

NICE support for commissioning for children and young people with cancer

February 2014

1 Introduction

Implementing the recommendations from NICE guidance and other NICE-accredited guidance is the best way to support improvements in the quality of care or services, in line with the statements and measures that comprise the NICE quality standards. This report:

- Highlights the key actions that NHS England area teams, strategic clinical networks, clinical commissioning groups (CCGs) and their partners should take to improve the care of children and young people with cancer. Priority actions are outlined in [table 1](#).
- Identifies opportunities for collaboration and integration at a local and regional level.
- Identifies the benefits and potential costs and/ or savings from implementing the changes needed to achieve quality improvement.
- Directs commissioners and service providers to support tools that can help them implement NICE and NICE-accredited guidance.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. The statements draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. For more information see [NICE quality standards](#).

NHS England's [CCG outcomes indicator set](#) is part of a systematic approach to promoting quality improvement. The outcomes indicator set provides CCGs

and health and wellbeing boards with comparative information on the quality of health services commissioned by CCGs and the associated health outcomes. The set includes indicators derived from NICE quality standards. By commissioning services in line with the quality standards, commissioners can contribute to improvements in health outcomes.

Commissioners can use the quality standards to improve services by including quality statements and measures in the service specification of the standard contract and establishing key performance indicators as part of tendering. They can also encourage improvements in provider performance by using quality standard measures in association with incentive payments such as NHS England's [Commissioning for quality and innovation 2013/14 guidance](#). NICE quality standards provide a baseline against which improvements can be measured and rewarded, enabling commissioners to address gaps in service provision, support best practice and encourage evidence-based care.

This report on the children and young people with cancer quality standard should be read alongside:

- [Children and young people with cancer](#). NICE cancer service guidance (2005).
- [Children and young people with cancer](#). NICE quality standard 55 (2014)
- National Cancer Peer Review Programme. [Cancer Quality Improvement Network System: Children](#) (2009–2013).

2 Overview of children and young people with cancer

Cancers are grouped into 3 broad categories: solid tumours, haematological malignancies and central nervous system malignancies. Cancers that develop in children are different from those that develop in adults. There is increased histological diversity and many tumours develop from embryonal tissue. Early diagnosis is challenging in children and young people because cancers are

rare and more diverse. The point at which the cancer is diagnosed can directly affect the outcome of any treatment.

In the quality standard for children and young people with cancer, young people are defined as aged 16–24 years though this is not a formal upper age limit as the needs and circumstances of individuals will vary, including their need to access age-specific services.

Services should be coordinated across all relevant agencies encompassing the whole care pathway for cancer in children and young people. Well coordinated services provide the most effective treatment and support for children, young people and their carers.

2.1 *Epidemiology of cancer in children and young people*

Cancers in children and young people are rare. In 2008–2010 in the UK each year, there was an average of approximately **3800** new cases of cancer reported for children and young people.¹

The most common types of childhood cancer are acute leukaemias (diagnosed in 1 in 3 children with cancer) and cancers of the brain and spinal cord (diagnosed in 1 in 4 children with cancer) ([National Registry of Childhood Tumours 2007](#)). 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.

3 Summary commissioning and resource implications

Commissioning for children and young people with cancer is complex. There are many different types of cancer, each requiring different interventions with a different care pathway. The coordination of services across the treatment

¹ All data compiled by the Office for National Statistics, published by [Cancer Research UK](#)

and care pathway involves health and social care teams in general practice, in the community, in acute general hospitals and in specialist centres.

Children are treated primarily in 13 children's principal treatment centres and teenagers at either the children's principal treatment centres or one of 13 teenage and young adult principal treatment centres. In addition (for children) there are about 90 shared care centres, or paediatric oncology shared care units. So as to provide care as close as possible to the child or young person's home, the principal treatment centres decide and direct which elements of specialist cancer care can be delivered in the shared care centres. The services offered by shared care centres are provided by district general hospitals outside the principal treatment centres. There are also various 'designated hospitals', commissioned to deliver cancer treatment and support to teenagers and young adults.

