

Manual for Cancer Services Teenage and Young Adults Measures

Version 1.0



VERSION CONTROL SHEET

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TYA MEASURES

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National Cancer Peer Review and The Manual for Cancer Services

1 Introduction

The National Cancer Peer Review Programme provides important information about the quality of clinical teams and a national benchmark of cancer services across the country. It aims to improve care for people with cancer and their families by:

- ensuring services are as safe as possible;
- improving the quality and effectiveness of care;
- improving the patient and carer experience;
- undertaking independent, fair reviews of services;
- providing development and learning for all involved;
- encouraging the dissemination of good practice.

The benefits of peer review have been found to include the following:

- provision of disease specific information across the country together with information about individual teams which has been externally validated;
- provision of a catalyst for change and service improvement;
- identification and resolution of immediate risks to patients and/or staff;
- engagement of a substantial number of front line clinicians in reviews;
- rapid sharing of learning between clinicians, as well as a better understanding of the key recommendations in the NICE guidance.

The Manual for Cancer Services is an integral part of Improving Outcomes: A Strategy for Cancer and aligns with the aims of the Coalition Government: to deliver health outcomes that are among the best in the world. The Manual supports the National Cancer Peer Review quality assurance programme for cancer services and enables quality improvement both in terms of clinical and patient outcomes. The Manual includes national quality measures for site specific cancer services together with cross cutting services such as chemotherapy and radiotherapy.

The Report of Mid Staffordshire NHS Foundation Trust Public Inquiry (Robert Francis Jan 2013) said the creation of a caring culture would be greatly assisted if all those involved in the provision of healthcare are prepared to learn lessons from others and to offer up their own practices for peer review. Whilst peer review will have a specific relevance in cases of practitioners where there may be concerns about substandard performance, it has a far more fundamental role in changing behaviour to ensure a consistent and caring culture throughout the healthcare services. Peer review therefore needs to be a key part of the delivery and monitoring of any service or activity, and those involved need to demonstrate that this element of monitoring and learning is integral to the process of compliance with fundamental standards and of improvement. Among the recommendations made is recommendation 49, Enhancement of monitoring and the importance of inspection, which states;

Routine and risk-related monitoring, as opposed to acceptance of self-declarations of compliance, is essential.

The Care Quality Commission should consider its monitoring in relation to the value to be obtained from:

- The Quality and Risk Profile;
- Quality Accounts;
- Reports from Local Healthwatch;
- New or existing peer review schemes;
- Themed inspections.

1.1 National Cancer Measures

The development of cancer measures is a dynamic process in order to:

- reflect new NICE Quality Standards and clinical guidelines and revisions to existing NICE guidance;
- allow greater influence by users of cancer services and their carers;

- allow greater influence by clinicians;
- take account of possible modifications to measures following peer review visits;
- ensure the scope of measures encompasses the broader implementation of the Improving Outcomes: A Strategy for Cancer;
- reflect new developments and initiatives in treatment and patient care;
- reflect the NHS Commissioning Board specialised service specifications.

1.2 Clinical Indicators/ Outcomes

Peer review is changing its emphasis to focus on both clinical and patient outcomes. In order to achieve this, clinical indicators have been introduced and form part of the review process along with a reduced number of structure and process measures.

2 Interpretation of the National Manual for Cancer Services

2.1 Guidance Compared to Cancer Measures

National guidance is exactly what it says - guidance in general and indeed is excellent for this purpose. Guidance involves giving advice and recommendations on how things should be done now, in the future and sometimes on how things should have been done for sometime already. It may involve describing in effect the "perfect" service, using phrases like "the best possible", "to all patients at all times", etc. It may involve all-inclusive, far-ranging objectives and aspirations involving many agencies in long, interlinked chains of events and tasks which all have to be fulfilled before the desired outcome of the guidance is achieved. A particular person's accountability for each task is often not stated. Without this underlying type of mind-set guidance would not inspire, lead, motivate or guide and would probably be almost unreadable.

The Manual for Cancer Services has to take a different approach. It is written for the specific purpose of being used to assess a service; to aid self assessment and team development; to be fair compared to visits to other services elsewhere and to past and future visits to the same service. Therefore, the measures have to:

- be objective;
- be measurable;
- be specific, clear and unambiguous;
- be verifiable;
- state who exactly is responsible for what;
- be discriminating;
- be achievable;
- be developmental - encourage continuous quality improvement and not produce destructive competition or a sense of failure.

2.2 "The Responsibility for Assessment Purposes"

This refers to the fact that someone, or some group, is always held nominally responsible for compliance with each one of the quality measures. This has to be specified or, in terms of organising the peer review and collecting the results, it would be unclear who was being held as compliant or non-compliant or who the results could be attributed to. Where it is unclear who has responsibility there tends to be inertia. This attribution of responsibility does not necessarily commit a given person to actually carrying out a given task - this can be delegated according to local discretion, unless it is clear that a given task really is limited to a certain group.

2.3 "Agreement"

Where agreement to guidelines, policies etc. is required, this should be stated clearly on the cover sheet of the three key documents including date and version. Similarly, evidence of guidelines, policies etc. requires written evidence unless otherwise specified. The agreement by a person representing a group or team (chair or lead etc.) implies that their agreement is not personal but that they are representing the consensus opinion of that group.

2.4 Confirmation of Compliance

Compliance against certain measures will be the subject of spot checks or further enquires by peer reviewers when a peer review visit is undertaken. When self assessing against these measures a statement of confirmation of compliance contained within the relevant key evidence document will be sufficient.

2.5 "Quality" Aspects of Cancer Service Delivery

The peer review process recognises the qualitative as well as quantitative aspects of review and in addition to the objective recording of compliance against the measures there is a narrative part to the report that provides an overall summary of a team's performance.

Manual for Cancer Services On-line

An on-line version of the Manual for Cancer Services has been developed. The on-line version allows individuals to identify and extract measures by tumour site, organisation type and subject area in a variety of formats.

The on-line manual can be accessed from the CQuINS web site at <http://www.cquins.nhs.uk>

TEENAGE AND YOUNG ADULT CANCER MEASURES

Introduction

The NICE Guidance on Improving Outcomes in Children and Young People with Cancer (the CYPIOG), requires a set of arrangements to be made for the age group of patients, from 16 to their 25th birthday, for the diagnosis and management of cancer. For the purposes of the measures and peer review, this age group will be considered to be the 'teenage and young adult' group (TYAs). The measures do not prevent patients in the lower part of this age range being treated within children's services if they so wish and if this is compatible with local agreements.

The arrangements for TYAs differ in some aspects, both from the requirements for children and also those for the rest of the adult population. One of the key added values intended to flow from these arrangements is the provision of an age-appropriate environment and support network for these patients, some of whose needs are rather specific to people at this time of life as they make the transition from childhood to adulthood. Another reason for certain needs being specific to this age group is the fact that cancer is in general a rarity in this group and therefore the patients become a rarity amongst their peers. These specific needs are both psychosocial and physical.

The spectrum of cancer types in this group covers firstly a large proportion of the patients who suffer from one or other of a small group of cancer types which, although relatively rare in the overall population, are amongst the commonest cancers in this age group. Secondly, there are a minority who develop one of the many cancer types typical of older adults but for various reasons they occur in this situation at an unusually young age.

One issue for implementing the service changes for young adults, as recommended by the CYPIOG, is to achieve the advantages of an age-appropriate environment and support network but without losing the advantages which have come in adult cancer treatment, associated with implementing the various site-specific IOGs and their accompanying practice constraints and changes. This is covered in the measures by a set of requirements for the relevant practitioners.

