

Children and young people with cancer

NICE quality standard

Draft for consultation

September 2013

This quality standard covers the provision of all aspects of cancer services for children and young people with cancer. Young people is defined as those 15 – 24 years though this is not a formal upper age limit as the needs and circumstances of individuals will vary and their need to access age specific services will also vary. For more information see the [topic overview](#).

Why this quality standard is needed

Cancers are grouped into 3 broad categories: solid tumours, haematological malignancies and central nervous system malignancies. Cancers that develop in childhood 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.

Cancers in children aged under 15 years are rare (less than 1% of all cancers in industrialised countries). The crude incidence rate shows that in the UK there are 160 new cancer cases for every million boys and 137 for every million girls each year. In 2008–2010, there was an average of 1603 new cases of childhood cancer (0–14 years) each year in the UK: 883 (55%) in boys and 720 (45%) in girls.

Cancers in teenagers and young adults (15–24 years) are also rare, equating to 269 cases per year for every million teenagers and young adults in the UK population. In

2008–2010, an average of 2214 new cases of cancer in teenagers and young adults were reported¹.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcomes frameworks published by the Department of Health:

- [NHS Outcomes Framework 2013/14](#)
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, [Part 1 and Part 1A](#).

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 [NHS Outcomes Framework 2013/14](#)

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	<p>Overarching indicator</p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p>ii <i>Children and young people</i></p> <p>Improvement areas</p> <p>Reducing premature mortality from the major causes of death</p> <p>1.4 Under 75 mortality from cancer*</p> <p>i <i>One- and ii</i> <i>Five-year survival from all cancers</i></p> <p>iii <i>One- and iv</i> <i>Five-year survival from breast, lung and colorectal cancer</i></p> <p>Reducing deaths in babies and young children</p> <p>1.6 iii <i>Five-year survival from all cancers in children</i></p>

¹ All data compiled by the ONS, published by [Cancer Research UK](#).

4 Ensuring that people have a positive experience of care	<p>Overarching indicator</p> <p>4b Patient experience of hospital care</p> <p>Improvement areas</p> <p>4.2 Responsiveness to in-patients' personal needs</p> <p>4.6 Bereaved carers' views on the quality of care in the last 3 months of life</p> <p>4.8 <i>Children and young people's experience of healthcare</i></p>
5 Treating and caring for people in a safe environment and protecting them from avoidable harm	<p>Overarching indicators</p> <p>5a Patient safety incidents reported</p> <p>5b Safety incidents involving severe harm or death</p> <p>5c <i>Hospital deaths attributable to problems in care</i></p> <p>Improvements areas</p> <p>5.4 Incidence of medication errors causing serious harm</p>
<p>Alignment across the health and social care system</p> <p>* Indicator shared with Public Health Outcomes Framework (PHOF)</p> <p><i>Indicators in italics are placeholders, pending development or identification</i></p>	

Table 2 [Public health outcomes framework for England, 2013–2016](#)

Domain	Objectives and indicators
4 Healthcare public health and preventing premature mortality	<p>Objective</p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities.</p> <p>Indicators</p> <p>4.3 Mortality rate from causes considered preventable**</p> <p>4.5 Under 75 mortality rate from cancer**</p>
<p>Alignment across the health and social care system</p> <p>** Indicator shared with Public Health Outcomes Framework (PHOF)</p> <p><i>Indicators in italics are placeholders, pending development or identification</i></p>	

Coordinated services

The quality standard for services for children and young people with cancer specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole cancer care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to children and young people with cancer.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality cancer service are listed in 'Related quality standards'. [Link to section in web version]

Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All health and social care practitioners involved in assessing, caring for and treating children and young people with cancer should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

List of quality statements

[Statement 1](#). Children (0-15 years) with cancer are reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

[Statement 2](#). Young people (16 - 24 years) with cancer are reviewed by a cancer site-specific multidisciplinary team and an age specific multidisciplinary team to agree the most effective treatment and support.

[Statement 3](#). Children and young people receiving chemotherapy have it prescribed via an electronic prescribing system.

[Statement 4](#). Children and young people with cancer and their families and carers are offered psychosocial support at the time of diagnosis.

[Statement 5](#). Children and young people who have had a central nervous system malignancy are offered a specialist neuro-rehabilitation care package for an agreed period during and following their treatment.

