

ISSUE 35: FEBRUARY 2010

News from the Network

LATEST NEWS:

**Leadership changes
for the NIHR Clinical
Research Network
Coordinating Centre
announced.
Full details on page 2**

“Delivering Clinical Research in the NHS.”

A report on the 2010 NIHR Clinical Research Network National Conference

‘Delivery’ was the strong theme which came through at this year’s NIHR Clinical Research Network National Conference, which took place at the ExCeL Conference Centre in London on 28 January.

This was the third Clinical Research Network national conference since the launch of the newest Topic Networks in 2005 and the aim was to promote a better understanding of what the Networks can offer and reflect on what had been achieved to date.

Professor Dame Sally Davies opened the conference with a thoughtful look at the last four years and what had been achieved since the launch of the National Institute for Health Research (NIHR) in 2006. She celebrated the progress made within the NIHR Clinical Research Network and congratulated those in the audience who had been a part of that success to date, thanking them for the hard work and dedication they had shown. She also highlighted the work still to do, reinforcing the strong commitment she had to ensuring that support would be available for those developing and delivering high quality clinical research in the NHS.

***“The conference is very worthwhile
for people who are involved in research”***

The morning sessions continued the theme of delivery with presentations describing work being done to support researchers, NHS Trusts and Industry. Mike Farrar, Chief Executive of NHS North West, gave an inspiring talk on the importance of clinical research within the NHS and his commitment to ensuring it became recognised as a part of the core business. He also touched upon work going on in the North West under the auspices of the North West Exemplar Programme and the positive results that were being achieved through close cooperation between the Networks, NHS Trusts and the companies taking part.

Delegates were given the opportunity to get involved in a number of interactive sessions over lunch with ‘surgeries’ covering topics such as the Research and Development Management Information System (RDMIS) and the NIHR Coordinated System for gaining NHS Permission (NIHR CSP). Most chose to browse the stand and poster exhibitions and used the opportunity to catch up with colleagues or find out more about what the Networks could offer in terms of support and guidance.

In the afternoon, topics such as ‘The impact of patient and public involvement’ and ‘Delivering the national ambition for clinical



Professor Dame
Sally C Davies
gives the
Keynote speech

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If you have feedback on any aspect of this newsletter please contact Emma Bender, NIHR CRN CC Communications Officer:

emma.j.bender@nhr.ac.uk

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research through the NIHR Clinical Research Network' continued the delivery theme, and delegates were given the chance to find out more about a series of initiatives that were being delivered through the NIHR Clinical Research Networks.

"A useful conference to understand where we are now and where we are heading"

Science writer and broadcaster Vivienne Parry, who recently delivered a four part series on clinical trials on BBC Radio 4, closed the conference with a challenging and upbeat talk on how the media and communications can help support the delivery of clinical research. She encouraged the assembled audience to get better at talking to the media and use journalists to their advantage to promote the benefits of clinical trials.

"An extremely useful and informative update from NIHR based on targets and ambitions"

Feedback has been incredibly positive from the 450 delegates who attended on the day and who ranged from a variety of different organisations which included NHS Trusts, pharmaceutical companies, charities and Clinical Trials Units. This feedback was extremely valuable and will be captured to help shape the development of future events and conferences.

Presentations and images from the day are available on the NIHR Clinical Research Network website at:

www.crnc.nihr.ac.uk/index/news/newsitems/news00157.html



NEWS IN BRIEF

NIHR CRN CC leadership changes announced

Professor Dame Sally Davies thanked Professors Peter Selby and Janet Darbyshire for their dedication and hard work as Joint Directors of the NIHR Clinical Research Network as she announced planned changes to the leadership of the NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC) at the NIHR CRN national conference in January.

In the first five years of its operation, the role of the Coordinating Centre has expanded to encompass not only Topic Network development and delivery but also the establishment of the NIHR Primary Care and Comprehensive Clinical Research Networks and the implementation of a series of high profile, national initiatives designed to streamline and support the delivery of clinical research in the NHS, such as the NIHR Coordinated System for gaining NHS Permission and Activity Based Funding. In funding terms this progression has been from £40 million a year to more than £300 million a year and the Coordinating Centre has grown from a staff of around 30 people to a staff of around 120.

Going forward, it has become clear that the future leadership of such a big operation has to have a much larger capacity. Discussions with the Department of Health have concluded that funding will therefore be provided for two new leaders: a full time Chief Executive Officer based in Leeds, probably from a background in NHS management, and a full time Medical Director. These two new posts will take over the leadership and management roles of Professors Peter Selby and Janet Darbyshire. Janet and Peter will continue as Joint Directors until these appointments are made and to cover the recruitment and settling in period of the new leadership team. More information will follow once further details are confirmed.

NEWS IN BRIEF

UKCRC transition to Partner-led model – Progress Report

The UK Clinical Research Collaboration's (UKCRC) transition to a Partner-led model nears completion with the appointment a new Partnership Manager.

Sarah Qureshi was appointed as UKCRC's Partnership Manager towards the end of last year. This is just one in a number of changes driven by the transition. At the UKCRC Board meeting in November 2009 the remaining mechanisms for delivery were agreed, with lead Partners identified and, where appropriate, supporting collaborative groups. All groups will review their work on an annual basis to assess whether there is a continued need for their activity.

Sarah Qureshi can be contacted on sarah.qureshi@ukcrc.org.

Further information is available in the UKCRC Winter Newsletter which is available to download from the UKCRC website: www.ukcrc.org/publications/updates/



What's New?

ASSOCIATE DIRECTOR OF DENDRON APPOINTED AS THE NEW NATIONAL CLINICAL DIRECTOR FOR DEMENTIA

Alistair Burns, Professor of Old Age Psychiatry at Manchester University and Associate Director for Dementia for the NIHR Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) has been appointed as the first National Clinical Director for Dementia by the Department of Health.



Professor Burns has been a key member of the leadership team responsible for establishing DeNDRoN. As National Clinical Director for Dementia he will promote better care of people with dementia within the NHS and social care communities and provide leadership for the implementation of the National Dementia Strategy.

Care Services Minister, Phil Hope said:

"Alistair's experience of dementia services gives him a unique understanding of what works for people with the condition and their carers. I am confident that he will help drive up standards of care across the country and look forward to working with him to build the best possible services for people with dementia."

Professor Alistair Burns, said:

"I am delighted to have been appointed to the post of National Clinical Director for Dementia. In the past few years, there has been a great deal of public interest in dementia and several influential initiatives, in particular the National Dementia Strategy and DeNDRoN. The challenge, now, is to build on this to make a real positive difference to people with dementia, their families and carers. I very much look forward to working with colleagues to realise this ambition."

Professor Burns will work closely with the new National Clinical Director for Older People, Professor David Oliver to ensure strong leadership in shaping the future of services for an ageing population.

Director of DeNDRoN, Professor Martin Rossor said:

"Although we are sorry to see Alistair move on, his appointment into this important post underlines the significance of research in dementia, both in developing evidence-based services and in seeking to better understand its cause, develop new treatments and hopefully find a cure."

A new Associate Director for Dementia will now be appointed in DeNDRoN to continue the progress started by Professor Burns, and to work closely with him in this new role towards integration of clinical research and patient care for the benefit of people with dementia and their carers.

For further information please contact press@dendron.org.uk



NCRN COORDINATING CENTRE NEWS

Staff news

Jane Beety joined the National Cancer Research Network (NCRN) Coordinating Centre on 1 February as Research Network Transition Coordinator - Anglia. Jane's role is a secondment for six months. She will support the reconfiguration and launch of a new Cancer Research Network in the East Anglia area incorporating all NHS Trusts that are currently operating within the Norfolk and Waveney Cancer Research Network, together with the Ipswich Hospital NHS Trust. In the second phase of the project Jane will support the development of a single seamless clinical research strategy across the two cancer Local Research Networks within the Anglia Cancer Network to support patient access into NIHR Cancer Portfolio studies.

National Cancer Director for England awarded a knighthood

Congratulations to Professor Mike Richards, National Cancer Director for England, who was awarded a knighthood in the New Year's Honours List. Professor Richards has been involved with NCRN and the National Cancer Research Institute (NCRI) from their beginnings; he served as Chair of the NCRI from 2006-2008 and is a member of the NCRI Board.

Best Practice Communications Guide Launched

A best practice communication guide entitled 'Developing links between Clinical Trials Units and Research Networks' is now available to download from the National Cancer Research Network (NCRN) website.

