

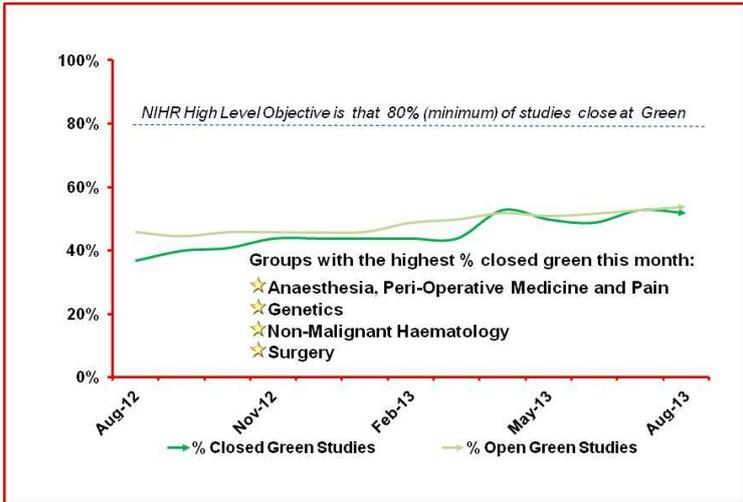
SPECIALTY GROUP NEWS

OCTOBER 2013 EDITION

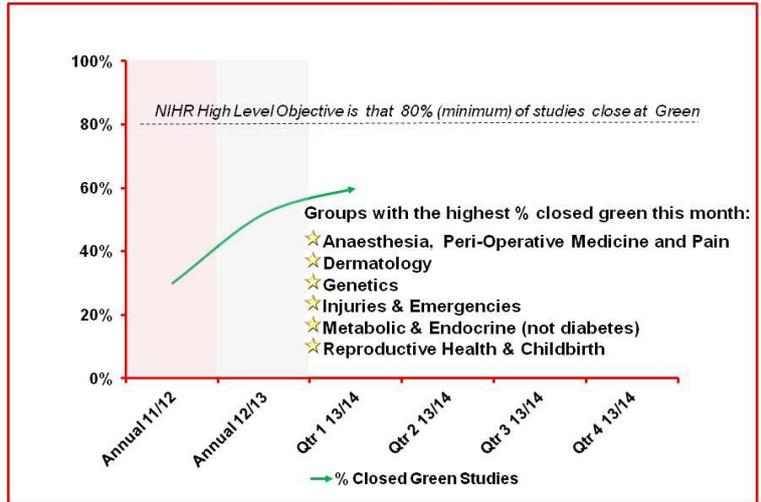
How are we doing? Take a look at this month's figures:

You may have noticed that our top stats section has changed this month. To reflect the High Level Objectives and the priority placed on performance at close and commercial research, we have streamlined this section to feature only open and closed green studies for non commercial and closed studies for commercial.

Non commercial open and closed green studies for all Specialty Groups



CCRN Commercial studies closing at green since 2011 to last Qtr



*Top Group in each category taken from the latest Specialty Group Reports; these do not include studies that are not actively managed by a Specialty Group
 ** Non commercial figures are based on data from the preceding month's Specialty Group report; commercial figures are from the published annual and quarterly reports.

Celebrating Success

Genetics Specialty Group working with Research Nurses and Counsellors

The Genetics Specialty Group held the third annual study day for GenRes on 28th June 2013, at Friends House in London. This group was formed to support Genetic Research Nurses, Counsellors and Coordinators who recruit to UKCRN portfolio studies.

The study day provided the opportunity for the GenRes group to meet and discuss portfolio studies and share good practice. The sixty attendees on the day listened to and learned from guest speakers and took part in discussions.

Professor Nazneen Rahman, from the Institute of Cancer Research, gave an overview on cancer genetics giving examples from studies currently on the CCRN portfolio. An 'Ethics and Genetic Research' session, led by Professor Michael Parker from the Ethox Centre (University of Oxford), stimulated debate and exchange of ideas. In the afternoon there was another discussion session 'Recipes for Recruitment'; ideas were shared between centres on ways to raise the profile of and increase recruitment to research studies. Lauren Roberts from SWAN UK, a patient organisation run by Genetic Alliance UK, gave an update on their activities.



The study day was brought to a close by Professor Sir John Burn, National Genetics Specialty Group Chair, who thanked the group for their hard work and commitment.

