

Cancer services for children and young people

Quality standard

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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.

Introduction

This quality standard covers the provision of all aspects of cancer services for children and young people with cancer. For this quality standard, children are defined as aged 0–15 years and young people as 16–24 years, though this is not a formal upper age limit because the needs and circumstances of individuals will vary, including their need to access age-specific services. 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 children and young people are complex and differ from those that develop in adults. 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. [Referral guidelines for suspected cancer](#) (NICE clinical guideline 27)^[1] contains recommendations on the referral of children and young people for investigations for cancer.

Cancers in children are rare (less than 1% of all cancers in industrialised countries)^[2]. 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 each year in the UK: 883 (55%) in boys and 720 (45%) in girls.

Cancers in young people are also rare, equating to 269 cases per year for every million young people in the UK population. In 2008–2010, an average of 2214 new cases of cancer in young people was reported^[2].

Because cancers in children and young people are rare and often complex, services need to be able to consider each case of cancer individually, taking into consideration the clinical and wider needs of each child and young person, and their families and carers.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measureable 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 3 outcomes frameworks published by the Department of Health:

- [Adult Social Care Outcomes Framework 2013–14](#)
- [NHS Outcomes Framework 2014–15](#)
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, [Part 1](#) and [Part 1A](#).

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 [Adult Social Care Outcomes Framework 2013–14](#)

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	<i>Overarching measure</i> 1A Social care-related quality of life*
3 Ensuring that people have a positive experience of care and support	<i>Overarching measure</i> 3A Overall satisfaction of people who use services with their care and support 3B Overall satisfaction of carers with social services
*Indicator complementary with NHS Outcomes Framework (NHSOF)	

Table 2 [NHS Outcomes Framework 2014–15](#)

Domain	Overarching indicators and improvement areas
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<p>1 Preventing people from dying prematurely</p>	<p>Overarching indicator</p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p><i>i Adults</i></p> <p><i>ii 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>2 Ensuring people feel supported to manage their condition</p>	<p>Overarching indicator</p> <p>2 Proportion of people feeling supported to manage their condition**</p>
<p>4 Ensuring that people have a positive experience of care</p>	<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 Improving the experience of care for people at the end of their lives</p> <p>4.8 Children and young people's experience of healthcare</p>
<p>5 Treating and caring for people in a safe environment and protecting them from avoidable harm</p>	<p>Overarching indicators</p> <p>5a Patient safety incidents reported</p> <p>5b Safety incidents involving severe harm or death</p> <p>5c Hospital deaths attributable to problems in care</p> <p>Improvements areas</p> <p>5.4 Incidence of medication errors causing serious harm</p>

Alignment across the health and social care system

*Indicator shared with Public Health Outcomes Framework (PHOF)

**Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)

Indicators in italics are 'placeholders', pending development or identification

Table 3 Public health outcomes framework for England, 2013–2016

Domain	Objectives and indicators
4 Healthcare public health and preventing premature mortality	<p><i>Objective</i></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities.</p> <p><i>Indicators</i></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 NHS Outcomes Framework (NHSOF)</p>	

Coordinated services

The quality standard 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](#).

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, supporting 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.

Role of families and carers

Quality standards recognise the important role families and carers have in supporting children and young people with cancer. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

^[1] This [clinical guideline](#) is currently being updated. When the update is complete a NICE quality standard will be developed for this topic.

^[2] All data compiled by the Office for National Statistics and published by [Cancer Research UK](#). The Office for National Statistics classifies children as aged 0–14 years and young people as 15–24 years.

List of quality statements

Statement 1. Young people (aged 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.

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

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

Statement 4. 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.

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

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.

Statement 7. 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 16–24 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

Structure

Evidence of local arrangements for all young people (aged 16–24 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: Local data collection.

Process

a) The proportion of young people (aged 16–24 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 16–24 years) diagnosed with cancer.

Data source: Local data collection.

b) The proportion of young people (aged 16–24 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 16–24 years) with cancer.

