

Leeds Cancer Centre and Yorkshire Cancer Network
Germ Cell Tumour Multidisciplinary Team
Standard Operating Procedure

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LEEDS CANCER CENTRE GERM CELL TUMOUR MULTIDISCIPLINARY TEAM STANDARD OPERATING PROCEDURE 1

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1. Introduction and Germ cell MDT Meetings

- This document is designed to be read and used in conjunction with the Yorkshire Cancer Network Germ cell tumour Guidelines and also the germ cell specific referral pathway document (appendix 2)
- The Leeds Cancer Centre Germ cell MDT meeting serves several functions:
 - ◇ The Specialist MDT for the Yorkshire Cancer Network (YCN) GCT team, serving the YCN and delivering treatment for GCT. This is the only such team in the Yorkshire Cancer Network.
 - ◇ The specialist MDT for the HYCCN GCT team. This is the only such meeting and team in that network.
- Operational Management Group
 - ◇ The functions and development of the multi-disciplinary clinical service are overseen by the Operational Management Group (OMG) for Urological cancers.
 - ◇ The OMG is chaired by the Trust lead for Urological cancer surgery and meets at least once a year
- Weekly Team Briefing
 - ◇ The MDT lead meets with the MDT admin staff weekly after each MDT to discuss any issues that have arisen and ensure prompt resolution of any problems
 - ◇

2. MDT Meetings Time and Location

- There is one meeting a week
- Friday 1430-15-30
- Location, Cookridge Conference Centre, MDT Room 1, Level 07, Bexley Wing, St James's University Hospital, Leeds. Video conferencing is in place with Hull Cancer Centre for joint working around HYCCN cases of suspected GCT.
- This meeting is a 1.0 hour programmed activity for the purpose of professional job planning.
- Managers and Clinical Directors should note that pathologists and radiologists require additional programmed activity to allow for preparation and review prior to the meetings and the issuing of review reports after the meetings.
- The Germ cell MDT follows a general urological cancer MDT, which is signified by a change of chairperson and other members. Separate recording of attendance and discussion exists for the GCT MDT.

3. Purpose and Functions of the MDT

Purpose:

- To facilitate but not delay the management of patients.
- The requirement for discussion at the MDT should not delay patient referral, discussion or transfer.
 - ◇ Where important for timely patient management- discussion, referral and transfer can and should happen between appropriate MDT members outside the context of the MDT meeting.
 - ◇ Patients managed in this way must however be discussed at the next MDT.

Functions:

- To establish or confirm diagnosis.
- To resolve ambiguities.
- To facilitate clinical radiological and pathological correlation.
- To alert the MDT to unexpected radiological or pathological findings suggesting GCT. These may have arisen in or outside LTHT urology services.
- To plan or confirm appropriate management of each patient including referral to the appropriate MDT member or other MDT as appropriate.
- To ensure maintenance of clinical standards and protocols to support clinical governance.
- To collect data according to a GCT cancer minimum dataset to facilitate audit and research.
- To consider and confirm eligibility for the GCT cancer clinical trials portfolio.
- To facilitate continuing professional education for all staff.

- Maintenance of professional relationships.
- The Germ Cell MDT in Leeds provides a cross-network service for Yorkshire and Humber and the Yorkshire Coast, for the assessment, management and monitoring of patients with GCT. This also includes providing the service for retroperitoneal lymph node dissections. This cross-network working is an extension and formalisation of previous working practices, and is new in 2009-10.

4. Referral of Patients to the Leeds GCT MDT

- All new GCT patients are to be reviewed at the MDT. It is the responsibility of the clinician to ensure that any patient who needs an MDT review is added to the meeting.
- Pathology slides and reports are collected by Dr Harnden's secretary for this MDT, supported by a request from the MDT chair.
- From within Leeds patients should be submitted using PPM.
- Clinicians unfamiliar with PPM may use the MDT request form. The latter should be submitted to the MDT Co-ordinator by post/hand or fax. (Appendix 1)
- The GCT MDT Co-ordinators will fax requests to radiology/ pathology secretaries. These secretaries must receive these requests by Wednesday 10.00am for the patients to be included on Friday's meeting. Any requests after this date and time will be included on the following week's MDT meeting
- If a case is urgent and this time frame cannot be fulfilled then the referring surgeon must personally contact the leads for radiology and pathology within the GCT MDT [currently Dr Harnden (Pathology) or Dr Swift (Radiology)] direct, who will liaise with the MDT Co-ordinator
- Most GCT referrals are from a urologist to Medical Oncology. Dr Stark, Amanda Rose and Carolyn Gosney will usually put such cases on the meeting. Where Urologists in the YCN have PPM access they can request cases onto the meeting, but this is no substitute for the usual faxed referral to Dr Stark to ensure the necessary urgency in GCT management is maintained.
- Referrals for Retroperitoneal lymph node dissection (RPLND) should go to Dr Stark in the first instance, with copy letter to Mr Joyce, Lead for RPND surgery. Patients discussed at MDT requiring RPLND will be referred at the meeting and by letter to Mr Joyce, with copy to Mr Paul.
- Referrals for consideration of intra-thoracic resection of residual masses will be to Mr Papagianopolous in Thoracic surgery.
- Referrals for consideration of resection or radiofrequency ablation of intra-hepatic residual masses will be to Mr Toogood in Hepatobiliary surgery.
- Each of these patients may require joint surgical approaches with vascular surgery and others.

5. Preparation of the MDT Meeting

- The MDT Co-ordinator will use PPM to prepare a single Meeting List of patients to be discussed
- Meeting lists are available and may be viewed on PPM. This access is currently restricted within LTHT and the Calderdale NHS Trust.
- The GCT MDT currently takes place without case notes and uses information from PPM.

6. Order of Cases to be Discussed on MDT

- It is intended that all core members of the MDT should attend the whole meeting. This may not always be possible, this should be realised over time through job planning.
- Nominated pathology, radiology, surgical and non-surgical expertise should remain for the duration of the meeting since they may be able to provide useful input to discussion and planning of patient management.
- All new cancer patients are to be discussed at a GCT MDT meeting.
- New cases will be discussed first followed by review patients.

7. Presentation of cases

- All cases should be presented in a clear and audible fashion.
- Clinicians presenting cases should start by stating which groups of clinicians are particularly important to the discussion i.e. surgeons or oncologists.

- It is essential that doctors presenting cases are adequately prepared to do so. Some preparation prior to the meeting will be necessary.
- The MDT room has full AV facilities. Clinicians are encouraged to supplement their presentations by OHP or digital projection via PowerPoint or similar. This would be particularly useful for trainees.

8. Conduct of the MDT Meeting

- There will be a nominated chairperson for each meeting who will have the responsibility of making sure that the meeting runs efficiently, and that the appropriate management plan for each case is typed into PPM.
- The Chairman of the meeting is Dan Stark.
 - ◊ In the absence of Dan Stark, Alan Paul will chair the meeting
 - ◊ In the absence of both Dan Stark and, Alan Paul, Adrian Joyce will chair the meeting
- The chairperson will arrange cover prior to leave.
- The PPM record for each patient will be projected during the meeting.
- The management plan and other notes completed by the chairperson summarising the discussion will be typed onto PPM by the MDT co-ordinator during and after the meeting.
- If detailed, speciality specific urgent notes of the discussion are required, these should be made directly into the patient's case notes by the relevant doctor immediately after the meeting. Less urgent notes can be included in the meeting note which will be available on PPM within 24 hours of the meeting and filed in the notes in due course.
- The cases referred from HYCCN will be discussed first in the meeting, followed by those from YCN. Radiology and pathology materials for these cases will be provided in a timely manner directly to the MDT by the diagnostic teams in HYCCN and YCN.
- The MDT is key to collecting data for Audit and description of the GCT practice, one of the largest in the UK. The Chair will make recordings of histopathological, staging and prognostic data onto a standardised data sheet for each case discussed, and these will be coded within PPM by the MDT administrators after the meeting.
- The MDT Co-ordinator will keep a list of all MDT members present in the meetings, and this will be entered into PPM.
- After the meeting, the MDT chairperson and/or Senior Nurse will liaise with appropriate clerical and secretarial staff, to ensure that the OPD appointments, scan appointments and theatre bookings agreed in the meeting are arranged.

9. Management plan

- Recording an accurate patient management plan is a vital endpoint to MDT discussion. It is vital that the recorded plan is "owned" and agreed by the whole of the MDT
- On completion of MDT discussion of the case, the key features and agreed management plan will be verbally summarised by the clinician referring the patient This summary will indicate:
 - ◊ Place of care- whether YCN or HYCCN
 - ◊ Whether further investigation is required
 - ◊ The suggested treatment modalities.
 - ◊ Whether further review of radiology or pathology or further MDT discussion is required. If required, agree date of next review and record this clearly in the patient's case notes and on the PPM database
 - ◊ Date of follow-up or date of next procedure to be agreed in each case
 - ◊ The chairperson will be responsible for noting management plan onto a case discussion form, for typing by the MDT coordinator within 24 hours of the meeting. This will be faxed to the patient's general practitioner within 24 working hour of the GCT MDT meeting.
- If the management plan deviates from the Network guidelines:
 - ◊ Reason for deviation should be recorded.
 - ◊ If this is due to a clinician operating outside the network guidelines, or contrary to the MDT plan consider inclusion of the case in the next clinical governance meeting.
- The management plan can be viewed from with LTH Trust on PPM within 24 hours of the meeting. PPM is available with full password security to all clinicians in the GC MDT from HYCCN, whether working in Leeds or Hull cancer centres.

- The typed summary sheet will be returned to the meeting chair person for signature at the following meeting, 1 week later. Any corrections can be made at this stage. The signed sheets will be returned to the MDT Co-ordinator for filing in the patient's case notes.

