NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Haematological cancers

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for haematological cancers. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development sources referenced in this briefing paper are:

Myeloma: diagnosis and management (2016) NICE guideline NG35

Haematological cancers: improving outcomes (2016) NICE guideline NG47

Non-Hodgkin's lymphoma: diagnosis and management (2016) NICE guideline NG52

2 Overview

2.1 Focus of quality standard

This quality standard will cover:

- diagnosing and managing haematological cancers in adults and young people (aged 16 years and over)
- diagnostic reporting for haematological cancers in children, young people and adults (all ages)
- the organisation of haematological cancer services for children, adults and young people (all ages).

2.2 Definitions, incidence and management

Haematological cancers

Haematological cancers affect the blood, bone marrow, and lymphatic systems. Some forms are highly aggressive, and others are so benign that they are often only discovered by chance. Symptoms may include:

- lumps caused by enlarged lymph nodes, characteristic of lymphomas
- bone fractures and kidney problems, characteristic of myeloma
- fatigue and vulnerability to infection and bleeding, which can be caused by most types of haematological cancer.

Haematological cancers include lymphoma, myeloma and also leukaemia, myelodysplastic syndromes and myeloproliferative neoplasms. They account for 8.4% of all malignant disease (excluding non-melanoma skin cancer) diagnosed in England in the years 2001 to 2010[1]. They vary in prevalence, incidence and survival rates. There are also borderline conditions such as aplastic anaemia and other non-malignant bone marrow failure syndromes (which overlap with hypoplastic myelodysplastic syndrome), and suspected cutaneous lymphomas that need specialised facilities for diagnosis and treatment.

Different levels of service are needed to manage different haematological cancers. There has been progressive and variable adoption of specialist integrated haematological malignancy diagnostic services (SIHMDS), aimed at improving diagnostic accuracy and expertise. Integrated diagnostic reports are well established in some centres but not everywhere.

Non-Hodgkin's lymphoma (NHL)

NHL accounts for 4% of cancers in men and women in the UK, with 12,180 new cases and 4436 deaths recorded in 2010. NHL incidence increases with age. It is the fourth most commonly diagnosed cancer in adults aged 25–49 years and the fifth most commonly diagnosed cancer in adults aged 50–74 years. The incidence rises sharply in people over 50 years and more than 70% of all cases of NHL are diagnosed in people over 60 years[2].

The age-standardised relative survival rates for NHL (all subtypes combined) in England over the period 2005–2009 show that 76% of men are expected to survive

[1] National Cancer Intelligence Network (2014)- Trends in incidence and outcomes for haematological cancers in England: 2001-2010
[2] NICE guideline NG52 final scope (2016)-Non-Hodgkin's Lymphoma: Diagnosis and management

for at least 1 year, with 61% surviving 5 years or more. The survival rates for women are slightly higher, with 79% expected to survive for 1 year or more and 66% surviving for at least 5 years[2].

Non-Hodgkin's lymphomas are a diverse group of conditions that are categorised according to the cell type affected (B cell or T cell), as well as the clinical features and rate of progression of the disease. Most people with a diagnosis of NHL (approximately 90%) have a B-cell lymphoma. The most common B-cell lymphomas are diffuse large B-cell and follicular lymphoma.

Using HMRN data[3] for 2004–2014, it is estimated that 48% of all NHL cases diagnosed in the UK are diffuse large B-cell lymphoma. This is an aggressive cancer that needs immediate treatment. The aim of treatment in most patients is a complete remission and cure[4].

Follicular lymphoma is the second most common type of NHL (19%). It frequently demonstrates slow growth, responds to initial therapy, but has a tendency to relapse after treatment.

Other less common types of B-cell lymphoma include mantle cell lymphoma, mucosa associated lymphoid tissue (MALT) lymphoma and Burkitt's lymphoma. Different subtypes of the disease have different clinical courses and requirements for therapy.

Diagnosing NHL and identifying the subtype is challenging, and optimising the diagnostic process is central to improved management. NHL treatment has led to the development of specific treatment strategies (now applied to many other forms of cancer), however there is a lack of large randomised clinical trials to define best practice in treating the various subtypes. As a consequence there are considerable differences between centres and countries in the ways in which some subtypes of the disease are diagnosed and managed.

There have been modest improvements in outcome for people with NHL in the last decade and there is still a need for improvement. This is a rapidly developing field, with a number of new therapies being developed.

Myeloma

Myeloma is a malignancy of the plasma cells that normally produce immunoglobulin. It affects multiple organs and systems, including the bones, kidneys, blood and immune systems.

Myeloma is the seventeenth most common cancer in the UK. In 2010, 4672 people in the UK were diagnosed with myeloma. It occurs most commonly in older people,

[3] Haematological Malignancy Research Network (2014) Statistics:2004-2014

[4] NICE guideline NG52 final scope (2016 Non-Hodgkin's Lymphoma: Diagnosis and management

with 71% of cases diagnosed in people aged 65 years and over. Incidence increases with age, peaking in those aged 85 years and over. It is more frequent in men and in people of African–Caribbean family origin. Diagnosis is often delayed because the symptoms are not specific to myeloma, and this leads to significant early morbidity and mortality.

Myeloma management is complex and challenging. Effective treatments have been developed over the past 15 years, and although myeloma is still incurable these treatments have led to improvements in overall survival and quality of life. However, myeloma treatment increasingly involves expensive drugs and frequent hospital visits. Complications of myeloma and its treatment cause an increasing long-term strain on supportive and palliative care services, and on carers.

2.3 National outcome frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS outcomes framework 2016–17

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults ii Children and young people 1b Life expectancy at 75 i Males ii Females ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer* i One- and ii Five-year survival from all cancers *v One- and vi Five-year survival from cancers diagnosed at stage 1 & 2*** **Reducing mortality in children** 1.6 Ii Five-year survival from all cancers in children
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition **Reducing time spent in hospital by people with long-term conditions** **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers** **Improving quality of life for people with multiple long-term conditions** *2.7 Health-related quality of life for people with three or more long-term conditions***</br>

4 Ensuring that people have a positive experience of care	***Overarching indicators*** ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving hospitals' responsiveness to personal needs** 4.2 Responsiveness to inpatients' personal needs **Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers' views on the quality of care in the last 3 months of life **Improving children and young people's experience of healthcare** *4.8 Children and young people's experience of inpatient services* **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment with Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 Public health outcomes framework for England, 2016–2019

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.19 Cancer diagnosed at stage 1 and 2*
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.05 Under 75 mortality rate from cancer *
Alignment with NHS Outcomes Framework * Indicator is shared	

3 Summary of suggestions

3.1 Responses

In total 11 stakeholders responded to the 2-week engagement exercise 09/09/2016-23/09/2016.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Non-Hodgkin's Lymphoma (NHL) **1.Diagnosis** • Type of biopsy • Diagnosing B-cell lymphomas: gene testing strategies **2.Staging using FDG-PET-CT** **3.Management of follicular lymphoma** • First-line treatment for stage IIA follicular lymphoma • Consolidation with stem cell transplantation **4. Management of diffuse large B-cell lymphoma** **5. Follow-up for people with diffuse large B-cell lymphoma** **6. Information and support**	SCMs
Myeloma **7. Communication and support** **8. Imaging investigations** **9. Service organisation** **10. Preventing and managing complications** • Preventing infection • Managing peripheral neuropathy	CCLG, MYUK, NHSE, SCMs
Haematological Cancers-Improving Outcomes **11. SIHMDS** • Integrated reporting • Clinical nurse specialist	BWE, CCLG, MAN, MYUK, NHSE, SCMs
Additional areas • Cancer Recovery Package • 2014 Care Act • Myeloma education for GPs • NICE Cancer Service Guideline (CSG7, 2005) Improving outcomes in children and young people with cancer • Treating advanced-stage asymptomatic follicular lymphoma • Vial sharing	BWE, CCLG, MAN, NHSE, RCGP, SCMs

BWE, Bloodwise
CCLG, Childrens' Cancer and Leukaemia Group / Childhood Leukaemia Clinician's Network
MAN, Macmillan Cancer Support
MYUK, Myeloma UK
NHSE, NHS England
RCGP, Royal College of General Practitioners
SCM, Specialist Committee Member

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 2045 papers were identified for haematological cancers. In addition, 9 papers were suggested by stakeholders at topic engagement and 5 papers internally at project scoping.

Of these papers, 8 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 NHL- Diagnosis

4.1.1 Summary of suggestions

Type of biopsy

One stakeholder supported the use of excision biopsies over core biopsies suggesting that when genome sequencing studies and the development of targeted drugs become standard core biopsies will no longer provide sufficient material for testing.

This stakeholder also reported that arranging excision biopsies can take up to 6 weeks which is unacceptable for patient care and wellbeing. Commenting that rapid excision biopsy services are therefore needed for timely diagnostic and treatment planning purposes.

