

**Quality Standards Advisory Committee 1**

**Cerebral palsy prioritisation meeting / haematological cancers post consultation meeting**

**Minutes of the meeting held on 2 March 2017 at the NICE offices in Manchester**

<b>Attendees</b>	<p><b><u>Standing Quality Standards Advisory Committee (QSAC) members</u></b>  Chair Bee Wee, Steve Hajioff, Ian Reekie, Ivan Bennett, Hugo Van Woerden, Alyson Whitmarsh, Sunil Gupta, Teresa Middleton, Amanda De La Motte, Arnold Zermansky, Gavin Maxwell, Gita Bhutani</p> <p><b><u>Specialist committee members</u></b>  <u>Cerebral palsy</u>  Charlie Fairhurst, Liz Keenan, Stephanie Cawker, Duncan Walsh</p> <p><u>Haematological cancer</u>  Peter Hoskin, Lesley Roberts, Barbara von Barsewisch, Bhupinder Sharma, Elizabeth Soilleux, Sam Ahmedzai, Chris Dalley, Morag Day</p> <p><b><u>NICE staff</u></b>  Mark Minchin (MM), Shaun Rowark (SR), Julie Kennedy (JK), Jamie Jason (JJ)</p>
<b>Apologies</b>	<p><b><u>Standing Quality Standards Advisory Committee (QSAC) members</u></b>  Helen Bromley, Jane Worsley, Phillip Dick, Hazel Trender</p> <p><b><u>Specialist committee members</u></b>  Cerebral palsy - Wendy Doyle</p>

Agenda item	Discussions and decisions	Actions
1. Welcome,	The Chair welcomed the attendees and the Quality Standards Advisory Committee (QSAC) members	

Agenda item	Discussions and decisions	Actions
<b>introductions and plan for the day (private session)</b>	<p>introduced themselves.</p> <p>The Chair informed the Committee of the apologies and reviewed the agenda for the day.</p>	
<b>2. Welcome and code of conduct for members of the public attending the meeting (public session)</b>	<p>The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow. It was stressed that they were not able to contribute to the meeting but were there to observe only. They were also reminded that the Committee is independent and advisory therefore the discussions and decisions made today may change following final validation by NICE's guidance executive.</p>	
<b>3. Committee business (public session)</b>	<p><b>Declarations of interest</b></p> <p>The Chair asked standing QSAC members to declare any interests that were either in addition to their previously submitted declaration or specific to the topic(s) under consideration at the meeting today. The Chair asked the specialist committee members to declare all interests. The following interests were declared:</p> <p><u>Specialist committee members</u></p> <p><u>Charlie Fairhurst</u></p> <ul style="list-style-type: none"> <li>• Clinical advisor NGA</li> <li>• Chair NICE Guideline - Cerebral palsy in under 25s (NG62)</li> <li>• Chair NHS England's Clinical Reference Group[ - Paediatric Neurosciences</li> <li>• Chair RCPCH's Specialist Advisory Committee on Neurodisability Trustee Whizz Kidz</li> </ul> <p><u>Liz Keenan</u></p> <ul style="list-style-type: none"> <li>• None.</li> </ul> <p><u>Stephanie Cawker</u></p> <ul style="list-style-type: none"> <li>• None.</li> </ul> <p><u>Duncan Walsh</u></p> <p>Duncan is an employee of PACE, a charity that works with children and young people with cerebral palsy and other motor disorders and their families. Duncan's wife works for Sunrise Medical as an Area Sales</p>	

Agenda item	Discussions and decisions	Actions
	<p>Manager.</p> <p><b>Minutes from the last meeting</b>            The committee reviewed the minutes of the last meeting held on 2 February and confirmed them as an accurate record.</p>	
<b>4. QSAC updates</b>	MM noted that standing members should have now received letters regarding the new QSACs.	
<b>5 and 5.1 Topic overview and summary of engagement responses</b>	SR presented the topic overview and a summary of responses received during engagement on the topic.	
<b>5.2 Prioritisation of quality improvement areas</b>	<p>The Chair and SR led a discussion in which areas for quality improvement were prioritised.</p> <p>The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team. The outcome of discussions is detailed below.</p>	

