1. Welcome and apologies

Please see the separate list of attendees and apologies uploaded on to the SWCN website [here](#). Co-Chair Mr Jaspal Phull sent his apologies due to unexpected surgical commitments.

2. Review of last meeting’s notes and actions

As there were no amendments or comments following distribution of the notes from the SSG meeting on 5th July 2018, the notes were accepted.

**Actions:**

**Living With and Beyond Cancer (LWBC) Initiative:** Treatment Summary templates for Prostate Cancer are now available on the website [here](#).

**Service evaluation on the use of enzalutamide and abiraterone:** The network pharmacists have been contacted to find out how to access the data.

**Suspected urological cancer referral form:** A request has been sent to the Cancer Manager in RUH Bath to ask the local CCG to add the missing PSA values to the form.

**Regional consensus of PSA assays:** The varied PSA assays used across the region have different age-specific raised reference ranges. It was agreed that this should be standardised across the region. The ranges to use will be decided outside the meeting.

**Cancer Research UK Multi-Disciplinary Team (MDT) Recommendations:** Deferred to the next meeting due to lack of representation from Consultant Urologists.

**Feedback on time saving modifications for the Somerset Cancer Register (SCR):** Consultant Urologist Salah Albuheissi sent a list of the improvements required to enable tracking of cystoscopy patients via the SCR. SCR representatives have explained that they are only able to process service developments that are agreed across the wider range of users, rather than bespoke requests, but it is hoped that the new tracking system may address some of the related issues.
3. Patient pathways

3.1 Prostate diagnostic pathway dataset review

The Cancer Alliance Transformation of the SW Prostate Cancer Diagnostic Pathway Project team has circulated a progress update. The prostate audit spreadsheet is now being completed in all of the different Trusts. An audit of MRI image quality and compliance with PIRAD2 technical criteria is underway. Results will be available towards the end of the year and will be fed back to individual departments.

Histopathologist colleagues have approached different departments to determine the minimum dataset that can be collected, and where standardisation might be possible. This was complicated due to the wide variety of different core biopsy samples sent for processing on a weekly basis. It would be beneficial to trial a standardised approach across all centres.

A Clinical Reference Group has been established and is meeting on the 17th October 2018 to draft referral and discharge guidance in consultation with the SSG, Local Medical Committee (LMC), Clinical Commissioning Groups (CCGs) and other relevant stakeholders.

Change management training events are being arranged in December. Interested parties are to contact Project Manager Sarah-Jane Davies: sarah-jane.davies@nhs.net

4. Living With and Beyond Cancer (LWBC)

4.1 Somerset Cancer Register: remote monitoring

Please see the presentation uploaded on to the SWCN website

Presented by Rachel McConnell (RM)

The SCR is developing three key areas to support monitoring and submission of LWBC activity:

- CNS Enhancements: Details on the completion of Holistic Needs Assessments, related care plans, treatment summaries and Wellbeing events can be recorded on the CNS contact page and exported to Excel after the autumn 2018 update. It will be possible to distinguish between activity recorded by the CNS or CSW. It is hoped that the exact metrics for measuring LWBC activity can be agreed in the near future.

- PSA / Breast / Colorectal Trackers: It will be possible to add patients to the tracker after the autumn 2018 release. This will produce a worklist of all patients’ latest tumour marker dates within SCR and highlight those patients that have exceeded their set alert level.
Remote Monitoring: A separate system is being developed for remote monitoring of breast cancer patients prior to rolling out to colorectal, urology and other cancer sites. This will interface with the SCR and other hospital information systems. Phase 1 will be released in Spring 2019. Future releases will have the facility to send alerts for overdue tests and results outside normal ranges to designated emails, or to mobile phones as text messages. Template letters and reports will be generated, and a portal for patients to view their reports and results will be made available by 2020.

A draft mock up for the system will be circulated to SSG members for their opinions/feedback.

It has not been possible to generate a report on CNS specific LWBC activity from the SCR in North Bristol Trust, and it only seems possible to extract the data by speciality. Requirements Analyst Rachel McConnell (RM) will liaise with Lead Cancer Nurse Carol Chapman (CC) to resolve the issue.

The remote tracking system will be available at an additional charge than that associated with the SCR contract.

The GP surgery attended by one of the User Representative members already had the capacity to provide patient access to PSA test results in a graphical format. This was not a service that was thought to be widely available to GP practices across the region.

It had been thought that the SCR and True North teams were working together on the development of tracking systems, but this was not the case.

The capacity for patients to be provided with a printout copy of their results should be taken into account, as not all patients have internet access and may prefer a paper copy.