[Statement 6](#). Children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

Questions for consultation

Questions about the quality standard

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

Quality statement 1: Agreeing treatment and support for children

Quality statement

Children (0-15 years) with cancer are reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

Rationale

The management of cancer in children can be very complex. The treatment and wider support required is varied and it is important that it is led by clinicians, with expertise in treating cancer in children and, if appropriate, in educational and psychosocial support for children. Ideally multidisciplinary team review and discussion should happen before treatment is started. However, if emergency treatment is needed, the discussion may occur soon after treatment has begun.

Quality measures

Structure

Evidence of local arrangements for all children with cancer to be reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

Data source: Local data collection.

Process

The proportion of children with cancer who are reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

Numerator – the number of children in the denominator who have their treatment and support reviewed and agreed by a children's multidisciplinary team.

Denominator – the number of children with cancer.

Data source: Local data collection.

Outcome

a) Proportion of children being treated in accordance with approved protocols.

b) Patient, parent or carer satisfaction with the support provided during treatment.

Data source: a) and b) Local data collection.

What the quality statement means for service providers, healthcare practitioners and commissioners

Service providers ensure that they have systems in place and written clinical protocols and processes for children with cancer to be reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

Healthcare professionals ensure that children with cancer are reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

Commissioners ensure that they commission services that have systems in place and written clinical protocols and processes for children with cancer to be reviewed by a children's multidisciplinary team to agree the most effective treatment and support.

What the quality statement means for patients, service users and carers

Children with cancer have their care discussed with a team of experts in treating and supporting children with cancer to agree on the best treatment and support.

Source guidance

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance CSGCYP (2005) section Multidisciplinary teams: page 93 paragraph 1; page 94, paragraph 1 and 4. Section Service organisation: Principal treatment centres, page 106; paragraph 2.

Definitions of terms used in this quality statement

Children's multidisciplinary team A dedicated multidisciplinary team with specialist expertise in cancers in childhood. The composition of the multidisciplinary team varies depending on the stage of the care pathway. 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
- specialist nurses
- nurses from inpatient and day care units
- specialist pharmacist
- dietician and other appropriate allied health professionals
- paediatric oncology or other speciality outreach nurse/key worker.

The multidisciplinary team should also facilitate access to any appropriate clinical trials that are open for children in their care.

Quality statement 2: Agreeing treatment and support for young people

Quality statement

Young people (16 - 24 years) with cancer are reviewed by a cancer site-specific multidisciplinary team and an age specific multidisciplinary team to agree the most effective treatment and support.

Rationale

Cancer in young people (16 years and over) is more similar to that experienced by adults. It is therefore important for them to be seen by a cancer site-specific multidisciplinary team within adult services. In addition to this, being reviewed by a teenage and young adult multidisciplinary team ensures that their specific psychological and social needs are also considered and relevant support provided, in collaboration with the cancer site multidisciplinary team, to help them manage the wider impact of cancer and it's treatment on their life.

Quality measures

Structure

Evidence of local arrangements for all young people with cancer to be reviewed by a cancer site-specific multidisciplinary team and an age-specific multidisciplinary team to agree the most effective treatment and support.

Data source: Local data collection.

Process

a) The proportion of young people (16 - 24 years) with cancer who are reviewed by a cancer site-specific multidisciplinary team to agree the most effective treatment and support.

Numerator – the number of young people in the denominator who were reviewed by a cancer site-specific multidisciplinary team to agree the most effective treatment and support.

Denominator – the number of young people (16–24 years) with cancer.

b) The proportion of young people (16-24 years) with cancer who are reviewed by an age-specific multidisciplinary team to agree the most effective treatment and support.

Numerator – the number of young people in the denominator who were reviewed by an age-specific multidisciplinary team to agree the most effective treatment and support.

Denominator – the number of young people (16 - 24 years) with cancer.

Data source: a) and b) Local data collection.

Outcome

Patient, parent or carer satisfaction with the support provided during treatment.

Data source: Local data collection.

What the quality statement means for service providers, healthcare practitioners and commissioners

Service providers ensure that they have systems in place and written clinical protocols for young people with cancer to be reviewed by a cancer site-specific multidisciplinary team and an age-specific multidisciplinary team to agree the most effective treatment and support.

Healthcare practitioners ensure that young people with cancer are reviewed by a cancer site-specific multidisciplinary team and an age-specific multidisciplinary team to agree the most effective treatment and support.

