



## *Service User Research Group England*

*Mental Health Research Network*

**Newsletter 2**

**Spring 2006**

### **What is SURGE?**

SURGE is the Service User Research Group in England and is the service user arm of the UK Mental Health Research Network (MHRN). We have been set up to support mental health service users and people from universities and NHS trusts as they work together on mental health research.

For more information on the MHRN and SURGE, please see our website at: [www.mhrn.info/surge.html](http://www.mhrn.info/surge.html)

## **Latest News**

### **Progress So Far**

After a period of restructuring, SURGE is up and running again, with Jan Wallcraft and Jonathan Bindman being joined by three new members of staff. The team, with its two dedicated research workers, Beate Schrank and Louise Morgan, and its administrator, Leonie Barron, is based at the Sainsbury Centre for Mental Health in London. The new staff are already making headway in various initiatives which will, we hope, lead to an increase in the level and effectiveness of service user involvement in research.

As you are probably aware, a major achievement of SURGE last year was the publication of its Good Practice Guidance booklet (download a copy at <http://www.mhrn.info/dnn/Portals/1/documents/MHRN%20SURGE%20Guidelines.pdf> or request a copy from the SURGE office), which contains a huge amount of useful information and advice on involving service users in mental health research. To complement this, and by popular request, we are now working on the production of a shorter document specifically to offer step-by-step, practical advice. This companion to the Good Practice Guidance will be quick and

easy to consult, and provide the basic tools for good practice in user involvement to all involved at all levels of mental health research.

We are pleased to report that new service user involvement development worker posts have been created in the North West and East Midlands hubs (filled by Tim Rawcliffe and Jean Sharp respectively), and recruitment is in progress at the Heart of England hub; sadly, though, Helen Phillips's post at the East Anglia hub will be finishing at the end of April. Contributions from Tim Rawcliffe and Helen Phillips can be found elsewhere in the newsletter. A priority for SURGE is to bring together all those who work in this area in the different hubs, so we will be hosting a meeting on 5<sup>th</sup> April at our offices in London where ideas can be pooled, support given and strategies discussed. A report on this meeting will appear in the next SURGE newsletter.

Work is continuing in the important matter of assessing and assisting good practice within each of the MHRN projects – see the separate article for a review of the findings of last year's survey, and how we are making progress in this area.

Following the success of the road show last year, hosted by the East Midlands hub in partnership with SURGE, we are hoping to organise a similar event in a different hub this summer. Meanwhile, members of the team have been raising the

SURGE profile by attending the Health R&D NoW “Bringing Users and Researchers Together” event in the North West hub in January (see Tim Rawcliffe's report) and the North London Hub Annual Conference in February; they will be also be attending a service user strategy group meeting in the North East hub on 28<sup>th</sup> March, and participating in the East Anglia hub event on 21<sup>st</sup> April entitled “Service User and Carer Involvement in Mental Health Research”.

## Mind Conference

The SURGE team was at the Mind Annual Conference on 15<sup>th</sup>-16<sup>th</sup> March, running a workshop on the Thursday afternoon entitled “Service User Involvement in Mental Health Research: Partnership or Co-option?”. The workshop was felt to be very useful and stimulated a great deal of lively debate. A full report will be included in our next newsletter.



Beate Schrank, Leonie Barron and Louise Morgan

## Service User Involvement in Research: Roles, Funding and Training

Last summer, SURGE carried out an audit of service user roles, payment and training within MHRN projects by sending out questionnaires to service users and academic researchers.

Although response rates were not very high and it was sometimes difficult to access information about individual projects, a picture emerged showing service users participating as: 1) hub committee and executive committee members; 2) research group members; 3) project advisory group members; 4) SURGE working group members; 5) survivor researcher associates and interviewers; and 6) service user involvement co-ordinators.

### Role Descriptions

Few service users involved had a written role description - although in some hubs, these were under development - and some had had no opportunity to discuss their role with an MHRN colleague. Most discussions which had occurred had been about expenses and the nature of the service user's involvement. In spite of the promising developments underway, it was evident that more clarity about the roles of service users was desirable.

