University College London Hospitals NHS
NHS Foundation Trust

Penile Supranetwork MDT (SNMDT)

Operational Policy

Agreed By: Mr Asif Muneer, Lead Clinician Penile SNMDT Date: 01/04/2016
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1.0 Introduction

Penile cancer is a rare genitourinary malignancy with an age standardised incidence of 1.2-1.5 per 100 000 population in England and Wales.

There are approximately 500-600 cases of newly diagnosed penile cancer annually with University College London Hospital (UCLH) managing between 15-25% of the national caseload at local, specialist and supranetwork levels. University College London Foundation Trust (UCLH) forms part of the London Cancer Network whose population is 1.6 million. The Trust serves the local catchment population of Camden & Islington CCGs, a total of approximately 410,000 residents. The Penile Supranetwork MDT is based at UCLH and receives tertiary referrals from within the London Cancer network as well as Thames Valley and St Luke's Alliance for the surgical management of penile cancer. The catchment area that is currently served is approximately 10 million.

Referrals are received from the referring centres listed in the Network Guidelines. The clinical management of patients is undertaken by the core team which consists of three Consultant Urological Surgeons namely Mr Asif Muneer, Professor Peter Malone and Mr Raj Nigam, and a Clinical Oncologist, Dr Anita Mitra. Professor Peter Malone oversees referrals from the Thames Valley Cancer Network and undertakes surgery at UCLH. Mr Raj Nigam oversees referrals from the St Luke's Cancer Alliance and again the patients undergo surgery at UCLH.

1.1 Facilities

The penile cancer service receives approximately 90 new referrals per year, which are discussed at a weekly MDT meeting based at the UCH Macmillan Cancer Centre. Patients within the London Cancer Network are seen in the outpatient facility in the UCH Macmillan cancer centre and introduced to the key worker.

All primary penile cancer surgery, lymphadenectomies and reconstructive surgery within the supra-regional network are performed in the host trust, University College London Hospital, under the direct clinical care of Mr Asif Muneer and the two in-reach surgeons Mr Raj Nigam and Professor Peter Malone. The service is supported by Professor Chris Bunker, Consultant Dermatologist who has a dedicated Genital Dermatoses Clinic for the diagnosis and management of premalignant penile conditions.

1.2 Network Configuration

The member Networks and liaising members who refer to the UCLH SNMDT include:

- Thames Valley Cancer Network
- St Luke's Cancer Alliance
- London Cancer incorporating UCLH, Bart's Health, Royal Free Hospital, Barnet and Chase Farm, Princess Alexandra, Barking Havering and Redbridge University Trust, Whittington Hospital, West Hertfordshire and Mount Vernon.
- Northwick Park Hospital and Imperial Healthcare NHS Trust refer cases on an individual patient preference basis due to easier travel
- Milton Keynes and Luton and Dunstable Hospital also refer cases based on patient preference

2.0 Background to the service

The penile cancer service based at UCLH offers a supra-regional service which has seen a gradual increase in the number of new referrals over the last 10 years and has now gained both a national and international reputation for the management, research and infrastructure related to penile cancer within the United Kingdom.

Currently there are two in-reach Surgeons at UCLH, Professor Peter Malone and Mr Raj Nigam, both of whom are contracted to attend the Penile Cancer SNMDT meeting followed by an inpatient operating list at UCLH for complex surgical procedures.

All patients are followed up at UCLH or the host hospitals of the in reach surgeons (Royal Berkshire and Royal Surrey Hospitals) if appropriate as per network guidelines.

3.0 Aims and Objectives of the Supranetwork MDT (SNMDT)

- All members to have a policy of agreed standards and process to provide quality patient focused care
- To review all new cases of suspected and confirmed Penile Cancer
- To discuss the initial and subsequent treatment of all patients diagnosed with Penile Cancer working in a collaborative way to contribute to the management plan for patients
- Ensure individual patient management is co-ordinated in a multidisciplinary way to support best practice
- Help foster Trust wide co-operation between those clinicians working for patients with Penile Cancer
- To use agreed operational standards in the management of Penile Cancer
- Ensure the service is fully compliant with IOG guidelines
- To hold annual Operational meetings to discuss policies, present audits and as a teaching forum
- For a member or members of the SNMDT to attend London Cancer Pathway Board meetings so that UCLH is appropriately represented.
- To participate in audit internal to the service and agreed audits with the London Cancer Pathway Board undertaking service improvement where required

4.0 The Multi-Disciplinary Team - Membership and Responsibilities

4.1 Lead Clinician Role and Responsibilities

The Lead Clinician for the SNMDT is Mr Asif Muneer.

