



## Service User Research Group England

Mental Health Research Network

Newsletter 3

Summer 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. The SURGE team currently consists of Jonathan Bindman, Jan Wallcraft, Louise Morgan and Leonie Barron.

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

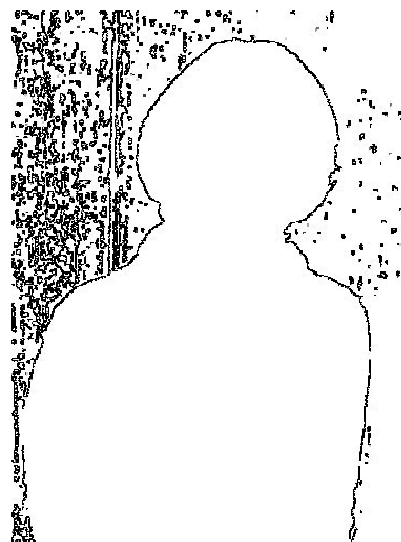
### Progress So Far

SURGE has witnessed some positive developments over the last few months as some of the work we have been doing has borne fruit.

#### *Good Practice Support*

Beate Schrank completed her overview of the state of service user involvement in MHRN-adopted projects, and this was reported to the MHRN executive. You can find an article about this work and its findings later in the newsletter, and we hope to see the implementation of some of her recommendations in the near future. The good news is that, following Beate's work, changes have already been made to the MHRN adoptions form and letter of acceptance, which will now directly encourage the involvement of service users in MHRN projects

from the moment of adoption. It is heartening to see the inception of our good practice support, and we can look forward to more positive changes in future. Sadly, Beate will not be with us to continue this work, as she has left SURGE to return to her native Austria.



The gap in the SURGE office

To fill the gap left by Beate (see illustration on P1), we are appointing a new member of staff who will be joining us in September.

Meanwhile, Louise Morgan is continuing the good practice support exercise, meeting each hub coordinator to discuss the state of service user involvement at the hub level. This will enable us to make further recommendations and support improvements where necessary.



**Lou: undaunted**  
Shouldering  
the workload

**Leonie: stoical**  
SURGE's loss  
is Austria's gain



### *Short Version of our Good Practice Guidelines*

Undaunted by Beate's absence and the additional workload, Louise is continuing her work on our short good practice guidelines, which are currently being revised to incorporate feedback from the second round of consultation. The guidelines will be divided into different sections for different audiences to ensure that people have access to all the information which is relevant specifically to them, and should be available in the autumn.

### *Standard Setting*

Another significant project we are working on will, we hope, lead to the adoption of a set of standards for service user involvement across the MHRN. The first step was a consultation meeting, held at our offices on 15th June, with a group of service user stakeholders from a variety of fields and areas of the country. This meeting produced a number of proposals, and a draft of the recommended standards is currently in consultation.

### *Networking Database*

Our research interest networking database, mentioned in our last update, is now up and running, and we have already had some success in putting projects and service users in touch for collaboration in research. If you would like to find out more about this database or be included on it, please ring Leonie on 020 7716 6778 or email her on [leonie.barron@surge.scmh.org.uk](mailto:leonie.barron@surge.scmh.org.uk). Alternatively, you can download a form from our website to return to us.



### **And how it used to be**

*\*\*It is to be hoped that the imminent purchase of a SURGE camera will ensure there are more interesting photos in future newsletters\*\**

## Mind Conference Harrogate, 15<sup>th</sup>-16<sup>th</sup> March

In our last newsletter we promised a full report of our trip to Harrogate for the 2006 MIND conference, which this year had the title *Feeling used? Making service user involvement real*. It was my first time at the MIND conference and I was somewhat in awe of the rich variety of events and discussions taking place. I found it an inspiring few days, connecting with the user movement and seeing the passion, dedication and hard work of activists past and present from around the country. And, of course, there was the added delight of Jan Wallcraft's impromptu sing along as part of the evening's entertainment!!

