Meeting of the SWAG Network Urology Site Specific Group (SSG)

Thursday, 26th February 2015 at The Chestnut Suite, Holiday Inn, Filton, 14:00 – 17:30

THIS MEETING WAS SPONSORED BY FERRING, SANOFI and ASTELLAS

Chair: Mr Ed Rowe

Notes
(To be agreed at the next Urology SSG meeting)

1. Welcome and Apologies

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

2. Review of the last SSG meeting minutes

All subject matters from the previous notes that are relevant for further discussion will be addressed within the current SSG meeting.

3. Clinical opinion on network issues

Network update and Peer Review

The cancer network is no longer called ASWCS. To reflect the addition of Gloucestershire Hospitals to the network it is now called Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services. Gloucestershire will be joining the SSGs where the patient referral pathways gravitate south, or where they might otherwise find it beneficial to network. Gloucestershire clinicians have been invited to attend the SWAG urology SSG, and representatives are attending the meeting today.

The SSG Support Manager, Helen Dunderdale (HD), and SSG Support Administrator, Samantha Larsen (SL), have now been in post for 6 months. Their posts will be funded for one year by the South West Strategic Clinical Network. Funding for the posts after this year will be provided by the acute Trusts, with the cost of the SSG service divided, based on Trust size (calculated from numbers of cancer treatments), plus the number of SSGs within the region in which each Trust would participate. This has been agreed by all Trusts for the next 5 years.

Any operational issues that are identified within the SSG meetings will be escalated to the Cancer Operational Group, and any funding issues will be escalated to the commissioning groups via the South West Strategic Network Cancer Manager, Jonathan Miller.

Commercial sponsorship will be sought to assist with funding venues and refreshments for SSG meetings.

Continuous Professional Development accreditation from the Royal College of
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Physicians will be applied for when the SSG meetings have educational content.

HD has been nominated by the SSG Chairs as the NHS member of staff responsible for user representatives’ issues and information. Four user representatives have been identified for the group via the Prospect Charity, so they are all ideally positioned to bring the voices of many patients’ or carers’ experiences to the group. Bernard Smyth has kindly attended today. HD is also in touch with the SWAG user involvement group. Although this group is not meeting at present, they are in touch via email. SSG members are to inform HD if they require patient and public feedback on any documentation, and then the group will be asked if they are willing to give their opinions.

The SSG Support Manager will create drafts of the following SSG key documents by April 2015 for approval by the group by the end of June 2015:

- Constitutions
- Clinical Guidelines
- Work Plans
- Annual Reports

The SSG support team have been granted access to add content to the South West Strategic Clinical Network website:

http://www.swscn.org.uk/networks/cancer/site-specific-groups/aswg-site-specific-groups-2/

Once notes and actions have been uploaded, the link will be emailed to the group. Sections have also been added where it is possible to upload GP referral information, information for SSG members, and patient and public information. SSG members are to inform the SSG support team if they have any content to add to the website.

The significant length of time it takes to complete surgical outcome data was discussed. It was suggested that 0.25 of a Supporting Professional Activities (SPA) time should be allocated to those entering the data. In Gloucestershire Hospitals (Glos), the surgeons have administrative support to assist with completion of the dataset. In RUH Bath, the SPA time is recognised in the surgeon’s job descriptions; surgeons in NBT are required to justify their SPA time. The group need to consider the management of this, whether the group should have an agreed response, or whether individual negotiations are to be made with each surgeon’s Trust. The service would potentially be decommissioned if the performance results from the audit were not completed. After seeking the opinion of Frank Healy, the subject will be revisited.

Due to patient referrals going both to the Midlands and to North Bristol Trust from Gloucestershire Hospitals (Glos), it would be necessary for representatives from Glos to attend both the SWAG and Midlands SSG group meetings.

The SSG meetings will remain focused on business for the foreseeable future until all guidelines and other relevant matters have been resolved. A longer, educational SSG meeting will be considered in the future.
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It was agreed that Taunton and Somerset Trust can discuss relevant patients at both the Royal Devon and Exeter (RD&E) and NBT complex MDTs, depending on the where they live and the tumour site. This may allow for more timely treatment when a particular cancer centre is under pressure to meet targets caused by a surge in workload, and also allows for patient choice.

