

**Patient Pathways for
Teenage and Young Adults with Cancer
in Greater Manchester and Cheshire Cancer Network
and Lancashire and South Cumbria Cancer Network
Version 4 agreed July 2012
Colorectal CSG Measures 11-1C-125d & 11-1C-126d**

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1. Overview

1.1. Basic principles

1.1.1. Objective

- Clinical and functional outcomes for teenage and young adult patients with cancer are worse than expected and improving slower than expected in comparison with both children with cancer and older adults with cancer
- At least part of the reason for this is considered to be the additional psychosocial impact of cancer at this age and the increased potential for biographical disruption
- Patients of this age gain significantly from peer support during their treatment and from central referral to units aimed at supporting this patient group
- There is significant patient pressure to have access to such units
- At the same time age specific support must be combined with cancer specific medical management
- Patient choice and self-determination should also be supported regarding place of care assuming appropriate services are available more locally. If patients choose not to be referred centrally to a specialist teenage unit, every effort should be made to provide appropriate age specific support within available resources.

1.1.2. Notification: all patients

- All patients aged 16 – 24 with a new diagnosis of malignancy must be notified to the Principle Treatment Centre (PTC)
 - Notification does not necessarily involve referral of the patient for management. It merely implies transfer of information.
 - It allows the TYA team to register the patient on the national database
 - It will trigger contact and an offer of psychosocial support at the earliest possible opportunity in conjunction with the local team and ensure as a minimum the patient is treated at a TYA Designated Hospital
 - It also implies that the patient has been told of specialist services that may be available for them, that their case will be notified to the central team and that they should receive information regarding their options for treatment delivery and support from the central team

1.1.3. Referral: patients aged 16 – 18

- All patients aged 16 – 18 with a confirmed diagnosis of cancer, or with a high suspicion of cancer should be referred to the TYA MDT for input with regard to their management.
- For childhood tumours they should be referred and treated at the Paediatric PTC
- For 'adult tumours' they should be referred to the TYA PTC
- They should be treated at the PTC where possible
- If the required surgical treatment is not available at the PTC then they should be treated initially at a TYA Designated Hospital

1.1.4. Informed choice: patients aged 19 -24

- Patients aged 19 – 24 years should be given appropriate information to allow them to make an informed decision regarding the place of care for their condition

1.1.5. Care at the TYA PTC –The Christie Young Oncology Unit

- The main services provided at the Christie are chemotherapy and radiotherapy. Some surgical services are also available. Patients referred for treatment at the Christie will always be managed by a consultant team which is specific to the condition (i.e. Haematology for leukaemia or site specific for solid tumours). The TYA component of care is psycho-social support from specialist nurses and AHPs

1.1.6. Shared care

- All patients are likely to benefit from some degree of sharing of care between central services and local services. Where possible elements of care will be offered to the patient through local services.

1.1.7. Support of patients who receive no medical care at the TYA PTC

- Outreach support during therapy is currently under development.
- However, in all cases contact can be made and patients offered access to attend Youth Support events and post-treatment survivorship groups
- Local support in TYA Designated Hospitals is also being developed

2. Summary map of centralised services for TYA patients with cancer

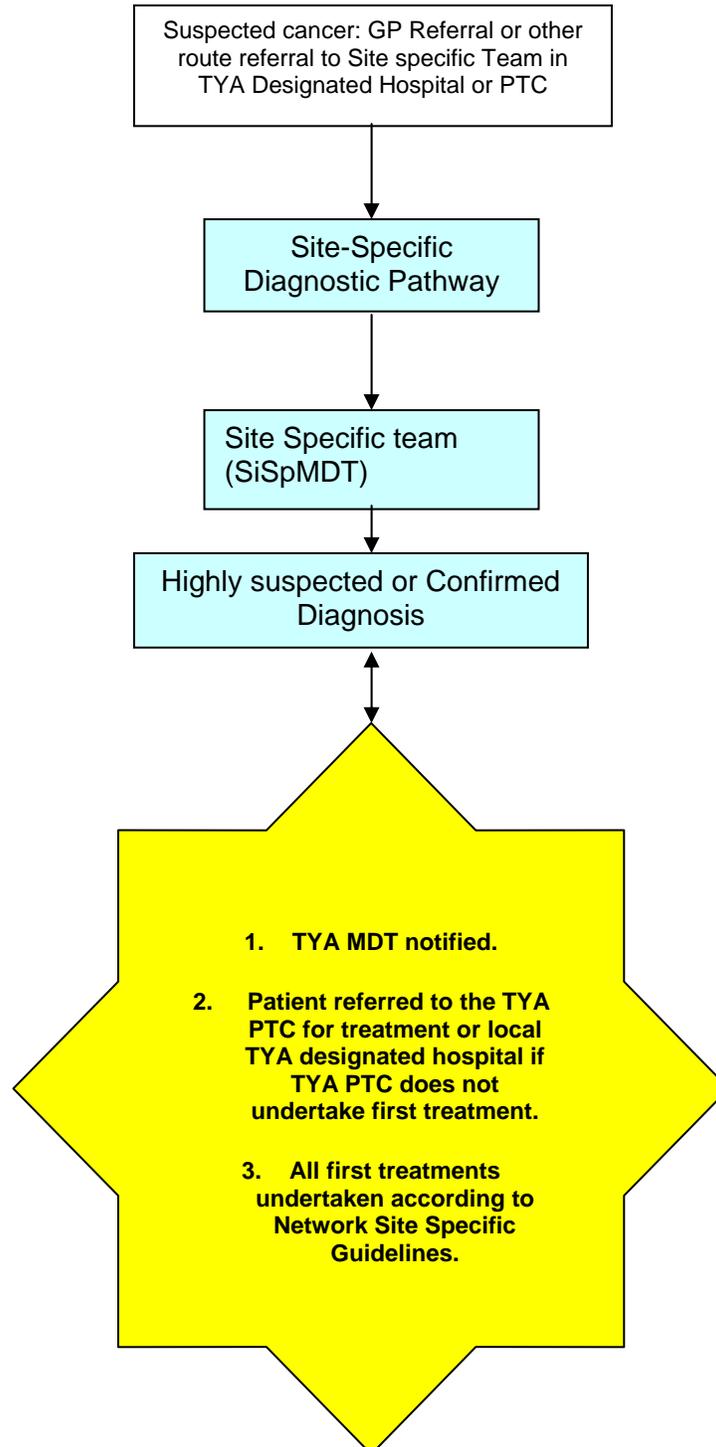
- The following table indicates the location of care for patients who are referred for TYA care centrally.
- Abbreviations
 - ELHT: East Lancashire Hospitals NHS Trust (Royal Blackburn Hospital, Burnley General Hospital)
 - BFWT: Blackpool Teaching Hospitals NHS Foundation Trust (Blackpool Victoria Hospital)
 - LTHT: Lancashire Teaching Hospitals NHS Trust (Royal Preston Hospital, Chorley Hospital)
 - UHMB: University Hospitals of Morecambe Bay NHS Trust (Royal Lancaster Infirmary, Furness General Hospital, Westmoreland General Hospital)
 - UHSM: University Hospital South Manchester (Wythenshawe Hospital)
 - Stockport: Stepping Hill Hospital
 - SRFT: Salford Royal Foundation Trust (Hope Hospital)
 - PAHT: Pennine Acute Hospital Trust (Royal Oldham Hospital, North Manchester General Hospital, Crumpsall, Rochdale Infirmary, Fairfield Hospital, Bury)
 - CMFT: Central Manchester Foundation Trust (Manchester Royal Infirmary)
 - RJAH: Robert Jones Agnes Hunt Orthopaedic Hospital, Oswestry
 - ROH: Royal Orthopaedic Hospital, The Woodlands, Birmingham
 - GMOSS: Greater Manchester Oswestry Sarcoma Service
 - CCC: Clatterbridge Cancer Centre NHS Trust

