



New event name, New venue, New NHS?

Welcome to the newly titled-Annual Sharing Best Practice event which replaces the LSCCRN Annual Conference this year. Since our last event we have seen a change in Government and policies relating to the NHS and the ways we work..

Times of change are nothing new to those of us who work in research and there has been no national guidance to suggest a change in our NHS funding to date. LSCCRN's strategy remains essentially unchanged– to provide equitable access to high quality cancer clinical trials throughout Lancashire and South Cumbria.

Our research nurse teams have expanded at each secondary care Trust with more to follow in the next few months. This has allowed us to expand the cancer trial portfolio into uncharted territories in some areas, such as renal cancer and capitalize on as many commercial trial opportunities as possible. You can find out more about our teams inside this newsletter.

More information regarding the LSCCRN's trials and recruitment levels can be found at our Network stand. We are on target to once again increase our recruitment levels on last year's performance but as well as that, we are increasing the opportunities for patients/volunteers to consider entering a research study or trial. Many people may decline the option, but we are proud that we give as many people as possible the choice. Their choice.

Equitable access to cancer trials remains an issue with so many tumour groups to account for and some trials are so specialised it is necessary to limit the sites within the UK that open them. Indeed we have hosted some such trials ourselves. Within Lancashire and South Cumbria we will be improving communication around research opportunities available for patients, in partnership with our neighbouring cancer research networks.

Rachel Bracewell, CRN Manager

HQ– we Focus on Sharing Best Practice, Trial set-up and Supporting our Staff

The Network HQ team's greatest success this year has been the introduction of the EDGE system and we would like to thank everyone for their patience. EDGE is a Trial Management System, which is currently being used by only the Nurses and Clinical Trial Administrators, however will be rolled out to other departments linked to Cancer Clinical Trials in due course. As well as managing trial patient data, EDGE stores version controlled trial protocols and other related information. The database enables us to extract accurate reports and analyze the data to improve recruitment. Every day in the HQ office is different (a different outfit of course) and challenging. With the entire Network



Dr. Andrew Hindley –
Clinical Lead

to support it can sometimes get hectic in here, but we relish our roles. We try to support the team to the best of our ability... even to the extent of baking them motivational goodies!

We love working together and feel we make a pretty good team: we consist of a baker, a chef, a seamstress and a fashion lover... the perfect combination... don't you agree? But who does what...?



Charlotte

Amanda

Rachel

Julie

SPECIAL POINTS OF INTEREST:

The NCRN logo is currently being reviewed ahead of our 10th anniversary in 2011.

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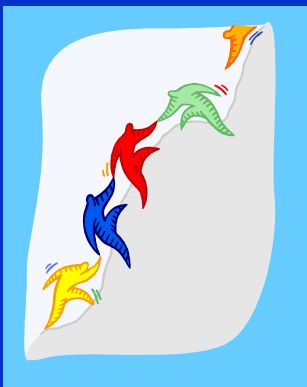
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“What makes a good research nurse?

Caring nature, enthusiasm, I.T. savvy and highly organized. Add a sense of humour and you're off..”

Rachel Bracewell, LSCCRN Manager



Network Progress



The year 2009-10 has been a brilliant year in terms of both increasing our Randomised Controlled Trials (RCT) recruitment (6.3% vs 5.4%) and also varying our portfolio as a result of our new associates in Upper GI, Respiratory and Palliative Care. All our staff and those we work alongside are determined to help the Network provide equitable access to high quality cancer studies for our patients. Evolution of relations with the Cumbria and Lancashire Comprehensive Research Network (C&L CLRN) and additional staff funding to support cancer activity has led to another year of improvements, change and compromise between both Networks and the Trusts involved.

Radiotherapy studies have done particularly well with regards to RCT recruitment this year, increasing by a whopping 400%, as well as a 210% increase in pre-malignant recruitment attributable to the BOSS study, supported to date by the Upper GI Speciality Group team. Non RCT recruitment has been maintained (4.1% vs 4.0%), despite delays in staff recruitment to

support such studies. In 2010-11 the Network is looking to develop and support effective, collaborative working arrangements for all personnel supporting NIHR cancer activity, which should translate as an increase in not only RCTs but overall recruitment.

