NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Haematological cancers

Date of quality standards advisory committee post-consultation meeting:
2 March 2017.

2 Introduction

The draft quality standard for haematological cancers was made available on the NICE website for a 4-week public consultation period between 11 January and 7 February 2017. 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 18 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 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 appendices 1 and 2.

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. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4 General comments

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

- General support for this draft quality standard with implementation and data collection possible if the systems and structures were available.
- Statements 2-6 of this draft quality standard are focused on Non-Hodgkin's Lymphoma (NHL) with a notable lack of myeloma specific statements (for example imaging, laboratory investigations for prognostic information and supportive care). Suggestion to include more haematological cancers in this standard.
- Include quality of life as an overarching outcome.

Consultation comments on data collection

- Statement 1 outcome measure (b) - The meaning of 'discontinuation of treatment' and its measurability needs clarification.
- Statement 4 - Quality of life for all follicular lymphoma patients is not currently routinely examined so would therefore require data management investment.

Consultation comments on resource impact

- Statement 1 - Including ward sisters and palliative care specialists within the multidisciplinary team (MDT) will be resource intensive. Also, further investment will be required to implement more specialist integrated haematological malignancy diagnostic services (SIHMDS) as current variation in access was reported.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Young people and adults with haematological cancers have their specialist integrated haematological malignancy diagnostic services (SIHMDS) validated

integrated report shared with the relevant haemato-oncology multidisciplinary team (MDT).

Consultation comments

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

- Implementation of most of this quality statement's elements will be possible and will enable more sites to be supported to provide the systems and infrastructure necessary for integrated diagnostic reporting via SIHMDS.
- The statement should cover all age groups as per recommendations 1.1.2 and 1.1.3 of NICE guideline NG47. By limiting the age group it may potentially reinforce unequal age-based standards of care.
- Sharing the integrated report with the MDT prior to treatment may cause delays as patients with acute leukaemia need urgent treatment. This delay could pose a risk to survival so producing a minimum report before initiation of treatment is advised with a full integrated report shared with all relevant members of the Haemato-Oncology MDT afterwards.
- Further clarification is needed on:
    - The purpose of integrated reporting whereby individual results are not distributed in isolation or interpreted by undesignated professionals and outside the context of the total investigations
    - The haematopathologist's role to establish the sequencing of information in which different results are included in the integrated report and presented to the MDT
    - The responsibility of organisations and departments to establish appropriate management structures such as overseeing laboratory processes, quality of diagnostic reporting and auditing needs to be highlighted.

5.2 Draft statement 2

Young people and adults diagnosed with specific non-Hodgkin's lymphoma subtypes are offered staging using fluorodeoxyglucose-positron emission tomography-CT (FDG-PET-CT).

Consultation comments

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

- FDG-PET-CT use before treatment was queried as delayed treatment may pose a risk for patients with localised disease.
- The focus on lower staged NHL patients was queried as this potentially limits access to PET scanning for many patients.
- Measurement issues were raised as not all patients will have CT criteria and some patients will only receive a PET-CT scan to minimise radiation exposure. Therefore measuring the number of patients who have a CT and subsequent FDG-PET-CT will be difficult.

5.3 Draft statement 3

Young people and adults with localised stage IIA follicular lymphoma are offered first-line local radiotherapy.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Expand the population to include young people and adults with localised stage IA follicular lymphoma.
- There should be an acknowledgement that not all patients with localised stage IIA follicular lymphoma are suitable for localised radiotherapy. For example, if there are several sites of disease or there is concern about the potential for secondary toxicity.
- There is a need to define follicular lymphoma.

5.4 Draft statement 4

Young people and adults with advanced-stage asymptomatic follicular lymphoma are offered rituximab induction therapy[1].

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Induction rituximab use should be considered and not recommended as a standard of care in this population.
- There is a lack of evidence for this recommendation.
- The licensing of rituximab was raised.

5.5 Draft statement 5

Young people and adults with diffuse large B-cell lymphoma that involves the breast, testis, adrenal gland or kidney, or with 4 or more risk factors for central nervous system relapse, are offered central nervous system-directed prophylactic therapy.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- The NICE guidelines for CNS prophylaxis in high grade lymphoma contradicts the current British Committee Society for Standards in Haematology (BCSH).
- There is a lack of evidence for this recommendation.
- Involvement in discussions about treatment decisions is key between healthcare professionals which must be acknowledged as patients are being refused treatment based on their age rather than their fitness.