Diagnosing B-cell lymphomas: gene testing strategies

One stakeholder supported the use of the genetic testing strategy FISH (fluorescence in situ hybridisation) for all people newly presenting with histologically high-grade B-cell lymphoma. This genetic knowledge was suggested to guide prevention, management and treatment of B-cell lymphoma.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Non-Hodgkin's Lymphoma- Diagnosis	**Type of biopsy** NICE NG52 Recommendations 1.1.1-1.1.3
	Diagnosing B-cell lymphomas: gene testing strategies NICE NG52 Recommendation 1.1.5

Type of biopsy

NICE NG52 – Recommendation 1.1.1

Consider an excision biopsy as the first diagnostic procedure for people with suspected non-Hodgkin's lymphoma at first presentation.

NICE NG52 – Recommendation 1.1.2

In people with suspected non-Hodgkin's lymphoma for whom the risk of a surgical procedure outweighs the potential benefits of an excision biopsy, consider a needle core biopsy procedure. Take the maximum number of cores of the largest possible calibre.

NICE NG52 – Recommendation 1.1.3

For people with suspected non-Hodgkin's lymphoma in whom a diagnosis is not possible after a needle core biopsy procedure, offer an excision biopsy (if surgically feasible) in preference to a second needle core biopsy procedure.

Diagnosing B-cell lymphomas: gene testing strategies

NICE NG52 – Recommendation 1.1.5

Consider using FISH (fluorescence in situ hybridisation) to identify a *MYC* rearrangement in all people newly presenting with histologically high-grade B-cell lymphoma.

4.1.3 Current UK practice

Type of biopsy

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Diagnosing B-cell lymphomas: gene testing strategies

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.1.4 Resource impact assessment

The resource impact assessment for NG52 did not identify any areas of significant resource impact (>£1m in England each year) due to the small populations involved.

4.2 NHL- Staging

4.2.1 Summary of suggestions

Stakeholders supported using FDG-PET-CT to confirm staging at initial diagnosis, reporting current UK variation in practice. They felt it would ensure accurate diagnosis, appropriate treatment and improved outcomes for the 3 types of NHL - stage I diffuse large B-cell lymphoma, stage I or localised stage II follicular lymphoma or stage I or II Burkitt lymphoma.

A stakeholder reported that outcomes in people with diffuse large B-cell lymphoma remain poor, with significant relapse rates after the completion of first-line therapy and optimal staging and therapy at first presentation is critical in improving outcomes.

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendation
NHL- Staging using FDG-PET-CT	NICE NG52 Recommendation 1.2.1

NICE NG52 Recommendation 1.2.1

Offer FDG-PET-CT imaging to confirm staging for people diagnosed with:

- stage I diffuse large B-cell lymphoma by clinical and CT criteria
- stage I or localised stage II follicular lymphoma if disease is thought to be encompassable within a radiotherapy field
- stage I or II Burkitt lymphoma with other low-risk features.

4.2.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.2.4 Resource impact assessment

The resource impact assessment for NG52 did not identify any areas of significant resource impact (>£1m in England each year) due to the small populations involved.

4.3 NHL- Management of follicular lymphoma

4.3.1 Summary of suggestions

First-line treatment for stage IIA follicular lymphoma

Radiotherapy for stage IA and IIA follicular lymphoma was supported by a stakeholder as potentially a curative treatment.

Consolidation with stem cell transplantation

One stakeholder acknowledged that although transplantation is resource intensive consolidation with stem cell transplantation should still be offered to people to whom it may benefit, for example, relapsed follicular lymphoma patients in second or subsequent remission and diffuse large B-cell lymphoma after first relapse.

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
NHL- Management of follicular lymphoma	**First-line treatment for stage IIA follicular lymphoma** NICE NG52 Recommendation 1.3.1
	Consolidation with stem cell transplantation NICE NG52 Recommendations 1.3.10, 1.3.11 and 1.6.7

First-line treatment for stage IIA follicular lymphoma

NICE NG52 Recommendation 1.3.1

Offer local radiotherapy as first-line treatment to people with localised stage IIA follicular lymphoma.

Consolidation with stem cell transplantation

NICE NG52 Recommendation 1.3.10

Offer consolidation with autologous stem cell transplantation for people with follicular lymphoma in second or subsequent remission (complete or partial) who have not already had a transplant and who are fit enough for transplantation.

NICE NG52 Recommendation 1.3.11

Consider consolidation with allogeneic stem cell transplantation for people with follicular lymphoma in second or subsequent remission (complete or partial):

- who are fit enough for transplantation and
- for whom a suitable donor can be found and
- when autologous stem cell transplantation has not resulted in remission or is
- inappropriate (for example, because stem cell harvesting is not possible).

NICE NG52 Recommendation 1.6.7

Offer consolidation with autologous stem cell transplantation to people with chemosensitive diffuse large B‑cell lymphoma (that is, there has been at least a partial response to chemotherapy) who are fit enough for transplantation.

4.3.3 Current UK practice

First-line treatment for stage IIA follicular lymphoma

In 2005, 3934 cases (19.1% of the NHL population) were recorded as receiving radiotherapy but with significant regional variation ranging from 15.2 to 25.8%[5]. Variation was also reported at trust level with some trusts delivering significantly more radiotherapy with curative intent compared to others.

No published studies on current practice were highlighted specifically for stage IIA follicular lymphoma; this area is based on stakeholder's knowledge and experience.

Consolidation with stem cell transplantation

Over 50 hospitals in England and Wales have facilities for autologous transplantation (using the patient's own bone marrow or peripheral blood stem cells) of which approximately 30 are centres with expertise in both autologous and allogeneic transplantation (which provide bone marrow transplants from matched donors)[6].

[5] National Cancer Intelligence Network (2015)- Working paper on variation in delivery of radiotherapy for patients with lymphoma
[6]NICE guideline NG47 (2016) Haematological cancers: improving outcomes

No current practice studies on the use of autologous transplantation in NHL were found, this area is based on stakeholder's knowledge and experience.

4.3.4 Resource impact assessment

The resource impact assessment for NG52 did not identify any areas of significant resource impact (>£1m in England each year) due to the small populations involved.

4.4 NHL- Management of diffuse large B-cell lymphoma (DBCL)

4.4.1 Summary of suggestions

Stakeholders supported central nervous system (CNS) directed prophylactic treatment to reduce the frequency of CNS relapse in high risk DBCL patients. They report that patient outcomes for those who have CNS relapse are extremely poor. They commented that standardising the use of CNS prophylaxis was required to ensure these higher risk people receive appropriate treatment.

4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
NHL- Management of diffuse large B-cell lymphoma	NICE NG52 Recommendations 1.6.4 and 1.6.5

NICE NG52 Recommendation 1.6.4

Offer central nervous system-directed prophylactic therapy to people with diffuse large B-cell lymphoma:

- that involves the testis, breast, adrenal gland or kidney or
- who have 4 or 5 of the factors associated with increased risk of central nervous system relapse listed in recommendation 1.6.3.

NICE NG52 Recommendation 1.6.5

Consider central nervous system-directed prophylactic therapy for people with diffuse large B-cell lymphoma who have 2 or 3 of the factors associated with increased risk of central nervous system relapse listed in recommendation 1.6.3.

4.4.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience on current UK variation of CNS prophylaxis.

4.4.4 Resource impact assessment

The resource impact assessment for NG52 did not identify any areas of significant resource impact (>£1m in England each year) due to the small populations involved.

4.5 NHL- Follow-up for people with diffuse large B-cell lymphoma

4.5.1 Summary of suggestions

A stakeholder highlighted the need to stop follow-up for people with DBCL as this may continue for many years after diagnosis and treatment which is resource intensive. This follow-up was also reported as lacking evidence for detecting recurrence.

4.5.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendation
NHL- Follow-up for people with diffuse large B-cell lymphoma	NICE NG52 Recommendation 1.10.1

NICE NG52 Recommendation 1.10.1

For people in complete remission after first-line treatment with curative intent for diffuse large B-cell lymphoma:

- offer regular clinical assessment
- consider stopping regular clinical assessment aimed at detecting relapse 3 years after completing treatment for people in ongoing complete remission
- offer urgent appointments to people who experience a recurrence of lymphoma symptoms or new symptoms that suggest disease relapse
- do not offer LDH surveillance for detecting relapse
- do not offer routine surveillance imaging (including chest X-ray, CT and PET-CT) for detecting relapse in people who are asymptomatic.

4.5.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.5.4 Resource impact assessment

The resource impact assessment for NG52 did not identify any areas of significant resource impact (>£1m in England each year) due to the small populations involved.

