Meeting of the Head and Neck Cancer Clinical Advisory Group (CAG) Tuesday 23rd November 2021, 13:00-17:00 Chapter House Lecture Theatre, Bristol Dental Hospital and MS Teams

Chair: Mr Ceri Hughes (CH)

REPORT

ACTIONS

1. Review of last meeting's notes and actions

As there were no amendments or comments following distribution of the notes from the meeting on Tuesday 15th September 2020, the notes were accepted.

Consultant Oral and Maxillofacial Surgeon Simon Whitley has joined the team in UHBW.

Headlines from the Work Programme actions

006/16: Progress with setting up a sentinel lymph node service in UHBW:

All the necessary staff are in place. However, due to the COVID-19 pandemic, the team has been unable to visit another unit to complete training on the technique.

A capital bid for a CT scanner has also recently been approved. It is therefore hoped that all elements to provide the service will be addressed in the next few months.

004/17: Implementation of MDT reforms:

COVID-19 has completely altered the way that the MDT meeting has been organised and is now felt to be better.

H Dunderdale conducted an impartial assessment of the MDTM prior to COVID using the MDT-Mode Assessment tool and has now reassessed the meeting in its new format; results will be presented at the next meeting. Initial findings show that the quality of conversations has improved in terms of the length of time given for discussion of each case. It was noticed that the CNS team may have less say now the meeting is held virtually.

010/19: MDT Chair rotation:

On occasion, the role of Chair is being rotated. A member of the RUH Team is also welcome to Chair.

001/20: Cancer Associated Thrombosis (CAT) Service at UHBW:

RUH has a service in place. A similar service is not available in UHBW at present.

Action: Provision of CAT Service in UHBW to be investigated.

016/20: Clinical Guidelines: Radiology colleagues are asked to standardise reporting of Ultrasound according to the Excellent, Indeterminate and Incomplete response definitions:

It is confirmed that this is now being completed for thyroid cases.

2. Coordination of patient care pathways

2.1 Rapid Diagnostic Ultrasound List

Presented by M Williams

A review of the Friday morning clinic was undertaken after set up of a new rapid way of working prior to the pandemic, where the pathologist is present.

The clinic routinely receives between 30 to 40 referrals per week from ENT and maxillofacial services for neck lumps requiring ultrasound. Neck lumps are also managed by other teams such as haematology and dermatology.

Previously, there were two clinics; one on a Friday morning with Max-Fax and pathology, and one at St. Michaels where pathology wasn't available. Often GPs would refer patients that didn't have a neck lump, and many other cancers would be identified at different times of the week when pathology was not available; there was concern about non-diagnostic biopsies and report turn-around time.

As an alternative, it was decided to prioritise the patients that had already been assessed as appropriate for neck ultrasound in a Secondary Care clinic. The second clinic has been stopped and now there are two Consultant Radiologists available at the Friday morning clinic, which has booked patients and approximately four slots for ad hoc referrals on the day. A second ultrasound machine has been purchased with funding provided by the Cancer Alliance, as has 0.2 funding for a biomedical scientist.

The clinic commenced in October 2019 and runs 9-11 with 8 hours of radiology and 4 hours of pathology cover.

Three months of data has been collected before and after making the change to assess its efficiency.

Results show a significant increase in the number of patients seen, from a wider variety of specialities, resulting in a 53% increase in biopsies which indicates that the referrals are being triaged more efficiently.

Waiting times for ultrasound have also reduced, and the clinic slots have been fully utilised throughout the pandemic.

The percentage of inadequate biopsies remains around the same as there will always be some more complex lesions, such as fibrous masses or sclerosing Hodgkin's that are difficult to diagnose without removing the node.

The Biomedical Scientists enjoy the work, hand staining the slides with good quality results, making it easier for the pathologist to diagnose, and the whole process safer and more efficient.



Discussion:

All requests are vetted each day and selected for the Friday list.

It was recommended that the data could be published.