[1] At the time of publication of the source guidance (July 2016) rituximab did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information. The evidence reviewed for the guideline supports the standard monotherapy dosage of 4 doses of 375 mg/m2 at weekly intervals information. The evidence reviewed for the guideline supports the standard monotherapy dosage of 4 doses of 375 mg/m^2 at weekly intervals.

5.6 Draft statement 6

Young people and adults who have been treated for non-Hodgkin's lymphoma have a discussion about their end-of-treatment summary plan when they complete their treatment.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- This plan should be focused on all haematological cancers and not just NHL.
- Based on the plan's actions the delivery of the Recovery Package (as recommended in the Cancer Strategy) is important.
- This plan should be fully explained and discussed with shared decision making between doctor or nurse and patient.
- Independent advocacy support for any older person with a haematological cancer was recommended to improve patient management of haematological cancers.

6 Suggestions for additional statements

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

- HIV testing for all young people and adults with lymphoma before starting anti-cancer treatment.
- PET CT scanning for all DLBCL patients at diagnosis.
- Tumour burden for patients with asymptomatic advanced stage follicular lymphoma which may affect the treatment decision.
- All haematological cancer patients have access to the full Cancer Recovery Package and clinical nurse specialist to meet their needs and improve patient experience.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[2]
Statement 1			
1	BMTCRG	1	This statement raised concern as it only refers to young people and adults whereas the NICE IOG 2016 guidance relates to all age groups. There is a risk that this re-enforces an age-based differential standard of care in integrated diagnostic services and MDTs at odds with the NICE recommendations.
2	BMTCRG	1	It is noted that the MDT should include ward sisters and palliative care specialists. This statement raised concern as palliative care specialists are a limited resource and unless further investment was made in palliative care services it is unlikely that they would be able to attend. In addition, ward sisters are a very limited resource and would be unlikely to have time to attend the meeting and, in addition, this would not be the best use of their time as they may not know or ever meet the patients being discussed.
3	BMTCRG	1	This statement assumes that all areas have an SIHMDS. In some areas this has not been achieved and further investment would be required to resource this.
4	BMTCRG	1	This statement raised concern as it is not always possible for the integrated report to be shared with the MDT prior to treatment commencing as some patients e.g. patients with acute leukaemia, need urgent treatment.
5	BMTCRG	1	This statement may be hard to measure because it is difficult to interpret “discontinuation of treatment”. Is this the number who complete the course of treatment, the number who stop treatment early due to toxicity or disease progression? It would be helpful if this could be made clearer as otherwise it may be difficult to collect this information.
6	BSH	1	We are disappointed that this quality standard has been written to apply only to young people and adults when the SIHMDS NICE guideline very specifically applied to all patients groups including those under 16. The aim of the NICE guidance was to eliminate any unequal standard of care based on age. The draft quality standard being applied only to young people and adults (implication being those over 16 year) potential reinforces inequitable age-based standards in integrated diagnostics and MDT functioning and is against the original NICE recommendations.
7	ICLG	1	MDT section – we do not feel it necessary to add that ward sisters should attend the MDT as this would add little to the discussion as the clinical nurse specialist are already present and also be an additional demand on their time.

[2]PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[2]
8	NCRICHOSG	1	This Quality Statement will hopefully mean that more sites are supported to provide the systems and infrastructure necessary for integrated diagnostic reporting via SIHMDS. It should be possible to implement most of the elements of this Quality Statement. However, the Quality Statement applies to only adults and young people, whereas the updated Haematological Cancers IOG clearly recommended the use of SIHMDS for all ages in order to eliminate an unequal standard of care based on age.
9	RCPath	1	The authors may consider expanding the Rationale to highlight the role of Haematopathologists in providing integrated reports, in particular regarding the sequence in which information sometimes becomes available. In many instances (Acute Myeloid Leukaemia is one example), integrated reports grow with sequential additions of information and multiple edits. This section may consider including a statement to reflect the responsibility of the validating Haematopathologist to establish the sequence in which different results are included in the integrated report and presented to the MDT.
10	RCPath	1	The rationale should also make it clear that the purpose of integrated reports is not only to "…avoid potential contradiction that may arise when investigations are carried out in separate laboratories…", but also to make sure that the individual results are not distributed in isolation or interpreted by undesignated professionals and outside the context of the totality of investigations carried out.
11	RCPath	1	The comment refers to the statement "The SIHMDS director's responsibilities include ensuring an overall quality management system is in place, that includes laboratory processes, the quality of diagnostic reporting, auditing, and communication within the SIHMDS and with relevant healthcare professionals." It would be essential for the Commissioners to have a clear understanding of the reality of organisation of SIHMDSs in the United Kingdom. At present few have under their immediate management control the full spectrum of laboratory investigations which can potentially be carried out under one management or single laboratory setup. It is more often the case that diagnostic services, particularly regarding molecular investigations, are undertaken in centralised molecular hubs, which have unrelated management and quality control. These laboratory services are shared for diagnosis by other cellular pathology subspecialties and it seems that this will be the future for the development of molecular diagnosis in the UK. In these circumstances, the paper must emphasise that it is the responsibility of the respective organisations/departments to establish appropriate management structure to oversee laboratory processes, quality of diagnostic reporting, auditing, etc specifically related to a particular subspecialty, in this case Haematological malignancies. This issue at present potentially hampers communication and effectiveness in the process of integration of data, quality control and introduction of upcoming technologies and tests. This has been argued and addressed in the recent Royal College of Pathologists documents on Standards for Integrated Reporting in Cellular Pathology (January 2017) (https://www.rcpath.org/resourceLibrary/g155-standardsintegratedreportingcellpath-jan17.html) and the Standards for

