# Northern Cancer Alliance

# Urology Cancer Clinical Guidelines

**Document Information**

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**Guidelines agreed by:**

EAG members agreed the Guidelines on:

**Date Agreed:** emailed to group for endorsement on 18.12.19 for formal endorsement by email.

**Review Date:** May 2021

**CONTENTS**

The North of England Cancer Network EAG for Urology have adopted in their entirety the European Association of Urology (EAU) Guidelines and use these in collaboration with NICE 2005 guidelines for urgent referral for urological cancers.

Adherence and reference to the following guidelines is also acceptable and used in clinical practise.

**EAU website link:**

http://uroweb.org/guidelines/compilations-of-all-guidelines/

**NICE**

**REFERRAL GUIDELINES FOR PRIMARY CARE**

NICE Prostate cancer: Diagnosis and Management 2019
https://www.nice.org.uk/guidance/ng131

NICE. Bladder cancer: Diagnosis and management 2015
https://www.nice.org.uk/guidance/ng2

## GENERAL RECOMMENDATIONS

A patient who presents with symptoms or signs suggestive of urological cancer should be referred to a team specialising in the management of urological cancer under the 2 week rule, depending on local arrangements. All patients referred on the 2 week wait (2ww) proforma would need their eGFR checked within two months of referral.

It is expected that these 2ww referrals are seen in appropriately dedicated clinic for faster diagnosis and have access to a CNS in those clinics.

## SPECIFIC RECOMMENDATIONS

### Prostate Cancer

Patients presenting with symptoms suggesting prostate cancer should have a digital rectal examination (DRE) and prostate-specific antigen (PSA) test after counselling. Symptoms will be related to the lower urinary tract and may be inflammatory or obstructive.

Prostate cancer is also a possibility in male patients with any of the following unexplained symptoms:

- erectile dysfunction
- haematuria
- lower back pain
- bone pain
- weight loss, especially in the elderly.

These patients should also be offered a DRE and a PSA test[1].

Urinary infection should be excluded before PSA testing, especially in men presenting with lower tract symptoms. The PSA test should be postponed for at least 6 weeks after treatment of a proven urinary infection. If a hard, irregular prostate typical of a prostate carcinoma is felt on rectal examination, then the patient should be referred urgently. The PSA should be measured, and the result should accompany the referral. Patients do not need urgent referral if the prostate is simply enlarged and the PSA is in the age specific reference range[2]. In a male patient with or without lower urinary tract symptoms and in whom the prostate is normal on DRE but the age-specific PSA is raised or rising, an urgent referral should be made. This should be a 2ww if PSA is above the age specific reference range. In those patients whose clinical state is compromised by other co-morbidities, a discussion with the patient or carers and/or a specialist in urological cancer may be more appropriate. Symptomatic patients with high PSA levels should be referred urgently. It is also important to answer MRI related questions in the 2ww proforma to enable faster diagnosis for patients.

If there is doubt about whether to refer an asymptomatic man with a borderline level of PSA, the PSA test should be repeated after an interval of 6-8 weeks. If the second test indicates that the PSA level is rising, the patient should be referred urgently.

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[1] The latest guidance from the prostate cancer risk management programme demonstrates no clinically significant rise in PSA any time after a DRE

[2] The age-specific cut-off PSA measurements recommended by the NCA EAG are: aged 50−59 years - 3.0 ng/ml; aged 60−69 years - 4.0 ng/ml; aged 70 years and older - 6.5 ng/ml and 20 ng/ml for men aged over 80 years

Treatment options and staging investigations for men with potentially localised prostate cancer are determined by the patients D'Amico risk classification and provisional treatment intent (radical or non-radical) as described in the most recent NICE guidance.

Each specialist MDT is expected to have an identified clinic or clinics slots for patients undergoing treatment and diagnosis of prostate cancer with access in those clinics to a CNS.
Treatment of prostate cancer can occur locally in the following cases:

- The diagnostic process
- Active monitoring
- Orchidectomy
- Medical hormone therapy
- Palliative chemotherapy

Patients requiring other treatments are treated in their respective specialist MDT units (Newcastle, Sunderland and Middlesbrough). Prostate brachytherapy for appropriate patients with prostate cancer is provided for patients across the network through the specialist MDT in Newcastle. Prostate cryotherapy for appropriate patients is provided for patients across the network through specialist MDT at Sunderland hospital.

**Bladder and Renal Cancer**
In patients with symptoms suggestive of a urinary infection who also present with visible haematuria, investigations should be undertaken to diagnose and treat the infection prior to consideration of referral. If infection is not confirmed the patient should be referred urgently.

All adults aged 45 years and older who present with visible haematuria and adults aged 60 years and older who present with non-visible haematuria with dysuria or an elevated white cell count should be referred on a 2ww proforma. It is important to note that in men, a digital rectal examination and a PSA test would be essential to rule out prostate cancer prior to referral.

In patients under 60 years of age with non-visible haematuria without raised WCC or dysuria, urine albumin/creatinine ration should be measured and if abnormal referred to a nephrologist. If there is no proteinuria and serum creatinine is normal, a non-urgent referral to a urologist should be made.

Any patient with an abdominal mass identified clinically or on imaging that is thought to be arising from the urinary tract should also be referred on a 2ww proforma.

**Testicular Cancer**
Any patient with a swelling or mass in the body of the testis should be referred urgently using a TWR proforma. An urgent ultrasound should be considered in men with a scrotal mass that does not transilluminate and/or when the body of the testis cannot be distinguished.
Testicular markers should be undertaken when there is significant concern.

**Penile Cancer**
An urgent referral should be made for any patient presenting with symptoms or signs of penile cancer. These include progressive ulceration or a mass in the glans or prepuce particularly but can involve the skin of the penile shaft. Lumps within the corpora cavernosa not involving penile skin are usually not cancer but indicate Peyronie's disease, which does not require urgent referral. All patients will be discussed at the supranetwork MDT based at Sunderland.

All referrals for penile cancer should be sent via email to this address cis-tr.PenileMDTCHS@nhs.net

## GUIDELINES AND PATHWAYS FOR KIDNEY CANCER

The network has agreed to use the European guidelines for diagnosis and assessment of primary and recurrent disease, including specific indications for CT, MRI and biopsy, types of nephrectomy, nephron sparing surgery and robotic surgery.

### Local Care

Procedures and treatments classed as local care may be delivered under the care of members of the local urology team. These include:

- The diagnostic process
- Imaging for tumour extent
- Nephrectomy, excluding the cases outlined below under "specialist care"
- Palliative chemotherapy
- Nephro-ureterectomy

The following cases need discussion with the host specialist MDT team for the formation of a treatment plan and further management.

Patients with kidney cancer potentially suitable for nephron sparing surgery should be discussed with a named specialist team, prior to either referral to that team or management by the local team. All nephron sparing surgical interventions are to occur in the respective host centre for the specialist MDT.

Options for treatment include:

- Open or Robotic Partial nephrectomy
- Radio frequency ablation at the Freeman hospital
- Cryotherapy at Sunderland Royal.

Patients with confirmed metastatic disease are considered for Systemic anticancer therapy and assessed by the MDT for possible resection of the primary and / or metastases by a named specialist team.

An abbreviated guideline is in appendix 2.

### For Bladder Cancer

Local MDT treatment and diagnosis can take place for the following**:**

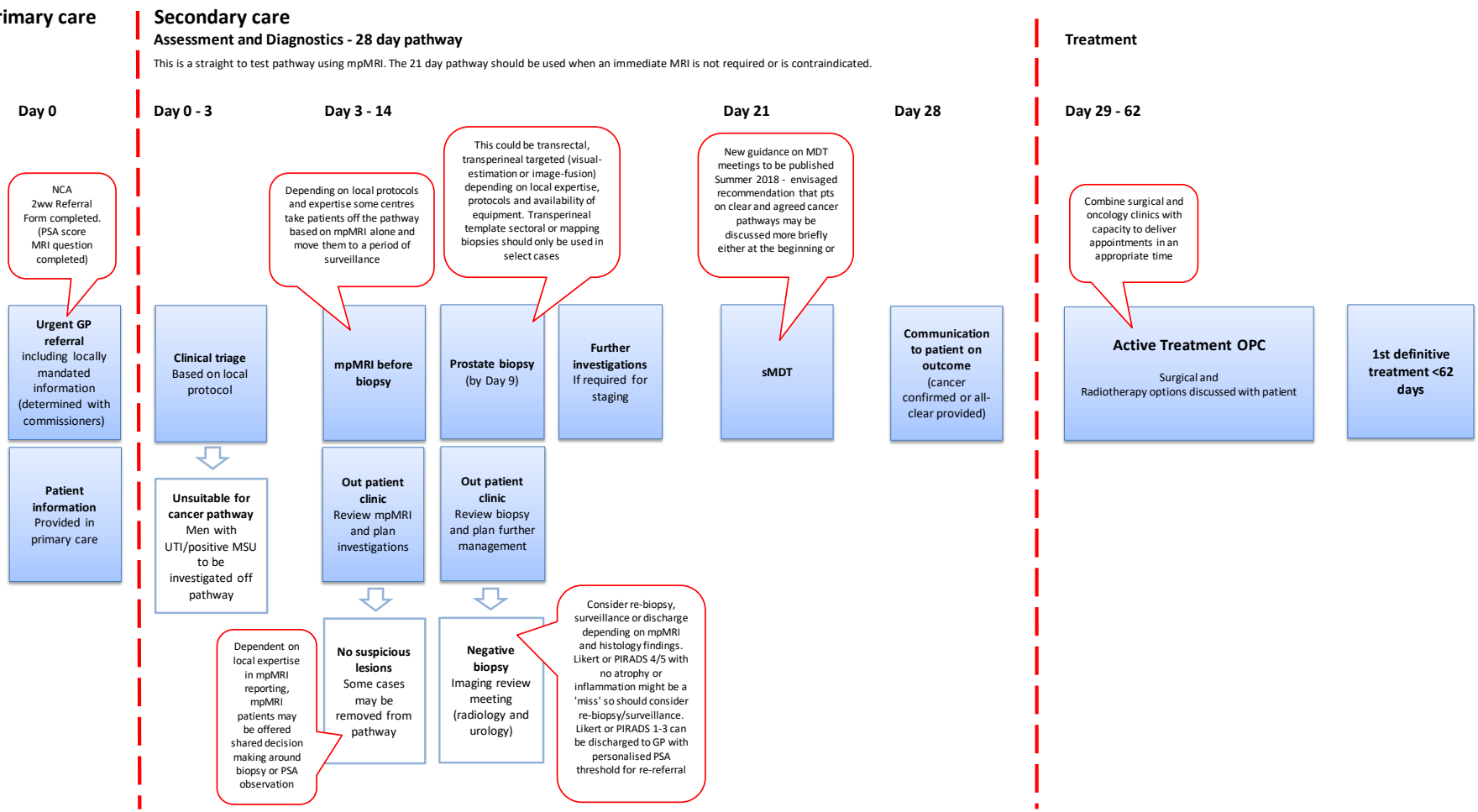
- The diagnostic process
- Trans-urethral resection (TUR)
    - For the diagnosis of newly presenting patients with suspected bladder cancer and determining tumour grade and invasion depth
    - As treatment for those initial cancers found to be low risk superficial i.e. pTa (G1 or G2); T1 (G1or G2)
    - As a follow up procedure for low risk recurrent superficial cancers
- Palliative chemotherapy.

The protocol for the cystoscopy surveillance accepted for the network centres is outlined in the NICE guidelines.

**Patient requiring specialist input should be referred by the local MDT to the specialist MDT and discussed within one week.**

**The teams are at Freeman hospital FRH, Sunderland Royal SRH, James Cook University teaching hospital JCUH.**

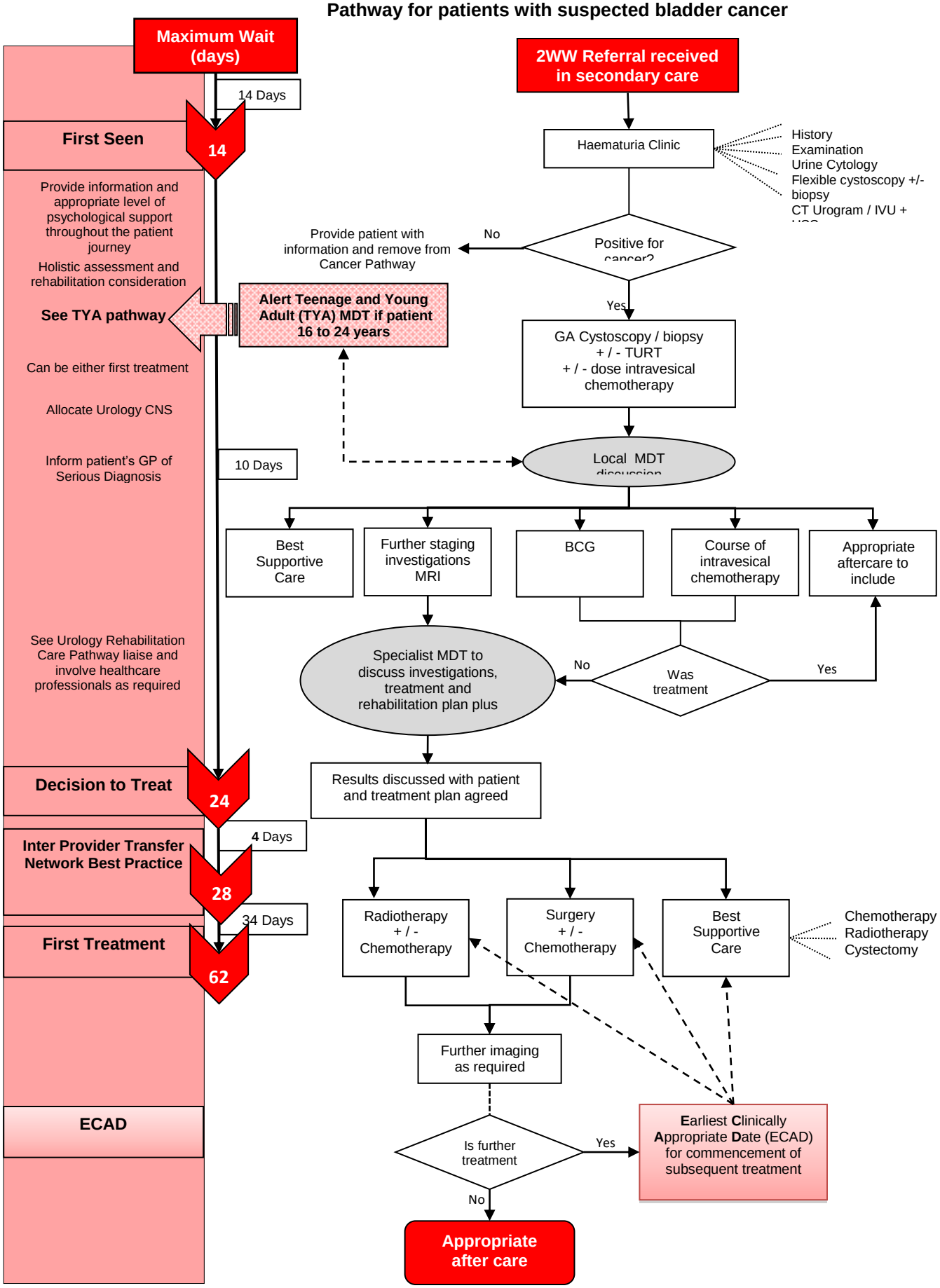
# Prostate Pathway



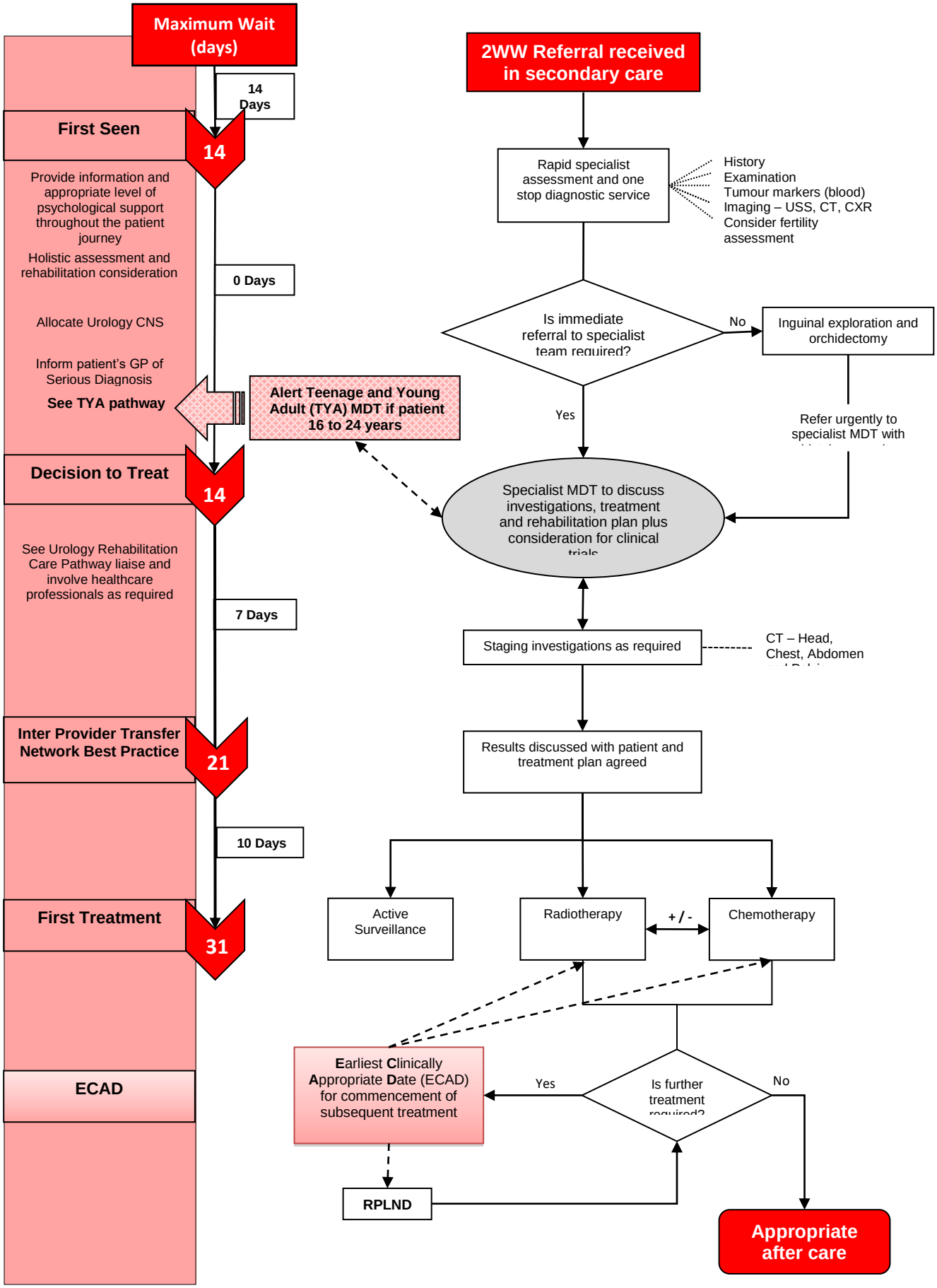

**Footnotes- Future state (1)**

1. Urgent GP Referral - Locally mandated information is determined with commissioners but should include demographics, investigation results (PSA, U&E/eGFR, urine dipstick (+MSU result if dipstick positive), and DRE), performance status, weight and BMI,medication, anti-coagulant history, and MRI scanning exclusion criteria. A PSA of >3ng/ml should be used as referral rate for men aged 50-69. A rectal swab may also be required.
2. No suspicious lesions reported – Some cases may be removed for the pathway. Likert or PIRADS 1/2 or Likert or PIRADS 3 with PSA density <0.15 or <0.12 depending on local clinical choice for threshold (currently in literature both are reported). Also consider risk factors (e.g. Family History). Dependent on local expertise in mpMRI reporting, mpMRI patients may be offered shared-decision making around biopsy or PSA observation.
3. Prostate biopsy (by day 9) – This could be transrectal, transperineal targeted (visual-estimation or image- fusion) depending on local expertise, protocols and availability of equipment. Transperineal template sectoral or mapping biopsies should only be used in select cases.
4. Negative biopsy- Imaging review meeting (radiology and urology) – Consider re-biopsy, surveillance or discharge depending on mpMRI and histology findings. Likert or PIRADS 4/5 with no atrophy or inflammation might be a "miss" so should consider re-biopsy/surveillance. Likert or PIRADS 1-3 can be discharged to GP with personalised PSA threshold for re-referral.
5. sMDT – It is envisaged that when the new guidance on multidisciplinary team meetings is published in summer 2018, there will be a recommendation that some patients on clear and agreed cancer pathways may be discussed more briefly either at the beginning, or end, of the MDT.