During 2009-10 the Network had 58 NIHR cancer portfolio trials open, of which 6 were NIHR commercial studies. In 2010-11 the Network will access the NIHR commercial trial income generated by the support of commercial studies as do all the departments that support such recruitment.

It is not only recruitment we are interested in... honest. The Network is a member of the NCRN Northern Regional Group which builds upon established relationships with the North West Cancer Research Networks. This now includes the NCRN Northern Regional Training and Education strategy. Investment in leadership and other team skills has been beneficial to the Network and will continue to develop and enhance our wonderful teams in 2010/11.

Let us not forget, it's all about patients.... Our Cancer Research Partnership Group continues to gain momentum with an audit having been undertaken regarding their first project to increase awareness to clinical trials through the use of a poster in waiting rooms. The results were analyzed and a new and improved poster will soon be winging its way into Oncology outpatient waiting rooms across our patch... keep your eyes peeled and let us know if you spot one!

The Network has been taking part in the North West Exemplar project to demonstrate speed of set up and recruitment to NIHR commercial studies and this has had a positive effect on all commercial studies. We have received many pats on the back, which has boosted our teams confidence no end. The NW Exemplar studies have also partially ironed out issues and highlighted improvements that could be made to the intricate and complex relationships which are necessary in the process of setting up a trial. These lessons have benefitted setup of all sorts of studies, not just commercial. For more information, please see the article on page 6.

Things to be proud of...

First two patients to be recruited into NCRN099 in the UK courtesy of the ELHT Team.

The Network have been ranked the 4th highest recruiting Network in England for the FRAGMATIC Trial and the 3rd highest recruiting Network for the PET- Neck Trial.

NCRN069 BFWH team were the first to recruit in the UK.

The LTHTR team were the first to recruit a patient to the NCRN094 study and are currently top recruiters in the UK.

We are currently ranked 21st out of 33 NCRN England Networks for overall recruitment.

This Sharing Best Practice Event! Well done to Charlotte and co for all the organization involved.

Team News

Departures-

Alison Smith, our dynamic Research Radiographer has moved to Gambia! Not anything we said we hope! Neil Wynne is helping us in the Radiotherapy department in the interim. Thanks Neil! Rose Ellard will be leaving the Preston team in late November to head to the Royal Marsden. Good luck Rose!

We have two team members aiming for retirement next year...we are locking the doors!

New Additions-

We daren't mention Rosemere radiotherapy centre's penchant for newborns in case any more staff go on maternity leave...haha!

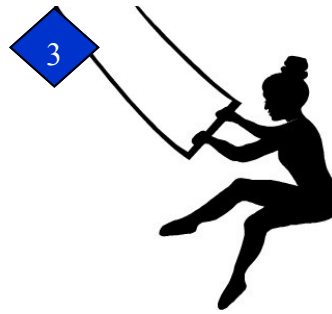
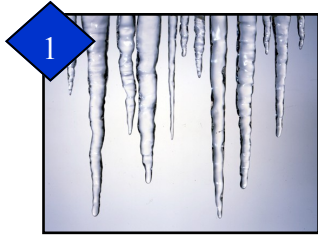
East Lancs welcomed Alison Sears a few months ago (Research nurse)

Blackpool welcomed Karen Gratrix undertaking the admin side of things.

Morecambe Bay are being joined by Gail Wiley and Debbie Powers in September /October.

Preston have Claire Hennigan in post for data now.

Name that Trial.... (Just for a laugh) Please see page 5 for the answers



Daffodils

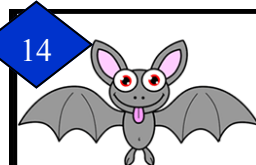
I wandered lonely as a cloud
That floats on high o'er vales and hills,
When all at once I saw a crowd,
A host, of golden daffodils;
Beside the lake, beneath the trees,
Fluttering and dancing in the breeze.