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			Specialist Laboratory Integration and Dataset for the Histopathological Reporting of Lymphomas (October 2015) (https://www.rcpath.org/resourceLibrary/dataset-for-the-histopathological-reporting-of-lymphomas.html). We would advise that this documents are quoted and the above clarification introduced in the text as in the current circumstances, as it stands, SIHMDS director's responsibilities cannot be exercised in majority of cases as suggested in the text.
12	RCPath	1	We would advise that the authors add to their source of guidance the two Royal College of Pathologists key documents: 1. Standards for integrated reporting in cellular pathology (January 2017) (https://www.rcpath.org/resourceLibrary/g155-standardsintegratedreportingcellpath-jan17.html) 2. Standards for specialist laboratory integration and dataset for the histopathological reporting of lymphomas (October 2015) (https://www.rcpath.org/resourceLibrary/dataset-for-the-histopathological-reporting-of-lymphomas.html)
13	RMFT	1	NICE state in their rationale for quality standard 1 that 'It is vital that integrated reports are shared promptly with the relevant Haemato-Oncology MDT when management decisions are being made and before treatment starts'. While the 'full' integrated report for each case can be shared with all the relevant Haemato-Oncology MDT members, it is important to recognise the varying urgency of treatment in individual cases. For example it is impossible with current technology to turn around all relevant results for inclusion in an integrated report before initiation of treatment where therapy is extremely urgent (e.g. acute promyelocytic leukaemia, critical organ compression due to myeloma/lymphoma, high count AML) and delays put the patient's life at risk. While this is not an issue in most cases we believe NICE guidance should recognise these circumstances. We would favour publication of a minimum reporting standard for these situations before initiation of treatment, and a separate standard for sharing of the full integrated report with all relevant members of the Haemato-Oncology MDT. NICE have recommended that a palliative care specialist (doctor or nurse) should be present at the MDT. If this is not possible, NICE recommends that the MDT needs to demonstrate that they are reviewing patients with a palliative care specialist regularly. Palliative care input at the MDT is appropriate for many haematological cancers, but this statement should not be mandatory for all haematology MDTs. For example a palliative care specialist does not routinely attend our lymphoma MDT at present, as the vast majority of lymphoma patients are treated with curative intent or are anticipated to achieve a durable remission following chemotherapy or radiotherapy. An MDT decision to refer an individual patient with lymphoma to the palliative care team where appropriate would be documented in the MDT note.
Statement 2			
14	BNMS	2	'Proportion of young people and adults diagnosed with stage I diffuse large B-cell lymphoma by clinical and CT criteria who receive staging using FDG-PET-CT'

