National Institute for Health Research

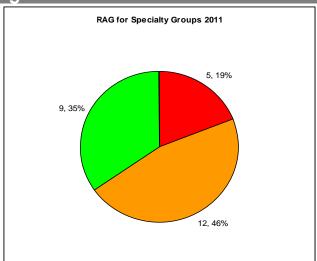
OCTOBER 2012 EDITION

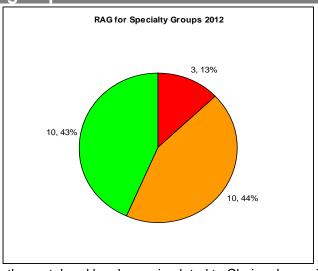
# How are we doing? Take a look at this month's figures.

41% of studies closed at Green	10% of studies are Black (are not reporting at all)	Upload engagement was 93%	46% of studies are currently Green (open studies)	Group of the Month (best average rank in all areas):
1% from last month	No change from last month	1% from last month	1% from last month	Anaesthesia, Peri- Operative Medicine and Pain Management
Oral and Dental	Age and Ageing, Anaesthesia, Peri- Operative Medicine and Pain Management, ENT	ENT	Age and Ageing	Most improvement in the last 3 months:  Age and Ageing

<sup>\*</sup>Top group in each category for this month \*\* You can view the latest Performance Management Report with descriptions of how the ratings are calculated on the SG Portal

### Progress Review 2012- Feedback for all groups





The report of the Specialty Group review is now available on the portal and has been circulated to Chairs along with specific feedback to each Group; <a href="https://portal.nihr.ac.uk/sites/ccrn/SpeC/Information%20Cache/2012SGreviewfinal.pdf">https://portal.nihr.ac.uk/sites/ccrn/SpeC/Information%20Cache/2012SGreviewfinal.pdf</a>.

The Review Panel considered that, in overall terms, Specialty Groups have continued to make a major contribution to the achievement of the CCRN's High Level Objectives. In particular, Specialty Groups had made a significant impact on delivering studies to time and target, engaging their research communities and raising awareness of what the NIHR Clinical Research Network and Specialty Groups have to offer, and developing productive relationships with other stakeholders, including charities, research funders, Royal Colleges, specialist societies and the commercial sector.

10 Specialty Groups were given a "green" rating, 10 an "amber" rating and 3 a "red" rating (the HSR Specialty Group has remained in suspension and was not rated). The proportion of "Green" rated Specialty Groups has increased from 35% in 2011 to 43% in 2012, with a concomitant fall in "Amber" and "Red" Groups demonstrating overall progress over the last 18 months.

# SPECIALTY GROUP NEWS — OCTOBER 2012

#### **INDUSTRY UPDATE**



39% of studies closed at Green	26% of open studies are currently Green	Top group for % industry studies closing green this year:	
7% from last month	1% from last month	Injuries and Emergencies, Metabolic and Endocrine (not diabetes) and Nervous System Disorders	

#### Global first patient for study CCRN 1033!

The CCRN CC Industry team are delighted to report that global first patient has been achieved by Dr Saralaya, Bradford for study CCRN 1033. This is a global study running in 22 countries on 3 continents and is looking at the long term safety of a new compound delivered by an inhaler over a 52 week period in patients with COPD and therefore falls under the remit of the Respiratory Specialty Group. Feedback has been received from the Company who are delighted with the outcome particularly as it sends a positive message about clinical research in the UK and they wish to extend their thanks to all involved in the Networks and Trusts, particularly those who were involved in expediting study start up.

#### Commercial eligibility and feasibility – NIHR CRN Service Improvement Programme (SIP)

Following on from information given in the August and September editions of Specialty Group News, review and revision of the current 'adoption process' for commercial studies has led to the design of a new process to allow Coordinating Centre Industry teams to provide a faster and more flexible service to Industry with **three defined services**:

- 1. Early feedback service (2 weeks): Managed by the Coordinating Centre for CCRN and conducted only if specifically requested by the company; members of the relevant Specialty Group will be asked to provide comments on the study design and its compatibility with UK practice.
  Eligibility: In order to assess eligibility for the portfolio, the company will be required to self-declare regarding the following questions that are required by the Department of Health: 1) Is there a research question? 2) Has the study been subject to high quality peer review?
- 2. Network intelligence on company identified sites (2 weeks): Information collated in agreement with the relevant Specialty Group lead will be provided by the CLRN for feedback to the company following a quality check by the Industry Coordinators at the Network CC. To avoid duplication of work the company will be asked to provide information on feasibility gathered to date.
- 3. Network identification of additional sites (3 weeks): The company will be asked specific questions about the requirements they have for new sites (using the company's own feasibility questionnaires if requested) so that the most appropriate sites for a study can be targeted by the Network. To aid discussions with potential sites, the company will be asked to confirm whether the study drug name and class can be shared outside of a confidentiality agreement. The company will be strongly encouraged to involve the CLRN Industry Managers in discussions with sites following return of feasibility assessments.

**Sign Off and Timelines**: To demonstrate accountability, the feasibility information provided will be 'signed off' by a senior member within the CLRN. While it is important that the process is completed in a timely manner, the CCRN CC will not accept requests for extremely tight timelines if they are unachievable or impractical.