NHS England commissions specialist cancer services for children and young people from children's PTCs and teenage and young adult principal treatment centres. NHS England also commissions services delivered at the shared care centres and designated hospitals for the treatment of teenagers and young adults (although some services offered will also be commissioned by CCGs). For a more detailed overview of these arrangements, see [2013/14 NHS Standard Contract for Paediatric Oncology](#) and [2013/14 NHS Standard Contract for Cancer: Teenagers and Young Adults](#).

Specialist cancer services for children and young people include:

- all cancer chemotherapy and radiotherapy
- specialist palliative care
- support for people living with and beyond cancer ('survivorship')
- long term follow-up
- specialist therapies and rehabilitation.

Clinical commissioning groups (CCGs) are responsible for commissioning local community-based palliative care services that are not highly specialised such as children's community nursing teams, specialist short-break (respite)

services and routine care delivered by children's hospices. Using the quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the [NHS Outcomes Framework 2013/14](#).

The cost of achieving the quality standard for cancer in children and young people depends on current local practice and the progress organisations have made in implementing NICE and NICE-accredited guidance.

Table 1 summarises the commissioning and resource implications for NHS England and could be used to inform provider services working towards achieving this quality standard. See section 4 for more detail on commissioning and resource implications.

Table 1 Priority commissioning actions and potential resource implications for children and young people with cancer

Quality improvement area	Commissioning implications	Resource implications
<p>Multidisciplinary teams for young people</p> <p>Access to clinical trials</p>	<p>NHS England through strategic clinical networks should work with CCGs to ensure that providers have a dedicated, age appropriate multidisciplinary team in place for young people, comprising members with the relevant specialist expertise, together with cancer site-specific multidisciplinary teams.</p> <p>NHS England and CCGs should seek assurance that providers have systems in place to monitor that suitable clinical trials are identified and support provided to the child or young person and their family on whether to participate.</p>	<p>The cost impact is not expected to be significant because the staff involved in delivering services as part of a site-specific and age-specific multidisciplinary team will generally already be employed by the NHS and should already be contracted to attend review meetings to determine the most effective treatment and support.</p> <p>Clinical trials are funded by the drug manufacturer; therefore no significant costs are expected.</p>
<p>Electronic prescribing of chemotherapy</p>	<p>NHS England through strategic clinical networks should work collaboratively to ensure that service providers have systems in place for all children and young people receiving chemotherapy to have it prescribed using an electronic prescribing system</p>	<p>The cost impact will vary and depend on whether systems are already in place. Potential benefits include improved efficiency and reduced costs associated with prescribing, reduction in medication errors and associated costs, and reduction in preventable adverse events and associated costs</p>
<p>Psychological and social support</p>	<p>Strategic clinical networks, should work with CCGs and third sector providers, to seek assurance that services are in place to assess the psychological and social needs of children and young people. Evidence of practice should be specified and requested by monitoring that this is taking place at key points on their care pathway and that support is received based on the outcome of their needs assessment</p>	<p>Provision of and access to psychological and social support is variable, dependant on locality. Where support is not part of the multidisciplinary team, other third sector providers that have better coverage could be used, or different approaches such as sharing expertise with neighbouring services could be considered. Costs would need to be assessed locally</p>
<p>Neuro-rehabilitation</p>	<p>Strategic clinical networks should work with CCGs to seek assurance that services</p>	<p>Although services should be included within the staffing configuration of</p>

	are in place to ensure that children and young people who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package	multidisciplinary teams practice may vary therefore costs would need to be assessed locally
Follow up and monitoring of late effects	CCGs should work with area teams to seek assurance that services are in place to provide children and young people, at the end of their treatment, with verbal and written information about the long term risks of their cancer and treatment, and the arrangements for monitoring, identifying and treating any potential problems as quickly as possible. This may involve collaboration with GP practices.	A high-quality aftercare program delivered locally with full support of the clinical expertise involved has benefits for the patient and the NHS from meeting individual needs in a timely manner. This may increase costs, however it could reduce clinic attendances and give capacity for services to cope with increased numbers of survivors in the future
Fertility support	Strategic clinical networks and CCGs should seek assurance that services are in place to ensure that each child and young person with cancer is assessed for potential fertility problems before treatment, and advised about appropriate options for fertility preservation	Access to services is likely to be variable, however specialist fertility services based in hospitals which have been designated as teenage and young adult cancer providers are likely to be in place. Because of the small number of affected patients, no significant costs are anticipated