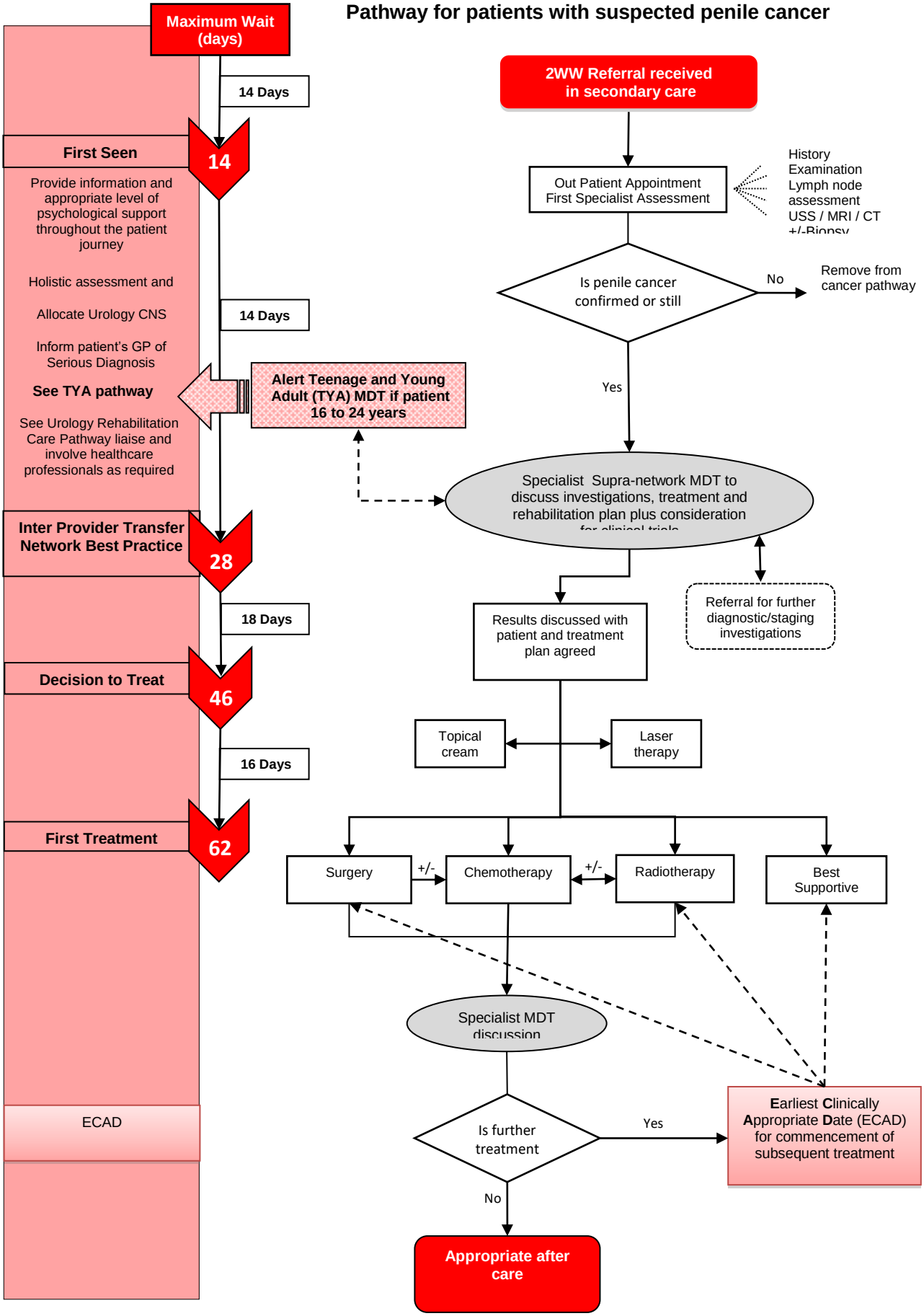
## Pathway for patients with suspected bladder cancer



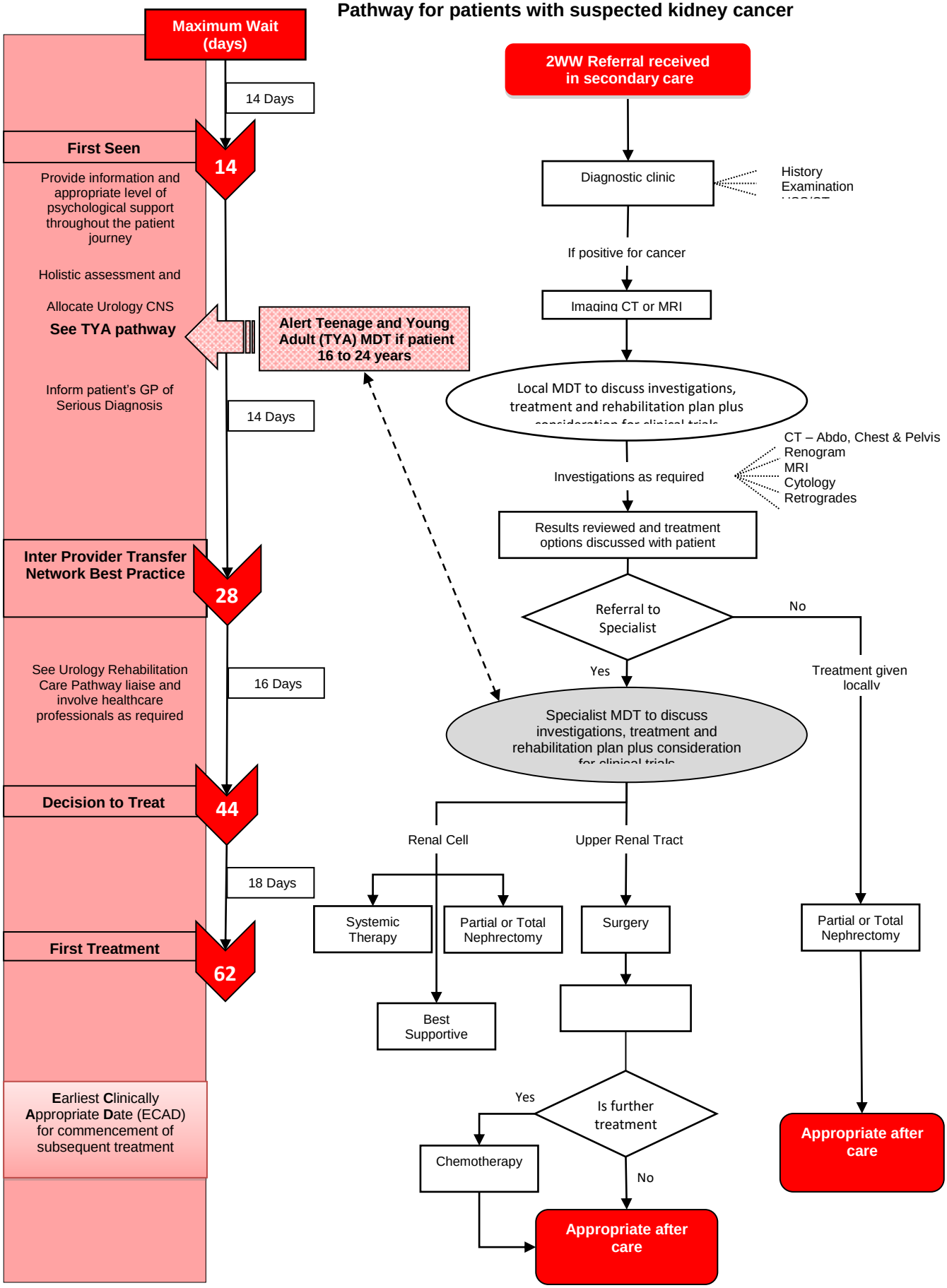
## Pathway for patients with suspected testicular cancer



## Pathway for patients with suspected penile cancer



## Pathway for patients with suspected kidney cancer



**Suspected Cancer in Adults Urology (2WW)**

NHS Northern Cancer Alliance

Date of referral letter: **Short date letter merged**

| Name | **Full Name** | DOB | **Date of Birth** | NHS No | **NHS Number** |
|---|---|---|---|---|---|

**Attach this form to the e-referral within 24 hours**

**If the ERS is not available, please send this form AND the 'Referral header sheet' by secure email or FAX**

**DO NOT USE for benign urological conditions. All patients referred on a cancer pathway who do not have cancer will be excluded from the pathway, and ongoing management will be according to local policy.**

**If you have clinical suspicion of cancer but the patient's symptoms do not fit the referral criteria, please contact the relevant consultant for guidance – Do not use the 2WW process**

- ☐ Patient has been informed that this is an urgent referral for suspected cancer
- ☐ The patient is available and willing to attend hospital for urgent tests/appointment within 14 days
- ☐ The patient has been given the 2WWPatient information Leaflet

Hyperlink to: **NICE GUIDANCE** **Patient info leaflet including easy read**

**NICE Guidance**

| | | | | | |
|---|---|---|---|---|---|
| **Suspected Cancer** | ALL patients must have had a blood test for **eGFR within 2 months** of this referral | | | | |
| | **Haematuria in Men – exclude prostate cancer by checking PSA and DRE** | | | | |
| **Bladder/ Renal** | ☐ Visible haematuria over 45 without UTI or recurs after treatment for UTI | | | | |
| | ☐ Non-visible haematuria without UTI – AGED OVER 60 **and DYSURIA** | | | | |
| | ☐ Non-visible haematuria without UTI – AGED OVER 60 **and RAISED WCC** | | | | |
| | ☐ Abdominal mass thought to be arising from the urinary tract found on imaging | | | | |
| **Testicular** | ☐ A suspicious lump or swelling in the body of the testis (not epididymis) | | | | |
| **Prostate** | ☐ Elevated or rising PSA compared to age specific range (PSA estimation should not be performed in presence of urinary tract infection) **WAIT 8 weeks before checking PSA after confirmed UTI** | | | | |
| | ☐ | Aged <50 | >2.5 ng/ml | | |
| | ☐ | Aged 50 -59 | >3.0 ng/ml | | |
| | ☐ | Aged 60 - 69 | >4.0 ng/ml | | |
| | ☐ | Aged 70 - 79 | >6.5 ng/ml | | |
| | ☐ | Aged 80 and over | >20 ng/ml | | |
| | ☐ With a hard irregular prostate **PSA must be sent before clinic appointment** | | | | |
| **MRI Checklist For PROSTATE referrals** | **DOES THE PATIENT HAVE THESE CONDITIONS?** | | | **NO** | **YES** |
| | Pacemaker | | | ☐ | ☐ |
| | Cranial aneurysm clip/implanted stent, filter or coil | | | ☐ | ☐ |
| | Orbital/facial metallic fragments | | | ☐ | ☐ |
| | Any implanted devices or prostheses | | | ☐ | ☐ |
| **Penile** | ☐ Progressive ulceration or a mass in the glans or prepuce but can involve the skin on the penile shaft, or unexplained or persistent symptoms affecting the foreskin or glans | | | | |
| **Consider NON URGENT referral for recurrent or persistent UTI in patients over 60 years** | | | | | |

☐ **Please indicate if this patient has had a previous 2WW referral to Urology**

**Reason for Referral – Compulsory** The clinical information is essential to safe and effective care of your patient

| Performance Status | | | |
|---|---|---|---|
| | ☐ | 0 | Fully active |
| | ☐ | 1 | Cannot carry out heavy physical work |
| | ☐ | 2 | Up and about more than half the day and can look after yourself |
| | ☐ | 3 | In bed or sitting in a chair for more than half the day and need help in looking after yourself |
| | ☐ | 4 | In bed or a chair all the time and need a lot of looking after |

| Description | Y | N | Description | Y | N |
|---|---|---|---|---|---|
| Anticoagulants including NOACs | ☐ | ☐ | Metformin | ☐ | ☐ |
| Antiplatelet e.g. Clopidogrel, Prasugrel | ☐ | ☐ | Insulin/Sulfonylureas | ☐ | ☐ |

| | | |
|---|---|---|
| **Cardiac:** | ☐ | Poorly controlled Angina/MI **within 3 months** |
| | ☐ | Prosthetic valve replacement, previous SBE or vascular graft **within one year** |
| **Diabetes :** | ☐ | |

**History of IHD, Diabetes and CKD:**

**NB: Information below only displays latest recording, Full list is displayed in Patient Medical History**

: Ischaemic heart disease...

**WEIGHT:** Single Code Entry: O/E - weight Single Code Entry: O/E - weight Single Code Entry: O/E - weight

## Blood tests within last 2 months – REQUIRED

**Referral may be rejected if there is no evidence that these have been done**

| **PSA** | ☐ **Requested** **Date:** | |
|---|---|---|
| PSA latest in 2 months | Single Code Entry: Prostate specific antigen... | Single Code Entry: Prostate specific antigen... |
| PSA last 3 results | Single Code Entry: Prostate specific antigen...<br>Single Code Entry: Prostate specific antigen...<br>Single Code Entry: Prostate specific antigen... | Single Code Entry: Prostate specific antigen...<br>Single Code Entry: Prostate specific antigen...<br>Single Code Entry: Prostate specific antigen... |

| **U&Es** | ☐ **Requested** **Date:** | | | |
|---|---|---|---|---|
| | **Result within last 2 months** | | **Latest Result** | |
| Sodium | Single Code Entry: Serum sodium | Single Code Entry: Serum sodium | Single Code Entry: Serum sodium | Single Code Entry: Serum sodium |
| Potassium | Single Code Entry: Serum potassium | Single Code Entry: Serum potassium | Single Code Entry: Serum potassium | Single Code Entry: Serum potassium |
| Urea | Single Code Entry: Serum urea level | Single Code Entry: Serum urea level | Single Code Entry: Serum urea level | Single Code Entry: Serum urea level |
| Creatinine | Single Code Entry: Serum creatinine | Single Code Entry: Serum creatinine | Single Code Entry: Serum creatinine | Single Code Entry: Serum creatinine |

**eGFR** result within last 2 months ☐ **Requested** **Date:**

| | | | |
|---|---|---|---|
| Single Code Entry: eGFR using creatinine (CKD-EPI) per 1.73 square metres... | Single Code Entry: eGFR | Single Code Entry: eGFR | Single Code Entry: eGFR using creatinine (CKD-EPI) per 1.73 |

**eGFR** latest result

| | | | |
|---|---|---|---|
| Single Code Entry: eGFR using creatinine (CKD-EPI) per 1.73 square metres... | Single Code Entry: eGFR | Single Code Entry: eGFR | Single Code Entry: eGFR using creatinine (CKD-EPI) per 1.73 |

Title Given Name Surname Date of Birth NHS Number

## Referrer details

| | | | |
|---|---|---|---|
| Name of Referrer: | | Date of Referral: | **Short date letter merged** |
| **Referring Organisation**<br>**Organisation Name, Organisation Full Address (single line)**<br>Tel: **Organisation Telephone Number**<br>Email: **Organisation E-mail Address**<br>Fax: **Organisation Fax Number** | | **GP details**<br>**Usual GP Full Name**<br>**Usual GP Organisation Name, Usual GP Full Address (single line)**<br>Tel: **Usual GP Phone Number**<br>Fax: **Usual GP Fax Number** | |
| Name of GP to address correspondence to, if different to accountable GP: | | | |

## Patient details

| | | | | | |
|---|---|---|---|---|---|
| Name: | **Full Name** | | Address: | **Home Full Address (stacked)** | |
| Gender: | **Gender(full)** | | | | |
| DOB and Age | **Date of Birth** Age: **Age** | | | | |
| NHS number: | **NHS Number** | | | | |
| Patient Contacts | Home: | **Patient Home Telephone** | Mobile: | **Patient Mobile Telephone** | |
| | Work: | **Patient Work Telephone** | Email: | **Patient E-mail Address** | |
| | **Carer/Advocate:** The patient has confirmed the following person should be included in correspondence – Name: Contact Details: | | | | |
| Contact Consent: | ☐ Can leave message on answer machine<br>☐ Can contact by text<br>☐ Can contact by Email | | NB: Not all services use Texts or Emails as a method of communication. | | |
| Ethnicity: | **Ethnic Origin** | | | | |
| Interpreter: | ☐ **Yes** Language: **Single Code Entry: Main spoken language** | | | | |
| Accessibility Needs: | ☐ Wheelchair access<br>☐ Deaf **Single Code Entry: Deafness**<br>☐ Registered Blind **Single Code Entry: Registered blind**<br>☐ Learning Disability **Single Code Entry: On learning disability register Single Code Entry: [X]Specific developmental disorders of scholastic skills**<br>☐ Other disability needing consideration<br>☐ Accompanied by Carer | | | | |
| Risks: | ☐ Vulnerable Adult (details below, if any recording in last 3 years) **Single Code Entry: Vulnerable adult Single Code Entry: Adult no longer vulnerable Single Code Entry: Failed or difficult intubation**<br>Other: | | | | |
| Other:<br>**Single Code Entry: Military veteran Single Code Entry: Left military service Single Code Entry: History relating to military service Single Code Entry: Occupation history**<br>**Single Code Entry: Has a carer Single Code Entry: Is no longer a carer Single Code Entry: Is a carer Single Code Entry: Carer** | | | | | |

## Accessible Information

Communication Support: Uses a legal advocate...
Professional Required: Interpreter needed - British Sign Language...
Contact Method: Requires contact by telephone...
Information Format: Requires information verbally...

