

**NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE**

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Children and young people with cancer

Date of Quality Standards Advisory Committee post-consultation meeting:

15 November 2013

2 Introduction

The draft quality standard for children and young people with cancer was made available on the NICE website for a 4-week public consultation period between 6th September and 4th October 2013. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 26 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include overarching outcomes, thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?
2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Concerns were raised about trying to cover quality improvement areas for children and young people within the same statements as the service specifications, cancer types and the needs for these populations are different.
- Stakeholders wanted clarification about how the quality standard will align with other national initiatives focusing on this topic.
- Stakeholders were concerned about whether the quality statements would be relevant to all parts of the service infrastructure for this population. For example, how Paediatric Oncology Shared Care Units (POSCUs) would be able to meet the quality statements was raised.

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- Stakeholders asked if the training competencies required to ensure the quality standards are met could be clarified.
- Stakeholders highlighted that there was some inconsistency in the age range used in some of the presented data in the introduction and that used for the quality statements.

Consultation comments on data collection

- In general stakeholders felt that the measures included for each quality statement were appropriate and measurable.
- One stakeholder suggested the quality statements needed to be more directive and that this would make them more measurable.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

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

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Stakeholders questioned whether this was an area for quality improvement for this population as it was felt there had been good progress made in this area.
- Membership of the MDT was highlighted for further consideration, including specific comment about the inclusion of a paediatric haematologist and whether a clinical psychologist should be included as a core member.
- Stakeholders asked whether the term '*reviewed*' could be changed to provide a clearer description of what the MDT's should actually be doing, for example are they agreeing the diagnosis and treatment plan
- Stakeholders questioned the separation of diagnostic and treatments MDT's stating that this model is not used in some principal treatment centres.
- Stakeholders suggested that the definitions for this statement should not be overly prescriptive as principal treatment centres can vary in the way they structure their services.
- Reference was made to the role of the key worker within the MDT and that this role needs to be clarified within the quality standard.

5.2 *Draft 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

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Stakeholders felt that the description of the types of cancer seen in young people was overly simplistic and should recognise that young people can experience cancers specific to that age group, late onset of the cancer types seen in children and early on-set of the cancer types seen in adults.
- Stakeholders asked whether the term '*reviewed*' could be changed to provide a clearer description of what the MDT's should actually be doing, for example are they agreeing the diagnosis and treatment plan?
- Stakeholders suggested that the statement is overly prescriptive as different settings have different service structures. For example some areas do not have cancer site specific MDT's. Stakeholders suggested that the key area for quality improvement should focus on young people being seen and cared for by people with relevant experience rather than what team they are in.
- Stakeholders asked that the term teenage and young adult MDT is used rather than age appropriate.
- Stakeholders asked that if 2 different MDT's discuss the diagnosis / treatment of a young person that the need for them to communicate clearly with each other and the young person is highlighted.
- Stakeholders asked if additional measures could be included concerning involvement in clinical trials and the identification of a key worker.

5.3 *Draft statement 3*

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

Consultation comments

- Stakeholders were split about whether this was a priority for quality improvement. No stakeholders thought it was a bad suggestion, some suggested that this was not a priority compared to other areas for quality improvement for this topic.
- Stakeholders asked how Principal Treatment Centres would be able to support Paediatric Oncology Shared Care Units to implement this quality statement.
- Stakeholders asked that the term 'electronic prescribing system' was clarified so it was explicit that the area for quality improvement is about using software to carry out calculations to inform chemotherapy regimens for children and young people.
- Some stakeholders raised concerns about how feasible this statement would be to implement due to the lack of suitable software that can be used to calculate chemotherapy regimens for children and young people.

5.4 *Draft statement 4*

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

Consultation comments

- Stakeholders were concerned that the quality statement only focuses on time of diagnosis and that access to psychosocial support should be available throughout and post treatment.
- Stakeholders asked that there was a separation between psychosocial care that is based on a clinical need and the more general support that should focus on the wider aspects of their life such as social care, education, employment, family relationships and peer support.
- Stakeholders suggested that a clearer timeframe is included about when the assessment for psychosocial needs should be carried out by.

5.5 *Draft 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.

Consultation comments

- Stakeholders wanted clarification about how long neuro-rehabilitation should be provided for and when it should start from.
- Stakeholders asked why the statement only focuses on children and young people with central nervous system cancers. A number of stakeholders highlighted other cancer types that are associated with high level rehabilitation needs.
- Stakeholders suggested that this quality statement may be difficult to implement for services not based within Principal Treatment Centres due to lack of available staff with sufficient capability and capacity.

5.6 ***Draft 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.

Consultation comments

- Stakeholders wanted clarification about how this statement aligns with the work of the Children and Young People's Survivorship work stream being led by the NHS Improving Quality initiative at NHS England.
- Stakeholders suggested that the scope of the statement should be broadened to include non-clinical issues that should continue to be supported and monitored following treatment.
- Stakeholders asked for further clarification about the timings for the development of the end-of-care treatment summary and care plan and the period of follow up. Stakeholders suggested that the statement wording could be made more specific to support this.
- Stakeholders were concerned that helping children and young people in the transition process between services was not explicitly referenced in the quality statement and supporting information.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Stakeholders suggested that there should be a focus on early diagnosis and referral to appropriate specialists. Additional suggestions linked to this area included ensuring appropriate tests were used, timescales from referral to diagnostic assessment and the communication of results
- Stakeholders noted that pain management and use of anaesthesia had not been prioritised at the QSAC prioritisation meeting and questioned this decision, reiterating their view that that these were areas for quality improvement.
- Stakeholders suggested that there should be a clearer focus on the provision of age appropriate care throughout the pathway.
- Stakeholders suggested an additional area for quality improvement should be improving integration of general practice and specialist cancer services to help support the general medical care of this population.
- Stakeholders suggested that there should be a specific statement concerning palliative care for this population.

Appendix 1: Quality standard consultation comments table

ID	Stakeholder	Section	Comments
1	British Society of Paediatric Dermatology	General	Ensure QS for cancer is signposted on cancer guidelines such as melanoma guidelines.
2	Department of Health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
3	The Christie NHS Foundation Trust	General	I feel that grouping children and young people together waters down some of the potential of these quality standards. If they were to be separated then there could be say 4 or 5 standards that are specific to each age group.
4	The Christie NHS Foundation Trust	General	It should be possible to collect the data that would say whether these quality standards were being met. It would be easier to do this if all young people were discussed at the TYA MDT, this still has to be the priority, we need to know who is out there before we can begin to collect the appropriate data. It also has to be recognised that if all young people do start being notified to the TYA MDT then the teams and support services that are currently in place are unlikely to be able to cope with the workload. However that would be a nice problem to have.
5	CLIC Sargent	General	Many of the statements cite 'local data collection' as the data source to measure adherence to the standards. There needs to be further details on what exactly these data sources are and whether they are sufficiently robust to be collated and compared on a national basis
6	University College London Hospital	General	<p>Please could there be clarity of how these standards will be implemented and evaluated. How do these standards fit with peer review standards, NCIN metrics and TYA CRG metrics.</p> <p>We are unclear as to how these quality standards are going to be measured.</p> <p>It would be helpful to differentiate further between children's and TYA cancer services. There is a need now for the separation of the quality standards into 2 separate documents, one for children and one for TYA patients.</p> <p>The blueprint of care needs to be considered and referenced in these quality standards</p> <p>It would be helpful if there was more in depth guidance around the training and competencies required</p>

ID	Stakeholder	Section	Comments
			by health and social care practitioners involved in assessing, caring for and treating children and young people with cancer. There is currently work been undertaken by TCT and the RCN around educational competencies for Nurses working with the TYA age group
7	British Association of Dermatologists (BAD)	General	Cancer presenting in the skin in children and young people is fortunately very rare, although there are a few rare genetic conditions that predispose them to skin cancer.
8	British Association of Dermatologists (BAD)	General	There should be additional quality statements added with regard to ensuring <i>early diagnosis</i> by referral to appropriate specialists, indicating 1) the appropriate timeframes within which patients should be seen by the appropriate consultants, 2) the tests undertaken, 3) the results given to the family, and 4) treatment commenced.
9	British Association of Dermatologists (BAD)	General	The core members of the MDT should also include the specialists involved, e.g. dermatologists, gastroenterologists, etc.
10	British Association of Dermatologists (BAD)	General	This set of quality standards for cancer should be signposted on cancer guidelines, e.g. the melanoma guidelines.
11	College of Occupational Therapists	General	We suggest consistency in the use of age ranges for young people. On the first page of the draft document, young people are defined as 15-24 years. However, pages 4 onwards, define young people as 16-24 years.
12	College of Occupational Therapists	General	<p>It is important that it is highlighted that one of the core members of the multidisciplinary team should include an Occupational Therapist.</p> <ul style="list-style-type: none"> • The College of Occupational Therapists has a document relevant to this area of practice. • College of Occupational Therapists (2010) <i>Children and young people with cancer: guidance for occupational therapists</i>. London: COT.
13	NHS England	General	CRG specifications already draw on existing quality standards and CRGs are keen to endorse any quality standards aimed at improving the outcomes and experience of young people undergoing treatment for cancer.

ID	Stakeholder	Section	Comments
			<p>However, we suggest that clarification is required to explain how these standards fit into the standards for TYA cancer care which already exist or are in preparation, including the peer review standards, NCIN metrics and TYA CRG metrics. How will these CYP quality standards be measured and acted upon?</p> <p>From an NHS England perspective, there are separate CRGs and service specifications for children with cancer (0-15) and Teenage and Young Adults with cancer. Linked to this it may be better to differentiate between these two areas and to have separate NICE Quality Standards for each group. Although this draft does now differentiate between children’s and TYA cancer services it is still very children’s focused. Given the significant developments in TYA services since the publication of CYP Improving Outcomes Guidance in 2005 there is a need for a) the separation of the quality standards into 2 documents, one for children and one for TYA patients, b) updating the IOG itself and associated peer review measures. It would be very helpful if NICE would consider these updates.</p> <p>It is also noted that the blueprint of care is not included in the evidence documents and it is important that this is referenced.</p>
14	NHS England	General	<p>Does this draft quality standard accurately reflect the key areas for quality improvement?</p> <p><i>Partially</i>, although reflects the needs of children more accurately than the needs of TYA patients. Some of the priorities in TYA cancer care are not reflected in these standards and include;</p> <ul style="list-style-type: none"> Improving speed of diagnosis Access to clinical trials and improving trial accrual Strategies for measuring patient experience and meaningful patient engagement (including proportion of 19-24 year olds offered choice between PTC and designated hospital) Access to specialist TYA staff and services Survivorship/Late effects
15	NHS England	General	<p>If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?</p>

ID	Stakeholder	Section	Comments
			<p><i>Partially</i>- however as the standards currently stand some would not be measurable without further details- see comments below</p> <p>Collecting some of this data, particularly accurate and helpful data on social and psychological support, might be difficult without some specific work with the voluntary sector as it is charities currently that fund and deliver a lot of this support. Capturing just what the NHS provides would be inaccurate and misrepresent the support that is available. Although it may be that the patient experience survey could capture it if that was considered accurate enough.</p>
16	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	General	The general approach conveyed by these quality standards is welcomed
17	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	General	Delayed diagnosis remains a concern for many patients / parents. The collection of data which seeks to attempt a definition of symptom interval and time from first consultation with symptoms consistent with the final diagnosis to that diagnosis is considered important. It is recognised however that this may be difficult to achieve and that such data may be subject to recall bias. It would however be appropriate for the QS Advisory Committee to consider this.
18	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	General	The age definitions for children and TYA vary in different settings. Cancer registration identifies children from 0-14 years and TYA from 15-25 years. The NCIN Cancer Outcomes and Services Dataset utilises 0-15 and 16-24 years but this is under review and may be amended to align with the cancer registration boundaries
19	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	General	Collection of any data item that requires collection from locally created systems may be difficult to mandate. Work should be done to align data collection with structures in place for MDT reporting via systems in established use such as Somerset etc. The major cancer information systems used by MDTs should be adjusting their content and format to meet the requirements of COSD
20	Paediatric Oncology Dieticians Interest Group (PODIG)	General	This is a clear written document which has the desired effect of discussing and setting clear guidance on measurable quality standards of care for children and young people with cancer.

