

## Research Network

# NETWORK NEWS

### Welcome to the November issue of Network News

Recruitment into randomised controlled trials has continued to increase this year and the balance across the portfolio has been maintained. The number of industry portfolio studies continues to rise with an expansion of activity into the palliative care portfolio.

Our work programme, which can be accessed on the Pan Birmingham Cancer Network website, details the importance of portfolio balance and delivery and the industry portfolio to Pan Birmingham Cancer Research Network contributing to the delivery of the NCRN 5 year strategy. Central to the delivery of our work programme was a key appointment to the core team, with the appointment of an Operations and Development Manager.

### Introducing the Operations and Development Manager - Suzanne Sumara

I am delighted to join the PBCRN team. (Some of you will remember that I was here in another life, in another role, but that is another story). You will be seeing me round and about, at NSSG meetings predominantly. One of my key areas is to support the development of the NCRN industry portfolio, I will be sending out the expression of interest forms for studies in the adoption pipeline and working with all the members of the team to ensure delivery to time and target. It will also be my responsibility to support the NSSGs and MDTs with their research measures and so I hope to be able to meet all the NSSG and MDT leads within the not too distant future.

For those of you who like a bit of background..... I have over 15

years experience of clinical research as a research nurse/research unit manager/lead nurse and trainer. I have worked with many of the major pharmaceutical companies and the trials units in the Universities of Oxford and Birmingham and Imperial College London. I have been involved in a rich mix of academic and commercial research at all stages of development from protocol design to study close out.

I have had the privilege of working nationally with the NIHR CRN CC, so I have a really good idea of the problems many of us face when recruiting to time and target. I look forward to working with you all to maintain the excellent reputation the PBCRN.

### Introducing the Network Data Manager - Richard Cawthraw

In my role as Network Data Manager it is important that I am available to assist heavy workloads, and maximise the opportunity of the sites within the network to recruit to time and target. The most common tasks include completing CRFs, responding to data queries and accessing source data for trial patients whose treatment pathway takes them across multiple hospitals. I have worked in Cancer Research for just under two years with the bulk of my experience coming from working as team administrator for the Haematology Trials Team at UCLH. I have taken an interest in research during this time and hope to continue developing on what I have learned thus far.

### Website

The Pan Birmingham Cancer Network is redeveloping its website and the Research Network pages are also being refreshed, with more information than is available currently. The new website will be launched shortly.