Suggested quality improvement area	Prioritised (yes/no)	Rationale for prioritisation decision	If prioritised, which specific areas to be included?
Multidisciplinary care	Yes	<p>The committee highlighted that there are 3 key areas within multidisciplinary care; urgent referral for identification of cerebral palsy, specialities represented within the multidisciplinary team (MDT) and management of referral routes.</p> <p>The committee agreed that the membership of the MDT can be addressed in the definitions of quality statements that reference multidisciplinary care.</p> <p>The committee discussed who should receive urgent referral for assessment by an MDT. They highlighted the need to follow up children who are at an</p>	<p><b>Urgent referral to MDT for 2 groups of children and young people:</b></p> <ul style="list-style-type: none"> <li>i) Children at an increased risk of developing cerebral palsy using <u>NICE NG62 Recommendations 1.1.1, 1.1.2, 1.3.1 and 1.3.3.</u></li> <li>ii) Children who present with delayed motor milestones using <u>NICE NG62 Recommendation 1.3.5, 1.3.6 and 1.5.1.</u></li> </ul> <p><b>Referral routes for specialist teams in managing comorbidities associated with cerebral palsy on a</b></p>

		<p>increased risk of developing cerebral palsy, which would typically present in infancy in hospital, and the referral of those who have delayed motor milestones, which would typically present in general practice. The committee agreed to prioritise both of these groups.</p> <p>The committee discussed the need for ongoing monitoring of children and young people with cerebral palsy and ensuring referral routes for specialist treatment are available. It was felt that the MDT was in the best position to do this. It was agreed to prioritise this area.</p>	<b>regional basis using NICE NG62 Recommendation 1.5.3 and 1.5.4.</b>
Management of spasticity		<p>The committee acknowledged that there is variation in care in accessing spasticity management services. However, they noted that cerebral palsy affects individuals differently and it would be difficult to prioritise one area over another.</p> <p>The committee felt that the monitoring of spasticity management was important as highlighted in the principles of care. However they felt this could be incorporated in a statement on referral routes for specialist teams.</p> <p>The committee therefore agreed not to prioritise this area.</p>	<b>No action</b>
Difficulties associated with cerebral palsy		<p>Similarly to management of spasticity the committee noted that cerebral palsy affects individuals differently and therefore it is difficult to prioritise one area of care over another.</p> <p>Again the committee felt that referral routes to these services was the priority and therefore they did not prioritise this area.</p>	<b>No action</b>

Care needs	No	<p>The committee discussed the ongoing care needs of children and young people with cerebral palsy. In particular they highlighted access to equipment as an improvement area given the costs associated.</p> <p>However, again the committee agreed that access to these services was the biggest area of variation, and that referral routes to these services was the priority. Therefore they did not prioritise this area.</p>	<b>No action</b>
Information and support	Yes	<p>The committee discussed the importance of parents and/or carers of children and young people with cerebral palsy having the right information about prognosis and relevant interventions. Additionally the committee discussed that all information on the children and young person should be stored in one place in order that they do not need to repeat themselves to different healthcare professionals.</p> <p>The committee agreed that all of this information could be captured in a personal folder.</p>	<b>Personal folder using <u>NICE NG62 Recommendation 1.6.5.</u></b>

Additional areas suggested	Committee rationale	Area progressed (Y/N)
National register	The committee acknowledged that while this is an important area, in order to know the true prevalence of cerebral palsy in children and young people, it is not within the remit of quality standards to mandate the use of national registries, and therefore it could not be progressed.	<b>N</b>
Training	The committee agreed that it is not within the remit of quality standards to include improvement areas on training and education as it is implicit within quality standards that all healthcare professionals involved in care are appropriately trained.	<b>N</b>
Dynamic spinal management	The committee agreed that as no NICE or NICE accredited guidance covers this	<b>N</b>

