

# McPin Public Involvement in Research Bulletin

## Issue 1: January 2015

Happy New Year! This is the first 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 be 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 let us know. You can email us at [contact@mcpin.org](mailto: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](http://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.***

# Introducing the McPin Foundation

Welcome to the first edition of the new quarterly McPin Public Involvement in Research bulletin! In these bulletins we will advertise opportunities for people to get involved in mental health research both within the McPin Foundation and beyond. Bulletins will contain in-depth articles about a wide range of mental health topics. The first entitled ‘the genetics of schizophrenia’ is on p9. Each edition will also have a book review and a short digest of mental health research stories that have appeared in the news. Although the focus of this bulletin is and always will be **involvement** in research we will advertise opportunities for people to **participate** in research from time to time.



You can listen to our Research Manager, Sarah Hamilton, speaking about the McPin Foundation by clicking [here](#)

website: [www.mcpin.org](http://www.mcpin.org):

“The McPin Foundation exists to transform mental health research by putting the lived experience of people affected by mental health problems at the heart of research methods and the research agenda.”

We work in three main ways:

- **We conduct user focused mental health research.** Running our own projects, or working as part of a collaborative team, we undertake [expert consultancy](#) and [innovative research](#) using [a range of methods to involve people with lived experience of mental health problems](#).

- **We build the capacity of others to conduct user focused mental health research.** We do this by [sharing knowledge and skills](#) about research methods, networking with others delivering user focused mental health research, by providing funding and by training and [employing peer researchers](#) to carry out research among people affected by mental health problems.
- **We seek to [influence methods, practice, and decision making](#) in mental health research.** By sharing innovation and good practice and raising awareness, we seek to ensure that the views of people with lived experience of mental health problems become central to research methods and the research agenda”

As well as doing research we support service user and carer involvement in mental health research. I started work with the McPin Foundation in May 2014. Since then I have been managing the Foundations ‘public involvement in research’ programme. You can read more about this [here](#). We very much welcome ideas and contributions for future articles in the bulletin. If you have any suggestions then please do get in touch.

You can email me at: [Thomas.kabir@mcpin.org](mailto:Thomas.kabir@mcpin.org) or phone 0207 922 7874. Our postal address is:

The McPin Foundation  
32-36 Loman Street  
London  
SE1 0EH

The McPin Foundation also produces a newsletter which will keep you updated on the work of the organisation as a whole. I encourage you to subscribe to this newsletter by signing up: [here](#)

Thomas Kabir – McPin Public Involvement in Research manager.

# Opportunities



## *Are you interested in mental health research?*

Would you like to get involved in helping a group of researchers develop a research proposal and advise on the study if they get it funded?

The topic is using online recovery narratives to support people with psychosis to manage their mental health and wellbeing.

