

PCRN N & Y NEWSLETTER

Spring 2011

The Primary Care Research Network Northern & Yorkshire is part of the NIHR Clinical Research Network, which supports research to make patients, and the NHS, better

Expanding Team

The Primary Care Research Network Northern & Yorkshire (PCRN N&Y) has recently adopted the **hub and spoke model** of organisation. With an **administrative base** in **Stockton-on-Tees** and the four spokes of:

- **Northumberland, Tyne & Wear**
- **County Durham/Tees Valley**
- **North & East Yorkshire & North Lincolnshire**
- **West Yorkshire**

We have adopted this model as the PCRN (N&Y) team has recently expanded with Research Facilitators and Research Nurses joining the study coordinators in each of the Spokes.

Although to our collaborators and stakeholders the changes may not be apparent, we

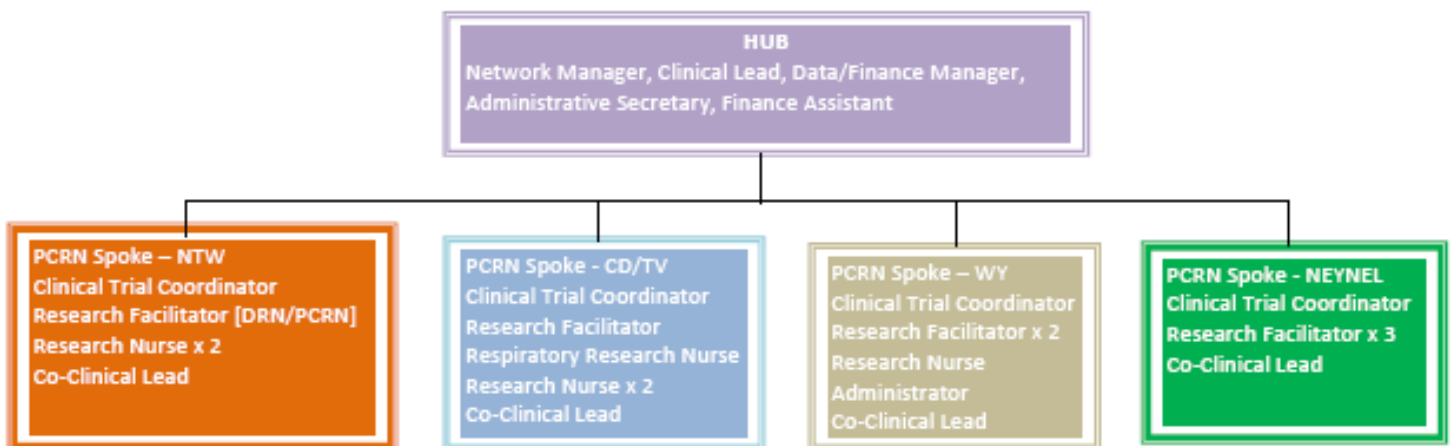
fully expect that by structuring our network this way you will be able to develop closer relationships with the local teams as it is through them the majority of information regarding studies and other PCRN activities will come, rather than from the Stockton office.

Publications will continue to arise from the central PCRN N&Y office in Stockton though your local CTC should be the first point of contact for study information or general questions. In the event that you are unable to contact your local team then please contact the central office on 01642 615600.

Submitted by:

John Hodgson
Clinical Trial Coordinator
PCRN N&Y/West Yorkshire Spoke

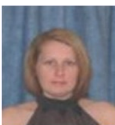
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Hub and Spoke model demonstrating current staff in post

Meet The New Team Members

West Yorkshire (John Hodgson is the Clinical Trial Coordinator) The new team members are:



Julie



Angela

The **Research Facilitators** are each looking after specific areas of West Yorkshire; **Julie Miller** - Leeds & Wakefield; **Satti Saggu** - Bradford, Calderdale & Kirklees. This way the practices and the Facilitators will soon get to know each other as it is through them the majority of study information will come. Their role is to liaise with the practices, inform you of new and upcoming studies, assist with set up and provide help and assistance, where necessary, as the study progresses. **Angela Wray**, Clinical Trial Nurse, is working across the West Yorkshire region and will be providing input to the studies which require more clinical or nursing input and will be able to support and advise on the practicalities of the study and be able to assist with research clinics if required. **Chris Bean**, Finance Administrator, is looking after the Service Support Costs and making sure that all of the practices in West Yorkshire receive their SSC's on a quarterly basis.