If you have any problem with this form or suggested changes, please control & click here to open direct email. (NB: NOT TO BE USED FOR REFERRING A PATIENT) 2WW NCA UROLOGY Referral Form – EMIS Web V3 Gateshead April 2018

**To be completed by the Data Team** (Insert Dates)
**Received: / / First Appointment booked: / /**
**First Appointment date: / / 1st seen: / /**
**Specify reason if not seen on 1st appointment:**

Title Given Name Surname Date of Birth NHS Number

| **Diagnosis:** **Malignant** ☐ **Benign** ☐ |
|---|

## GUIDELINES FOR TEENAGE AND YOUNG ADULTS

### Teenage and Young Adults Peer Review Measures (Functions of the Network Site Specific Groups for TYA)

### 1. Teenage and Young Adult Pathway for initial Management

The EAG has received the document named 'NCA Teenage and Young Adult Cancer Pathway Guidance Paper' and agrees to follow the generic TYA Pathway with any site specific variations to be documented. Please see Appendix 1 for pathway.

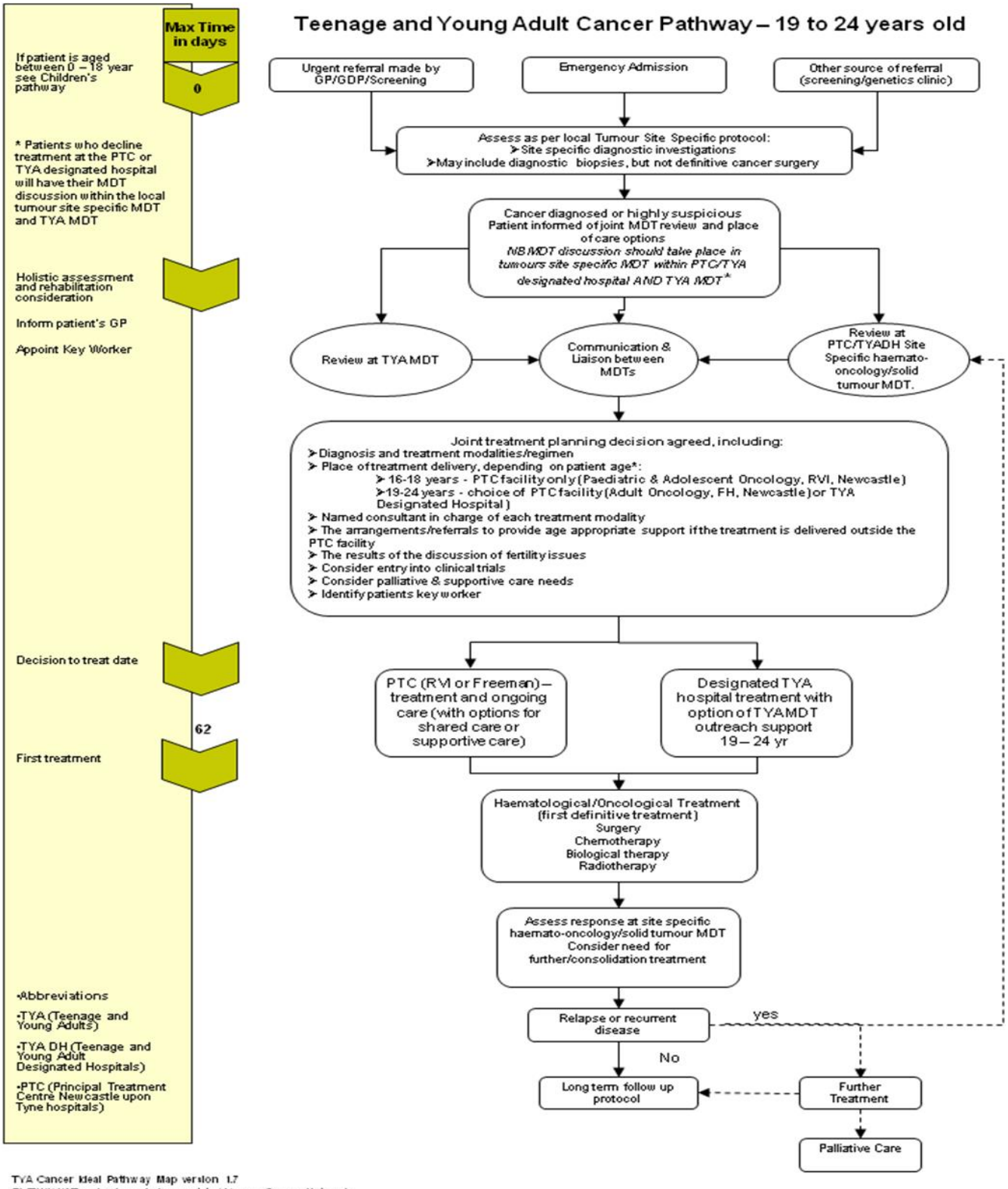
### 2. Teenage and Young Adult Pathway for Follow up on completion of first line treatment

The EAG has received the document named 'NCA Teenage and Young Adult Cancer Follow up Pathway on completion of first line treatment Paper' and agrees to follow the generic TYA Pathway with any site specific variations to be documented. Please see Appendix 1 for pathway.

### 3. Pathways for cases involving Specialised NHS services (Only Gynae and Sarcoma)

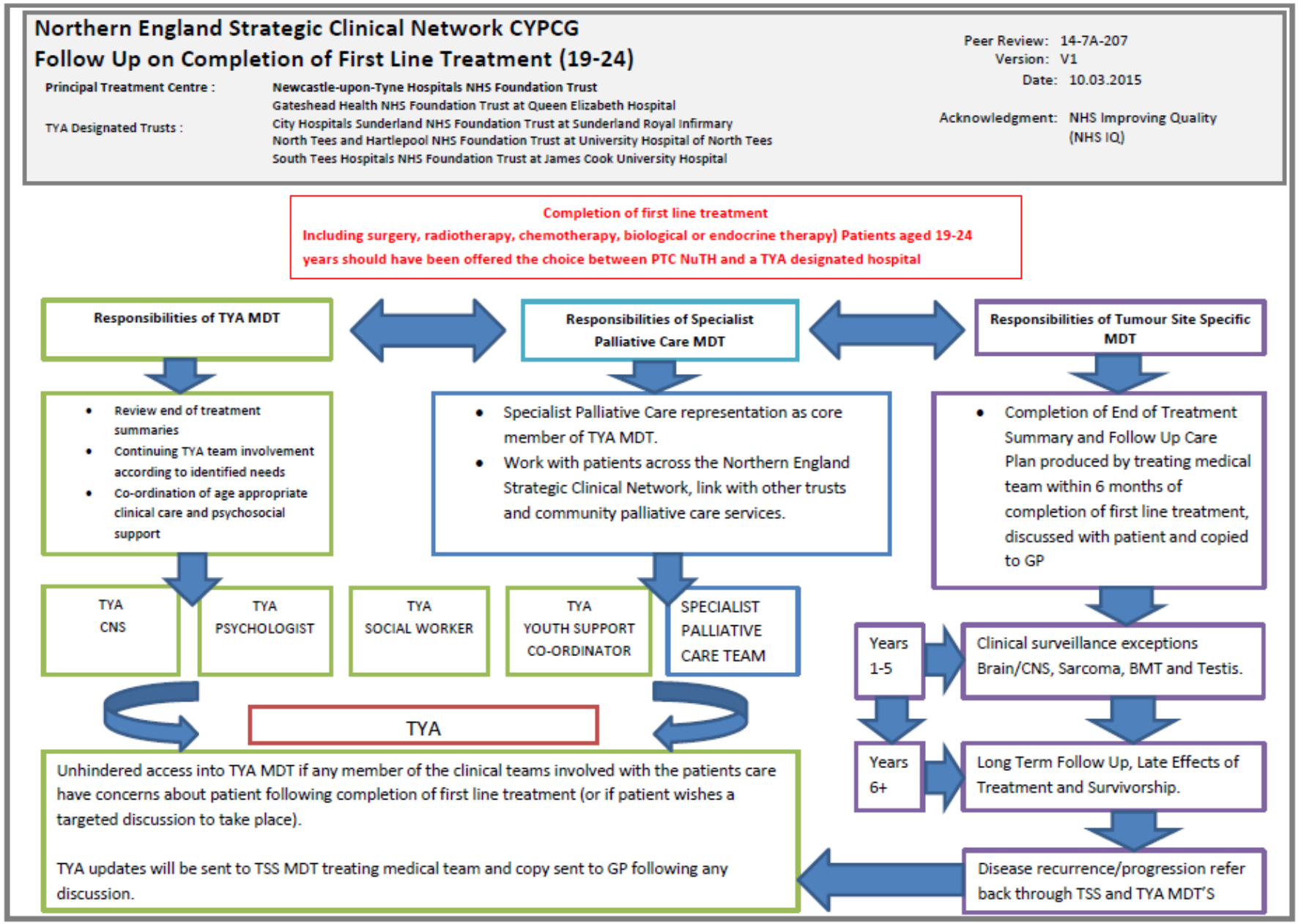
The Gynae EAG and SAG reviewed and agreed the Specialised NHS Service pathway for patient's age 16-24 years. This is attached in Appendix 2.

## Appendix 1 – Teenage and Young Adult Pathway for initial Management




TYA Cancer Ideal Pathway Map version 1.7
EL/TH/KJ/ST and acknowledgement to Wessex Cancer Network

## TYA Follow up on completion of first line treatment



| Contact Information | MDT RESPONSIBILITIES | | | Transition to TYA Transition to Adult |
|---|---|---|---|---|
| | TYA MDT | SPECIALIST PALLIATIVE CARE MDT | TUMOUR SITE SPECIFIC MDT | |
| These are the trusts that are designated to treat TYA patients within the Northern Region Strategic Clinical Network:<br><br>PTC: Newcastle-upon-Tyne Hospitals NHS Foundation Trust — 16-18 Great North Children's Hospital. 19-24 Freeman Hospital<br>Switchboard 0191 2336161<br><br>DH: City Hospitals Sunderland Foundation Trust Sunderland Royal Infirmary — 19-24 only<br>Switchboard 0191 5656256<br><br>DH: Gateshead Health NHS Hospitals Trust Queen Elizabeth Hospital — 19-24 only<br>Switchboard 0191 4820000<br><br>*DH: North Tees and Hartlepool NHS Foundation Trust* University Hospital of North Tees — 19-24 only<br>Switchboard 01642 617617<br><br>*DH:South Tees Hospitals NHS Foundation Trust* James Cook University Hospital — 19-24 only<br>Switchboard 01642 850850 | Location: NuTH<br>Time: Thursdays, 12:00-14:00<br>Lead Clinician: Dr Emma Lethbridge<br>Lead Nurse: Mr David Short<br>Coordinator: Sharon Buckley<br>Phone: 0191 233 6161<br>email: tnu.tr.tyamdt@nhs.net<br><br><u>TYA MDT</u><br>Review end of treatment summary<br><u>TYA CNS</u><br>• Co-ordination of clinical care.<br>• Acts as point of contact/reference<br><u>TYA Psychologist</u><br>• Continue to provide level 3+4 support according to need.<br>• Involvement in end of treatment/ Survivorship clinic/event.<br><u>TYA Social Worker</u><br>• Continue to provide support according to need<br>• Introductory letter sent with information and offer of grant at time of diagnosis and relapse<br>• More in depth service offered based on assessed need<br><u>TYA Youth Support Co-ordinator</u><br>• Continue to invite patients to support activities for up to 2 years post first line treatment<br>• Involvement in end of treatment/ Survivorship clinic/event | Location: NCCC Freeman Hospital<br>Time: Wednesdays, 09:30-11:30<br>Lead Clinician: Dr M. Comiskey<br>Coordinator: Kerry Halliday<br>Phone: 0191 2138606<br>email: kerry.halliday@nuth.nhs.uk<br><br>1. Specialist Palliative Care representation as core member of TYA MDT.<br>2. All site specific MDT outcomes notified to palliative care lead clinician.<br>3. Patients reviewed at any point along the pathway (diagnosis, relapse, long term follow up, end of life care).<br>4. Holistic needs assessment to include family/carers.<br>5. Work with patients across the Northern England Strategic Clinical Network, link with other trusts and community palliative care services.<br>6. MDT outcomes documented on Somerset. | • Completion of end of treatment summary and follow up care plan produced by treating medical team within 6 months of completion of first line treatment, discussed with patient and copy to GP<br>Treatment Summaries should be assigned a level of care.<br>• Level 1: Supported self-management with contact info about how to reconnect back into LTFU.<br>• Level 2: Planned coordinated care with support from the primary treatment centre and local services. Low level care required such as monitoring with echocardiograms.<br>• Level 3: Complex care requiring follow-up in the long-term follow up clinic usually requiring input from the multi-disciplinary team.<br>YEARS 1-5<br>• Clinical surveillance for disease recurrence and treatment toxicity monitoring (including history, clinical examination, laboratory investigations, imaging studies and invasive procedures where indicated according to tumour site specific follow up protocols)<br>YEARS 6+<br>• Long term follow up for late effects of treatment, consider survivorship issues<br>• Consider referral to long term follow up/late effects MDT if disease free after 5 years from completion of first line treatment<br>• Consider extended clinical follow up to 10 years+ in selected patient groups as defined by the TSS MDT's (e.g. brain/CNS, sarcoma, BMT, testis) | Transition into adult services is planned for and discussed with patients well in advance. Transition at a time of crisis e.g. relapse, intensive chemotherapy will be avoided wherever possible. Transition will be facilitated by the keyworkers |

## Contact Details

| List of designated MDTs at Principal Treatment Centre and TYA Designated Hospitals (19 - 24 years) | | | | |
|---|---|---|---|---|
| **Name of NHS Trust and designated hospital site** | **Name of MDT** | **TYA Lead Clinician** | **TYA Lead Nurse** | **Contact Number** |
| **Principal Treatment Centre** | **All MDTs:**<br>Breast<br>Colorectal<br>Gynaeoncology (diagnostic)<br>Haematology<br>Head & Neck<br>Lung<br>Neurooncology (Brain/Spinal, Pituitary, Skull Base)<br>Sarcoma<br>Specialist Skin<br>Specialist pancreatic<br>Supra T-cell Lymphoma<br>Teenage and Young Adult MDT<br>Testicular<br>Thyroid<br>Specialist Upper GI<br>Specialist Urology | Dr Emma Lethbridge | David Short<br>david.short@nuth.nhs.uk | 0191 2448858<br>(Dect48858) |
| **Gateshead Health NHS Foundation Trust - at Queen Elizabeth Hospital** | Specialist Gynaeoncology | Ms Christine Ang | rachelmugnai@nhs.net | 0191 4456148 |
| **City Hospitals Sunderland NHS Foundation Trust - at Sunderland Royal Hospital** | Haematology<br>Specialist Urology *(testicular only)*<br>Thyroid Surgery | Dr Scott Marshall | Faye Laverick<br>faye.armstrong@chsft.nhs.uk | 0191 5656256 |
| **North Tees and Hartlepool NHS Foundation Trust - at University Hospital of North Tees** | **All MDTs:**<br>Haematology<br>Local Urology<br>Thyroid<br>Breast<br>Colorectal<br>Lung<br>Local Upper GI | Dr Padmaja Lokireddy | Kat Dawson<br>Katherine.Dawson@nth.nhs.uk | 01642 617617 ext 24697 |
| **South Tees Hospital NHS Foundation Trust - at James Cook University Hospital** | **All MDTs:**<br>Specialist Gynaeoncology<br>Breast<br>Colorectal<br>Haematology<br>Head & Neck<br>Lung<br>Neurooncology<br>Specialist Skin<br>Thyroid<br>Specialist Upper GI<br>Specialist Urology | Dr Dianne Plews | Jill Linton<br>jill.linton@nhs.net | 01642 854381 |

## Appendix 2 – NHS Specialised Services Pathway

### Specialist Teams for Treatment of Urological Cancers

The specialist teams in each designated hospital should counsel patients with potentially curative muscle invasive bladder cancer (clinical T2 and mobile T3 tumours) and organ confined prostate cancer with referral being made through the appropriate specialist MDT.

Patients with high risk superficial bladder cancer should be discussed at the specialist MDT and in appropriate cases should be considered for radical surgical treatment. Patients requiring Intravesical immunotherapy or chemotherapy can have this supervised by their local MDT. Patients with high grade recurrence following BCG treatment should be considered for radical surgical treatment if appropriate, such patients should be referred to the specialist MDT.

Patients who are potentially eligible for complex surgery included caval thrombectomy, resection of local recurrence, metastectomy or nephron sparing surgery will be discussed with the specialist MDT and where appropriate patients will be assessed and surgery offered by the specialist MDT.

| CCG populations | Designated Hospital | Lead Clinician |
|---|---|---|
| Newcastle West<br>Newcastle North and East<br>Northumberland<br>North Tyneside<br>Gateshead<br>Cumbria | Newcastle upon Tyne Hospitals NHS Foundation Trust<br><br>Freeman Hospital | Mr M Johnson<br>0191 |
| South Tyneside<br>Sunderland<br>North Durham<br>(Easington 60%) | City Hospitals Sunderland NHS Foundation Trust<br>Sunderland Royal Hospital | Mr K Sahadevan<br>0191 5656256 |
| Durham Dales, Easington & Sedgefield (excl Easington 60%)<br>Darlington<br>South Tees<br>Hartlepool and Stockton<br>Hambleton, Richmondshire & Whitley | South Tees Hospitals Trust<br><br>James Cook University Hospital | Mr B Chaplin<br>01642 850850 |

### Specialist Teams for Referral and Treatment of Testicular Cancers

| CCG | Population * | Designated Hospital | Lead Clinician |
|---|---|---|---|
| Newcastle | 293 | Newcastle upon Tyne Hospitals NHS Foundation Trust<br><br>Freeman Hospital | Dr Sophie Haney<br>0191 2138466 |
| Northumberland | 319 | | |
| North Tyneside | 204 | | |
| Gateshead | 205 | | |
| South Tyneside | 150 | | |
| Sunderland | 277 | | |
| Durham Dales, Easington & Sedgefield | 275 | | |
| North Durham | 249 | | |
| Darlington | 106 | | |

| | | | |
|---|---|---|---|
| South Tees | 277 | | |
| Hartlepool & Stockton | 290 | | |
| Hambleton, Richmondshire & Whitby | 153 | Total population | |
| North Cumbria | 318 | **3,116** | |

Source - Mid-2017 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk

The specialist MDT at James Cook and Sunderland video conference to the MDT held at Newcastle. A detailed clinical proforma is used for all patients and is sent to Newcastle for each patient discussed.

