



## Cambridgeshire and Norfolk Hub

UK Mental Health Research Network

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### CN-Hub Update

Our fourth newsletter and we have some introductions to make. First, we would like to officially welcome Professor Amanda Howe as our Hub's Primary Care Lead. Amanda will be spearheading the primary care aspects of our work (p. 2). Next we would like to welcome our Clinical Studies Officers, Emma Leggett is based in Norwich and our Cambridge based CSO, Barbara Lee, will be starting in June (p.2). Last, though by no means least, a further welcome to Helen Phillips, our User / Carer Co-ordinator (p.2). Helen is based in the Cambridge office.

We would also like to thank Professor Geoff Shepherd who, due to time constraints, is sadly unable to formally take up the role of Social Care Lead. He has been a useful 'care-taker' of the Social Care Lead position and will help us in finding a suitable replacement.

In the last few months we have also been trying to make contact with our Mental Health and So-

cial Care colleagues in Suffolk. If you are one of these and have as yet not returned a completed 'Register of Interests' form to us please do so at your earliest convenience. This information is vital to the proper functioning of the Hub within the national Network.

The Hub Research Interests Groups have now been set up to run as members-only discussion groups on YAHOO (p.4) Please join these as this is your opportunity to influence the research agenda for the future!

We also have a number of new projects and are still actively looking for more help in recruiting to the **Balance** as well as the **Genetics in Anorexia Nervosa** trials (p. 3). If you feel you can help or have any suggestions please get in touch with Marijcke (contact details on p. 6). Finally, do have a look at the UK-MHRN National Scientific Conference details (p.5)

[www.mhrn-cnhub.org.uk](http://www.mhrn-cnhub.org.uk)

### UK-MHRN Update

#### New Appointments in the UK MHRN Coordinating Centre

Dr Rachel Parker will be joining the UK MHRN on 16<sup>th</sup> May 2005 as Manager of the Network. Rachel has a PhD in Neurobiology and worked over five years carrying out post-doctoral pre-clinical neuroscience. She subsequently acquired an in depth knowledge of research portfolio management and a detailed overview of the workings of major UK research funders through her post as Science Programme Officer within the Science Funding Division of the Wellcome Trust. After the Wellcome Trust she took up the post of Research Coordinator for the Cardiovascular Research Funders' Forum. This is a body established by the government to plan and promote a strategic coordinated approach to UK cardiovascular research. Within this role she compiled, reviewed and disseminated strategic analyses regarding the Forum's research interests and managed, coor-

inated and facilitated the flow of information between the ten participants of the Forum.

The interview for the contracts manager will be held on May 3<sup>rd</sup> 2005. The post holder will be responsible for all aspects of projects during the set-up phase; from adoption of projects through to the beginning of recruitment.

#### Research Creativity

The UK MHRN received an overwhelming response to its call for research groups. A total of twenty-two applications were received. The UK MHRN supplements the work of the Hubs and the SURGE by establishing a network of Research Groups with interests in particular research topics. These groups are the creative drive of the Network, developing research proposals that could be run on the infrastructure provided by the Hubs. Eight research groups have been selected and these groups are currently being notified of their success.

### UK-MHRN

#### Aims:

- To organise and deliver large-scale research projects to inform policy and practice as it develops, and to help services implement change.
- To broaden the scope and capacity of research, including full involvement of service users and carers in commissioning and delivering research.
- To help identify the research needs of mental health (particularly in health and social care), working with frontline staff, service users and carers.
- To develop research capacity through a range of initiatives at a local, regional and national level.

#### Benefits:

- Provides instant access to a number of clinical and academic centres.
- Brings together research and providers of mental health and social care services.
- Offers a broad scope, covering all mental health disciplines .
- Offers support and guidance on research governance issues, data protection and ethical matters.
- Co-ordinates the management of all subcontracts to individual centres.

#### How to run a project on the Network

Application to run a project on the MHRN must be made to the MHRN Adoptions Committee.