	GMCCN			LSCCN		
	Diagnosis	Surgery	Non-surgical Oncology	Diagnosis	Surgery	Non-surgical Oncology
Leukaemia	UHSM, SRFT, PAHT, CMFT, Stockport	N/A	Christie	ELHT, BFWT, LTHT, UHMB	N/A	Christie
Lymphoma	UHSM, SRFT, PAHT, CMFT, Stockport	N/A	Christie	ELHT, BFWT, LTHT, UHMB	N/A	Christie
Testis	UHSM, SRFT, PAHT, CMFT, Stockport	UHSM, SRFT, CMFT, Stockport Urology teams for orchidectomy Christie RP team for RPLND	Christie	ELHT, BFWT, LTHT, UHMB Urology teams	ELHT, BFWT, LTHT, UHMB for orchidectomy, Christie RP Team for RPLND	Christie
Bone Sarcoma	RJAH, Oswestry	GMOSS	Christie	ROH Birmingham	ROH Birmingham	Christie / CCC
Soft tissue sarcoma	CMFT	GMOSS	Christie	LTHT soft tissue diagnostic service	GMOSS / Merseyside Sarcoma Service	Christie / CCC
Brain / CNS	Salford Royal Infirmary	Neuro-Oncology Service, Salford Royal Infirmary	Christie	Neuro-Oncology Service, Lancashire Teaching Hospitals NHS Trust	Neuro-Oncology Service, Lancashire Teaching Hospitals NHS Trust	Christie
Skin / Melanoma	UHSM, SRFT, CMFT, Stockport	UHSM, SRFT, CMFT, Stockport Christie Onco-plastic	Christie	ELHT, BFWT, LTHT, UHMB	Specialist onco-plastic / Christie	Christie
Gynae	UHSM, SRFT, PAHT, CMFT, Stockport	CMFT, UHSM, SRFT	Christie	ELHT, BFWT, LTHT, UHMB	LTHT Specialist Gyane-Oncology team	Christie
H&N	UHSM, SRFT, PAHT, CMFT, Stockport	CMFT, PAHT	Christie	ELHT, BFWT, LTHT, UHMB	ELHT, LTHT Head and Neck specialist teams	Christie
Urology (other than testis)	UHSM, SRFT, PAHT, CMFT, Stockport	UHSM, SRFT, CMFT, Stockport Uro-oncology Teams	Christie	ELHT, BFWT, LTHT, UHMB	ELHT, LTHT Uro-oncology teams	Christie
Upper GI OG	UHSM, SRFT, PAHT, CMFT, Stockport	UHSM, SRFT, CMFT, Specialist OG oncology Teams	Christie	ELHT, BFWT, LTHT, UHMB	LTHT, Specialist OG oncology team	Christie
Lower GI	UHSM, SRFT, PAHT, CMFT, Stockport	UHSM, SRFT, PAHT, CMFT, Stockport	Christie	ELHT, BFWT, LTHT, UHMB	ELHT, BFWT, LTHT, UHMB	Christie
HPB	UHSM, SRFT, PAHT, CMFT, Stockport	CMFT, PAHT	Christie	ELHT, BFWT, LTHT, UHMB	ELHT Specialist HPB oncology team	Christie
Lung / Thorax	UHSM, SRFT, PAHT, CMFT, Stockport	UHSM Cardio-thoracic surgery Unit	Christie	ELHT, BFWT, LTHT, UHMB	BFWT specialist cardiothoracic surgical centre	Christie
Breast	UHSM, SRFT, PAHT, CMFT, Stockport	UHSM, SRFT, PAHT, CMFT, Stockport	Christie	ELHT, BFWT, LTHT, UHMB	ELHT, BFWT, LTHT, UHMB	Christie