ID	Stakeholder	Statement number	Comments[2]
			Not all patients with stage 1 or 2 lymphoma will have had a CT. Therefore you should consider in Proportion of young people and adults diagnosed with stage I diffuse large B-cell lymphoma by clinical (and CT criteria if performed) who receive staging using FDG-PET-CT. Proportion of young people and adults with stage I or localised stage II follicular lymphoma for whom radiotherapy would be technically possible who receive staging using FDG-PET-CT – similarly you need to define how this has been diagnosed. The PETCT is the imaging staging investigation.
15	BSH	2	The number of patients with stage 1 DLBCL or stage I or localised stage II follicular lymphoma by CT criteria who get a PET scan is relatively easy to measure. Similarly this is true for patients who potentially have low risk Burkitts lymphoma.In many centres, however, such patients do not have a CT scan but simply receive a PET-CT so as to minimise radiation exposure. It may therefore be hard to measure how many patients who have a CT subsequently go on to a PET. As a group, we would like to record that we fundamentally disagree with the quality standard however and have commented to NICE during the guideline development. In our opinion this measure is unnecessarily prescriptive and potentially limits access to PET scanning for many patients. After our comments the standards were changed to allow physicians to consider PETCT in patients with higher stage disease but it disappointing that the quality standard focuses only on the lower stage patients. To summarise: i) In our view, improving accuracy of staging with baseline PET-CT is of significant relevance for FDG avid lymphomas other than stage I DLBCL and stage I/II FL, e.g.: - Stage II DLBCL that would be suitable for limited chemotherapy followed by IFRT to allow accurate IFRT planning. - For DLBCL and follicular lymphoma of all stages, accurate staging information is essential for correct IPI and FLIPI group allocation of DLBCL and FL, respectively. This is important for correct prognostication and for translation of international trial data into clinical practice. · In addition, in DLBCL the additional sensitivity of PET-CT compared to conventional CT, particularly in detection of extranodal and bone marrow disease, is critically important. This is particularly pertinent in aiding the decision-making with respect to CNS-direct chemoprophylaxis. As the quality standard acknowledges. data indicate that in patients with DLBCL the number and localisation of extranodal sites of disease, as detected by PET-CT, is highly predictive of the risk of CNS relapse:

ID	Stakeholder	Statement number	Comments[2]
			omitting PET-CT at diagnosis will make it more difficult for us to reduce the risk of this devastating complication of DLBCL. · Response criteria for definition of PR and SD take into account difference of FDG avidity compared to baseline and therefore require both baseline and end-of-treatment assessments.. ii) In addition to our concerns that many patients will miss out on potential benefits of PET scanning, we are concerned that to comply with the guidance treatment may potentially be delayed for good risk patients with localised disease. To comply with the guidance all patients will first undergo CT and bone marrow biopsy to establish whether they have localised disease, before their eligibility for PET-CT scanning can be determined. Patients with localised disease will then have to wait for the PET-CT to be performed before starting therapy. We are concerned that these patients' treatment will be significantly delayed as a consequence of this strategy.
16	RMFT	2	Baseline PET is only recommended in very limited stage disease-stage I DLBCL, stage I/II Burkitt lymphoma and stage I/II follicular lymphoma as per the NICE guidance in July 2016. We have previously commented on this as per our response to the NICE guidance in July 2016 below. · Improving accuracy of staging with baseline PET-CT is of significant relevance for FDG avid lymphomas other than stage I DLBCL and stage I/II FL, e.g.: - Stage II DLBCL that would be suitable for limited chemotherapy followed by IFRT to allow accurate IFRT planning. - Essential for correct IPI and FLIPI group allocation of DLBCL and FL, respectively. This is important for correct prognostication and for translation of international trial data into clinical practice. · Response criteria for definition of PR and SD take into account difference of FDG avidity compared to baseline and therefore require both baseline and end-of-treatment assessments.
Statement 3			
17	BSH	3	Should this statement not apply to stage 1A disease as well as stage IIA?
18	RMFT	3	There should be an acknowledgement in this statement that not all patients with localised stage IIA follicular lymphoma are suitable for the localised radiotherapy approach (if there are several sites of disease, or there is concern about the potential for secondary toxicity). For completeness it should also be stated that this is for follicular lymphoma grade 1/2 and 3a only (in the "definition of terms used for this quality statement")
Statement 4			
19	BMTCRG	4	This statement raised concern as it was felt there was a lack of evidence for this recommendation.