4. Review of clinical guidelines

Amendments to the clinical guidelines were sent to HD prior to the meeting. The group had a general discussion about the updates. The clinical guidelines will be sent to the group to proof read following their completion.

Prostate

It was suggested that patients with suspected prostate cancer should be referred straight to Magnetic Resonance Imaging (MRI), prior to biopsy. TST and Glos are already doing this and set aside an estimated amount of MRI appointments in order to manage it. This is not done for those patients where it is clinically obvious that radical treatment is required. Setting this procedure as a standard should streamline the patient pathway and improve cancer waiting times in North Bristol Trust.

RUH had followed this process in the past, but problems occurred with radiology’s capacity to cope due to junior staff referring a high number of inappropriate patients for MRI. Currently, patients who have an elevated Prostate Specific Antigen (PSA) test result can be referred. It was agreed that a selection process for referral straight to MRI would need to be clearly defined prior to making this change.

Evidence from an audit undertaken in UCL suggests that radiological diagnosis is comparable to diagnosis by biopsy. Their radiologists have trained themselves by looking through the MRI scans of previous patients diagnosed with radical prostatectomies. This is something that is to be encouraged at local centres. Results of their audit will be fed back to the group.

The tendency is to refer patients straight for a template biopsy, but an MRI targeted biopsy is thought to be just as accurate. It is hoped that the research trial PROMIS will answer the questions that will enable a standardised process for biopsy and imaging to be developed.

Dr Jes Green, an MRI expert from Glos, is to be invited to the next meeting to advise the group on ideal MR imaging techniques for detecting prostate cancer. Radiologists from across the network will be encouraged to attend this meeting.

Treatment with brachytherapy as monotherapy for patients with low risk prostate cancer is now available at the Bristol Haematology Oncology Centre (BHOC)

The management of hormonal therapies, Abiraterone and Enzalutamide, for prostate cancer was discussed. Commencement of treatment pre or post chemotherapy was considered in light of the potential toxicities that might result. The key to managing this was to tailor the sequencing of doses to the individual patient, depending on the
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Chemotherapy they were receiving, the patient’s wishes, comorbidities and prostate cancer symptoms.

Enzalutamide is a NICE approved treatment option for adults with metastatic hormone relapsed prostate cancer who have been treated with chemotherapy containing Docetaxel. The urologists were asked if they were routinely prescribing Enzalutamide, as often carried out by urologists in Europe. The consensus of the group was that hormone castrate resistant prostate cancers should be referred to the oncologists for management of systemic therapy.

Following the suggestion to use dexamethasone in place of Stilboestrol, it was agreed to retain Stilboestrol in the network guidelines, as it was considered a beneficial treatment for elderly frail men who were not suitable for chemotherapy.

Radium 233 therapy should be considered in the pre and post chemotherapy setting for men with skeletal metastases due to castration resistant prostate cancer.

The group were asked if patients on long term hormone therapy were being sent for a DEXA scan at some point in their follow up. This is not routinely performed across the network and was thought to be impractical for various reasons. The NICE guidelines state ‘consider assessing fractures in line with osteoporosis guidelines’. It was agreed that selective assessment based on clinical judgement, and use of the WHO Fracture Risk Assessment Tool, FRAX, would determine how these patients would be managed. Exercise to assist in building bone density is routinely recommended.

All patients on long term hormone therapy are to be offered the option of intermittent treatment. The effect that this could have on progression and the potential for a reduction in side effects will be explained.

A potential project for the group would be to monitor the physiological and biological characteristics of PSA response to testosterone replacement therapy.

**Bladder**

The NICE guidelines for the treatment of bladder cancer are currently being updated. The changes to the guidelines will be finalised once they have been published. It is thought that patients with low risk bladder cancer will be discharged from follow up after one year, whereas a radical follow up regime will be recommended for patients with muscle-invasive bladder cancer.

With reference to page 39 in the current guidelines: T1, G2 tumours are to be removed from the list of those patients who need to be discussed at a regional MDT. In addition, the biopsy of the prostatic urethra should be amended to an optional, rather than a mandatory evaluation.