Action: To alter the patient information sheet that states that ultrasound and biopsy will be performed on the same day as the Max-Fax Friday morning clinic,

as this is not always the case.

Max-Fax Team

2.2 Lymph Nodes for Tuberculosis (TB) Culture

Please see the presentation uploaded on to the SWAG website

Presented by A Thompson

A Thompson is an Infectious Diseases and Microbiology Registrar who works across the Bristol sites. The work being presented was completed last year for the purpose of analysing the diagnostic pathway for patients with lymph node TB.

In the TB service, many patients are seen who have undergone multiple neck node aspirations and biopsies, resulting in delays in diagnosis and treatments. It was therefore necessary to quantify the problem and identify ways to reduce this happening.

There is a database of TB diagnoses available in the BRI, and this enabled a search for numbers of Lymph node TB who had undergone an aspiration or biopsy between 2016 and 2020.

Results on the 49 patients identified, the majority of which were referred via ENT, respiratory and oral surgery, showed that most referrals from ENT and oral surgery needed to go on for a repeat procedure as the first sample had not been sent for a TB culture. Respiratory routinely do this.

Case studies were presented that highlighted delays caused by the need for repeat procedures, risk factors and symptoms that should trigger suspicion of a TB diagnosis. These are detailed within the presentation.

The South West are currently one of the worst performing regions for the time taken from identifying symptoms to being started on treatment.

Action: If TB is clinically suspected, the team are to contact the TB service at the earliest opportunity: <u>TBTeam@uhbw.nhs.uk</u> 01179543066

There is no need to wait until a positive culture has been returned, as sometimes treatment commences before the result comes through, as it can take some time to report.

The process could perhaps be improved by modifying the Integrated Care Environment (ICE) hospital information system to flag up high risk patients and alert the need to send a sample on to the micro-pathology lab in addition to pathology.



Discussion:

If a flow sample is sent for lymphoma but also labelled as query TB, there is a problem with processing this.

The Interferon test has not been found to be useful as it does not distinguish between active and latent TB.

The way that granulomatous inflammation is reported may need to be clarified to result in an action to be flagged to the TB team.

Although cases of TB are rare, there is a resurgence at present, with more cases being identified in the last few months than in the last 2 years.

The TB service is appreciated, and the team are invited to the neck lump clinic to see how samples are processed.

2.3 Rapid Diagnostic Service (RDS) Project

Please see the presentation uploaded on to the SWAG website

Presented by B Hill

SWAG Cancer Alliance Project Manager B Hill has been tasked with helping to implement the rapid diagnostic principles which are about to be introduced for Head and Neck Cancer. A draft copy of a national 28 day Faster Diagnosis Standard (FDS) for Head and Neck cancer was circulated for comments prior to the meeting.

RDS services started off as a way to improve the pathway for patients with vague symptoms that do not fit a specific cancer pathway and is now being rolled out to all cancer pathways.

The seven RDS principles, which are part of the NHS E Long term plan to implement in all cancer pathways by 23/24, are intended to facilitate meeting the 28 day Faster Diagnosis Cancer Waiting Time Target (patient informed of diagnosis).

The principles include:

- Early identification
- Timely referral
- Broad assessment of symptoms
- Coordinated testing
- Timely diagnosis
- Appropriate onward referral
- Excellent patient coordination and support.

Support is offered by the Cancer Alliance to help implement upgrades to the service; CAG members are invited to contact B Hill about how the service could be improved so that the Cancer Alliance can work with providers to get agreement for relevant changes to be adopted.

When the finalised FDS document is circulated, this will also include some baseline audit tools that can help identify areas for improvements.

Discussion:

The site specific RDS can be best described as a way to access national funding to upgrade existing two week wait pathways.

Problems in the pathway have yet to be identified and there is currently no data available on scan waiting times or other waiting times in the pathway to be able to analyse if and where any bottle necks exist.

It could be possible to identify issues by analysing the Patient Tracking List.

Head and Neck patients generally follow a very standardised pathway.