ID	Stakeholder	Statement number	Comments[2]
	BSH	4	In terms of measurability, it is relatively easy to measure the proportion of patients treated using this strategy. There is no national mechanism in place to measure PFS or quality of life as one would in a clinical trial. One would need to seek this information on a case-by –case basis. It would, of course, be more informative to do that within the context of measuring PFS and quality if life for all patients with follicular lymphoma but again this is not routinely undertaken and would require investment in data management. The bigger issue here in our opinion is the guidance itself. We object to the statement that 'rituximab is the optimal strategy for asymptomatic patients with advanced stage follicular lymphoma'. The study by Ardeshna et al (Lancet Oncol 2014: 15:424-35) showed that time to next treatment was increased if rituximab induction was given but showed no improvement in overall survival and no improvement in quality of life. It remains to be seen whether early rituximab therapy has an impact on cellular resistance later in the course of the disease: follow up is too short to allow an assessment of impact on OS. In our opinion, this should be considered rather than offered. It should be noted specifically that this recommendation in NG52 was made purely on health economic grounds, with limited clinical data. In addition, on a practical level, rituximab has no licence for use in this way and there has been no NICE TA to approve its use and therefore the option of rituximab induction is currently unfunded as we understand it.
20	ICLG	4	We, the lymphoma specialists at Imperial College Healthcare NHS Trust, do not agree with Statement 4 ("Young people and adults with advanced-stage asymptomatic follicular lymphoma are offered rituximab induction therapy"). There is no evidence to support this approach. The study it is based on randomised between therapy (rituximab) and no therapy. To conclude that the patients who had received this therapy then had a longer time until their second therapy was necessary compared to the non-treated patients requiring their first therapy is comparing apples with oranges. In addition, to give single agent rituximab to a patient with newly diagnosed follicular NHL also exposes them to the theoretical risk that a later progression will take place in a CD20-negative clone, which is less likely to happen if they had received the combination of rituximab and chemotherapy in the first place. The USA National Comprehensive Cancer Network (NCCN 2017) specifically addresses this question and advise, observation only for asymptomatic advanced-stage follicular lymphoma a category 1 recommendation, furthermore they conclude that this use of

ID	Stakeholder	Statement number	Comments[2]
			rituximab is NOT recommended. We would be grateful if this controversial guidance, with which we strongly disagree, could be removed."
21	RSCH	4	The use of Rituximab in asymptomatic patients with follicular lymphoma is not standard of care. The Ardeshna data on which this standard is presumably based does not demonstrate a survival advantage for early Rituximab treatment, but a prolonged time to first treatment and a benefit to Quality of Life. Many might argue that such a quality of life benefit can also be achieved by supporting and informing patients on "Watch and Wait". Even the authors of this study conclude that early Rituximab treatment should be considered (rather than be standard of care) in this patient group.
Statement 5			
22	BSH	5	These outcomes are relatively easy to measure but we believe PET CT scanning for all DLBCL patients at diagnosis will better allow identification of the at risk group which needs to be targeted for intervention.
23	OPAAL	5	"Central nervous system-directed prophylactic therapy means that patients will be exposed to an increase in toxicity, resulting in an increased rate of morbidity. The increased risk of central nervous system disease in older patients specifically with the toxicity involved in repeat lumbar punctures should be considered and the patient should be involved in these difficult treatment decisions." OPAAL has real concerns that there may be occasions when patients are rejected for treatment based on their age as opposed to considered based on how fit they are to withstand that treatment. Involvement in discussions about treatment decisions is the optimum opportunity for independent advocacy support for patients. An advocate will ensure that the patient is fully informed and their voice heard ahead of any decision being made. In many cases, information is complex and hard to remember in stressful environments with many older people not confident enough to raise questions and deferring to their doctor on decisions about treatment and care, sometimes when this is not best for them. With an independent advocate alongside them, older people can be equipped to ask the right questions of their clinician and aided to retain important information. It remains OPAAL's belief that NICE Quality Standards should overtly call for the universal provision of independent peer advocacy support to ensure optimum opportunity for a positive patient experience. Whilst this does have resource implications for the NHS we see potential for major cost savings as a result of its use.
24	RSCH	5	The NICE guidelines for CNS prophylaxis in high grade lymphoma contradict the current British Committee Society for Standards in Haematology (BCSH) Guidelines. Using a quality standard which is contradictory to the evidence based guidelines produced by UK experts in the field creates an obvious tension, as many departments will make active and appropriate decisions to follow the BCSH guidelines, which have been very helpful in providing clarity in this area. Of note, the evidence to support intrathecal