Data source: Local data collection.

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

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 16–24 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 16–24 years) with cancer.

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

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

Young people with cancer (aged 16–24 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

- [Children and young people with cancer: improving outcomes in children and young people](#)

- [with cancer](#). NICE cancer service guidance (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 [Children and young people with cancer: improving outcomes in children and young people with cancer](#), Multidisciplinary teams: page 92, table 4; and National Cancer Peer Review Programme [Manual for cancer services: teenage and young adults cancer measures 11-7D-201](#) Lead clinician and core team membership]

Cancer-site-specific multidisciplinary team

A dedicated multidisciplinary team with specialist expertise in treating cancer in specific sites.

[Adapted from [Children and young people with cancer: 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 0–24 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

Structure

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

Data source: Local data collection.

Process

a) The proportion of children and young people (aged 0–24 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 0–24 years) with cancer and eligible for a clinical trial.

Data source: Local data collection.

b) The proportion of children and young people (aged 0–24 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 0–24 years) with cancer and eligible for a clinical trial.

Data source: Local data collection.

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

Service providers ensure that multidisciplinary teams discuss the eligibility of children and young people (aged 0–24 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 0–24 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 0–24 years) identify relevant clinical trials and support participation.

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

Children and young people with 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

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance (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 0–24 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

Structure

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

Data source: Local data collection. National Cancer Peer Review Programme [Manual for cancer services: children's cancer measures: 11-7B-161](#) Computer generated prescriptions.

Outcome

The number of patient safety incidents in children and young people (aged 0–24 years) related to chemotherapy prescriptions.

Data source: Local data collection.

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

Service providers ensure that an electronic prescribing system is in place for children and young

people (aged 0–24 years) receiving chemotherapy.

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

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

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

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

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance (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 0–24 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

Structure

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

Data source: National Cancer Peer Review Programme [Manual for cancer services: children's cancer measures](#): 11-7B-322 PTC psychosocial assessment guidelines.

b) Evidence of local arrangements to ensure that children and young people (aged 0–24 years) with cancer, and their families and carers, can access services delivering psychological and social support.

Data source: National Cancer Peer Review Programme [Manual for cancer services: children's cancer measures](#): 11-7B-322 PTC psychosocial assessment guidelines.

Process

a) The proportion of children and young people (aged 0–24 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 0–24 years) with cancer reaching a key point in their care pathway.

Data source: Local data collection.

b) The proportion of children and young people (aged 0–24 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 0–24 years) with cancer reaching a key point in their care pathway.

Data source: Local data collection.

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

Data source: Local data collection.

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

Data source: Local data collection.

Outcome

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

Data source: Local data collection. National Cancer Peer Review Programme [Manual for cancer services: teenage and young adults measures: 11-7D-210 TYA cancer measures patient experience exercise](#).

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

Service providers ensure that the psychological and social needs of children and young people (aged 0–24 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 0–24 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 0–24 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.

What the quality statement means for patients, service users 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

- [Children and young people with cancer: improving outcomes in children and young people](#)

- with cancer. NICE cancer service guidance (2005), Psychosocial care: page 74, paragraphs 1, 2, 3 and 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 Children and young people with cancer: 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 [Children and young people with cancer: 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 life-threatening illness.

[Adapted from [Children and young people with cancer: 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 0–24 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

Structure

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

Data source: Local data collection.

Process

The proportion of children and young people (aged 0–24 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 neuro-rehabilitation care package.

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

Data source: Local data collection.

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

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

Healthcare professionals ensure that children and young people (aged 0–24 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 0–24 years) who have had central nervous system malignancy.

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

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

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance (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 [Children and young people with cancer: improving outcomes in children and young people with cancer](#). 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 0–24 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

Structure

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

Data source: Local data collection.

Process

a) The proportion of children and young people (aged 0–24 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 0–24 years) completing treatment for cancer.

b) The proportion of children and young people (aged 0–24 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 0–24 years) treated for cancer with an end-of-treatment summary and care plan.