4 Commissioning and resource implications

This section considers the commissioning implications and potential resource impact of implementing the recommendations to achieve the NICE quality standard for children and young people with cancer.

4.1 *Multidisciplinary teams for young people*

Quality statement 1: Multidisciplinary teams for young people

Young people (16–24 years) with cancer have their diagnosis, treatment and support agreed and delivered by a cancer site-specific multidisciplinary team

and a teenage and young adult multidisciplinary team.

Quality statement 2: Access to clinical trials

Children and young people (0–24 years) with cancer should be offered the opportunity to take part in clinical trials if they are eligible.

Cancer in young people is often more similar to cancer experienced by adults than to cancers common in children. It is therefore important for them to be seen by a cancer site-specific multidisciplinary team within adult services. In addition, young people should be reviewed by a teenage and young adult multidisciplinary team to consider their specific psychological and social needs. This ensures that relevant support is provided, in collaboration with the cancer site-specific multidisciplinary team, to help them manage the wider impact of cancer and its treatment on their life.

Expert opinion suggests that it is much less common for teenagers and young adults to be reviewed by a multidisciplinary team than it is for children. Data published by the [National Cancer Intelligence Network](#) showed that referrals to teenage and young adult multidisciplinary teams based in PTCs are highly variable; by region, by cancer type and by age grouping.

The same concerns were not identified in current practice information for children (0–15 years).

Area teams need to ensure that there is sufficient workforce capacity for young people with cancer to be reviewed by age-specific and cancer site-specific multidisciplinary teams. Multidisciplinary teams (for both children and young people) should be able to identify opportunities to access clinical trials and to provide support to the child or young person's family in deciding whether to participate. Clinical trials are funded by the drug manufacturer. No significant costs are anticipated, however where emergency hospital treatment is needed for adverse effects, there will be a cost to the NHS.

Area teams may also wish to consider asking for evidence that written protocols are in place for multidisciplinary team reviews to happen as standard, and that agreement is reached on the most effective treatment and support at each review.

For diagnosis the core members of the multidisciplinary team should be:

- oncologist/haematologist
- radiologist
- surgeon/neurosurgeon
- pathologist/cytogeneticist
- clinical oncologist.

For treatment the core members of the multidisciplinary team should be:

- treating oncologist
- key worker
- paediatric haematologist (for children aged 0–15 years)
- adult haematologist (for young people aged 16–24 years), with specialist experience in treating this age group
- specialist nurses
- nurses from inpatient and day care units
- specialist pharmacist
- dietician and other appropriate allied health professionals
- a specialist outreach nurse/key worker, appropriate to the age group being supported.

Best practice guidance on the configuration of children's cancer services is set out in the [Manual for cancer services - children's cancer measures](#) (2009). This outlines the structure of multidisciplinary teams including the responsibilities of team members. The manual incorporates recommendations from [Improving outcomes in children and young people with cancer](#) (NICE cancer service guidance) and other NICE guidance. It identifies the characteristics of services that are likely to have a significant impact on health outcomes. These characteristics should help those involved in planning, commissioning, organising and providing cancer services to identify gaps in

provision and check the appropriateness and quality of existing services. The measures also provide a specification for the commissioning of cancer services within a given locality.

Commissioners and others can refer to a University of Wales exercise, run in support of NICE guidance, to estimate staff costs required at PTCs to provide a safe and sustainable service for children and young people with cancer.