Forthcoming deadline for applications: **June 21st 2005**

Application forms can be downloaded from : [www.mhrn.info](http://www.mhrn.info)

## CN-Hub General Staff Contact and Role Details

### Research Co-ordinator

Dr Marijcke Veltman  
 UK-MHRN CN-Hub, Douglas House, 18b Trumpington Road, Cambridge, CB2 2AH  
 email: mwmv2@cam.ac.uk tel. 01223 746131 Fax: 01223 746002

**Responsibilities:** General daily manager, responsible for the development and management of appropriate infrastructure and staff necessary to support the development of the CN-Hub. This involves liaison with national organisations, research & clinical teams, and research management staff. Contributes to the education and development programmes of Trusts within the CN-Hub region. Supports the CN-Hub committee, project groups, as well as Hub Research Interest Groups. To build capacity of clinicians, service-users and carers to participate in the research process and maintain a database of researchers, clinicians and specialist services. Monitors and supports recruitment, completion and dissemination of UK-MHRN adopted, CN-Hub hosted studies. Development, contribution to and editing of CN-Hub websites and newsletters. Identifies funding opportunities and contributes to research funding applications.

### Clinical Studies Officers (All cover Cambridgeshire, Norfolk & Suffolk)

Barbara Lee (from June 2005)  
 UK-MHRN CN-Hub, Douglas House, 18b Trumpington Road, Cambridge, CB2 2AH  
 email: Barbara.Lee@cambsmh.nhs.uk tel. 01223 746087 Fax: 01223 746002

Emma Leggett  
 UK-MHRN CN-Hub, Research Office, Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE  
 email: Emma.Leggett@nwmhp.nhs.uk tel. 01603 421334 Fax: 01603 421294

**Responsibilities:** To help to conduct UK-MHRN adopted research projects. To provide information and support for participants involved in clinical research projects in the CN-Hub, to assist in project administration, including database management and maintaining ethical approval and governance standards of projects, and to actively promote research to service users and carers, clinicians and other professionals.

### User/Carer Co-ordinator

Helen Phillips  
 UK-MHRN CN-Hub, Douglas House, 18b Trumpington Road, Cambridge, CB2 2AH  
 email: Helen.Phillips@cambsmh.nhs.uk tel. 01223 746144 Fax: 01223 746002

**Responsibilities:** To support the co-ordination and partnership development of the service-user and carer development programme of the UK-MHRN in the CN-Hub. This includes close liaison with service user and carer groups in the region as well as research teams, relevant wards and NHS and Trust departments, the voluntary sector, as well as with appropriate Research & Development Departments, and to actively promote research service users and carers. Builds capacity of service-users and carers to participate in the research process and maintain a database of expertise and special interests.

## Primary Care—Update

Amanda Howe, our Primary Care Lead reports:

### Why a primary care lead for the CN-Hub?

The UK-MHRN has decided to appoint a primary care lead to each hub, in order to:

- Bring a primary care perspective to the research aims;
- Engage primary care staff and patients in research projects;
- Ensure that some of the adopted studies reflect the common mental health problems dealt with by primary care.

To this end two national interest groups have already been set up: one on the best use and therapeutic context for antidepressant treatments, the other on consultation skills and their role in mental health problem detection and management. In addition, some of the adopted national projects already involve primary care researchers, and this is likely to continue, because patients are rarely only cared for by specialist mental health teams, and most interventions will need evaluation with primary as well as secondary care.

Some readers may struggle with a definition of primary care, especially in a mental health context. Does it mean a setting, where patients with mental health problems go to get repeat prescriptions, or to deal with other health problems? Is it a type of clinician, such as a GP or a practice nurse? Or is it a philosophy of care? The last is my assertion, and is very well described

by Ian Mawhinney, a lead author from 'family medicine', as it is known throughout the rest of the world: "The unifying aspect of family medicine is a discipline based on long-term relationships in a particular community, using a patient-centred clinical method to:

- Define and interpret diseases and their experience of these to the patient & family;
- Find common ground with the patient about their problems and how to manage these;
- Enhance the clinician - patient relationship to maximise therapeutic benefit;
- Incorporate prevention and health promotion into the routine care of individuals, family units, & the local community;
- Manage care effectively within the context of the team, time and other resources such as patient support groups, utilizing the current evidence base appropriately."

