National Institute for Health and Care Excellence

Non-Hodgkin's Lymphoma Scope Consultation Table 8th November – 5th December 2013

ID	Туре	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
23	SH	Association for Palliative Medicine of Great Britain	1	4.3.1 a 4.5 a	Re support and information needs of NHL patients and carers – we feel that the guidance could stress the role of palliative care services for patients with more advanced disease, even during 'treatment'.	Thank you for your comment. We feel this is covered by sections 4.3.1a and 4.3.1r.
					This could be better done by referral to palliative care specialists in secondary care, i.e. hospital out-patients and wards, rather than hospices and community.	Thank you for this information. Advice on this topic has already been produced by NICE (Improving Supportive and Palliative care for adults).
24	SH	Association for Palliative Medicine of Great Britain	2	4.3.1 r 4.5 x	Again, we feel that the guidance should stress the role for palliative and supportive care in supporting patients who are 'survivors' but have continuing symptoms and psychological issues. For example, role for hospital-based palliative care specialists in shared care of survivors who develop avascular necrosis of joints many years after chemo/high dose steroids.	Thank you for your comment. Palliative care issues will be address under section 4.3.1r.
25	SH	Association for Palliative Medicine of Great Britain	3	4.4 c & e	We feel that the guidance should include the role of hospital palliative care in earlier stages and of community and hospices for very end of life (but be mindful of potential problems about access to blood product support).	Thank you for your comment. This is not an exhaustive list and the GDG will determine the appropriate outcomes for each question that is being addressed.
27	SH	Bayer plc	1	4.3.1	The key issues that will be covered do not appear to include the management of relapsed or refractory non-Hodgkin's lymphoma. The description of current practice under section 3.2 discusses different phases of treatment, including at the point of and after relapse, and second/third-line. We suggest that this should be covered under the remit of this guideline.	Thank you for your comment. Section 3.2 gives a brief overview of the epidemiology of non-Hodgkin's lymphoma. However, we are unable to cover all types of non-Hodgkin's lymphoma or clinical scenarios relating to the management of non-Hodgkin's lymphoma within this guideline.

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22	SH	Department of Health	1		This organisation responded and said that they have no comments to make.	Thank you.
28	SH	Gilead Sciences Ltd	1	General	To ensure that the Guidelines remain current for as long as possible, Gilead Sciences Ltd. suggests that the guidelines incorporate new technologies / medicines that are due to become available within the timeframe of guideline development.	Thank you for your comment. We are aware of this issue and we will run update searches before we complete development of the guideline. Any new drugs will be looked at under the NICE technology appraisal programme and can also be included in the NICE Pathway.
15	SH	Lymphoma Association	1	General	The Lymphoma Association welcomes the development of guidelines to clarify areas of uncertainty and variation in practice. It would be helpful, to avoid confusion or misunderstanding, to state specifically in the title of the guidelines or the remit that the guidelines are not intended to be comprehensive but to look at selected non-Hodgkin lymphomas in selected situations.	Thank you for your comment. Unfortunately we are unable to change the title or remit of the guideline. We hope sections 4.1.1 and 4.1.2 clarify what is being covered within the scope.
					There is some difficulty in the development of the guideline over a 12-18-month period when new and exciting drugs are being developed which have the potential to transform the treatment of non-Hodgkin lymphoma and yet which cannot be considered as part of this review	We are aware of this issue and we will run update searches before we complete development of the guideline. Any new drugs will be looked at under the NICE technology appraisal programme and can also be included in the NICE Pathway.
					As so many people with non-Hodgkin lymphoma are diagnosed are older, with co-morbidities, it would be useful for all the appropriate topics to include separate assessment of the impact of the most common co-morbidities on treatment.	We are aware that there may be differences in treatment options based on age or co-morbidities and where evidence exists, relevant recommendation will be drafted.
16	SH	Lymphoma Association	2	4.1.2 b	The separate development of guidelines for CLL and SLL is needed as there is too much variation in practice around the country.	Thank you for your comment. CLL and SLL are not included in the scope of this guideline and therefore would require separate guidelines which have as yet not been referred by NHS England.
17	SH	Lymphoma Association	3	4.3.1 a	This section is important and should include generic as well as lymphoma-specific information.	Thank you for your comment. Generic information is covered in the Patient

