



Comments provided by Liz Darlison, Nurse Consultant (Mesothelioma)

Appeal Ground One: NICE has failed to act fairly and in accordance with the Appraisal Procedure set out in the Guidance to the Technology Appraisal Process

1a That NICE has given insufficient weight to the opinions of those with a particular expertise in Mesothelioma.

The FAD failed to give clear reasoning on the Committee's decision "that pemetrexed disodium is not recommended for the treatment of malignant pleural mesothelioma" after the "Committee heard from clinical and patient experts that pemetrexed cisplatin is valued as a potential treatment opinion.." (para 4.3.2).

Patients are often aware that this is the only licensed drug and inability to access it on the NHS seems to heighten individual's desire for the drug. Often physician experts in mesothelioma want to prescribe it on the NHS, when they are prevented, sometimes patients challenge the funders for access via law suits, media and political lobbying. One questions if this is an effective use of scare resources NHS?

1b NICE has failed to act fairly in its practices – of using the best available evidence. The decision appears to go against United Kingdom (and international) clinical opinion given that Scotland and London Lung Cancer groups have approved the use of this drug.

Does this mean that UK's leading lung oncology experts were all wrong? It is not clear in the FAD that the Appraisal Committee understood how 'low the bar is with Mesothelioma'. Patients are looking for small improvements in treatment options to improve their quality of life and hopefully length of life. They enter into treatment fully informed.

Appeal Ground Two: NICE has prepared Guidance which is perverse in the light of the evidence submitted

2a It is perverse to promote bad practice rather than clinical excellence. The FAD does not take into account that clinicians use expert clinical judgement when deciding who should get a drug and who should not.

This group of patients are vulnerable, they are not strong and their life is limited. It is inappropriate for them to fight for their right to access licensed medication and it is not clear from the FAD what alternative there is for these patients - unlicensed medication or no treatment.

Given that it is NICE's duty is to promote clinical excellence, it is perverse to advocate what may hamper further research. The FAD recognises that further studies are necessary and vital but does not seem to have considered the wider implications for denying these drugs to this group of patients. Drug companies may be put off researching treatments for rare cancers.

2b It is perverse to ignore patient choice. The Department of Health current policies promote patient choice. The FAD seems to ignore this. The number of Mesothelioma patients who are likely to require access Pemetrexed is small and therefore the overall cost will not be unmanageable and would not set to increase drastically (para 2.3). Oncologists are cost conscious and most would not use such agent in futile situations.