Data source: a), b) Local data collection and National Cancer Peer Review Programme [Manual for cancer services: children's cancer measures: 11-7B-211 Follow up and care planning decision](#), and 1-7B-212 Late effects MDT follow up and long term sequelae protocol.

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

Service providers ensure that services and systems are in place for children and young people (aged 0–24 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 0–24 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 0–24 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.

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

Children and young people who 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

- Scottish Intercollegiate Guidelines Network (SIGN) (2013) [Long term follow up of survivors of](#)

- childhood cancer (SIGN clinical guideline 132), 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 0–24 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

Structure

Evidence of local arrangements to ensure that 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.

Data source: Local data collection.

Process

The proportion of children and young people (aged 0–24 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 0–24 years) diagnosed with cancer.

Data source: Local data collection.

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

Service providers ensure that processes are in place for children and young people (aged 0–24 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 0–24 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 0–24 years) with cancer for potential future fertility problems before they start cancer treatment and advise them about their options for fertility preservation.

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

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

- [Children and young people with cancer: improving outcomes in children and young people with cancer](#). NICE cancer service guidance (2005), Long-term sequelae: page 78, paragraph 8.
- Fertility (NICE clinical guideline 156), recommendation [1.16.1.2](#).

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 alongside the documents listed in [Development sources](#).

Information for commissioners

NICE has produced [support for commissioning](#) that considers the commissioning implications and potential resource impact of this quality standard. This is available on the NICE website.

Information for the public

NICE has produced [information for the public](#) about this quality standard. Patients, service users and carers can use it to find out about the quality of care they should expect to receive; as a basis for asking questions about their care, and to help make choices between providers of social care services.

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, 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

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.

- [Fertility](#). NICE clinical guideline 156 (2013).
- [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 (2005).

Policy context

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

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

- Teenagers and Young Adults with Cancer (2012) [Blueprint of care for teenagers and young adults with cancer.](#)

Definitions and data sources for the quality measures

- National Cancer Peer Review Programme (2013) [Manual for cancer services: 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:

- Haematological malignancies.
- 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.

Membership of this committee is as follows:

Dr Michael Rudolf (Chair)

Consultant Physician, Ealing Hospital NHS Trust

Mr Barry Attwood

Lay member

Professor Gillian Baird

Consultant Paediatrician, Guys and St Thomas NHS Foundation Trust

Mrs Belinda Black

Chief Executive, Sheffcare Ltd

Dr Ashok Bohra

Consultant Surgeon, Dudley Group of Hospitals NHS Foundation Trust

Mrs Julie Clatworthy

Governing Body Nurse, Gloucestershire Clinical Commissioning Group

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Consultant Gynaecological Oncologist/Chief of Service, The James Cook University Hospital Foundation Trust

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Consultant in Anaesthesia and Pain Medicine, Barts Health NHS Trust

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Assistant Director of Quality Assurance, Marie Curie Cancer Care

Ms Kay MacKay

Director Enhancing Quality and Recovery Kent, Surrey and Sussex

Mr David Minto

West Sector Operations Manager, Northumbria Healthcare

Mrs Alison Raw

Head of Integrated Health and Care, Lewisham

Dr Lindsay Smith

GP, West Coker, Somerset

The following specialist members joined the committee to develop this quality standard:

Mr Chris Gibbs

Lay member, Childhood Cancer Parents Alliance

Professor Brenda Gibson

Professor of Paediatric Haematology, Royal Hospital for Sick Children

Dr Robert Carr

Consultant Haematologist, Guys and St Thomas' Hospital London

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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](#).

This quality standard has been incorporated into the [NICE pathway for fertility](#).

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Changes after publication

April 2015: minor maintenance

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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](#)
- [Teenagers and Young Adults with Cancer](#)
- [Royal College of Occupational Therapists](#)
- [CLIC Sargent](#)
- [Royal College of Paediatrics and Child Health](#)