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					T loads most sacrified comment in a new few.	experience in adult NHS services NICE Guideline 2012 (CG138) and the Improving Supportive and Palliative care for adults with cancer NICE service guidance 2004. We will be able to cross refer to both of these guidelines in the
18	SH	Lymphoma Association	4	4.3.1 i	It is not clear from the wording that this means the role of 'watch and wait' so clarification would be helpful.	final NHL guideline where appropriate. Thank you for your comment. We have amended sections 4.3.1i and 4.5k to clarify this.
19	SH	Lymphoma Association	5	4.4 e	Add: and mortality	Thank you for your comment. We have amended section 4.4 to add mortality.
20	SH	Lymphoma Association	6	4.5 a	Add a new bullet point after 'during treatment': 'at the end of treatment/at discharge'	Thank you for your comment. We have amended section 4.5a to include 'after treatment'.
21	SH	Lymphoma Association	7	4.5	For the sake of clarity, it would be helpful to make it clear that the question is whether immediate chemotherapy or deferred chemotherapy is the more effective treatment for 'certain ' people with advanced asymptomatic follicular lymphoma 'and if so how these patients should be selected'.	Thank you for your comment. The recommendations will be based on the evidence and these will take into account certain patient subgroups, where evidence is available.
30	SH	Napp Pharmaceuticals Ltd	2	General	How will NICE deal with indications for the rarer histologies in both B- and T- cell lymphomas where no medicine is currently indicated or licenced? The medicines used to manage (maybe via the Cancer Drugs Fund) these rare conditions may not have, due to the size of the patient population, a robust Phase III driven evidence base. Will NICE be able to make recommendations in this situation?	Thank you for your comment. Unfortunately we are unable to cover all types of non-Hodgkins lymphoma Therefore we have included those subtypes which have an incidence of >1% the total,
31	SH	Napp Pharmaceuticals Ltd	3	General	When discussing the treatment of 1 st line follicular lymphoma will co-morbidities (e.g. renal disease, cardiovascular disease etc.) be taken into account when selecting treatments e.g. R-CHOP or alternatives such as bendamustine-R?	Thank you for your comment. Where evidence exists, relevant recommendation will be drafted taking into account any co-morbidities. The use of bendamustine is being assessed under the NICE technology appraisal programme and therefore will not be

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						looked at within this guideline.
32	SH	Napp Pharmaceuticals Ltd	4	General	Will the role of Rituximab maintenance therapy be included? Outcomes for patients on R-maintenance may be dependent on response to the first-line treatment. Evidence suggests that patients on R-maintenance with a CR to initial treatment may have a better overall response compared to those with a PR¹. This may also influence the choice of first-line therapy in an attempt to gain the best possible response. 1. Van Oers et al J. Clin Oncol 2010, 28: 17 2853- 2858	Thank you for your comment. In order to address this topic, the GDG may request to either cross-refer, incorporate or update TA65 within the guideline. Should NICE agree to the TA being incorporate or updated, the NICE TA team will prepare a technology review proposal to inform stakeholders. Further details can be found in the NICE guidelines manual 2012.
29	SH	Napp Pharmaceuticals Ltd	1	4.1.2 4.1.3 General	Thank you for the opportunity to comment on the draft scope. The scope is very comprehensive however we have noticed that no reference is made to Waldenström macroglobulinaemia. Will this rare form of NHL be included?	Thank you for your comment. Waldenström macroglobulinaemia is rare (incidence < 1% of all non-Hodgkin's lymphomas) and therefore will not be included in the remit of this guideline.
14	SH	NHS Direct	1	General	Welcome guidance and have no comments on the scope as part of the consultation	Thank you for your comment.
13	SH	NHS England	1	General	Thank you for the opportunity to comment on the draft scope for the above clinical guideline. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you for your comment.
12	SH	Roche Products	1		This organisation responded and said that they have no comments to make.	Thank you.
1	SH	Royal College of Nursing	1		This organisation responded and said that they have no comments to make.	Thank you.
26	SH	Royal College of Paediatrics and Child Health	1	General	NHL accounts for about 5% of malignancy in children (16yrs and younger); a similar proportion to the adult disease. This document gives no clear reasons why this group of patients should be excluded from the Guideline. There is no clear epidemiological reason (such as a bimodal distribution) to justify this exclusion, and while there are age-	Thank you for your comment. Children (16 years and under) have been excluded because the treatment protocols are often very different and require separate consideration and expertise, and the number of cases are very low relative to the adult population.