4.6 NHL- Information and support

4.6.1 Summary of suggestions

One stakeholder highlighted the need for clear patient information to raise awareness on treatment options and potential long-term treatment side effects with sufficient time allowed to consider the treatment being offered. It was reported that these side effects can have life changing results so careful consideration of treatment is required.

4.6.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 9 to help inform the committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
NHL-Information and support	NICE NG52 Recommendation 1.9.1 NICE NG52 Recommendations 1.11.1-1.11.3

NICE NG52 Recommendation 1.9.1

To help people with non-Hodgkin's lymphoma (and their family members or carers as appropriate) to make decisions about care, follow the recommendations in the NICE guidelines on patient experience in adult NHS services, improving outcomes in haematological cancers – the manual (patient-centred care), improving supportive and palliative care for adults with cancer and care of dying adults in the last days of life. Pay particular attention to the following areas:

- establishing the best way of communicating with the person
- timing and format of information
- information about treatment, including benefits, short-term risks and late effects
- financial support and benefit advice
- fertility issues
- sexual function
- support groups
- access to wellbeing services and psychological support.

NICE NG52 Recommendation 1.11.1

Provide end-of-treatment summaries for people with non-Hodgkin's lymphoma (and their GPs). Discuss these with the person, highlighting personal and general risk factors, including late effects related to their lymphoma subtype and/or its treatment.

NICE NG52 Recommendation 1.11.2

Provide information to people with non-Hodgkin's lymphoma when they complete treatment about how to recognise possible relapse and late effects of treatment.

NICE NG52 Recommendation 1.11.3

At 3 years after a person with non-Hodgkin's lymphoma completes a course of treatment, consider switching surveillance of late effects of treatment to nurse-led or GP-led services.

4.6.3 Current UK practice

Approximately 70% NHL patients reported that their views were taken account and were involved in decisions regarding their treatment and care; similar to all cancer patients. However, the findings suggest an unmet need in relation to information given on longer-term side effects for NHL patients[7].

4.6.4 Resource impact assessment

The resource impact assessment for NG52 did not identify any areas of significant resource impact (>£1m in England each year) due to the small populations involved.

[7]NICE guideline NG52 (2016) Non-Hodgkin's Lymphoma: Diagnosis and management

4.7 Myeloma -Communication and support

4.7.1 Summary of suggestions

One stakeholder highlighted that the availability of good quality information (including follow up and integrated care) and systems for capturing patient preferences is important as myeloma is a complex, long-term condition which is particularly challenging to treat. Also information provision at diagnosis was highlighted to enable shared decision-making on treatment which is also beneficial to quality of life.

Another stakeholder reported the significant emotional burden for carers supporting people through multiple relapses and complex chemotherapy regimens. Giving injections and understanding and managing disease complications and treatment side effects was also highlighted. This requires specific skills and support from carers.

4.7.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 10 to help inform the committee's discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Myeloma	**Communication and support** NICE NG35 Recommendations 1.1.1, 1.1.2 and 1.1.5 QS15 Patient experience in adult NHS services : Statement 6

Communication and support

NICE NG35 Recommendation 1.1.1

Provide information and support to people with myeloma or primary plasma cell leukaemia and their family members or carers (as appropriate), particularly at diagnosis, at the beginning and end of each treatment, at disease progression and at transition to end of life care.

NICE NG35 Recommendation 1.1.2

Consider providing the following information in an individualised manner to people with myeloma and their family members or carers (as appropriate):

- the disease process, relapse and remission cycle, and the person's overall prognosis
- the treatment plan, including (if appropriate) the process and the potential benefits,
- risks and complications of stem cell transplantation
- symptoms of myeloma and treatment-related side effects (including steroid-related side effects, infection and neuropathy)
- lifestyle measures to optimise bone health and renal function
- how to identify and report new symptoms (especially pain and spinal cord compression)
- the role of supportive and palliative care
- how to access peer support and patient support groups.

NICE NG35 Recommendation 1.1.5

Advise family members or carers (as appropriate) about the range of available local and national support services at diagnosis, at the beginning and end of each treatment, at disease progression and at transition to end of life care.

Patient experience in adult NHS services QS15 (2012): Statement 6

Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.

4.7.3 Current UK practice

Macmillan estimates that around 500,000 people living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment that affects the quality of their lives on a long-term basis. One of their recommendations focuses on patient and carer support as they lack knowledge about their condition or level of risk, and are not prepared for the physical, psychosocial or financial impact of cancer and its treatment[8].

The National Cancer Patient Experience Survey (2015) surveyed over 4000 myeloma patients. The findings on communication and support were as follows:

[8] Macmillan (2013) Throwing light on the consequences of cancer and its treatment

- NHS care experience was positive overall with 58% rating it as ‘excellent’ and 33% rating is as ‘very good’.

- However 3 in 10 reported that they were not as involved as they wanted to be in treatment and care decisions.

- 1 in 5 of these patient reported that they did not receive information on support or self-help groups but would have liked to[9].

4.7.4 Resource impact assessment

This area was not included in the resource impact report for NG35. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

[9] Myeloma UK (2016)- Raising the bar on myeloma patient experience- A snapshot report of findings from the National Cancer Patient Experience Survey

4.8 Myeloma - Imaging investigations

4.8.1 Summary of suggestions

One stakeholder highlighted that early and accurate diagnosis for myeloma is a significant issue with variable access to specialist diagnostic testing, such as cytogenetic testing and whole body imaging. This can impact on the speed and accuracy of diagnosis, and information to guide clinical decision making and prognosis.

This stakeholder also cited research which reported that myeloma patients are more likely to be diagnosed late and often present as an emergency in secondary care with bone lesions and fractures or renal failure. This can lead to increased distress at diagnosis, results in treatment challenges and impacts negatively on survival and quality of life.

4.8.2 Selected recommendations from development source

Table 11 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 11 to help inform the committee's discussion.

Table 11 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Myeloma- Imaging investigations	NICE NG35 Recommendations 1.3.1-1.3.4

NICE NG35 Recommendation 1.3.1

Offer imaging to all people with a plasma cell disorder suspected to be myeloma.

NICE NG35 Recommendation 1.3.2

Consider whole-body MRI as first-line imaging.

NICE NG35 Recommendation 1.3.3

Consider whole-body low-dose CT as first-line imaging if whole-body MRI is unsuitable or the person declines it.

NICE NG35 Recommendation 1.3.4

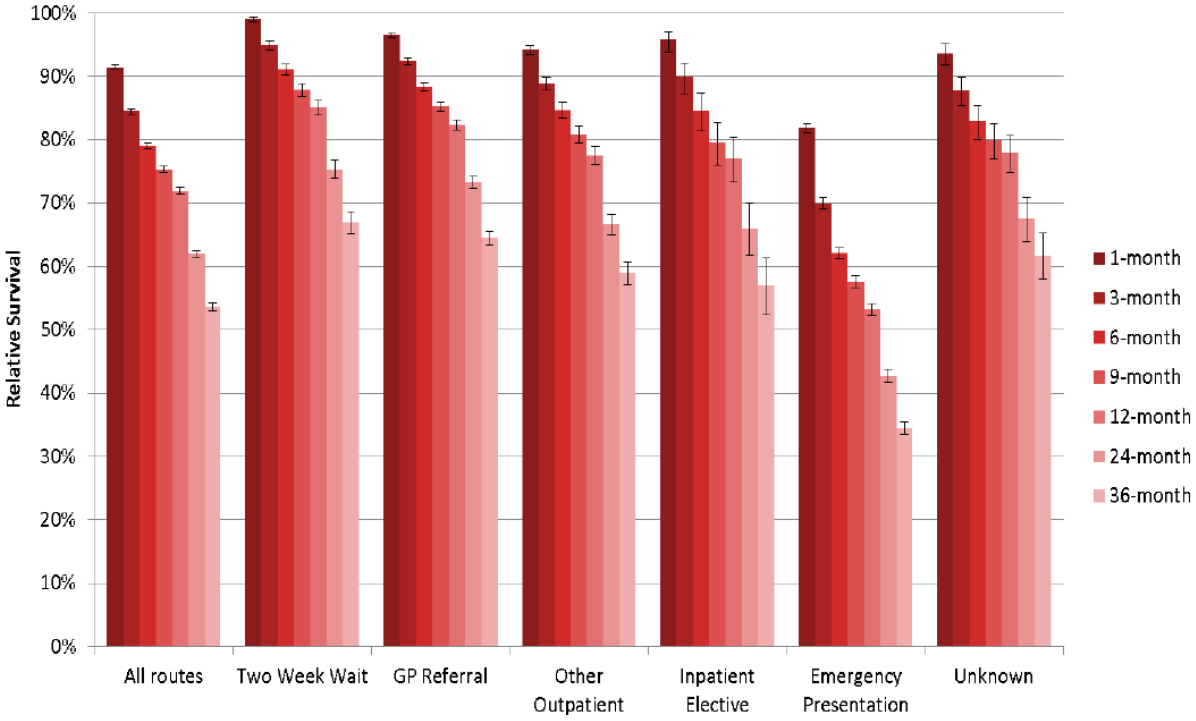
Only consider skeletal survey as first-line imaging if whole-body MRI and whole-body low-dose CT are unsuitable or the person declines them.