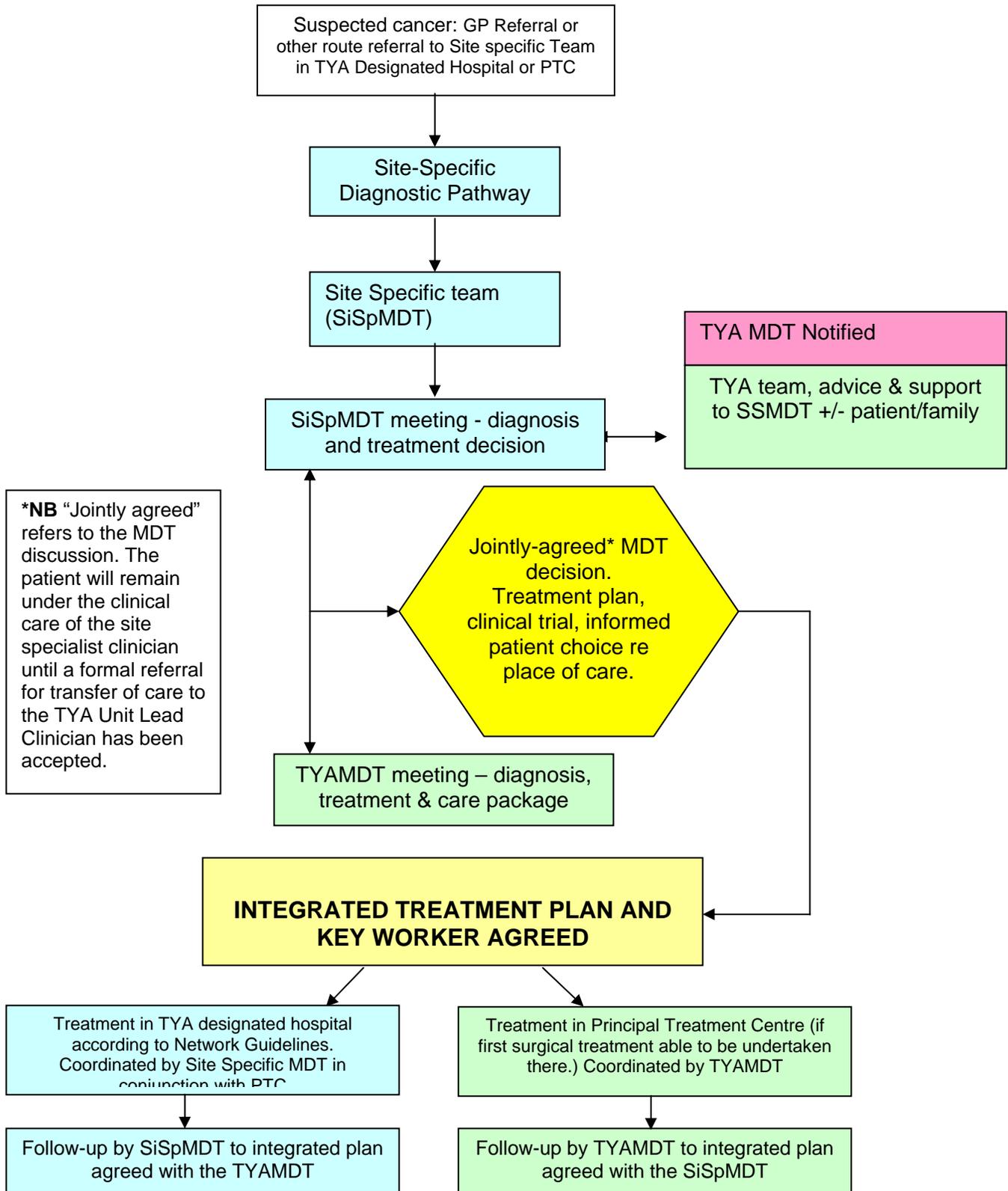
3. Generic Pathway for 16 – 18yr olds

TEENAGE AND YOUNG ADULT PATHWAY 16-18 YEARS INCLUSIVE

TYA Designated and Non Designated Hospitals

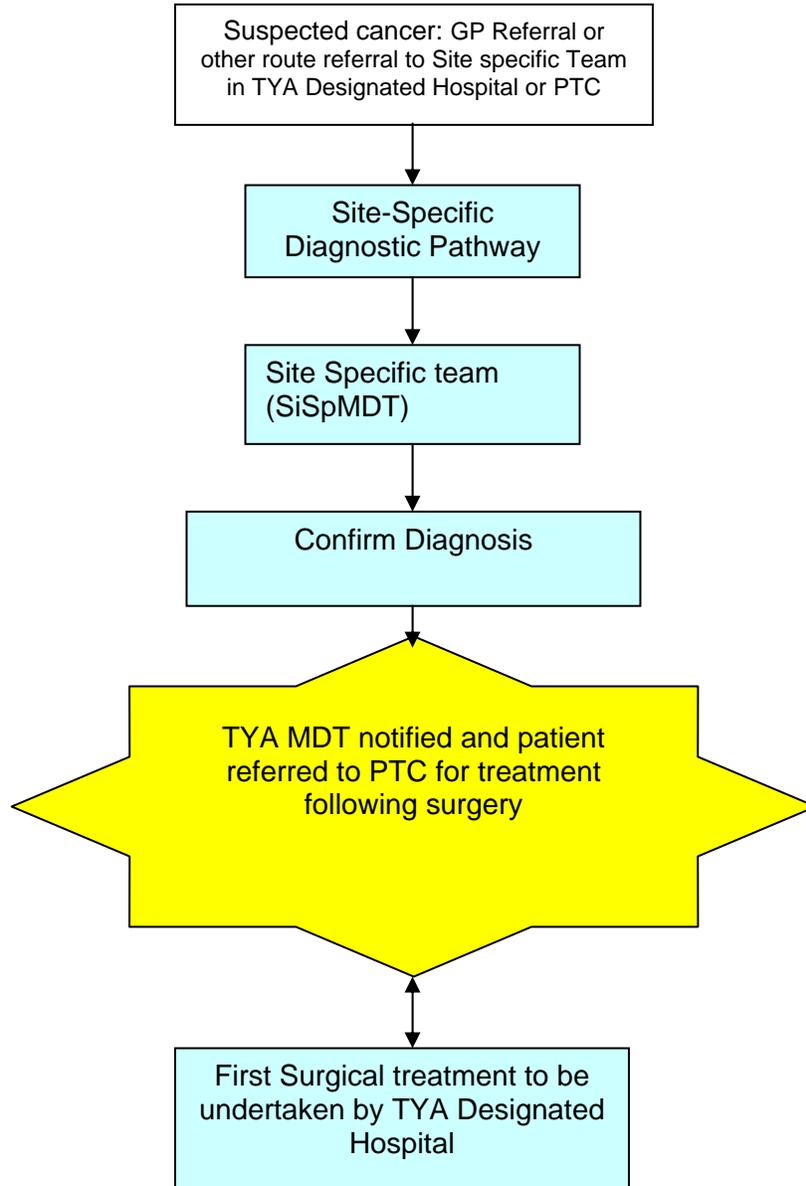


4. Generic Pathway for 19 – 24 yr olds from TYA Designated Hospitals



NB The agreed Network site specific diagnostic and treatment guidelines for each site specialty (e.g. breast, neuro, skin, urology etc) should be adhered to.

5. Generic Pathway for 19 – 24 yr olds from TYA non-designated hospitals



NB The agreed Network site specific diagnostic and treatment guidelines for each site specialty (e.g. breast, neuro, skin, urology etc) should be adhered to.

6. Notification of new cases to the PTC

- All new cases of cancer or haematological malignancy should be notified to the PTC
- By agreement with this policy all Clinical Sub Groups and their constituent MDTs agree to this notification process

6.1. Who should notify?

6.1.1. Local Clinician to PTC TYA Clinician

- Direct contact from the diagnosing clinician to one of the core members of the PTC TYA MDT is preferable where possible
- Where personal contact is not possible the next best method should be by phone to allow discussion.
- If the local clinician knows which clinician to contact at the PTC they should establish contact directly or through the secretary or hospital switchboard
- If the local clinician is not sure who to speak to, a message should be left with the PTC MDT co-ordinator who will arrange a phone back at the earliest opportunity by the most appropriate clinician on the TYA MDT

6.1.2. Local MDT co-ordinator to PTC TYA MDT co-ordinator

- Whether or not there has been direct contact from the diagnosing team clinician to the PTC TYA MDT clinician, the MDT co-ordinator for the local MDT should liaise with the PTC TYA MDT co-ordinator at the earliest possible opportunity to transfer the notification dataset

6.2. Sending and receipt of notification

- Notification should occur as soon as a cancer diagnosis is confirmed or deemed highly likely based on radiological or pathological findings. Notification should not be delayed for review at a site-specific MDT (SSMDT) and can be initiated by doctor including pathology or radiology, or clinical nurse specialist
- Notification will be by completion and sending of the specific TYA notification proforma to the TYA MDT Co-ordinator
- The notification form is shown in Appendix 1 and is available electronically or by e-mail from the MDT Coordinator

6.3. Notification dataset

- Required information includes:
 - Patient demographics
 - Date of referral
 - Type of referral and target clock start and breach dates if applicable (e.g 2 week wait; 31/62 day target etc)
 - Name of the consultant team the patient is currently under at the local hospital
 - Details of any referral already made to other consultants
 - Date first seen at the local hospital and by whom