	improvement area it should not be progressed.	
Transition to adult's services	The committee acknowledged the importance of this area for children and young people with cerebral palsy. However they agreed that no specific statements were required in this area as it has been addressed by the quality standard on transition to adult services.	<b>N</b>
<b>6. Resource impact</b>	The committee considered the resource impact information presented for each of the quality improvement areas discussed and were satisfied that none of the areas prioritised for statement development would have a significant impact on resources.	
<b>6.1 Overarching outcomes</b>	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on Cerebral palsy. It was agreed that the Committee would contribute suggestions as the quality standard was developed.	
<b>6.2 Equality and diversity</b>	The NICE team explained that equality and diversity considerations should inform the development of the quality standard, and asked the committee to consider any relevant issues. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
<b>7. QSAC specialist committee members (part 1 – open session)</b>	SR asked the QSAC to consider the constituency of specialist committee members on the group and whether any additional specialist members were required.  It was noted that Wendy Doyle (social worker) is an SCM who was unable to attend this meeting but will be consulted throughout the development of the quality standard.	
<b>8. Next steps and timescales</b>	The NICE team outlined what will happen following the meeting and key dates for the cerebral palsy quality standard.	
<b>Lunch</b>		
<b>9. Welcome and code of conduct for members of the public attending the meeting (public session)</b>	The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow. It was stressed that they were not able to contribute to the meeting but were there to observe only. They were also reminded that the committee is independent and advisory therefore the discussions and decisions made today may change following final validation by NICE's guidance executive.	
<b>10. Committee business (public session)</b>	<b>Declarations of interest</b> The Chair asked standing QSAC members to declare any interests that were either in addition to their previously submitted declaration or specific to the topic(s) under consideration at the meeting today. The	