### Payment Issues

Further clarification is also desirable on the issue of payment

as, although most service users did receive some kind of payment, rates varied a lot; in addition, the complexities of the benefits system meant that some service users were financially disadvantaged by their involvement. On the positive side, in some instances, funding policies were under development.

### Training

It was clear that awareness of and access to training varied by region, with most training courses reflecting local collaboration between trusts, universities and service user groups.

### Further Work Needed

While the survey produced enough data to give a useful overview of service user involvement within the MHRN, there were gaps (many service users in MHRN projects could not be reached by the survey, and things have also moved on in recent months) which SURGE hopes to fill.

By identifying the service users involved in projects and contacting them and other research staff to ask them about their successes, their problems and their needs, SURGE will assess, and subsequently provide, the kind of support needed for the practical implementation of its Good Practice Guidance (available at <http://www.mhrn.info/dnn/Portals/1/documents/MHRN%20SURGE%20Guidlines.pdf>), thereby improving service user involvement within the MHRN and beyond.

# Being Involved

## Research Interest Networking Database

SURGE is setting up a database of people with experience of mental health problems/using mental health services or those identifying as survivors who would like to be involved in mental health research within the Mental Health Research Network (MHRN). We would also like to encourage research staff to contact us with details of opportunities for involvement.

This way, we aim to link interested service users/survivors with research staff looking to involve service users/survivors. We hope this will become a great way of connecting people but it can only work if both service users and researchers keep us informed of their areas of interest and activity.

So if you are looking to involve service users, please get in touch with details of your work. Likewise, if you are a service user/survivor and would like to get involved, please do register on the database. We can then send you information about opportunities for involvement in your chosen areas when we receive matching requests from MHRN hubs and projects. We will only use your details to contact you with information of opportunities for involvement and/or training, and we will not pass on your details to

anyone else without first seeking your permission. If you would like to register on the database, there is a form at the end of this newsletter that you can detach, fill in and return to us.

## *The Survivor Researcher Network (SRN)*

*The SRN is an informal network of people who have experience of mental health problems or emotional distress. We are interested in sharing experiences of being researchers in the mental health field. Feel free to come and join us if you are a service user or survivor doing research. We meet up in London every quarter and reasonable travel expenses will be paid. For more information, please contact Sarah Gillespie on [sgillespie@mhf.org.uk](mailto:sgillespie@mhf.org.uk) or 020 7803 1155.*

# Reports from across the MHRN

## **Justine Schneider**

Co-ordinator, MHRN Social Capital  
Research Group

### WHAT MAKES FOR A GOOD LIFE? BRINGING IDEAS ABOUT SOCIAL CAPITAL TO BEAR ON MENTAL HEALTH RESEARCH

People who become service users often lose their social networks. They may find themselves living in a place they have not chosen, among people whose values they do not share.

‘Social capital’ is a concept which is used widely in economics, geography and even in criminology, but which we don’t use much in mental health research. It focuses attention on the situation in which people live, particularly on aspects of these situations which are associated with recovery. Social capital is described as the non-economic resources to which people have access. This includes the social networks they possess: family, friends and acquaintances. It also includes aspects of the places where they live, amenities, levels of community participation, the area’s desirability or otherwise in terms of crime, pollution, schools and transport. Finally, social capital is also about my perceptions of my living environment: do I feel I am secure there? Do I exchange

favours with my neighbours? Am I hoping to get away soon?

The social capital research group is interested in the effect of social capital on recovery from mental health problems, and in the role of mental health services in creating or undermining social capital. More broadly, we are also interested in social capital and wellbeing in general. We are working with Making Waves, a service user group in Nottingham, to develop fundable research proposals. We hope that the results will ultimately guide service development and inform our understanding of how society and service users can affect each other, for good or ill.

