



# Cancer services for children and young people

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This standard is based on CSG7 and CG156.

This standard should be read in conjunction with QS15, QS78, QS73, QS106, QS124, QS130 and QS146.

## Quality statements

<u>Statement 1</u> Young people (aged 16 to 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.

<u>Statement 2</u> Children and young people with cancer (aged 0 to 24 years) should be offered the opportunity to take part in clinical trials if they are eligible.

<u>Statement 3</u> Children and young people receiving chemotherapy have it prescribed using an electronic prescribing system.

<u>Statement 4</u> Children and young people 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.

<u>Statement 5</u> Children and young people who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.

<u>Statement 6</u> 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.

<u>Statement 7</u> Children and young people with cancer are assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.

# Quality statement 1: Multidisciplinary teams for young people

## Quality statement

Young people (aged 16 to 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.

#### Rationale

Children's services have well-established models of care to ensure that children with cancer are seen by a children's cancer multidisciplinary team. However, there is variation in access to age-appropriate care for young people. In addition to cancers more commonly found in their own age group, young people can also experience cancers more common to children or adults. It is therefore important for them to be seen by both a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team, to ensure that they have a correct diagnosis and receive the most effective treatment.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements for all young people (aged 16 to 24 years) with cancer to have their diagnosis, treatment and support agreed and delivered by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

#### **Process**

a) The proportion of young people (aged 16 to 24 years) diagnosed with cancer who have their diagnosis, treatment and support agreed by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.

Numerator – the number of people in the denominator who have their diagnosis, treatment and support agreed by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.

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

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

b) The proportion of young people (aged 16 to 24 years) with cancer who have their treatment and support delivered by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.

Numerator – the number of people in the denominator who have their treatment and support delivered by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.

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

Data source: The National Cancer Registration and Analysis Service Cancer Outcomes and Services Main Dataset includes the type of multidisciplinary team meeting at which the person's treatment and support is discussed (CR3190).

# What the quality statement means for different audiences

**Service providers** ensure that cancer-site-specific multidisciplinary teams and a teenage and young adult multidisciplinary team are in place to agree and deliver the diagnosis, treatment and support for young people (aged 16 to 24 years) with cancer.

Health and social care practitioners work collaboratively across cancer-site-specific and

teenage and young adult multidisciplinary teams to agree and deliver the diagnosis, treatment and support for young people (aged 16 to 24 years) with cancer.

**Commissioners** ensure that they commission cancer services for young people (aged 16 to 24 years) that include provision of cancer-site-specific multidisciplinary teams and a teenage and young adult multidisciplinary team for young people with cancer.

**Young peoplewith cancer** (aged 16 to 24 years) have their diagnosis, treatment and support agreed and delivered by a team of experts in the specific type of cancer that they have and a team of experts in treating and supporting young people with cancer.

## Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), Multidisciplinary teams: page 93, paragraph 1; page 94, paragraphs 1 and 4; and Principal treatment centres: page 104, paragraph 2

## Definitions of terms used in this quality statement

#### Teenage and young adult multidisciplinary team

A dedicated multidisciplinary team with expertise in cancer-related issues for teenagers and young adults, and their families and carers. The composition of the multidisciplinary team varies depending on the stage in the care pathway, but may include a:

- lead oncologist/haematologist with experience in teenage and young adult cancer
- principal treatment centre lead nurse
- specialist nurse
- psychologist or level 3 psychology support
- young people's social worker
- youth worker or activity coordinator
- teenage and young adult key worker.

[Adapted from NICE's guideline on improving outcomes in children and young people with cancer, Multidisciplinary teams: page 92, table 4]

### Cancer-site-specific multidisciplinary team

A dedicated multidisciplinary team with specialist expertise in treating cancer in specific sites. [Adapted from NICE's guideline on improving outcomes in children and young people with cancer, Multidisciplinary teams, page 94, paragraph 1]

# Quality statement 2: Access to clinical trials

## Quality statement

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

#### Rationale

Involvement of children and young people with cancer in clinical trials has made an important contribution to improved childhood cancer survival rates. Multidisciplinary teams should identify suitable trials for children and young people, and key workers should provide support to the patient and their family in deciding whether to participate. The decision to participate should be an informed choice.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements to ensure that children and young people (aged 0 to 24 years) are assessed for eligibility for relevant clinical trials and offered the opportunity to take part.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

#### **Process**

a) The proportion of children and young people (aged 0 to 24 years) with cancer and

eligible for a clinical trial who are offered the opportunity to take part.

Numerator – the number of people in the denominator offered the opportunity to take part.

Denominator – children and young people (aged 0 to 24 years) with cancer and eligible for a clinical trial.

