Meeting of the SWAG Network Urological Cancer Clinical Advisory Group

Thursday 6th July 2023, 13:00-17:00

DoubleTree by Hilton Bristol North, Woodlands Lane, Bradley Stoke, Bristol, BS32 4JF / MS Teams

Chairs: Jon Aning and Lucinda Poulton

REPORT	ACTIONS
(To be agreed at the next CAG Meeting)	

1. Welcome and apologies

Please see the separate list of attendees and apologies uploaded on to the SWAG website here.

2. Meeting reboot / last meeting's report and actions

Due to the significant gap since the last meeting, caused by multiple different factors, the plan is to now reboot and re-energise Urological Cancer CAG.

Attendees were asked to share the outcomes that they want CAG to prioritise over the coming year:

- Ensure that pathology services are consulted prior to introduction of any additional service developments
- Get a better understanding of CAG aims
- Encourage research activity
- Network with regional colleagues
- Educational updates
- Communicate needs with managers across the region and ensure equity of access to the best medical practice
- Reduce treatment variation and share good practice
- Embed genetic testing into standard practice
- Identify future projects.

As there were no comments following distribution of the report from the previous meeting on 18th November 2021, the report was accepted as finalised. **AGREED**

3. Research

3.1 Clinical trials update/incentivising cross-centre referrals

Please see the presentation uploaded on to the SWAG website

Presented by Research Delivery Manager Claire Matthews

National clinical trial recruitment from April 2023-June 2023 shows that 2,439 patients have been recruited to urological cancer trials across the 17 research networks; 16,530 patients were recruited in 2022/23. The majority were non-commercial trials with an even split between observational and interventional.

A comparison between national and regional recruitment levels shows the SWAG region performing well and moving towards pre-pandemic recruitment. This has further been broken down into recruitment by site.

The trials open across the region in the last twelve months and in set up are documented within the presentation.

Action: The full list of trials will be circulated **C Matthews**

IP7-PACIFIC has been open in YDH for some time and is currently behind in recruiting to time and target. It is looking at a double randomisation between bi-parametric and multi-parametric MRI, followed by a randomisation to visual-registration targeting versus image-fusion targeting biopsies. It has taken a while for sites to coordinate how to achieve this. The trial is due to open in NBT soon which should improve recruitment numbers.

The Question 58 in the National Cancer Patient Experience Survey 'Cancer research opportunities were discussed with the patient' scored below average across SWAG (42%) and lower for urology (29%) in comparison with the national average.

Patient Representative feedback is to let the patient know that research trials have been considered, even if the outcome is that there is no eligible trial available. CAG are asked to consider how to increase conversations about research.

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.

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

A new scheme has been launched called the Principal Investigator Pipeline Programme (PIPP) to support research nurses, midwives and dentists to become PIs, with the first cohort being trained this autumn.

Please save the date for a CRN West of England Cancer Research Event on 17th November 2023 in Bristol.

NIHR website links and team contact details are available within the presentation. Dr Amit Bahl is the Research Sub-Specialty Lead for the CAG.

Discussion:

Further work needs to be undertaken to ensure that the trials open across the region can be considered within MDT meetings.

Recruitment has been affected in GRH as a research nurse is no longer allocated to attend the MDT; this is the same in RUH, where recruitment of trial staff is particularly complex.

A regular centralised update on the trials open and eligibility criteria could facilitate cross-referrals. This is achieved by some of the other CAGs by circulating updates among themselves; data from the CRN is not always complete. Lung CAG has a WhatsApp group for this purpose.

Ideally the list of trials would be made available on the SWAG website and updated on a quarterly basis.

Consultant Urologist S Mathur experiences the same issues in GWH. The problem is keeping abreast of all of the different trials available and recalling this information when in Consultation with the patient.

Action: To compile a list of research nurses at each site to produce a regular update of trials in each centre. — **C Matthews / H Dunderdale**

4. Service Development

4.1 Genomic Prostate Cancer Testing for Olaparib

Please see the presentation uploaded on to the SWAG website

Presented by Solid Tumour Lead Scientist for the Genomic Medicine Service Alliance (GMSA) Laura Yarram-Smith

All work on solid tumour genetics is undertaken in the South West Genomic Laboratory based in Southmead, Bristol.