One of the most common problems is inappropriate GP referrals which overload the two week wait system. Provision of education to Primary Care would be of benefit, as it is not possible for the Secondary Care team to triage and downgrade these referrals.

In RUH, the team have started to downgrade some referrals by directly contacting the GP and providing advice and guidance.

Cancer Manager H Marder confirmed that it is not possible to reject or downgrade two week wait referrals without getting the GP to retract the referral. This can often be time consuming and it can end up being quicker to review the patient in clinic.

The FDS applies to all patients that go through the pathway, including those with benign conditions.

Action: Cancer Alliance to look into providing GP education on two week wait referrals. Increased caution is needed as many recent patients have not been physically examined by their GP prior to referral. It is not clear if it would be possible to make this mandatory.	Cancer Alliance RDS Team
Action: To undertake an assessment of the number of patients who have seen their GP prior to referral.	To be allocated

Action: B Hill is to email the group to request ideas. B Hill



3. Research

3.1 West of England Clinical Research Network (CRN) Update

Please see the presentation uploaded on to the SWAG website

Presented by C Matthews

C Matthews has replaced D Rea as the West of England Clinical Research Network Research Delivery Manager for Cancer, and works closely with H Winter, Clinical Specialty Lead for Cancer and Sub-Specialty Lead Professor S Thomas for Head and Neck cancer.

Despite all the difficulties caused by the pandemic, when looking at the national overview of recruitment to trials, over 2000 patients had still been recruited to head and neck trials. Thanks were given for continued efforts to conduct research in these pressured times.

There are now 60 studies open to recruitment and 288 on the portfolio, mainly non-commercial and observational, and recruitment has gradually started to recover.

The list of studies open within the SWAG region is detailed in the presentation. If there are any missing, or recruitment numbers look incorrect, CAG members are to contact C Matthews.

PETNECK 2, HoT - Hemithyroidectomy or Total-Thyroidectomy in 'low-risk' thyroid cancers and PD-1/TIM-3 & PD-1/LAG-3 vs. Nivolumab In Patients With Advanced and/or Metastatic Oesophageal Cancer are in set-up.

National studies that are open to new sites are also listed, should anyone want to express an interest in opening these locally.

As usual, the Clinical Research Network (CRN) remains accountable to the Department of Health and Social Care for delivering the High-Level Objectives detailed in the presentation, in order to secure continued funding. Recruitment to Time and Target is less of a focus, and now there are three 'Efficient Study Delivery' metrics, as detailed in the presentation.

A process called Managed Recovery was implemented over the summer to ensure that the UK continues to be an appealing place to undertake cancer trials. Funders were asked to nominate the priority studies to complete within the appropriate timeline. There are approximately 200 studies on the list, three of which are related to Head and Neck. TORPEdO is open in the South West.

Another measure is to collect data on patient participation by distributing the Participant Research Experience Survey (PRES). The target this year is 1155, which is high as based on recruitment in the previous year; 928 surveys have been returned to date.

Action: CAG members handing out the survey need to document the study name on the PRES for it to be included in the metric, and can contact C Matthews or R&D Departments for copies of PRES.

CAG Members

Links for additional information and contact details are within the presentation.

It is felt that non-commercial Head and Neck radiotherapy studies are not prioritised and take months to set up due to insufficient resources. West of England CRN has limited ability to influence but can flag concerns about this to the Clinical Trials Unit.

There have been funds diverted to Trusts to support research; the Radiotherapy Operational Delivery Network should be able to help as they have to demonstrate increased recruitment to research.

3.2 PETNECK II Trial

Please see the presentation uploaded on to the SWAG website

Presented by B Main and S Thomas

Recently appointed Consultant B Main is funded by NIHR for dedicated time to undertake H&N research.

PETNECK II is a study that was conceived by the Birmingham team. This has been built on the success of the PETNECK I trial, which explored if PET could be used for active surveillance to avoid neck dissection. It will now be established if low risk Head and Neck cancers can be discharged to patient initiated follow up (PIFU) following a PET-CT one year after finishing treatment, with easy access back into the service should red flag alert symptoms present. Patients would receive education on self-examination at the point of discharge. Current follow up practices are intensive, require a significant amount of resources, and may be possible to be safely reduced.