The Shape of the Service

- Teenage & Young Adult Cancer has been defined as a prescribed specialised service and is commissioned according to a national service specification by NHS England. The service specification reflects the measures below.
- Outside the remit of the measures and peer review, there has been a prior agreement with area teams that there should be one TYA principal treatment centre (TYA PTC) sited in the same city as the facilities of each children's PTC, with one associated TYA MDT. This is for practical considerations concerning the scale and efficiency of provision of facilities.
 - *Note: Hereafter, in this document, the TYA PTC will simply be referred to as the PTC.*
- There is a recommendation for PTCs to have certain minimum requirements for staff and to have dedicated inpatient and day case facilities.
- By analogy with the children's measures, and for similar reasons of organisation there is a requirement for an overall co-ordinating group for the teenage and young adults' cancer network (TYACN). This group is termed, for the purpose of peer review, the teenage and young adults' cancer network coordinating group (TYACNCG). The CYPIOG specifies that there should be coordination of commissioning across the whole pathway. For TYA patients, the TYACNCG fulfils this requirement to support coordination, including designation of services and consistency of policies.
- The concept of the TYA MDT, using that term, has entered common usage, but its function is different to that of the purely site specific MDTs in the adult cancer measures and the diagnostic and treatment MDT in the children's measures. Thus not all of the measures which apply to these MDTs apply to the TYA MDT and some aspects of the measures are unique to the TYA MDT.
- There are a number of guidelines and pathways needed to be locally agreed covering the following aspects of the service.
 - referral guidelines;
 - sharing of care between the PTC and treatment facilities in other hospitals;
 - sharing of responsibility for patient management between the TYA MDT and site specific MDTs;
 - sharing of follow up between the MDT and other MDTs.
 - These guidelines and policies are addressed in the measures by a requirement to agree patient

pathways for TYAs.

- There are measures for site specific MDTs and network groups regarding the way they approach the management of TYAs.
- The TYACNCG is required to designate certain hospitals outside the PTC which are the hospitals to be recommended to TYAs of 19 to their 25th birthday, should they choose not to be treated in the PTC. TYAs in this age group should be treated either in the PTC or a designated hospital. The hospitals so designated will be subject to a set of specific measures for TYA designated hospitals. These measures in effect form the minimum criteria for designated hospitals. The TYACNCG at their discretion may define additional criteria (not in the measures) by which to aid their designation process. Any hospital may be put forward for designation by the TYACNCG. Hospitals which are neither host hospitals of a PTC nor TYA designated hospitals will still be subject to all relevant measures in the rest of the Manual of Cancer Services, as will the PTC and designated hospitals. In particular, this includes the 'adult' chemotherapy and acute oncology measures.
- Patients from 16 to the end of their 18th year should be treated in the PTC
- Exceptions to these pathways for TYAs may arise in cases of very rare clinical situations, requiring management by national services provided for under the NHS Highly Specialised Services specifications and arrangements. There is a measure for the TYACNCG to agree pathways for these patients with the relevant highly specialised services.

All new patients in the TYA age range should be notified to the TYA MDT and have a joint treatment planning decision between the TYA and site specific MDTs, even those who decline all the TYA-focussed provision outlined below, and choose treatment in a non-designated hospital.

- All the TYAs of the age range 19 to their 25th birthday should be offered the choice of treatment in the PTC or if they prefer, and if the relevant service is available, treatment in one of certain TYA designated hospitals outside the PTC. Patients in this age range should be treated in either the PTC or a designated hospital. These designated hospitals (and only these, out of the various hospitals outside the PTC) are required to provide certain additional features (in addition to those required by any other relevant cancer measures) for the special benefit of TYAs being treated for malignancy. Thus, only the designated hospitals should be put forward for review against the specific measures for designated hospitals in section [14-1D-1z](#).
- The PTC, as the specialist centre for TYA treatment, is put forward for review against its own specific set of hospital TYA measures, in section [14-7D-100](#) which are more rigorous and extensive than those for the designated hospitals. It is assumed that certain aspects of a patient's care may be shared across PTC and designated hospital providers, with agreement between providers as long as this is in compliance with the site specific and other relevant cancer measures such as those for chemotherapy, acute oncology and radiotherapy. Thus all this is against the baseline of the rest of the cancer measures in the Manual for Cancer Services. All hospitals treating patients with malignancy (whether PTC, TYA designated or other hospitals), are subject to all relevant measures in the rest of the Manual.

The TYACNCG is required to agree and name those hospitals in the TYACN which are to be the TYA designated ones.

Sub-specialty Nomenclature

Adult Oncology

Some malignancies are most commonly treated non-surgically by haematologists. This area of practice is termed '**haemato-oncology**' in the measures. Some malignant diseases are most commonly treated non-surgically by oncologists who are not haematologists and not surgeons. This area of practice is termed '**solid tumour oncology**'. Some malignant diseases fall variably into either or both areas of practice, depending on local working practice. The relative boundaries of both areas of practice are a matter entirely for local discretion and definition and are not a matter for the measures or peer review. The area of practice which deals with the treatment of adults with malignant disease is termed '**adult oncology**' in the measures. Solid tumour oncologists are divided into medical oncologists who treat using drug treatment and **clinical oncologists** who may use both drug treatment and radiotherapy.

Paediatric Oncology

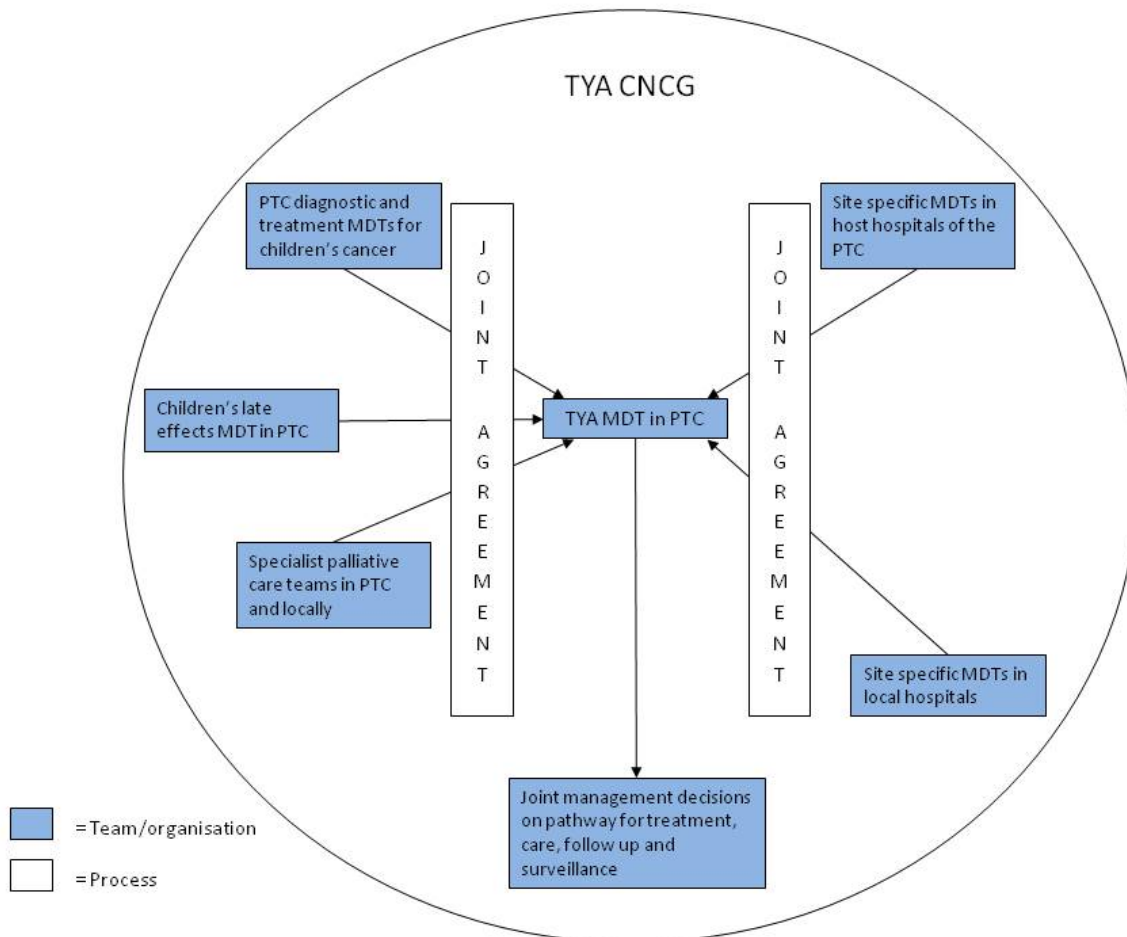
The area which deals with the non surgical treatment of children with malignant disease using drugs is termed '**paediatric oncology**'. Within this group there is usually subspecialisation into **paediatric solid tumour** treatment specialists and specialists in the treatment of **paediatric haematological malignancy**. The term paediatric haematology is, for the purpose of peer review, taken to mean the specialty which treats children

with non-malignant haematological disorders and is outside the scope of the measures and peer review. The treatment of children with radiotherapy is carried out by the clinical oncology specialty, usually by specialists who also have an adult radiotherapy practice.