Responsibilities of the SNMDT lead are to:

- Develop and review clinical practice standards, policies and protocols.
- Ensure that the objectives of the SNMDT are met and for the development of the MDT and its activities
- Ensure that designated specialists work effectively together such that decisions regarding all aspects of diagnosis, treatment and care of individual patients and decisions regarding the team's operational policies are multidisciplinary decisions
- Ensure that care is given according to recognised guidelines (including those for onward referrals) with appropriate information being collected to inform clinical decision making and to support clinical governance/audit
- Ensure mechanisms are in place to support entry of eligible patients into clinical trials subject to patients giving fully informed consent
- Take overall responsibility for ensuring that the MDT meeting and team meet peer review quality measures
- Ensure attendance levels of core members and cover are maintained, in line with quality measures
- Ensure that the target of 100% of cancer patients discussed at the MDT is met, each patient discussed has a clear treatment plan and that the meeting runs to time
- Provide a link to London Cancer either by attendance at meetings or by nominating another MDT member to attend
- Lead on or nominate a lead for service improvement
- Lead on the development of a penile cancer research programme and recruitment to clinical trials
- Ensure Public and Patient involvement in the ongoing research programme
- Organise and chair an annual meeting examining the function of the team and reviewing operational policies and collate any activities that are required to ensure optimal functioning of the team (e.g. training for team members)
- Ensure MDT's activities are audited and results documented
- In the absence of the Lead Clinician, Professor Peter Malone or Mr Raj Nigam will chair the SNMDT
- Ensure that the outcomes of the meeting are clearly recorded and clinically validated, and that appropriate data collection is supported
- Ensure the target of communicating MDT outcomes to primary care is met
- Hold the presenting clinician responsible for carrying out any action plan e.g. contact the patient, arranging for further tests
- Have overall Governance responsibility for all areas of practice

- Ensure that all core members of the team who have direct clinical contact with patients apply for and attend the National Advanced Communications skills training course

4.2 The Supranetwork Penile MDT Core and Cover Membership

14-2G-401

Position	Name	Cover	Organisation
Consultant Urological Surgeon & Lead Clinician	Mr Asif Muneer	Professor Peter Malone	UCLH
Consultant Urological Surgeon	Prof Peter Malone	Mr Raj Nigam	Thames Valley Cancer Network
Consultant Urological Surgeon	Mr Raj Nigam	Mr Asif Muneer	St Luke's Cancer Alliance (Surrey, W. Sussex & Hampshire Network)
Consultant Clinical Oncologist	Dr Anita Mitra	Dr Noan -Minh Chau	UCLH
Consultant Medical Oncologist	Dr Noan-Minh Chau	Dr Anita Mitra	Bart's/UCLH
Histopathologist	Dr Charles Jameson	Dr Giorgia Trevisan Dr Alex Freeman Dr Marzena Ratynska	UCLH
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Radiologist	Dr Miles Walkden	Dr Clare Allen Dr Navin Ramachandran Dr Doug Pendse Dr Alex Kirkham	UCLH
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CNS	Clare Akers	Hilary Baker	UCLH
MDT Co-ordinator	Jacob Goodman	Sally Howe	UCLH

4.3 Other Duties of the Core Team **14-2G-401**

- All consultants managing penile cancer patients must be members of the core team in accordance with IOG.
- All core members undertaking cancer surgery must attend 66% of the SNMDT meetings.
- The SNMDT lead ensures that patients are screened and recruited into local and national clinical trials
- Clare Akers as the CNS is responsible for user's issues and information and is the level 2 practitioner for the psychological support of cancer patients/ carers and will receive 1 hour's clinical supervision per month by a level 3 or 4 practitioner
- All core team members who have direct clinical contact with patients have now attended the national advanced communications skills course.

4.4 Extended Members of the MDT

Position	Name	Organisation
Consultant Urologist (Total Phallic Replacement)	Mr David Ralph	UCLH
Consultant Urologist (Total Phallic Replacement)	Mr Nim Christopher	UCLH
Consultant Vascular Surgeon	Mr Toby Richards	UCLH/RFH
Consultant Plastic and Reconstructive Surgeon	Mr Ash Mosahebi	UCLH/RFH
Consultant Plastic and Reconstructive Surgeon	Mr Ibby Younis	UCLH/RFH
Consultant Dermatologist	Professor Christopher Bunker	UCLH
Specialist Palliative Care	Dr Caroline Stirling Sue Hutton	Camden PCT
Consultant Nuclear Medicine	Dr Jamshed Bomanji	UCLH

Social Worker/Counsellor	Marianne Kilcoyne	UCLH
Psychosexual Counsellor	Dr Mike Perring	UCLH
Consultant Clinical Psychologist	Dr Sahil Suleiman	UCH Macmillan Cancer Centre
Macmillan Information	Kat Bowers	UCLH
Consultant Pain Specialist	Dr Ali Mofeez	UCLH

4.5 Clinical Nurse Specialists (CNS)

The SNMDT has one dedicated Clinical Nurse Specialist based at UCLH and there are additional CNS based at Reading and Guildford to manage patients locally with the following agreed responsibilities:

- To contribute to the multidisciplinary discussion and patient assessment/care planning decision of the team at their regular meetings.
- To provide expert nursing advice and support to other health professionals in the nurse's specialist area of nursing practice
- Involvement in clinical audit such as GP 24 hr notification and patient experience
- To lead on patient's and carer's communication issues and co-ordination of the patient pathway for patients referred to the team
- To act as the key worker or, responsible for nominating the key worker for the patient's dealings with the team
- To ensure that the key worker's name is clearly and prominently recorded in the patient's notes on a proforma
- To ensure the GP of the patient is informed on a new diagnosis of cancer by the end of the following work day and recording this information.
- To contribute to the management of the service e.g. manage the referrals to palliative care, the welfare benefits service and key contributors to community team e.g. District Nurses
- Inform the patients on the services offered and required for the patients e.g. around diagnostics, treatment and welfare benefits
- To utilise research into their specialist areas of practice in order to constantly seek improvements in patient care / practice, and patient information
- To undertake and act upon patient satisfaction surveys annually.

There are cross cover arrangements between the Penile CNS and cover from the Urology CNS for annual leave, sickness etc.

4.6 SNMDT Coordinator Responsibilities

- Facilitate and co-ordinate the functions of the SNMDT meetings
- Ensure that appropriate patients are discussed at SNMDT meetings
- Help with the introduction and changes to proformas used to ensure all patients are discussed and that outcomes of discussions are recorded and reviewed
- Ensure that patients' diagnoses, investigations and management plans are completed and added to the patients notes
- Manage systems that inform GP's of patient's diagnosis, decisions made at out-patient appointments and at other times where key events occur
- Work with staff to ensure all patients have a booked first appointment, investigation and procedure and record details of patients coming via a different route
- Work with key SNMDT members to identify areas where targets are not achieved and undertake process mapping to identify bottlenecks
- Undertake demand and capacity studies where appropriate

- Report changes to SNMDTs on a monthly basis
- Data collection and recording of data for peer review including new referrals and referring hospitals and waiting times
- Manage the systems according to guidelines, monitoring milestones and submitting the required report in the given format and required times
- Keep a comprehensive diary of all team meetings
- Record the attendance at the SNMDT meetings
- Ensure, along with the SNMDT lead clinician, that MDT proformas are updated with details of discussions occurring during the SNMDT meeting including an action plan such that they form minutes of each discussion which are available to all members of the team on the server and CDR and are sent to involved clinicians outside the SNMDT by e-mail and hard copy
- Be instrumental in the development of databases to capture patient information and report this information to the clinicians on a weekly basis
- Inform lead cancer manager of waiting times for patients when these exceed appropriate targets
- Ensure lists of patients to be discussed at meetings are prepared and distributed in advance of the SNMDT meeting
- Ensure that all correspondence, notes, imaging, clinical photographs, results, etc. are available for the meetings
- Assist in capturing cancer data on all patients and assist in the development of systems to complement the cancer audit system
- Ensure members or their deputies are advised of meetings and any changes of date, venue, etc.

4.7 Key Worker **14-2G-412**

The Key Worker will be defined as 'The person who, with the patient's consent and agreement, takes a key role in co-ordinating the patients care and promoting continuity, ensuring the patient knows who to access for information and advice' (NICE 04).
The single named key worker is Clare Akers.

Identification of the Key Worker

- The identification of the Key Worker will be the responsibility of Claire Akers, CNS and core member of the SNMDT.
- A single key worker for the patient's care at a given time is to be identified by the MDT for each individual patient
- The Key worker can be any member of the MDT agreed with the patient and this must be documented by the MDT.
- The name and contact number of the agreed Key Worker will be clearly documented within the patient's case notes. It is important to ensure that the patient and carer understand the role of the Key Worker as early as possible on the patient's pathway of care.
- It is recognised that the Key Worker will change over time as the patient's needs change during their journey. Any changes will be negotiated with the patient and carer prior to implementation, and a clear handover provided to the next Key Worker.

Responsibilities of the Key Worker

With the agreement of the patient, the Key Worker will:

- Ensure the named principal clinician is identified and made known at each stage of the patient's journey

- Act as the main contact person for the patient and carer at a specific point in the pathway.
- Offer support, advice and provide information for patients and their carers', accessing services as required.
- Ensure continuity of care along the patient's pathway and that all relevant plans are communicated to all members of the MDT involved in that patient's care.
- Ensures that the patient and carer have their contact details, that these contact details are documented and available to all professionals involved in that patients care.
- Ensure that when handover of the Key Worker role is indicated, it is implemented in full consultation with the patient and carer and the patient is provided with revised contact details.
- Ensure that the next Key Worker has the appropriate information about the patient to fulfil the role.
- Support the patient in identifying their needs, review these as required and co-ordinate care accordingly.
- Liaise and facilitate communication between the patient, carer and appropriate health professionals and vice versa.
- Assist to empower patients as appropriate.

5. 0 Referral Pathways

5.1 Referral Procedures into the SNMDT from Local and Network Hospitals

The majority of patients will have undergone a biopsy at a local/network level; although not all patients are required to have this performed if there is a strong clinical suspicion of penile cancer in which case patients should be referred without delay. Referral to the Supranetwork Team (SNT) is made via either a standard pro-forma that is available to all referring MDTs or by using an urgent referral letter faxed to UCLH.