## Helen Phillips

Service User & Carer Co-ordinator,  
East Anglia Hub

I have been in this post since May, 2005. This was a new half-time role (initially for 6 months, then extended to a year) with an ambitious job description. I approached it by giving talks and meeting as many key people and service user and carer groups as possible in the region, nationally and across Norfolk, Suffolk and Cambridgeshire so that I could listen to issues and concerns, share information, and publicise the work of the MHRN and East Anglia Hub.

Following publication of the SURGE Good Practice Guidance, I felt there was a need for a shorter version for users and carers wanting to know more about getting involved in mental health research, so I produced one for our area, suitable for adaptation by other hubs.

From a selfish point of view, it was unfortunate that there was a hiatus between Sarah Gibson leaving and the new SURGE team getting into post, as it led to a loss of impetus on important issues - e.g. actual involvement by users/carers in adopted projects - which had a knock-on effect on what we were trying to achieve out in the sticks. Fortunately, things are now looking up, but it's probably too late for me.

I found little evidence of research activity involving service users and carers as researchers in our region, and most of it was more aligned to

Trust R&D activity, i.e. service evaluation, audits etc., where such involvement is now more common. There needs to be further research capacity building between R&D departments, universities, the MHRN and other partners to ensure that users and carers interested in becoming researchers can get involved as it suits them, and be given the relevant information, opportunities, training and support. Trusts and R&D departments are best placed to continue leading on locally based research, quality and capacity building activity, with hubs providing a national perspective, opportunities for joint events, networking, etc. This may develop a route from small- to large-scale research and create a pool of people interested in all types and levels of research involvement.

Service user and carer involvement in research is government and MHRN policy, but mutual suspicion between some researchers, users and carers and indifference to the relevance of collaborative working seem hard to overcome. Until a body of evidence demonstrates that such involvement makes for more meaningful research, this is likely to remain the case. Research needs to be commissioned to provide such evidence and move the debate - and practice - forward.

Finally, it may be better not to have a dedicated 'user/carers' post in the hubs. That way, ensuring their involvement has to become everyone's concern.

## Rogan Wolf

User Representative,  
North London Hub

The North London hub has paid for me to act as their user representative, and I give them a few hours a week. Half of the rest of my week is given to acting as User Support Worker for Westminster. In that role, I have helped develop a professional code of conduct for meetings such as ward rounds and CPA meetings which has been adopted as policy by several Trusts now, and has been commended by NIMHE, who have offered help in promoting it nationally. I have also helped develop a model of user involvement in staff recruitment which entails a separate user panel who assess candidates on their core relationship skills. The panel takes part in interviews for consultant psychiatrists and senior managers. Recently it was involved in some major tendering-out interviews. This model has been commended by CHI. More details on these and other initiatives can be found on [www.hyphen-21.org](http://www.hyphen-21.org)

I think user involvement in research is important and potentially valuable, but will be difficult to do right and in a way that is both genuine and genuinely effective. User involvement is all about questioning and thinning that screen which so easily goes up between helper and helped, order and disorder, observer and observed, us and them. And medical research on mental health

issues is arguably an activity where that screen is going to be thickest of all. Just as an example, the language of research is a particularly specialist and cerebral one, almost separatist, and the average research conference is very hard for lay people to sit through, let alone take a real and active part in. How can user involvement in the hubs be anything more than just an extended recruiting exercise for research projects already fixed and decided?

Here is my own little list of initiatives that might be made to count.

As far as the North London hub is concerned, the users so far involved have taken part very usefully in interviews for CSOs (Clinical Studies Officers) and were able to pick up on some important features. Above all, they must have the core relationship skills, and a user panel is surely the best tool for testing for these.

Most of my time, though, has gone into thinking through and developing a service user website for North London hub. The main argument for it is that the North London hub covers a huge geographical area and I cannot realistically expect to establish effective working relationships with users or user groups whom I can only visit very occasionally. Nor do I think it realistic to expect a working group of interested people to form

with any meaningful frequency when several would have to travel real distances to get to the meeting place.