**Supranetwork Team for Referral and Treatment of Penile Cancer**

Radiotherapy and Chemotherapy for penile cancer is delivered by James Cook University Hospital, Freeman, and North Cumbria University Hospital.

| CCG | Population * | Designated Hospital | Lead Clinician |
|---|---|---|---|
| Newcastle | 293 | City Hospitals Sunderland NHS Foundation Trust | Mr P Keegan |
| Northumberland | 319 | | |
| North Tyneside | 204 | | |
| Gateshead | 205 | | |
| South Tyneside | 150 | | |
| Sunderland | 277 | | |
| Durham Dales, Easington & Sedgefield | 275 | | |
| North Durham | 249 | | |
| Darlington | 106 | | |
| South Tees | 277 | | |
| Hartlepool & Stockton | 290 | | |
| Hambleton, Richmondshire & Whitby | 153 | Total population | |
| North Cumbria | 318 | **3,116** | |

Source - Mid-2017 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk

**Specialist Teams - Counselling**

To enable patients with penile cancer to select a primary treatment option, counselling services are provided at City Hospitals Sunderland by the Clinical Nurse Specialist Fiona Geary supported by other CNS colleagues.

## PALLIATIVE CARE

The Network wide publication '*Palliative and End of Life Care Guidelines: Symptom control for cancer and non-cancer patients'* is available either as a hardcopy booklet or downloadable via the Northern Cancer Alliance website where other guidelines and links will be available.

http://www.northerncanceralliance.nhs.uk/pathway/palliative-and-end-of-life-care/end-of-life-care/

Palliative and End of Life Care must be at the heart of an integrated approach to care and support the national "Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020" is being promoted network wide by the Networks Supportive, palliative and End of Life Care Group. Copies of the document are available on the link detailed below;

http://endoflifecareambitions.org.uk/

We also feel it can be helpful to give an explanation of some of the different terms often encountered when 'palliative care' is discussed.

**Supportive Care**
"Umbrella" term for all services which help patient and family to cope with the condition and its treatment – from pre-diagnosis, through diagnosis and treatment, to cure, continuing illness or death and into bereavement. Aims to help patient maximise benefits of treatment and to live as well as possible with the effects of the disease should be given equal priority alongside diagnosis and treatment.

Supportive care includes:
- Self help and support
- User involvement
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- End of life and bereavement care

**Palliative Care**
Part of, and embraces many elements of, supportive care.

Defined (NICE 2004) thus: "the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments".

Key features of palliative care:

- Affirm life and regard dying as a normal process.
- Provide relief from pain and other distressing symptoms.
- Integrate the psychological and spiritual aspects of patient care.
- Offer a support system to help patients live as actively as possible until death.
- Offer a support system to help the family cope during the patient's illness and in their own bereavement.

General Palliative Care is that care delivered by health professionals whose main role is not working with palliative care patients but who necessarily come across these patients in their work. This care is therefore delivered by a majority of healthcare professionals.

Specialist Palliative Care is delivered by professionals for whom the majority of their working role is in managing patients with palliative care needs. These professionals would therefore manage, or be advising in the care of, patients and their families whose needs are more complex, challenging, time consuming and refractory to usual input, and where this demand exceeds that which can reasonably be expected to be delivered by a professional whose main role is in another discipline.

**End of Life Care**

An approach that enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

Key features of end of life care:

- Anticipation and management of deterioration in the patient's condition
- Advance care planning in accordance with patient preferences as detailed in the *Deciding right* Guidance which is available via this link
- Patient choice about place of care and death
- Effective co-ordination of care across all teams and providers of care (in statutory, voluntary and independent sectors) who are involved in the care of patient and family

**Care of the Dying**

- Care of the patient and family in the last hours and days of life.
- Incorporates four key domains of care, physical, psychological, social and spiritual
- Supports the family through this phase and into bereavement.

**References**


- Department of Health (2007) Operating Framework 2007/08: PCT baseline review of services for end of life care
- National Council for Palliative Care Palliative Care Explained (2007)
- National Institute for Clinical Excellence (2004) Improving supportive and palliative care for adults with cancer. The Manual. London

## LIVING WITH AND BEYOND CANCER

Achieving World Class Cancer Outcomes, A Strategy for England 2015 – 2020, emphasises the importance of improving quality of life for people after cancer treatment. This was further supported by the Secretary of State for Health when he committed to ensuring that every cancer patient receives the interventions known as the 'Recovery Package', and support stratified follow-up pathways by 2020, as set out in the cancer strategy.

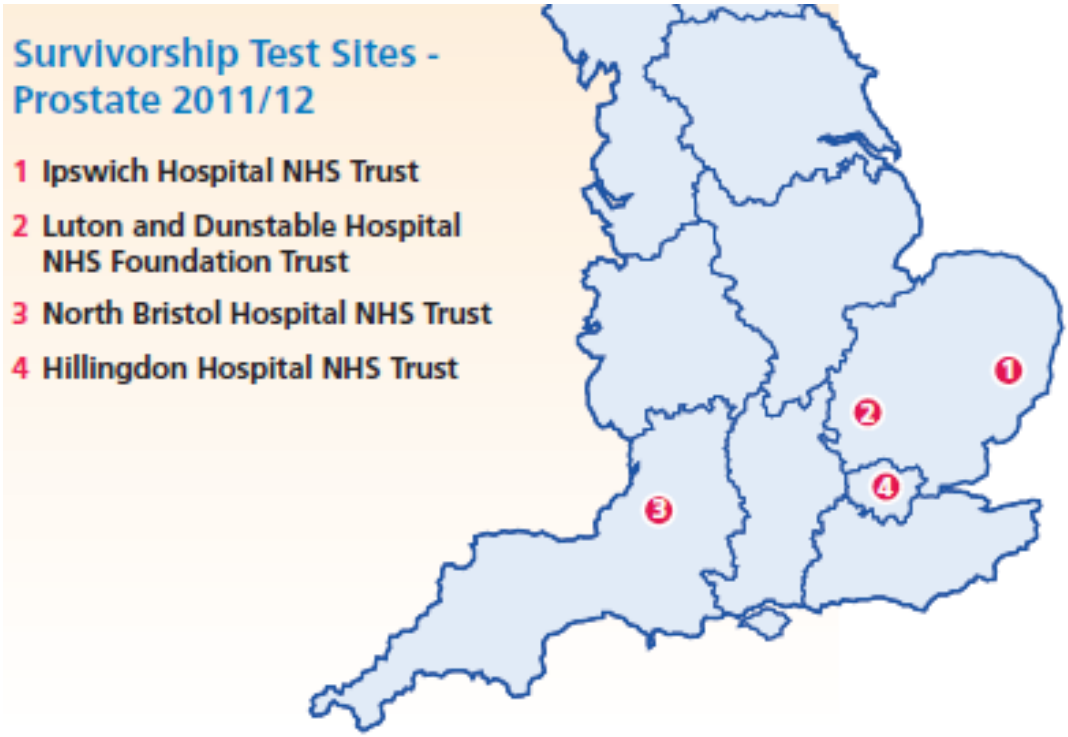
We will endeavour to implement the Recovery Package, which is a set of essential interventions designed to deliver a person-centred approach to care for people affected by cancer. This includes:

- Treatment Summary
- Holistic Needs Assessment (HNA) and care planning
- Health and wellbeing events
- Cancer care review

**PROSTATE CANCER STRATIFIED FOLLOW UP**

Prostate cancer is the most common cancer in men in the UK. Majority (84%) of men diagnosed with prostate cancer do live beyond 10 years. The incidence and prevalence of prostate cancer continues to increase thereby putting pressure on available resources. Moreover, current practice of prostate cancer management is not meeting all of the needs of those living with and beyond cancer.

To this effect, NHS improvement has been working as part of the National Cancer Survivorship Initiative (NCSI) to improve the quality and effectiveness of care and support to those living with and beyond cancer. This initiative tested stratified prostate cancer follow up at four test sites.




The interesting findings from the pilot were

- Majority (80%) of patients felt fairly or very confident in managing their own health
- Patients required better information on signs and symptoms to look out for
- Better management of erectile dysfunction
- Better continence management

These findings add to the existing body of information that strengthens the approach to better inform our patients and primary care practitioners, perform a thorough assessment of patient's needs, risk assess and arrange appropriate follow up.

The aim of Norther Cancer Alliance is aligned to National Cancer Survivorship Initiatives supported by NHS Improvement (Cancer) and NICE guidance, is to ensure

- All individuals diagnosed with prostate cancer receive personalised information and appropriate support to enable them to live actively and well following the end of their cancer treatment.
- A safe, robust and transparent system is utilised to manage prostate cancer surveillance and ongoing care/support.
- Timely, safe and appropriate systems back into specialist services are in place in the event that a concern arises.
- Each individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.
- The pathway incorporates NCSI Recovery Package interventions (Holistic Needs Assessment and care plan, Treatment Summary, Cancer Care Review, Health and Wellbeing event) to improve outcomes and co-ordination of care.

To this effect, following risk stratification and clinical parameters were discussed and agreed between the representatives from regional units.

## PATIENTS AFTER RADICAL PROSTATECTOMY

It is understood that patients undergoing prostatectomy will be looked after as currently with more formal needs assessment and stratified follow up. If discharge criteria are met then care will be transferred over to primary care for ongoing follow up. The criteria is as follows:

- Discharge criteria
    - PSA <0.1 or PSA stable under 0.1 (depending on the analyser), with no rise during the hospital follow up
    - Functional, social and psychological issues are addressed and satisfied
    - No new symptoms to address
    - Understands the follow schedule required
    - Health needs assessment repeated
    - Treatment completion summary given to patient and GP

### Risk stratification following final histology

- Low risk
    - All patients with organ confined prostate cancer with negative margins and focal positive margins (pT2 R0 and focal R1)
    - All patients with extracapsular extension with negative margins (pT3a R0)
    - All patients with negative nodes (N0)
- High risk
    - All patients with organ confined prostate cancer with extensive positive margin (pT2 R1 , >3mm positive margin)
    - All patients with extracapsular extension with any positive margin (pT3a R1)
    - All patients with seminal vesicle invasion irrespective of margins positivity
    - All patients with positive nodes (N1)

### Risk stratified follow up

- Low risk
    - First outpatient appointment (OPA) at a maximum of 3 months for histology. (It is understood that local units may manage this differently either via a letter or CNS led clinic etc.)
    - Second OPA and third OPA at 4 monthly intervals
    - Discharge to GP at 12 months (after 3$^{rd}$ post op appointment) if discharge criteria met with following recommendation
        - PSA to be measured on a 4 monthly basis for the first two years, 6 monthly for further 2 years and then yearly for 6 further years
- High risk
    - First outpatient appointment (OPA) at 3 months for histology
    - Subsequent OPA at 4 monthly intervals for two years in total
    - Discharge to GP at 24 months (after 6$^{th}$ post op OPA) if discharge criteria met and with following recommendation
        - PSA to be measured on a 4 monthly basis for the first two years, 6 monthly for further 3 years and then yearly for 5 further years
        - Any PSA rise should be followed up by a further measurement between 6-8 weeks

**Primary care follow up notes**

1. Please follow recommended schedule at discharge for PSA monitoring
2. Any PSA rise should be followed up by a further measurement between 6-8 weeks
3. Following criteria should prompt a referral via urgent referral to the respective units (not a 2ww referral)
    a. If PSA rises to 0.2 ng/ml
    b. Any new frank haematuria, new lower urinary tract symptoms not controlled by conventional treatment
    c. New unexplained bone pain lasting more than 6 weeks that has not improved with analgesia
4. Please refer to individualized end of treatment summary for your patients

## PATIENTS AFTER RADICAL RADIOTHERAPY

With advances in radiology in general and evidence emerging to support aggressive local treatment, increasing number of patients are being treated with radiotherapy. Although risk stratification according to stage of disease is practical, given the various salvage treatment options available, it was felt that reassessment of patients if and when they have either clinical or biochemical recurrence was thought to be prudent.

**Stratified follow up**

On completion of RT and first post RT appointment with oncology, patients are transferred on to urology follow up. It is essential to have an end of treatment summary and HNA performed at discharge from oncology to identify any ongoing urgent needs and length of hormonal treatment.

- First out patients appointment (OPA) at 4 months
- Subsequent appointments at 6 monthly interval until 1 year after hormone manipulation has been stopped
- Discharge to GP if PSA measurements have not shown an increase (nadir PSA value to be clearly stated on discharge summary) and HNA satisfactory and treatment summary completed

**Primary care follow up**

1. Following criteria should prompt a referral via an urgent referral pathway (not a 2WW referral)
    a. If the PSA is 2ng/ml more than the nadir PSA (nadir= the lowest PSA reading following RT). Please do note that the patients have their prostates in situ and need to ensure there is no UTI or any instrumentation that could rise PSA level prior to re-referral
    b. Please refer to end of treatment plan for alternative PSA threshold for your patient
    c. Any new frank haematuria, new lower urinary tract symptoms not controlled by conventional treatment
    d. New unexplained bone pain lasting more than 6 weeks that has not improved with analgesia
2. Please refer to individualized end of treatment summary for your patients

## ACTIVE SURVEILLANCE

This area of practice felt to be the most complex and quite varied practices prevail amongst urologists. It was agreed that there will be local variations and the broad concept of stratified follow up was agreed.

### Follow up schedule

- PSA testing 4 monthly for 2 years, 6 monthly for 3 further years
- Yearly DRE
- MRI with or without biopsies at local unit discretion depending on the initial biopsy strategy. The frequency between 1 and 4 years (taking into account MRI capacity available locally)
- Assess patient wishes, choice of treatment suitable for that particular patient and plan discharge
- Discharge to primary care with individualized PSA threshold (PSA density, doubling time, PSA velocity could be used)
- Please refer to individualized end of treatment summary for your patients

## WATCHFUL WAITING

Following diagnosis, a HNA, patient wishes, treatment modalities discussed with patient.

### Follow up schedule

- OPA at 6 month from diagnosis
    - Assess HNA, discuss end of treatment summary
    - Discharge if PSA < 20% increase, no symptoms to palliate
    -

### Primary care follow up

1. Assess PSA on a 6 monthly basis, could be every year depending the rate of rise
2. Any of the following criteria should prompt an urgent (not a 2ww referral)
    a. If the PSA is >50ng/ml. Please do note that the patients have their prostates in situ and need to ensure there is no UTI or any instrumentation that could rise PSA level prior to rereferral
    b. Alkaline phosphatase >200u and rising, associated with bone pain
    c. Any new frank haematuria, new lower urinary tract symptoms not controlled by conventional treatment
    d. New unexplained bone pain lasting more than 6 weeks that has not improved with analgesia
3. Please refer to individualized end of treatment summary for your patients

## HORMONE MANIPULATION

Majority of patients with metastatic disease require hormones. They do have significant side effects and we appreciate that HNA for this group of patients is particularly important and should include bone health, emotional and physical well being.

### Follow up schedule

- OPA at 6 month from diagnosis

- Assess HNA, discuss end of treatment summary
- Discharge if PSA shows >90% reduction, no symptoms to palliate

**Primary care follow up**

- Please refer to individualized end of treatment summary for your patients
- Assess PSA on a 6 monthly basis, could be every year depending the rate of rise. Please do note that the patients have their prostates in situ and need to ensure there is no UTI or any instrumentation that could rise PSA level prior to re-referral
- Any of the following criteria should prompt an urgent referral (not a 2ww referral)
  - If the PSA shows 3 consecutive rises (please refer to end of treatment plan for alternative PSA threshold)
  - Alkaline phosphatase >200u
  - Any new frank haematuria, new lower urinary tract symptoms not controlled by conventional treatment
  - New unexplained bone pain lasting more than 6 weeks that has not improved with analgesia

**References:**


1. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer
2. https://www.nice.org.uk/guidance/ng131

## CLINICAL TRIALS

In 2015 the Independent Cancer Taskforce published the report - Achieving World-Class Cancer Outcomes: a strategy for England 2015-2020. This acknowledges that “Research continues to be pivotal to developing our understanding and preventing, managing and curing cancer”.

The Service Network and the Clinical Research Network: North East and North Cumbria (CRN: NENC) will work collaboratively to promote integration of research into routine practice.

The CRN: NENC works towards achieving National Institute of Health Research (NIHR) CRN High Level and Specialty Objectives which include;

- To increase;
    1. the number of participants recruited into NIHR CRN Portfolio studies,
    2. the proportion of studies in the NIHR CRN Portfolio delivering to time and target,
    3. the number of commercial contract studies delivered through the NIHR CRN.
- To reduce the time taken to recruit first participant into NIHR CRN Portfolio studies.
- Delivering a portfolio of studies including challenging trials in support of national priorities.

The EAG will review NIHR CRN Portfolio activity within their specialty to identify strategies to support the above and to promote equity of access for patients in relation to research studies.

**APPENDIX 1 GUIDELINES FOR THE MANAGEMENT OF TESTICULAR TUMOURS**

# GUIDELINES FOR THE MANAGEMENT OF TESTICULAR TUMOURS

**Document Information**

| | |
|---|---|
| Title: | NCA Guidelines for the Management of Testicular Tumours |
| Authors: | David Thomas, Consultant Urologist |
| Circulation List: | Urology EAG |
| Contact Details: | Urology EAG Chair |
| Telephone: | 0191 2754743 |

***Version History:***

| | | | | | |
|---|---|---|---|---|---|
| Date: | February 2013 | Version: | v6.1 BEP amendment | Review Date: | May 2015 |
| | June 2019 | | Membership arrangements updated | | June 2021 |

**CONTENTS**

## INTRODUCTION

Broadly speaking the network follows the EAU guidelines with some minor local modifications. This document is a guideline for the management of patients with testicular tumours. It will act as an aid to health practitioners involved in management from primary care through referral, treatment and follow-up.

Testicular tumours are rare but important because they occur in the young. The peak incidence for teratoma is between 20 and 30 years and for seminoma between 30 and 40 years. Lymphoma of the testis occurs mostly in the over 60s.

Testicular tumours have an excellent overall prognosis with a 95% cure rate.

Seminoma presents as disease limited to the testis in over 80% of patients. Radiotherapy or adjuvant chemotherapy results in 5 year survivals of 98%.

Teratoma of the testis presents with metastatic disease in over 50% of patients. Those without metastases have an excellent prognosis. Some cases are managed by surveillance alone and others are offered chemotherapy.

Patients with metastases are grouped into prognostic categories using the International Germ Cell Consensus Classification (Appendix A). In summary:

- 56% of patients have a good prognosis (92% 5 year survival).
- 28% of patients have an intermediate prognosis (80% 5 year survival).
- 16% of patients have a poor prognosis (48% 5 year survival).

