Meeting of the South West Academic Gynae-Oncology Group for Education and Research (SWAGGER)

Friday 8th October 2021, 11:00-13:30, MS Teams

Chair: Claire Newton (CN)

NOTES **ACTIONS**

(To be agreed at the next SWAGGER meeting)

1. Introductions, Attendees Enter Roles into MS Teams Chat

Details of all those in attendance were collected at the start of the meeting.

2. Setting Up South West Lynch Syndrome (LS) Team in Endometrial Cancer

Please see the presentation uploaded on to the SWAG website

Presented by Neil Ryan, South West Clinical Lead for LS

LS is the most common inherited cause of cancer, occurring in approximately 1 in 278 of cases. Up to 95% of people are unaware that they are carriers of LS gene alterations. Increasing awareness can lead to introduction of risk reducing strategies, such as use of aspirin, surveillance, prophylactic surgery and personalised care at cancer diagnosis.

The Manchester International Consensus Group have created clinical guidelines for the management of LS that are now due to be rolled out across the UK, plus there are also European guidelines that echo the same message; best practice is to test all patients with endometrial cancer for the syndrome.

A Next Generation Sequencing (NGS) gene panel for gynaecological cancer is currently being validated to improve the screening process.

A handbook to support local systems with implementing testing and surveillance pathways is available and has been circulated.

Germline testing is in the National Test Directory and therefore funded by NHSE Specialist Commissioning, with the test processed by the regional Genomic Laboratory Hubs. CCGs are responsible for funding surveillance.

The Genomic Medicine Service Authority (GMSA) works with the GLH to coordinate all genetic related clinical care to ensure equity of access for all patients.

A regional expert MDT panel, comprising a broad range of specialists, will be set up during autumn/winter 2021/22 and will meet every one to two months. All local centres now have a named LS representative with the exception of Gloucestershire Hospitals.

Patients identified and verified as 'at risk' can receive colonoscopy surveillance and a gynaecological review.

The South West, including Severn Laboratories, were doing well with identifying a proportion of cases although, when compared with the number of

endometrial cancers referred, it is likely that some diagnoses are being missed.

A UK-wide survey was undertaken to see if there are any common barriers that affected access to the test. Further regional specific information is required to understand local barriers, including local software systems, as there is concern about a mismatch of IT systems and accessing records of tests.

Action: H Dunderdale will send N Ryan details of MDT software and the main hospital software used in each local centre **H Dunderdale**

Local IT solutions may be needed until a national product can be developed. PH England plan to develop a way to collect the data in the future.

A regional LS MDT Coordinator will be recruited to capture data from local centres and maintain a central registry to track surveillance and interventions.

There are also plans to develop an application to remind patients of their surveillance schedule and appointments; it may be possible to add an annual patient questionnaire.

Dr T Miles has undertaken the role of Director of Nursing and Midwifery for the SW Genomic Medicine Centre and will liaise with clinical genetics and a team of Clinical Nurse Specialists who will be appointed across the region to ensure that the right test is done at the right time. The aim is to appoint four BRCA CNSs and four LS CNSs.

Genomics testing is constantly evolving, and whole genome sequencing may be possible from November 2021. Mainstreaming BRCA testing is ongoing. All clinical teams need access to genomics education and guidance. Currently there is a lack of LS educational partnerships across the South West. From 29th October 2021, T Miles will begin to liaise with local LS Leads to identify Clinical Nurse Specialist knowledge gaps.

3. South West Genomics Laboratory Hub Update

Please see the presentation uploaded on to the SWAG website

Presented by Laura Yarram-Smith

The National Genomic Test Directory is updated on an annual basis, and can be found here. Please see the list of tests currently available within the presentation.

For gynaecological cases, the main focus has been on testing for BRCA1, BRCA2 and LS gene alterations, however, it is now understood that testing for Homologous Recombination Deficiency (HRD) is of particular importance to offer, as over half of all high grade serous ovarian cancers have HRD involvement, and these patients have a significantly improved progression free survival if able to access a PARP inhibitor.

For HRD analysis, tissue slides need to be sent to Myriad Genetics, USA (currently very expensive and funded by AstraZeneca), including a marked hematoxylin and eosin (H&E) slide. Tumour testing can identify both somatic and germline mutations, but cannot distinguish between them.

Germline mutations, which occur in around 15% of women with endometrial cancer, can be identified from blood samples and, in future, it may be possible to identify variants from circulating tumour cells in plasma.

A request form is available on the GLH website. The pathway needs to optimised to ensure samples are packed and couriers arranged in a timely manner. In August, a new assay was introduced that has greatly reduced sample failure rate.

During 2022, it is hoped that the test will be set up in some of the GLHs, with the assays developed checked to ensure that they are comparable with the outcomes from Myriad.

Tumour BRCA test for second and third line tumours remains available via the regional hub. Other future developments include whole genome sequencing.

It is recommended that the GLH send results to a team generic email address along with the requesting clinician's email to mitigate the risk of results being missed. **CAG Recommendation to GLH**

The role of the five Genetics Clinical Nurse Specialists will include optimising the patient pathway and resolving any errors or concerns.

4. Single Centre Experience of Ovarian Adult Granulosa Cell Tumours

Please see the presentation uploaded on to the SWAG website

Presented by Claire Newton on behalf of Jo Moffatt

SWAGGER is asked to submit the dataset on Granulosa Cell Tumours from all centres across the South West.

Action: SWAGGER to submit data to J Moffatt and C Newton for analysis / to develop a paper for national publication **SWAGGER Teams**

Tumours are most commonly identified at Stage 1A or Stage 1C1 (it will be useful to identify those cases where the ovary ruptures during surgery) with fertility sparing surgery as the main treatment option, as per current ESMO Guidelines, after which patients follow a standardised surveillance schedule and receive de-bulking surgery as necessary for recurrence.

