

Join Service Users in Research by filling in this form

If you would like to have this form in larger type, please contact *Service Users in Research* on 020 7848 0644 or email Thomas.Kabir@kcl.ac.uk

Your contact details

1. Name

2. Address

3. Telephone

May we leave a message on this number?
 Yes No

4. Email address

We will usually contact you by email.
 Please tick here if you do NOT want to be contacted by email.

5. If you are a representative of an organisation, please tell us the name of the organisation:
.....
.....

More about you

Answering this question will help us make sure we are reaching people with experience of mental health problems from all cultural backgrounds.

1. I would describe myself as:

White British <input type="checkbox"/>	Asian British <input type="checkbox"/>	Mixed – White/Asian <input type="checkbox"/>
White Irish <input type="checkbox"/>	Asian Indian <input type="checkbox"/>	
White other background (please specify) <input type="checkbox"/>	Asian Pakistani <input type="checkbox"/>	Mixed – other background (please specify) <input type="checkbox"/>
	Asian Bangladeshi <input type="checkbox"/>	
	Asian other background (please specify) <input type="checkbox"/>	
Black British <input type="checkbox"/>		Other group (please specify) <input type="checkbox"/>
Black Caribbean <input type="checkbox"/>		
Black African <input type="checkbox"/>		
Black other background (please specify) <input type="checkbox"/>	Chinese <input type="checkbox"/>	
	Mixed – White/Black Caribbean <input type="checkbox"/>	I prefer not to answer this question <input type="checkbox"/>
	Mixed – White/Black African <input type="checkbox"/>	

2. Are you: Male Female

3. How old are you?

under 18 <input type="checkbox"/>	35-44 <input type="checkbox"/>	65-74 <input type="checkbox"/>
18-24 <input type="checkbox"/>	45-54 <input type="checkbox"/>	75+ <input type="checkbox"/>
25-34 <input type="checkbox"/>	55-64 <input type="checkbox"/>	

4. Do you have a disability? Yes No

If yes, please describe your disability.
.....
.....

I prefer not to say

Your background

It is useful for us to have some information about your background. Please tick all the boxes that apply.

I am a user or former user of mental health services.

I am a carer or friend of someone with a mental health problem.

I am a mental health or healthcare professional.

Other. *Please specify*.....
.....

About research

1. Have you had any experience of taking part in mental health research as a participant? Yes No

2. Have you had any experience of taking part in mental health research in any other way? Yes No

3. Are there any areas of mental health research you are particularly interested in or you think mental health researchers should prioritise?
.....
.....

How did you hear about Service Users in Research?

Data Protection (confidentiality)

All the information that you give to Service Users in Research will remain confidential and will not be passed on to anyone else (including other service users) without your permission. If you are interested in attending training courses and hearing about other MHRN events, you need to give us permission to pass on your contact details. Please tick ONE of the boxes:

I am happy for *Service Users in Research* to pass on my contact details to other MHRN staff.

Service Users in Research must get my permission to pass on my contact details to other MHRN staff.

Signed

Please send the completed form to:

Freepost Plus RSAY-JJZB-BSLG
MHRN Service Users in Research
PO77
Institute of Psychiatry
16 De Crespigny Park
London SE5 8AF



Involving service users in Recovery Programme Research

by Liz Pitt

The NIHR Recovery Programme Research involves five research projects in Greater Manchester focusing on psychological approaches to understanding and promoting recovery from psychosis. It was inspired by a piece of user-led research looking at service users' experiences of recovery from psychosis¹. The research projects within the Programme were initiated by a group of academics and clinical psychologists led by Professor Tony Morrison, including Professor Christine Barrowclough, Professor Richard Bentall, Professor Gillian Haddock, Professor Steven Jones and Professor Nick Tarrier.

Service user researchers Liz Pitt and Martina Kilbride were consulted about the plans for the research, and were invited to be grant applicants responsible for overseeing the service user involvement in the Programme. Additional consultation took place with other local service users. The service user researchers were also able to collaborate on plans for service user involvement in the research. The experience indicates the benefits of involving service users as early as possible in the research process and the need to ensure that funding is available nationally to enable this to happen.

Plans for involving service users in the Recovery Programme Research were made at three levels. Firstly, the employment of three service user researchers who would be involved in all stages of the research including consultation, recruitment, interviewing and dissemination. Secondly, the involvement of service user consultants at a project level, according to the needs of individual research projects. And thirdly, the establishment of a Service User Reference Group (SURG) to meet bi-monthly in order to provide ongoing service user input into the Programme.