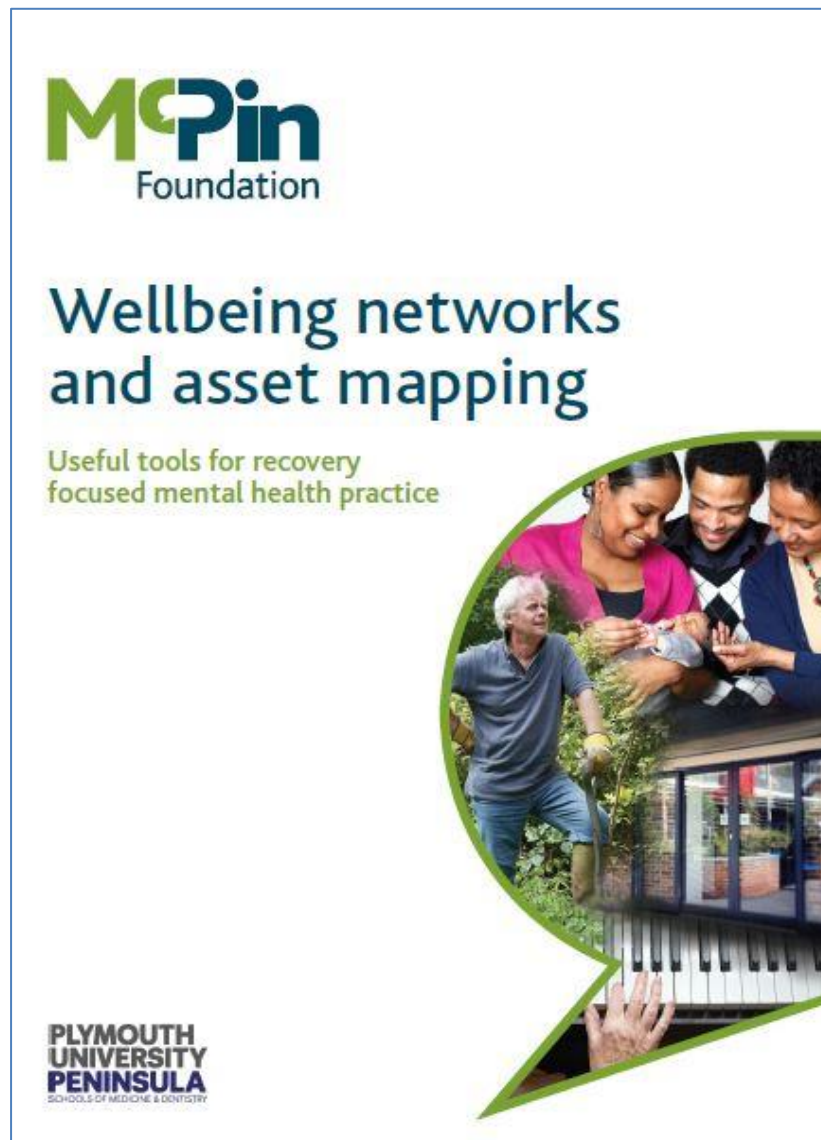
We are holding a meeting for those people interested on Monday 23<sup>rd</sup> February 2015 in London. Travel expenses will be provided and a payment for your time. We are particularly looking for people who:

- Live in Nottingham, East London or South London
- Have a mental health experience relevant to a study on psychosis and recovery
- Have an interest in mental health recovery initiatives

Interested? Please contact Thomas Kabir: 02079227874 [thomaskabir@mcpin.org](mailto:thomaskabir@mcpin.org)

The study is led by Professor Mike Slade, Kings College London. This meeting is being organised by the McPin Foundation ([www.mcpin.org](http://www.mcpin.org)). Registered charity: 1117336.

## News

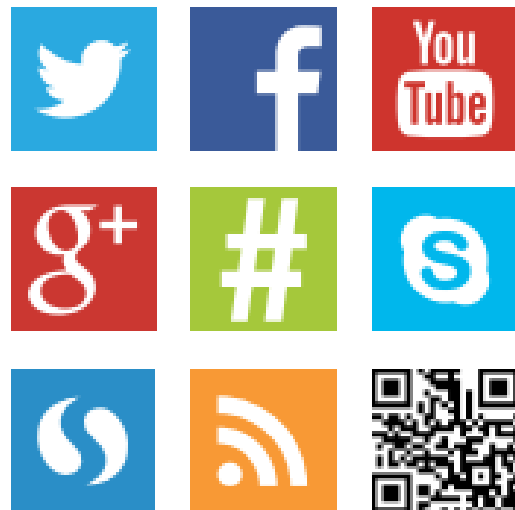


We are really pleased to launch [our briefing paper](#) which was written for the Shared Decision Making in Medication – Evidence, Efficacy and Alternative Paradigms conference in London, Wednesday 28th January 2015. The paper describes wellbeing networks to support mental health recovery. It draws on a research project the McPin Foundation and Plymouth University, with other collaborators, completed in 2013 funded by the National Institute of Health (NIHR). In order to communicate more clearly ideas contained in the research we have worked with Daryll Cunningham, a cartoonist. Do take a look at the report and let us know if you feel this type of approach has something to offer the mental health community. Might wellbeing networks offer a recovery focused approach to managing mental health problems? Email to share your views; [karenjames@mcpin.org](mailto:karenjames@mcpin.org)

**INVOLVE**

**NHS**  
*National Institute for  
Health Research*

**Guidance on the use of social media  
to actively involve people in research**



November 2014

INVOLVE have released a new resource entitled 'Guidance on the use of social media to actively involve the public in research'. By social media we mean things such as Facebook, YouTube, and Twitter. To download the document click [here](#) or visit the INVOLVE website at: [www.invo.org.uk](http://www.invo.org.uk).

