

Meeting of the SWAG Network Urological Cancer Clinical Advisory Group

Thursday 18th January 2024, 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 <u>here</u>.

2. Prostate Cancer Info-Pool

Please see the presentation uploaded to the SWAG website

Presented by Prostate Cancer Research UK Programme Manager, Susannah Ramsay

Prostate Cancer Research was set up in 1988 by Professor John Masters, and continues to grow, with £15 million invested in research across 23 different projects.

The vision of Prostate Cancer Research is to create a world free from the impact of prostate cancer.

Info-pool is a new, free, patient information website for men diagnosed with prostate cancer. It evolved from a social research project, involving surveys with health care professionals, patients, and families, during which 5 key problems were identified:

- Information that was not suitable for everyone
- Numerous treatment options with differing impacts
- Information that was not available to certain patient populations, in particular for the black community where prostate cancer is more prevalent
- Treatment regret
- Access to clinical research opportunities.

Info-pool is designed to help address these problems.

Information has been co-designed with clinicians and patients, produced to a reading age of 8-12 years old, and accredited by the British Association of Urological Nurses (BAUN) and the Patient Information Forum. Further accreditation is underway as the resource evolves.

The National Lottery funded the post holders who developed the resource.

Over 900 patient stories are available on the website: Home | Infopool(theinfopool.co.uk). Any patient can share their story via the menu bar on the left hand side.

A treatment comparison tool can be used in clinic to go through different options; these can be selected to show patients the expected frequency of treatments, risks and benefits.

Many videos are available to support the information for each treatment type; an example was played to the group. Frequently Asked Questions are also available.

A Quality of Life Survey is also on the website and has been completed by 1500 people to date, which will become increasingly useful over time.

Discussion:

The website is being used in the new result clinic at NBT and the Clinical Nurse Specialist (CNS) team provide a pamphlet for all patients.

The challenge will be navigating patients to the correct information for them. It would be helpful to guide patients to the correct sub-section of the website once treatment options are known, which could be sent in an email.

The clinical research trials section is particularly useful, as it is difficult to keep track of the new trials available across the country in day to day practice.

It is important to clarify where areas that are unknown still exist, for example, the mortality incidence ratio for black men is still open to debate and shouldn't be presented as a hard fact; this information is not embedded in the info-pool website.



Info-pool was considered a valuable resource by the group.

It is hoped that mortality information will be included in the Prostate Cancer Dashboard.

Action: Cancer Alliance representatives will investigate if it is possible to add a link to info-pool on to the charity section of the SWAG website.

N Gowen

- 3. Service development
- 3.1 Focal therapy for prostate cancer in RUH Bath

Please see the presentation uploaded to the SWAG website

Presented by Consultant Urologist Lucy Simmons

High Intensity Focussed Ultrasound (HIFU) is now being offered in RUH Bath to increase access to focal therapy outside London; it is one of the first centres to do so; now all treatment options are available within the SWAG region.

HIFU is only for men who require treatment, not for men who are appropriate for surveillance, and offers an alternative to radical prostatectomy or radical radiotherapy for localised disease in certain areas of the prostate.

The RUH Team are using the international HEAT registry to collect data on focal therapy outcomes.

The longest held data from other centres is nearing 18 years of age and shows positive cancer control rates with minimal risks of incontinence and erectile disfunction compared with radical treatments.

Funding for the service requirements, including the relevant equipment, has been provided by the Prostate Charity for the first year. The charity was set up by a man who fought to get focal treatment in London and is determined to make it equally accessible in other areas.

NICE guidance states that focal therapy can be provided outside a clinical trial as long as all treatments are monitored via the appropriate registry.

The RUH strategy for focal therapy is aligned with the strategy deployed in Imperial and UCL Leads, who are the mentors of L Simmons.



The treatment will be available to men with localised prostate cancer with a PSA <20 who are suitable for a general anaesthetic, with up to radiological T3A Stage disease for a lesion in no more than one quadrant on MRI.