It would be possible for PSA results to be automatically imported into the SCR if Trusts decide to purchase the import function.

Any queries about SCR developments can be emailed to cancerreg@tst.nhs.uk.

5. Patient experience

5.1 User Representative update

Prospect hold coffee mornings for new patients at the Macmillan Centre at Southmead Hospital on the first Thursday of every month; 20 patients attended the last event. Referrals are made by the CNS team at NBT, who see all patients who are on the pathway in Bristol. Cancer Support Workers in UH Bristol will be made aware of the mornings. The CNS team in the BHOC will be emailed to disseminate the information.
A member of Prospect who is on the active surveillance pathway did not receive their MRI scan result within the expected timeframe. The majority of centres write to a patient and their GP, or a CNS would contact a patient directly to give results; the clinician requesting an investigation is ultimately responsible for acting on the results.

It is important to give realistic reporting timeframes to patients to manage their expectations, and also ensure that a patient can contact their CNS to chase up results should an unexpected delay occur. Although Prospect promote making contact with the CNS team, there is often the perception that a patient has not met them, and doesn’t know how to contact them. All patients with a prostate cancer diagnosis in NBT will have met their CNS contact, as a member of the team will have given them their diagnosis. The Patient Information Leaflet which includes contact details has been revised recently in response to patient feedback, so hopefully this perception will improve. Additional support is now available to patients provided by the recently employed Cancer Support Workers.

It was noted that open prostatectomies can still be performed if clinically necessary, but the centres in the SWAG region routinely perform laparoscopic or robotic assisted prostatectomies. The number of robots available across the UK to specialist centres needs to be rationalised so that a minimum number of procedures per annum can justify the expenses related to purchase and maintenance of the kit.

Prospect members were recently invited to attend a prostate cancer support group in St Pauls to talk about Prospect and help promote awareness among the Afro-Caribbean community, for whom prostate cancer was known to be three times more prevalent, and yet Prospect currently has few Afro-Caribbean members, as was the case with the Gloucestershire support group. This will hopefully improve the diversity of membership, and it is hoped that the recent surge in referrals caused by celebrity endorsements will also increase referrals from this community.

Prospect members were thanked for their work, which was so important in consolidating the information given by the treating centres, and allows patients to discuss queries that might not immediately occur in the hospital setting.

5.2 Body Image Issues and Attitudes Towards Exercise in Men Diagnosed with Prostate Cancer Undergoing Androgen Deprivation Therapy (ADT)

Please see the presentation uploaded on to the SWCN website

Presented by Caterina Gentili (CG), PhD candidate Centre for Appearance Research, University of the West of England

Supervisors include SSG members Professor Raj Persad and Consultant Oncologist Amit Bahl.

ADT is the gold standard treatment for approximately 50% of patients diagnosed
with prostate cancer, helping to slow tumour growth. The side effects from ADT affect Quality of Life (QoL), sexuality and body image. This PhD study will explore the impact of ADT induced appearance and functionality changes on patients’ body image, and investigate patients’ attitudes to exercise and potential exercise barriers. Previous research studies have found that the majority of patients are unlikely to seek help; preliminary evidence that exercise can be used as a practical coping strategy that evidence has shown is beneficial for body image.

The method used and results from the first year of the study are detailed in the presentation.

Conclusions:

- ADT side effects can have an impact on patients’ body image and masculine identity
- Body image issues are mostly dependent on body feminization
- Physically active patients find an effective coping strategy in exercise.

Future directions:

- The topic will be further explored quantitatively
- Some patients may benefit from information and support for body image concerns
- Patients who are not physically active may benefit from an exercise intervention.

A freedom of information request about the provision with psychological support for me with prostate cancer had been circulated. Information from this, and from other relevant contacts that are running initiatives to assist this patient group across the region, will be shared with CG.

It needs to be emphasised that symptoms will cease at the end of treatment.

6. Coordination of patient care pathways

6. Prostate cancer risk stratified follow up

Presented by Bristol North Somerset, South Gloucestershire Clinical Lead for Cancer, Dr Alison Wint (AW)

There is an urgent need to safely stratify follow up processes and release outpatient capacity which requires CCGs to seek information systems capable of delivering immediate solutions. The True North PSA tracker, which allows patients to access their results, is in use in RUH Bath and Gloucestershire. The NBT team had looked into buying the system, but were told that it would not be compatible with existing hospital information systems; AW will investigate this further. The SCR remote monitoring solution was 2 years away from completion and patient access was not due to occur until the last phase. It would have been preferable if this had been prioritised, as patient ownership of results is one of the key aspects
to stratifying the pathway.