## **NIHR new media competition – special prize for public involvement in research**

*The following text is taken from the INVOLVE website ([www.invo.org](http://www.invo.org))*

### **Round 5 of the NIHR New Media Competition has now launched**

If you are involved in NIHR Research (as a researcher, a patient or a member of the public) and are interested in communicating your research, then enter the NIHR New Media Competition.

#### **To enter you need to be:**

- a member of the [NIHR Faculty](#)
- have recently completed your NIHR funded research
- a patient/member of the public involved in NIHR research

#### **Category 1 Raising awareness of your research**

This category is for films that have been made specifically for the competition and explain clearly why the research is important, how it is being done and any impacts that have already arisen or may happen.

#### **Category 2 Recruitment to NIHR clinical trials/encouraging participation in a research study**

If you have a short film that you have made to help to recruit participants into an NIHR research study you can enter this video here.

#### **Special Prize- how patient or public involvement has added value to a research project**

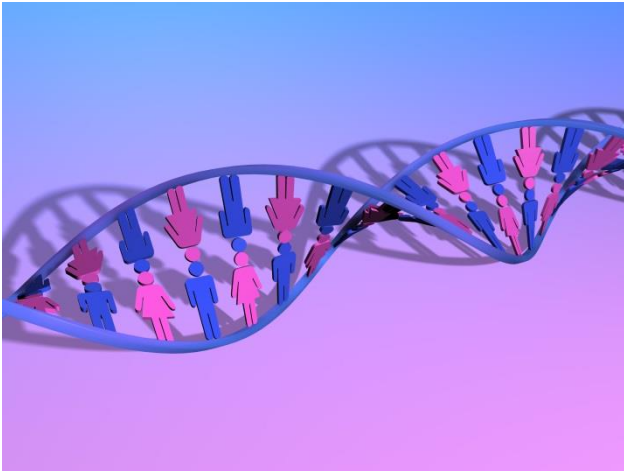
There will be a special prize for the film in either category that shows how public involvement (not only participation) has been embedded into a research project and how it made a difference.

Further information is available on how to enter, assessment criteria and special prizes: <http://www.nihr.ac.uk/our-faculty/new-media-competition.htm>

***Closing date is Tuesday 31 March 2015***



## The genetics of schizophrenia



To say that schizophrenia is a controversial diagnosis would be putting it mildly. Almost everything relating to schizophrenia has been contested, often ferociously. Putting that to one side, there is a lot of research into schizophrenia particularly to understand causation and treatments. We have known for a while that there is some evidence that schizophrenia [runs in families](#). We have just got a bit closer to perhaps finding out why. In July 2014 the results of some research led by researchers at the University of Cardiff was published in the journal [Nature](#). The research

is part of a larger programme of work being carried out by the Psychiatric Genome Consortium.

The research was reported on in most of the daily newspapers such as the Independent ('DNA hope on schizophrenia: Research breakthrough points at over 100 genes'). The paper got quite a bit of attention in the news too with the [BBC](#) reporting on it as well as other broadcasters over the world.

So what was so exciting? Well the paper looked at the DNA of 37,000 people with schizophrenia in 35 different countries. These people's DNA was then compared to 110,000 people who did not have schizophrenia. The researchers found around 108 'points' across around 80 genes where there were significant differences.

In the world of psychiatric genetics this is a breakthrough -check out this [chart](#). The 2014 study means that we now know of five times the number of genetic differences between people who do and do not have schizophrenia compared with 2013. To find out more about what exactly a gene is please click [here](#). If you would like to find out more about the actual study then please, please, (I beg you!) read this great [summary](#) of the paper on the NHS Choices website.

Aside from this it is important to note that all human beings pretty much have the same set of around 24,000 genes. There are some [differences](#) between men and women but these not large. So if we all pretty much have the same genes how come we all look so different? Good question. It's complicated. It's partly genetics and partly the environment. Genes come in lots of varieties. It's a bit like hair colour. Within any one colour there are lots of different shades. And so it is with genes. There are many different versions of the same gene. This is why one person may be blonde but another brunette.

