

## Aintree HaNC Patient Research Forum minutes 2/10/15

1. In attendance: John Richardson, Brenda Roberts, Linda Kearns, Dominic Macareavy, Mike McGovern, Austin Kirwan, Carmel McLoughlin, Anne Richardson, Simon Rogers, Ida Ryland, Ana Laycock, Paul Banks, Rob Warburton, Gill Amos, Sarah Allen

2. Apologies: Jackie & Malcolm Gregson, Shirley Pringle, Peter Moore, Adrian Midgley, Vince Killen, Sally Lane.

### 3. Clinical Trials Update

HOPON – investigating the effectiveness of HBOxygen as a preventative measure for patients who undergo surgical procedures following RT. Trial ongoing in several centres and 66 patients recruited. There is a TSC meeting in November – DM and JR to attend.

DAHACA – investigating the effectiveness of HBOxygen as a healing aid in patients with ORN

SEND – Early oral cancers with no nodal involvement investigating whether any benefit from undergoing neck dissection. Study closed

TRISMUS – comparison of Therabite device vs wooden spatulas as aid to promote mouth opening following RT. Study closed, Conclusions awaited

MULTIKINE – Drug trial involving injections over a 4 week period prior to surgery. Potential delay in commencement of surgery may be a bar to recruitment. Also problems identifying patients who fit criteria for recruitment. However, observed effects of the drug have shown significant reduction in size of tumour.

PATHOS – investigating reduced treatment in HPV-positive Oropharyngeal patients to reduce side effects whilst maintaining survival rates. Forum discussed the dilemma faced by patients whose primary aim is likely to be cure rather than focussing on side effects. However later in the journey the side effects of radical treatment may become more of an issue – especially younger patients who may have to manage side effects over a long period and with increased chance of deteriorating side effects. First patient has now been recruited and careful explanation to potential recruits will be essential.

AWARE- study funded by Research Forum investigating reasons for delayed presentation. Study is progressing well and Juliet Bell is due to commence the second phase - interviewing the matched cancer free subjects. The AWARE team will be reporting to the Forum in February 2016.

The Forum discussed the wider issue of awareness; posters in surgeries; warnings on packaging of over the counter products. One of the aims of the AWARE study is ultimately to develop a public health campaign.

The Forum discussed potential awareness initiatives eg poster campaigns, football clubs, field hospital.

Interaction Analysis in HNC - joint study between AUH and St Andrews University analysing PCI and management of patient concerns.

Forum discussed issue of lack of consultant time to deal with individual concerns and possibility of relieving time pressure by delegating to other clinicians eg Nurse-led clinics.

4. PhD study/social inequalities – investigating whether the PCI might improve outcomes for patients from socially deprived background. Sarah Allen will commence PhD study shortly and has agreed to present the study protocol to the Forum. The Forum will consider any study materials/questionnaires as required.

#### 5. Exercise study

A feasibility study to assess whether an exercise test might be used in a larger study. To evaluate whether HNC patients would engage in an exercise programme to aid recovery.

The Forum expressed support for an exercise programme.

Forum to provide feedback on content of questionnaire

#### 6. Video/blogs

CM, AK and MM have carried out some sterling work producing vlogs. It is proposed to recruit patients in clinic over a 4 week period with a view to developing a comprehensive bank of vlogs – organised by cancer type, stage etc. The resource would be password protected.

The work by CM and AK has established that the method is technically possible. The next step is to assess in clinic whether patients will be willing to engage in the project.

The Forum expressed enthusiasm for the project and felt that such a resource would provide reassurance for patients uncertain about outcomes.

It was agreed that funding is available to cover initial expenses in connection with the 4 week pilot – although it is not anticipated that there will be any significant initial expenses.

The mechanics of administering the project in clinic needs to be decided/approved and personnel allocated. Ethical approval required.

The Forum discussed funding options possibly involving a PhD/Masters.

#### 7. Tracheostomy study

SNR reported that the questionnaire phase was complete and data analysis would start very shortly. There would be a report for the next meeting

#### 8. Advanced Cancer Study

IR agreed to provide an update and abridged version for Forum to consider

#### 9. AOB

Trust governors have expressed an interest in visiting patient groups - DM to invite them to attend a Forum meeting

Accounts – balance of £65.9K as at end of August 2015 (cf £57.5 at end August 2014)

Mr Biswass has invited attendance at the inaugural meeting of a patient group he is setting up in Portsmouth. MM is planning to attend (DM can possibly attend if need be)

10. Next meeting – 5/2/16 Main focus will be the AWARE update DM to invite Steve Brown and Juliet Bell.

PB to book room

