

Patient expert statement for NICE Health Technology Appraisal of pegaptanib and ranibizumab for the treatment of age-related macular degeneration

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Personal view on the use of pegaptanib and ranibizumab in the NHS

Having been nominated as patient expert by RNIB and the Macular Disease Society, the views presented below reflect the position of these two organisations as well as my own personal views.

Summary

RNIB and the Macular Disease Society advocate the approval of both pegaptanib and ranibizumab for the treatment of patients with wet AMD. We feel that it should be left to the treating clinician to decide which treatment is most suited to each individual patient. Since no head-to-head trials have been conducted on these treatments we feel that it is best to allow clinicians to use both of them in clinical practice providing alternatives if patients do not respond to the initial treatment chosen or have contra-indications to one of them. Maximum choice will ensure maximum chances of successful treatment and reduce the risk of permanent sight loss in the majority of patients eligible for treatment. We feel that this is the only responsible position to take in view of the impact that sight loss through wet AMD has on the quality of life of people with the condition, and in view of the costs of sight loss to the NHS, Social Services and society in general.

The impact of sight loss through AMD on an individual's quality of life

The negative impact of sight loss through AMD on an individual's quality of life has been documented through quality of life studies, reports from practitioners in the area of low vision rehabilitation and accounts given by individuals themselves. More often than not the effects of sight loss are compounded by the patchy nature of support provided to people with sight loss resulting in loneliness, isolation and emotional distress. These in turn cause:

- Early retirement
- Clinical depression requiring NHS treatment
- Loss of independence and dependence on benefits

- Increased costs for visual aids, transport and domestic help
- Increased risk of falls
- Dependence on carers and spouses
- Loss of independent mobility
- Loss of confidence and self-esteem
- Difficulty with activities of daily life.

When measured against the experiences of people without sight loss, people with AMD score 45 per cent lower on the NEI-VFQ-25 scale that measures vision related functional status and 13 per cent lower in terms of their health status as measured by the EuroQoL Questionnaire. Equally significant, people with sight loss through AMD have 30 per cent higher anxiety levels than people without sight loss and their depression scores are 42 per cent higher.

It is therefore not surprising that 9 out of 10 people say that sight is the sense they most fear losing. This fear also accounts for the fact that an increasing number of people are currently contacting RNIB and the Macular Disease Society for help when they realise that they just cannot afford the private treatment that has been offered to them as their only chance of saving their sight. Supporting these people through the process of applying for funding on the NHS in the absence of NICE guidance has been so time-consuming that we have recently set up an Advocacy Service called “Action on AMD Treatment”. In as little as five weeks the service has started supporting more than 90 patients with wet AMD. Each of them has his or her own story to tell:

- The 84-year-old ex-service man who is the sole carer of his disabled wife and has exhausted his savings to pay for private treatment.
- The 71-year-old widow who lives on £800 a month and just cannot afford private treatment.
- The well-publicised story of the elderly couple who were diagnosed within one week of each other and chose to pay for treatment for one of them.

Our submission to NICE contains a number of case studies that describe the impact of blindness through wet AMD on people’s

lives. We recognise that it is NICE's role to take a rational view of the cost-effectiveness of new treatments. The Appraisal Committee may therefore be reluctant to look at individual cases that make the impact of AMD more real. However we feel that this should be part of the process of deciding on the availability of treatment especially since the negative impact of sight loss on a person's life is well documented.

The impact of sight loss on the NHS, Social Services and society in general

Going back to the economic argument, we feel that the impact of sight loss on the NHS and Social Services tends to be underestimated. In the NHS preventing sight loss is not a priority and this is reflected in the lack of targets associated with sight loss. Whereas other disease areas have National Service Framework that establish specific targets and are therefore a priority for Commissioners, sight loss related targets are hidden in the National Service Frameworks for Diabetes and Older People and are indirect rather than direct targets. The impact of sight loss on the use of health resources needs to be taken more seriously. In the UK a study commissioned by the AMD Alliance International showed that a person with sight loss due to AMD uses eight times more health resources than a person from a control group.

In addition, the Assessment Report shows a lack of understanding of the nature of low vision rehabilitation. This is not a one-off cost as assumed by the authors of the report but involves repeat assessments and the provision of new low vision devices and training in mobility and daily living skills over the patient's lifetime. The economic models used for the cost-effectiveness analysis should reflect this.

The benefits of treatment

The benefits of treatment are obvious. The new treatments provide a unique chance to allow the majority of people with wet AMD to avoid blindness. Without head-to-head trials it is not possible to say which of the two treatments is the more effective. Especially patients who have been diagnosed early and have lost little of their sight have an excellent chance of continuing their lives without major changes, whether they are treated with pegaptanib or ranibizumab. The only impact for them will be the need of continuous treatment which, given the high compliance rates in clinical practice, does not appear to be a problem.

The inequity of allowing people to lose their sight if they are unable to pay for private treatment

As explained above, an increasing number of people are contacting our advocacy service to seek help with access to treatment. 90 may seem to be a small number. However, this is merely a reflection of the fact that this service has not been advertised widely, mainly for fear of an avalanche of cases that we may not be able to take on.

Given the negative impact of sight loss on individuals and their families and based on its costs to the NHS, Social Services and society in general, everybody should have access to these sight-saving treatments regardless of their ability to pay.

We hope that NICE guidance will establish equity of access by approving both pegaptanib and ranibizumab for use on the NHS for all who can benefit.

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