If a lesion is MRI negative but the biopsies show that disease has only been identified in one quadrant, these can also be treated if there is confidence that biopsies have been undertaken in all areas.

Gleeson 7 and 8 and very large Gleeson 6 can be considered for HIFU as can an index lesion and low volume Gleeson 6 disease in a few different areas.

A HIFU referral form has been circulated. It is hoped that this will be sent along with the patient's Cancer Register In-Patient Tracking (IPT) form via the MDT Coordinator to ensure all relevant information is provided.

Referrals are sent to a generic email inbox which is screened by Consultant Urologists L Simmons and J McFarlane. If the patient is found to be ineligible for the treatment, the IPT form will be returned, and the patient will be contacted by the RUH Team to explain why they are not suitable and provide the recommended alternative treatment option/s.

When a referral is accepted, the IPT form will be transferred to RUH along with the relevant images. The patient will then be invited to a face to face Consultation to talk through HIFU, gain consent, and hopefully attend a pre-operative assessment on the same day wherever possible.

Post-operative, all men will need a trial without catheter (TWOC) 10-14 days post HIFU. This can be done by the RUH or locally if this can be arranged. RUH will provide support as necessary.

Follow up involves a telephone conversation at 3 months and a locally arranged PSA. The PSA can go up or down at this point. If the PSA has started to fall, an MRI will be arranged at RUH after 12 months. If it hasn't fallen or has risen, an MRI may need to be arranged sooner; PSA monitoring is more nuanced with focal therapy.

All patients will be discussed in the RUH MDT. Staging will not be repeated unless any concerns are raised, which will be managed on a case by case basis.

Ongoing follow up is as detailed in the presentation, which is the same as the Imperial College model.



Failure of treatment is defined as clinically relevant residual disease in the intended treatment area (greater than small volume G3+3). This will be assessed by reviewing MRI and repeating biopsies. It is possible that disease progression can occur as focal therapy does not treat the whole gland, but this will not be defined as failure.

A second focal treatment can be offered in areas amenable to retreatment or additional focal areas according to patient choice, or the patient could decide to go on for salvage radical prostatectomy or radiotherapy.

In addition to the national registry, local governance processes are in place for closely monitoring the service, which include all patient outcomes that would routinely be expected to be monitored.

Some referrals have been received directly from patients, or via their GP, bypassing the hospital involved in the diagnostics. In the event that this occurs, the RUH Team will contact the relevant MDT coordinator / Clinical Nurse Specialist to inform the team that this has occurred and request further information to assess if the patient may be eligible.

Ideally, referrals will be sent via the diagnostic centre.

Discussion:

In the experience of Cheltenham MDT, patients often bypass the hospital to self-refer to the London centres.

As the London centres generally manage all focal therapy follow up, the main query about the RUH service would be who is responsible for each step.

It is confirmed that the RUH CNS will be the main contact for patients receiving HIFU.

Guidelines on re-treatment are that 1-2 out of 5 men may need a retreatment with HIFU after 5 years, and 1 in 25 may need a salvage treatment with prostatectomy or radiotherapy. A patient information leaflet is available that details all of the risks.

It is possible to do an additional treatment where, for example, a small area of disease is still apparent following treatment of a large lesion.

The possibility of causing a rectal fistula can be avoided with careful patient selection. Historically, it was thought to be mainly caused by treating patients who had previously had brachytherapy or radiotherapy.



Posterior tumours are more likely to be eligible than anterior tumours, but these may still be accepted if considered uncomplicated to reach. Ideally, Cryo-Focal therapy will also be made available, which is better for treating anterior tumours, however, any focal lesions can be referred to undergo the screening process.

Capacity for the treatments is growing, having recently expanded from one list a month to two. Senior management are aware and supportive that it may need to expand further.

The Histopathologist in RUH will not be expected to re-review the pathology sent from referring centres.