Standard treatment for metastatic disease is BEP chemotherapy (Bleomycin, Etoposide and Cisplatin). The EAG has agreed that all BEP chemotherapy will only be delivered at the specialist centres with referral from the Specialist MDTs. Surveillance for non-metastatic disease will continue at North Cumbria University Hospital, as will Carboplatin chemotherapy for seminomas. See Appendix E for updated protocols.

Patients are usually referred after orchidectomy on an urgent basis.

Testis cancer patients will normally be referred to the MDT (Multi Disciplinary Team) by urologists. Rarely direct referral from a general practitioner or Accident and Emergency department may occur.

A supra-network Specialist Multi Disciplinary Team covering the North East and North Cumbria has been established incorporating specialists from Freeman Hospital, James Cook University Hospital, Sunderland Infirmary and University Hospital North Cumbria. A video-conference meeting is held fortnightly.

## OUTCOME MEASURES

### Referral

All patients with a swelling in body of the testis should be referred urgently to an urologist.

All patients should be seen by an urologist within 2 weeks of referral.

### Investigations

All appropriate investigations are carried out at the first appointment with an urologist.

### Treatment

- **Pre-surgery**

Referral to an oncologist should be made prior to surgery in all patients where there is suspicion of metastatic disease.

Fertility should be considered prior to orchidectomy. Sperm cryopreservation may be appropriate particularly in patients with a solitary testis or an abnormal contralateral testis. Patients should be counselled regarding a testis prosthesis.

- **Surgery**

Orchidectomy shall occur within 14 days of GP referral.

Orchidectomy is carried out via an inguinal incision with division of the spermatic cord at the level of the internal inguinal ring.

Biopsy of the contralateral testis is only considered in individuals at a high risk of CIS according to EAU guidelines.

The option of a testicular prosthesis should be discussed with all patients prior to orchidectomy.

- **Post-surgery**

All staging investigations (i.e. histological review of tissue samples, CT scan chest, abdomen and pelvis and post-operative tumour markers) are organised by the urologist following orchidectomy.

- **Oncology Referral**

All patients should be referred to a designated oncologist from the Specialist MDT (see contacts, appendix F) following surgery, unless referred prior to surgery.

All patients fulfilling the criteria for urgent referral (as detailed on pages 7 and 8) should be referred directly to an Oncologist by telephone and should be seen within 24 hours of referral.

All **pathology** should be reported, and slides forwarded for review by multidisciplinary team histopathologists within 1 week of orchidectomy.

All **radiology** CT scans should be reported by the multidisciplinary team radiologists within 2 weeks of orchidectomy.

**Multidisciplinary Team Working**

All staging CT films must be reviewed at the SMDT.

All pathology must be reviewed by the designated SMDT pathologists within 2 weeks of orchidectomy.

All post-chemotherapy CT scans to assess response, suspected relapses and any complex cases where management is uncertain will be reviewed at the SMDT.

**Oncological Management**

All patients are seen by a designated oncologist within 2 weeks of orchidectomy.

Radiotherapy treatment should start within 4 weeks of a decision to treat.

Chemotherapy should start within 2 weeks of a decision to treat.

Urgent chemotherapy should start within 24-48 hours of referral to the oncologist.

All patients receiving Cisplatin chemotherapy should have an audiogram prior to treatment.

All patients receiving Bleomycin chemotherapy should have lung function tests prior to chemotherapy.

Sperm cryopreservation should be discussed with all patients before chemotherapy.

All patients receive written information regarding the intended treatment and its potential side effects.

**Management of Residual Masses after Chemotherapy – Teratoma**

All teratoma patients with a residual mass greater than 1cm on post-chemotherapy CT scan should be referred to a specialist surgeon (Mr Thomas or Mr Paez, Freeman Hospital))

## Follow-up Management

All patients are followed-up on protocol by the designated oncology team.

All patients at high risk of CIS in the remaining testicle, who elect not have a biopsy at time of orchidectomy, should be offered the opportunity to consider a contra-lateral biopsy 2 years following completion of any chemotherapy treatment and ultrasound review.

## Patient Care

All patients will be offered written information on their disease and its implications, treatment options and potential side effects.

All patients should have a contact number for the Nurse Practitioner given at their first appointment with the oncology team.

## Primary Care Team

GPs will be notified of treatment plans within 5 working days of first consultation with the oncologist.

GPs will be notified within 24 hours of a patient's discharge.

GPs will receive an evaluation of the patient's condition after each follow-up appointment.

## Membership Arrangements

MDT Co-ordinator: Anne Izatt, Cancer Services, Freeman Hospital, Ext 27304
Email: anne.izatt@nuth.nhs.uk

The Supra-Network Testicular MDT consists of the following core and extended members:

| Members | Name | Location | Specialising In | Cover |
|---|---|---|---|---|
| Urological Surgeons | Mr D J Thomas | Freeman | RPLND | Named Surgeons |
| | Mr E Paez | | | |
| Gen Surgery | Prof D Manas | | | |
| Cardiothoracic | Mr S Barnard | | | |
| Vascular Surgery | Mr T Lees | | | |
| Oncology Team | Dr I Pedley | NCCC | Clinical Oncology | Oncology Colleagues |
| | Dr R McMenemin | | | |
| | Dr Ansari | | | |
| | Dr A Azzabi | | Medical Oncology | |
| | Dr A Rathmell | JCUH | Clinical Oncology | |
| | Dr A Humphreys | | Medical Oncology | |
| | Dr Amin Rahman | Cumberland Infirmary | Clinical Oncology | |
| Pathology Team | Dr A L Sharif | RVI | Histopathology | Pathology Colleagues |
| | Dr A Hussein | | | |
| | Dr B Disep | | | |
| | Dr J Majo | | | |
| | Dr S Nagarajan | JCUH | | |
| | Dr A Mutton | | | |
| | Dr M Bhattacharjee | | | |
| | Dr M. Devaraj | | | |
| Radiology Team | Dr P Haslam | Freeman | Radiology | Radiology Colleagues |
| | Dr K Anderson | | | |
| | Dr G Naisby | JCUH | | |
| Specialist Nursing Team | Helen Showler | NCCC | Oncology | Nursing Colleagues |
| | Pauline Bagnall | North Tyneside | Uro-oncology | |
| | Lorraine Montgomery | Queen Elizabeth | | |
| | Susan Godfrey | Hexham | | |
| | Jill Ferguson | Wansbeck | | |
| | Susan Richardson | | | |
| | Mark Davis | Freeman | Tests-Urology | |
| Administrative Support | Anne Izatt | Freeman | MDT Co-ordinator | Cancer Services Team |
| | James Johnson | | Data Co-ordinator | |
| Extended Members | Sister Susan Besford | Hospice | Palliative Care | |
| | Sharon Erb | Freeman | Clinical Trials Officer | |

## REFERRAL GUIDELINES

Tumours of the testis can grow rapidly. Delay in referral for urological opinion adversely affects the long-term outcome for the patient and the intensity of treatment.

All patients suspected of having a testicular malignancy should be urgently referred for urological assessment and seen within 2 weeks (See Referral Guidelines for Suspected Cancer Consultation Document, DOH Steering Group, November 1999).

**Any swelling in the body of the testis in a man aged 15-55 years is an indication for urgent referral and should be seen within 2 weeks (DOH Steering Group 1999).**

### Common Presenting Symptoms Indicating Need for Referral to a Urologist

1. 80-90% of patients will present with an enlarged testicle or lump in the testicle. This may be painless but 15% have pain. In 97% of patients a lump is present on examination. If this is clearly within the testis there is a high probability of cancer.

2. Newly developing hydrocele.

3. A tender lump or enlargement persisting 10 days after starting antibiotics – (infection is an uncommon cause of testicular symptoms in men under 40 years old).

4. Other suspicious features include a dragging sensation.

5. A history of testicular mal descent is present in 10% of patients. There is no association with vasectomy.

### Urgent Referral to Oncologist

Rarely, a patient will present with advanced metastatic disease, requiring emergency admission. Findings may include:

- Backache, due to enlarged para-aortic nodes.
- Cough, breathlessness or haemoptysis, due to pulmonary metastases.
- Renal impairment due to ureteric obstruction from abdominal metastases.
- Gynaecomastia, due to production of excessive HCG by the tumour.
- Poor general condition associated with abnormality in testis.
- HCG >5000 or AFP >1000
- Brain Metastases

Patients with symptoms suggestive of advanced disease should be referred immediately by telephone or Fax. A pathological diagnosis is not a prerequisite for referral in these circumstances.

## INVESTIGATIONS

Pre-operative assessment of patients suspected of having testicular malignancy should include:

- AFP (alpha feta protein)
- B-HCG (beta human chorionic gonadotrophin)
- LDH (lactate dehydrogenase)
- Chest x-ray
- Palpation of abdomen and neck for metastases
- Urgent ultrasound scan of the testis if required to confirm the diagnosis
- LFT's, BFT's & FBC

Investigations should be carried out at the patient's first appointment with the urological team.

Where lymphoma is suspected (which occurs more commonly in the older population (i.e. >60) full blood count (FBC) and erythrocyte sedimentation rate (ESR) should also be carried out.

If a diagnosis is certain pre-operatively on clinical grounds and lymphadenopathy is suspected, a CT scan of the chest, abdomen and pelvis should be requested pre-operatively and a referral to the oncologist should be initiated after discussion with the patient.

If patients present with signs of advanced metastatic disease, as above, CT scan of the chest, abdomen and pelvis will be required but may be best undertaken after patient transfer. CT of the brain will also usually be required.

## SURGICAL MANAGEMENT

### Pre-surgery

Preparation for surgery will include:

1. Informed consent
2. Investigations (as above)
3. Further investigations where appropriate (as above).

Histological diagnosis is not always necessary before referral to an oncologist as clinical near certainty can be achieved by ultrasound of the testis, tumour markers and physical examination. Orchidectomy can be undertaken after chemotherapy.

Fertility should be considered prior to orchidectomy. Sperm cryopreservation may be appropriate particularly in patients with an abnormal contralateral testis.

### Surgery

Surgery has two aims – diagnostic and therapeutic:

1. Histological diagnosis
2. Excision of the primary tumour

Surgery should occur within 14 days of GP referral.

The preferred orchidectomy approach involves an inguinal incision with division of the spermatic cord at the internal inguinal ring.

Orchidectomy via a scrotal incision is usually contra-indicated.

Biopsy of the contralateral testis should be considered for individuals at high risk of carcinoma in situ (CIS) (i.e. <31 years and testicular volume <12ml or with a history of mal descent) (Harland et al 1998). About 5% of men with testicular cancer have CIS of the contralateral testicle, CIS is thought to progress to invasive germ cell tumour (GCT) in 50% of these cases within 5 years and it is believed that in time all will develop invasive malignancy. This progression can be greatly reduced by testicular radiotherapy (at the price of fertility).

**The option of a testicular prosthesis should be discussed with all patients prior to orchidectomy.**

### Post-surgery

Post-operative investigations should be organised by the urologist. These investigations should include:

1. Histological review of tumour by specialist Histopathologist.

2. CT scan of chest, abdomen and pelvis.
3. Post-operative AFP, HCG and LDH.

These investigations should be reported within two weeks of orchidectomy.

**Oncology Referral**

Although further treatment may not be required, all patients should be referred to the designated oncologist at the Cancer Centre by fax within 24 hours of surgery.

Results of all pre-op and post-op investigations should be faxed to the oncologist as soon as they are reported.

**Radiology** CT films and **pathology** results should be forwarded to the SMDT cancer centre for review within 2 weeks of orchidectomy.

**ONCOLOGY MANAGEMENT**

**Multidisciplinary Team Working**

All cases of testicular cancer should be referred to a specialist centre following initial diagnosis where they should be managed by a multidisciplinary team (MDT) with a special interest in testicular tumours (NICE 2002).

A video-conferenced SMDT covering North East and North Cumbria is held fortnightly on Thursdays at 3 pm to 5 pm. All cases of GCT are registered and complex cases are discussed.

A video conference SMDT will be available for JCUH patients on alternate Thursdays to discuss all new and complex testis cancer patients.

The aim of the SMDT is ensure the highest standard of care for testicular cancer patients. All new referrals are discussed and relevant pathology and radiology will be reviewed at the SMDT, prior to reaching a treatment decision based on the expertise of those involved. In addition to new referrals, all post chemotherapy CT scans to assess response, suspected relapses and any complex cases where management is uncertain will be reviewed.

Attendance records and minutes of the meetings are kept for audit purposes. Decisions reached at the SMDT are entered into the patient's notes. Decisions are communicated to the GP following consultation with the patient.

All pathology and radiology must be received by the MDT by the Monday afternoon prior to the appropriate meeting to ensure patient's case history can be discussed at the SMDT within 3 weeks of orchidectomy.

**Pathology**

Slides from all cases should be reviewed by the Specialist Pathologist within 2 weeks of the orchidectomy.

**Radiology**

CT scans from all cases should be reviewed by the Specialist Radiologist within 2 weeks of orchidectomy.

These are maximum times and earlier referral of imaging and pathology will expedite patient management.

**Treatment Regimens**

Patients should be seen with the results of their staging investigations and MDT review within 2 weeks of orchidectomy by the designated consultant oncologist at a Regional Cancer Centre. This facilitates a consultation at which a definitive decision on further management can be made.

Management depends on the histological type and stage of the disease. A combination of the Royal Marsden Hospital staging system and the International Germ Cell Consensus Classification (1997) is used to define stage and prognosis *(see appendices A and B).*

**Arrangements for chemotherapy**

All combination first line and second line chemotherapy e.g. BEP is given in 2 main oncology centres in the network which include the host centre for the Supraregional MDT at the Northern Centre for Cancer Treatment NCCT. This also includes high dose and chemotherapy involving transplant patients.

Any of the satellite centres can deliver adjuvant carboplatin in stage I seminoma, adjuvant radiotherapy in same and also therapeutic radiotherapy in IIA seminoma.
And also provide surveillance protocols to patient locally.

**Seminoma**

Radiotherapy for seminoma patients is delivered by Dr Rhona McMenemin, Dr Ian Pedley and Dr John Frew, consultant clinical oncologists and members of the testis MDT.

**Spermatocytic Seminoma**

Spermatocytic seminoma is rare and occurs in an older population (> 60 years). They rarely metastasise and are managed with a policy of surveillance. Long term follow up is not required.

**Stage I Seminoma**

**OPTIONS**

- Chemotherapy: Carboplatin (AUC x 7) x 1 cycle.

- Surveillance: Option for patients with tumours <4 cm with no rete testis involvement and no lymphovascualr invasion. This may be as part of the ongoing TRIST study

- Radiotherapy: 20 Gray (Gy) in 10 fractions to para-aortic strip (extended to include ipsilateral pelvic nodes in a dog- leg field, if previous inguinal or scrotal surgery or tumour penetrates the tunica albuginea) *(see appendix C).*

- Radiotherapy will not usually affect fertility but testicular dose should be measured and should be < 50cGy (or under 8d). Radiotherapy is now rarely used for Stage I seminoma.

**Metastatic Seminoma**

- There are a number of options for the treatment of metastatic seminoma *(appendix C).*

- Low bulk disease with a para-aortic mass less than 4cm can be treated with radiotherapy 20 Gy (+ boost, 16 Gy) to dog leg field.

- Chemotherapy can also be used and is probably indicated in masses exceeding 5cm in diameter (stage IIc and above). Three cycles of BEP is equivalent to 4 cycles of EP and either can be used. For older patients particularly those who smoke, it may be appropriate to use the 4 cycle regimen and avoid Bleomycin.

- More advanced cases of seminoma who fall into the intermediate prognosis category should receive 4 cycles of standard 5 day BEP.

- Radiotherapy combined with a single cycle of adjuvant Carboplatin has been written up but has never been subjected to a formal clinical trial.

- For older patients, Carboplatin (AUC x 7) x 4 cycles may be considered as an alternative.

**Stage I Teratoma**

Patients are categorised into high (40%) or low (20%) risk of recurrence according to the presence or absence of lymphatic or vascular invasion as defined by histological review by the designated pathologist.

Low Risk Cases

These patients will enter the surveillance protocol.

High Risk Cases

There are two options for these patients after appropriate counselling:

- Surveillance – associated with a relapse rate of 40% (within 3 years). Salvage at relapse involves BEP chemotherapy (usually 3 cycles x 3 days) and possible surgery.

- Adjuvant therapy – two cycles of BEP (3 day) associated with relapse rate of 1-2%. (Total Etoposide dose 360mg per cycle).

**Good Prognosis* Metastatic Disease**

**BEP** 3 day x 3 cycles over 9 weeks (Bleomycin, Etoposide, Cisplatin). (Total Etoposide dose 500mg per cycle).

**Intermediate and Poor Prognosis* Metastatic Disease**

**BEP** 5 day x 4 cycles over 12 weeks. (Total Etoposide dose 500mg per cycle).

**Non Germ Cell Tumours of the Testis**

Sertoli Cell Tumours and Leydig Cell Tumours

Indolent malignant tumours which rarely metastasise. Recommend CT staging and then limited follow up for 5 years. The optimum management for metastatic disease is uncertain.

Testicular Lymphoma

Urgent referral to a specialist haematologist and management in accordance with relevant lymphoma protocol.

**Pre-treatment Management**

For patients with intermediate or poor prognosis disease, or with >10 lung metastases visible on CXR, CT brain is required to complete staging investigations. A bone scan should be carried out on those with an elevated alkaline phosphatase or symptomatic of bone metastases.

Radiotherapy

Baseline investigations should be undertaken as per staging protocol *(see appendix D).*

Chemotherapy

Baseline investigations should be undertaken, as per chemotherapy treatment protocol.

To minimise the risk of dental sepsis during neutropenia, all patients should have dental status assessed and be considered for specialist referral.

All patients should have an audiogram before Cisplatin treatment begins.

All patients should have GFR assessed either by EDTA or 24 hour urine collection creatinine clearance.

All patients should be offered sperm cryopreservation before chemotherapy.

Lung function tests should be requested for all patients who are to receive Bleomycin chemotherapy.

All patients should be offered entry into appropriate clinical trials where they exist.

Patients should be given written information to reinforce verbal explanations, regarding their treatment and potential side effects, prior to giving consent *(see Patient Care section, page 35).*

**Management during treatment**

Radiotherapy

Radiotherapy should start within 4 weeks of the decision to treat (Joint Council for Clinical Oncology, 1993). Patients will be reviewed weekly during treatment and a FBC will be taken. The radiation dose to the contralateral testis will be measured during treatment and will not exceed 50cGY (or see pre-treatment management above).

Chemotherapy

Urgent chemotherapy for advanced metastatic disease should start within 24 hours of referral to the oncologist.

Chemotherapy with adjuvant or curative intent should start within 2 weeks of the decision to treat.

Blood tests should be undertaken, as per the chemotherapy treatment protocol.

**Bleomycin toxicity**

Patient should have chest X-ray and clinical assessment performed prior to each cycle of BEP as an assessment for Bleomycin toxicity. The diagnosis is a clinical one and pulmonary function tests are of little assistance.

