



National Cancer Action Team  
Department of Palliative Medicine  
St Thomas' Hospital  
London SE1 7EH  
Tel: 020 7188 4728/35  
Fax: 020 7188 4727

**To: Directors, Specialised Commissioning Groups**  
**cc: Cancer Network Directors**  
**Cancer Network Medical Directors**  
**Cancer Leads for SCGs**

Dear Colleague

**8th September 2008**

**Improving Outcomes in Children and Young People with Cancer  
Guidance on Commissioning Services for Young People – Gateway reference 10393**

We are writing to highlight the circulation of the attached guidance document, "Key messages for Commissioners of Cancer Services for Teenagers and Young Adults" Principal Treatment Centres, Multidisciplinary Teams and Shared Care for Young People with Cancer".

This has been developed at the request of the Children and Young People Improving Outcomes Guidance (CYPIOG) Advisory Group, that we jointly chair, to support the implementation of National Institute of Health & Clinical Excellence (NICE) Improving Outcomes for Children and Young People with Cancer guidance, as it pertains to teenagers and young adults; a small but in many ways uniquely vulnerable group of cancer patients. This document has been developed by the National Cancer Action Team, with advice and support from an expert working group and has been reviewed by clinicians from different disciplines as well as Specialised Commissioners and Cancer Network Leads.

This is a particularly complex and challenging area, and it is key for you to note this may require new clinical collaborations that cross cancer site-specialised practice models, and adult and paediatric services. This may lead to changes to existing ways of working for a number of clinical teams, and we are aware of some concerns about establishing these new models of care. However, the need for all young people with cancer patients to benefit from the expertise of both site-specific multidisciplinary teams (MDTs) and the new Teenage/Young Adult MDTs and have unhindered access to an age-appropriate care environment and psychosocial support is an essential aspect of the NICE Improving Outcomes for Children and Young People with Cancer Guidance.

Specialised Commissioning Groups are currently working with Cancer Networks to produce a summary about how they intend to configure and commission services for their area to comply with the NICE Improving Outcomes Guidance's recommendations. A copy of the summary will be submitted to the Cancer Action Team by the end of September 2008. The attached guidance is to be considered as a supplement to the NICE recommendations, and we believe it will provide a useful tool in developing local implementation plans to deliver high quality services for young people with cancer.

Yours sincerely,

**Mike Richards**  
National Cancer Director

**Sheila Shribman**  
National Director for Children

**DH INFORMATION READER BOX**

Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
<b>Clinical</b>	Social Care / Partnership Working

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<b>Gateway Reference</b>	10393
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<b>Circulation List</b>	Cancer Network Directors, Cancer Medical Directors, Cancer Leads for Specialised Commissioning Groups & SHA Cancer Leads
<b>Description</b>	Key messages to support commissioners when commissioning and developing cancer services for teenagers and young adults in line with guidance from the National Institute for Health and Clinical Excellence.
<b>Cross Ref</b>	Cancer Reform Strategy NICE Improving Outcomes Guidance for Children and Young People
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<b>Contact Details</b>	Debra Young Cancer Policy Team 411 Wellington House 133-155 Waterloo Road London , SE1 8UG 020 972 4802
<b>For Recipient's Use</b>	



**National Cancer Action Team**

## **Improving Outcomes for Children and Young People with Cancer**

### **Key Messages for Commissioners of Cancer Services for Young People.**

#### **Key Principles**

In order to provide equitable access to services that are compliant with the National Institute of Health and Clinical Excellence's Improving Outcomes Guidance for Children and Young People with Cancer, it is strongly recommended that the following principles be applied when commissioning cancer services and care pathways for young people with cancer.

- All patients aged 16-18 years inclusive should be referred to a Principal Treatment Centre (Young People) for treatment.
- All patients aged 19-24 years inclusive should be offered referral to a Principal Treatment Centre (Young People) for treatment.
- All patients aged 16-24 years inclusive should be discussed at both a site-specific MDT meeting and a TYA MDT meeting.
- Referral of patients to a PTC (Young People), or review by both a site-specific and a TYA MDT should not be allowed to delay the start of urgent cancer treatment.
- For each patient, a lead medical clinician should be identified, who will have overall responsibility for their treatment.
- The provision of treatment on a shared care basis is not precluded in delivering CYPIOG-compliant services for young people. These arrangements should be developed in partnership with the PTC (Young People) and agreed by commissioners.
- The TYA MDT at the PTC (Young People) should have a role in coordinating treatment, psychosocial care and peer contact/support for young people wherever they are treated.
- It is recognised that all the core defining services required of a PTC (Young People) may not be available in a single location. Provision of PTC services may involve more than one Trust, but these should not cross city boundaries.
- Robust arrangements should be in place for planned transition between children and young people's services and between young people's and adult services.