	<p>Chair asked the specialist committee members to declare all interests. The following interests were declared:</p> <p><u>Specialist committee members</u></p> <p><u>Sam Ahmedzai</u></p> <ul style="list-style-type: none"><li>• NIHR National Specialty lead for Cancer Research Outside the Acute Hospital (current)</li><li>• Clinical Adviser to NICE guideline development group on service delivery in last year of life (current)</li><li>• Clinical Lead of Royal College of Physicians National Audit of End of Life Care (finished 30 June 2016)</li><li>• Chair of NICE guideline development group for Care of the dying adult in last days of life (finished December 2016)</li><li>• NIHR HTA research grant (effectiveness of early palliative care for advanced non-small cell lung cancer patients – study closed May 2016)</li><li>• Prostate Cancer UK research grant (development and validation of an online holistic needs assessment and care plan for prostate cancer patients – study closed December 2015)</li><li>• MRC research grant (clinical trial of saracatinib for bone cancer pain – continuing till August 2017)</li><li>• Royalty fees from Oxford University Press (Textbook of Supportive Care in Respiratory Disease)</li><li>• Lecture fees for annual University of Amsterdam Masterclass on Palliative Care</li><li>• PhD external examiner for University of Odense, Denmark</li><li>• Honoraria for lectures on cancer pain management – Grunenthal, Mundipharma</li><li>• Consultancy and advisory boards for cancer pain management – Grunenthal, Mundipharma</li><li>• Consultancy and advisory board for management of opioid-induced constipation – AstraZeneca, Mundipharma.</li></ul> <p><u>Barbara von Barsewisch</u></p> <ul style="list-style-type: none"><li>• NICE Guideline Committee Member on Updating Haematology Guidelines (2014/2015)</li><li>• Gilead Idelalisib pneumonitis discussion facilitator (22/10/2015)</li><li>• AbbVie participate in interview to evaluate Navigate programme for Idelalisib (29/04/2016)</li><li>• AbbVie clinical nurse specialist advisory group meeting for venetoclax (11/05/2016)</li></ul>	
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	<p><u>Chris Dalley</u></p> <ul style="list-style-type: none"><li>• Chris chaired an educational meeting held by Pfizer and the honorarium was paid to the departments haematology fund (June 2015)</li><li>• Chris chaired an educational meeting held by Celgene and the honorarium was paid to the departments haematology fund (Sep 2015)</li></ul> <p><u>Morag Day</u></p> <ul style="list-style-type: none"><li>• None.</li></ul> <p><u>Peter Hoskin</u></p> <ul style="list-style-type: none"><li>• Grants from Varian, Astellas, Bayer, Millenium for trials in Prostate cancer paid to Department through E&amp;N Herts NHS Trust</li><li>• Payment to E&amp;N Herts NHS Trust by Gilead for participation in lymphoma research trials (unrelated to subjects considered in NICE GDG).</li><li>• Member, Medical Advisory panel, Lymphoma Association</li></ul> <p><u>Lesley Roberts</u></p> <ul style="list-style-type: none"><li>• None.</li></ul> <p><u>Bhupinder (Bhuey) Sharma</u></p> <ul style="list-style-type: none"><li>• Full time NHS consultant with private work undertaken at Alliance Medical and BUPA Cromwell in evenings.</li><li>• NICE Non-Hodgkin's Lymphoma Guideline committee member (2014 – 2016)</li><li>• NICE Haematological Cancers, Improving Outcomes Guideline committee Member (2015 – 2016)</li></ul> <p><u>Elizabeth Soilleux</u></p> <ul style="list-style-type: none"><li>• Honoraria received in the last 2 years from:<ul style="list-style-type: none"><li>◦ Novartis (for attending the UK Myeloproliferative Neoplasm Steering Group meeting)</li><li>◦ Adept Field Solutions (telephone-based research study)</li></ul></li></ul>	
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	<ul style="list-style-type: none"> <li>○ Porterhouse (telephone-based research study)</li> <li>• Meeting sponsorship/ hospitality, March 2016, Roche-Ventana.</li> <li>• Ad hoc employment as the trial pathologist for the UK CHOP-OR trial funded by GlaxoSmithKline.</li> <li>• Ad hoc consultancy work for Oxford Cancer Biomarkers.</li> <li>• Ad hoc medicolegal work for a range of law firms and occasionally for private individuals.</li> <li>• Ad hoc remunerated teaching for the Oxford FRCPath course, St Hugh's College, Oxford, and other colleges within Oxford University.</li> <li>• Receive free registration for meetings and reimbursement of travel and accommodation costs for Pathological Society meetings because of my position as Education Subcommittee Chair of the Pathological Society of Great Britain and Ireland.</li> <li>• Speaker at the British Lymphoma Pathology Group/British Division of the International Academy of Pathology joint meeting, travel and accommodation costs were paid by these organisations(May2014)</li> <li>• Speaker at the British Division of the International Academy of Pathology Molecular Pathology meeting, travel costs were paid by this organisation (March 2015)</li> <li>• Involved in the following patent, which may, in the future (1 – 2 years hence, at least) form the basis of a diagnostic reagent: <ul style="list-style-type: none"> <li>• G. Ogg, E. Soilleux and M. Salimi: T-cell Monotypia and Clonality. UK Patent Application No. 1417498.1 for ISIS Innovation Limited (7261 / BB Ref. JA74505P.GBA) Filed 3.10.2014.</li> </ul> </li> <li>• In collaboration with Roche-Ventana, Leica-Novocastra and Zytovision in many areas of diagnostics. Have received a variety of free reagents from them, as well as considerable staff time in terms of providing technical expertise.</li> <li>• Elizabeth is supervising a trainee pathologist, who is undertaking a collaboration with Biocartis/ Janssen, who are loaning a machine and providing all reagents free of charge for a small study.</li> <li>• Elizabeth holds grants from the following sources: <ul style="list-style-type: none"> <li>○ Celgene – approx. £300, 000 (final figure under discussion)</li> <li>○ The Pathological Society of Great Britain and Ireland – £10,000</li> <li>○ The Medical Research Council - £65,200</li> <li>○ Oxford Health Sciences Research Committee (£81,000 – split between 3 grants)</li> <li>○ Coeliac UK (£26,500)</li> <li>○ Julian Starmer-Smith Lymphoma (Fund £10,500)</li> <li>○ Lymphoma and Leukaemia Research – funding for 1 day per week's salary</li> <li>○ Oxford Biomedical Research Centre – funding for 1 day per week's salary</li> </ul> </li> <li>• Elizabeth assists by providing pathology support for a number of clinical trials, none of which she receive honoraria for, although may be an author on publications resulting from these.</li> </ul>	
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	<ul style="list-style-type: none"> <li>Refreshments and occasionally venue hire fees for intermittent educational meetings and multidisciplinary team meetings in the Thames Valley Region are regularly sponsored by: Alexion, Amgen, Astellas, Bayer, The Binding Site, Biostest, Celgene, Chugai, Gilead, GlaxoSmithKline, Janssen, Napp, Novartis, Pfizer, Pierre Fabre, Roche, Sanofi and Takeda.</li> <li>Attended the Ventana annual symposium in Tucson, Arizona, and this is being sponsored (i.e. paid for in entirety) by Roche-Ventana (March 2016)</li> <li>Roche-Ventana sponsored an educational day for histopathology trainees in the Oxford deanery ran by Elizabeth.</li> </ul>	
<b>11. Recap of prioritisation exercise</b>	<p>JK presented a recap of the areas for quality improvement discussed at the first QSAC meeting for haematological cancers:</p> <p>At the first QSAC meeting on 3 November the QSAC agreed that the following areas for quality improvement should be progressed for further consideration by the NICE team for potential inclusion in the draft quality standard:</p> <ul style="list-style-type: none"> <li>Staging using FDG-PET-CT</li> <li>NHL- Management of follicular lymphoma (FL) and diffuse large B-cell lymphoma (DBCL)</li> <li>Follow-up, communication, information and support</li> <li>Specialist integrated haematological malignancy diagnostic services (SIHMDS)</li> </ul> <p>The full rationale for these decisions is available in the prioritisation meeting minutes which can be found <a href="#">here</a>.</p>	
<b>12. Presentation and discussion of stakeholder feedback and key themes/issues raised</b>	<p>JK presented the committee with a report summarising consultation comments received on haematological cancers. The committee was reminded that this document provided a high level summary of the consultation comments, prepared by the NICE quality standards team, and was intended to provide an initial basis for discussion. The committee was therefore reminded to also refer to the full list of consultation comments provided throughout the meeting.</p> <p>The committee was informed that comments which may result in changes to the quality standard had been highlighted in the summary report. Those comments which suggested changes which were outside of the process, were not included in the summary but had been included within the full list of comments, which was within the appendix. These included the following types of comment:</p> <ul style="list-style-type: none"> <li>Relating to source guidance recommendations</li> </ul>	

