

**Working together with service users, carers and clinical researchers:  
Opportunities and challenges**

**Friday 19<sup>th</sup> October 2007**

NOWGEN, Grafton Street, Near Manchester Royal Infirmary, Manchester

- 09:00 – 09:15 *Coffee and Registration*
- 09:15 – 09:30 **Introduction:** Karina Lovell, Professor of Mental Health, School of Nursing, Midwifery and Social Work, University of Manchester
- 09:30 – 09:45 **'Our experience of user involvement in research'**  
Martina Kilbride and Liz Pitt, Service User Researchers, Psychology Services, Bolton, Salford and Trafford Mental Health Trust
- 09:45 – 10:00 **A Carer Perspective: Connect-Support:**  
John Mainwaring
- 10:00 – 11:15 **Groups Discussion - Issues in user involvement**
- 11:15 – 12:00 **INVOLVE: Promoting Public Involvement in Research**  
Dr Jane Royle, Research Programmes Liaison Manager, INVOLVE
- 12:00 – 12:45 **User-Focused Monitoring (UFM) Applied to Psychological Therapies**  
Dr Diana Rose, Co-director Service User Research Enterprise, Institute of Psychiatry, London
- 12:45 – 14:00 *Lunch*
- 14:00 – 14:20 **Partnerships in research and practice**  
Nicky Lidbetter, Chief Executive National Phobics Society  
Karina Lovell, School of Nursing, Midwifery and Social Work, University of Manchester
- 14:20 – 14:40 **User involvement in training**  
Peter Bullimore: Service User Consultant/Trainer – 'Hearing Voices Network', Sheffield
- 14:40 – 16:00 **Groups Discussion: Solutions to User Involvement**
- 16:00 – 16:30 *Summary*

This one day workshop aims to facilitate collaboration between service users, carers and clinical researchers in order to enhance the quality of research being conducted across all aspects of psychological therapies and to ensure that the research priorities, methodology and implementation of research findings is carried out in collaboration with the people who engage with the treatment. The day will partly consist of a small number of presentations from service users, carers and clinical researchers to illustrate some of the challenges and successes associated with these groups working together. In addition, the workshop will encourage attendee participation in small groups to allow the opportunity to generate ideas and strategies for improving research and for planning future initiatives. We hope the day will facilitate closer and more integrated relationships between clinicians, researchers, service users and carers.

More about the Psychological Therapies Network at:  
[www.ihsmanchester.ac.uk/ResearchNetworks/psychologicaltherapies/](http://www.ihsmanchester.ac.uk/ResearchNetworks/psychologicaltherapies/)

About the Institute of Health Sciences [www.manchester.ac.uk/ihsm](http://www.manchester.ac.uk/ihsm) The Psychological Therapies network is an activity of the Institute of Health Sciences a networked organisation of health science research groups in the University of Manchester and our local NHS partner trusts – primary care, acute and mental health.

## **Speakers**

**Peter Bullimore:** I first started to hear voices in childhood. This was, I believe, linked to the sexual and physical abuse I received from a babysitter. I was never able to speak to anyone about the abuse or voices. When the abuse stopped at aged 13 the voices went away but the trauma laid buried. Years later when becoming a parent and running a million pound business the past came back to haunt me. Through severe pressure and mental torture everything spilled out. I was sectioned under the Mental Health Act, given a diagnosis of chronic schizophrenia, and told I would never work again.

I was given vast doses of antipsychotic medication but nothing stopped the voices. I spent over ten years in the system often forcibly detained under the Mental Health Act. Through the help of a very good worker and the Hearing Voices Network I was able to gain control of the voices and reclaim my life. I now run my own training and consultancy agency and deliver workshops and lectures across the world on hearing voices and paranoia, averaging a 60-70 hour working week. [www.hearing-voices.org/](http://www.hearing-voices.org/)

**Martina Kilbride and Liz Pitt** are service user researchers with Psychology Services at Bolton, Salford and Trafford Mental Health Trust. They have completed two user led research projects on recovery from psychosis and the impact of diagnosis on people who experience psychosis. They are responsible for the user involvement in a large programme grant in 'Psychological Therapies for Recovery from Psychosis'. They are committed to extending the involvement of service users in all stages of the research process. [www.bstmht.nhs.uk](http://www.bstmht.nhs.uk)

**Nicky Lidbetter** has worked with the National Phobics Society since 1997. Prior to this she was an active volunteer within the organisation, working alongside the founder, Harold Fisher. She is particularly interested in agoraphobia and panic disorder, and has a background in neuroscience.

Nicky has been a non executive director of Manchester Mental Health & Social Care NHS Trust, a director of the company 'Anxiety Disorders Conference' and holds the position of Manager of Self Help Services - a mental health charity within the Big Life Group. Additionally she has been a consultant to Greater Manchester Public Transport Executive and Manchester University. Nicky is currently studying on the University of Manchester's MSc in Advanced Practice Interventions in Mental Health. [www.phobics-society.org.uk/](http://www.phobics-society.org.uk/)

**Karina Lovell** is Professor of Mental Health in the School of Nursing, Midwifery and Social Work at the University of Manchester. Her programme of research has focused on alternative, accessible and innovative forms of service delivery for common mental health problems. She continues to work in both primary and secondary care settings as a CBT therapist. She has published widely in the both academic and professional journals. She is a past president of the BABCP and is also a patron of the National Phobic Society. [www.nursing.manchester.ac.uk/staff/KarinaLovell](http://www.nursing.manchester.ac.uk/staff/KarinaLovell)

**John Mainwaring** is a Carer and has worked in both the Voluntary Sector and the NHS. His work has included involvement in a large RCT, providing Carer Support, developing and implementing Family Services, delivering 'Family Interventions' and staff training. He has recently set up a new Carer organisation called 'Connect Support'.

**Diana Rose** is a mental health service user and a social scientist. In the early part of her working life, she kept these two identities separate for fear of stigma. Eventually this attempt to hide her psychiatric condition failed and she was medically retired from a research and teaching post at the age of 35. She then spent five years 'living in the community', an experience which was very distressing.

In 1985 she became part of the fledgling service user /survivor movement in the UK. Service user research was in its infancy but she decided to bring her two identities as service user and researcher together and do survivor research. This began with developing the model of User Focused Monitoring (UFM) in a London charity. Six years ago she joined the Service User Research Enterprise (SURE) at the Institute of Psychiatry at King's College London. This unit employs staff who are mostly service users or ex-service users. The unit aims to be collaborative as between service user researchers and clinical academics. Diana now co-directs it with a Professor of Psychology. [hsr.kcl.ac.uk/sure](http://hsr.kcl.ac.uk/sure)

**Jane Royle** is the Research Programmes Liaison Manager for INVOLVE. Jane leads on advising and supporting the National Institute for Health Research (NIHR) research programmes to have active public involvement in their commissioning processes. INVOLVE is a national advisory group funded by the Department of Health and part of the NIHR research programmes. INVOLVE's aim is to promote active public involvement in research and development in the NHS, public health and social care. [www.invo.org.uk/](http://www.invo.org.uk/)