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			methotrexate for CNS prophylaxis is of poor quality, and of questionable relevance in the Rituximab era. This therefore seems a very inappropriate quality standard as one of just 6 across the breadth of haematological malignancy.
25	RMFT	5	CNS prophylaxis for patients with DLBCL and 4+ risk factors. Limiting prophylaxis to just patients with 4+ risk factors is more rationalised in this quality statement than what has been suggested in the recent NICE guidance (where it is recommended that can also be considered for patients with 2-3 risk factors), considering that administration of prophylaxis for patients with 2+ risk factors could be up to 70% of all DLBCL patients (as per R-CHOP 14 v 21 cohort) which would have a significant implication for patients and service provision.
Statement 6			
26	RCGP	6	It can be agreed that people who get to the end of a course of treatment should have a discussion, and that a record of the discussion should be given to them and sent to their GPs., However, if a discussion is thought to be a measure of high quality, then the risk is that it becomes a box ticking exercise, without any meaningful dialogue between doctor/nurse and patient. How does the group propose to ensure that this is a full discussion, involving patients in shared decision making etc. There is something curious that this idea that appears to be so good is only to apply to those with non-Hodgkin's lymphoma. I assume that it has arisen because some primary research has shown benefits in this field and not anywhere else. But would it not be helpful for words to be added that it is likely to be helpful in other areas? Otherwise this quality standard might have the perverse effect of denying the benefits to those with other forms of cancer (DJ)
27	APMGBI	6	We wonder why the end of treatment plan is only for those who have had NHL? Surely it would be sensible for anyone who has completed treatment for any haematological cancer to be offered this. Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement? https://www.england.nhs.uk/wp-content/uploads/2016/03/ca1-enhncd-supprtv-care-guid.pdf
28	NHSE	6	I agree with this statement however this should be the case for all blood cancer patients, not just those being treated for Non-Hodgkin's Lymphoma. It is also important that action is taken in response to this assessment such as through delivery of the Recovery Package, as recommended in the Cancer Strategy.
29	OPAAL	6	"The end-of-treatment summary plan should be clearly explained and discussed with the young person or adult (and their family members, carers or care workers, if appropriate). Information provided should be provided in a clear format and in a language

ID	Stakeholder	Statement number	Comments[2]
			suited to the person's needs and preferences." Older people affected by cancer tell us that they often struggle to understand and take in everything that they are told by health professionals. As a result, they lose confidence in themselves. An example of how this can be overcome, is explained by Tony, one of our service-users: "Moving forward with the assistance of my advocate I became more confident and better enabled to meet with health professionals. I would be encouraged to write a list in relation to my physical symptoms prior to appointments. This allowed me to ensure that all my symptoms would be addressed and that I would leave my medical appointment fully mentally satisfied. My advocate would also attend them with me which gave me reassurance that I had an independent person with me. My advocate would also take notes during the appointments which we would then discuss straight after. This has helped me feel more in control and I feel better safeguarded." Diane, another service-user, notes: "Andy's (her advocate's) continued involvement over a wide range of issues has been invaluable and he has been the most important person in my cancer survivorship experience. He supports me at meetings as well as talking through my treatments and their possible consequences." Service-user Carol says: "If Joanna (her advocate) was not with me, I don't think I would go to these appointments. Even if I did, I would be a nervous wreck. In the appointment, Joanna takes notes so I can ask her afterwards if there is anything I have not taken in. It's so hard to take everything in at the time if you are on your own." It is in light of such evidence that OPAAL calls on NICE to enshrine the provision of independent advocacy support for any older person with a haematological cancer who needs it into this Quality Standard. In doing so, it will support improvement in patient management of haematological cancers.
30	BW	6	We agree that young people and adults who have been treated for non-Hodgkin's lymphoma have a discussion about their end-of-treatment work plan upon completing treatment. However, we would argue that beyond this, it is important that patients have access to the full Cancer Recovery Package. Furthermore, this should be the case for all blood cancer patients, not just those being treated for non-Hodgkin's lymphoma. Blood cancer is the fifth most common cancer in the UK, and third biggest cancer killer. In addition, because of the differences in blood cancer to solid tumour cancers, there are crucial differences in the ways treatment and care are provided. This has led to the Cancer Recovery Package not being accessed by blood cancer patients as effectively as in other cancer types. At