4.8.3 Current UK practice

No published studies on current practice in relation to imaging access were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

However in relation to late emergency presentations it was reported that approximately one third of myeloma patients are diagnosed following an emergency admission to hospital. Survival for these specific patients ranged from 82% at one month to 34% at three years after diagnosis[10].

Graph A: Relative survival for multiple myeloma, 2006 to 2013



4.8.4 Resource impact assessment

The resource impact report for NG35 states the following recommendations may be have an impact, depending on local service configuration and capacity:

- Recommendation 1.3.2 - Consider whole-body MRI as first-line imaging

[10] National Cancer Intelligence Network Short Report (2016)- Routes to diagnosis 2015 update: multiple myeloma (ICD-10 C90)

Skeletal survey is currently the standard first-line imaging investigation for myeloma. However, NG35 established that MRI is the most cost-effective first-line investigation

Providers may not have the capacity to perform whole-body MRI scans. However it is not realistic to expect organisations to buy new equipment based on this guidance alone. Organisations should consider their overall demand and capacity for MRI scans as part of their long term capital procurement strategy. The guidance committee used a cost of £203.06 for an MRI scan based on the 2013/14 reference costs, with an assumed cost of £108.82 for a skeletal survey (guidance committee assumption), to give an increase in costs of £94.24 for each person who has an MRI instead of skeletal survey.

Reducing the use of skeletal survey for first-line imaging may help to offset the costs of more frequent whole-body MRI scanning.

- Recommendation 1.3.3 - Consider whole-body low-dose CT as first-line imaging if whole-body MRI is unsuitable or the person declines it

Whole-body low-dose CT was found to be the second-best option after whole-body MRI, and the guideline recommends it as an alternative if whole-body MRI is unsuitable or declined. Whole-body MRI can be a long and uncomfortable experience, and some people decline to have the scan

As with whole-body MRI, providers may not have the capacity to perform whole-body low-dose CT scans. This may be because they do not have the machines or staff needed. However it is not realistic to expect organisations to buy new equipment based on this guidance alone. Organisations should consider their overall demand and capacity for CT scans as part of their long term capital procurement strategy. The cost used by the guidance committee when considering whole-body CT was £147.17, based on 2013/14 reference costs with a corresponding cost of £108.82 for skeletal survey to give an increase in cost of £38.35 for every person who has whole-body CT instead of skeletal survey.

Reducing the use of skeletal survey for first-line imaging may help to offset the costs of more frequent whole-body low-dosage CT scans.

4.9 Myeloma - Service organisation

4.9.1 Summary of suggestions

Stakeholders commented that robust 24-hour emergency therapeutic apheresis are needed to support emergency and planned treatment of specific haematological cancer complications. The provision of these services to support stem cell harvesting for autografts in lymphoma and myeloma was also raised.

4.9.2 Selected recommendations from development source

Table 12 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 12 to help inform the committee's discussion.

Table 12 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Myeloma	**Service organisation** NICE NG35 Recommendations 1.4.1 - 1.4.4
Haematological cancers: improving outcomes	**Other facilities** NICE NG47 Recommendation 1.2.8

Service organisation

NICE NG35 Recommendation 1.4.1

For guidance on the facilities needed to provide intensive inpatient chemotherapy and transplants for people with myeloma, and the structure and function of multidisciplinary teams (MDTs), see the NICE cancer service guidance on Haematological cancers: improving outcomes

NICE NG35 Recommendation 1.4.3

Each hospital treating people with myeloma who are not receiving intensive inpatient chemotherapy or a transplant should provide local access to:

- an MDT specialising in myeloma
- supportive and palliative care, supported by:

- psychological support services
- a 24-hour acute oncology and/or haematology helpline
- physiotherapy
- occupational therapy
- dietetics
- medical social services

- critical care

- clinical trials via the MDT specialising in myeloma
- dental services.

NICE NG35 Recommendation 1.4.4

Each hospital treating people with myeloma should provide regional access through its network to:

- therapeutic apheresis

Other facilities

NICE NG47 Recommendation 1.2.8

Ensure that there is rapid availability of blood counts and blood components for transfusion. **[2016]**

4.9.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.9.4 Resource impact assessment

This area was not included in the resource impact report for NG35. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.10 Myeloma - Preventing and managing complications

4.10.1 Summary of suggestions

A stakeholder reported current variation of practice in therapeutic apheresis services which are nationally provided by different providers and in different specifications. The need to prevent and monitor peripheral neuropathy was also highlighted as it is a disabling side effect of drugs used to treat myeloma.

4.10.2 Selected recommendations from development source

Table 13 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 13 to help inform the committee's discussion.

Table 13 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Myeloma- Preventing and managing complications	**Preventing infection** NICE NG35 Recommendation 1.8.6
	Managing peripheral neuropathy NICE NG35 Recommendations 1.8.8-1.8.12

Preventing infection

NICE NG35 Recommendation 1.8.6

Consider testing for hepatitis B, hepatitis C and HIV before starting myeloma treatment.

Managing peripheral neuropathy

NICE NG35 Recommendation 1.8.8

Explain the symptoms of neuropathy to people with myeloma, and encourage them to tell their clinical team about any new, different or worsening neuropathic symptoms immediately.

NICE NG35 Recommendation 1.8.9

If people who are receiving bortezomib develop neuropathic symptoms, consider immediately:

- switching to subcutaneous injections and/or

- reducing to weekly doses and/or
- reducing the dose.

NICE NG35 Recommendation 1.8.10

Consider reducing the dose if people are taking a drug other than bortezomib and develop neuropathic symptoms.

NICE NG35 Recommendation 1.8.11

Temporarily stop neuropathy-inducing myeloma treatments if people develop either of the following:

- grade 2 neuropathy with pain
- grade 3 or 4 neuropathy.

NICE NG35 Recommendation 1.8.12

If neuropathy does not improve despite stopping myeloma treatment and further treatment is needed, consider switching to myeloma treatments less likely to induce neuropathy.

4.10.3 Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.10.4 Resource impact assessment

This area was not included in the resource impact report for NG35. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.11 Specialist integrated haematological malignancy diagnostic services (SIHMDS)

4.11.1 Summary of suggestions

Integrated reporting

Stakeholders highlighted the need for SIHMDS to produce integrated pathology reports which would ensure appropriate treatment and improve outcomes.

One stakeholder suggested the role of haematopathologists within the SIHMDS was also important to aid discussions with clinicians on case findings.

Clinical nurse specialist

A stakeholder highlighted how access to a clinical nurse specialist for one to one support as a central point of contact would improve patient experience throughout the care pathway.

4.11.2 Selected recommendations from development source

Table 14 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 14 to help inform the committee's discussion.

Table 14 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Haematological Cancers-Improving Outcomes	**SIHMDS** NICE NG47 Recommendations 1.1.2-1.1.4 **Haematopathologist** NICE NG47 Recommendation 1.3.9
	Clinical nurse specialist NICE NG47 Recommendation 1.3.15

SIHMDS

NICE NG47 Recommendation 1.1.2

All SIHMDS should:

- have a full range of protocols covering specimen handling, diagnostic pathways and compilation of integrated reports

- ensure that their location, organisation, infrastructure and culture allow effective day to day and ad hoc communication for rapid resolution of diagnostic uncertainty and accurate diagnosis

- have clear and reliable systems for communicating with relevant healthcare professionals outside the SIHMDS

- produce integrated reports that include all information needed for disease management, and share these with the relevant multidisciplinary team. **[new 2016]**

NICE NG47 Recommendation 1.1.3

All SIHMDS should have a predefined diagnostic pathway that is followed for

each specimen type or clinical problem. The pathway should ensure that:

- there is a robust process for report validation, including double reporting. **[new 2016]**

NICE NG47 Recommendation 1.1.4

All SIHMDS should have an IT system that allows:

- integrated reporting

- two-way communication between SIHMDS and healthcare professionals using the SIHMDS. **[new 2016]**

Core members- Haematopathologist

NICE NG47 Recommendation 1.3.9

Each haemato-oncology MDT should include sufficient core members for the

following people to be present in person or remotely (for example via video

conferencing) at every meeting:

- Haematopathologist: at least one haematopathologist from the SIHMDS should be present; to provide the diagnostic information.

- Nurses: at least one clinical nurse specialist, also ward sisters from hospitals which provide high-intensity chemotherapy.