Continuous as the stars that shine
And twinkle on the milky way,
They stretched in never-ending line
Along the margin of a bay:
Ten thousand saw I at a glance,
Tossing their heads in sprightly dance.

The waves beside them danced; but they
Out-did the sparkling waves in glee:
A poet could not but be gay,
In such a jocund company:
I gazed—and gazed—but little thought
What wealth the show to me had brought:

For oft, when on my couch I lie
In vacant or in pensive mood,
They flash upon that inward eye
Which is the bliss of solitude;
And then my heart with pleasure fills,
And dances with the daffodils.

William Wordsworth



BONUS POINTS for the CLOSED Trial Name

East Lancs and their Phenomenal Recruitment



Vivienne Tickle is the LSCCRN's Senior Research Nurse and is based at Royal Blackburn Hospital. Recruitment has seen a 300+% rise in the

last year thanks to the consultants and excellent work of Viv, Sue Ashworth, Karen Beard and now also, Alison Sears.

Viv's answers for Charlotte:-

What has been your favourite trial to work on and why?

Stampede because it gives people a choice of additional treatment now rather than waiting until [prostate] disease becomes problematic. Many patients prefer this option, it also helps psychologically to cope with a cancer diagnosis and overall well-being.

What makes a good research nurse?

Someone who can multi-task, good attention to detail, not afraid to be a patient advocate and good communication and organisational skills.

What's your team's biggest strength?

Working together to support each other.

Name something your team has done for the first time this year?

We've opened our first cancer NIHR Commercial trial and recruited the first two UK patients! It was part of the NW Exemplar Project as well so very high profile.

What is your next work challenge?

Building on the success of recruitment in 2009/10 We started at quite a low level and we want to keep the momentum up!

Our intrepid secretary, Charlotte Sugden, has been on a mission to find out more about what makes our research teams "tick". Looking after patients often doesn't leave time to reflect upon the wider view.

"There are many opportunities to attend training events locally or around the country".

Lancashire Teaching Hospitals-housing the Cancer Centre and Radiotherapy for Lancashire and South Cumbria and Supporting both NIHR and NON-NIHR Portfolio Cancer Studies

The oncology directorate within Lancashire Teaching support oncology research by funding their own senior research nurse, Nina Vekaria. Nina works very closely with the LSCCRN manager, Rachel Bracewell to ensure that as many cancer clinical trials are available at the Trust as possible. These trials do not need to be NIHR only due to Nina's funding. The Rosemere Cancer Foundation also fund a Clinical Trial Administrator whilst they build up the commercial cancer trial side of the portfolio for the Trust.

Commercial activity at the Trust is going very well with an excellent reputation having been earned over the last twelve months.

Three band 5 staff members are due to join the team very shortly to increase support for cancer activity and will be warmly welcomed!

The current team consist of Stephanie Cornthwaite, Nita Desai, Rose Ellard, Carolyn Hatch, Claire Hennigan, Pat Knight as well as Nina.

What has been your greatest achievements in the last 12 months?

Got the first patient in the UK into some trials such as Inspire and Squire (lung commercial trials). 6th Highest recruiter to Chhip-globally!

Doubled the number of commercial trials at this site, despite some staff shortages.

Nina designed worksheets to collect specific data for certain trials and these have been

adopted to be used by the pharmaceutical companies across the country as they are so good!

How has working in research changed over the last year?

Increasing commercial trials means more intense and meticulous data collection which is accompanied by an increase in monitor visits when someone from the company comes to go through the data for 2-3 days every few weeks— need more room!

What makes a good research nurse?

Patience. Great interpersonal skills. Multi-tasking proficiency, amongst others.

What makes a good Clinical Trial Administrator?

A good pair of running shoes – chasing consultants for signatures!

What annoys you most about your job?

Identifying target lesions!



Blackpool— How’s the view from the Top of the Tower...?

