



Service Users in Research
Mental Health Research Network



**National Institute for
Health Research**

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Service Users in Research Bulletin

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Thank you very much for joining Service Users in Research. This is the first of what will be a series of regular bulletins that we send out to members via post or email. In these bulletins we will advertise opportunities for people to get involved in the MHRN and mental health research generally. **If anyone has anything that they would like to be in the bulletin then please let us know. You can email us at: mhrnppi@kcl.ac.uk or phone 0207 848 0644.** We are also preparing the next edition of the Service Users in Research newsletter which will be sent to members before Christmas.

MHRN PPI Conference

The MHRN will be holding a one day conference for both service users and carers on the 8th of March 2010. The conference will be free of charge and will be held at Goodenough College. The venue is close to both Kings Cross and Euston Stations in London. Further details about the conference will be sent out shortly (hopefully in late December or in January 2010).

Service Users and Carers needed for proposed research project looking at ways that mental health services can be improved for black service users.

A study team based at Kings College London will be holding a meeting for service users and carers at 2.30pm on the 7th of January 2010 to discuss a research proposal looking at ways that mental health services can be improved for black people in South London.

The following summary of the proposed project has been provided by the study team:

“In the last few years there has been considerable debate and concern about the way that people from ethnic minorities are treated when they need treatment from mental health services. There is evidence that Black people are more likely to be admitted to psychiatric hospitals as compulsory patients or through the courts, and are more likely to receive only drug treatment and experience restraint and seclusion. Policy makers are aware of these problems and have tried to introduce guidance to make sure that Black people receive the best treatment possible which is sensitive to their cultural needs. However, it seems that NHS staff lack confidence in talking about issues of race and culture and how it affects their practice. So far, top-down guidelines and directives do not seem to have had a great impact in ensuring better treatment for Black people with serious mental health problems.

This project takes a “bottom-up” approach, giving Black mental health service users and staff who work with them a chance to think about and design service improvements and share these with managers and policy makers. The research method we will use is called “Photovoice” and involves asking people to take photos about important aspects of their lives. We want Black service users and staff who work with them to share their ideas about making services better through their photos. The exhibitions they make can be viewed by other audiences as well; managers, policy makers and local community members. We hope that this work will improve communication between Black mental health service users and people in the NHS who provide services for them. We also hope that the people who take part in the study will come up with some practical ideas about improving services which will have a direct impact on the treatment of Black mental health patients”

The meeting will be held in Waterloo, London at 2.30pm on the 7th of January 2010. Payment of £15 will be offered to users and carers. This payment will include reimbursement for any travel expenses and refreshments will also be provided. If you would like to attend the meeting please email Thomas Kabir at thomas.kabir@kcl.ac.uk or phone 0207 848 0644.

Service Users needed for the IMPACT study team in London

A friendly team of researchers based at the Institute of Psychiatry in south London is looking for service users with experience of schizophrenia or bipolar disorder to help them with their study. The IMPaCT study (Improving physical health and reducing substance use in severe mental illness) is actually a series of individual studies which aims to improve the physical health of people who suffer from psychosis. Another aim of the study is to help people who suffer from psychosis deal with any substance misuse problems that they may have. You can find out more about the IMPaCT study at <http://www.iop.kcl.ac.uk/projects/?id=10249>.

The IMPaCT study team has meetings once a month at the Institute of Psychiatry. Payment is offered to service users and reasonable travel expenses will be met.

If you are interested in getting involved in the IMPaCT study then please email Thomas Kabir at thomas.kabir@kcl.ac.uk or phone 0207 848 0644.

Health Talk Online

Health Talk Online is an award winning website of a charity called DIPEX. The website (<http://www.healthtalkonline.org/>) consists of a series of videos of people with a range of health problems talking about their experiences. There is a whole section of the website dedicated to people talking about mental health problems such as depression.

Some researchers from the University of Oxford would like to ask people with experience of schizophrenia to talk about their experiences for the Health Talk Online website.

The interview will be conducted from your home unless you prefer somewhere else and travel expenses would be paid.