## **Key Messages: Principal Treatment Centres**

1. Principal Treatment Centres (PTC) for Young People hosting the Teenage and Young Adult (TYA) multidisciplinary team (MDT) will need to be in locations where established services for the cancers that predominate in this age group (lymphoma, leukaemia, testicular/germ cell tumours, brain/CNS tumours and sarcoma), adult site-specific MDTs and a PTC (children) exist within the same city. Ideally all these services would be located in a single hospital Trust but where this is not possible, robust local solutions to support sustainable CYPIOG-compliant services will be required.
2. The lower age range and geographical area covered by the PTC (young people) will need to be locally determined to dovetail with the upper age range of teenagers cared for in the linked PTC (children). There should not be gaps between the two age ranges, and reasonable flexibility at the age boundaries will be required to enable place of care decisions to be made in the best interest of individual patients. All Trusts will need to ensure that they comply with guidance on safeguarding vulnerable children and young people.
3. PTCs will need to have an age-appropriate cancer facility (not with younger children or much older adults) with sufficient activity to develop and sustain an IOG-compliant TYA haematology/oncology workforce capable of delivering the most complex and intensive chemotherapy regimens, and an on-site intensive care unit that provides critical care services for the PTC's defined age range.
4. There will need to be very careful and close collaboration between the PTC and with other adult Cancer Centres within each designated regional area. Due to the small numbers of young people with any single cancer type, it is highly unlikely that any transfer of activity to the PTC will render any adult cancer service unsustainable.
5. The PTC will have a co-ordinating function for MDT review and notification to national TYA cancer registry, treatment, psychosocial support and peer contact/support for young people with cancer. All young people will have access to treatment at the PTC. Agreed pathways of care will be needed to ensure such access is commissioned and delivered.

**Key Messages: Multidisciplinary Teams**

6. All teenagers and young adults aged 16-24 inclusive will be discussed both at a site-specific MDT meeting and a TYA MDT meeting. Depending on local service configuration, in some PTCs the age range for the TYA MDT may include teenagers aged 13-15 years. The diagnosis and treatment plan for young people will be determined in the site-specific MDT meeting, and discussed and agreed with a TYA MDT, using jointly agreed treatment/care pathways for the most common clinical situations. The TYA MDT will additionally direct and advise on all other aspects of care for young people. The order in which these MDT discussions take place is less important than the communication, collaboration and joint decision-making between the MDTs. Clear lines of medical responsibility should be documented for each individual patient.
7. The core TYA MDT will include at least one medical representative of each of the most commonly related site-specific MDTs, i.e. sarcoma, lymphoma/leukaemia, germ cell tumours, brain/CNS tumours and paediatric tumours. Outside these tumour groups, joint diagnostic/treatment planning discussions will usually take place at the relevant site-specific MDT meeting with representation from the TYA MDT. MDTs will need to be adequately resourced to achieve this.
8. Coordinating the development and delivery of agreed patient-specific treatment plans for all teenagers and young adults with cancer is an important function of the TYA MDT, and will require setting up appropriate systems for joint working, combining expertise and establishing the optimum place or places of care, in close collaboration with all relevant site specific MDTs and the children's cancer service.
9. Each Children and Young People's Network, area will need to develop and agree guidelines for referral of young people by primary care practitioners to site-specific or TYA MDTs that are specific to the configuration of services and MDTs in the area. These will need to be consistent with the NICE Referral Guidelines for Suspected Cancer (June 2005)
10. To avoid diagnostic and treatment delay, mechanisms for rapid notification of all newly diagnosed young people to the PTC will need to be developed to ensure timely discussion at a TYA MDT meeting.

11. The TYA MDT grouping that addresses psychosocial issues throughout the treatment pathway should meet separately from the TYA diagnostic/treatment planning MDT meeting, although at least one person (e.g. a CNS) should be a core member of both, with a particular responsibility for ensuring psychosocial issues are considered in treatment planning. Arrangements for discussing ongoing treatment management, late effects and palliative care will be developed locally at the PTCs by the TYA MDT.