10. Procedure when MDT Recommendations are not followed

- On occasions the recommendation of the MDT that the patient attend for consultation at the Cancer Centre may not be followed.
 - ◇ If the patient fails to attend the clinic, the consultant in charge of that clinic will record that the patient has failed to attend in the case notes. The patient's GP will be informed.
 - ◇ The referring clinician and appropriate CNS should be informed of the non-attendance and will be responsible for liaising with the patient locally.
 - ◇ A further appointment should be offered where appropriate.
 - ◇ If the patient still fails to attend then the case should be discussed in the next clinical governance meeting.
 - ◇ Refer back to the MDT for information.
- In some instances the MDT recommendations will not be appropriate due to the patient's co-morbid conditions.
 - ◇ A record of these occurrences will be kept on PPM.
- In other instances the MDT recommendations will not be acceptable to the patient.
 - ◇ A record will also be kept on PPM of cases where modifications to the treatment plan are made after discussion of options with the patient
- The frequency of deviations from the MDT agreed plan will be the subject of ongoing audit.
- To facilitate such audit responsible clinician should record the reasons for deviation from the agreed plan in the patient's medical notes and on the PPM record

11. Communication of a New Diagnosis of Cancer to Patient's General Practitioner

- The patient, and hence their GP, has usually been informed of their diagnosis by their local MDT clinician prior to referral to the Specialist MDT.
- It is agreed that a copy of the MDT notes generated by the MDT co-ordinators from the MDT discussion and held in the cancer database Patient Pathway Manager (PPM) will be sent by Dr Stark's secretary after the MDT meeting by fax. These notes will be accompanied by covering notes from the MDT Leader giving an explanation as to what has been discussed and when the patient will be informed of this information.

It is the aim to ensure GPs receive this information at least within the following working day of the patient being informed of their diagnosis.

12. Provision of Information to Patients

It is anticipated that if the patient has a problem or needs further information that they will contact the germ cell support nurse, or the consultant's team responsible for the current phase of care or follow-up. For patient's undergoing chemotherapy or radiotherapy, specific patient information booklets are issued which specify the contact names that patient's should need.

At the time they are given a cancer diagnosis, the patient will be offered the opportunity to have a permanent record of their consultation which will be completed by the surgeon in clinic.

A record of the key worker and the offer of the permanent consultation will be made within the cancer database Patient Pathway Manager (PPM).

Identification of the Key worker

All patients will be allocated a key worker, who will take the lead in co-ordinating the care and promoting continuity for the patient through his/her pathway. The name and contact details of this key worker will be given to the patient and recorded on PPM. This key worker will be either the germ cell support nurse, or a Teenage and Young Adult Cancer Clinical Nurse Specialist.

Where possible, the MDT Meetings will be the forum for discussion and agreement of each patient's Key Worker.

It is anticipated that the key worker will need to change as the patient progresses through their pathway of care especially when having specific treatments and care e.g. chemotherapy, radiotherapy and palliative care. Such changes will be agreed on a patient by patient basis and with agreement and communication with the staff involved and the patient.

The following principles are to be used as a guide for identification of a key worker for urology-oncology patients, but will obviously be based on the needs of the individual.

All patients with germ cell tumours who receive post-operative non-surgical treatment aged <40 years, and those over 40 years who have a particular reason to require this service, are offered sperm storage as part of new patient and follow-up appointments with written and verbal information given.

In YCN there is not a policy of offering pre-orchidectomy sperm storage routinely, although there are specific indications for an offer of pre-orchidectomy sperm storage in the network guidelines.

13. IT Infrastructure to the Germ cell tumour MDT

- Patient pathway manger (PPM) is the system for data collection.
- Patient Pathway Manager (PPM) is used to collect the NHS cancer minimum data set, including the Urological cancer chapter and it's specific data items.
- It is also used to arrange the MDT meetings, produce lists of patients to be discussed and to hold the conclusions of those meetings.
- PPM contains contact information for all members of the MDT and will be used to manage this information. The contact list from PPM is at the end of the SOP document.
- PPM links to PAS so that the demographic data is uploaded from PAS and kept up-to-date automatically.
- PPM holds a copy of all of the clinical word processed notes produced by secretaries in Urology, medical and clinical oncology. These can prove invaluable in patient management
- PPM holds information about the entire cancer journey, from referral to death, and should be used by all specialities within Urological services.
- PPM is also used to monitor and manage the returns for cancer waiting time analysis.
- Work is ongoing across the Network to ensure that information regarding the entire cancer journey is shared between the Cancer Units and Cancer Centre so that a complete dataset is held in all locations, according to the policy agreed with the chair of the NSSG.
- PPM is available to any computer connected to the Trust network. It functions using MS Windows terminal server technology so that no data is held on the local computer. Response times are very rapid, so that use in real time is encouraged.
 - ◊ Work is ongoing to explore the use of PPM over the NHS Network to selected IP restricted computers used by outreach consultants in the course of their clinics in Cancer Units
- PPM enabled computers are available in all clinical locations used by the urology oncology team.
- Access to PPM may be arranged through Martin Waugh, Cancer Centre IT manager.
- It is not necessary to have a high specification computer since all data processing is carried out on the file server.

14. Data Collection

- The MDT admin staff are responsible for the quality and integrity of this data set.
- PPM may be used in the clinics and on the wards. This is an opportunity for clinicians to check the accuracy of the data and update or correct it when necessary.

- Centre surgeons and their subspecialty trainees are encouraged to contribute to the completeness and accuracy of data collection by entering operation details directly into PPM which will produce a typed operation note for filing in the patient's medical records.

15. Multidisciplinary Team Members

- Dr Dan Stark is the MDT Lead Clinician
- MDT contact details, including joining and leaving dates, are stored on the PPM database, this list is maintained by the MDT co-ordinator.
- The contact list will indicate the role of each contact and whether they are a core or extended member of the team
- According to the cancer standards we are required to identify the cover arrangements for each core member of the team. This information will also be recorded in the list.
- Any additions, deletions, changes or corrections should be notified to the MDT co-ordinator.
- The Table shown below (produced by PPM) shows the current contact details for MDT members. Please notify any changes to the MDT co-ordinator
- MDT members with ULTH Trust e-mail addresses stored within PPM can be sent meeting lists and reports by e-mail directly from PPM
- Please Note Patient details including meeting lists CANNOT be sent to email addresses outside the Trust other than by special arrangement (through Martin Waugh) with individual Trusts which hold outreach clinics.
- With the low death rate from testicular cancer referral to palliative care is relatively infrequent compared to some other cancer MDTs, and regular core palliative care input to the MDT is not good use of resources. However for patients with specific symptom control needs (even at diagnosis where treatment intent is curative not palliative) referral to specialist palliative care for symptom control management advice and procedures is available through a written referral pathway. Referral to specialist palliative care is also made to general palliative care services local to the patient when treatment intent is no longer radical including end of life care for some patients.
- There is specialist core psychology membership of the germ cell MDT. For patients with psychological difficulties adapting to their illness, where supportive care within the Germ cell team is not effective, referral to psychosocial oncology services for counselling or more specialist care is available through a written referral pathway. For teenage and young adult patients with testicular cancer dedicated TYA clinical psychology attendance at the weekly clinic is frequent to advise, support and detect emerging problems.

Name and Contact Details	Role	Contact Details	Identified Cover
Consultant Urologists			
Mr Alan Paul	Core	Tel: 0113 2065385 Mob 07811358355 Email: alan.paul@leedsth.nhs.uk	Adrian Joyce
Mr Adrian Joyce	Core	Tel: 011302066993 Email: Adrian.joyce@leedsth.nhs.uk	Alan Paul
Mr Stephen Prescott	Ext	Tel: 0113 2066796 Email: Stephen.prescott@leedsth.nhs.uk	
Mr Sunjay Jain	Ext	Tel: 0113 2065815 Email: Sunjay.jain@leedsth.nhs.uk	
Mr Jon Cartledge	Ext	Tel: 0113 2064214 Mob: 07766332580 Email: Joh.Cartledge@leedsth.nhs.uk	
Mr William Cross	Ext	Tel: 0113 20 64207 Mob;07659518908 Email: William.Cross@leedsth.nhs.uk	
Mr Ian Eardley	Ext	Tel: 0113 2066994 Email: ian.Eardley@leedsth.nhs.uk	
Mr Stuart Lloyd	Ext	Tel: 0113 2066795 Mob: 07803891621 Email: Stuart.Lloyd@leedsth.nhs.uk	
Mr Neil Harris	Ext	Tel: 0113 2064209 Email: Neil.Harris@leedsth.nhs.uk	
Consultant Histopathologists			
Dr Patricia Harnden	Core	Tel: 0113 2064891 Email: Patricia.Harnden@leedsth.nhs.uk	Sameer Chilka, Selina Bhattarai
Dr Sameer Chilka	Core	Tel: 0113 2067212 Email: Sameer.Chilka@leedsth.nhs.uk	Patricia Harnden, Selina Bhattarai
Dr Selina Bhattarai	Core	Tel: 0113 20 65693 Email: Selina.Bhattarai@leedsth.nhs.uk	Patricia Harnden, Sameer Chilka
Consultant Radiologists			
Dr Tze Wah	Ext	Tel: 0113 2064330 Email: Tze.Wah@leedsth.nhs.uk	
Dr Henry Irving	Ext	Tel: 0113 2064330 Email: Henry.Irving@leedsth.nhs.uk	
Dr Jonathan Smith	Ext	Tel : 0113 2067480 Email: Jonathan.Smith@leedsth.nhs.uk	
Dr John Spencer	Ext	Tel: 0113 2066140 / Fax: 2066259 Email: John.spencer@leedsth.nhs.uk	
Dr Brendan Carey	Core	Tel: 0113 3924281 Email: Brendan.Carey@leedsth.nhs.uk	Sarah Swift
Dr Sarah Swift	Core	Tel: 0113 3924281 / 0113 2065231 Email: Sarah.Swift@leedsth.nhs.uk	Brendan Carey
Dr Michael Weston	Ext	Tel: 0113 2064330 Email: Michael.Weston@leedsth.nhs.uk	
Consultant Clinical Oncologists			
Dr Carmel Loughrey	Core	Tel: 0113 3927548 Email: Carmel.Loughrey@leedsth.nhs.uk	Dr Di Gilson
Specialist Palliative Care			
Dr Joy Lyle (Specialty Doctor)	Ext	Tel: 0113 20 64563 Email: Joy.Lyle@leedsth.nhs.uk	