Service users were invited to a launch of the Recovery Programme Research in March 2008. They were identified through existing service

user contacts and local service user groups. Efforts were made to ensure that the launch event was accessible to service users. Fourteen service users were recruited at the launch to be involved as service user consultants. They are now involved in a diverse range of activities, including input into the development of a measure of symptom recovery; input into the

Experience indicates the benefits of involving service users as early as possible in the research process and the need to ensure that funding is available nationally to enable this to happen.

development of a *Recovery Guide*; feedback on the measures being used in research; and feedback on interview schedules used for qualitative interviews. Service users have also participated in staff recruitment; provided advice about participant recruitment; helped to design recruitment leaflets; and been involved in conducting some qualitative research on what research participants gain from being involved in research. The SURG meets bi-monthly and provides input into management meetings for the Recovery Programme Research. Service users are

reimbursed for their involvement at a rate of £10 per hour plus travel expenses. Service user involvement fees were costed into the budget from the outset.

Involving service users to this extent in a large research programme involves a learning curve for all involved. Advice and support from Tim Rawcliffe, the Service User Development Officer for the MHRN North West Hub, has been invaluable. Plans are in place to interview service user consultants about their motivation for getting involved in mental health research, and their experience of being involved in the Programme. Equal opportunities monitoring will also take place to measure whether the involvement reflects the diversity of service user experience. The lack of representation from black and ethnic minority communities is already a cause for concern. It is hoped that we can learn from the experience of service user involvement in the Recovery Programme Research in order to extend and ensure more representative involvement in mental health research in the future.

■ Liz Pitt is a Service User Researcher in Psychology Services at Greater Manchester West Mental Health NHS Foundation Trust, liz.pitt@gmw.nhs.uk

■ Project 3 in the Recovery Programme Research – *Recovery-focused self-help therapy for psychosis* – has been given the Gold Award from the MHRN for the *Best Example of Service User Involvement in a Portfolio Project adopted by the MHRN*.

1. Liz Pitt, Martina Kilbride, Sarah Nothard, Mary Wellford and Tony Morrison, (2007), *Researching Recovery from psychosis: a user-led project. Psychiatric Bulletin*, 31, p 55-60.



Research News

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Join *Service Users in Research*

Simply fill in the membership form
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The 2009 MHRN Scientific Conference will be held at the East Midlands Conference Centre in Nottingham on 20-22 May. See page 4

Introducing... **Service Users in Research**

Welcome to the first issue of the new *Service Users in Research* newsletter. *Service Users in Research* is part of the National Institute for Health Research (NIHR) Mental Health Research Network (MHRN) and aims to promote service user involvement in the research studies supported by the MHRN. The MHRN actively supports more than 170 research projects across the country and is adopting new studies all the time.

Service Users in Research helps service users to get involved in the MHRN. We also help the eight MHRN offices (called Hubs) involve service users in their work, and develop good practice guidelines and policies about the best way to do that. We support service users to develop research proposals by getting involved in MHRN Clinical Research Groups (see page 3). And we promote awareness throughout the MHRN of the value of including

service users in all stages of a research study.

Service Users in Research is holding a launch event on Tuesday 24 March 2009 at The Wellcome Trust in London. Service user researchers are speaking at the event, and the annual MHRN award for *Service User Involvement* is being presented to Christine Barrowclough of Manchester University for her study *Recovery-focused self-help therapy for psychosis: an evaluation of different modes of delivery*

and patient preferences (page 6).

The *Service Users in Research* office is based at the Institute of Psychiatry in London. The full-time Coordinator of the group is Thomas Kabir (see page 2) and our contact details are on page 4. If you would like to receive updates about our work and copies of the newsletter on a regular basis, please fill in the membership form on page 5.

We look forward to working with service users to develop *Service Users in Research*. We would like suggestions on how best to do this, and are particularly keen to develop our website (www.mhrn.info) and then click on the 'service users and carers' tab). Please let us know how we can improve the website to make it as useful as possible. Email Thomas.Kabir@kcl.ac.uk with suggestions and comments.