ID	Stakeholder	Section	Comments
21	Royal College of Physicians (RCP)	General	<p>The Royal College of Physicians (RCP) welcomes the opportunity to provide feedback on this important document. It has been reviewed by the RCP’s Young Adult and Adolescent Steering Group.</p> <p>Our experts believe that there needs to be a focus on age and developmentally-appropriate care throughout the document and a clear separation between the needs of children, adolescents and young adults. By defining the 0-15 year age group as ‘children’ fails to recognize the change in care required to meet the needs of adolescents (WHO definition 10-19). A problem with the original 2005 IOG has been that there has not been clear enough separation of Children’s Cancer care and older Teenage and Young Adult Cancer care. The issues, and process of delivery of cancer care for children with cancer and young adults with cancer are entirely separate (with an increasingly small overlap for 16 - 17 year olds). The NICE Quality standards must provide separate standards for children, adolescents and young adults, even if some of the same standard appears under each age-group heading.</p> <p>There is no mention of the DH ‘You’re Welcome’ Quality standards for Young Person Friendly Health Service which could act as a potentially useful benchmarking of services in the provision of age and developmentally appropriate care in the adolescent and young adult age group. This document includes standards around access, publicity, confidentiality and consent, environment, staff training, joined up working with other agencies, involving young people and other health issues relevant to young people. To improve care for this age group and provide a consistent message to commissioners and services this document should be sited in the NICE Quality standards.</p> <p>Some of the phraseology could result in quality standards not generally being met. For example the use of ‘agreed’ site-specific and age-appropriate (TYA) care often doesn’t necessarily translate into action. Wherever this is stated (for example in the final 3 para on p10) it should be qualified by the statement ‘.... with defined pathways for, and evidence of delivery of the agree care plan’.</p> <p>Psychological and social support should include the importance of encouraging self-advocacy and self-efficacy in managing their own healthcare including when appropriate lone consulting in both the adolescents in the ‘children’ group and in the TYA group. TYA psychological support must be delivered by a Clinical Psychologist with appropriate training and experience in support of Teenagers and Young Adults (and not by a Social Worker, as implied on P17 of the QSAC briefing paper). [IOG evidence: Para 2, P74; Table 4 P92, which states Psychological Services Professional].</p>

ID	Stakeholder	Section	Comments
			<p>There is a lack of focus on the importance of offering fertility preservation in adolescents and young adults. The NICE Quality standards should emphasise this in both the 'children group' and the TYA group.</p> <p>Relating to long-term effects while some patients could be provided with advice and need for monitoring some of which could be delivered by primary care, there are also a group of complex patients that require detailed specialist multidisciplinary follow up. The NICE Quality standard should emphasis a need for such a service to be available.</p> <p>We have suggested the following Quality Statements for TYA are:</p> <ol style="list-style-type: none"> 1. TYA (16-24 years) must have: <ol style="list-style-type: none"> a) Diagnosis and treatment reviewed and delivered by the Tumour Site Specific MDT (with expertise in their particular tumour at this age), with a named site specific Key Worker. b) Age-appropriate psycho-social supportive care must be approved, agreed and delivered by a specialist Teenage and Young Adult multi-disciplinary Team (TYA MDT). c) The Tumour SS MDT and TYA MDT must work together to ensure that all management is age-appropriate, with clear lines of communication between the two teams. 2. All TYAs with a malignancy must be under the direct care of a TYA MDT with, at minimum: a named Lead TYA Cancer Nurse (TYA Key Worker) and a Specialist TYA clinical psychologist who will deliver supportive care through diagnosis, treatment and post treatment follow-up. Families (parents and siblings) should be offered support as required. 3. All TYAs must be offered entry into clinical treatment trials relevant to their malignancy. (They should be informed of any additional appropriate trials open at other centres and offered transfer to such centres where the trial(s) are open). 4. There must be a clear end of treatment pathway for: <ol style="list-style-type: none"> a) Malignant disease follow-up and monitoring by the site specific treatment MDT. b) Post treatment follow-up by the TYA MDT, to include: <ol style="list-style-type: none"> i. Treatment late effects monitoring

ID	Stakeholder	Section	Comments
			<ul style="list-style-type: none"> ii. Psychological support iii. Fertility monitoring and support iv. Dietary advice in the immediate post-treatment period <p>5. All TYA patients must be referred for overall management of their malignant disease at a Principal Treatment Centre, or Designated Hospital where both staff and infrastructure are in place for all the above standards to be met.</p> <p>6. CNS tumours must have an appropriate post treatment rehabilitation care package (as for children).</p>
22	Yorkshire and Humber Strategic Clinical Network and Senate	General	Organisations and group members welcome the opportunity to comment on the draft NICE Quality Standards for Children and Young People (CYP) with cancer to drive measurable quality improvements and co-ordinate care across the whole cancer pathway.
23	Yorkshire and Humber Strategic Clinical Network and Senate	General	Outcome measures that take quality of life measure in to account would be appropriate.
24	Yorkshire and Humber Strategic Clinical Network and Senate	General	These standards don't seem to have referred to the NHS commissioning standards for paediatric neuro rehabilitation E9d.
25	Yorkshire and Humber Strategic Clinical Network and Senate	General	<p>Page 10 contains the text: Commissioners ensure that they commission services that have systems in place and written clinical protocols for young people with cancer to be reviewed. This is misleading- these are not protocols, but pathways.</p> <p>Page 11- A suggested amendment: rather than: 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.</p> <p>This could better read; A dedicated multidisciplinary team with expertise in cancer-related issues for young people, their parents, carers and family. They have primary responsibility for the delivery the social, psychological and educational needs of young people with cancer and their families, which</p>

ID	Stakeholder	Section	Comments
			<p>integrates and supports the delivery of the clinical treatment protocol.</p> <p>Page 11 contains a typographical error; ‘This multidisciplinary team should also to any appropriate clinical trials; should read; This multidisciplinary team should also promote entry to any appropriate clinical trials</p> <p>Page 16-17 reads: 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:</p> <ul style="list-style-type: none"> • family information needs and coping skills • practical supportive issues • social and cultural circumstances • educational and employment needs • the needs of siblings <p>This could better read: 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 <u>alongside other aspects</u>; respite care, palliative care and bereavement counselling for families. An assessment should be carried out that includes, <u>alongside other aspects</u>:</p> <ul style="list-style-type: none"> • family information needs and coping skills • practical supportive issues • social and cultural circumstances • educational and employment needs

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			<ul style="list-style-type: none"> • the needs of siblings <p>Otherwise the paper may be interpreted as if the two lists are the sole requirements of the assessment and care.</p> <p>Page 17 reads: agreed with the child and family. This could better read 'agreed with the child, young person, family and other carers'. Otherwise it does not fully serve the needs of young people, only children remaining in the family context.</p> <p>Statement 6: could better read: Children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up, monitoring <u>and supported self-care</u> arrangements.</p>
26	The Society and College of Radiographers	General	There is a lack of relating this to the shared care centre (POSCU). Most quality standards work for both PTC and POSCU, but it probably needs to be made clear how that pathway works.
27	Teenagers and Young Adults with Cancer (TYAC)	General	TYAC feels strongly that these quality standards need to be significantly improved if they are going to be fit for purpose with regards Teenagers and Young Adults. Below is an amalgamation of comments from members of the organisation. We feel that there is definitely scope to split the standards into children and TYA specific.
28	Royal College of General Practitioners	General	I have previously signalled that the integration of GP and specialist services for the purpose of general medical care of these patients leaves a lot to be desired. This is not addressed by this standard (perhaps because it would be difficult to measure).
29	The Royal College of Surgeons of Edinburgh	General	The Royal College of Surgeons of Edinburgh support the NICE Quality Standards guideline for children and young people with cancer. The College believes that the guidelines presented are reasonable.
30	Teenage Cancer Trust	Introduction	This distinguishes that childhood cancers are different from those that develop in adults, but not that cancers in young people differ and are also distinct in that they include the late onset of cancers most common in children, the early onset of cancers most common in adults as well as cancers that are most common in this age group (Birch classification 2006).
31	NHS England	Introduction	Defines young people aged 15-24 yrs- this fits in with the statistics provided in the document but the

ID	Stakeholder	Section	Comments
			<p>rest of the document describes services and uses the age range 16-24 years.</p> <p>The document should define TYA as 16-24 in line with service specification and NICE IOG</p>
32	NHS England	Introduction	<p>Cancers that occur in the TYA population include the late onset of children’s cancer, the early onset of adult cancers as well as those cancer types defined as “true” TYA cancers that peak in this age group (Birch Classification 2006).</p>
33	NHS England	Introduction	<p>Would be helpful if there was more guidance depth in this paragraph.</p> <p>‘Professionals caring for patients aged 16-24 with cancer should have training in the management of young people in this age-group.’</p> <p>This could be measured from the proportion of TYA-trained professionals among the named specialist professionals in the TYA MDT and TYA wards where care is delivered. Regionally or at a central level, commissioners could purchase the NHS clinical capacity to allow release for training for TYA specialist staff to attend regional programmes of specific initial training and then CPD via the existing systems provided by the multi-professional organisations ‘Teenagers and Young adults with cancer and the Teenage Cancer Trust). Source document- Blueprint of Care for TYA (Teenage Cancer Trust).</p>
34	The Society and College of Radiographers	Introduction	<p>Second sentence down – age range is 15 – 24, but is 16-24 on other pages.</p>
35	Teenagers and Young Adults with Cancer (TYAC)	Introduction	<p>Young people are referred to as being 15-24 but for the rest of the document they are 16-24. it should be 16-24 all the way through in line with IOG.</p>
36	Teenagers and Young Adults with Cancer (TYAC)	Introduction	<p>This distinguishes children’s cancers but we should also distinguish/identify TYA cancers more clearly This seems to be missing altogether. Cancers that occur in the TYA population include the late onset of childrens cancer, the early onset of adult cancers as well as those cancer types defined as “true” TYA cancers that peak in this age group (Birch Classification 2006).</p>