The study will be opening in UHBW in the near future. It is a huge study, funded by the NIHR Programme Grant for approximately 2.6 million over 6 years. Co-Chief Investigators are P Nankivell and H Mehanna; B Main and S Thomas are co-applicants and B Main is the local Principal Investigator. It is not in set-up in RUH at present, but it is hoped that this will be discussed at a later date.

A lot of work has already been undertaken to develop the educational intervention:

- Development of an app
- Qualitative work to identify barriers
- Focus groups with surgeons, nurses and oncologists.

Patients with Head and Neck squamous cell, oral cavity, oropharynx, hypopharyngeal and laryngeal carcinomas who get to one year recurrence free will be randomised either to routine surveillance versus PET-CT and PIFU plus education, delivered by whichever health care professional is deemed most suitable at each site, for example, by a Speech and Language Therapist or H&N CNS.



The primary outcome is overall survival and there are several secondary outcomes including time to recurrence etc.

In the immediate future is the feasibility study, which will open in UHBW to assess how easy it is to recruit patients. Previous patient involvement work has indicated that there would be enthusiasm for patients to participate. The study will recruit 30 patients across 7 sites, so that would only require 5-6 to be recruited here. A site engagement visit will take place with the Birmingham team. The PET-CT team in NBT have been informed.

It could be that the trial provides evidence of the need for further investment in the CNS team.

Discussion:

There is some concern from ENT surgeons about including early stage larynx which is hard to detect without clinical examination, and that the patient cohort who agree to participate may be skewed towards a certain demographic. The trial will aim to resolve these issues, with a parallel study being undertaken to ensure recruitment is correctly undertaken.

Patient Representative opinion is that the regular follow up does serve as a comfort blanket which, in personal experience, had recently been disrupted due to COVID, with the three month follow up occurring at 7 months. It has now been decided to move to 6 monthly follow up. If symptoms had been detected during this period, contact with the team would have been made, and the service had been accessed with a symptom of concern, resulting in a quick scan and follow up last year.

There was some concern that a recent recurrence had not been symptomatic and picked up following a scan. According to published evidence, this is uncommon, and the majority of recurrences are detected by patients.

Other cancer sites (gynae for example) have found that patients prefer PIFU as it is swifter to access the clinic if worried about symptoms.

Patients already frequently access the H&N service directly by calling the CNS team. However, there are patients that do not attend follow up, who are tracked and contacted by the CNS team, but who are likely not to present back if control is entirely left to them.

It is thought that PIFU will pay off in terms of freeing up routine follow up to prioritise symptomatic patients.

The trial criteria may be adapted to look at a specific group of patients; concerns about including T1 larynx will be taken into consideration.



4. Clinical Guidelines

4.1 Spinal Cord Compression Protocol

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

Presented by S Hargreaves

Newly Appointed Consultant Clinical Oncologist S Hargreaves provides CAG with an update on management of cord compression on behalf of M Beasley, in response to a recent clinical event.

Important take home message:

If there is any suspicion of malignant spinal cord compression, either radiological or clinically, immediately bleep the on-call oncology registrar (2490 for UHBW).

It is the on-call registrar's role to act as the spinal cord coordinator and will organise everything required.

Current Trust guidelines are written with oncology teams in mind, and it would be beneficial for these to be updated to include 'radiological suspicion'.

Commencement of high dose dexamethasone (16 mg PO/IV STAT) will be recommended.

Approximately 4,000 patients or 5% of cancer patients per year get spinal cord compression in the UK. It is generally metastatic patients, and it is frequently vague in the way symptoms present.

About 30% of patients will live another year; Quality of Life is an important consideration.

Tumour type often determines the time to progression, as does the angulation and response to initial treatment.