The GMSA has been set up to deliver NHS England's Long Term Plan to support mainstreaming genomic medicine.

BRCA testing was previously only available via clinical genetics, and mainstreaming aims to make availability more equitable at the earliest point in the pathway. However, this will not replace the need for expertise in the genetics service, who will remain available whenever there is a need to provide support, particularly with genetic counselling.

The GMSA are now working through the logistics to ensure the right tests are available at the right time, delivering training, and providing all the relevant resources required.

A number of national transformation projects are underway with input from the regional GMSAs. A recent example is mainstreaming genomic testing for inherited breast cancer gene variants.

Following publication of the NICE Technology Appraisal (TA) Guidance on Olaparib for previously treated BRCA mutation-positive hormone-relapsed metastatic prostate cancer (May 2023), AstraZeneca has negotiated with NHS England to be able to provide this for your patients.

All the tests available via NHS E can be found in the National Genomics Test Directories, found here: NHS England » National genomic test directory

BRCA1 and BRCA2 are involved in a process called homologous recombination repair to ensure damage to the DNA is repaired, as are many other genes butn for prostate cancer, the focus is currently only on BRCA1 and 2 at present.

The PARP inhibitor Olaparib prevents PARP from fixing cells with a BRCA mutation, which then die.

Germline variants are inherited and present in every cell, whereas somatic variants are not passed on, are caused by an environmental factor and are only present in the tumour. Details on the testing methods and the ideal pathway developed by NHS E, which involves somatic Next Generation Sequencing first (NGS) on a fresh tissue sample, followed by germline testing via a blood sample, are within the presentation.

All patients with BRCA1/2 variant should be referred to the Clinical Genetics Service for genetic counselling.

There are two ways to access germline testing for prostate cancer.

- R444: for those where somatic tumour testing has failed
- R430: for those who meet high risk family history criteria for inherited prostate cancer.

Further tests are becoming available for prostate, bladder and renal cell cancer.

NTRK 1,2 and 3 give access to tumour agnostic NTRK inhibitors.

Email address for queries to the Clinical Genetics Team: nbn-tr.swglhcancer@nhs.net

Discussion:

Some patients do not have tissue available for the somatic test and it is hoped that access to circulating tumour (ct)DNA tests will be available at some point in the future.

A national project is underway, starting with lung cancer, to bring in ctDNA testing and roll out to other tumour sites within a couple of years. In the first instance, a patient with no tissue should get a germline test.

At present, men are biopsied at diagnosis and BRCA is requested approximately 3 years later when considering access to Olaparib. Pathology colleagues will be asked if it is appropriate to start reflex testing these patients at the point of diagnosis.

Decisions about testing early on in the pathway need to be communicated to pathology and the laboratory as this will significantly increase workload.

Consultant Pathologist J Oxley emphasised that the extra work associated with preparing the samples for NGS is unfunded. All blocks are stored off-site. It costs £20.00 to have the block returned, which takes around 2-3 days. The Consultant Pathologist's time is required to decide which block contains the right tissue. A form then needs to be completed and submitted. Once submitted, there is no oversight as to when the sample will be processed.

As the report does not come through on the Integrated Care System (ICE) the Consultant's secretary needs to manually cut and paste this onto the system to ensure that it is available.

It is recommended that the genetics reporting system is integrated within ICE, which would save a significant amount of time.

It is also recommended to carry out up front testing of a cohort of younger men with high grade prostate cancer before tissue is sent for storage (to be defined). **CAG Recommendation**

IT integration is underway but is expected to take some time to resolve. **CAG Recommendation**

National work on improving genomic pathways is also being undertaken by BAUS.

Action: Further training is required to understand how to interpret the test results. **GMSA Team**

5. Patient experience

5.1 Personalised Care and Support (PCS) Regional Update

Presented by Lead Clinical Nurse Specialist Lucinda Poulton

A request was sent to the Clinical Nurse Specialists for an update on PCS activity, such as provision of Holistic Needs Assessments (HNAs) and Care Plans, to see if there are any initiatives to share or concerns to flag considering current workload pressures.