Other specialists-Clinical nurse specialist

NICE NG47 Recommendation 1.3.15

A clinical nurse specialist should be the initial point of contact for patients who feel they need help in coping with their disease, its treatment or consequences.

This nurse should be able to arrange re-admission, clinical review, or meetings between patients and support staff such as those listed above. Networking between nurses with different types of expertise should be encouraged. **[2003]**

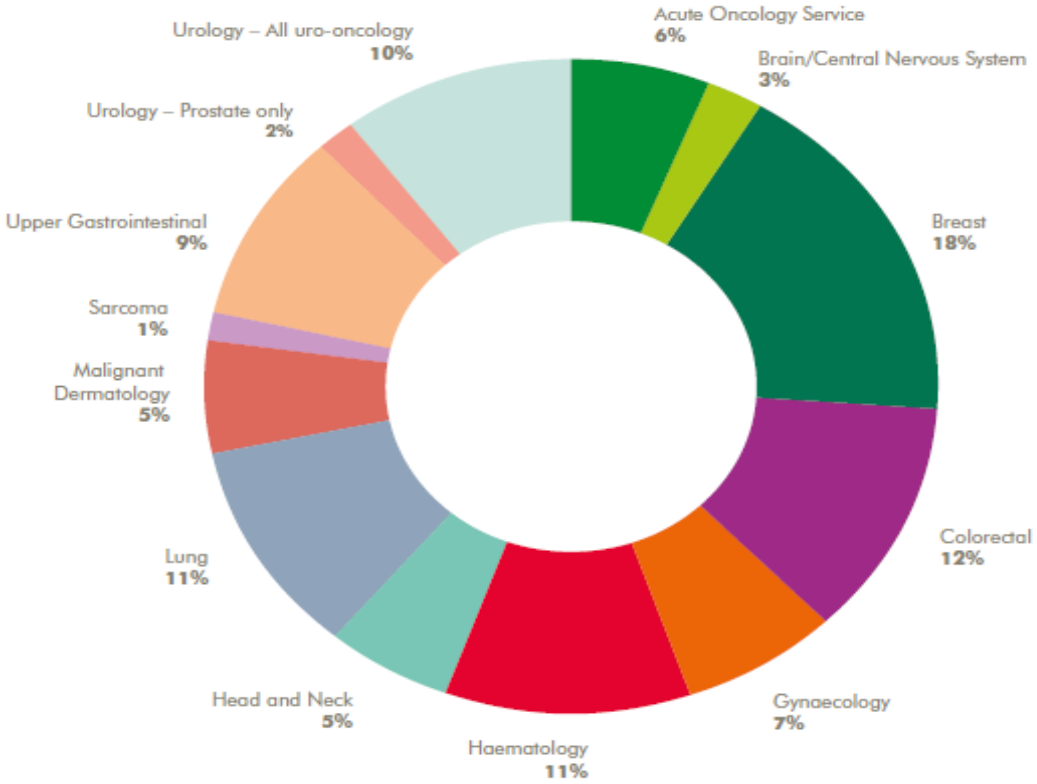
4.11.3 Current UK practice

Access to a clinical specialist nurse specialist for myeloma patients is steadily improving with 88% of over 4000 myeloma patients surveyed reporting that they had the name of a clinical nurse specialist in charge of their care[11].

The total of clinical nurse specialists by area of practice is highlighted in pie chart A. Haematological cancers has the 4th highest distribution of cancer nurse specialists[12].

The role of the clinical nurse specialist is also required in the Cancer Strategy Recommendation 61[13].

Pie chart A. Total clinical nurse specialists by area of practice, percentage, England, 2014[12]



[11] Myeloma UK (2016) Raising the bar on myeloma patient experience- A snapshot report of findings from the National Cancer Patient Experience Survey
[12] Macmillan (2014) Specialist adult cancer nurses in England, A census of the specialist adult cancer nursing workforce in the UK
[13] Independent Cancer Taskforce (2015) Achieving world-class cancer outcomes- A strategy for England (2015-2020)

4.11.4 Resource impact assessment

The resource impact report for NG47 states that services may have to make some staffing changes to follow recommendation 1.1.2.

The recommendation for a formal SIHMDS director role (responsible for service operation, design of the diagnostic pathway, resource use and reporting standards) could lead to additional costs, and additional PAs in clinical job plans may be needed to deliver this role. Other staff roles may also need to be expanded or reduced, depending on how current services differ from the recommendations in this section of the guideline.

It was identified as an area which may have a significant resource impact (>£1m in England each year) and it was recommended that organisations assess staffing levels locally.

4.12 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 03 November 2016.

Cancer Recovery Package

Stakeholder highlighted that The Cancer Strategy recommends by 2020 all patients should have access to the different elements of the Recovery Package including carer support. There are no guideline recommendations on the use of the Cancer recovery package.

2014 Care Act

A stakeholder highlighted the 2014 Care Act which supports carers and deliver needs assessments. Quality standard statements do not cover areas already covered by legislation.

Myeloma education for GPs

A stakeholder raised that as myeloma is a more rare cancer GP education on symptoms is essential. Quality standard statements do not cover the training and education of healthcare professionals.

NICE Cancer Service Guideline (CSG7, 2005) Improving outcomes in children and young people with cancer

Stakeholders highlighted that the interdependency and integration of services for all children with cancer must be recognised. They referred to NICE cancer service guidance for general guidance on staffing and service organisation for children with cancer.No specific suggestions were made and there is a published quality standard in the library for QS55 on cancer services for children and young people.

Treating advanced-stage asymptomatic follicular lymphoma

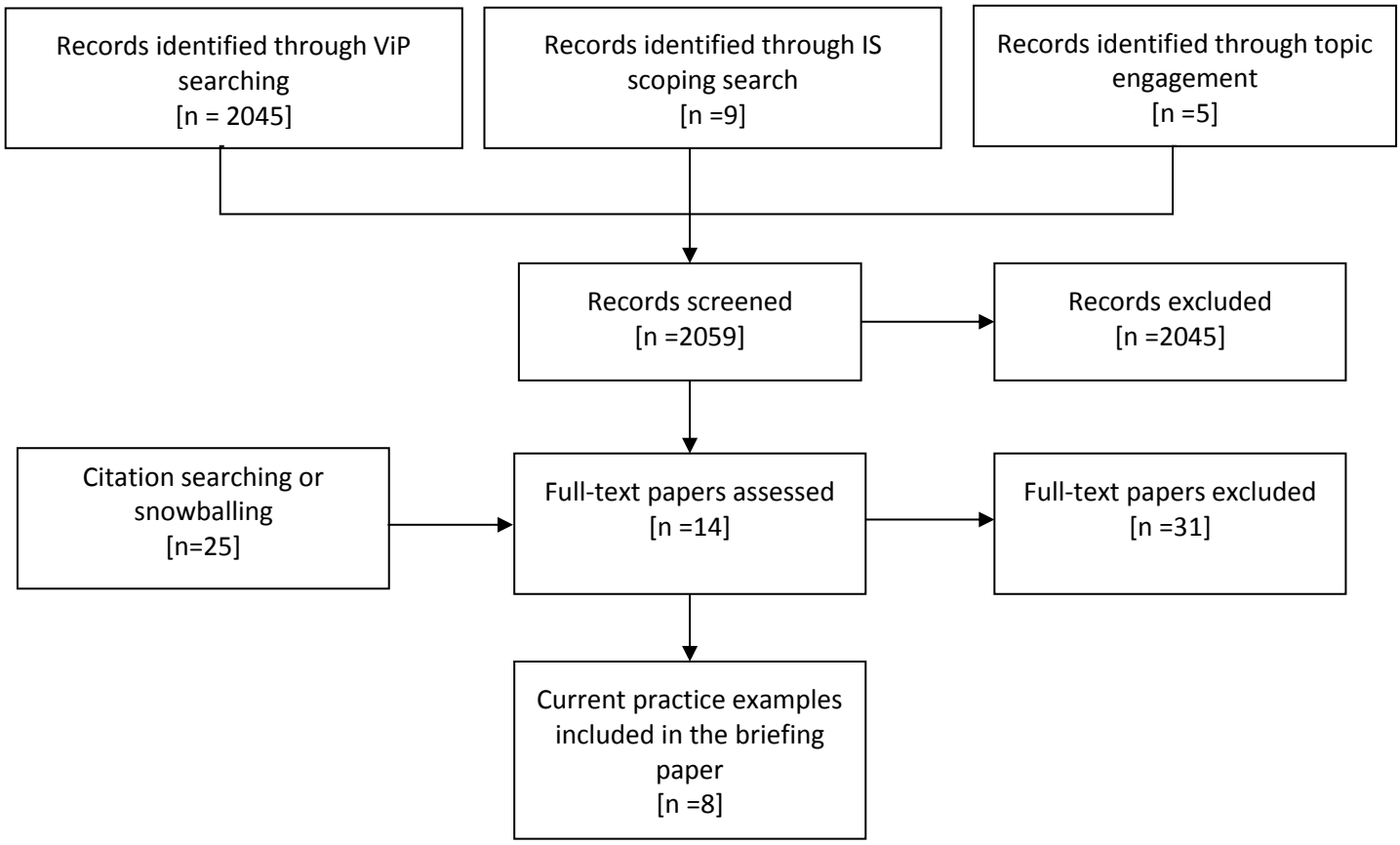
A stakeholder also highlighted offering Rituximab[14] for treating advanced stage III and IV asymptomatic follicular lymphoma as a cost effective, low toxicity intervention. This is NICE Technology appraisal guidance [TA243].