SURGE facilitated a workshop entitled *Service Use Participation in Clinical Trials: Partnership or Co-optation?* This explored the potential power of involvement, as well as possible dangers and limitations, and focused specifically on trials funded by pharmaceutical companies. This understandably generated significant debate about how service users felt about working with pharmaceutical companies, and the importance of avoiding tokenistic involvement. This in turn raised questions about research ethics and the necessity of incorporating service user standpoints into ethics processes, as well as making these processes more transparent. There was also discussion about the challenge of

reconciling working with the pharmaceutical industry with the urgent need for service users to have greater influence over the nature of research that is carried out. For us, it was a useful opportunity to engage in debate about some of the barriers to involvement in research with an extremely mixed audience which included both established survivor researchers and individuals new to the field.

Jan also spoke in the final plenary session of the conference, *How Tangoing Saved My Life*, in which a panel of survivor activists shared inspirational stories. Jan read a powerful passage from one of her favourite books, *Women Who Run With The Wolves* by Clarissa Pinkola Estes, drawing a parallel between this and her own wish to move beyond the identity of service user and 'survivor' – an identity which maintains the centrality of distress and difficulty – towards an emphasis on the power and potential of personal growth and freedom.



Louise Morgan  
SURGE Research Worker

## **SURGE and the COREC Consultation**

COREC is the Central Office for Research Ethics Committees, part of the National Patient Safety Agency. It provides help and leadership for research ethics committees (RECs) and the REC system. Among other things, this involves implementing standards to ensure consistency nationwide, and providing training for REC members.

Between January and April this year, COREC ran a consultation on the implementation plan for Department of Health recommendations. We felt it was important for SURGE to give feedback to ensure that procedures would enable service users to be fully and usefully involved on ethics committees. We want a research ethics service that embraces user involvement both in its own work and in the work that it is reviewing, one that recognises that service users and patients may have an alternative point of view on the ethics of a study, and that their view ought to be sought and heard.

In our response to the COREC implementation plan, we expressed disappointment that the need to ensure the representation of service user perspectives in the research ethics service was not adequately addressed. We also highlighted the need for a more flexible approach to the payment of non-NHS lay members to take into

account problems posed by the benefits system. In addition, we suggested more proactive and effective ways to implement the Department of Health recommendations, which clearly mandate the representation of service user and patient views on RECs. Finally, we were able to express our views on how both training and recruitment procedures could be improved to better serve the cause of user involvement.

According to COREC, the comments received have been reviewed and the revised implementation plan has been submitted to the Department of Health. Once recommendations have been received from the Department of Health, the agreed implementation plan will be disseminated. There is no fixed time scale for this, but we'll try to keep you informed; in any case, COREC advises those interested to keep an eye on its website at [www.corec.org.uk](http://www.corec.org.uk) to track developments.

### ***\*\*Wondering What We're On About?\****

*We can sometimes forget that some of the terms we use are not familiar to the general reader. At the back of this newsletter, you'll find a brief explanation of some common MHRN terms. If you think there are other terms which we use too freely without explanation, please get in touch and we'll try to clarify them.*

## Meeting of Service User Involvement Development Workers

On 5<sup>th</sup> April, SURGE hosted the first meeting for those working to develop service user involvement in research at the various MHRN hubs. With a representative from each hub present, the aim was to pool knowledge and ideas and come up with strategies for improving the situation. We also hoped to encourage those hubs with no dedicated SU involvement development worker to employ one. Many issues were brought up: how SURGE can collaborate with the local workers in the hubs; the importance of having well functioning systems in place to facilitate user involvement; how to build capacity both in terms of getting more service users involved and developing more opportunities for that involvement; the desire for more training for everyone in research about service user involvement.

Much advice was traded on how to go about employing somebody dedicated to service user involvement, and some hubs are now making progress in recruiting: Louise will shortly be representing SURGE on the interview panel for such a post in the Heart of England. However, it was sad to hear that Helen Phillips's post in East Anglia was coming to an end; while Helen had already achieved a huge

amount, it was clear that there was still plenty more to be done.

Meetings are now taking place on a regular basis, and a second meeting was hosted by the East Midlands hub on 20<sup>th</sup> July.

Among the subjects discussed in this second meeting were honorary contracts for service users involved in research, the role of CSOs, and the Department of Health shake-up of research and development. Concern was voiced that the government's plans for new research structures will take away research activity from smaller trusts and invest only in bigger organisations, representing a loss of existing work. There was also discussion of the ethical issues surrounding the "adding on" of new studies to MHRN projects which have already been adopted.

The next meeting is to be hosted by the North London hub on 16<sup>th</sup> November.