This definition is important because it expresses the unique opportunities of primary care, and locates the perspective from which our research strategy is focused. Primary care is about holistic care, generalist approaches where the diagnostic category is less important than the way symptoms are affecting quality of life and function, and increasingly it is where the patient's opportunity to come to terms with their problems is most consistently available. Yet the standard of primary care from the perspective of mental health service users is very variable, and the research evidence often weak. This is why each Hub has a primary care lead, and we are at your service. If you have ideas about research that may relate to this area please feel free to contact myself, amanda.howe@uea.ac.uk, or Marijcke Veltman (see above).

## CN-Hub hosted projects

### Newly adopted projects:

#### GAN

(Genetics of Anorexia Nervosa)  
Anorexia Nervosa in Relatives Project

Anorexia Nervosa (AN) is a chronic and often fatal disorder that affects ~0.3% of women and the mortality rate is 5% per decade. In addition to environmental influence, family and twin studies demonstrate substantial heritability for AN. Because the causation of this devastating illness is not known a pilot study to examine the genetic underpinnings showed some interesting preliminary results. As such, this international, multi-centre, collaborative study will strive to collect 400 affected relative pairs with AN. Over a 5 year period, the 11 collaborative groups will collect diagnostic and other phenotypic data and blood samples.

**This project is looking for clinicians and potential 'relative pairs' to take part in the research.**

**Clinicians:** The research team, with help from CN-Hub staff, would like to search through past/present patient files. If you agree in principle the research team would send you the study protocol, the MREC approval information, standard letters to patients as well as information sheets and consent forms. The CN-Hub would assist with Ethics, research governance, R&D, honorary contracts and other issues. CN-Hub staff may even be able to assist in looking through the patient files. Further information as to how this would all work in practice can be obtained from Marijcke (see contact details on p.6).

**Patients:** If you come from a family where there are 2 or more people who have or have had anorexia, the team would like to contact you about possibly taking part in this project. If you think you might be willing or able to help with this project please get in touch with the project team directly (Sam Waitere: tel. 07932 506518, email: [s.waitere@iop.kcl.ac.uk](mailto:s.waitere@iop.kcl.ac.uk)). There is a financial reward on completion to compensate you for the time and effort involved in taking part in this study.

Chief UK Investigator: Janet Treasure (Institute of Psychiatry, London)  
Funder: National Institutes of Health (USA)

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Forthcoming deadline for applications:

- June 21st 2005

Application forms can be downloaded from :

[www.mhrn.info](http://www.mhrn.info)

### Ongoing Projects

#### ADAPT:

Adolescent Depression, Antidepressants & Psychotherapy Trial

Chief Investigators: Ian Goodyer (Cambridge) & Bill Deakin (Manchester).

Funder: The NHS Health Technology Assessment Programme.

#### BALANCE:

An international randomised trial of maintenance treatment for bipolar disorder

Chief UK Investigator: John Geddes (Oxford).

Funder: The Stanley Medical Research Institute (USA).

#### BECCA:

Befriending and the Costs of Caring

Chief Investigator: Shirley Reynolds (UEA).

Funder: The NHS Health Technology Assessment Programme.

#### PsyGRID:

E-Science to facilitate clinical trials and longitudinal studies in first episode psychosis

Chief Investigator: Shôn Lewis (Manchester).

Funder: The Medical Research Council.

#### ROOTS:

How do patterns of risk predict the evolving nature of psychopathology in post-pubertal adolescents?

Chief Investigator: Ian Goodyer (Cambridge).

Funder: The Wellcome Trust.

#### SR-CBT:

Improving Social Recovery in Early Affective and Non-Affective Psychosis

A Randomised Controlled Trial Of Social Recovery Oriented Cognitive Behaviour Therapy

Chief Investigator: David Fowler (UEA).

Funder: The Medical Research Council.

#### SuperEDEN:

A national evaluation of early intervention in psychosis services

Chief Investigator: Max Birchwood & Helen Lester (Birmingham).

Funder: The Department of Health.