Cancer Support Workers have been found to be invaluable in helping to complete HNAs; the extra work that they undertake in addition to these also needs to be recognised.

The Care Plans that are generated need to be revisited to measure if the plans put in place have resulted in improvements.

The two responses received indicated that HNAs are still being provided, but in restricted volumes, and not to all cancer sites.

GRH are providing HNAs to prostate only due to manpower; NBT are providing to prostate and bladder.

Provision of Treatment Summaries also varies across the region.

Project Manager C Neck has been redeployed to monitor PCS progress due to a vacancy in the SWAG CA core team, and recognises that, although there is an expectation to report back numbers to the national team, this needs to be balanced with other priorities.

Many other tasks come under the remit of the Clinical Nurse Specialists, such as the genomics consenting previously discussed.

There is a need to look at the wider unregistered workforce and how they can best support the patient pathway. This could be Navigators and other Administrators based in the community.

It is also recognised that supportive conversations happen every day that are not recorded as a formal HNA but could be. The approach of how these are delivered and by who will be revisited by the PCS Working Group. Treatment Summaries will also be looked at again to ensure that the mechanisms to provide these are streamlined, and it is clarified at what point each of these are provided.

In the SWAG area there are now Primary Cancer Care Facilitator Roles in the community which have provided feedback that the Treatment Summaries greatly facilitate the provision of Primary Cancer Care reviews. They save time, avoid the patient having to repeat what they have gone through and make it a more meaningful conversation.

Another of the National Deliverables is to have a fully operational and sustainable personalised stratified follow up (PSFU) pathway in place for prostate cancer. This is felt to be in place across SWAG, although implemented differently across Trusts. It is also about not bringing patients back to routine follow up and giving patients the tools to self-manage wherever possible to free up clinic space.

A positive outcome of COVID has been to review how people are followed up. More appointments are now virtual, and there is a mechanism is in place to get patients back into services when concerned, rather than just via routine surveillance.

There is a need to now prioritise the other tumour sites, as this could have a significant impact on the Quality of Life for patients on bladder, renal, and germ cell cancer surveillance.

Action: To establish which centres have risk stratified follow up schedules for other urological cancer sites — **L Poulton**

Renal cancer patients are not provided with support via an HNA until a histological diagnosis is made, and it would be preferable if this came earlier in the patient's pathway.

Where HNAs are being recorded has also changed in NBT to make it more accessible to other members of the team, as it was not accessible to all who needed it when recorded on the Somerset Cancer Register (SCR).

Consultant Urologist N Trent is also the Clinical Safety Officer for SCR. There are a number of updates happening to improve SCR and it is hoped that more Consultants will register to use the system. It is useful for the HNA to be uploaded there as this gets reported in the national dataset.

Action: SCR updates to be shared at a future meeting. — **N Trent/SCR Team**

SCR is used in all Trusts except for GRH.

My Medical Record (MMR) has been partially adopted in some Trusts, but it has now become very expensive, with additional costs for each patient, cancer site or function included.

There will also be costs for SCR to include additional functions, and it doesn't function as well as MMR.

MMR and SCR are NHS organisations and should not be charging in the same way as commercial companies. — **AGREED**

6. Quality indicators, audits and data collection

6.1 PSMA-PET-CT for staging very high risk localised prostate cancer: The Bristol Pilot

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Clinical Oncologist Tom Bird

PSMA-PET CT is a mode of functional imaging using the PSMA tracer, which is the most sensitive for prostate cancer. In the recent study proPSMA, it has been found to be more accurate than conventional imaging using CT and bone scans and has the potential to improve outcomes from stage migration.

In the prostate cancer community, there is some concern that it may have some unknown negative impacts. As outcomes are not known for a number of years, it is unclear if the different test at the beginning will have any impact. It may produce equivocal results, have resource implications, and could affect the length of the patient pathway.

Current guidelines need further evidence; it is now a requirement to provide this in upcoming clinical trials. Other centres are also providing PSMA-PET-CT so there is also a need to ensure that there is equity of access across the region.

Its use is also driven by patient queries as those who have a PET scan following surgery that shows metastatic disease may question why a PET was not performed prior to surgery.