**Key Messages: Shared Care**

12. A single PTC (young people) is likely to operate shared care with both child and adult services. Consistency between the levels defined for child and adult-based shared care services is important for practical reasons, for clinical governance and to ensure that young people are not disadvantaged by the age limits of local services. It is proposed that the levels of shared care for children's services are extended, to develop a parallel framework for shared care for young people with adult services. An illustration of how these levels may be applied to TYA cancer services is provided below.
13. Radiotherapy for young people aged over 16yrs that are under the care of the PTC may be administered in a specified local radiotherapy centre if there is close clinical collaboration and agreement on treatment delivery between the site-specific clinical oncologist at the PTC (young people) and the appropriate site-specific clinical oncologist at the local service. Patients should be offered a choice of location for radiotherapy in these instances, and all should have access to age-appropriate support via the TYA team based at the PTC.
14. Young adults aged 19 and above may make an informed choice to receive all their cancer treatment in adult services outside a PTC (Young People). Such arrangements are acknowledged and supported as 'TYA Network Partnership' care, within Level 3 shared care. These patients will be notified to the TYA MDT at the PTC (young people) at the earliest opportunity, and their treatment and care plan will be discussed and agreed with the TYAMDT. Treatment will be delivered within the local adult cancer service under the direction of an appropriate site-specific MDT, according to jointly agreed treatment care/pathways, with ongoing communication and liaison with the PTC. TYA psychosocial MDT members (e.g. Young People's Social Worker, Youth Worker/Activity Co-ordinator and TYA CNS) will work in support

of the local MDT key worker to enable these young people to access age-appropriate psychosocial support whenever needed.

15. Whereas children in a paediatric oncology shared care unit are automatically cared for in an age-appropriate environment, this will be more difficult in adult wards providing shared care for young people. Implementation of this IOG should provide an additional lever for change, to ensure that in-patient and outpatient areas providing care for patients under the age of 19 years are included in each Trust's strategy for delivering the National Service Framework for Children and Young People, Standards for Hospital Services (March 2007).

**Endnote:**

**Equality Impact Assessment (EQIA)**

*This commissioning guidance supports the development of age appropriate services for teenagers and young adults. It will help to redress inequalities in provision of services for this group of patient, which has been highlighted in both the Cancer Reform Strategy EQIA and the Manual for Cancer Services EQIA as an area for improvement.*

### Levels of Shared Care with Adult Services for Young People with Cancer

Level	Core Components
<p><b>Level 1 Shared Care</b></p>	<p><b>Inpatient supportive care:</b> Examples - febrile neutropaenia management, non-neutropaenic infections, enteral feeding support, rehabilitation support, local palliative care support.</p> <p><b>Outpatient supportive care:</b> Examples - Central line flushes, re-pass NG tubes, blood product support.</p> <p><b>Outpatient clinic:</b> May include interim assessments, short and long term follow-up, dispensing of oral chemotherapy and dose adjustment within agreed guidelines</p> <p>Blood sampling &amp; testing: As required for patient monitoring and clinical trials.</p> <p><b>Bolus I.V. chemotherapy</b></p> <p><b>Multidisciplinary “Treatment Management” meetings at least monthly</b></p> <p><b>Exclusions – Day Case infusion chemotherapy, in-patient chemotherapy and all exclusions listed in Level 3</b></p> <p><i>Opting out of any of the above criteria may be locally agreed between PTC, SCU and commissioners, in exceptional circumstances. The decision may be based on adequacy of experienced 24-hour medical cover.</i></p>
<p><b>Level 2 Shared Care</b></p>	<p><b>All the components within level 1 and in addition, day case infusion chemotherapy.</b></p> <p><b>Multidisciplinary “Treatment Management” meetings at least fortnightly</b></p> <p><b>Exclusions – in-patient chemotherapy and all exclusions listed in Level 3</b></p> <p><i>There is no allowance to opt out of components in Level 2.</i></p>
<p><b>Level 3 Shared Care</b></p>	<p><b>All components within Level 2 and in addition, in-patient chemotherapy regimens requiring 24-hour hospital care.</b></p> <p><b>Weekly multidisciplinary “Treatment Management” meetings.</b></p> <p><i>There is no allowance to opt out of components in Level 3.</i></p> <p><b><u>Specific exclusions</u> to Level 3 shared care, include:</b></p> <ul style="list-style-type: none"> <li>▪ <b>Final diagnosis and determination of treatment plan</b> – this must be discussed with TYAMDT</li> <li>▪ <b>Complex &amp; hazardous chemotherapy regimens</b> - as specified by</li> </ul>