Commissioners ensure that they commission services that have systems in place and written clinical protocols for young people with cancer to be reviewed by a cancer site-specific multidisciplinary team and an age-specific multidisciplinary team to agree the most effective treatment and support.

What the quality statement means for patients, service users and carers

Young people with cancer have their care discussed by a team of experts in the type of cancer they have and also by a team of experts in treating and supporting young people with cancer.

Source guidance

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance CSGCYP (2005), section Multidisciplinary teams: page 93, paragraph 1; page 94 paragraphs 1 and 4 and section Principal treatment centres: page 106, paragraph 2.

Definitions of terms used in this quality statement

Age-specific multidisciplinary team

A dedicated multidisciplinary team with expertise in cancer-related issues for young people, their parents, carers and family. They consider the social, psychological and educational needs of young people with cancer and their families. This multidisciplinary team should also facilitate access to any appropriate clinical trials open to young people in their care.

Cancer site-specific multidisciplinary team

A dedicated multidisciplinary team with specialist expertise in treating specific sites for cancer. This multidisciplinary team should also to any appropriate clinical trials open to young people in their care.

Quality statement 3: Electronic prescribing of chemotherapy

Quality statement

Children and young people receiving chemotherapy have it prescribed via an electronic prescribing system.

Rationale

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. Chemotherapy regimens for children and young people are varied and often very complex, and there is a high risk of error in calculating the correct doses, fluid volumes and scheduling for children and young people. 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 and support safer prescribing.

Quality measures

Structure

Evidence of local arrangements to ensure that all children and young people receiving chemotherapy have it prescribed via an electronic prescribing system.

Data source: Local data collection.

Process

The proportion of children and young people receiving chemotherapy that have it prescribed via an electronic prescribing system.

Numerator – the number of children and young people in the denominator that had a prescription via an electronic prescribing system

Denominator – the number of children and young people receiving chemotherapy

Data source: [National Cancer Peer Review Programme](#), Children's cancer measure : 11-7B-161 - Computer generated prescriptions

Outcome

The number of patient safety incidents in children and young people related to chemotherapy prescriptions.

Data source: Local data collection.

What the quality statement means for service providers, healthcare practitioners and commissioners

Service providers ensure that they have systems in place for all children and young people receiving chemotherapy to have it prescribed via an electronic prescribing system.

Healthcare practitioners use electronic prescribing systems for prescribing chemotherapy regimens for children and young people.

Commissioners work with service providers to ensure that children and young people receiving chemotherapy have it prescribed via an electronic prescribing system.

What the quality statement means for patients, service users and carers

Children and young people receiving chemotherapy have the correct amount of drugs and fluids and when to take them calculated by an electronic prescribing system.

Source guidance

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance CSGCYP (2005), section Chemotherapy: page 39, paragraph 4.

Definitions of terms used in this quality statement

Electronic prescribing system

A computer package that calculates the correct chemotherapy doses, fluids and scheduling for each child and young person based on previously entered and verified data. The system should be suitable for use with paediatric chemotherapy regimens.

Quality statement 4: Psychosocial support

Quality statement

Children and young people with cancer and their families and carers are offered psychosocial support at the time of diagnosis.

Rationale

The impact of a diagnosis of cancer, its prognosis and its treatment can be devastating and wide-ranging for children and young people, their families, carers and friends. The provision of psychological and social support via the appropriate multidisciplinary team is important in helping patients and their families come to terms with the diagnosis and prognosis. It also helps patients and their families to cope with subsequent treatment and its complications, both immediate and long term. Psychosocial support should be offered at the time of diagnosis and on an ongoing basis, depending on need.

Quality measures

Structure

Evidence of local arrangements to ensure that all children and young people with cancer and their families are offered psychosocial support at the time of diagnosis.

Data source: [National Cancer Peer Review Programme](#), Children's cancer measure 11-7B-322 PTC Psychosocial Assessment Guidelines.

Process

The proportion of children and young people with cancer and their families who receive psychosocial support at the time of diagnosis.

Numerator – the number of children and young people and their families in the denominator who receive psychosocial support at the time of diagnosis.

Denominator – the number of children and young people who have been diagnosed with cancer and their families.

Data source: Local data collection.

Outcome

Patient experience of psychosocial support received during care.