So let the website carry up-to-date information, clearly written, “translated” by interested service users into user-friendly lay-language. Let it have a chat-room, managed by interested service users, meeting regularly, and having access to researchers who might be able to answer technical questions. Let it carry a glossary of terms, reviewed regularly, to help people find their way through some of the research terminology and abbreviations. Let it carry other items of interest and appeal to service users, which might draw people to the site as an online community that can create an interest in research. For many people do not otherwise see the relevance of research to their lives, or think of visiting a site that deals with it.

The site is pretty well finished now, though at the time of writing we are still exploring some issues of control and ownership. Assuming we can resolve those, we shall soon be advertising the site among user groups and mental health services across the North London hub area, and we’ll be asking other service user websites to link over to us. In turn we shall be providing links to other hubs and, of course, to SURGE.



## Tim Rawcliffe

Service User Development Officer,  
MHRN NW

### HEALTH R&D NoW 'BRINGING USERS AND RESEARCHERS TOGETHER' EVENT

On 17<sup>th</sup> January, a pilot event took place at Liverpool John Moores University that aimed to bring interested clinical and academic researchers and mental health service users together to consider future collaborative relationships, and to explore the potential for the latter to become more actively involved in the research process. I co-chaired the event with Mark Gabbay, Acting Director of Health R&D NoW and Primary Care Lead for the North West MHRN.

Approximately 60 delegates from Merseyside and Cheshire attended the day, which was divided into a morning of presentations from guest speakers in the field of Mental Health Research and an afternoon of workshops.

Dr Sara Morris of HRDNoW opened the day with an overview of the research process and the different levels at which service users could become involved, from policy to participation at every stage of research. She also highlighted the many benefits that active service user involvement could bring, not least the pursuit of citizenship for an all too often marginalised population.

This was followed by a critical account by Professor David Pilgrim, who sounded a cautionary note by highlighting some of the tensions that exist between the 'critical' agenda pursued by some in the service user movement and the demands facing Health and Social Care providers to involve the public in Mental Health policy developments. (For a full account, see his chapter in the Sainsbury Centre publication *Beyond the Water Towers*, (Bell, A. and Lindley, P. (eds.) 2005).

Dr Sue Spiers from the National Forensic Mental Health R&D Programme spoke of involving service users in commissioning research and the significant achievements of the Rampton Patients' Council in reviewing research proposals.

Dr Danielle Oliver and Suzi Curtis discussed the use of service user researchers in the INVOLVE project, which is currently being run on the MHRN, and the potential for improved research validity by employing service users to carry out interviews with individuals about their experiences following detention under the Mental Health Act.

The morning session concluded with an account by Dr Mohammed Ashur, from the Liverpool Healthy Mind Project, of the difficulties facing Somali refugees living in the UK. He pointed to the negative impact and continuing present-day

legacy of Western imperialism in 19th century Africa, which imposed alien conceptions of mental health on traditional methods of dealing with mental health and distress.

Delegates had the choice of attending four workshops in the afternoon:

- i) Underlying principles for user/carer involvement in mental health research;
- ii) User involvement in doing research;
- iii) Training and skills development for users/carers wishing to get involved in mental health research;
- iv) User involvement in reviewing research proposals.

Feedback from the four workshops revealed a number of recurrent themes, including, *inter alia*: the existence of ongoing service user research; the importance of full participation in the research process wherever possible; the related issue of the need for a sense of 'ownership' of any research undertaken; financial recompense for any work undertaken; the value of qualitative research methodologies and the need for the research priorities of service users to be taken seriously. It became clear that further joint training was needed, as were opportunities for collaborative discussion, and the notion of establishing 'research interest groups' was put forward as a way in which 'professionals' and 'service users' might mutually benefit.

Although formal evaluation of the event is ongoing, the perception I had of the day, from conversations with delegates, was that the majority considered it to have been interesting and beneficial. Many thought that the achievements of the day should be pursued and the ideas generated developed further.

I promised that the formal report of the day would be circulated to everyone who asked to be kept informed of our next steps, and once that is available, I will contact all interested parties. In addition, SURGE, the service user arm of the MHRN, invited individuals with particular research interests and concerns to contact them at [info@SURGE.scmh.org.uk](mailto:info@SURGE.scmh.org.uk)

I hope my account does not differ greatly from the experience of everyone present, and I would appreciate comments and feedback that were not expressed on the day.