### Learning the lessons:

An evaluation of pilot community services for adults with personality disorder

Over recent years concerns have been expressed about the quality of services for people with personality disorder (PD). As part of a package of measures aimed at addressing these concerns the Department of Health has funded eleven community-based pilot services for people with PD. Little is known about the impact that organisational form and function of specialist services have on the their ability to engage users or improve their mental health and social functioning. The impact of specialist services on existing health and social services is also poorly understood. The aim is to evaluate the 11 pilot services against measures of process and outcome and use findings to make recommendations for the development of future services for people with PD. The study will examine the organisational form, function and activity of pilot services and compare these with national guidelines for the management of people with PD; measure changes in service utilisation, clinical and social outcomes, and the direct costs of care among a cohort of patients using the pilot services and investigate factors associated with positive and negative outcomes from patient perspectives.

Chief UK Investigator: Mike Crawford (Imperial College, London)

Funder: NHS Service Delivery and Organisation R&D Programme

## Hub Research Interest Groups: The regional creative drive

We have now set up some virtual **Hub Research Interest Groups (HRIGs)**. These groups are 'members only' discussion groups hosted by Yahoo Groups. It hoped that these groups will bring together service users, carers, clinicians and academics with similar research interests.

We would like to invite you to take part in these restricted membership, email-discussion groups. Please let Marijcke (see contact details on p.5 of the Newsletter) know which of these you would like to join, although you may already have received an email inviting you to join.

Alternatively, if you have a particular grouping in mind and would like to convene it you could contact Marijcke who may be

able to offer some assistance. The idea is that each group would be a 'virtual' group generating research ideas through email discussion led by a group-chosen convenor. Groups will only continue and be supported if there is enough expression of interest.

If these groups prove to be productive and of interest they could potentially feed in to the work of the UK-MHRN's research groups thereby giving our regional groups a national voice.

**Please join!**

Get in touch with Marijcke:

[mwmv2@cam.ac.uk](mailto:mwmv2@cam.ac.uk)

## HRIGs

Mirroring the UK-MHRN Research & Scoping Groups we have established regional email-discussion groups (hosted by YAHOO) in:

- Early intervention in Psychosis
- Self-Help
- Anti-depressants
- Mental Health in the Elderly
- Mental Health in Children
- Social Care (convened by NECSR—see section below)
- Carers

## CN-Hub Research Development Fund (RDF)

The first of the RDF funded development days took place in Norwich on the 11th April 2005. Norfolk and Waveney Mental Health Partnership hosted an Awareness Day for people interested in the possibility of setting up a Norfolk Service User Research Forum. The day was organised by Ray George, Research Facilitator for Service Users and Carers, and supported financially by the Cambridge and Norfolk Hub of the Mental Health Research Network. The purpose of the day was to gather together information about service user involvement in research at national, regional and local levels and to discuss the possibility of a creating a forum to support service users involved in research, promote service user involvement in research at all levels and to feed service user research priorities into the research strategy of the Trust.

The day began with a short talk from Peter Beresford, Director of the Centre for Citizen Participation at Brunel University and chair of *Shaping Our Lives*, the national user network. He is also a Visiting Fellow at the School of Social Work and Psycho-social Studies at the University of East Anglia, a long term user of mental health services and active in the mental health service users/survivors movement. Peter concentrated on the role of mental health service users in the research process from generating ideas and questions, through collaboration and consultation to service user led research. He emphasised the positive benefits of involving service users in research from the point of view of both producing high quality research that was effective and relevant to the needs of mental health service providers and for empowering service users to have a say in the development of those services.

The next speaker was Marijcke Veltman, Research Co-ordinator for the Cambridgeshire and Norfolk Hub of the Mental Health Research Network. Marijcke gave an overview of the purpose and structure of the national network and the regional hub and emphasised the commitment of the Hub to involving service users in the research adopted onto the network.

Sarah Gibson from SURGE (Service User Research Group England) next gave an overview of how SURGE was working closely with the Mental Health Research Network to give a practical focus to their policy of encouraging service user involvement. SURGE have developed good practice guidelines for service user involvement in re-

search which will be published in the next month and currently working on providing support and training for service users wishing to become involved with research.