This document has been developed through the work of the Trials Units and Research Networks Working Group (TU-RN), which is a working group of the National Cancer Research Institute (NCRI) Accredited Trials Units Heads Committee. The group comprises representatives from Accredited Trials Units and Cancer Research Network Managers. It is the culmination of many discussions leading to a shared understanding of each others' roles. The Guide is intended to help optimise communication in order to facilitate the running of NCRN studies. It has been discussed and endorsed by Committee of NCRI-Accredited Trials Unit Heads.

NCRN welcomes feedback on the guide. Please send comments to Jodi Baxter, NCRN Portfolio Administrator, (j.baxter@ncrn.org.uk).

The 'Best Practice Guide - a communication guide' and associated documents are available to download from: http://ncrndev.org.uk/index.php?option=com_content&task=view&id=145&Itemid=285

NCRI News

NCRN and NCRI will jointly celebrate their tenth Anniversary in 2011 and will be working together over the coming year to consider how to mark this occasion and celebrate achievements to date.

Updates on various NCRI initiatives are detailed in the latest edition of their newsletter which also features an article on the forthcoming NCRI 2010 Conference as it moves to a new location in Liverpool. The newsletter is available to download from www.ncri.org.uk



What's New?

PCRN BIDS A FOND FAREWELL TO PROFESSOR GREG RUBIN, CLINICAL LEAD FOR PCRN NORTHERN AND YORKSHIRE

Professor Greg Rubin was fundamental in producing the successful bid to establish the PCRN in the North East and he works tirelessly to build the Network across the region. His contribution to PCRN will be sorely missed but PCRN wishes him well for the future and looks forward to delivering his studies.

Dr Raghu Raghunath, Senior Clinical Director Hull York Medical School, (HYMS) writes,

"I am fortunate to have known Greg for nearly two decades. Despite the accolade and acclaims deservedly acquired through the years, Greg is firmly rooted in the world of "real" general practice; this combined with his academic, research, organisational, leadership and multitude of other skills has endeared him to the medical fraternity at large, primary care in particular."

The PCRN in our region and by any standards has been a huge success, thanks to the strategic and inspiring leadership and vision provided by Greg and his team.

Greg's personal research interests in the areas of gastroenterology and cancer have resulted in several peer reviewed publications in high impact factor journals. In his recently appointed role as Professor of Primary Care at the School for Health, University of Durham, Greg is already beginning to make a significant impact in the development and delivery of services through the Primary Care Trust (PCT) as well as research.

Greg's absence will be profoundly felt and his personal charm and leadership hard to

replace. However, he is leaving behind a strong, committed and well trained workforce and infrastructure that he helped to establish. I, on behalf of all the staff of the PCRN, take this opportunity to thank Greg and wish him the very best in his future endeavours."



LONDON'S CHILDREN: SUPPORTING PAEDIATRIC RESEARCH IN 2010

On 4 February the South East, North Central and East (SENCE) Medicines for Children Research Network (MCRN) hosted a conference at the Wellcome Collection in London to re-launch the Network as a new *inclusive* London Network along with a brand new name and logo.

With over 100 delegates, 40% of them from the west of London, the aim of the conference was to introduce the Local Research Network (LRN) and to give delegates the opportunity to network with key representatives from MCRN, all London Comprehensive Local Research Networks (CLRNs), the Royal College of Paediatrics and Child Health (RCPCH), Paediatric Pharmacy and Formulations, the Neonatal Network (NPEU) and Greater London Primary Care Research Network (PCRN-GL).

Aptly titled 'London's Children: Supporting Paediatric Research 2010', the conference was opened by members of the renamed 'London and South East LRN' Young Person's group led by Adrian Green, Senior Research Nurse. Adam Lai, Lucy Atkinson, Chloe Johnson, Anjuli Kumar, Kieran Rose, Jake Setters and Jake McManus each introduced segments of the first session including a DVD which they filmed specifically for the conference and also a short message from Boris Johnson, Mayor of London.

Professor Rosalind Smyth, MCRN Director, described the first three years of operation of the Network. She focused on the NIHR triennial review in January 2009 highlighting key outcomes and aims for the future the further development of working relationships and initiatives with London CLRNs, and to increase research capacity for paediatric medicine, both in the MCRN Portfolio of clinical studies but also for non-medicines paediatric research.

London and South East MCRN Director, William van't Hoff introduced the new pan-London Network. This will benefit not

only the individual researchers, their NHS institutions and respective academic affiliations but also will enable London to make a pivotal contribution to children's health. London and South East MCRN has already made progress on this initiative by establishing key collaborations with the cystic fibrosis team at Royal Brompton and the Vaccine Group at St George's Hospital, Tooting. They are committed to developing this formula across the whole of London to all paediatric researchers.

For further information please contact Dr Sharon Barrett, London & South East MCRN Clinical Research Manager, (wallas@gosh.nhs.uk).

Below: Director of the London and South East LRN and members of the Young Persons Group welcoming delegates to the conference.

Left to Right; Dr William van't Hoff, Kieran Rose, Adam Lai, Jake McManus Lucy Atkinson, Chloe Johnson, Anjuli Kumar and Jake Setters.



What's New?

PRIMARY CARE RESEARCH RECRUITMENT: A PRACTICAL GUIDE – UPDATED VERSION NOW AVAILABLE



The Primary Care Research Recruitment Guide has been developed by the NIHR Primary Care Research Recruitment Methods Group (see www.nspcr.ac.uk), in conjunction with the NIHR Primary Care Research Network (PCRN). The guide is intended as a practical resource to help researchers in primary care with participant recruitment. It draws on information from a variety of experienced research-active professionals from a range of settings who shared information about how they and their organisations approach the task of recruiting to studies in primary care. It is hoped that by sharing their ideas and practices through this resource, others will be inspired to adopt procedures which they may not have previously thought of and that in doing so will achieve their targets.

This updated version of the guide includes quotes and comments from a range of stakeholders including funders, chief investigators and trial managers which help to illustrate the issues and ideas tackled by this useful document and provide a insight into the experiences of research professionals.



The document can be accessed via the PCRN website: www.crnc.nihr.ac.uk/index/networks/primarycare/researchers.html

CCRN COORDINATING TEAM NEWS

In January the Comprehensive Clinical Research Network (CCRN) Coordinating Team welcomed Clare Shaw, Specialty Group Coordinator. Clare will be working alongside Samantha Scarlett to support the work of the CCRN National Specialty Groups. Clare can be contacted on clare.shaw@nihr.ac.uk.



NIHR CLINICAL RESEARCH NETWORK (CRN) COORDINATING CENTRE NEWS



Interim Portfolio Lead

Dr Joanna Olliver, Senior Fellow – Experimental Medicine, has been appointed as Interim Portfolio Lead until the position can be advertised and appointed to. Dr Olliver will work in this role for four days a week and will ensure any essential Experimental Medicine work stream activities are progressed in her remaining day.

Head of Communications

Louise Wood, Head of Communications, joined the Coordinating Centre on 1 February. Louise is looking forward to meeting Network representatives with a responsibility for communications at the NIHR CRN Communications Working Group meeting on 1 March. Louise is keen to ensure that this becomes a valuable forum for sharing best practice and new ideas for effective communications.

Interim Heads of Research Management and Governance

John Wardle (Lead RM&G Manager, Cumbria and Lancashire CLRN) and Phil Smith (Lead RM&G Manager, Essex and Hertfordshire CLRN) have been appointed to the post of Interim Head of RM&G for the NIHR CRN CC. This will be a 'job-share' arrangement, with Phil and John each working 50% WTE in the role. These appointments are with effect from 1 February, for four months in the first instance, and are intended to provide cover until recruitment to the substantive post is complete.

For further information please email crnc.info@nihr.ac.uk

PENINSULA SRN REAPS BENEFITS OF JOINT WORKING



Peninsula Stroke Research Network (SRN) is developing links with the Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLARHC). This alliance has already proved beneficial as Peninsula SRN have had two research ideas prioritised as first and joint second in a recent stakeholder prioritisation round. This means that PenCLARHC will be working with Peninsula SRN to take these two projects forward– one on thrombolysis and one on a rehabilitation scheme developed by Action for Rehabilitation from Neurological Injury (ARNI). Two of Peninsula SRN's lay members have also become involved in the PenCLARHC Patient and Public Involvement (PPI) group.

Peninsula SRN has also been working closely with the Peninsula Heart and Stroke Network, and will be running some public information days in collaboration with them. The aim is to share best practice, increase public awareness of research and increase involvement across both of the Networks.

