headandneck 5000

Scientific Newsletter
Issue 1 - November 2016

Introduction

Welcome to our first scientific newsletter.

Over nine years ago I started work on our programme grant application. When the programme started on the 1st January 2009 we were confident that we could recruit 5000 people with head and neck cancer into a clinical cohort. And we thought we could do this with over two years with ten centres!

It in fact took us nearly four years and 76 centres to recruit 5000 people with head and neck cancer. We also didn't anticipate the amount of data checking and recoding that would be required before the data would be ready for use. So though it is a (little?) later than planned I am proud that we have achieved our goal.

As this newsletter and our website show we now have a DNA backed longitudinal resource for the study of head and neck cancer that we are now starting to interrogate. Furthermore, we are committed to run this as a resource for scientists and we welcome collaboration. The more our study is used to answer important scientific questions the happier I will be.

Thank you again for your patience and support. I look forward to working with you over the next few years.

Head and Neck 5000 - methods and recruitment

We completed recruitment at the end of December 2014 and the one year follow up at the end of 2015. Our final total of people recruited was 5,511 from 76 sites across the UK. This is a remarkable achievement made possible by the hard work of the study team, research staff in local centres and to the willingness of so many people to take part in this study – thank you all! We have described our methods and recruitment in two papers listed below - both are open access. We provide further information on our study website along with study materials (www.headandneck5000.org.uk). We are still checking these original data so these figures may change (slightly) with each data release.

Ness AR et al. Establishing a large prospective clinical cohort in people with head and neck cancer as a biomedical resource: head and neck 5000. *Bio Medical Central Cancer* 2014; **14**: 973.

Ness AR et al. Recruitment response rates and characteristics of 5511 enrolled in a perspective clinical cohort study head & neck 5000. *Clinical Otolaryngology* 2015 [Epub ahead of print]

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

DNA extraction, genotyping and genetic analysis

We have extracted DNA from all blood samples. We hope to be able to extract DNA from saliva samples and tumour samples but we will require further funding to do this.

We are part of an international genetic consortium led by Paul Brennan at the International Agency for Research on Cancer. We contributed 1,034 cases to the 6,034 cases and 6,585 controls from Europe, North America and South America included in this genome wide association study. The results have just been published in Nature Genetics and we will feature these exciting findings in a future newsletter. We are in the process of importing these genetic data so they sit alongside our other stored data.

We hope to do carry out further genetic studies on both the blood and tissue samples but we will require further funding to do this. We also plan to carry out preliminary epigenetic and metabolomics studies – we will include more on this in future newsletters.

Head and Neck 5000 Follow up Study

The Follow-up Study is nearly ready to start. We have REC and HRA approval and portfolio adoption has been confirmed. We are currently in the process of getting the local R&D approvals and are hoping that our first centre will open before the end of the month. The study involves a further questionnaire to be sent out to participants and a further data capture form to be completed by site staff. We would like all of the sites that took part in H&N5000 to take part in the Follow-up Study; for those that have not yet expressed an interest it's not too late for you to take part. Contact us on 0117 3429536 or e-mail headandneck5000@uhbristol.nhs.uk to let us know that you are keen to be part of the largest head and neck cancer study in the UK.

Human papilloma virus status in Head and Neck 5000

Human papillomavirus (HPV) is an important cause of oropharyngeal cancer and associated with better outcomes. The role of HPV in the aetiology and prognosis of head neck cancer at other sites is less clear and an issue we hope to be able to address in Head and Neck 5000. We are working with Tim Waterboer and Michael Pawlita at the German Cancer Center (DKFZ) in Heidelberg and they have already measured HPV serology in 4,530 blood samples. We are currently checking these data and carrying out preliminary analyses. We will describe our findings in future studies. We are still collecting and cataloguing formalin fixed tissue samples. We anticipate that we will have tissue on over half those recruited. We plan to assess HPV status in these samples so that we will have these measures alongside our blood serology and reported clinical HPV assessments.

Head and Neck 5000 Access Policy and Data Release

The Head and Neck 5000 study is now ready to accept project proposals to use collected data and bio-samples. Alongside the projects we have been doing within the Head and Neck 5000 research group we have already received a number of project proposals from collaborators, which are listed on our website. Our website also includes a range of resources to help you to prepare project proposals, including

Information on using the resource

http://www.headandneck5000.org.uk/information-for-researchers/usingtheresource/

Access Policy

This includes a detailed overview of the study and the resources available to collaborators, and policies relating to the use of the resource.

The Research Proposal Form

This is the application form that you need to complete in order to apply to use the resource.

An up-to-date description of the resource

http://www.headandneck5000.org.uk/information-for-researchers/resourcedescription/

Bio-samples

We collected saliva, blood and tissue samples from participants. In this document you can find details of how many samples were collected, the transportation, processing and storage and any assays completed to date.
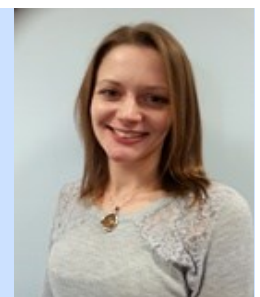
Data Manual

This includes a list of all variables in the main Head and Neck 5000 dataset with accompanying descriptive statistics. This should be used in the planning of your project proposal and to identify specific variables to request when your project has been approved.

Rhona Beynon's work on Head & Neck 5000 data

My PhD is being funded by the Wellcome Trust. The main focus of my research will look at markers of prognosis in head and neck cancer, using data collected from H&N5000. I will look to see whether biological, clinical and lifestyle factors measured at baseline predict outcomes one year and three years post-diagnosis.

I am particularly interested to see how modifiable health behaviours, primarily smoking tobacco and drinking alcohol, influence cancer progression and outcomes, and whether this varies by tumour site and HPV status. I am hoping to analyse DNA methylation profiles and metabolite profiles of blood collected at baseline to see whether there are differences in people who have a history of heavy tobacco and alcohol consumption compared to those that do not.

The eventual goal of my PhD is to develop a prognostic model that incorporates clinical, biological and lifestyle risk factors. The model could be used in clinical decision making and individuals may then make an informed choice about what health advice, if at all, they choose to follow.

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

Scientific Team

The scientific team is a collaboration of experienced clinicians and academics at the School of Oral and Dental Sciences, University of Bristol.

- Professor Andy Ness: Professor of Epidemiology
- Dr Miranda Pring: Consultant Senior Lecturer in Oral Maxillofacial Pathology
- Professor Steven Thomas: Professor in Oral and Maxillofacial Surgery
- Dr Andrea Waylen: Senior Lecturer in Social Sciences

From left to right :
Miranda Pring, Andy Ness, Steven Thomas and Andrea Waylen

Co-ordination Team

The co-ordination team, led by senior research nurse Katrina Hurley, run the field-work component of the study and co-ordinate its day-to-day management:

- Ms Katrina Hurley: Programme Manager
- Mrs Shirley Jenkins: Management Assistant
- Mrs Chris Lippiatt: Data Co-ordinator
- Dr Vanessa Marshall: Management & Administration
- Dr Christopher Penfold: Research Associate in Statistics
- Ms Inga Rowley: Data Co-ordinator
- Ms Samantha Thompson: Histopathology Research Assistant
- Mr Stu Toms: Database Manager
- Mrs Christine Wood: Study Research Co-ordinator

From left to right :
Christine Wood, Chris Lippiatt, Inga Rowley, Stu Toms, Chris Penfold, Miranda Pring and Katrina Hurley