Signs and symptoms:

- Backpain
- Weakness
- Upper motor neurone signs
- Autonomic disturbance (loss of sphincter function is a really late sign)
- Sensory disturbance.

Neurological symptoms are often difficult for patients to verbalise.

Once suspicion has been confirmed, a whole-body MRI will be arranged to elucidate any areas that might be treatable.

Every patient will be discussed with neurosurgery as there are certain patients with fragments that are easy to remove, good performance status and stable disease that will do well with surgery followed by radiotherapy.

Some patients will respond better to chemotherapy such as haematological or germ cell patients.



It is challenging to coordinate a randomised controlled Phase III trial for evidence in this patient group. The SCORAD trial looked at 8Gy/1F versus 20Gy/5F as 8Gy is often used in the palliative setting. Nearly 700 patients were recruited. Results showed that 20Gy/5F was still the best regimen for fitter patients, with 8Gy/1F considered for patients who are more frail.

Patients tend to do better if identified when still ambulatory.

Radiotherapy outcomes, detailed in a retrospective study of 1852 patients, showed that 39% of patients had improved neurology and 47% no progression.

Side effects are dependent on where the cord compression occurs.

Discussion:

It would be ideal if radiology could flag unexpected concerning scans directly to the Acute Oncology Team. This process does already occur for some patients.

If a radiology request doesn't contain 'query cord compression' the radiologist may not look for it.

The particular incident in mind was documented in a report, although it would have been preferable if it had stated 'spinal cord compression' to trigger action.

Reporting of complex metastatic patients has increased, as more patients are living with extensive disease.

Action: Head and Neck radiologists to pass on information to other radiologists about stating 'spinal cord compression' in reports, and this automatically generating an alert to refer to Acute Oncology.

H&N Radiologists

5. Quality Indicators, Audits and Data Collection Issues

5.1 Audit of Head and Neck Cancer Outcomes

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

Presented by E Botha

A retrospective audit of free flap type and survival over the last 10 years was undertaken.

Data, sourced from ITU admissions, identified 237 patients.

Demographics:

- Females 80
- Males 159
- Average age 62 years old. Range 26-87
- Average female weight 64kg. Range 39-120
- Average male weight 81kg. Range 49-157
- Average number of days on ITU 3 days. Range 1 13.



The majority of flaps were Radial (193) and the remaining cases were fibula and ALT.

Three flaps did not survive and had to be removed (nearly a 99% success rate) 2 of which were radial and 1 fibula.

Reasons for flap failures included comorbidities, rapid recurrence of disease, and venous obstruction.

There is confidence that all flap failures had been identified.

It would be helpful to develop a UK Head and Neck flap registry for national comparison.

It is difficult to generalise why flaps fail based on small patient numbers, but it appears that comorbidities may have had an effect, although this should not inhibit patient selection as the numbers are so low.

5.2 Audit of Dental Extraction Healing Time Prior to Radiotherapy

Please see the presentation uploaded on to the SWAG website.

Presented by A Gormley

The reason for assessing healing time prior to radiotherapy is to prevent osteoradionecrosis (ORN), which is a common complication for head and neck cancers.

A service evaluation of UHBW patients from 2015-19 identified 332 patients, 6.6% of which developed ORN. This is comparable to similar figures reported by RUH (6.9%), Guys and St Thomas's (5.5%) and an international meta-analysis (7%).

To reduce the risk, every head and neck cancer patient who is due to be treated with radiotherapy should have a dental screen to identify teeth of poor prognosis (decay, severe gum disease, root infections and partially erupted teeth) in the radiotherapy field and extract these prior to radiotherapy.

Guidelines are from Royal College of Surgeons (2018).

There is some observational evidence to suggest that those who have a shorter time period for healing time may be at higher risk of ORN and that ideally, there should be three weeks healing time before the patient is treated with radiotherapy, although the downside is delaying treatment. Other authors have suggested waiting around 2 weeks, but the current gold standard is a minimum of 10 days.