For further information please contact Jacqueline Briggs, Peninsula SRN Network Manager, email jacqueline.briggs@rdeft.nhs.uk

The Clinical Research Network Portfolio

The UK Clinical Research Network (UKCRN) Portfolio comprises the NIHR Clinical Research Network (NIHR CRN) Portfolio in England, and the corresponding portfolios of Northern Ireland, Scotland and Wales. Each of these portfolios can be viewed on the Portfolio Database at <http://public.ukcrn.org.uk/search/>

The NIHR CRN Portfolio Database is a national resource of studies which are eligible for NIHR CRN support and is being used to inform the allocation of NHS infrastructure funding in England, ensuring that resources are targeted appropriately to support the recruitment and follow-up of patients in clinical trials and other well designed studies.

RECRUITMENT DATA INFORMATION

The table below shows the latest UKCRN Portfolio recruitment figures.



Snapshot at 15 February 2010

TOPIC	Current Total Number of Studies Open or In Set Up
Comprehensive	1254
Primary Care	111
Cancer	405
Dementias and Neurodegenerative Diseases	109
Diabetes	141
Medicines for Children	123
Mental Health	234
Stroke	93
TOTAL	2470

For further information about the NIHR Clinical Research Network Portfolio contact the NIHR CRN CC Portfolio team: crncc.portfolio@nihr.ac.uk

*Topic led only - Where a study relates to more than one Topic, the recruitment data is shown against the lead Topic.

Cumulative figures this financial year (1 April 2009– 31 March 2010) at 15 February 2010

TOPIC	Number of Studies Open to Recruitment during 2009/10	Total Number of Studies Reporting Recruitment, during 2009/10	Total Recruitment, 2009/10
Comprehensive	1308	1154	160141
Primary Care	144	133	58737
Cancer	402	378	31733
Dementias and Neurodegenerative Diseases	114	107	6009
Diabetes	137	121	29899
Medicines for Children	99	90	5421
Mental Health	209	186	23696
Stroke	88	74	6745
TOTAL	2501	2243	322,381

*Topic led only - Where a study relates to more than one Topic, the recruitment data is shown against the lead Topic.

NCRN PORTFOLIO NEWS

Latest estimates for 2009/10 forecast a further increase in recruitment of cancer patients to Randomised Controlled Trials in the National Cancer Research Network (NCRN) Portfolio. The cancer Local Research Networks (LRNs) also recruit a significant number of additional individuals who have consented to participate in NCRN Portfolio studies. These individuals do not have a diagnosis of cancer at the point of consent and are reported by NCRN, although they are not included in the NIHR Clinical Research Network Coordinating Centre reported figures which report cancer patients only. These additional recruits include patients with a pre-malignant disease which unless otherwise treated will develop into cancer. This includes individuals without a diagnosis of cancer who are enrolled into screening and prevention trials and individuals who participate as case controls in other studies. In the first six months of 2009/10 such individuals numbered over 6500; lower than in previous years due to closure of a large screening trial.

Further information is available from Rachel Moser, NCRN Business and Research Activity Manager (r.moser@ncrn.org.uk).



Working with Industry

NOVARTIS UK RECRUITS FIRST PATIENT IN THE WORLD THANKS TO THE NORTH WEST EXEMPLAR PROGRAMME

For the first time in five years Novartis UK has recruited the first patient in the world into a global study, thanks to the processes that have been put in place as part of the North West Exemplar Programme.

The Programme is a collaboration between the NIHR Clinical Research Network (NIHR CRN), the pharmaceutical industry and the NHS which is being piloted in the North West of England and aims to demonstrate the improved commercial trials performance that can be achieved when the systems and processes put in place by the NIHR CRN, such as the Industry Costing Template and the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) are used to their optimum effect. The hope is to achieve trial performance which is as good as or better than the European best and to develop detailed best practice guidance which can then be implemented across the NHS in England, and throughout the NIHR Networks and Industry to support the delivery of commercial trials.

To date, eight commercial studies have gone through the NIHR CSP process to gain NHS Permission. Seven of those studies were ahead of the Industry target of 70 calendar days with the average time taken to achieve NHS Permission at the first site being 52 days (interquartile range 32-57). A further eight studies have started the NHS Permission process and it is expected that all 20 Exemplar studies will have gained NHS Permission at their first site by the end of April 2010.

Twelve companies have signed up to be part of the North West Exemplar Programme to date and all are praising the dedication and hard work being done by the Local Research Networks in the North West to help deliver their studies.

Study performance is being closely monitored and comprehensive performance data from Phase I of the project (study set up/NHS Permission) is expected to be published in May/June. Phase II will focus on effective study recruitment. Regular updates are provided on the North West Exemplar Programme website at <http://nwexemplar.nihr.ac.uk>

NCRN INDUSTRY UPDATE

Jenny Gray joined the National Cancer Research Network (NCRN) Coordinating Centre as Industry Lead in January. Jenny previously worked within the NIHR Clinical Research Network (CRN) Coordinating Centre Industry team where she had responsibility for overseeing the development of the Comprehensive Clinical Research Network Industry Portfolio. Jenny also worked closely with Clare Morgan, Director for Industry, to support study delivery processes for Industry trials across all of NIHR CRN.

Key priorities for the NCRN industry work stream include identifying a key costing and contracts contact in each Cancer Local Research Network (LRN). This individual may be asked to provide local feedback on proposed costings as part of the adoption process and may also provide a 'post adoption' costing and contract trouble shooting role for companies setting up a commercial study site within their Network. Costings and contracts are important checks for commercial studies with the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) process, so a level of input and coordination by the LRNs may be required to ensure this does not hold up the NHS approvals process.

NCRN also plan to involve LRN Managers more actively in the feasibility and adoption process when companies approach the Network with studies that have pre selected sites. It is felt that LRNs need to be aware of these sites, and any potential issues because once the study is adopted NCRN have a responsibility both nationally and locally to ensure its delivery to target on time. It is hoped that this change in process will help link the LRNs to these sites earlier and allow them to more effectively manage their industry portfolio and resources.

As of January 2010 NCRN have discussed 271 commercial studies with 62 different companies and of these 130 have been considered for adoption. 124 have been adopted and 46 studies are currently open and 41 in set up. A total of 21 have closed to recruitment.

Jenny can be contacted on (j.gray@ncrn.org.uk).



PCRN INDUSTRY NEWS

Recruitment to a very large expedited swine flu vaccine study which was adopted by the Primary Care Research Network (PCRN) in August 2009 has now been completed. The study successfully managed to recruit over 9000 participants in just over six weeks. In total 70 PCRN sites participated recruiting an average of 93 participants each. The PCRN Coordinating Team would like to say 'well done' to all participating sites and PCRN Local Research Networks for all the work that went into making this study such a resounding success.

PCRN is currently working on several studies which are in set-up including many co-adopted studies in which PCRN is working to identify and support practices that are taking on the role of 'Patient Identification Centres'; practices that are not actively recruiting but are able to assist recruitment to studies by referring patients on to research active practices or centres.

For further information please contact Louise Forster, PCRN Industry Liaison Manager, (louise.forster@nihr.ac.uk).



Patient and Public Involvement (PPI)

MAKING A DIFFERENCE – PRIORITIES FOR DIABETES RESEARCH FROM THE PATIENT PERSPECTIVE

The second Diabetes Research Network (DRN) Patient and Public Involvement (PPI) conference was held on 4 December last year in central London. The event was open to patient and public representatives working with either the DRN Coordinating Centre or Local Research Networks (LRNs) in England, as well as to representatives of DRN partner organisations and other interested parties. It was well attended by more than 70 delegates, including around 50 patient advocates.

The aim of this one-day conference was to further explore the topics raised at last year's conference and to discuss priorities for diabetes research from the patient and carer perspective.

The event comprised a mixture of presentations and workshops. The morning session began with a presentation by Professor Des Johnston, DRN Director, who gave an overview of the progress made during DRN's first four years of operation. Dr Eleanor Kennedy, DRN Project Manager, then gave an update on the progress of DRN studies, showing the range of topics on the DRN Portfolio and stressed the importance of the collaborative nature of the NIHR Clinical Research Networks.

Martin Lodemore, DRN Patient and Public Liaison Officer, gave a presentation that stressed the need for more patient and public involvement in research. He gave a brief overview of the DRN's successful outreach and involvement programmes, showing how the DRN had benefited from including patient and carer perspectives, as well as how the research community in general is responding positively to an increase in patient and public involvement. This was followed by a joint presentation by two patient advocates, Diane Munday and Alex Mendoza, who discussed their work with the Public Involvement in Research Group at the Centre for Research in Primary and Community Care based at the University of Hertfordshire. They confirmed that the researchers who had engaged with the group had taken full consideration of the patient and carer views.

