NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Children and young people with cancer

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 10th July 2013

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for children and young people with cancer. It provides the Committee with a basis for discussion and prioritising quality improvement areas for developing quality statements and measures, which will be drafted for public consultation.

Structure

The structure of this briefing paper includes a brief overview of the topic followed by a summary of each of the suggested quality improvement areas followed with supporting information.

Where relevant, guideline recommendations selected from the key development source below are presented to aid the Committee when considering specific aspects for which statements and measures should be considered.

Development source

Unless otherwise stated, the key development source referenced in this briefing paper is as follows:

- Children and young people with cancer: improving outcomes in children and young people with cancer. NICE cancer service guidance CSGCYP (2005).

Where relevant, guideline recommendations from the key development source are presented alongside each of the suggested areas for quality improvement within the main body of the report.

2 Overview

2.1 *Focus of quality standard*

This quality standard will cover provision of all aspects of cancer services for children and young people with cancer.

2.2 *Definition*

There is a wide range of conditions that come under the definition of cancer. Cancers are grouped into three broad categories: solid tumours, haematological malignancies and central nervous system (CNS) malignancies. Cancers that develop in childhood are different from those in adult life. There is increased histological diversity and many tumours develop from embryonal tissue. A specific classification system is used for childhood cancers called the International Classification of Childhood Cancer (ICCC). This is used by the National Registry of Childhood Tumours to collate national incidence and prevalence data.

Incidence and prevalence[1]

Cancers in children aged less than 15 years old are rare, causing less than 1% of all cancers in industrialised countries. The crude incidence rate shows that there are 160 new cancer cases for every million boys in the UK, and 137 for every million girls. In 2008-2010, there was an average of 1,603 new cases of childhood cancer (0-14 years of age) each year in the UK: 883 (55%) in boys and 720 (45%) in girls.

Cases of cancer in teenagers and young adults (15-24 year olds) are also rare equating to 269 cases per year for every million 15-24 years old in the UK population. In 2008-2010, an average of 2,214 new cases of cancer in teenagers and young adults were reported.

2.3 Management

Services for children with cancer are delivered through a network of specialist centres across the UK and Ireland. The network is supported through the Children's Cancer and Leukaemia Group (CCLG). The CCLG represents the disciplines involved in the care of children and young people with cancer who are part of the network of treatment centres across the UK.

Some centres have dedicated beds for adolescents and there are also specialist Teenage Cancer Trust units, designed specifically for teenagers and young adults, including access to specialist staff for this age group.

The centres for children and young people do not cover all aspects of care required for all cases of cancer in their locality. For specialist interventions children and young people are referred out of regions sometimes for specialist treatment. For example, many centres do not have access to radiotherapy on site.

The most commonly recorded procedures in childhood cancer patients are diagnostic and therapeutic spinal puncture for the management of leukaemia. Other common procedures include insertion of central venous lines, diagnostic bone marrow aspirate, and administration of chemotherapy and immunotherapy[2].

2.4 National Outcome Frameworks

The table below shows the indicators from the frameworks that the quality standard could contribute to:

NHS Outcomes Framework 2013/14	
Domain 1 Preventing people from	**Overarching indicators** **1a** Potential Years of Life Lost (PYLL) from causes considered amenable to health care **i** Adults **ii** Children and Young people **1b** Life expectancy at 75 **i** males **ii** females

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[1] All data compiled by the ONS. This analysis reported by Cancer Research UK

[2] NICE Guidance on cancer services

dying prematurely	**Improvement areas** **1.4** Under 75 mortality from cancer **i** One and **ii** Five -year survival from all cancers **1.4.iii** One and **iv** Five-year survival from breast, lung and colorectal cancer **1.6. iii** Five-year survival from all cancers in children
Domain 4 Ensuring people have a positive experience of care	**Improvement areas** **4.8** (Placeholder) Children and young people’s experience of healthcare. **4.9** (Placeholder) People’s experience of integrated care (in development).

3 Summary of suggestions

3.1 Responses

In total 15 stakeholders responded to the 2-week engagement exercise all of which submitted suggestions for quality improvement. Suggestions were also provided by specialist committee members.

Table 1 Summary of suggested quality improvement areas

Stakeholders were asked to suggest up to 5 areas for quality improvement. These have been merged and summarised in the table below for further consideration by the Committee (incorporating stakeholder and specialist committee member suggestions). The full detail of the suggestions is provided in appendix 1 for information.

Suggested area for improvement	Stakeholder
Diagnosis i. Faster access to diagnostic services ii. Diagnostic testing at specialist centres	RCP, NHSE, BCRT, CCLG, SCM
Organisation of care	
i. Multidisciplinary Teams	BSPD, CLIC S, TCT, NHSE
ii. Specialist treatment centres	CCLG, NHSE
iii. Information sharing between services	NHSE
iv. Key worker / named nurse	CLIC, BCRT, TCT, SCM
Access to clinical trials	TCT, NHSE, SCM
Patient safety Electronic Prescribing and administration of chemotherapy	CCLG, NHSE, SCM
Care environment	RCOR, CLIC, BCRT
Psychological / social support	AFTSP, CLIC, CCLG, RCN, SCM
Surgical procedures	RCSE, NHSE
Specialised services	
i. Pain management	FPM
ii. Anaesthesia	FPM
iii. Fertility preservation	BFS
Rehabilitation	CCLG, TCT, NHSE
Palliative care	RCPCH, CCLG, RCN, TFSL, SCM

Suggested area for improvement	Stakeholder
Transition	TFSL
Staffing levels	RCOR, RCN, NHSE, SCM
Information provision	BCRT & SCM
Patient experience survey	BCRT, RCN, TCT, NHSE, RCOR, SCM
Cancer registry	SCM
Staff training	RCN
Best possible clinical outcomes	RCR, NHSE, SCM, NHSE, BSPD

Table 2 Stakeholder details (abbreviations)

The details of stakeholder organisations who submitted suggestions are provided in the table below.

Abbreviation	Full name
AFTSP	Association for family therapy and systemic practice
BFS	British Fertility Society
BSPD	British Society for Paediatric Dermatology
BCRT	Bone Cancer Research Trust
CCLG	Children’s Cancer and Leukaemia Group
CLIC	CLIC Sargent
FPM	Faculty of Pain Medicine of the Royal College of Anaesthetists
NHSE	NHS England
RCN	Royal College of Nursing
RCOP	Royal College of Pathologists
RCOR	The Royal College of Radiologists
RCPCH	Royal College of Paediatrics and Child Health
RCSE	Royal College of Surgeons of Edinburgh
SCM	Specialist Committee Member
TCT	Teenage Cancer Trust
TFSL	Together for Short Lives

4 Suggested improvement area: Diagnosis

4.1 Summary of stakeholder suggestions

The pathway for diagnosis of cancer in children and young people was prioritised by a number of stakeholders. Stakeholders highlighted the importance of diagnostic testing being done in centres with staff with appropriate specialist expertise in analysing samples from children and young people. Stakeholders reported that the biopsy samples are often small and the cancers are different to those in adults.

The role of GPs and wider primary care services was referenced, increasing awareness of certain cancers that can be harder to identify and improving the time between initial presentation at the GP to referral to the relevant service for diagnostic investigation was specifically highlighted.

To help improve accuracy of diagnosis, access to interventional radiology services for biopsy of challenging areas or where the child is too sick for a surgical procedure was also highlighted. The effects of delayed diagnosis and erroneous diagnoses were referenced as a rationale for why this aspect of the care pathway is so important.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	Available recommendations from the development source
Faster access to diagnostic services	NICE Guidance CS for CYP Section - Presentation and referral
Diagnostic testing at specialist centres	NICE Guidance CS for CYP Sections: • Diagnosis - Pathology • Diagnosis - Imaging

4.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

Presentation and referral

- Specific education for professionals in primary and secondary care in the recognition and referral of suspected CNS malignancy and other solid tumours in children and young people should be established.
- Cancer networks should ensure that there are agreed local arrangements for referral of children and young people with suspected cancer from primary care to named clinicians or to specified clinics

Diagnosis

Pathology

- Pathology and histopathology services for children should be provided in the long term only by paediatric pathologists and those with relevant specialist expertise. This is a matter of training, experience and governance.
- Paediatric pathology should be concentrated at selected specialist paediatric surgical/oncological and tertiary referral maternity sites. It should cover all post mortem examinations and all surgical and oncological work.

Imaging

- Specialist paediatric histopathologists should be involved with the pathological diagnosis of solid tumours in children. Access to expertise in specific tumour site pathology should be available for the diagnosis of tumours in young people.
- Specialist techniques such as immunohistochemistry, cytogenetics, molecular genetics or spinal fluid cytology should be available in all departments dealing with tumour samples.

4.3 Current UK practice

A review of routes taken by children and young people to receiving a diagnosis showed significant variance between age groups, cancer type and also region[3]. For patients 0-14 years old the most common route was via emergency presentation (54%). Amongst those 15-24 years 26% were via non-two week wait GP referrals, with 24% via emergency presentations. When looking at cancer types, leukaemias had the highest proportion across both age groups for diagnosis coming through emergency presentation (0-14 years nearly 70% and 15-24 years approximately 60%).

Stakeholders and specialist committee members specifically reference delayed diagnosis in brain and bone tumours. The route to diagnosis for both these areas was shown to be predominantly through emergency presentation for both children

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[3] National Cancer Intelligence Unit (2013) . Routes to diagnosis: investigating the different pathways for cancer referrals in England for teenagers and young adults.

and young people. The Bone Cancer Trust reported that the average diameter of bone tumours by the time of correct diagnosis is 10cm, with the average time taken for patients to receive a correct diagnosis of bone sarcoma being 16 weeks from the onset of symptoms.

A report by the National Imaging Board[4] about improving imaging services for children, recommended that a paediatric radiology service should be part of an integrated pathway for the management of site-specific cancers and integrated in the care pathways of Children's Cancer Centres. A review of imaging services for children[5] published following the National Imaging Board report found that children were imaged in 84% of adult hospitals from which responses were obtained and estimates provided by respondents indicated that more children were imaged in adult than children's hospitals. Only 32% of adult hospitals reported having a lead radiographer, who specialised in a paediatric imaging. However, responses did indicate that in 60% of adult hospitals staff attended paediatric training courses.

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[4] National Imaging Board (2010) Delivering Quality Imaging Services for Children

[5] Mathers et al (2010) College of Radiographers, A survey of imaging service for children in England Wales and Scotland

5 Suggested improvement area: Organisation of care

5.1 Summary of stakeholder suggestions

A number of stakeholders highlighted the role of multidisciplinary teams (MDTs) in agreeing and coordinating care for children and young people with cancer. MDTs were deemed to be best placed to ensure the full needs of children and young people are assessed and provided for.

Stakeholders also suggested that one member of the MDT should perform the role of a named key worker, who will be the main contact and should coordinate care for their patient.

Two stakeholders identified the importance of care provision for this patient group being provided via nationally commissioned specialist paediatric oncology and haematology principal treatment centres

Where care is provided as part of a network of service providers across sites, 1 stakeholder prioritised the need for good information sharing between sites to ensure the best possible care for children and young people with cancer.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Multidisciplinary teams	Section – Multidisciplinary teams
Key worker / named nurse	Section – Continuity of Care
Specialist treatment centres	Section – Principal treatment centres
Information sharing between services	No specific recommendations were identified

5.2 Selected recommendations from the development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion

NICE Guidance CS for CYP

i. Multidisciplinary Teams

Care should be delivered throughout the care pathway by MDTs, including all relevant staff (see Tables 4–6). Decisions should be recorded and disseminated to all relevant health professionals. Where care involves more than one treatment setting or specialist team, the remit and membership of the MDTs should reflect the arrangements for shared care.

There are several tumour types whose management and treatment planning should be undertaken by either a specialist tumour-specific MDT or through liaison with other subspecialists. These include:
- tumours of the CNS
- bone sarcoma
- soft tissue sarcomas (particularly in young people)
- retinoblastoma
- lymphomas (for specialist pathological review)
- malignant thyroid tumours

ii. Key worker / named nurse

A key worker should be identified for each child or young person and their family to coordinate services and assess their support needs. There should be clear routes of communication between different care/treatment settings.

iii. Specialist treatment centres

The definitive investigation of children and young people with a suspected diagnosis of cancer should only take place in principal treatment centres, which should have the appropriate staff and resources to meet the waiting time requirements of the *NHS Cancer Plan* [27, Appendix 1] and the *Wales National Cancer Standards* [21, Appendix 1].

The care of each child and young person with cancer should be directed from an identified principal treatment centre by a dedicated MDT with expertise in the cancer-related issues of this age group and their families. Written guidelines for referral, admission, communication at discharge and follow-up should be in place.

iv. Information sharing between services

No specific recommendations were identified to support this area.

5.3 Current UK practice

Multidisciplinary teams & Specialist treatment centres

Data published by the National Clinical Intelligence Network showed that referrals to teenage and young adult’s multi-disciplinary teams based in principal treatment centres (PTC) are highly variable; by region, by cancer types and by age groupings. The report looked at 2 separate age groups; 15-18 years olds and 19 to 24 years olds.

Between 2003 and 2005 64% of 15 to 18 year old cancer patients were admitted for treatment to a PTC, compared to 46% of 19 to 24 years olds.

For both age groups, those with bone tumours were most likely to be admitted to a principal treatment centre (90% for 15 to 18 yr olds and 82% for 19 to 24 yr olds). Patients with a melanoma or skin carcinoma diagnosis were least likely to be referred (34% and 33%).