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			NO		related histological variations, inclusion of young adults (16-24) have been proposed to be different to older adults as children are to YP. There are trials in childhood cancer and an NCRI subgroup devoted to leading on such investigations. The 2013 CMOs report highlighted our national lack of focus on CYP in prevention and treatment and any such exclusion needs to be very carefully and explicitly justified.	r lease respond to each comment
34	SH	Royal College of Pathologists & The British Society for Haematology (joint response)	2		Elderly NHL not included	Thank you for your comment. In compliance with the NICE equalities policy we do not discriminate on age, therefore this group is covered by the scope. We are aware that there may be differences in treatment options based on age or co-morbidities and where evidence exists, relevant recommendation will be drafted.
35	SH	Royal College of Pathologists & The British Society for Haematology (joint response)	3		Transplantation in Follicular lymphoma is a very vast topic	Thank you for your comment. We agree, and we have recruited a transplant haematologist to the GDG, who has vast knowledge in this area.
36	SH	Royal College of Pathologists & The British Society for Haematology (joint response)	4		Risk of guideline being out of date by the time it is produced	Thank you for your comment. We are aware of this issue and we will run update searches before we complete development of the guideline. Any new drugs will be looked at under the NICE technology appraisal programme and can also be included in the NICE Pathway.
37	SH	Royal College of Pathologists & The British Society for Haematology (joint response)	5		Consider adding Fields of Radiotherapy	Thank you for your comment. We have expanded the review question in section 4.5j to include fields of radiotherapy.
38	SH	Royal College of	6		Under exclusions: mention should be made of marginal zone	Thank you for your comment. Marginal

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		Pathologists & The British Society for Haematology (joint response)			lymphoma, CNS lymphoma, mediastinal large cell lymphoma	zone lymphoma will be covered as a subtype of MALT lymphoma in sections 4.3.1j and 4.5m.
						Mediastinal large cell lymphoma is a subtype of diffuse large B-cell lymphoma and will be covered in a number of topics.
						CNS lymphoma has been added to the list of groups that will not be covered in section 4.1.2g.
39	SH	Royal College of Pathologists & The British Society for Haematology (joint response)	7		Clarity required on which T cell lymphoma entities are included	Thank you for your comment. We have clarified which T cell lymphoma entities will be excluded and included. Please see sections 4.1.2d and 4.3.1l.
33	SH	Royal College of Pathologists & The British Society for Haematology (joint response)	1	General	Haphazard selection of topics – too large a remit	Thank you for your comment. We have focused the scope to the areas of controversy or variation in practice. Therefore we have included those subtypes which have an incidence of >1% the total.
3	SH	Royal College of Radiologists	1	3.2 f	The RCR notes that radiotherapy and immunotherapy as treatment options should be added to this paragraph; there is also a variation in the use of radiotherapy. Without this amendment, it reads as though only chemotherapy and high dose chemotherapy are used for treatment,	Thank you for your comment. We have amended section 3.2 to reflect this.