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37	Teenagers and Young Adults with Cancer (TYAC)	Introduction	<p>Would be helpful if there was more guidance depth in this paragraph. All healthcare professionals and social care practitioners working with CYP should have appropriate training and an identified training, education and competence framework as defined by an appropriate professional body or organisation i.e. Nursing Competences are defined by the Royal College of Nursing, Medical competences are defined by ??</p> <p>It was felt that the issue of competence and training within the TYA world would warrant its own Quality Standard. It would be measurable from the numbers of appropriately trained professionals that are part of the TYA MDT and the TYA specific treatment areas.</p>
38	Teenage Cancer Trust	Introduction,	<p>Young people are defined here as 15-24 but the age group normally used is 16-24 and this is referred to in other sections of the document</p>
39	Children's Cancer and Leukaemia Group (CCLG)	Quality statement 1	<p>Our members in some centres questioned whether it was necessary for a paediatric haematologist to be a core member of the MDT</p>
40	Teenage Cancer Trust	Quality Statement 1	<p>This statement is not relevant to young people with cancer</p>
41	Faculty of Pain Medicine of the Royal College of Anaesthetists	Quality Statement 1	<p>A clinical psychologist should be a core member of the treatment multidisciplinary team</p>
42	Faculty of Pain Medicine of the Royal College of Anaesthetists	Quality Statement 1	<p>Radiological investigations continue throughout treatment. A radiologist should be a core member of the treatment multidisciplinary team</p>
43	The Christie NHS Foundation Trust	Quality Statement 1	<p>I do not disagree that this is important but I imagine this already happens especially with all children's cancer services being organised by Children's PTC's. I think this measure could either be lost or replaced by a different one. I appreciate that there are other national measures that are dealing with topics such as early diagnosis but I think the issue of Early Diagnosis would be a better QS especially for young people. There is still a long way to go in ensuring that young people are diagnosed as early as possible, this involves education of young people, primary care and the elimination of delays in the diagnostic pathway in hospital.</p>
44	CLIC Sargent	Quality Statement 1	<p>Quality statement Referral to an age appropriate multi-disciplinary team (MDT) is an absolutely crucial element of getting the best treatment for children and young people with cancer and, as such, is a key element of the NICE</p>

ID	Stakeholder	Section	Comments
			<p>guidance on improving outcomes for children and young people with cancer. We would highlight, however, that this is one area on which good progress has already been made and may therefore not be the best topic to select as a priority for improvement.</p> <p>Further specific comments:</p> <ul style="list-style-type: none"> • Some concern over the ‘one size fits all’ approach to MDTs – this must be sufficiently flexible to apply to all principal treatment centres (PTCs) depending on their patient intake. Because of smaller patient numbers, some PTCs will have a diagnostic MDT covering all cancers and a psychosocial MDT; bigger centres may have several tumour site-specific MDTs which combine diagnostic and treatment discussions for those patients. Both approaches are appropriate and it is therefore important that these standards focus on ensuring the right clinicians and other professionals are involved in the right decisions at the right time, as well as ensuring they have sufficient numbers in any given area to develop the expertise. • Including specialist oncology social workers in the list of MDT members • Needs to be a greater emphasis on age-appropriate care in both the explanation and definition, which for instance might include access to play therapy for children <p>Data collection</p> <p>At present the National Cancer Patient Experience survey is only offered to patients 16 or over. There therefore exists no robust national survey of patient experience meaning it will be quite difficult to measure this. The statement says that ‘local data collection’ will be used to measure ‘patient, parent or carer satisfaction with the support provided’. It will therefore be important to ensure that if local data (e.g. hospital surveys) is to be used, that this is sufficiently robust to be able to be compared and collated on a national basis.</p>
45	University College London Hospital	Quality Statement 1	Children should be defined at 0-15 years and TYA’s from 16-24 years. However, please note that some 13-16 year olds are treated within TYA services and benefit from this.
46	NHS England	Quality Statement 1	<p>Quality statement</p> <p>Referral to age appropriate MDT is a crucial element of getting the best treatment for children with cancer and is a key element of the NICE guidance on improving outcomes. Can there be a greater emphasis on age appropriate care in the explanation and definition, which could for example, include access to play therapy for children?</p> <p>Under ‘definitions of terms used in this quality statement’, NICE have separated diagnostic and</p>

ID	Stakeholder	Section	Comments
			<p>treatment MDTs and we do not understand the reasons for this. (The concept for a separate diagnostic and treatment MDT is new and there are no current structures in place to support the data collection required to evidence the functioning of such an MDT.)</p> <p>We would want the treatment MDT to also include paediatric surgeons, neurosurgeons, clinical oncologists and social workers.</p> <p>Quality measures</p> <p>It would be helpful if the local data collection could also focus on the membership of the MDTs.</p> <p>Under quality measures - <i>part b) Patient, parent or carer satisfaction with the support provided during treatment</i> - will be linked to local data collection sources. At present the National Cancer Patient Experience survey is offered to patients aged 16 and over and therefore excludes patients in this age group. If local data collection is to be the main data source for this, there is a need to ensure that methodologies and structures for data capture are consistent across local areas to be able to compare and collate data at a national level.</p>
47	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	Quality Statement 1	<p>The wording of this measure should recognise that there may be more than one type of children’s MDT operating at an individual PTC – for example neuro oncology, leukaemia/malignant haematology, solid tumour. Under such circumstances the definition of the membership of the specific MDT will appropriately vary.</p> <p>How will ‘approved protocol’ be defined? Approved by whom and under what circumstances? The purpose of the MDT is to achieve consensus about such issues and if, therefore, a child’s care is discussed at an MDT, it might be assumed that this outcome has been achieved.</p> <p>It will be important to standardise an approach to measurement of parental / patient satisfaction with support provided during treatment. This is not a single point measure as responses are likely to vary at different stages of the treatment and in relation to outcome. A generic measure of satisfaction may be attempted but its value might be limited</p>

ID	Stakeholder	Section	Comments
48	Paediatric Oncology Dieticians Interest Group (PODIG)	Quality Statement 1	General Comment on Children's multidisciplinary team Please change spelling of dietician to dietitian (this spelling is more commonly used in the UK) Question 1: the quality draft standard accurately reflects the key areas for quality improvement Question 2: it should be possible to collect data for the proposed quality measures
49	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 1	Do we assume that where it reads ONCOLOGIST / HAEMATOLOGIST that means either/or? Suggest this actually needs defining more narrowly as a Paediatric Oncologist and a Paediatric Haematologist
50	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 1	Not sure about implied distinction between 'diagnostic' and 'treatment' MDT - but would welcome a review of required membership of a diagnostic and treatment MDT to ensure best use of time and best outcome for patient. The statement should include a reference to clinical trials as part of the value of the MDT should be ensuring that all eligible patients are considered for appropriate clinical trials.
51	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 1	Key worker is listed as a lone figure that might be any one person in the team but then it is also mentioned in last line too. Would it be better to have a statement at the end of the list that one core member must take role of key worker for each patient? Why are dieticians singled out above other AHP in this list? Either it is a list of core members thought necessary or it is able to be interpreted by local teams as to which AHP are key to each patient group. What about play specialists, physiotherapy, occupational therapy, speech and language, ,psychol/neuro psychol, education rep.
52	The Royal College of Radiologists	Quality Statement 1	The RCR does not understand why diagnostic and treatment MDTs are separated. We are particularly concerned that the treatment MDT does not include paediatric surgeons/neurosurgeons or clinical oncologists. It could be argued, conversely, that clinical oncologists are not usually involved in the diagnosis of paediatric cancer. The RCR feels the Quality Standard is suggesting something more akin to a "care co-ordination" meeting with the "treatment MDT" – in which case it needs to be define that this is referring to the Team rather than the meeting process. The RCR therefore suggests some clarification is needed.
53	Royal College of Nursing	Quality Statement 1	Haematology MDTs do not require all the staff listed currently and many areas run these MDTs separately to oncology MDTs. This needs to be made more specific.

ID	Stakeholder	Section	Comments
54	The Society and College of Radiographers	Quality Statement 1	<p>Suggested additional comment for bottom of the page. 'Children and young people should always be treated in an appropriate paediatric /young person centre. This should be approved or accredited by a relevant agency e.g. CCLG'</p> <p>Definition of terms – 'For treatment the core members of the multidisciplinary team should be:':</p> <ul style="list-style-type: none"> • One of the core members should be a therapeutic radiographer (preferably a paediatric specialist) – some centres have found this very useful as the clinical oncologist will not necessarily be aware of all the technical considerations related to any proposed radiotherapy. It also serves to engage the radiographer team at an early stage – it is useful to have preparation as to potential patients so that visits to view the department and meet members of the treatment team can be arranged. • We do not think it is enough to rely on the phrase 'dietician and other appropriate allied health professionals' to ensure this is the case.
55	The Society and College of Radiographers	Quality Statement 1	<p>We do not understand why NICE have separated diagnostic and treatment MDTs. In particular we are concerned that the treatment MDT does not include paediatric surgeons/neurosurgeons or clinical oncologists. Are you suggesting a "care co-ordination" meeting with the "treatment MDT"? If this is the case then it needs to be defined that the document is referring to the Team rather than the meeting process.</p>
56	Royal College of General Practitioners	Quality statement 1 & 2	<p>The new definition of children (under 15s) and young people (yp) (16-24) is different from the legal definition of children (under 18s). This QS is taking for granted a separate yp service. The new social care bill suggests transition to adult services begins at 14. I agree for the need for transitional services. Should we call them children's and transitional services so to have more relaxed boundaries and be clearer of the concordance with legal and GMC guidelines? Many areas have different transitional arrangements so these might be difficult to measure unless DNA rates by the child were measured against type of service</p>
57	Royal College of	Quality	<p>I like the emphasis on multi-disciplinary care. When GPs refer a child with cancer the child and family are</p>