The same concerns were not identified in current practice information regarding the younger age group.

Keyworker named nurse & Information sharing between centres

No current practice information was identified

6 Suggested improvement area: Access to clinical trials

6.1 Summary of stakeholder suggestions

A number of stakeholders prioritised children and young people with cancer being given access to appropriate clinical trials, referencing evidence of beneficial clinical outcomes for patients who take part in high quality national / international trials.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Access to clinical trials	Section - Research

6.2 Selected recommendations from the development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

NICE Guidance CS for CYP

Research

Principal treatment centres should ensure that all eligible children and young people are offered the opportunity to be treated within relevant specific clinical trials, where these are available, and that this must be an informed choice

6.3 Current UK practice

The NICE guidance on cancer services for children and young people states that recruitment to clinical trials is lower in young people (15-24 yrs) compared with children up to the age of 15 years, and also varies according to the principal place of treatment; fewer are enrolled from adult settings than from paediatric settings. This is seen in tumours where the same protocol is used for treatment, such as osteosarcoma and Ewing’s sarcoma. One stakeholder highlighted the fact that 5 year survival rates are lower amongst this older age group where clinical trial participation is low.

7 Suggested improvement area: Patient safety – Electronic prescribing and administration of chemotherapy

7.1 Summary of stakeholder suggestions

Stakeholders prioritised the use of electronic prescribing of chemotherapy for children and young people. A further suggestion referred to the administration of chemotherapy being managed electronically. Due to the high potential of serious harm if doses are miscalculated, stakeholders prioritised this area as a key patient safety priority.

The following specific area for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Electronic prescribing and administration of chemotherapy	<u>Section</u> - Chemotherapy

7.2 Selected recommendations from the development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

<u>NICE Guidance CS for CYP</u>

<u>Chemotherapy</u>

Funding should be made available for provision and maintenance of an Electronic Prescribing System for chemotherapy

7.3 Current UK practice

No current practice information relevant to children and young people was identified.

8 Suggested improvement area: Care environment

8.1 Summary of stakeholder suggestions

Three stakeholders identified the environment within which children and young people are treated as being a priority for quality improvement. One stakeholder emphasised the need for more children and young people to be offered the option to be treated at home, where this is a safe option. The stakeholder highlighted that many children, young people and their families have to travel long distances to access principal treatment centres and that surveys of children and young people suggest that they would like to be able to spend more time at home during periods of treatment.

Two stakeholders prioritised the need for the facilities where children and young people receive care to be age appropriate. They highlighted how the environment can have a significant impact on the mental wellbeing of a patient, enabling them to be more at ease during treatment. The environment included staff being able to communicate in an appropriate manner and the use of techniques such as play to help facilitate the treatment process.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	Available recommendations from the development source
Treatment at home	Section - Chemotherapy
Age appropriate environment	Section – Principal treatment centres

8.2 Selected recommendations from the development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

NICE Guidance CS for CYP

Chemotherapy

Where safe administration of chemotherapy in the home is possible, either by appropriately trained community nursing teams or families, this should be developed, supported and adequately resourced.

Principal treatment centres

There should be designated principal treatment centres for teenagers and young adults.

Whatever the age of the patient they should have access to:

- expertise in the management of the malignant condition
- age-appropriate facilities
- appropriate MDTs.

All care for children and young people under 19 years old must be provided in age-appropriate facilities [35, Appendix 1]. Young people of 19 years and older should also have unhindered access to age appropriate facilities and support when needed.

8.3 *Current UK practice*

In a survey of young people with cancer carried out by CLIC Sargent, 89% of respondents said that they felt it was important to be able to spend more time at home during periods of treatment, enabling them to keep in contact with family and friends. A further piece of research conducted by CLIC Sargent looked at wider issues concerning accessing treatment for children and young people. Using data from the 10,000 children and young people supported by CLIC Sargent, they found that 77% of childhood cancer patients do not live in a city with a principal treatment centre (PTC), with 42% of children young people and their families making round trips of over 50 miles when undergoing treatment at a principal treatment centre[6].

Current practice information concerning treatment in age appropriate environments suggests that for children it is now common practice that they receive treatment at principal treatment centres based within units specially designed for children. There does appear to be some variation in relation to teenagers and young adults however. Since the publication of the NICE guidance in 2005 13 trusts in England have Teenage and Young Adult PTC status along with designated ‘shared care’ institutions. Despite this, a review of notifications to the cancer registry for teenagers and young adults by the National Cancer Intelligence Network showed that 62% of patients aged 15 to 18 years were notified by a PTC or CCLG centre and only 34% of patients aged 19 to 24 years were notified. For 15 to 18 year olds percentage notifications ranged from 21% for skin carcinomas and melanomas to 87% for bone tumours. The pattern was the same for patients aged 19 to 24 years; 14% for skin carcinoma and melanoma patients to 69% for bone tumours. A large number of non-PTC trusts were recorded as treating non-notified patients[7]

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[6] CLIC Sargent

[7] National Cancer Intelligence Network (2013) Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010 (April 2013)

9 Suggested improvement area: Psychological and social support

9.1 *Summary of stakeholder suggestions*

The need for social and psychological support as part of the integrated multidisciplinary care package was highlighted by stakeholders. One stakeholder made specific reference to the availability of family therapy services, recognising the impact of a child or young person being diagnosed with cancer and the resulting treatment can have on the whole family.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	Available recommendations from the development source
Access to psychological and social support	Section – Psychosocial support
Access to systemic family therapy	No specific recommendations were identified

9.2 *Selected recommendations from the development source*

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

NICE Guidance CS for CYP

Psychosocial Care

All children and young people with cancer and their families, in particular siblings, should be offered the advice and support of a social worker to ensure that the needs of the wider family are addressed.

There should be access to expert psychological support with clear routes of referral in principal treatment centres and other treatment settings. This should include identified psychologists or other members of psychological services with expertise in the care of children and young people with cancer. It is important that use is made of existing services and that access to these is facilitated.

A structured psychosocial assessment at significant points throughout the care pathway should be provided, including:

- at diagnosis
- during treatment

- at end of treatment
- during long-term follow-up
- at relapse
- during palliative care
- at bereavement.

9.3 *Current UK practice*

CLIC Sargent have looked at the social impact on children and young people diagnosed with cancer and how absence from school and their wider social network has impacted on their wellbeing. A survey of parents published in 2012[8] found that:

- 47% said their child had grown apart from friends because of their diagnosis and treatment.
- 36% thought their child did not receive the extra help they needed to keep up with school after their diagnosis and treatment
- More than one in three (35%) parents said their child had experienced bullying or teasing from their peers because of their cancer diagnosis and treatment

Several stakeholders highlighted the psychological impact a diagnosis can have on the child and young person and how ensuring that children and young people receive treatment from appropriate PTC's should enable them to access integrated psychological and social support. Current practice previously referenced concerning the proportion of children and young people receiving care at a PTC would suggest that access to the wider care provision available from the multidisciplinary teams at the PTC's is variable.

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[8] CLIC Sargent No child with cancer left out

10 Suggested improvement area: Surgical procedures

10.1 Summary of stakeholder suggestions

Two stakeholders highlighted surgical procedures in relation to treatment for children and young people with cancer. One suggestion focused on ensuring patients in whom surgery is being considered have their case discussed with a suitably experienced MDT. The other suggestion concerned surgery only being conducted at centres with minimum activity volumes. The stakeholder referenced the complexity of carrying out surgery with this patient group and that it was important that surgical teams were carrying out a sufficient number of cases to retain their expertise. To support this process, stakeholders suggest that surgical networks should be in place to ensure access to suitably qualified professionals.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Pre-surgical referral to relevant MDT	Section - Surgery
Surgical networks / minimum activity volumes	Section - Surgery

10.2 Selected recommendations from the development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

NICE Guidance CS for CYP

Surgery

Diagnostic biopsy or definitive surgery in children known to have, or suspected of having, a malignant tumour should only be carried out by surgeons appropriately trained either in paediatric oncological surgery or other appropriate surgical specialities, working in a centre with appropriate support from paediatric anaesthetists and intensive care facilities.

Referral systems should be in place, if necessary across cancer networks, to provide easy access to a variety of other surgical specialists.

The surgical management of tumours in children and young people should be discussed by the appropriate paediatric or specialist MDT, including preoperative discussion, in all cases except emergencies.

Surgery for retinoblastoma, bone tumours and certain liver tumours requires very specialist expertise that should only be provided in supra-regional centres.

10.3 Current UK practice

One of the stakeholders reported current practice where problems occur in some patients due to surgery being agreed and performed as the initial treatment. In some cases this is not appropriate and can cause problems with future interventions. They therefore suggest that any patients where surgery is being considered are discussed with a suitably experienced MDT. They do suggest that there are relatively well established pathways for surgical procedures in children and young people with cancer. However that these would be strengthened through the development of a surgical network, where a general surgeon can get advice if required to be sure that surgery is the correct option.

The stakeholder that prioritised minimum volumes for surgical team references evidence from adult services showing improved outcomes in centres with higher activity volumes. They also reference evidence from practice in the Netherlands who have reviewed the impact of minimum activity levels within children’s services.

11 Suggested improvement area: Access to specialist services

11.1 Summary of stakeholder suggestions

One stakeholder prioritised the need for children and young people being treated for cancer being able to access specialist pain management and anaesthesia services. The stakeholder highlights cases where children and young people have pain management issues that exceed routine pain management protocols and require access to specialists who can use more complex pain management interventions. The need for easy access to specialist anaesthesia services is also prioritised. The stakeholder suggests that children and young people requiring surgery, radiotherapy and other invasive procedures require long term vascular access as part of their treatment. They state that the provision of specialised anaesthesia and acute pain management is integral to the success and patient experience of these interventions.

One stakeholder prioritised access to fertility support services where young people may be at risk of losing their fertility.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Pain management	Section – Pain Management
Specialist anaesthesia services	Section – Pain Management
Fertility preservation	Section – Long- term sequelae

11.2 Selected recommendations from the evidence source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

NICE Guidance CS for CYP

Pain management & anaesthesia

Multidisciplinary protocols should be in place to support the safe and effective use of analgesia and these should be available in all care settings.

Ready access to specialist multidisciplinary pain services should be available for advice and support in complex pain management

There should be adequate provision of general anaesthesia for patients undergoing regular painful procedures (for example, bone marrow and lumbar puncture).

Long- term sequelae

The potential risk of infertility should be considered by the treating oncologist, and there should be fertility advice by appropriately trained personnel for all patients and/or their families at the time of diagnosis and referral to an Assisted Reproduction Treatment Unit as appropriate. There should be access to semen storage for peripubertal and postpubertal boys. The issue of egg storage is currently being researched. Further advice is necessary as children mature and patients should have access to appropriate endocrine and fertility services in accordance with the NICE Clinical Guideline *Fertility: Assessment and Treatment for People with Fertility Problems*.

11.3 Current UK practice

One stakeholder reported that The National Pain Audit and Atlas of Variation demonstrates that access to pain management services is variable throughout the country. Highly specialised pain management services for children and young people have been recognised as a prescribed service and require development.

The NICE guidance for cancer services in young people states that 15% of children and young people with cancer have a high risk of early and irreversible gonadal failure. Work by CLIC Sargent highlights that one of the areas many young people report concerns about is the impact of their cancer and the treatment they receive may have on their fertility[9].

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[9] CLIC argent ‘ More than my Illness’ (2010)

12 Suggested improvement area: Rehabilitation

12.1 Summary of stakeholder suggestions

Rehabilitation was identified by three stakeholders as a priority area for quality improvement. Improvements in care has led to excellent survival rates which results in increasing numbers of children and young people with significant rehabilitation needs. Children who have received treatment for brain tumours were identified as being most likely to require complex rehabilitation support. One stakeholder highlighted the concerns that patients have after treatment from cancer ranging from longer term physical effects to the impact on their schooling and social life.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	Available recommendations from the development source
Rehabilitation	Section - Rehabilitation

12.2 Selected recommendations from the evidence source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion

NICE Guidance CS for CYP

Rehabilitation

There should be clear, agreed routes of referral for rehabilitation, including self-referral, throughout the patient pathway. These routes should be agreed across cancer and children's networks.

Rehabilitation should extend into the community setting, where the involvement of community paediatricians may be beneficial. All children and young people with CNS malignancy should have access to a neuro-rehabilitation service, even years after treatment.

Cancer networks should liaise with other NHS Trusts, primary care trusts/local health boards and other agencies to establish robust rehabilitation equipment strategies and strategies for psychosocial support and for communication with education services.

12.3 Current UK practice

The Teenage Cancer Trust published findings from work they have done with teenagers who have had cancer about their concerns following treatment[10]. The young people they spoke to highlighted concerns around aftercare due to the late effects of treatment, including issues such as managing the significant weight gain due to treatment, or dealing with mobility problems caused by their cancer. Many young people reported that they didn't feel that sufficient support was available to support them with both the physical and psychological impact of having cancer and the resulting treatments.