[Improving outcomes in children and young people with cancer](#): economic analysis (appendix B Estimated staff costs).

4.2 *Electronic prescribing of chemotherapy*

Quality statement 3: Electronic prescribing of chemotherapy

Children and young people (0–24 years) receiving chemotherapy have it prescribed using an electronic prescribing system.

There are a number of risks associated with prescribing and administering chemotherapy. Electronic prescribing of chemotherapy is recommended in all settings; it is widely used in adult cancer care but is not available in all children's chemotherapy services. Drug dose and fluid volume calculations are based on weight and body surface area. Children vary in weight and size much more than adults, for whom doses are more standardised. Electronic prescribing systems perform the calculations, support safer prescribing and reduce doses being miscalculated.

There is a high potential for serious harm if chemotherapy doses are miscalculated, therefore this is a key patient safety priority. NHS England and CCGs should work collaboratively with providers to ensure that an electronic prescribing system is in place for children and young people with cancer.

Cost benefits of electronic prescribing include:

- reduced medication costs with formulary control
- improved control of medication in children and young people with allergies or adverse reactions reducing the risk of litigation
- improved recording of medication history may help reduce the prescription of ineffective treatments
- restriction of prescribing rights for high-risk medication, for example cytotoxic chemotherapy
- reduced costs for preventable adverse events.

The cost impact for funding purposes will depend on whether an electronic prescribing system is in place and can be integrated with other systems such as the pharmacy stock control system. The cost of electronic prescribing is likely to vary locally depending on current systems and infrastructure.

4.3 *Psychological and social support*

Quality statement 4: Psychological and social support

Children and young people (0–24 years) with cancer and their families and carers have their psychological and social needs assessed at key points on their care pathway and receive support based on their identified needs.

The cost impact of providing psychological and social support for children and young people with cancer and their families and carers from diagnosis to active cancer therapy and long-term follow-up is not anticipated to be significant as use could be made of existing services, such as [improving access to psychological therapies](#) (IAPT). This may also include social support which is usually funded through third sector (charity) resources such as [CLIC Sargent](#).

For service providers that have a shortage of psychological and social support resources, methods for sharing expertise with neighbouring service providers may be considered.

An example of hourly costs relating to psychological and social needs assessment is provided in table 2 below.

Table 2: Hourly cost of staff in child and adolescent mental health service team who may perform initial psychological and social needs assessments

Job title	Hourly cost (£) ¹	Hourly cost (face-to-face contact) (£) ²
Consultant: psychiatrist	72	186
Clinical psychologist	32	72
Nurse (mental health)	18	34
Child and adolescent psychotherapist	26	34
NHS community occupational therapist	18	23 ³
Community speech and language therapist	18	23 ²

¹All costs are taken from 2013-14 Agenda for Change midpoint pay rates except the consultant: psychiatrist, which is taken from [Pay Circular](#) (M&D) 1/2013. Employer pension contributions and employer national insurance contributions were added to these pay rates. The hourly rate was worked out by dividing the total annual pay and contributions by 44 (annual number of weeks worked) and 37.5 (hours worked per week, except consultant: psychiatrists who work 40 hours per week).

²The hourly cost of face-to-face contact was calculated using the ratios provided in the [Unit Costs of Health and Social Care \(2012\)](#) document.

³The hourly cost for face-to-face contact was worked out by increasing the hourly cost by 30% which is the same percentage increase in the child and young people's psychotherapist's normal hourly cost and hourly cost of face-to-face time.

4.4 Neuro-rehabilitation

Quality statement 5: Neuro-rehabilitation

Children and young people (0–24 years) who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.

Central nervous system tumours (both invasive and non-invasive) form the second most common group of cancers in children, accounting for more than a quarter (27%) of all childhood cancers overall (National registry of childhood tumours / Childhood cancer research group 2006-2007). Data from the UK

childhood cancer study group suggests that brain tumours occur in about 5 per 100,000 children per year, equating to approximately 525 new cases in England.