After a short coffee break Anne-Laure Donskoy, Research Co-ordinator of *User Focused Monitoring* Bristol MIND described how service user monitoring of specific services was taking place in Avon and Wiltshire Mental Health Partnership. *User Focused Monitoring* have a service level agreement with the Trust to look at aspects of the services they provide and to feed their reports into the service development process of the Trust. She discussed both the theoretical reasoning behind the project and its practical implementation.

The final speaker of the morning was Helen Macdonald, Research Manager of Norwich Primary Care Trust. Helen described the *Public and Patient Involvement in Research (PPIRes)* project run throughout Norwich PCT. This project has created a database of volunteers who wish to be involved in healthcare research throughout the Norfolk and Waveney area. Helen described both how people got involved with the project, good practice guidelines the project had drawn up and how it promoted the service to local academic and clinical researchers.

A light sandwich lunch allowed those attending the day to informally discuss the many issues that had been raised by the very stimulating talks in the morning sessions. The afternoon began with Anne-Laure Donskoy describing the *Avon and Wiltshire Service User Forum (SURF)*. She described the aims of the Forum, how it was funded and the positive and challenging aspects of running the Forum. Her talk raised many issues relevant to the creation of a similar group in Norfolk.

The second talk of the afternoon was given by Elizabeth Smith and Sue Taylor from *INFORM*, a group of service user researchers based in Norwich. They described the project the group is currently working on and the lessons they had learnt from taking part in the work. Their presentation reflected the high level of commitment that was needed for the project and where things were difficult, for example in getting resources and in getting the project through the Ethics Committee system.

(continued on p.5)

**RDF (continued from p. 4)**

The last session of the day was an opportunity to reflect on what had been presented and highlight issues which would need to be taken forward in creating a Norfolk Service User Research Forum and was facilitated by Ray George and Sarah Gibson. Many issues

prompted debate and will need to be addressed if such a Forum is to succeed. It was agreed that there was sufficient interest in the creation of such a Forum and it was proposed that the first meeting should take place on Monday 25<sup>th</sup> April.

**CN-Hub Research Development Fund**

It is with regret that we can not accept any further applications to the RDF until further notice.

**UK-MHRN National Scientific Conference: *The latest and best in UK research***

The UK-MHRN conference aims to be multidisciplinary, bridging basic clinical science

through to public mental health. The focus will be to showcase high quality, international research; the key to better understanding of causes and treatments of individual disorders in real life settings. The format will be plenary sessions and two strand parallel sessions.

The conference will be held at The Manchester Conference Centre, 17-18 November 2005.

*The event will be CPD accreditable*

**If you are interested in attending as a delegate or are interested in presenting a poster please get in touch with Mrs Pat Smith** (contact details left).

**Conference contact details:**

Mrs Pat Smith  
University of Manchester  
Division of Psychiatry  
2<sup>nd</sup> floor  
Education & Research Centre  
Wythenshawe Hospital  
Manchester M23 9LT

Tel: 0161 291 5888  
Fax: 0161 291 5882

**Topics to be covered include:**

- **Current advances in the understanding and treatment of:** Mood disorders; Early Psychosis; Eating Disorders; Dementias; Substance Misuse
- **Measuring clinical outcomes**
- **Imaging in health and disorder**

The CN-Hub will probably be able to provide **sponsorship** for a number of people from our region to attend this conference. Exact details of eligibility for this sponsorship are yet to be determined. However, please get in touch with Marijcke (contact details on p.6) if you are interested in receiving more details about this potential conference sponsorship.

**SURGE Update**

SURGE has now proposed and finalised its work plan for facilitating development of Service user involvement around the MHRN.

Our work from now until July 2005 will include

- Setting up and facilitating joint SURGE/ UK-MHRN Hub road-show workshops covering Good Practice in involvement, Mental Health Research and local opportunities for collaborative working at a couple of UK-MHRN Hubs
- Investigating the current roles and working arrangements on paper and in practice for service users involved at all levels in the UK-MHRN:

Hubs, projects, research interest groups, committees etc.

- Investigating and summarising payment arrangements for service users involved as above
- Forming a list of training providers and content which might be available to service users and Hubs around service user involvement and research.