Following lunch, Professor Simon Heller, Chair of DRN's Clinical Studies Advisory Group, emphasised the importance of a robust method for priority setting and how it was vital to get patient and

carer input into this process. He then explained the methods that would be used in the four parallel workshops, which would begin to bridge the gaps between clinicians, patients and researchers, and engender a greater understanding of the challenges of turning ideas into fundable research questions. The workshops covered:

- ▶ Treatment and care for people with Type 1 diabetes
- ▶ Treatment and care for people with Type 2 diabetes
- ▶ Prevention and diagnosis of diabetes
- ▶ Education and support for people affected by diabetes

The workshops proved challenging because the wide variety of views on offer made it difficult to reach agreement about which topics should be given highest priority. Feedback from these workshops will inform the priority-setting initiatives that will be conducted by the Clinical Studies Advisory Group during 2010.

Professor David Matthews, the DRN's Associate Director for Advocacy, closed the event with a passionate and sobering presentation about the worldwide challenge of diabetes, focusing on the Type 2 diabetes epidemic sweeping the globe.

Feedback from the delegates following the event has been very positive. It enabled researchers and patient advocates to discuss the DRN's progress and direction, as well as research priority areas.

A full report on the event is available from Martin Lodemore, DRN Patient & Public Liaison Officer, (m.lodemore@imperial.ac.uk).



DENDRON PPI FORUM TAKING SHAPE

The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) Patient and Public Involvement (PPI) Forum meeting took place in London on 24 February. The aim of the day was for this group of lay people to formulate a list of priorities and actions which will be taken forward across DeNDRoN.

Prior to the meeting the group requested information from DeNDRoN-related researchers around the country. These researchers were asked to state what they believe are the chief obstacles a) preventing people from across the country from being able to participate in clinical research, and b) preventing overall improvements to the quality and speed of research.

The responses were collated and the PPI Forum then considered how PPI work can help to address these obstacles. Challenges identified so far include: navigating the complexity of NHS research systems (such as when referring patients on to other Trusts); relating inclusion/exclusion criteria more closely to "real life" situations; blocks to opening up new sites and populations; the need for openness around what funders are viewing as research priority areas; and a whole range of patient recruitment challenges.

For further information please contact Terry McGrath, DeNDRoN PPI Coordinator, (terry.mcgrath@dendron.org.uk).



Patient and Public Involvement (PPI)

THE UK STROKE FORUM – A LAY MEMBERS PERSPECTIVE



Eleven of the Stroke Research Network's (SRN) national lay members attended the UK Stroke Forum (UKSF) event which was held in Glasgow from 1-3 December.

Feedback from lay members was very positive,

"The UKSF Conference was a wonderful and inspirational experience. The opportunity to hear about current stroke research was very useful and greatly encouraging and provided insights to possibilities and boundaries as to what is achievable. The opportunity to 'network' was extremely valuable. All the SRN staff there were incredible helpful and supportive."

The event was a valuable experience and the significance of stroke research was effectively summed up by Graham McGuire, a stroke survivor attending the UK Stroke Forum, who was quoted in the press as saying;

"Research plays such an important role in improving what has been to me a devastating illness. I hope that myself and others may benefit from some of the research being developed and discussed here today."

The SRN lay members also held their bi-annual meeting at the conference and discussed issues such as how to drive forward Patient Carer and Public Involvement (PCPI) in the SRN over the next five years; how to disseminate results of research studies and how to work more closely with lay members from the Stroke Local Research Networks.

For further information on both of these items please contact Jo Spencer, SRN PR and Communications Manager, (jo.spencer@ncl.ac.uk).

THIRD ANNUAL STROKE SURVIVOR AND CARERS EVENT



The Yorkshire Stroke Research Network (SRN) has announced its third annual public event. The *Stroke Survivor and Carers Event* will take place on 5 May in Bradford. The keynote speaker will be Professor Allan House, Director of the Leeds Institute of Health Research and Professor of Liaison Psychiatry. Previous events have attracted around 70 stroke survivors and carers who have helped to shape the work of Yorkshire SRN, worked with local research teams and learned about the outcomes of stroke research. For further information please contact Cathy Hulin, (cathy.hulin@bradfordhospitals.nhs.uk)

NEWS IN BRIEF

INVOLVE Conference 2010: Call for presentations

INVOLVE's seventh conference will take place on 16-17 November at East Midlands Conference Centre, Nottingham.

A call for presentations is now open. The focus of the conference is on innovation and impact including:

- ▶ ways in which the public are involved in research
- ▶ understanding the impact of public involvement - how it makes a difference
- ▶ providing a platform for research on public involvement in research.

The closing date for proposed presentations is **12 April 2010**. Booking forms for attending the conference will be available from mid June 2010. Further information is available on the INVOLVE website: <http://invo.org.uk/Conference.asp>

NEWS IN BRIEF

A Critical Assessment of the Development of Patient and Public Involvement in the UK Clinical Research Collaboration: Lessons Learned

In 2009, in response to plans for the transition to a Partner-led UKCRC, the Board Subgroup for Patient and Public Involvement (PPI) commissioned a project to identify and share lessons learned from the experience of developing PPI in the Collaboration. The primary audience for this assessment is people who have a responsibility for taking forward PPI within a research organisation.

The project was carried out between August and November 2009. Methods used included:

- ▶ A review of relevant internal documents
- ▶ Development of a timeline of activity and key milestones
- ▶ Individual and group interviews with key stakeholders
- ▶ A survey of the UKCRC Board members

The resulting report identifies a number of impacts of PPI on the UKCRC, such as changes in Board members' attitudes, and on its Partner organisations, such as taking learning from the UKCRC into Partner organisations. The assessment goes on to identify a series of lessons that can be learned from the UKCRC's PPI experience. In the report these are grouped under three key themes:

- ▶ What to think about when developing PPI
- ▶ Building relationships
- ▶ Be realistic

The Lessons Learned Report is being disseminated to and beyond the UKCRC's Partner organisations and is available to download from the UKCRC website:

www.ukcrc.org/patientsandpublic/ppi/understandingppi/



Network Communications

PROMOTING THE PALLIATIVE CARE LOCAL SPECIALTY GROUP IN NEYNL CLRN

The North and East Yorkshire and Northern Lincolnshire Comprehensive Local Research Network (NEYNL CLRN) Palliative Care Specialty Group, chaired by Dr Miriam Johnson, held a conference 'Including the excluded – research in people with advanced disease', on 13 and 14 January 2010 at the Royal Hotel, York.

The event was well attended by staff in the Palliative Care arena, including consultants, researchers, research nurses and therapists. Professors David Currow, Chief Executive Officer of Cancer Australia gave two keynote addresses; 'Research in Palliative Care' and 'Opioids for breathlessness: how much does it take'. Other presentations over the two days were given by Dr Stephen Oxberry, Professor Andrew Clark, Dr Anthony Maraveyas, Dr Debra Howell, Ms Kate Flemming, Professor Michael Bennett, Dr Rachael Barton, Professor David Torgerson, Dr Louise Girardier and Dr Paul Taylor. Professor Marie Fallon and Dr Pat Ansell also contributed to an expert panel session. All presentations provoked much discussion amongst delegates, as well as sharing successes, solutions and encouragement within research.

The NEYNL CLRN Palliative Care Specialty Group is currently in set-up and will provide a forum to bring together all researchers (clinical academics, university researchers, allied health Professionals) interested in this specialty area and will facilitate recruitment in NIHR Clinical Research Network Portfolio trials.

For further information please contact Miriam Johnson, NEYNL CLRN Local Specialty Group Lead, (miriam.johnson@hyms.ac.uk) or Jane Ash, NEYNL CLRN Special Projects Administrator, (jane.ash@nhs.net).



Professor Currow and Dr Johnson

MHRN NATIONAL SCIENTIFIC CONFERENCE 19-21 APRIL 2010, BRISTOL

This will be the fifth MHRN Scientific Conference, which follows on from four successful meetings in Manchester, Newcastle, London and Nottingham. The conference will be multidisciplinary, bridging basic and 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. There will be a workshop on methodological issues on the first day followed by a reception in the evening. The main conference programme will then follow over two days and will comprise plenary and parallel sessions.

Conference programme highlights include:

- ▶ Genes x environment in depression
- ▶ Treatment issues in primary health care
- ▶ Understanding psychotic symptoms
- ▶ Child and adolescent depression
- ▶ Late life depression
- ▶ Psychology of depression
- ▶ Neurobiology of depression
- ▶ How service users and researchers can work together

POSTER ABSTRACT SUBMISSIONS

These should be submitted via the registration site. The last date for receiving abstracts will be Friday 19 March. The poster size should be portrait A1 size.