Data was analysed that identified 50 patients treated with dental extractions, the date the tooth was extracted / any mucosal checks / date commencing radiotherapy.

Results are documented in the presentation.

Actions points for the restorative dentistry clinic after screening and identifying the need for extractions include emailing the management team to identify the earliest slot available for oral surgery, at this point a mucosal check up is booked for 14 days later to check there has been healing of the site.

The service evaluation has now been repeated and 100% have had greater than 10 days between extraction to radiotherapy and increased numbers of mucosal cases reviewed.



A number of patients have cancelled the mucosal review, with reasons commonly being that they are about to commence radiotherapy and want to wait until afterwards.

Action: Communication of the reasons why the mucosal checks are being undertaken prior to radiotherapy needs improvement.

Compliance with Royal College of Surgeon Guidelines has improved.

There are time and economic consequences to implementing the mucosal checks.

Three patients that came for mucosal checks were re-reviewed at a second appointment before it could be confirmed that healing had been achieved prior to commencing radiotherapy.

A service evaluation is also underway with Max-Fax looking at the number of follow up appointments required for those patients with ORN.

It is planned to complete the second cycle of the evaluation, identify further actions, and then repeat again.

Discussion:

Patients are being told why the mucosal check is important, but it is most likely difficult for them to recall at a time when people have to process so much information about their diagnosis.

When patients call to cancel the appointment, they may have spoken with someone from the appointments department who needs to be made aware of the importance of the mucosal check.

Action: Audit results to be shared with RUH who may want to undertake a comparable audit

H Dunderdale

The mucosal check hasn't been found to delay the patient pathway to radiotherapy.

5. Patient Experience

5.1 Recent Thinking on Early Physiotherapy and Rehabilitation

Please see the presentation uploaded on to the SWAG website.

Presented by K Cave

Newly appointed Senior Physiotherapist for the Head and Neck Service, K Cave has undertaken a 1 year scoping project to identify the unmet needs of patients with H&N cancer.

Part of the role involved holding a clinical case load. The role is funding for Band 6 time for 2.5 days per week, which is available until April 2022; after which the post will be advertised.

Prehabilitation is delivered by physiotherapy colleagues in the surgical division of UHBW. Patients are contacted a number of weeks prior to surgery, aiming to optimise their health and improve recovery.

Work has been undertaken with the team at RUH to ensure that the pathway is streamlined and there is no duplication.

Restorative Dentist Team



It has been decided as part of the scoping project that prehab will be offered to all RUH patients by the UHBW team.

Further work could be done; currently generic information is provided on strength and conditioning, and it could be appropriate to provide more targeted information on neck and shoulder exercises.

Historically, there has been inconsistent provision of post-operative physio. Now, all H&N patients will be referred and reviewed in an out-patient clinic post major surgery, with patients being seen sooner, thus reducing complications, improving outcomes, and reducing demand on MSK services. Positive feedback has been received, with patients who have been treated with recurrence stating that they wish the service had been made available previously.

As resources are limited, it is only possible to offer a set number of interventions, with a maximum of 4 appointments before referring on to follow up services. At present, the majority of appointments are phone based, with issues around clinic space.

For the post chemotherapy/radiotherapy patient population, previously there was no routine Physiotherapy input for H&N patients post chemo-radiotherapy or radiotherapy. Now this is routinely provided via the Multidisciplinary Allied Health Professional and H&N Clinical Nurse Specialist Macmillan Support Clinic Follow Up clinic.

After speaking with MSK physio department, onward referrals will be categorised as an urgent new patient appointment as long as it is received within 6 weeks of completion of treatment for all cancer types.

The scoping project and clinical case load will continue until April 2022. Now that sustainable funding has been secured, a permanent B60.5 WTE can be appointed.

Many unmet needs have been identified and there is a need to protect what the service can currently offer and not overstretch it while resources are limited, whilst also aspiring to do more in the future.

Discussion:

The CNS team refer patients to prehabilitation, who then refer the patients on to K Cave. In the event that this doesn't happen, then the inpatient Physiotherapist or Occupational Therapist can refer on Medway via the Macmillan Therapy Team. Non-surgical patients will be seen in the Macmillan clinic.