The following is feedback on the True North system:

- Safe and fit for purpose now
- Delayed feedback of results to patients so that a raised result can be discussed prior to a patient independently viewing it
- Somewhat cumbersome in Gloucestershire at present and requires some improvements
- Reliant on a team to monitor rather than an individual
- Can be used from the beginning of the pathway for all patients with prostate cancer so that they get used to using the system prior to discharge
- Feedback from other regional centres has shown that it has released outpatient capacity
- It can be used for other long term follow up conditions such as thyroid and diabetes remote monitoring
- Flags up when a required blood test has not occurred within a 2 week window
- Patients who don’t have computers can still go on it and be monitored by the secondary care team
- There is an upfront cost and a cost per patient entered
- Accessible to the patient and secondary care team only.

The system was felt to be the most viable solution, and the next steps will be for AW and LWBC Lead Catherine Neck (CN) to look further into the costs and the feasibility for this to be implemented in other centres, and seek evidence from elsewhere.

Some patients have found that GPs are refusing to perform PSA tests in Gloucestershire and Bristol practices. This is currently under investigation.

7. Clinical opinion on network issues

7.1 MDT reforms

To be discussed at a future meeting.

8. Research

8.1 Effect of a lower-intensity PSA-based screening intervention on prostate cancer mortality: the CAP randomized clinical trial (RCT)

Please see the presentation uploaded on to the SWCN website

Presented by Professor Richard Martin (RM), University of Bristol

The objective of the CAP randomised controlled trial, the largest trial of its kind in the world to date, was to estimate the effect of an invitation to a single PSA screen
versus standard practice on median 10 year survival. In the future it will answer questions on when PSA monitoring should be stopped, and on the probability of recurrence. Please see the presentation for further details.

Findings indicated at a median of 10 years, a lower intensity screening intervention (a single PSA test):

- Had no discernible effect on PCa-specific mortality
- Increased detection of early-stage, low-grade PCa
- Did not detect some lethal cancers
- Long-term follow-up will ascertain if lower-intensity screening reduces over-detection while achieving mortality gains.

The current findings do not support single PSA-testing for population-based screening.

More effective methods for detection of prostate cancer are required, for example looking at protein markers, genetic test panels and the use of multi-parametric MRI (mpMRI). The next step will be to perform modelling exercises looking at mpMRI; the CAP study team would welcome involvement from the SWAG Urology SSG.

A series of online resources to explain the results to the public and national screening committee have been published, and feedback from patients (including from the patient representative members of the SSG) have been received that will be used to further understand how to disseminate complex messages from trial results.

RM will attend an SSG meeting in approximately 6 months to present the plans for future research.

7.2 Clinical trials update

Please see the presentation uploaded on to the SWCN website

Presented by Constance Shiridzinomwa, North Bristol Trust

Recruiting trials:

Add-Aspirin: A Phase III, double-blind, placebo-controlled, randomised trial assessing the effects of aspirin on disease recurrence and survival after primary therapy in common non-metastatic solid tumours. There are 3 groups, including placebo, aspirin at 75 mg, or aspirin at 300 mg (if under 75 years of age) for patients with prostate cancer. The study is also open to recruitment for patients with Breast, Bowel and Oesophagus or Stomach cancer. Recruitment rate has reduced following a recent publication of media folklore.

IROC: A Phase III multicentre randomised controlled trial (RCT) to compare the efficacy of Robotically Assisted Radical Cystectomy (RARC) and intracorporeal
urinary diversion with Open Radical Cystectomy (ORC) in patients with bladder cancer. Recruitment has proved challenging due to the associated travel for follow up appointments at 3 and 12 months.

**Prostate cancer – Exercise and Metformin Trial (Pre-EMpT):** Organised by the National Institute for Health Biomedical Research Centre (Nutrition), which is funded by the National Institute for Health Research and is a partnership between the University Hospitals Bristol NHS Foundation Trust and the University of Bristol. RCT with 3 arms, including Metformin, Metformin and exercise, or standard care. Recruitment has been challenging due to not being able to recruit diabetics (even if diet controlled only), and patients’ reluctance to take trial drugs.

**Prostate Health Index (PHI)- to Refine prostate Imaging by MRI (PRIM):** To refine prostate imaging by MRI. This has been easy to recruit to, with the only extra research related activity being an extra blood sample; patients can be approached while waiting for biopsies.

Trials in follow-up:

POUT, Boxit, Radicals, Source and MASTER. Centres are currently not recompensed for follow up activity; Radicals is due to continue until 2031.

Further details of clinical trials in set up can be found in the presentation and on the information for SSG members page on the SWCN website [here](#).

**Date of next meeting:** To be confirmed

-END-