Newsletter No. 6. June 2013



Welcome to all the new sites that have come on board in 2013!





I'll eat my hat.....

At one of the first Head and Neck workshops we were pleased to be able to invite Sonia Duffy to come and speak. During discussions about the planned size and potential of the Head and Neck 5000 cohort, Sonia was heard to say that "she would eat her hat" if the cohort reached 5000 as planned!

Given that we have now reached over 2000 we are investigating sources of edible hats so that Sonia can fulfil her promise! Watch this space!



Meet the team

Katrina Hurley: Head & Neck 5000 Senior Research Nurse

I've been involved with Head & Neck 5000 from the beginning but have now taken on a full time role managing the study. I have worked as a research nurse since 2002; before moving into research I was the ward manager for a Maxillofacial and Urology ward at the Bristol Royal Infirmary. I enjoy yoga, Pilates and rock climbing and am looking forward to climbing outside again now that the weather is warmer.

Occasionally members of our team move on to pastures new.....

Bina Nausheen, previously Project Manager for H&N 5000, moved to a new post in January 2013.

Beki Garvey, previously Data Co-ordinator for Head & Neck 5000 has also moved to a new post in March 2013.

We would like to wish them both good luck in their new roles!

And a new member joins our team... Welcome Chris Lippiatt as our new Data Co-ordinator!!

H&N5000 website: www.headandneck5000.org.uk

What's new?

- We're pleased to announce that the no-cost extension to the study has been awarded by NIHR! This means that we can continue to recruit until the end of December 2014 so increasing our chances of reaching the magic 5000!
- Currently 61 sites are open and just over 2000 patients have been recruited. 8 sites are currently in set up and 11 further sites have expressed interest! Keep up the good work and help Sonia eat her hat!!
- We will continue to send feedback reports about recruitment: from June 2013 these will be sent out on a quarterly basis. If you have any queries concerning the reports please contact Christine Wood on 0117 34222519 or by email on christine.wood@uhbristol.nhs.uk and we'll do our best to help you!
- We are working on an ethics amendment for the study. This will be submitted in June 2013 and we hope to have approval by July 2013.



Data Collection

- As you all know, this study has the potential to be a unique resource and one of the most comprehensive studies of head and neck cancer in the world!
- However, if we are to succeed then it is important that we are vigilant in collecting as much data as possible and that you are vigilant in sending us all of the data that you generate.
- To that end, we ask that you return all data as soon as possible.
- In order for us to keep on top of data entry and data queries please can data capture forms be sent to Bristol no later than 4 weeks after the patients baseline / 4 month / 12 month time point.
- Please do not leave any boxes blank on the data capture forms.
- Please ensure that ICD codes and TNM staging are recorded for all patients

We would like to remind all sites of the process for returning forms, samples and reports to us

At the beginning of every month we have to report our recruitment numbers to the UKCRN. The Head & Neck 5000 planning group also meets mid month to discuss the current progress of the study. It is therefore very important to have data that are as up-to-date as possible.

To help us achieve this, please ensure that your monthly recruitment figures and the 'eligible but not consented log' are returned to us by the 8th of every month.

If they are not returned by this date then expect us to be chasing you very shortly afterwards!

Please send us only the current months recruitment log. Please scan and e-mail the recruitment log if possible, if you are unable to scan please send it by fax.

Please post us a copy of the patients consent form within one week of consenting the patient

Please send us the electronic 'eligible but not consented log' by e-mail. If you do not have a copy of the spreadsheet please let us know.

Tissue samples

Please ensure that histology proformas, tissue blocks and pathology reports contain the Head & Neck 5000 study ID and the patient's initials but no other patient identifiers. We have been receiving some blocks and forms that have not had the patients name and hospital number removed.

Please note that tissue blocks will not be returned to sites so can only be sent to us if they are surplus to clinical requirements.

Blood and Saliva samples

These no longer need to be refrigerated if taken on a Friday. They can now be posted straight away to reach the lab on the Monday or Tuesday. We will keep you informed of any changes in arrangements that need to be made at Bank Holidays.

