

News from the Network



Issue 8
April 2006

FOREWORD

Welcome to the April issue of '*News from the Network*'. This newsletter aims to update you with all the latest news from the UKCRN Coordinating Centre (UKCRN CC), as well as sharing information and news from across our partner organisations, the Topic Specific and the Local Research Networks.

This month our lead article focuses on Patient and Public Involvement and the ways in which UKCRN are working to ensure that patient and public representatives have the opportunity to become involved in all that we do. We also feature an update on the Primary Care Research Network - England, and look at the progress that's being made towards establishing Local Research Networks in this area. Finally, an update on the UK Clinical Research Collaboration's strategic analysis of health research funding, the first phase of which is due to be published in May.

As usual, our regular updates from the Topic Specific Research Networks, the calendar of events and regulatory and governance update highlight particular points of interest this month. I hope you'll find this month's issue of interest and would welcome your feedback. Please circulate it to any colleagues in Topic Specific or Local Research Networks who you feel would find it useful. If you have any other comments on this month's issue, please contact me on l.bleasdale@ukcrn.org.uk

Next month's issue will be circulated on 1 May 2006. **Louise Bleasdale, UKCRN Communications Manager.**

Patient and Public Involvement at UKCRN

The needs and views of patient/public representatives are important to UKCRN and patient/public involvement (PPI) is fundamental to improving clinical research in the UK. A national strategy for PPI is being developed to ensure such involvement occurs from the outset and we are adopting a coordinated, strategic approach in a number of key areas:

■ Developing relationships

Working relations have been established between the UK Clinical Research Collaboration (UKCRC), UKCRN and a range of partners (including INVOLVE, the Medical Research Council, the Royal College of Physicians and the Wellcome Trust) via the development of a UKCRC Patient/Public Involvement Group. This group will discuss and advise on setting an agenda that adds value to current PPI activities on a national level to avoid any duplication. The group also plans to address high profile issues regarding clinical research and PPI that cannot easily be tackled by individual organisations. UKCRC recognise the importance of this work and are seeking to appoint a Programme Manager for PPI and the Research Workforce to join the core team. Plans to appoint an Associate Director for PPI at UKCRN are also in progress. A new Public Involvement Coordinator has been appointed at INVOLVE to take forward work to promote and support PPI in clinical research, and particularly the work of UKCRC/UKCRN.

■ Activities across the networks

Each of the Topic Specific Research Networks has committed resources to support PPI within its own disease areas. Dedicated Consumer Liaison Officer posts have been established and staff are already in post in the Medicines for Children Research Network (MCRN) and the Diabetes Research Network (DRN). The well-established Service User Group England (SURGE) forms part of the Mental Health Research Network (MHRN) and recruitment to similar posts in the National Cancer Research Network (NCRN), Stroke Research Network (SRN) and Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) is also underway.

Each network has begun to develop its own programme of PPI activities and Marianne Miles, Patient/Public Liaison Lead at UKCRN, is working with them to ensure a coordinated and generic approach where appropriate. This includes sharing information, offering guidance, developing common systems/good practice, training and mentoring opportunities and measuring levels of PPI.



Marianne Miles

Further information is available from Marianne Miles on 0113 392 4398 or email m.miles@ukcrn.org.uk

Stroke Research Network (SRN)

Local Research Networks

Staff from the SRN and UKCRN Coordinating Centres have been involved in a series of teleconferences with the Clinical Leads of the proposed Local Research Networks to agree financial and management plans. It is hoped that the networks will begin operating this month. Job descriptions for key posts within the networks have also been developed and shared with Clinical Leads.

Clinical Studies Groups

Seven Clinical Studies Groups (CSGs) have been established to date and all have now met, at least once, either face to face or via teleconference. Work is ongoing to establish further CSGs, in Biostatistics and Informatics, over the coming months.

Stroke Research Network Meeting

The inaugural meeting of the SRN Operational Steering Group will take place in London on Thursday 4 May following a meeting of the Local Research Network Directors earlier in the day. The Group includes SRN Directors, Local Research Network Leads, representatives from UKCRN and representatives from Scotland, Wales and Northern Ireland.

