabetes and severe mental illness survey

Researchers at City University London would like to recruit people with Type 2 diabetes who are aged 18 or over and have a severe mental illness (psychosis, schizophrenia, schizoaffective disorder or bipolar disorder) to take part in a short survey to find out about the diabetes care they receive and their experiences:

https://goo.gl/ghxi7q

For more information please contact Frederique:

Frederique.lamontagne-godwin.1@city.ac.uk
Which research questions about Bipolar are most important?

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

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

Effective research can help improve care and treatment: please visit https://www.surveymonkey.co.uk/r/ZHZKCVM until noon on April 15th to complete the survey, or you can request a paper copy by contacting:

Rebekah Hayes
Bipolar UK
11 Belgrave Road
London SW1V 1RB

Tel: (0333 323 4008)

E-mail: rhayes@bipolaruk.org.uk

[NB: you can find out more about the Bipolar Priority Setting Partnership here]
Other opportunities

A number of other organisations are currently advertising jobs or opportunities for people to get involved in mental health research.

These include

- The National Service User Network (NSUN) Click here to view these opportunities
- People in Research (www.peopleinresearch.org)
  
  People in Research is a website that is operated by INVOLVE. Currently the University of York is looking for service users to get involved in a community pharmacy alcohol study. Other opportunities are regularly added.

- Sussex University is currently advertising for a post-doctoral research fellow to ‘examine the feasibility of positive written disclosure as an intervention to improve the physical and psychological health of older caregivers of people with psychosis’. You can view the job advertisement here

- The University of Worcester has a number of mental health PhD studentships currently available. For full information on all these studentships please visit: www.worcester.ac.uk/discover/phd-studentships.html
  
  1. Exploring borderline personality disorder diagnosis in bipolar disorder in the UK

     Closing date: Tuesday 7th June 2016

     For more information please click here

  2. Adult mental health with a focus on student suicide prevention (2 studentships)

     Closing date: Tuesday 7th June 2016

     For more information please click here

  3. The influence of Emotional Intelligence on attentional biases for emotion and stress reactivity in adolescence

     Closing date: Friday 29th April 2016

     For more information please click here
In the world of mental health this report is big news and its worth looking through carefully. The report was originally commissioned by the Chief Executive of the NHS, Simon Stevens. The following is taken from the website of NHS England: “Formed in March 2015, the independent Mental Health Taskforce has brought together health and care leaders, people using services and experts in the field to create a Five Year Forward View for Mental Health for the NHS in England. This national strategy, which covers care and support for all ages, was published in February 2016 and signifies the first time there has been a strategic approach to improving mental health outcomes across the health and care system, in partnership with the health arm’s length bodies.

The taskforce was chaired by Paul Farmer, Chief Executive of Mind. The vice chair was Jacqui Dyer who is an expert-by-experience and a carer. It included members from partner arm’s length bodies who hold critical responsibilities related to the planning and delivery of care, as well as representatives from the voluntary sector and professional bodies”

See: https://www.england.nhs.uk/mentalhealth/taskforce for more information. The report makes a number of recommendations to be implemented within the next five years. These include:

“1. An end to the practice of sending people out of their local area for acute inpatient care
2. Providing mental health care to 70,000 more children and young people
3. Supporting 30,000 more new and expectant mothers through maternal mental health services
4. New funding to ensure all acute hospitals have mental health services in emergency departments for people of all ages
5. Increasing access to talking therapies to reach 25% of those who need this support
6. A commitment to reducing suicides by 10%”

See www.gov.uk for more details.
I don’t intend to comment too much on the content of the report. Others have already done a very thorough job. These include The National Service User Network (NSUN), The Kings Fund, and The Guardian. Many other organisations such as Mind and the Royal College of Psychiatrists put out press releases.

It is pleasing that there are a number of mentions of research in the report, and a task and finish group was convened, which McPin Foundation joined, to help shape content and recommendations. Mental health research hasn’t ever had a particularly high profile. I can’t help but feel that the profile of interest in mental health research is slowly rising alongside evidenced based practice and evaluations of complex interventions. The word ‘research’ gets mentioned forty five times in the report. Indeed, there is an entire chapter starting on p37 of the report entitled ‘innovation and research to drive change now and in the future’. It is encouraging that involvement in research is explicitly mentioned in the report:

“We will have a more co-ordinated approach to research between government, private, public and philanthropic sectors over the long term and the involvement of people with lived experience of mental health problems as standard” (p40)

There are other mentions of involvement of people with lived experience in the contexts of service design, delivery of services, and so on.

There is a specific recommendation about research. Recommendation 26 on p41: “The Department of Health, working with all relevant parts of government, the NHS ALBs, research charities, independent experts, industry and experts-by-experience, should publish a report one year from now setting out a 10-year strategy for mental health research”.