Data source: Local data collection.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers ensure that systems are in place for all children and young people with cancer and their families to be offered psychosocial support at the time of diagnosis

Healthcare practitioners ensure that they offer all children and young people with cancer and their families psychosocial support at the time of diagnosis

Commissioners ensure that they commission services that have systems in place for all children and young people with cancer and their families to be offered psychosocial support at the time of diagnosis.

What the quality statement means for patients, service users and carers

Children and young people with cancer and their families are offered psychological and social support to help them cope when they are diagnosed with cancer

Source guidance

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance CSGCYP (2005), section Psychosocial care: page 74 paragraphs 1 and 2.

Definitions of terms used in this quality statement

Psychosocial support

Psychosocial support is the psychological and social supportive care received by a child or young person and their family during active cancer therapy and long-term follow-up, and includes respite care, palliative care and bereavement counselling for families. An assessment should be carried out that includes:

- family information needs and coping skills
- practical supportive issues
- social and cultural circumstances
- educational and employment needs
- the needs of siblings.

The assessment should result in a care plan to meet those needs, agreed with the child and family, and with access to relevant services.

Quality statement 5: Neuro-rehabilitation

Quality statement

Children and young people who have had a central nervous system malignancy are offered a specialist neuro-rehabilitation care package for an agreed period during and following their treatment.

Rationale

All children and young people who have had cancer are likely to need some form of rehabilitation. Those who have had cancer affecting their central nervous system (such as brain tumours) are likely to require complex rehabilitation over a long period of time (in some patients for the rest of their life). Access to skilled neuro-rehabilitation can make a significant difference, enabling children and young people to become independent adults and reducing the need for on-going complex care packages.

Quality measures

Structure

Evidence of local arrangements to ensure that all children and young people who have had a central nervous system malignancy are offered a specialist neuro-rehabilitation care package for an agreed period during and following their treatment.

Data source: Local data collection.

Process

The proportion of children and young people who have had a central nervous system malignancy who have a specialist neuro-rehabilitation care package for an agreed period during and following their treatment.

Numerator – the number of children and young people in the denominator who receive a specialist neuro-rehabilitation care package.

Denominator – the number of children and young people who have had a central nervous system malignancy.

What the quality statement means for service providers, health and social care practitioners and commissioners

Service providers ensure that they have systems in place for all children and young people who have had a central nervous system malignancy to be offered a specialist neuro-rehabilitation care package during and following their treatment.

Healthcare practitioners ensure that all children and young people who have had a central nervous system malignancy are offered a specialist neuro-rehabilitation care package for an agreed period during and following their treatment.

Commissioners ensure that they commission services that have systems in place for all children and young people who have had a central nervous system malignancy to be offered a specialist neuro-rehabilitation care package for an agreed period during and following their treatment.

What the quality statement means for patients, service users and carers

Children and young people who have had cancer that has affected their central nervous system (such as brain tumours) are given care and support by a team of specialists to help them recover as fully as possible during and after their treatment.

Source guidance

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance CSGCYP (2005), section rehabilitation: page 69 paragraph 2.

Definitions of terms used in this quality statement

Specialist neuro-rehabilitation care package

A care package including services that will take into account the effects of the cancer and its treatment on neurological, physical, psychological and academic function, recognising that these effects can become more evident over time. The specialist team should cover but not be limited to: speech and language therapy, physiotherapy, occupational therapy, neurology and psychology (including

neuropsychology). The rehabilitation programme should continue for as long as it is needed and can make a difference.

Quality statement 6: Management and review of late effects

Quality statement

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

Rationale

Children and young people who have had cancer are at risk of long-term adverse effects from the cancer and its treatment. At the end of their treatment they should be provided 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.

Quality measures

Structure

Evidence of local arrangements to ensure that all children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

Data source: Local data collection.

Process

a) The proportion of children and young people treated for cancer who have an end-of-treatment summary and care plan developed at the end of their treatment.

Numerator – the number of children and young people in the denominator who have an end-of-treatment summary and care plan developed at the end of their treatment.

Denominator – the number of children and young people treated for cancer.

b) The proportion of children and young people treated for cancer who had their end-of-treatment summary and care plan reviewed 5 years after the end of their initial treatment.

Numerator – the number of children and young people in the denominator who had their end-of-treatment summary and care plan reviewed 5 years after the end of their initial treatment.

Denominator – the number of children and young people treated for cancer.

c) The proportion of children and young people treated for cancer who had their end-of-treatment summary and care plan reviewed when discharged from long-term follow-up by the oncologist or the long-term follow-up clinic.

