

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

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

#### **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 young people e.g. in relation to child protection.
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 be the co-ordinating centre for intensive 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.

## **Multidisciplinary Teams**

6. All Teenagers and Young Adults aged 15-24 inclusive will be discussed at a TYAMDT meeting. In order to ensure that all patients benefit from site-specific expertise, they will also need to be discussed at an appropriate site-specific MDT meeting. The order in which these MDT discussions take place is less important than the communication, collaboration and joint decision-making between the MDTs.
7. Site-specific MDTs will direct and advise the TYA MDT on diagnosis and treatment for young people in their area of expertise. The TYA MDT will direct treatment delivery and care planning for all young people in their care.
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. There is an expectation that the core TYA MDT should include representatives 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 need to take place either at the relevant site-specific MDT meeting or a TYAMDT meeting. MDTs will need to be adequately resourced to achieve this.
10. 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)
11. To avoid diagnostic and treatment delay, all site specific MDTs will need to develop mechanisms for rapid notification of all newly diagnosed young people to the PTC to ensure timely discussion at a TYA diagnostic and treatment planning MDT meeting.

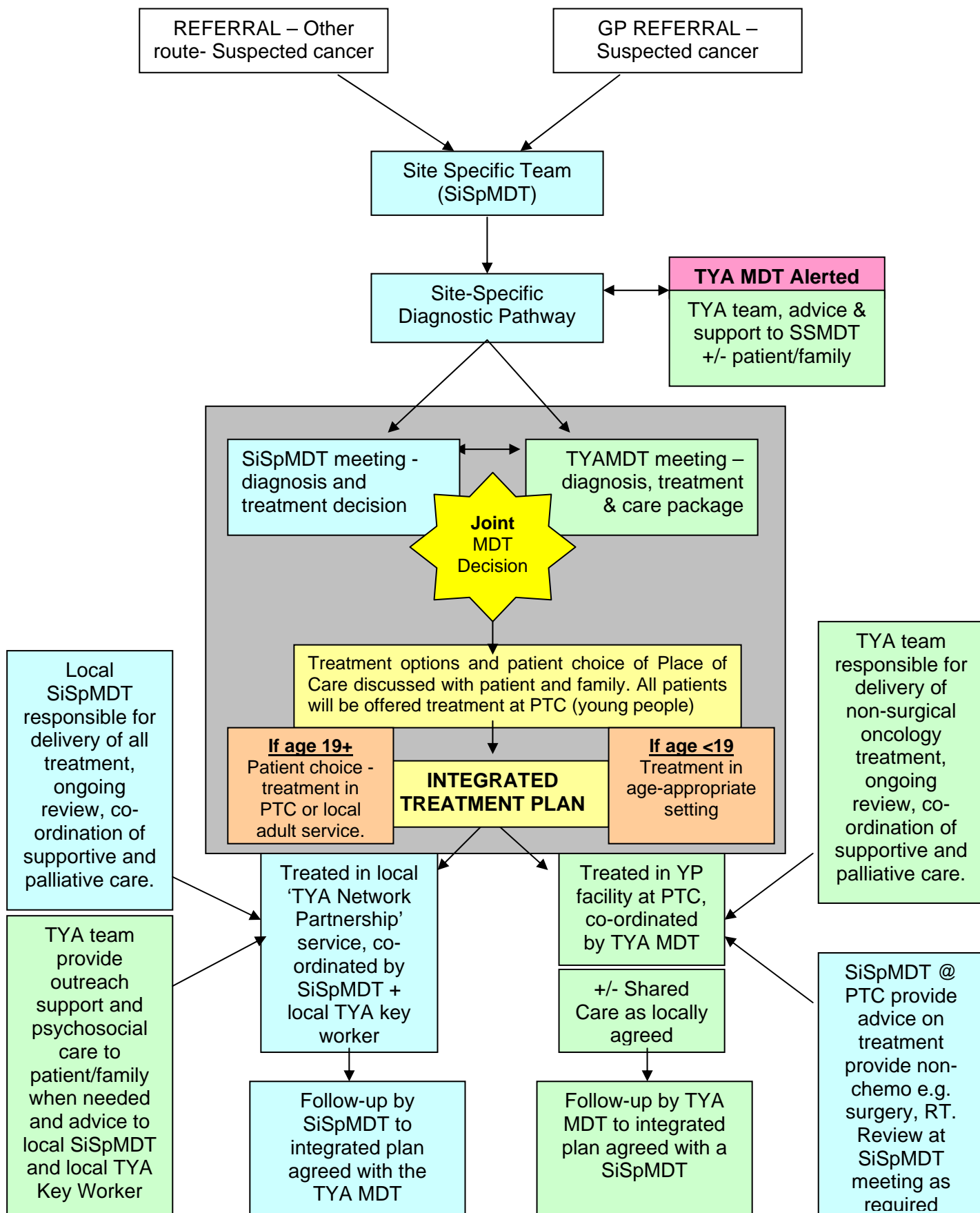
12. The TYA MDT grouping that addresses psychosocial issues should meet separately from the TYA diagnostic/treatment planning MDT meeting, and arrangements for discussing ongoing treatment management, late effects and palliative care will be developed locally at the PTCs by the TYA MDT.

