

**Meeting of the Head and Neck Cancer Clinical Advisory Group (CAG)  
Tuesday 17<sup>th</sup> January 2023, 13:00-17:00  
Chapter House Lecture Theatre, Bristol Dental Hospital and MS Teams**

Chair: Mr Ceri Hughes (CH)

**REPORT**

**ACTIONS**

**1. Introductions and review of last meeting's notes and actions**

The list of attendees and apologies are available on the SWAG website [here](#).

As there were no amendments requested to the previous report from Tuesday 17<sup>th</sup> May 2022, the report was accepted as finalised.

Highlights from the Work Programme:

**Action: Setting up a sentinel lymph node biopsy service in UHBW:**

The team has secured funding and purchased a gamma probe. A project group met on a number of occasions to arrange the practicalities and it is hoped that the service will commence in the near future after a training session has taken place.

**Action: To highlight guidelines on the management of PET positive thyroids to all relevant MDTs:**

**To be allocated**

Guidance will be drafted to clarify that PET positive thyroid nodules should be booked to have a fast track ultrasound in the neck lump clinic and alert the Head and Neck MDT Coordinator.

The guidelines will be circulated to the MDT Leads across the region and uploaded on to the SWAG Website.

**Action: To explore options for electronic forms for MDT referrals that are available to access online:**

The online referral system *Refer a Patient* has been explored but may not be the ideal option. The referral proforma had been updated and this is currently emailed by I Galdies to referrers as there are ongoing problems with adding patients to the intranet workspace. It may be necessary for IT to close the workspace if the issues cannot be resolved. Set up of a Head and Neck nhs.net joint email is under discussion, which could be viewed by multiple members of the team when the MDT Coordinator is on leave.

Improvements will be made to the record keeping of Staging data and eligibility for clinical trials by using the prompts that are already available in the MDTM discussions.

**Action: To project the MDT outcome on the screen or in the MS Teams chat to be ratified in real time by someone other than the Chair of the meeting:**

This process is now in place. Three Consultants share outcome ratification; however, one will go on maternity leave in Spring 2023 and cover needs to be arranged.

**Action: Thyroid team to arrange triage of low-risk thyroid cases working group / look at existing protocols from the Oxford team:**

**G Porter / M Beasley**

There are some cases that fit certain criteria which could be triaged straight to protocolised care but kept on the MDT list as a safety net. This will be considered further outside the meeting.

**Action: The Clinical Research Network are looking at ways to improve access of information to the trials open across the region:**

This action remains ongoing.

All other open actions are on the agenda today.

## **2. Clinical opinion on network issues**

### **2.1 Peninsula Head and Neck Cancer Clinical Advisory Group**

**Please see the presentation uploaded on to the SWAG website**

**Presented by H Dunderdale**

In June 2022, Peninsula H&N CAG held their first meeting since the beginning of the pandemic. H Dunderdale attended to facilitate the hybrid meeting and to share the presentations from the meeting with the SWAG team, should these be of interest:

- MDT service updates/ regional top tips for optimising the pathway. Service improvements including appointment of a designated Band 5 nurse to triage referrals using the HaNC-RC v.2 (2019) Symptom Based Risk Calculator for Head And Neck Cancer Referrals
- Advances in palliative management – PDL1 inhibitors
- Audit to evaluate patient satisfaction with face to face versus telephone conversation - it was agreed to continue to offer both
- Trans-oral robotic surgery
- BTA U grading versus ACR TI-RADS Service Evaluation which agreed to continue with the BTA U grading
- Difficult case studies
- Research Trials, including a commercial Phase II trial open to regional referrals until 2023 - Lenvatinib in Combination With Pembrolizumab vs. Standard Chemotherapy and Lenvatinib Monotherapy in Participants With Recurrent/Metastatic Head and Neck Squamous Cell Carcinoma That Progressed After Platinum Therapy and Immunotherapy
- Paediatric Thyroid Cancer Referrals (no presentation available)
- Recurrent Laryngeal Nerve re-innervation in Thyroid Surgery (no presentation available).

**Action: CAG Members can contact H Dunderdale for the full presentations**

**CAG Members**

**Action: H Dunderdale will send the information shared on paediatric thyroid cancers to**

**G Porter**

**H Dunderdale**

## **Discussion**

The Getting It Right First Time (GIRFT) team are starting to focus on Head and Neck services. Consultant Maxillo-Facial Surgeon J Graystone from John Radcliffe, Oxford, is leading on the project which is anticipated will lead to a cross-table meeting with all specialties / Allied Health Professionals.