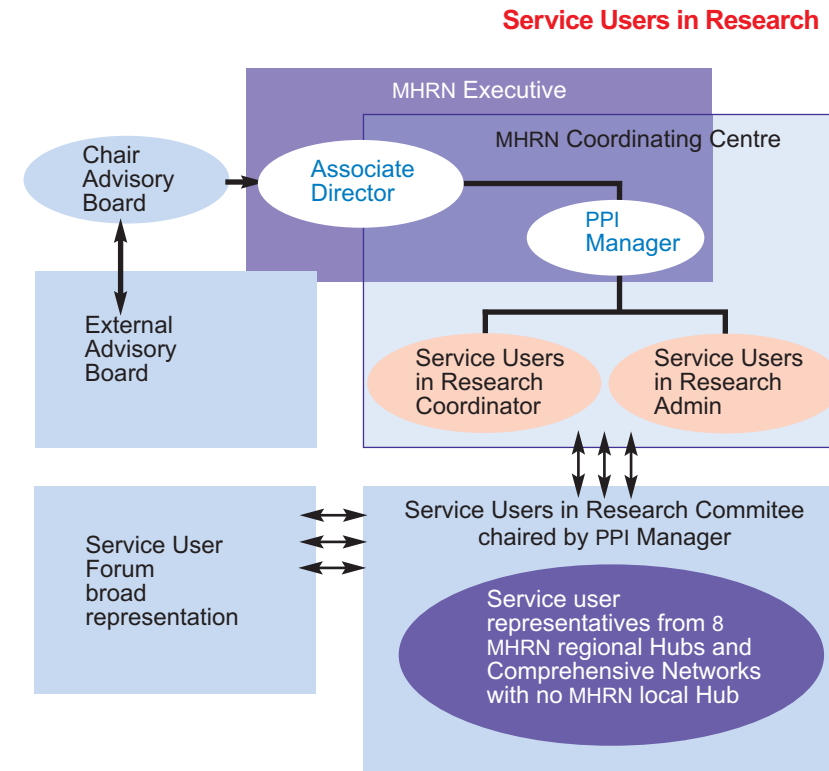
Service Users in Research: People and Structure

This is a diagram showing the structure of *Service Users in Research*. The two main bodies are an external Advisory Board and Committee. Both are made up almost exclusively of service users.

The MHRN Coordinating Centre
The staff of *Service Users in Research* are all part of the MHRN Coordinating Centre which is hosted jointly by the Institute of Psychiatry in London and the University of Manchester.



The MHRN Associate Director for User and Carer Involvement is Professor George Szmukler (pictured above) who is an experienced researcher at the Institute of Psychiatry. The Patient and Public Involvement (PPI) Manager is Joanne Ashcroft (pictured right) who is based at the University of Manchester. *Service Users in Research* is now recruiting an administrator who will also work with FACTOR, the MHRN network for carers with an interest in mental health research.



Service Users in Research Coordinator

Thomas Kabir is the new *Service Users in Research* Coordinator. A service user from London, he was a mental health advocate in the capital for three years and is active with his local service user group. He is also involved in the NHS *Improving Access to Psychological Therapies* (IAPT) programme for London. (www.iapt.nhs.uk)

He says: 'We are really keen to hear your views of what you would like from *Service Users in Research*. Over the next few months, I will be visiting each of the eight MHRN Hubs to speak to service users and staff. If you have any suggestions about how *Service Users in Research* might develop, please contact me.' Thomas.Kabir@kcl.ac.uk

Committee

The Committee comprises staff from the MHRN Coordinating Centre (PPI Manager, Joanne Ashcroft, pictured below, and Thomas Kabir) and two service user representatives from each MHRN office or Hub, plus service user representatives from parts of England not covered by the eight MHRN Hubs. The Committee is chaired by Joanne Ashcroft and meetings will take place every two months. The first meeting will be held in April.

The *Service Users in Research* Committee will share ideas and good practice and will provide a support network for service users in the MHRN.



What are MHRN Clinical Research Groups?

These groups allow carers, clinical academics, clinicians, researchers and service users from a wide range of disciplines to come together to identify areas of strength and weakness in research, pinpointing suitable topics and producing research proposals to run on the MHRN.

Service User Forum for Research

The Forum will be open to any service user or service user organisation with an interest in mental health research. It will provide an opportunity to discuss new ideas concerning *Service Users in Research* and service user involvement in the MHRN. The Forum will meet once a year.

Service Users in Research Advisory Board

The external Advisory Board is chaired by Sue Collinson. Sue has a PhD in History and has held academic posts in health policy and community-based medical education. She has worked as a service user researcher, has served on mental health research Steering Groups, and has been a Trustee of Depression Alliance. She has also been chair of a Local Government Committee in her local constituency, and chair of School Governors. Sue currently works with a multi-disciplinary service for people with tuberculosis who have complex needs.

Membership of the Advisory Board will be drawn from a range of professional and organisational backgrounds. The aim is that all members are service users. The Advisory Board will meet twice a year and will advise on strategic questions as well as offering external perspectives on the work of *Service Users in Research*.