Patient and Carer Involvement

The next meeting of the Patient and Carer Involvement Working Party is scheduled for 2 May. The meeting will once again be hosted by the Stroke Association at their London headquarters.

Study Adoption

Following ongoing discussions with the UKCRN Coordinating Centre, the SRN is defining the process for the adoption of new studies into its portfolio. Clinical Studies Groups are currently working to identify existing studies to discuss the possibility of adoption into the SRN portfolio with Chief Investigators and funders.

Recruitment of SRN Coordinating Centre Staff

The Coordinating Centre is looking forward to the arrival of a new Administrator, Gillian Watson, on 10 April. Interviews took place last month to appoint a Patient and Carer Involvement Manager, however the SRN were unable to make an appointment. This post is currently being re-advertised and it is hoped an appointment will be made in the near future.



<http://www.uksrn.ac.uk>

Diabetes Research Network (DRN)

Diabetes UK

Diabetes UK's Annual Professional Conference was held in Birmingham on 29 - 31 March. As the UK's leading charity for people with Diabetes, this conference attracts around 3000 healthcare professionals from a wide range of specialisms within the Diabetes field. The DRN co-hosted a stand at the conference, together with the National Audit Team and the National Diabetes Support Team. DRN used this opportunity to speak to delegates about the network's progress and to highlight the numerous possibilities for getting involved in clinical research.

The first meeting of the Clinical Leads for the proposed Local Research Networks also took place at the conference.

DRN Website

The DRN website has been redesigned and the new look went live on 14 March. The website was officially launched at the Diabetes UK Conference.

The main changes are to the structure of the site, the navigation and the content to ensure that it conforms to website accessibility standards.

The DRN are keen for other Topic Specific Research Networks to link to the new site and would welcome any feedback on its content or design.

Advocacy and Patient Involvement Group

The second meeting of the Advocacy and Patient Involvement Group took place on 1 March in Oxford. Both Sarah Buckland and Roger Steel from INVOLVE attended and their help in preparing the patient and public involvement pages for the new website has been invaluable. The next meeting will take place on 4 April when Marianne Miles (UKCRN Patient and Public Liaison Lead), Bill O'Leary (National Diabetes Support Team) and Emma Cox (Diabetes UK) will join the group.

More information is available at the DRN website: <http://www.ukdrn.org.uk>



Mental Health Research Network (MHRN)



UK Mental Health Research Network

■ MHRN Research Groups

The MHRN portfolio of studies aims to cover the full range of mental health research, including biological, psychological and social issues across the spectrum of mental health diagnoses. Focused fixed-term MHRN Research Groups allow internationally renowned researchers to respond proactively, with germane research questions of the day, and dynamically, to research funder strategies and initiatives. Their purpose is to provide the creative drive to the Network. Each Research Group is expected to turn research ideas into funded studies that are suitable for running in the MHRN.

The groups:

- Comprise a multidisciplinary group of leading academics, clinicians, service users and carers, convened and chaired by an internationally recognised researcher
- Consider new research questions in relation to MHRN scoping group findings, national research priorities and the current MHRN portfolio
- Generate clinically relevant research studies important to the aims of MHRN
- Secure funding from UKCRC members for vital new, large scale, high quality research in mental health and social care
- Submit applications to the independent MHRN Adoptions Committee for the research proposals to run on the MHRN
- Are able to provide expert advice as required
- Are funded for a fixed term of two years, with possible renewal on a competitive basis.

<http://www.ukmhrn.info>

International trials and research studies proposed by those outside Research Groups are considered by the independent MHRN Adoptions Committee, which considers the feasibility of, and advises appropriately on, all projects requested to run on the network. In addition, the Adoptions Committee oversees existing MHRN-adopted studies of other researchers. The MHRN has strong links with research funders through the Mental Health Research Funders Forum, which provides a forum for strategic analysis of strengths and opportunities for future research support and for the development of the MHRN portfolio.

■ Current call

A total of 21 applications were received in the 2006 call for Research Groups. These applications are currently out for external peer review and the successful groups will be announced later this month.