Referrals by fax or email should be sent to the SNMDT Coordinator or Penile Cancer CNS, Clare Akers. Other referrals (two week wait rule and non-two week wait rule) are co-ordinated via the PA of the SNMDT Lead together with the Penile Cancer CNS in order to expedite review.

All referrals are seen by the urology consultant and patients are booked into the penile cancer clinic within a week and by at least two weeks.

14-2G-409

Patients with early (stage 1) penile cancer will be offered a joint meeting with a surgeon and oncologist in the presence of a specialist nurse. This clinic is held on a Wednesday morning in the Macmillan Cancer Centre. The clinic is identified by the clinic code AM53A. Claire Akers, CNS and core member of the SNMDT is scheduled to attend.

Referring hospitals with designated Specialist Centres in their Networks (Thames Valley and St Luke's Cancer Alliance) will refer to their Specialist Centre in order to facilitate post op follow-up arrangements.
Minimum data required for referral are as follows:

- Demographics: Name, Date of Birth, Address, Contact Telephone number(mobile and landline)
- Hospital Number (for referring hospital)
- NHS number
- Name and contact of referring clinician and GP
- Histology (if biopsy has already been performed)
- Imaging (if already performed)

The histology and imaging if performed locally is sent to the SNT prior to discussion at the MDT meeting. Patients with suspected penile cancer may be referred directly to the SNT without undergoing a biopsy in order to avoid delay when the penile cancer is clinically obvious.

All patients with histologically-proven penile cancers and patients diagnosed with carcinoma in situ must be reviewed at the SNMDT. If a penile biopsy confirms penile cancer or carcinoma in situ which has been reviewed by pathologists at the local network MDT, then it must be sent for further review to the UCLH uropathologists. Patients with carcinoma in situ are reviewed to ensure that representative biopsies have been performed ensuring that they are deep enough to exclude an invasive component.

Patients emanating from the agreed Specialist Centres should also be discussed at the Supranetwork MDT. The Specialist Centres act as coordinating hospitals for their respective networks for follow-up and local radiotherapy/chemotherapy if required.

Referrals to the SNMDT via the local network MDTs are mainly from urologists, but other clinicians to whom patients with cancers of the penis may present include dermatologists (referral via the skin MDT), genitourinary physicians, plastic surgeons and general surgeons. Guidelines for referral have been distributed to all these specialties throughout the networks contributing to the Supranetwork MDT.

14-2G-406

The SNMDT for UCLH covers a wide referring network. It has been agreed, in order to minimise travelling for patients and undue distress for family members, specific surgical procedures such as diagnostic biopsies may be carried out at the local referring hospital. The procedures can only be carried out if agreed at the SNMDT and the operating surgeon has the appropriate training and skills. All complex cases are carried out at a single site at UCLH:

The following procedures are defined as complex:

- All penile preserving surgery for cancer – glans resurfacing, large wide local excision, glansectomy and any procedure requiring skin grafting
- Locally advanced penile tumours – partial and total penectomy
- Dynamic sentinel lymph node biopsy
- Superficial modified inguinal lymphadenectomy
- Radical inguinal and pelvic lympadenectomy
- Abdominal/genital reconstruction
- Total Phallic Reconstruction

Under exceptional circumstances where the patient is either medically unstable or refuses to be treated at UCLH can complex surgery be undertaken at Royal Berkshire or Royal Surrey Hospitals after discussion at the MDT meeting, however, it must be undertaken by a surgical member of the core team.