ID	Stakeholder	Section	Comments
	General Practitioners	statement 1 & 2	lost to a tertiary care centre for many months and little information filters back. The GP has to pick up scraps of information from other members of the family. The GP may be upset and feeling shocked and guilty at any delay, however small, in referral. MDT care needs to be reported back to the GP. No wonder families then complain that the GP is “not involved”! Easy to measure receipt of MDT meeting summary and contacts by the GP and PREM of family satisfaction.
58	Royal College of Paediatrics and Child Health	Quality Statement 1 & 2	Can the denominator for cancer cases be from the specialist cancer registries rather than local data?
59	British Society of Paediatric Dermatology	Quality Statement 1 & 2	The core members of the MDT should also include the specialist involved eg dermatologist, gastroenterologist etc
60	The Society and College of Radiographers	Quality Statement 1 & 2	Section called ‘Definition of terms used in this quality statement’ – This section does not state how a paediatric or young adult should be referred through to a MDT. Also we feel it is helpful to have a rehab team member present at the MDT meeting.
61	Faculty of Pain Medicine of the Royal College of Anaesthetists	Quality statement 2	“facilitate access” is missing from the final sentence
62	Children’s Cancer and Leukaemia Group (CCLG)	Quality statement 2	For common paediatric cancers e.g. ALL, rhabdomyosarcoma it may be that the paediatric team manage younger TYA patients. To mandate they are managed by adult site-specific team is not practical for many units. The detailed arrangements of who manages which patients varies from centre to centre. The principle should be that the patient is managed by a team with expertise in the patient’s condition.
63	Teenage Cancer Trust	Quality Statement 2	<p>This is an important statement and area of improvement. We’re concerned some of the drafting suggests there is a lack of understanding of the issues here for young people with cancer.</p> <p>We’d recommend that the terminology is changed from ‘age specific MDT’ to ‘TYA MDT’ which is used in practice and makes it clear which MDT this statement refers to.</p> <p>The statement suggests that the site specific MDT prescribes the treatment and the TYA MDT provides the psychosocial element of care, but this is not an accurate reflection of current practice. Many TYA MDTs are providing treatment planning with input from both TYA consultants and site specific consultants and from both paediatric and adult services. The TYA MDT also has expertise regarding</p>

ID	Stakeholder	Section	Comments
			<p>access to appropriate clinical trials for young people, advises on the right treatment protocols and pathways and on psychosocial assessment and care packages.</p> <p>In the Rationale it states that cancer in young people is more similar to adults but this is not correct, as referenced above cancers in young people differ are also distinct in that they include the late onset of cancers most common in children, the early onset of cancers most common in adults as well as cancers that are most common in this age group (Birch classification 2006).</p> <p>This data is extremely important to collect, but there may be some challenges. Through TYAC registration it is possible to collect data about notification to the TYA MDT. However, this system is due to change with the introduction of the new COSD registration system. It is important that this information continues to be collected and reported on through the transition to the new system and within the new system, so this statement should help make collection of this data a continued priority.</p>
64	Faculty of Pain Medicine of the Royal College of Anaesthetists	Quality Statement 2	A clinical psychologist should be a core member of the treatment multidisciplinary team
65	The Christie NHS Foundation Trust	Quality Statement 2	This definitely needs to be a QS. There are still a large percentage of young people that are not being notified to a TYA MDT. Linked in with this is young people being offered an appropriate choice of place of treatment, I think this also needs to be mentioned within the QS.
66	CLIC Sargent	Quality Statement 2	<p>Quality statement CLIC Sargent is supportive of the inclusion of this quality statement; at present, teenage and young adult (TYA) referral to an age-appropriate is variable and we hope this will help to embed progress on this important issue.</p> <p>As we noted in our response to the call for evidence, access to cancer key workers for TYAs 16-24 is also low, despite CLIC Sargent’s own evidence suggesting young people really value having a named worker to coordinate the support they need. We would therefore like to see the statement make more explicit reference to access to key workers for 16-24 year olds with cancer.</p> <p>As with statement 1, this should include a list of health and care professionals who should make up these MDTs. This could be drawn from the existing TYA cancer measures.</p> <p>Data collection</p>

ID	Stakeholder	Section	Comments
			As well as collating data on access to MDTs, data collection must also focus on the membership of these MDTs. Similarly, the data measures for children include reference to patient reported outcomes / experience; this should also be included for 16-24 year olds and could be taken from the existing National Cancer Patient Experience survey.
67	University College London Hospital	Quality Statement 2	<p>General terminology now in use is TYA MDT instead of age-specific MDT. The purpose of the TYA MDT is to ensure that the TYA has access to appropriate clinical trials, is on the correct treatment protocol and has access to all available psychosocial support no matter where they choose to be cared for.</p> <p>Page 10 – Commissioners ensure that they commission services that have systems in place and written clinical protocols (should be pathways) for young people with cancer to be reviewed by a cancer site-specific MDT and a TYA MDT to agree the most effective treatment and support</p> <p>Page 11 – This multidisciplinary team should also to any appropriate clinical trials open to young people in their care. Should read this multidisciplinary team should also facilitate access to any appropriate clinical trials open to young people in their care</p> <p>Strategies for measuring patient experience, proportion of 19-24 year olds offered choice between PTC and TYA Designated Hospitals and patient engagement also needs to be considered. For treatment the core members of the multidisciplinary team should also include psychological support and social</p>
68	College of Occupational Therapists	Quality Statement 2	Adjust sentence on page 11 of 29, paragraph 4 to read: This multidisciplinary team should also refer to any appropriate clinical trials open to young people in their care.
69	NHS England	Quality Statement 2	<p>Quality Statement</p> <p>Following the publication of IOG in 2005, the NHS has adopted the term TYAMDT (for young people 16-24). This is now firmly embedded in practice and therefore unhelpful to use an alternative term – ie age specific MDT when universally we are using TYAMDT.</p> <p>Rationale:</p>

ID	Stakeholder	Section	Comments
			<p>It is inaccurate to say that cancer in young people is more similar to adults. The types of cancer seen in the TYA group is different to both children and adults, although rarely paediatric or adult type cancers may also be seen in this age group.</p> <p>Other sections: TYA MDT should replace age-specific MDT</p> <p>The whole of Statement 2 reads that that the site specific team prescribes the treatment and the TYAMDT ensures the psychosocial element. This is not an accurate reflection of the NICE IOG requirements for how TYAMDTs should operate. The purpose of a TYAMDT is to ensure that the TYA has access to appropriate clinical trials, is on the correct treatment protocol and has the right psychosocial assessment and care package in place.</p> <p>7 Page 10 contains the text: Commissioners ensure that they commission services that have systems in place and written clinical protocols for young people with cancer to be reviewed. 'Pathways' needs to replace 'protocols'</p> <p>8 Page 11- I suggest an amendment: rather than: 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 could better read; A dedicated multidisciplinary team with expertise in cancer-related issues for young people, their parents, carers and family. They have primary responsibility for the delivery the social, psychological and educational needs of young people with cancer and their families, which integrates and supports the delivery of the clinical treatment protocol.</p> <p>9 Page 11 contains a typographical error; 'This multidisciplinary team should also to any appropriate clinical trials; should read; This multidisciplinary team should also promote entry to</p>

ID	Stakeholder	Section	Comments
			<p>any appropriate clinical trials</p> <p>It is relatively easy to measure the number of TYAs reviewed by a cancer site specific MDT and a TYA MDT, but not currently easy to measure whether these teams initiate the most effective treatment and support or how they communicate this to each other and to the patient. There is also a lot of detail in statement 1 around the core membership and roles of the children’s MDT; given the difficulties that many TYA services have with both membership of the MDT and professionals to fill essential roles, particularly therapy staff, it would be helpful to include this level of detail needs in section 2.</p> <p>Quality measures</p> <p>It would be helpful if the local data collection could also focus on the membership of the MDTs</p> <p>With regard to <i>‘patient, parent or carer satisfaction with the support provided during treatment’</i> this should be included for 16-24 year olds and should be taken from the existing National Cancer Patient Experience Survey.</p>
70	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	Quality Statement 2	The COSD CYP section (mandated for collection by all trusts in England since July) incorporates a data item requiring recognition of which, and how many MDTs (age or site specific) have discussed the patient. This item should therefore be collected through COSD and not need the creation of separate local systems
71	Paediatric Oncology Dieticians Interest Group (PODIG)	Quality Statement 2	<p>General Comment: Would it be feasible to list the MDT members as has been done for the children’s MDT group –this would aid in collecting the data for the proposed quality measure and assist in local services in identifying which AHP (and other multi-disciplinary team members) resources are required.</p> <p>Question 1: the quality draft standard accurately reflects the key areas for quality improvement</p> <p>Question 2: it should be possible to collect data for the proposed quality measures</p>
72	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 2	<p>This should read- a <u>timely</u> review, not left as ‘soon after’ but either prior to first cancer treatment, or at the MDT meetings immediately following first cancer treatments.</p> <p>As in the children’s measure, the number of patients treated on ‘approved protocols’ should be included.</p>

ID	Stakeholder	Section	Comments
			This presents a helpful challenge to the clinical community, which will yield improvements in care and innovations in treatment. Moreover there is now an infrastructure and route to achieve this. Site-specific groups (CCLG, NCRI) should define (with the relevant CRGs) an annual list of approved management protocols for frequent typical disease presentations (referred to as standards of care in the USA) and concordance with that should be benchmarked and sequentially audited.
73	The Royal College of Radiologists	Quality Statement 2	The RCR fully supports this standard.
74	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	We need to use the term TYA MDT and not age specific MDT. TYA MDT is the established term and anything else will be unhelpful
75	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	The wording of QS 2 needs to promote close working between the site specific and the TYA MDT's with reference to robust communication between the groups. There should be recognition that there will be different models of TYA MDT. It needs to stated that the TYA MDT needs to be based/ hosted by the PTC with clear formal relationships identified with the TYA designated hospitals. This needs to evidenced.
76	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	It is not necessarily the case that cancer in young people is more similar to that experienced by adults. Some cancers are similar to adults, some similar to children and some are TYA specific.
77	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	There needs to be reference to TYA's being treated on approved protocols as in QS1. This is an achievable goal with the structures that are now in place nationally. QS2 also reads as though the site specific MDTs prescribe all the treatment whilst the TYA one is all just psychosocial, this is increasingly not the case. TYA MDT's are made up of a wide range of clinicians fromm the paediatric and adult worlds that are in apposition to question proposed treatments and suggest a more appropriate alternative. The TYA MDT should be key in ensuring TYA agreed protocols are delivered.
78	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	Should state that notification to the TYA MDT is done in a timely manner without causing a delay to treatment but ideally the TYA MDT should be able to discuss the patient prior to first treatment or at the first MDT after treatment has commenced.
79	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	There should be record of inclusion onto clinical trials. Clear evidence of a TYA key worker and also evidence that consideration has been given to the continuation of education or employment.
80	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 2	Clear number of TYA's recruited to clinical trials and if not why not.