Specialist Psychological Care			
Dr Sarah Catesby, Consultant Clinical Psychologist	Ext	Tel: 0113 20 67748 Email: Sarah.Catesby@leedsth.nhs.uk	
Consultant Medical Oncologists			
Dr Dan Stark	Core	Tel: 0113 2068266 Email: Amanda.Rose@leedsth.nhs.uk	Dr Sheryl Sim (Locum consultant Medical Oncologist)
Dr Satinder Jagdev	Ext	Tel: 0113 20 68218 Email: Satinder.Jagdev@leedsth.nhs.uk	
Dr Sheryl Sim	Ext	Tel: 07951 953655 Email: Sheryl.Sim@leedsth.nhs.uk	
Dr Mohammed Butt (HYCCN)	Ext	Tel: 01482 461303 Email	
Specialist Nurses			
Carolyn Gosney germ cell support nurse)* and service user lead	Core	Tel: 0113 20 67676 Email: Carolyn.Gosney@leedsth.nhs.uk	Gemma Glover This is a research nurse not a clinical nurse specialist, which is a concern/risk for continuity of care
Gemma Glover (research Nurse) and clinical trials lead	Ext	Tel: 0113 20 67759 Email: Gemma.Glover@leedsth.nhs.uk	Hannah Wigginton
Hannah Wigginton (research Nurse)	Ext	Tel: 0113 20 67983 Email: Hannah.Wigginton@leedsth.nhs.uk	Gemma Glover
MDT Administrators			
Janice Hoddell	Core	Tel: 0113 20 66909 Email: Janice.Hoddell@leedsth.nhs.uk	David Hammond, Collette Gunn
David Hammond	Core	Tel : 0113 2067098 Email: David.Hammond@leedsth.nhs.uk	Janice Hoddell, Collette Gunn
Collette Gunn	Core	Tel: 0113 20 66793 Email: Collette.Gunn@leedsth.nhs.uk	David Hammond. Janice Hoddell

16. Signature

Signed by: MDT Leader Testicular Team Leeds Cancer Centre	Date:
Date of SOP:	Date for Review:

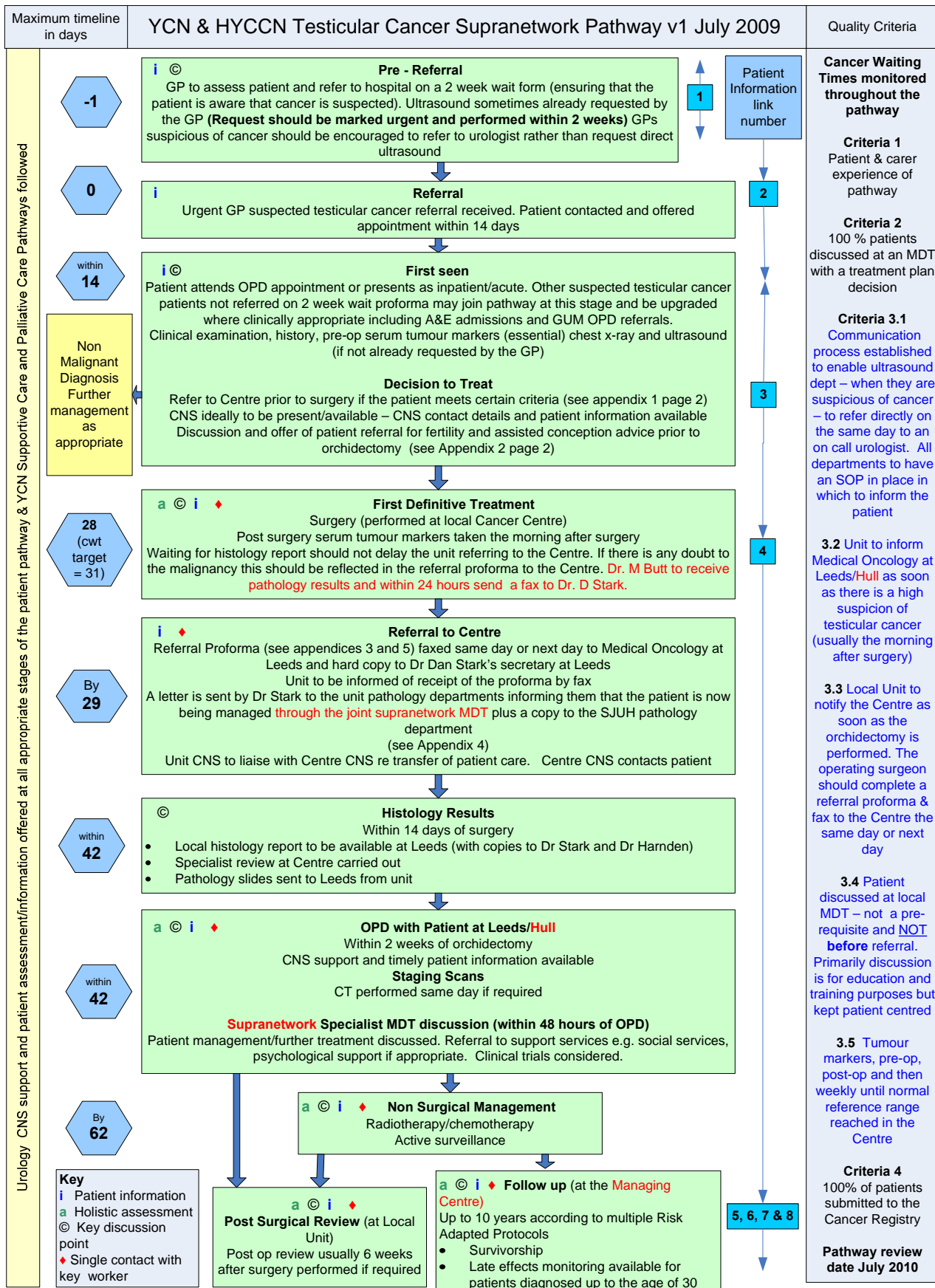
Appendix 1

Referral proforma Regional/supra-regional Germ cell MDT, Bexley Wing Leeds

Send to Medical Oncology at Leeds (0113 2068842) FAO Dr Dan Stark

Please send hard copy of this pro-forma to Dr Dan Stark's secretary (Amanda Rose, Oncology, Level 4, Bexley Wing, St James's Institute of Oncology 0113 2068266)

Patients name		
Local hospital reference/case note number		
NHS number		
Date of birth		
Address		
Contact telephone number for the patient (for telephone contact from Leeds to arrange imaging and clinic appointment)		
Urology/other lead consultant		Urology/other (please specify).....
Patient awareness	Has the patient been told cancer is a possible diagnosis for their testicular swelling	Y/N
	Has the patient been informed they will have contact from the Germ Cell Tumour Service in Leeds as a result of this surgery	Y/N
Approximate length of history (in months)		
Pre-operative findings	Chest X-ray result	Normal/Abnormal
	Testicular ultrasound result	
	Laterality of tumour	
	Inguinal orchidectomy date	
	Pre-operative tumour markers sent	Y/N
Other notes/concerns (The patient will be seen within 14 days of orchidectomy unless problems are raised here).		



The Supranetwork Testicular Cancer pathway incorporates the YCN Supportive and Palliative Care Pathways. Key discussion points, key information, key worker contacts and holistic assessments are identified by symbols along the Testicular pathway. The Testicular pathway is supported by a tumour specific Patient Information Pathway. The Patient Information Pathway supports the steps in the testicular pathway such as referral, diagnostic procedures and tests, diagnosis, treatments and side effects and support services. Each stage is numbered from 1 to 8 indicating when the information might be offered. Additional national resources to meet assessed or expressed patient/carer information needs may be offered at any stage along the pathway

Appendix 1: Criteria for referral to centre prior to surgery

The indication for discussing this between the managing Urologist and Dr Dan Stark (or deputy) in Leeds should be:

- **Metastatic disease visible on chest X-ray**
- **Abdominal mass clinically evaluable or palpable**
- **Clinically significant cervical or axillary lymphadenopathy**
- **Weight loss >10% in the presence of a clinical testicular mass.**

A consideration in these patients may well be performing ultrasound abdomen as well as ultrasound testis in the local hospital prior to telephone discussion with Leeds Medical Oncology with the result. Then planning for surgery, chemotherapy and definitive staging can take place simultaneously in Leeds.

Appendix 2: Criteria for discussion and offer of patient referral for fertility and assisted conception advice prior to orchidectomy to include

- **Bi-lateral tumours**
- **Known pre-existing oligo or azoospermia**
- **A high risk of testicular intertubular neoplasia (manifest by testicular atrophy, volume <12mls in a patient less than 40 years, gross calcification on ultrasound)**

If the patient is unwell early telephone or fax referral to Dr Dan Stark in Leeds allows us to co-ordinate staging, fertility advice, chemotherapy and orchidectomy within a single team in Leeds, and is better than splitting the process between a regional centre and Leeds

Appendix 3: Referral to Centre Process

Referral to be made to Medical Oncology at Leeds by faxed pro-forma (see page 3), or letter with all the information from the pro-forma if that is preferred. The responsibilities for this falls to the operating surgeon performing orchidectomy. It should be completed so that it is received in Leeds within 36 working hours of orchidectomy.