- Details of diagnostic investigations performed so far
- Summary of history to date
- What level of involvement from the PTC MDT is required

6.4. Actions upon receipt of referral

- Telephone discussion of urgent cases is likely to be essential and the timing of the respective MDTs must not delay the starting of urgent treatments.
- MDT co-ordinator absence will be covered by other members of the TYA MDT team

6.4.1. Confirmation of receipt of referral

- Confirmation of receipt of notification will be sent by the MDT coordinator within one working day by email or Fax. (Appendix 2) This will include the planned date and time of the TYA MDT meeting at which the patient's case will be discussed
- Relevant TYA MDT members responsible for providing psychosocial support will be informed of the notification. A member of the TYA MDT will then make contact with the referrer to ascertain the appropriateness of contacting and arranging to meet the young person, family and other carers as soon as is reasonably possible.
- For patients referred to the PTC for treatment, the TYA MDT Coordinator will collect relevant reports, notes etc for review.

6.4.2. Preparations for timely treatment for a patient referred to be seen and managed at the PTC

- The TYA MDT co-ordinator or relevant medical secretary will:
 - liaise with the Consultant / SpR to ensure that initial diagnostic investigations are arranged for the TYA's first visit
 - organise an outpatient appointment within 1 working week, or arrange in-patient admission as urgently as clinically necessary, usually within 48 hours
 - notify the referring surgeon/physician of the date and time of the appointment, and the name of the clinician who will see the patient
 - Notify the patient's general practitioner of the date and time of the appointment, and the name of the clinician who will see the patient
 - Notify the patient / family of the date and time of the appointment, and the name of the clinician who will see them

6.4.3. For patients referred for a visit to the PTC prior to deciding on place of treatment

- The TYA MDT Coordinator or Nurse Consultant will identify a suitable clinic appointment with the local team for that discussion, and arrange for the patient to be informed.

6.4.4. Administration before the TYA MDT meeting

- The TYA MDT co-ordinator will:-
 - prepare a single meeting list of patients to be discussed. The meeting list will be sent in a password protected e-mail to the TYA MDT team as a draft document on the Wednesday before the meeting, and then on a Thursday as a final document to individual MDT members

- invite attendance from the local or site-specific MDTs to present the patient and report on proposed management plan. Cases can be presented by medical or nursing staff. Video-linking technology will be used where possible and will facilitate the participation of the referring clinician.