### **Shared Care**

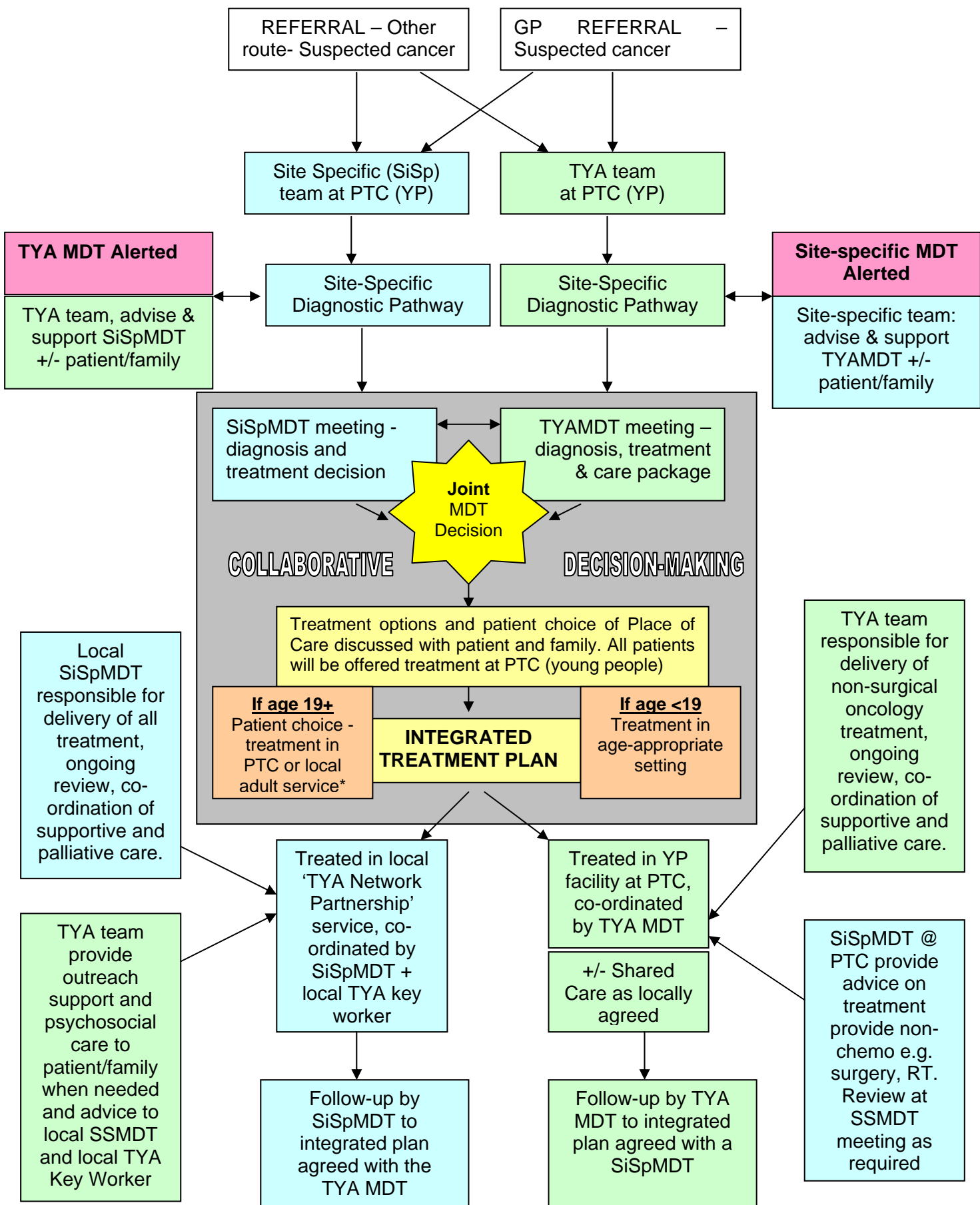
13. A single PTC (young people) is likely to operate shared care with both children's and adult services. Consistency between the levels defined for child and adult-based shared care services is important for practical reasons, for clinical governance and to ensure that young people are not disadvantaged by the age limits of local services. It is proposed that minimal changes are made to the framework of agreed levels of shared care for children's services, to develop a parallel framework for shared care with adult services.
14. A significant difference is that 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 within the scope of TYA Level 3 shared care and described as 'TYA Network Partnership' care in this document. These patients will be notified to the PTC (young people) for discussion in the TYAMDT, and their treatment and care plan will be determined jointly by the TYAMDT and the site-specific MDT in the patient's local treating hospital. Treatment will be delivered within the local adult cancer service under the direction of the local site-specific MDT. TYA MDT outreach from the PTC (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. All in-patient and outpatient areas that provide care for patients under the age of 19 years need to be included in the Trust's strategy for delivering the National Service Framework for Children and Young People, Standards for Hospital Services (March 2007).

### 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)**



\* In the PTC host Trust the 'local adult service' will be always provided within the TYA facility, other than in exceptional cases of patient choice.