**Kidney**

For the staging of renal cancer, the assessment of distant metastases by chest x-ray will be omitted and CT imaging only recommended as the standard. In cases of metastatic
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disease, a palliative nephrectomy by either open or laparoscopic techniques should be considered.

It was noted that patients with Inferior Vena Cava (IVC) involvement were being referred for surgery to the Brompton following the retirement of the surgeon who used to provide this service at the Heath. As Mr Owen Hughes has now picked up this practice at the Heath, referrals can be made there again. Referrals may also be able to be made to UH Bristol at some point soon, as a cardiac surgeon based at the Bristol Heart Institute is interested in providing the service.

It was noted that the 2nd line treatment axitinib can only be used after the first line therapy with sunitinib.

There is a new follow up protocol of renal tumours post nephrectomy which will be incorporated in the guidelines.

Penile

David Dickerson (DD) is planning to rewrite the penile cancer section with assistance from Amit Bahl. Administrative support will be offered by HD.

An updated list of all Clinical Nurse Specialists is to be sent to HD.

5. Research update

Please see the uploaded presentation on the SWSCN website

Presentation by Maxine Taylor

The Clinical Research Networks (CRN) is now aligned with the Academic Health Science Networks. This does not exactly match the old Avon Somerset and Wiltshire SSG. However, the Cancer Research Delivery Managers in both regions, Maxine Taylor (MT) for the West of England CRN, and Wendy Cook (WC) for the South West Peninsula CRN, will continue to support the meeting by providing the data for all Trusts. The West of England Network now consists of Gloucester, Swindon, Bristol, Bath and Weston. Taunton and Yeovil are in South West Peninsula CRN. MT will attend each SSG meeting.

A research lead for SSG and the CRN is needed to ensure that the group is Peer Review compliant, and to assist in meeting the objectives of the CRN. As the majority of clinical trials for urology are oncology related, oncologist Dr Amit Bahl is to be asked if he would like to undertake the role. There is no SPA for this role, but the research network will fund expenses incurred when attending National research meetings.

A list of potential new clinical trials can be found via the following link:

http://csg.ncri.org.uk/portfolio-maps/

The CNSs role in trial recruitment was discussed. It was felt that there was often insufficient time for CNSs to discuss research within clinic appointments, due to strains on
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capacity and staff shortages. It was also challenging to keep up to speed with which trials were open and patient eligibility criteria. The CNSs at NBT have asked research nurses to attend the urology clinics to ensure collaboration in their work. This process is working successfully in some of the other Trusts in the network. The benefit of identifying eligible patients at MDT was also raised.

A clinical trials leaflet is included in patient information packs supplied by the CNs. In general, it was thought that expressing a positive attitude to patients about research, and assuring them that taking part would not exclude them from treatment, was the main function that CNSs could contribute to improving trial recruitment. To talk in more depth about clinical trials, GCP training would be required.

It was noted that although the PROMIS trial extended the patient’s treatment pathway, there is an opt-out clause enabling patients on the study to be excluded from the report of cancer waiting times.

6. Patient Pathways

Review of prostate cancer pathway and the 62 day target

Meeting the 62 day target for the prostate cancer patients was seen as a problem for all of the Trusts within the network. In part, this was thought to be due to an ever increasing ageing population. The quality of the two week wait referral process needs to be improved in order for the service to be managed more efficiently. A revised referral form will be developed after the NICE referral guidelines for suspected cancer have been published in May 2015. An electronic referral system with mandatory data fields was raised as an ideal alternative for development.

The current draft referral guidelines prompted discussion about the possibility of routinely downgrading referrals of patients under 60 who presented with microscopic haematuria, and a PSA under a certain level. 97% of people referred to the service have a non-cancerous diagnosis; this has a negative impact on those patients waiting for their treatment who do have cancer. GPs would have to be contacted individually to give permission for their patient to be removed from the 2WW pathway. Better management of the process could be achieved by ensuring GPs made appropriate referrals.

It was noted that the referral parameter of a renal mass being found on imaging had been removed from the referral for suspected cancer guidelines. This was assumed to be an editing error.