The environment obviously plays a big part too. If you grow up in the vicinity of a nuclear disaster zone without much food then you are likely to turn out a bit differently to someone raised in a very unpolluted and affluent area.

When scientists speak of finding a 'new' gene for something (say schizophrenia) they do not usually mean that they have discovered an entirely new gene. Usually they mean that

they have discovered a particular **version** of a gene that has identified as having a role to play in something. In this context the bottom line is that the researchers from the consortium led by Cardiff University have found around eighty particular versions of genes that are more commonly found in people with schizophrenia. There is no such thing as a “gene for X, Y, or Z” as we all pretty much have the same set of genes. What is actually often meant is that “if you have this particular version of a gene then it may increase your likelihood of having X, Y or Z”.

But why is this research important? Well nobody is claiming that this research is going to lead to a better way of helping people with schizophrenia anytime soon. But finding differences between someone with a health condition and those that don't is very often the first step towards developing new ways of managing and treating people.

Take breast cancer as an example. Two [genes](#) have been discovered called BRACA1 and BRACA2. If you have these genes you are at a higher risk of developing breast cancer compared with the general population. Once these genes were discovered, a way of testing if people had them was quickly found. Testing people for these two genes together with other advances has meant that survival rates for people with breast cancer have [improved significantly](#).

There are significant ethical issues that arise from genetic research. Could people who test positive for genes that might cause disease be discriminated against? Could people refuse to employ you based on your genes? What do you do if you want to have a family? There are so many ethical issues that arise from the genetics of mental health conditions. If you would like to know more please do read this 1998 [report](#) from the Nuffield Foundation.

There are other problems too. Genetics is **massively** complicated. Even if you do test positive for a disease linked gene, all it does is increase the chance that you might get the illness. In fact there is only one condition ([Huntingdon's disease](#)) where if you test positive for the gene you will get the disease. It's a numbers game. Genetic testing only tells you something about your 'risk' of developing an illness or disease. Aside from this it's clear that genetics is not the whole answer. What happens to you in your life also has a big effect. Needless to say this is particularly the case in mental health.

The genetics of mental health is not well understood. In fact we are probably behind many other areas of health here. This could be for two reasons. 1. Mental health problems don't have a strong genetic component. 2. Not enough research has been done into the genetics of mental health. Things are changing though and the Nature paper should be welcomed.

What is a bit worrying is the lack of lived experience in genetic research. From what I have seen, service user and carer involvement in mental health genetics is relatively underdeveloped. I wouldn't say that there is **no** involvement in research into the genetics of mental health, I just don't see very much. And given the complexity of genetics research and the issues that it raises, we probably need quite a bit more service user and carer involvement not less. A number of articles were published about the research in the July 24<sup>th</sup> 2014 edition of Nature to accompany the research paper itself. Whilst one of the articles did include a very brief account of someone who had schizophrenia there was little direct focus on who's surely most important here: people with schizophrenia. To their credit, the following week Nature published an [article](#) entitled 'cause is not everything in mental

health', by someone with lived experience of mental illness in response to the research published in the July 24<sup>th</sup> edition.

On the other hand there is no lack of goodwill or of people trying to explain what genetic research means. In fact there are some wonderful and innovative resources available (for example: <http://www.geneticseducation.nhs.uk/>)

But history teaches us that we that we need to be very careful. For example, there have been suggestions in the past that people with 'undesirable or defective' traits should be sterilised to prevent them from passing these on to future generations. A whole field of study developed around this called [eugenics](#). And we aren't simply talking about the Nazi's here. Winston Churchill was in favour of "the confinement, segregation, and sterilization of a class of persons contemporarily described as the "feeble minded.". If you don't believe me click [here](#).

There is massive scope for the findings of genetics research to be badly communicated. Both geneticists and the press have probably been guilty of this in the past. The results of the ensuing misunderstandings can be severe. There are certainly people who have made bad choices or decided not to have children based on newspaper headlines or a false interpretation of genetic tests. Many of these issues have been tackled admirably in areas of health, such as cancer, but not so much in mental health. We would do well to actively involve people with lived experience of mental illness very early on in genetic research studies to proactively work through all of the issues that I have raised in this article, and more. Indeed a [report](#) from INVOLVE shows that "public involvement throughout a study can help to make research more ethical".