Registration for the conference is now open via the following link www.eazybook.com/inanyevent/registration/eb-event-1a.php?eventid=205



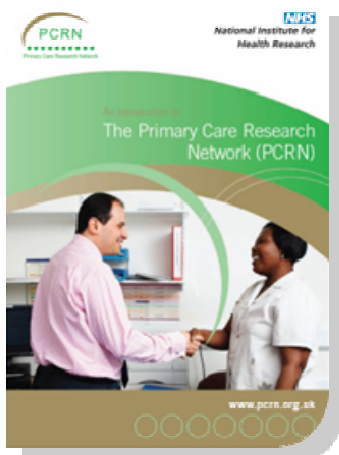
Mental Health
Research Network

NEW PCRN INFORMATION BOOKLET LAUNCHED

The Primary Care Research Network (PCRN) Coordinating Team recently worked with the NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC) Communications team to develop a general information booklet about PCRN. The first version of the booklet is now complete and is available to download from the PCRN website.

Each Primary Care Local Research Network will be provided with copies and further copies will be distributed at various conferences and Network events throughout the coming months.

For further information please contact Tracey Devlin, PCRN Operations Assistant, (tracey.devlin@nihr.ac.uk).



UK-wide Working

NEWS IN BRIEF

CHANGES TO THE STRUCTURE OF NISCHR

Following the review commissioned by the Minister for Health and Social Services into the structure of R&D in Wales, a number of changes to the structure of National Institute for Social Care and Health Research (NISCHR) have been announced.

The Minister has accepted the recommendation of the review that there should be one health and social care research and development body, and that it should sit within the Welsh Assembly Government. The new organisation will be called the National Institute for Social Care and Health Research (NISCHR). Previously responsibility for R&D policy and strategy in health and social care lay with the Wales Office of Research and Development for Health and Social Care (WORD) - a division of the Department of Public Health and Health Professionals (DPHP) - and NISCHR was a planned 'virtual' organisation intended to undertake delivery functions of R&D in health and social care. As a result of combining WORD and NISCHR in one body, the civil service base will effectively be expanded to incorporate functions formerly intended for the virtual organisation.

The strategic responsibilities of NISCHR will remain a discrete area within the new organisation to ensure the separation of functions where appropriate.

The use of the name National Institute for Social Care and Health Research (NISCHR) will be phased in but in the meantime the Wales Office of Research and Development (WORD) will be used to maintain continuity with our UK partners.

NISCHR Registered Research Groups announced

As part of the recommissioning of the clinical research infrastructure in Wales, 17 groups have been successful in achieving NISCHR Registered Research Group (RRG) status. This includes the nine current Thematic Research Networks, along with the Wales School of Primary Care Research, the Wales Cancer Trials Unit, a Patient Safety and Healthcare Quality group, and new groups in the areas of Cardiovascular Disease, Lung Disease, Kidney Disease, Arthritis and Chronic Musculoskeletal Conditions, and Microbiology and Infection. WORD will also support a medical imaging group which will work across the remits of a number of RRGs.

Information about the nine existing Thematic Research Networks is available on the Clinical Research Collaboration-Cymru website:

www.wales.nhs.uk/sites3/home.cfm?orgid=580

Further information about NISCHR is available in from:

The Welsh Assembly Government website:

<http://wales.gov.uk/topics/health/research/?lang=en>

The NISCHR newsletter:

<http://wales.gov.uk/docs/dhss/research/091201nischrnewsletterdec09en.pdf>

NEW RESEARCH STRATEGY FOR SCOTLAND

A new research strategy has been published by the Chief Scientist Office in Scotland - 'Investing in Research | Improving Health'. The strategy provides details on plans relating to funding and infrastructure for research in the NHS. It includes details on development of NHS Research Scotland, the system for handling NHS approval of multicentre studies. Download the report at www.cso.scot.nhs.uk/Publications/research.pdf.

Experimental Medicine

EXPERIMENTAL MEDICINE DIRECTORS' FORUM, 1 DECEMBER 2009

The second Experimental Medicine Directors' Forum meeting of 2009 was held on 1 December 2009 at the Wellcome Trust in London. The meeting was attended by around 50 delegates from across the NIHR experimental medicine infrastructure including Clinical Research Facilities, Experimental Cancer Medicine Centres and Biomedical Research Centres and Units.

The morning session included an update on progress on actions from the summer Experimental Medicine Directors' Forum meeting from Dr Cyril Clarke, Professor William Rosenberg and Dr Joanna Olliver. Cyril updated the Group on the project he is leading to identify commercial experimental medicine facilities that could be accessible to academic investigators. William provided an update on a project he is leading on behalf of the NIHR to develop model collaborative agreements and Joanna reported on progress to develop a suite of information describing the potential models of collaboration.

In addition to this update on progress, the morning included one session on the Wellcome Trust and Department of Health site visits to the millennial Wellcome Trust Clinical Research Facilities (WTCRF) from the perspective of both the Wellcome Trust and one of the WTCRF Directors. The final session before lunch provided an update on the NIHR Biomedical Research Centres from both the national (Dr David King) and local (Professor Richard Trembath) perspectives.

Plenty of time was provided over lunch for networking, one of the key aims of the Experimental Medicine Directors' Forum. The afternoon session commenced with a presentation from the Medicines and

Healthcare products Regulatory Agency (MHRA) on Phase I accreditation of non-commercial clinical research units. The MHRA were keen to explore with the Directors' the need and appetite for an accreditation scheme for non-commercial units conducting phase I studies. Professor William Rosenberg also described to the Forum plans for the new NIHR Office for Clinical Research Infrastructure (NOCRI) after which breakout groups discussed the implementation of NOCRI and its potential impact on their activity.

The meeting closed with an update from Dr Catherine Elliott from the Medical Research Council (MRC) on the UK Clinical Research Collaboration's (UKCRC) recent Clinical Research Imaging Survey. The final report was submitted to the UKCRC Experimental Medicine Funders Group in December 2009 after achieving an approximately 80% return rate. The Forum was impressed by the response rate and felt that the main conclusions provided useful and informative data. The MRC and the NIHR CRN Coordinating Centre would like to thank all the Clinical Research Network staff who facilitated data collection for this survey.

More information on NOCRI and its impact on the NIHR Clinical Research Networks (CRNs), in particular the Experimental Medicine work stream of the NIHR CRNs, will be provided in a future News from the Network article.

For further information please contact Dr Joanna Olliver, Senior Fellow – Experimental Medicine, NIHR CRN Coordinating Centre, (joanna.r.olliver@nihr.ac.uk).

Workforce Development

Forthcoming NIHR Clinical Research Network training courses

MARCH 2010

GCP and the EU Directive in Primary Care

2 March 2010, London

Introduction to Good Clinical Practice (GCP):

A practical guide to ethical and scientific quality standards in clinical research

16 March 2010, London

GCP and the EU Directive for Pharmacy Staff

29 March 2010, London

APRIL 2010

Introduction to Good Clinical Practice (GCP):

A practical guide to ethical and scientific quality standards in clinical research

22 April 2010, Leeds

GCP Facilitator Development Programme

27-29 April 2010, Reading

MAY 2010

Introduction to Good Clinical Practice (GCP): A practical guide to ethical and scientific quality standards in clinical research

21 May 2010, Manchester

The following online courses are also available:

- GCP and the EU Directive
- Information Governance Advanced
- Information Governance Foundation
- Valid Informed Consent

Further information is available on the NIHR CRN CC website

Training pages www.crncc.nihr.ac.uk/index/training.html

or by contacting the NIHR CRN CC Training and Education team:

Tel: 0113 343 0377 Email: crncc.training@nihr.ac.uk

FREE TRAINING SESSIONS FOR MCRN STAFF



The Medicines for Children Research Network (MCRN) Clinical Trials Unit (CTU) are running free training sessions in Liverpool specifically aimed at MCRN staff.

The first course entitled *Quality of Life* took place in January and was facilitated by Professor Ann Jacoby. The second entitled *Systematic Reviews* took place in February and was delivered by statisticians from the MCRN CTU.

Over the coming months MCRN CTU hope to run further courses on the *Human Tissue Act* and *Preparing for Audit and Inspection*. Further information is available from Joanne Hollett, (jhollett@liverpool.ac.uk).