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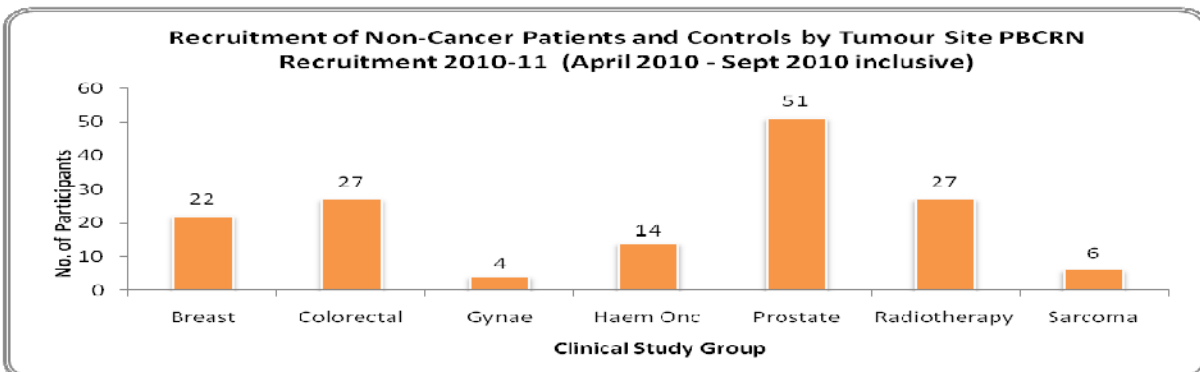
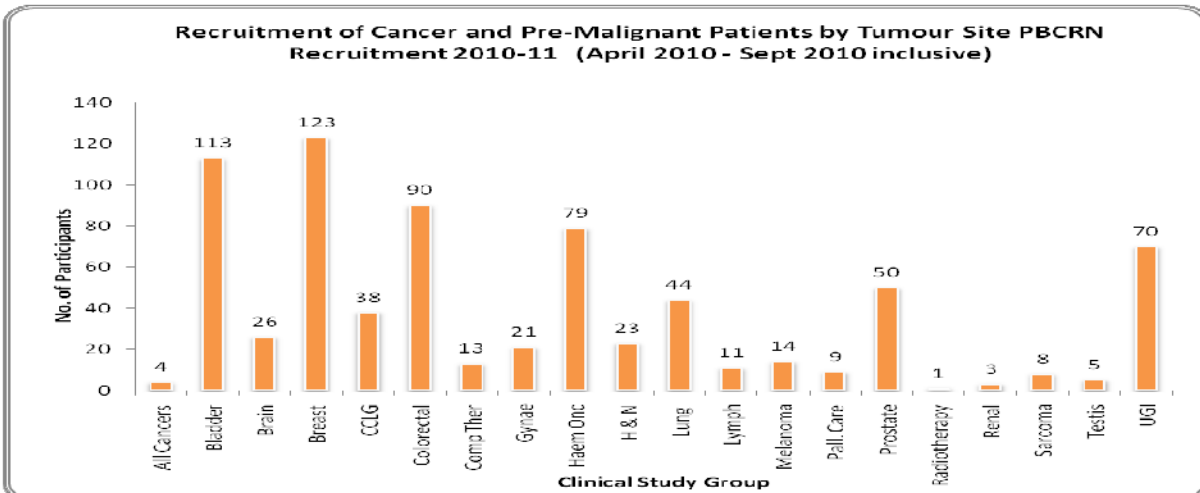
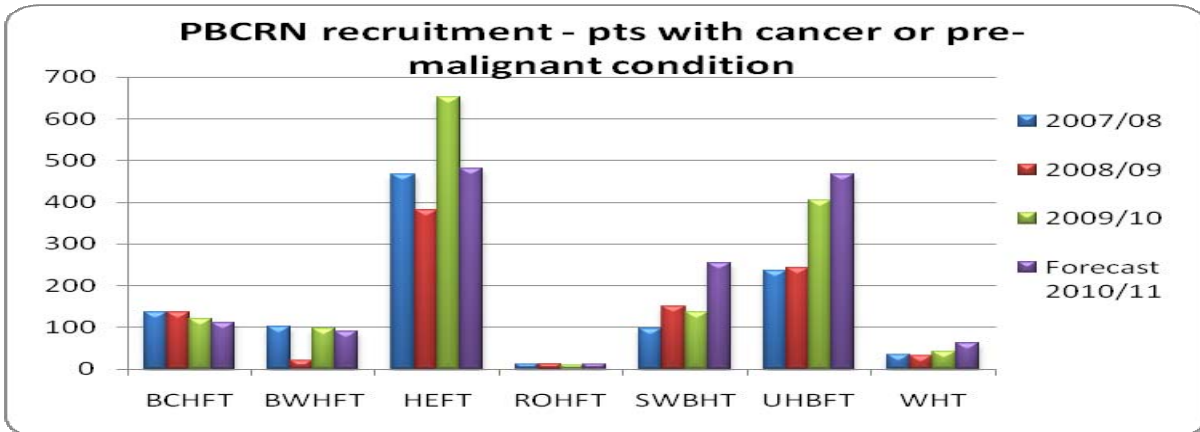
The Pan Birmingham Cancer Research Network operates as part of the NIHR National Cancer Research Network in England. It is part of the National Institute for Health Research and forms part of the UK Clinical Research Network.

The Networks support and deliver high quality clinical research studies.

# PAN BIRMINGHAM CANCER RESEARCH NETWORK RECRUITMENT PERFORMANCE

The reporting of recruitment into National Cancer Research Network (NCRN) Portfolio studies is presently quite complex. The NCRN was established as part of the cancer plan and as a result all of our primary targets are associated with recruitment of patients with a cancer diagnosis. Cancer patients recruitment now includes patients with diagnosis of a pre-malignant condition. In order not to over report participation, patients that are involved in sub-studies are recorded as 'non-cancer' along with volunteers recruited into screening, prevention and diagnostic studies and controls.

