Dear Dr Longson

The Mouth Cancer Foundation wishes to appeal against the Final Appraisal Determination on behalf of head and neck cancer patients in England and Wales.

We wish to make the following points of appeal under the following categories:
Ground 1: The Institute has failed to act fairly and in accordance with its published procedures ("procedural unfairness")
Ground 2: The Institute has prepared a FAD that is perverse in the light of the evidence submitted ("perversity")

GROUND 1

1) Our comments were submitted at the ACD stage and I did receive confirmation of this, but that for some reason they did not appear on the web site as coming from our organisation but for some reason have been listed under 'Other 2' on page 53 of the 54 page 'Response to consultee, commentator and public comments'. But there is already an 'Other 2' respondent on page 50, indicating an error in catergorisation of the MCF response. This is clearly inadequate. The MCF is one of the leading charities supporting people with head and neck cancer. Was the Institute aware that the response echoed the views of patients and not that of an individual? We are not assured whether our comments have been considered and answered sufficiently.

GROUND 2

1) Our experience and knowledge of head and neck cancer patients tell us that they would appreciate treatments that had less side-effects than the current chemotherapy treatments available. The inability to access a treatment available in Scotland, Europe and the USA is distressing to people living with head and neck cancer in England and Wales. The comments from the MCF online support group (discussion board) support this. The decision not to consider or consultant with other bodies in these countries with regard to why they were able to approve its use and deny this treatment to patients in England and Wales is perverse. To not do so, and then speculate that the submissions to SMC and NICE may not have been identical is perverse.

2) On the other hand, the FAD suggests that carboplatin, an unlicensed treatment with no clinical data to support it, be included in NICE guidance. The Committee concluded that because carboplatin-based chemoradiotherapy can be given as an alternative to cisplatin-based chemoradiotherapy in the group of patients for which there is an evidence base, it could not recommend cetuximab as a treatment for patients with contraindications to cisplatin. The Committee was aware that although carboplatin does not have a UK marketing authorisation for the treatment of locally advanced squamous cell cancer of the head and neck, it is being used to treat this condition in UK clinical practice. Patients will fail to understand why the demand for rigorous evidence is demanded for cetuximab use but not carboplatin and why they should suffer the side-effects of carboplatin when there is an alternative. That is perverse.

3) Treatment with cetuximab has shown to be effective, has less side-effects, and its use has been robustly supported by various patient focused organisations, professional organisations and H&N oncologists. Yet, NICE denies its use to patients because it needs stronger clinical evidence. Patients will be made to suffer the greater side effects of the present available treatments or not have these treatments because their bodies can't tolerate them because of this decision. They will have to wait until May 2009 before NICE even consider looking at cetuximab in H&N cancer again. Many of these patients will be dead by then. This is perverse. It would be more reasonable to allow the treatment to be available while the evidence to refine its indications for use is collected. Especially so, when the cost and impact of allowing this is not substantial in monetary or resource costs.

THE MOUTH CANCER FOUNDATION HOPES THAT NICE WILL RECONSIDER ITS DECISION.

Yours sincerely

Dr Vinod K Joshi BDS, DRDRCDS, FDSRCPS, FDSRCS
Chief Executive, Mouth Cancer Foundation