## 2.2 Advances in Immunotherapy

Many of the Cancer Clinical Advisory Groups have discussed the rapid rate of new NICE Technical Appraisals (Tas) that have been approved for use with no additional resources allocated for the treatments to be delivered. This was discussed most recently at the South West Immunotherapy Group (SWIG) where it was recommended that no individual hospital should be put into the position of having to decide which new drugs they can or cannot offer, and asked for a National response.

SWIG also recommended that NICE calculate the projected patient numbers, additional appropriate levels of clinical and pharmaceutical staff, day beds, toxicity and follow up clinics to safely support those patients, as part of the TA approval process.

This message was escalated to the National Cancer Board and assigned to National Clinical Director for Cancer P Johnson. The following response was received:

*It is a legal requirement for the Trust to provide these treatments, however, if you find yourself in a position where it is not possible to offer a treatment, this should be added to the Corporate Risk Register as High Risk.*

P Johnson is now putting together a Working Group to look at SACT pressures across the tumour sites.

### Discussion:

At present, Head and Neck oncology does not have as many new treatments as some of the other tumour sites and haven't had to limit treatment options, but the knock-on effect on chemotherapy slots has meant that patients are waiting much longer (approximately 5-7 weeks) to commence treatments.

Capacity was noted to be better when chemotherapy day beds were moved to the Dental Hospital during the pandemic.

It takes a considerable amount of time to train staff and find extra physical space to accommodate treatments for new indications, and problems with capacity in BHOC has already been on the Risk Register for some time.

**Action: To check the risk rating of BHOC capacity on DATIX** To be allocated

Patients are categorised to ensure that those receiving curative treatment are prioritised.

It may be possible to utilise Weston more effectively, but there is a problem with accessing the different chemotherapy prescribing system.

**Action: H&N CAG will escalate the need to review provision of SACT services to the Chief Executive Officer of UHBW** H Dunderdale

### 3. Research

#### 3.1 Head and Neck 5000: Identifying factors affecting survival and secondary physical effects of treatment at 10 years

Please see the presentation uploaded on to the SWAG website

Presented by S Thomas

The spread of applicants from this Bristol based study, funded by Cancer Research UK, will cover patients with late effects from surgery, oncology, pathology, dental, and hopefully more so involving ENT.

Aims:

- To describe, at 10-year follow-up, the late effects - including the frequency and severity of secondary physical morbidities - of treatment for head and neck cancer
- Identification of factors at baseline, 12 months, and 3 years that may determine survival and/or further cancer presentation in human papillomavirus-positive and negative cases at 10-years.

Objective 1:

Using a questionnaire, we will follow up participants in the NIHR Head and Neck 5000 study at 10 years. We will assess the frequency and severity of secondary physical effects of cancer treatment 10 years after diagnosis.

Hypotheses

Hypothesis 1a: The prevalence of secondary physical effects of cancer treatment are high and persist to 10 years.

Hypothesis 1b: Secondary physical effects of cancer treatment at 10 years are affected by genetics, treatment modality, lifestyle factors and comorbidity at the time of diagnosis.

Objective 2:

We will follow-up the whole Head and Neck 5000 cohort, linking to available routinely collected data through NHS Digital, to identify further cancer diagnoses, date and cause of death and further health problems.

Hypotheses

Hypothesis 2a: In patients considered cancer free at completion of treatment, genetic- and bio-markers, comorbidity and continued risk factor exposures are important determinants of survival and further cancers.

Hypothesis 2b: The patterns of distant metastasis in human papilloma virus (HPV) positive oropharyngeal cancer differ from those of non-HPV HNCs, occur later and at different anatomical sites.

Grant start date: 1<sup>st</sup> April 2023, running for three years

The dataset is the most extensive world-wide in terms of the cohort of patients and level of detailed information that has been collected.

### 3.2 PETNECK2

PETNECK2, which is in set up at UHBW, is a randomised controlled trial looking at standardised follow up versus patient initiated follow up (PIFU) in patients with head and neck cancer 12 months after treatment.