Please note: This accrual graph includes **all** data for Solihull Hospital. Not all of these patients are attributed to PBCRN as recruitment at Solihull Hospital is undertaken by a visiting Arden CRN Oncologist



PBCRN Trusts-  
 Birmingham Children's Hospital NHS Foundation Trust (BCHFT), Birmingham Women's NHS Foundation Trust (BWHFT), Heart of England\* NHS Foundation Trust (HEFT), Royal Orthopaedic Hospital NHS Foundation Trust (ROHFT), Sandwell & West Birmingham Hospitals NHS Trust (SWBHT), University Hospital Birmingham NHS Foundation Trust (UHBFT), Walsall Hospital NHS Trust (WHT)

\* (Solihull Hospital shared with Arden Network)

## **Hermits, Fiddlers, Horseshoes and Kings: cancer research and a novice nurse**

I do not really believe in astrology. Like Freud I am inclined to believe that pinning your hopes on star signs, the power of inanimate objects, or the ultimate goodness of the X-Factor are strategies by means of which reassurance may be gained in the face of a capricious and uncertain world. All faith in deities appears irrational - like whistling in the dark. A typical Aquarian then. If, however, I did believe in the power of the stars to shape human destiny, I would consider the unluckiest of the constellations to be the sign of the crab-cancer. As Sontag<sup>[1]</sup> points out, there are just too many negatives, not a nice place to be. So, three months in to an oncology secondment, what do I think? It is a fair bet that few nursing journals or textbooks have attempted to classify any nursing role development based upon crustaceans. There are, compelling reasons for using this classification in the oncology setting because of both the obvious symbolism and the fact that, like a crustacean, you are fairly low in the food chain.

***Paguroidea<sup>[2]</sup>. These crabs steal second hand shells to hide in. Will seek protection by burying itself in the sand...***

Take the first day in clinic for example, mentor by my side, all my good intentions, all the yearning to make a positive difference. Yet despite this I do not want to leave the warm sanctuary of the room I have been most kindly assigned by an HCA who has forgotten more than I have ever learned. I will just stop here after all, it is safe here, there is plenty of work to do. I have 17 protocols to read with all their inclusions and exclusions, tissue blocks, biopsies, and chemotherapy cycles. Would that be neo-adjuvant or adjuvant? What cycle number? Is that day one, day eight or day fifteen? At this point everyone will inform you that second thoughts are common. Starting to question your ability to assimilate this information and also your own abilities is also common.

***...The Hermit***

***Ocypodidae<sup>[3]</sup>, These crabs communicate via a series of ritualised waves and gestures...***

Eventually, full of trepidation, you will stand in clinic and listen to the soft hum of conversation and be confused - Names, treatments and timelines bandied about with consummate and familiar ease. You will become increasingly aware that the time frame for treatment and trial enrolment is compressed considerably. You will not know what to say to people who desperately crave information and you will be scared of making a bad situation worse through a misplaced word or deed. You must become familiar with a vast array of new drugs, drugs whose names seem like an assemblage of letters generated completely by chance. Let's face it, no one will convince me that Panitumumab, as a word, is inherently useful in any other context than its ability to generate a triple word score. It certainly does not lend itself to ease of pronunciation. You will see cases of

"hand-foot syndrome" and experience first hand "foot-mouth syndrome". You will notice too, how everything goes on smoothly around you and wonder if you have a role in all this. You stand there hoping not to be noticed, please do not ask me anything. It becomes immediately apparent that you know nothing. If you do not know anything immediately, you are absolutely no good. You know it and you know that they know it. So, I stand there, wanting to know if there is anything I can do but too afraid to ask.

***...The Fiddler.***

***Limulus polyphemus<sup>[4]</sup>. These crabs are living fossils but have a very thick shell...***

Eventually, however, things will start to come together. Little seedlings will start to form and small accretions of knowledge will form and grow. Hold on to these. Learn the "little things" like arranging a Groschung line insertion a CT scan, the "chemo talk" and the first dreaded cycle of chemotherapy. Hold on and before you know it, you will begin to master it. Always remember that there are intensely knowledgeable and experienced staff (king crabs, to continue the crustacean theme) and through their support, always freely given, their knowledge will pass to you, a kind of gilt by association. You will learn to manage the large administrative burden in which information may be required surrounding events that happened decades ago. Fewer and fewer of your data queries will find their way to New York's Times Square on New Years Eve, ending up as so much ticker-tape. You will be expected to be competent and autonomous and team members and patients will start to rely on you to get things done. Just remember "keep calm and carry on".