It was therefore decided to undertake a pilot which aimed to select 30 patients using the modified STAMPEDE criteria for very high risk disease who were being considered for radical curative treatment.

An ambitious pathway was developed with assistance from the MDT Coordinator and PET Provider aiming to get the results back to the MDT for discussion within 14 days. The pilot will evaluate if the pathway can work without causing a delayed diagnosis, if the correct patients are being selected, if equivocal results cause uncertainty for MDT outcomes and result in further imaging requests, and the resulting treatments.

Results were gathered over 7 months and 31 MDTs with 37 PSMA-PET-CT scans arranged. 1 patient out of the 37 selected didn't meet the criteria.

It was concluded that PSMA-PET-CT can be incorporated in to the staging pathway as 86% were reported within 21 days, equivocal PET-CT results not a major issue, PSMA-PET had a higher sensitivity for N1 compared to MRI and a higher sensitivity for M1 compared to CT/BS; 95% were eligible for Surgery or RT.

It would be useful to have a PET Radiologist in the MDT.

Discussion:

PSMA-PET-CT is rarely used in the Urology MDT at RUH due to access issues; PET-CT is the usual imaging without PMSA.

UHBW achieved it by arranging a ring-fenced slot with Alliance Medical that could be given away to other patients if not booked.

GRH use COBALT for PET; they can only be requested by the oncologist due to supply issues; there is currently a 6-9 week delay. There is a move to use for this purpose when possible.

GWH experience from referring to Oxford is that the referral criteria commence at a lower Stage of disease. The oncologists preference is PSMA-PET, but they do get a lot of equivocal results and subsequently further imaging requests.

Action: To repeat the audit in GWH **S Mathur**

6.2 Kidney Cancer Quality Performance

Tabled for discussion

SWAG Cancer Alliance have requested that Uro CAG respond to the section in the Kidney Cancer Quality Performance Audit Report which states that 'renal cell carcinomas diagnosed in SWAG have a significantly lower probability of radical nephrectomy than the population average' (Page 9).

The audit was undertaken over a two year period using data sourced from the SCR in 2017/18.

The paper was emailed to the Kidney experts in each of the SWAG centres.

In the opinion of Consultant Pathologist J Oxley, it is very rare that a kidney biopsy is not followed by receipt of a radical nephrectomy.

It may indicate that more patients are offered watch and wait surveillance, however the data is not thought to reflect what happens across the region.

Action: To look at radical nephrectomy data in more detail. **SWAG Lead Kidney Experts**

6.3 National Treatment Variation: *Investigate why high-risk locally advanced disease are not for radical treatment*

Please see the presentation uploaded on to the SWAG website

Presented by Project Manager Winnie Lo

The Cancer Alliance have asked Uro CAG to respond to the request from the National Treatment Variation Team who have stated that teams should investigate why patients with high risk locally advanced disease are not considered for radical treatment.

Data sourced from the National Cancer Prostate Cancer Audit (2019) showed that 71% of men went for radical treatment within 12 months of diagnosis, equating to 29% of men being 'potentially under-treated'.

- Numerator: No. of patients having radical prostatectomy, radiotherapy or brachytherapy within 12 months of diagnosis
- Denominator: No. of men with high-risk/ locally *advanced*prostate cancer.

The National ambition is to work towards 75% of men to undergo radical treatment within 12 months of diagnosis. Two NHSE workshops will be arranged to share ideas for how to meet this target; 2 clinical experts will be invited to attend from each Cancer Alliance (CA), along with the CA Treatment Variation Lead.

The role of the CA is to oversee implementation of the recommendation, help Trusts formulate an action plan with equity across the SWAG region, and provide project management support and funding to deliver the plan.

Addressing health inequalities is also a key focus to be considered when formulating the action plan, and the Core20PLUS5 approach to reducing healthcare inequalities will be embedded in every project.

Recording ethnicity needs to be optimised due to the relation between this and uptake of radical therapies.

Once the action plan has been implemented, data collection will continue for two quarters to ensure that the recommendation has been fully embedded and will be reviewed annually.