**Data source:** The <u>NHS National Cancer Patient Experience Survey</u> includes whether cancer research opportunities were discussed with people aged 16 and over (Q58).

b) The proportion of children and young people (aged 0 to 24 years) with cancer who are recruited into a clinical trial for which they are eligible.

Numerator – the number of people in the denominator recruited into the clinical trial.

Denominator – the number of children and young people (aged 0 to 24 years) with cancer and eligible for a clinical trial.

Data source: The <u>National Cancer Registration and Analysis Service Cancer Outcomes and Services Main Dataset</u> includes whether a person who is eligible for a cancer clinical trial is taking part (CR1290).

## What the quality statement means for different audiences

**Service providers** ensure that multidisciplinary teams discuss the eligibility of children and young people (aged 0 to 24 years) with cancer for relevant clinical trials and promote participation in research and development.

**Healthcare professionals** from the multidisciplinary teams identify relevant clinical trials for children and young people (aged 0 to 24 years) with cancer, assess eligibility and offer opportunities to take part.

**Commissioners** ensure that the cancer services they commission for children and young people (aged 0 to 24 years) identify relevant clinical trials and support participation.

Children and young peoplewith cancer are offered the opportunity to take part in clinical

trials (which carry out research into new treatments) that have been identified as suitable for them and are supported to participate in these trials if they want to.

## Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), Research: page 124, paragraph 2

## Equality and diversity considerations

When providing support for children and young people to access clinical trials, any potential difficulties in participation, which may include distance, disability and financial barriers, should be taken into account.

# Quality statement 3: Electronic prescribing of chemotherapy

## Quality statement

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

#### Rationale

There are a number of risks associated with prescribing and administering chemotherapy. Electronic prescribing of chemotherapy should be used in all settings to help reduce the risks. However, at present it is widely used in adult cancer care but 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. Drug dose and fluid volume calculations are based on weight and body surface area. Electronic prescribing systems perform the calculations and support safer prescribing.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements to ensure that all children and young people (aged 0 to 24 years) receiving chemotherapy have it prescribed using an electronic prescribing system.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

# What the quality statement means for different audiences

**Service providers** ensure that an electronic prescribing system is in place for children and young people (aged 0 to 24 years) receiving chemotherapy.

Healthcare professionals use electronic prescribing systems for prescribing chemotherapy regimens for children and young people (aged 0 to 24 years).

**Commissioners** work with service providers to ensure that children and young people (aged 0 to 24 years) receiving chemotherapy have it prescribed using an electronic prescribing system.

Children and young people with cancer receiving chemotherapy have the correct amount of drugs and fluids, and when to have them, calculated by a computer-based prescribing system.

## Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), 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. [Expert opinion]

# Quality statement 4: Psychological and social support

## Quality statement

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

#### Rationale

The impact of a diagnosis of cancer, its prognosis and its treatment can be devastating and wide-ranging for children and young people, and their families and carers. As the child or young person progresses through their care pathway, their psychological and social needs, and those of their family, are likely to change. To help address this, their psychological and social support needs should be reassessed at key points to inform their care plan and to assess the need for specialist services such as psychologists.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements to ensure that children and young people (aged 0 to 24 years) with cancer, and their families and carers, have their psychological and social needs assessed at key points on their care pathway.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

#### **Process**

a) The proportion of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway who have their psychological and social needs assessed.

Numerator – the number of people in the denominator who have their psychological and social needs assessed.

Denominator – the number of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

b) The proportion of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway whose family and carers have their psychological and social needs assessed.

Numerator – the number of people in the denominator whose family and carers have their psychological and social needs assessed.

Denominator – the number of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

c) The proportion of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway who receive support with identified psychological or social needs.

Numerator – the number of people in the denominator receiving psychological or social support.

Denominator – the number of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway with identified psychological or social needs.

Data source: Data can be collected from information recorded locally by healthcare

professionals and provider organisations, for example from patient records.

d) The proportion of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway whose family and carers receive support with identified psychological and social needs.

Numerator – the number of people in the denominator receiving psychological or social support.

Denominator – the number of children and young people (aged 0 to 24 years) with cancer reaching a key point in their care pathway whose family and carers have identified psychological or social needs.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

#### Outcome

Children and young people with cancer, and their families and carers, feel supported during their care.

**Data source:** The <u>NHS National Cancer Patient Experience Survey</u> includes whether people got enough care and support at home from community or voluntary services during treatment (Q50) and enough emotional support after treatment (Q53).

# What the quality statement means for different audiences

**Service providers** ensure that the psychological and social needs of children and young people (aged 0 to 24 years) with cancer, and their families and carers, are assessed at key points in their care pathway, and that protocols are in place for referral to the appropriate specialists, such as psychologists.