### *Posts around the Hubs*

- Tim Rawcliffe: Service User Coordinator, North West Hub
- Jean Sharp: Patient and Public Involvement in Mental Health Research Liaison Officer, East Midlands Hub
- Heart of England Hub: recruiting

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## Good Practice Support

SURGE exists to support good practice for user involvement in the MHRN, and to do this, we need to build up a clear picture of how things are currently done in the projects, hubs and research groups of the MHRN.

We started with the projects, and this is the report of the results of our work with them. We're also engaged in a similar exercise with the hubs, and hope to start work with the research groups soon.

We made a two-pronged approach: contacting staff at all the projects to talk to them, and looking at plans for user involvement at the adoptions stage. This was so we could see how far initial plans were carried through as projects got going.

### *Early Plans for Involvement*

It soon became clear that there was often no relation between the early plans for service user involvement and later implementation – a phenomenon due largely to a lack of clarity in the original proposals. To improve this situation, we have proposed that the MHRN should, through the adoptions process, encourage the development of clear plans for service user involvement at the earliest possible stage. The adoptions committee should assess these plans, ensuring they are clear and feasible, with details for the involvement of service users at different stages of the project. To

make sure that these plans have a meaningful budget, the MHRN should encourage funding organisations to provide budget lines for service user involvement.

### *Meaningful Involvement: The Picture which Emerged*

Our attempts to contact the projects yielded information from 25 out of 35 of them – not everybody, but we still gained a fair view of the state of user involvement.

We found service user involvement of a significant nature in very few of the studies: there were just five which had service users as employed research workers or steering committee members.

Since one of the aims of the exercise was to find out how user involvement worked from the inside, we interviewed as many of these service users as possible, and the following facts emerged.

### *Service User Researcher Experiences*

Those employed as research workers did, of course, have a contract and written role description (though these were not always thought accurate), and were paid for their work. However, although such things are necessary, they proved insufficient for a positive experience of user involvement, as we found out.

The research role tended to cover carrying out qualitative interviews and interpreting qualitative data, as well as recruiting participants. The

recruitment aspect of the role threw up some difficulties specific to a service user background: researchers felt under pressure to recruit patients even if they doubted the ability of potential recruits to give informed consent; and researchers could, given their own experience, be affected by a personal emotional involvement with interviewees.

Service user researchers, generally motivated by a personal desire to improve service users' experiences with services, could feel that their aims were incompatible with the actual work they were having to do. We interviewed one person who had been responsible for setting up a part of the study, and this person felt a high and satisfying level of control over the study; however, most felt they had limited control over their work, with little say in any important decision-making for the project. In addition, several interviewees mentioned the tension arising from working in a highly competitive, institutionalised, academic environment.

### *Improving the Experience*

When it came to identifying areas for improvement, there was a pressing desire for more supervision, more support, and more open communication, with time and space away from the workplace allocated for this. There was also a feeling that tension generated by "suspicion" on the part of some non-service-user researchers could be relieved by

open discussion about the possibility of the service user researcher falling ill.

### *The Way Forward*

The positive examples of service user involvement that we uncovered may not have been the norm, but they did show that it can work and it does. It is for SURGE to strive to make it work more widely. Our proposal regarding clear plans in adoptions proposals and tackling funding has already been mentioned. We're also asking that MHRN hubs encourage projects to seek advice from SURGE at a very early stage and continue to liaise with us throughout the life of the project. Finally, we want to ensure that the MHRN makes our Good Practice Guidance booklet available to all projects at the earliest possible stage in their development.

### *Carrying On the Work*

We expect our work with the hubs and research groups will prove equally illuminating and lead to further improvements in the state of service user involvement. In our next newsletter, we should be able to report on the work we are currently undertaking with the hubs.

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# Being Involved

## Training

As the service user arm of the UK Mental Health Research Network, SURGE comes under the umbrella of the UK Clinical Research Network (UKCRN). This body organises training courses on many subjects, including an introduction to clinical research, valid informed consent and working with industry. A new course, proposed by SURGE and currently under development, will be an introductory guide to mental health research for lay people; we are hoping that this course will be on offer later in the year. You can find a full list of the courses the UKCRN runs on their website at <http://www.ukcrn.org.uk/index/training.html>. The courses – and this includes *all* courses run by *any* of the “disease networks” in the UKCRN – are free to UKCRN employees. In addition, service users involved in any MHRN activity are eligible for free places, as long as you get a signature on their application from the relevant hub coordinator.