Blackpool has experienced quite a few staff changes over the last twelve months and plan a few more over the next six months. The fact that Blackpool has maintained 2009/10 recruitment levels is admirable. Blackpool is the haematology tertiary centre so recruits well to complex haematology studies as well as a wide range of solid tumour groups. The current line up is Vicky Carson, Karen Gratrix (data), Joyce Jones and Leanne Smith.

What has been your greatest achievement in the last twelve months?



Joyce Greta

Implementation of a nurse-led clinic. This has allowed us to recruit more epidemiology patients which is very worthwhile as it increases our recruitment levels but more importantly it allows more patients be involved in what we do.

How has working in research changed for you over the last twelve months?

It’s got even busier, if that is possible! We all have bigger workloads as a result so it can be challenging.

What makes a good Clinical Trial Administrator?

Lots of training ha-ha You need to be proactive, competent and eager.

What is your teams biggest strength?

Camaraderie.

Name something your team has done for the first time this year?

As well as the nurse-led clinics we have

opened a lymphoma study as part of the NW Exemplar Project.

Would you recommend a job in research and why?

Yes, we need more committed, driven staff and its quite an autonomous role so you can really get your teeth stuck in to your work. Very rewarding.

What is your next work challenge?

To ensure all the upcoming trials are processed, opened and we enroll to them as smoothly as possible. This is while welcoming new staff and working jointly on haematology and oncology studies rather than one or the other.



Vicky



Karen Leanne

University Hospitals of Morecambe Bay— Team Players



Lancaster and Barrow house our team, with work also taking place in Kendal. The current team consist of Claire Bartlett, Mary Robinson (data), Samaher Swaitti & Clare Tibke. They have just been joined by Gail Wiley and Debbie Powers.

What has been your greatest achievement in the last 12 months?

Closing all the outstanding queries related to our studies...

What’s your teams’ biggest strength?

Working as a team. We all take great pride in any task we undertake, we regard ourselves as industrious and

have the ability to think analytically...We feel we are confident with a friendly, approachable manner.

What annoys you most about your job?

Waiting... to see patients in clinic...for information, reports, doctor signature etc. Some days you feel you haven’t achieved a lot, but these days are counterbalanced by the satisfaction of recruitment.

Would you recommend a job in research and why?

If you find learning about the theory of new treatments interesting and think that being part of the “machine” that provides evidence based practice is exciting...if you like working with patients with different cancers...if you like the responsibility of your own workload whilst still working

in a team...if you like the idea of no two days being the same...think about being a Research Practitioner!

What excites you most about coming to work?

As we are all enthusiastic regarding our roles in the Network, we are excited to learn new skills and take on new challenges. Recruiting the first patient to a new trial is always exciting! Overall we are always given the opportunity to fulfill our potential and the opportunity to bring our different skills, professionalism and enthusiasm to the network for the benefit of both patients and other members of staff.



“What excites you most about coming to work?”
Pay Day!
LSCCRN
Team, Anon

Answers for Name that Trial:
 (1) ICICLE, (2) ET, (3) TRAPEZE, (4) CHHIP, (5) BOSS, (6) FOXTROT, (7) SCOT or ARCTIC, (8) SOCS, (9) PG-SNPS, (10) PET-NECK, (11) COSTAR, (12) LAMB, (13) POETIC, (14) BATMAN, (15) TANGO.

Cancer Peer Review— What does this mean for the LSCCRN?

The National Cancer Peer Review (NCPR) is a National quality assurance programme for NHS cancer services. The programme involves both self-assessment by cancer service teams and external reviews of teams conducted by professional peers, against nationally agreed “quality measures”.

The Cancer Research Network is reviewed as well as the Cancer Service Network and all the Network Site Specific Groups (NSSGs) and Multi-disciplinary Teams (MDTs). The LSCCRN provide recruitment and portfolio guidance to all the NSSGs and MDTs as they must evidence their groups support of research and further development, this is within our Work Programme.