Anyone with Gleeson 3 plus 3 will be encouraged to remain on active surveillance. Psychological input will be arranged for those who struggle with this option. Treatment should be avoided for low volume Gleeson 6.

Low volume Gleeson 8 can be treated with focal therapy, but high volume is more suitable for radical treatment.

It will not be possible for the RUH Team to attend the regional MDTs. However, every patient referred for focal therapy will be discussed at the RUH MDT.

The RUH MDT will always comprise one focal therapist along with the other oncologists and urologists. In the event that a case is not obviously appropriate for focal therapy, a second opinion will be sought from the Imperial MDT.

Imaging quality varies across the region. The 12 month MRI follow up will be performed at RUH and, thus far, local imaging has been acceptable.

If there are any concerns about imaging and biopsies, the RUH would offer to repeat it. The burden of MRIs following focal treatment is less than that for active surveillance.

A pathway for managing any potential complications needs to be defined.



Action: A plan will be put in place for a management of complications

pathway.

L Simmons

Action: Regular updates on HIFU outcomes will be provided at future

CAG meetings

L Simmons

Further on in the follow up pathway, MRI could be performed locally; this will be reviewed on a case by case basis. The images would need to be transferred for reporting by the RUH team as local radiologists will not be familiar with reporting post HIFU response assessments. A regional minimum biopsy requirement has been defined following review of the local prostate dashboard, but this was not considered sufficient for patients referred for focal therapy in London, who undertake additional biopsies.

To avoid the patient undergoing biopsies on two separate occasions, the minimum biopsy set required by RUH needs to be defined.

A quadratic and targeted biopsy to an MRI lesion to sample the anterior, posterior, right and left, and index lesion, plus any other lesion PIRAD 4 and above was the minimum biopsy requirement.

This differs from the previously agreed regional protocol and will need to be clarified in writing.

Action: To clarify HIFU biopsy protocol

L Simmons

Action: To provide a standardised Patient Information Leaflet for regional Consultants on the potential risks and benefits to ensure conversations are equitable across the region.

L Simmons

Action: The presentation will be made available on the SWAG website

tomorrow

H Dunderdale



4. Clinical opinion on network issues

4.1 Prostate Working Group/Cancer Alliance 2024/25 planning

Please see the presentation uploaded to the SWAG website

Presented by Consultant Urologist Nick Burns-Cox and Programme Manager Nikki Gowen

As discussed in the previous meeting, The National Treatment Variation Workstream, which is informed by data compiled from national audits, tasks urological cancer services to investigate why some men with high-risk/locally advanced disease do not receive radical treatment.

Data from the National Prostate Cancer Audit (2020) showed the number of men having radical treatment as similar across Trusts, ranging from 69-76%.

Clinical Representatives from SWAG attended the first national workshop held in June 2023 to discuss this further, along with Project Manager W Lo.

The National Team ask that current data is analysed throughout the year and subsequently the Cancer Alliance has supplied a data script to cancer analysts across the region.

SWAG have managed to get some initial data in good time in comparison with other Cancer Alliances, but need to ensure that the data is of high quality that reflects actual service provision.

The first quarter of data has been received which shows a lot of variation in the number of patients going for radical treatment; this was open to interpretation due to the low patient numbers.

It had not been possible to use the funding assigned in 2023/24 as it was not possible to appoint an individual to investigate if there were any opportunities to reduce variation, or if any undertreatment had occurred.

It is expected that the workstream will continue into the next financial year, and it would be ideal if the Cancer Alliance team could work with Uro CAG to ensure future funding can be used to deliver the project.

A qualitative researcher is required to capture additional information on why individuals with advanced high risk disease decide not to go for treatment.



Draft guidance from the national cancer programme is also focused on bladder cancer as well as prostate, which again will come with transformation funding for the purpose of reducing unwarranted variation.