■ Hub Leads meeting

The last Hub Leads meeting was on 16 March.



National Cancer Research Network (NCRN)

■ Workload and Complexity Project

A joint workload and complexity project, spearheaded by two Network Managers (Julie Berridge and Jacqueline Briggs) is being run under the auspices of the NCRN in conjunction with the EORTC and in collaboration with the Wales Cancer Trials Network (WCTN). The aim of the project is to collect detailed data on the amount of time that members of the research team spend on tasks associated with trial set-up, implementation (including accrual, treatment and follow-up), data management and closure. Data will be collected for around 20 trials in the implementation phase and the project is anticipated to run in approximately 40 hospitals across 15 cancer research networks in England, Scotland and Wales. The workload data will then be used to validate a complexity weighting model.

The project team are currently training network-based staff in the use of the data collection tools and Richard Harpin, NCRN Information Systems Officer is building

a database to capture all the information generated by the project. Data collection will start this month and each participating site will be asked to collect data on a pre-defined list of NCRN trials over a 6 month period. Further information is available from Julie Berridge, email jberridge@ncht.trent.nhs.uk or Jacqueline Briggs, email jacqueline.briggs@velindretr.wales.nhs.uk.

■ Staff news

NCRN welcomes Joanne Shill as the new Research Network Manager for Dorset. Joanne was previously Trust Research Manager at Clatterbridge Centre for Oncology and before joining the NHS, worked as a GCP Advisor and Study Facilitator for a site management organisation setting up commercial studies in the NHS. Joanne can be contacted on joanne.shill@ferndown.nhs.uk

<http://www.ncrn.org.uk>



Medicines for Children Research Network (MCRN)



■ **Local Research Networks**

The MCRN Coordinating Centre are currently working with the UKCRN Coordinating Centre and the proposed Local Research Networks (LRNs) to finalise their operating budgets and management structures. LRN contracts can start from 1 April 2006, or soon after that date, once they are agreed with the Department of Health.

■ **Health Technology Assessment (HTA) Call**

A number of proposals were submitted in response to the medicines for children call issued by the HTA programme in 2005. MCRN is still awaiting confirmation of the funding for these studies.

■ **Staff news**

Vanessa Poustie returns from maternity leave on 3 April to resume her role as Assistant Director of MCRN. Sarah Dyas will continue to work alongside Vanessa until the end of May.

<http://www.mcrn.org.uk>

Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)



■ **Local Research Networks**

Seven Local Research Networks were proposed, following interviews which took place earlier this year, and discussions to agree contracts and budgets are currently ongoing between the Clinical Leads of the proposed networks, the DeNDRoN Coordinating Centre and the UKCRN Coordinating Centre. More information will following in a subsequent issue.

■ **Clinical Studies Groups**

Clinical Studies Groups are being established to cover Dementia, Parkinson's Disease, Motor Neurone Disease, Huntington's Disease, Primary Care, Genetics, and Neuropathology and Brain Banking. Chairs have now been identified for most of the groups and work is ongoing to select members.

Further information is available on the UKCRN website at <http://www.ukcrn.org.uk>

Update: UKCRC Strategic Analysis of Health Research Funding

In October 2004, the UKCRC Board agreed to the development of a central database of the biomedical and health portfolios of the major health research funding organisations. The aim was to classify the portfolios, using a bespoke research classification system, and then publish a subsequent analysis of research funding as the first major step in providing a comprehensive national picture of research activity in the UK.

Over the past few months, the database development has progressed and it now brings together the research portfolios of the MRC, the four Health Departments, the three largest medical charities (Wellcome Trust, Cancer Research UK, British Heart Foundation), plus the health relevant portfolios of three other research councils (ESRC, EPSRC and BBSRC). This represents the overwhelming majority of non-commercial health related research in the UK.

The database is a 'snapshot' of research taking place during 2004/2005, holding a total of 9638 award records. It includes research awards that are associated with clear research objectives that can be classified and analysed - it is intended to be useful for monitoring and analysing research activity trends.