One of the key words here is ‘experts-by experience’. I wonder how and when people with lived experience of mental health problems will be able to feed into this work. It will need to be soon if the report is to be ready within a year. It’s nice to see research charities get a mention too.

I had to look up what ‘NHS ALBs’ are. Apparently it stands for NHS Arm’s Length Bodies. You can find a list of these bodies here. As an aside the Kings Fund has produced an excellent video on how the NHS is currently structured.

What will actually come of the report and its recommendations is a matter of fierce debate. If you would like to get a taste of what’s being said then search Twitter using the hashtag #MHTaskforce. There are clearly potential opportunities for people with lived experience to contribute to all the work that will flow from the report. But these opportunities need to be made public and openly offered to all.

Article by Thomas Kabir, The McPin Foundation
Schizophrenia and the immune system

There has been quite a lot of interest in the idea that the immune system has a role to play in some mental health problems. It’s only been in the last few years that real evidence has begun to emerge that this indeed might be the case for schizophrenia.

In February’s edition of Nature magazine the strongest evidence to date about the role of the immune system in schizophrenia was published. One researcher I heard described it as a ‘game changer’. Slowly but surely all the pieces of the puzzle seem to be falling into place… The title of the paper in question was rather unpromising: ‘Schizophrenia risk from complex variation of complement component 4’ by Secklar et al.

The paper was meant to be important. But the article was rather dense so I started to look for other ways to work out what the research was all about. The title of an article in the ‘news and views’ section of the same February 11th 2016 edition of Nature was a little more informative: ‘Schizophrenia: From genetics to physiology at last’. I’ve written previously on the genetics of schizophrenia in the January 2015 edition of the Bulletin. It turned out that this research takes the work that I commented on much further. In 2014, one hundred and eight ‘differences’ in the DNA were identified in people with schizophrenia compared with people who did not have any known history of mental health problems. Well it now turns out that some of the most significant differences are in genes that have a role to play in the body’s immune system.

More specifically these differences are in genes that carry the instructions for making something called the ‘major histocompatibility complex’ or MHC. The MHC is aptly named. It’s a complex menagerie of different proteins that have a key role to play in the body’s immune system. Proteins are ‘nature’s robots’. They do everything from fighting infections to carrying oxygen around the body.

From a genetic point of view the MHC is very hard to analyse. The authors of the ‘news and views’ article only half-jokingly said that researchers often wish that they find things of interest anywhere but the MHC.

Many of the MHC proteins form a structure that sits on the surface of cells in the body. It functions as a kind of marker. To put it crudely the MHC labels cells as being ok or not ok. If the cell is not ok then it gets destroyed by the body’s immune system.

But some of the most intriguing genetic differences are in a protein that forms part of the MHC called ‘Complement component 4’. It’s a rather long-winded name for a protein that moves freely throughout the blood stream. This protein is known to play a role in autoimmune diseases such as
rheumatoid arthritis (an autoimmune disease is one in which the body’s immune system starts attacking healthy cells). As a rule of thumb the higher the level of the protein the more active or severe the disease. For this reason levels of this protein are often monitored using a blood test in people with autoimmune diseases.

But here’s the thing … The authors of the Nature paper have shown that the genetic differences in people with schizophrenia lead to higher than normal levels of the complement component 4 protein being produced… Could it be that schizophrenia has some similarities with autoimmune diseases? Could approaches that work with autoimmune diseases help some people with schizophrenia? The McPin Foundation is already supporting a large study that is exploring such an approach for some people with psychosis.

Furthermore, by doing experiments other researchers have shown that high levels of the protein ‘complement component 4’ result in connections between brain cells being cut. There is already some real evidence that there are fewer connections between cells in certain parts of the brain in people with schizophrenia. The implication is the genetic differences identified in people with schizophrenia lead to connections in the brain being severed. The current thinking is that this mostly happens early on in life.

We still need be cautious here. Nobody is claiming that schizophrenia is simple. Nobody is claiming that there is one cause or even one possible ‘treatment’ that will help. But we now know much more about the physical causes of schizophrenia. This gives us important clues that might lead to the development of new ways of treating schizophrenia. As Francis Bacon once famously wrote; “knowledge is power”. And so it is.

Article by Thomas Kabir, The McPin Foundation

Further reading

Overactive brain pruning in teens could cause schizophrenia (New Scientist, January 2016)

Schizophrenia breakthrough as genetic study reveals link to brain changes (The Guardian, January 2016)

Schizophrenics may lose nerve links (Nature, November 2002)

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.
Useful resources

This is a new section of the Bulletin. In this section we will include details of anything that might help people get a better understanding of research (or involvement in research). If anyone knows of anything that would be useful to put in this section then please do get in touch.

**EUAPTI (the European Academy of Therapeutic Interventions).**

As the name suggests EUAPTI is a European project funded by the EU. I went to the launch event of the project a few years ago in Denmark. This is from the EUPATI website:

“We focus on education and training to increase the capacity and capability of patients to understand and contribute to medicines research and development and also improve the availability of objective, reliable, patient-friendly information for the public”.