Doing this would ensure that we have some worked out solutions and approaches to the particular issues that genetics research into mental health raises. Who could be better placed to help develop these solutions and approaches than people with actual lived experience of mental illness? Many abuses in medical research have happened when things are 'done to' rather than 'done with' people. I would never ever want to imply or suggest that the researchers from the Psychiatric Genome Consortium have done anything wrong -far from it, but we need more involvement of people with lived experience of mental illness involved in genetic research and we need it soon.

I don't want to end on a downbeat note. We need to understand mental illness better. The paper published in Nature potentially brings us one step closer to understanding what part genetics plays in schizophrenia. To all the researchers of the Psychiatric Genome Consortium I say 'thank you'!

Thomas Kabir – McPin Public Involvement in Research manager.

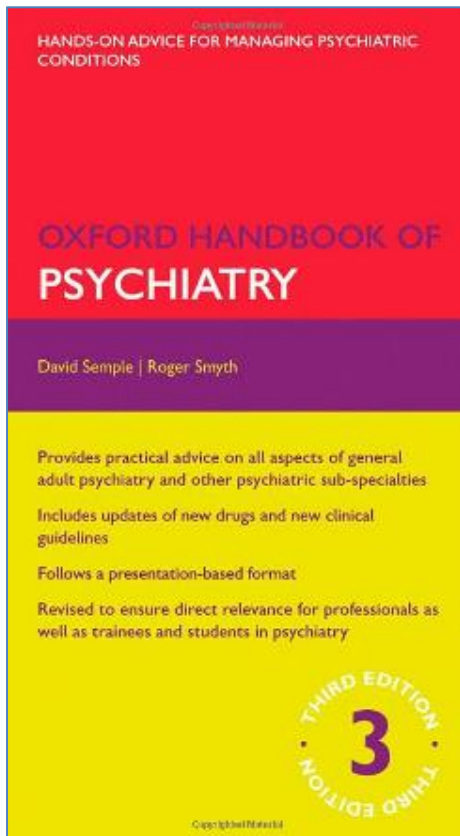
### **Further resources**

To listen to a great Naked Genetics podcast on recent advances in psychiatric genetics please click [here](#). Or go to: <http://www.thenakedscientists.com/HTML/podcasts/genetics>

**OMIM** ([www.omim.org](http://www.omim.org)). OMIM is a database of all genes known to play a part in any illness or disease. To have a look at a full list of genes sorted by illness or disease click [here](#).

'Mental health: Depression needs large human-genetics' studies by Steven Hyman. Nature, November 2014. Volume 515 p189-191. Please click [here](#) to read the full article.

## Book Review



### Oxford Handbook of Psychiatry

By David Semple and Roger Smyth

Published by Oxford University Press

RRP: £29.99

ISBN: 0199693889

I was sceptical when I first caught sight of this book. It's just over a thousand pages long and the text seemed to be quite dense when I first flicked through it. Is this actually going to be useful? I thought as I considered buying it.

How wrong I was! This is one of a series of handbooks (and the book does indeed fit into the hand) covering every conceivable area of medicine. These handbooks are generally aimed at medical students and newly qualified doctors and are something of a survival guide for junior doctors. If you think of a junior doctor doing a nightshift with no or limited access to help from anyone else then it's these handbooks that are meant to help them get through the night. So coming back to the Handbook of Psychiatry; the book begins with an 'acute presentation index' (i.e. what do you do if a service user comes to you in an emergency?). The index looks to be quite comprehensive covering everything from alcohol withdrawal to postpartum psychosis.

There is quite an interesting and detailed section on 'manipulative patients' on p994! The book begins with quite a useful introduction to psychiatry in general.

The next chapter is focused on how to carry out a psychiatric assessment.



Subsequent chapters mainly focus on different mental health conditions such as depression, schizophrenia, and eating disorders. There are some real gems in there, and also is an entire chapter on reproductive psychiatry, sexual dysfunction, and sexuality. The chapter gives some quite good information about the options (there aren't that many) for treating sexual dysfunction arising from medications used in mental health. It's quite hard to find reliable information about this elsewhere. Chapter 21 provides a succinct guide to British law and mental health.