The NHS Improvement Centre has published a report on work to develop pathways to benefit patient aftercare in cancer services[11]. In the report they reference work conducted by CLIC Sargent with 7-13 years olds that showed within this younger group psychological distress was raised as a key issue. Specific areas raised were;

- anxiety about death, particularly when a friend had died of cancer
- problems with tiredness
- concerns about intellectual deficits following treatment,
- falling behind with school work

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[10] Teenage Cancer Trust (2012) 'Young voices – Transforming the lives of young people with cancer'
[11] NHS Improvement (2011) Designing and implementing pathways to benefit patient aftercare : Continuing to build the evidence

13 Suggested improvement area: Palliative care

13.1 Summary of stakeholder suggestions

A number of stakeholders and a specialist committee member prioritised better access to palliative care for children and young people with cancer where treatment will not lead to a cure. Stakeholders highlighted that the palliative phase can be quite long in some instances and that the palliative care provision needs to be an integrated part of the care package with members of the MDT working alongside palliative care specialists. Two stakeholders highlighted the need for 24 hour end of life care to be available at home for patients where this is requested and appropriate.

The following specific areas for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Palliative care as part of the MDT	Section – Palliative care
Access to 24 hour end of life care at home	Section – Palliative care

13.2 Selected recommendations from the evidence source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion

NICE Guidance CS for CYP

Palliative Care

To ensure there is equitable access to palliative care, which encompasses the core elements in Table 3, there should be a paediatric palliative care network that has:

- a comprehensive community children's nursing infrastructure
- MDTs
- coordination and continuity of care through a system of named key workers
- skilled medical support from general paediatricians with an interest and some training in paediatric palliative care (one per NHS Trust) and from tertiary specialists, either a palliative care nurse or medical consultant (one per principal treatment centre)
- appropriate links with voluntary services and other statutory children's services, including local children's clinical networks
- appropriate medication and specialist equipment should be available. Sensitivity should be shown to a family's needs and wishes with regard to the introduction and later removal of equipment.

Teenagers and young adults with palliative care needs require special provision, again encompassing the core elements in Table 3, which will often entail the development of partnerships between children's and adults' services. These patients require individual packages of care that:

- recognise teenagers and young adults as a distinct group with special needs
- give full involvement in all aspects of decision-making
- are provided by multidisciplinary, multi-agency services
- provide coordinated joint working or transitional care with adult services where appropriate
- address specific staff training needs regarding both palliative care and the management of young people.

There should be sufficient numbers of medical and nursing specialists, the majority of whom are POONS, to provide 24-hour advice and support to families and to local health and social care professionals when patients are receiving palliative care.

13.3 Current UK practice

Data published by the National Cancer Intelligence Network[12] shows that during 2000-2009, there were 2,611 cancer patients who died before 15 years of age and 2,975 who died at age 15-24 years in England. An analysis of the place of death (where this data was available) showed that among children, 47% died in hospital, 39% in their own home, 11% in a hospice or SPCU and 3% in a care home or other place. Among teenagers and young adults, 52% died in hospital, 32% in their own home, 13% in a hospice or SPCU and 3% in a care home or other place.

The Palliative Care funding review commissioned by the Secretary of State for Health was published in 2011.The review highlighted that there is significant variation in palliative service provision for children and young people. One area that was highlighted was the low proportion of state funding provided to the Hospice sector, both within the voluntary sector and in relation to hospices based within NHS services.

Together for Short Lives, an umbrella group for children's hospices reported that in 2011/12 only 113 children with oncology conditions were referred to children's hospices across the UK. However, cancer was the reported cause of death for 250 children and young people in 2010.

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[12] NCIN Place of Death for Children, Teenagers and Young Adults with Cancer in England (2010)

14 Suggested improvement area: Transition

14.1 Summary of stakeholder suggestions

One stakeholder highlighted the need for improved transition periods for young people moving from paediatric services to adult's services. For many young people with cancer the level and range of services they may be receiving can be complex, making the transition particularly difficult.

The following specific area for quality improvement and potential development by the QSAC were highlighted, shown in the table below alongside relevant sections from the source guidance. (Please note the recommendations do not have numbers – therefore the relevant section heading has been used)

Suggested quality improvement area	**Available recommendations from the development source**
Transition	Section - Continuity of care Section – Long-term sequelae

14.2 Selected recommendations from the evidence source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion

NICE Guidance CS for CYP

Continuity of care

The written care/treatment plan should include the individual arrangements for transition from paediatric to adult services and should be informed by protocols/guidelines drawn up by the respective services.

Long-term sequelae

Where possible, patients should be reviewed by an MDT with good communication between paediatric and adult services and age appropriate transitional services.

14.3 Current UK practice

Marie Curie Cancer Care and Together for Short Lives conducted a joint piece of work to look at the experience of young people with palliative cares needs moving into adult services[13]. The primary focus of the report was on the fact that whilst paediatric services have made significant progress in developing transition protocols

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[13] Marie Curie & Together for Short Lives (2012) " Don't let me down"

and working with the young person and their family to prepare them for transition to adult services, transition planning has not had the same level of priority given to it by Adult services. The experiences reported by those who took part in the survey were that adult services were much more impersonal and do not consider the broader aspects of their needs that were more likely to be considered when in paediatric services. Needs such as support to deal with the potential social and mental well-being issues caused by their cancer and its treatment, were referenced.

15 Other suggested improvement areas

A summary of other suggested improvement areas deemed not appropriate for quality statement development or covered by other areas is provided below.

i. Information provision and provision of a care plan

A stakeholder and an SCM raised these as separate points. It was felt that these points would be covered through any drafted statements about age appropriate environment and service provision. The role of an MDT and a key worker / care co-ordinator could include provision of age appropriate information and development of a care plan.

ii. Training

One stakeholder suggested improved provision of training for nurses and allied health professionals. This is covered in a generic paragraph for all topics concerning staff being able to access relevant training to deliver their role.

iii. Cancer registry

One stakeholder highlighted the need to improve submissions to the cancer registry. This aspect of improvement is covered by the work of the cancer registry itself and it was therefore deemed inappropriate for a quality statement.

iv. Development of a patient experience national survey

Several stakeholders suggested including the development of a national cancer patient experience survey similar to that for adults. This is outside the scope of this quality standard as it would need a national policy decision rather than action taken by local commissioners or providers of cancer services. Therefore, this was deemed to be not appropriate for quality statement development.

v. Staff ratios

Several stakeholders prioritised staffing levels within specialist cancer services. The majority of suggestions focused on the need for sufficient levels of trained nursing staff within Principal Treatment Centres and Paediatric Oncology Shared Care Units. The NICE guideline does provide details of the potential cost associated with running a PTC. However, it was decided that as there aren’t any evidence based recommendations on specific staff ratio’s that this was not an appropriate area for a quality statement

vi. Best possible clinical outcomes

Stakeholders prioritised the need for services to ensure that they are adhering to the most recent guidelines and best practice to ensure that all children and young people with cancer have access to the best possible treatment and care. This outcome describes the overarching goal of the quality standard and was therefore not deemed appropriate for a specific quality statement.

Appendix 1 Suggestions from stakeholder engagement exercise

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
The Royal College of Pathologists	Pathology diagnosis in specialist centres	Paediatric cancer samples are small biopsy samples requiring special handling. Paediatric cancers are different from adults requiring specialist interpretation of ancillary investigations such as imunohistochemistry and molecular diagnostics participation in MDTs.	There are data on the implications of delayed or erroneous diagnoses. Vujanić GM, Sandstedt B, Kelsey A, Sebire NJ. Central pathology review in multicenter trials and studies: lessons from the nephroblastoma trials. *Cancer.* 2009 May 1; 115(9):1977-83. Accurate and timely diagnosis is a key component of three of the current diagnostic indicators: five year survival from all cancers in children; 31 day wait from urgent GP referral for suspected cancer to first treatment and referrals, diagnosis and cancer care plan.	Recognition of requirement for specialist commissioning of specialist paediatric surgical pathology and also recognition of paediatric pathology as a separate specialty.
British Society for Paediatric Dermatology (BSPD)	Ensure that the QS for children with cancer signpost to the Guidelines on skin cancer including melanoma.			
British Society for Paediatric Dermatology (BSPD)	Cutaneous malignancies are discussed at local MDT meetings as regional meetings may not be so relevant.			
British Society for Paediatric Dermatology (BSPD)	Ensure close interdisciplinary working (oncology, dermatology, plastic surgeons etc			
The Royal College of Radiologists	**Paediatric Radiotherapy Top Quality clinical outcomes**	1a) Optimal treatment technique for each patient even if this requires referral to another centre. Refer to a different centre if a more beneficial technique is not delivered locally (Intensity Modulated Radiotherapy, Image Guided Radiotherapy, Stereotactic techniques,	The success, or otherwise, of an intervention with radiotherapy is based upon the quality of radiotherapy technique used. In particular cases the modality of radiation therapy used can significantly affect outcome (survival and long term toxicity).	

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		Brachytherapy, Proton Beam Therapy) 1b) Treatment given in clinical trials (NIHR or International). All children treated within a trial protocol when a protocol is available. When not available or appropriate then treatment plans should be in accordance with CCLG clinical, or other, guidance 1c) New radiotherapy techniques to be critically evaluated before widespread introduction 1d) Clinical oncologists fully involved in national and international groups developing clinical trials of multi-modality treatment for children's cancers 1e) The beneficial and adverse effects of radiotherapy to be continually assessed and the effect of changes in practice and interventions to modify outcomes	Trials offer a child the latest in treatment strategy, and given the rarity of paediatric tumours trials are the best way to assess effectiveness of a given strategy over time New radiotherapy techniques should be evaluated by departments prior to widespread use, and should be subject to the usual research/audit processes to ensure that treatment is appropriately evaluated Radiotherapy is a key element in many treatment protocols in this age group and it is essential that clinical oncologists inform such debates to improve outcomes for patients Regular audit on a centre by centre/national basis is required to provide evidence of outcome. Only by doing this can changes in practice be monitored to show corresponding improvement in outcome. Enrolment in national trials is also key to standardising care and monitoring effectiveness	
The Royal College of Radiologists	**2 Paediatric Radiotherapy Excellent patient safety**	2a) Access to specialist paediatric anaesthetic service and PLS. Paediatric General Anaesthetic Service available during the treating day. Paediatric life support	Access to a readily available paediatric anaesthetic service reduces the need for delays in patient treatment if anaesthetisation is the only option for reliable immobilisation during preparation and treatment for radiotherapy. Children who are/become unwell whilst receiving radiotherapy require	Refer to NICE 'Improving Outcomes in Children and Young People with Cancer'/Radiotherapy/Page 47 and RCR/CCLG/SCoR Good Practice Guide for Paediatric

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		equipment available and maintained. Appropriately qualified staff available to deliver life support. 2b) Access to review by paediatric medical and nursing teams. Adequately qualified paediatric trained medical and nursing staff to review patients on treatment if they become unwell, and robust arrangements in place should an escalation of care be required.	appropriate life critical support to be available. Toxicity varies over a course of radiotherapy and regular review is required. In addition, issues not related directly to this treatment should be recognised in a timely way and care appropriately referred/escalated.	Radiotherapy
The Royal College of Radiologists	**3 Paediatric Radiotherapy Good patient experience**	3a) Careful and age appropriate preparation for XRT with play specialists as required. Appropriately trained play specialists available to prepare children for radiotherapy and to support them through treatment 3b) Staff with interpersonal skills and experience to engage with children, teenagers and their families and have the required time and resources available. Appropriately trained staff with experience in the field of paediatric care, access to specialist paediatric radiographer, play specialists and key workers	Play preparation is key to alleviating anxiety in a child undergoing treatment and has been shown to improve the ability of radiotherapy to be given in a safe and timely way (E.g. refer to 'Minimising the use of sedation/anaesthesia in young children receiving radiotherapy through an effective play preparation programme', Scott L *et al* http://www.ncbi.nlm.nih.gov/pubmed/12849605#'). Appropriate and timely engagement with children and families facilitates the radiotherapy pathway and reduces anxiety. Available knowledgeable staff is key to patient/family confidence in the treatment being delivered.	Refer to NICE 'Improving Outcomes in Children and Young People with Cancer'/Radiotherapy/Page 47 and RCR/CCLG/SCoR Good Practice Guide for Paediatric Radiotherapy Also refer to NICE QS15 Quality Standard for 'Patient Experience in adult NHS Services'. NB Information submitted here is felt to be outside the provisions of QS15, hence its inclusion in our response
The Royal College of	**4 Paediatric Radiotherapy**	4a) Adequate numbers of staff in all disciplines including	Given the time critical nature of delivering	Refer to NICE 'Improving Outcomes in Children and Young

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
Radiologists	**Human and financial resources**	paediatric anaesthesia, clinical oncology, dosimetry, physics, radiography and support staff. Full involvement of clinical oncologists and therapy radiographers in the MDT and planning meetings 4b) Adequate time specified in job plans and available in practice to devote to the paediatric radiotherapy component of work 4c) Access to sufficient equipment and staff to enable timely radiotherapy without delays or uncompensated interruptions	radiotherapy in this age group, there should be robustness in the human resourses available (with appropriate expertise) to be able to provide continuity of service in the event of absence/leave. It is important that clinical oncologists are involved from the outset in determining the best treatment for a child. Involvement of other radiotherapy centre staff helps facilitate scheduling and other requirements for preparation Clinic appointments and radiotherapy planning/delivery are time intensive and adequate time is required to deliver a safe service as well as provide an excellent patient experience Given the time critical nature of delivering radiotherapy in this age group, there should be robustness in the technologies available in the event of radiotherapy equipment failure	People with Cancer'/Radiotherapy/Page 47 and RCR/CCLG/SCoR Good Practice Guide for Paediatric Radiotherapy
The Royal College of Radiologists	**5 Paediatric Radiotherapy Child, Teenager and family-friendly environment**	5a) Comfortable and pleasant waiting areas fully equipped with age appropriate toys and amusements 5b) Treatment room equipped with child friendly features 5c) Facilitation of easy access including transport, parking and hotel/hostel family accommodation as required	It is widely accepted that a paediatric friendly environment, with appropriate distractions, alleviates anxiety in patients attending for consultation and treatment As Above Radiotherapy is a multi-day treatment for most paediatric patients. It is essential that travel times are manageable for patients/families and accomodation be available for those patients/families living some distance away (given some regions are geographically disparate and supra-regional referrals may not be uncommon)	Refer to RCR/CCLG/SCoR Good Practice Guide for Paediatric Radiotherapy
Association for Family Therapy and Systemic	. Availability of systemic family therapy services for children and young	Cancer affects families, not only individuals. When cancer occurs in a family, roles and relationships are affected in	NICE guidance (Improving outcomes in children and young people with cancer: Manual Update. NICE, 2005) acknowledges that: 'The dependence of	Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*. Standard 7:

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
Practice	people with cancer and their families and carers	ways which can impact on the health and well-being of all family members. This is especially significant for children and young people with cancer. There is good evidence that appropriate and effective psychological supports can drive significant improvements in the quality of life and relationships of all family members when a child or young person has cancer. Cancer's impact on the psychological and emotional well being of parents, and the importance of supporting parents and carers in their caring role is widely acknowledged. Recent evidence indicates that it is not just informal carers who are impacted upon by cancer, but is felt across wide reaching networks and relationships. Psychological support in cancer care needs to broaden its scope and vision, to connect with wider relational systems. For example, strong evidence now suggests serious implications to the emotional well-being of siblings of children with serious physical illness if their own needs are overlooked or minimised by parents and	children and young people on their families and the profound effect severe ill health and/or death of a child or young person has on other family members are additional important factors that significantly affect all service planning and delivery.' It also stresses that: 'Psychosocial care comprises the psychological and social supportive care for a child or young person and his/her family during active cancer therapy, long-term follow-up and palliative care, as well as for families after bereavement, and includes respite care.' While social care services are recommended to support families, psychological care is too often offered to the individual child or young person alone: *'All children and young people with cancer and their families, in particular siblings, should be offered the advice and support of a social worker to ensure that the needs of the wider family are addressed.* *There should be access to expert psychological support with clear routes of referral in principal treatment centres and other treatment settings. This should include identified psychologists or other members of psychological services with expertise in the care of children and young people with cancer. It is important that use is made of existing services and that access to these is facilitated*./' Many UK paediatric hospitals and services have no staff highly trained and skilled in psychological therapies for *families* affected by serious illness. Family and Systemic Psychotherapists provide effective interventions for families experiencing serious and complex difficulties. Systemic trainings	Hospital Services, Chapter 3: Hospital Standard Part One Child-Centred Services 3.2, p 13 Department of Health, (October 2006) The critically sick or injured child in the District Hospital Setting. Department of Health, (June 2008) Better Care; Better Lives: Improving outcomes and experiences for children and young people with life threatening illness Department of Health (2008) Transitions: moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability Commissioning Children and Young People's Palliative Care Services: A Practical Guide for NHS Commissioners DH, November 2005 Forbat et al (2009) Better cancer care: A systemic approach to practice. Dunedin, Edinburgh. Kyle, RG,. Nicholl, A,. Forbat, L and Hubbard, G (in press) Adolescents' awareness of cancer risk factors and associations with health-related behaviours. *Health Education Research.*

Stakeholder	*Key area for quality improvement*	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		professionals. Department of Health (DOH) and other government reports emphasise the importance of seamless access, reliable consistent support and information for families of critically sick or injured children, children who are palliative or with life threatening diseases and issues involving the transfer of care Systemic Family Therapy works with people in close relationship to help each other by enabling them to express and explore difficult thoughts and emotions safely, to understand each other's experiences and views, appreciate each other's needs, build on family strengths and make useful changes in their relationships and their lives. Family therapy interventions draw on a range of conceptual ideas including systemic, narrative, cognitive-behavioural, and psychodynamic. Family and Systemic Psychotherapists (aka family therapists) in hospital paediatric services engage with families at admission in ways that can help de-stigmatise supportive	support other professionals in recognising and responding to the needs of the child or young person with cancer *and* the important people in their lives, developing family members' and carers' strengths and understandings and helping those in close relationships help each other.	Malcolm, C,. Adams, S,. Anderson, G,. Gibson, F,. Forbat, L. (in press) A relational understanding of sibling experiences of children with rare life-limiting conditions: findings from a qualitative study. *Journal of Child Health Care.* Malcolm C; Hain R; Gibson F; Adams S; Anderson G; Forbat L (2012) Challenging symptoms in children with rare life-limiting conditions: Findings from a prospective diary and interview study with families. *Acta Paediatrica*. 101(9):985-92 Hubbard, G,. Illingworth, N,. Rowa-Dewar, N,. Forbat, L, and Kearney, N. (2010) Treatment decision making in cancer care: The role of the carer. Journal of Clinical Nursing. 19 (13/14): 2023-2031. Illingworth, N,. Forbat, L,. Hubbard, G,. Kearney, N. (2010) The importance of relationships in the experience of cancer: a re-working of the policy ideal of whole-systems working. *European Journal of Oncology Nursing.* 14 (1): *23-28.*

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		interventions. Family and Systemic Psychotherapists also offer consultation and supervision to a wide range of medical and non medical professionals involved in patient care, aiming to improve working relationship between individuals and systems, facilitating open dialogue between staff and a greater coherence of bio/psycho/social approaches to patient and family care		*Sloper, P (2000).* Experiences and support needs of siblings of children with cancer*. Health & Social Care in the Community, Vol 8, Issue 5 p298.* Sloper, P, and While, D (1996) Risk factors in the adjustment of siblings of children with cancer. *Journal of Child Psychology and Psychiatry*, 37, 597-607.
Association for Family Therapy and Systemic Practice	The list of indicators should include data on availability of psychological support for patients and families/carers, not only data on physical health	As above	As above	As above
CLIC Sargent	Access to a cancer key worker for every child and young person with cancer	A key worker for every child or young person with cancer (0-24) was a key recommendation of the NICE *Improving Outcomes in Children and Young People with Cancer* guidance. The cancer key worker takes a lead role in coordinating the provision of care & support at home and in school with the treatment children and young people are receiving in hospital. They ensure community teams, education and social care are involved in developing the interventions the patient and their family need. This both ensures that	Unfortunately despite the NICE guidance being published in 2005, there is a still a significant gap in access to key workers, particularly for the 16-24 age group. In 2010 CLIC Sargent secured a charity of the year partnership with Tesco which was focused solely on funding a three year pilot project to meet this gap in provision and evaluate the impact of implementing a holistic key worker model for children and young people with cancer. This has enabled us to fund 19 specialist nurse key workers throughout the UK, focused on supporting children with cancer, aged 0 to 18-years-old, based at each of the 19 principal treatment centres in the UK. However, we believe this is a priority area for continued improvement as provision is still heavily dependent on the voluntary sector and should be a baseline service to ensure that children and young people and their families receive the best care and support possible. Access to cancer key workers for teenagers	CLIC Sargent (2008) *More Than My Illness: Delivering quality care for children with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%200%20to%2018%202008.pdf CLIC Sargent (2010) *More Than My Illness: Delivering quality care for young people with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%20original.pdf Further details: http://www.clicsargent.org.uk/content/more-my-illness CLIC Sargent (2013) *Young*

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		the care and support the patient receive is coordinated as well as enabling them to spend as much time at home during treatment as possible. There is also evidence that the key worker is greatly valued by patients themselves and contributes to an enhanced experience. The cancer key worker role has the capacity to influence optimal outcomes in all 5 domains of the NHS Outcomes Framework.	and young adults (TYAs) 16-24 is also low, despite CLIC Sargent's own evidence suggesting young people really value having a named worker to coordinate the support they need.	*person's community worker evaluation report* (to be published later this year)
CLIC Sargent	Provision of age-appropriate care	A key feature of NICE guidance is that children and young people with cancer should have their care managed by an age-specific multi-disciplinary team (MDT). CLIC Sargent's *More Than My Illness* report also highlighted the important role of the MDT in providing tailored support to meet young people's individual and changing needs, based on skilled, multi-disciplinary needs assessments.	Whilst the model for paediatric care is fairly well established, we are aware that teenagers and young adults (TYAs) 16-24 are not always being referred to the appropriate TYA MDT. As a result, they may lose out on access to crucial psychosocial and other support services. This is particularly important for those patients aged 19-24 who may choose to have some of their treatment delivered in a local adult cancer centre. Age appropriate care for children should also include adequate access to play specialists who, (particularly for the younger child) help them to make sense of their experience. In adult care improving outcomes in this area has been driven by Advanced Communication Skills Training. For children play specialist provision is being eroded due to financial pressures and because young children do not have the voice to fight for this need.	CLIC Sargent (2008) *More Than My Illness: Delivering quality care for children with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%200%20to%2018%202008.pdf CLIC Sargent (2010) *More Than My Illness: Delivering quality care for young people with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%20original.pdf
CLIC Sargent	Access to specialist oncology social care and holistic needs assessment	The NICE guidance also highlights the importance of psycho-social care for children and young people with cancer at all stages of the pathway. The provision of specialist social care support, activity and group work (including	The specialist oncology social worker has an important role to play in assessing the family's non-clinical needs, including in relation to education and employment, developing a care plan and delivering against this plan. They also work closely with the key worker (often a specialist nurse) to ensure social care and support for the child or young person is delivered.	CLIC Sargent (2008) *More Than My Illness: Delivering quality care for children with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%200%20to%2018%202008.pdf

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		access to peer support) are all important contributors to this holistic approach. The Teenage and Young Adult cancer measures also explicitly mention the need for social work professionals to work with the 16-24 age group, but remains an oversight in children's guidance	CLIC Sargent is the UK's leading provider and funder of social care to children and young people with cancer and their families. We currently register approximately 85% of children and young people who are diagnosed with cancer in the 0-24 age group, demonstrating that gaps still exist. Similarly, there is still a gap in the provision of activity and group work for young people with cancer, as this is often not funded by the NHS.	CLIC Sargent (2010) *More Than My Illness: Delivering quality care for young people with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%20original.pdf CLIC Sargent (2012) *No child with cancer left out: the impact of cancer on children's primary school education* http://www.clicsargent.org.uk/content/no-child-cancer-left-out
CLIC Sargent	Spending time safely at home during treatment	CLIC Sargent published two reports in the *More Than My Illness* series which highlighted the fact that most children and young people with cancer would prefer to spend more time at home during treatment whenever this is safe to do so. 97% of those children who took part *More Than My Illness* said it was important to be able to go home during treatment. 89% of young people said it was important to get clinical support at home.	As part our *A Long Way from Home* research, CLIC Sargent found that 77% of childhood cancer patients under the age of 18 do not live in a city with a principal treatment centre and that the average round trip distance travelled (by road) is 60 miles, taking around one hour 50 minutes. For patients in day care, this can mean travelling 60 miles in a single day on a regular basis. Our *Counting the Costs of Cancer* report found that travel and car parking were one of the top three additional expenses that families face as a result of cancer. It is therefore important that patients are able to receive as much care as close to home as possible. This ties in with the cancer key worker quality statement as the key worker can help to facilitate safe care in the community and at home.	CLIC Sargent (2008) *More Than My Illness: Delivering quality care for children with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%200%20to%2018%202008.pdf CLIC Sargent (2010) *More Than My Illness: Delivering quality care for young people with cancer* http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%20original.pdf CLIC Sargent (2010) *More Than My Illness: Summary of Consultation* *http://www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/More%20Than%20My%20Illness%200%20to%2018%20summary%20of%20consultation%202008.pdf* CLIC Sargent (2010) *A Long Way From Home: The impact of travel on children and young people with*

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
				cancer http://www.clicsargent.org.uk/content/long-way-from-home-report CLIC Sargent (2011) *Counting the Costs of Cancer: the financial impact of cancer on children, young people and their families* http://www.clicsargent.org.uk/content/counting-costs-cancer-report CLIC Sargent (2010) *The Impact of Cancer on a Child's World* http://www.clicsargent.org.uk/content/impact-cancer-childs-world
Royal College of Surgeons of Edinburgh	Surgical Procedures	The Royal College of Surgeons of Edinburgh recommends that surgical procedures, including biopsy, should not take place in a child with suspected cancer until the case has been discussed with the regional paediatric oncology team. Most of the problems that arise in children and young people with cancer occur in cases where there was ill-advised surgery up front.	This is a key area for improvement because it will reduce preventative problems and increase better care.	
Royal College of Surgeons of Edinburgh	Presence of a formal children's surgical network	In most regions there are clear clinical pathways, and children with suspected cancer are referred to Tertiary services, usually the paediatric oncologists rather than paediatric surgeons. The presence of a formal children's surgical network can strengthen these pathways, so that if a general surgeon is in doubt, they can contact the	This is a key area for improvement because it will strengthen pathways, to provide reassurance and reduce doubt.	