Satti



Chris

North & East Yorkshire and North Lincolnshire (Yvonne Coverdale is the Clinical Trial Coordinator) The new team members are:

Denise Williams is a qualified nurse with a BSc (hons) in Health Sciences. She has worked in General Practice for 13 years and became involved with research trials when she joined Whitby Group practice in 2005 as a Practice Nurse. The role evolved into a full time research post in 2009. She joined the NEYNL team as a **Research Facilitator** last year and presently combines the two roles which she finds challenging but extremely rewarding.

Monica Lloyd, BSc degree, RGN and HV qualification, joined the PCRN as a **Research Facilitator** in November 2010. She previously worked in primary care research for 18 years, for the MRC, and managed research for a practice group alongside the PCRN. She still has passion for research and hopes to make a small contribution to improving the quality of research in the area. She still finds time to indulge in sport and her interest in Art and Culture. Monica has three grown up children.

Carla Bratten is the latest **Research Facilitator** to join the team. She has 8 years experience in research mainly working on large International Trials. She is also a qualified Nurse and practising Midwife with a Masters Degree in Public Health. She has recently moved with her family from Leeds to York and is enjoying everything York has to offer.



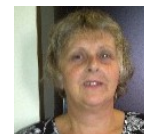
(from left to right) Denise Williams, Monica Lloyd, Carla Bratten and Yvonne Coverdale

Co Durham & Tees Valley (Sarah Daniel is the Clinical Trial Coordinator) The new team members are:



Heather Maughan, Research Nurse, has been a nurse since 1978 and during this time has worked in a number of senior clinical and managerial roles, many in primary and community care. Currently working on a doctorate in nursing, Heather hopes that the role of Research Nurse will give her a greater understanding of research in practice.

Pat Brown, Research Nurse, is a registered nurse with research background in Phase 1 of drug development and as trial monitor in the Pharmaceutical industry. A relatively recent "returner" to nursing and to working in the NHS, Pat joins the CDTV team from an enhanced community care team and community hospital. She is enjoying working within a diverse team and getting to grips with a new caring role.



June Battam, Respiratory Nurse, is a registered Nurse with 20 (plus) years experience, specialising in Respiratory Medicine, Palliative and End of Life Care. June enjoys the research challenge, meeting a new and varied selection of people within Primary and Secondary care. June has been very impressed by the support given to her and feels privileged to be part of the PCRN/CLRN team and looks forward to being involved with future studies, taking the NHS forward, improving the health of people for future generations, and meeting the new challenges that this will provide.

Northumberland, Tyne and Wear (Louise Warner is the Clinical Trial Coordinator) NTW have a different set up:

Research Facilitators and Nurses are employed using CLRN-funds via the PCT's in NTW, with line management also at the PCT's. **Linda Tinkler** is the **Research Nurse** for South of the Tyne and covers Sunderland, Gateshead and South Tyneside. **Jill Ducker** is the **Diabetes Specialist Primary Care Research Nurse** covering the North of Tyne PCT's of Northumberland, North Tyneside and Newcastle. **Susan Tremble** is the exception and is the joint **PCRN/DRN Research Facilitator** for the entire NTW region. Susan is employed via DRN and managed by PCRN. **Louise Jones** is a **Research Nurse** employed at Northumbria Care Trust (primary care provider arm) and supports portfolio studies across district and tissue viability nurses in the community. **Karen Morgan** is the **Research Facilitator** for practices across west Northumberland and encourages development and delivery across the area.

A day in the life of a Research Nurse

How did you start as a Research Nurse?

First of all I'm not really a full-time Research Nurse. Yes, that's what I'm called when I deal with the networks and the drug company monitors, but most of my week I'm a practice nurse spending my time doing diabetes and asthma clinics, which are the diseases that interest me most, along with the usual duties and repeat checks - all of which take up more than the hours I'm meant to work as it is.

But currently I am funded by the networks for 6 hours a week to concentrate on the trials we do here.

It is quite easy to just get dragged into normal practice work

I know at the minute new study details go through the Practice Manager and I think it would be good if I also saw what was coming up as that is what I'm here to do for 6 hours a week. It's easy picking up your normal tasks when things are quiet but very difficult to get out of it once everyone knows you are around.

As I am paid for it, I am more than

to remove patients who just would not be suitable for a trial. The patients we remove are those who are known to be non-compliant or just too ill and frail to approach about any studies, and this can help the GPs by reducing the number of people they have to screen.

We have over 10,000 patients registered - it is impossible for every member of staff to know everyone individually

Therefore it does mean looking things up on the system to check, which can increase the time it takes to decide.

There is always a pile of queries and data clarification requests which I have to reply to. I deal with my emails picking out those which are about the trials we are running and have a look at any study information that has been passed on from our Practice Manager as we always decide on trials during our practice meeting. There may be some follow up information to collect and enter and on occasion we do have to complete adverse event forms but these don't ever seem to be too common.