So why do I think that this book is worth looking at? Its long and it's quite technical in places, but well, to put it crudely 'knowledge is power'. One of the strengths of this book is that there is simply so much information in there. The book covers everything from what anti-psychotic medication causes most weight gain ([perphenazine](#) - 5.8kg on average), to least ([pimozide](#) - you lose 2.7kg on average). But the book isn't just a dry collection of facts; it also contains detailed suggestions for doctors on how to **deal with** commonly encountered problems in mental health. In the case of weight gain from antipsychotic medication, the answer seems to be warn people of the potential of weight gain, monitor peoples weight, prescribe the lowest possible dose, and consider using more than one antipsychotic. I think that the idea with the last suggestion is that if someone is on a medication such as clozapine then you can cut the dose used by adding in another antipsychotic drug with a lower weight gain profile. What I am trying to say is that you can get some sense of how a psychiatrist might go about treating a problem before actually having to see one.

In an odd way it's not just a survival guide for junior doctors, it can form part of a survival guide for you too. At £30 the book is a bit expensive but for me it was money well spent.

Book review by Thomas Kabir

# Mental health research in the news

## Is depression a kind of allergic reaction?

Life & style > Health & wellbeing

### Is depression a kind of allergic reaction?

A growing number of scientists are suggesting that depression is a result of inflammation caused by the body's immune system

Caroline Williams  
The Guardian, Sunday 4 January 2015 17.00 GMT  
[Jump to comments \(345\)](#)



Could depression be a form of 'sickness behaviour'? Photograph: Mads Perch/Getty Images

An exciting article from the Guardian here. To read the text in full please click [here](#). There is an increasing amount of interest amongst researchers about the role of the immune system in mental health.

The immune system is the body's defence system against infections. It's the immune system that protects us from everything from virus's (well sometimes it fails!) to getting cancer from someone else. The Wellcome Trust has put together an excellent guide to the immune system which you can download by clicking [here](#) or visiting <http://bigpictureeducation.com/>.

But going back to the Guardian article. The piece does a good job on reporting on the suspected link between some forms of mental health problem and the body's immune system. The article picks up on the fact that many people feel a bit down or depressed when they are ill. Mostly people had put this down to the fact that being ill causes pain and stress which in turns can cause mood problems. But could it be that the immune system which is highly active when you get an infection that's causing the problem? Another interesting aspect which is picked up in the article is the nature of the stigma that surrounds mental illness. If the cause of mental illness is even partly physical could it help mental illness to become less stigmatising?

Interested in immunology and mental health? In the next edition of the bulletin we will look at this in more detail. Indeed the McPin Foundation is providing the service user and carer involvement to a study looking at the link between the immune system and people treated for schizophrenia.

## Placebo Response in Antipsychotic Clinical Trials: A Meta-analysis.



This paper is really interesting. The placebo effect is something that until quite recently has not received as much attention from researchers as you would expect. So what is a placebo? A placebo is a sham treatment.

The important bit is that the person receiving the treatment does know that it's a sham. The Wikipedia entry on placebos is actually quite informative: [en.wikipedia.org/wiki/Placebo](http://en.wikipedia.org/wiki/Placebo).



The interesting thing is that it is sometimes the case that even when you do give someone a placebo in place of the real thing he or she says that they feel better. This is known as the placebo effect. The placebo effect is quite mysterious and people are still trying to work out how it works. Explaining the placebo effect is quite complicated though there is an excellent video featuring Ben Goldacre on the NHS Choices website.

**The Placebo effect:**  
[www.nhs.uk/video/pages/placeboeffect.aspx](http://www.nhs.uk/video/pages/placeboeffect.aspx)

Some researchers from Columbia and New York have just published a paper in the journal JAMA Psychiatry looking at the placebo effect in clinical trials of antipsychotic medication between 1960 and 2013. You can read the abstract of the paper by clicking [here](#). In total 105 clinical trials were included in the study. So what did the researchers find? Well the researchers provide a succulent conclusion to their work: “The average treatment change associated with placebo treatment in antipsychotic trials increased since 1960, while the change associated with medication treatment decreased. Changes in randomized clinical trials leading to inflation of baseline scores, enrolment of less severely ill participants, and higher expectations of patients may all be responsible”