Appendix 4: Histology report

Upon receipt of a referral in the Leeds Germ Cell team; using the fax pro-forma (see Appendix 5) a standard histology request letter will be sent by that team to the local Pathology department. By copying this letter to Dr Pat Harnden's secretary in Urological Pathology at St James' with the full patient details we can provide earlier notice to Pathology that central review is going to be required, making it more likely that the standard is met of local pathology report and slides being available within 16 days of surgery for definitive decision making in the Regional Germ Cell MDT in Leeds.

As soon as the patient is diagnosed with testicular cancer and if age appropriate, refer patient to the Teenage and Young Adult Unit (TYAS) at Leeds and follow the YCN Teenage and Young Adult with cancer pathway

Appendix 5: Fax referral Pro-Forma

Send to Medical Oncology at Leeds (Fax number: 0113 2068842) FAO Dr Dan Stark
Please send hard copy of this pro-forma to Dr Dan Stark's secretary (Amanda Rose, Oncology, Level 4, Bexley Wing, St James's Institute of Oncology, Telephone: 0113 2068266)

Patients name		
GP details		
Local hospital reference/case note number		
NHS number		
Date of birth		
Address		
Contact telephone number for the patient (for telephone contact from Leeds to arrange imaging and clinic appointment)		
Patient awareness	Has the patient been told cancer is a possible diagnosis for their testicular swelling	Y/N
	Has the patient been informed they will have contact from the Germ Cell Tumour Service in Leeds as a result of this surgery	Y/N
Approximate length of history (in months)		
Pre-operative findings	Chest X-ray result	Normal/Abnormal
	Testicular ultrasound result	
	Laterality of tumour	
	Inguinal orchidectomy date	
	Pre-operative tumour markers sent	Y/N
Other notes/concerns (The patient will be seen within 14 days of orchidectomy unless problems are raised here).		

Appendix 3

- LEEDS CANCER CENTRE
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- MULTIDISCIPLINARY TEAM LEADER
- JOB DESCRIPTION

The Leeds Cancer Centre supports a large number of cancer site-specific multi-disciplinary teams. Each team is made up of a defined, core group of staff and a number of extended members who provide services when requested. Each team has administrative and data management support.

Each team is led by a MDT Leader – a clinically based professional who takes responsibility for a particular team. Appointments are made on a three-year basis.

1. Professional Background

- 1.1 Multidisciplinary Team Leaders will possess recognised standing within their specific area of expertise and established organisational skills.
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 - 2. *Role and Responsibilities*
- 2.1 Ensure that the MDT meetings occur at weekly or fortnightly¹, are well organised and documented to the standard expected by the Manual for Cancer Standards.
- 2.2 Ensure development meetings are arranged for the team at least twice a year.
- 2.3 Represent the team on Leeds Cancer Centre and/or Acute Trust related activity and developments, where appropriate.
- 2.4 Where necessary, work closely with Trust Managers on planned developments of the service.
- 2.5 Ensure the team works towards meeting the quality measures outlined in the Manual for Cancer Standards.
- 2.6 Lead the MDT through peer review, as required, by ensuring the development and delivery of action plans to meet the relevant IOG measures, the collation of evidence files and that adequate preparation for the review meetings takes place.
- 2.7 Be responsible for identifying and promoting the development/adoption of guidelines and protocols relating to their cancer site.
- 2.8 Ensure that the MDT has patient pathways in place that facilitate meeting the cancer waiting times standards and that the MDT supports the patient tracking processes necessary to assure compliance with these targets.
- 2.9 Stimulate appropriate high quality clinical audit and research, working closely with the Yorkshire Cancer Research Network.
- 2.10 Review patterns of referral within the cancer site in order to ensure the existence of an appropriate and clear referral process between the Leeds Cancer Centre and General Practitioners/Cancer Units.

¹ * As determined by local need and/or requirements outlined in the Manual for Cancer Services

- 2.11 Closely supervise the work of the MDT administrative support team, ensuring these staff are given clear direction in their role and are supported in managing and developing the administrative processes of the team. Meet with these staff on a regular basis.
- 2.12 Contribute to the reporting and monitoring process relating to the Leeds Cancer Centre. This will include the preparation of the Leeds Cancer Centre Annual Report, together with the Cancer Centre Lead Clinician and support staff.
- 2.13 Work with the Cancer Services Improvement Partnership, the Leeds Patient Improvement Team and primary care to review pathways of care.
- 2.14 Represent the Cancer Centre in the site-specific meeting of the Yorkshire Cancer Network, to plan appropriate service patterns for that cancer site across the Network and to offer professional advice to Commissioners and Trusts on general issues relating to their cancer site.
- 2.15 Represent the cancer site-specific team on appointment processes that will have an impact on the team e.g. the Consultant Advisory Appointment Committees
- 2.16 Attend appropriate meetings of the Leeds Cancer Centre, including the MDT Leaders forum.

3. Accountability

- 3.1 The MDT Leaders will be accountable, through the Leeds Cancer Centre Lead Clinician or Deputy, to the Trust's Executive Director Cancer Lead.

4. Notes

- 4.1 The Cancer Services Support Team is available as a resource and support. The MDT Leader is encouraged to work closely with this team to enhance the pathways of care and MDT processes locally.
- 4.2 The Cancer Services Support Team will provide specific support and professional development opportunities for the MDT administrative support team.

Agreed by:	Agreed by:
[MDT Leader] Alan Anthony	[Lead Clinician, Leeds Cancer Centre]
Date:	Date:
Job description reviewed: 1st March 2009	Date for review: 1st March 2012

**Appendix 4
THE LEEDS TEACHING HOSPITALS NHS TRUST**

Job Title : Clinical Nurse Specialist

Reports To : Matron

Accountable To : Matron

Band : 6

Unit/Department :

Location :

Date : October 2008

JOB PURPOSE

The jobholder is responsible for the management of a defined caseload. The jobholder carries continuing responsibility for the assessment of care needs, the development, implementation and evaluation of programmes of care and the setting of standards of care. The jobholder will provide specialist nursing care and advice to a specific patient group and will contribute to the development of the speciality service. The jobholder will ensure cost effective use of resources.

JOB DIMENSIONS

The post holder will:

Carry responsibility for a defined caseload of patients with diagnosed cancer in their area

Provide expert nursing advice and support to those patients and other health professionals in relation to this patient group.

As a core member of the MDT, contribute to multidisciplinary discussion and patient assessment/core planning decision of the team at the MDT meetings.

Will contribute to the management of service

Lead on patient and carer communication issues including patient information and coordination of the patients pathway

Act as the key worker or be responsible for allocating the key worker.

ORGANISATIONAL CHART - see additional page

KNOWLEDGE, SKILLS AND EXPERIENCE REQUIRED

Qualifications

Registered Nurse (Level 1)

Recognised teaching/assessing qualification

Post registration in specialty

Understanding of relevant National Service Frameworks (if appropriate)

Awareness of Leeds Teaching Hospitals Trust guidelines and policies

Understanding of organisational structures

PRINCIPLE DUTIES AND AREAS OF RESPONSIBILITY

Acts in accordance with the Nursing and Midwifery Code of Conduct

See Job description

Clinical

Clinical care delivery

- Provide a clinical lead and role model to nursing staff by delivering high quality care.
- Manage a caseload of patients with sarcoma.
- Undertake clinical procedures where dexterity and accuracy are required.
- Maintain a safe working environment
- Undertake holistic assessment of patient needs in line with National Guidelines.

Responsibilities for patient and client care

- Assesses, plans, implements and evaluates care and treatments using specialist knowledge and skills.

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- Organises own clinical workload
- Receives supervision of clinical care and outcomes from Matron.
- Act as a core member of the MDT, contributing to multidisciplinary discussion and decision making, acting as patient advocate.

Freedom to act

- Refer patients as appropriate to other members of the multidisciplinary team.
- Make clinical assessments and treatment decisions within clearly defined policies and protocols

Communication

- Maintains accurate clinical and other records using the Leeds teaching Hospitals Trust's documentation.
- Support patients and their families communicating sensitive condition related information and ensuring they receive required information to enable them to participate in their care delivery.
- Liaise with Community Services (as appropriate) to ensure seamless provision of care delivery.
- Contribute to the development of an agreed patient information pathway.

Education and Training

- Provide training and education of learners and other junior staff
- Actively participate in the development of own personal development plan and performance review.
- Provide education and training to patients and their carers.

Experience

At least 3 years at Band 5 or equivalent of which at least 2 years should be within a relevant specialty area and during which the following experience should have been gained:

Clinical audit and standard setting

Service development and/or change management (desirable)

Skills

Communication

Teaching

Leadership

IT skills

Knowledge

Experience and knowledge of specialty

Current issues in healthcare

Standards of professional practice

Personal Attributes

Excellent interpersonal skills

Innovator

Motivator

Assertiveness

Flexibility, adaptable, capable of lateral thinking

CORE VALUES

Commitment to delivering high quality evidence based care

Commitment to working in a multidisciplinary team

Commitment to the specialty area, valuing the contribution of all team members, encouraging a positive and creative working environment

Commitment to own personal and professional development and to the development of others within the team.

CORE BEHAVIOURS AND SKILLS

Communication skills

Teaching and assessment skills

Organisational skills

Time management skills

Change management skills

Understanding of research based practice - research conscious

Team player

Conflict Management

Managing stress

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Uses initiative to resolve issues within their own control
Ability to act professionally at all times.

CORE KNOWLEDGE AND UNDERSTANDING

Understanding of the local and national nursing agenda
Leadership and management

- Investigate and respond to accidents, complaints, untoward incidents and other significant events.