Vial sharing

A stakeholder highlighted that vial sharing would improve cost efficiency for pharmacy. There are no guideline recommendations identified on this area for quality improvement.

[14] At the time of publication (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.

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
1.Diagnosis					
01	SCM1	Rapid excision biopsy service for diagnostic and treatment planning purposes	To arrange for excision biopsies can take up to 6 weeks – this is unacceptable in terms of target patients/ breaches, starting cancer treatment in a timely fashion and the impact on a patient's mental health during the long wait	Core biopsies will not provide sufficient material in future when studies on genome sequencing and the development of targeted drugs become standard	
02	SCM2		The use of gene testing strategies in diagnosing B-cell lymphomas is recommended within NICE NHL [NG52] 2016 Guidelines 1.1.5 and 1.1.6.		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
03	SCM1	Genetic testing for haematological disorders/ discussions around FISH	Genetic knowledge will guide in the prevention, management and treatment of disease	Long term patient health outcome	
04	SCM2		Suggested Quality Standard- has FISH (fluorescence in situ hybridisation) been considered to identify a MYC rearrangement in all people newly presenting with histologically high-grade B-cell lymphoma?		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
2. Staging using FDG-PET-CT					
05	SCM3	Use of PET CT in staging stage I and II DLBCL, Follicular lymphoma and Burketts	Evidence based intervention which may alter management	Currently use of PET in staging is patchy with no consistent practice across UK	NICE NG 52
06	SCM2	The diagnosis (differentiation of) of Burkitts's lymphoma from diffuse large B-cell lymphoma (DLBCL).	The differentiation of Burkitt's lymphoma from diffuse large B-cell lymphoma (DLBCL) at initial diagnosis is critical to ensure appropriate patient treatment (different treatment regimes being applicable to these 2 histological subtypes), in order to improve patient outcomes from these conditions- Burkitt's lymphoma	Misdiagnosis of Burkitt's from diffuse large B-cell lymphoma (DLBCL) remains a problem within the NHS – leading to poor patient outcomes. Correct diagnosis at outset enables appropriate patient treatment, which should lead to improved outcomes.	Non-Hodgkin's lymphoma: NICE guideline [NG52] July 2016.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			being particularly aggressive.		
07	SCM2	Staging using FDG-PET-CT (fluoroxyglucose-positron emission tomography-computed tomography) in people diagnosed with diffuse large B-cell lymphoma.	Outcomes in people with diffuse large B-cell lymphoma remain poor, with significant relapse rates after the completion of 1st line therapy. Optimal staging and therapy at 1st presentation is critical in order to try to improve outcomes. The use of FDG-PET-CT to confirm staging for people diagnosed with stage I diffuse large B-cell lymphoma by clinical and CT criteria is recommended by NICE NHL [NG52] 2016 Guideline 1.2.1. Suggested Quality Standard-	Outcomes in people with diffuse large B-cell lymphoma remain poor, with significant relapse rates after the completion of 1st line therapy. Optimal staging and therapy at 1st presentation is critical in order to try to improve outcomes. The treatment of stage I DLBCL is different from the treatment of stage II-IV DLBCL, accurate diagnosis of stage I disease is therefore critical to avoid patient under-treatment (and adverse outcome).	Non-Hodgkin's lymphoma: NICE guideline [NG52] July 2016.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			has FDG-PET-CT been used to confirm staging for people diagnosed with stage I diffuse large B-cell lymphoma by clinical and CT criteria.		
3. Management of follicular lymphoma					
08	SCM3	Use of radiotherapy for stage I and !! follicular lymhoma	Potentially curative treatment; US population based studies suggest only 30-40% of patients	US population based studies suggest only 30-40% of patients actually receive RT and those that do not have worse survival. No comparative UK data currently available	Pugh et al Cancer 2010 116; 3843-51 Vargo et al Cancer 2015 121: 3325-34
09	SCM3	Delivery of autologous or allogeneic transplant to relapsed follicular lymphoma patients in second or subsequent	Transplant in these patients who obtain a good remission with conventional second line chemotherapy and have no liiting co-morbidity will improve DFS and OS.	Transplant is resource intensive but should not be denied those who may benefit from this intervention. Onward referral to a transplant unit will be needed for many patients which demonstrate effectiveness of network	NICE NG 52

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		remission and DLBCL after first relapse.		pathways and capacity for transplant work.	
4. Management of diffuse large B-cell lymphoma					
10	SCM3	Use of CNS prophylaxis in high risk patients with DLBCL	High risk factors for CNS relapse can be identified as definied in NG52.	Current use of CNS prophylaxis is variable across the UK; this would help to standardise the use of CNS directed therapy and ensure those patients with higher risk features received appropriate treatment.	NICE NG52
11	SCM2	Central nervous system (CNS) prophylaxis for diffuse large B-cell lymphoma (DLBCL).	Patient outcomes for Central nervous system (CNS) lymphoma, a devastating complication, remain extremely poor. Appropriate consideration for the potential requirement for CNS prophylaxis is a critical step in order to try to reduce the	Patient outcomes for CNS lymphoma, a devastating complication, remain extremely poor. Appropriate consideration for the potential requirement for CNS prophylaxis is a critical step in order to try to reduce the frequency of this complication.	Non-Hodgkin's lymphoma: NICE guideline [NG52] July 2016.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			frequency of this complication. Consideration of CNS prophylaxis is mandated within NICE NHL [NG52] 2016 Guidelines 1.6.2-1.6.5. Suggested Quality Standard- has the requirement for central nervous system (CNS) prophylaxis been considered in people with diffuse large B-cell lymphoma (DLBCL) at baseline (documented at Multidisciplinary meeting- MDM).		
5. Follow-up for people with diffuse large B-cell lymphoma					

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
12	SCM3	Follow up in patients with DLBCL	Lack of evidence for use in detecting recurrence	Major resources are used in follow up which may continue for many years after diagnosis and retment.	NICE NG 52
6. Survivorship					
13	SCM4	Giving clear information on possible long term side effects of treatments.	People need to be aware that long term side effects can have life changing results and be given time to carefully consider accepting the treatment offered.		NICE Guideline Survivorship.
7. Communication and support					
14	Myeloma UK	Patient preferences and information	Myeloma is a complex and highly individual relapsing and remitting cancer which is particularly challenging to treat.	NCPES data showed that 3 in 10 myeloma patients were not as involved as they wanted to be in decisions about treatment and care	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			The treatment pathway is also very complex and patients and clinicians face challenging treatment choices. Many treatments have significant toxicities and difficult side-effect profiles. This makes the availability of good quality information and systems for capturing patient preferences particularly important. As a long term and incurable cancer it is also essential that good information is provided in relation to follow-up and integrated care.		
15	Myeloma UK	Carer support	Caring for someone with an incurable cancer like myeloma is particularly challenging. There is a significant emotional burden in supporting patients	Data from research conducted by Myeloma UK shows that 39% of carers would like to have been offered professional support at the time the person with myeloma was diagnosed;	Living with multiple myeloma: experiences of patients and their informal caregivers (Molassiotis et al, 2011)