Health and social care practitioners carry out psychological and social needs assessments for children and young people (aged 0 to 24 years) with cancer, and their families and carers, at key points in their care pathway, and use the results to inform the care plan and offer appropriate specialist support.

**Commissioners** ensure that they commission services that assess the psychological and social needs of children and young people (aged 0 to 24 years), and their families and carers, at key points in their care pathway. They should commission services to provide specialist psychological and social support to children and young people with cancer, and their families and carers.

Children and young people with cancer, and their families and carers, have their psychological and social needs assessed at different stages during and after their treatment. These assessments should result in a care plan that can be used to get extra help and support if they need it.

### Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), Psychosocial care: page 74, paragraphs 1 to 4

## Definitions of terms used in this quality statement

### Psychological and social needs assessment

An assessment of psychological and social support needs that includes:

- patient information needs and coping skills that are age-appropriate
- family information needs and coping skills
- financial support
- practical support
- · social and cultural circumstances
- educational and employment needs
- the needs of siblings
- relationships with peers
- spiritual needs.

The assessment should result in a care plan to meet the identified needs, agreed with the child or young person, and their family or carers. [Expert opinion and adapted from NICE's guideline on improving outcomes in children and young people with cancer, Psychosocial care: page 74, paragraph 4]

#### Key points in their care pathway

The key points in a care pathway when psychological and social needs should be assessed are:

- at diagnosis
- · during treatment
- at the end of treatment
- during long-term follow-up
- at relapse
- · during palliative care
- following bereavement (for families and carers).

[Adapted from NICE's guideline on improving outcomes in children and young people with cancer, Psychosocial care: page 74, paragraph 3]

#### Psychological and social support

Psychological and social support is the supportive care received by a child or young person and their family or carers during active cancer therapy and long-term follow-up, and it may include respite care, palliative care and bereavement counselling for families and carers. Psychological or social support may help with:

- how the child or young person perceives the challenge of the disease, its symptoms and the side effects of treatment
- problems experienced by the child or young person with body image, relationships with peers and potential partners, difficulties with schooling and other education, or difficulties with employment

- the disruption of the normal transition for young people from dependence on their family to independence
- the shock and grief a family experiences when a member of the family has a lifethreatening illness.

[Adapted from NICE's guideline on improving outcomes in children and young people with cancer, Psychosocial support: page 73, paragraph 2]

## Equality and diversity considerations

When providing psychological and social support for children and young people with cancer, any potential difficulties in accessing services, which may include distance, disability and financial barriers, should be taken into account.

## Quality statement 5: Neuro-rehabilitation

## Quality statement

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

#### Rationale

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

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements to ensure that all children and young people (aged 0 to 24 years) who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

#### **Process**

The proportion of children and young people (aged 0 to 24 years) who have had treatment

for a central nervous system malignancy who receive a specialist neuro-rehabilitation care package.

Numerator – the number of people in the denominator receiving a specialist neurorehabilitation care package.

Denominator – the number of children and young people (aged 0 to 24 years) who have had treatment for a central nervous system malignancy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** ensure that specialist neuro-rehabilitation care packages are available for children and young people (aged 0 to 24 years) who have had a central nervous system malignancy.

**Healthcare professionals** ensure that children and young people (aged 0 to 24 years) who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.

**Commissioners** ensure that they commission services that provide specialist neuro-rehabilitation care packages for children and young people (aged 0 to 24 years) who have had central nervous system malignancy.

Children and young people who have had cancer of the central nervous system (such as a brain tumour) are supported by a team of specialists to help them recover as fully as possible (called neuro-rehabilitation).

## Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), Rehabilitation: page 69, paragraph 2

## Definitions of terms used in this quality statement

#### Specialist neuro-rehabilitation care package

A package of support that takes into account the effects of the cancer and 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. [Adapted from <a href="NICE's guideline on improving outcomes in children and young people with cancer">NICE's guideline on improving outcomes in children and young people with cancer</a>, Rehabilitation: page 68, paragraph 6]

## Equality and diversity considerations

When providing neuro-rehabilitation services for children and young people with cancer, any potential difficulties in accessing services, which may include distance, disability and financial barriers, should be taken into account.

# Quality statement 6: Follow-up and monitoring of late effects

## Quality statement

Children and young people (aged 0 to 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.

#### 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 and identifying potential problems and treating them as quickly as possible.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements to ensure that children and young people (aged 0 to 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.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

#### **Process**

a) The proportion of children and young people (aged 0 to 24 years) completing treatment for cancer who have an end-of-treatment summary and care plan.

Numerator – the number of people in the denominator who have an end-of-treatment summary and care plan.