ID	Stakeholder	Section	Comments
81	The Society and College of Radiographers	Quality Statement 2	Fully support
82	Oxfordshire Clinical Commissioning Group	10 Quality statement 2 & 3	<p>a. List of quality statements, on p.4 statement 2; for 16-24yr olds those up to 19yrs i.e. those in full time education may continue to be under the paediatric TSSG which is not a cancer site specific TSSG until they are 19. However, most will also be under the Neuro Onc MDT/TSSG or the Sarcoma MDT but the rest of the solid tumours and the leukaemias will be under the paediatric oncologists and haematologists rather than adult oncologists and haematologists. They will all be under the TYA MDT (TSSG). But it is unlikely that all > 16yrs will be exclusively under adult TSSGs for many years to come, until TYA centres/facilities are functioning in the way that the paediatric PTCs do with shared care and all supportive services including education. Certainly for haematological cancers a paradigm shift will be required before adult haematologists at the PTC</p> <p>11 will be discussing or treating < 18yr olds with leukaemia.</p> <p>b. Statement 3; re electronic prescribing, p.12. This is what we all wish to achieve but the electronic prescribing packages bought by most trusts with adult oncology are not safe to use for paediatric protocols. Using them is not safer and indeed currently accounts for more errors. There is one system that is far more paediatric protocol friendly which will be safe but is different from the adult prescribing which causes problems with sharing chemotherapy prescription and delivery on other sites that only use the adult system. The quality standard is good because it highlights the need; however it has to acknowledge the inherent problems in achieving the quality standard.</p>
83	Children's Cancer and Leukaemia Group (CCLG)	Quality statement 3	Agree with quality measure, although a caveat is that currently there are individual cases that may be difficult to be set up on an electronic system and will require written prescriptions. This may be feasible in the future but with chemocare at present would be unlikely. Hence unlikely to achieve 100 %
84	Teenage Cancer Trust	Quality Statement 3	Whilst this may improve some quality, we feel there are other areas of improvement for young people with cancer that could be included which would take priority. These are:

ID	Stakeholder	Section	Comments
			<ul style="list-style-type: none"> • Earlier diagnosis • Access to clinical trials and new treatments • Patient experience including choice • Access to specialist staff • Improved data collection about young people with cancer
85	Royal College of Paediatrics and Child Health	Quality Statement 3	Local data for e-prescribing; should be clear if the reporting is per-prescribed course or per-patient. A failure of 1 per patient may look pretty good if recorded on a cycle basis, but not on a per-patient basis.
86	The Christie NHS Foundation Trust	Quality Statement 3	I am not convinced that this needs to be one of only six quality standards, but the committee obviously felt strongly about it.
87	CLIC Sargent	Quality Statement 3	<p>Quality statement CLIC Sargent is supportive of this quality statement and the focus on patient safety. To further development the standard, CLIC Sargent thinks it would be helpful to have a hub-and-spoke model of electronic prescribing in which paediatric oncology shared care units (POSCUs) are linked to the PTC system. This would mean that the expertise for putting the paediatric protocols into the system comes from the PTC and is accessed by the POSCUs. The alternative is that each POSCU is responsible for uploading and signing off the paediatric protocols on their adult Trust systems. It has taken some of the PTCs years of work to get these protocols onto the systems and the POSCU clinicians will be stretched for time to get this done for much lower numbers of patients and will have to maintain all the updates – taking them away from clinical time. They are also potentially less expert at this than the PTC. A hub and spoke model could potentially be safer and more cost effective.</p> <p>Data collection No further comments</p>
88	University College London Hospital	Quality Statement 3	<p>Agree – however it is not clear how this will be achieved across the entire pathway for example PTC's, POSCU's and Community Nursing teams. Shared care for TYA's is not well established and there are currently different prescribing systems in use which do not allow for a shared care approach to chemotherapy administration across different sites.</p> <p>Also unsure of how the number of patient safety incidents in children and young people are going to be captured and reported centrally in order to give meaningful data</p>

ID	Stakeholder	Section	Comments
89	NHS England	Quality Statement 3	<p>Quality statement We fully endorse this quality statement</p> <p>Quality measures</p> <p>We agree with the quality measure as set out for capturing data linked to the statement but at present this would be potentially challenging as there is no national system in place linked to the denominator.</p>
90	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	Quality Statement 3	<p>Whilst electronic prescribing has obvious advantages, it is still underdeveloped for paediatric use and current systems do not address all elements of chemotherapy, for example oral chemotherapy (representing a major challenge in the care of children and young people with acute lymphoblastic leukaemia. Nor is it clear how the process will take account of prescribing in a shared care setting.</p> <p>In considering how the agreed quality standards might be prioritised for introduction, the considerable cost of further developing and implementing electronic prescribing across all trusts (i.e. POSCs as well as PTCs) needs to be considered.</p> <p>Is there robust evidence that electronic prescribing will significantly reduce errors? Basic data such as age, size/weight may still be recorded incorrectly.</p>
91	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 3	No comments
92	The Royal College of Radiologists	Quality Statement 3	The RCR fully supports this standard.
93	Royal College of Nursing	Quality Statement 3	There is no national e-prescribing chemotherapy product for paediatrics yet that has been widely adopted or shown to reduce incidents if other systems are in place such as pre-printed prescriptions. Chemocare does not calculate oral doses so is not a full system. Therefore this standard although may be desirable will be difficult to achieve for many centres.
94	The Society and College of Radiographers	Quality Statement 3	Fully support
95	Royal College of General Practitioners	Quality statement 4	The Map of Medicine guide for cancer includes spiritual support in “psycho-social”. We need not be afraid of including spiritual too. Measures could be verbal or written contacts; also application/receipt of appropriate benefits; contact with support organisations, charities etc.

ID	Stakeholder	Section	Comments
96	Children's Cancer and Leukaemia Group (CCLG)	Quality statement 4	<p>Psychosocial care needs to be offered not only at diagnosis, but as needed through the cancer journey. Support should be assessed at key points throughout treatment using holistic needs assessment tool and care adjusted according to need.</p> <p>The concept is very much supported, however the availability of funding for this type of intervention is limited and this would make the target unachievable</p> <p>Depending on the definition of psychosocial support it may be that the current support to families from our Clic Sargent/Macmillan Nurses and Social Workers and TYA Worker would fulfil this role.</p>
97	Teenage Cancer Trust	Quality Statement 4	<p>This is an important area of improvement for young people with cancer. However, the psychological needs of young people are very different to those of children and are not just relevant to the diagnosis of cancer but also ongoing needs.</p> <p>Change at time of diagnosis to from time of diagnosis to ensure this is clear the support starts at diagnosis and continues through into follow up care or palliative care.</p> <p>This support can be measured through peer review, wellbeing assessments, auditing of key worker through- out pathway, recording of discussion at the MDT</p>
98	Faculty of Pain Medicine of the Royal College of Anaesthetists	Quality Statement 4	<p>We are pleased to see that psychosocial support has been selected as a quality statement. Psychosocial support is very wide ranging depending on individual requirements and is delivered by practitioners with varying backgrounds. The briefing paper for the QSAC identifies that there should be access to expert psychological support in principal treatment centres. We think that this expert support should be led and supervised by a clinical psychologist and that this should be explicit in the quality statement.</p>
99	The Christie NHS Foundation Trust	Quality Statement 4	<p>This quality standard needs to be expanded to include unhindered access to age appropriate psychological support throughout the diagnosis, treatment and post treatment phases. I might be wrong but again I think this is much more of a priority for young people, due to their stage of development, life circumstance etc.</p>
100	CLIC Sargent	Quality Statement 4	<p>Quality statement</p> <p>CLIC Sargent welcomes the inclusion of a quality statement focusing on the psychosocial needs of children and young people and their families. Whilst the reference to psychosocial needs as a whole is consistent with the NICE guidance, we would suggest that this needs further explanation within the text. For instance, psychological support is a specific clinical need for some children and young people and is something that should be measured separately. However, access to specialist oncology social care has</p>

ID	Stakeholder	Section	Comments
			<p>an important role to play in assessing the child or young person and family’s non-clinical needs, including in relation to education and employment, family relationships, peer support, self-esteem and confidence building, and the need to develop a care plan addressing these care components and delivery against this plan. Expanding the explanation to be specific about non-clinical needs is therefore really important. Furthermore, the outcome on patient experience is not really an outcome as such – it would be more appropriate to refer to the patient and their family feeling well supported and informed. This could be captured in the National Cancer Patient Experience survey (for those patients over 16).</p> <p>Further specific comments:</p> <ul style="list-style-type: none"> • The explicit definition of psychosocial support needs to be improved in line with the comments above. Specifically, this must refer to non-clinical needs, including support with education, employment, building confidence and self esteem, managing family and peer relationships and practical issues (e.g. benefits), rather than narrowly focusing on palliative and respite care • The assessment in the definition should also refer to palliative and end of life care needs, including bereavement • The statement refers to support ‘at the time of diagnosis’; this should be expanded to diagnosis and throughout treatment. This is essential to ensure services are not limited to the diagnosis phase only • In the rationale section, instead of saying ‘depending on need’, this should say ‘tailored to individual need’ • Health practitioners (excluding psychologists) will not provide this psychosocial support themselves but will rather help ensure access to these services • For very young children, the role of the play specialist is essential in both managing their needs and preventing escalation to higher levels of psychological support <p>Data collection</p> <p>It is important to highlight that many psychosocial support services for children and young people with cancer and their families are not directly provided by the NHS but rather are provided by third sector organisations, including CLIC Sargent, on a voluntary basis. As such, there may be some challenges in measuring adherence to this standard and it will require further work on the definition of exactly what these services are and who provides them.</p> <p>One measure for which data could be more easily collected would be the number of children with a holistic needs assessment and a care plan in place. This data could be collected by the child or young person’s key worker.</p>

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ID	Stakeholder	Section	Comments
101	University College London Hospital	Quality Statement 4	<p>We fully agree that all TYA's should be offered psychosocial support at diagnosis, however it is essential that psychosocial support is available throughout the treatment pathway, including survivorship and/or end of life.</p> <p>This could be quite difficult to measure especially if the TYA is receiving care outside of a PTC in a designated hospital. Psychological support is not the only thing that is required and often the support required is in the form of practical, social, educational or employment support. Support needs to be what the patient wants and needs at any particular time and this could be very difficult to measure. Timing of this for all TYA's and their families and carers will be different. It may be better to ascertain what support is available for every patient and what type of support is required. This could be evidenced on a holistic needs assessment tool which is standard across the TYA service or captured better in the patient experience survey that patients and families feel well supported and informed.</p> <p>This also needs to be considered across the entire pathway and not just for patients treated within a PTC</p>
102	College of Occupational Therapists	Quality Statement 4	<p>The use of the term 'psychosocial support' needs to be consistent and not interchanged with 'psychological and social support'. Psychosocial support directly relates to the needs for support following trauma or distress and is the consistent term used by other cancer charities and organisations.</p> <p>http://www.cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer/understandingpsychosocialsupportservices/index</p>
103	College of Occupational Therapists	Quality Statement 4	<p>Psychosocial support should include mental health counselling as this is an essential therapy.</p> <p>Department of Health, (June 2008) Better Care; Better Lives: Improving outcomes and experiences for children and young people with life threatening illness.</p>
104	NHS England	Quality Statement 4	<p>Quality statement</p> <p>We endorse this quality statement but would like to it be expanded to include support at the time of diagnosis and on an on-going basis. It is essential that psychosocial support is available throughout treatment and afterwards, through to survivorship or palliative care. Support should be assessed at key points throughout treatment using holistic needs assessment tools.</p> <p>As a general comment, we would recommend strengthening the statement by saying that all families will receive psychosocial support. We would also like to suggest that with regard to non-clinical needs that there is strong reference to the important role that social care, education, employment, family</p>

ID	Stakeholder	Section	Comments
			<p>relationships, peer support, self-esteem and confidence building plays in the overall treatment and care planning process, all of which impact on the child and their family.</p> <ul style="list-style-type: none"> • Process: • This requires greater clarification and is not straightforward to measure. In a recent UCLH survey looking into young people’s experience all patient had felt supported, predominantly by ward nurses, clinical nurse specialists and social workers. Only half of patients were interested in joining groups or having more specialised psychological input eg psychology, psychotherapy, psychiatry. • • ‘Support’ needed may be psychological but may also be practical, social (benefit, parking etc) or education. Any measurement of support thus needs to take account of how the support available meets the needs of individual patients; what type of support is required and does the patient want/need it? • <p>It may be helpful to be more prescriptive and in line with previous peer review measures including;</p> <ul style="list-style-type: none"> • Patient has an identified key worker from time of diagnosis • Patient has had a recorded discussion of psychosocial issues at a TYAMDT • Patient has been assessed using a validated assessment tool e.g. holistic needs assessment • • Outcome: • Again clarity of definition is required. The current statement is not an outcome as such. The outcome would be ‘ patient and parents feel well supported and informed’. This could be captured through the patient experience survey. • <p>12 What the statement means for providers and commissioners:</p> <ul style="list-style-type: none"> • Requires reference to the role of charities, who often fund key posts involved in the provision of supportive care.