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		network prior to surgery/biopsy.		
Faculty of Pain Medicine of the Royal College of Anaesthetists	Pain management refractory to the WHO guidelines and analgesic ladder	Some cancer pain, particularly neuropathic pain and diffuse pain in the terminal stages of illness, is not well controlled by the WHO guidelines. Access to specialist pain management services enables the use of interventional procedures, adjuvant drugs and opioid rotation that are not always familiar to oncology and palliative care physicians.	Pain relief is a basic requirement, which in the hospital environment is entrusted to healthcare professionals (1). The National Pain Audit (2) and Atlas of Variation (3) demonstrate that access to pain management services is variable throughout the country. Highly specialised pain management services for children and young people have been recognised as a prescribed service and require development (4). Further information on cancer pain management is available from the British Pain Society (5).	1. Department of Health. Getting the right start: National service framework for children. Standard for hospital services. DH, London 2003. 2. National Pain Audit. Dr Foster and the British Pain Society 2012 3. Atlas of Variation. Right Care 2011 4. National Programmes of Care and Clinical Reference Groups. E2b Highly Specialist Pain Management Services for Children and Young People. 5. Cancer Pain Management. British Pain Society 2010.
Faculty of Pain Medicine of the Royal College of Anaesthetists	High quality specialised anaesthesia and acute pain management services	Children and young people with cancer undergo surgery, radiotherapy, invasive procedures and require long term vascular access as part of their treatment. The provision of specialised anaesthesia and acute pain management is integral to the success and patient experience of these interventions.	Improving Outcomes in Children and Young People with Cancer recognises the importance of specialised anaesthesia and acute pain management services (1). Critical interdependencies are well described and referenced in the service specification for Paediatric Oncology (2).	1. Guidance on Cancer Services. Improving Outcomes in Children and Young People with Cancer: The Manual. NICE 2005. 2. National Programmes of Care and Clinical Reference Groups. E4 Paediatric Oncology.
Bone Cancer Research Trust	Improving diagnosis times for CYP cancers in order to increase survival rates.	While the overall survival rates for children's cancers as a whole has increased from around 60% to around 80% since the 1980's; the five year survival rate for bone sarcoma patients has plateaued at	The correlation between tumour size at the time of diagnosis and decreased survival has already been demonstrated, as has the increased chance of metastases with tumour size at time of diagnosis. The average diameter of bone tumours by the time of correct diagnosis is 10cm (the size of a can of beans).	NCIN Report Number R12/05: Bone Sarcoma Incidence and Survival; October 2012. West Midlands Cancer Intelligence Unit Grimer RJ; Size Matters for Sarcomas! *Ann R Coll Surg Engl*

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		around 50%. One of the driving factors in the low survival rates for these cancers is thought to be delayed diagnosis, caused by repeated misdiagnoses in primary care. In patient consultation sessions ran at BCRT's 2012 patients conference, early diagnosis was identified as one of the top three priorities for patients and their supporters.	The average time taken for patients to receive a correct diagnosis of bone sarcoma is 16 weeks from the onset of symptoms, although this drops to 44 weeks for chondrosarcoma patients. BCRT is deluged with anecdotal evidence of misdiagnoses and delays in referral from primary care for X-ray, and subsequently to specialist Bone Cancer Centres for bone biopsies and diagnosis (See BCRT website) The key factors to improved diagnosis here are: 1) Increased GP awareness of primary bone cancers and other CYA cancers. 2) Faster GP referral for X-ray when presented with symptoms that suggest a possible diagnosis of primary bone cancer.	2006; 88: 159-524 CancerStats: Childhood Cancer – Great Britain & UK report November 2010, Cancer Research UK CancerStats: Teenage and Young Adult Cancer report March 2013, Cancer Research UK
Bone Cancer Research Trust	Provision of age-appropriate care environments for children and young people (CYP) with cancer.	The NICE guidance on Improving Outcomes in Children and Young People with Cancer (2005) makes a series of recommendations in this area, including: • All aspects of care for children and young people with cancer should be undertaken by appropriately trained staff • All care for children and young people under 19 years old must be provided in age-appropriate facilities. Young people of 19 years and	The NICE guidance recommendations on providing age-appropriate care are not being implemented in practice. Teenagers and young adults (TYA) who are too old for children's wards often placed in adult wards alongside elderly cancer patients. This alone can be very distressing for young patients, but in addition the placing of TYA patients in adult wards means that these patients do not have access to the age-specific health information and specially trained staff that provide the best care for this age group. The BRIGHTLIGHT study, funded by the National Institute for Health Research, began recruiting TYA cancer patients in 2012. This study aims to follow the progress of all TYA cancer patients diagnosed in 2012-2013 in England, in order to quantify the health outcomes of age-appropriate care. The fact that this	NICE guidance: http://www.nice.org.uk/nicemedia/pdf/C&YPManual.pdf The BRIGHTLIGHT study: http://www.brightlightstudy.com

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		older should also have unhindered access to age-appropriate facilities and support when needed. We would support these criteria as being key measurements of care in this area.	study is being undertaken suggests that age-appropriate care does vary in England. This variation in quality is not acceptable as it has a significant detrimental impact on patient experience.	
Bone Cancer Research Trust	CYP cancer patients should all have access to a named Clinical Nursing Specialist (CNS) during their diagnosis, treatment and recovery.	The importance of this can be summed up with the following quote form the 2011/12 CPES: 'In 2011/12 the importance identified in 2010 of patients having the name of a Clinical Nurse Specialist (CNS) is confirmed. Perhaps the most important finding of both the 2011/12 and 2010 CPES is that on almost all questions, patients with a CNS give more positive scores than do patients without a CNS'.	CNS are a crucial source of information and support for young cancer patients and their families. All TYA patients should be provided with a named CNS who is trained in providing care for TYA patients. However, not all patients are allocated a CNS and as such their experience is less positive and at times very frustrating compared to those that do have a CNS. The provision of such specially trained staff is also recommended in the Improving Outcomes in Children and Young People with Cancer (2005).	Cancer Patient Experience Survey 2011/2012, Department Of Health NICE guidance: http://www.nice.org.uk/nicemedia/pdf/C&YPManual.pdf
Bone Cancer Research Trust	The inclusion of CYP in the Cancer Patient Experience Survey (CPES)	The CPES has been used to inform guidance around cancer care, by highlighting groups of cancer patients whose level of care is not satisfactory. The youngest patients questioned in this survey are 16 years old at the time of diagnosis. This means that the experiences of younger patients are not formally monitored and so areas for	Cancer is the leading cause of disease-related death in children and young adults. Over 1500 young people under the age of 14 are diagnosed with cancer each year. Anecdotal evidence presented to BCRT shows that the levels of care offered to young people vary across the UK but there is currently no formal measure to assess this. The 2012 NCPES showed that the youngest patients questioned (16 years) were among the least satisfied groups of patients surveyed.	CancerStats: Childhood Cancer – Great Britain & UK report November 2010, Cancer Research UK CancerStats: Teenage and Young Adult Cancer report March 2013, Cancer Research UK Cancer Patient Experience Survey 2011/2012, Department Of Health

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		service improvement are not identified.	This is a strong indication that more research needs to be done to identify the key factors that are diminishing the experience of cancer care for young patients. A first step to this would be extending the age range of the survey to identify whether the experiences of under-16s are similarly bad, and to extend the breadth of the survey to cover questions about age-specific care provision.	
Bone Cancer Research Trust	Provision of age-appropriate levels of information about cancer and about the tests, procedures and treatments that the CYP cancer patients are likely to undergo	Young people have less experience of the NHS, hospitals and healthcare in general than older adult patients. Therefore, younger patients require more information about their cancer, tests, procedures etc. than older patients. The NHS Choices Information Prescriptions system aimed to meet some of these needs, with specific information pathways for both bone sarcoma patients and CTYA patients. However with the closure of NCAT and the future of NHS Choices currently undecided, the Information Prescriptions System is currently live online but it is impossible for partner charities to modify content or upload new information.	The 2011/12 CPES states that the youngest patients surveyed (ages 16-25) have a more negative experience of their cancer care than older patients, and breaks down the reasons behind this: 'As in 2010, clear themes emerge in relation to young patients, related specifically to ensuring that explanations of treatment, condition, tests etc. are given in a fashion which recognises the lack of hospital experience which many of this age group will have at the time they start treatment' The CPES showed that only 50% of patients aged 16-25 fully understood their cancer diagnosis, compared to 70% or more of patients aged 50 and over. Of additional interest for BCRT is the data showing that sarcoma patients were the group least likely to be given specific information about their condition. Only 44% sarcoma patients agreed that they had been 'Given easy to understand information about the type of cancer they had'.	Cancer Patient Experience Survey 2011/2012, Department Of Health
Royal College of Paediatrics and Child Health	Brian: was submitted in this format, may need separating as appropriate 1. Combination of better			• Noyes J, Hastings RP, Lewis M, Hain R, Bennett V, Hobson L, et al. Planning ahead with children with life-limiting conditions and their

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
	cure rate and developments in palliative care techniques mean that it is impractical for oncologists to sustain competencies in symptom control. 2. Nevertheless, 25% children with cancer still die from it, so it is a significant issue. Oncologists need to work with palliative care teams. 3. Improvements in time to progression mean that the 'palliative phase' can be very long - especially for children with brain tumours - so even more of an issue. 4. Increasing emphasis on giving choice to families about place of care and death means domiciliary visits by doctors (as well as nurses) increasingly important - difficult to manage for oncologists due to time constraints.			families: development, implementation and evaluation of 'My Choices'. BMC Palliat Care. 2013;12:5. Epub 2013/02/07. • Gomes B, Calanzani N, Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. Palliat Med. 2012;26(2):102-7. Epub 2012/01/20. • Rudolph KD, Dennig MD, Weisz JR. Determinants and consequences of children's coping in the medical setting: conceptualization, review, and critique. Psychol Bull. 1995;118(3):328-57. Epub 1995/11/01. • Vickers J, Thompson A, Collins GS, Childs M, Hain R. Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. J Clin Oncol. 2007;25(28):4472-6. • Vickers JL, Carlisle C. Choices and control: Parental experiences in pediatric terminal home care. Journal of pediatric oncology nursing. 2000;17(1):12-21.

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
				- O'Leary M, Krailo M, Anderson JR, Reaman GH. Progress in childhood cancer: 50 years of research collaboration, a report from the Children's Oncology Group. Semin Oncol. 2008;35(5):484-93. Epub 2008/10/22. - Hain R, Heckford E, McCulloch R. Paediatric palliative medicine in the UK: past, present, future. Arch Dis Child. 2012;97(4):381-4. Epub 2011/11/01.
Children's Cancer and Leukaemia Group	Provision of age-appropriate Diagnostic Radiology and Imaging Services for children with cancer	Access to specialist diagnostic services is essential for the timely diagnosis and treatment of children with cancer. Delay in diagnosis adversely affects outcome, may cost lives or result in avoidable long-term disability. The Headsmart Campaign (see supporting information) has recently highlighted delay in access to imaging as a major cause of relatively poor outcomes for children with brain tumours in the UK.	Recent recommendations to improve access to high quality imaging services for children and young people have not yet been fully implemented ('*Delivering quality imaging services for children*' Department of Health, March 2010).: The service should ensure that all appropriate imaging and image- guided biopsy modalities are available to patients in a timely manner. The service should agree imaging modalities and their specific indications. Where specific investigations are not available in a particular trust, clear and timely arrangements should be made for them to be carried out in other centres as agreed by the commissioners – this is especially important for advanced modalities such as PET (positron emission tomography) which are available in only a few specialist centres but have an increasingly important role in the diagnosis and staging of lymphoma and other tumours.	*Delivering quality imaging services for children*. Department of Health, 13732 March 2010 Headsmart Campaign: www.headsmart.org.uk

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			All services should be supported by a three-tier imaging network. Within the network; it should be clearly defined which imaging test or interventional procedure can be performed and reported at each site Robust procedures should be in place for image transfer for review by a specialist radiologist, supported by appropriate contractual and information governance arrangements, and arrangements should be in place for patient transfer if more complex imaging or intervention is required Common standards, protocols and governance procedures should be applied. All radiologists, and radiographers should have appropriate training, supervision and access to continuing professional development All equipment should be optimised for paediatric use and use specific paediatric software wherever appropriate, to ensure optimum performance and to keep the dose of ionising radiation as low as possible.	
Children's Cancer and Leukaemia Group	Palliative care coordination and planning	Well coordinated palliative care can improve the quality of life for children with incurable disease and their families. Palliative care should include proactive symptom management, access to hospice and short break care, access to therapies, and practical, emotional and spiritual support for the child, parents, siblings and extended family. Palliative care is best delivered by a coordinated multi-disciplinary multi-agency team.	Coordination of care across different organisations (acute and community NHS services, voluntary sector, education and social care) is time-consuming and demanding. The Department of Health has set up a pilot study to gather the information needed for the creation of a new funding system for palliative care, for adults and children, and to consider the proposals of the independent Palliative Care Funding Review Report. It is anticipated that the new tariffs for palliative care will be launched in 2015. It is important that the new tariffs are supported by appropriate quality standards, including standards relating to joint working by different sectors.	http://palliativecarefunding.org.uk/wp-content/uploads/2011/06/PCFRFinal%20Report.pdf https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/146960/dh_131546.pdf.pdf
Children's Cancer	Provision of psycho-social	Children with cancer and their	Psycho-social assessment and support is frequently	Please see research evidence