Oncology

Where the measures use the words **oncology** or **oncologist**, they could refer to any of the non-surgical oncology sub-specialties and any more specific meaning should be apparent from the context.

See the following diagram showing the team relationships.



Teenage and Young Adult Cancer Network Co-ordinating Group Measures

| Introduction The responsibility for review purposes for measures dealing with the functions of the TYACG lies with the chair of the TYACG. | | |
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| Key Theme Structure and Function | | |
| Objective <i>Patients have access to appropriate care supported by best practice guidance.</i> | | |
| Measure | Notes | Evidence |
| 14-7A-201 | Network Configuration | |
| <p>The TYACNCG should agree the named hospitals in the TYACN which are to be the TYA designated hospitals.</p> <p>The TYACNCG should agree the name and location (i.e. the host hospital) of a single TYA MDT for the TYACN.</p> <p>All the above arrangements, which constitute the configuration of the TYA cancer clinical network, should be agreed by the directors of the relevant area teams responsible for specialised commissioning.</p> | | Constitution. |
| 14-7A-202 | TYACN Leadership | |
| <p>The TYACN should have the following named lead roles each with specified responsibilities and time available for the role. (1)</p> <p>There should be a single named lead clinician for the PTC who should be a consultant. The time available should be at least 0.2WTEs. The 0.2 WTEs should be in addition to the 0.5 WTEs of oncologists' time (see measure 11-7D-104), if the lead clinician is an oncologist. (1)</p> <p>There should be a single whole time named lead nurse role for the PTC.</p> | <p>(1) <i>Outline lists of responsibilities are attached for illustration only as appendices to the measures.</i></p> <p>(2) <i>This person would be considered to be the lead clinician for TYAs for the host hospital of the PTC and for the TYACN.</i></p> | Constitution. |
| 14-7A-203 | TYACNCG Membership | |
| <p>There should be a single teenagers and young adults' cancer network co-ordinating group (TYACNCG), having the following membership: (1,2)</p> <ul style="list-style-type: none"> a single named chair of the TYACN with specified time and description of the role agreed by the director of the relevant area team. The description of the role of chair should specify the relationship between the chair of the TYACN and the statutory bodies in terms of: <ul style="list-style-type: none"> the relative accountabilities of the various parties; the authority delegated to the chair of the | <p>(1) <i>There may be additional agreed members and attendance at an individual meeting need not be limited to the agreed members.</i></p> <p><i>Any one individual may fulfil more than one of the roles on the list, compatible with their discipline and status.</i></p> <p>(2) <i>The representatives should have delegated authority to make decisions</i></p> | <p>Constitution.</p> <p>Annual Report including meeting attendance spread sheet.</p> <p><i>The spread sheet should include names, roles and hospital represented.</i></p> |

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| <p>TYACN and, as a corporate body, the TYACNCG;</p> <ul style="list-style-type: none"> the balance between the advisory and executive role of the chair and, as a corporate body, the TYACNCG; the lead clinician of the PTC; the lead nurse of the PTC; a lead (lead clinician or lead nurse) from each of the TYA designated hospitals in the TYACN; a representative from the trusts at director level (a single representative for the TYACN will suffice); a representative from commissioners; two user / carer representatives; (3) one of the NHS employed members of the TYACNCG should be nominated as having specific responsibility for user/carer's issues and information for patients and carers; a member of the TYACNCG nominated as responsible for ensuring that recruitment into clinical trials and other well designed studies is integrated into the function of the TYACNCG; named secretarial/administrative support. <p>There should be terms of reference agreed for the TYACNCG which include: (4)</p> <ul style="list-style-type: none"> the provision of clinical opinion on issues relating to TYA cancers for the network; the development of patient pathways and clinical guidelines; the co-ordination and consistency across the network for TYA cancer policy, practice guidelines, audit, research and service development. | <p><i>on behalf of all their sector across the TYACN, if necessary, when acting as a member of the TYACNCG.</i></p> <p><i>(3) If there are no user / carer representatives, there should be an agreed mechanism for obtaining user advice.</i></p> <p><i>(4) There may be additional points in the agreed terms of reference.</i></p> <p><i>(5) The TYACNCG does not have ultimate accountability for TYA's cancer services This belongs to the statutory bodies involved. The TYACNCG is accountable within its terms of reference, to the constituent statutory bodies of the TYACN.</i></p> | |
| <p>14-7A-204 TYACNCG Meetings</p> | | |
| <p>The TYACNCG should meet at least quarterly and record attendance.</p> | <p><i>There are no fixed measures for minimum attendance but it is expected that named NHS employed members of the TYACN will personally attend a substantial proportion of the meetings rather than rely on deputies. The reviewers should examine the attendance records and use their judgement. A marked lack of compliance with attendance should be a major issue in the report from the peer review.</i></p> | <p>Constitution. Annual Report including meeting attendance spread sheet.</p> |
| <p>14-7A-205 Work Programme and Annual Report</p> | | |
| <p>The TYACNCG should produce an annual work programme in discussion with the strategic clinical network (SCN) and agreed with the medical director of the relevant area team for specialised commissioning. It should include details of any planned service</p> | | <p>Work Programme. Annual Report.</p> |

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| <p>developments and information on how the TYACNCG is addressing any inequalities of care and improvements in cancer outcomes. It should specify the personnel responsible and the timescales for implementation.</p> <p>The TYACG should have produced an annual report for the SCN and relevant area team.</p> <p>The annual report and work programme should be sent to its constituent local authorities, statutory and voluntary health care providers and commissioners.</p> | | |
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Key Theme

Co-ordination of Care / Patient Pathways

Objective

All patients receive co-ordinated care.

| Measure | Notes | Evidence |
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14-7A-206