Numerator – the number of children and young people who had their end-of-treatment summary and care plan reviewed when discharged from long-term follow-up by the oncologist or the long-term follow-up clinic.

Denominator – the number of children and young people treated for cancer.

Data source: a), b) and c) [National Cancer Peer Review Programme](#), Children's cancer measures : 09-7B-211 - Follow up and care planning decision and 09-7B-212 - Late effects MDT follow up and long term sequelae protocol.

What the quality statement means for service providers, health and social care practitioners and commissioners

Service providers ensure that systems are in place for all children and young people who have been treated for cancer to have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

Healthcare practitioners ensure that all children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

Commissioners ensure that they commission services that have systems in place for all children and young people who have been treated for cancer to have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.

What the quality statement means for patients, service users and carers

Children and young people who have had treatment for cancer should have a plan developed at the end of their treatment. This plan should detail the treatment they received, any possible problems that they may experience, how checks for possible problems should be carried out and details of any further appointments.

Source guidance

- Scottish Intercollegiate Guidelines Network (SIGN) (2013) [Long term follow up of survivors of childhood cancer](#) (SIGN publication no. 132), sections 3.6 (page 11, paragraph 5), section 11.2 (page 35, paragraph 4) and section 11.3 (page 35, paragraph 6).

Definitions of terms used in this quality statement

End-of-treatment summary and care plan

A plan that should include details of all the chemotherapeutic agents and their cumulative doses, details of radiotherapy and surgery, and information on existing or potential late effects associated with the child or young person's cancer or treatment. It should detail the follow-up required for the individual child or young person, where this should happen, and with whom, and the arrangements for monitoring for:

- relapse or recurrence
- immediate and late effects of treatment
- risk of second malignancy.

Follow-up and monitoring arrangements As a minimum, the care plan should be available and revised: (1) at the end of treatment; (2) at the time of entry into long-term follow-up (usually 5 years after completing therapy); and (3) when discharged from formal follow-up by the oncologist or the long-term follow-up clinic.

Status of this quality standard

This is the draft quality standard released for consultation from 6 September to 4 October 2013. It is not NICE's final quality standard on children and young people with cancer. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 4 October 2013. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the [NICE website](#) from March 2014.

Using the quality standard

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [What makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of

100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered by commissioners, providers, health and social care practitioners, patients, service users and carers alongside the documents listed in 'Development sources'.

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments are available.

Good communication between health and social care practitioners and children and young people with cancer is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people with cancer should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties

Development sources

Further explanation of the methodology used can be found in the quality standards [Process guide](#) on the NICE website.

Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- [Long term follow up of survivors of childhood cancer](#). Scottish Intercollegiate Guidelines Network clinical guideline 132 (2013).
- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance CSGCYP (2005).

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- [Young voices: transforming the lives of young people with cancer](#). Teenage Cancer Trust (2012).
- [Health care service standards in caring for neonates, children and young people](#). Royal College of Nursing (2011).
- [Improving outcomes: a strategy for cancer](#). Department of Health (2011).
- [Manual for cancer services: teenage and young adults](#). Department of Health (2011).
- [Commissioning cancer services](#). Department of Health (2011).
- [Cancer pain management](#). The British Pain Society (2010).
- [Delivering the cancer reform strategy](#). National Audit Office (2010).
- [Cancer reform strategy](#). Department of Health (2007).

Definitions and data sources for the quality measures

[National Cancer Peer Review Programme](#), Children's cancer measures.

Related NICE quality standards

Published

- [Patient experience in adult NHS services](#). NICE quality standard 15 (2012).

Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Cancer chemotherapy.
- Haematological malignancies.
- Radiotherapy services.
- Referral for suspected cancer.
- Sarcoma.
- Skin cancer (including melanoma).
- Transition between child and adult services.

Quality Standards Advisory Committee and NICE project team

Quality Standards Advisory Committee

This quality standard has been developed by Quality Standards Advisory Committee 2. For further information about the standing members of this committee see the [NICE website](#). The following specialist members joined the committee to develop this quality standard:

Prof Brenda Gibson

Professor of Paediatric Haematology Royal Hospital for Sick Children

Miss Rachel Hollis

Lead Nurse for Children's Cancer Leeds Teaching Hospitals Trust

Dr Meriel Jenney

Consultant Paediatric Oncologist Cardiff and Vale University Health Board

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About this quality standard

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. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

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