INTRODUCTION TO CLINICAL RESEARCH TRAINING EVENT



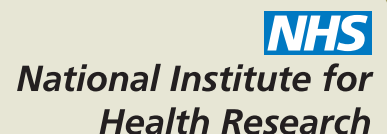
Trent Stroke Research Network SRN held a training event in Leicester on 9-10 February aimed at new research staff across all NIHR Clinical Research Networks in the region. This event builds on the success of a similar course delivered in October last year. Both events to date have been over subscribed and further events are planned for 22-23 June and 5-6 October.

NIHR Clinical Research Network staff within the Trent Comprehensive Local Research Network (CLRN), Leicestershire, Northamptonshire and Rutland CLRN or South Yorkshire CLRN areas who would like to attend should contact their Network Manager.

Further information is available from Donna Richardson, Trent SRN Manager, (dr16@le.ac.uk).

NEWS IN BRIEF

Invitation to Apply for NIHR / CNO Clinical Doctoral Research Fellowships



Following the launch of a major joint initiative for a Clinical Academic Training Programme for Nurses, Midwives and Allied Health Professionals, the NIHR and the Chief Nursing Officer (CNO) for England are pleased to announce round two of the NIHR / CNO Clinical Doctoral Research Fellowship scheme. This scheme, managed by the NIHR Trainees Coordinating Centre, is aimed at developing research capacity to support the NHS.

The NIHR / CNO Clinical Doctoral Research Fellowship (NIHR C-DRF) is aimed at graduate (post-degree) nurses, midwives and allied health professionals sited in England who have at least 1 year's experience of clinical practice since graduating; have had sufficient research experience or research training to prepare them to undertake a PhD; and wish to obtain a PhD by research whilst still developing their clinical skills.

Individuals who can demonstrate a role in, or contribution to, improving health, health care delivery or services are eligible. The fellowships provide funding for salary and research costs appropriate for a research training award.

The deadline for applications is 27 April 2010.

Application packs and further information are available on the website of the NIHR Trainees Coordinating Centre (NIHR TCC) at <http://www.nihrtcc.nhs.uk/cat/>.

CCRN PORTAL DEVELOPMENTS

The Comprehensive Clinical Research Network (CCRN) Finance Management Tool, a budgeting tool for 2010/11 for the Comprehensive Local Research Networks (CLRNs), was launched in December last year. Prior to the launch user testing was carried out to incorporate user feedback. The tool is now available via the CCRN portal for staff who have the necessary permissions.

Work is underway on the development of Patient and Public Involvement (PPI) Action Learning Sets portal site within the CCRN portal site collection. The site will be accessed by group members of the Action Learning Sets in the different regions, and will provide forums for sharing ideas, dates of forthcoming meetings and document libraries. The PPI Action Learning Sets portal launch is planned for the end of February.

Further CCRN portal plans for the coming months include developing the portal contacts lists and related information so that the CCRN portal becomes the primary source of information for all CLRNs and for the NIHR Clinical Research Network Coordinating Centre. Each CLRN will take responsibility for maintaining a data set of basic information directly. This new system will ensure that updates, for example contact details and board member updates, will be instantaneous. It will replace current manual systems which are only updated periodically, are more time consuming and less reliable. Further information regarding these portal developments will be communicated in March.

For further information please contact Laura Phillpott, CCRN Operations Officer, (laura.g.phillpott@nihr.ac.uk) or Alex Barnard, CCRN Clerical Assistant, (alex.barnard@nihr.ac.uk).

NEWS IN BRIEF

New centres of excellence for NIHR Technology Assessment Reviews (TARs)

Ten contracts have been awarded by the NIHR to centres of excellence for Technology Assessment Reviews (TARs). Three new centres of expertise in Technology Assessment Reviews (TARs) join seven existing NIHR TAR centres. TARs provide a reliable and rigorous evidence assessment of the benefits, harms and costs of particular healthcare treatments for those who plan, provide or receive care in the NHS.

TARs are commissioned to meet the urgent needs of national NHS decision-making bodies and policy customers, such as the National Institute for Health and Clinical Excellence (NICE). TARs are most commonly produced to inform NICE Appraisal Committee guidance on the use of new and existing medicines, treatments and procedures within the NHS in England and Wales.

Further information is available on the HTA website: www.hta.ac.uk/news/newsitem180110.shtml

MARCH

2 March 2010, London

NIHR Regional Research Tour

www.nihr.ac.uk/events/Pages/Regional_conferences.aspx

3-4 March 2010, Sheffield

Late Effects in Cancer Survivors 3rd Biennial Meeting

www.late-effects.group.shef.ac.uk/

3-5 March 2010, Liverpool

Diabetes UK Annual Professional Conference 2010

www.diabetes.org.uk/Annual-Professional-Conference-2010/APC-2009-home/

4 March 2010, Clayton Le Moors

East Lancashire Hospice Widening Access to Palliative Care Conference: Using our Hands, Hearts and Minds to Overcome Social Exclusion

denise.williams@eastlancspct.nhs.uk

4 March 2010, Plymouth

Peninsula SRN Patient, Carer and Public Involvement (PCPI) Information Day

jacqueline.briggs@rdeft.nhs.uk

8 March 2010, London

MHRN: Patient and Public Involvement Conference

www.mhrn.info/index/news/newsItems/PPI-Conference-2010.html

11 March 2010, London

Promoting Excellence in Health Research: What does the future hold for health research in the UK?

www.universitiesuk.ac.uk/Events/Pages/Promoting-Excellence-in-Health-Research.aspx

12 March 2010, London

Workshop on Biobanking in Support of Clinical Trials

www.oncoreuk.org/pages/events_forthcomingevents.html

16 March 2010, London

Workshop Roadshow: Ethical Principles Relating to Consent for Use of Anonymised Samples in Research

www.oncoreuk.org/ / <http://events.npsa.nhs.uk/nres/295>

18 March 2010, Warwick

West Midlands (South) CLRN 2nd Annual Conference

sarah.sutton2@uhcw.nhs.uk

18 March 2010, Cornwall

Peninsula SRN Patient, Carer and Public Involvement (PCPI) Information Day

jacqueline.briggs@rdeft.nhs.uk

18-19 March 2010, Cambridge

Wellcome Trust - Translating Clinical Proteomics into Clinical Practice

https://registration.hinxton.wellcome.ac.uk/display_info.asp?id=123

23 March 2010, Edinburgh

Life Sciences – Investing in Discovery Conference

www.publicserviceevents.co.uk/event/overview.asp?ID=132

continued

Forthcoming Events

24 March 2010, Sunderland

North East SRN joint PPI event with The Stroke Association and North East Cardiovascular Network

penny.williams2@nhs.uk

24-25 March 2010, tbc

Patient Partner Southern European Regional Workshop: Defining the Needs and Means for More Partnership Between Patients, Patient Organisations and Other Stakeholders in Clinical Research Trials

www.efgcp.be/Conference_details.asp?id=245&L1=10&L2=1&TimeRef=1

24-25 March 2010, London

SMI's Accelerating Patient Recruitment and Retention in Clinical Trials conference

www.smi-online.co.uk/events/overview.asp?is=4&ref=3199

APRIL

6 April 2010, Exeter

4th Folk.us Conference: Turning the Tide: Research by, for and with service users

www.folkus.org.uk

13 April 2010, London

Clinical Discovery Workshop - IRAS - A Practical Guide

www.events4healthcare.com/Clinical-Discovery-2010.html

14 April 2010, Hull

Yorkshire SRN - Launch Day for Humberside

cathy.hulin@bradfordhospitals.nhs.uk

14-15 April 2010, Cardiff

Wales Cancer Conference 2010

www.walescancerconference.org.uk/

15-16 April 2010, Salford

International Functional Electrical Stimulation Society (UK and Ireland Chapter) (IFESS) 1st Annual Conference

ukifess@salford.ac.uk

19-21 April 2010, Bristol

MHRN National Scientific Conference

www.eazybook.com/inanyevent/registration/eb-event-1a.php?eventid=205

21-22 April 2010, Warwick

RCPCH (The Royal College of Paediatrics and Child Health) Annual Conference 2010

www.rcpch.ac.uk/Education/Events/Conference2010

22 April 2010, tbc

Peninsula SRN Conference 2010: Joining Forces - Linking Stroke Care Communities in the South West

jacqueline.briggs@rdefnhs.uk

23 April 2010, London

Thames SRN 3rd Annual Conference

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

continued

SRN ANNUAL CONFERENCE ANNOUNCED



The date for the fourth annual Stroke Research Network (SRN) Conference has been announced as 16-17 June, Newcastle upon Tyne. Further details will be available on the SRN website shortly:

www.uksrn.ac.uk/

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH CONFERENCE (RCPCH) 2010



The RCPCH 2010 Conference, will take place on the 20-22 April 2010 at Warwick University. The event will provide a forum for the presentation of basic and clinical science, together with updates in clinical practice, and will also include a large exhibition. The Medicines for Children Research Network (MCRN) will be exhibiting at this event, encouraging engagement with Paediatricians and other Paediatric related colleagues who have a research interest. For further details and an outline of the programme visit the RCPCH website:

www.rcpch.ac.uk/Education/Events_and_Courses/RCPCH-Annual-Conference-2010

NEWS IN BRIEF

NHS R&D Forum's Annual Conference 2010 – Open for delegate and exhibitor bookings

This year's NHS R&D Forum Annual Conference will be held on 24 and 25 May 2010 at The Lowry, Salford Quays, near Manchester. It will follow the same format as the 2009 conference: opening at midday on 24 May, a drinks reception and dinner in the evening, and then a full day on 25 May.