7. Establishing level of input from PTC

- All patients aged 16 to 18 years should be referred to the PTC MDT and should be treated at the PTC when clinically appropriate
- Patients aged 19 to 24 years should have unhindered access to treatment at the PTC when clinically appropriate

7.1. Levels of input available

1. Notification only, no contact
2. Notification, care to be delivered locally, psychosocial support requested
3. Notification, care to be shared between local services and PTC and psychosocial support provided from PTC
4. Notification, transfer of all care to PTC

7.1.1. Notification only, no contact

- This would be appropriate for some patients aged 19 – 24 who have been offered referral and support from PTC and have declined both, opting for all care to be given at the local hospital, where that hospital is a TYA Designated Hospital and has capability and capacity to offer the required treatment
- The patient's history and presentation will be briefly reported at the TYA MDT meeting once their case has been through the local MDT meeting and a management plan has been defined including eligibility for clinical trials
- The patient's dataset will be registered with the national database

7.1.2. Notification, care to be delivered locally, psychosocial support requested

- This would be appropriate for some patients aged 19 – 24 who have been offered referral and support from PTC and have opted for treatment to be given at the local hospital, where that hospital is a TYA Designated Hospital and has capability and capacity to offer the required treatment, but would like to have contact with the PTC for psychosocial support
- The patient's case will initially be briefly reported at the TYA MDT meeting
- The patient's dataset will be registered with the national database
- Contact will be made with the patient by the TYA Youth support worker (post or phone)
- Information will be sent to the patient / family about the facilities available
- The patient will be invited to attend the YOU to be seen by the TYA consultant nurse or other nurse or AHP in the team for assessment
- The patient's case will then be re-listed for discussion at the TYA MDT meeting with an invitation to the referring team to attend to present discuss the patient's care including eligibility for clinical trials
- Psycho-social support will be provided as appropriate

7.1.3. Notification, care to be shared between local services and PTC and psychosocial support provided from PTC

- This would be appropriate for patients aged 16 – 18 where some element of their care cannot be provided at the PTC. In most cases this would be a requirement for surgery not undertaken at The Christie
- This would also be appropriate for some patients (at any age) where shared care is either most clinically appropriate or specifically requested by the patient. Examples might include patients presenting with advanced incurable cancer requiring palliative care
- The patient's case will initially be briefly reported at the TYA MDT meeting
- The patient's dataset will be registered with the national database
- A referral letter should be sent from the local hospital consultant team to a named consultant at the PTC
- Contact will be made with the patient / family by the consultant's team to arrange a new patient attendance within 1 week
- At the first attendance, there will be a standard medical assessment by the consultant and the patient and family will be allocated a key worker and information will be given to the patient / family about the facilities available
- The patient's case will be presented and discussed at the relevant site specific MDT meeting
- The patient's case will then be re-listed for discussion at the TYA MDT meeting with an invitation to the referring team and centre treating team to attend to present discuss the patient's care including eligibility for clinical trials
- Psycho-social support will be provided as appropriate

8. Pathways for specific malignant conditions

8.1. Leukaemia

8.1.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with leukaemia in distinction to adult patients with leukaemia. The provision for presentation and diagnosis of patients with leukaemia will be managed and developed by the Haematology NSSGs.
- In brief, most patients will be diagnosed initially from a full blood count
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.1.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to the Haematology service at the Christie NHS Foundation Trust for management in the PTC
- Patients aged 19 – 24 may choose to receive their treatment at a more local Level 3 Haematology service at a TYA Designated Hospital. Units should undertake work according to the guidance for staffing and experience set out in the 2009 BCSH guidelines (www.bcs guidelines.co.uk).

8.1.3. Variations to the pathway

- None

8.1.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the haematology NSSGs
- A follow-up care plan should be provided to the patient by the haematologist
- TYA MDT input outwith the involvement of Haematology MDT members who are also TYA MDT members will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the haematologist.

8.2. Lymphoma

8.2.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with lymphoma in distinction to adult patients with lymphoma. The provision for presentation and diagnosis of patients with lymphoma will be managed and developed by the Haematology NSSGs.
- In brief, most patients will be diagnosed initially from a lymph node biopsy
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.2.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to the Lymphoma service at the Christie NHS Foundation Trust for management in the PTC
- Patients aged 19 – 24 may choose to receive their treatment at a more local Level 3 Haematology service at a TYA Designated Hospital. Units should undertake work according to the guidance for staffing and experience set out in the 2009 BCSH guidelines (www.bcsguidelines.co.uk).

8.2.3. Variations to the pathway

- None

8.2.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Haematology NSSGs
- A follow-up care plan should be provided to the patient by the haematologist / oncologist
- TYA MDT input out with the involvement of Lymphoma MDT members who are also TYA MDT members will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms

- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the haematologist / oncologist.

8.3. Testis

8.3.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with testicular cancer in distinction to adult patients with testicular cancer. The provision for presentation and diagnosis of patients with testicular cancer will be managed and developed by the supra-network Testis MDT.
- In brief, most patients with suspicious symptoms or signs of a testicular mass will be referred to their local TYA designated urology service. Formal confirmation of the diagnosis of testicular cancer is usually obtained by orchidectomy (i.e. post-operatively) although the diagnosis is often strongly suspected pre-operatively and some patients may present with very advanced disease and obtain a diagnosis pre-operatively. Once a diagnosis of testicular cancer has been made their case will be presented at the supra-regional MDT meeting at The Christie
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.3.2. Places of recommended treatment delivery

- Orchidectomy – should be performed by the local TYA designated urology team unless the patient is suitable for pre-operative treatment as defined by the supra-regional Testis MDT
- Chemotherapy and radiotherapy – patients aged 16 – 18 should be referred to an oncologist on the supra-regional Tests MDT at PTC (The Christie) and their care managed jointly by the Testis MDT and TYA MDT at the PTC with options for shared care with the local referring consultant explored and discussed as appropriate. Chemotherapy should be given on the YOU and radiotherapy should be given at The Christie. Patients aged 19 – 24 should have the option of referral to the PTC for treatment or treatment locally as discussed above.
- Retroperitoneal lymphnode dissection. All patients should be referred to the retroperitoneal surgical team at The Christie in compliance with the network guidelines produced by the supra-regional Testis MDT