5.2 Referral Pathway to Penile Supranetwork Penile MDT

14-2G-408

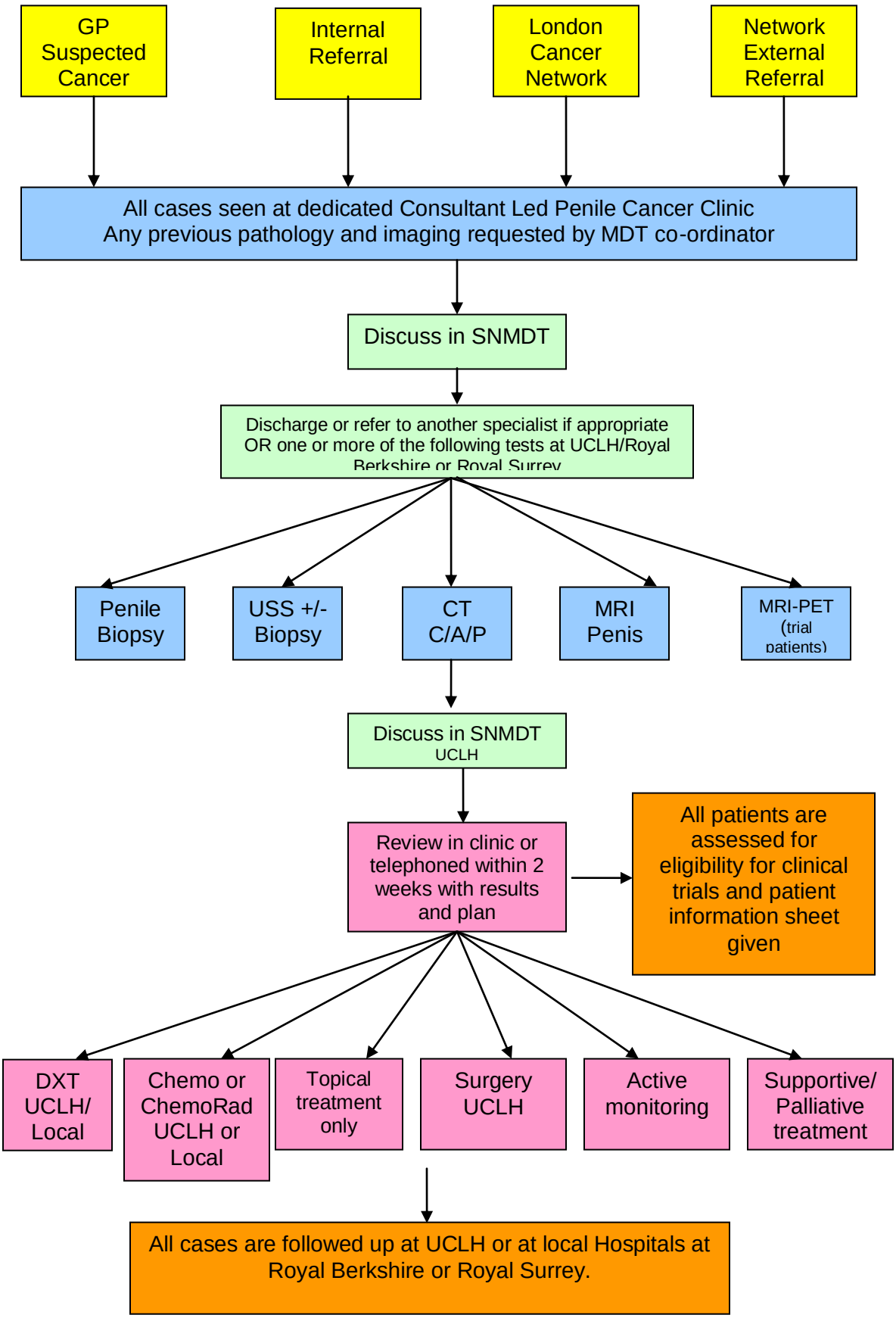

Fig 1

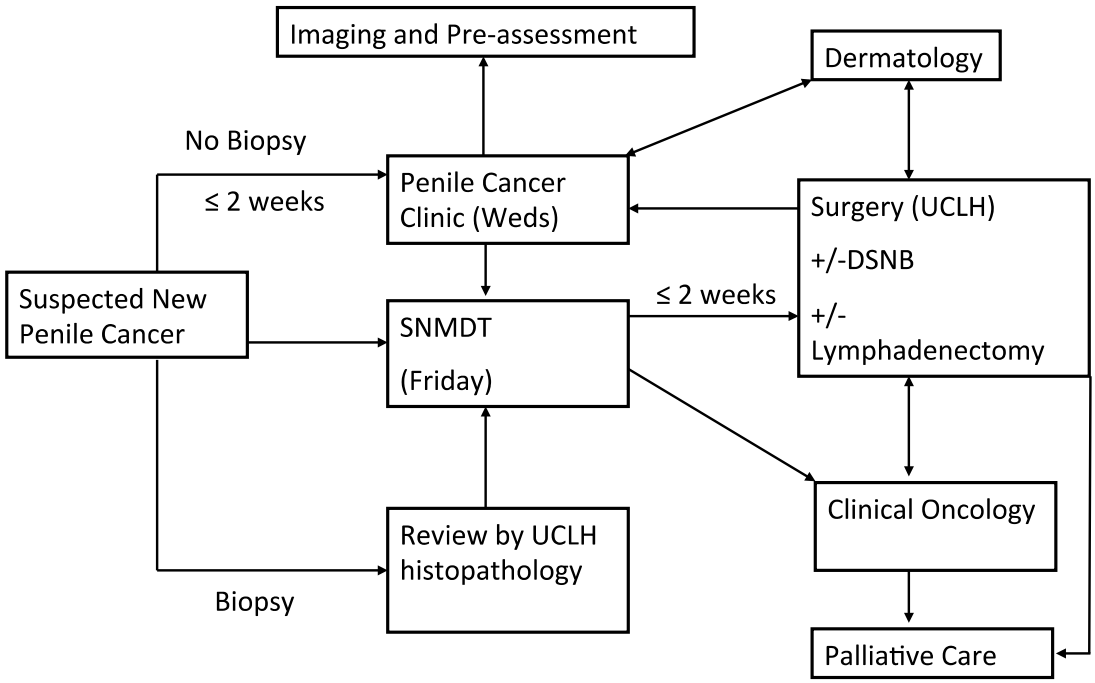

Fig 2: Time frame for newly diagnosed patients entering the pathway.