	<ul style="list-style-type: none"> <li>• Suggestions for non-accredited source guidance</li> <li>• Request to broaden statements out of scope</li> <li>• Inclusion of overarching thresholds or targets</li> <li>• Requests to include large volumes of supporting information, provision of detailed implementation advice</li> <li>• General comments on role and purpose of quality standards</li> <li>• Requests to change NICE templates</li> </ul>	
<b>13. Discussion and agreement of final statements</b>	The committee discussed each statement in turn and agreed upon a revised set. <b>These statements are not final and may change as a result of the editorial and validation processes.</b>	

Draft statement 1	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)
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).	<ul style="list-style-type: none"> <li>• Statement will enable more sites to provide the systems and infrastructure necessary for integrated diagnostic reporting via SIHMDS.</li> <li>• The statement should cover all age groups in line with the guidance.</li> <li>• Sharing the integrated report with the MDT prior to treatment may cause delays as patients with acute leukaemia need urgent treatment.</li> </ul>	<p>The committee discussed the stakeholder suggestion to expand the population to cover children, young people and adults of all ages in line with the NICE guidance. The committee acknowledged that this is supported by the guidance but questioned if this happens in practice and if it is feasible. The specialist committee members advised that all age groups must have the report and emphasised that it is important that all ages are covered by the statement.</p> <p>The committee discussed the issue that the statement could exclude some people with haematological cancers because of the way it is currently worded. It was suggested that amending the word 'their' to 'a' and adding 'that is' after 'report' would resolve this issue.</p> <p>The new wording of statement would be as follows:</p> <p><b>People with haematological cancers have a SIHMDS validated integrated report that is shared with the relevant haemato-oncology MDT.</b></p>	<p><b>Y</b></p> <p><b>NICE team to:</b></p> <ul style="list-style-type: none"> <li>- <b>Expand population to cover all ages</b></li> <li>- <b>Amend wording of statement as per committee rationale</b></li> <li>- <b>Review NG47 for supplementary information that will clarify that treatment should not be delayed by the sharing of the report.</b></li> </ul>

