# Haematological cancers: improving outcomes

## Consultation on draft scope
## Stakeholder comments table

## 14/04/15 to 30/04/15

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| 3 | Roche | General | General | Specific consideration should be given to the appropriate assessment of geriatric patients based on biological age, to ensure that this patient population is treated optimally. | Thank you for your comment. Consideration will be given to all age groups that are specified in the scope, and we will ensure that the issues of co-morbidities and frailty are appropriately addressed. |
| 5 | Napp Pharmaceuticals | General | General | No comments | Thank you. |
| 7 | Department of Health | General | General | No comments | Thank you. |
| 16 | Royal College of Nursing | General | General | No comments | Thank you. |
| 24 | MDS UK Patient Support Group | General | General | Diagnostic pathway must be standardised.<br>SIHMDS should be an integrated diagnostic service provided by a co-located laboratory facility that solely provide haematological cancer diagnosis and critically is closely supervised and run by clinical haematologists that provide clinical interpretation of tests.<br><br>The tests should include morphology, flow cytometry, molecular analysis including next generation sequencing and be closely allied to NHS Genomic Medicine Centre.<br><br>Strongly emphasise the need for the involvement of the caring haematologist who will interpret the results.<br><br>MDS is still a diagnosis that is made morphologically and it is a | Thank you for your helpful suggestions. We will take note of these when developing the guidance.<br><br>MDS is included in the scope and therefore all |

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| | | | | diagnosis that is sifted out from many patients with cytopenias of one form or another and a bit of dysplasia, by experienced morphologists using additional tests appropriately.<br><br>Whilst genetic testing will undoubtedly improve the diagnostic process, morphology remains the starting point and we need to maintain these skills in the hospitals where these elderly patients are going to be initially assessed and then looked after.<br>HMDS in Leeds has been a great success and is the model that should be recommended.<br><br>However, for a long time MDS diagnosis was not so robust compared to lymphoma diagnosis with certain MDS subtypes not diagnosed at all. This has been fixed by appointing the appropriate staff but is perhaps a lesson that these things need to be set up carefully.<br><br>If, with time, the morphology skills are lost at the referring hospital then more and more of the 'sifting' will be required to be done at the SIHMDS. Such increasing separation of clinical from laboratory joined up care carries some risks, most importantly for the patients but also for haematology as an integrated specialty throughout the UK.<br><br>Critically important that the staff who see the patients, are trained to look at the morphology and then decide the appropriate tests. In that order.<br><br>The challenge will be not to divorce the clinician from assessment of pathology on the one hand and on the other to make sure the clinician has the appropriate morphology, flow cytometry and molecular genetic skill set to interpret the tests incl next | subtypes of MDS will be considered. We have amended section 1.1 of scope to make this clearer. |

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| | | | | generation seq data. RCPath should help lead here. | |
| 25 | MDS UK Patient Support Group | General | General | MDS must have recognised Centres of Excellence | Thank you for this suggestion. This is an important issue and we will take note of it when developing the guidance. |
| 26 | MDS UK Patient Support Group | General | General | Must be a more systematic reporting of MDS cases – via NCIN for example | Thank you for this suggestion. This is an important issue and we will take note of it when developing the guidance. |
| 27 | MDS UK Patient Support Group | General | General | More CNS posts - Better advanced nurse practitioners and better research nurses | Thank you for this suggestion. This is an important issue and we will take note of it when developing the guidance. |
| 28 | MDS UK Patient Support Group | General | General | Must be better provision for study leave for nurses and protected time and support for further training | Thank you for your comments. However these issues are outside the scope of the guideline, and therefore we will not be able to comment on them. |
| 29 | MDS UK Patient Support Group | General | General | Morphology training for haematologists – and involvement of the Royal College of Pathology | Thank you for your comments. However these issues are outside the scope of the guideline, and therefore we will not be able to comment on them. |
| 30 | MDS UK Patient Support Group | General | General | Availability of communication workshops for physicians – to help with general patient doctor communication – especially regarding Breaking Bad News – this used to be compulsory a few years ago. | Thank you for your comment. Patient/Doctor communication would apply across all cancers and is already covered by NHS peer review standards. |
| 31 | MDS UK Patient Support Group | General | General | **Bio-banking, patient data and research**<br><br>Increased and improved bio-banking facilities<br><br>Improve and standardise research consent forms nationwide – with emphasis on clearer communication, less complex terminology<br><br>Better patient databases – I.e. A mandatory requirement that hospitals have disease specific databases that allow outside inspection of disease specific patient outcomes in each hospital. | Thank you for your comments. We agree that increased and improved bio-banking facilities, standardised consent forms and patient databases would be useful. However these issues are outside the scope of the guideline, and therefore we will not be able to comment on them. |