ID	Stakeholder	Section	Comments
			<ul style="list-style-type: none"> Definition: 13 Page 17 reads: agreed with the child and family. This could better read ‘agreed with the child, young person, family and other carers’. Otherwise it does not fully serve the needs of young people, only children remaining in the family context. Quality measures 14 Linked to the above comments, we would like to see the quality measures reflect the need for on-going support.
105	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	Quality Statement 4	<p>The quality standard states that patients/parents should be <u>offered</u> psychosocial support but the numerator is the number who <u>receive</u> this. This is inconsistent.</p> <p>The wording would be better stated that psychosocial support is offered <u>from</u> the time of diagnosis as the need is ongoing and evolves: some families may not perceive a wish to have support at the outset but come to require / wish for it later on.</p>
106	Paediatric Oncology Dieticians Interest Group (PODIG)	Quality Statement 4	<p>General: should this section include details of the team expected to deliver psychosocial support?</p> <p>Question 1: the quality draft standard accurately reflects the key areas for quality improvement</p> <p>Question 2: Collecting data may be difficult since the term psychosocial support is difficult to define and no guidance ins given regarding who would deliver/administer this support</p>
107	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 4	<p>The statement defines what an assessment should contain but it is not always possible to do everything with a psychologically fragile family immediately they have the diagnosis before they are discharged home. There is a need to define a time frame over which this diagnostic assessment should be expected to take place? And put in a statement that this may need to be done over the first 6 or 8 weeks in more than one visit since needs may change very quickly.</p> <p>Both 'psychosocial support' & neuro-rehab standards both need to be more robust in identifying just what should be offered, and that when thinking about the commissioning of services it should be not just what is offered, but what the service is able to provide.</p>
108	The Royal College of Radiologists	Quality Statement 4	<p>The RCR fully supports this standard.</p>

ID	Stakeholder	Section	Comments
109	Together for Short Lives	Quality Statement 4	<p>We welcome the standard’s recognition of the role of respite, palliative care and bereavement counselling for families as part of the psychosocial support which should be made available to children, young people and families with cancer. Bereavement services for parents and siblings before and following the death of a child can help to mitigate the need for other service interventions later in their lives. We ask that the term ‘respite’ is replaced by the term ‘short-breaks’ as this reflects more positively the breaks that such services provide for both disabled people and those caring for them.</p> <p>We suggest that the words “and at critical times thereafter” should be added to the end of the title of this statement. This would enable the statement to apply to scenarios which include:</p> <ul style="list-style-type: none"> • A relapse. • A recognition that the aim of treatment is palliative rather than curative. 15 • Diagnosis of the end of life stage. 16 • End of life care. 17 • Bereavement support for families. 18 <p>We believe that comprehensive psychosocial support for families can also contribute to improving outcomes associated with the NHS Outcomes Framework improvement area 2.4 ‘Enhancing quality of life for carers’</p>
110	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 4	The opening statement should not specify ‘at the time of diagnosis’ but rather needs to include the whole cancer pathway/ journey whether that’s to a curative point or end of life, psychosocial support should always be available.
111	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 4	There needs to be completion of a formal assessment and a record that this is done. There then needs to be a formal action plan / care plan. If appropriate there should be access to specialist psychology support.

CONFIDENTIAL

ID	Stakeholder	Section	Comments
			There should be evidence that continued engagement with training, employment or education have been considered and plans made during the treatment process for reintegration after treatment.
112	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 4	Successful reintegration with activities post treatment. Documented evidence that support has been offered this could be very prescriptive such as whether a key worker has been identified, has a validated assessment tool been used etc.
113	The Society and College of Radiographers	Quality Statement 4	Fully support
114	Royal College of Paediatrics and Child Health	Quality Statement 4 & 5	Conflict between the statement (“offered”) and the measure (“received”). We think offered is correct – some will turn down support – and it may be interesting to report both the % offered, and the % received. Large differences between units may then reflect different approaches which require further exploration.
115	Royal College of Nursing	Quality Statement 4 & 5	Need to ensure that wording is strong enough to be measured as ‘offer’ may be hard to capture. All these patients require and should receive these services.
116	Royal College of Nursing	Quality Statement 4 & 5	Should this measure be extended out to other patients that require intensive rehabilitation such as ‘bone tumours’?
117	Children’s Cancer and Leukaemia Group (CCLG)	Quality statement 5	Neurorehab discusses ongoing review for 'a defined period' needs clarification. Not all patients with CNS malignancy need specialist neurorehabilitation so to use number of patients with CNS malignancy as denominator is misleading - OR it needs to be clear what % is expected/acceptable based on existing evidence e.g 60-80% of patients expected to receive this. Currently, again, have limited resources. We are in the process of increasing the number of dedicated physiotherapy hours available for neurorehab, but this will still not be enough We would also like to see support in a quality statement for physiotherapy for non CNS tumours who suffer significant disabilities as a result of their treatment. For example vincristine neuropathy, dexamethasone bone complications and disuse myopathy in the poorly mobile patients.
118	Teenage Cancer Trust	Quality Statement 5	Whilst this may improve some quality, we feel there are other areas of improvement for young people with cancer that could be included which would take priority. These are: <ul style="list-style-type: none"> • Earlier diagnosis/improved diagnostic experience • Equitable access to clinical trials and new treatments • Patient experience including choice • Access to specialist staff

ID	Stakeholder	Section	Comments
			<ul style="list-style-type: none"> Improved data collection about young people with cancer
119	Royal College of Paediatrics and Child Health	Quality Statement 5	The phrase “agreed period” implies duration, where the text states very sensibly “should continue for as long as it is needed and can make a difference”. Can an alternative phrase be found which reflects this more clearly?
120	The Christie NHS Foundation Trust	Quality Statement 5	I know the committee thought that neuro rehab was important but I would argue that there needs to access for all young people into better rehab programmes and support. We are lucky in Manchester to have a TYA physio and OT that facilitate exercise programmes and various different elements of rehab just for TYA’s.
121	CLIC Sargent	Quality Statement 5	<p>Quality statement We welcome the inclusion of this statement. The only suggestion would be to replace ‘academic function’ in the section on the specialist neuro-rehabilitation care package with ‘learning’ as this may also cover non-academic learning. In addition, education support and assessment must be included if other elements are defined as this will be necessary in all cases.</p> <p>Data collection No further comment</p>
122	University College London Hospital	Quality Statement 5	Agree – but why have you just chosen a central nervous system malignancy as there are several other conditions that will have complex physical rehabilitation needs for example sarcoma patients with limb surgery. It would be helpful to broaden this statement to include all patients with significant disability post treatment have access to specialised rehabilitation services
123	NHS England	Quality Statement 5	<p>Quality statement It is unclear why this measure is only restricted to this patient group. Many other TYA cancer patients also have complex physical rehabilitation needs e.g. sarcoma patients with limb surgery, ALL patients with severe AVN etc. It would be helpful if the scope of this statement was broadened to ensure that all patients with significant disability post treatment should have access to specialised rehabilitation services.</p> <ul style="list-style-type: none"> • • Definition of specialist neuro rehab package: the term ‘academic’ should be replaced with ‘learning’ in order to encompass non academic learning. •

ID	Stakeholder	Section	Comments
			<p>We would also recommend strengthening it saying that all families will receive neuro-rehabilitation support and recommend that the statement is expanded to outline what is contained within the list of neuro-rehab care and that the rehab is linked to clear and specific goals</p> <p>Quality measures</p> <ul style="list-style-type: none"> • With reference to the quality measure relating to children with a central nervous system malignancy, it is worth noting that not all children with CNS need specialist neuro rehab so to use the number of patients with CNS malignancy as denominator could be misleading - or it may be that there needs to be further clarity with regard to what % is expected to receive this based on existing evidence.
124	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	Quality Statement 5	<p>The emphasis on a need for better rehabilitation for brain tumour patients is welcome but these are not the only patients who require rehabilitation. Moreover, some patients with brain tumours may have limited requirements for specialist neuro rehab / neuro psychology. It would be better if this standard could recognise that all patients defined as having a rehabilitation need have those needs assessed and met.</p> <p>Educational support / specialist advice should be identified within the definition of the specialist neuro rehab package.</p>
125	Paediatric Oncology Dieticians Interest Group (PODIG)	Quality Statement 5	<p>General Comment on Specialist neuro- rehabilitation care package</p> <p>Please could you add dietitian to the specialist team list as many of these patients require nutrition support during treatment and ongoing support during their post-treatment rehabilitation</p> <p>Question 1: the quality draft standard accurately reflects the key areas for quality improvement, however specifying a time frame for intervention has to take into account the needs of the individual patient</p> <p>Question 2: it should be possible to collect data for the proposed quality measures provided further guidance on the timeframes for rehabilitation, nature of the rehabilitation services expected, access to specialist centres etc</p>
126	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 5	<p>Should be all young people have physical ability assessed and if impaired be offered physical, neurological or other specialised rehabilitation. This should have a wider scope than CNS tumours only</p>
127	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 5	<p>The quality standard states there is a defined 'an agreed period of their treatment and follow up' when this should be offered but then the definition leaves it open ended to continue while 'needed and can make a difference'.</p> <p>What if the professionals and the parents have differing opinions of 'need and making a difference'?</p>