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and Leukaemia Group	assessment and support for families of children with cancer	families undergo a profoundly traumatic experience as they come to terms with a cancer diagnosis and its implications. The effects on families are wide-ranging and long-lasting. All children and their families should have access to support by a wider multiprofessional team, including but not limited to clinical nurse specialists, play specialists, social workers, counsellors and psychologists/psychotherapists. Evaluation and assessment of children and families' psycho-social needs is an important first step in planning and providing appropriate emotional support with a view to improving quality of life for children and their families and enabling long-term adjustment and reduction of long-term psychological morbidity	provided by the voluntary sector, with uncertain revenue streams. It is important to recognise the importance of providing this support to families by defining appropriate standards for assessing, planning and delivering supportive care.	N Mammone et al Bereaved parents' perspectives on their needs Palliative & Supportive Care (2008) 6, 33–41 Anne E. Kazak Evidence-Based Assessment, Intervention and Psychosocial Care in Pediatric Oncology: A Blueprint for Comprehensive Services Across Treatment Journal of Pediatric Psychology pp. 1–12, 2007 doi:10.1093/jpepsy/jsm031
Children's Cancer and Leukaemia Group	Rehabilitation for children after treatment for cancer	It is recognised that the excellent survival from childhood cancer results in increasing numbers of children with significant rehabilitation needs. Children who have received treatment for brain tumours represent the largest and most severe group. Rehabilitation is recommended in the NICE guidance for children and young people with cancer across the range of tumours treated.	There are currently no standards for the provision of rehabilitation services following treatment for childhood cancer in the UK. There are no agreed standards for assessment or evaluation of interventions. Furthermore access to therapies essential for rehabilitation is non-uniform and subject to geographical variation. Some therapies such as Speech and Language therapy and Psychology are not accessible to many patients to allow them to re-integrate into their communities and reach their full potential.	Please see proposed Specialist Commissioning Service Specification for Paediatric Neuro-rehabilitation https://www.engage.england.nhs.uk/.../e9dservicespec.pdf
Children's Cancer and Leukaemia	Organisation of care	Children and younger teenagers diagnosed with	As outlined clearly in NICE Improving Outcomes Guidance for Children and Young People with	[1] The Royal College of Radiologists, Society and College

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Group		cancer or leukaemia should be treated in nationally commissioned specialist paediatric oncology and haematology principal treatment centres, in conjunction with accredited paediatric oncology shared care units, with equity of access to the best care possible regardless of geography or social circumstances. Treatment plans should be formulated by discussion in appropriately constituted multi-disciplinary team meetings. Where possible, they should be offered the opportunity for treatment in NIHR portfolio national or international clinical trials. When these are not available or appropriate, treatment plans should be in line with national guidance (eg CCLG guidelines) where available. Children and younger people requiring radiotherapy should be treated in accordance with national good practice guidance for paediatric radiotherapy [1] and molecular radiotherapy [2]	Cancer 2005	of Radiographers, Children's Cancer and Leukaemia Group. Good Practice Guide for Paediatric Radiotherapy. London, the Royal College of Radiologists, December 2012. ISBN 978-1-905034-59-8. [2] British Institute of Radiology Molecular Radiotherapy Working Party. BIR Report 23: Molecular Radiotherapy in the UK: Current status and recommendations for further investigation. London, The British Institute of Radiology, 2011. ISBN13: 978-0-905749-70-9.
Children’s Cancer and Leukaemia Group	Electronic prescription of chemotherapy for all children and young people with cancer	It is recognised that systems for electronic prescription of chemotherapy reduce errors and increase safety in this high-risk area. Whilst robust	Safety in prescribing of chemotherapy is of paramount importance. Manual systems not only increase the risk of errors but do not allow for easy collection of data to identify what treatment has been given. Few of the systems currently used in adult	

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		and effective adult systems are in routine use, only a minority of children's cancer services have access to these systems.	practice are suitable for the complex prescribing in children's cancer and there is in effect exclusion of children from these systems. Standards are required to guide service providers in the procurement of systems such that the needs of children cannot be overlooked.	
Royal College of Nursing	1) Robust nurse staffing levels and skill mix and training for paediatric oncology patients	Expert nursing is central to the safe care of children and young people with cancer. Complex chemotherapy regimens and the requirement for timely supportive care mean that much of the care they require falls into the domain of the registered nurse. It is recognised that paediatric oncology patients have high levels of dependency.	Peer Review reports have shown that there is variation in staffing levels in both Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs) nationally. Only 54% of PTCs are compliant with Peer Review Measure on Ward Staffing derived from Improving Outcomes Guidance for Children & Young People with Cancer There is no Peer Review Measure in relation to Day Care nurse staffing, and yet treatment (both chemotherapy and supportive care) is often and increasingly administered in the Day Care setting	NICE (2005) Improving Outcomes Guidance for Children & Young People with Cancer National Cancer Peer Review Programme Manual for Cancer Services: Children's Cancer Measures (V2) 2011 National Cancer Peer Review Programme Report 2011/12 (Children's) Royal College of Nursing (2003) Defining staffing levels in children's and young people's services Royal College of Nursing (2010) Guidance on safe staffing levels in the UK
Royal College of Nursing	2) Improve access to training and education for nurses and AHPs	There is a lack of access to appropriate post-graduate training, as number of nurses requiring such training are small in any one Higher Education Institution. There is a lack of collaboration in provision and commissioning of education nationally.	Provision of nurse training in PTCs and shared care is locally determined and variable - Only 62% of PTCs have the required number of nurses trained to the 'external training' level required by Peer Review - There are a limited number of universities offering post-graduate training in cancer care for children & young people (none in the north of England currently) There is very little access to formal training for Allied Health Professionals (AHPs) in the care of children and young people with cancer. There are opportunities for inter-professional and	NICE (2005) Improving Outcomes Guidance for Children & Young People with Cancer National Cancer Peer Review Programme Report 2011/12 (Children's)

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
			multidisciplinary training.	
Royal College of Nursing	3) Improve access to 24 hour End of Life care at home for children and young people with cancer	Access to 24 hour End of Life Care is fundamental to providing choice in the place of death for children, young people and their families.	There is variable provision of Children's Community Nursing services across the UK, with variations in whether they provide a 5 or 7 day service. Few provide a 24 hour service, although some will do so for End of Life Care outside formally commissioned and funded services. There is variation in the age ranges that both adult and children's community teams operate, which means that patients between the age of 16 & 18 years can fall between Children's Community teams (may go up to 16 years only) and Adult teams (may take over 18 years only).	
Royal College of Nursing	4) To develop a national patient experience survey for children and young people with cancer	The adult cancer patient experience survey has driven many of the improvements in cancer care and support, but there is no national survey of the views of children, young people and their families.	The 'adult' cancer patient experience survey only includes patients over 16 years; the experiences of patients from 16 – 25 years in the survey are less positive than for patients aged 25 - 75. There is not a national mechanism for listening to, and hearing, the voice and experience of children and young people.	Department of Health (2012) Cancer Patient Experience Survey
Royal College of Nursing	5) Improve integration of care for children and young people with cancer across health and social care settings	The need for integrated care is recognised not only in the IOG for Children and Young People with cancer, but also in the report of the Children and Young People's Health Outcomes Forum. A clinical network is the best way to provide integrated care across the patient and family pathway.	Peer Review reports show that provision and integration of shared care services remain variable across the country and the commissioning of services within PTCs, Paediatric Oncology Shared Care Unit (POSCU) and Primary Care remains fragmented; there is a risk this will deteriorate with changes to health and social care organisations (including the demise of the cancer networks). There is patchy provision of Children's Community Nursing services across the country and differences in age boundaries between different organizations and teams.	NICE (2005) Improving Outcomes Guidance for Children & Young People with Cancer Department of Health (2012) Report of the Children and Young People's Health Outcomes Forum
Teenage Cancer Trust	1. Reported patient experience satisfaction	We know that across the pathway young people with cancer have a different experience and specific challenges of health services than other groups of patients.	Over recent years in the UK there have been significant developments in the recognition of the specific health service needs of teenagers and young adults with cancer, which was first acknowledged in the NICE Improving Outcomes Guidance for Children and Young People with Cancer, 2005. Since the	NICE Improving Outcomes Guidance for Children and Young People with Cancer, 2005 http://www.nice.org.uk/nicemedia/pdf/C&YPManual.pdf

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		The 13-24 year old group of cancer patients have a different biology and also have different cancers most common to this age group which affects treatment practice and protocols. They also face challenges around traditional health service structures which are fixed around paediatric and adult services. These are not reflective of the age appropriate needs of teenagers and young adults.	publication of this guidance there has been a system response of approving Principal Treatment Centres for Teenagers and Young Adults with Cancer, peer review measures for Teenage and Young Adult Cancer Services, and most recently a specialised commissioning Teenage and Young Adult Clinical Reference Group. A recent publication sets out an updated version of the quality of care needed to improve outcomes for teenagers and young people with cancer called The Blueprint of Care for Teenagers and Young Adults with Cancer. In surveys run by Teenage Cancer Trust at our Find Your Sense of Tumour conference with over 200 young people with cancer we've found that 1 in 4 young people with cancer had to visit their GP four times or more before being referred for a diagnosis. These findings have now been substantiated by research from the Royal College of GPs national audit of cancer diagnosis and analysis of results from the National Cancer Patient Experience Survey responses to questions about diagnosis. The National Cancer Patient Experience Survey findings from 2010 and 2012 also demonstrated that cancer patients aged 16-25 often have less positive views about their treatment, and there are clear areas relating specifically to communication and choice which young people report worse experience on than other age groups.	The Blueprint of Care for Teenagers and Young Adults with Cancer http://symphony.teenagecancertrust.org/workspace/documents/Blueprint-of-care.pdf Teenage and Young Adults Cancer Measures http://www.england.nhs.uk/npc-crg/group-b/b17/ Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England *Georgios Lyratzopoulos, Richard D Neal, Josephine M Barbiere, Gregory P Rubin, Gary A Abel,* www.thelancet.com/oncology Published online February 24, 2012 DOI:10.1016/S1470-2045(12)70041-4 Report for the National Awareness and Early Diagnosis Initiative 'Cancer in Primary Care AN ANALYSIS OF SIGNIFICANT EVENT AUDITS (SEA) FOR DIAGNOSIS OF LUNG CANCER AND CANCERS IN TEENAGERS AND YOUNG' Mitchell E, Macleod U, Rubin G Updated: August 2009

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
				Smith S, Davies S, Wright D, et al. The experiences of teenagers and young adults with cancer — results of 2004 conference survey. Eur J Oncol Nurs ; 11(4): 362–368. Royal College of GPs National Audit of Cancer Diagnosis in Primary Care http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/media/Files/Policy/National%20Audit%20of%20Cancer%20Diagnosis%20in%20Primary%20Care%20Document%20FINAL%20with%20amends%201Dec11%20RW.ashx National Cancer Patient Experience Survey findings report: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf.pdf
Teenage Cancer Trust	2. All young people with cancer to be notified to the teenage and young adult multi disciplinary team at the teenage and young adult principal treatment centre	Notification of individual patients ensures they are discussed by the specialist team and their individualised care is planned accordingly. Notification of the patient group provides high quality diagnostic details and identifies the institutions where	A recent study by the National Clinical Intelligence Network shows that referrals to the teenage and young adults multi-disciplinary teams is highly variable across the country, by cancer types, and by age groupings. Some very low levels of notifications to the PTC were found in this study, which must be addressed to ensure all young with cancer have access to the appropriate care and support enabled through the	Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010, NCIN, Children, Teenagers and Young Adults SSCRG http://www.google.co.uk/url?sa=t&rct=j&q=ncin%20tyac%20notificati

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		patients are managed which helps identify how different pathways ultimately influence outcomes	PTCs TYA MDT : • 62% of patients aged 15 to 18 years were notified by a PTC or CCLG centre • 34% of patients aged 19 to 24 years were notified. • For 15 to 18 year olds percentage notifications ranged from 21% for skin carcinomas and melanomas to 87% for bone tumours. The pattern was the same for patients aged 19 to 24 years; 14% for skin carcinoma and melanoma patients to 69% for bone tumours. • For patients aged 15 to 18 years the percentage of patients notified ranged from 48% to 74% across GORs and from 35% to 87% across cancer networks. • For the 19 to 24 year olds percentage notifications ranged from 20% to 54% across GORs and from 6% to 70% across cancer networks. • An additional 7% of patients who were not notified were identified as receiving treatment at a PTC. • A large number of non-PTC trusts were recorded as treating non-notified patients.	ons&source=web&cd=2&ved=0CDMQFjAB&url=http%3A%2F%2Fwww.ncin.org.uk%2Fview%3Frid%3D2124&ei=Bs2lUdOsE-Wr0AXPuoGACw&usg=AFQjCNE0DKMFCH_aXAL9AsgsIsM-6yUfPA&bvm=bv.47008514,d.d2k National Cancer Patient Experience Survey findings: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf.pdf
Teenage Cancer Trust	3. Access to age specific care and support, managed by a Teenage and Young Adult Clinical Nurse Specialist	This is in line with NICE guidance which states that patients with cancer should have unhindered access to a key worker who should be a nurse specialist whose role is to provide continuity of care and support. The National Cancer Patient Experience Survey findings have validated the role CNS play in improving patient experience, demonstrating their important role in the care	As detailed above, the teenage and young adult cancer speciality has grown significantly over the past 20 years. It is important that the staff working with TYAs are appropriately qualified and competent to meet the needs of this group of patients. Teenage Cancer Trust is currently leading work with the Royal College of Nursing to define TYA cancer nursing competencies together with an education and training framework. This will be published through the RCN in spring 2014. Teenage Cancer Trust also funds a specialist professional course in the care of Teenagers and	The Blueprint of Care for Teenagers and Young Adults with Cancer http://symphony.teenagecancertrust.org/workspace/documents/Blueprint-of-care.pdf National Cancer Patient Experience Survey findings: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		pathway. This is particularly important in this patient group to ensure that have informed choice and access to age appropriate care and pathways.	Young Adults with Cancer at Coventry University. It is essential that this support and training for nurses working with TYAs is available and accessible so the specialty can continue to grow and	National-Report-2011-12.pdf.pdf
Teenage Cancer Trust	4. Unhindered access to appropriate clinical trials	In such a small and specialist group accrual to clinical trials is essential if care is to advance and ultimately outcomes for all are to improve. Despite this the trial is not open in many centres where young people are treated. Access to clinical trials is a proven way of improving patient outcomes.	There is significant variation in survival rates by type of cancer in teenagers and young adults, with very low survival of around 55% for cancers like soft tissue sarcomas, acute myeloid leukaemia and bone tumours. 5 year survival is lower in teenagers and young adults compared with children for several cancer sites, low levels of participation in clinical trials for TYAs may explain some of the difference. Effective treatment for teenagers and young adults may differ from what works best for children or adults and for some cancer survival is worse than for children and adults because: • Different cancer biology • Different treatment protocols • Different response to treatment • Poorer access to age appropriate clinical trials and services There's a substantial fall in accrual to clinical trials from age 14 onwards, and in a test period from 2005 – 2007 it was shown that clinical trials don't exist for some of the commonest cancers in this age group, for example there were not clinical trials for patients aged 0-17 with Hodgkin's Lymphoma. Recruitment to clinical trials among TYAs is much lower than in children with cancer. Around 50 – 70% of children with cancer in England/UK enter clinical	Cancer Research UK TYA Cancer stat's report, 2013 http://publications.cancerresearchuk.org/publicationformat/formatfactsheet/tyakeyfacts.html NCRN, Lorna Fern research papers http://www.ncri.org.uk/csg/annual_reports/NCRI_TYA_CSG_-_Annual_Report_2011-12.pdf UK ALL 2003 clinical trial, UCLH, Dr Rachael Hough http://www.ctsu.ox.ac.uk/research/mega-trials/leukaemia-trials/ukall-2003