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| 32 | MDS UK Patient Support Group | General | General | **Treatment Guidelines**<br><br>Standardise treatment pathway<br><br>Development of a single test where possible to diagnose MDS<br><br>Use of alternative testing methods (peripheral blood vs biopsies for cytogenetics and mutations) which are available and proven reliable and effective – and would greatly improve the quality of life of patients normally undergoing repeat biopsies.<br><br>Enforcing NICE guidelines<br><br>Increased use of treatment guidelines nationwide. | Thank you for these suggestions. They are important issues and we will take note of them when developing the guidance.<br><br>The implementation of NICE guidelines is an issue for individual organisations and the wider NHS. |
| 18 | MDS UK Patient Support Group | 2 | 12 | The elderly should be receiving special consideration, as it has been shown this group of patients is frequently under-treated in MDS specifically and haematological cancers generally.<br><br>In addition special attention should be paid to improving communications with GP's and geriatricians about their care. | Thank you for your comment. Consideration will be given to all age groups that are specified in the scope, and we will ensure that the issues of co-morbidities and frailty are addressed.<br><br>Primary care and care in the community was not prioritised for inclusion within the scope of the update of the guideline, because of the specialised nature of the diagnostic pathway and the levels of care for intensive therapy. This is a generic issue and is not specific to haematological cancer. |
| 13 | NCRI/RCP/ACP | 2 | 17 & 18 | MGUS is a major cause of mortality in its own right and a pre-cursor of myeloma. It is a condition that is often undiagnosed and should receive much closer attention and be included in the guidelines | Thank you for your comment, this is included in the diagnostic area of the scope. However, once MGUS is confirmed it is not covered by the scope of the guideline as MGUS is not a haematological malignancy. |
| 19 | MDS UK Patient Support Group | 2 | 19 | Haematological cancers must include all sub-types of MDS, as well as CMML (not just hypoplastic MDS) | Thank you for your comments, this is included in the scope and therefore all subtypes of MDS |

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| | | | | MDS must be clearly recognised as a form of blood cancer by all stakeholders, health departments and organisations – and consistently listed and counted as an individual disease – as opposed to be included with AML figures. | will be considered. We have amended the scope for clarity.<br><br>We do not feel that it is appropriate to include the figures for MDS data in the scope as it is only an approximate number for 2011, we would also need to include the figures for all other borderline conditions for which there is no reliable data. |
| 4 | Roche | 2 | 23 | **Settings that will be covered**. New models of care may be appropriate in regard to the NHS England Five Year Forward View. All options of care should be considered including those that may be delivered in primary care or community. | Thank you for your comment, primary care and care in the community was not prioritised for inclusion within the scope of the update of the guideline, because of the specialised nature the diagnostic pathway and the levels of care for intensive therapy. This is a generic issue and is not specific to haematological cancer. |
| 17 | Leukaemia and Lymphoma Research | 2 | 3 | There is a lack of mention of the elderly in the scoping document. According to data from the Haematological Malignancies Research Network: "80% of people with haematological malignancy are over 50 years old and about 50% are over 70". Given the differences in treatment and in support requirements in these groups (distinct from younger adults), we recommend to recognising these as separate subgroups, as has been done with children and young people. Our proposal is to divide them into three subgroups: younger adults (24 to 50 years), adults (50 to 70 years) and elderly (over 70 years). | Thank you for your comment. Consideration will be given to all ages that are specified in the scope, and we will make appropriate recommendations once the evidence has been appraised. |
| 12 | NCRI/RCP/ACP | 2 | 7 | The age breaks at 16 between children and teenagers and 24 between young adults and adults are arbitrary and sometimes do not take account of particular diagnosis and disease symptoms. There should be a degree of caution advised at these break points | Thank you for your comment. We agree that the age breaks are arbitrary but they were defined in the NICE Improving outcomes guidance in children and young people with cancer (2005). |
| 33 | Leukaemia CARE | 2 | 15-16 | Could it please be explained why cancers in children will not be covered, and where the relevant alternate provisions are/will be? | Thank you for your comment. Children (under 16) will be considered within the diagnostic pathway. Treatment and care of children is |