With good training making such a difference to people’s experience of being involved in research, it is hoped that service user researchers will be able to benefit from the courses on offer, and find the obstacles they may encounter in future less difficult to overcome.

## REACT

REsearch in ACTION, or REACT, is a course designed specifically for service user and carer researchers. Based on the experience, over five years, of research managers delivering training to groups of service users and carers, it provides the training that service users and carers said they needed in order to carry out research projects. The course covers finding a topic, designing questionnaires, training to do interviews and dealing with data. It also covers confidentiality and managing difficult situations. It has involved service users and carers throughout its development and the various parts of the course have been tested out whilst carrying out service user led research projects.

REACT is based on action learning principles and is built around real experience of carrying out a small research project – learning by doing. It is an introductory course and follows the research process, with each stage introducing participants to another skill and element of the research journey. It aims to:

- introduce people to the research process and all that it involves.
- develop knowledge and understanding of research skills.



- facilitate user involvement in research, user-centred research and evaluation, and user-led research.

It is for anyone who has used or is using health or social care services, volunteers, those looking to gain skills or experience to return to work, or those who simply want to get involved in health and social care services.

The course is divided into 3 parts:

- Introductory unit – how to search for information and how to use it.
- Designing and carrying out a study – how to find a question to research, writing a proposal, designing a study, gathering information, using data, writing reports.
- Presentation skills – how to present findings in different ways.

Each part can be taken separately or the course can be done as a whole. The course is also accredited by the Open College Network so that anyone wanting to gain a qualification can submit evidence to show that they have fulfilled the requirements for a selection of mandatory and optional OCN units.

The course development team have written a course outline for participants and trainers. They also plan to put together various materials that might be useful, and over the next few months, they will have these printed to circulate to

others who might be interested in doing something similar.

For further information about the course, contact Dr Virginia Minogue on 0113 2952360 or [Virginia.minogue@leedsmh.nhs.uk](mailto:Virginia.minogue@leedsmh.nhs.uk) or Barrie Holt (Project Coordinator) on [Barrie.holt@swyt.nhs.uk](mailto:Barrie.holt@swyt.nhs.uk)

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*Research Interest Networking Database*  
 SURGE runs a database of people with experience of mental health problems or services, or who identify as survivors, who would like to be involved in mental health research within the Mental Health Research Network. We aim to link interested service users/survivors with research staff looking to involve service users/survivors. If you wish to register on the database, we will send you information about opportunities for involvement in your chosen areas when we receive matching requests from MHRN hubs and projects. Download a form on our website or contact Leonie Barron on [leonie.barron@surge.scmh.org.uk](mailto:leonie.barron@surge.scmh.org.uk) or 020 7716 6778 for more information.

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## Events



**West Hub**

UK Mental Health Research Network



### MENTAL HEALTH RESEARCH IN THE SOUTH WEST ANNUAL CONFERENCE

30<sup>th</sup> November 2006, 9am–5pm  
Lyngford House, Taunton

This conference is for everyone involved in mental health research, including healthcare professionals, researchers, service users and carers.

We are inviting abstracts for speaker presentations, posters and workshops in all areas of mental health, including:

- Primary care
- Secondary care
- Social care
- Service user involvement/ led
- Pharmaceutical trials

Abstracts can refer to both completed studies or ones currently in progress, but should include details of impact, relevance and importance to practice. We would like the event to include both the research and the experiences of being involved in research. There will be prizes for the best speaker and poster presentations, and also reimbursement of reasonable travel expenses for non service users, and all travel expenses for service users.

To book a place at the conference, please visit our website at <http://www.mhrn.info/dnn/ServiceUserInvolvement/tabid/98/Default.aspx> to download the form, and return it to [louisa.bolt@bristol.ac.uk](mailto:louisa.bolt@bristol.ac.uk). For more information, email as above or telephone 0117 331 0921.

#### ***\*\*Proposed national network to support mental health service user and survivor groups: FAQ and DVD\*\****

A copy of frequently asked questions about this proposed national network is included with this newsletter.