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			through multiple relapses and some aspects of treatment and care also need particular skills and support from carers. This can include helping the patient with complex chemotherapy regimens, giving injections and understanding disease complications and treatment side effects and how to manage them.	42% were not given enough information at diagnosis about how myeloma would affect them. In addition 49% of carers are not able to speak to healthcare professionals on their own about their worries but would like to. It should also be noted that 74% of those who provide care or support to someone with myeloma do not see themselves as a carer. This means they may not be accessing important assessments and services for carers 50% of all carers had not heard of a carers assessment and 6% of carers had had a carers assessment	- http://www.ntcrp.org.uk/Myeloma_unmetNeeds_qualitative.pdf A life in limbo: A Myeloma UK research report on the experiences of myeloma carers in the UK (in press)
8. Imaging investigations					
16	Myeloma UK	Early and accurate diagnosis	Early and accurate diagnosis is a particularly significant issue for myeloma patients. Research shows that myeloma	In the NCPES 20% of myeloma patients reported visiting their GP five or more times prior to diagnosis compared to 9%for all cancers.	Multiple Myeloma Routes to Diagnosis 2015 NCIN Short Report file:///C:/Users/shelagh.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			patients are more likely to be diagnosed late and often present as an emergency in secondary care with bone lesions and fractures or renal failure. This compounds the distress of their diagnosis, presents treatment challenges and impacts negatively on survival and quality of life.	Approximately one third of myeloma patients are diagnosed following an emergency admission to hospital, one of the highest rates across all cancer types. Myeloma patients diagnosed through emergency presentation have significantly lower survival rates than other routes to diagnosis: 30% of these patients die within the first three months after diagnosis. Access to specialist diagnostic testing, for example cytogenetic testing and whole body imaging is variable between areas and centres. This can impact on the speed and accuracy of diagnosis, and information to guide clinical decision making and prognosis.	mckinlay/Downloads/Multiple_Myeloma_Routes_to_Diagnosis_2015_update.pdf NICE 2016 guidelines have recommendations on diagnostic tests, including imaging. https://www.nice.org.uk/Guidance/NG35
9. Service organisation					
17	NHS England	Availability of robust 24 hour therapeutic	Any service diagnosing and treating patients with	Variable provision around the country. Are all services accredited eg by FACT-	Apheresis services are provided by different

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		apheresis services to support haematological cancer treatments e.g. emergency plasma exchange for hyperviscosity, stem cell harvesting for autografts in lymphoma and myeloma, sibling and unrelated donor stem cell harvesting for allografts and extracorporeal photophoresis for acute and chronic graft versus host disease.	haematological cancer MUST have access to robust, accredited, adult and paediatric (as appropriate) services so that therapeutic apheresis can be used where necessary to support emergency and planned treatment of specific haematological cancer complications and is essential to the provision of stem cell harvests to support a haematological transplant service.	JACIE.? Guideline should specify whether only accredited services should be used	providers and in different specifications round the country. Robust 24 hour emergency therapeutic apheresis is not reliably provided for all haematological cancer patients. NHSBT provides this service at all its sites and has service level agreements with some hospitals. Guidance on the expected level of provision of apheresis, SLA's and its accreditation should be provided.
10. Preventing and managing complications					

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
18	SCM5		Preventing and monitoring peripheral neuropathy	It is such a disabling side effect	Personal experience
11. SIHMDS					
19	SCM1	Availability of final integrated SIHMDS reporting	Correct diagnosis leads to correct treatment		NICE Haem guidelines 2016
20	SCM2	Specialist Integrated Haematological Malignancy Diagnostic Services (SIHMDS) – Integrated Report.	Accurate pathological diagnosis of haematological malignancy is critical in order to ensure appropriate patient treatment and improve patient outcomes. Specialist Integrated Haematological Malignancy Diagnostic Services (SIHMDS) – Integrated Reporting is	An integrated pathology (SIHMDS) report is considered a key step to improve patient outcomes. There has been poor take-up of the 2003 NICE IOG (Improving Outcomes Guidance).	NICE guideline [NG 47] May 2016 (IOG). Poor take up of NICE 2003 IOG.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			recommended within NICE guidance (NICE guideline [NG 47] May 2016). Suggested Quality Standard- is a SIHMDS (Integrated) Report available to the Multidisciplinary team (MDT) at the time of the patient management decision.		
21	SCM4	Communication.	Patients need to know that communication between healthcare professionals involved in their care, is seamless and accurate.		personal experience.
22	SCM2	Specialist Integrated Haematological Malignancy Diagnostic	Accurate pathological diagnosis of haematological malignancy is critical in order to ensure appropriate patient treatment and improve patient	An integrated pathology (SIHMDS) report is considered a key step to improve patient outcomes. There has been poor take-up of the 2003 NICE IOG (Improving Outcomes Guidance).	NICE guideline [NG 47] May 2016 (IOG).

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Services (SIHMDS) – Haematopathologist.	outcomes. Specialist Integrated Haematological Malignancy Diagnostic Services (SIHMDS) – Integrated Reporting is recommended within NICE guidance (NICE guideline [NG 47] May 2016). Effective bilateral clinical communication between centres and the SIHMDS is critical for effective patient management. Suggested Quality Standard- is a SIHMDS Haematopathologist available at 98% (?100%) of the Multidisciplinary team meetings (MDTs) / annum to discuss patient management	Bilateral discussion of cases between clinicians and a specialist haematopathologist from the SIHMDS is a key requirement to ensure optimal data interpretation and explanation of results.	Poor take up of NICE 2003 IOG.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			with clinical teams / discuss SIHMDS Report findings.		
23	CLLG	Haematological cancer diagnostic pathways in paediatric malignancy	Haematological cancer diagnostic pathways in paediatric malignancy differ from those in adult medicine and well defined diagnostic pathways are centred around primary treatment centres, not SIHMDS	The CCLG has separately highlighted concerns about the recommendation in the the published haematological cancers guideline, particularly with regard to integrated diagnostic reporting. (See separate letter)	
24	NHS England	Access to a Cancer Clinical Nurse Specialist (CNS)	There is strong evidence from NHS England's Cancer Patient Experience Survey (CPES) that for patients, the ability to access a CNS as a central point of contact is the most important contributing factor in improving the quality of their experience throughout their pathway. This is recognised	CPES shows that access to a CNS is lower for blood cancer than for solid tumour cancers – 86% of blood cancer patients accessed a CNS, equating to approximately 5000 patients not having access. For patients with rarer blood cancers, the figure falls to 77%. (Average for all cancers is 91% of patients having access).	The Cancer Strategy sets out the desire for all patients to access a CNS, and the Cancer Patient Experience Survey shows that blood cancer patients are experiencing less access than solid tumour cancers.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			by the Cancer Strategy recommendation (no. 61) that NHS England "should encourage all providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards."	There is geographical variation in the provision of CNS care with highly specialist care requirements, particularly for less common blood cancers not being uniformly available.	Emerging good practice – there are examples of good practice at cancer vanguard sites, with Clinical Nurse Specialists with expertise in blood cancer sharing their knowledge with nurses at the local District General Hospital.
25	Macmillan	Clinical nurse specialist	There is evidence that access to one to one support from a clinical nurse specialist improves patient experience. Discussions around treatment, access to a key worker are both stated in the Cancer Quality Standards: There	Access to clinical nurse specialists in haematological malignancies varies across England. A census identified the variation in whole time equivalent clinical nurse specialists employed in trusts to support haematological multidisciplinary teams.	Please see the CNS census http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/macmillan-census-report-england.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			should be an operational policy whereby a single named key worker for the patient's care at a given time is identified by the MDT for each individual patient and the name and contact number of the current key worker is recorded in the patient's case notes.		Which identified considerable variation across what were then SCNs of ratios of incidence and two year prevalence per WTE haematology cancer nurse specialists from 58 :1 to 273:1. Manual of Cancer Services Haemato-oncology Cancer Measures April 2013 measure 12-2H-113 Key worker Which identified considerable variation across what were then SCNs of ratios of incidence and two year prevalence per WTE

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					haematology cancer nurse specialists from 58 :1 to 273:1. Manual of Cancer Services Haemato-oncology Cancer Measures April 2013 measure 12-2H-113 Key worker
26	Bloodwise	Access to a Clinical Nurse Specialist	There is strong evidence from CPES that for patients, the ability to access a CNS as a central point of contact is the most important contributing factor in improving the quality of their experience throughout their pathway. This is recognised by the Cancer Strategy recommendation (no. 61) that NHS England "should	CPES shows that access to a CNS is lower for blood cancer than for solid tumour cancers – 86% of blood cancer patients accessed a CNS, equating to 4,940 patients not having access. For patients with rarer blood cancers, the figure falls to 77%. Access to a CNS is inconsistent. Large teaching hospitals may have many nurses with specific knowledge of	The Cancer Strategy sets out the desire for all patients to access a CNS, and the Cancer Patient Experience Survey shows that blood cancer patients are experiencing less access than solid tumour cancers.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			encourage all providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards."	individual blood cancers, and who are therefore ready understand and support the needs of their patients. Other District General Hospitals may only have one haemato-oncology nurse covering all blood cancer patients. We note that for some cancers, accessing a key worker rather than a CNS can be a valid alternative model for care. However, we would advise against this model being rolled out across all cancers without first assessing whether the specific patient needs could be managed by a non-clinical member of staff.	Emerging good practice – there are examples of good practice at cancer vanguard sites, with Clinical Nurse Specialists with expertise in blood cancer sharing their knowledge with nurses at the local District General Hospital.
27	Myeloma UK	Access to CNS	Research shows that patient experience and outcomes are consistently better when patients have access to a clinical nurse specialist (CNS).	Research and national cancer plans recognise the value of clinical nurse specialists. While trends in this area have improved, targets have still not been fully met and	National Cancer Patient Experience Survey NCPES snapshot https://www.myeloma.org.uk/wp-