**Management post- treatment**

Radiotherapy

Patients will be reviewed in the Radiotherapy Review Clinic at the end of their treatment and a follow up appointment will be made in the follow up clinic within 2 months, as per relevant follow-up protocol.

Chemotherapy

Patients should complete their planned 3 or 4 cycles of therapy.

Investigations will be undertaken as per the chemotherapy protocol.

Metastatic disease should be re-assessed by CT within 3 weeks of commencing the final cycle of chemotherapy. Patients should have a CT scan of all previously abnormal areas to assess response.

If markers are still elevated but stable or falling, they should be observed weekly. Persisting elevation of AFP may be congenital (up to 25) or due to liver toxicity from chemotherapy.

**Management of life threatening advanced metastatic disease**

Occasionally patients will present with immediately life threatening metastatic disease where urgent referral to the oncologist and transfer to the cancer centre is needed so that chemotherapy can commence as soon as possible.

**Aims**

To obtain the diagnosis and initiate treatment with minimum delay.

**Initial Assessment**

The patient should be managed within the NCC. Full history and examination should be carried out, with attention to general physical status, particularly hydration and nutrition.

**Essential Investigations**

The following are mandatory before chemotherapy starts:

- Blood tumour markers, (AFP and B-HCG) should be sent for urgent analysis.

- Confirmation of metastatic disease, e.g. with chest X-ray or abdominal ultrasound scan.

- Assessment of renal function by serum creatinine clearance can be calculated using the Cockcroft formula ([1.25 x (140-age) x weight (kg)] divide by serum creatinine). If creatinine is elevated (> 125), the cause of renal dysfunction should be determined:

    - pre renal – due to dehydration
    - abnormality in the kidney – rare in these patients
    - post renal – due to ureteric obstruction (from metastatic disease)

- An EDTA GFR should be arranged urgently.

**Initial Treatment**

- Patients may be severely dehydrated and require additional intravenous fluids as well as usual chemotherapy pre-hydration.

- Post renal obstruction is an indication for ureteric stent or external drainage prior to any chemotherapy – refer urologist on-call.

- Those with bulky metastatic disease are at risk of tumour lysis syndrome (Pentheroudakis et al 2001) and Allopurinol 300mg OD should be commenced immediately on admission.

- Thrombo-embolism prophylaxis should be administered if there is bulky metastatic disease adjacent to major vessels. This should be continued at home until re-scan shows resolution.

- Symptomatic treatment with analgesia and anti-emetics may also be required.

**Chemotherapy**

Standard treatment is with BEP chemotherapy (Bleomycin, Etoposide and Cisplatin) and 5-day BEP should be commenced until full staging has been completed.

**Further Investigations**

If not done before treatment, the following can be completed during working hours:

- Blood samples taken before chemotherapy for AFP, B-HCG and LDH can be stored in the lab for later analysis. These provide important prognostic information and assist in treatment monitoring.

- Ultrasound scan of the testes.

- Full staging with CT scan of thorax, abdomen and pelvis. Intermediate and poor prognosis patients, or those with > 10 lung metastases visible on chest x-ray, also require a CT head scan.

- Accurate assessment of renal function by EDTA clearance following correction of pre renal and post renal causes of dysfunction. Assessment of renal function using the COCKCROFT formula should Always be made where an EDTA is not immediately available.

- Bone scan if alkaline phosphatase is elevated or symptomatic.

- Baseline audiometry.

- Baseline lung function tests (gas transfer and lung volumes) if patient is to receive Bleomycin.

- Sperm banking should be offered.

- The Nurse Practitioner should be contacted as soon as possible following admission to provide further information and support, and to co-ordinate the necessary investigations and future appointments.

## MANAGEMENT OF RESIDUAL MASSES AFTER CHEMOTHERAPY

All cases should be reviewed by the MDT within one week of completing radical treatment.

### Seminoma

Resection of post-chemotherapy residual masses of **less than 3 cm** is not routinely indicated for seminoma as surgery is difficult and potentially dangerous. A policy of surveillance is adopted as residual masses usually shrink over 12-24 months. CT scans are performed 6 monthly until complete remission or disease stabilisation. Biopsy is recommended if masses increase in size. PET scans can be helpful in assessing residual disease.

However, in masses **greater than 3 cm** there is an increased risk of the mass containing viable tumour and these patients should be referred for a surgical opinion to the designated specialist urologist at the cancer centre. **Surgery is only appropriate where the mass is likely to be resected completely.** There is no evidence that radiotherapy after chemotherapy for residual masses in seminoma influences long term outcome.

**Teratoma**

Residual masses may remain after chemotherapy and marker normalisation. They may contain viable tumour, differentiated teratoma or fibrosis/necrosis. The aim of surgery is complete excision of the residual mass and associated abnormal tissue and may involve template clearance of para-aortic nodes. Incomplete excision is associated with poor prognosis.

This type of surgery is rare and should only be undertaken by a specialist surgeon.

***Indications for RPNLD in NSGCC***

1. New patients at risk should be identified at presentation and discussed in outline at the SMDT.

2. Men with residual masses of 1 cm or those where there is < 70% shrinkage should be referred for RPNLD. Any men with smaller masses, particularly those of low attenuation should be discussed.

3. Markers should have normalized before surgery.

4. Surgery should be performed as a planned procedure after completion of 1st line chemotherapy.
5. An exception is “growing teratoma syndrome” with negative markers during chemotherapy. Resection should be done as soon as safely possible without completing chemotherapy.

6. In patients with multiple masses the retroperitoneal mass should usually be resected first because if only fibrosis is present, surgery for the other masses can usually be avoided. The exception is if the other masses are significantly larger than the retro-peritoneal masses.

7. "Desperation" surgery should be considered in patients with rising markers who have completed at least two regimens of chemotherapy.

8. Surgery should not be carried out in patients whose masses have *completely resolved* in the final post chemotherapy CT.

**Counselling for node dissection**

1. Indications as above.
2. Rationale is diagnosis of residual masses and removal with the intention of cure if TD present. Identification of persistent cancer may require further chemotherapy.
3. Information about outcomes in literature and personal surgical experience.
4. Open RPNLD involves a long (usually midline, occasionally transverse) incision and a hospital stay of about 5 to 10 days.
5. Risk of death is 1% in post-chemotherapy patients.

6. Risk of small bowel obstruction or ileus is 5-10%.
7. Risk of lymphocoele requiring percutaneous drainage is 5 to 10%.
8. Weak or absent ejaculation occurs, the precise incidence depends on the size and nature of the mass, and on the operative procedure required.
9. Chylous ascites may result.

## Indications and counselling for laparoscopic node dissection

1. Post chemotherapy laparoscopic node dissection remains under evaluation, is not standard treatment, and long-term outcome not yet clear. Not recommended by NICE.
2. Precise estimates of operative complications and incidence of open conversion not yet clear because of small number in the world literature.
3. Laparoscopic RPLND is not available locally in Northern regions.

## Indications for RPNLD in Seminoma

1. Infrequent and confined to patients with solitary, surgically resectable (i.e. globular) masses >3 cm after second-line salvage chemotherapy, surgery being carried out to exclude non-seminomatous elements.

Further chemotherapy should be considered where there has been incomplete excision and/or pathology confirms viable GCT in the resected specimen.

## Orchidectomy

All patients treated with emergency chemotherapy prior to orchidectomy should be referred for orchidectomy following chemotherapy treatment

## MANAGEMENT OF RECURRENT DISEASE

Management will depend upon the stage of disease at diagnosis and previous treatment.

### Seminoma

Patients who relapse following radiotherapy for stage I disease will usually receive EP chemotherapy. Patients who relapse after adjuvant Carboplatin chemotherapy for stage I disease and who have stage IIa or b at relapse, should be considered for dogleg radiotherapy (36Gy). Patients who relapse with stage IIc, good prognosis disease or above should receive BEP or EP chemotherapy.

Patients who fall into the intermediate prognosis group should receive BEP.

**Teratoma**

For patients who relapse more than 2 years after initial therapy at an isolated site, surgical excision of the site of relapse should be considered before systemic chemotherapy.

Marker negative relapse may be due to teratoma differentiated and a biopsy is essential prior to any systemic therapy. Complete excision may be possible, rendering chemotherapy unnecessary.

Patients who relapse on surveillance should be treated with BEP chemotherapy.

Patients who relapse after first line BEP chemotherapy should receive second- line TIP (Taxol/Ifosfamide/Cisplatin) for 4 cycles followed by reassessment.

Patients who do not achieve complete remission on standard chemotherapy for metastatic disease may be considered for high dose chemotherapy with peripheral blood stem cell rescue.

Patients should be offered entry into appropriate clinical trials for relapsed disease if possible.

All second-line chemotherapy for relapsed disease should be in a Supra-network Cancer Centre by an oncologist with a special interest in GCT.

**MANAGEMENT OF CENTRAL NERVOUS SYSTEM**

CNS metastases are rare but may be seen in three circumstances:

- at initial presentation (usually in the context of gross wide spread disease with very high serum markers)
- as an apparently isolated relapse site
- in the context of chemotherapy resistant systemic relapse.

The first two presentations are potentially curable.

Patients with resectable lesions who are fit for surgery should be evaluated by a neurosurgeon. At initial presentation surgery and chemotherapy is preferred rather than radiotherapy. Newly diagnosed patients should also receive combination chemotherapy (as per Treatment Regimens p.16).

Radiotherapy is useful for isolated CNS relapse (with or without surgery) or as palliation in end stage disease.

## FOLLOW UP MANAGEMENT

All patients should be followed-up on protocol by the designated oncology team.

The Nurse Practitioner will co-ordinate care and offer counselling/support for all patients.

Patients at high risk of carcinoma in situ in the remaining testis (i.e.: under 30 years of age at primary diagnosis and with a testicular volume less than 12ml, or with a history of testicular mal descent), who did not have a biopsy at the time of orchidectomy, should be offered the opportunity to consider a contra-lateral biopsy 2 years after completion of treatment (see Management of the Contralateral Testis, below).

## MANAGEMENT OF THE CONTRALATERAL TESTIS

Optimum management of the contralateral testis is controversial because of the potential complications of treatment. Patients with a testicular GCT have an overall increased risk of a second testicular tumour of approximately 2-5%. However, it is possible to identify a sub-group who are at greater risk.

There are three factors which are associated with an increased risk.

- an early age at diagnosis of first primary (less than 31 years), **and** a low testicular volume (less than 12 mls).
- or a history of mal descent.

Within this subgroup, the risk a second testicular tumour rises to approximately 35%. For those identified at a higher risk, the option of a biopsy of the contralateral testicle will be discussed. This issue may be raised by the surgeon at the time of orchidectomy or by the oncologist at a later date. It can be carried out at the time of the first orchidectomy or following treatment.

The reason for a biopsy is to detect any signs of pre-cancerous cells in the healthy testicle which may develop into a malignant cancer at a later date. This is known as carcinoma in situ or CIS. The risks of CIS progressing into cancer over five years are 50%, but it is believed that this will occur in all patients with CIS if follow up is long enough
.
The biopsy is carried out under general anaesthetic. A small incision is made in the scrotum and a small amount of testicular tissue is removed for analysis. If the patient has been treated with chemotherapy, it is important to wait for at least two years following completion of the treatment. This is so that a reliable result is obtained as chemotherapy can affect healthy cells in the short term and obscure the result.

If CIS is diagnosed, there are two options for management. One is close surveillance of the remaining testicle with an annual ultrasound scan to assess for signs of a developing tumour. At the first sign that the CIS is progressing into malignant cancer, a second orchidectomy would be recommended.

The long term side effects of a second orchidectomy are

- Permanent infertility
- Hormonal failure requiring lifelong hormone replacement with testosterone.

In addition, there is the risk that the tumour is not detected before it has metastasised, reducing the overall prognosis and potentially exposing the patient to the harmful side effects of cytotoxic chemotherapy or radiotherapy.

The other option following a CIS positive biopsy is treatment up-front to prevent progression. Treatment involves radiotherapy of 20Gy in 10 fractions to the testicle. This will reduce the risk of cancer to virtually 0%, but unfortunately has the unpleasant side effects noted above, (i.e.: infertility and potential hormonal failure, though the risk of total hormonal failure is less).

If the biopsy is negative, then the risks of developing a second tumour are virtually nil.

The side effects will be discussed in detail with the patient before a decision is reached. It is important to remember that the risk of a second tumour for those in the high risk group is less than 40% and that, because patients usually detect second tumours themselves early through testicular self examination, they have a very good prognosis and are often cured with orchidectomy alone.

## PATHOLOGY

Testicular tumour orchidectomy specimens should be handled in accordance with the latest version of the relevant Minimum Dataset published by the Royal College of Pathologists, available at www.rcpath.org. These guidelines are evidence based and specify minimum data set criteria for the specimen gross description and microscopic diagnosis sections of the pathology report and also include abbreviated British (BTTP) and WHO testicular tumour classification systems for reference. Comprehensive descriptions of gross and microscopic appearances of tumours and aids to diagnosis are available in standard surgical pathology texts. Key points on reporting testicular tumours are noted below.

### Orchidectomy

Specimen Handling

It is advisable to remove the spermatic cord blocks prior to handling, to avoid tumour spillage. A block of the cord margin is usually taken, plus blocks from lower in the cord (depending on its length and whether or not tumour involvement is suspected). The size of the testicular tumour should be recorded, its gross appearance described (e.g. cystic areas, necrosis, haemorrhage) and an assessment made of whether or not the tumour shows macroscopic spread into paratesticular structures.

Block selection should be generous, to include at least one tumour block per centimetre, sampling areas with variable appearances, the testicular parenchyma adjacent to the tumour and the rete testis and epididymis. Suspected areas of spread through the tunica albuginea should also be sampled.

Microscopy

Testicular tumours should be classified according to the latest WHO system (WHO classification of Tumours of the Urinary System and Male Genital Organs. 4th Edition. IARC: Lyon 2016). The BTTP classification may also be included.

For germ cell tumours, it is important to distinguish Seminoma from Non-Seminomatous Germ Cell Tumours (NSGCT) and to identify Combined Tumours by a thorough search for different components. Where tumours are mixed, the various components present should be specified, with an indication of approximate proportions.

Tumour Typing

The diagnosis of tumour type is based on assessment of H&E appearances, but immunohistochemical stains may be helpful in highlighting focal components or in excluding differential diagnoses.

Classical seminomas are OCT4, PLAP and CD117 (membranous) positive, cytokeratin (e.g AE1/AE3 and CAM 5.2) negative. They may contain HCG positive

syncytiotrophoblastic giant cells (5% of tumours), but this does not represent a choriocarcinoma component. Seminomas may be confused with lymphoma or non-germ cell tumours, such as Sertoli cell tumours (inhibin positive), necessitating use of immunostains to separate these diagnoses. Spermatocytic tumours are negative with both PLAP and CD117 and show different morphology. They need to be distinguished because of their different behaviour, which is usually benign unless sarcomatoid transformation is present.

Embryonal carcinoma is CD30 positive (but may be negative post-chemotherapy), shows uniform staining with cytokeratins such as CAM 5.2, is usually CD117 negative (but can show cytoplasmic staining) and shows patchy positive staining with PLAP and OCT4. Yolk sac tumour is rarely pure (except in childhood) and shows highly variable morphology, but with less nuclear variability than embryonal carcinoma. AFP and glypican3 staining is variable. Pure choriocarcinoma is rare, is HCG positive and shows frequent vascular invasion.

EMA may be helpful in distinguishing embryonal carcinoma or seminoma from a metastatic carcinoma, as it is usually negative in these germ cell tumours. Oct 4 is a newer marker, positive in classical seminomas, embryonal carcinoma and sex-cord stromal tumours.

The in-situ element of germ cell neoplasia in situ (GCNIS) is demonstrated well with OCT4, PLAP and CD117. This is not usually necessary, however, as GCNIS is frequently easily identified adjacent to germ cell tumours. Immunostains for GCNIScan be helpful if there is doubt about the diagnosis of germ cell tumour or if a contra-lateral testicular biopsy is being assessed.

Other features

A comment should be made in the report if there is evidence of:

- tumour regression (as apparent tumour size may therefore be an underestimate)
- tumour transformation - sarcomatoid, carcinomatous etc

**Staging**

The histology report should also indicate the extent of tumour spread, stating whether there is:

- vascular invasion - this should be sought in parenchyma adjacent to the tumour, with care being taken not to over call carry-over tumour fragments from friable tumour as vascular invasion.

and/or invasion of

- rete testis,
- tunica albuginea, tunica vaginalis

- epididymis,
- spermatic cord
- scrotal structures

.
The pathological TNM stage should be stated. Size and number of any lymph node metastases affects the 'N' stage.

Retroperitoneal Lymph Node Dissection (RPLND)

Lymph node masses are usually removed post-chemotherapy. Margins of these specimens should be inked to enable completeness of excision of any residual tumour to be assessed, and the lymph nodes masses should be measured.

The histology report should specify whether the lymph nodes show areas of necrosis and fibrosis, and if viable tumour is present whether this is purely differentiated teratoma or includes malignant elements, with a description of the latter. Atypical/dysplastic epithelium lining cystic teratomatous elements should still be regarded as differentiated teratoma. Completeness of excision should be assessed and recorded.

Cases Referred to Cancer Centre for Review/ Presentation at Testicular MDT

The following should be dispatched to the Urology MDT Co-ordinator:

- Copy of original histology report and any relevant previous histology reports
- All of the original slides and any previous relevant previous histology slides where appropriate

Blocks are not required initially but may be requested.

The slides and blocks will be returned as soon as possible after review and the MDT meeting, along with a copy of the review histology report.

## RADIOLOGY

Staging CT of the chest abdomen and pelvis should be carried out at the Cancer Unit and reported within 2 weeks of orchidectomy. (Refer to the Royal College of Radiologists guidelines for undertaking staging scans on testicular tumour patients).

The films should be forwarded immediately to the Cancer Centre for review by the designated radiologist within 3 weeks of surgery.

## PATIENT CARE

Patient care will be co-ordinated by the relevant Nurse Practitioner for Testicular Tumours. Patients will be provided with a contact number for the Nurse Practitioner and a telephone number to enable the patient to contact the oncology centre 24 hours a day.

The Nurse Practitioner is available to provide information, support and counselling to all patients with testicular tumours and their families throughout their diagnosis, treatment and follow-up.

Patients will be provided with information on:

- The nature of the disease
- Diagnostic procedures
- Treatment options
- Likely outcomes
- Potential side effects
- Information on testicular self-examination
- CIS and the risk of a second testicular tumour
- Signs of relapse
- Potential psychosocial and psychosexual problems associated with the diagnosis and treatment

All patients requiring chemotherapy or radiotherapy to the testis (for CIS) will be offered sperm cryopreservation before treatment.

Further information is available from:

BACUP
3 Bath Place
Rivington Street
LONDON
EC2A 3JR

Cancer Support Service 020 7613 2121
Freeline 0808 800 1234
Website: www.cancerbackup.co.uk
www.cancernet.co.uk

Patients will be provided with written information on their disease, treatment options and potential side effects and other information relevant to their diagnosis.