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
			trials, compared with less than 20% of patients aged 15-24. When trials are developed around the specifics of teenagers with cancers dramatic improvements in outcomes, such as trials in Acute Lymphoblastic Leukaemia was adapted from a children's trial to include patients aged up to 24 and showed nearly 25% increased 5 year survival for this older age group	
Teenage Cancer Trust	4. Access to long term follow up care	This is an area something young people feel strongly about and is identified as a priority in national guidance.	Teenage Cancer Trust's Young Voices report highlighted the many concerns young people with cancer have about survivorship, ranging from late effects of treatment to the continuation of education. This is an area of great concern to patients and there are clearly areas where services are not meeting their needs. This may be due to processes for ensuring continuation of care is continued and followed up appropriately outside of the hospital environment. It is important that we understand more about what are important outcomes for this patient group. We believe there should be more use of psychosocial assessment tools to better understand the ongoing needs of this patient group. The work of the National Cancer Survivorship Initiative has made important progress in this area of work and this should be highlighted and built on. This is also the focus of a retrospective study currently being undertaken by Professor Jeremy Whelan so there will be more evidence soon	Teenage Cancer Trust Young Voices report: http://www.teenagecancertrust.org/workspace/documents/Young-Voices-report.pdf National Cancer Survivorship Initiative report on children and young people: http://www.ncsi.org.uk/wp-content/uploads/CYP-October-Publication.pdf
Together for Short Lives	Palliative care	When it is decided that curative treatment for a child with cancer is no longer realistic, the child and their family should be given a choice of place of death, including hospital, home or	Despite significant improvements in children's cancer care in recent years, sadly, many young people continue to die from cancer. When all curative treatment options have been exhausted, it is vital that children have access to comprehensive palliative care services.	**Evidence or information that care in the suggested key areas for quality improvement is poor or variable and requires improvement** • In 2011/2012 only 113

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		hospice. Advanced care plans can give the child and their family an opportunity to express their wishes over treatment and place of care at the end of the child's life. Choices on bereavement care can also be expressed. Closer working between oncology teams, children's palliative care teams and clinical networks can ensure that knowledge, good practice and expertise is shared. This can also prevent advanced care plans and rapid discharge pathways from being duplicated. It is difficult to know when a child with a life-limiting or life-threatening condition has entered their end of life phase. End of life parallel planning allows for scenarios in which the child lives or dies. Many regions now use palliative care pathways. Shared pathways, common to all conditions, enable better understanding across health and social care services. Involving a child or young person with cancer who is approaching the end of their life in decisions about their	In general, children who die as a result of cancer receive very good end of life care. However: • We believe that many children are not given a choice over the place in which they receive end of life care; this could include a hospital, their home or a children's hospice. • Practice in terms of advance care planning, do not attempt resuscitation (DNAR) orders, rapid discharge pathways and palliative care pathways varies across local areas. The following actions are needed to ensure comprehensive palliative care for children with cancer: • Advance care planning. • Closer working between oncology and children's palliative care teams. • Parallel planning. • Greater use of palliative care pathways.	children with oncology conditions were referred to children's hospices across the UK (Children's Hospices UK, now Together for Short Lives). • However, cancer is the cause of death in a fifth of all childhood deaths, accounting for 250 deaths among children aged 1 to 14yrs in 2010 (Cancer Research UK). **National data sources that collect data relating to our suggested key areas for quality improvement** • Together for Short Lives 'Count me in: Children's Hospices Services Provision 2011/2012'. • Cancer research UK. • Office for National Statistics.

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		care can improve their outcomes. Where children do not wish to receive end of life care in an acute setting and are able to specify another option, palliative care services in children's hospices or in the community have potential reduce the burden on hospital services.		
Together for Short Lives	Transition	It is vital that young people with cancer undergo smooth and well planned transitions from children's to adult's services when they reach adulthood. There are more than 40,000 children and young people aged 0-19 in England who have long-term health conditions which, for most, will eventually end their lives and for which they may require palliative care. This represents a 30 per cent increase over ten years. The highest rate of increase is among those aged 16-19, who now account for 4,000, or one in ten, of 0-19-year-olds who need palliative care. Successful transition needs to address both the transfer of responsibility for young people from children's to existing adult's social care, health and education services and the development of new adult's services tailored to	Many young people and their families find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of agencies and professionals. The result can be gaps in services or fewer or less appropriate services. Given their situation, these young people and their families cannot afford to wait and adult agencies need to ensure that their responses are timely and appropriate. At present, there is significant local variation in the planning which takes place for such transitions.	**Evidence or information that care in the suggested key areas for quality improvement is poor or variable and requires improvement** • Marie Curie Cancer Care and Together for Short Lives (2012). Don't let me down: ensuring a good transition for young people with palliative care needs. Available online at: http://www.mariecurie.org.uk/Documents/press-and-media/News-Comment/Dont-Let-Me-Down.pdf • Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives.

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		young people's additional needs. Once a young person with cancer has reached the age of 14, a range of children and adult services should come together to agree a five-year rolling transition plan, encompassing all relevant local services. This plan should taper services to make transition less of a "cliff edge" for families. All information about young people with cancer should travel with them across organisational boundaries. This should be in the form of a transition plan that covers clinical, social and educational needs and which supports the process of transition. Children's palliative care services should reflect on their role in preparing young adults with cancer for planning conversations ahead of transition to adult's services. (Non-palliative) health services should build on common practice of emergency care planning by incorporating open (but sensitive) discussion of preferences for the end of life and consider reaching out to palliative care services for help with confidence-building and training.		**National data sources that collect data relating to our suggested key areas for quality improvement** Office for National Statistics.

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British Fertility Society		Fertility preservation and fertility review. With increasing numbers of young people surviving cancer. Quality of life is an important issue and fertility and the ability to become a parent and/or the understanding of consequent fertility limitations is an important part of this implicated not only in personal quality of life but the ability to form relationships and found a family	The NICE review of fertility guidance has addressed the issue of fertility preservation for the first time in 2013 including an emphasis on funding. Whilst options may be more limited for young people it is still important that it is addressed and even if formal treatment is not undertaken it is important that consequent issues are reviewed with them and addressed appropriately at a later stage	NICE 2013 Fertilty Guidelines Joint RCOG/RCR/RCP Working Party Report 2007
NHS England	Higher volume POSCUs. Resources, minimum activity volumes, staffing (expertise and time allocation) of the necessary MDT staff for POSCUs to deliver level 3 services needs to be redefined	Once a diagnosis and treatment plan has been established at the PTC, much of this could be delivered safely at a high volume POSCU providing they have a sufficiently robust depth and breadth of staffing and experience. This would allow more children to have care closer to home	The current staffing requirements for POSCUs are insufficient to deliver level 3 services in any but the largest POSCUs. Minimum activity levels should be defined (numbers of patients). This would enable more devolved follow up.	
NHS England	Timely information sharing between clinical sites delivering care in partnership	There are potential clinical risks in relying on parents to be the conduit for clinical information following an acute episode of care and current systems are inefficient in exchanging information between PTCs and POSCUs	A more integrated care record for childhood cancer care patients that can be viewed by all health care professionals involved in their care should reduce risks of treatment errors and also will form the basis for a timely high quality end of treatment summary to improve follow up and survivorship	
NHS England	Pathology diagnosis in specialist centres	Paediatric cancer samples are small biopsy samples requiring special handling. Paediatric cancers are different from adults requiring specialist interpretation of ancillary investigations such as imunohistochemistry and	There are data on the implications of delayed or erroneous diagnoses. Vujanić GM, Sandstedt B, Kelsey A, Sebire NJ. Central pathology review in multicenter trials and studies: lessons from the nephroblastoma trials. *Cancer.* 2009 May 1;115(9):1977-83. Accurate and timely diagnosis is a key component of	Recognition of requirement for specialist commissioning of specialist paediatric surgical pathology. Recognition of paediatric pathology as a separate specialty

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
		molecular diagnostics. participation in MDTs	three of the current diagnostic indicators: five year survival from all cancers in children; 31 day wait from urgent GP referral for suspected cancer to first treatment and referrals, diagnosis and cancer care plan.	
NHS England	Rehabilitation for children after treatment for cancer	It is recognised that the excellent survival from childhood cancer results in increasing numbers of children with significant rehabilitation needs. Children who have received treatment for brain tumours represent the largest and most severe group. Rehabilitation is recommended in the NICE guidance for children and young people with cancer across the range of tumours treated.	There are currently no standards for the provision of rehabilitation services following treatment for childhood cancer in the UK. There are no agreed standards for assessment or evaluation of interventions. Furthermore access to therapies essential for rehabilitation is non-uniform and subject to geographical variation. Some therapies such as Speech and Language therapy and Psychology are not accessible to many patients to allow them to re-integrate into their communities and reach their full potential.	Please see proposed Specialist Commissioning Service Specification for Paediatric Neuro-rehabilitation https://www.engage.england.nhs.uk/.../e9dservicespec.pdf
NHS England	Electronic prescription of chemotherapy for all children and young people with cancer	It is recognised that systems for electronic prescription of chemotherapy reduce errors and increase safety in this high-risk area. Whilst robust and effective adult systems are in routine use, only a minority of children's cancer services have access to these systems.	Safety in prescribing of chemotherapy is of paramount importance. Manual systems not only increase the risk of errors but do not allow for easy collection of data to identify what treatment has been given. Few of the systems currently used in adult practice are suitable for the complex prescribing in children's cancer and there is in effect exclusion of children from these systems. Standards are required to guide service providers in the procurement of systems such that the needs of children cannot be overlooked.	
NHS England	Referral pathways for access to interventional radiology for biopsy of challenging areas or the child is too sick for a surgical procedure	Children should have the best opportunity to be diagnosed with least risk and the highest likelihood of achieving a definitive diagnosis. Not all centres have well established	There are several anecdotal reports of adverse events following surgical procedures that might have been avoided by an interventional radiology route. Data probably remains within centres rather than being published.	Neil J. Sebire . Derek J. Roebuck. Pathological diagnosis of paediatric tumours from image-guided needle core biopsies: a systematic review. Pediatr Radiol (2006) 36: 426–431

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		paediatric interventional radiology on site.		Garrett KM, Fuller CE, Santana VM, Shochat SJ Hoffer FA, Percutaneous Biopsy of Pediatric Solid Tumors CANCER August 1, 2005 / Volume 104 / Number 3, 644-65
NHS England	Paediatric oncology surgery – minimum activity volumes for complex procedures	There is substantial evidence in the adult cancer surgical world that outcomes for patients (survival and function) are improved when complex operations are performed by high volume teams. The Dutch Childhood Oncology Group has reviewed the applicability of this to childhood cancer and concluded that complex procedures should be undertaken by teams doing 20 cases or more per year where possible.		Rob Pieters. " Paediatrics as a model of centralised management of rare cancers". Dutch Childhood Oncology Group. The Netherlands. Presentation to ECCA meeting, Stockholm 2012
NHS England	Robust nurse staffing levels and skill mix and training for paediatric oncology patients	Expert nursing is central to the safe care of children and young people with cancer. Complex chemotherapy regimens and the requirement for timely supportive care mean that much of the care they require falls into the domain of the registered nurse. It is recognised that paediatric oncology patients have high levels of dependency.	Peer Review reports have shown that there is variation in staffing levels in both Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs) nationally. Only 54% of PTCs are compliant with Peer Review Measure on Ward Staffing derived from Improving Outcomes Guidance for Children & Young People with Cancer There is no Peer Review Measure in relation to Day Care nurse staffing, and yet treatment (both chemotherapy and supportive care) is often and increasingly administered in the Day Care setting	NICE (2005) Improving Outcomes Guidance for Children & Young People with Cancer National Cancer Peer Review Programme Manual for Cancer Services: Children's Cancer Measures (V2) 2011 National Cancer Peer Review Programme Report 2011/12 (Children's) Royal College of Nursing (2003) Defining staffing levels in children's and young people's services Royal College of Nursing (2010)