Further questions that could be addressed by compiling a regional dataset:

- Is the laparoscopic approach safe? Current evidence shows no detrimental effect on oncological success with laparoscopic surgery
- Is fertility preserving surgery safe? Does it increase recurrence risk? Fertility preserving surgery seems to have a higher rate of recurrence over 10 year period but overall survival appears unchanged. Completion surgery should be considered when family is complete
- What is the optimal management of recurrence? The majority of

current data supports surgery over chemotherapy. Complete cytoreduction at time of surgery reduces risk of further recurrence. The role of chemotherapy as first line management for recurrence is currently controversial.

Fourteen cases have been identified from the UHBW data available to date from 2006 to the present day. It is possible that some cases may have been missed due to coding errors. It was not possible to access notes for two of the patients.

Out of the 12 remaining case reviews, 92% were Stage 1 at presentation; 6 were Stage 1A, 5 were 1C and 1 case was uncertain as the data was not available within the region. The median age was 50, with five patients <45 years-old. Eight patients had tumour markers taken prior to surgery and five patients underwent a hysterectomy. One third of cases had a cyst rupture either at the time of surgery or prior to surgery. All had no residual disease post-surgery.

Four patients had disease recurrence identified from radiological surveillance. The length of time between each subsequent recurrence did not reduce, as was expected; the average length of time between the second and third recurrence was longer, being >23 months.

Recurrences were managed with further surgery, although one case had to be managed just with surveillance due to comorbidities. At third recurrence, 1 patient had chemotherapy and 2 had surgery and chemotherapy. Surgical complications include 1 pelvic collection at first recurrence and 1 vascular injury at 2nd recurrence.

Two deaths had been reported; the first occurred within one month after surgery due to peritonitis. The other patient died nine years after diagnosis.

Of the two patients who had fertility sparing treatment, there has been one live birth and one is currently pregnant. Two patients are alive with disease and eight are disease free.

Action: SWAGGER considers it feasible to gather retrospective data on approximately 100 patients over the past 20 years.

The change of hospital systems at UHBW makes it complicated to access patient data before 2016, but it should be possible to collect further data via the Somerset Cancer Register and pathology records.

5. Endometrial Cancer Pathway

Post-Menopausal Bleeding (PMB) Pathway at Royal Cornwall Hospitals (RCH) Trust

Please see the presentation uploaded on to the SWAG website

Presented by Sophia Julian

In the first twelve months of menopause, one in ten women report PMB, with atrophic vaginitis the most common cause and serious pathology more likely in older age groups. Approximately 5-15% of women with PMB have endometrial cancer.

Vulval, vaginal and cervical cancer may also be present with PMB.

In 2016, the UK had 9,314 new diagnoses of endometrial cancer, and there were 88 new diagnoses in 2018 in Cornwall alone.

Following audit of the RHC One-Stop Clinic from January 2018-2019, it was found that 1233 women were referred; the equivalent of 30 patients a week, 7% of which were diagnosed with endometrial cancer (1.7 patients per week).

Due to the size of the hospital facilities, clinics were often overbooked to manage the workload, but often breaches to Cancer Waiting Times occurred.

After a critical appraisal, it was determined that the clinic was largely non-value adding, consumed vast resources, and was non patient centred; further details are within the presentation, and the priority was to ensure appropriate and timely access to transvaginal ultrasound (TVS) and out-patient hysteroscopy (OPH) to reassure those that don't have cancer, and diagnose/ treat those that do within 62 days of referral.

After agreeing a new pathway with the Clinical Commissioning Group in December 2019, services were then hit by the COVID-19 pandemic, and a hybrid emergency model was developed until the service could be properly implemented in May 2020.

The pathway now allows patients to be booked for TVS within one week at one of 5 hospital locations. Results are then discussed at a virtual PMB clinic, held every Friday, within a maximum of 9 days after referral. The virtual clinic then coordinates all the required next steps.

A comprehensive patient information leaflet has been developed, as has a more extensive PMB pathway two week wait referral form.

The service has mostly received positive patient feedback and has streamlined the pathway.

Cancer Waiting Time Performance in May 2021:

- 14 day: 93%
- 28 day: 87%
- 31 day: 100%
- 62 day: 100%.

The pathway is proving to be flexible with the V-PMB concept; safe, having no missed cancers, and acceptable to staff and the majority of patients, but there is more that can be optimised.

The 28 day target is challenging to improve due to delays caused by patient choice. Further telephone appointments need to be incorporated and quicker histopathology results would improve timescales.

It is important to note that 2 week wait referrals for PMB have been consistently 250% higher for the last 2 months. The Consultants screen referrals every day, and the time is job planned.

The UHBW team has two Consultants triaging two week wait referrals every day. They ensure that CT or MRI scans are completed before the patients attend clinic. Administrators have the use of document templates. Some elements are job planned but the process always takes longer than the PA allocated.

In the Peninsula, GPs are deluged with patients suffering from period problems. There is a massive increase in abnormal cervix referrals. Many of these cases will not be cancer. This is also the case in Bristol, where it is thought that patients are not receiving a clinical examination prior to referral.

6. Any Other Business

A number of very early discussions are underway about the potential to introduce hyperthermic intraperitoneal chemotherapy (HIPEC) surgery in the region. There is some research funding available, and the treatment is already available in The Christie, Birmingham Royal and The Royal Marsden. It could be that this develops into a treatment that would be suitable for commissioning.

There were no further items for discussion. C Newton thanked all members for attending today.

Date of next meeting: Friday 7th October 2022.

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