Finally, acknowledgement is due to Maggie Clifton of Health R&D North West for the time and energy that she put into organising the day, and for ensuring that it proved to be the success that I believe it was. Cheers, Maggie!

Tim Rawcliffe  
Service User Development Officer  
MHRN (NW)  
The Lantern Centre, Vicarage Lane, Fulwood, Preston, PR2 8DY.

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## **Ann Priddey**

### **East Midlands Hub Co-ordinator**

The East Midlands Hub held its launch event in October 2005. At this event, we continued the debate around the tensions that exist when trying to involve service users and carers in mental health research. We did this by commissioning a piece of theatre to explore the issues. The script was written by a local steering group which included local service users, service user researchers and carers. We filmed the theatre piece at the launch so that we would have a teaching tool which we and other hubs could use in the future. If you would like a copy, please contact me on [ann.priddey@nottingham.ac.uk](mailto:ann.priddey@nottingham.ac.uk). We are continuing this debate and further exploring the issues at a wider stakeholder event that we are holding in May this year.

Another exciting development locally is that we have joined with Nottinghamshire Healthcare NHS Trust to fund a Patient and Public Involvement in Mental Health Research Liaison post. The post has been advertised and will be for a year and part time. We see the post as a facilitative one, enabling more people and organisations to be involved in mental health research and mental health research studies. This includes both the national mental health research studies hosted by the UK MHRN and locally generated studies. The local research studies will be both collaborative projects and service user led projects, and

will have the potential to be hosted nationally in the future. One of the key tasks for the new post holder will be to develop the mechanisms and support required for people to be involved in mental health research, including training and the identification of research questions that are important to service users and carers. Our aim is to try and increase capacity for involvement locally, so that individuals and organisations who have never been involved before can participate not only locally, but nationally in the work of the UK MHRN.

## **Jill Thompson**

### **North East Hub Co-ordinator**

The issue of service user involvement is going to consultation in the North East Hub. The first meeting of the steering group, comprised of local service user representatives from the four Trusts involved in the Hub Consortium, NIMHE, independent groups, SURGE personnel and members from the Hub Executive Committee, is organised for 29th March, 2006. It is hoped that a clear strategy for implementing the SURGE Good Practice Guidance in hub activities will emerge from this meeting, and that we will become clearer about the next steps required to secure user representation on the Hub Executive Committee.

Watch this space!

## Marion Clark

### SURESearch

An exciting development for user and carer involvement is the new Centre of Excellence in Interdisciplinary Mental Health (CEIMH) based at Birmingham University. The Centre will work within higher education and the mental health sector nationally and internationally to improve and expand on what is currently taught to students about mental distress and mental health.

For users and carers, recognition of their crucial role in developing a more profound understanding of mental health and improving responses to people experiencing mental health difficulties is welcome, especially when it is underpinned by resources. The Centre will help bring together the wonderful work done by users, carers and their allies and ensure their vision is central to the education of future professionals.

Central to this work is a commitment to interdisciplinary working and learning between professional groups, and to ensuring that the body of knowledge held by users and carers is integrated on an equal basis with other disciplines into teaching and learning programmes.

To implement its aims, the CEIMH uses innovative approaches such as creating a Virtual Centre which will house a multimedia repository of mental-health-related learning

objects and provide online forums to enable the communication of ideas that promote excellence in interdisciplinary teaching, learning and practice.

The physical Centre will open later this year and provide a welcoming space for information, training and exchange of ideas.

The Centre's partners include the Heart of England Mental Health Research Hub, the Mental Health in Higher Education project (mhhe), NIMHE, the Triple project on Interprofessional Education (IPE), the NHS Institute for Innovation and Improvement, and SURESearch, a user-led training and research partnership based at the University of Birmingham. A core team is in place which includes two user involvement co-ordinators and a user network co-ordinator.