Dr Gill Bothwick, Genetics Specialty Group Administrator

Search for studies on the Portfolio [HERE](#)

Industry Update

Sharing Best Practice for Industry: New innovative strategies to maximise recruitment potential up and running in Newcastle Tyne and Wear (NTW) CLRN.

NTW CLRN have been developing their Industry portfolio, and have put some key strategies in place to maximise recruitment into commercial studies, and ensure delivery to time and target.



The Musculoskeletal Research Team at Newcastle's Freeman Hospital has successfully introduced new working systems over the past year to promote clinical trials. These include:

- A tracking database to monitor all studies
- An internal website
- Specialist nurses and research staff both at the Clinical Research Facility and Freeman Hospital, as well as an on-call research nurse to help support industry studies.
- Implementing an "Industry Trials Strategy" throughout the CLRN up to Executive level.
- Providing information packs to study teams to ensure a clear understanding by, and subsequent engagement of, the key stakeholders to ensure delivery of their studies to time and target.
- A model for assessing feasibility which provides guidance to study teams to help them check that their study can take place within the NHS. It also recommends that attention should be paid to realistic targets and advises on preparation, planning and engagement with the right people at an early stage.

For further information you can look on the [NTW CCRN Website](#), or contact [Karen Hutchinson](#) (NTW Industry Manager), [Dr Tony De Soyza](#) (Associate Director for Industry studies and Industry Lead for the Respiratory Specialty Group) or [Prof Fai Ng](#) (Musculoskeletal Disorders Specialty Group Lead for NTW CLRN).

Feature Article

NIHR CCRN National Specialty Groups Administrator's Day; 26 September 2013

The annual National Specialty Groups Administrator's Day provides the Administrator(s) for each of the national groups the opportunity to meet and share good practice. It also enables the CCRN Coordinating Centre to introduce new processes to the entire Specialty Groups administrative team and get feedback on current ways of working. This year's event was held on 26th September, at Friends House in London.



In the morning Jonathan Gower, Assistant Director CCRN, reflected on the achievements of the past year, as well as looking forward to the future with an update on the transition of the Network. The great progress made by the Network was described, and the Administrators' integral contribution to this success was highlighted, and thanked. Louise Wood, Director of Communications, NIHR CRN then spoke about external communications, and Clare O'Loughlen, Network Liaison Manager, NETSCC gave an overview of the different NETSCC funding streams. Sarah Cooper, Specialty Groups Operations Manager, then explained the CRN Funder Engagement Pilot which aims to ensure funders and the Network are working more collaboratively, and intelligence provided by the national Administrators is a key part of the information that is shared.

The afternoon session was focussed on the day to day operational activities of the Administrators, starting with a workshop related to aspects of portfolio management including study closure, identifying struggling studies and making changes to study records. The Administrators were also introduced to the CRN's Open Data Platform, which they can use to access 'live' performance management data on the studies in their specialty. Finally Julia Steele, Specialty Groups Business Support Coordinator, led a session on meetings and membership processes, where she sought agreement on some new procedures.



We hope that the Administrators found the day interesting and informative. Some of the items discussed on the day will be followed up over the next couple of months. As a result it may be that the Administrators come back to the Specialty Group with ideas of how things could be done a bit differently, and we would encourage any change of working practise that improves productivity and efficiency!

Involving Patients



Shaping the role of Patient Research Ambassadors The [Involvement4access \(I4A\)](#) project is encouraging patients, carers and the public to improve opportunities for research participation in local NHS services by embedding “Patient Research Ambassadors” into NHS Services. Full details can be found on the I4A pages of the [CRN website](#).

Research Changed My Life...; Using inspirational stories to raise clinical research awareness The CRN are looking for patients

or carers who will share their experiences as part of the “Research Changed My Life” project. Further information is available on [the website](#).



Clinical Research on TV..... A programme about clinical research in the NHS will be broadcast on the Health Sector TV in October (<http://www.healthsector.tv/>). This channel can be accessed on Sky 212 and Freesat 402, and the programme will be shown on 20 and 21 October at 17.30 & 26 October 12.00. For further information please contact [Tracy Gregg](#) in the Comms Team, and keep an eye out on [The Message](#) for an update in late October.

.....and PPI in the Press The Times Higher Education supplement has recently published an article on research entitled '[patient involvement in research pays dividends, says study](#)'. Click on the link to read the article.