The programme includes two parallel sessions on 25 May that are entitled "open". In order to ensure that this conference explores the issues that are most important to its audience the NHS R&D Forum are seeking topic suggestions for these "open" sessions and potential facilitators. Suggestions should be submitted to

info@rdforum.org.uk

The conference also incorporates an exhibition where commercial and non-commercial organisations are present to share their information and news with delegates. Live demonstrations will take place during lunch where delegates can drop in to see and try out live systems.

For full details about the conference please visit the NHS R&D Forum website:

www.rdforum.nhs.uk/004c.asp?entryid=171

Forthcoming Events

27 April 2010, London

ABPI Conference and Dinner 2010

enquiries@events4healthcare.com

27-28 April 2010, Crieff

Scottish School of Primary Care (SSPC) Annual Conference 2010:

Focusing our Research on Patients

www.sspc.ac.uk/events/sspc_conference2010.htm

MAY

6 May 2010, London

Joint MND (Motor Neurone Disease) Conference

www.stchristophers.org.uk/bookingform

11 May 2010, Norwich

DeNDRoN East Anglia Annual Conference

ann.luck@nhs.net

16-19 May 2010, Baltimore

Society for Clinical Trials 31st Annual Meeting

www.sctweb.org/meeting.cfm

19 May 2010, Milton Keynes

Statistical Methods for Outbreak Detection Conference

<http://statistics.open.ac.uk/SMOD/>

19 May 2010, Manchester

Clinical Discovery Workshop - IRAS - A Practical Guide

www.events4healthcare.com/Clinical-Discovery-2010.html

24-25 May 2010, Salford

NHS R&D Forum Annual Conference 2010

www.rdforum.nhs.uk/004c.asp?entryid=171

A comprehensive list of events is available on the Clinical Research Network website events pages:

www.crncc.nihr.ac.uk/index/events.html

NEWS IN BRIEF

Ethical Principles Relating to Consent for Use of Anonymised Samples in Research – Roadshow 2010

A roadshow of one-day workshops entitled *Ethical Principles Relating to Consent for Use of Anonymised Samples in Research* will be held in a number of locations across the UK during 2010.

The workshop programme has been developed as a collaboration between onCore UK and the National Research Ethics Service (NRES), and is aimed at a broad research audience including Researchers, R&D officers/managers and Research Ethics Committee Members and Co-ordinators.

Workshops are planned in London, Scotland, South-West, Central and North-East England. Each workshop will follow the same programme content although individual speakers may vary. The London workshop will be held on 16 March 2010. The programme and online registration can be accessed via the NRES website.

Objectives:

- ▶ To understand the implications of the Human Tissue Act 2004 and associated Regulations for the storage and use of human tissue for research purposes, in particular the requirements for ethical approval and consent.
- ▶ To understand the revisions to the HTA's code of practice on consent and the scope of the new code of practice on research in relation to ethical issues.
- ▶ To explore ethical issues associated with storage of human tissue and data for use in research, in particular the principles relating to whether and when consent is or is not required for use of anonymised samples in research

Who should attend?

- ▶ REC Members and Co-ordinators
- ▶ Researchers
- ▶ R&D Officers/Managers

Please contact onCore UK or NRES for more details:

www.oncoreuk.org

<http://events.npsa.nhs.uk/nres/295>



NEWS IN BRIEF

Workshop on Biobanking in Support of Clinical Trials

12 March, London

Biological samples are being increasingly collected and banked as part of clinical trials. Concerns are often raised about the best means of managing clinical trial related sample collections to ensure compliance with ethics, laws, quality management requirements and recommended good practice. This Workshop will be of practical value to those planning or currently managing a clinical trial or the sample collection / biobank aspect of a trial and will include presentations on topics such as:

- ▶ Why clinical trialists want to collect samples
- ▶ Patient participation, ethics and governance
- ▶ Ownership, custodianship, access and usage of samples
- ▶ Practical considerations for sample collection, processing, storage and release in international multicentre trials
- ▶ What biobankers can offer trialists
- ▶ Quality management of biobank resources and compliance with clinical trials requirements.

For further information and online registration visit

www.oncoreuk.org/pages/events_forthcomingevents.html



Research Opportunities and Funding Calls

NIHR funding opportunities

Fifth call for Stream 1 - i4i Feasibility study

The Invention for Innovation Programme wishes to invite project proposals of up to 12 months to investigate first whether a piece of prior basic research or an innovative use of an existing or emerging technology could provide a solution to a healthcare need.

The deadline for electronic submissions is 5pm on 5 March 2010.

The deadline for receiving the Declarations and Signatures page is 5pm on Friday 12 March 2010.

www.nihr-ccf.org.uk/site/programmes/i4i/

Programme Grants for Applied Research - Competition 8

Applications are invited from leading research groups for an NIHR Programme Grant for Applied Research award, of up to £2m over a period of three to five years. Each programme grant funds a coherent series of related projects to tackle high priority health issues. Proposals should comprise health services research and/or innovation (e.g. introduction of new technologies), where there is potential gain for patients within the relatively near future, i.e. 'near market' research with application in the NHS within three to five years of the end of the funding period.

The deadline for submission of stage 1 applications is 15 March 2010.

www.nihr-ccf.org.uk/site/programmes/programmegrants/default.cfm

Service Delivery organisation (SDO) Programme – Responsive call

The SDO programme invites research proposals in three main areas:

- ▶ Follow-on studies to existing SDO or NIHR Health Technology Assessment (HTA) research
- ▶ Evidence synthesis (which draw on past primary research within the SDO programme and/or on research funded elsewhere)
- ▶ Scoping reviews for future research needs (aimed at identifying and tackling major topic areas of future research need relevant to the SDO programme and its mission).

The deadline for outline proposals is 18 March 2010.

[www.sdo.nihr.ac.uk/10_1008.html?](http://www.sdo.nihr.ac.uk/10_1008.html?utm_source=NIHR_JAN&utm_medium=web_posting&utm_campaign=10_1008_call)

[utm_source=NIHR_JAN&utm_medium=web_posting&utm_campaign=10_1008_call](http://www.sdo.nihr.ac.uk/10_1008.html?utm_source=NIHR_JAN&utm_medium=web_posting&utm_campaign=10_1008_call)

SDO Programme - Patient safety in healthcare organisations

The SDO programme invites proposals on aspects of patient safety particularly in the following topic areas:

- ▶ Translating knowledge about patient safety into service delivery
- ▶ Patient/user involvement in safety improvement
- ▶ Financial costs and benefits and trade-offs in patient safety
- ▶ Boundaries between care processes, services and organisations

The deadline for outline proposals is 24 March 2010.

[www.sdo.nihr.ac.uk/101007.html?](http://www.sdo.nihr.ac.uk/101007.html?utm_source=NIHR_JAN&utm_medium=web_posting&utm_campaign=10_1007_call)

[utm_source=NIHR_JAN&utm_medium=web_posting&utm_campaign=10_1007_call](http://www.sdo.nihr.ac.uk/101007.html?utm_source=NIHR_JAN&utm_medium=web_posting&utm_campaign=10_1007_call)

NIHR Public Health Research (PHR) programme – Researcher-led proposals

The NIHR PHR programme invites research proposals to evaluate non-NHS public health interventions intended to improve the health of the public and reduce inequalities in health.

The deadline for applications is 1pm on 10 May 2010.

www.phr.nihr.ac.uk/fundingopportunities/researcher_led.asp

Office for Life Sciences - Therapeutic Capability Clusters

The Office for Life Sciences invites applications from NHS/academic centres that are interested in forming part of Therapeutic Capability Clusters in two key areas: Inflammatory Respiratory Diseases and Joint and Related Inflammatory Diseases. An Open Meeting is being held on 3 March 2010 to provide more information about the concept of Therapeutic Capability Clusters.

