

*This vision does not represent government policy but provides useful insight into how haematological cancer services might develop over the next 5 years*

## **Annex E**

### **Haematological cancers 2015**

#### Epidemiology

1. The incidence and prevalence of haematological cancers (leukaemia, lymphoma and myeloma) is expected to increase over the next 5 years due to:
  - a. an aging population (haematological cancers are more common in older people);
  - b. an increasing age-adjusted incidence of some haematological cancers e.g. large cell lymphoma;
  - c. an improvement in the reporting of incidence in the over 75s;
  - d. an increase in incidence of people treated for other primary cancers developing haematological cancers as second cancers;
  - e. an increase in low grade tumours (most not needing treatment) due to improved access to diagnostics and incidental identification of such cases;
  - f. the immigration pattern from Eastern Europe and Africa possibly leading to an increase in incidence of HIV-related haematological cancers;
  - g. successful HAART therapy for patients with AIDS meaning that more of them will be living long enough to present with HIV-related haematological cancers;
  - h. increasing numbers of patients who have had solid organ transplants surviving on long-term immunosuppression and presenting with post-transplant lymphoproliferative disorders.
2. By 2015 there needs to be:
  - a. accurate reporting of haematological cancer incidence (including in the over 75s);
  - b. recording of prevalence as well as incidence for haematological cancers.

#### IOG implementation

3. The Improving Outcomes Guidance (IOG) will have been revised and brought up to date. It will incorporate a proposal for updating rapidly changing elements such as specific treatment recommendations and introduction of new drugs between new editions of the IOG.
4. The key priority for people with haematological cancers is that the IOG is fully implemented across the country. This should lead to networked multi-disciplinary teams working to a uniformly high standard across the country.
5. By 2015 there should have been at least 5 years of an IOG compliant service across the NHS, assuming that the service is compliant as from 2010. An increase in workforce (particularly clinical nurse specialists (CNSs), consultant haemato-oncologists, microbiologists, histopathologists, immunologists and clinical scientists) will be needed to support this, as will adequate funding.

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### Prevention

6. While there is no consensus about trigger factors for haematological cancers (especially environmental factors) and the position is unlikely to have changed by 2015, there is sufficient concern about a link to smoking to support continued efforts to persuade people to refrain or desist. There is also a need to counter increasing rates of obesity and its complications which seriously compromise the potential success of intensive chemotherapy and stem cell transplantation.
7. By 2015 there needs to be more epidemiological research taking place (including on environmental factors) to inform the debate on prevention.
8. It is possible that some second cancers could be prevented by modifying treatments for initial primary cancers but changes to treatment regimens for other cancers are unlikely to have a major impact, if any, by 2015.

### Screening

9. There will be no evidence to support national screening for haematological cancers by 2015. Some haematological cancers have a familial link (e.g. CLL) but evidence is not sufficient to warrant familial screening for haematological conditions other than through a funded research programme. However, with the move towards greater patient choice, where there is a family history of disease some family members might choose to be tested.
10. A number of haematological cancers are picked up opportunistically as part of screening when blood samples are taken for analysis. By 2015 it is likely that there will be an increase in the use of commercial laboratories for blood analysis. There is a possibility that they may not pick up and report on abnormalities indicating haematological cancers in the same way as an NHS laboratory if they do not routinely have access to the interpretive skill of a consultant haematologist. Conversely, there is also the possibility that “protocolised” reporting in such laboratories may overstate the possibility or significance of abnormalities, leading to additional demand on services by the “worried well”. By 2015 it is important that there be uniform standards in place for referral for specialist investigation whether in commercial or NHS laboratories.
11. A concern with wider use of screening tests is a greatly increased rate of detection of clinically silent prodromal conditions (MGUS and MBL) in the healthy older population where the risk of progression to frank malignancy is very low. It will be necessary to plan how follow-up should be managed in these cases. In each case there is early evidence that additional tests may identify sub-populations at higher risk of progression although this would have cost and resource implications that would need to be addressed.

