NHS England

NICE EVALUATION DOCUMENT (ECD) FOR ECULIZUMAB FOR ATYPICAL HAEMOLYTIC URAEMIC SYNDROME – Additional Information Request

In addition to the comments we submitted in December 2013 our only comment on the ECD is:

1. We agree that it is factually correct; and
2. We understand why the committee was unable to formulate a recommendation, but that in consequence we find it difficult to comment meaningfully.

In response to the additional information you require:

1. *What is the total budget for specialised and highly specialised services?*

   The total budget for Specialised Services in 13/14 was £13.1bn. The Highly Specialised Services element of that budget was £544m.

2. *What is the scale of the NHS investment in areas of medicine comparable to atypical Haemolytic Uraemic Syndrome?*

   The high cost drug spend was £156m.

3. *What considerations relating to the management of the (highly)specialised commissioning budget should be taken into account when formulating a recommendation?*

   The price quoted by the manufacturer is £340k per patient per year. There are 170 patients therefore potentially there could be a cost in year 1 of £57.8m. This would represent 37% of the drug budget. It is anticipated that there would be approximately an additional 20 new patients/year and that in year 5 the cost could be £82m which would represent 52% of the budget. This would be a considerable cost pressure to the budget.