National Institute for Health and Clinical Excellence

Pegaptanib and ranibizumab for the treatment of age-related macular degeneration

Royal College of Nursing

Introduction

With a membership of over 400,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. The RCN promotes patient and nursing interests on a wide range of issues by working closely with Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

The RCN welcomes the opportunity to review and comment on the report of the additional analyses and Decision Support Unit for the technology appraisal of Pegaptanib and Ranibizumab for the treatment of age-related macular degeneration.

RCN Response

We were pleased to note that there has been a positive change in the overall recommendations which will result in greater number of patients suffering from this visually devastating condition getting NHS funded treatment.

We commend the Appraisal Committee for taking into account, not only the research evidence base but also the comments from consultees in drawing up the recommendations in the second appraisal consultation document.

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Despite the change, we still feel, that treatment should not be restricted to just patients with best corrected vision equal to or better than 6/60. As to do so will restrict access for a number of patients, that the evidence base clearly shows benefit in visual and thus improved quality of life outcome if they receive anti-Vegf treatment.

It must be noted that objective measurement of visual acuity in the clinical area is only one way of assessing a patient's suitability for treatment and can be variable depending on a number of issues that are not always predictable i.e.- patient compliance, anxiety due to stressful situations etc. We understand the need to set a visual limit, but strongly advise that the threshold be reduced. The clinician can then have greater power to decide whether or not individual patients' retina is amenable to treatment and judge whether or not that patient has a chance of benefiting from treatment.

From clinical experience we would suggest that no retinal specialist will subject a patient to an interventional procedure unless they thought that it was in the patient's best interests.

The Committee needs to clarify the point 'there is no structural damage to the central fovea'. How are we to interpret this? The majority of patients by the fact that they are suffering with Wet ARMD will have some structural damage to the fovea!

The recommendation that beyond 14 injections the cost of treatment should be met by the manufacturer is certainly an innovative way of limiting NHS funds to essential treatments. We would support this recommendation but have reservations as to how this will be implemented nationally.

It would require very prescriptive rules as to how the funding will be released to the NHS should the patient require greater number of treatments. We would not

want to see a case where the patient was delayed from receiving treatment because NHS and manufactures were in dispute over the funding.

Also, what would be the time delay from last NHS injection to the time of requiring further treatment? We could have a scenario that a patient having received 14 injections in the first 24mths then had a recurrence at 30mths and needed additional treatment. Would this be classed as a new course of treatment or failure of existing course?

We note that the Committee is not recommending Pegaptanib for patients with ARMD, we would like to suggest that they give the retinal experts the flexibility of offering this treatment to the patients for whom Lucentis may not be an option by making a recommendation in the final guidance that in these circumstances Pegaptanib can be offered on the NHS.

Conclusion

Finally, we would urge the NICE Appraisal Committee to consider the recommendation that anti-VegF treatment be made available on NHS for all Wet AMD patients as a matter of urgency.

We consider that limiting the guidance to Lucentis could be problematic in some cases and that ophthalmologists should be allowed to choose the best health technology appropriate for the individual patient.

We are already experiencing difficulties with some local providers delaying funding decisions on the premise that they are awaiting NICE recommendations! We are aware of many PCTs with different 'interim' recommendations. This is totally an unmanageable and unethical situation for both clinicians and patients.