		<p>Amending the wording in this way would ensure that the statement focuses on all people with haematological cancers having a report and having it shared with the relevant team rather than just focusing on the report being shared.</p> <p>The committee discussed the concerns raised about the potential for delaying treatment. They felt that this is not an issue in terms of healthcare professionals acting promptly. Not all diagnostic results are available when treatment needs to start and supplementary reports can be made available after treatment has started. The specialists advised that the guidance the statement is based on provides further clarification on this issue.</p>	
Draft statement 2	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)
Young people and adults diagnosed with specific non-Hodgkin's lymphoma subtypes are offered staging using fluorodeoxyglucose-positron emission tomography-CT (FDG-PET-CT).	<ul style="list-style-type: none"> <li>• FDG-PET-CT use before treatment was queried.</li> <li>• The focus on lower staged NHL patients was queried.</li> <li>• 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.</li> </ul>	<p>The committee discussed the query that was raised about the population covered in the statement. It was agreed that the population should cover lower staged NHL patients only in line with the source guidance.</p> <p>The committee discussed the issues raised about the measures. They agreed that if 'by clinical and CT criteria' was removed from process measure (a) this would resolve the issue of not all patients having CT criteria. The statement should apply to all people diagnosed with stage 1 diffuse large B-cell lymphoma so this is an appropriate change.</p> <p>The committee also agreed that the statement should say 'have had staging' rather than 'are offered staging'.</p>	<b>Y</b> <b>NICE team to:</b> <ul style="list-style-type: none"> <li>- Amend statement wording to say 'have' instead of 'are offered'</li> <li>- Remove reference to clinical and CT criteria from process measure (a)</li> </ul>
Draft statement 3	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)

Young people and adults with localised stage IIA follicular lymphoma are offered first-line local radiotherapy.	<ul style="list-style-type: none"> <li>• Expand the population to include young people and adults with localised stage IA follicular lymphoma.</li> <li>• Acknowledge that not all patients with localised stage IIA follicular lymphoma are suitable for localised radiotherapy.</li> <li>• Define follicular lymphoma.</li> </ul>	<p>The committee discussed the proposal to expand the population but agreed it should not be changed as the suggestion is not supported by the guideline.</p> <p>There was a discussion about the issue that not all patients with localised stage IIA follicular lymphoma are suitable for localised radiotherapy. The committee felt that this could be acknowledged in the rationale section. It does not need to be reflected in the statement or measures as clinical judgement will be used when making decisions about treatment.</p> <p>Defining follicular lymphoma was discussed. The committee questioned whether a definition was needed as healthcare professionals working with this group of patients will know what this means. However, it was highlighted that the World Health Organisation (WHO) define follicular lymphoma and the committee agreed this could be added to the supporting information for the statement.</p>	<b>Y</b> <b>NICE team to:</b> <ul style="list-style-type: none"> <li>- Add a definition of follicular lymphoma</li> </ul>
<b>Draft statement 4</b>	<b>Themes raised by stakeholders</b>	<b>Committee rationale</b>	<b>Statement revised (Y/N)</b>
Young people and adults with advanced-stage asymptomatic follicular lymphoma are offered rituximab induction therapy.	<ul style="list-style-type: none"> <li>• Use of induction rituximab should be considered and not recommended.</li> <li>• Lack of evidence for this recommendation.</li> <li>• The licensing of rituximab was raised.</li> </ul>	<p>The committee discussed the concerns raised by stakeholders about the evidence base for the guideline recommendation and the drug not being licensed for this indication. The specialists advised that it is a major change in practice for most providers and suggested this might explain why significant concerns were raised during consultation. The committee questioned whether the quality standard should contain a statement that involves such a major change in current practice.</p> <p>The committee were advised that the drug is licensed in the UK but not for the specific indication that is outlined in the draft statement.</p> <p>The evidence base for the recommendation within NG52 was discussed, the committee were advised that a health economic model was developed to help inform recommendations made</p>	<b>Y</b> <b>Technical team to remove the statement.</b>