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			Bloodwise, we have begun a project to enable us to fully understand why this is the case, and to work up solutions as to how this can be resolved. Therefore, if the Quality Standard could include a statement requiring all blood cancer patients having access to the Cancer Recovery Package in a way that meets their needs, that would support the work we are doing to improve the current Recovery Package and ultimately help to improve patient experience. In addition, we refer to our formal consultation response to this QS which references the fact that a higher number of blood cancer patients do not have access to a Clinical Nurse Specialist compared to solid tumour cancers. Whilst we understand the financial pressures on the NHS, and the lack of availability of specialist nurses in the UK, we would argue that the level of care provided by a CNS is hugely beneficial to those blood cancer patients able to access one, both during treatment and once treatment has ended. The Quality Standard should seek to safeguard access to a CNS wherever possible, and where not possible, an appropriate alternative model of care should be provided.
General comments			
31	BMTCRG	General	This draft quality document does not accurately reflect the key areas for quality improvement as it only focuses on non-Hodgkin's lymphoma and does not include other haematological malignancies including myeloma, leukaemia, CLL, Hodgkin's lymphoma. There is an over-emphasis on follicular lymphoma. It is unclear why the other conditions are not included as recent NICE guidance has been published on myeloma and IOG.
32	BMTCRG	General	Concern was raised that this document had not been widely circulated as members of the CRG who have multiple roles had not been sent the document by their trusts or other external sources.
33	BSH	General	We feel that this publication, as a draft quality standard for haematological cancers, by no means represents the breadth of haematological malignancy. There have been 3 NICE guidelines in haematological cancer published in the last year: Improving Outcomes (NG47), Lymphoma (NG52) and Myeloma (NG35). One of the quality statements related to NG47 and 5 relate to non-Hodgkin lymphoma. None of the standards relate specifically to myeloma. There are of course numerous other topics which are not covered, except by statement 1, including acute myeloid leukaemia, chronic myeloid leukaemia, acute lymphoblastic leukaemia, chronic lymphocytic leukaemia, myelodysplasia, myleloproliferative disease, Hodgkin lymphoma etc. Even within the statements made there were opportunities to be more generic but these have not been taken – eg in statement 6 regarding end of treatment plans. We are unaware of any direct contact made by NICE regarding the development of these quality standards with either the chair (Prof Curly Morris) or the clinical lead (Guy Pratt) or any of the 4 Haematology Consultants involved in the published NICE

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			myeloma guideline. There is not a single quality statement relating to the recommendations made in the NICE myeloma guideline. In view of this we feel the process for developing these quality standards is flawed and that NICE need to justify why there is no myeloma- related quality standard and make clear whether there was appropriate engagement made with the myeloma medical community in the UK. Quality standards could cover a number of areas in the published myeloma guideline that could include quality statements on imaging for suspected myeloma, laboratory investigations for prognostic information and on laboratory investigations for suspected myeloma. There are also other areas of such as supportive care that could be covered by quality statements.
34	NCRIHOCSG	General	We understand that the aim of Quality Standard is to provide clinically useful indicators for potential inclusion within the Clinical Commissioning Groups Outcome Indicator Set (CCGOIS), which is important for commissioning of high quality services. However, the current proposed draft Quality Standard falls short of this goal as it fails to be relevant to the majority of Haematological Cancer practice. We would have expected the process to have an agreed principle to produce a balanced set of Quality Statements around the NICE Haematological Cancers IOG, NICE Myeloma and NHL Guidance documents covering the whole of Haemato-oncology. The lack of any specific mention of Myeloma in the Quality Standard is notable, despite there being an equivalent NICE Myeloma guideline to the NHL Guideline featuring in the briefing documents. The Quality Standard re-enforces an inequitable age-based differential standard of care in integrated diagnostics and MDTs at odds with the published NICE IOG recommendations. We think there are failed quality improvement opportunities based on lack of breadth to cover the specialty of Haemato-oncology, and, where appropriate, all age ranges.
35	RCGP	General	A systematic review of haematological cancer patients shows that they have a poor Quality of Life (QoL) or health-related QoL regardless of the type of disease, the treatment modality and the stage of the disease.1 None of the quallity statements address the issue of improving quality of life. (MH) 1. Allart-Vorelli P, Porro B, Baguet F, Michel A, Cousson-Gélie F. Haematological cancer and quality of life: a systematic literature review. Blood Cancer Journal. 2015;5(4):e305-. doi:10.1038/bcj.2015.29.