These organisations were approached but did not respond:

Abbott Molecular
Addenbrookes Hospital
Aintree University Hospital NHS Foundation Trust
Amgen UK
Association of Anaesthetists of Great Britain and Ireland
Association of Chartered Physiotherapists in Oncology and Palliative Care

Barnsley Hospital NHS Foundation Trust

Boehringer Ingelheim

Boots

British Dietetic Association

British HIV Association

British Medical Association

British Medical Journal

British National Formulary

British Nuclear Cardiology Society

British Nuclear Medicine Society

British Psychological Society

British Red Cross

British Society of Gastrointestinal and Abdominal Radiology

BSPGHAN

Cancer Commissioning Team

Cancer Research UK

Care Quality Commission (CQC)

Counselling for prisoners network

Covidien Ltd.

Croydon Clinical Commissioning Group

Croydon University Hospital

Department of Health, Social Services and Public Safety Northern Ireland

East and North Hertfordshire NHS Trust

East Kent Hospitals University NHS Foundation Trust

Ethical Medicines Industry Group

Faculty of Dental Surgery

Five Boroughs Partnership NHS Trust

Gloucestershire Hospitals NHS Foundation Trust

Greater Manchester & Beyond Coalition of PLW & HIV

Greater Manchester, Lancashire, South Cumbria Strategic Clinical Network

Health & Social Care Information Centre

Health and Care Professions Council

Health Quality Improvement Partnership

Healthcare Improvement Scotland

Healthcare Infection Society

Healthwatch East Sussex

Herts Valleys Clinical Commissioning Group

Lancashire Care NHS Foundation Trust

Lanes Health

Leukaemia & Lymphoma Research

Leukaemia CARE

Local Government Association

London cancer alliance

Macmillan Cancer Support

Medicines and Healthcare products Regulatory Agency

Milton Keynes Hospital NHS Foundation Trust

Milton Keynes NHS Foundation

Ministry of Defence (MOD)

National Clinical Guideline Centre

National Collaborating Centre for Cancer

National Collaborating Centre for Mental Health

National Collaborating Centre for Women's and Children's Health

National Deaf Children's Society

National Institute for Health Research Health Technology Assessment Programme

National Institute for Health Research

National Patient Safety Agency

NHS Barnsley Clinical Commissioning Group

NHS Connecting for Health

NHS Cumbria Clinical Commissioning Group

NHS Health at Work

NHS Improvement

NHS Medway Clinical Commissioning Group

NHS Plus

NHS Sheffield

NHS South Cheshire CCG

NHS Wakefield CCG

NHS Warwickshire North CCG

NICE TLOC GDG

North of England Commissioning Support

North West London Hospitals NHS Trust

Nottingham City Council

Oxfordshire Clinical Commissioning Group

Pfizer

PHE Alcohol and Drugs, Health & Wellbeing Directorate

Primary Care Pharmacists Association

Primrose Bank Medical Centre

Public Health Wales NHS Trust

Public Health Wales NHS Trust

Queen Elizabeth Hospital King's Lynn NHS Trust

Royal College of Anaesthetists

Royal College of General Practitioners

Royal College of General Practitioners in Wales

Royal College of Midwives

Royal College of Obstetricians and Gynaecologists

Royal College of Physicians

Royal College of Physicians and Surgeons of Glasgow

Royal College of Psychiatrists

Royal College of Surgeons of England

Royal Pharmaceutical Society

Royal Surrey County Hospital NHS Trust

Scottish Clinical Virology Consultants Group

Scottish Intercollegiate Guidelines Network

Serious Hazards of Transfusion

Sheffield Teaching Hospitals NHS Foundation Trust

Smith & Nephew UK Limited

Social Care Institute for Excellence

Society and College of Radiographers

South London & Maudsley NHS Trust

South West Yorkshire Partnership NHS Foundation Trust

Staffordshire and Stoke on Trent Partnership NHS Trust

Stockport Clinical Commissioning Group

Takeda UK Ltd

TB Action Group

Teenage Cancer Trust

Teenagers and Young Adults with Cancer

Teva UK

The Institute of Cancer Research

The Patients Association

University Hospital Birmingham NHS Foundation Trust

University Hospitals Birmingham

Velindre NHS Trust

Welsh Government

Western Sussex Hospitals NHS Trust

Wigan Borough Clinical Commissioning Group