There is evidence that neuro-rehabilitation is most effectively delivered by a coordinated team of specialists. The specialist team should cover but not be limited to: speech and language therapy, physiotherapy, occupational therapy, neurology and psychology (including neuropsychology). Strategic clinical networks and CCGs should ensure that systems are in place for children and young people who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.

Access to neuro-rehabilitation is variable. In particular, access to speech and language therapy and physiotherapy is not uniform across the country. A multidisciplinary team is a core element of recovery and rehabilitation, and an effective service can reduce hospital length of stay and outpatient attendances. This could improve recovery rates and improve outcomes for children and young people with cancer.

Neuro-rehabilitation services should be accessible within multidisciplinary teams; however where practice varies, costs may need to be assessed locally for funding purposes. An indication of the resourcing requirements for core health professionals needed to support neuro-rehabilitation is given in [Improving outcomes in children and young people with cancer](#): economic analysis (appendix B Estimated staff costs).

4.5 Follow up and monitoring of late effects

Quality statement 6: Follow up and monitoring of late effects

Children and young people (0–24 years) who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

The increase in the number of children and young people who survive cancer will increase secondary care costs for follow-up and monitoring over the medium and long term. NICE [cancer service guidance](#) recommends that services maintain lifelong contact with childhood cancer survivors. PTCs may explore the potential for primary care providers to carry out investigations that are currently conducted in the secondary care setting.

There are over 40,000 survivors of childhood cancer in the UK with 60% of childhood cancer survivors experiencing at least one adverse late effect of cancer treatment ([NHS Improving Quality](#) – cancer 2011). A high-quality aftercare programme delivered locally with full clinical team support has benefits for the patient and the NHS by meeting individual needs in a timely manner. This may increase costs; however effective collaborative working with primary care may reduce clinic attendances, or allow earlier access to clinics which can support speedy recovery.

4.6 Fertility support

Quality statement 7: Fertility support Children and young people (0–24 years) with cancer are assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.

Approximately 15% of patients have a high risk of future fertility problems because of their cancer treatment. Children and young people with cancer should have the risks discussed with them and their parents or carers, and should be advised about appropriate options for fertility preservation before their cancer treatment starts. Early identification and appropriate assessment and treatment of fertility problems are important in preventing later morbidity. The treatment summary, which provides a record of the patient's previous therapy and any significant complications, is of value for those providing follow-up and for other healthcare professionals whom the patient may consult. For example, providing a record of exposure to radiotherapy or anthracyclines that may lead to complications during pregnancy.

For further information about endocrine and fertility services, see [Fertility: assessment and treatment for people with fertility problems](#) (NICE clinical guideline 156).

Access to fertility advice by trained healthcare professionals for children and young people is likely to be variable. See the costing report for [Fertility: assessment and treatment for people with fertility problems](#) for potential costs associated with fertility problems.

5 Other useful resources

5.1 Policy documents

- NHS England (2013) [NHS standard contract for paediatric neurosciences: neurorehabilitation](#)
- NHS England (2013) [NHS standard contract for cancer: chemotherapy \(children, teenagers and young adults\)](#)
- NHS England (2013) [NHS standard contract for paediatric oncology](#)
- NHS England (2013) [NHS standard contract for cancer: teenagers and young adults](#)
- Teenage Cancer Trust (2012) [Young voices: transforming the lives of young people with cancer](#).
- National Audit Office (2010) [Delivering the cancer reform strategy](#).

5.2 Useful resources

- National cancer survivorship initiative (2013) [The Recovery Package - supporting commissioning](#).
- National Cancer Peer Review Programme (2013) [Manual for cancer services: children's cancer measures](#).
- National Cancer Peer Review Programme (2013) [Manual for cancer services: teenage and young adults measures](#).

- Teenagers and Young Adults with Cancer (2012) [Blueprint of care for teenagers and young adults with cancer.](#)
- Royal College of Nurses (2011) [Competence framework for long-term follow-up and late effects for the care of children and young people after cancer](#)

5.3 NICE pathways

- [Fertility](#)

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