A free DVD is now available of the Birmingham service user conference, *Doing It For Ourselves*, which was held in February this year to discuss the proposed new network. Copies can be obtained from:

Laura Schofield,  
Assistant to Anne Beales,  
Director of Service User Involvement,  
TOGETHER (working for wellbeing),  
1st Floor, 82a Wick Street,  
Littlehampton,  
BN17 7JS.  
Tel: 01903 733433

Further information about the planned network and minutes of the network planning group can be found on this website:

<http://www.together-uk.org/index.asp?id=3932>



**South London Hub**  
UK Mental Health Research Network

## SERVICE USER INVOLVEMENT IN MENTAL HEALTH RESEARCH CONFERENCE

22<sup>nd</sup> September, 2006  
One, Birdcage Walk, Westminster

Representatives from service user groups in all NHS trusts covered by the South London Hub of the MHRN are invited to attend. Places are limited. Please contact Lauren Noto on 020 7848 0699 or [lauren.noto@iop.kcl.ac.uk](mailto:lauren.noto@iop.kcl.ac.uk) for more details. The conference is free to attend. Lunch will be provided and there will be a drinks reception at the end.

### Speakers

Diana Rose, Gerry Bennison, Steve Gillard, Vicky Turk.

### Workshops

- *Involving black and ethnic minority communities* (Dele Olajide)
- *Outputs from service user involvement focusing on training* (Premila Trevedi)
- *Demystifying research* (Gerry Bennison)
- *What areas should be researched?* (SURE - Service User Research Enterprise)
- *Different ways to get involved* (SURGE)

**Plus...** 'Fantasy Mental Health Service Manager' game.



**North East Hub**  
UK Mental Health Research Network

## MHRN ANNUAL SCIENTIFIC CONFERENCE

18<sup>th</sup>-19<sup>th</sup> January, 2007  
The Sage, Gateshead

This multidisciplinary conference, open to anyone, will range in subject matter from basic and clinical science to public mental health. Service user involvement in mental health research will also be on the programme, and SURGE will be hosting an introductory meeting for any service users attending before the conference proper gets going.

More information about this conference is now available on MHRN the website, and we hope to bring you more details in our next newsletter.

### *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

## Freya Mellor

Clinical Studies Officer  
East Anglia Hub

### **Public Involvement in Health Research: More than a Box-ticking Exercise?**

This thought-provoking and enjoyable event was jointly hosted by the East Anglia Hub, the Norwich Primary Care Trust and the University of East Anglia (UEA). The conference was held in the UEA Sports Park which provides invigorating views over an athletics field, climbing wall and gigantic pool. The sun was shining and there were tempting café and sports facilities. It was a testament to the quality of presentations that the conference rooms remained buzzing throughout.

It was encouraging to see a genuinely diverse audience. I met many skilled representatives from wide-ranging service user and carer organisations. Most of these people had already gained considerable experience of working or participating in research, but some were simply curious about the issues. I also spoke to academics and health professionals from a variety of training backgrounds and learnt more about their different specialities in physical and mental health.

The introduction to the conference was given by Professor David Scott from the Norfolk and Norwich University Hospital. He contextualised public involvement and gave an outline of the talks to follow. His welcome speech was informative and set a positive tone for the day.

The first presentation was by Roger Steel from INVOLVE. He explained the benefits of public involvement and highlighted the need for true collaboration at all stages in the research process.

The second presentation was by Professor Nicky Britten from the London Primary Care Studies Programme. She described her own in-depth research into the experiences of consumers who had assisted with a variety of health research projects. A central conclusion was that user involvement is beneficial to research processes and outcomes as well as to participants.

The next three presentations were given by staff from the UEA and described examples of public involvement in the local area. Professor Amanda Howe talked about the Patient and Public Involvement in Research programme, which recruits and trains volunteers. The scheme has clearly been popular and successful

in the region. Dr Fiona Poland described the BECCA study, which is investigating the utility of befriending for carers, and Liz Lenaghan talked about the SCOOP study, which is examining the efficacy of screening for osteoporosis. Both of these projects sought out and have benefited from public involvement from the outset.

There were four workshops. I attended a session led by Peter Beck and Jef Wilson about Expert Patient courses. These courses are run by patients for patients to empower people to manage health problems. Many who had attended had found the courses life changing. Other workshops focused on informed consent (Reg McKenna and Debbie Roberts), issues and priorities for service users (Penny Vicary, Dinah Thompson and Nikki Morris) and the lessons to be learnt in applying the benefits of public involvement (Kay Sheldon and Debbie Halliday). Judging from the lively feedback session, the workshops were a success. The day was then brought to a close.

