

FACTOR Update *February 2009*

Families/Friends And Carers Together in Research

WELCOMES AND FAREWELLS

In December, Dorothy Rutherford moved to Oxford and we lost an valuable colleague and efficient administrator – we hope to be able to advertise another permanent post soon. On a positive note, I am very glad to have a new colleague - Dr Thomas Kabir started as Coordinator of SURGE in January, now renamed Service Users in Research. We share a PPI Manager, Joanne Ashcroft, and Associate Director, Professor George Szumukler. I look forward to working with Thomas.

The MHRN Conference is being held in Nottingham in May. There will be a Pre-Conference Gathering for service users and carers and a talk on Carer Related Research (more information overleaf).

CARERS GET INVOLVED

FACTOR continues to involve carers in MHRN research activity in two main ways; by joining research teams working on current projects, and in working with the MHRN's Clinical Research Groups (CRGs) which draw up proposals for future research.

We have gathered a group of eight carers to work on the PUMP IT study which is looking at improving physical health and reducing substance use in severe mental illness. While being well aware of the difficulties, carers often know what has worked for their relative, whether through their own efforts or seeing care coordinators and support workers try to motivate the service user to lead a more healthy lifestyle. The Impact team has told us how valuable they have found the discussions with carers.

We have also involved two relatives of people in the forensic system in the SUCESS (Service Users and Carers' Experience in Secure Settings) meetings. We are keen to avoid token involvement and to use carers' experience and knowledge to best advantage, so we run separate briefing and discussion meetings for carers with one or two researchers before the main CRG meeting. The carers have shared with the team what it is like to be a forensic carer, including difficulties in getting information, visiting their relatives in a secure hospital, and the double stigma of mental illness and offending which they experience in their neighbourhoods. All of this information will potentially be useful in the development of research projects for this CRG.

Geraldine Mason, FACTOR Coordinator

MHRN SCIENTIFIC CONFERENCE 20th - 22nd May 2009

This year's Scientific Conference is being held at the East Midlands Conference Centre, Nottingham. We are running an informal Pre-Conference Gathering for service users and carers attending the Conference, from 3:00 to 5:00pm on Wednesday 20th May, with registration from 2:30pm. It will take place in the Gallery of the Conference Centre. This is an opportunity to meet with other carers and service users who are attending, in a relaxed and convivial atmosphere, before the main conference begins. You will have been sent the conference flyer and programme along with this bulletin. If you would like to attend the conference please let us know as we can offer funding for places to a small number of carers. Alternatively please contact your local hub.

Are you (or have you been) already involved in mental health research?

We would still like you to contribute to a folder that we are producing of **Service User and Carer Involvement and Research**.

This is a collection of reports and accounts from service users and carers, of their experience in mental health research. It can include research both in and outside the MHRN, and involvement around research, such as input to research proposals, and activities in the MHRN hubs. We want this to be an ongoing folder showing the breadth of user and carer involvement nationally.

So if you are, or have been, involved in any capacity in research in mental health, please feel free to contribute as much or little information as you feel comfortable. It could be in the form of a list of activities, or a descriptive account of your experience(s) or any format you feel comfortable with. Please contact Geraldine on 020 7848 0643 for more information.

YOUR RESEARCH PRIORITIES

FACTOR is currently producing a document called Carers' Research Priorities, which is mainly based on the workshops in last year's Factor Us In conference, meetings with carers' support groups, and the responses to the survey questions in your applications to join FACTOR.

An application is being made to set up a Clinical Research Group in MHRN on a carer-related theme; this document provides important information on the issues which carers want researched. When the Clinical Research Group is set up there will be opportunities for carers to comment and discuss the research proposals being developed. We will update you on the progress with this soon.

WE'RE WIDENING OUR NET!

The FACTOR Network has grown to over 100 carers who receive our information and newsletter. Some people attend events and conferences, and some want to be more actively involved in research.

FACTOR was recently asked to find parents of children up to 18 years old to work with CAPSS - Child and Adolescent Psychiatric Surveillance System a reporting system which provides a means of studying rare childhood mental disorders. Therefore we are currently trying to reach a wider group through Supporting Carers Better, and the Institute of Psychiatry's Mental Health Care website. We will also be producing a flyer for students and staff of King's College London who might also be carers.

Contact us

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