The PIFU arm will involve a PET-CT scan and, if no disease recurrence is detected, an educational session with the CNS and use of an application to facilitate self-monitoring for alert signs with advice to contact the team with any symptoms of concern, which would result in an appointment within 2 weeks. Although this will involve more appointments at the beginning of the pathway, there will be significantly less in the long run.

The study needs to recruit 1-2 patients per month until Aug 2025.

Recruitment should be able to commence next month when the final agreements for provision of PET-CT have been signed off.

Regular 1-2 PETNECK2 clinic slots will be organised on a Friday morning.

Initial conversations about the study will happen at the first normal follow up appointment, after which (the following week) the patient will be invited to a Consent/Randomisation double appointment.

It was recognised that the CNS team already offer PIFU alongside the standardised follow up.

A more detailed presentation and discussion will be provided to ENT colleagues to see if any ENT patients may be appropriate to approach about the study. Any interested patients could be referred to the PETNECK2 clinics.

#### **Discussion:**

It should be possible to include the ENT Consultants on the delegation log so that they can also recruit to the trial.

The cost benefit, in terms of the number of appointments saved or not, will be calculated.

Socio-economic data and the use of the educational tools will also be assessed.

It may help manage patient anxiety as the current three month follow up schedule is felt to be stressful, although it is recognised that the regular follow up is wanted by some patients.

Although PIFU may not be appropriate for some patients, there is an existing body of evidence that the majority of recurrences are identified by the patient rather than at regularly scheduled follow up appointments.

Ideally, there should be representatives from all members of the multi-disciplinary team taking part in research, for example, it would be helpful to have involvement from radiology to facilitate trial set up.

### **3.3 West of England Clinical Research Network Update**

**Please see the presentation uploaded on to the SWAG website.**

#### **Presented by C Matthews**

Research Delivery Manager C Matthews manages the cancer portfolio for West of England CRN.

National clinical trial recruitment from April 2022- January 2023 shows that 2,897 patients have been recruited; this may exceed the previous year's target.

A comparison between national and regional recruitment levels from pre-Covid to present day shows a very similar pattern of recovery.

Data is missing on RUH Bath from the list of Trusts participating in trials.

There are 12 open head and neck cancer trials across the SWAG region and, although quite a few are highlighted as not recruiting to time and target at present, there has still been significant recruitment activity.

The HoT trial was noted to have particular barriers to recruitment in terms of patient choice and seeing patients within an appropriate time frame. Information on recruitment barriers will be fed back to the national groups that monitor the research targets.

SAVER is just about to open in UHBW.

Two trials are in set-up in the region: XRAY VISION in SFT, and NANORAY-312 in UHBW and Cheltenham.

Another two trials that are in set-up nationally which are open to new sites are RAPTOR and salivary proteomic biomarkers for head & neck cancer: a case-control study. UHBW have had initial discussions with the RAPTOR trial team.

An NIHR 6-month Associate Principal Investigator (PI) role is open to any interested clinician who doesn't have research in their current role. It allows associates to work alongside current PIs on studies (as documented in the presentation) signed up to the scheme; there is currently one person recruited.

Any PI interested in getting help from an associate while helping their personal development is to get in touch.

NIHR website links and team contact details are available within the presentation.

A trainee from ENT will be sought to join the API scheme.

Consultant Maxillofacial Surgeon S Thomas was the Research Sub-Specialty lead for H&N and now hands the role over to Consultant Oncologist S Hargreaves.

## 4. Quality Indicators, Audits and Data Collection

### 4.1 National Plan for Audit

The original Head and Neck Audit, DAHNO was replaced with HANA, which was unfortunately unsuccessful and provided no outputs. Now BAHNO are exploring different options for generating a national audit dataset, one of which may be to forge links with the London School of Tropical Medicine who already provide audit support for Breast, Prostate and Upper GI. BANHO have a meeting to discuss this further on 31<sup>st</sup> January 2023. Support from the Government is currently not available, but BAHNO will keep trying to find solutions. In the interim, teams are to continue to collect as much data as possible on local hospital information systems.

There are many data fields in the Somerset Cancer Registry that are not used and, if they were, useful data could be pulled out.

Funding to support improving data collection could possibly be sought from Macmillan.

A few data fields could be identified that may help to inform if any practice needs to be changed.

**Action: To arrange a demonstration of SCR data fields.**

**H Dunderdale**

It is important that the data collected and submitted to national audits is then made open for interrogation, as was the arrangement with DAHNO.

