



# *Service User Research Group England*

## *Mental Health Research Network*

**Newsletter 1**

**Autumn 2005**

### **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 are 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](http://www.mhrn.info/surge)

## **Progress so far**

### **Good Practice Guidance**

Following an extensive review of the literature, contributions from SURGE partners and visits to case sites, The SURGE Good Practice Guidance for service user involvement in research projects and programmes within the MHRN have been produced. The Good Practice Guidance consists of a literature review, case studies and guidance for good practice and is available to download now at [www.mhrn.info/surge](http://www.mhrn.info/surge)

### **Field Report**

A brief scoping exercise has also been carried out to generate an understanding of service user activity within and around MHRN Hubs. This report identified the following needs for development:

- spaces to meet, talk and develop
- information, advice and guidance
- financial support
- training and development

### **Roles, Funding and Training**

SURGE is currently examining roles, role descriptions, working arrangements, funding and payments for service users in all kinds of roles in the MHRN. We are also collecting information about training that has been accessed by service users so far. This information will be used to help further development of Good Practice in Service User involvement around the UK-MHRN

## The Connect Roadshow

On 29<sup>th</sup> June, SURGE co-hosted a SURGE/Hub Road show in the East Midlands, which provided space for regional networking and information exchange between service users and other stakeholders in Mental Health research. The roadshow offered opportunities to hear and learn about Mental Health research, the MHRN and Good Practice in involving service users and survivors in research. It also allowed people to make connections with local research projects and discuss future plans for research and involvement. It is hoped that other roadshows will be held at other MHRN Hubs across the UK in the future

## All change as SURGE enters it's second year

As SURGE enters its second year, there will be a number of changes to its organisation. The office has now moved from the Mental Health Foundation (MHF) to the Sainsbury Centre for Mental Health, where it will benefit from the friendly and supportive office environment, though SURGE remains independent of its Sainsbury 'hosts'.

Sadly, Sarah Gibson, the SURGE Co-ordinator during the first year, is remaining at the MHF in a full time capacity as a survivor researcher, though she will continue to provide occasional support to SURGE. We are very grateful to Sarah for her work during a successful first year, which has seen the production of the Good Practice Guidelines, the first of what we hope will be a programme of local 'road shows', and a number of other pieces of work described elsewhere in this newsletter.

Jan Wallcraft, previously associated with SURGE through the Working Group (which represents the service user organisations involved in SURGE at its beginning), is now taking up a more direct role as SURGE Operational Manager. She will be joined by two more researchers to be appointed in the autumn, which will continue the work of supporting service user involvement in the work of the MHRN around the country.

Jonathan Bindman, formerly a researcher at the Institute of Psychiatry, is also joining SURGE as Associate Director for User and Carer Involvement in the MHRN, and will represent SURGE on the MHRN Executive. There will also be changes to the Working Group, which will become a new Advisory Group, chaired by Professor Peter Beresford. The new contact address for SURGE is

[info@surge.scmh.org.uk](mailto:info@surge.scmh.org.uk).

## Hello from Jan Wallcraft

Hi, I'd like to introduce myself as the new SURGE manager. I will be working one day a week, normally at the Sainsbury Centre office. I will pick up the reins from Sarah Gibson, and my key task will be to ensure that everyone in the MHRN knows about the Good Practice Guidelines and has the support and information they need to start trying to implement them. This will mean that we (myself and the new staff when appointed) will be available to help set up regional roadshows and training events and to offer whatever help we can by phone, email etc.

Other priorities for the coming year include:

(a) to discuss the issues arising from closer working with the pharmaceutical industry – what are the implications for service user involvement?

(b) to create a step by step guide or checklist based on the Good Practice Guidelines, to help Hubs and project leads implement and monitor good practice in involvement

(c) to help to network service users involved in research across the country, to keep them up to date with the national mental health research agenda, specifically the work of Surge and MHRN, and opportunities for service users to become more involved.

For more information, or if you want to get involved, please contact me at [j.wallcraft@surge.scmh.org.uk](mailto:j.wallcraft@surge.scmh.org.uk)

## Goodbye from Sarah Gibson – Outgoing SURGE Coordinator

We learn more from working together. I count it a privilege to have met and worked with such a wide variety of people in differing roles across the MHRN and other organisations working towards the development of good practice in service user involvement, over the last year.

Developing service user involvement in research is about investing in the building of working relationships and opportunities for people from differing backgrounds and experience to listen to and learn from each other.

This work takes time and a great deal of energy and commitment. I'm pleased to have been able to start to lay a foundation for establishing good practice in the MHRN. However there is still a long way to go. Good practice guidance needs to be worked out into practice. Roles and opportunities for involvement need to be better defined and there's lots of networking, coordination and awareness raising to do locally, regionally and nationally.