Work with Matron to promote development of nurses undertaking the CNO 'Ten Key Roles' as considered appropriate

Under the direction of Matron participates in or leads the development of specific elements of nursing practice, reflecting the CMT and Nursing Directorate business plans
Participates in the setting, monitoring and improvement of standards and the quality of patient care, including those standards in the National Benchmarks for Essential Care
Promote evidence based practice, wherever possible
Engages users and carers views on service delivery and development.
Implement policy and practice guidelines specific to the clinical speciality, proposing changes where appropriate
Contribute to policy and protocol development for specialty area
Contribute to the management of the sarcoma service.

Exercises a personal duty of care in relation to equipment, resource and stock control utilising equipment and supplies appropriately.

Research and Audit

Contribute to the research agenda

Undertake audit programmes specific to client group, treatments and developments

Participate in clinical trials as appropriate

Utilise research evidence in relation to the care of the patient group

HEALTH AND SAFETY/RISK MANAGEMENT

All staff are responsible for working with their colleagues to maintain and improve the quality of services provided to our patients and other service users. This includes complying at all times with the Leeds Teaching Hospitals NHS Trust Policies, including Health and Safety policies, in particular by following agreed safe working procedures, and reporting incidents using the Trust Incident Reporting system.

INFECTION CONTROL

The jobholder must comply at all times with the Leeds Teaching Hospitals NHS Trust Infection Control Policies, in particular by practising Universal Infection Control Precautions. Hand hygiene must be performed before and after contact with patients and their environment.

EQUALITY AND DIVERSITY

The jobholder must comply with all policies and procedures designed to ensure equality of employment and that services are delivered in ways that meet the individual needs of patients and their families. No person whether they are staff, patient or visitor should receive less favourable treatment because of their gender, ethnic origin, age, disability, sexual orientation, religion etc.

PATIENT AND PUBLIC INVOLVEMENT

The Trust has a statutory duty to involve patients and public in evaluating and planning services. All staff have a responsibility to listen to the views of patients and to contribute to service improvements based on patient feedback.

TRAINING AND PERSONAL DEVELOPMENT - CONTINUOUS PROFESSIONAL DEVELOPMENT

The jobholder must take responsibility, in agreement with his/her line manager, for his/her own personal development by ensuring that Continuous Professional Development remains a priority. The jobholder will undertake all mandatory training required for the role.

RESPECT FOR PATIENT CONFIDENTIALITY

The jobholder should respect patient confidentiality at all times and not divulge patient information unless sanctioned by the requirements of the role.

COMMUNICATION AND WORKING RELATIONSHIPS

Matron

All grades nursing staff

Allied Health Professionals

Medical Staff

Members of Clinical Management Team

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Primary Care Trusts

PHYSICAL EFFORT

There is a frequent requirement for the jobholder to spend substantial proportion of the working time sitting or standing in a restricted position and an occasional requirement to exert moderate physical effort.

MENTAL EFFORT

There is a frequent requirement for the jobholder to concentrate where their work pattern may be unpredictable.

EMOTIONAL EFFORT

The nature of the clinical and none clinical duties will require the jobholder to be involved in occasional exposure to unpleasant or highly unpleasant working conditions.

THE LEEDS TEACHING HOSPITALS NHS TRUST

Person Specification

Post Title	Nurse Specialist
Band	6
Department	
Location	LGI

Criteria	Essential	Desirable	Evidence Obtained from :
Qualifications	Registered Nurse (Level 1) Recognised teaching/assessing qualification	Post registration qualification in speciality	Application form NMC
Experience	At least 3 years post Registration experience at Band 5 or equivalent at least 2 years of which must be within a relevant specialty Audit & Standard setting	Service development and/or change management	Application form Interview
Training	Evidence of continued professional development Willing to undergo training as necessary		Application form Interview
Special Knowledge	Current issues in healthcare. Understanding of the needs of patients with sarcoma		Interview
Behaviours	Capable of lateral thinking		Interview
Practical Skills	Excellent written and verbal skills. The ability to communicate effectively with patients and carers Ability to organise and prioritise own and others workload	IT Skills	Application form interview
Other requirements	Able to fulfil Occupational Health requirements for the post		Occupational Health Screening

Appendix 5

Yorkshire Cancer Network Guideline on the management of testicular tumours

This is a section of the YCN guideline for urological tumours, extracted for Peer review

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Management of Testicular tumours

17. Introduction

The initial diagnosis and surgical management of Testicular Germ Cell Tumours is a Cancer Unit activity but the further investigation and management of the patient should be by a Specialised Multidisciplinary Team at the Cancer Centre. Urgent referral for this is paramount for successful outcomes. A successful Germ Cell Tumour Service requires a Multidisciplinary Team ethos and a full range of supportive services such as Specialised Nursing, Pharmacy, Radiology, Social Services, Psychological Support Services for Fertility Issues and Specialist Surgical Services (abdominal and thoracic). The regional service in Leeds is involved in clinical trials and studies at local, national and international levels (MRC, EORTC and NCRI) supported by Research Nurses based locally.

Guidelines on the diagnosis and treatment of testicular cancer already exist at the national level and in particular the Royal College of Radiologists, Clinical Oncology Information Network (COIN) in association with the Scottish Intercollegiate Guidelines Network (SIGN) Guidelines) on the Management of Adult Testicular Germ Cell tumours have already been adopted by the testicular tumour service in Yorkshire and should for the most part be followed.

Screening

There is no good evidence that screening programmes for men are indicated in this disease which is rare and the detection rate is likely to be small.

18. Presentation and early diagnosis

Testicular cancer has high growth rates and early detection and diagnosis is important. Delaying presentation is a greater problem than delaying referral and education programmes aimed at young men to inform them about the disease and its curability should be supported.

General Practitioners will see only infrequent cases of testicular cancer and need to have a low threshold for referral to specialist services for men presenting with scrotal masses. Between 80% and 90% present with an enlarged testicle or a lump on the testicle; pain is not usually a feature although the patient may complain of a dragging sensation in the groin or scrotum. Some patients may present with a decrease of size of the affected testis and rarely patients can present with a hydrocele, gynecomastia or backache as the presenting non-specific symptom. Patients need careful clinical assessment of the testis to distinguish between masses arising from the body of the testis and other intra-scrotal swellings and an ultrasound of the testis is very helpful in making this distinction. The ultrasound request should be urgent and performed within two weeks. If this investigation is requested by a GP and is positive there should be a direct route for referral from the Radiology Department to the local Urologist (same or next working day). Urgent direct referral from the GP to the local Urologist may achieve a quicker diagnosis with easier access to testicular ultrasonography, and any patient suspected of having a testicular malignancy with a lump in the testis, doubtful epididymo-orchitis or orchitis not resolving within two weeks should be referred urgently for urological assessment and the patient should be seen urgently (within two weeks of referral).

19. Primary investigation and treatment

Having been referred to a Urological Surgeon in the local cancer unit the patient should be subjected to the following investigations:

Ultrasound of both testes (if not already performed). This investigation is highly specific for the diagnosis of intra-testicular masses. Ultrasonography of the abdomen is also advisable in the presence of testicular lump for the detection of possible enlarged abdominal lymph nodes. A chest x-ray will often determine whether the patient has pulmonary metastases or not. The serum tumour markers, Alpha Feta Protein (AFP) and Human Chorionic Gonadotrophin (HCG) and the non-specific serum enzyme lactate dehydrogenase (LDH) are central for staging, determining prognosis, treatment and follow-up of testicular germ cell tumours. One or more of these is raised in 75% of cases of teratoma and 35% of cases of seminoma. Pre-operative assays of these markers is of paramount importance. Then further assays should be repeated at least once post-operatively prior the referral of the patient to the cancer centre. Post-operative tumour markers on day 1 after orchidectomy are sufficient. Patient recall to Urology for post-operative markers is not necessary if day 1 post-operative markers are performed and the results examined. If the markers have increased telephone referral to the Germ Cell Services in the cancer centre is advised. If they are stable or have fallen standard referral by fax is sufficient. If day 1 markers have not been performed post-operative markers should be arranged and reviewed as soon as this becomes apparent by the referring cancer unit Urology team. Further staging investigations can be deferred until after the orchidectomy and performed by the Germ cell team.

NB. Patients with high serum tumour markers and wide-spread metastases at presentation should be referred immediately to the regional germ cell clinic for primary chemotherapy prior to orchidectomy, which can be delayed until potentially life-saving chemotherapy has been delivered at the cancer centre. The indication for discussing referral to the cancer centre prior to surgery with Dr Dan Stark (or deputy) in Leeds should be
Metastatic disease visible on chest Xray
Abdominal mass clinically evaluable, palpable on ultrasound
Clinically significant cervical or axillary lymphadenopathy
Weight loss >10% in the presence of a clinical testicular mass
Any one of these is sufficient for pre-operative discussion.

20. Primary Surgical Management

An orchidectomy should be performed through an inguinal incision with division of the cord at the internal ring. Prior to this the testis having been delivered through the wound and the cord occluded using non-crushing clamps the testis is inspected and if the mass is cancerous the operation is completed. On the rare occasion when the diagnosis is in doubt, representative biopsies may be sent for frozen section and if malignancy is not confirmed then the testis can be reconstituted and replaced and the patient placed on close follow up. Scrotal exploration should usually be avoided with testicular masses, but if performed for what was thought to be an inflammatory non-malignant condition, then an orchidectomy is performed with the division of the cord as high as possible. There are three things which need to be considered prior to orchidectomy in cases of testicular lump/swelling.

Firstly, prior to orchidectomy should be a consideration of the patient's fertility. If he has been having difficulty in fathering a child or has a history of infertility, referral for potential sperm banking prior to the orchidectomy is recommended, since only the diseased testis may be capable of active spermatogenesis. Referral for sperm banking would normally delay the operation of orchidectomy by only a few days, and so is unlikely to adversely affect eventual outcome.