At this stage, the database excludes industry funded research, research funded by UKCRC partners which is taking place outside the UK, research funding by smaller not-for-profit organisations, research taking place in the UK funded by non-UK funding organisations and HEFCE funded support.

The first phase analysis of this data will be published in May 2006. Following publication, discussions will begin on the feasibility of collecting information on research funded by smaller charities and industry. More information is available at <http://www.ukcrc.org>

In brief

Primary Care Research Network (PCRN - E)

A call for expressions of interest, issued in November last year, resulted in eight applications from groups wanting to become Local Research Networks within PCRN - E. The applications cover the whole of England and all eight have now been asked to provide more detailed bids prior to interviews which take place on Monday 5 June. The PCRN - E Local Research Network selection process will be based on the same principles as were used to select topic specific networks. A Primary Care Research Network Manager has been appointed to oversee this development. More details are available from Christopher Button, Research Network Lead, email c.button@ukcrn.org.uk

APRIL

3 - 4 April

“Science for all: is public engagement engaging the public?” Wellcome Trust
Manchester Conference Centre
<http://www.wellcome.ac.uk/node6235.html>

4 - 5 April

Institute of Clinical Research Annual Spring Conference
Manchester International Convention Centre & GMEX
<http://www.instituteofclinicalresearch.org>

5 April

Scottish School of Primary Care Annual Research Conference, Perth, Scotland
<http://www.nes.scot.nhs.uk/events/items/default.asp?id=205>

6 April

“Shaping the future: the provision challenge for primary and community care”
NHS Confederation Conference, London
http://www.nhsconfed.org/events/conferences/shaping_the_future.asp

18 April

“Medicine and me: breast cancer - the patients journey”
Royal Society of Medicine, London
<http://www.rsm.ac.uk/academ/XA-Breast.htm>

NEW 24 April

Experimental Medicine Symposium
Academy of Medical Sciences, London
<http://www.acmedsci.ac.uk/p45evid50.html>

25 April

“Continuing the journey: exploring new frontiers in non-medical research”
Aintree Hospitals NHS Trust
http://www.rdforum.nhs.uk/otherconferences/aht_250406_lt.doc

26 April

“Living with cancer” 2006 conference
University of Glamorgan
Email aattard@glam.ac.uk for more information

27 April

“Working together?”
MidREC - The Royal College of General Practitioners (Midland Faculty) and R&D for Birmingham and Solihull PCT Consortium Annual Research Conference
http://www.rdforum.nhs.uk/otherconferences/mid_270406.doc

MAY

9 May

5th National SDO Conference: “Delivering better health services”
Savoy Place, London
<http://www.healthcare-events.co.uk>

9 - 10 May

NHS R&D Forum Annual Conference
Bristol Marriott Hotel
<http://www.rdforum.nhs.uk/events.htm>

10 May

“Proactive risk management: beyond incident reporting”
Manchester Conference Centre
<http://www.healthcare-events.co.uk>

11 May

“Public involvement in health research: more than a box ticking exercise?”
MHRN East Anglia Hub/Public and Patient Involvement in Research Project, Norwich
Email: barbara.staffa@norwich-pct.nhs.uk

11 May

“Clinical research: learning from the past, exploring the future”
Wellcome Trust Clinical Research Facility, Manchester Postgraduate Science Centre
Email: janice.richardson@manchester.ac.uk

11 - 12 May

Enforcing the Human Tissue Act
Royal College of Obstetricians and Gynaecologists, London
http://www.rdforum.nhs.uk/otherconferences/nbp_120506.pdf

16 - 17 May

Mental Health 2006
Savoy Place, London
<http://www.healthcare-events.co.uk>

19 - 20 May

12th Annual BACP Conference: “The consumer and counselling research”
<http://www.bacp.co.uk/research/conference2006>

21 - 24 May

Society for Clinical Trials (US) Conference
Orlando, Florida
<http://www.sctweb.org>

26 May

National Research and Development Support Unit (RDSU) Conference
<http://www.national-rdsu.org.uk/conference>

Please contact Louise on l.bleasdale@ukcrn.org.uk as soon as possible if you are presenting at any forthcoming conferences, on behalf of UKCRN or the Topic Specific Research Networks, to allow us to highlight this.