8.3.3. Variations to the pathway

- None

8.3.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the supra-regional Testis MDT
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input outwith the involvement of Testis MDT members who are also TYA MDT members will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required

- Palliative care MDT input for patients diagnosed with incurable advanced disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.4. Bone sarcoma

8.4.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with bone sarcoma in distinction to adult patients with bone sarcoma. The provision for presentation and diagnosis of patients with bone sarcoma will be managed and developed by the supra-network Sarcoma Service (GMOSS – Greater Manchester and Oswestry Sarcoma Service)
- In brief, patients with suspicious symptoms or signs or abnormal radiology will be referred by preference to Robert Jones Agnes Hunt Orthopaedic Hospital, Oswestry for biopsy and work up
- Once a diagnosis of bone sarcoma has been made their case will be presented at the GMOSS MDT meeting
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.4.2. Places of recommended treatment delivery

- Patients who require surgery alone and no chemotherapy or radiotherapy (e.g. low grade chondrosarcoma)
 - Limb salvage surgery and specialist endoprosthetic implants – Tumour Unit, Robert Jones and Agnes Hunt Orthopaedic Hospital Oswestry
 - Consultant in charge: GMOSS Orthopaedic surgeon, RJAH
 - Amputation – referral to the most appropriate orthopaedic service close to the patients home
 - Consultant in charge: GMOSS Orthopaedic surgeon, RJAH
- Patients who require surgery and either chemotherapy or radiotherapy or both
 - Limb salvage surgery and specialist endoprosthetic implants – Tumour Unit, Robert Jones and Agnes Hunt Orthopaedic Hospital Oswestry
 - Consultant in charge: GMOSS Orthopaedic surgeon, RJAH
 - Amputation – referral to the most appropriate orthopaedic service close to the patients home
 - Consultant in charge: GMOSS Orthopaedic surgeon, RJAH
 - Non-surgical oncology – The Christie
 - Consultant in charge: GMOSS Consultant oncologist

8.4.3. Variations to the pathway

- Some patients may be referred to another Nationally Commissioned Bone Sarcoma Treatment centre (e.g. Royal Orthopaedic Hospital, Birmingham)
 - For patients requiring surgery alone, psycho-social support from the PTC will be offered
 - For patients requiring surgery and either chemotherapy or radiotherapy or both
 - Non-surgical oncology – The Christie

- Consultant in charge: GMOSS Consultant oncologist
- Site specific variations
 - Spinal tumours, maxillo facial and skull tumour
 - Options include Neurosurgical units at Salford Royal Infirmary, Lancashire Teaching Hospitals Trust, and the spinal team at RJAH

8.4.4. Pathway for follow-up on completion of first line therapy

- Surgical follow-up should be provided by the operating surgical team in all cases for at least 5 years
- Oncological follow-up should follow the protocols defined by GMOSS for each bone sarcoma
- A follow-up care plan should be provided to the patient by the surgical team if no chemotherapy or radiotherapy has been given and by the oncologist if the patient has had chemotherapy or radiotherapy
- TYA MDT input out with the involvement of GMOSS MDT members who are also TYA MDT members will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable advanced disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. For patients having surgery alone, this should be provided by the operating surgical team. For those who have had chemotherapy and or radiotherapy this should be provided by the oncologist.

8.5. Soft tissue sarcoma

8.5.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with soft tissue sarcoma in distinction to adult patients with soft tissue sarcoma. The provision for presentation and diagnosis of patients with soft tissue sarcoma will be managed and developed by the supra-network Sarcoma Service (GMOSS – Greater Manchester and Oswestry Sarcoma Service)
- In brief, GMCCN patients with suspicious symptoms or signs or abnormal radiology will be referred by preference to Soft Tissue Orthopaedic Service at CMFT for biopsy and work up. Patients in LSCCN will be referred to the Soft Tissue Diagnostic Service at Lancashire Teaching Hospitals Trust
- Once a diagnosis of soft tissue sarcoma has been made their case will be presented at the GMOSS MDT meeting
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.5.2. Places of recommended treatment delivery

- Patients who require surgery alone and no chemotherapy or radiotherapy (e.g. low grade sarcoma)

- Limb salvage surgery– Soft Tissue Orthopaedic Service, MRI or Tumour Unit, Robert Jones and Agnes Hunt Orthopaedic Hospital Oswestry, or Onco-Plastic service, The Christie NHS Foundation Trust
 - Consultant in charge: GMOSS surgeon
- Amputation – referral to the most appropriate orthopaedic service close to the patients home
 - Consultant in charge: GMOSS Orthopaedic surgeon
- Patients who require surgery and either chemotherapy or radiotherapy or both
 - Limb salvage surgery– Soft Tissue Orthopaedic Service, MRI or Tumour Unit, Robert Jones and Agnes Hunt Orthopaedic Hospital Oswestry, or Onco-Plastic service, The Christie NHS Foundation Trust
 - Consultant in charge: GMOSS Orthopaedic surgeon
 - Amputation – referral to the most appropriate orthopaedic service close to the patients home
 - Consultant in charge: GMOSS Orthopaedic surgeon
 - Non-surgical oncology – The Christie YOU
 - Consultant in charge: GMOSS Consultant oncologist and core member of TYA MDT