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| | | | | | already covered by the NICE Improving outcomes guidance in children and young people with cancer (2005). |
| 34 | Leukaemia CARE | 2 | 17-18 | Could it please be explained why MGUS or monoclonal B-cell lymphocytosis will not be covered, and again where the relevant alternate provisions are/will be? | Thank you for your comments. Diagnosis of MGUS and monoclonal B-cell lymphocytosis is included and we have amended the scope to make this clearer. |
| 6 | NHS England | **3** | 10 | I suspect this is planned anyway, but the 2003 guidance refers to the 2004 supportive and palliative care guidance – the latter is in line to be revised so this will need to be made clear in this updated guidance. Otherwise I agree the palliative care section does not need to be updated. | Thank you for your comment. The NICE guidance on 'Improving supportive and palliative care for adults (2004)' is not due to be reviewed for update until 2017. Therefore the cross reference to the 2004 version will remain. |
| 15 | NCRI/RCP/ACP | 3 | 11 | This update provides an opportunity to improve alignment between NICE guidance and clinical research. NICE is well positioned to identify important research questions and facilitate trial delivery, and better engagement with the clinical research community could have huge benefit for both parties. | Thank you for your comment. We agree, and will make appropriate recommendations once the evidence has been appraised. |
| 14 | NCRI/RCP/ACP | 3 | 6-14 | There have been important changes in best practice in some of these areas and it is important that NICE guidelines are updated | Thank you for your comment. These areas were prioritised for an update in discussion with NHS England. |
| 2 | Roche | 4 | 12 | **Staffing and Facilities**. Route of administration should also be considered with regard to staffing and facilities required as the impact may be significant | Thank you for this information. We will consider this when developing the review questions for staffing and facilities (levels of care). |
| 9 | Celgene | 4 | 19 | Appropriate levels of staffing should be guaranteed to provide services for the assessment of comorbidities.<br><br>Geriatric assessments for the elderly and the use of comorbidiy assessments should be standardised and guaranteed when required. | Thank you for your comment. Consideration will be given to all age groups that are specified in the scope, and we will ensure that the issues of co-morbidities and frailty are appropriately addressed. |
| 8 | Celgene | 4 | 2 | Celgene believe that the guideline should set out the need for consistency of diagnostics. Currently there is regional variation in access and speed of delivery in diagnostics. For example, cytogenetic testing. | Thank you for your comment and is the reason why NICE is updating this guidance. |
| 10 | Celgene | 4 | 22 | Where clinically appropriate, services should be offered in the | Thank you for your comment. Primary care and |

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| | | | | community, bringing treatment closer to the patient's home and reducing the burden on services in NHS hospitals. | care in the community was not prioritised for inclusion within the scope because of the specialised nature of the diagnostic pathway and the levels of care for intensive therapy. This is a generic issue and is not specific to haematological cancer. |
| 11 | Celgene | 5 | 18 | The scheduled technology appraisal for lenalidomide for mantle cell lymphoma should be included in the list of NICE guidance in development that is closely related to this guideline.<br><br>It should be added and read:<br><br>lenalidomide for treating relapsed or refractory mantle cell lymphoma. NICE technology appraisal. Publication date to be confirmed. | Thank you for your comment. This was missed in error and has now been included in section 2.1. |
| 35 | Leukaemia CARE | 11 | General | With regards to the statistics – The references to the number of leukaemia cases differ. Initially the figure quotes is 8600, but the breakdown further down the page only adds up to 7483 (3233 + 2921 + 675 +654). As such, could the confusion be clarified? | Thank you for your comment. The figures 3233 + 2921 + 675 + 654 only relate to the 4 main subtypes. However, to avoid confusion we have deleted them. |
| 20 | MDS UK Patient Support Group | 11 | 11 | Figures for new cases of MDS per year must figure here too – approx. 2500 | Thank you for this information. We do not feel that it is appropriate to include these data in the scope as the figure you quote is only an approximation for 2011. |
| 21 | MDS UK Patient Support Group | 11 | 11 | MDS accounts for 13% of all deaths 5 years from diagnosis (LLR figure) | Thank you for this information. |
| 23 | MDS UK Patient Support Group | 12 | 13 | MDS requires very specific diagnostic pathways due to the complexity of the condition. | Thank you for your comment. |
| 22 | MDS UK Patient Support Group | 12 | 5 | MDS also need to be featured as needing specialised facilities for diagnosis and treatment. | Thank you for your comment. MDS is included in the scope of the guideline and we have amended section 1.1 to make this clearer. |