Denominator – the number of children and young people (aged 0 to 24 years) completing treatment for cancer.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

b) The proportion of children and young people (aged 0 to 24 years) treated for cancer who have their end-of-treatment summary and care plan reviewed 5 years after the end of their initial treatment.

Numerator – the number of people in the denominator who have 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 (aged 0 to 24 years) treated for cancer with an end-of-treatment summary and care plan.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

# What the quality statement means for different audiences

**Service providers** ensure that services and systems are in place for children and young people (aged 0 to 24 years) 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 professionals ensure that children and young people (aged 0 to 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, and ensure that the plan is reviewed 5 years after the end of initial treatment.

**Commissioners** ensure that they commission services that provide children and young people (aged 0 to 24 years) who have been treated for cancer with an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements. This should include commissioning services with long-term follow-up clinics to deliver the agreed care plan.

Children and young peoplewho have had treatment for cancer should have a care plan developed at the end of their treatment. This plan should include the treatment they have received, possible problems that they may experience, details of future appointments that have been agreed, how checks for possible problems should be carried out and who to contact if they have any concerns after their treatment.

### Source guidance

<u>Long term follow up of survivors of childhood cancer. SIGN clinical guideline 132</u> (2013), sections 3.6 (page 11, paragraph 5), 11.2 (page 35, paragraph 4) and 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:

- treatment, including chemotherapeutic agents and their cumulative doses, radiotherapy and surgery
- existing or potential late effects associated with the cancer or treatment
- agreed follow-up, including where and with whom
- monitoring for:
  - relapse or recurrence

- immediate and late effects of treatment
- risk of second malignancy.

As a minimum, the care plan should be available and revised at:

- the end of treatment
- entry into long-term follow-up (usually 5 years after completing therapy) and
- discharge from formal follow-up by the oncologist or the long-term follow-up clinic.

The care plan should also be used by key workers to support transition from children's services to young people's services and from young people's services to adult services. [Expert opinion]

## Quality statement 7: Fertility support

## Quality statement

Children and young people (aged 0 to 24 years) with cancer are assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.

#### Rationale

The late effects of cancer treatment are well-recognised and involve most organ systems. Approximately 15% of patients have a high risk of future fertility problems because of their cancer treatment. Children and young people with cancer and their parents or carers should have the risks discussed with them and be advised about their options for fertility preservation before cancer treatment starts.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

#### Structure

Evidence of local arrangements to ensure that children and young people (0 to 24 years) with cancer are assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.

**Data source:** Evidence can be collected from information recorded locally by provider organisations, for example from clinical pathways.

#### **Process**

The proportion of children and young people (aged 0 to 24 years) with cancer who are

assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.

Numerator – the number of people in the denominator who are assessed for potential future fertility problems before treatment and are advised about their options for fertility preservation.

Denominator – the number of children and young people (aged 0 to 24 years) diagnosed with cancer.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

# What the quality statement means for different audiences

**Service providers** ensure that processes are in place for children and young people (aged 0 to 24 years) with cancer to be assessed for potential future fertility problems and advised about their options for fertility preservation before treatment for cancer is started.

**Healthcare professionals** ensure that children and young people (aged 0 to 24 years) with cancer are assessed for potential future fertility problems before treatment for cancer is started and are advised about their options for fertility preservation.

**Commissioners** ensure they commission services that assess children and young people (aged 0 to 24 years) with cancer for potential future fertility problems before they start cancer treatment and advise them about their options for fertility preservation.

Children and young people with cancer have the risk of future fertility problems caused by their cancer or its treatment assessed before their treatment is started, and are given advice about their options for freezing some sperm, eggs or embryos for use at a later date (called cryopreservation).

## Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), Long-term sequelae: page 78, paragraph 8



## **Update** information

Minor changes since publication

May 2024: Changes have been made to align this quality standard with current data sources. Links and quality measures have been updated throughout.

October 2023: We updated data sources in statement 1.

## 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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about <u>how NICE quality standards are developed</u> is available from the NICE website.

See our <u>webpage on quality standards advisory committees</u> for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## Diversity, equality and language

Equality issues were considered during development and <u>equality assessments for this</u> quality standard are available. Good communication between health and social care

practitioners and children and young people with cancer, and their parents or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and 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, and their parents or carers (if appropriate), 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

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## **Endorsing organisation**

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Royal College of Surgeons of Edinburgh
- Children's Cancer and Leukaemia Group
- Teenage Cancer Trust
- Society and College of Radiographers (SOR)
- Teenagers and Young Adults with Cancer
- Royal College of Occupational Therapists (RCOT)
- CLIC Sargent
- Royal College of Paediatrics and Child Health