Patient Pathways for Initial Management

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| <p>The TYACNCG should produce patient pathways (i.e. the named services, hospitals and MDTs which a TYA patient should be referred to according to named indications). The pathways should include the relevant contact points for the services, hospitals and MDTs (1,) and include the following:</p> <ul style="list-style-type: none"> • TYAs from all catchment areas; • TYAs with all types of malignancies; • they should specify within the context of shared responsibility for the patient, the specific contributions of the TYA MDT, the site-specific MDT meeting and the specialist palliative care MDT and the preferred order of referral and events along the pathway; • they should specify the places of recommended treatment delivery or in the absence of clear recommendation, the patient options for place of treatment delivery; • they should specify the consultants (post and specialty, not person) who are in final charge of each potential modality involved with the definitive treatment of the cancer; • they should cover at least the pathway from presentation as a new primary diagnosis to completion of the first line definitive treatment or decision to give supportive care only as the management; • they should specify any cancer site-specific variations to the pathway; • they should comply with the following underlying requirements; <ul style="list-style-type: none"> • all cases even those who choose to be treated outside of either the PTC or a designated hospital are reported to the PTC and discussed at both the site specific and TYA MDT meetings; | <p><i>(1) This should include, where relevant, any services, hospitals or MDTs outside those associated with the TYACNCG.</i></p> | <p>Constitution.</p> |
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| <ul style="list-style-type: none"> the treatment plan of all cases, as above is jointly agreed by the site specific and TYA MDTs according to relevant agreed clinical guidelines; final responsibility for the diagnostic process lies with the site specific MDT; final responsibility for the arrangements to provide age appropriate support and an age appropriate environment lies with the TYA MDT; TYAs of 16 to the end of their 18th year should be treated in the PTC; TYAs of 19 to their 25th birthday should be offered the choice of treatment in the PTC or in a TYA designated hospital. | | |
| <p>14-7A-207 Patient Pathways for Follow up on Completion of First Line Treatment</p> | | |
| <p>The TYACNCG should, in consultation with the NSSGs from the constituent adult networks, produce patient pathways for TYAs for the TYACN, which fulfil the following criteria:</p> <ul style="list-style-type: none"> they should cover TYAs from all catchment areas; they should cover TYAs with all types of cancer; they should cover the ongoing care of the patient from the time of completion of the first initial definitive treatment or following the decision to give supportive care only; they should cover recurrence; they should specify the relative roles in the patient's care, of the following teams; <ul style="list-style-type: none"> the TYA MDT; the site-specific MDT; the specialist palliative care MDT. the indications for referral to each type of team; which type of team has responsibility for which aspects of care and monitoring; the methods to be used for monitoring for disease recurrence and the late effects of treatment; they should require (and specify who is responsible for the production of) an end of treatment summary, for each patient to be provided within six months of completion of first line treatment; they should require (and specify who is responsible for the production of) a follow up care plan for each patient which describes the pathway as applied to their individual case; they should specify any site-specific variations to the pathways. | <p><i>(1) This should include, where relevant, any services, hospitals or MDTs outside those associated with the TYACNCG.</i></p> <p><i>(2) Rehabilitation pathways should include reference to the NCAT rehabilitation pathways.</i></p> | <p>Constitution.</p> |
| <p>14-7A-208 Patient Pathways for Highly Specialised Services</p> | | |
| <p>The TYACNCG should, in consultation with the relevant adult network groups and in agreement with the relevant national service provider and in line with the agreed national service specifications, produce patient pathways for TYAs for the TYACN, for cases which involve the following NHS Highly Specialised Services including:</p> | | <p>Constitution.</p> |

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| <ul style="list-style-type: none"> • Choriocarcinoma; • Eye Cancer Treatments; • Primary Malignant Bone Cancer Treatment; • Proton Beam Therapy. <p>There should be a pathway for each of the above, which fulfils at least the following:</p> <ul style="list-style-type: none"> • within the context of shared responsibility for the patient, it states the specific contributions of the TYA MDT, the PTC, the site-specific MDT and the national service provider; • it specifies the preferred order of referral and events along the pathway; • it covers at least the initial management and the arrangements for follow-up on completion of first line treatment. | | |
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Key Theme

Patient Experience

Objective

All patients receive patient centred care with respect and dignity which takes account of their holistic needs.

| Measure | | Notes | Evidence |
|---|--------------------|-------|----------------|
| 14-7A-209 | Patient Experience | | |
| In the course of their regular meetings, the TYACNCG should annually review patient feedback of their associated MDTs and any actions implemented, and should agree an improvement programme with them. | | | Annual Report. |

Key Theme

Clinical Outcomes / Indicators

Objective

All patients receive treatments intended to provide the best possible outcomes, consistent across the MDTs.

| Measure | | Notes | Evidence |
|---|---|---|-----------------------------------|
| 14-7A-210 | Clinical Outcomes Indicators and Audits | | |
| In the course of their regular meetings, the TYACNCG should annually review the progress (or discuss the completed results, as relevant), of their associated MDTs' outcome indicators and audits, which should have been carried out, or the data examined across all its associated MDTs: | | <p><i>Information from the cancer outcomes and service dataset (COSD) should be used where relevant.</i></p> <p><i>The compliance for this measure relates to the discussion of the data.</i></p> | Annual Report. Work Programme. |
| <ul style="list-style-type: none"> • Any TYA cancer outcome indicators for hospital practice, required by Clinical Commissioning Group Outcomes Indicator Set (CCGOIS). • Clinical indicators identified in section 2 of the measures. | | | |

| Objective | | |
|---|---|---|
| <i>All patients have equitable access to treatments that could potentially improve outcome.</i> | | |
| Measure | Notes | Evidence |
| 14-7A-211 | Discussion of Clinical Trials | |
| <p>The TYACNCG should discuss at least annually a report from each of the site specific MDTs dealing with at least the following malignancies:</p> <ul style="list-style-type: none"> • Leukaemia; • Lymphoma; • Germ cell malignancy; • Bone and/or soft tissue sarcoma; • Brain and CNS malignancy; • Malignant melanoma. | <p><i>The TYACNCG may judge that there are no trials/studies, suitable for TYAs for some of the above malignancies but all those malignancies above, should at least be considered in this process.</i></p> | <p>Annual Report. Work Programme.</p> |

TYA PTC Core Measures

| Introduction The responsibility for review purposes for the 7D measures lies with the lead clinician of the PTC. | | |
|--|---|---------------------|
| Key Theme Structure and Function | | |
| Objective <i>Patients receive treatment from specialists that have the skills and expertise to ensure the best possible outcomes.</i> | | |
| Measure | Notes | Evidence |
| 14-7D-101 | Lead Clinician | |
| There should be a single named lead clinician for the PTC who should be a consultant. The time available should be at least 0.2WTEs. The 0.2 WTEs should be in addition to the 0.5 WTEs of oncologists' time (see measure 14-7D-103), if the lead clinician is an oncologist. (1) | (1) <i>Outline lists of responsibilities are attached for illustration only as appendices to the measures.</i> | Operational Policy. |
| 14-7D-102 | Lead Nurse | |
| There should be a single whole time named lead nurse role for the PTC with specified responsibilities and time available for the role. (1) | | Operational Policy. |
| 14-7D-103 | Medical Staffing | |
| <p>There should be 0.5 WTEs of time of consultant solid tumour and/or haemato-oncologist(s) with a practice, in one or more of the following malignancies, which includes patients in the TYA age range:</p> <ul style="list-style-type: none"> • Leukaemias; • Lymphomas; • Germ cell malignancy; • Bone and/or soft tissue sarcomas; • Brain and CNS malignancy. <p>The 0.5 WTEs should be specified in the job plan(s) as being spent in the care of patients in the TYA age range. (1)</p> <p>There should be 1.0 WTE of time of medical staff of at least ST3 level in oncology or haematology or NCCG in oncology or haematology.</p> <p>The time should be specified in the job plan or timetable for the practitioner to be available on call for the care of TYAs with malignancy. (2)</p> | <p>(1) <i>The 0.5 WTE is the total minimum overall staffing level, not the level for each cancer type, and the commitment can be spread over more than one member of staff.</i></p> <p>(2) <i>This time may be made up of time slots worked by a number of individuals.</i></p> <p><i>The individuals may be on call at the same time for the rest of adult solid tumour or haemato-oncology.</i></p> <p><i>It is expected that this dedicated cover would be for the normal working hours of weekdays. Out of hours cover arrangements are not subject currently to review save that it would be subject to the measures on this in the higher levels of chemotherapy service.</i></p> | Operational Policy. |