ID	Stakeholder	Section	Comments
			<p>Is it a standard if each centre sets its duration by their ability to meet the need with the staff they have?</p> <p>Instead of agreed parents should patients have “access to specialist rehabilitation through to transition to adult services”</p> <p>There should be some defined review points for the rehabilitation package to be reviewed eg at diagnosis, end of treatment, referral to late effects, or annually from diagnosis there after? Having a package in the first instance if important but rehab needs change over time (some improve some get worse) There needs to be a way of trying to ensure needs are continued to be reassessed and met. Could this tie into time frames in standard 6 in some way for these patients?</p>
128	The Royal College of Radiologists	Quality Statement 5	The RCR fully supports this standard but suggests that it should include a statement about educational support for children who have been treated for brain tumours, to enable them to attain their fullest academic (and functional) potential.
129	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 5	TYAC feels strongly that it is not appropriate to single out Neuro rehab. There needs to be comprehensive rehabilitation package for all young people that are diagnosed with any cancer. This is far from happening at the moment. There needs to be clear rehabilitation plans for all young people, there needs to greater physio and OT provision, very few teams have TYA specific support services. TYAC agree that neuro patients are complex and can have huge rehab needs but this is equally true of many cancer types for example young people with ALL seem to be encountering problems with avascular necrosis.
130	Association of Paediatric Chartered Physiotherapists (APCP)	Quality Statement 5	Specialist Neuro-rehab care package – this would be need to be undertaken locally amongst the POSCU’s, as well as the POC’s. Often there is good specialist therapy provision at POC’s but currently this is one of our biggest problems in discharging neuro-oncology patients back to their local POSCU’s with no provision of Paediatric Therapy Services. If good therapy provision can be provided at POC’s and POSCU’s with good community therapy support once discharged home, it takes away the need of specialist rehab centres which are notoriously difficult to fund places for and often far away for families to travel to. The statement also suggests for an agreed period of time – I wonder if this needs some clarity as to who agrees this, criteria for length of rehab etc
131	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 5	Specialist service may not be available within local services and rehabilitation is best done close to home.
132	Yorkshire and Humber Strategic Clinical	Quality Statement 5	Agrees period in time or in achieved goals. What happens if they have the input but don’t achieve the goals?

CONFIDENTIAL

ID	Stakeholder	Section	Comments
	Network and Senate		
133	The Society and College of Radiographers	Quality Statement 5	Fully support but feel this should include a statement about educational support for children who have been treated for brain tumours to enable them to attain their fullest academic (and functional) potential.
134	Royal College of General Practitioners	Quality statement 6	This seems to presume that children we be followed up by the same team at the same address and the care plan is still owned by the oncology team. A good way of measuring outcomes would be if the child was given a personalised care plan with some sort of contract about mutual responsibilities, even on moving away
135	Children's Cancer and Leukaemia Group (CCLG)	Quality statement 6	No mention of Transition - needs specific link to TYA and transition. Late effects is a misleading term. Consequences of care reflects practice especially for those who experience debilitating issues early ie GVHD, AVN, endocrine, neurodisability. Also unclear if there is no time-frame or named people to undertake, if these tasks will get done.
136	Teenage Cancer Trust	Quality Statement 6	<p>This is an important area of improvement but may be too simplified so as not to capture the true need for improvement in this area which goes beyond treatment follow up.</p> <p>Again there are differences in this for children compared to young people. Young people aged 16 -24 may face a vast range of different circumstances to cope with from returning to school at a critical time in exams, to returning to work, to returning to a family home they had moved out of or returning to their own young family. Young adults also face issues around fertility and relationships which are specific to this age group and require specialist support.</p>
137	Royal College of Paediatrics and Child Health	Quality Statement 6	The standard should reference the work of the National Cancer Survivorship Initiative as well as the SIGN guidelines.
138	The Christie NHS Foundation Trust	Quality Statement 6	I don't disagree that this is important but it does seem to repeat work that is being done by NHS IQ. They currently have a workstream that is tasked with just this issue and getting end of treatment summaries and plans in place for TYA's. If it is felt to be necessary to have it in workstreams with both groups then fair enough. It might be more beneficial to suggest that all young people have access to an end of treatment programme, so something that is more productive and interactive than the care plan and summary.
139	CLIC Sargent	Quality Statement 6	<p>Quality statement CLIC Sargent is supportive of this statement. We would suggest wording and explanation could be</p>

ID	Stakeholder	Section	Comments
			<p>drawn from the work of the children and young people’s workstream of the National Cancer Survivorship Initiative (NCSI) [http://www.ncsi.org.uk/what-we-are-doing/children-young-people/]. For example, this should again make reference to non-clinical issues as well to ensure a ‘normality’ of life following a cancer diagnosis and treatment. Non-clinical and psychosocial needs should also be referenced in the ‘definition’ section.</p> <p>Data collection No further comments</p>
140	University College London Hospital	Quality Statement 6	<p>Agree – it would also be useful to include supported self-care arrangements for young people in the care plan elements listed in the statement.</p> <p>Follow-up and monitoring arrangements – would be helpful to determine where these will be measured as some long term follow-up may be provided by GP’s, self management or the POSCU. It is unclear if these quality standards will apply to the POSCU or designated hospital environment. Also no mention of transition from TYA services to adult services and how this area will be addressed.</p>
141	NHS England	Quality Statement 6	<p>Quality statement We endorse this statement. We would also recommend that the rationale and definition makes reference to the wider non clinical support that is part of the care planning process. (See the National Cancer Survivorship Initiative (NCS)) at http://www.ncsi.org.uk/what-we-are-doing/children-young-people/.)</p> <p>It would be useful to include ‘supported self-care arrangements’ for young people in the care plan elements listed in the statement</p> <p>It is also important to include the sense that survivorship should begin from the day of diagnosis. Please see quite below re this measure from one of the patient representatives on the CRG;</p> <p>‘ I would just try and place the emphasis on long-term follow-up beginning from day one. As an example, I know fertility services/preservation have improved but I’ve still heard many horror stories from people who were not told that there fertility could be affected or not offered fertility preservation. Surely some potential late effects need to be discussed early on?’</p>

ID	Stakeholder	Section	Comments
			It also mentions revision of the care plan when discharged from long-term follow-up clinic. Do we need to emphasise that many of these patients (if not nearly all) will require lifelong follow-up and that this should be portrayed in a positive sense - that any potential late effects will be picked up. It may be a lot to take in if all of the potential late effects are discussed at diagnosis as there is a great deal to think about but it is similarly difficult to be told that you are in remission but now you need to think about x, y and z that may occur in the future due to treatment.'
142	National Cancer Intelligence Network - Children Teenage Young Adult Clinical Reference Group	Quality Statement 6	There is a discrepancy between the description of process under item b) (which states that patients should have their treatment summary and care plan reviewed <u>at 5 years after the end of initial treatment</u>) and the definition of follow and monitoring arrangements (which state that this should include (2) at entry to long term follow up (<u>usually at 5 years after completing therapy</u>).
143	Yorkshire and Humber Strategic Clinical Network and Senate	Quality Statement 6	<p>The inclusion of this statement will help integration with late effects earlier in the pathway. However, the first half of this standard is very confusing as terminology what is 'end of treatment', 'end of relapse follow up' and 'long term late effects' is very similar. The quality statement seems to be talking about end of treatment i.e. as patients comes of chemotherapy or radiotherapy. Then suddenly the process section introduces multiple time points too. The definition in final paragraph starts to bring it together but it is a bit late if the reader is confused by all that went before.</p> <p>Could the Quality standard include a sentence stating this must be shared with family and patient where age appropriate at end of treatment, reviewed with then at 5 years from treatments and at discharge from any follow up?</p>
144	The Royal College of Radiologists	Quality Statement 6	The RCR fully supports this standard
145	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 6	There needs to reference to transition pathways into adult services where appropriate. These should reflect the need for age appropriate advice and support, particular areas that may be missed include fertility preservation and function during and after treatment. Late effects management needs to be considered much earlier in the young person's cancer pathway, with transition pathways identified early on in treatment.
146	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 6	It would be possible to measure whether late effects are being discussed and documented in initial MDT discussions, end of treatment summaries and end of treatment care plans. The availability of End of Treatment programmes that are facilitated by the TYA teams would also be measurable.

CONFIDENTIAL

ID	Stakeholder	Section	Comments
147	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 6	There is something in this standard that needs to reflect the potentially massive workload that would come from providing comprehensive late effect services. Should all this lie within the health care setting, should some responsibility lie with social agencies.
148	Teenagers and Young Adults with Cancer (TYAC)	Quality Statement 6	There is a lot of work being done by the NHS IQ team on this particular issue, could this standard be dropped for a different one in light of that work? is there a duplication of work?
149	Association of Paediatric Chartered Physiotherapists (APCP)	Quality Statement 6	Would be excellent for all survivors of childhood cancer to have access to rehab/therapy in long term follow up clinics to address the often multiple but relatively unaddressed problems and sequelae of their cancer treatment including chemotherapy, radiotherapy, surgery etc once this has finished.
150	The Society and College of Radiographers	Quality Statement 6	Fully support.
151	Together for Short Lives	Question 1	<p>It is vital that young people with cancer undergo smooth and well planned transitions from children's to adult's services when they reach adulthood.</p> <p>There are more than 40,000 children and young people aged 0-19 in England who have long-term health conditions which, for most, will eventually end their lives and for which they may require palliative care. This represents a 30 per cent increase over ten years. The highest rate of increase is among those aged 16-19, who now account for 4,000, or one in ten, of 0-19-year-olds who need palliative care.</p> <p>Successful transition needs to address both the transfer of responsibility for young people from children's to existing adult's social care, health and education services and the development of new adult's services tailored to young people's additional needs.</p> <p>Many young people and their families find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of agencies and professionals. The result can be gaps in services or fewer or less appropriate services. At present, there is significant local variation in the planning which takes place for such transitions.</p> <p>Given their situation, these young people and their families cannot afford to wait and adult agencies need to ensure that their responses are timely and appropriate.</p>

ID	Stakeholder	Section	Comments
			<p>Once a young person with cancer has reached the age of 14, a range of children and adult services should come together to agree a five-year rolling transition plan, encompassing all relevant local services. This plan should taper services to make transition less of a “cliff edge” for families.</p> <p>All information about young people with cancer should travel with them across organisational boundaries. This should be in the form of a plan that covers clinical, social and educational needs and which supports the process of transition.</p> <p>Children’s palliative care services should reflect on their role in preparing young adults with cancer for planning conversations ahead of transition to adult’s services. Non-palliative health services should build on common practice of emergency care planning by incorporating open (but sensitive) discussion of preferences for the end of life and consider reaching out to palliative care services for help with confidence-building and training.</p>
152	Faculty of Pain Medicine of the Royal College of Anaesthetists	Question 1	<p>We note that pain management and anaesthesia were considered by the QSAC, but not selected for a quality statement. We feel that this is a serious omission. Pain, and its management, is universal in the care pathway of all children and young people diagnosed with cancer. Pain relief is a basic human requirement, which in the hospital environment is entrusted to healthcare professionals. It is essential that this responsibility is discharged safely and effectively. Domain 4 of the NHS Outcomes Framework, ensuring that people have a positive experience of care, will be adversely affected if pain is not addressed and managed efficiently.</p>
153	Together for Short Lives	Question 1	<p>Despite significant improvements in children’s cancer care in recent years, sadly, many young people continue to die from cancer. Cancer is the cause of death in a fifth of all childhood deaths, accounting for 250 deaths among children aged 1 to 14yrs in 2010 (Cancer Research UK).</p> <p>When all curative treatment options have been exhausted, it is vital that children have access to comprehensive palliative care services. A child and their family should be given a choice of place of death, including hospital, home or hospice.</p> <p>We call for a statement on palliative care to be included in this quality standard.</p> <p>In general, children who die as a result of cancer receive very good end of life care. However:</p> <ul style="list-style-type: none"> • We believe that many children are not given a choice over the place in which they receive end of

