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Dear Dr Longson

Health Technology Appraisal: Ranibizumab and Pegaptanib for the treatment of age-related macular degeneration

Thank you for your letter of 7 June 2007 inviting comments on the Appraisal Consultation Document for the Health Technology Appraisal of Ranibizumab and Pegaptanib for the treatment of age-related macular degeneration.

Age Concern does not believe that all of the relevant evidence has been taken into account in developing the appraisal consultation. We believe that the provisional recommendations of the Appraisal Committee are not sound and that they do not constitute a suitable basis for the preparation of guidance to the NHS.

Directions from the Secretary of State require NICE, in the exercising of its functions, to have regard to 'the broad clinical priorities of the Secretary of State....as set out, for instance, in National Priorities Guidance and in National Service Frameworks'. We could find no evidence that NICE has followed this requirement in the preparation of the Appraisal Consultation Document. The priorities and strategic direction for health and social care have been set out clearly in a White Paper, *Our health, our care, our say* (Department of Health, 2006). This places emphasis on putting people more in control of their own care, rapid and convenient access to high-quality, cost effective care, and enabling an supporting health, independence and well-being. The strategic approach emphasises a shift for the NHS from responding to crises to early intervention to promote good health and well-being. This has been given further focus in the Operating Framework for the NHS for 2007/08 and the draft commissioning framework for health and social care.

It is clear from the Secretary of State's Directions to NICE that its work and recommendations are not meant to exist in a vacuum but to actively promote Government priorities. We could find no evidence that NICE has followed these Directions, as there does not appear to be an analysis of Government priorities and the role which the technology under review might play in achieving them. The recommendation to wait until there is a problem in the second eye before intervening appears to be in direct contradiction of the direction of Government policy.

Furthermore we do not believe that NICE has taken sufficient account of the impact of wet AMD on the quality of life of sufferers. Age Concern has worked with the RNIB to identify that the quality of life of patients with wet AMD is affected as much as the quality of life in patients who have had a stroke, severe cardiovascular disease, coronary artery disease or cancer.

In a Canadian study (Public Awareness and Attitudes about Age-Related Macular Degeneration, An Environics Poll commissioned by CNIB, unpublished, presented to the Symposium on the Cost of Blindness, Toronto, February 2004) those who had reached the threshold of being registered partially sighted (6/60) were willing to trade off 60% of their remaining life to regain vision.

In comparison to a control group with normal visual function, people who have lost their sight through wet AMD have:

- Only one third of the ability to perform everyday activities such as reading a newspaper, cooking and reading street signs.
- Half of the ability to recognise faces and watch television
- Twice the risk of developing clinical depression due to the loss of independence associated with wet AMD
- Four times increased assistance needs overall with particularly high assistance needs in the areas of transportation and administrative tasks.
- Double the risk of falls and therefore the risk of fractures and treatment for falls

We hope therefore that the Appraisal Committee will return to the impact on the quality of life of people with wet AMD and that formal consideration will also be given to the links between this appraisal and established Government policy.

I hope that these comments will be helpful

Yours sincerely

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