The pilot is planned to start in October for studies submitted to CCRN and DRN and was officially launched at the **National Industry Event in London on the 25<sup>TH</sup> October,** with full roll out across other Networks to follow. An update on the Costing and Contracts SIP, also well under way, will be provided in the next newsletter.

# SPECIALTY GROUP NEWS — OCTOBER 2012

#### OCTOBER UPDATES

#### **CCRN Staff updates**

The Specialty Groups Team say farewell to Janey Sheperson as Administrator. Please continue to submit your enquiries to crncc.specialty@nihr.ac.uk in the meantime. Janice Paterson has joined the team as maternity cover for Catherine Bennett in the Specialty Groups Information Coordinator role.

The Portfolio Team are pleased to welcome back Claire Eckert from maternity leave to her post alongside Catherine Whibley as CCRN Portfolio Delivery Manager and also welcome Nicola McMillan joining as a new part-time Portfolio Support Assistant.



## Attributing the costs of health and social care Research and **Development (AcoRD)**

The Department of Health has published guidance entitled "Attributing the costs of health and social care Research and Development" (AcoRD) to provide a framework for the NHS and its partners to identify, attribute and recover the various costs associated with research in the NHS, in a transparent, robust and consistent manner. This guidance superseded earlier guidance contained in Attributing Revenue Costs of non-commercial research in the NHS (ARCO).

A Working Group has been set up to implement AcoRD and please contact the CRN Business Lead, Amber O'Malley, if you have any queries about this. Further details will be circulated as implementation is rolled out.

(amber.o'malley@nihr.ac.uk, t: 0113 343 0313).

# **Involving Patients**

We held our first Specialty Group PPI teleconference seminar on 16 October. Focussed on 'Getting Started' it was a well attended discussion, with representatives from five of the national Groups dialling in as well as other individuals; one from a charity, and a number from CLRNs and NHS Trusts.

Thank you to those who contributed. This seminar facilitated a varied discussion, and included highlighted examples of activities undertaken by the national Specialty Groups which have led on the incorporation of PPI in their work, as well as local initiatives. Approaches to practice were shared amongst participants, with a number of generic points discussed which Groups could consider when approaching PPI:

- Invite patient representatives (at least two) to attend the national meetings of the Group
- Collate a glossary of commonly used medical and clinical jargon
- Use generic patient videos to promote research, if specialty-specific ones are not currently available
- Include a sentence on research in Trust patient information leaflets, and develop specialty-specific leaflets/posters which could be displayed in patient waiting areas
- Advise colleagues to invite patient panels to review lay summaries and patient information sheets at the grant application stage
- Include PPI as a standing agenda item for national Specialty Group meetings

Following the success of this seminar, a second 'Getting Started' teleconference is planned, for mid-December. In order to facilitate meaningful discussion the number of attendees will be limited, and priority will be given to members of the national Specialty Groups. If you would like to be involved then please contact Emma Chambers, Specialty Group Operations Manager to register your interest.

#### **News from NETSCC**

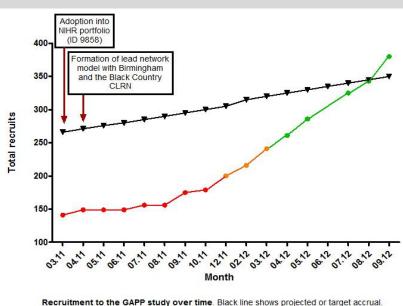
The latest NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) bulletin for the NIHR Clinical Research Network includes an update on the NIHR Pandemic Influenza research portfolio, provides information about Patient and Public Involvement and details current funding opportunities. It also highlights the recruitment opportunities to become involved as an advisory group member or external reviewer. To view this bulletin, please visit: www.netscc.ac.uk/bulletin/08\_October\_2012.asp

#### STUDY OF THE MONTH

## **GAPP - Non-Malignant Haematology Specialty Group**

The GAPP (genotyping and platelet phenotyping) study was adopted onto the NIHR portfolio of the Non-Malignant Haematology Specialty Group in January 2011. The study looks at patients with excessive bleeding to see if they have an underlying platelet defect and to classify the nature of the defect, in addition to uncovering the genetic reason for the change in platelet function. The principal investigators are based in Birmingham, Bristol and Sheffield.

Recruitment was initially within the red zone. The support of the Non Malignant Haematology Specialty Group and the Birmingham and the Black Country CLRN was vital to the success of the GAPP project, as it enabled us to access support via the Birmingham and the Black Country CLRN to create a lead network model for the study. This drove applications for NHS Permissions in several new centres (many centres are required as inherited platelet disorders are rare). From October 2010 to May 2012 the number of centres with NHS permissions rose from 3 to over 20.



Recruitment to the GAPP study over time. Black line shows projected or target accrual. Red / amber / green line shows actual accrual, coded according to whether recruitment fell within the NIHR red (less than 65% target), amber (65-80% target) or green (over 80% target) zones. As of September 2012 the project was recruiting to over 100% of its time projected targets.

"As our number of centres increased, recruitment rates increased six fold. We are now recruiting at over 100% of our target according to time, and have been helped to set up a portal to contain study data by the Information Team at the Birmingham and the Black Country CLRN. The support of both the CLRN and NMH group has been vital in ensuring success in this project, and we have several publications containing our results in preparation and under review."

Dr Gillian Lowe, University of Birmingham and NMH Specialty Group Lead for Birmingham and the Black Country CLRN.

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