***...The Horseshoe crab or King crab.***

Before the advent of hospitals, monasteries enabled death and illness to be confronted through faith, that the two concepts were intimately related. Indeed, the concept of the "good death" is still enshrined in dialogues concerning cancer in particular. Although there is a huge amount of research being undertaken into the causes and treatment of cancer, in many ways we are still whistling in the dark. Whilst it may be true that many more people die "with" rather than "of" cancer, much more needs to be done. So yes, faith may assume a greater importance in relationships with cancer sufferers but it is not necessarily the more traditional religious faith. It is more the faith in the ability of humankind to overcome adversity, to assuage the ills that beset us, the ability of dedicated individuals to find practical answers. It is faith in the indomitability of the human spirit in which optimism remains despite suffering. So come and see what you are missing for, despite all these negative emotions, there are equally as many positive ones. This closer acquaintance with oncology is the most intense yet rewarding experience I could have wished for.

**Brian Gammon  
Research Nurse, SWBH**

References:

1. Sontag S. (1991) *Illness as metaphor and AIDS and its metaphors*. Penguin. London.
- 2, 3, 4 [http://en.wikipedia.org/wiki/Hermit\\_crab](http://en.wikipedia.org/wiki/Hermit_crab).

## Forthcoming Events

### BBC CLRN Industry Showcase Event

*The main aims of the day are: To facilitate networking between local clinicians /Investigators and industry; To enhance engagement in industry sponsored research; To enhance the delivery of industry sponsored research within BBC CLRN NHS Trusts; For non research-active clinicians to find out more about how they might participate in industry sponsored research. It would also be an ideal time to review the past 12 months of the new NIHR industry process: Is it working? Are there improvements in the time taken to both approve studies and recruit to targets? Are there any perceived or real blocks to participation?*

Contact [BBCCLRN@uhb.nhs.uk](mailto:BBCCLRN@uhb.nhs.uk)

15 February 2011  
Birmingham

### 8<sup>th</sup> Birmingham Symposium on Current Trends in Urological Cancer

*The programme includes: Current Trends in Testicular Cancer; Future Trends in Kidney and Prostate Therapy; Non-muscle Invasive Bladder cancer; Emerging Trends in Invasive Bladder cancer; BC2001 Update; Current and Future Trials in Urological Malignancies*

Contact: Karen James on 0121-414 3289 or [k.e.james@bham.ac.uk](mailto:k.e.james@bham.ac.uk)

16 March 2011  
Birmingham

### Rehabilitation in Cancer Care

*Key themes: An overview and rehabilitation of some of the most common cancers; Management of anxiety and fatigue; Management of lymphoedema; Cancer related pain; Metastatic spinal cord compression; Communication skills and breaking bad news.*

Contact: 0161-446 3403 or [education.events@christie.nhs.uk](mailto:education.events@christie.nhs.uk)

22 & 23 Mar 2011  
Manchester

### Research Ethics Approval in the NHS

Cambridge  
Chelmsford

23 March 2011  
24 March 2011

*This workshop will provide: A general overview of research ethics in the NHS; An overview of the process for seeking an ethical opinion using IRAS; A practical guide to using IRAS; · A practical guide to preparing an IRAS application and supporting documents; · A practical guide to responding to the RECs post-review comments*

Contact: Dr Leslie Gelling 0845 196 2529 or [leslie.gelling@anglia.ac.uk](mailto:leslie.gelling@anglia.ac.uk)

### Living with Cancer: symptom management from treatment to survivorship

*The aim of this conference is to promote research which is relevant to the practice of nurses and allied health professionals working in cancer care.*

*Speakers will be sharing information about cutting edge research. Theses will include: Symptoms and symptom management during cancer treatment; Late and long-term effects; Survivorship*

Contact: [education.events@christie.nhs.uk](mailto:education.events@christie.nhs.uk)

7 April 2011  
Manchester

### NCRI Survivorship After Cancer and End of Life Care Research

The NCRI Survivorship After Cancer and End of Life Care Research Grantsmanship Gateway, has been launched to direct early career researchers to sources of expert advice on writing successful funding applications. The microsite can be found at [www.ncri.org.uk/grantsmanship](http://www.ncri.org.uk/grantsmanship) covers a variety of topics including: How to find out about upcoming grants; What information to include in a grant application; Where to get advice on study design; How to involve consumers in the development of a study idea; What to consider when setting up a research study; Where to find guidance on costings; What resources you can use to expand your research ideas or highlight the potential impact of your research

NIHR Training is available to all staff working on NIHR Portfolio Studies including Medical Staff. Details of training available can be found on the NIHR CRC CC Website <http://www.crnc.nihr.ac.uk/training> . Contact Maggie should you have a specific training need.

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