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				evidence from a Myeloma UK analysis of the National Cancer Patient Experience Survey (NCPES) showed a slight but consistent downward trend in the number of patients who reported being able to contact their CNS when they need to. This confirms the need to continue to measure not just whether patients have a named CNS, but how easy it is to access them and whether patients receive the information they need throughout their treatment pathway.	content/uploads/2016/07/Myeloma-UK-Cancer-Patient-Experience-Survey-Snapshot-2016.pdf Myeloma patients' self-reported experiences of care and treatment (Galinsky et al, 2016) - http://journals
28	NHS England	The Cancer Recovery Package	The Recovery Package is the main support package to help patients after their treatment has ended. The Cancer Strategy recommends that by 2020, all patients should have access to the different	Delivery of the recovery Package is often modelled around the disease trajectory for patients with solid tumours and the relapsing nature of many blood cancers, or watch and wait approach to the management of other blood cancers does not easily fit with this model. Patients care and support needs can	Emerging good practice – there are current examples of good practice for remote management of blood cancer patients "watch and wait" patients at Barts and Oxford

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			elements of the Recovery Package.	easily be unmet by Recovery Package service, and patient feedback suggests they are frequently nt even referred to such services.	University Hospitals, which shows how this patient population can be effectively managed.
29	Bloodwise	The Cancer Recovery Package	The Recovery Package is the main support package to help patients after their treatment has ended. The Cancer Strategy recommends that by 2020, all patients should have access to the different elements of the Recovery Package.	We know that at present, the Recovery Package is not meeting the needs of many blood cancer patients. This is sometimes due to the nature of their disease, while others may be on “watch and wait” so have yet to start treatment, but still require support. Some blood cancer patients have tried the Recovery Package but found it does not meet their needs. Others are never told about the package, as their clinician does not regard it as an appropriate model of care. Though the current Recovery Package does include support for those living with cancer as a long term condition, it is not	Our Patient Need research showed that when patients were asked what their greatest need was, 21% said “advice on what happens next, and how to get back to leading a normal life”. In addition, 80% said they had a need for lifestyle advice, emotional and psychological support, and of those that received it, half were dissatisfied with the service they received.

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				sufficiently tailored to the needs of blood cancer patients. For example, patients on “watch and wait” have tended not to have access to the support they need. Bloodwise is about to embark on a long term research project to look at how the current Recovery Package works for blood cancer, identify barriers to gold standard care, and make recommendations on how the Package can be amended to deliver for this patient population.	Emerging good practice – there are current examples of good practice for remote management of blood cancer patients “watch and wait” patients at Barts and Oxford University Hospitals, which shows how this patient population can be effectively managed.
30	Macmillan	2014 Care Act	In the NICE guidelines on social care for older people with LTC’s the quality standard is expressed as: Domain 3 Ensuring that people have a positive experience of care and support	The Care Act highlighted the need to support carers and deliver needs assessment. Carers can be eligible for support in their own right. The threshold is based on the impact their caring role has on their wellbeing.	The Care Act 2014 Care and Support Statutory Guidance DOH Sept 2016 Please see Under Pressure: the growing

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			Outcome measure Carers feel that they are respected as equal partners throughout the care process 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for. Carers can be eligible for support in their own right. The threshold is based on the impact their caring role has on their wellbeing.	Macmillan has highlighted the growing strain on cancer carers in a recent report Under Pressure which highlights that a growing number of carers experience stress, anxiety or depression and over half are not getting the right support to care	strain on sandwich generation carers a report researched by You Gov for Macmillan Cancer Support which found: • 89% of cancer carers are also juggling a job with their caring responsibilities • The majority (70%) of all cancer carers are now aged 45 or over, up from 57% in 2011 The overall number of cancer carers has risen by nearly a third (31%) to almost 1.5 million in the last five years

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31	SCM5		Earlier diagnosis	Most GPs won't see a Myeloma patient for most of their career – so education re symptoms is essential	"
32	SCM1	Routine virology screening of Hepetitis B and HIV and all new patients coming into the haematology service	Previous exposure to viral infections require prophylactic treatment for patients undergoing immune suppressive drugs including Rituximab	Long term patient health outcome	
33	CLLG	Quality standards need to be developed from existing CYP IOG	NICE has previously recognised that the needs of children and young people with cancer differ from those of older adults and have set standards and measures for the service provision with clear organisational structures	The existing CYP IOG should be embedded into these quality standards and the unique features of organisation of age appropriate services needs to be recognised. It is unclear why a new set of quality standards is required when the CYP IOG measures are already in place	

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34	CLLG	Recognition of key integration with all children's cancer services	CYP IOG deals with service provision for a group of cancer patients specifically NOT defined by tumour type but by age	Separate quality standards for children with haematological cancers fails to recognise the interdependency and integration of services for all children with cancer	
35	CLLG	Recommendations on service organisation and diagnostic services must take in to consideration specific paediatric haematology training	Paediatric haematology is a hard pressed, under-filled speciality with unique training requirements	Any proposed re-organisation of particularly laboratory diagnostic services must ensure continued high standard of training of UK paediatric haematologists as dual clinicians and pathologists	
36	SCM4	At diagnosis for patient to have as much information as they wish in a format they understand to allow	This will allow patients to consider the treatment being offered as the best option for their particular type of disease and is beneficial in the coping		NICE Guideline Patient Information

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		planning and control of the life they live.	mechanism of achieving good quality of life.		
37	SCM3	Rituximab for stage 3 and 4 asymptomatic follicular lymphoma	Cost efficacy shown and low toxicity intervention	Major change in standard management which would otherwise be ‘watch and wait’	NICE NG 52
38	SCM1	Vial sharing	Vial sharing to improve cost efficiency for pharmacy	The NHS is under financial strain and there are areas for improvement to be made that appear quite simp[le (eg brentuximab vial sharing)	
39	RCGP		Diagnosis of Multiple Myeloma	In 2014 The International Myeloma Working Group (IMWG) has updated its criteria for diagnosing myeloma. The revised definition is new definition of active multiple myeloma is: Clonal bone marrow plasma cells ≥10% or biopsy-proven bony or extramedullary plasmacytoma and any one or more of the following CRAB features and	

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				myeloma-defining events: • Evidence of end organ damage that can be attributed to the underlying plasma cell proliferative disorder, specifically: • Hypercalcemia: serum calcium >0.25 mmol/L (>1mg/dL) higher than the upper limit of normal or >2.75 mmol/L (>11mg/dL) • Renal insufficiency: creatinine clearance <40 mL per minute or serum creatinine >177μmol/L (>2mg/dL) • Anemia: hemoglobin valure of >20g/L below the lowest limit of normal, or a hemoglobin value <100g/L • Bone lesions: one or more osteolytic lesion on skeletal radiography, CT, or PET/CT. If bone marrow has <10% clonal plasma cells, more than one bone lesion is required to distinguish from solitary plasmacytoma with minimal marrow involvement In addition to the four classic CRAB	

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				features, the revised IMWG criteria incorporate the following three “myeloma defining events” into the definition of myeloma: Any one or more of the following biomarkers of malignancy (MDEs): • 60% or greater clonal plasma cells on bone marrow examination • Serum involved / uninvolved free light chain ratio of 100 or greater, provided the absolute level of the involved light chain is at least 100mg/L (a patient’s “involved” free light chain—either kappa or lambda—is the one that is above the normal reference range; the “uninvolved” free light chain is the one that is typically in, or below, the normal range) • More than one focal lesion on MRI that is at least 5mm or greater in size. Diagnosis could be potentially improved with: 1. Prompts with blood results that	

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				potentially fit the CRAB criteria back to clinicians. • 2. Computer searches on GP clinical systems to suggest diagnosis.	
40	RCGP	Diagnosis of Non Hogkins lymphoma	Primary care should have a low threshold for referral for ultrasound and possible biopsy of neck, axilla and groin lumps. This, however, requires access to radiology services who are currently have a severe workload crisis in the UK The shortage of radiologists in the U.K. is getting worse, according to a census released by the Royal College of Radiologists (RCR) in September 2016. RCR Clinical radiology UK workforce census 2015.www.rcr.ac.uk/system/files/publication/field_publication_f		

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			iles/bfcr166_cr_census.pdf. A key finding is that 99% of U.K. radiology departments could not meet scan and x-ray reporting demands.This points to an insufficient number of radiologists to meet the ever increasing demand for imaging and diagnostic services. Diagnostic screening tests that are not so reliant on radiology services need to be developed		
41	SCM1	Additional evidence sources for consideration	BCSH Guidelines		
42	NCD- end of	No Comments			
43	RCN	No Comments			

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44	RCPCH	No Comments			