The SURGE Good Practice Guidelines for Service User Involvement in Mental Health Research are now being finalised for production in hardcopy and download from the UK-MHRN website. SURGE also hopes to produce an MHRN Service user involvement newsletter for distribution around the network.

Please send suggestions or information to contribute to any of our work themes as above to Sarah Gibson at SURGE.

**SURGE Contact details:**

Sarah Gibson  
SURGE Co-ordinator  
Mental Health Foundation  
Sea Containers House  
20 Upper Ground  
London SE1 9QB

Tel: 020 7803 1116

Email: [sgibson@mhf.org.uk](mailto:sgibson@mhf.org.uk)

**NECSR**

A bid has been made by Jenny Secker and Peter Huxley on behalf of NECSR to the ESRC seminar series call.

**Contact Details:**

Sarah Thurlow  
NECSR, NEMHPT  
Homelands Retail Park  
Cuton Hall Lane, Springfield  
Chelmsford CM2 5PX

Tel: 01245 318434  
Fax: 01245 318401  
Email: [sarah.thurlow@nemhpt.nhs.uk](mailto:sarah.thurlow@nemhpt.nhs.uk)

A number of groups and organisations, including NECSR, are currently working separately to promote social perspectives on mental health and to prioritise research in this area. The aims of the proposed seminar series are to enable these groups to work together to identify key social research questions, with input from a broader range of disciplines than is currently involved, and to develop cross-disciplinary proposals for external funding. **If the bid is successful, the funding will cover venues and refreshments for six half day seminars, to be held in London for ease of travel. Fingers crossed!**

Other news is that interim results are now available from the NIMHE MHRN scoping exercise on social research priorities in mental health as part of a larger programme of work on the development of research groups. We hope many readers

received and returned the questionnaire, which was widely distributed. The survey asked for ratings of 27 priority areas, with space for 3 additional ones of the respondent's choosing. A second section asked for respondents to supply examples of research capacity issues in the social research field.

Two different methods of ranking the priorities produced almost identical issues in a different order. However, a consistent result does emerge in terms of the top two priority areas for research which were:

- Social inclusion / social capital / social networks
- Social factors that enable resilience and recovery

For full details of the interim results on research priorities and research capacity issues, please contact NECSR.

**CN-HUB**  
**CONTACT DETAILS**

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**Hub Director & Research Lead** Professor Ian Goodyer  
(University of Cambridge)  
**Hub Deputy Director & Clinical Lead** Professor Shirley Reynolds  
(University of East Anglia)  
**Primary Care Lead** Professor Amanda Howe  
(University of East Anglia)  
**Social Care Lead** To be appointed

**CN-Hub Consortium**

- University of Cambridge
- University of East Anglia
- Cambridgeshire & Peterborough Mental Health Partnership NHS Trust
- Norfolk & Waveney Mental Health Partnership NHS Trust
- Suffolk Mental Health Partnership NHS Trust (*linked clinical site*)

[www.mhrn-cnhub.org.uk](http://www.mhrn-cnhub.org.uk)

**Keeping in touch**

Full Name:

Address:

Email:

Telephone:

Fax:

Profession:

Are you a:

Service User

Carer

Clinician

Researcher

Preferred way of receiving communications from us:  Email

Post

Telephone

Please indicate your broad areas of interest (tick ✓ as many as apply):

Addiction	<input type="radio"/>	In-patient care	<input type="radio"/>
Adult Mental Health	<input type="radio"/>	Out-patient care	<input type="radio"/>
Assertive Outreach	<input type="radio"/>	Community care	<input type="radio"/>
Child & Adolescent Mental Health	<input type="radio"/>	Social care	<input type="radio"/>
Forensic Mental Health	<input type="radio"/>	Primary care	<input type="radio"/>
Older People Mental Health	<input type="radio"/>	Learning Disabilities	<input type="radio"/>
Dementia	<input type="radio"/>		
Other (please specify)	<input type="radio"/>		

Please provide more specific areas of interest:

**Please indicate your preferred level of involvement:**

Receiving the newsletter

Hub Research Interest Groups

Research Participation

Other (please specify):

When completed please send to Marijcke Veltman at the address provided at the top of this page.