Secondly patients may suffer an alteration of body image having undergone an orchidectomy and consideration should be given to the placement of a prosthesis either at the time of the orchidectomy or in the future and patients should be advised about this possibility.

Thirdly consideration should be given to biopsying the contralateral testis in patients at high risk of having carcinoma in situ (intratubular germ cell neoplasia, ITGCN) in that testis. ITGCN occurs in approximately 5% of men with testicular cancer in the opposite testis and is thought to progress to invasive germ cell tumour in almost 100% of cases within a ten year time frame. Patients at risk are of younger age (less than 30 years of age), have a small contralateral testis (less than 16ml), a history of maldescent of the testis or a previous history of subfertility/low sperm count. If a biopsy is considered this should be performed as a separate procedure to the orchidectomy (regowning and regloving, separate instruments) the specimens should be separate to the orchidectomy specimen and consideration given to referral for central pathology review. Patients with intratubular germ cell neoplasia will be offered a course of radiotherapy to that testis after consideration of fertility issues (see later).

21. Pathology of the Primary Specimen

There should be a local protocol for the handling and preservation of the testis. Valuable information may be lost to the Pathologist through over-energetic disruption by the operating surgeon. The specimen should be bi-valved through the testis and epididymis either in theatre or as soon as it arrives in the Pathology Department to allow for proper fixation in an adequate volume of formaldehyde fixative. Multiple blocks should be taken and in addition to a description of the macroscopic and microscopic appearances of the specimen (using the classification of the British Testicular Tumour Panel and Registry and the World Health Organisation) the Pathologists should comment upon the presence or absence of invasion of blood vessels or lymphatic vessels by tumour extension of the tumour into the rete testis, epididymis tunica vaginalis and spermatic cord and whether there is involvement of the cut end of the cord or not.

Central review of the pathology by the cancer centre and multidisciplinary team pathologist is mandatory. This process of review should be commenced by the cancer unit pathologist at the point they become aware of the germ cell tumour is either the diagnosis or within their pathological differential diagnosis. The processing and reporting on testicular specimens at the local level should be undertaken as high priority and ideally a histology report be issued within one week of the operation and forwarded to the germ cell MDT pathologist.

Referral to the Cancer Centre

As well as the assaying of serum tumour markers post-operatively, referral to the cancer centre multidisciplinary team should be a matter of priority. The YCN referral pro-forma should be completed by the surgeon performing the orchidectomy within 36 hours of the completion of the operation and referred to Dr Stark by Fax using the Yorkshire Cancer Network Pathway. This ensures the patient can be seen at the centre within two weeks of the orchidectomy. It is not acceptable for an orchidectomy to be performed and an outpatient appointment made for the patient, typically one month ahead, and for the referral to be made at that stage. Nor is it acceptable for orchidectomy specimens to be booked to local MDT meetings with referral following that. If there are specific reasons for review or pathology prior to referral, these merit a discussion of the case with the germ cell MDT members to avoid unacceptable patient delays. There is no need (in fact it is often unhelpful) for further investigations for staging purposes to occur in the cancer unit, since this will be undertaken at the cancer centre and there is good evidence that, where examination such as serum tumour markers and CT scanning are going to be performed on a regular basis, these investigations are best performed according to the same protocol using the same techniques and the same hardware and report by the same laboratory and clinical staff.

22. Investigation and staging

There is good documentary evidence that the treatment of testicular cancer in the specialised centre leads to improved results. At the point of clinical suspicion of germ cell tumour, prior to final pathological confirmation, patients should be referred to the cancer centre lead clinician and MDT. The patient would normally be seen on the Wednesday morning germ cell clinic within two weeks of surgery if the referral pro-forma is faxed within 36 hours of orchidectomy including the required details. With timely referral patients will also be contacted by the germ cell support nurse by telephone ahead of that appointment. Therefore it is crucial the patient is made aware of the potential cancer diagnosis explicitly before discharge after orchidectomy. It is of note that if pathology and tumour marker results are not available at the time of referral these reports will be sought from the cancer centre. If the level of pre and operative serum tumour marker results and histology are available, including them with the accompanying fax is very helpful, but not essential. But it is essential they have been sent for testing.

At the patients first attendance of the Germ Cell Tumour Clinic the relevant clinical history will be confirmed and further details regarding the duration of symptoms,
Post-operative progress,
history of maldescent and inguinal hernia repair in infancy or childhood,
family history of testicular cancer,
history of infertility,
paternity and wishes about the possibility of further paternity will be obtained relevant previous medical history and clinical examination.
Clinical examination will include
orchidectomy scar examination
examination of the remaining testis for lumps, size and nature.
examination for masses in the abdomen or in regional or distant lymph nodes.

At the initial attendance the patient will have a further estimation of his serum tumour markers, full blood count and routine biochemistry performed. If the referral from unit to centre is timely staging CT scan of chest, abdomen and pelvis will be performed on the day of initial clinic attendance in the centre, always within one week of that appointment and the result is available for the next week's clinic. The CT scan should be performed according to a defined protocol and should be reviewed by a Radiologist experienced in the interpretation of germ cell tumour patient's investigations. Any previous radiology should also be reviewed by this Radiologist. The overall clinical scenario with the outcome of the initial germ cell clinic attendance, central specialist review of staging investigations and tumour pathology will take place at the regional MDT meeting, within 48 hours of new patient assessment if referral and transfer of materials has been timely, always within two weeks of the first germ cell clinic visit.

The patient has the diagnosis confirmed to them based upon local pathology report and is made aware of the possible therapeutic options and likely percentage chances of cure, although final definition of the latter will have to wait until staging examinations are completed and reviewed. Patients should be encouraged to bring their partner/parents or other relative/significant other person to be present at the consultation. Patients should have easy access to the Specialist Nurses present in that clinic, to be able to re-visit areas of concern or in need of clarification. At that first attendance there should be the facility for referral either then or at a later date to Specialist Social Work Support, Psychological Support (initially through a Clinical Nurse Specialist) and for sperm banking (currently at the Assisted Conception Unit Leeds Teaching Hospitals NHS Trust) if it is envisaged that the patient may require chemotherapy or radiotherapy.

Other considerations at the primary consultation at the germ cell tumour clinic will include involvement of Specialist Nurses/Social Workers from the Teenage and Young Adult Regional Principal Treatment Centre at Leeds Teaching Hospitals Trust who regularly attend the clinic for those patients in their teenage years/early twenty's, consideration of support for those in education/higher education with regard to course work/examinations etc, financial and other considerations arising as a result of the diagnosis and its possible treatment, and an enquiry made as to whether the patient has critical illness insurance cover on which a claim may be made.

The serum tumour markers, (LDH, AFP and hCG) having been performed prior to orchidectomy, day 1 post-operatively, and then at the new patient review in germ cell clinic two weeks later, they will be repeated weekly if elevated until they have fallen within the normal reference range, before starting any adjuvant treatment for Stage I disease..

Patients will be staged according to the anatomical staging system devised at the Royal Marsden Hospital (RMH) – see table 1 - based upon the clinical examination and the CT scan. Magnetic resonance imaging is equivalent to CT scanning for the detection of pelvic or abdominal lymph nodes and involves no ionising radiation but is of little value in the evaluation of the chest. This modality of imaging may become more important for follow-up in the near future.

Patients with evidence of metastases will also be assessed according to the International Germ Cell Cancer Collaborative Group Prognostic Grouping (see table 2) that divides patients into good, intermediate and prognostic groupings according to the pathological tumour type, site of the primary tumour, the levels of serum tumour markers and the presence or absence of non-pulmonary visceral metastases. This classification is of clinical value in advising patients of their relative prognosis and in determining the therapeutic approach. Thus the majority of patients should be made aware within three weeks of referral to the germ cell tumour clinic, 3 weeks and two days from surgery, of the management approach to be adopted in their particular case. In particular the patient should be aware of the nature, extent and likely success of the treatment proposed. There may be some medical delay in those patients with serum tumour markers which are still falling post-orchidectomy but according to the natural half life of the particular marker until normalisation to distinguish stage 1 disease from stage 1M.

Management of testicular Intratubular germ cell neoplasia (carcinoma in situ – CIS).

Patients identified as having intratubular germ cell neoplasia (ITCGN) are at great risk of developing a second invasive cancer in the remaining testis. This risk increases over time; 50% at 5 years, 70% at 7 years. These patients often have low sperm count or azoospermia, poor Leydig cell function, with elevation of luteinising hormone (LH), and a reduction in testosterone levels. In the first instance endocrine and fertility function may be monitored for some months in many patients to allow recovery from the surgical and non-surgical managements' impact upon endocrine and fertility function. Management plans are made in the light of

Patients who wish to father children

The nature of the necessary treatment for the primary malignancy.

Patients need to be warned early of the markedly increased risk of subsequent malignancy if treatment is not given. Management options include:

The germinal epithelium can be ablated easily with radiation and patients will be offered a two week course of radiation to the remaining testis (a dose of between 16 and 20 Gys in 10 Fractions over 2 weeks) to prevent progression to invasive disease whilst at the same time trying to preserve the hormonal function of the supportive stroma of the testis and thus hormone production. These patients also need to be made aware of the possibility of testicular failure and the potential need for hormone replacement therapy in the future. It is also recommended that the patient undergo a further testicular biopsy approximately six to nine months following radiation to ensure that the germinal epithelium has been ablated

Orchidectomy is a possibility for patients who have completed their wish for family and already have or accept the need for endocrine failure.

Systemic chemotherapy is not adequate treatment for intratubular germ cell neoplasia as late relapse has been described.

Management of Stage 1 disease

Patients with Stage 1 disease have no clinical, radiological or serological evidence of persistent disease following orchidectomy. Patients with negative CT scans and clinical examination but still have raised tumour markers which do not fall to normal levels post orchidectomy are staged as Stage 1M (RNH staging) and are treated as for metastatic disease (see below).