I'm pleased that SURGE is now in the process of appointing two workers to carry on with the work we've started and will be pleased to encourage them and all involved in developing the MHRN in the future.

# Service user involvement across the MHRN

**Gina Smith,  
South London Hub Coordinator**

“The South London Hub has two service user representatives on the Hub committee, one of whom joined us only very recently. The recent SURGE questionnaire that was circulated throughout the UK MHRN alerted the Hub to the fact that no role description exists for Hub service user representatives. This is something the South London Hub is seeking to rectify as soon as possible. The Hub Coordinator will work closely with the two service user representatives to produce a role description to be agreed at the next Hub Committee meeting. The Hub is currently working on several ideas of ways to increase service user involvement in the Hub.

The Hub also has two service user representatives on a Project Site Implementation Group. They have both been in this role since March 2005 and do have full role descriptions. All the Hub Service User Representatives have made insightful and constructive contributions and have found the experience to be a positive one. The Hub would like to take this opportunity to thank them for their work so far”.

For more information,  
contact Gina on  
G.Smith@iop.kcl.ac.uk  
or 020 7848 0691  
contact Debbie on  
debbie.mayes@scmh.org.uk

**Debbie Mayes,  
Service User Representative,  
South London Hub**

“I am one of two service users who sit on the South London Hub. Initially I found it very intimidating because I recognised some of the names of the other committee members as being high up in their field. As a result I had this sense that I wouldn't have anything to add. However I decided to persevere and for the first few meetings I was struggling to understand what it was all about and how I could make a contribution.

The paperwork seemed never ending and I didn't understand why we had projects to look at and discuss when they had already been accepted, so we could not effect any change. I still don't really understand the logic of that, although I think it is the other way round and a chance for us to help the projects.

From a service user view point, I often feel that there is little for me to contribute but I see it as my task to keep my eyes and ears open for anything relating to service users that might need discussing.

I do wonder sometimes if my main role is to ensure that the 'service user involvement' box can be ticked, however despite that nagging doubt I also believe that there is a desire for greater service user involvement and that the only way that will happen is for people like me to keep their bums on their seats and be there to speak up for service users as and when the opportunity arises”.

## **David Richards, Self-Help Research Interest Group**

“The Self-Help Interest Group of the Mental Health Research Network of the UKCRC is a collaboration of service users, service managers, clinicians and academic researchers. The group has met a number of times in order to enable the diverse range of stakeholders interested in improving access to mental health care for people with common and serious mental health problems, to discuss both their shared and different objectives.

The interest group has identified four main areas of research, which are to be taken forward and developed into proposals:

1. Research enabling users to participate in research including researching self-help itself
2. Health services research (cost effectiveness of self-help, effectiveness, service design and evaluation)
3. Clinical efficacy trials for self-help
4. Epidemiological issues - how people utilise self-help in their daily lives

The complete interest group will continue to meet and develop its proposals and to share the participants' different perspectives on self-help. With one funding application already prepared and submitted, the group continues to benefit from the opportunity for diverse stakeholders to contribute to the development of research questions and proposals. The process of topic identification has

involved all interested parties including those representing service user views. Our next task is to capitalise on the generation of ideas and to support group members as they develop proposals”.

For more information contact David on [dr17@york.ac.uk](mailto:dr17@york.ac.uk)

## **Ann Priddey, Hub Coordinator, East Midlands Hub**

“We have developed a questionnaire asking people what their research interests are, what they would like to be involved in and how they would like to be involved. We are currently putting together a database of interested people and hope to link them by their research interests into research interest groups. We will also put them in touch with local research studies, which may be of interest to them and link them with national hosted studies.

We also have series of workshops planned in both Nottinghamshire and Lincolnshire in partnership with both local R&D departments to take forward the outcomes from the Connects Roadshow. We are going to develop this into a rolling programme of MHRN PPI in Research shaped by the needs of local Service Users and Carers and their respective organisations.

Finally, we are soon to recruit an MHRN PPI Research Development Worker and we are liaising with SURGE as to how to take this work forward”. For more info contact [Ann.Priddey@nottingham.ac.uk](mailto:Ann.Priddey@nottingham.ac.uk)

## **Iliana Rokkou, User and Carer Research & Development Manager, Cambridge and Peterborough Mental Health Partnership Trust**

“I have been appointed as the new User and Carer Research and Development Manager to support the development and growth of active involvement of service users and carers in R&D activities across Cambridge and Peterborough Mental Health Partnership Trust. I currently meet with key professionals, voluntary sector agencies, service users and carers to identify ideas for good practice in involvement and how to take this forward. Key themes that will emerge from this consultation will inform a strategy for collaborative and user/carer-led research projects.