You can read more at: [www.eupati.eu](http://www.eupati.eu)

One of the big things that EUPATI does is to produce information about research that is aimed at the public. One drawback of the project is that it is very medically orientated. Much of the information on the website is about clinical trials and drug development.

But the information that there is on the website is nevertheless very useful indeed. It does give rather a good ‘in’ into the world of medicine.

**INVOLVE Jargon Buster**

INVOLVE is one of the Department of Health’s oldest Public and Patient Involvement (PPI) organisations. INVOLVE has long produced a whole host of useful resources on involvement in health and social care research.

Most of the useful resources are listed under the ‘resources’ tab of the INVOLVE website ([www.invo.org.uk](http://www.invo.org.uk)).

One of the most useful resources is the *jargon buster*.

It doesn’t cover everything but it does cover many of the terms that you tend to come across when getting involved in research.
Mental health research in the news

Recent publications

Denmark the 'happiest country' and Burundi 'the least happy'

The 2016 World Happiness Report has just been published. The title of a BBC article on the report gave a lot away: ‘Denmark the 'happiest country' and Burundi 'the least happy'’. The UK came 23rd in the rankings. See p20 of the report.

Since the last report Nicaragua has shown the biggest increase in happiness. Greece showed the biggest decrease in happiness.

‘Majority of mental health apps based on flimsy evidence, if any at all, research finds’

This is the headline of an Australian Broadcasting Corporation (ABC) news article. The title of the article is however slightly misleading. Although the article is very clear and well written the article actually refers to a research paper looking at ‘mindfulness based iPhone apps’. The paper was written by Madhaven Mani of Queensland University of Technology, Australia. Mani looked at all the iPhone mindfulness apps that he could find at the time. There were 700 in total. Only 23 apps made the authors deemed eligible to be assessed using the ‘recently-developed expert rating scale, the Mobile Application Rating Scale (MARS)’

The conclusions of the paper state that: “Though many apps claim to be mindfulness-related, most were guided meditation apps, timers, or reminders. Very few had high ratings on the MARS subscales of visual aesthetics, engagement, functionality or information quality. Little evidence is available on the efficacy of the apps in developing mindfulness”

‘The medical approach to mental illness has been a success’

The title of this article is quite intriguing. Whilst it is not so unusual for people who do not believe that the medical approach to mental health is useful the reverse is a bit rarer. The article is of course, an opinion piece. See what you think.
And elsewhere in the news

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

‘Cognitive therapies for depression in adults: let’s just stick to the facts’

The subject of this offering from Ioana Cristea of the Mental Elf is quite wide ranging.

It’s basically a review of an ‘highlight’ by the NIHR Dissemination Centre. I was not exactly sure what a ‘highlight’ is but this helpful extract from the article in questions does explain matters:

“you can find out about important new NIHR research which adds to our knowledge about when, and for whom, cognitive therapies might work. You will also hear from people living with depression, and people working with them, about what this new evidence means to them”

The highlight essentially considers three NIHR funded studies on cognitive based therapies for depression. When I looked at this article I realised that I didn’t actually know what a ‘cognitive therapy’ was. According to Wikipedia “cognitive therapy (CT) is a type of psychotherapy developed by American psychiatrist Aaron T. Beck. CT is one of the therapeutic approaches within the larger group of cognitive behavioral therapies (CBT) and was first expounded by Beck in the 1960s”.

The conclusions of this Mental Elf review by Ioana Cristea are stated as:

“While the latest large trials of cognitive therapies are undoubtedly exciting and worthy of public attention, I am concerned that this new NIHR Highlight presents a somewhat edulcorated [more palatable] representation of computerised CBT as an effective low-intensity intervention and overplays the evidence for mindfulness based cognitive therapy as an alternative to antidepressants for relapse prevention”

Click here to read the full article.

Other highlights include:

Commonly prescribed psychiatric drugs: do they work?

Click here to read the article.

Should we stigmatise smokers?

Click here to read the article.
IPT and CBT best for depression in children and young people, says network meta-analysis (by McPin’s very own Laura Hemming!)

Click here to read the article.

Building RAPPORT between researchers and lay people

Click here to read the article.

Work Capability Assessments linked with increase in suicides

Click here to read the article.

Exhibition

States of Mind: Tracing the edges of consciousness

This is the latest free exhibition from the Wellcome Trust. The following text is from the website of the Wellcome Collection (www.wellcomecollection.org):

“Following on from 'Ann Veronica Janssens: yellowbluepink', this changing exhibition will examine perspectives from artists, psychologists, philosophers and neuroscientists to interrogate our understanding of the conscious experience”

It’s running at the Wellcome Collection on Euston Rd, London, until October 2016. You can find out more about the exhibition by clicking here. The Wellcome Collection is open every day except Monday.

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