The national target still states that more than 75% of men should receive radical treatment, and that they also want to work with providers to help improve the faster diagnostic targets where performance is less than 60%. The expectation is that a baseline analysis of the pathway is undertaken, and SWAG already have the prostate dashboard in place to provide this; use of the dashboard will be further promoted.

The dashboard has been found to be a very useful audit tool for monitoring quality indicators and has been used to change management.

Completing the dashboard can be challenging as it is time consuming, however there is work underway with the Somerset Cancer Register to see what data items can be exported automatically.

In Somerset, the data has been used to make some significant improvements. This needs to be demonstrated to other centres, who ideally should be given the time to look at their own data and consider what changes can be made on the back of this evidence.

There are three Trusts where the focus will be on improving faster diagnostic times: Salisbury, NBT and GRH. Other Trusts within the region are currently achieving the target.

As prostate referrals are due to be separated from other urology referrals when looking at cancer waiting times, all Trusts will soon not meet the target, which is currently balanced by the speed of the haematuria pathway.

Further details of the national programme focus for 2024/25 are detailed in the presentation.

Nurse-led LATP biopsy services may be further optimised.

Investments can be made in support staff to meet the targets.

It was noted that project management support needs to be embedded in the MDT so that they function as part of the team.

Quick wins for the prostate pathway would be converting to straight to test referrals.



Teams need dedicated investment and time to consider how to convert data into actions that improve patient care and are asked to consider models that may help this to be achieved.

GRH has not had any administrative support to collect the prostate dashboard data for over three years. The dashboard had previously been presented at the Clinical Governance meeting by L Poulton, but members of the team did not consider it a priority at this time.

Further discussion of the benefit could be had with members of the GRH team and an expression of interest in funded dedicated time to complete the data offered.

In order to engage teams in the current time poor environment, it was recommended to listen first to the priorities identified by the teams in each centre, starting with a personal discussion based on the GIRFT model.

Consultant Urologist N Trent from SFT is keen to engage in the project, who, along with M Williams, is working with the Cancer Manager to create a new 'front door' for prostate cancer patients and has appointed an administrator to navigate patients through the diagnostic pathway; progress can be shared at a future meeting.

The dashboard has been found to be very helpful, but the data is 3 months out of date and ideally should be available live. It is also about ensuring equity of standards across the region, and a number of Trusts still need to be engaged in the data collection.

Urology CAG supports using the prostate dashboard with equity across the region with recognition of the challenges involved in its completion.

The Cancer Alliance are expected to make an action plan with the CAG to deliver the national requirements; completion of the dashboard will be part of this, or another solution will be required.

Potential future agenda item



5. Clinical guidelines

5.1 Prostate cancer staging modalities: A review of practice

Please see the presentation uploaded to the SWAG website

Presented by Consultant Urologist Jon Aning

In order for the CAG to identify tangible actions and outputs to manage variations in practice, a project to look at prostate cancer staging, which is used to guide treatment options, is proposed.

Since the recent transition from low, intermediate and high risk Staging to the integration of the Cambridge Prognostic Groups, prediction of mortality has improved, and shows how long CPG category 1 and 2 patients are likely to survive.

A whole range of staging scans are routinely undertaken to check for distant disease in all patients, some of which may be unnecessary and lengthen the patient pathway. This had been discussed at a previous CAG meeting in relation to the bone scan audit undertaken in NBT.

There is now further data from Cambridge on 700 patients with local or locally advanced disease. This revealed that Bone and CT scans did not contribute to the majority of these patients' management plans. They have since changed the MDT approach to only offer a bone scan to those who meet CPG 4 and 5 criteria, a CT scan to CPG 4 if the PSA is >50 and a CT scan to all CPG 5. Applying this to the group of patients analysed would have saved 186 scans.

Use of PSMA PET also varies across the region. This does identify more lesions, but it is not accessible to all patients, lengthens the pathway, and there is currently no evidence that it improves overall survival. It can change management in certain patients.

There is an opportunity to get consensus in practice in these areas.

