Response to 2nd ACD Dec 2007 from Jennifer Nosek

On reviewing the second ACD re- Pegaptanib and Ranibizumab for the treatment of age-related macular degeneration I was 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.

I would like to express my thanks to the appraisal committee for taking into account, not only the research evidence base but the comments from consultee's.

Despite the change I still feel we should not restrict treatment 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 patients suitability for treatment and can be variable depending on a number of issues that aren't always predictable i.e.- patient compliance, anxiety due to stressful situation etc. I 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 to whether or not that patient has a chance of benefiting from treatment.

It is my experience that no retinal specialist will subject a patient to an interventional procedure unless they thought that it was in the patient's best interests.

I suggest 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 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. I 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. I wouldn't 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?

I note that the committee is not recommending Pegaptanib for patients with ARMD, I 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.

I would like to conclude my comments by urging the NICE appraisal team to recommend that anti-VegF treatment be made available on NHS for all Wet AMD patients as a matter of urgency.

We are already experiencing local providers delaying funding decisions on the premise that they are awaiting NICE recommendations! We currently have at

least 7 PCT’s in our locality and surrounding area all with different ‘interim’ recommendations which is totally an unmanageable and unethical situation for both clinicians and patients.

Jennifer Nosek
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