EudraVigilance

EudraVigilance is the European electronic data management system for case safety reports (post-marketing surveillance) and reports of Suspected Unexpected Serious Adverse Reactions (SUSARs) from clinical trials. EMEA has announced a programme of courses on EudraVigilance that are being held in London throughout 2006 and run over 3 days with a reduced fee (€ 770) for non-commercial organisations. This training is required for electronic submission of safety reports to EudraVigilance via the EVWeb (a free web-based application). Currently, safety reports from clinical trials in the UK are submitted on paper to MHRA. What will be required in the future is still uncertain. At the present time, UKCRN would not encourage attending this training as the option of a centralised reporting process is being explored. More information at <http://eudravigilance.emea.eu.int/human/training.asp>

1st EudraVigilance Information Day: 8 May 2006

The EMEA have organised a one-day course to share knowledge about the current implementation status and the next developments within the community. The course will be held in London and there is a reduced rate of € 150 for non-commercial organisations. Further information at: <http://eudravigilance.emea.eu.int/human/docs/EV%20Info%20Day%20Final.pdf>

Consultation on the future of NHS Research Ethics Committee Services

This consultation has been launched to implement the recommendations of the 'Report of the Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees' which was published in June 2005. One key area is to reconfigure the research ethics committee service, to include the establishment of an independent group of National Research Ethics Advisers. Of note, these plans only apply within England and Northern Ireland. The consultation paper is available for comment until **21 April 2006** and can be found at <http://www.corec.org.uk/applicants/consultation.htm>

New guidance papers issued to NHS Research Ethics Committees

COREC has issued new guidance to NHS Research Ethics Committees relating to the suspension or termination of ethics approval. In summary, the document states that an ethics committee may not suspend or terminate a clinical trial, however committees may raise any new ethics concerns that emerge during the trial. The guidance paper can be found at the following link: http://www.corec.org.uk/applicants/docs/guidance_on_%20suspension_of_ethical_opinion.doc

COREC has also issued new guidance to NHS Research Ethics Committees relating to indemnity for GPs and other independent practitioners in primary care. The full guidance paper can be found at the following link: http://www.corec.org.uk/applicants/docs/guidance_for_RECs_on_GP_indemnity.doc

Ethical review of medical devices

COREC is planning to introduce new arrangements for the review of medical devices research. Twelve NHS Research Ethics Committees have been identified as having the appropriate experience to review this type of research. Effective 3 April 2006, all applicants are required to book their applications through the central allocation system <http://www.corec.org.uk/applicants/index.htm#060322c>

“Making a difference: safe and secure data sharing between health and adult social care staff”: report

The Department of Health have released a report which clarifies the policies and guidance around security, confidentiality and sharing of patient identifiable information. The plans include issuing a single set of guidance in September 2006 on the secondary uses of personal information for medical research, population health and management. This will take account of the recommendations of the Academy of Medical Sciences and the Council for Science and Technology, the views of frontline staff and appropriate patient and service user groups. The report is available at: http://www.cabinetoffice.gov.uk/regulation/documents/mad/data_sharing.pdf

Better regulation executive: Davidson review of the implementation of EU legislation

The main purpose of this review is to support the productivity of the UK economy by ensuring that EU legislation has not been implemented in a way that results in unnecessary regulatory burden. The report is available at: http://www.cabinetoffice.gov.uk/regulation/documents/davidson_review/evidence.pdf

Human Tissue Authority licensing requirements

Any establishment storing tissues or cells for human application will need to apply for a licence by **31 March 2006**. Further information is available at <http://www.hta.gov.uk/news/story/?item=11>

News from the Network is compiled by Louise Bleasdale, UKCRN Communications Manager. If you have any comments or questions about this month's issue please contact Louise on l.bleasdale@ukcrn.org.uk or call 0113 392 4401. The next issue of the newsletter will be circulated on **Monday 1 May**. Please send contributions for the next issue to Louise by **Monday 17 April**.