With your agreement the interview will be video recorded and you would have the opportunity to look at the footage of the interview before it was placed online and remove any sections that you did not like. **If you do not wish to be video recorded and you would like to take part anonymously then the researchers can still carry out an interview with you by either audio recording the interview or by simply writing down what you would like to say. The transcript of the interview can then be anonymised to protect your identity.**

If you are interested in being interviewed for the Health Talk Online website then please contact:

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www.healthtalkonline.org
www.dipex.org

Declaration on Mental Health Research

The Declaration on Mental Health Research was launched on October 14th 2009 by the Institute of Psychiatry and the Mental Health Foundation to encourage increased funding for research in mental health so that it begins to match the level of disability. The Declaration also informs the public and members of parliament that mental health research is currently underfunded. In addition we hope to set up a national charitable fund to support mental health research.

What can you do?

1) We would like encourage you to go to www.researchmentalhealth.org.uk and sign the Declaration. We hope to get 10,000 signatures so please encourage others to sign also.

2) We need further support from MPs to sign the Early Day Motion - currently there are 62 but we need at least 100 to get noticed and 200 to get a debate.

Below is the text of the Declaration and a press commentary on why this is important. Following that is information on the Early Day Motion and how to find your MP.

MENTAL HEALTH RESEARCH IN THE UK

THE LONDON DECLARATION 2009

Declaration made on 14th October 2009 by the undersigned:

"Mental ill health is a leading cause of suffering, economic loss, social problems and death in the UK. Our understanding of mental illness has not improved as fast as that of cancer or heart disease.

"Only proper investment in mental health research will bring the major breakthroughs that are possible in the next 20 years. These could dramatically change our understanding of mental illness and our ability to prevent and treat it. They could also change our understanding of how mental health affects physical health enabling us to improve both. The breakthroughs we seek can occur across biological, psychological and social science but may also arise from integrating findings across disciplines."

"We commend the Government's strategy Best Research for Best Health and commitment to develop healthcare solutions based on solid research evidence. This must continue. But such research on mental illness is still massively under-resourced compared with research for major physical illnesses, despite causing a comparable or larger disease burden.

"We call upon the Government, the NHS, research funding bodies, research institutions, the pharmaceutical industry and the third sector to commit to a joint strategy to rectify this. This means taking the following steps in the next three years:

1. Government should continue to increase the proportion of research money that is spent on mental health research as well as encouraging other funders to do so. It should bring together the key players to develop a joint strategy, with a timescale, for investment.
2. The major research funders need to re-balance their existing portfolios to ensure mental health gets the priority it deserves.
3. Although currently only a minor contributor, leading mental health charities need to focus more effort on supporting, publicizing and resourcing mental health research.
4. Research institutions should continue to invest in the skills and understanding necessary to develop strong research proposals.

"The long term aim must be to put mental health research on the same footing as that for physical illness and to ensure that it reflects the enormous health, social and economic burden imposed by mental illness."

ENDS

Press Commentary

Many people are surprised to learn that the disease burden of mental illness is comparable to that of cancer but only receives a fifth of the research investment. Thanks to significant funding in research, cancer survival rates have doubled in the last 30 years and people are living longer with once fatal conditions such as heart disease. Sadly, success stories of this nature cannot be told about mental illness.

That is why the Research Mental Health initiative has been launched. Led by the Institute of Psychiatry and the Mental Health Foundation, and backed by leading scientists, academics and clinicians, it has established a charitable research fund for more investment in mental health research.

Whilst treatments for mental illnesses have improved, our understanding of mental illness is moving at a snail's pace. We have expert researchers, scientists and organisations working in the field but need to bring them together and give them more resource if we are really going to help those who suffer from mental illness. Research studies on a much larger scale are needed to effect significant change. Mental illness studies are often small and can prevent researchers from drawing valid conclusions, making them less credible in the eyes of clinicians, the general public and policy makers.

Research could measure the success of new therapies, or help in the development of diagnostic tools to help professionals spot mental health problems early on. Trials could test the effectiveness of drugs to find, or try and find the genes that play a part in the development of mental health problems to inform future research about treatment. The possibilities are vast.

Greater investment in mental health research would bring about a number of benefits. The delivery of new treatments and improvements to services would not only help to reduce the personal suffering caused by mental illness to individuals and their families, but it would also bring down the associated economic and social costs that currently stand at £100 billion in the UK, equal to that of the total National Health Service budget.

WRITING TO YOUR MP

To find out whether your MP has signed go to - <http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=39279> but a letter would still be helpful even if they haven't.

To find out how to contact your MP go to: http://www.parliament.uk/mps_lords_and_offices/mps_and_lords/alcm.cfm