A timed pathway for the prostate cancer referrals will be created and shared with the commissioners to show where challenges occur when attempting to meet the cancer waiting times.

7. Patient experience

User representative input

Bernard Smyth (BS) was interested in whether a prostate cancer screening programme
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**Review of the National Patient Experience Survey**

*Please see the presentation uploaded on the SWSCN website*

The Clinical Nurse Specialists (CNSs) discussed the results from the National Patient Experience Survey, looking at Trust level best practice to be shared, Trust / network level priorities identified for pathway improvements, and the actions required to address identified priorities, as detailed in the presentation. The methodology of the survey was considered questionable. While access to CNSs was proven to improve the patient experience, a recent survey on CNS provision established that 50% of urology oncology nurses across the UK are due to retire in the next 5 years. It was considered an unpopular CNS role due to the patient numbers and ever accumulating caseloads resulting from increased survival rates. The potential effect that loss of CNS numbers would have on services over the next 5 years will be brought to the attention of Peer Review.

**8. The National Survivorship Programme**

Implementation of the recovery package associated with National Survivorship Programme is underway. Catherine Neck (CN), the Macmillan Lead for Survivorship, has been assisting the urology oncology team to undergo a risk stratified redesign of the follow up pathways. This would aim to identify patients that can safely move on to self-supported management, remote monitoring or nurse led follow-up.

The Living Well events, which could potentially replace a follow up appointment, may not suit all patients’ requirements. This will be considered during the redesign of the pathways. Patients may well be offered different follow up options.

A further service development called Prehabilitation is being piloted for patients diagnosed with renal carcinomas. This serves as an extension to the enhanced recovery programme. Renal patients were chosen for the pilot due to manageability of patient numbers, and the challenges that present when recovering from a kidney resection. Patients who consent to the programme are contacted fortnightly for one hour, and provided with advice to assist them in optimising their health prior to surgery, encouraging them to take control of their own health and wellbeing from the point of diagnosis.

An audit of patients with lung cancer has provided evidence of the benefits to patients’ recovery after their engagement in the prehabilitation programme.

A National trial looking at the effect of exercise and nutrition on the behaviour of tumours, could hopefully define the most beneficial exercise and nutrition for recommendation to patients.

Another potential self-management project, in the form of a secure patient information portal, is currently being trialled for prostate patients in RUH Bath. Miranda Benney (MB) and colleague from Prostate Cancer UK are leading on this. The project, which enables
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patients to look up their own PSA results and their trigger point PSA on their discharge summary, will run for the next year. MB will bring the results of the project to the next SSG meeting.

9. Quality indicators, audits and data collection

Surgical outcome data

There is an ongoing project looking at streamlining the data collection for the NPCA audit.

The Peer Review process is being reviewed at present and it is not known how this will be conducted. The recommendation is to carry on with completing internal assessments as per usual.

10. Service development

In NBT, several new nurses have been recruited to the CNS team since November.

Glos now has robotic assisted (da Vinci) surgery facilities and so far have treated 80 patients. A detailed, independent capacity and demand study has recently been completed to document everything required for the development of the service. The service is short of 3 Consultants at present, but it is hoped that the study will enable them to employ more Consultants, CNSs and, in addition develop a high dose brachytherapy service.

Staffing in Taunton and Somerset Trust (TST) and Yeovil District Hospital (YDH) was reported as sufficient. Patients are referred for surgery to Royal Devon and Exeter Hospitals, where a robotic service is also available.

Consultant Matt Gogh was appointed to Weston Area Health Trust (WAHT) on the 24th December. The CNSs in WAHT were reported to be overstretched and there was a lack of junior staff. Theatres are going to be refurbished, so problems meeting the cancer waiting times are anticipated.

Clarity Ultrasound for tracking prostate cancer and delivering image guided radiation therapy was highlighted as a possible area for service development.

11. Any other business

In view of requests received by WAHT CNSs to give patients their trial without a catheter (TWOC) who are previously unknown to Weston urology services, it was agreed that a patients TWOC should be performed by a centre in which they are a previously known patient. If the patient is sent back to their referring centre for their TWOC, the operation note should be forwarded in a timely manner.

Agreed

12. Date of next meeting – to be confirmed

-END-
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