6.0 The Supranetwork Penile Multi-Disciplinary Team Meeting

The Penile SNMDT meets on a weekly basis on a Friday from 9.30am-11.00pm in the MacMillan Cancer Centre 4th floor seminar room.

All core members are required to attend the meeting in person or video into the meeting. Corresponding members of all contributing networks are notified the week prior to the meeting, with a list of patients to be discussed being circulated by email. Attendance is recorded at each meeting.

6.1 MDT Quorum **14-2G-402**

In order for the MDT meeting to be quorate the following core members or their cover will be present:
• One urological surgeon;
• One clinical oncologist;
• One medical oncologist (where responsibility for chemotherapy has not been taken by the clinical oncologist);
• One imaging specialist;
• One Histopathologist;
• One urology nurse specialist;
• One MDT co-ordinator

6.2 Meeting Process

A list of new, post-operative, and follow-up patients with details, to be discussed must reach the MDT co-ordinator no later than Wednesday 2pm prior to the scheduled Friday meeting. Details are to include the reason for presentation and a short history. Each patient will be presented by the clinician responsible for their care.

The final agenda will be circulated on Thursday at 2.30pm to the team to include the consultant histopathologists and consultant radiologists so that they can review the cases and prepare their presentations.

14-2G-403

The SNMDT discusses the management of all NEW and current cases of proven or suspected penile cancer, all suspected recurrences and discusses any matters of business relevant to the team. Patients will be presented again at the SNMDT after each surgical intervention, chemotherapy and/or radiotherapy at an interval that will be decided when the MDT refers them on for such treatment. The result of the patients' holistic needs is taken into consideration for the decision making.

The Lead Clinician or CNS will record all agreed decisions in the meeting on each patient's named MDT proforma. An individual proforma is produced for each patient with details including:

- Patient identity
- The diagnosis, at the time of making the referral decision
- Referring clinician, hospital and network
- Presenting symptoms
- Previous treatments (if applicable)
- Diagnostic test dates and results
- Relevant clinical details including co-morbidities

The following details of the meeting are recorded and produced by the MDT Coordinator:

- An MDT Attendance List signed by the core team and other attendees
- Individual treatment and management plans agreed by the SNMDT including reasonable therapeutic options, checked by a Consultant
- A Key Worker allocated and recorded on the proforma
- MDT outcomes are reported to the referring networks via the CNS and MDT Coordinator (key liaison workers are designated in these hospitals)
- The MDT proforma is made available on the same day as the SNMDT electronically on the UCLH CDR system and a copy filed in the patients case notes

The proforma includes: **14-2G-410**

- Patient identity and diagnosis
- MDT treatment plan decision (surgery, radiotherapy, palliative care, surveillance, topical treatment)
- A confirmation that the holistic needs have been taken into consideration
- A record of any referral to a neighbouring network

The consultant in charge of the patient and the Clinical Nurse Specialist is responsible for the communication of any planning decisions to the patient. For referrals from the SNMDT to another internal team the proforma is electronically sent by the referrer to the appropriate clinician or clinicians followed by a formal referral letter

All patients diagnosed with penile cancer will be reviewed by a core surgical team member of the Supranetwork MDT and specialist nurse, with access to a joint meeting with an Oncologist. The patient's diagnosis, MDT recommendations and treatment options will be

discussed with the patient. The patient will be given a named Key Worker contact details for the specialist nurse, and relevant patient information.

7.0 Joint Treatment Planning for Teenage and Young Adults (TYAs)

For a patient in the TYA age group (16-24 yrs old), following the review of diagnostics, diagnosis and treatment recommendation, the SMDT should refer the patient for discussion and endorsement of a joint treatment plan as follows:

1. The Consultant in charge of the patient (or one of the medical team) or the patient's key worker should complete a TYA Referral Form.
2. The form should be forwarded to the TYA MDT Co-ordinator for inclusion on the next TYA MDT meeting.
3. The TYA Co-ordinator will inform the referring clinician and/or key worker of the date and time of the next MDT meeting at which their patient will be discussed.
4. A member of the SMDT should attend the TYA MDT to present the patient for discussion and to gain agreement on joint treatment planning. Failure to attend will result in the patient not being discussed and postponed to a subsequent meeting.
5. The proforma summarising the TYA MDT discussion and agreed actions will be uploaded to CDR (UCLH patients). It will include details of the MDT planning decision, treatment type and the named consultants in charge of the treatment modality and age-appropriate support and care environment (including those when the treatment is delivered outside the PTC)
6. The proforma will be emailed to the referring SMDT clinician and Key Worker
7. If the patient's care requires further discussion, the Chair of the TYA MDT will contact the referring clinician.

Patients in the TYA age range of 19 to the end of their 24th birthday will have their choice of treatment location recorded by the MDT on the stored MDT proforma, whether it is at UCLH or another designated TYA hospital.