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				Guidance on safe staffing levels in the UK
NHS England	We would strongly support attention being given to the development of a national patient experience survey for children and young people with cancer	The adult cancer patient experience survey has driven many of the improvements in cancer care and support, but there is no national survey of the views of children, young people and their families.	The 'adult' cancer patient experience survey only includes patients over 16 years; the experiences of patients from 16 – 25 years in the survey are less positive than for patients aged 25 - 75. There is not a national mechanism for listening to, and hearing, the voice and experience of children and young people.	Department of Health (2012) Cancer Patient Experience Survey
NHS England	Ensure CYP are treated in line with national (NCRN) or international protocols or network agreed guidelines and have access to all clinical trials that are available for their tumour type.	Access to clinical trials is the standard of care for CYP with cancer and has been the foundation of the improvements in survival in childhood cancer	There is variation in the range of clinical trials open in different treatment centres, and in the infrastructure (research nurses, data managers) in place to support clinical trials activity.	
NHS England	Referral practice for paediatric brain tumours	There is good evidence of delayed presentation of paediatric brain tumours in the UK compared to the rest of Europe. Late presentation risks worse curvival and neuro-cognitive outcomes	Clear pathways (available to GPs) for all hospitals, outlining referral of patients with suspected brain tumour. Rapid access to MRI (not CT) for any patient with suspected brain tumour.	Wilne et al ***Lancet Oncol*** **2007; 8: 685–95** http://www.headsmart.org.uk
NHS England	Nurse numbers and training for paediatric oncology patients	Ward staffing is locally determined, and variable. Oncology patients have known very high dependency. Provision of nurse training in PTCs and shared care is locally determined and variable	Management of paediatric oncology patients requires additional skills, and delivery of these is not possible without adequate numbers. Lack of numbers of appropriately trained staff was a feature of the Stafford inquiry.	National Cancer Peer Review Programme Manual for Cancer Services: Children's Cancer Measures Version 2.0 NURSE NUMBERS AND TRAINING LEVELS (Measures 11-7B-111 to 11-7B-121)

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NHS England	MDT functioning	MDT operation is now the recognized way do determine appropriate decisions for treatment in oncology.	Provision of a complete MDT with appropriate cross cover for all meetings	
NHS England	**<u>Additional recommendations</u>** Further consideration could be given to the following: 1 Children and younger teenagers requiring radiotherapy should be treated in accordance with national good practice guidance for paediatric radiotherapy [1] and molecular radiotherapy [2]. 2 Children and younger teenagers diagnosed with cancer or leukaemia should be treated in nationally commissioned specialist paediatric oncology and haematology principal treatment centres, in conjunction with accredited paediatric oncology shared care units, with equity of access to the best care possible regardless of geography or social circumstances. 3 Following timely and complete investigation of radiological, pathological and molecular parameters to allow full staging and risk stratification, treatment plans should be formulated by discussion in appropriately constituted multi-disciplinary team meetings. 4 Where possible, children should be offered the opportunity for treatment in NIHR portfolio national or international clinical trials. When these are not available or appropriate, treatment plans should be in accordance with CCLG clinical guidelines or guidance about treatment options. 5 All children and their families should have access to support by a wider multiprofessional team, including but not limited to clinical nurse specialists, play specialists, social workers, clinical psychology and psychotherapy. One professional will be named as the keyworker for each child. This support should be available from diagnosis through treatment and into long term follow-up.			
SCM	Earliest diagnosis	Early diagnosis is addressed in a number of NICE guidelines and DOH initiatives. Delayed diagnosis may result in disease spread, increase the treatment burden and lead to poorer outcomes. Even in the absence of an adverse outcome delayed diagnosis negatively influences the relationship between the patient and the professionals providing care.	Despite a number of initiatives to improve early diagnosis and referral, patients and their families continue to report problems, which occur at the level of both primary and secondary care. In other areas targeted education / red flags/alerts have improved awareness. Cancer awareness in children is particularly challenging because of the rareness of the diseases and there diversity.	Please see Headsmart , NICE Guidance on Early Diagnosis and NICE Cancer Service Guidance CSGCYP (2005).
SCM	Availability / recruitment	Regulation of clinical trials	There is evidence, although from some time ago, that	See NCRI CCL CSG portfolio.

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	into clinical trials, both for de novo and relapsed disease.	/MHRA compliance has resulted in fewer open trials for children with cancer and more children treated on guidelines/treatment recommendations with outcome data not collected. Treatment on a clinical trial represents the gold standard of care.	children treated on clinical trials do better than those not treated on trials. At a minimum toxicity and outcome data should be collected for patients treated on guidelines / treatment recommendations. Without this data, the effectiveness and toxicity of these guidelines / treatment recommendations are not monitored.	
SCM	MDT – local and national	There is some evidence that outcomes are improved if diagnosis/ treatment are discussed at an appropriate MDT. Some tumours in children are so rare that they may be more appropriately discussed at a national, rather than local MDT, to allow wider expertise.	Some cancers in children and young adults are very rare and the management complex. Wider discussion than would be available locally may benefit the decisions for any patient but also have a wider educational role.	NICE Cancer Service Guidance CSGCYP (2005).
SCM	Electronic prescribing and administration	There is good evidence that electronic prescribing improves patient safety through standardisation.	Despite the evidence for the benefit to patient safety of electronic prescribing, this remains variable across the country.	NICE Cancer Service Guidance CSGCYP (2005). HDL Safe Administration of Chemotherapy (2005)
SCM	Collection of cancer registry data	The collection of cancer registry data in children and young adults has historically been collected through the CCRG, Oxford, but will now be part of the national system for England and will not include the devolved nations. There is clear benefit to this data being collected UK wide.	Clearly it is important that data on incidences and outcomes be collected for international comparison. Childhood cancer is rare and the data should be collected on a UK basis.	NICE Cancer Service Guidance CSGCYP (2005).
SCM	Nursing levels on inpatient and day case wards.	Many patients with cancer have high levels of dependency. There is a huge burden of intravenous and chemotherapy administration. Pressures on nursing levels can compromise patient care.	Poor compliance with peer review.	Defining staffing levels in children's and young people's services Royal College of Nursing (2010) Guidance on safe staffing levels

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				in the UK
SCM	Access to key worker for all areas.	Support for patients at individual level. Critical communication link between patient and service.	The importance of a key worker is recognised across all areas of cancer.	www.cquins.nhs.uk Cancer measures for children
SCM	Access to clinical trials or nationally agreed protocols for children and young people with cancer.	Tumours in children and young people are rare and there is evidence (eg ALL in 16-24 year olds) that outcomes may be compromised if patients treated on incorrect protocol. This has also been recognised and implemented through the Quality Measures.	Increasing challenges in opening clinical trials in centres. Access can be difficult for patients in rural areas and is dependent (particularly for young people) on trials opening in TYA Centres. The infrastructure to do this is not in place in all areas.	www.cquins.nhs.uk Children's Measures and Teenagers and Young Adult Measures
SCM	Pathways for management of acute complications of cancer therapy for teenagers and young adults	Patients receiving intensive chemotherapy for cancer are at high risk of life threatening complications. TYA patients in particular may be receiving care a cancer centre a long way from home. The will need to access urgent care when necessary but the pathways may not be clear	The new development of TYA centres and the complexity of the protocols these patients are on. The standard pathways of care may not work. This issue is highlighted in cancer in adults within the acute oncology measures	*www.cquins.nhs.uk/ acute oncology measures*
SCM	Undertaking Bone Marrow Transplantation in units accredited through JACIE	These are key standards for the delivery of care in patients undergoing BMT	BMT is a complex high risk procedure. Historically this has been undertaken in paediatric units around the country. There are now clear standards for this service provision and the governance of this procedure both for autologous and allogeneic procedures .	www.ebmt.org/jacie
SCM	Improving routes to diagnosis for children and young people with cancer and in particular those with brain and bone tumours where there is evidence that pathways to	Whilst there is equivocal evidence of the impact of delayed diagnosis on survival outcome across all cancers there is an undoubted impact on patient experience. Late presentation of brain & CNS	The majority of children & Teenagers and Young Adults with cancer present as an emergency; some will have already presented on a number of occasions to primary care. There is good evidence of delayed presentation of paediatric brain tumours and bone tumours in TYAs in the UK compared to rest of Europe. Delayed	NCIN (2013) *Routes to diagnosis : investigating the different pathway for cancer referral in England for Teenagers and Young Adults* Wilne SC, Collier J, Kennedy C,

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
	diagnosis are longer.	tumours risk worse survival and neuro-cognitive outcomes.	diagnosis in brain tumours results in increased symptoms which impacts on neuro-cognitive function. The Report of the Children and Young People's Outcome Forum has recommended the development of a new outcome indicator – time from 1st NHS presentation to diagnosis.	Koller K, Grundy R, Walker D. Presentation of childhood CNS tumours: a systematic review and meta-analysis Lancet Oncol. 2007 Aug; 8(8):685-95. 'Headsmart' – www.headsmart.org.uk Department of Health (2012) *Report of the Children and Young People's Health Outcomes Forum*
SCM	Nurse staffing levels and skill mix on wards and in day care services	Complex chemotherapy regimens and supportive care mean that much of the care CYP with cancer falls into the domain of the registered nurse. It is recognised that these patients have high levels of dependency.	Peer Review reports have shown that there is variation in staffing levels in both Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs) nationally. Only 54% of PTCs are compliant with Peer Review Measure on Ward Staffing derived from '*Improving Outcomes Guidance for Children & Young People with Cancer'*. There is no agreed staffing tool for use in Day Care setting.	National Cancer Peer Review *Programme Report 2011/12 (Children's)* Royal College of Nursing (2003) *Defining staffing levels in children's and young people's services* Royal College of Nursing (2010) *Guidance on safe staffing levels in the UK*
SCM	Improve access to 24 hour End of Life care at home for children and young people with cancer	Access to 24 hour End of Life Care is fundamental to providing choice in the place of death for children, young people and their families. There is a potential 'gap' in service provision for patients between the age of 16 & 18 years.	There is variable provision of Children's Community Nursing services across England, specifically whether they provide a 5 or 7 day service. Few provide a 24 hour service, although some will do so for End of Life Care outside formally commissioned and funded services. There is variation in the age ranges that both adult and children's community teams operate, which means that patients between the age of 16 & 18 years can fall between Children's Community teams (may go up to 16 years only) and Adult teams (may take over 18 years only). A review of 'Place of Death' in 2011 showed that 47% of children and 52% of Teenagers and Young Adults (TYAs) died in hospital.	NCIN (2011) *Place of Death for Children, Teenagers and Young Adults with cancer in England*

Stakeholder	*Key area for quality improvement*	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
SCM	To develop a national patient experience survey for children and young people with cancer	The adult cancer patient experience survey has driven many of the improvements in cancer care and support, but there is no national survey of the views of children, young people and their families.	The 'adult' cancer patient experience survey only includes patients over 16 years; the experiences of patients from 16 – 25 years in the survey are less positive than for patients aged 25 - 75. There is not a national mechanism for listening to, and hearing, the voice and experience of children, young people and their families.	Department of Health (2012) *Cancer Patient Experience Survey*
SCM	Improve integration and continuity of care for children and young people with cancer across health and social care settings	The need for integrated care is recognised not only in the IOG for Children and Young People with Cancer, but also in the report of the Children and Young People's Health Outcomes Forum. A clinical network is the best way to provide integrated care across the patient and family pathway.	Peer Review reports show that provision and integration of shared care services and TYA designated hospitals remain variable across the country and the commissioning of services within PTC, POSCU and Primary Care remains fragmented; there is a risk this will deteriorate with changes to health and social care organizations (including the demise of the cancer networks). There are in some cases differences in age cut-offs between PTC and POSCU. There is patchy provision of Children's Community Nursing services across the country and differences in age boundaries between different organizations and teams. Teenagers between the age of 16 & 18 years can fall between Children's Community teams (may go up to 16 years only) and Adult teams (may take over 18 years only). There is variation in the caseload of Clinical Nurse Specialists, Outreach Nursing teams and other (predominantly nursing) Key Workers.	Department of Health (2012) *Report of the Children and Young People's Health Outcomes Forum* National Cancer Peer Review *Programme Report 2011/12 (Children's)* NCIN (2013) *Shared care and survival from childhood cancer in the UK 1997-2009*
SCM	Ensure Children & TYAs treated in line with national (NCRN) or international protocols or network agreed guidelines and have access to all clinical trials available for their	Access to clinical trials is the standard of care for CYP with cancer and has been the foundation of the improvements in survival in childhood cancer.	There is variation in the range of clinical trials open in different treatment centres, and in the infrastructure (research nurses, data managers) in place to support clinical trials activity.	

Stakeholder	***Key area for quality improvement***	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
	tumour type.			
SCM	Additional indicator • All CYP with cancer should receive a Treatment Summary and Care Plan at the end of treatment			