The national view is not to change practice and adopt the Cambridge guidelines as this is based on data from one centre.

Patients could also question why the pathway is not following normal conventions.

As an alternative, regional evidence could be gathered, and local guidelines ratified via the group.



First, each unit could be contacted to gather baseline information on current practice, which can then be shared with the CAG.

Secondly, a registrar led joint regional project could be undertaken, with the patient identification process coming via the MDT to make it as low intensity as possible; this could be supported with funding from the Cancer Alliance and conducted over a set time period.

Once the results have been produced and the output ratified by the group, the aim will be to produce a paper suitable for publication.

PSMA PET is a separate topic that should continue to be audited. Following the audit undertaken by Consultant Oncologist T Bird which was presented at the last meeting, it was agreed that Swindon would repeat the audit; funding also needs to be provided and an appropriate person allocated to ensure that this can be achieved.

The Consultant Urologists present are supportive of the project.

Finding the relevant registrar to collate the data will be a challenge, but it is hoped that the incentive of funding from the Cancer Alliance will make this possible.

It will not be possible to pull the data automatically as different systems will need to be accessed to identify which patient had bone scans for example. The amount of time to analyse each patient record would need to be calculated to estimate the cost of the project.

Action: As a minimum to gather the staging scans routinely undertaken by each centre.

J Aning/H Dunderdale N Gowen

Action: To source funding for the Swindon PMSA PET audit

It would simplify the process to get a list of all patients from radiology who have had bone scans along with their NHS numbers and then marry this up with the NHS numbers from MDTs to reduce the need for accessing individual patient records.

The reason why the outcomes from the previous bone scan audit undertaken in NBT had not been adopted by the CAG, was due to the need to repeat it in other centres.

The information that each centre requires in order to be willing to change practice will be defined at the beginning of the project.



When the proposal is circulated to centres to request interest in the project, people will be asked to propose an alternative if they are not willing to take part.

The Peninsula will also be invited to take part.

- 6. Quality indicators, audits and data collection
- 6.1 Somerset Cancer Register (SCR): new developments

Please see the presentation uploaded to the SWAG website

Presented by Operations Manager Ruth McCarthy and Senior Requirements Manager Ben Snook

An update was provided on the following topics:

- Remote Monitoring System (RMS)
- Prostate Dashboard
- Active Surveillance Module
- MDT Efficiency.

Dataflows for the whole patient pathway are incorporated in SCR. These are not routinely used across all Trusts. At a minimum, it is used to report Cancer Waiting Times (CWT), the Cancer Outcomes and Service Dataset (COSD,) national mandatory audits, and MDT meeting outcomes.

The RMS for tracking follow up will interface with a patient portal at some point in the future. Agreed protocols have been used to set up the follow up schedule for all urological cancers, which helps the CNS team manage follow up remotely and refer back to the MDT when clinically appropriate.

Work is now underway to auto-populate the Prostate Cancer Dashboard with referral diagnosis and treatment data which should result in reducing the burden of data collection by approximately 75%. This will rely on the data being accurately inputted and validated.

The new Active Surveillance module will cover pre-cancer, pre-treatment, and early diagnosis management, which will help flag when a PSA is rising. It is at the planning stage and anyone can get involved with the change group developing the module.

SCR is developing further and looking to move to the cloud. They have also worked with Guy's and St. Thomas' and Deontics to integrate the



Deontics software which improves MDT meeting efficiency via triage of cases. The team were asked if this would be considered a useful project to pursue in different centres.

Discussion:

Active Surveillance and Remote Monitoring are the same for prostate cancer, and it was questioned if a separate module was required.

The Active Surveillance module will be used for different cancer sites and so needs to be a separate part of the system.