ID	Stakeholder	Section	Comments
			<p>life care; this could include a hospital, their home or a children’s hospice. In 2011/2012 only 113 children with oncology conditions were referred to children’s hospices across the UK (Children’s Hospices UK, now Together for Short Lives).</p> <ul style="list-style-type: none"> • Practice in terms of advance care planning, do not attempt resuscitation (DNAR) orders, rapid discharge pathways and palliative care pathways varies across local areas. 19 <p>The following processes are needed to ensure comprehensive palliative care for children with cancer:</p> <ul style="list-style-type: none"> • Advance care planning - this can give the child and their family an opportunity to express their wishes over treatment and place of care at the end of the child’s life. Choices on bereavement care can also be expressed. • Closer working between oncology, children’s palliative care teams and clinical networks - this can ensure that knowledge, good practice and expertise is shared. It can also prevent advanced care plans and rapid discharge pathways from being duplicated. Secondary care teams should liaise closely with community and primary care teams if a child or young person requires palliative care at home. 20 • Parallel planning - it is difficult to know when a child with a life-limiting or life-threatening condition has entered their end of life phase. End of life parallel planning allows for scenarios in which the child lives or dies. 21 • Palliative care pathways, which many regions now use; Shared pathways, common to all conditions, enable better understanding across health and social care services. 22 • Involving children and young people with cancer who are approaching the end of their lives in decisions about their care. This can improve outcomes; where children do not wish to receive end of life care in an acute setting and are able to specify another option, palliative care services

ID	Stakeholder	Section	Comments
			<p>in children’s hospices or in the community have potential reduce the burden on hospital services.</p> <p>A process indicator could be developed on the number of children with oncology conditions who are referred to children’s palliative care services.</p> <p>This proposed standard would help to address the improvement areas 4.6 (Bereaved carers’ views on the quality of care in the last three months of life) and 4.8 (Children and young people’s experience of healthcare) set out in the NHS Outcomes Framework 2013/14.</p> <p>An additional standard could be supported by outcome measures on:</p> <ul style="list-style-type: none"> • The experience of care for children and young people at the end of their lives. • The number of children and young people with end of life plans who die in the place of their choice.
154	British Society of Paediatric Dermatology	Question 1	Consider a further quality statement of ‘Ensure early diagnosis by referral to appropriate specialist’
155	Brain Tumour Research	Question 1	<p>A number of the quality statements will be very helpful for young people with brain tumours. Psychosocial care will be extremely beneficial to patients and their family; the stress of discovering that one’s young child has brain cancer is a significant one and as such a counselling service for the patient and family would help the NHS meet Domain 4: ensuring that people have a positive experience of care.</p> <p>A specialist neuro-rehabilitation care package would also significantly help those with brain tumours as speech or use of one side of the body can often be impaired. With neuro-rehabilitation these conditions can be mitigated.</p> <p>A written end of treatment and summary plan is also of key importance and we welcome this. In the 2013 Cancer Patients Experience Survey only 22% of patients were offered a written care plan – this should be improved.</p>
156	Teenage Cancer Trust	Question 1	We believe that this draft quality standard more accurately reflect the needs of children than those of young people.

ID	Stakeholder	Section	Comments
			<p>It does not appear that the significant developments in practice and structures in Teenage and Young Adult (TYA) cancer care since the publication of the NICE Improving Outcomes for Children and Young People with Cancer Guidance in 2005 have been reflected in this quality standard. These developments have seen TYA cancer guidance being separated from children because the cancers in teenagers and young adults differ to those in children, and young people also have very distinct age specific psychosocial needs. The services required for TYAs with cancer are therefore significantly different, and are also at a different stage of development than well established paediatric services.</p> <p>Teenage Cancer Trust represents teenagers and young adults with cancer aged 13-24; we now have 26 operational units across the UK following the model set out in the CYP IOG and fund over 30 specialist staff working in these age appropriate environments. We were part of the guideline development group for this IOG and at the time the inclusion of young people with cancer up to the age of 24 had a huge impact on the development of the TYA cancer care. Over the last 8 years this specialty has grown significantly largely due to this recognition by NICE.</p> <p>The follow on work of the CYP IOG was the establishment of a CYP IOG group, which Teenage Cancer Trust continued involvement with until it disbanded recently. This group led work on peer review measures to assess children and young people’s cancer services. It was agreed early on that measures for children needed to be separated from those of the teenage and young adult population who’s service needs were at a hugely different stage to the established paediatric services. This work has defined the Principal Treatment Centres and designated centres for the care of TYAs. The separate measures now being used in peer review can be found here: http://www.cquins.nhs.uk/?menu=resources</p> <p>Following on from this, the new commissioning system in NHS England has now also recognised the need for children’s cancer services and TYA services to be separated. A TYA Clinical Reference Group is now being set up, as well as there being a Paediatric Oncology Clinical Reference Group, to advise on the specialist commissioning of these services. More information on this can be found here: http://www.england.nhs.uk/ourwork/d-com/spec-serv/crg/</p> <p>There are several professional working groups, including:</p> <ul style="list-style-type: none"> • Teenagers and Young Adults with Cancer (TYAC) – professional membership organisation • North West Cancer Intelligence Service – designated cancer registry for TYA cancers

ID	Stakeholder	Section	Comments
			<ul style="list-style-type: none"> • National Cancer Research Institute TYA Clinical Studies Group • National Cancer Intelligence Network Children, Teenagers and Young Adult Site Specific Clinical Reference Group • National Cancer Survivorship Initiative Children and Young People’s Group <p>The developments in teenage and young adult cancer services have been documented in the Blueprint of Care for Teenagers and Young Adults with Cancer, which also needs to be referenced in the policy context documents list.</p> <p>If the quality standard is to effectively help inform commissioners, support service providers and professionals, and inform patients and their families it seems important that it reflects these structures. We would like to see a separate quality standard for teenagers and young adults, or if this is not possible additional statements developed which specifically focus on the needs of young people.</p>
157	University College London Hospital	Question 1	Partially – I don’t believe it goes far enough and needs to be more directive. It will be extremely difficult to measure some of this data, particularly accurate data on the social and psychological support. Some more work needs to be done on the current patient experience survey to fully capture accurate data on all aspects of TYA support and care. More joined up work with the charity sector who currently work in this area may be helpful.
158	Paediatric Oncology Dieticians Interest Group (PODIG)	Question 1	Comment on question 1 1. Yes the draft quality standard does accurately reflect the key areas for quality improvement. 2. For most of the proposed standards it would be possible to collect data
159	Yorkshire and Humber Strategic Clinical Network and Senate	Question 1	A key standard that is not defined in this Quality Standard for CYP is the <u>provision of age-appropriate care</u> for patients aged 16-24. We would suggest: “Patients should all be offered an informed choice of access to an age-appropriate environment, alongside other young people, managed by staff with training and experience of cancer in TYA”. This should be measured as documented in both site-specific and age-appropriate MDT meetings, and cross-referenced with the content of patient and carer questionnaires.
160	Yorkshire and Humber	Question 1	None of the quality standards specifically address training and competencies, although it is described in

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	Strategic Clinical Network and Senate		<p>an underpinning principle that ‘professionals should have training and competencies’ in the patient group they are managing. This is currently not freely available in relation to Young people aged 16-24 with cancer, because insufficient professionals have specific training in TYA patients’ needs. This could usefully form another statement; “Professionals caring for patients aged 16-24 with cancer should have training in the management of young people in this age-group”</p> <p>This could be measured from the proportion of TYA-trained professionals among the named specialist professionals in the TYA MDT and TYA wards where care is delivered. Regionally or at a central level, commissioners could purchase the NHS clinical capacity to allow release for training for CYP and TYA specialist staff to attend regional programmes of specific initial training and then CPD via the existing systems provided by the multi-professional organisations ‘Teenagers and Young adults with cancer and the Teenage Cancer Trust). Source document- Blueprint of Care for TYA (Teenage Cancer Trust).</p> <p>There is a very real issue in staff being able to access relevant education (whether in children of TYA cancer) and a quality standard that addresses this would add great value.</p>
161	Teenagers and Young Adults with Cancer (TYAC)	Question 1	<p>The key area that the Quality standards do not address is that of the “provision of age appropriate care” for the 16-24 year old age group. For the 19-24 year olds this should be informed choice and for 16-18 year olds this should be treatment in a TYA PTC. This would be measurable through the site specific and TYA MDT’s and cross referenced with experience questionnaires.</p>
162	Brain Tumour Research	Question 2	<p>For most of the proposed systems and quality statements we believe that it will be possible to collect the required data.</p> <p>Ultimately, we feel one- and five- year survival rates for brain tumours should be included along with breast, lung and colorectal cancer in Domain 1.4. Brain tumours kill more under-40s than breast, lung, colorectal or any other common cancer. The quality standard should bear this reality in mind. We also recommend survey data, as in the 2013 Cancer Patients Experience Survey continue to be collected, perhaps with a particular focus on child cancer patients.</p>
163	University College London Hospital	Question 2	<p>Partially – it will be difficult to measure some of the standards as they currently stand especially if some care is provided outside of the PTC in the TYA designated Trusts. A more robust way of collecting the data will need to be developed especially around areas such as psychological and social support</p>

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164	Yorkshire and Humber Strategic Clinical Network and Senate	Question 2	Each standard remains measureable, using the data from existing MDT meetings, common assessments and NHS peer review datasets.
165	The Society and College of Radiographers	Question 2	What data would be collected, who would collect it and where would it be stored?
166	Oxfordshire Clinical Commissioning Group	Briefing paper	<ul style="list-style-type: none"> a. P.6 section 2.3 - re diagnostic bone marrow, should be plural: diagnostic bone marrows<u>s</u> (in keeping with central venous line<u>s</u>), also far more bone marrows are done for response assessments as well as diagnosis, so in the list of frequently performed procedures I'd put diagnostic and response assessment bone marrows instead. b. Same page, put lumbar punctures rather than spinal (unless spinal was put in for the general public then put Lumbar (spinal) punctures