| 14-7D-104 | Nurse Staffing | |
|--|---|---|
| <p>The nursing establishment for the inpatient beds of the TYA facility should be such as to provide a minimum of two nurses during the day and one nurse at night, who have:</p> <p>Either: successfully completed a programme of training in oncology for nurses in their specialist area of practice, which has been accredited for at least 20 credits at 1st degree level. (1)</p> <p>Or: trained and satisfied the hospital's chemotherapy service competency requirements for the administration of chemotherapy, as specified in the chemotherapy measures (topic 3S).</p> <p>The nursing establishment for the day case unit of the TYA facility should be such as to provide a minimum of one nurse on duty during each shift of each working day that the unit is open for chemotherapy who has:</p> <p>Either: successfully completed a programme of training in oncology for nurses in their specialist area of practice, which has been accredited for at least 20 credits at 1st degree level. (1)</p> <p>Or: trained and satisfied the hospital's chemotherapy service competency requirements for the administration of chemotherapy, as specified in the chemotherapy measures (topic 3S).</p> | <p>(1) <i>The training in the specialist area of practice may be:</i></p> <ul style="list-style-type: none"> • <i>training in oncology or haemato-oncology for nurses;</i> • <i>training in oncology for nurses, specialising in one or more of the malignancies common to the TYA age range (as listed elsewhere in this document);</i> • <i>a course specifically in TYA oncology.</i> | <p>Operational Policy. Annual Report.</p> |
| 14-7D-105 | Other Staffing | |
| <p>There should be 2.0 WTEs of social worker time.</p> <p>There should be 1.0 WTEs of youth worker/activity co-ordinator time.</p> <p>There should be 0.8 WTEs of dieticians' time.</p> <p>There should be 1.0 WTE of physiotherapists' time.</p> <p>There should be 0.2 WTEs of occupational therapists' time.</p> <p>There should be 1.0 WTE of time of a person agreed as providing psychological support.</p> | <p><i>The times may be made up by more than one individual.</i></p> <p><i>Where relevant to professionals who are listed as mandatory core members of the TYA MDT, the above includes the time for MDT meeting attendance.</i></p> <p><i>Social workers and youth workers may have an outreach role relating to these functions in the designated hospitals. This is not mandatory for an individual's compliance with this measure. The WTEs of social workers or youth workers refer to time spent on the support of TYAs whether in an outreach role or not.</i></p> | <p>Operational Policy. Annual Report.</p> |

Objective

Patients receive treatment from specialists that have the skills and expertise to ensure the best possible outcomes.

| Measure | | Notes | Evidence |
|---|----------------|-------|---------------------|
| 14-7D-106 | PTC Facilities | | |
| <p>There should be an in-patient facility which is covered by a management policy governing its use whereby it is reserved for the use of patients within the TYA age range with malignant disease and non-malignant haematology.</p> <p>There should be a day care facility (room or rooms) which is covered by a management policy governing its use whereby, while it is in use for TYAs, it is:</p> <ul style="list-style-type: none">• reserved for a minimum of the relevant half day at a time;• for patients of the TYA age range;• for chemotherapy or other outpatient/day case aseptic treatment or procedures. <p>Either: There should be an intensive care unit (ICU) which accepts patients of the TYA age range, on the same site as the PTC inpatient facility.</p> <p>Or: Where such a unit is not on-site, there should be transfer arrangements agreed between the PTC and the providers of any ICU(s) which are used.</p> | | | Operational Policy. |

TYA PTC MDT Measures

Introduction

Many of the general functions of an MDT for the patients which this team deals with will be fulfilled necessarily by their site-specific MDT with which the final confirmation of diagnosis rests and with which the final treatment planning decision is agreed. The measures in this section therefore deal specifically with the added role of the TYA MDT, and should not be compared with the measures for a site-specific MDT. The rest of the requirements of MDTs regarding a patient who happens to be a TYA are covered not only by the pre-existing measures for each site-specific MDT but also, by additional new measures which each site-specific MDT will be reviewed against but which relate specifically to its TYA practice.

The responsibility for review purposes for measure [14-7D-201](#) lies with the cancer lead clinician of the host trust. The responsibility for the subsequent measures lies with the lead clinician of the MDT.

Key Theme

Structure and Function

Objective

All patients benefit from expert multidisciplinary discussion of their diagnosis and treatment without delay.

| Measure | Notes | Evidence |
|--|---|---|
| 14-7D-201 Core Membership | | |
| <p>There should be a single named lead clinician with agreed list of responsibilities for the TYA MDT who should then be a core team member. (1,2)</p> <p>The lead clinician should be a consultant oncologist or haemato-oncologist with a clinical practice in one or more of the following malignancies which includes patients in the TYA age range.</p> <ul style="list-style-type: none"> • Leukaemias; • Lymphomas; • Germ cell malignancy; • Bone and/or soft tissue sarcomas; • Brain and CNS malignancy. <p>The lead clinician should be a core member of a site specific MDT(s) for the cancers for which they have a practice.</p> <p>The MDT should provide the names of core team members and their cover for named roles in the team. (3)</p> <p>The core team specific to the TYA MDT should include:</p> <ul style="list-style-type: none"> • the lead clinician; • a consultant oncologist with a practice in leukaemias which includes patients in the TYA age range and who is a core member of a site-specific MDT for leukaemia which has an exclusive catchment population for referral for patients with leukaemia, of at least 500 thousand; • a consultant oncologist with a practice in lymphoma which includes patients in the TYA age range and who is a core member of a site-specific MDT for lymphoma which has an exclusive catchment population for referral for patients with | <p>(1) <i>The role of lead clinician of the MDT should not of itself imply chronological seniority, superior experience or superior clinical ability.</i></p> <p>(2) <i>The MDT lead clinician may be the lead clinician of the PTC, but need not be so.</i></p> <p>(3) <i>Where a medical specialty is referred to, the core team member should be a consultant. The cover for this member need not be a consultant. Where a medical skill rather than a specialty is referred to, this may be provided by one or more of the core members or by a career grade non-consultant medical staff member.</i></p> <p><i>All consultants responsible for the delivery of any of the main treatment modalities should be a core member of the MDT.</i></p> <p>(4) <i>The definition of the levels may be found in appendix 4.</i></p> <p>(5) <i>The co-ordinator/secretary role needs different amounts of time depending on team workload.</i></p> | <p>Operational Policy. Including confirmation of any specific requirements of the roles.</p> <p>Annual Report including meeting attendance spread sheet.</p> <p><i>The spread sheet should include the dates of all scheduled meetings and the names and roles of core members.</i></p> |

| | | |
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| <p>lymphoma, of at least 500 thousand;</p> <ul style="list-style-type: none"> • a consultant oncologist with a practice in germ cell malignancy which includes patients in the TYA age range and who is a core member of a site-specific MDT for testicular cancer which has a catchment population for supranetwork referral of testicular cancer of at least two million; • a consultant oncologist with a practice in brain and CNS tumours which includes patients in the TYA age range and who is a core member of a brain and CNS neuroscience MDT; • a consultant oncologist with a practice in soft tissue sarcoma which includes patients in the TYA age range and is a core member of a sarcoma MDT which deals with at least 100 cases of soft tissue sarcoma per year; • a paediatric oncologist; • the PTC lead nurse; • a specialist nurse in addition to the lead PTC nurse; • a person agreed as able to offer psychological support for patients at, at least Level 3. They should have completed the training necessary to enable them to practice at level 3 for the psychological support of cancer patients and carers, and should receive a minimum of 1 hours clinical supervision by a level 3 or level 4 practitioner per month; (4) • a young people's social worker; • person agreed as performing the role of youth worker/activity co-ordinator; • a MDT co-ordinator/secretary; (5) • at least one clinical core member of the team with direct clinical contact, an NHS-employed member of the core or extended team should be nominated as having specific responsibility for users' issues and information for patients and carers; • a NHS-employed member of the core team should be nominated as having specific responsibility for late effects issues and information; • a member of the core team nominated as the person responsible for ensuring that recruitment into clinical trials and other well designed studies is integrated into the function of the MDT. | | |
| 14-7D-202 | MDT Quorum | |
| <p>The MDT should have treatment planning meetings scheduled every week unless the meeting falls on a public holiday.</p> <p>The attendance at each individual scheduled treatment planning meeting should constitute a quorum, for 95% or more, of the meetings. (1)</p> <p>The quorum for the TYA cancer MDT is made up of the following core members, or their cover: (2)</p> <ul style="list-style-type: none"> • Three consultant oncologists with a clinical practice in one or more of the following | <p>(1) <i>The % should be calculated over the 12 months prior to the assessment.</i></p> <p>(2) <i>The members counting towards the quorum should be drawn from the list of named core members or their named cover as specified in the core membership measures and are therefore</i></p> | <p>Annual Report including meeting attendance spread sheet.</p> <p><i>The spread sheet should include the dates of all scheduled meetings and the names and roles</i></p> |