Management of Stage 1 Seminoma

Patients with Stage 1 Seminoma have between a 12 and 32% chance of harbouring metastatic disease in the para-aortic lymph nodes or elsewhere. The MRC study TE19 has reported initial and follow up results indicating equivalence in terms of efficacy of one course of Carboplatin (AUC7) chemotherapy and para-aortic radiotherapy in the management of Stage I seminoma. There was lower short-term morbidity and greater patient convenience in the Carboplatin arm and a suggestion, provisional at this time, of a smaller number of contra-lateral new primary tumours in the group treated with Carboplatin. Therefore patients may choose between chemotherapy given as per this trial and radiotherapy.

Adjuvant radiotherapy for Stage I seminoma is given as 20 Gys in 10 daily fractions over two weeks.

The cancer specific survival of either management plan, or surveillance, approaches 98%.

10% of seminoma patients require a “dog-leg” shaped radiation field because of previous inguino-scrotal surgery or a scrotal orchidectomy, to cover the inguino-pelvic lymph nodes as well as the para-aortic nodes because of disruption of lymphatic drainage of the testis.

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Patients make an informed choice between adjuvant chemotherapy and Carboplatin, adjuvant radiotherapy and surveillance. The clinicians are guided by two pathological prognostic factors in providing patients who wish with a recommendation; tumour size >4cm, and the presence of invasion of the rete testis.

Surveillance is an effective management strategy of stage 1 seminoma> in electing for surveillance clinicians should consider whether the patient has a reliable serum tumour marker, whether follow up with regular CT scanning represent a satisfactory practical plan which the patient will comply with, and whether the radiation from CT scanning required is acceptable to the patient. The patient understanding that will receive three cycles of BEP chemotherapy if they relapse. In less fit patients this is intensive treatment. The small but relevant risk of reduced fertility with any chemotherapy treatment

Relapses often occur more than 5 years after orchidectomy so follow up often needs to be prolonged. The frequency of examinations and comparison between CT and MRI is currently subject to an MRC randomised controlled trial led internationally by Dr Jonathon Joffe.

Patients with combined seminoma/teratoma of the testis should be treated as though they had teratoma

Management of Stage 1 Teratoma

Patients with combined seminoma/teratoma of the testis should be treated as though they had teratoma. Patients with Stage 1 teratoma without high-risk features (lymphovascular invasion in the primary tumour histologically) should be managed by surveillance provided that the patient agrees to comply with the follow up schedule. Consideration when selecting a patient for surveillance, as in seminoma, include whether the patients tumour is known to make serum markers, The acceptability for surveillance regimen in terms of compliance and radiation. The patient understanding that will receive three cycles of BEP chemotherapy if they relapse. In less fit patients this is intensive treatment. The small but relevant risk of reduced fertility with any chemotherapy treatment

The follow up schedule is intensive in terms of visits for serological and plain X-ray surveillance. The patient is required to attend monthly for the first year, bi-monthly for the second year, quarterly for the third year, six monthly until five years have elapsed post-orchidectomy and then annually to the tenth year, although the patient can always seek an earlier appointment should he suspect a recurrence is occurring. Serum tumour markers have to be performed at every attendance and CT scanning is undertaken twice according to the outcome of the MRC TE08 study. The patient undergoes routine clinical examination at every attendance and also undergoes further investigations should he develop significant symptoms. The relapse rate for low-risk stage 1 teratoma patients is approximately 25 to 30%. If surveillance is judged impractical or unacceptable then consideration should be given to adjuvant chemotherapy with the same regimen as used in high risk Stage I teratoma (see below).

Management of Stage 1 teratoma high-risk patients

Patients with negative post-operative staging investigations but with lympho-vascular invasion in the primary tumour pathology have between a 40 and 60% risk of relapse and an MRC study whereby two cycles of adjuvant BEP chemotherapy (Etoposide 360mg per metre squared per course) was shown to reduce this risk of relapse to 1 to 2% and this approach is now the standard for this condition.

PET scanning has been examined to provide further risk stratification in Stage I non seminoma but there is insufficient sensitivity and specificity to be used at present(c.f. MRC study TE22).

For those patients with persistently elevated tumour markers or markers rising post-operatively (stage 1M) these patients have metastatic disease and should receive chemotherapy as per good prognosis metastatic non seminomatous germ cell tumour (three cycles of BEP).

Metastatic Seminoma

More than 80% of seminoma patients present with stage 1 disease; however, approximately 15% fall into the stage 2 category. The majority of those have stage 2A disease, with lymph node involvement less than 2cm in maximum diameter. Patients with Stage 2A, and Stage 2B disease of less than 3cm are currently managed with a single dose of Carboplatin AUC 7 followed by para-aortic lymph node irradiation giving 30 to 35-36 Gys over 15 to 18 fractions of radiotherapy to a dog-leg field.

Patients with 2B, C or D disease, with a more than 3cm transverse diameter tumour are treated with multi-drug Platinum based chemotherapy (BEP or EP) according to their general health. Patients with seminoma tend to be older than teratoma patients on the whole. Consequently, the chemotherapy for patients with metastatic seminoma is often individualised to the patient circumstances/fitness; older patients are more likely to have co-morbid conditions, including impaired renal function and to have a worse smoking history, which is the risk factor for toxicity rather than age of itself. Carboplatin may be used in combinations as alternative to Cisplatin in exceptional circumstances in these patients. For patients with metastatic seminoma stage 3 and 4, there is no good evidence that Bleomycin adds to the efficacy of treatment.

Metastatic teratoma of the testis

Considerable research effort at national and international levels has led to the development of successful regimes for this condition and emphasis being placed on the greater acceptability and convenience for patients with regimes in recent years without compromising effectiveness. The internationally standard regime for all patients with teratoma of the testis metastatic is BEP (500 mg/m² per cycle of etoposide). The IGCCG classification divides patients in to good, intermediate or poor prognosis depending on the highest assay of their serum tumour markers prior to chemotherapy, the presence of a mediastinal primary or non-pulmonary visceral metastases. Patients with good prognosis are treated with three cycles of BEP chemotherapy but if four cycles are used then Bleomycin is omitted for the fourth course since the recommended maximum dose of Bleomycin should not normally exceed 270,000 international units (270 mgs). A recently reported joint MRC/EORTC randomised controlled trial (2 x 2 factorial design) has shown that three courses of "American" (Etoposide 500 mg per meter squared per course) BEP is effective as four courses and also that this treatment can be delivered without detriment to results over three days rather than five days. Thus three cycles of American BEP delivered over a three night stay in hospital is now the standard treatment in Yorkshire for metastatic non-seminomatous germ cell tumours, including teratoma, although there is scope for individualisation of treatment and particularly for those patients with potentially compromised renal or lung function, treatment can be taken rather more slowly and more than three courses of chemotherapy can be given for patients with anatomically high volume disease and for those patients with intermediate or poor prognosis who are unwilling to enter relevant clinical trials.

For intermediate and poor prognosis patients no treatment has been shown to be superior than four cycles of BEP chemotherapy (Etoposide 500 mgs per metre squared per course) as standard treatment. Studies currently open examining intensifying BEP using GCSF support ('accelerated BEP'). Studies open in poor prognosis metastatic disease include an intensive multi-drug regimen within the TE23 national study.

One of the keystones to successful treatment for metastatic teratoma is the maintenance of the dose-intensity of treatment and the adherence to the treatment schedule. Patients' treatment cannot be delayed due to blocked beds and admissions have to be pre-arranged and if necessary take precedence over other patients having chemotherapy for non-curable conditions. This has been facilitated in the last ten years by the development of supportive agents such as granulocyte colony stimulating factor (GCSF) and the development of improved anti-emetic regimes (e.g. 5HT₃ antagonists). The local indications for GCSF in germ cell tumour management are
Dose delay due purely to neutropenia, not restricted by recovery of oral mucositis or low platelets.
Acute support for life threatening septic shock with end organ failure
Support for very unwell patients who are unlikely to tolerate neutropenia with sepsis.
It is easy to forget that this type of treatment in itself is potentially life threatening, and so patients and staff have to be regularly reminded of the potentially fatal consequences of ignoring symptoms of neutropenic sepsis and the need for a very rapid response in such circumstances. Potential neutropenic sepsis is a medical emergency.

23. Post Chemotherapy masses

Seminoma

Resection for post chemotherapy residual masses in seminoma is not routinely indicated for the complete remission rate for seminoma is extremely high and viable tumour is rarely found in resected specimens. Surgery is likely to be difficult and potentially dangerous due to lack of clear tissue planes. Radiological assessment of residual masses is advised with the possibility of post-chemotherapy/radiotherapy at a later stage for persistent masses which are increasing in size. However, the routine use of radiotherapy for residual masses is not recommended.

Teratoma

Residual masses may remain after chemotherapy and marker normalisation in teratoma patients. About 15 to 20 % of these masses will contain viable tumour and of the remaining 80%, half will contain mature teratoma differentiated (TD) and half scar & fibrous tissue. Any masses greater than 1cm in diameter should be removed surgically to resect TD and identify residual viable tumour, within 4-6 weeks of completion of chemotherapy, if recovery from chemotherapy allows, and if this is not possible should be kept under very close follow up radiologically. Retroperitoneal lymph node dissections should use a template, not be resection simply of radiologically or macroscopically involved nodes. The attempts at surgical intervention must be radical e.g. it may be necessary to sacrifice a kidney or resect an inferior vena cava etc, and this work should be undertaken by a limited number of surgeons. Such work is undertaken by two Urological Surgeons and one Thoracic Surgeon in Leeds at the present time. The pathology of the resected specimen should be undertaken or reviewed by a specialist pathologist working in the germ cell Multidisciplinary Team.

