Comments from Jennifer Nosek, Specialist Nurse in Ophthalmology concerning report by NICE decision support group

Having read the appraisal documents I note how comprehensive and vast the information presented to us is and I commend NICE for their efforts. Despite this I still feel disillusioned, frustrated and weary with this lengthy protracted process.

I'm aware we have to work with often limited resources and that as NHS clinicians we must be accountable for the best use of finances for the greater good. But as a nurse that is faced daily with desperate patients trying to remain independent as their vision is failing I find it difficult that we are yet again faced with pages and pages of models of cost effectiveness based on yet more assumptions. None of us will ever know the true long term cost to the NHS until we implement and monitor these new treatments.

What we can be certain of is at his point in time we know from the clinical trails that ranibizumab, the intravitreal treatment which targets all isotypes of vascular endothelial growth factor (VEGF), for the first time in the history of AMD treatments, results in a significant increase in visual acuity in patients with neovascular AMD. Overall, antiangiogenic approaches provide vision maintenance in over 90% and substantial improvement in 25–40% of patients.

The primary purpose of disease management in AMD is to minimize visual loss and related physical and emotional impairment and to optimize vision related quality of life. The time has come to allow experienced retinal specialists, that during the past decade monitoring and treating patients with AMD, have developed an in-depth understanding of what is best for individual patients and CNV lesion subtypes.

I note from the appraisal document that re-modeling took in to account the fact that patients do not require a full assessment and treatment at every monthly visit but will require some form of monitoring visit. I agree that this is a sensible approach but would be cautious in assuming that this reduced frequency regime based on the PRONTO study is representative of the wider population as there were only 37 patients in the study and from one centre.

Despite this word of caution, it is believed by many clinicians that have a vast amount of experience in this field that combination of antivegF with occlusive therapies like photodynamic therapy (PDT) potentially offers a reduction of re-treatment frequency and long-term maintenance of the treatment benefit which is what we all wish for.

I'm confident that leaving the decision with the retinal specialist will result in the most cost effective use of NHS money. They will choose the most effective treatment plan on an individual patient by patient basis as is everyday common practice.

This individualized planning, with monitoring visits allowing treatment as required when leakage activity and or lesion growth recurs offers maximal systemic and ocular safety and the most practical management of patient numbers in the NHS.

I note that despite pegabtanib treated patients showing a treatment benefit after 2yrs over patients receiving only 1 year of pegabtanib treatment. A mean of 16 out of 17 possible injections were administered to patients over 24 months. The therapeutic benefit has been demonstrated comparable to the one obtained with PDT monotherapy, with a lower number of treatments needed with PDT. Therefore reluctantly I accept your findings that this may not be a cost effective option for the NHS.

However, all of your cost effective analysis was based on predominately classic CNV subtypes but both pegabtanib and ranibizumab are suitable for a wider spectrum of lesions and the prognosis appears to be independent of lesion size and composition.

The current unmet need of patients suffering from occult CNV must be addressed and I yet again urge NICE to consider this group by allowing all CNV lesion types to benefit from NHS treatment.

To exclude this group would be devastating both for patients and for clinicians. We will still have the unenviable distressing job of informing our patients of their inevitable poor prognosis, sight loss and thus their independence!