As we were leaving, I saw a group of people ascending the climbing wall, and it reminded me of some of the themes from the day. We should work together to overcome obstacles, and aim for public involvement at the top, so that we can achieve our most highly pertinent and helpful research.

## **Sandra O'Sullivan**

### **North London Hub Coordinator**

The North London Hub is working closely with service users in the area. We have designed a service user website, [www.sunlows.org.uk](http://www.sunlows.org.uk), which is maintained and updated weekly by a member of our service user steering group, Michael Ekejiuba. We have received good feedback about it, and are continually looking to add items of interest and importance. If you would like us to post anything you feel would be useful, contact me at [s.osullivan@imperial.ac.uk](mailto:s.osullivan@imperial.ac.uk).

Another exciting development is our Service User Involvement in Research conference, to be held on 3rd November at Friends House in London. This is being put together by our service user steering group and promises to be exciting and informative. Details will be posted on our website soon.

We aim to actively involve service users in research from the outset, and we are pleased to announce that a member of our service user steering committee, Fenella Lemonsky, will be working with our hub lead and deputy lead in putting together a funding proposal following the new call for research for patient benefit.

Finally, we are continually looking at ways for people to be involved in research, including training and identification of research questions that are of importance and relevance to service users.

## Tony Kendrick

### MHRN Depression Treatment Research Group

This group is chaired by Tony Kendrick, Professor of Primary Medical Care at Southampton, and meets twice a year in London. Members of the group are involved in a number of collaborative projects:

- A qualitative study involving interviews and focus groups to address the ethical issues around the need to mislead participants about the treatment they are receiving in placebo controlled trials of antidepressants is being led by Chris Dowrick from Liverpool.
- Exploratory trials of case management are being carried out by Dave Richards (York) and Steve Pilling (UCL) and their colleagues. The Depression Treatment Research Group plans to bid for funding from the MRC for a definitive multi-centre trial of enhanced care for depression, building on the experience of these projects. Discussions are taking place with potential NHS Trust partners, and possibly commercial partners, in Bristol, Southampton, Birmingham and South London, with the aim of joining the study with the York and UCL groups.
- Linda Gask and Tony Kendrick are asking members of the group to help identify qualitative interviews already in existence from previous studies of people with depression, looking at issues

around the meaning of depression and what works for sufferers. The aim is to conduct secondary analyses of these interviews, which would involve a wide range of geographical areas and types of participant. A funding bid for this secondary analysis will be prepared in due course.

- Following the introduction of incentive payments for assessing the severity of depression using patient questionnaire measures prior to treatment, Tony Kendrick is leading a study of GP prescribing and referral behaviour. This will involve interviews with doctors and patients and an audit of their treatment decisions.

### **\*\*Get Involved!\*\***

*The user representative on this research group is not always able to attend, so we would like to recruit at least one more service user to give a user perspective on grant applications proposed by the group and discussed at meetings. Previous experience as a research participant would be an asset, but is not essential - a commonsense view is what we need most. Ideally, we would like someone whose service use has largely been in general practice, rather than in psychiatric outpatients and hospital. If you would like more information about the role, please contact Tony Kendrick on 023 8024 1050 or [A.R.Kendrick@soton.ac.uk](mailto:A.R.Kendrick@soton.ac.uk). The next meeting is on 24<sup>th</sup> November in London. Travel expenses are paid to all members of the group.*

## Jean Sharp

Patient and Public Involvement in  
Mental Health Research Liaison  
Officer, East Midlands Hub

We are very fortunate to have funding into my post from the Research and Development Department at Nottinghamshire Healthcare Trust. I have been in post since March part time, and full time for the last few weeks.

On 7th July, we had an exciting meeting between people involved in PPI in the East Midlands and Louise Morgan from SURGE. This was a good opportunity for SURGE to learn more about how we manage PPI in the East Midlands and to strengthen our local links with SURGE. I had hoped that a larger number of service users would attend; however some were unable to attend because of other commitments. One of the strategies we have agreed with SURGE is that email and telephone contact can be used to link them with service users so that people can express their views about research and services without having to attend meetings.