Action: Jon Aning and Ruth McCarthy to discuss the value of potentially pursuing integration with Deontics

J Aning/R McCarthy

- 7. Research
- 7.1 Clinical trials update

Please see the presentation uploaded to the SWAG website

Presented by Research Delivery Manager Claire Matthews

National clinical trial recruitment from April 2023-January 2024 shows that 9,825 patients have been recruited to urological cancer trials across 18 research networks. This is slightly slower than in 2022/23 where 16,983 patients were recruited. The majority were non-commercial trials and about one third commercial with an even split between observational and interventional.

There are 38 trials open across the region, 19 of which opened in the last 12 months. The full list of trials open and in set-up will be circulated.

The Question 58 in the National Cancer Patient Experience Survey 'Cancer research opportunities were discussed with the patient' scored below average across SWAG and lower for urology 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.

This is felt to be related to the timing of these conversations, which often happen at the point of diagnosis and can be forgotten amidst all the information given at that time.



A website is now available where patients can proactively register their interest in participating in research: Lwant to take part in a research study | NIHR and there is also e-learning for staff to help facilitate research conversations: https://learn.nihr.ac.uk/.

It would be helpful to know the percentage of patients that have an applicable research trial, as not 100% of patients would be eligible, and 41% being asked may actually be very good.

Results from the Participant in Research Experience Survey are documented within the presentation.

The NIHR 6-month Associate Principal Investigator (PI) scheme is still 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.

The second cohort of the Principal Investigator Pipeline Programme (PIPP) to support research nurses, midwives and dentists to become PIs, is due to commence in March 2024.

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

A list of research nurses at each site has been compiled and the list of the trials open across the region requested. When ready, this will be shared with the regional MDT Coordinators.



8. Patient experience

8.1 National Cancer Patient Experience Survey (NCPES 2022)

Please see the presentation uploaded to the SWAG website

Presented by Lead Cancer Nurse (LCN) Ros Helps, representing the regional LCNs

The survey is to look at national progress in cancer care. Local results can be looked at in comparison to other centres across England and used to drive local quality improvements.

It is sent to all adults over 16 with a cancer diagnosis who are seen as an inpatient or day case between April to June each year. It does not get sent to anyone who is only seen as an outpatient.

Response rates are very good across SWAG. No questions scored below the expected range.

Urology responses are split into prostate and 'other' urology. The overall standard of care was scored 8.8/10.

There were 11 questions that scored above 90% as documented in the presentation and 10 that scored below 60%.

Action: The Cancer Alliance needs to look at the information provided on the management of medium and long term side effects.

R Helps

The survey reflects the whole of the patient pathway from Primary Care referral to care after discharge from hospital, and a lot of the focus is on improving access to the cancer care review by the GP, which is supposed to take place 3-12 months after diagnosis.

Feedback from GPs is that treatment summaries from Secondary Care are essential to help facilitate the cancer care reviews.

As there were under 10 responses to the question about immunotherapy, the results were not published. This is expected to change next year given all of the new treatments that have become available since 2022.

It is important to celebrate that, overall, the results are very positive.

Strategies to get better responses and further analyse the data to produce additional useful actions are underway.



Picker, the survey provider, redesigned many of the questions in 2021.

Given the drive to treat more people as outpatients, the survey needs to be sent to these patients as well; this has been fed back to Picker and is being investigated.

It is recommended that Picker widen the time period over which the survey is sent.

Although numbers were still low, responses from different ethnicity groups were highest in SWAG in comparison with the rest of the country.

A video has been produced to encourage black men to complete the survey, which is hoped will prove help.

The free text comments are found to be most useful for identifying areas for improvements.

8.2 Clinical Nurse Specialist (CNS) update

Lead CNS and CAG Co-chair Lucinda Poulton has made the decision to retire in April and will stand down from the role of Chair. Urology CAG was the first CAG to have the joint chair model, which has worked well and will hopefully continue.

Action: H Dunderdale will email a request for Expressions of Interest in the role.

H Dunderdale

GRH are struggling with workforce fatigue due to the increased responsibilities that have been transferred across to plug gaps and workforce shortages.