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	NCRIHOCSG	General	Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement? NO, IT FAILS TO ACCURATELY REFLECT THE KEY AREAS AS MOST OF THE STATEMENTS ARE NOT DIRECTLY RELEVANT TO THE MAJORITY OF HAEMATO-ONCOLOGY PRACTICE. We query whether there been a misunderstanding or an unusual type of 'process' resulting in most of Haematological Cancer practice i.e. acute leukaemia, myeloma, MDS, MPN, CLL (and even Hodgkin's lymphoma) being neglected, as these Quality Statements refer only to NHL? One specific type of NHL, follicular lymphoma, is particularly over-represented. Even the potentially generic standard of 'end of treatment summary' refers only to NHL. Question 2 Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place? NO, AS THE QUALITY STATEMENTS ARE NOT DIRECTLY RELEVANT TO THE MAJORITY OF HAEMATOLOGICAL CANCERS AS QUALITY STATEMENTS 2-6 REFER TO NHL ONLY Question 3 Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted THIS QUESTION IS NOT DIRECTLY RELEVANT TO THE NCRI CLINICAL STUDIES GROUP IN HAEMATO-ONCOLOGY AS QUALITY STATEMENTS 2-6 REFER TO NHL ONLY Question 4 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. THIS NOT DIRECTLY RELEVANT TO THE MAJORITY OF HAEMATOLOGICAL CANCERS AS QUALITY STATEMENTS 2-6 REFER TO NHL ONLY. THERE MAY LIMITED ENTHUSIASM TO IMPLEMENT BY THE MANY HAEMATO-ONCOLOGISTS WHO FOCUS ON AREAS OTHER THAN NHL.

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36	JN	General	We have reviewed the quality standards and note that a broad range of relevant perspectives have been consulted and considered in developing these standards. We therefore believe that key areas of quality improvement are accurately reflected and that collection of data would be possible if the systems and structures were available. We have no further comments or questions to add at this time.
Additional areas			
37	BHIVA	Additional area	BHIVA considers that it is a great shame that again NICE has failed to ensure that all young people and adults with lymphoma have an HIV test before starting anti-cancer treatment, as the anti-cancer treatment will have significant deleterious effects on the health of people with untreated HIV infection and result in higher death rates.
38	RMFT	Additional area	Tumour burden should be mentioned as a factor affecting the treatment decision for patients with asymptomatic advanced stage follicular lymphoma, so that it is clear that we can give R-chemotherapy to patients with asymptomatic advanced stage disease e.g. on the ground of bulk disease (but this is also not included in the NICE guidelines).
39	BW	Additional area	We agree that young people and adults who have been treated for non-Hodgkin's lymphoma have a discussion about their end-of-treatment work plan upon completing treatment. However, we would argue that beyond this, it is important that patients have access to the full Cancer Recovery Package. Furthermore, this should be the case for all blood cancer patients, not just those being treated for non-Hodgkin's lymphoma. Blood cancer is the fifth most common cancer in the UK, and third biggest cancer killer. In addition, because of the differences in blood cancer to solid tumour cancers, there are crucial differences in the ways treatment and care are provided. This has led to the Cancer Recovery Package not being accessed by blood cancer patients as effectively as in other cancer types. At Bloodwise, we have begun a project to enable us to fully understand why this is the case, and to work up solutions as to how this can be resolved. Therefore, if the Quality Standard could include a statement requiring all blood cancer patients having access to the Cancer Recovery Package in a way that meets their needs, that would support the work we are doing to improve the current Recovery Package and ultimately help to improve patient experience. In addition, we refer to our formal consultation response to this QS which references the fact that a higher number of blood cancer patients do not have access to a Clinical Nurse Specialist compared to solid tumour cancers. Whilst we understand the financial pressures on the NHS, and the lack of availability of specialist nurses in the UK, we would argue that the level of care provided by a CNS is hugely beneficial to those blood cancer patients able to access one, both during treatment and once treatment has ended. The Quality Standard should seek to safeguard access to a CNS wherever possible, and where not possible, an appropriate alternative model of care should be provided.

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40	BSH	Additional area	These outcomes are relatively easy to measure but we believe PET CT scanning for all DLBCL patients at diagnosis will better allow identification of the at risk group which needs to be targeted for intervention.

Registered stakeholders who submitted comments at consultation

- Association for Palliative Medicine of Great Britain and Ireland (APMGBI)
- Blood Marrow Transplant CRG (BMTCRG)
- Bloodwise (BW)
- British HIV Association (BHIVA)
- British Nuclear Medicine Society (BNMS)
- British Society for Haematology (BSH)
- Department of Health (DoH)
- Imperial College Healthcare NHS Trust – Lymphoma group (ICLG)
- Janssen (JN)
- NCRI Haemato-oncology Studies Group CSG (NCRIHOCSG)
- NHS England (NHSE)
- Older People's Advocacy Alliance (OPAAL)
- Royal College of General Practitioners (RCGP)
- Royal College of Nursing (RCN)
- Royal College of Paediatrics and Child Health (RCPCH)

- Royal College of Pathologists (RCPath)
- Royal Surrey County Hospital (RSCH)
- The Royal Marsden NHS Foundation Trust (RMFT)