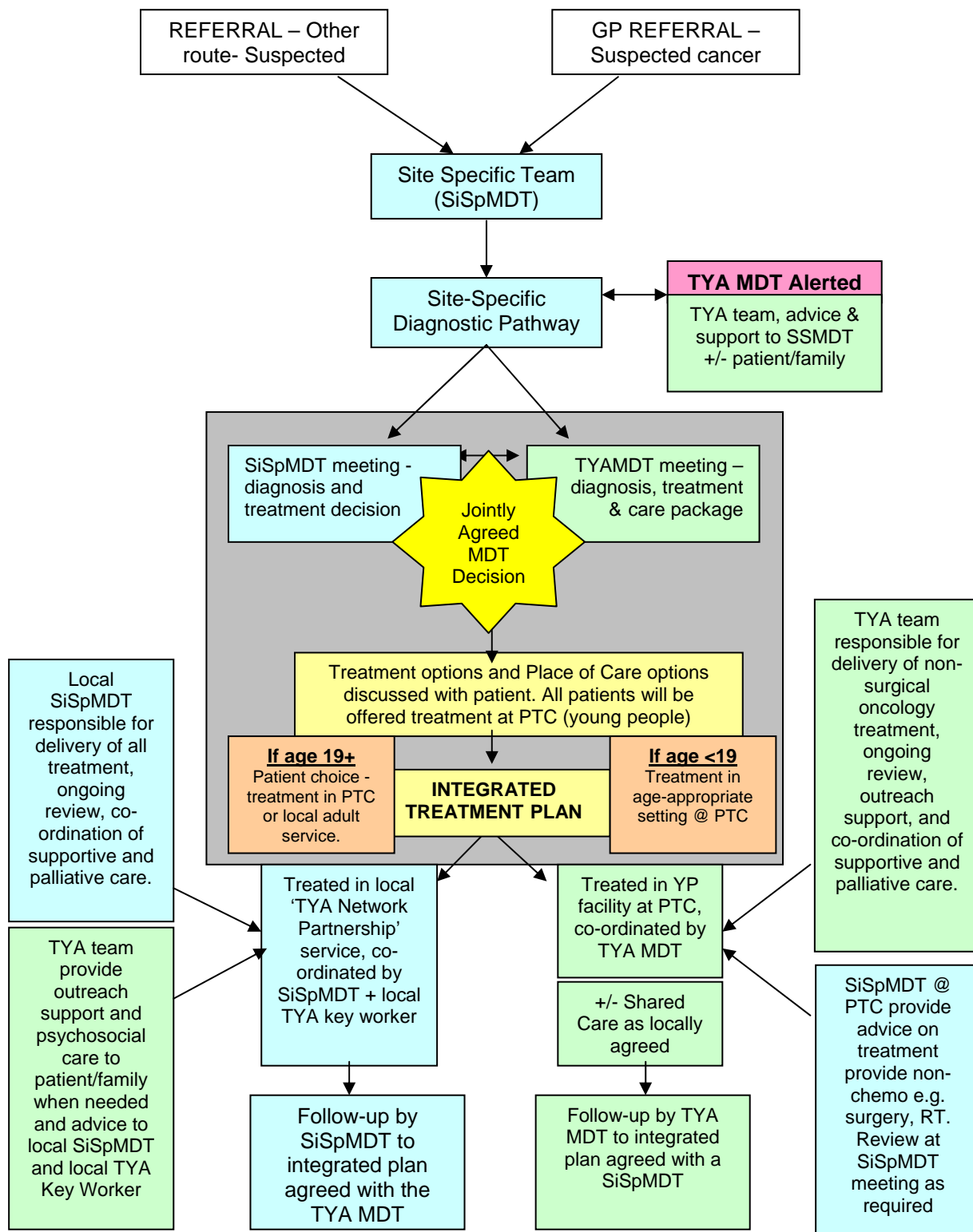
<p><b>Level 3 continued</b></p>	<p>the PTC/Network, that require expertise, monitoring, or resources unavailable at a particular SCU.</p>
<p><b>TYA Network Care</b></p>	<p><b><u>“Opt-ins”</u></b></p> <p><b>1. Provision of an intrathecal chemotherapy administration service in full compliance with National (HSC 2003- 010) &amp; Local Guidance. Only to be provided with agreement of PTC.</b></p> <p><b>2. TYA Network Care – where patients aged 19 and over, having been offered referral for treatment at a PTC, make an informed decision to receive all of their treatment in local adult services, under the direction of an appropriate site-specific MDT. This must be delivered only in services that have been specifically identified by commissioners, and are supported by the PTC. Treatment and care is provided in adult cancer services following individual case discussion, to a treatment plan agreed by the local site-specific MDT and the TYA MDT at the designated PTC (Young People).</b></p>