## The Mental Elf



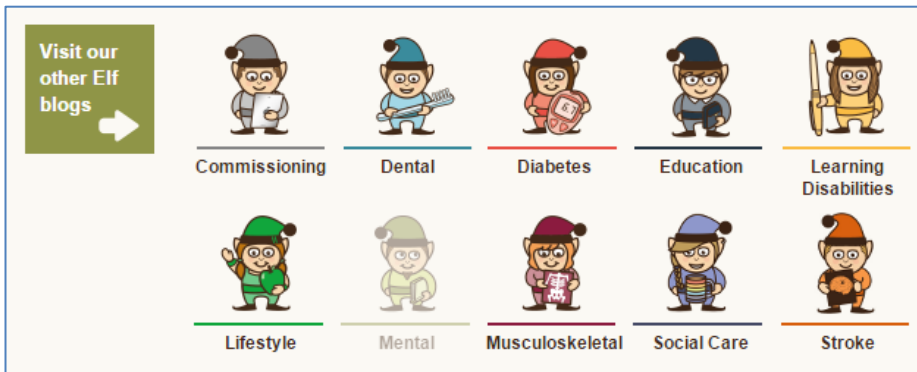
I love the Mental Elf. The Mental Elf was found by André Tomlin in 2011. André is an information scientist. He runs a healthcare consultancy based in Oxford. So what exactly is the Mental Elf? Well it’s basically a review and summary writing service.

The service has gone from strength to strength. Nearly a hundred ‘Elf’s’ who are mostly students, academics, and researchers produce: “short and snappy summaries that highlight evidence-based publications relevant to mental

**The Mental Elf:** [www.thementalelf.net](http://www.thementalelf.net)

health practice in the UK and further afield”

The Mental Elf website goes on to state that: “You can be the first to hear about key guidance, systematic reviews and high quality research and information. No jargon, no misinformation, no spin, just what you need”. And that’s not all. There are ten ‘Elf’ services covering everything from dental to social care research. There are even apps that are



available so that you read Elf summaries on your smartphone. Indeed, the Mental Elf simply keeps on innovating. The day after I finished writing this article a Mental Elf newsletter was launched with links to all latest summaries and articles. You can have a look at

the first edition [here](#).

Recent Mental Elf highlights include:

### **Joint Crisis Plans: empowering service users with psychotic disorders**

Click [here](#) to read the article

### **Eating disorders: how can we care for carers?**

Click [here](#) to read the article

### **The impact of PPI [Public and Patient Involvement] on service users, carers, and communities**

Click [here](#) to read the article

## **Wellcome Trust to digitise 800,000 pages of documents from public and private asylums from the 18<sup>th</sup> and 19<sup>th</sup> centuries**



The Wellcome Trust is to digitise 800,000 pages of documents from public and private asylums from the 18<sup>th</sup> and 19<sup>th</sup> century. This is very welcome news (no pun intended). We tend to think of asylums and ‘institutions’ as rather barbaric places. And in many cases they were. But there was an amazing variety of approaches that asylums took towards treating people. This point is picked up on by the [Guardian article](#) reporting on the Wellcome Trusts [announcement](#). The archive includes the *Gartnavel Minstrel*, the earliest known publication written and edited by hospital patients in 1845. Far from being dry history I suspect that the documents in this archive will have lessons for us today.



And finally, the following came up in a debate on mental health in the House of Lords on 15<sup>th</sup> January 2015:

“Despite mental health problems affecting one in four of us, funding for mental health stands at less than 6% of all health research funding. A commitment to parity in funding must be consistent across government and health services. In 2014 Monitor announced a funding decision to cut mental health services by 20% more than NHS hospital trusts. I know that Ministers did not approve of that, or like it, but none the less, the funding was cut. Reports found that 77% of clinical commissioning groups have frozen or cut their children and adolescent mental health services budget between 2013-14 and 2014-15, alongside 60% of local authorities in England having cut or frozen their budgets since 2012” **Lord Patel (cross-bencher)**

“For every £1 that the Government spend on cancer research, the general public invest £2.75; for heart and circulatory problems it is £1.35. For mental health research, the figure is 0.003p”. **Lord Bradley (Lab)**

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**Thank you for reading our first 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](http://www.mcpin.org)**