The LSCCRN were required to produce three documents that contained evidence to support our peer review. The documents include an Annual Report, a Constitution and a Work programme. This material is also available to the local health economy and the general

public. Copies are available on our CD in your SBPE packs. The documents are now combined to include evidence for cancer peer review as well as to report to the NIHR about our activities. How we spend tax payers money (our budget allocation) is reported on separately, twice a year.

Dr Hindley and Rachel Bracewell met with our NCRN and cancer service network panel in Leeds in September 2010. A patient representative was present.. This is when the contents of the documents are checked for compliance against the peer review measures and detailed discussions ensue regarding the network’s progress and future plans. It is a very useful opportunity to flag up issues nationally as well as share best practice with other cancer research networks.

The formal outcome of our peer review is not yet published but verbal reports suggest we are performing very well.

NW Exemplar Project

The North West Exemplar Programme aims to demonstrate the improved clinical trial performance that is possible when the NIHR Clinical Research Network works closely with partners in the pharmaceutical and biotechnology industries and across the NHS.

The Programme is capturing best practice on the delivery of 20 industry sponsored studies adopted by the NIHR Clinical Research Network running at research sites in the North West. Study progress through set up and delivery at these sites is being closely monitored and key performance indicators are being measured.

The first phase of the North West Exemplar Programme has focused on effective study set-up. A key indicator of success in this area is first patient enrolment. Seventeen Exemplar studies have now gained NHS Permission and seven of them have gone on to enrol the first global patient. Coupled with a median set-up time of 53 days across the Exemplar programme, this is further evidence that NHS research studies can compete with trial set-up in Europe.

How has the LSCCRN be involved?

We have three trials that we support within this Project.

NCRN069 (ORCHARRD). This is a Lymphoma trial looking at the use of Ofatumumab in previously treated Lymphoma patients. This study was the sec-

ond Exemplar study to be implemented at Blackpool Victoria Hospital and took only 36 days to open from R&D validation to NHS permission. To date the team have recruited 2 patients in to the study.

NCRN094 (PISCES). This is a randomised double-blind cross-over patient preference study of pazopanib versus sunitinib in treatment of locally advanced or metastatic renal cell carcinoma. We are proud to say Royal Preston Hospital were the first UK site to recruit a patient into the study and are also the current highest recruiters in the UK.

NCRN099-this is a phase III trial of IV vinflunine versus an alkylating agent in patients with metastatic breast cancer previously treated with or resistant to an anthracycline, a taxane, an antimetabolite and a vinca-alkaloid. Dr Martin Hogg, Clinical Oncologist became the UK’s Chief Investigator when we took the trial on. Royal Preston were the first UK site to open to recruitment and have enrolled 3 patients to date. We are proud to say East Lancashire also opened this study and were the first in the UK to recruit a patient into the study. This marks East Lancashire’s first foray into cancer NIHR commercial work.



Noteworthy Dates:

27th October– GCP Training

7th-10th November– NCRI Conference

1st December- LSCCRN Trial Practitioner Day

8th December- CRPG AGM

CRPG Poster Progress

Some time ago the CRPG created a poster to promote awareness of cancer clinical trials. Having been out in the Networks' four Trusts, we thought we should evaluate whether the poster was getting noticed. A brief 2 sided questionnaire was created, that asked for thoughts on the poster and the demographics of the patient or carer completing the form. Having gained the relevant Trust permissions the questionnaires were put into the oncology clinic waiting rooms for a 4 week period. The returned questionnaires were analysed and produced some surprising results. The response rate although disappointing, brought about some lively

discussions about 'Questionnaire Fatigue' - something that the members will be producing an article on separately. Those who had noticed the poster indicated that the poster gave them more confidence to ask about trials. However, it was noted that the poster needs to be larger in size and more prominent, soon to be addressed. On a positive note, the sentence that is now included in the initial appointment letter to say cancer clinical trials are taking place in the hospital, did increase awareness.

Well done to the group on their first project!

