NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Health Technology Appraisal

Ranibizumab and pegaptanib for the treatment of age-related macular degeneration (AMD)

Report to the Appraisal Committee summarising comments received from the public on the second Appraisal Consultation Document (ACD2), issued December 2007

Introduction

The enquiry handling team received a total of 61 individual comments via post, email and over the phone in response to the ACD2 on pegaptanib and ranibizumab for the treatment of age-related macular degeneration (AMD). A petition signed by approximately 10,000 people was also received.

Petition

The petition was coordinated by the Royal National Institute of Blind People (RNIB). The statement on this petition was:

> 'Thank you for your commitment to make sight-saving treatments for AMD available on the NHS.
>
> I welcome your new draft guidance, but I urge you to lower the treatment threshold so more people's sight can be saved.
>
> Please ensure there are no delays in issuing final guidance – every day counts when you are losing your sight.'

Individual responses

Comments on timeliness of guidance

The greatest concern was with the issue of timeliness. Nineteen respondents commented that NICE should aim to issue this guidance as soon as possible.

Reasons given were that the condition progresses very quickly and most cannot afford to pay for these treatments privately. The following are typical of some of the comments received:

> *“Further treatment would not help as there had been too much delay in starting treatment. My right eye is therefore a "lost cause" and I live in hope for the other eye”*

> *“My father in law has been quoted £25,000 as costs of this drug. He is ninety, a "tough little miner", but this is breaking his heart.”*

Comments on the second Appraisal Consultation Document

Preliminary recommendations

Of the 61 responses, 37 agreed with the recommendations in ACD2, 8 partially agreed but raised some concerns, 8 did not state their position and 8 respondents indicated that they did not understand the document and so were unable to comment. None stated that they fundamentally disagreed with the recommendations.

There was concern about the 6/60 cut-off point for treatment. Three respondents disagreed with this, as they felt it was too stringent and would mean that patients who may benefit from treatment would be denied it. One commented that:

> *“I think it is a shame to deny someone with poorer vision the opportunity for some improvement in their sight. In fact, it could be argued that the worse the sight, the more a person needs treatment.”*

Six respondents disapproved of the decision not to recommend pegaptanib. One stated that:

> *“A blanket decision does not allow for clinicians to consider the individual circumstances of their patient.”*

Two respondents were concerned about the administrative arrangements for the potential dose-capping scheme, commenting that:

"It will be a great pity if the treatment is not made available because, after all, Novartis will not fulfil its promise."

There was 1 comment on testing for disease progression.

"Para 1.1 should include 'or changes in ocular coherence tomography (OCT) appearances'. In my case, this test proved more sensitive to signs of disease progression."

Impact of AMD on patients' and families' quality of life

Eleven respondents stressed the impact of blindness on themselves and their families. A key concern was the impact on carers:

"My husband and I are in our eighties and he is a very sick man suffering from cancer and heart failure. If my sight deteriorates to the extent that I can't look after him, 'what then'?"

"I am registered blind, the result of AMD. I had no idea just how isolated I would become as the result of sight loss, nor had I any idea of how debilitating the condition could be."

Costs considerations

One respondent commented on the cost impact on the NHS of restricting treatment:

"The combined costs to the NHS and care agencies for the treatment of blindness, together with the general health hazards connected with failing vision, should be taken fully into account when calculating cost-effectiveness."

Six respondents commented on the wider costs to society and asked that the Committee take these costs into account when assessing the cost of blindness.

"Had my mother in law not received treatment for AMD she would now be unable to move safely around her home, unable to distribute the

daily batch of medicines for herself and her husband, and they would both need very expensive permanent care."

Comments on treatments already received

Fourteen respondents commented on their own experience of treatments for AMD. Three respondents said they had experienced successful treatment with ranibizumab. Seven respondents stated that they had tried bevacizumab, which had either halted deterioration or improved sight in all but 1 case. Six commented that bevacizumab should be appraised by NICE as it seems to work and is considerably cheaper than ranibizumab and pegaptanib. Three respondents had tried photodynamic therapy but only 1 was successful.

Four respondents commented that they had been paying for their own treatment and were concerned about whether or not they would be able to transfer to NHS care.

Cost-effectiveness model

There were 3 comments on issues related to cost-effectiveness modelling:

"I note that the calculation of ICER is based on the assumption that 8 injections will be required in the first year and 6 in the second. In practice, some patients (how many?), treated early, reach stabilisation of CNV after only 3 monthly injections."

"The cost of treatment is given as day patients, not outpatients. I see no reason why a day-case bed should be occupied, under normal circumstances."

"I think one should be wary of extrapolating from 2 years treatment to what will or will not happen during the following ten"