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Where viable germ cell cancer is found in the resected specimens further chemotherapy should be considered

Treatment of relapsed disease

Following treatment, patients are kept under review (see section on follow up) and following adequate treatment less than 10% of patients with good prognosis disease will relapse. This is rather higher in patients with intermediate and poor prognosis disease. The timing of relapse is important.

Patients who progress on or relapse shortly after primary treatment are likely to have 'primary platinum resistant' disease and need an aggressive approach, as their prognosis is poor. In these circumstances alternative chemotherapy regimes may be used but if the disease is apparently localised to one anatomical site then a "desperation" operation may be performed urgently with potential curative results.

Fortunately the majority of relapses recur after many months or possibly years after primary treatment and, again depending on the anatomical extent of the disease, the primary approach may well be surgical plus chemotherapy. One concern for physicians at the diagnosis of relapse is that growing disease sites may consist of growing teratoma differentiated, for which further chemotherapy will be ineffective. The radiological and tumour marker profile as well as the previous histology may help to judge the probability of growing teratoma differentiated syndrome in an individual patient. Growing TD can involve many retroperitoneal structures and although not metastatic local invasion can be life-limiting. Moreover residual unresected TD can undergo malignant transformation to undifferentiated germ cell tumour, carcinoma, sarcoma or mixed tumours.

Patients with rising markers after first line treatment require urgent restaging, which may need to include the brain and contralateral testis if the site of recurrence is not apparent on initial CT body. Some patients have rising markers with no apparent anatomical recurrence- we recommend surveillance and re-imaging in this situation, while accepting this is psychologically very difficult for most patients.

Patients relapsing after standard chemotherapy should be considered for clinical trials if possible. TIP (Taxol, Ifosfamide and Platinum) and VIP (Vinblastine, Ifosfamide and Platinum) are considered in relapsed good/intermediate, and relapsed poor prognosis disease respectively. Both has approximately equivalent efficacy and stem cell harvest is more straightforward after VIP.

However, as with primary management, surgery should be considered as central to the treatment for late relapse and there may be an indication for surgery post chemotherapy in these patients.

At second relapse options are limited but include resection, palliative radiotherapy, re-induction chemotherapy followed by high dose treatment with Carboplatin/Etoposide/Cyclophosphamide with peripheral blood stem cell rescue.

Central nervous system metastases

CNS metastases may occur at either initial presentation, as an apparently isolated relapse site or as part of a chemo-resistant systemic relapse. All patients with intermediate or poor prognosis disease should have CT screening for CNS metastasis at initial assessment. Patients presenting with brain metastases at initial presentation or at relapse following adequate treatment for other sites should be treated with curative intent and if possible referred for urgent neuro-surgical resection of operable lesions. Radiotherapy has a role in the relapsed patient with CNS disease, either as primary treatment or as an adjuvant to surgical resection. Patient with CNS disease following chemotherapy generally have a poor prognosis.

24. Follow up for testicular cancer

The functions of follow-up are:

- to detect relapse at an early stage.
- to monitor and treat treatment-related toxicities.
- to detect contralateral testicular tumours
- to support the patient with regard to other consequences of cancer and its treatment, such as employment, fertility etc.

The follow up of testicular cancer varies widely we have precise protocols, risk stratified, which are followed at Yorkshire Cancer centre, which would form an ideal opportunity for audit.

The essential message to the patient about follow up is that the patient can request an early appointment or a further appointment at any time should be suspect that there is a recurrence or the development of a second primary tumour.

Intratubular germ cell neoplasia

These patients are being followed up usually for a primary tumour on the contralateral side and care must be taken not to overlook the affected residual testis. There is an indication for monitoring this testis with ultrasound scans if radiotherapy treatment is to be delayed for consideration for fertility issues.

Following radiotherapy, a biopsy should be performed between 6 and 12 months after the completion of radiotherapy to prove adequate ablation of the germinal epithelium and the patient should be followed up for a minimum of ten years, usually according to the schedule for the primary contralateral testis tumour.

In YCN follow up schedules are protocolled. The following provide illustration of that;

Follow-up protocol for Stage I Seminoma after adjuvant radiotherapy

Enter month of completion of most recent treatment (surgery, chemo or RTx) in red box below, in the format Jun-03

Jun-09

Patient name	
d.o.b	
Hosp No.	

Interval (months)	OPA date	Investigations required
3	Sep-09	AFP, hCG, LDH; CXR
6	Dec-09	AFP, hCG, LDH; CXR
9	Mar-10	AFP, hCG, LDH; CXR
12	Jun-10	AFP, hCG, LDH; CT scan
16	Oct-10	AFP, hCG, LDH; CXR
20	Feb-11	AFP, hCG, LDH; CXR
24	Jun-11	AFP, hCG, LDH; CXR
30	Dec-11	AFP, hCG, LDH; CXR
36	Jun-12	AFP, hCG, LDH; CXR
42	Dec-12	AFP, hCG, LDH; CXR
48	Jun-13	AFP, hCG, LDH; CXR
60	Jun-14	AFP, hCG, LDH; CXR

Discharge at 5 years, or to long term follow-up if were aged up to their 30th birthday at the point of diagnosis (unless in a trial and protocol dictates otherwise)

Follow-up protocol for Stage I Seminoma after adjuvant chemotherapy (usually single-dose carboplatin)

Enter month of completion of most recent treatment (surgery, chemo or RTx) in red box below, in the format Jun-03

Jun-09

Patient name

d.o.b

Hosp

No.

Interval (months)	OPA date	Investigations required
1	Jul-09	AFP, hCG, LDH; FBC
3	Sep-09	AFP, hCG, LDH; CXR
6	Dec-09	AFP, hCG, LDH; CT scan
9	Mar-10	AFP, hCG, LDH; CXR
12	Jun-10	AFP, hCG, LDH; CT scan
16	Oct-10	AFP, hCG, LDH; CXR
20	Feb-11	AFP, hCG, LDH; CXR
24	Jun-11	AFP, hCG, LDH; CT scan
30	Dec-11	AFP, hCG, LDH; CXR
36	Jun-12	AFP, hCG, LDH; CXR
42	Dec-12	AFP, hCG, LDH; CXR
48	Jun-13	AFP, hCG, LDH; CXR
60	Jun-14	AFP, hCG, LDH; CXR

Discharge at 5 years, or to long term follow-up if were aged up to their 30th birthday at the point of diagnosis
(unless in a trial and protocol dictates otherwise)

Follow-up protocol for Stage I Seminoma followed up with surveillance only

Enter month of completion of most recent treatment (surgery, chemo or RTx) in red box below, in the format Jun-03

Jun-09

Patient name
d.o.b
Hosp No.

Interval (months)	OPA date	Investigations required
3	Sep-09	AFP, hCG, LDH; CXR
6	Dec-09	AFP, hCG, LDH; CT scan
9	Mar-10	AFP, hCG, LDH; CXR
12	Jun-10	AFP, hCG, LDH; CT scan
15	Sep-10	AFP, hCG, LDH; CXR
18	Dec-10	AFP, hCG, LDH; CT scan
21	Mar-11	AFP, hCG, LDH; CXR
24	Jun-11	AFP, hCG, LDH; CT scan
28	Oct-11	AFP, hCG, LDH; CXR
32	Feb-12	AFP, hCG, LDH; CXR
36	Jun-12	AFP, hCG, LDH; CT scan (abdo only)
42	Dec-12	AFP, hCG, LDH; CXR
48	Jun-13	AFP, hCG, LDH; CT scan (abdo only)
54	Dec-13	AFP, hCG, LDH
60	Jun-14	AFP, hCG, LDH; CT scan (abdo only)

Discharge at 5 years, or to long term follow-up if were aged up to their 30th birthday at the point of diagnosis (unless in a trial and protocol dictates otherwise)

RMH staging

I No evidence of disease outside the testis
IM As above but with persistently raised post-op tumour markers

II Infradiaphragmatic nodal involvement
IIA Maximum diameter < 2 cm
IIB Maximum diameter 2-5 cm
IIC Maximum diameter 5-10 cm
IID Maximum diameter > 10 cm

III Supra and infradiaphragmatic node involvement
Abdominal nodes A, B, C, as above
Mediastinal nodes M +
Neck nodes N +

IV Extralymphatic metastases
Abdominal nodes A, B, C, as above
Mediastinal or neck nodes as for stage 3
Lungs:

L1 < 3 metastases

L2 Multiple metastases < 2 cm maximum diameter

L3 Multiple metastases > 2 cm in diameter

Liver involvement H +

Other sites identified (Br- brain, Bo- bone, Ad-adrenal)

IGCCC PROGNOSTIC GROUPING

TERATOMA (NSGCT)	SEMINOMA
<p>GOOD PROGNOSIS with all of: Testis/retroperitoneal primary No non-pulmonary visceral metastases AFP < 1000 ng/ml HCG < 5000 iu/l LDH < 1.5 upper limit of normal</p>	<p>Any primary site No non-pulmonary visceral metastases Normal AFP Any HCG Any LDH</p>
<p>56% of teratomas 5-year survival 92%</p>	<p>90% of seminomas 5-year survival 86%</p>
<p>INTERMEDIATE PROGNOSIS with all of: Testis/retroperitoneal primary No non-pulmonary visceral metastases AFP > 1000 AND < 10000 ng/ml or HCG > 5000 AND < 50000 iu/l or LDH > 1.5 normal < 10 normal</p>	<p>Any primary site Non-pulmonary visceral metastases Normal AFP Any HCG Any LDH</p>
<p>28% of teratomas 5-year survival 80%</p>	<p>10% of seminomas 5-year survival 73%</p>
<p>POOR PROGNOSIS with any of: Mediastinal primary or non-pulmonary Visceral metastases AFP > 10,000 ng/ml or HCG > 50,000 iu/l or LDH > 10 normal 16% of teratomas 5-year survival 48%</p>	<p>No patients classified as poor prognosis</p>