The following is a quote from one of the people who attended the SURGE meeting: "For too long, mental health has been the Cinderella of the NHS and has failed to attract the funding it so badly needs. A lot of hard work needs to be done to define the research that is currently going on and establish what will be needed

in the future, and then to draw it all together as well as bringing on board all interested parties. If this can be achieved I am confident that opinion can then be mobilised to convince the politicians to make proper funds available to mental health services in general. It will then be someone else's turn to be the poor relation!"

We are establishing a steering group for PPI in mental health research. This will mean that the whole process will be accountable to service users, carers and the public as well as to researchers.

I am currently working on the provision of training for service users so they can take part in research on the experience of service users of Crisis Resolution and Home Treatment Teams. The training covers good clinical practice, informed consent, skills in interviewing and dealing with distress arising during the interviews. This will also enable them to build their skill and knowledge base so that they can be involved in the local hub work. And who knows? The research may go on to be a pilot study run on the network.

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## Rupert Waddington

Heart of England Hub Coordinator

The Heart of England Hub has seen two promising developments.

We held our first annual stakeholders' conference on 28<sup>th</sup> June. This was well attended by service users and user group representatives. With Jan Wallcraft absent due to illness, Mary Nettle stepped in to chair a group discussion and as a representative on the panel discussion. Many constructive remarks were also made on the evaluation forms. It is impossible to ignore the urgent need to develop greater, more meaningful service user involvement in all aspects of our research, and pleasing to observe how broadly this is now welcomed.

In our second development, timely in the light of the above, we have advertised for a Service User Development Officer to work for one year scoping service user involvement across the hub and produce recommendations and an action plan to help us to achieve improvements and growth. Although later than some hubs in making this appointment, we are confident that the delay will prove advantageous in maximising integration and collaboration with the current work of SURGE, based on the Good Practice Guidance. There will be a one-day event halfway through the year, and stories and experience from around the country will be especially welcome.

## Marion Clark

SURESearch

The Heart of England Hub conference at the end of June included presentations of innovative research from the Heart of England, a research marketplace to learn about stakeholder research, individual themed research meetings for speciality topics (addictions, early psychosis, social care, primary care, eating disorders, neuroscience and imaging, ethnicity and mental health, service user research), and an open panel discussion to plan for the future in the hub.

There were many opportunities for exchange of information, discussion and networking. SURESearch, a partner in the hub, played an active role in the conference and had a stall in the research marketplace. Those looking after the stall had a very busy day, with lots of interest shown in user research. Three pieces of work which SURESearch helped to produce disappeared very quickly: *Transforming Services: Changing Lives – A Guide for Action* from the *Working for User Involvement in Mental Health Services* range; and *Claiming Disability Living Allowance and Mental Health and Incapacity for Work* from the range *Promoting Mental Health and Social Inclusion: Combating Poverty*. These can be downloaded from the website of the Centre for Excellence in Interdisciplinary Mental Health, [www.ceimh.bham.ac.uk](http://www.ceimh.bham.ac.uk).



# End Note - Have your say

The aim of this newsletter is to inform people across the Mental Health Research Network, as well as those with an interest in getting involved in the MHRN, about the work of SURGE and the development of service user involvement in research across and around the network.

We hope to 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 piece about 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. We'd also love to have more pictures from you – photographs of events, cartoons or anything else – to liven up our pages.

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.

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## **\*\*Wondering What We're On About?\*\***

Here are explanations of some of the terms used in this newsletter. If you have any suggestions for further clarifications, please get in touch – sometimes we stop noticing our own jargon!

### **MHRN hub**

The Mental Health Research Network consists largely of eight different “hubs”, each covering a specific geographical area. The hubs comprise NHS trusts, research institutions and service user and carer groups. Altogether, the hub areas cover more than 60% of the population of England. Research projects run on the MHRN are based at one or more of these hubs. The hubs are: East Anglia, East Midlands, Heart of England (based in the Midlands), North East, North London, North West, South London and West (based in the South West).

### **MHRN research group**

Research groups identify areas of strength and weakness in research, pinpointing suitable topics and producing research proposals to run on the MHRN.

### **Clinical studies officer**

A clinical studies officer, or CSO, is a hub employee who assists researchers in a number of ways, principally identifying potential participants for the project and providing information and support for those participants.

### **SURESearch**

SURESearch is a user-led training and research partnership based at the University of Birmingham.