

2009 Haematology Survey Local Health Boards in Wales

2009 Survey into Access to Treatment for Haematological Cancers

Following a survey in 2008 by Leukaemia CARE, this survey aims to ascertain if the recent improvements made to the Health Technology Appraisal (HTA) processes (both the AWMSG and NICE) have been reflected in the care received by people experiencing haematological cancers. It is supported by Peter Black AM and Leukaemia CARE.

Where possible, we would be most grateful if this survey could be completed by the person to whom it was addressed, to allow for continuity in the results.

The information in this survey is requested under the Freedom of Information Act 2000. All data will be kept anonymous.

Name

Position

Organisation

Contact Number

E mail

An electronic copy of this survey is available on request from louise@insightpa.com

Please return the completed survey to:

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Supported by an educational grant from Celgene UK

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PART 1 HAEMATOLOGICAL CANCERS

1. What guidelines do you follow for the treatment of the following haematological cancers (please tick)?

	Multiple myeloma (MM)	Myelodysplastic Syndromes (MDS)	Acute-Myeloid Leukaemia (AML)	chronic myelo-monocytic leukaemia (CMML)	Chronic Lymphocytic Leukaemia (CLL)	Follicular Lymphoma	Non-Hodgkin's Lymphoma (NHL)
Supranational (e.g. European)							
AWMSG Guidance							
NICE Guidance							
Regional							
Cancer Network							
Local							
Other (please specify)							

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PART 2 ACCESS TO TREATMENTS PRE-HTA APPROVAL

2. What horizon scanning mechanisms have you implemented to ensure your Health Board is prepared for treatments newly licensed for use in the UK?

3. Which of the following methods do you use to decide whether to make a treatment available to patients when there is no indication that either the AWMSG or NICE intend to assess that treatment for cost effectiveness?

- Local Guidelines decided at HEALTH BOARD level
- Follow Cancer Network Guidelines
- Individual Funding Referrals
- Do not make treatments available that are not approved by NICE
- Other, please state

4. Under what circumstances have these treatments been made available (please tick):

	Routinely funded	Only available through 'Individual Funding Referrals'	Not funded	Have not received a request for this treatment
Ibritumomab Tiuxetan in Adult Rituximab relapsed refractory follicular B Cell NHL				

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5. Which of the following methods do you use to decide whether to make a treatment available to patients which will be appraised by the AWMSG/ NICE, but for which guidance has not yet been published?

- Under the criteria of agreed guidelines
 - Decided by a Clinical Priorities Group or equivalent
 - Guidance from the London Cancer New Drugs Group
 - Guidance from an alternative new drugs group, please specify: _____
 - Individual Funding Referrals
 - Do not make treatments available that are not approved by AWMSG / NICE
 - Other, please state
-

6. In deciding whether to make a haematological cancer treatments available to patients funding requests, are there any other methodologies you might use?

- Cancer Network
 - Other, please state
-

7. Do you have guidelines for processing and responding to 'Individual Funding Requests?'

- Yes
 - No
-

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8. Is your LHB currently implementing national guidance which allows patients to purchase additional treatment privately without losing their right to treatment on the NHS?

- Yes
 - No
-

9. If so, how do you make information about this option available to patients?

- Through clinicians when appropriate
 - Patients are made aware of this option at all stages of the patient journey
 - Only through a central point (website etc.)
 - No information is made available to patients about 'top up' options
 - Other, please state
-

10. Do you have systems in place to record how many people have chosen to access treatments through additional 'top up' payments in the past year?

- Yes
 - No
-

11. If so, how many patients have chosen to use this option?

- None
 - Fewer than 10
 - 10 – 15
 - More than 15
 - Don't know
-

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12. Under what circumstances have these treatments been made available (please tick):

	Routinely funded	Only available through 'Individual Funding Referrals'	Not funded	Have not received a request for this treatment
Azacitidine for the treatment of MDS, AML or CMML				
Dasatinib for imatinib-resistant or intolerant CML				
Nilotinib for imatinib-resistant or intolerant CML				

PART 3 **ACCESS TO TREATMENTS FOLLOWING A POSITIVE AWMSG** **/ NICE INDICATION**

13. Since NICE issued a positive Appraisal Consultation Document (ACD) to recommend the use of lenalidomide for people who have received at least one prior therapy, under what circumstances has this treatment been made available?

	Routinely funded	Only available through 'Individual Funding Referrals'	Not funded	Have not received a request for this treatment
Lenalidomide for MM in people who have received two or more prior therapies				

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14. Once Final Guidance is published by AWMSG / NICE recommending a treatment for use in the NHS, when would you anticipate funding from:

- Earlier than final guidance, from publication of the FAD
- From Day 1 of Final Guidance
- Within 90 Days of Final Guidance
- From exactly 90 Days following Final Guidance
- From more than 90 days following Final Guidance
- Will not fund

15. Are your timelines for implementing AWMSG/ NICE guidance different for cancer treatments?

- Yes
- No

16. If so, what are these timelines?

PART 4 **ACCESS TO TREATMENTS POST AWMSG / NICE APPRAISAL**

17. What horizon scanning mechanisms have been implemented in your LHB to ensure funding is available for treatments that are anticipated to be recommended for use in the NHS by NICE in the current financial year?

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18. When your LHB receives new guidance from the AWMSG or NICE, how do you implement this guidance? Who is responsible and what is your process?

19. Under what circumstances have these treatments been made available (please tick):

	Routinely funded	Only available through 'Individual Funding Referrals'	Not funded	Have not received a request
Bortezomib at first relapse MM				
Rituximab for symptomatic III and IV follicular lymphoma in previously untreated patients				
Fludarabine for first line treatment of CLL				

20. Once a treatment has been approved for use by the AWMSG / NICE do you make this treatment available:

- On a more restricted basis than that recommended by NICE?
- Exactly in line with NICE recommendations?
- On a wider basis than recommended by NICE?

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21. If your LHB makes treatments available on either a wider or more restricted basis, what is your criteria for making the following treatments available:

Lenalidomide?

Bortezomib?

Rituximib?

Fludarabine?

PART 5: OTHER

24. Do you have any further comments, either on the suitability of recent Government reforms or challenges you face with implementing decisions from the AWMSG or NICE?