8.5.3. Variations to the pathway

- LSCCN patients may be referred to the Merseyside Sarcoma Service in which case their chemotherapy and radiotherapy will be delivered at Clatterbridge Cancer Centre or Alder Hey (chemotherapy only).
- Site specific variations
 - Spinal tumours, maxillo facial and skull tumour
 - Patients will be managed between GMOSS and the most appropriate specialist spinal or neurosurgical MDT
 - Options include Neurosurgical units at Salford Royal Infirmary, Lancashire Teaching Hospitals Trust, and the spinal team at RJAH
 - Retroperitoneal sarcoma
 - Patients will be managed between GMOSS and the most appropriate specialist retroperitoneal surgical MDT
 - Options include The Christie Pelvic / Retroperitoneal surgical service
 - GI sarcoma including GIST
 - Patients will be managed between GMOSS and the most appropriate specialist TYA designated GI MDT
 - Gynae sarcoma
 - Patients will be managed between GMOSS and the most appropriate specialist TYA designated Gynae MDT
 - Head and Neck soft tissue sarcoma
 - Patients will be managed between GMOSS and the most appropriate local TYA designated specialist Head and Neck MDT
 - Breast sarcoma
 - Patients will be managed between GMOSS and the most appropriate local TYA designated specialist Breast MDT
 - Patients from LSCCN may be managed through the team at the Royal Liverpool Hospital

8.5.4. Pathway for follow-up on completion of first line therapy

- Surgical follow-up should be provided by the operating surgical team in all cases for at least 5 years
- Oncological follow-up should follow the protocols defined by GMOSS for each type of soft tissue sarcoma
- A follow-up care plan should be provided to the patient by the surgical team if no chemotherapy or radiotherapy has been given and by the oncologist if the patient has had chemotherapy or radiotherapy
- TYA MDT input outwith the involvement of GMOSS MDT members who are also TYA MDT members will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable advanced disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. For patients having surgery alone, this should be provided by the operating surgical team. For those who have had chemotherapy and or radiotherapy this should be provided by the oncologist.

8.6. Brain CNS tumours

8.6.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with CNS / brain tumours in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with CNS / brain tumours will be managed and developed by the Neuro-Oncology NSGs
- In brief, most patients will be diagnosed initially following a CT or MRI scan
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.6.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to the Neuro-Oncology service at the Christie NHS Foundation Trust for management in the PTC. Surgical treatment should be undertaken at a TYA Designated Hospital.
- Patients aged 19 – 24 from Lancs and South Cumbria Cancer Network may choose to receive their treatment at the Neuro-Oncology Service at Lancashire Teaching Hospitals Trust

8.6.3. Variations to the pathway

- None

8.6.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Neuro-Oncology NSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input out with the involvement of Neuro-Oncology MDT members who are also TYA MDT members will be:

- To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.7. Skin / Melanoma

8.7.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with skin cancer / melanoma in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with skin / melanoma will be managed and developed by the Skin NSSGs
- In brief, most patients will be diagnosed initially following a skin biopsy
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.7.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to the Skin / Melanoma MDT at the Christie NHS Foundation Trust for management in the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.7.3. Variations to the pathway

- None

8.7.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Skin NSSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.8. Gynaecological tumours

8.8.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with gynae malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with gynae cancer will be managed and developed by the Gynae Oncology NSGs
- In brief, most patients will be diagnosed initially following referral to a local gynaecological service and will then be referred to the relevant specialist gynae-oncology MDT
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.8.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to the local TYA designated Gynae Oncology MDT. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.8.3. Variations to the pathway

- None

8.8.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Gynae NSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be coordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.9. Head and Neck malignancies

8.9.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with head and neck malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with head and neck cancer will be managed and developed by the Head and Neck Cancer NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.9.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to a designated TYA specialist Head and Neck MDT. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.9.3. Variations to the pathway

- None

8.9.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Head and Neck NSSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.10. Urological tumours other than testis

8.10.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with urological malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with urological cancer will be managed and developed by the Urology NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.10.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to the local TYA designated Urology MDT. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.10.3. Variations to the pathway

- None

8.10.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Urology NSSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:

- To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.11. Upper GI malignancies

8.11.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with upper GI malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with upper GI cancer will be managed and developed by the OG / Upper GI Cancer NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.11.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to one of the local TYA designated specialist Upper GI MDTs for surgery. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.11.3. Variations to the pathway

- None

8.11.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the OG / Upper GI NSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.12. Lower GI malignancies

8.12.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with lower GI malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with lower GI cancer will be managed and developed by the Lower GI Cancer NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.12.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred one of the TYA designated lower GI MDTs for surgery. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.12.3. Variations to the pathway

- None

8.12.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Lower GI NSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.13. Hepato-biliary malignancies

8.13.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with hepato-biliary malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with HPB cancer will be managed and developed by the HPB NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.13.2. Places of recommended treatment delivery

- Patients aged 16 – 18 should be referred to one of the local TYA designated specialist HPB MDTs for surgery. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.13.3. Variations to the pathway

- None

8.13.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the HPB NSSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.14. Lung / Thoracic malignancies

8.14.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients lung / thoracic malignancies in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with lung cancer will be managed and developed by the Lung Cancer NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.14.2. Places of recommended treatment delivery

- Patients aged 16 – 18 from GMCCN should be referred to the Lung MDT at University Hospital South Manchester for surgery. Patients from LSCCN should be referred to the Lung MDT at Blackpool for surgery. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.14.3. Variations to the pathway

- None

8.14.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Lung NSSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms
- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

8.15. Breast tumours

8.15.1. Presentation, initial diagnosis and referral pathway

- No special factors apply to TYA patients with breast cancer in distinction to adult patients with these tumours. The provision for presentation and diagnosis of patients with breast cancer will be managed and developed by the Breast Cancer NSSGs
- Notification to the TYA PTC will be accepted as soon as the diagnosis has been made

8.15.2. Places of recommended treatment delivery

- Patients aged 16 – 18 from GMCCN should be referred to the local TYA designated Breast Cancer MDT for surgery. Patients from LSCCN should be referred to their local MDT in a TYA designated hospital. Any non-surgical oncology will be given at the PTC
- Patients aged 19 – 24 may choose to receive their treatment through their local MDT assuming the services are provided in hospitals designated for TYA care

8.15.3. Variations to the pathway

- None

8.15.4. Pathway for follow-up on completion of first line therapy

- Follow-up should follow the protocols defined by the Breast Cancer NSSGs
- A follow-up care plan should be provided to the patient by the oncologist
- TYA MDT input will be:
 - To offer attendance at survivorship groups, events and meetings
- In the event of relapse, if the patient is under the age of 25 then re-referral to the PTC TYA MDT is required
- Palliative care MDT input for patients diagnosed with incurable disease will be co-ordinated though the clinician most involved in the patients care up to that point. Referral will depend on the degree and severity of the patient's symptoms

- An end of treatment summary should be provided to the patient (with a copy to the GP) within 6 months of the end of treatment. This should be provided by the oncologist.