The Centre of Excellence in Interdisciplinary Mental Health can be found at:

[www.ceimh.bham.ac.uk](http://www.ceimh.bham.ac.uk)

or at the University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Tel: 0121 414 5734.

# End Note - Have your say

The aim of this newsletter is to inform people across the Mental Health Research Network about the work of SURGE and the development of service user involvement in research across and around the network.

This will provide a national forum for you to share your experience, ideas and priorities as we seek to develop good practice in working together across the network.

If you have any comments on this newsletter or wish to contribute a short summary of your experience as a service user or survivor involved in or around the MHRN or your experience of developing work alongside service users and survivors in research around the network, we'd love to hear from you.

You can send your ideas, articles, questions or comments about SURGE work to [info@surge.scmh.org.uk](mailto:info@surge.scmh.org.uk) or SURGE, SCMH, 134-138 Borough High Street, London SE1 1LB, or phone us on 020 7716 6778.

Hard copies of this newsletter can be requested by contacting us at the above address.

## Research Interest Networking Database

If you would like to be included on the database (see the article on P4 of this newsletter for further details), please fill in this form as fully as possible. We will only use your details to contact you with information of opportunities for involvement and/or training, and we will not pass on your details to anyone else without first seeking your permission.

My research interests are:

(Please tick as many as apply to you.)

- |  |  |
|--|--|
| <input type="checkbox"/> User-led Research                     | <input type="checkbox"/> Older People                                    |
| <input type="checkbox"/> Recovery                              | <input type="checkbox"/> Black & Minority Ethnic Issues in Mental Health |
| <input type="checkbox"/> Social Perspectives                   | <input type="checkbox"/> Refugees/Asylum Seekers                         |
| <input type="checkbox"/> Personality Disorder                  | <input type="checkbox"/> Women's Mental Health                           |
| <input type="checkbox"/> Bi-Polar Disorder                     | <input type="checkbox"/> Sexuality                                       |
| <input type="checkbox"/> Self Harm                             | <input type="checkbox"/> Early Intervention                              |
| <input type="checkbox"/> Eating Disorders                      | <input type="checkbox"/> Primary Care                                    |
| <input type="checkbox"/> Psychosis                             | <input type="checkbox"/> Crisis and Acute Care                           |
| <input type="checkbox"/> Depression                            | <input type="checkbox"/> Physical Disability/<br>Sensory Impairment      |
| <input type="checkbox"/> Schizophrenia                         | <input type="checkbox"/> Complementary/<br>Alternative Therapies         |
| <input type="checkbox"/> Psychotherapy                         |  |
| <input type="checkbox"/> Child and Adolescent<br>Mental Health |  |

Other (please specify):

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My **specialist skills** are:

(Don't let this question put you off; we are equally keen to hear from people new to research or wanting to build up skills in this area.)

Previous research experience

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Relevant qualifications

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Would you like **training** in research skills? If so, please specify:

- Research methods
- Writing research proposals/applications
- Research design/methodology
- Research funding and networking opportunities
- Research governance
- Statistical analysis
- Non statistical (i.e. qualitative) data analysis

Other (please specify):

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Would you be willing to act as a mentor/buddy for service users new to research?  Yes  No

Name: \_\_\_\_\_

Email address: \_\_\_\_\_

Postal address: \_\_\_\_\_

\_\_\_\_\_ County: \_\_\_\_\_

Postcode: \_\_\_\_\_

Please tick this box if you agree for your details to be stored on our networking database. We will not pass on your details to any one else without your permission.

Please tick this box if you would also like to receive our quarterly newsletter.

Please note we cannot offer any guarantee of involvement. This database is intended as a starting point to link people with similar interests together. You will need to negotiate the actual terms of involvement and any details of payment with research staff.

**Please return this form to: SURGE, Sainsbury Centre for Mental Health, 134-138 Borough High Street, London SE1 1LB.**

Thank you for registering your interest in becoming involved in mental health research within the UK MHRN.

If you have any questions about this form or the networking database, do not hesitate to contact us at: [info@surge.scmh.org.uk](mailto:info@surge.scmh.org.uk) or 020 7716 6778.