8.0 Emergency decisions between MDT meetings **14-2G-403**

In the event that a patient requires management prior to the next meeting, referrals are made between team members (in person, by phone or email) so that any emergency investigations and treatment decisions can be undertaken. The consultant in charge of the patient contacts other members of the team as appropriate as well as the SNMDT Lead.

The decisions are made by all relevant clinicians and the discussion takes place via phone call or personal contact where possible. The treatment plans are then discussed in retrospect at the following SNMDT meeting and the treatment decision is verified and then documented.

Emergency decisions on patient management taken between meetings should be documented in the patient's notes and communicated to the SNMDT coordinator to add to the next meeting list.

The treatment options are discussed with the patient in clinic as appropriate and with relevant members of the team; a Clinical Nurse Specialist is always present. The GP is informed of the diagnosis within 24 hours and a copy of that letter is sent to the patient.

9.0 Communication with Patients, GPs and Referring Clinicians

14-2G-414

All patients will be offered the opportunity of a permanent record or summary of a consultation at which their diagnosis, treatment options of their diagnosis and follow up were discussed, in line with the Trust policy. They can choose to decline. It is standard practice to copy all clinical correspondence to patients, GPs and referring clinicians. MDT proformas will be faxed to GPs and referring clinicians following each SNMDT meeting within 24 hours.

All patients have access to the members of the MDT to discuss problems or concerns regarding diagnosis, treatment or any other matter. This access is principally via their Key Worker contact. The Key Worker ensures that the patients / carers have their details.

10.0 Protocol for patient follow-up

Follow up of patients following a diagnosis and treatment for penile cancer should take place in the clinics of each core member of the Supranetwork MDT. Patients are followed up at UCLH or the host centre, Royal Berkshire Hospital or Royal Surrey County Hospital. All histology is presented at the SNMDT following any surgical intervention, where further treatment or clinical/radiological follow up is planned in line with the clinical guidelines.

The schedule for follow-up is a modified version of the EAU 2014 recommendations (http://www.uroweb.org/gls/pdf/12%20Penile%20Cancer_LR.pdf) as follows with a minimum follow up of 5 years:

Management	Follow-up	Years 1 & 2	Year 3-5	
Local Management	Conservative Therapy	3 monthly	6 monthly	
	Partial/Total Penectomy	3 monthly	Annually	
Lymph Node Management	Surveillance	3 monthly	6 monthly	
	pN0	3 monthly	Annually	
	pN+	3 monthly	6 monthly	

Physical examination is required at each visit. The value of routine imaging (i.e. in the absence of symptoms) has not been established but a useful adjunct is the availability of inguinal ultrasound for pN0 disease which has undergone dynamic sentinel lymph node biopsy and CT/MRI for surveillance of pN+ disease.

11.0 Palliative Care

The Supranetwork MDT appreciates the importance of palliative care input, both in the community and as an inpatient. Palliative care arrangements will involve GPs, community (e.g. Macmillan) home care teams, social workers, district nurses and palliative care physicians. These will be co-ordinated by the Clinical Nurse Specialist(s) for the Supranetwork team.

12.0 Patient and Carer Feedback and Involvement **14-2G-414**

- In line with the Trust communication policy all patients will be sent a copy of their Outpatients consultation letter as a permanent record of consultation unless they specifically choose to opt out. All patients will be informed of this at the time of their outpatient consultation.
- Patients will receive a copy of their consent form for chemotherapy or radiotherapy or surgery as appropriate. If treatment is to be chemotherapy, the patient will be provided with a diary into which the chemo-care nurse records all upcoming appointments and blood results.
- If an inpatient, a copy of the discharge summary will be given to the patient on the day of discharge.

13.0 Patient Information **14-2G-413**

The MDT will provide clear and comprehensive written information for patients diagnosed with penile cancer including information specific to the local/specialist MDT team and the provision of services offering treatment at the Supranetwork centre. Written information will include:

- Information specific to penile cancer about the disease and its treatment options
- Information specific to the local/specialist MDT team
- Provision of services offering treatment at the Supranetwork centre
- Patient involvement and self-help groups
- Psychological social and spiritual/cultural support

Booklets available include:

- MDT Leaflet
- What to expect from your clinical nurse specialist
- Penile Cancer - Information for Patients and carer
- Partial Penectomy
- Total penectomy
- Glans resurfacing/glansectomy plus skin graft
- Understanding Lymphoedema
- Understanding Radiotherapy
- The Cancer Guide – Macmillan
- Close relationships and cancer
- Dynamic Sentinel Node Biopsy in Penile Cancer
- Inguinal lymphadenectomy
- Endoscopic and minimally invasive lymphadenectomy

Information delivery will shortly follow the principles of the NHS Information Prescription (www.informationprescription.info) for which UCLH was a pilot site.

We aim to implement NHS Information Prescription Services (IPS) hosted by NHS Choices for all our patients. All Patients will be assessed and offered an 'Information Prescription' with personalised and tailored information to meet their needs and/or their carers' at that point in their cancer journey.