Service users have already played a key role in some research projects in the Trust. Further steps are planned to encourage more meaningful and purposeful service user and carer involvement in research and widen participation”. For more information, contact Iliana on [iliana.rokkou@cambsmh.nhs.uk](mailto:iliana.rokkou@cambsmh.nhs.uk) or 07770 876 208

## **Helen Phillips, Cambridge and Norfolk Hub User/Carer Co-ordinator**

“I took up the role of part time User/Carer Co-ordinator in May. My first priority is to meet with as many groups and individuals as I can across the Hub area so that I can find out what initiatives have already been developed to involve service users and carers in all aspects of research activity. This is proving extremely helpful, as have been my contacts with SURGE, national and local statutory and voluntary agencies working with mental health. Once I have completed this phase, I should be in a better position to start working with SURGE to produce information, for example leaflets and a glossary of research terms, and possibly to co-ordinate training and support events across the Hub”. For further information, please contact Helen on [Helen.Phillips@cambsmh.nhs.uk](mailto:Helen.Phillips@cambsmh.nhs.uk)

## **Ray George, User/Survivor Research Facilitator for Norfolk & Waveney Mental Health Trust**

“The Norfolk & Waveney Service User/Survivor Research Forum (NorSurf) met for the first time on the 29<sup>th</sup> April 2005, following an ‘Awareness Day’ which, with SURGE support, aimed to introduce and explore some of the issues surrounding service user / survivor research involvement. NorSurf has now met three times and as adopted a set of aims, including providing mental health service users/survivors the means to share experiences and ideas about research, making research more accessible to service users / survivors, to be a contact point for research projects wanting mental service user / survivor involvement, providing support and helping disseminate and implement research findings.

In the future NorSurf plans to commission a local service user/survivor research group – INFORM - to carry out a Delphi study into research priorities of service users/survivors and to develop an audit tool for service user/survivor involvement in research projects. For the time being the aim is to build on the foundations that have been successfully laid down over the past three months. In particular, the aim is to increase membership and awareness of the forum amongst service users / survivors and the local research community”. For more information contact Mary Cubbit, Research Manager on 01603 421340 or email [mary.cubitt@nwmhp.nhs.uk](mailto:mary.cubitt@nwmhp.nhs.uk)

### **A review of the Connect Roadshow by Becky Shaw**

“I had been invited to go to the Connect Road show after finding out about it through a project I am involved in as a service user researcher. It was great to see such a mix of people from mental health service users and carers to academics and other professionals coming together for one aim to listen, discuss and help each other with research.

The speakers got us all thinking through the issues surrounding research and it gave me confidence to hear of other service user / survivor research that had been successfully undertaken and what had been learnt during the process. I also felt supported by other researchers and professionals in the room that I was not on my own, that I can do research with support and at one time they were new to research as well.

There was a feeling in the room that mental health service user/survivor and carer research was important and the way forward. One concern was raised over the validity and robustness over this kind of service user led research. Raising the issues in my mind “What is valid research if its not brought about from the hearts and minds of the people it concerns? Is this not more a valid a reason to be involved? To have a passion and help make a difference through research?” I might not have a lifetime of research study behind me but I do have passion and given the right tools, information and support I can do research as valid and robust as anyone else.

It was great that there was such diversity of views and that the topics like this were discussed and debated openly by all. It is a start to think about the reasons why service user led research has evolved? Why it is important and how it can be supported and nurtured?

The group sessions around the tables, discussing projects, was for me, the most useful part of the day. There was a buzz in the air with all the chatter and mini debates. It gave my fellow researchers and I an opportunity to discuss the research proposals we had brought along with academics,

professionals and other service users and carers. It helped us to think about issues I had not thought about, giving a fresh pair of eyes to look at and critique the ideas we had brought. It was also an opportunity to help us find solutions to our questions, but I came away with not only more ideas and some answers, but also more questions.

I personally found it useful and informative to talk with different people around the room all coming from different backgrounds and perspectives, a real diverse mix of views.

I don't think the Connect Road show's work is over, the new connections people have made and the ideas people have got will be taken away and followed up. The networks made with other people and information gained during the day will also stay with me and will prove to very useful indeed. It gave me new drive to move the projects I am involved in along and helped me overcome the areas I had been stuck on.

I hope the road show is run again, if not for me, for other service users who might have research ideas that they want to take forward. It also seemed to be a great forum for all to debate the current and ongoing issues in research as well as hear of new projects".

## **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.

Send your ideas, articles, questions or comments about SURGE work to [info@surge.scmh.org.uk](mailto:info@surge.scmh.org.uk) or leave us voicemail on 0207 716 6778

Hard copies of this newsletter can be requested from SURGE, 1<sup>st</sup> Floor SCMH, 134-138 Borough High Street, London SE1 1LB