Any member of the team can refer a patient via Medway.

Thanks were given as the service has already made a huge difference to H&N patients.



5.2 Quality of Life National Survey

Please see the presentation uploaded on to the SWAG website.

Presented by J Chambers

As well as the regional SWAG Cancer Alliance Patient Representative, J Chambers is also a Patient Representative within the National Cancer Programme that has developed a National Quality of Life (QoL) survey and attends today to explain why this has been developed, who will be surveyed when, how it works and how the evidence gathered can be used to inform service improvements.

One of the ambitions from the NHS Long Term Plan is to give every patient diagnosed with cancer the opportunity to complete a survey to identify long term QoL issues.

Although long term effects of cancer treatments are well recognised, it is hoped that the survey will provide an individualised record that will help facilitate conversations between patients and clinicians on management of long-term symptoms and inform improvements in Living With and Beyond Cancer Work Programmes.

From relaying personal experience of her own and that of a prostate cancer patient, the importance of understanding the benefits of treatment versus the wide range of physical and psychological effects post treatment from an individual perspective of their lifestyle priorities was demonstrated. For example, infertility, peripheral neuropathy, chemo brain, fatigue post chemotherapy versus a percentage improvement in survival outcome. The difficulty at the end of treatment when everyone celebrates this success while patients are still undergoing the consequences was also emphasised.

The survey will be sent to patients 18 months post-diagnosis to ensure that the majority of patients, including those with metastatic disease, are included.

A pilot of the survey was completed in 2019 when it was sent to 10% of patients diagnosed with breast, prostate and colorectal cancer, identified via the national cancer register. It was rolled out to 100% of patients with these disease sites in September 2020 and rolled out to 10% of all patients diagnosed with cancer last summer, and then 100% of patients in October 2021.

People will be sent an invite to complete the survey online, although this includes a paper copy for those patients who would rather not complete the digital version. It has been translated into many different languages and a support line is available to get as wide and diverse a response as possible. Initial results have shown a lower response rate from London which is being investigated to see how this can be improved. The response rate in SWAG and the Peninsula has been the highest in the country to date.

Examples of questions are within the presentation; these have been sourced from EQ-5D and EORTC questionnaires. It takes approximately 10 minutes to complete. Results can be used to share best practice and also provide the patient with a patient summary.



The survey does not have an end date so data will continually be updated and data analysis developed. Head and Neck patient responses will be included in reporting from 2022.

The SWAG Cancer Alliance point of contact for the project is Personalised Care and Support Lead H Shallcross.

It is thought that the results will mirror the issues identified in completion of Holistic Needs Assessments and start to address the disparity in all things concentrated at the front end of the pathway, whereas long term effects have not had that input in adult services.

Action: C Hughes will contact J Chambers to see if it would be possible for an abstract on the subject to be submitted to BAHNO.

C Hughes

Data can be analysed by provider Trust, cancer site, cancer grade and age group. There are some complications that need to be addressed due to the way some cases are coded.

6. Coordination of Patient Care Pathways

6.1 Thames Valley 'Closer to Home' Evaluation

Presented by D Graham

At the SWAG Cancer Alliance's Clinical Leads meeting on Friday 19th November 2021, Catherine Neck, NHS South Central & West Commissioning Unit Clinical Services Programme Lead, presented an evaluation of patients receiving treatment closer to home in Thames Valley.

CAG members are recommended to read the presentation which has been circulated.

The team set up tertiary multi-disciplinary clinics to negate the need for patients to travel. This was undertaken in the South West a long time ago, and is definitely something to consider.

Patients evaluated it highly and it has reduced DNAs.

It may be possible to consider providing a CNS service to patients in Weston.

Action: To assess the distribution of patients numbers across the patch. H Dunderdale

Date of next meeting: Tuesday 17th May 2022, Chapter House Lecture Theatre

-END-