### Raising Awareness / Improving referral

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12. The symptoms of haematological cancers can be vague and non-specific and it can be hard to pinpoint a possible haematological malignancy. Issues such as persistence of symptoms may be a trigger but GPs need further support in stratifying risk and, potentially, financial incentives to implement any new strategy.
13. A substantial proportion of haematological referrals that come via the 2 week wait referral system do not have haematological cancers and triaging by a consultant may reduce the number of inappropriate referrals thus making the system more cost effective. Although the 2 week wait has been established to increase early diagnosis of cancers early diagnosis for a patient with haematological cancer may not always affect the overall outcome. It is assumed that patients would prefer an earlier diagnosis but this is not established in the case of low grade abnormalities where such conditions are likely to remain unchanged for many years.
14. It should be noted that haematology departments are coming under increasing pressure so it is important to ensure that effective triaging systems are commissioned and are in place to look at results, prioritise risks and avoid the potential for over-investigation, for example with bone marrow or lymph node biopsies where these are not needed. Specifically, patients in low risk categories need not necessarily be seen by specialist haematologists; structured advice, information provision and follow up could be co-ordinated through primary care for such cases.
15. There is patchy implementation of the Choose and Book system, both manually and electronically, which results in inefficiency of referral pathways.
16. By 2015 further work needs to have taken place to:
  - a. support primary care in the identification and stratification of possible cancer;
  - b. identify what interventions may be most effective;
  - c. set up and support effective triaging systems;
  - d. clarify the cost of rapid investigation in terms of the potential for over-investigation;
  - e. improve consistency across all commissioners and referring physicians in the use of efficient electronic referral.

#### Diagnostics/Staging

17. Consultant haematologists are now more involved in clinical care (including MDTs) and therefore have less time in the laboratory. The impact of this is unclear in terms of diagnostic quality but in some centres it has led to an increasing amount of real time reporting by trainees.
18. There is also some concern about technology development i.e. where such developments do not bring high profits for a company they will not invest in their further development and this may conflict with potential diagnostic/clinical gains. An example of this was automated plasma viscometry - a diagnostic tool that would pick up the presence of paraproteins at an early stage. This has fallen out of use

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because the company did not release a second generation model and yet some laboratories found it a useful diagnostic tool.

19. There will be an increased need for MRI over the next 5 years. In addition, PET scanning is expected to play a key role in the management of haematological cancer cases over the next 5 years with baseline scans highly recommended. In addition it is likely that all patients with the main histological subtypes of lymphoma (Hodgkins disease, diffuse large B cell NHL and follicular lymphoma) will need a diagnostic and end of treatment scan by 2015. It is also likely that there will be emerging evidence on mid-treatment scans as a prognostic tool. There are some concerns that mobile PET scanning units will not be able to provide sufficiently high quality imaging and this needs to be considered further.
20. There are concerns that the trend towards moving more diagnostic services into the independent sector over the next 5 years could lead to a reduction in overall service quality to the individual patient if private providers are not directly associated with haematological centres, especially in respect to reducing ease of clinical communication which is fundamental to effective and efficient clinical practice. For example, there will be little chance that tests will be analysed by someone with a previous knowledge of the patient's case history and significant changes in results of tests may not be seen by those best qualified to care for the patients concerned. In essence, fragmentation of systems will result in lack of continuity which is not beneficial for patients with chronic haematological disorders. This problem already exists in metropolitan areas where GPs and patients have access to multiple labs, the results from some of which are not accessible to their specialist carers.
21. Specialist haematopathology diagnostic services must be implemented and funded across England and must also be directly linked to specialist clinicians responsible for patients' direct clinical management. There is a continuing problem with the accuracy of diagnosis of haematological malignancies. IOG recommendations on the establishment of specialised haematopathology diagnostic services serving large populations have not yet been implemented in many parts of England. The collection of accurate data on incidence and prevalence depends on robust diagnostic services at the point of ascertainment. In addition, more detailed diagnostics and new diagnostic technologies are becoming more important especially with the advent of targeted therapies. The implementation and integration of these services requires haematopathology diagnostic services to be well-organised and specialist to allow the efficient adoption and cost-effective use of these new technologies. More advanced diagnostic services (including immunophenotyping by flow cytometry, molecular diagnostics and cytogenetics including FISH) need to be available in all specialist centres. At the moment provision and access are patchy across the country.
22. By 2015:
  - a. there need to be fully integrated specialist haemato-oncology diagnostic services across the country as part of IOG compliance. These will need to

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- include histology, immunohistochemistry, cytogenetics and molecular diagnostics in a single integrated service;
- b. there needs to be national access to fixed-site PET scanning for patients with haematological cancers and better access to MRI;
- c. clear quality standards for functional imaging in both the NHS and the independent sector need to be available.