| | | |
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| <p>malignancies which includes patients in the TYA age range:</p> <ul style="list-style-type: none"> • Leukaemias; • Lymphomas; • Germ cell malignancy; • Bone and/or soft tissue sarcomas; • Brain and CNS malignancy. <ul style="list-style-type: none"> • one specialist nurse; • one MDT co-ordinator. | <p><i>subject to the definition of acceptable core members or their cover.</i></p> <p><i>This measure does not imply any policy for what to do when an MDT meeting is not quorate. This is left to the MDT members' discretion.</i></p> | <p><i>of core members.</i></p> |
| <p>14-7D-203 MDT Review</p> | | |
| <p>There should be an operational policy whereby all new patients should be reviewed by the multidisciplinary team for discussion of their initial treatment plan. (1)</p> <p>The policy should specify that the results of patients' holistic needs should be taken into account in the decision making.</p> <p>There should be a written procedure governing how to deal with referrals which need a treatment planning decision before the next scheduled meeting (2).</p> | <p><i>(1) Other occasions when a patient should require MDT discussion should be covered in the agreed patient pathways.</i></p> <p><i>It should be understood that any patient may be referred outside the policy, at any stage, at an individual clinician's discretion.</i></p> <p><i>(2) e.g. Letters emails or phone calls between certain specified members, retrospective discussion at the next scheduled meeting.</i></p> | <p>Operational Policy.</p> |
| <p>Objective</p> <p><i>Patients receive treatment from specialists that have the skills and expertise to ensure the best possible outcomes.</i></p> | | |
| <p>Measure Notes Evidence</p> | | |
| <p>14-7D-204 Core Members Attendance</p> | | |
| <p>All core members of the MDT should attend at least two thirds of the number of meetings.</p> | <p><i>The intention is that core members of the team should be personally committed to the MDT which is reflected in their personal attendance at a substantial proportion of meetings.</i></p> | <p>Annual Report including meeting attendance spread sheet.</p> <p><i>The spread sheet should include the dates of all scheduled meetings and the names and roles of core members.</i></p> |

| Key Theme | | |
|---|--|--|
| Co-ordination of Care / Patient Pathways | | |
| Objective | | |
| <i>All patients receive co-ordinated care.</i> | | |
| Measure | Notes | Evidence |
| 14-7D-205 | Patient Pathways | |
| The MDT should agree the network-wide patient pathways specified in measure 14-7A-206 to 14-7A-208 . | | Operational Policy. |
| 14-7D-206 | Joint Treatment Planning Decision | |
| The MDT should agree and record individual patient's treatment plans, jointly agreed with the relevant site specific MDT. (1) A record should be made of the treatment plan. The record should include: <ul style="list-style-type: none"> the identity of patients discussed; the multidisciplinary joint treatment planning decision, including: <ul style="list-style-type: none"> the diagnosis and treatment modalities / regimen; the place of delivery of each modality (in particular, whether the PTC facility is to be used or whether the patient is being offered the choice of treatment in a TYA designated hospital); the named consultant in charge of each treatment modality; the arrangements/ referrals to provide age appropriate support if the treatment is delivered outside the PTC facility; the results of the discussion of fertility issues; the record of agreement by both the site specific and the TYA MDT; confirmation that the holistic needs have been taken into account. | (1) <i>The date of finalising the agreement by both teams may be later than the date of the discussion by the TYA MDT.</i> | Operational Policy. Example of treatment plan to be available for PR visit. |
| 14-7D-207 | Attendance at the TYACNCG | |
| The lead clinician of the MDT or representative should attend at least two thirds of the TYACNCG meetings. | | Annual Report including meeting attendance spread sheet. |
| Key Theme | | |
| Patient Experience | | |
| Objective | | |
| <i>All patients receive patient centred care with respect and dignity which takes account of their holistic needs.</i> | | |
| Measure | Notes | Evidence |
| 14-7D-208 | Key Worker | |
| There should be an operational policy whereby a single named key worker for the patient's care at a | | Operational Policy. |

| | | |
|--|--|---|
| <p>given time is identified by the MDT for each individual patient and the name and contact number of the current key worker is recorded in the patient's case notes. The responsibility for ensuring that the key worker is identified should be that of the nurse MDT member(s). The policy should have been implemented.</p> | | <p>Examples of patient notes should be available for PR Visit.</p> |
| <p>14-7D-209 Patient Information</p> | | |
| <p>The MDT should provide written material for patients and carers, specific to TYAs which includes:</p> <ul style="list-style-type: none"> • information about patient involvement groups and patient self-help groups; • information about the services offering psychological, social and spiritual/cultural support, if available; • information about services available to support the effects of living with cancer and dealing with its emotional effects. | <p><i>Where available, it is recommended that the information and its delivery to patients and carers should be in the format of the NHS Information Prescription.</i></p> <p><i>It is recommended that the information is available in languages and formats understandable by patients including local ethnic minorities and people with disabilities. This may necessitate the provision of visual and audio material.</i></p> <p><i>For the purpose of self-assessment the team should confirm the written information which is routinely offered to patients.</i></p> | <p>Operational Policy. Examples should be available for PR Visit.</p> |
| <p>14-7D-210 Patient Feedback</p> | | |
| <p>The MDT should have undertaken an exercise during the previous two years prior to review or completed self-assessment to obtain feedback on patients' experience of the services offered.</p> <p>The exercise should at least ascertain whether patients were offered:</p> <ul style="list-style-type: none"> • a key worker; • assessment of their physical, emotional, practical, psychological and spiritual needs (holistic needs assessment); • the TYA MDTs information for patients and carers (written or otherwise). <p>The exercise should have been presented and discussed at an MDT meeting and the team should have implemented at least one action point arising from the exercise.</p> | <p><i>The exercise may consist of a survey, questionnaire, focus group or other method.</i></p> <p><i>There may be additional items in the exercise. It is recommended that other aspects of patient experience are covered.</i></p> <p><i>As an alternative to the measure the relevant local results of the national patient survey may be offered as compliance with this measure.</i></p> | <p>Annual Report / Service Profile.</p> |

Key Theme

Clinical Outcomes / Indicators

Objective

All patients receive treatment intended to provide the best possible outcomes that is consistent across the network.

| Measure | | Notes | Evidence |
|---|------------------------------------|---|--|
| 14-7D-211 | Clinical Indicators Review / Audit | | |
| <p>The MDT should annually review their data, discuss the progress of their audit or discuss the completed results, as relevant, of the following outcome indicators and/or audits, with the TYACNCG, at one of the regular TYACNCG meetings:</p> <ul style="list-style-type: none">any TYA cancer outcome indicators for hospital practice, required by the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS);clinical indicators identified in section 2 of the measures. | | <p><i>Information from the cancer outcomes and service dataset (COSD) should be used where relevant.</i></p> <p><i>The compliance for this measure relates to the discussion of the data.</i></p> | <p>Annual Report / Service Profile.</p> <p>Work Programme.</p> |

Designated TYA Hospitals Measures

| <p>Introduction</p> <p>These measures apply to TYACNCG designated hospitals outside the PTC.</p> <p>The responsibility for review purposes for the 7D measures lies with the lead clinician of the designated hospital.</p> | | |
|--|---|---------------------|
| <p>Key Theme</p> <p>Structure and Function</p> | | |
| <p>Objective</p> <p><i>Patients receive treatment from specialists that have the skills and expertise to ensure the best possible outcomes.</i></p> | | |
| Measure | Notes | Evidence |
| 14-1D-101z | Lead Clinician | |
| <p>There should be a single named lead clinician for TYAs for the hospital. The lead clinician should have a list of responsibilities of the role. (1)</p> <p>The time available (expressed in whatever units are used in their contract) for those responsibilities, proportional to the workload, should be specified.</p> <p>The lead clinician should have a practice, worked in the designated hospital in one or more of the following malignancies which includes patients in the TYA age range.</p> <ul style="list-style-type: none"> • Leukaemias; • Lymphomas; • Germ cell malignancy; • Bone and/or soft tissue sarcomas; • Brain and CNS malignancy. | <p><i>(1) Outline lists of responsibilities are attached for illustration only as appendices to the measures.</i></p> | Operational Policy. |
| 14-1D-102z | Lead Nurse | |
| <p>There should be a named lead nurse for the TYA designated hospital. The lead nurse should have an agreed list of responsibilities of the position.</p> <p>The time available (expressed in whatever units are used in their contract), for those responsibilities, proportional to the workload, should be specified.</p> | <p><i>(1) Outline lists of responsibilities are attached for illustration only as appendices to the measures.</i></p> | Operational Policy. |
| 14-1D-103z | Social Worker | |
| <p>There should be time specified in the job description(s) of a social worker(s), for the care of TYAs with malignant disease, being dealt with by the hospital.</p> <p>The social worker(s) should have agreed a list of responsibilities for the post.</p> <p>The social worker(s) should be from the core membership of the TYA MDT at the PTC.</p> | | Operational Policy. |