The first workshop is on Friday 7th July 2023 from 14:00-15:30.

Other CA work is focused on incorporating patient and family feedback into each project, especially when implementing best practice timed pathways to establish what went well and what required further improvements so that learning can be shared.

A Workforce Strategy is also underway to look at how to address the shortage of clinical specialists and see if it is possible to upskill staff and provide support from non-clinical staff where appropriate. Educational sessions are also being provided.

Action: Information will be provided about the Immunotherapy Education Forum and Mainstreaming Genomics Training. **W Lo / H Dunderdale**

Discussion:

The South West National Cancer Dashboard does not collect the information necessary to address the needs of the Treatment Variation Project. The data presented was routinely collected for the National Prostate Cancer Audit.

It is predicted that the outcomes around treatment decisions are made on a case by case basis, taking into consideration the frailty of each patient and their suitability for radical treatment.

It has been of interest to the group for many years to look at outcomes in comparison to social deprivation, which has always been difficult to obtain from existing data collection sources.

Existing data sources will be investigated to see what is already available from the Trusts.

There are many problems with data quality at present due to reduced manpower to input it with accuracy.
Ideally, it should be possible to interrogate the Somerset Cancer Register (SCR) for the data, but this is often not possible, with much of the data entered into free text boxes.

A meeting will be held in the near future to see if SCR and the prostate dashboard can be integrated. Social deprivation and

ethnicity could be included. SCR are hoping for clinician input into future updates.

6.4 Management of MRI for PIRAD 3 disease / working group update

Presented by Consultant Urologist Raj Persad

The prostate dataset for quality assurance of the diagnostic pathway has been completed now for over 4 years. All relevant contributors can access their individual data.

It gathers information on the two week wait referrals, including MRI and biopsy results, and has generated many useful outputs. Further data analysis will be undertaken in the near future.

One thing that it has shown is that systematic biopsies for PIRAD 5 lesions are not necessary in addition to targeted biopsies. SFT have also gained enough confidence to remove antibiotic prophylaxis from the pathway, and this is also about to change in NBT. Changes in practice should be guided by looking at individual centres' data on infection rates.

Guidelines are being developed for GPs to improve referral quality, including what to do for patients discharged with P1/P2.

There is an ongoing need to standardise PSA test guidance across the region.

A risk calculator is being developed in collaboration with Rotterdam.

A meeting will be held on Thursday 28th September 2023 to further discuss the data.

Management of PIRAD 3 disease is being investigated with the intention to reduce variability and standardise practice and answer questions such as 12 versus 24 systematic biopsies or will 3T MRI allow for greater confidence in reporting PIRAD 3, and whose management can be informed by PSA density and family history.

Reducing the number of biopsies required will reduce stress for patients and release the pressures on our pathology departments.

Discussion:

MRI reports have been outsourced in RUH Bath, which has caused some concern and involved re-reporting the scans. It has not been outsourced for prostate in NBT and SFT. It is routinely outsourced in Weston and the reporting has just started to be outsourced in GRH; a number of amendments have already been made within the MDT.

It is felt that it would not be possible to avoid biopsy in PIRAD 1 and 2 cases if there are uncertainties about the quality of the specialist knowledge of those completing the reports.

Action: To work with outsourcing companies to ensure that the people with the right expertise are undertaking MRI prostate assessments. — **R Colliver/SWAG Radiologists**

It is important to add this information to the QA dashboard so that the performance can be measured. Reporting of PIRAD 3 can be used as the barometer of the results.

Action: L Poulton and N Burns-Cox will meet to discuss restarting the data collection with help from the Cancer Alliance / GRH Cancer Manager. — **L Poulton**

7. Clinical Guidelines

7.1 SWAG Clinical Guidelines

Please see the presentation uploaded on to the SWAG website

Presented by Cancer Clinical Advisory Group Manager Helen Dunderdale

The Cancer Clinical Advisory Groups require agreed Clinical Guidelines to comply with Quality Surveillance.

The SWAG Urological Cancer Clinical Guidelines drafted in 2015 involved sending individual sections on renal, bladder, prostate and penile cancer to be reviewed and updated by multiple CAG members.