The H&N Research Council set up last year will make a decision about whether to engage with the London School of Tropical Medicine in the near future.

One of the subjects for BAHNO next year is likely to be focused on data collection.

## 5. Patient Experience

### 5.1 National Cancer Patient Experience Survey Results (2021)

**Please see the presentation uploaded to the SWAG website**

**Presented by R Hendy**

The annual survey, which is commissioned and managed by NHS England, has been redesigned, so it is not possible to directly compare results from surveys discussed in previous meetings.

It is undertaken to monitor progress in cancer care and drive local quality improvements.

The SWAG region had 3,319 responses, 121 of which were for Head and Neck cancers. Only 1.5% of responders recorded their ethnicity as other than white.

The SWAG overall rating of care was 9.0, compared to the national average of 8.9, and the majority of scores either matched with or were above the expected range in comparison with the national average.

There are a number of questions that in general score lower and, as there is variation between tumour sites, the Cancer Alliance asks CAGs to assess their data and make recommendations for improving these areas.

Unfortunately, it was not possible to filter this iteration of survey for tumour specific patient comments which, historically, had been found to be the most useful data. Following feedback, this will be made available in the next set of results.

The survey is sent to patients diagnosed with cancer who have an inpatient or day case stay between April-June. Work is underway to try and capture those patients who are treated as outpatients.

The highest scores ( $\geq 90\%$ ), of which there were 12, compare very favourably in comparison with other cancer sites and the national average, despite being provided at a challenging time during the COVID-19 pandemic.

The lowest scores ( $\leq 60\%$ ) mainly relate to out of hospital care and correlate with the national average lowest scores. An online focus group, along with GP G Beard, has been held with patients to discuss these issues, many of which are caused by communication gaps between Primary and Secondary care.

It was recommended that the question 'were you expecting to get support from your GP' should be added to further understand the problems.

The Lead Cancer Nurses are meeting tomorrow to discuss how to address the priorities and have asked local teams to form action plans.

The Clinical Research Network has also been contacted about the low score that relates to availability of research trials.

H&N MDT discuss if trials are available for all patients, but generally wouldn't tell a patient that this process had been undertaken.

**Action: To communicate to patients' research trial eligibility discussions.**

CAG members

The low score on being able to bring someone with you when you are told your diagnosis is probably caused by the need for clinic letters to be changed back to pre-COVID wording.

**Action: Clinic letters need to be updated**

To be allocated

Feedback from patients on the wording 'enough' in the question 'patient was given enough information about the possibility and signs of cancer coming back or spreading' was to deliver the information that you have said will be provided at the time it is expected, for example, when a follow up scan report can be expected in a realistic timeframe.

Priorities identified from the survey for each Trust are documented in the presentation.

It is clear from the survey that provision of Personalised Care and Support (PCS) activity has had a positive effect on the patient experience.

The patient cohort who are sent the survey is felt to be skewed, as none of the patient's receiving radiotherapy as their main treatment will be captured.

It would be more helpful to have survival outcomes / details on the patients' quality of life after treatment.

**Action: Support will be sourced to enable distribution of the survey to all patients and data collection of responses, which may be tweaked to answer additional questions**

R Hendy/H&N  
MDT



Personalised Care and Support (PCS) used to be called Living With and Beyond Cancer (LWBC), and prior to that was referred to as Survivorship, and it includes the following interventions as mandated in the NHS England long term plan:

- Holistic Needs Assessments at diagnosis and at relevant points in the patient pathway
- Attendance at 'Living Well Events'
- End of Treatment Summaries
- GP Cancer Care Reviews.

Delivery of this activity is measured via data entry into the SCR which is then exported as part of the COSD dataset, and it would be interesting to look at data accuracy to see if this reflects what is being delivered.

## 5.2 CNS Update

CNS J Bostock has joined the team to bridge the gap of support required for those patients that sit between the complex Skin Cancer / Plastics / ENT and Head and Neck services. He will concentrate on mapping the pathway, aiming to integrate the support system into the wider CNS service provision.

Frequently, there are delays at various stages in the Skin Cancer pathway.

**Action: Examples will be sought to find ways to optimise processes.**

**J Bostock**

Another CNS will be recruited in the near future to cover maternity leave.