Julie Ditchfield, CRPG Co-Chair

Lancashire & South
Cumbria
**Cancer
Research
Partnership
Group**

A message from Judith

I would like to extend my thanks and gratitude to all those who have supported me over the last 12 months. As some of you may know I was diagnosed with stomach cancer last year. At the 2009 Annual Research Conference I attended the Upper GI workshop, where I learnt that the survival rate was 30%... This, in hindsight, was possibly not my greatest choice of workshop. Knowing this has made me appreciate life and although at times my journey has been frightening and stressful, it has also been rewarding. I have had many laughs along the way and met wonderful people, which is something not many expect. I feel it is important for people to understand that joy and humour can come out of such an experience. I also feel that being part of the CRPG put me in good stead to deal with this period in my life and would like to thank Bill for graciously stepping into my stylish shoes.

Judith Palin, CRPG Co-Chair

CRPG: 12 Month Whistle Stop Tour

October 2009 saw the Annual Research Conference (now named the Sharing Best Practice Event) take place at the Garstang. A good day was had by all. Some of the presentations were a little bit over our heads but it was brilliant to see some familiar faces I hadn't seen in a while. I was honoured to be asked to present and I talked about my personal journey as well as that of the Group. We held our Annual General Meeting in December and had a delicious Christmas meal; a very generous gesture from the Research Network and most enjoyable.

2010: a new year and new challenges. In March we had an informative Workshop to learn more about the role of a Clinical Trials Nurse which enabled the group to better understand the challenges that research entails. We had a great turnout from the Nurses and Radiographers, patients and carers and the Network staff. We relished the role-play demonstrations of different clinical scenarios where clinical staff gave good and bad ways to present a trial to the patient, which threw up some interesting comments. Unfortunately we had to say goodbye to Helen Spickett from the Network who has moved on to a new role in Blackpool's, she will be missed by all. In the last few meetings we have had guest speakers such as Karen Inns from the NCRN who spoke about patient involvement the group could be involved with, alongside other

groups, across the country. This gave the group something to consider as a future venture, in order to learn how other groups function and what they have achieved. Professor Chris Moore from NW Medical Physics based at The Christie came to talk about the development of imaging techniques and equipment in Radiotherapy. The new equipment gives a 4D image (3D image shown in real-time) which will not only improve the accuracy of treatment and scans but also reassure the patient during a treatment which is often thought of as quite stressful. The group were invited to participate in several ongoing projects for the NW Medical Physics, which was greatly appreciated and many members seemed interested. Jane Huddlestone, Research Grant Officer from the Lancashire Teaching Hospitals also spoke to the group about patient involvement in a more local research project. Jane asked for our opinions on the possible pitfalls and benefits of this study, so hopefully our views will be considered. Two of our members attended the Conference for Radiographers earlier this year in Manchester. Once again some of the presentations were hard to follow but it was great when we realised we were the only two patient representatives to be involved. We feel this was quite an achievement for our partnership group. Members have gained bursaries to attend the NCRI



Bill, Julie and Judith

National Cancer Conference in Liverpool and we are also presenting a poster at the Involve Conference in Nottingham. Considering the number of meetings our small group hold in a year, I feel that we have been involved in rather a lot.

It is great to have Judith back at the helm, after coming through surgery and treatment. She has been missed dearly by the group and we wish her well with her ongoing recovery.

As a group, I know we all enjoy our involvement with the CRPG. Everyone feels able to express their opinions and are well looked after by the Network Staff, who make us feel welcome at any time and deal with any difficulties or problems as soon as possible. I feel that the CRPG is an excellent example of true partnership in action.

The CRPG are very much looking forward to more of the same over the next 12 months.

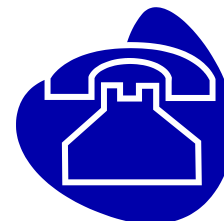
Bill Ryder, CRPG Vice Chair

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The Lancashire and South Cumbria Cancer Research Network operates as part of the NIHR National Cancer Research Network. It is part of the National Institute for Health Research and forms part of the UK Clinical Research Network. The Network support and deliver high quality clinical research studies.