| | | | |
|--|---|---------------------|-----------------|
| 14-1D-104z | Youth Worker / Activity Co-ordinator | | |
| <p>There should be time specified in the job description(s) of a person(s) agreed as a youth worker/activity co-ordinator for the care of TYAs with malignant disease, being dealt with by the hospital.</p> <p>The person(s) should have agreed a list of responsibilities for the post. (1)</p> <p>The youth worker/activity co-ordinator should be from the core membership of the TYA MDT at the PTC.</p> | | Operational Policy. | |
| <p>Objective <i>Patients receive treatment from specialists that have the skills and expertise to ensure the best possible outcomes.</i></p> | | | |
| | Measure | Notes | Evidence |
| 14-1D-105z | TYA Designated Hospital Facilities | | |
| <p>There should be a written policy whereby inpatient chemotherapy for TYAs should only be given on a named ward where it is agreed as part of the ward's regular activity and to which such patients are admitted in preference to other wards. (1)</p> <p>When outpatient or day case chemotherapy for TYAs is being given in wards/areas other than those specified above, it should only be given in specified room(s) covered by a policy whereby:</p> <p>On the days that chemotherapy is being given the room(s) should only be used for this purpose for TYAs or other outpatient/day case aseptic treatment or procedures for TYAs. (2)</p> | <p><i>(1) Day case chemotherapy may also be given on such wards.</i></p> <p><i>Wards with stricter policies than above, e.g. those reserved exclusively for chemotherapy, are also considered compliant with this measure.</i></p> <p><i>(2) Such terms as departments, units, suites and facilities, etc are all difficult to define with precision but they are all made up of a room or rooms.</i></p> | Operational Policy. | |

Section 2 Clinical Indicators/Lines of Enquiry

Introduction

The clinical indicators identified in this section have been identified by clinicians within the service as key aspects that reflect the quality of treatment and care provided. These indicators should form the basis of discussion by teams enabling them to identify areas for improvement. The team should comment on these indicators in their self assessment report and any plans for improvement should be included in their work programme.

Clinical Indicators

TBA

Appendix 1 Ground Rules for Networking

Ground Rules for Networking

Introduction

These ground rules preserve the principles underpinning clinical networking. The principles may be summarised as follows:

- They prevent destructive competition between MDTs for their catchment populations.
- They prevent destructive competition between NSSGs for their associated MDTs.
- They allow the development of consistent, intra- and inter-team patient pathways which are clinically rational and in only the patients' best interests instead of in the vested interests of professional groups or of NHS statutory institutions.

Network Groups

- The network group should be the only such network group for the MDTs which are associated with it.
- For cancer sites where there is only one level of MDT, the network group should be associated with more than one MDT.
- For cancer sites where there is a division into more than one level of MDT, i.e. into local and specialist/supranetwork MDTs, the network group need only be associated with one specialist/supranetwork MDT as long as it is associated with more than one MDT for the cancer site overall.

Notes:

*The network group **need** only be associated with one specialist/supranetwork type MDT but **may** be associated with more than one.*

Cross Cutting Groups

These currently include network groups for:

- Chemotherapy
- Radiotherapy
- Acute Oncology

These services are required to have local multiprofessional management teams. These are not equivalent to the site specific groups and are treated differently in the measures. The ground rules for MDTs do not apply to them.

The network group for a given service should be the only such group for that service for all the hospitals/services it is associated with.

- The equivalent reciprocal ground rules to this for hospitals and services would be; any given hospital should be associated with only one network group for any given service, and any service should be associated with only one network service group.

Note:

Hospitals and services are mentioned separately because, for the purposes of peer review and data gathering, it has been necessary to clearly define individual services and delineate their boundaries in terms of staff and facilities. Sometimes a declared 'service' may cross more than one hospital.

MDTs

For MDTs dealing with cancer sites for which the IOG and measures recommend only one level of MDT (i.e. no division into local and specialist or their equivalent. e.g. Breast MDTs):

- The MDT should be the only such MDT for its cancer site, for its catchment area.

Notes:

The principle of a given primary care practice agreeing that patients will be referred to a given MDT is not intended to restrict patient or GP choice. A rational network of MDTs, rather than a state of destructive competition can only be developed if i) there is an agreement on which MDT the patients will normally be referred to and ii) the resulting referral catchment populations and /or workload are counted, for planning

purposes. It is accepted that individual patients will, on occasion, be referred to different teams, depending on specific circumstances.

This ground rule does not apply to the carcinoma of unknown primary (CUP) MDT or the specialist palliative care (SPC) MDT. This is because, for this ground rule to be implementable, it is necessary to define a relevant disease entity in terms of objective diagnostic criteria which governs referral at primary care level. This is not possible for CUP or SPC, by the nature of these practices.

- The MDT should be the only such MDT for its cancer site on or covering a given hospital site.

Note:

This is because for patient safety and service efficiency, there should be no rival individuals or units working to potentially different protocols on the same site.

This does not prevent a given MDT working across more than one hospital site. Neither does it prevent trusts which have more than one hospital site, having more than one MDT of the same kind, in the trust. This ground rule does not apply to SPC MDTs, since there may be more than one distinctive setting for the practice of SPC on a single given hospital site.

- The MDT should be associated with a single named network group for the purposes of coordination of clinical guidelines and pathways, comparative audits and coordination of clinical trials.

Note:

MDTs which are IOG compliant but deal with a group of related cancer sites, rather than a single site, may be associated with more than one network group, but should have only one per cancer site. e.g. A brain and CNS tumours MDT also dealing with one or more of the specialist sites such as skull base, spine and pituitary could be associated with a separate network group for each of its specialty sites.

For cancer sites for which there is a division into local, specialist and in some cases, supranetwork MDTs, the following apply to the specialist/supranetwork MDTs. The above ground rules still apply to the 'local' type MDTs.

- The specialist/supranetwork MDT should be the only such specialist/supranetwork MDT for its cancer site, for its specialist/supranetwork referral catchment area.
- The specialist/supranetwork MDT should be the only such specialist/supranetwork MDT for its cancer site on or covering a given hospital site.
- The specialist MDT should act as the 'local' type MDT for its own secondary catchment population. If a supranetwork MDT deals with potentially the whole patient pathway for its cancer site, this ground rule applies to the supranetwork MDT. If it deals with just a particular procedure or set of procedures, not potentially the whole patient pathway, it does not apply.

Note:

This is in order that the specialist/supranetwork MDT is exposed to the full range of clinical practice for its cancer site.

- The specialist MDT should be associated with a single named network group, (or possibly one per individual cancer site, as above) for the purposes of coordination of clinical guidelines and pathways, comparative audits and coordination of clinical trials.

Appendix 2 Roles and Responsibilities

Roles and Responsibilities

Introduction

Role of the Network Group

The network group should be multidisciplinary; with representation from professionals across the care pathway; involve users in their planning and review; and have the active engagement of all MDT leads from the relevant associated organisations.

The network group should:

- agree a set of clinical guidelines and patient pathways to support the delivery of high quality equitable services across the network;
- review the quality and completeness of data, recommending corrective action where necessary;
- produce audit data and participate in open review;
- ensure services are evaluated by patients and carers;
- monitor progress on meeting national cancer measures and ensure actions following peer review are implemented;
- review and discuss identified risks/untoward incidents to ensure learning is spread;
- agree a common approach to research and development, working with the network research team, participating in nationally recognised studies whenever possible.