## PRIMARY CARE TEAM

General Practitioners will have access to referral guidelines.

General Practitioners will be notified of the patients' treatment plan within 5 working days of a decision being made and of the patients discharge within 24 hours.

General Practitioners will receive an evaluation of the patients' condition after each follow-up appointment.

## FAMILIAL DISEASE

An increased risk of developing testicular germ cell cancer has been noted in first degree relatives, though the risk to fathers or sons of cases has been reported to be less than the risk to brothers (Heimdal et al 1996, Forman et al 1992). The relative risk to brothers of testicular cancer patients has been found to lie between 6 and 10 (Tollerud et al 1985, Forman et al 1992, Heimdal et al 1996) – the absolute risk is still low.

Patients who have a history of testicular cancer in their first-degree relatives or multiple cases in their extended family are of interest to researchers.

## REFERENCES

EAU Guidelines on Testicular Cancer – P Albers et al 2009. www.uroweb.org.guidelines/online-guidelines.

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JOINT COUNCIL FOR CLINICAL ONCOLOGY, Reducing Delays in Cancer Treatment: Some TARGETS London Royal College of Radiologists. 1993.

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HARLAND S J ET AL (1998) Intratubular Germ Cell Neoplasia of the Contralateral Testis in Testicular Cancer: Defining a High Risk Group, Journal of Urology 160; Oct, pp1353-1357.

HEIMDAL K ET AL (1996) Familiar Testicular Cancer in Norway and Southern Sweden, British Journal of Cancer 73 (7) 964-969.

HORWICH A (Ed) (1991) Testicular Cancer Investigation and Management, Chapman and Hall Medical, London.

MEIDAHL PETERSON P ET AL (2002) Effect of graded testicular doses of radiotherapy in patients treated for carcinoma-in-situ in the testis. Journal of Clinical Oncology V20, N6, 16 Mar pp 1537-1543.

PENTHEROUDKIS G ET AL (2001) Spontaneous acute tumour lysis syndrome in patients with metastatic germ cell tumours. Report of two cases (short communication), supportive care in cancer, 9(7) pp 554-557.

SAETER G, Fossa D and Norman N (1987) Gynaecomastia Following Cytotoxic Therapy for Testicular Cancer, British Journal of Urology, 59, 348-352

TOLERUD D J ET AL (1985) Familiar Testicular Cancer and Urogenital Developmental Anomalies, Cancer SS, 1849-1854.

## APPENDICES

## Appendix A

| **PROGNOSTIC GROUPS IN METASTATIC NSGCT**<br>*International Germ Cell Consensus Classification 1997* |
|---|
| **GOOD PROGNOSIS**<br>56% teratoma. 5 year survival – 92%<br>Testis / retroperitoneal primary<br>**&**<br>No non-pulmonary visceral (NPV) metastases<br>**&**<br>Good markers – all of<br>AFP < 1,000 mg / ml<br>B-HCG < 5,000 iu / l<br>LDH < 1.5 x ULN |
| **INTERMEDIATE PROGNOSIS**<br>28% teratoma. 5 year survival – 80%<br>Testis / retroperitoneal primary<br>**&**<br>No NVP metastases<br>**&**<br>Intermediate markers – any of<br>AFP > 1,000 < 10,000<br>B-HCG > 5,000 < 50,000<br>LDH > 1.5 x < 10 x ULN |
| **POOR PROGNOSIS**<br>16% teratoma. 5 year survival – 48%<br>Mediastinal Primary<br>**or**<br>NVP metastases<br>**or**<br>Poor markers – any of<br>AFP > 10,000<br>B-HCG > 50,000<br>LDH > 10 x ULN |
| **PROGNOSTIC GROUPS FOR METASTATIC SEMINOMA** |
| **GOOD PROGNOSIS**<br>90% seminoma. 5 year survival – 82%<br>Any primary site<br>**&**<br>No NPV metastases<br>**&**<br>Normal AFP, any B-HCG, any LDH |
| **INTERMEDIATE PROGNOSIS**<br>10% seminoma. 5 year survival – 72%<br>Any primary site<br>**&**<br>NPV metastases<br>**&**<br>Normal AFP, B-HCG, any LDH |
| **No seminoma patients classified as poor prognosis** |

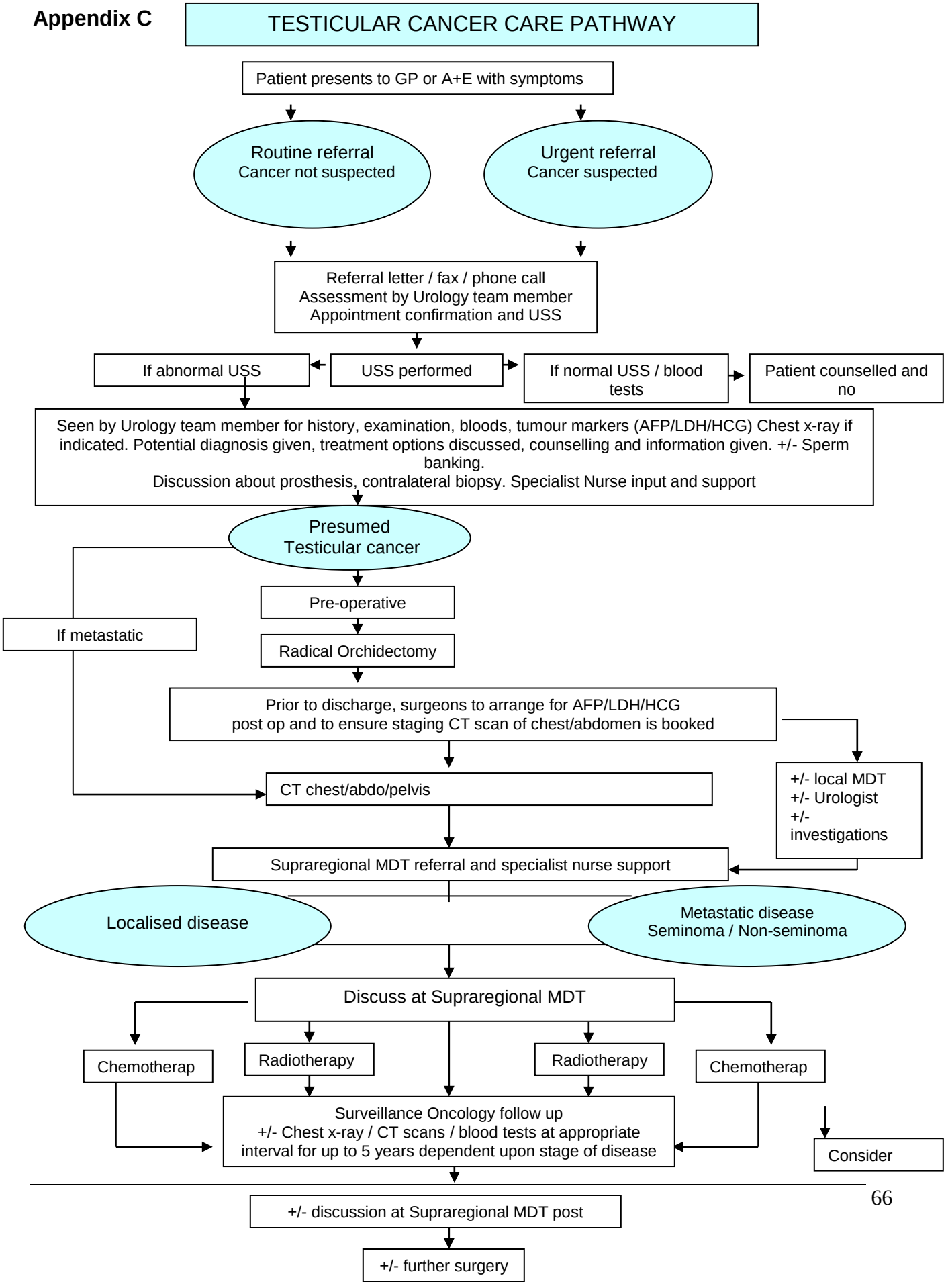
Adapted from International Germ Cell Collaborative Group (1997) International Germ Cell Consensus Classification: A Prognostic Factor Based Staging System for Metastatic Germ Cell Cancers, Journal of Clinical Oncology 15(2) February, 594 – 603.

**Appendix B**

| | | **Royal Marsden Hospital Staging Classification** |
|---|---|---|
| **Stage** | | **Definition** |
| **I** | | Confined to testis |
| **1m** | | Rising post-orchidectomy markers only |
| **II** | | Abdominal Lymphadenopathy |
| | A | < 2cm |
| | B | 2-5cm |
| | C | > 5cm |
| **III** | | Supradiaphragmatic Lymphadenopathy |
| | O | No abdominal disease |
| | ABC | Abdominal node size as in Stage II |
| **IV** | | Extralymphatic Metastases |
| | L1 | < 3 lung mets |
| | L2 | > 3 lung mets all < 2cm diameter |
| | L3 | > 3 lung mets 1 or more > 2cm |
| | H+ | Liver involvement |
| | C | Cerebral metastases |
| | O | Bony metastases |

Source: HORWICH A (Ed) (1991) Testicular Cancer Investigation and Management, Chapman & Hall Medical, London, page 11.

**Appendix C**


TESTICULAR CANCER CARE PATHWAY
Patient presents to GP or A+E with symptoms
Routine referral
Cancer not suspected
Urgent referral
Cancer suspected
Referral letter / fax / phone call
Assessment by Urology team member
Appointment confirmation and USS
If abnormal USS
USS performed
If normal USS / blood tests
Patient counselled and no
Seen by Urology team member for history, examination, bloods, tumour markers (AFP/LDH/HCG) Chest x-ray if indicated. Potential diagnosis given, treatment options discussed, counselling and information given. +/- Sperm banking.
Discussion about prosthesis, contralateral biopsy. Specialist Nurse input and support
Presumed
Testicular cancer
Pre-operative
Radical Orchidectomy
If metastatic
Prior to discharge, surgeons to arrange for AFP/LDH/HCG
post op and to ensure staging CT scan of chest/abdomen is booked
+/- local MDT
+/- Urologist
+/- investigations
CT chest/abdo/pelvis
Supraregional MDT referral and specialist nurse support
Localised disease
Metastatic disease
Seminoma / Non-seminoma
Discuss at Supraregional MDT
Chemotherap
Radiotherapy
Radiotherapy
Chemotherap
Surveillance Oncology follow up
+/- Chest x-ray / CT scans / blood tests at appropriate interval for up to 5 years dependent upon stage of disease
Consider
+/- discussion at Supraregional MDT post
+/- further surgery

**Appendix D**
**SEMINOMA**

| Stage | Standard treatment |
|---|---|
| Stage I | Carboplatin AUC 7 x 1<br><br>SURVEILLANCE<br><br>Para-aortic radiotherapy 20 Gy<br>(dog-leg for selected patients)<br>[Surveillance] |
| Stage IIA & IIB | Dog-leg radiotherapy 20 Gy with para-aortic boost 16 Gy<br><br>3 cycles BEP<br><br>4 cycles EP<br><br>(Carboplatin 4 cycles if EP contraindicated) |
| Stage II– IV (good prognosis) | 3 cycles BEP<br><br>4 cycles EP<br><br>(Carboplatin 4 cycles if EP contraindicated) |
| Stage II-IV (intermediate prognosis) | 4 cycles BEP |

## NON-SEMINOMA GERM CELL TUMOUR (NSGCT)

| Stage | Standard treatment |
|---|---|
| Stage I (low risk) | Surveillance<br>(RPLND) |
| Stage I (high risk) | Surveillance<br>2 cycles of BEP<br>(RPLND) |
| Stage II-IV<br>(good prognosis) | 3 cycles BEP |
| Stage II-IV<br>(intermediate prognosis) | 4 cycles BEP |
| Stage II-IV<br>(Poor prognosis) | 4 cycles BEP |

**RELAPSED GERM CELL TUMOUR**

**Relapse is diagnosed by a progressive rise in tumour markers and new or persistent radiological abnormalities. Persisting but not rising markers and rising markers without radiological abnormality are not an indication for retreatment with chemotherapy (exclude brain metastases and new testicular primary).**

| Diagnosis | Standard treatment |
|---|---|
| **RELAPSE FROM SURVEILLANCE** | |
| Seminoma/NSGCT | Manage as appropriate for seminoma or NSCGT if previously untreated |
| **RELAPSE POST-RADIOTHERAPY** | |
| Seminoma | Manage with appropriate chemotherapy option as under seminoma, usually not eligible for clinical trials |
| **RELAPSE POST-CHEMOTHERAPY** | |
| First post-chemotherapy relapse<br><1yr - Never achieved CR<br>1-2yr – Achieved CR | Management remains contentious<br>Consider high dose chemotherapy +/- stem cell transplant<br>TIP<br>VIP<br>M-BOP<br>Clinical trials |
| Late relapse >2yr | Radical surgery may be appropriate for operable relapse to exclude mature teratoma<br>Otherwise as above |
| Salvage surgery | RPLND |
| Second testicular tumours | Orchidectomy<br>Rarely partial orchidectomy |

**Appendix E surveillance protocols**

# Follow up Schedule Sertoli and Leydig cell high risk

| Clinic Visit | | | Markers | CXR | CT Scan |
|---|---|---|---|---|---|
| Year | Month | | | | |
| 1 | 1 | First visit after treatment allocation to F/U schedule | | | |
| | 3 | | X | X | |
| | 6 | | X | X | |
| | 9 | | X | X | Book CT for 12/12 |
| 2 | 12/0 | | X | | |
| | 6 | | X | X | |
| 3 | 12/0 | | X | X | Book CT |
| | 6 | | X | X | |
| 4 | 12/0 | | X | X | Book CT |
| | 6 | | X | X | |
| 5 | 12/0 | | X | X | |
| | 6 | | X | X | |
| >5 | | | Discharge | X | |

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. It is not definitive in the management of the patient.

**Appendix E surveillance protocols**

# Follow up Schedule Seminoma Stage 1 (post treatment)

| Clinic Visit | | | Markers | CXR | CT Scan |
|---|---|---|---|---|---|
| Year | Month | | | | |
| 1 | 1 | First visit after treatment allocation to F/U schedule | | | |
| | 3 | | X | X | |
| | 6 | | X | X | |
| | 9 | | X | X | Book CT for 12/12 |
| 2 | 12/0 | | X | | |
| | 6 | | X | X | |
| 3 | 12/0 | | X | X | |
| | 6 | | X | X | |
| 4 | 12/0 | | X | X | |
| | 6 | | X | X | |
| 5 | 12/0 | | X | X | |
| | 6 | | X | X | |
| >5 | | | Discharge | X | |

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. It is not definitive in the management of the patient.

**Appendix E surveillance protocols**

# Follow up Schedule Sertoli and Leydig cell low risk

| Clinic Visit | | | Markers | CXR | CT Scan |
|---|---|---|---|---|---|
| Year | Month | | | | |
| 1 | 1 | First visit after treatment allocation to F/U schedule | | | |
| | 3 | | X | X | |
| | 6 | | X | X | |
| | 9 | | X | X | Book CT for 12/12 |
| 2 | 12/0 | | X | | |
| | 6 | | X | X | |
| 3 | 12/0 | | X | X | Book CT |
| | 6 | | X | X | |
| 4 | 12/0 | | X | X | |
| | 6 | | X | X | |
| 5 | 12/0 | | X | X | |
| | 6 | | x | X | |
| >5 | | | Discharge | | |

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. It is not definitive in the management of the patient.

**Appendix E surveillance protocols**

## Follow up Schedule Teratoma Stage 1 (Post-adjuvant chemo)

| Clinic Visit | | | Markers | CXR | CT Scan |
|---|---|---|---|---|---|
| Year | Month | | | | |
| 1 | 0 | Referral visit treatment, allocation to F/U Schedule | | | |
| | 2 | | X | X | |
| | 4 | | X | X | Book CT for 6/12 |
| | 6 | B/P | X | | |
| | 8 | | X | X | |
| | 10 | | X | X | Book CT for 12/12 |
| 2 | 12/0 | B/P | X | | |
| | 2 | | X | X | |
| | 4 | | X | X | |
| | 6 | B/P | X | X | |
| | 8 | | X | X | |
| | 10 | | X | X | Book CT for 24/12 |
| 3 | 12/0 | B/P | X | | |
| | 3 | | X | X | |
| | 6 | | X | X | |
| | 9 | B/P | X | X | |
| 4 | 12/0 | | X | X | |
| | 6 | B/P | X | X | |
| 5 | 12/0 | | X | X | |
| | 6 | B/P | X | X | |
| >5 | Annual F/U | B/P | Discharge | | |

CT scans “chest, abdomen and pelvis” unless otherwise indicated on notes.
This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. It is not definitive in the management of the patient.

**Appendix E surveillance protocols**

## FOLLOW-UP PROTOCOL NON SEMINOMATOUS GERM CELL TUMOUR SURVEILLANCE (High Risk **)

| Clinic visit | | | | Tumour markers | Chest X-ray | CT (abdomen only) § |
|---|---|---|---|---|---|---|
| YEAR | DATE | Month | | | | |
| YEAR 1 | | First visit | | □ | □ | |
| | | 1 | | □ | □ | |
| | | 2 | | □ | □ | Book CT 3/12 |
| | | 3 | | □ | □ | See Dr * |
| | | 4 | | □ | □ | |
| | | 5 | | □ | □ | Book CT 6/12 |
| | | 6 | | □ | □ | See Dr * |
| | | 7 | | □ | □ | |
| | | 8 | | □ | □ | Book CT 9/12 |
| | | 9 | | □ | □ | See Dr * |
| | | 10 | | □ | □ | |
| | | 11 | | □ | □ | Book CT 12/12 |
| YEAR 2 | | 12 | | □ | □ | See Dr * |
| | | 2 | | □ | □ | |
| | | 4 | | □ | □ | |
| | | 6 | | □ | □ | |
| | | 8 | | □ | □ | |
| | | 10 | | □ | □ | |
| YEAR 3 | | 12 | | □ | □ | |
| | | 3 | | □ | □ | |
| | | 6 | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | **9** | | □ | □ | |
| **YEAR 4** | | **12** | | □ | □ | |
| | | **4** | | □ | □ | |
| | | **8** | | □ | □ | |
| **YEAR 5** | | **12** | | □ | □ | |
| | | **6** | | □ | □ | |
| **YEAR 6** | | **12** | | □ | □ | |
| **YEAR 6-10** | | **12** | | □ | □ | Consider stopping in uncomplicated cases |

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. This is not definitive in the management of the patient.

**The single most important histological feature of high-risk subgroups is blood vessel and/or lymphatic invasion, with a recurrence risk of approximately 40% in the presence of testicular vein or lymphatic tumour invasion.