October Updates

New Starters within the Specialty Groups Team: Louise Humphrey (CEL CLRN); Louise joins the **ENT Specialty Group** on 14 October as their new national Administrator, taking over the role from Helen Blackshaw. Louise was able to attend the National Administrator’s Day, and so has had an opportunity to meet most of the other Administrators already. We welcome Louise to the team, and also thank Helen for the work that she has undertaken whilst in this role.

Tracey Crofts has left us for a six month career break, as of the end of September. **Mark Walsh** from Cheshire and Merseyside CLRN will be covering the portfolio management activities for the **Metabolic and Endocrine and Respiratory Specialty Groups**, with additional support also being provided by Cheshire and Merseyside CLRN for the Groups administration. We therefore also welcome Mark to the team.

Transition Update: As announced in last month’s newsletter, the Hosts for the 15 Local Clinical Research Networks have now been announced. This is a major milestone and the Host organisations are now in the process of appointing to the Clinical Director and Chief Operating Officer positions, the role outlines of which have been published. The role outline for the **Local Clinical Specialty Leads** has also been approved and is available on the [portal](#). The final draft of the new contracts has been shared with the Hosts, and this along with the associated performance and outcomes framework, will shortly be signed off.

The DH has agreed the branding for the network, including the names for the 15 LCRNs and 30 Specialties. Some of the names of the Specialties have changed following consultation with the Specialty Group Chairs and a revised structural map can be found on the [portal](#).

There is also a dedicated “[Evolving the NIHR Clinical Research Network](#)” page on the CRN website which is regularly updated.

Summary analysis of 12/13 CCRN expenditure now available The [Summary Analysis](#) and [Analysis](#) of 2012-13 CCRN expenditure are now available on the Specialty Group Portal for your information (via the above links).

Funding and Partnership Opportunities for Implantable Devices Event: 6th November. The [NIHR Office for Clinical Research Infrastructure \(NOCRI\)](#) and the [Efficacy and Mechanism Evaluation \(EME\) Programme](#) are co-hosting a FREE meeting to launch a new EME funding call for implantable devices. This meeting will enable industry delegates to explore funding and partnership opportunities for research into implantable devices. Full details, including how to register, can be found on their [website](#).

Report of a Royal College of Physicians and National Institute for Health Research workshop – developing research capacity to ensure successful study development and delivery.

The October 2013 issue of *Clinical Medicine* contains a report on the event held last year at the Royal College of Physicians jointly between the Royal College and the NIHR CRN. This year we are following on from this event by holding another workshop in December which will focus on future healthcare needs involving Age and Ageing, Genetics and Metabolic and Endocrine Specialty Groups. The report is available to subscribers on the [RCP Website](#).

Study of the Month: HCV Research UK; Host and viral factors associated with outcomes of infection with hepatitis C virus (UKCRN 11582): Hepatology Specialty Group

This is an observational study in 10,000 patients with laboratory evidence of HCV infection, either past or current. All enrolled patients will be genotyped at key IL-28B loci known to influence disease outcome. Analysis of this IL-28B genotype data together with routinely collected clinical and laboratory data, alongside disease outcome data, will allow analysis of the contribution of a range of host and viral factors to disease outcome, and determination of the clinical utility of routine IL-28B genotyping in the management of HCV-infected patients in the UK. The study comprises the collection and long-term storage of study-specific blood samples, plus blood and liver biopsy tissue taken for routine clinical management purposes but surplus to clinical and/or diagnostic requirements in a biobank, with an intention of maintaining the biobank for at least 10 years.

The study faced challenges around successful start up across sites, and lack of local resources. The Hepatology Specialty Group helped by working with the CLRNs to provide extra nursing resource, enabling 19 additional sites to be opened that were not covered by the original funding package.

CLRN sites have so far contributed over 600 patients to the study, which is approximately 15% of the current recruitment total. By the end of recruitment in December 2014, it is anticipated that these sites will have contributed around 2000 patients.

Having a national biobank and clinical database for researchers to draw on will be a very powerful tool. This has been recognised by Liver and Infectious Disease centres across the UK and many have consequently expressed a wish to join the venture. The resource required to recruit 10,000 patients and obtain blood samples for biobanking along with the clinical data for the patients will be considerable. Such an undertaking would not be possible without the support of the NIHR and CRN.

For further information please contact [Professor Will Irving](#), Chief Investigator for the study.



If you would like your study highlighted in SG News, please submit a summary through 'Study of the Month' on the SG Portal



Many thanks for taking the time to read this Newsletter.

If you have any ideas for future editions, or would like to provide us with some feedback, please contact [Catherine Morrison](#) by email or call 0113 343 0308.