<p><b>PTC</b></p> <p><b>Young People’s Principal Treatment Centre</b></p>	<p><b>Definitive diagnosis and determination of treatment plan via a designated MDT as outlined in NICE IOG for CYP with Cancer Table 4, 5, 6, 9, &amp; 10, decision-making regarding treatment delivery at PTC or Shared Care Unit, supervision and direction of care within Shared Care arrangements.</b></p> <ul style="list-style-type: none"> <li>▪ <b>Teenage/Young Adult specific “Diagnosis”, “Treatment Management”, “Psychosocial Support”, “Palliative Care” and “Late Effects” MDTs as defined in the IOG (pgs 91-94).</b></li> <li>▪ <b>PTCs may provide secondary, tertiary and/or quaternary services.</b></li> <li>▪ <b>Administration of the full range of chemotherapy treatment regimens available in the UK for young people on phase III clinical trials, standard treatment regimens, and for those young people whose disease does not have a recognised standard treatment.</b></li> <li>▪ <b>Provision of an intrathecal chemotherapy administration service in full compliance with National (HSC 2003- 010) &amp; Local Guidance.</b></li> </ul>
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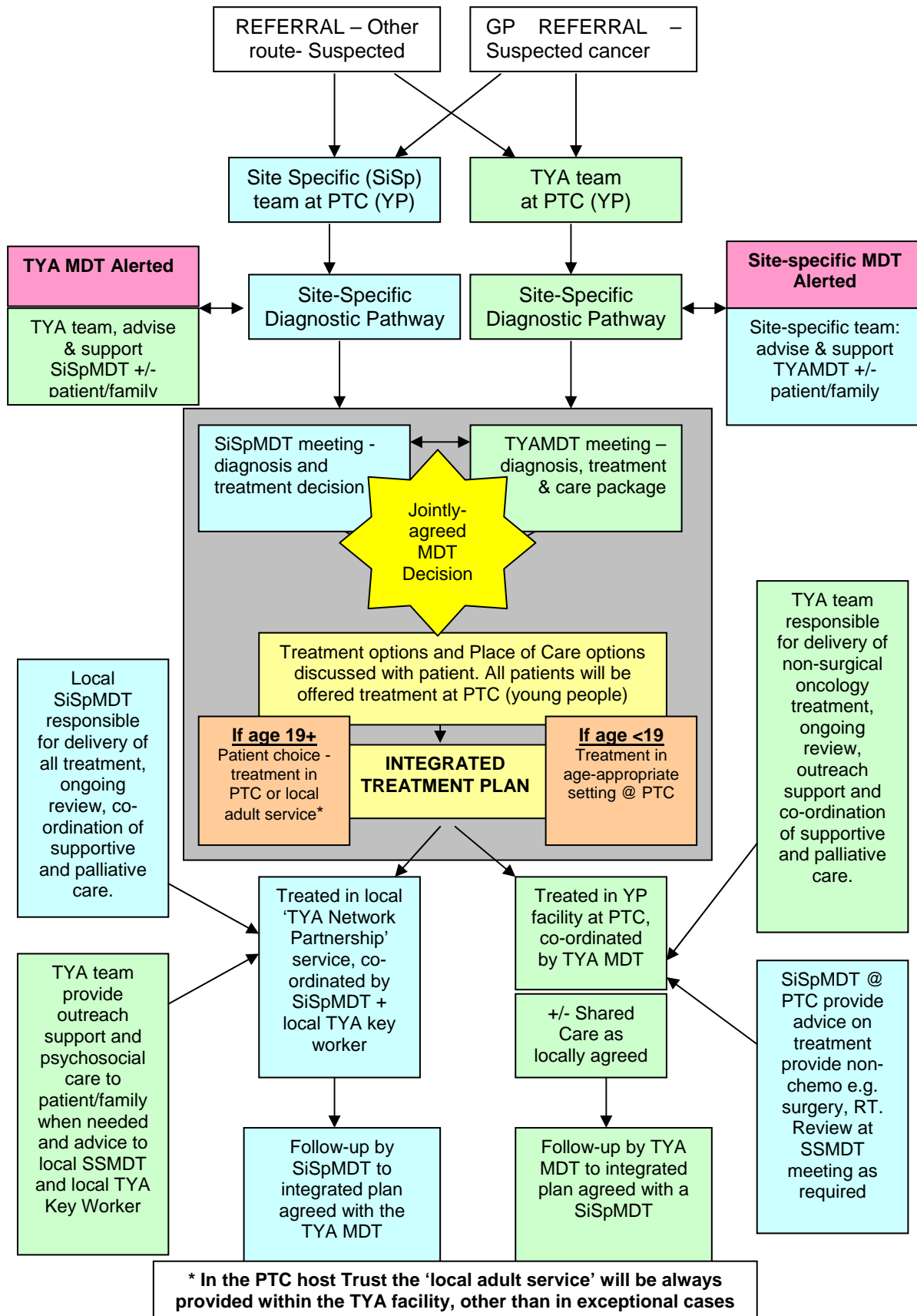
<b>PTC continued</b>	<ul style="list-style-type: none"><li>▪ <b>Site-specific adult, or paediatric oncology surgery:</b> or referral to supra-regional surgical services for conditions as indicated in IOG p43.</li><li>▪ <b>Site-specific adult, or paediatric radiotherapy</b> service for radical and palliative radiotherapy.</li><li>▪ <b>High dependency care:</b> access to High dependency ward care and Intensive Care services for teenagers.</li><li>▪ <b>Supportive care</b> for chemotherapy, radiotherapy, surgery &amp; palliative care.</li><li>▪ <b>Co-ordination of rehabilitation services</b> for young people affected by cancer, either within the PTC host Trust, or through other Acute Trusts or Primary Care Trusts.</li><li>▪ <b>Outreach nursing services: to support shared care and palliative care in liaison with community</b> nursing teams /palliative care team</li><li>▪ <b>Recruitment and co-ordination of care for young people on Phase I &amp; Phase II clinical trials</b></li><li>▪ <b>Allogeneic and autologous stem cell transplantation services:</b> if JACIE accredited or pending accreditation.</li></ul>
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**ILLUSTRATIONS OF EXAMPLE CARE PATHWAYS**

