Scope

3 Need for the guideline

The group felt that Sections 3.1 (epidemiology) and 3.2 (current practice) did not fully explain the need for the guideline. It was suggested that some additional background information about the variations in practice should be included.

3.1 Epidemiology

The group felt it was important to ensure the GDG included representatives who reflected the diversity of the patient population (older age and of Afro-Carribbean family origin).

3.2 Current Practice

Section 3.2 f - The group suggested including disease response and existing neuropathies as well as co-morbidities.

4.1 Population

4.1.1 Groups that will be covered

The group discussed separating high-risk myeloma patients from plasma cell leukaemia (PCL) patients but it was agreed that it is difficult to reliably identify high-risk groups.

There was further discussion about including asymptomatic, smouldering and non-secreting myeloma but it was agreed that this would extend the scope significantly.

The transition between MGUS and myeloma was also considered important in improving late diagnosis. However, the group recognised that the management of MGUS would be too large to cover within the scope of this guideline.

4.1.2 Groups that will not be covered

The group had no additional comments on this section.

4.2 Healthcare settings

There was a query whether hospices were included under NHS-funded care. It was confirmed they are.

4.3 Clinical Management

4.3.1 Key clinical issues that will be covered

Topic A

The group acknowledged that this is a large area to cover and there are guidelines already available that can be cross-referred to. The aim of this topic is to cover the specific issues for myeloma (including treatment-related toxicity and supportive care).

Topic B

The group wanted ‘suspected’ added before myeloma. There was a discussion whether topic b and c could be merged but it was felt that topic b was about service specification whilst topic c was about the technologies and therefore they should be kept separate.

Topic C

Suggestion to add immunophenotyping to the list of diagnostics.

Topic D

The group highlighted that access to specialised imaging has unintended geographical restrictions. It was noted that recommendations made in the guideline should help to promote equitable access.

Topic E

Access to myeloma specialist nurses was discussed. Local district hospitals often have a haematological specialist nurse rather than a myeloma specialist nurse. It was agreed it was important to have good links with regional myeloma nurse specialists for support and advice.

Topic F

The group noted that there are two different pathways under discussion (and subject to different NICE appraisals) – transplant viable and not transplant viable patients. There was some discussion about whether these should be listed as two topics but it was agreed that as they are already separated out in the clinical questions there was no need.

Topic G

The group suggested adding ‘relapsed and refractory’ to refine the patient group.

Topic H

The group noted this is an evolving field, suggesting that the patient perspective is key to this issue.

Topic I

The group noted that it was confusing to have standard (transplant) and non-standard (consolidation) therapy together and suggested separating them. They also agreed thath the topic should explain this would be after primary disease management.

There was some discussion about the side effects of transplants, specifically mucositsis and whether it required an additional topic. It was noted that this may be covered by the Non-Hodgkin’s Lymphoma guideline and if so, it would not need to be done twice.

Topic J

No comments on this topic.

Topic K

The group discussed the need to include the management of spinal disease. It was agreed that spinal disease should be considered separate to bone disease. It was noted that there is a NICE guideline on the management of spinal cord compression which covers a lot of the issues in spinal disease, but there are still some areas specific to myeloma that would need to be considered within this guideline.

Topic L

No comments on this topic.

Topic M

The group noted an ongoing, large UK study (TEAMM trial) looking at early mortality in patients with myeloma.

Topic N

No comments on this topic.

Topic O

The group discussed both survivorship and rehabilitation issues here (noting that there is overlap with general issues and some additional ones specific to myeloma).

Additional topics suggested

- Pain management / management of treatment side effects (e.g mucositis)
- Issues of survivorship and rehabilitation
- End of life care and access to specialist palliative care.

4.3.2 Issues that will not be covered

The group noted that ‘asymptomatic’ patients would be covered by the topics already listed.

After a further discussion on whether ‘smouldering’ myeloma should be included, the group noted that this group of patients are often treated differently (usually avoiding treatment altogether which from a patient perspective, is often not easy to understand). A specific topic was not deemed necessary. The group noted however, that this issue is also relevant to NHL patients.

4.4 Main Outcomes

The group discussed the main outcomes. Additional outcomes suggested included: renal response; response rate; progression free survival; and relapse free survival.

Diagnostic accuracy should be reworded to include prognostic factors. The group noted that diagnostic accuracy specifically relates to the topic on imaging.

Survivorship and end of life outcomes (such as place of death) should be included in the patient related outcomes.

Socio-economic consequences (such as prolonged treatment and ability to return to work) were discussed but noted that the health-related quality of life outcome should cover this.

4.5 Review Questions

It was noted that these questions are only draft and subject to change at the first meeting of the Guideline Development Group

Question a - End of life should be added to the list.

Question b – There was a discussion about what tests should be done, where they should be done and what the quality standards should be. Getting the results of genetic tests may sometimes cause delays in starting treatment. Involvement in clinical trials may preclude patients from some future treatment options. It was noted that downstream treatments should have some degree of flexibility.

Question c – The group suggested adding a question on laboratory diagnostics, and the optimal molecular / cytogenetic strategy.

Question d – The group had no changes to this question.

Question e – The group suggested re-wording this question for clarity.

Question f – The group suggested including bisphosphonates here as there is a variation in practice in their use.

Question g – The group suggested separating out patients who are candidates for transplant and those who are not. The wording was changed from 'chemotherapy' to 'systemic therapy'.

Question h – The wording was changed from 'chemotherapy' to 'systemic therapy'. The group also discussed patients with poor performance status who are not candidates for transplant and the need to cover conservative management of this group.

Question i –This question was removed as it was considered to be covered in questions g and h.

Question j - The wording was changed from 'chemotherapy' to 'systemic therapy' and 'salvage' to 'relapsed or refractory' were added for clarity.

Question k – 'Primary or salvage' was removed. The group decided this should be considered as one question for now and then separated out later when the GDG draft the PICOs.

Question l - The group had no changes to this question.

Question m – The groups considered combining question m and n but noted that prevention is distinct from treatment and they should remain separate.

Question n – The group noted pain management should be considered as an outcome.

Question o – 'Aspirin, heparin and warfrain' were removed from the question as other interventions are also available.

Question p – The group suggested adding 'vaccination' and 'growth factors' to the interventions.

Question q – The group noted that renal response and renal outcomes would be particularly important for this question.

Question r - The group noted that the patient perspective is particularly important. Consideration should be given to exercise and lifestyle change, and supportive care such as physiotherapy. There was further discussion about anaemia and fatigue in this patient population because of the use of EPO/blood transfusion. The group felt that this was an important area which needed a question in the guideline.

Proposed membership of the GDG

The group agreed there was no need for two palliative care physicians. It would be better to have one palliative care physician and one palliative care nurse.

The group decided to keep the two clinical nurse specialists but ensure they cover different hospital types and geographical areas.

The group discussed whether the GP should be on the main group or not. It was noted that this will depend on the final list of topics but currently, only the topic on follow up care related to primary care and they are unlikely to be needed at all meetings.

The group suggested the following additional expert advisors:

- Pharmacist
- Dietician
- Microbiologist or infectious disease specialist
- Cytogeneticist
- Physiotherapist/OT
- Lab diagnostic technician