Responsibilities of the MDT lead clinician

The MDT lead clinician should:

- ensure that designated specialists work effectively together in teams 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 guidelines 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;
- overall responsibility for ensuring that the MDT meetings and team meet peer review quality measures;
- ensure attendance levels of core members are maintained, in line with quality measures;
- provide the link to the network group either by attendance at meetings or by nominating another MDT member to attend;
- ensure MDT's activities are audited and results documented;
- ensure that the outcomes of the meeting are clearly recorded, clinically validated and that appropriate data collection is supported.

Responsibilities of the PTC Lead Clinician

Purpose of the Role

The purpose of the role is to provide leadership and support to medical colleagues in the provision of specialist and age-appropriate care within the PTC and across designated TYA hospitals. The lead clinician works in close collaboration with the TYA lead nurse, and with site-specific MDT leads and the TYA leads at designated TYA hospitals. He/she will be expected to work in partnership with the lead cancer clinician in the PTC host trust and cancer networks to contribute to the strategic development of TYA cancer services.

The Role of the PTC Lead Clinician includes:

1. Leadership of the TYA MDT, ensuring that objectives of MDT working are met.
 - ensure TYAMDT outcomes/recommendations are discussed or communicated in a timely manner to site-specific MDTs to achieve a jointly-agreed treatment plan for each patient.
2. Agree treatment policies with NSSGs and the TYA CN Coordinating Group including:
 - tumour types to be treated, both to deliver primary treatment and on a shared care basis;
 - appropriate treatment protocols for each tumour treated;
 - clinical trials to be open for recruitment (with R&D approval) and delivery at which hospitals (PTC and designated TYA hospitals), for each tumour type.
3. Liaison with the Designated TYA hospitals:
 - Establish a pathway for management of patients aged 16 to 18, and 19 to 24 years.
 - Establish a pathway for management of each tumour type, including shared care where appropriate.
 - Establish the process for registration of all new patients diagnosed within the designated hospital's catchment area.
 - Establish for each patient, in discussion with other MDTs, responsibility for each component of the patient pathway. In particular who is the most appropriate key worker, and whether support is to be provided by the PTCs TYA team or designated hospital team, or a combination of the two.

Responsibilities of the PTC Lead Nurse

Purpose of the Role

The overriding purpose of the lead nurse role is to provide professional and clinical leadership and support to nursing staff within the Principal Treatment Centre. Post-holders will be responsible for all elements of the nursing services and will also be expected to contribute to the strategic development of the whole service in line with the individual hospital trust.

Core Elements

The Lead Nurse:

- is an expert in the care of young people with cancer;
- advances the development and practice of evidence-based TYA cancer nursing in the trust, in line with national recommendations and measures where available;
- collaborates with all members of the multidisciplinary team in ensuring the advancement of patient focused cancer care and support;
- develops and implements communication arrangements with nursing and members of the multidisciplinary team across the network;
- works clinically on a regular basis, (this should be a least 20%) thus demonstrating expert clinical practice, professional competence, authority and credibility;
- works with the trust / network to co-ordinate the nursing elements of preparation for peer review visits or self-assessment;
- provides professional advice, leadership and support on haematology / oncology issues to the designated hospitals within the region;
- is responsible for continuing management and strategic planning of the Regional TYA haematology /oncology service.

Responsibilities of the Lead Clinician of the Designated Hospital

Purpose of the Role

The purpose of the role is to provide leadership and support to medical colleagues in the provision of specialist and age-appropriate care within their trust and in collaboration with the TYA MDT at the TYACN

Principal Treatment Centre. He/she will be expected to work in partnership with the PTC to contribute to the strategic development of TYA cancer services in line with the individual hospital Trust and TYA Cancer Network.

The Role of the Lead Clinician is to:

1. Coordinate age-specific care for TYAs with malignant disease within the host hospital's catchment area.

This will include:

- bringing together a team of medical, nursing and AHP staff who have expertise in managing patients in the TYA range treated at the hospital;
 - liaising with all relevant site-specific leads in the area served.
2. Agreeing treatment policies with the TYA CN Coordinating Group including:
- tumour types to be treated, both to deliver primary treatment and on a shared care basis;
 - appropriate treatment protocols for each tumour treated;
 - clinical trials to be open for recruitment (with R&D approval) and delivery at the Designated Hospital, for each tumour type.
3. Liaison with the PTC
- Establish a pathway for management of patients aged 16 to 18, and 19 to 24 years.
 - Establish a pathway for management of each tumour type.
 - Establish the process for registration of all new patients diagnosed within the Designated Hospital's catchment area.
 - Establish for each patient, in discussion with the TYA MDT at the PTC, responsibility for each component of the patient pathway. In particular who is the most appropriate Key Worker, and whether support is provided by the Designated Hospital team, the outreach team from the PTC.

Responsibilities of the Lead Nurse of the Designated Hospitals

Purpose of the Role

The role is to provide local coordination of TYA care, liaison with the TYA MDT at the PTC, and leadership and support to provide age-appropriate care to TYA cancer patients within their Trust. Post-holders will be expected to work closely with the local TYA clinical lead and the PTC lead TYA nurse, and to contribute to the strategic development of TYA cancer services in line with the individual hospital trust.

Core Elements

The TYA nursing lead:

- advances the development and practice of evidence-based TYA cancer nursing in the Trust, in line with national recommendations and measures where available;
- collaborates with the TYA multidisciplinary team in ensuring all patients are reviewed and agreed plans for nursing care and support are delivered at local level;
- develops and implements communication arrangements with nursing and members of site-specific multidisciplinary teams in their Trust regarding TYA cancer care.

Appendix 3 Psychological Support Levels

Introduction

This appendix gives the definitions, for the purpose of the measures and peer review, of the service levels. The term 'Health Professional' as used in the definitions of levels 1 and 2, implies a professional in a discipline other than the psychiatry/psychology/counselling disciplines themselves, since it is assumed that basic qualification in these disciplines would exempt a practitioner from level 2 training.

Level 1

Is defined as a degree of psychological screening, intervention and support which is deliverable by any qualified health or social care professional, without any further psychological training other than that provided by the basic training in their own discipline.

Note: Level 1 does not feature directly in the measures but it is specified here to set a baseline for comparison with the higher levels and to put them in perspective.

Level 2

Is defined as a degree of psychological screening, intervention and support which requires a practitioner who is a health or social care professional who has received further psychological training, as specified below, in addition to that provided by the basic training in their own discipline.

The additional training is as follows:

I. Attendance on the National Advanced Communications Skills Training course from one of the nationally approved programmes.

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II. Participation in a network based training programme, relevant to cancer patients and their carers which covers basic psychological screening, psychological assessment and basic psychological intervention skills.

The detailed content of the training programme will be agreed by the network and is not subject to peer review, but for illustration purposes examples of the training in screening are: Jenkins, K. & North, N. (2008) 'Psychological Assessment Skills: A training course for all health and social care staff working in cancer services'. Salisbury NHS Foundation Trust; or, training in the use of a Holistic Needs Assessment tool such as the Distress Thermometer.

For illustration purposes, examples of the training in psychological intervention skills are: Training in Solution Focussed Techniques, or Anxiety Management, or Problem Solving, or Cognitive Behavioural Therapy.

Level 3

Is defined as a degree of psychological screening, intervention and support which requires a practitioner who is one of the following:

- a counsellor, accredited by the one of the national voluntary regulatory bodies for counselling;
- an NHS psychotherapist accredited by one of the national voluntary regulatory bodies for psychotherapy.

Level 4

Is a degree of psychological screening, intervention and support which requires a practitioner who is one of the following:

- a consultant psychiatrist;
- a consultant liaison psychiatrist;
- a clinical or counselling psychologist.

Note:

All of the above should have completed an induction at level 3. that meets the British Psychosocial Oncology Society (BPOS) and SIGOPAC requirements.