The Cancer Support Worker who was seconded to another team has now retired and the role will shortly be going out to advert again.

NBT Team are also struggling to recruit. Two jobs have gone out to advert last month and no appropriate candidates have been identified.

Historically, the urology CNS role was a developmental step from working on the urology ward. Now the dedicated wards have gone, other solutions for developmental roles need to be established; this is currently being worked on in RUH Bath.

Potential future agenda item

Working autonomously is a very different way of working when moving from the team-based collaborative ward environment. It takes at least a couple of years training to build up the skill and confidence.



RUH have a CNS based in Oncology who works closely with the CNSs based in Urology to provide seamless care across the treatment pathway.

The CNSs in GRH sit under Urology but also cover the oncology part of the pathway and have an advanced nurse practitioner to care for patients with metastatic disease.

A workforce workstream is underway to help attract people to work in cancer; funding is available to create training opportunities.

The ACCEND programme is also underway which is a cancer career education and development framework that links education and competence for staff at all levels. Some early pilots are already underway.

An advert for a 2 year secondment to work on ACCEND at Band 8a will be circulated in the near future.

9. Personalised Care and Support

9.1 Genomic Medicine Service Alliance (GMSA) update

Presented by Consultant Colorectal Surgeon Frank McDermott

The project for metastatic castration resistant prostate cancer patients who are eligible for Olaparib, initially involves sending formalin fixed paraffin embedded tissue samples for somatic testing. If the sample fails, the patients will then be eligible for germline testing which involves a consent process.

There is also a different germline test available for men with metastatic prostate cancer under the age of 60 with a strong family history.

Additional details can be found on the National Genomic Test Directory:

NHS England » National genomic test directory

A pathway is being developed by the prostate cancer working team to share with Trusts; it will be individualised to meet the needs of each organisation.

Since the presentation in June provided by Laura Yarram-Smith on the NICE guidance published in May 2023, greater than 100 somatic samples have been processed from across the South West. The failure rate is approximately 12%; this is in line with national findings and due to older samples where degradation of the DNA occurs.



Those 12% failures should result in 12% of samples being sent in for germline testing, but this has not happened to date.

Action: Individual Trusts to check that men who have a somatic test failure are consented for the germline test and a sample sent.

Named Consultant

The work underway to mainstream genetic testing in other cancer sites has relied on support from the CNS teams, and it was useful to note the current job pressures faced by the Urology CNS teams.

Many CNSs have fed back that they enjoy the addition of genomics as a different skill set to the role. The networks need to look at workforce planning to ensure that the extra work is properly integrated into future job planning. This has already happened in the Wessex Cancer Alliance.

Access to Clinical Genetics also needs to be scaled up as waiting times can be up to a year at present.

Uro CAG are encouraged to contact the team with any queries including any CNS members that may be interested in looking at the competency framework toolkit for mainstreaming genomics.

Discussion:

Action: Failure rates for each Trust will be presented at the next meeting, as recommended by Consultant Histopathologist J Oxley.

GMSA representative

Histopathologists in some centres are declining to process samples over 5 years and request that these men are referred straight to germline testing.

Failure rate is thought to be low in the South West and the reasons why there is national variation need to be clarified when more data is available.

9.2 Risk stratified follow up pathways for renal and bladder cancer

Units across the region confirm that risk stratified follow up pathways are in place for bladder and renal cancer.

The renal cancer service in RUH had to stop temporarily due to staff changes but has now recommenced.



10. Any other business

The national prostate treatment variation workshop is going to be on Friday 22nd March 2024. Details will be sent to the prostate cancer working group.

The group expressed sincere thanks to Co-Chair Lucinda Poulton for her 45 years of service to the NHS, urology patients and to the CAG.

Date of next meeting: To be confirmed / DoubleTree by Hilton Bristol North, Woodlands Lane, Bradley Stoke, Bristol, BS32 4JF / MS Teams

-END-