It was raised that the numerous positive results from NCPES were due to the high-quality service provided by the CNS team.

## 6. Coordination of Patient Care Pathways

### 6.1 Two-Week Wait Referrals: Neck Lump Service

#### Presented by M Williams

Post centralisation of Head and Neck services, some of the neck lump ultrasound services stayed at NBT. This has resulted in a 9 month waiting time for routine scans due to the lack of resources in the department.

NBT accepted approximately 1000 referrals last year, 20 of which were upgraded to urgent and sent to the UHBW clinic. Although the majority of cases are likely to be benign, there may be additional cases relevant to upgrade, hidden within the backlog.

To safely manage this, it is proposed that the patients should be discharged back to their GP with advice to re-refer to the UHBW Head and Neck Team if there is still cause for concern following an up to date clinical examination. The same process has been undertaken for the low-risk paediatric population following consultation with the CCG.

A letter has been drafted to send to the GP and patient which reflects the most up to date NICE guidelines, which may result in increased referrals to the Head and Neck clinic. All neck lumps should be sent via this route and not to the lymphoma service, unless there is wide spread lymphadenopathy.

Hyper or hypothyroidism or goitres shouldn't be routinely scanned.

It is important for all thyroid nodular disease to be sent via the Head and Neck two week wait service. If there is global enlargement of the gland, these can still be referred to NBT.



A separate pathway could be organised for thyroid so that relevant patients can be sent straight to test, discharged at that point if benign, or then seen in clinic with their results. This process is organised by the fast-track team for some of the cancer sites.

Taking on the NBT referrals will involve arranging an extra list per week.

The guidance for GPs on the clinical features that merit an ultrasound will be adopted across the board.

**Action: M Williams will amend the letter and circulate for ratification**

**M Williams**

## **6.2 Primary Care Service Update**

**Please see the presentation uploaded to the SWAG website.**

**Presented by G Beard**

Primary Care are contracted to provide Essential Services between 08:00-06:30, Out-of-hours services, Additional services, for example, minor surgery, and Enhanced services, such as vaccination programmes. Primary Care networks (PCNs) have been established via an enhanced service agreement.

Practices can also opt into other locally commissioned services which may be commissioned by non-NHS organisations such as local authority public health departments.

The service needs to be delivered within a cash equivalent of £93.46 per patient a year, with the left over practice income shared between the practice partners.

For cancer, Primary Care are responsible for maintaining a register of patients with cancer, undertaking cancer care review within 12 months of diagnosis, and offering support within 3 months of diagnosis as per the Quality Outcomes Framework.

The PCN Directly Enhanced service (2022/23) also requires Primary Care to review referral practice, improve uptake of Bowel and Cervical Cancer Screening Programmes, teledermatology, Prostate Cancer Case Finding and Non Site Specific Symptom Service.

The Investment and Impact Fund (IIF) is an incentive scheme that rewards Primary Care Networks for delivering objectives set out in the NHS Long Term Plan and GP contract agreement, which includes increasing the number of lower gastrointestinal two week wait (fast track) cancer referrals accompanied by a faecal immunochemical test result.

There is also the aspirational target to diagnose 75% of cancers early (Stage 1) by 2028.

At present, it is a very challenging time for Primary Care to deliver all these and multiple other targets. There are 1,500 fewer Whole Time Equivalent GPs in post in comparison to 5 years ago. Demographic demand is rapidly increasing as patients are living longer with complex care needs, and there has been a spike in the number of GPs under 30 leaving the NHS. It is for these reasons that patients are finding it difficult to get GP appointments.

Despite this, GP activity has increased and face to face appointments have risen back up to 70%.

To manage the workforce shortage, receptionists have been trained into care navigators so that they can direct the patient to the most appropriate person, and numerous other healthcare roles are being developed. This may lead to variation in the quality of referrals received in Secondary Care; numerous educational resources are being made available to try and address this.

**H&N CAG can raise any recurring problems arising from Head and Neck referrals**

**H&N CAG**



*Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services*

#### **8. Any Other Business**

BAHNO full membership is £80.00 a year and is open to all Allied Health Professionals. Educational resources are available as are research grants. All members of H&N CAG are encouraged to join. The next conference is on Friday 12<sup>th</sup> May 2023 in London.

**Date of next meeting: To be confirmed, Autumn 2023**

**-END-**