I have always enjoyed the studies where patients need to come into the practice for study visits as this makes a nice change from all the paperwork that comes with any trial.

If there is one thing you could change about the trials you do, what would it be?

The paperwork, or at least a system where information could be transferred automatically.

We would like to thank the Research Nurse for talking to John Hodgson, Clinical Trial Coordinator



How do you fit those hours in?

I work part time - 20 hours per week - and the additional funding allows me to do a 9.00 a.m. to 3.00 p.m. day most weeks, which fits in with the kids' school hours so doesn't cost me extra in childcare.

I sometimes struggle when there is little activity or at least when the majority of the set up and patient search work is done, and there are plenty of other things I could be doing.

happy to do the searches and the other administration bits that need doing but at the minute I don't get to know about things. I realise that the main contact is the Practice Manager as they don't do clinics so are more likely to be available when we aren't.

How did the day progress the last time you did your 'research day'?

To the surgery after dropping kids off. If we have just done a search for a study, I often go through them

PURPOSE - Pressure Ulcer Programme Of Research

This nurse-led, 2 million pound, 5 year programme of research is funded by the **National Institute of Health Research (NIHR)** and is sponsored by the **University of Leeds** in collaboration with **Leeds Teaching Hospitals NHS Trust**.

The aim of the programme is to reduce the impact of pressure ulcers (PU's) on patients through:

- Early identification of patients at risk of progression to severe Pus, and
- The development of methods to capture patient reported outcomes including health-related quality of life (HRQoL) and health utilities for routine clinical use and in clinical trials.

The programme comprises of the following 5 research studies:

Study 1 – Pain:

Includes a prevalence survey to assess the type and severity of localised PU pain in “pressure areas” and a cohort study to explore the role of pain as an early predictor of Grade 2 PUs.

Study 2 – Severe PUs:

Includes a retrospective study to develop a detailed understanding of the individual and organisational factors involved in the development of severe PUs and develop a critical incident/adult neglect investigation methodology for the review of severe PUs.

Study 3 – Risk Assessment:

We will update the risk factor systematic review and using consensus methods and findings from studies 1 and 2, develop a patient level risk factor minimum data set. We will then develop, pilot, evaluate and

implement a risk assessment framework.

Study 4 – Patient Reported Outcome Measures:

Gold standard psychometric methods will be used to develop a psychometrically rigorous, patient – reported outcome measure of HRQL in patients with PUs.

Study 5 – Health Utility Measure:

We will undertake a valuation survey and develop a utility algorithm for the patient reported outcome measure developed in Study 4.

If you have patients in the **Derwentside** to **Darlington** area you think may be suitable for either **Study 1** or **Study 4**, or you would like further information on this research, please contact Linda Wells, Research Nurse (linda.wells2@nhs.net) Tel. 0191 5876063 or 07776470876.

The National Institute for Health Research (NIHR) is committed to the Department of Health's national strategy which puts patients at the centre of all NHS related activity.

To ensure that ‘patient benefit’ is not simply based on the views and options of research professionals and clinicians, the national strategy highlights the importance of involving patients, carers and the public at all stages of the research process.

The Primary Care Research Network is committed to actively involve patients and members of the public in all relevant aspects of its work to the benefit of patients.

Locally the PCRN N&Y is exploring new ways of engaging patients and

the public in research.

With this in mind we will be looking for PPI Advocates:

- To help raise awareness of research taking place in our area
- To raise awareness of all the NIHR Networks, not just PCRN, within the public and professional domain
- To engage with patient groups and panels

We are in the planning stage at the moment, looking at different ideas, designing promotional literature, and drafting a process from advertising to selection of Advocates and are hoping to engage a few members of the public to assist in this process.

Public Patient Involvement (PPI)

Patients and public can be involved:

- as patients/participants voluntarily taking part in clinical or other well designed studies
- as patients and public members working with research professionals and clinicians (e.g. doctors, nurses) and getting actively involved in the different stages of research and related activities.

We will keep you informed with regular progress updates.

The Teenage Hayfever Study - Intensive training for healthcare professionals in the management and treatment of intermittent allergic rhinitis and its impact on adolescents' quality of life: pragmatic cluster randomised controlled trial in primary care

Hayfever is a global health problem affecting males and females of all ages from all ethnic and social backgrounds. About 30% of the general population are affected, going up to about 40% in 13 -14-year olds.