The information prescription provided will be recorded in the patient's notes. If an information prescription is declined by the patient or, if following assessment, it is determined that an Information Prescription is not appropriate at that time, this will also be documented.

14.0 Data Collection

The Supranetwork MDT, in agreement with the London Cancer Network, will collect the Network agreed Minimum Data Set (MDS) for Urology.

In January 2013 the COSD replaced the previous National Cancer Dataset as the new national standard for reporting cancer in the NHS in England. It incorporated a revised generic Cancer Registration Dataset (CRDS) and additional clinical and pathology site specific data items relevant to different tumour types. The MDT will collect the minimum dataset (MDS) as nationally agreed.

This is submitted within 25 working days after the end of the month and the repository of this data is the Trust-wide IT system Infoflex.

In addition to this the Cancer Waiting Times dataset including Going Further on Cancer Waits in accordance with DSCN 20/2008 and in conjunction with related DSCN 22/2002, DSCN 27/2004 and DSCN 16/2007 to the specified timetable as specified in the National Contract for Acute Services – currently within 25 working days after the end of the month.

15.0 MDT Agreement to Supranetwork Guidelines for Penile Cancer

14-2G-407

1. The SNMDT has agreed the Supranetwork-wide clinical and referral guidelines for the diagnosis, assessment and MDT discussion
2. The SNMDT has agreed the Supranetwork-wide clinical and referral guidelines defining specialist and supranetwork care for the network
3. The SNMDT has agreed the written follow-up guidelines between the SNMDT and its referring teams

The Supranetwork guidelines form a separate document.

16.0 Research and Audit

14-2G-416,14-2G-417

- An annual report summarising the ongoing clinical trials and a programme for improvement will be produced and presented at the annual meeting
- The current trials portfolio at a local and national level together with the MDTs recruitment to the trials will be discussed in the annual report
- A Network Audit programme is agreed annually with the NSSG which the MDT will actively take forward
- Audit of all cases will take place at least annually. One core member of each referring network will be required to review cases with at least one core member of the supranetwork team
- Patients should be regularly involved in surveys and user groups. Their views should be sought on all aspects of the penile service, including: service redesign, patient information leaflets and feedback of service received. Information from patient surveys should be discussed at MDT, an action plan formulated and reviewed to ensure that at least one action has been implemented.
- In line with the UCL public and patient involvement, the penile cancer support group at UCL provides a forum for engagement as well as the NCRI penile CSG which is attended by Mr Muneer.

- The MDT through its Lead will agree to take part in London Cancer's approved list of clinical trials and other well designed studies, producing an annual response to trial recruitment
- Wherever an appropriate trial or other well designed study is available a patient should, through informed consent and agreement, be entered and ensure public and patient engagement in the consultation phase and steering group.
- Any remedial actions arising from the recruitment results will be agreed with London Cancer.
- Research and Audit leading to evidence should be the basis of the practice of the whole team. All professions should be encouraged to share findings.

17. Patient Support Group and Feedback **14-2G-415**

A penile cancer patient support group meets on a monthly basis in the MacMillan Cancer Centre and is coordinated by Clare Akers, Penile Cancer CNS.
Core and extended members of the SNMDT attend by invitation in order to deliver talks and allow patient engagement.

This provides an opportunity for the SNMDT to gain feedback directly from the patients and to conduct surveys and questionnaires.

These will specifically assess whether patients were:

- Offered a key worker
- Holistic needs assessment
- Written or otherwise MDTs information for patients and carers
- Permanent record or summary of the consultation discussing treatment plans

18. Annual General Meeting

The MDT will hold an annual general meeting to discuss, review, agree and record operational policies. Findings of patient surveys and audits conducted during the year will be discussed at this meeting. Invitations will be extended to core and extended members of the MDT and the network referrers. Cases will be discussed with the network referrers.

19. Cryopreservation (Sperm Storage)

All patients, whereby treatment could impact on fertility, are offered semen cryopreservation. Patient' are counselled prior to undergoing blood tests to check their Hepatitis B, C and HIV status. Referrals are then made on their behalf using a specific template, by the CNS, to the Fertility and reproductive medicine laboratory located on the lower ground floor of the University College Hospital Elizabeth Garrett Anderson Wing. The forms are emailed to the fertility team via fertilitylab@uclh.nhs.uk, with a copy of the blood test results. The Laboratory contact the patients directly to arrange an appointment with them at their convenience. This is a free service.

20. Network Guidelines

The SNMDT agrees to abide by the London Pathway Board clinical guidelines for Penile and Testicular cancer published in April 2016.The SNMDT will provide representation to all the Urological London Cancer Board meetings.

- The SMDT will engage with Urological London Cancer to develop and implement network-wide clinical, referral, imaging and pathology guidelines
- The SMDT may collect additional data in support of a London Cancer Network Audit project and will present the results for discussion at one of the Urological London Cancer meetings. The Audit is normally agreed on an annual basis

21. Patient Pathways

The SNMDT agrees to abide by the London Pathway Board network-wide patient pathways for Penile and Testicular cancer published April 2016.