The deadline for submitting applications is 29 March 2010.

www.nihr.ac.uk/about/Pages/Office_for_Life_Sciences_call.aspx

NIHR Public Health Research (PHR) programme - Commissioned research

The NIHR PHR programme invites research proposals in the following areas:

- ▶ Regeneration programmes.
- ▶ Relationship between reduction in alcohol availability and measures of community alcohol health related harm and/or consumption.
- ▶ Community engagement approaches to improve health and reduce health inequalities.

The deadline for applications is 1pm on 14 April 2010.

www.phr.nihr.ac.uk/fundingopportunities/commissioned.asp

NIHR Funded Masters Studentships in Medical Statistics

The NIHR invites applications for Masters Studentships in Medical Statistics in England. The funding aims to build research capacity in medical statistics, as there is currently a shortage of individuals with sufficient training and expertise in this area to support current volumes of applied health research. Successful organisations will receive funding for up to four studentships per annum for an initial period of 3 years.

Tenders must be submitted by 1pm on 3 March 2010.

Further information is available on the NIHR Trainees Coordinating Centre website: : www.nihrtcc.nhs.uk/researchmethodsprogramme/medical%20statistics

Efficacy and Mechanism Evaluation (EME) programme

The EME programme is funded by the Medical Research Council (MRC) and managed by the NIHR as the lead organisation for clinical trials and evaluation. The EME programme is broadly aimed at supporting science driven studies with an expectation of substantial health gain. The clinical studies are likely to be mostly randomised controlled trials but other forms of evaluation appropriate for the intervention under study will also be supported. The EME programme is an ongoing research funding opportunity. Applicants are welcome to submit a preliminary application at any time, however there are three submission deadlines each year.

The submission deadline for consideration in the next round is 1pm on 16 March 2010.

Please visit www.eme.ac.uk for more details.

Regulatory and Governance (R&G) Update

News

Regulatory and governance update from Health Services Research Network (HSRN) now available:

www.nhsconfed.org/Publications/Pages/TheNewResearchGovernanceLandscape.aspx

Stem cell Toolkit launched:

www.sc-toolkit.ac.uk/

Wales Office of Research & Development for Health & Social Care (WORD) newsletter now available:

<http://wales.gov.uk/topics/health/research/word/news/dec09/?lang=en>

Summary of Responses to the Consultation on the Additional Uses of Patient Data:

www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_109310

UKCRC Winter 2009 update newsletter published:

www.ukcrc.org/index.aspx?o=3148

Chief Scientists Office report published - Investing in Research: Improving Health:

www.cso.scot.nhs.uk/Publications/research.pdf

Department for Business, Innovations and Skills - National Action Plan for researchers published:

www.bis.gov.uk/nap

Revised 'Defining Research' leaflet published by NRES:

www.nres.npsa.nhs.uk/news-and-publications

MHRA response to the European Commission review of the Clinical Trials Directive:

www.mhra.gov.uk/Howweregulate/Medicines/Medicinesregulatorynews/CON068367

UKPubMed Central (UKPMC) resource – beta-version released:

<http://beta.ukpmc.ac.uk/>

Life Sciences 2010: Delivering the Blueprint progress report published:

www.dius.gov.uk/~media/publications/O/OLS-Delivering-Blueprint

From 1 April 2010, regulations will require NHS providers to complete a statement in their Quality Accounts regarding their participation in clinical research:

www.nihr.ac.uk/Pages/QualityAccounts.aspx

European Medicines Agency and the US Food and Drug Administration (EMA – FDA) Good Clinical Practice Initiative:

www.emea.europa.eu/pdfs/general/direct/internationalcoop/53841408en.pdf

Preparing raw clinical data for publication: Guidance for journal editors, authors, and peer reviewers – new guidance published:

www.bmj.com/cgi/content/full/340/jan28_1/c181

Guidance on requesting amendments to health and social care records launched:

www.nigb.nhs.uk/the-nigb-have

NEWS IN BRIEF

Earlier access to new medicines in the UK

The Ministerial Industry Strategy Group (MISG), an initiative that brings together relevant UK government ministers and pharmaceutical industry chief executives, asked the Medicines and Healthcare products Regulatory Agency (MHRA) and the Association of the British Pharmaceutical Industry (ABPI) to explore the feasibility and desirability of introducing a scheme in the UK to make certain new and promising medicines available to patients before they are formally licensed. The report describing the key elements of the scheme, the reports of the work undertaken to gauge the views of the public and healthcare professionals and the minutes of the working group that developed it have now been published on the MHRA's website:

www.mhra.gov.uk/Howweregulate/Medicines/MISGNewTechnologiesAdvisoryPanel/Earlieraccesstonewmedicinesintheuk/index.htm

The MHRA will undertake a 12-week public consultation on the scheme and how it will operate in the New Year, with a view to finalising the scheme for introduction in the UK later in 2010.

Regulatory and Governance (R&G) Update

Consultations

Summary of Responses to the Consultation on the Additional Uses of Patient Data report published

The Department of Health undertook a consultation on patient consent and confidentiality in relation to using patient information for research at the end of 2008. The [report](#) of that consultation has now been published on the DH website. The DH website states: "It is clear that the public expects their consent to be sought if the data used is identifiable. This means we need to test out how best to secure that consent and properly inform patients about the use of their identifiable medical records. We intend to set up a number of pilots in Hampshire, the Isle of Wight, Birmingham and Nottingham which will explore means of patients opting out of having their records viewed for research purposes. We will report back on testing and offer a preferred mechanism by June 2010."

www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_109310

Responses to the National Information Governance Board for Health and Social Care (NIGB) Consultation on Guidance on Requesting Amendments to Health and Social Care Records published

The NIGB have now published [guidance](#) on requesting amendments to health and social care records. This includes a section on records used for secondary uses which includes research.

www.nigb.nhs.uk/the-nigb-have

UK response to the European Commission's consultation on the Clinical Trials Directive

The UK response to the European Commission's consultation on the Clinical Trials Directive that has been submitted by the MHRA is available on the MHRA website.

www.mhra.gov.uk/Howweregulate/Medicines/Medicinesregulatorynews/CON068367

NEWS IN BRIEF

The Changing Regulatory and Governance Environment for Health Research Across the UK - a Guide for Researchers

In November UKCRC published a booklet for researchers describing the initiatives that have been put in place by Partners and stakeholders to streamline the regulatory and governance (R&G) environment across the UK.

It provides an overview of how the clinical research landscape has been dramatically transformed in recent years with the introduction of a range of measures intended to reduce bureaucracy, support world class research and ultimately benefit patients.

The booklet describes the introduction of the Integrated Research Application System (IRAS) and its use as the preferred system for all applications for permissions and approvals, including ethics review and Research and Development (R&D) permissions across the UK. Information on the UKCRC R&G Advice Service, model agreements and the Research Passport is also provided, along with sources of further information.

The initiatives described in the booklet have been made possible by an ambitious programme of collaborative work involving many organisations. Whilst there is still more to be done, the booklet demonstrates the considerable progress that has been made in addressing many of the issues that were having a detrimental effect on health research in the UK. The booklet can be downloaded from the UKCRC website at: www.ukcrc.org/index.aspx?o=3058



FURTHER INFORMATION

Further information about the NIHR Clinical Research Network Coordinating Centre and the NIHR Clinical Research Networks can be found on the following websites:

NIHR Clinical Research Network Coordinating Centre:

www.crncc.nihr.ac.uk

NIHR National Cancer Research Network (NCRN):

www.ncrn.org.uk

NIHR Dementias and Neurodegenerative Diseases Network (DeNDRoN):

www.dendron.org.uk

NIHR Diabetes Research Network (DRN):

www.ukdrn.org

NIHR Medicines for Children Research Network (MCRN):

www.mcrn.org.uk

NIHR Mental Health Research Network (MHRN):

www.ukmhrn.org.uk

NIHR Primary Care Research Network (PCRN):

www.pcrn.org.uk

NIHR Stroke Research Network (SRN):

www.uksrn.ac.uk

NIHR Comprehensive Clinical Research Network (CCRN):

www.crncc.nihr.ac.uk/index/networks/comprehensive

Or by emailing crncc.info@nihr.ac.uk

If you have feedback on any aspect of the newsletter please contact Emma Bender, NIHR CRN CC Communications Officer, email: emma.i.bender@nihr.ac.uk



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