It is widely accepted that hayfever can impair quality of life, sleep and leisure activities. The Teenage Hayfever Trial aimed to evaluate the effect of intensive hayfever training for health care professionals (HCPs) on quality of life in teenage hayfever sufferers. The study ran for two summers in primary care practices in Scotland and England. General practices were recruited very successfully with the help of the Primary Care Research Network Northern & Yorkshire (PCRN N&Y) and an equivalent network in Scotland (SPRCN). In total 38 practices were recruited and 20 were randomised to receive the training intervention. The intervention practices nominated a HCP to attend the training, and then to see patients aged 12-18 years for a hayfever consultation. Patients aged 12-18 years in the control practices were seen by a nominated HCP who received no training. A total of 341 teenagers consented to take part in the trial, and complete data was available from 246, enough to detect any difference between the two groups.

Despite an improvement in the confidence, knowledge and skills of the HCPs in the intervention group, this did not translate into a difference in quality of life scores in the teenagers, only modest improvements were seen in both groups from baseline. We would have expected more con-



sultations in the intervention group if the training had achieved a sustained change in clinical practice. However, although the intervention group tended to have more consultations and prescriptions in total and

more consultations for other respiratory conditions, the figures for rhinitis did not differ greatly between the two groups.

Our findings are important in considering training programmes for HCPs. One-day workshops may be cheaper in terms of time out of practice than more sustained training programmes, but may not be cost-effective as measured by improvement in patient outcomes.

As with all trials, recruitment of practices and patients is always difficult, and this is particularly so with a cluster trial, as a larger sample size is required due to the design. The PCRN N&Y facilitated recruitment over two summer periods very efficiently and the practices and staff who agreed to take part engaged with the trial to make it successful and reported that they enjoyed working with the teenagers.

The research team from the University of Edinburgh would like to take this opportunity to thank the PCRN N&Y, all participating practices and patients for their help.



Submitted by:
Vicky Hammersley
Research Fellow
University of Edinburgh



May 2011

RESEARCH UPDATE

PRIORITY STUDY

DRN514 - The Vildagliptin Study This is a single-centre, double-blind, randomised, placebo-controlled, parallel-group study to assess the effect of 24 weeks of treatment with vildagliptin on insulin sensitivity and its underlying mechanisms in patients with type 2 diabetes treated with metformin. Eligible patients are referred to the new, high-tech purpose built research facility at the Campus for Ageing and Vitality at the Newcastle Northern General Hospital site where they will receive numerous tests over 24 weeks and 12 visits. This is a commercial study with primary care identifying patients for referral only. Patients are reimbursed for their time and involvement as well as meeting other patients in the same study during study meetings. Open for recruitment NOW in NTW.

This issue includes:

- Studies currently open
- Study opening soon

For more information about any of the studies included in this booklet please contact the PCRN N&Y office on 01642 615600 or email:

The PCRN N&Y frequently produce a **Study Update Booklet** providing summary information about new studies coming into the area.

The booklet can be accessed through the PCRN website (www.nyren.co.uk) via the 'newsletters' tab. They are PDF documents so should open easily on all computers.

If you wish to sign-up for an emailed reminder please contact your local Clinical Trial Coordinator or email to

enquiries@nyren.co.uk or telephone the main office on 01642 615600

Browse the
British Medical Journal
for published
research articles

SAPC Northern Conference

The Society for Academic Primary Care

The Academic Unit of Primary Care, **University of Leeds** in association with the **University of Huddersfield** are this year's hosts of The SAPC Northern conference in Kendal on 24th and 25th November 2011

Keynote speakers for 2011 include:

- Professor Trisha Greenhalgh
- Professor Helen Lester
- Professor Ed Peile
- Professor John Spencer

Book your conference place using the online registration form on the University of Leeds website, where you can also download the flyer and draft programme: <http://www.leeds.ac.uk/lihs/pc/conferences.html>

If you would like to submit an abstract to present at the conference please follow the guidelines on the website; poster and workshop submissions are also welcome.

Abstracts (no more than 400 words) should be emailed to e.m.luff@leeds.ac.uk by 5.00 p.m. on 30th June 2011

Please note all presenters **must** register on the conference as a full (£225) or day delegate (£115).

Any queries should be directed to Lizzie Luff, Education Manager on (0113) 3434180 e.m.luff@leeds.ac.uk

PCR N&Y Contact Details

Interested in a trial or study?

If you have any queries, are interested in participating in a clinical trial or study mentioned in this newsletter, or would like to know which studies are being carried out in your geographical area, please contact the **Clinical Trial Coordinator** for your area or the PCR N&Y main office.

Clinical Trial Coordinator	Geographical Area	Email Address
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John Hodgson	West Yorkshire	john.hodgson@nyren.co.uk
Yvonne Coverdale	North & East Yorkshire and North Lincolnshire	yvonne.coverdale@nyren.co.uk



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