Service user involvement in the North West Hub

by Tim Rawcliffe

There are currently grounds for cautious optimism with respect to service user involvement in mental health research in the North West. On page 6, Liz Pitt describes the NIHR Recovery Programme Research and parallels can be drawn with the current work around psychosocial research into bipolar disorder.

The Spectrum Centre for Mental Health Research at Lancaster University opened in 2008, and has a close relationship with the North West MHRN Hub. From the outset, there has been a demonstrable commitment to including an experiential perspective to the research agenda. Two of the earliest members of staff recruited had had direct personal experience of bipolar disorder, and their presence has had a significant influence on both the work and the culture of the Centre.

The research team at the Centre was recently successful in securing a NIHR Programme grant for *Psychological approaches to bipolar disorder and comorbid problems* (acronym PARADES), with one of the service user researchers named as a co-applicant on the bid, leading on service user involvement across the Programme and having a key role in the study addressing psychoeducation interventions delivered by 'expert patients' and clinicians. Other studies within the Programme include service user-led qualitative interviews of individuals' experience of both anxiety and substance misuse to inform the development and evaluation of treatment manuals; the issue of suicidality; and whether advance directives impact on the lives of people with bipolar disorder. The overall research Programme will have the support of a service user reference group.

The foundations for future collaboration between the Centre and the MHRN are also in place, with the Centre currently hosting the second North West based

MHRN-funded Clinical Research Group. The healthy presence of service users on this Group, including representation from the Manic Depression Fellowship, is having a positive impact on the projects under development.

The North West Hub, in collaboration with the North West Mental Health R&D Alliance, recently staged a conference to acknowledge the local achievements of academic researchers and service users in the region. The Recovery Programme Research and PARADES were among six projects showcased for their demonstration of partnership work between service users and the academic community. The clear message that came across at the conference from both speakers and audience was that these research programmes, with their high level of service user involvement, would do much to shape the future of mental health services.

I began this piece with cautious optimism: the Recovery Programme Research and PARADES are commendable in their involvement of those who have direct experience of using mental health services. However, if the MHRN is 'to broaden the scope and capacity of research in mental health, including full involvement of service users and carers', then these relations demand nurturing and fostering, until the exceptional becomes the norm.

■ Tim Rawcliffe is Service User Development Officer, North West MHRN, Tim.Rawcliffe@Lancashirecare.nhs.uk

Service Users in Research work

Service Users in Research is just starting out and will be hard at work over the next few months. We will be updating the popular good practice guidelines for involving service users in research, and our future work will be shaped by the *Service Users in Research* Committee and Advisory Board (see pages 2 and 3). Here are some examples of our current work.

Scientific Conference

Service Users in Research, together with FACTOR, is organising a service users' and carers' pre-conference gathering at the MHRN Annual Scientific Conference which will be held in Nottingham, 20-22 May 2009. To find out more about the conference, visit www.mhrn.info/index/about/conference.html. There are some free places for service users and carers and you can apply for these by contacting your local Hub. To find out where your local Hub is, check online at www.mhrn.info/index/research.html. If you click on the area in which you live, the contact details of the Hub covering your region will appear.

Lay summaries

At the end of a research project, the findings are written up for publication in professional journals. The language that researchers use in these journals is often very technical and hard to understand. A lay summary is a short report of a research project or research findings, written in plain English. The aim of this is to make mental health research as easy to understand as possible.

Some lay summaries have been produced by service users and placed on the website of the North London MHRN hub: SUNLOWS (www.sunlows.org.uk). These lay summaries have been well received and *Service Users in Research* will build on this good work in future and will commission a lay summary for every research study that is supported by the MHRN. These summaries will then be available to everyone through the MHRN website.

Some lay summaries of mental health research studies going on in the UK are available on the TriMe (Trials Information for Mental Health) website, www.trime.org.uk

MHRN DVD

Service Users in Research is involved in producing a short film which explains the work of the MHRN and how service users can get involved in mental health research. The film will include interviews with service users who participate in research and service users who undertake research. It will also include information about some key MHRN documents, such as the well-used good practice guidelines for involving service users in research.

Join Service Users in Research

Membership of *Service Users in Research* is free and open to anyone with an interest in mental health research. Organisations are also welcome to join. Members can choose to receive the *Service Users in Research* newsletter, email updates, and information about *Service Users in Research* and other MHRN activities. To join, please fill out the membership form on page 5 and return it to the Freepost address printed on the form.



The SUNLOWS website: www.sunlows.org.uk

Events

MHRN Annual Scientific Conference
Nottingham
20-22 May 2009

Some funded places for service users and carers will be available from your local MHRN Hub. For more information, visit www.mhrn.info

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