9. Patient pathways for cases involving NHS specialised Services

9.1. General pathway

- Patients diagnosed with conditions that require referral out of area for NHS specialised services (Nationally Commissioned Services) require additional co-ordination and liaison. This should not be allowed to delay referral for appropriate treatment.
- All such patients should be notified at diagnosis to the PTC as described above. In some cases the diagnosis will be made prior to referral to a national centre and in other cases the diagnosis will be made by the national centre.
- Where diagnosis is made prior to referral, the diagnosing team has the option of involving the PTC early to support the patient through diagnosis. This is preferable. In this case there are two options for arranging the referral to the national centre: either by the local hospital team or by the TYA MDT. Which is most appropriate will depend on individual details of each case

9.2. Specific tumour types

9.2.1. Female choriocarcinoma

- Patients are likely to be diagnosed through local DGH gynae services. It is likely that their case will be referred to the relevant specialist gynae oncology MDT as well as to the national centre
- The preferred national centre for TYA patients diagnosed with this condition in the GMCCN or LSSCN is the Sheffield Trophoblastic Disease Centre

9.2.2. Eye cancer

- The preferred national centre for TYA patients diagnosed with this condition in the GMCCN or LSSCN is the Liverpool Ocular Oncology Centre

9.2.3. Retinoblastoma

- The preferred national centre for TYA patients diagnosed with this condition in the GMCCN or LSSCN is the Retinoblastoma Service at Birmingham Children's Hospital

9.2.4. Primary Malignant Bone Cancer

- GMOSS is one of the nationally commissioned services for primary malignant bone cancer and is the preferred centre for TYA referrals from Greater Manchester and Cheshire Cancer Network and Lancashire and South Cumbria Cancer network in view of the easier liaison within a single team rather than managing a patient across different teams
- Historical referral pathways still lead to some patients being referred to Royal Orthopaedic Hospital, Birmingham

9.2.5. Proton Beam Therapy

- Assessment for referral to international centres for Proton Beam Therapy requires that the patient is first referred to the relevant site specific MDT (GMOSS or Neuro-Oncology). They will co-ordinate application to the national board for approval of funding to send the patient for treatment.

10. Appendix 1: TYA Notification proforma



The Christie 
NHS Foundation Trust

11. Appendix 2: Notification receipt letter



Wilmslow Road
Withington
Manchester, M20 4BX

Direct Tel: 01610918-7485
Hospital Tel: 0161 446 3000
Email: kerrie.waterhouse2@christie.nhs.uk
kerrie.waterhouse@nhs.net

Dear

Re:

Many thanks for alerting the TYA Cancer MDT of a new cancer in a patient aged 16-24 inclusive. We have received the request and will process it immediately.

We are planning to discuss the care of your patient at the Teenage and Young Adult Cancer Care MDT in the Manchester Principal Treatment Centre on --/--/---- The meeting is in YOU Seminar Room at The Christie Hospital and starts at 08:30 am for approximately one hour.

You are extremely welcome to attend the meeting, in person or by video-link if we have compatible facilities. If you wish to come please tell us, as we will prioritise the meeting to suit your timings.

Following the meeting we will send you the outcome as a summary, and inform you of the next plans to treat. If you have questions please do not hesitate to contact either:

Dr Mike Leahy, Consultant Medical Oncologist, mike.leahy@christie.nhs.uk, 0161 446 8602

Kerrie Waterhouse TYAMDT Coordinator, kerrie.waterhouse2@christie.nhs.uk, 0161 918 7485

Yours Sincerely

Dr Mike Leahy, Consultant Medical Oncologist
Kerrie Waterhouse TYAMDT Coordinator
Greater Manchester and Lancs and South Cumbria TYA MDT

13. Appendix 3: MDT Outcome letter



Clinical Referral to the Teenage and Young Adults Cancer MDT- Outcome

Patient:	<NAME>	<DOB>	<POSTCODE>
NHS Number			
Date of TYA MDT			
Diagnosis/Stage /Place of treatment			
Treatment intent and prognosis			
Current Psychosocial input	<u>Key worker</u>		<u>Named Consultant</u>
Previous MDT Discussion	<u>Name & Date of SSMDT</u>	<u>Named Consultant</u>	<u>Outcome</u>
Clinical trials	No <input type="checkbox"/>	Not eligible <input type="checkbox"/>	Offered <input type="checkbox"/> Taken <input type="checkbox"/>
TYA decision plan	Follow up MDT <input type="checkbox"/>	Support groups/contacts <input type="checkbox"/>	TYA team to contact patient <input type="checkbox"/>
Meeting notes	TYAC Registration <input type="checkbox"/> Other <input type="checkbox"/>		
TYA MDT Feedback	GP <input type="checkbox"/>	Site Specific MDT <input type="checkbox"/>	Referring Hospital <input type="checkbox"/> Other <input type="checkbox"/>
Wallace Class	<input type="checkbox"/> 1 - Simple (single simple surgery or low risk chemo); <input type="checkbox"/> 2 - Medium (combination chemo +/- low dose cranial irradiation); <input type="checkbox"/> 3 - Complex (standard dose RT or intensive chemotherapy)		
Specific patient issues			
	<u>Name</u> Kerrie Waterhouse-TYAMDT Coordinator -0161-718-7485 Dr M Leahy-TYAMDT Lead Consultant	<u>Signature</u> 	18/05/12