Each clinic visit involves an assessment of symptoms, clinical examination, chest X-ray and tumour markers (AFP and HCG). LDH has not been shown to be helpful in the follow up in patients with germ cell tumours.

§ may include CT of pelvis as well (if prior inguinoscrotal surgery).

** patient given option to be seen in consultant clinic post scanning.

**Appendix E surveillance protocols**

**FOLLOW-UP PROTOCOL METASTATIC NON SEMINOMATOUS GERM CELL TUMOUR**
**Post chemotherapy +/- resection of residual masses**

| Clinic visit | | | | Tumour markers | Chest X-ray | CT § |
|---|---|---|---|---|---|---|
| YEAR | DATE | Month | | | | |
| YEAR 1 | | First visit | | □ | □ | CT SCANS OF ABNORMALITY UNTIL NORMAL |
| | | 1 | | □ | □ | |
| | | 2 | | □ | □ | |
| | | 3 | | □ | □ | |
| | | 4 | | □ | □ | |
| | | 5 | | □ | □ | |
| | | 6 | | □ | □ | |
| | | 8 | | □ | □ | |
| | | 10 | | □ | □ | |
| YEAR 2 | | 12 | | □ | □ | |
| | | 3 | | □ | □ | |
| | | 6 | | □ | □ | |
| | | 9 | | □ | □ | |
| YEAR 3 | | 12 | | □ | □ | |
| | | 6 | | □ | □ | |
| YEAR 4 | | 12 | | □ | □ | |
| | | 6 | | □ | □ | |
| YEAR 5 | | 12 | | □ | □ | |
| YEAR 6 | | 12 | | □ | □ | |
| YEAR 7 | | 12 | | □ | □ | |

| | | | | | | |
|---|---|---|---|---|---|---|
| **YEAR 8** | | **12** | | □ | □ | |
| **YEAR 9** | | **12** | | □ | □ | |
| **YEAR 10** | | **12** | | □ | □ | DISCHARGE |

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. This is not definitive in the management of the patient.

Each clinic visit involves an assessment of symptoms, clinical examination, chest X-ray and tumour markers (AFP and HCG). LDH has not been shown to be helpful in the follow up in patients with germ cell tumours.

§ may include CT of pelvis as well (if prior inguinoscrotal surgery).

If CT appears normal, no further routine CT scans. If post-treatment CT is abnormal, then ongoing imaging of the area of abnormality is required. The frequency of these will be directed by mdtm meeting and discussion.

**Appendix E surveillance protocols**

# Follow up Schedule Seminoma Stage 2 B/C 3, 4

| Clinic Visit | | | Markers | CXR | CT Scan |
|---|---|---|---|---|---|
| Year | Month | | | | |
| 1 | 0 | First visit after treatment with results of 1/12 post chemo scan, allocation to F/U schedule | | | |
| | 1 | | X | X | |
| | 2 | | X | X | |
| | 3 | | X | X | |
| | 4 | | X | | |
| | 5 | | X | X | |
| | 6 | | X | | |
| | 8 | | X | X | |
| | 10 | | X | X | Book CT for 12/12 |
| 2 | 12/0 | | X | X | |
| | 3 | | X | X | |
| | 6 | | X | X | |
| | 9 | | X | X | |
| 3 | 12/0 | | X | X | |
| | 6 | | X | X | |
| 4 | 12/0 | | X | X | |
| | 6 | | X | X | |
| 5 | 12/0 | | X | X | |
| | 6 | | X | X | |
| >5 | Annual F/U | | Discharge | X | |

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol. It is not definitive in the management of the patient.

**Appendix E surveillance protocols**

# Follow up Schedule Seminoma Stage 1 (Surveillance)

| Clinic Visit | | | Markers | CXR | CT Scan |
|---|---|---|---|---|---|
| Year | Month | | | | |
| 1 | | Referral visit & allocation to appropriate follow-up schedule | | | |
| | 0 | | X | X | CT @ 0/12 |
| | 3 | | X | X | |
| | 6 | | X | | CT @ 6/12 |
| | 9 | | X | X | |
| 2 | 12 | | X | | CT @ 12/12 |
| | 3 | | X | X | |
| | 6 | | X | | CT @ 18/12 |
| | 9 | | X | X | |
| 3 | 12 | | X | | CT @ 24/12 |
| | 4 | | X | X | |
| | 8 | | X | X | |
| 4 | 12 | | X | X | CT @ 36/12 |
| | 6 | | X | X | |
| 5 | 12 | | X | X | CT @ 48/12 |
| >5 | 12 | | X | X | CT @ 60/12 |

CT scans “chest and abdo” unless previous inguinal/scrotal surgery

This schedule has been designed to be used as a guide and to help the clinician in charge in forecasting which examinations are needed according to the protocol.

## Appendix F CONTACTS

Testis MDT Co-Ordinator: Anne Izatt, Cancer Services, Freeman Hospital

01912336161 Ext 27304

anne.izatt@nuth.nhs.uk

| Members | Name | Location | EMAIL | Dect phone |
|---|---|---|---|---|
| Urological Surgeons | Mr D J Thomas<br>Mr E Paez | Freeman<br>Freeman | david.thomas@nuth.nhs.uk<br>edgar.paez@nuth.nhs.uk | 48321 |
| Oncology Team | Dr I Pedley<br>Dr R McMenemin<br>Dr J Frew<br>Dr A Azzabi<br>Dr S Haney<br>Dr M Kagzi | NCCC<br>NCCC<br>NCCC<br>NCCC<br>JCUH<br>JCUH | ian.pedley@nuth.nhs.uk<br>rhona.mcmenemin@nuth.nhs.uk<br>jonathon.frew@nuth.nhs.uk<br>ashraf.abassi@nuth.nhs.uk<br>Sophie.haney@stees.nhs.uk | 39351<br>39362<br>39220<br>39361 |
| Pathology Team | Dr H Turner<br>Dr A El-Sherif<br>Dr J Ness<br>Dr B Disep<br>Dr J Majo<br>Dr S Nagarajan | RVI<br>RVI<br>RVI<br>RVI<br>RVI<br>JCUH | helen.turner@nuth.nhs.uk | 21555 |
| Radiology Team | Dr P Haslam<br>Dr K Anderson<br>Dr G Naisby | Freeman<br>Freeman<br>JCUH | philip.haslam@nuth.nhs.uk | |
| Specialist Nursing Team | Helen Showler<br>Mark Davis | NCCC<br>Freeman | | 39313<br>48277 |

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**APPENDIX 2 GUIDELINES FOR THE MANAGEMENT OF RENAL CANCER**

# Renal Cancer guidelines

## 1.0 CLINICAL ASSESSMENT

1. All suspected cases of kidney cancer should be referred to the local urologist with an interest in cancer management.
2. Haematuria should be fully investigated according to local protocol.
3. The 2 week rule pathway should be used whenever possible.
4. Many cases are asymptomatic and identified incidentally on imaging. The radiologist should flag suspicious scan results to the referring clinician and local urologist and should consider ordering further imaging directly.

## 2.0 STAGING OF RENAL CANCER

**Primary tumour**

1. T1a tumour ≤ 4cm limited to kidney
2. T1b tumour 4 - 7cm limited to kidney

T2 tumour > 7cm limited to kidney

1. T3a invasion into adrenals or perinephric tissues
2. T3b extension into renal vein or infradiaphragmatic vena cava
3. T3c extension into supradiaphragmatic vena cava

T4 extension beyond gerota's fascia

**Regional Lymph nodes**

NX cannot be assessed

1. N0 no metastases
2. N1 metastases in 1 node
3. N2 metastases >1 node

**Histology**

**Staging**

Stage I T1, N0, Stage II T2, N0, Stage III T3; N1 Stage IV T4; N2; M1

Recent immunohistochemistry and genetics has facilitated subclassification of RCC into Clear cell (60%), Papillary (7-14%), Chromophobe (6-11%), Oncocytoma (7- 10%), Collecting duct and Medullary cell types (<1%).

Biological behaviour and response to therapy appear different across tumour types. Localised Chromophobe and Papillary Cell type appear to be associated with a favourable prognosis unlike Collecting duct and Medullary tumours which typically present with metastases.

## 3.0 RADIOLOGICAL EVALUATION.

Many cases will be identified incidentally on ultrasound examination for another condition. The size and site of the mass should be recorded, as well as the condition of the other kidney. All solid and complex cystic lesions require further imaging. Where available

Doppler USS can be useful for assessing the status of the veins or the extent of IVC involvement.

CT scan is the main modality for assessment of renal masses, with pre- and postcontrast enhanced scanning of the abdomen, pelvis and chest. Assessment of the primary tumour, local and regional lymph nodes, adrenals, liver and lungs should be made. Assessment of the renal veins and IVC should be made.

Tumours with typical characteristics and significant enhancement by > 15 Hounsfield units should be regarded as significant.

Bone scans are not routinely recommended, unless there is clinical or biochemical suspicion of bony metastatic disease. Suspicion may arise from bone pain, abnormal serum alkaline phosphatase or calcium, or a lesion identified on CT scan.

Magnetic resonance imaging (MRI) may be helpful in cases of renal insufficiency or contrast allergy preventing the use of intravenous contrast. MR scanning may also be helpful in the assessment of IVC thrombus or on clarifying the anatomy of individual renal lesions.

Radio-isotopic renal function assessment, including split renal function should be undertaken in patients with impaired renal function before undergoing surgery.

## 4.0 MANAGEMENT OF LOCALISED DISEASE

1. All patients should be discussed at an MDT meeting for management planning, with full history, results and imaging available, and preferably involving a professional who has met the patient.

2. Management decisions shall be recorded and communicated within 24 hours to the patient's GP (and the referring clinician).

3. Referral onwards to the renal specialist MDT (SMDT) shall be made when the case falls under the definition of complex renal cancer as defined by the IOG guidance and listed below.

### 4.1 Complex kidney cancer

- Tumours which have, or which may have invaded major blood vessels. Patients with IVC involvement should undergo treatment at the specialist centre. Cases with suprahepatic involvement may require joint operating with cardiac surgeons at FRH and JCUH.
- Patients with metastatic disease who are considered fit for further treatments.
- Patients who may benefit from resection of metastases
- Patients with an indication for nephron-sparing surgery as discussed with the SMDT.

- Patients who have von-Hippel-Lindau disease or hereditary papillary renal cancer.
- Patients where the operability of a solitary renal tumour is in doubt.
- Patients with impaired renal function.
- Resection of bilateral primaries
- Resection of non-renal cell kidney cancer, excluding transitional cell carcinoma treated by nephro-ureterectomy

### 4.2 Localised Disease

Preferred treatment for renal cancer is surgical, normally radical nephrectomy.
Open/Laparscopic radical nephrectomy is the treatment of choice for renal tumours. Larger >7cm and locally advanced tumours with renal vein involvement should be considered for open operations.
Adrenalectomy is not necessary if pre-operative imaging confirms a normal ipsilateral adrenal gland; except in large upper pole tumours with risk of direct invasion, or tumours over 7cm in diameter where there is a greater risk of metastatic spread.

Laparoscopic nephrectomy may be considered as an alternative to open radical surgery in suitable tumours.

Nephron-sparing surgery should be considered in the following indications:
**Absolute:** Anatomical or functional solitary kidney. Chronic renal insufficiency, whereby nephrectomy would result in need for dialysis. Bilateral and/or multiple renal cancers, or genetic predisposition resulting in a likelihood of developing further tumours in future.
**Relative:** Functioning opposite kidney, but the presence of other condition that may predispose to accelerated loss of renal function following contralateral nephrectomy;
e.g. Diabetes, Chronic Kidney Disease, hypertension, chronic pyelonephritis, renovascular disease, renal stone disease.

**Elective:** Unilateral renal cancer with a healthy opposite kidney.

**Cryotherapy** and **radiofrequency ablation** may be considered for treating suitable lesions, particularly where definitive histology may not be required, or in patients with multiple simultaneous or metachronous small lesions where renal function is an important consideration. These modalities may also prove helpful in treating small renal lesions in patients unfit for, or unwilling to undergo, open or laparoscopic treatment.

- Patients requiring nephron-sparing surgery should be referred to the SMDT.
- Patients with severe co-morbidities precluding surgery should be considered for palliative/expectorant or minimally invasive therapy, as appropriate.
- Specialist urology nurse input should be available at an early stage. MacMillan nurse support and/or palliative care team involvement should be sought early.

### 4.3 Small renal lesions

Large studies of renal lesions under 2.5 cms show an average growth rate of 0.28cm per year with only 1% progressing to develop metastatic disease during follow up.

- Factors to be considered in deciding treatment should include age, co-morbidity and surgical risk, risk of malignancy and renal symptoms.
- Early active treatment should be considered for younger patients, patients with renal symptoms, high index of suspicion, changing tumour size and tumours size of >3cm.

### 4.4 Role of biopsy

5.6.1. Biopsy rarely alters therapeutic options and may be considered where a) unusual radiological findings or b) clinical or radiological suspicion of alternative diagnosis eg lymphoma if no surgical incision is planned.

It should be considered as part of the treatment regiment for RFU (FRH) or cryotherapy (SRH) to confirm the diagnosis either prior or during therapy.

In patients with presenting with a significant metastatic burden, biopsy is indicated prior to consideration of systems treatment.

## 5.0. MANAGEMENT OF ADVANCED DISEASE

The biology of RCC is variable with some patients having a relatively indolent disease that can safely be observed over many years. Occasionally, spontaneous remissions have been observed although these are rarely prolonged. In the assessment of a patient with metastatic disease the following factors should be weighed up to in deciding the appropriateness and timing of systemic therapy:

• Performance status
• Co-morbidites

Site and volume of disease Prognostic score

### 5.1 Prognostic Scores in Advanced Disease

One of the most widely used prognostic scores is the Memorial Sloan-Kettering Cancer Centre score (MSKCC score or Motzer score)[1].

The network is presently running an audit evaluating the assessment of follow up regimens using this scoring system to risk stratify patient following nephrectomy with clear cell histology.

## 6.0 PATHOLOGY

1. Pathology specimens should be handled and reported in accordance with the most recent Royal College of Pathologists (RCPath) “Dataset for histopathological reporting of adult renal parenchyma neoplasms” November 2017.

2. The lead (core MDT) urological pathologist in each Trust should participate in the national uropathology EQA scheme. All other pathologists reporting renal cancers should also be encouraged to participate.

## 7.0 FOLLOW UP

Follow up of patients with renal cell cancer after surgical treatment may be offered in order to detect local recurrence and distant metastases as early as possible. This will permit additional treatment when indicated and possible. Such therapy may include resection of pulmonary metastases or local recurrences; certain cases may also be candidates for immunomodulating therapy.
Follow up strategies may be modified in order to target more frequent visits to those with more risk of developing recurrent disease. Categorising risk groups will vary, but the following is one suggested scheme.

- **Low risk**: 6 monthly follow up in the first year followed by annual review up to 5 years.
- **Intermediate /high risk**: 6 monthly follow up for first 2 years and then annually up to 5 years. FBC, biochemistry, CT chest/abdo annually to 5 years.

Follow up for advanced disease is dependent on individual circumstances. Patients with stable metastatic disease who may be candidates for subsequent systemic therapy may be reviewed at regular intervals (3 monthly) to determine the time point of progression before deterioration in performance status. This will normally be offered by the medical oncology service.

Site of follow up will initially be at the operating centre and will normally revert to the local team once the patient is stable.

## 8.0 MDT REFERRAL AND COMMUNICATION

1. Specialist MDTs (SMDT) are established at Freeman hospital, (FRH) Sunderland Royal (SRH) and James Cook University Hospital (JCUH) which provide the IOG defined service for kidney cancer cases from local MDTs within the North East and North Cumbria.
2. After each local MDT it is the responsibility of the MDT coordinator to inform the SMDT coordinator of which patients need to be discussed at the SMDT and arrange for the completed referral form to be transferred for the SMDT meeting.
3. The local MDT coordinator should establish the video link and ensure the IT suite is functional throughout the meeting.
4. The patient's x-ray file should be sent and loaded onto PACS by the SMDT co-coordinator prior to the meeting. Pathology slides can be sent with referral to the SMDT if a second opinion is necessary.

5. Each listed case will be discussed by the SMDT. The Chair will ensure that an action plan is formulated by consensus agreement and that the action plan is recorded at the meeting. It is the responsibility of the SMDT coordinator to transcribe the action plan to the electronic format and for this to be reviewed by the Chair.
6. In some cases the chairman may also dictate a letter to the referring NECNconsultant with a copy to the GP and other relevant clinicians summarising the treatment options to be recommended. The MDT action plan will include the name of the key worker who will be a core member of the MDT.
7. If it is intended that the SMDT provides treatment, patients will be contacted by the SMDT clinical key worker to inform them that their case has been discussed and that they will be seen the following week by the appropriate member of the core team.
8. Patients who are referred back to the local MDT for further management will be contacted by the local MDT clinical key worker to inform them of the outcome and arrangements will be made for them to be seen the following week by an appropriate core member of the local MDT.
9. The MDT action plan, relevant case files and imaging files will be prepared by the relevant local MDT team and forwarded to the clinic. This process will be co-ordinated centrally by the Specialist Nurses.
10. After the SMDT, the MDT coordinators liaise with the clinical nurse specialist (CNS) to ensure all clinical plans are carried out. Details of available trials that have been considered will also be included. Where appropriate the patient is contacted by the CNS to arrange an outpatient clinic appointment.
11. Copies of all operation notes, discharge summaries and follow up letters undertaken outside the patient's local hospital should be sent to the referring clinician and GP, at the time of writing.

## SPECIALIST PALLIATIVE CARE

Palliative Care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and caring for the psychological, social and spiritual aspects of life are paramount. The goal of palliative care is achievement of the best quality of life for patients and their carers. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer or other treatment.

There are some patients who are particularly likely to require specialist palliative care expertise. Referral should be made as early in the patient's disease course as is possible.

These include:
Patients with pre-existing psychological problems.
Patients in families with young children.
Patients with complex or multiple symptom control problems. Patients with disfiguring illness.
Patients with personality change e.g. glioma
Patients with problems caused by local fungation of their tumour

### Common symptom control problems

Whenever problems are anticipated early referral should be made to the local Specialist Palliative Care Team.

Issues of hydration and nutrition are often problematic for patients, carers and health care professionals. Where no improvement can be achieved by further treatment of the tumour, time must be given to gentle and through explanation of the situation, and what can realistically be achieved. Specialist palliative care input may be required to assist with these discussions.

It is inappropriate to try to stimulate appetite (e.g. with steroids) when ingestion is painful, limited or difficult. Patients are usually able to take sufficient, often in the form of nutritional liquid supplements, to satisfy thirst and appetite.

Meticulous attention must be paid to:
Mouthcare – seek specialist nurse advice.
Pain control – use of regular non-oral medication.
Anti-emesis – delivered via subcutaneous infusion where necessary.
Relief of constipation – regular non-bulk forming laxative plus rectal measures as necessary.