**Example A. Patient aged 16-24yrs Referred to a Site-specific MDT that is NOT based at a Principal Treatment Centre (Young People)**



**Example B – Patient aged 16-24 years Referred to a TYA MDT or Site-Specific MDT that IS based at a Principal Treatment Centre (Young People)**



## **Definitions**

### **Age Range**

In the National Service Framework, children and young people are defined as under 19 years. However it acknowledges the age ranges for service provision will vary according to the different agencies' statutory obligations. The scope of the NICE Guidance Improving Outcomes for Children and Young People with cancer included young people with cancer into their early twenties, and this has been further clarified to include those aged 24 years.

In this document all age ranges given are inclusive, 'under' an age means up to that year birthday, and 'over' an age means from the date of that year birthday.

### **Multidisciplinary Teams**

A distinction is made between a multidisciplinary team, and a multidisciplinary team meeting; the diagnostic/treatment planning meeting fundamental to the safe delivery of cancer services, commonly referred to in adult services as 'the MDT'. In this document where 'MDT' is used it refers to a team of people, an MDT meeting is described as such.

### **Note on Choice of Place of Care for Young People**

It has become apparent that providing support for patient choice over place of care is fundamental in underpinning implementation of the IOG as it relates to young people aged 19-24 years inclusive. A nationally-available core of decision-making support materials will be developed for use by all clinical teams who are caring for these young people around the time of their diagnosis, to deliver the 'unhindered access' to age-appropriate care and support provided by the PTC (young people), required by the IOG.