### Treatment

23. By 2015 there will be more targeted therapies and a likely associated increase in intravenous chemotherapy requirements. There is also likely to be a reduction in side effects from these treatments and the potential to provide more chemotherapy away from centres e.g. through outreach services. Many treatments will be used in addition to, rather than to replace, existing modalities which will place increased demand on capacity and funding.
24. Many more patients with haematological cancers will be living longer, surviving initial treatment and going in and out of remission. There will therefore be an increase in the number of courses of treatment given over the lifetime of patients. Therefore, services need intelligent planning and commissioning and more efficient and effective delivery. It is fundamental that patients should have equal access to new therapies that have the potential to extend and/or improve their quality of life when relapses can be treated successfully. It is important however that treatment is costed and funded as a package which takes into account, for example, clinicians' time, administration time and specialist monitoring, not just the acquisition cost of a drug. Funding streams should take account of these overall packages and should not be fragmented. Commissioning must be of an overall service of "year of care" as opposed to current "activity-based" measures which do not address complexity or content of haematological care.
25. Long term treatment with specialised medication is indicated in a number of conditions and prescribing restrictions in some situations and localities mandate extra hospital attendances. Working with providers from the community or private sector should not disrupt the overall packages of care designed to ease the load both on patients and clinical teams. Some common treatments currently delivered intravenously will increasingly be delivered by sub-cutaneous formulations which could facilitate a shift in the point of delivery of these treatments.
26. There is also likely to be an increase in the use of radioactive isotope/antibody therapies over the next five years. The use of radiotherapy is likely to remain about the same but speed of access will need to have improved by 2015.
27. In addition, the use of autologous and allogeneic transplantation is expanding as a treatment of choice in nearly all haematological malignancies and cellular therapy is also being used for certain malignancies. The balance of capacity against demand for these therapies remains unclear and requires further study as do the regional and national costing and billing systems which support them.

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28. Ethnic minority access to healthcare remains an issue and was highlighted recently in the area of bone marrow transplantation where the ability to find an unrelated donor for a non-Caucasian patient is nearly 4 times less likely due to the vast majority of donors on registries are Caucasian. The development of public banks and cord transplant studies is improving accessibility for these patients.
29. Clinical trials will ensure that new therapies are identified but it is important that potential funders' annual funding thresholds do not discriminate against larger trials. In addition, data collection performed as part of clinical trials frequently continues long after the recruitment period in order to evaluate long-term outcome. This can have the effect of saturating the capacity of individual centres to collect follow-up data once a critical number of patients have been recruited. This is already becoming a limiting factor for trial recruitment, and the problem is likely to get steadily worse with time. In order to allow centres to continue to recruit new patients into trials, a progressive increase in resource for data collection is required.
30. By 2015:
  - a. New approaches to cancer drug pricing and funding will have been developed to reflect the challenges posed by determining cost effectiveness in end stage disease and smaller patient groups. Cost effectiveness assessments should also better reflect the wider societal costs of ill-health. These approaches should reduce variation in the availability of treatments;
  - b. commissioning should address the cost of the whole treatment package or "year of care" not just the cost of the drug;
  - c. there should be better planning for new drugs on the horizon and all cancer networks should be using the C-PORT capacity planning tool;
  - d. chemotherapy should be moved closer to home where possible; different models can be adopted including outreach clinics and mobile units;
  - e. radiotherapy capacity needs to have expanded and the 31 day waiting times target needs to have extended to cover all treatments not just first definitive treatment to ensure that patients requiring radiotherapy after initial treatment are seen promptly;
  - f. transplant centres should have been expanded and the issue of a shortage of non-Caucasian donors addressed when the banks are expanded;
  - g. there needs to be sufficient resource to fund a large portfolio of trials with equal access to these trials for patients around the country and capacity to enable collection of follow-up data.

#### Supportive & Palliative Care

31. There needs to be improved communication between primary, secondary and tertiary care clinicians as well as with patients at all stages in the pathway. There needs to be a streamlined process to ensure that patients receive the information they need in the format they need it (including written and visual communications in multiple languages and a recording of their consultation if they wish) at the right

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time for them. There should be more integration in the planning, funding and delivery of care between health and social services.

32. The clinical nurse specialist (CNS) has a large impact on patient experience, playing a key role as a patient journey coordinator, patient advocate and information resource. However, this can be hard to physically measure – their posts are therefore often under threat as CEs don't see their value when they have to make budget cuts. Measurement of patient experience needs to be improved and formalised including the impact of the CNS role on this experience. An integrated approach to optimising year-round, 7-day access to specialist nursing should be developed as a priority.
33. Primary care needs to be fully informed of their patients' progress so it can support patients and carers appropriately. There needs to be full implementation by secondary and primary care of initiatives such as the Gold Standards Framework which offer benefits to patients as well as to the management of hospital capacity. Use of remote imaging technology may make it feasible for GPs to electronically "sit in" at MDT sessions discussing their patients.
34. Earlier discussions on preferred place of care will facilitate a reduction in acute sector admissions for terminal care.
35. Better staffing and provision of specialist palliative care will also be necessary to support delivery of optimal care to patients with haematological malignancy and to support haematologists managing the late stages of the various haematological malignancies.
36. Better integration with elderly care services should be an objective as this would be beneficial given the epidemiology of the majority of haematological cancers. Social and co-morbidity factors significantly influence the treatment and care options for such patients.
37. Although the introduction of MDTs has led to improved communication between clinicians involved in the care of a cancer patient there are still improvements needed in communication across disciplines so that patients understand better which condition is leading to a particular problem if there are non-cancer comorbidities.
38. Relapse treatment plans should be discussed with the MDT to assist in targeted more effective usage of treatments.
39. The role that national and local support groups can play in supporting patients and carers needs to be acknowledged and supported; these organisations have much to offer that may be unavailable through the NHS in the management of survivorship.
40. By 2015 it will be important that:

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- a. all medical and nursing members of the MDT continue to be required to attend Advanced Communication Skills Training to ensure they are equipped to fully support their patients. Central funding should continue to support this training programme;
- b. a central registry of information available in different languages is established;
- c. there are better links between clinicians from different disciplines;
- d. there are better links with national and local support groups;
- e. access to healthcare for all minority groups needs to be supported;
- f. there are improved methods to assess patient experience and link this back to the service provided including the role of the CNS i.e. high quality, nationally comparable tools should have been developed and be in standard practice. These should be conducted in such a way that does not place unnecessary strain on clinical teams but supports them in identifying areas for improvement;
- g. Charities and hospital groups providing assistance for those surviving cancer must be supported.

#### Follow up and Chronic Disease Management

41. The role of follow-up (both for re-occurrence and identification of late effects of treatment) needs to be clarified and the focus should be on meeting the needs of the patient rather than a rigid service model. There should be more integration in the planning, funding and delivery of care between health and social services.
42. Children, adolescents and young adults will, in particular, have specific follow up needs, not least in terms of identifying the late effects of treatment.
43. The number of adult haematological cancer survivors is increasing but is unlikely to be supported by a proportionate increase in haematologists or specialist nurses and thus the need for traditional clinic-based follow-up in secondary care may overstretch resources.
44. Work by the National Cancer Survivorship Initiative (NCSI) highlights the low uptake of a care plan for patients following cancer treatment. Providing patients and their GPs with such a care plan should be a key standard for all patients and their GPs to provide information on healthy living, what to look out for in terms of recurrence and late effects of treatment as well as where to go for advice and follow-up. Specialist programmes of in-service training for GPs may be valuable in optimising their contribution to follow-up and to increase their confidence in when to refer patients with possible relapse or treatment-related morbidity.
45. Most haematological malignancies are incurable and run a relapsing and remitting course so that lifelong access to specialist care and supervision will be required. They should be thought of as long-term conditions and they do not therefore conform to traditional “follow up” concepts. Rapid access back to specialist support when needed will be a key requirement of services.

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46. The lack of a systematic approach to provision and availability of phlebotomy services in the community is a major block to rationalising patient hospital visits and moving to self-managed follow-up with planned coordinated access to clinical surveillance tests, a key requirement for supervision of many haematological conditions. By 2015 this should have been addressed.

#### Underpinning programmes

##### *Commissioning*

47. There is a strong argument for the commissioning of complex haematological malignancy care to be carried out at a national level due to the highly specialist nature of this area of cancer care. There is concern that commissioning will become fragmented and parochial if devolved to GP commissioners and that a national body to oversee their performance will be unable to compensate for that loss of cohesion.

##### *Supporting Services*

48. Developments and delivery of changes and improvements in haematological malignancies will be conditional on key improvements and integration in the provision of basic supporting services across health communities such as phlebotomy services and integrated transport services for pathology samples.

##### *Workforce & Training*

49. The workforce at consultant and CNS level is too stretched to provide an adequate service and this will worsen by 2015. The main reason is the increasing complexity of cases and intensity of management combined with rising incidence. For example, in the past 10 years the number of consultant haematologists has increased by 50% but the volume of work has doubled. Lab work has increased steadily year on year but clinical work has increased much more with growing intensity of treatment and more involvement in MDTs. In addition, haematologists often support oncologists that visit rather than are based as a particular hospital. The haematologist often has to take on the follow up support, particularly for the consequences of side effects of therapy.
50. An increase in consultant numbers is essential but not the only answer. Since its foundation the Royal College of Pathologists has included clinical scientists among its fellowship and their role in diagnostics (molecular, in particular) has increased in recent years and could expand further. Trainees have been assumed to be an integral part of the workforce but their availability may drop if training numbers are cut or remain static. The role of CNSs will also become increasingly important in delivering care to compensate for the changes in SpR training. Over the next five years the focus should be on skills rather than job titles.
51. By 2015:
  - a. the workforce review team needs to be reactivated. It needs to enumerate the required number of additional training posts by speciality per annum to meet an agreed target number by a set date;

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- b. the work of skills for health needs to re-start with an initial focus on biomedical scientists.

*Information*

- 52. By 2015 there needs to be sound audit data for haematological cancers. All MDTs will need to participate in robust data registration in order for this to be achieved.

***Improving Outcomes: A Strategy for Cancer Stakeholders***  
**December 2010**