		<p>by the guideline developers. Use of the rituximab for this indication was found to be the cost effective strategy.</p> <p>The technical team advised that as the recommendation the draft statement is based on is an offer recommendation the evidence is considered strong enough to support the statement.</p> <p>The committee found it difficult to agree whether the statement should be progressed which led the Chair to ask committee members to vote on the issue. The outcome of the vote was that the statement should not be progressed.</p>	
Draft statement 5	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)
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.	<ul style="list-style-type: none"> <li>• NICE guidance for CNS prophylaxis in high grade lymphoma contradicts the current British Committee Society for Standards in Haematology (BCSH).</li> <li>• Lack of evidence for this recommendation.</li> <li>• Treatment decisions through discussions between healthcare professionals and patient which must be acknowledged.</li> </ul>	<p>The committee discussed the contradiction between the NICE guidance and the BCSH standards. While the BCSH guidance is not accredited NICE guidance and therefore cannot be used to inform quality standards, they were felt to be used more frequently by haematologists. This raises questions about how much impact the statement would have.</p> <p>As the contradiction between the NICE guidance and BCSH standards concerns a lack of agreement on what risk the factors should be the committee discussed not stating risk factors and just saying people at high risk. They also discussed focusing on breast and testes only. However, it was agreed that the statement should reflect the detail in the NICE guideline recommendations.</p> <p>In light of the issues raised about evidence for risk factors and the misalignment between the NICE guidance and the BCSH standards the committee agreed that the statement should not be progressed.</p>	<b>Y</b> <b>Technical team to remove the statement.</b>
Draft statement 6	Themes raised by stakeholders	Committee rationale	Statement revised

			(Y/N)
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.	<ul style="list-style-type: none"> <li>• Plan should be focused on all haematological cancers.</li> <li>• Based on the plan's actions the delivery of the Recovery Package is important.</li> <li>• Plan should be fully explained and discussed with shared decision making between clinician and patient.</li> <li>• Independent advocacy support for any older person with a haematological cancer.</li> </ul>	<p>The committee discussed expanding the population to include young people and adults with all haematological cancers. They agreed that recommendation 1.1.1 from NG35 could be used to expand the population to include people with myeloma.</p> <p>The committee were advised that NG47 does not contain any recommendations that support the inclusion of all haematological cancers in the statement. Committee members highlighted NICE CG138 Patient experience in adult NHS services as guidance that could potentially support including this population. The technical team agreed to explore this option.</p>	<b>Y</b> <b>NICE team to:</b> <ul style="list-style-type: none"> <li>- Expand population to include people with myeloma.</li> <li>- Explore including all people with haematological cancers</li> </ul>

Additional statements suggested	Committee rationale	Statement progressed (Y/N)
Suggestion to include more haematological cancers.	<p>The committee discussed the concerns that were raised about the focus on NHL patients. The areas on myeloma that were raised by stakeholders at topic engagement recommendations from the first committee meeting were discussed again. The technical team reminded the committee of why they were not prioritised at the first meeting.</p> <p>The committee discussed imaging but agreed that the priority areas for imaging were only supported by consider recommendations. It was therefore agreed that this area it was not appropriate to develop a statement on imaging at this time.</p> <p>Laboratory investigations were discussed but the committee agreed that it isn't necessary to have a separate statement on this area as it is covered by statement 1.</p> <p>The committee felt that the expansion of the population covered by statement 6 sufficiently increased the coverage of myeloma.</p>	<b>N</b>
HIV testing for all young people and adults with lymphoma before starting anti-cancer treatment.	This area was not progressed as it overlaps with other quality standards within the published library.	<b>N</b>

PET CT scanning for all diffuse large B-cell lymphoma (DLBCL) patients at diagnosis.	PET CT scanning for all DLBCL is not supported by NICE guidance. PET CT scanning for people with stage I DLCBCL has is incorporated into draft quality statement 2.	<b>N</b>
Tumour burden for asymptomatic advanced stage follicular lymphoma patients may affect the treatment decision.	This area was not considered suitable for the development of a quality statement.	<b>N</b>
Access to the full Cancer Recovery Package and clinical nurse specialist to meet their needs and improve patient experience.	This area is not supported by NICE guidance.	<b>N</b>

<b>14. Overarching outcomes</b>	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on haematological cancers. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
<b>15. Equality and diversity</b>	The NICE team explained that equality and diversity considerations should inform the development of the quality standard, and asked the committee to consider any relevant issues. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
<b>16. Next steps and timescales</b>	The NICE team outlined what will happen following the meeting and key dates for the haematological cancers quality standard.	
<b>17. Any other business (part 1 – open session)</b>	No items were raised under AOB  <b>Date of next QSAC1 meeting: 4 May 2017</b>	