The resulting 52 page document was then ratified by the MDT Leads, signed off by the then Cancer Network Managing Director, and uploaded to the website to comply with Peer Review Guidelines.

Biennial reviews were completed in 2017 and 2019; separate COVID guidance was drafted in 2020.

Since Peer Review has been replaced with Quality Surveillance (2017), the related Quality Indicator states that Clinical Guidelines should reflect National Guidelines, and now many of the regional documents have been reduced to a table of links.

Recently, the Cancer Alliance Managing Director has instructed that sign off by the CA is no longer mandated.

For the 2023/24 version, it is proposed that the MDT sign off is also removed and the document reduced from 52 pages to 28, to include links to a relevant national and international guideline, and the following additional sections agreed regionally:

- CT Kidneys, Ureter and Bladder (KUB) will replace CT Urogram for visible haematuria in patients ≥50 to reduce the risks associated with radiation exposure: Agreed by CAG once the paper has been Peer Reviewed / Published 24th June 2021
- Prostate Specific Membrane Antigen (PSMA) PET Guidelines: Ratified by CAG 24th June 2021 following update from Amar Challapalli
- Penile Cancer Guidelines: Ratified by CAG 18th November 2021 following update from Aditya Manjunath.

The ratification process for new additions will be via circulation of the reports following future meetings. **AGREED**

Action: To circulate the 2023 version for opinions from the group. **H Dunderdale**

8. Clinical opinion on network issues

Regional MDT Service / MDT reforms

Consultant Urologist Jon Aning / MDT Leads

Swindon: The MDT is working well. A change in MDT Coordinator is imminent. Attendance by J Aning and A Koupparis is welcomed whenever their availability allows. Workload seems to be steadily on increasing, with approximately 30 case discussions per week.

UHBW - Weston site: The MDT list is felt to be long for a District General Hospital with approximately 60-70 case discussions per week.

SFT: There are usually around 40 case discussions per week; two Consultants have allocated preparation time. Oncology presence is very good. It is hoped to go back to in-person meetings soon.

RUH: Overall the meeting runs well with 30-40 case discussions per week. It has been running online since the pandemic, but now is returning to face to face. This is challenging for the oncologists as they can only attend hybrid due to issues with timetabling and problems with the online kit. There is felt to be room for some streamlining with a Consultant now preparing the MDT list the day before.

GRH: The MDT routinely discusses approximately 70 cases a week, not including those referred from Hereford. Worcestershire are about to rejoin, which will make the list even longer; work needs to be undertaken to further streamline cases and remodel the meeting. The plan is to split it according to disease site.

NBT: The MDT routinely discuss approaching 100 case discussions per week for bladder and prostate. Renal cancer cases, which are split into a parallel meeting are usually around 50 cases per week. The meeting functions well but is inevitably very tiring.

There is published proof that the addition of a break in the MDT improves the quality of the discussion.

The renal MDT could benefit from additional attendance by a second urologist.

BAUS Oncology now have MDT streamlining advice available online.

The Artificial Intelligence tool Deontics has worked well but is reliant on individuals inputting the data. The algorithms within it autogenerate outcomes accurately. IT set-up so that it auto-populates and ongoing costs are the main issues.

Action: To circulate BAUS Deontics extract **J Aning**

9. Any other business

Consultant Urologist L Simmons has trained in focal therapy for prostate cancer at UCL and hopes to set up a focal therapy service in RUH to which regional referrals would be welcomed. A more detailed presentation will be provided at the next meeting. Currently focal therapy is only available in London. A charity is providing capital funding to help with the initial set up. It will be for men with intermediate prostate cancer and is NICE approved.

The service will be funded centrally.

Action: To provide a presentation on focal therapy at the next meeting. **L Simmons**

National Cancer Patient Experience Survey results will be published next month and should be more useful as the free text comments will be made available on this occasion.

A new project called ACCEND is a career development programme for all levels of nurses and AHPs and provides a comprehensive competency programme. Further information will be provided at the next meeting.

Date of next meeting: Thursday 18th January 2024, DoubleTree by Hilton Bristol North, Woodlands Lane, Bradley Stoke, Bristol, BS32 4JF / MS Teams

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