

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Highly Specialised Technology Programme

Eculizumab for treating atypical haemolytic uraemic syndrome (aHUS) [ID703]

Response to consultee and commentator comments on the provisional matrix of consultees and commentators

Version of matrix of consultees and commentators reviewed:					
Provisional matrix of consultees and commentators sent for consultation					
Summary of comments, action taken, and justification of action:					
	<i>Proposal:</i>	<i>Proposal made by:</i>		<i>Action taken:</i> Removed/Added/Not included/Noted	<i>Justification:</i>
	Move Public Health England to 'Associated Public Health Group – commentator'	NICE Secretariat		Moved	This organisation has been re-classified as 'Associated Public Health Group – commentator'
	Move Public Health Wales NHS Trust to 'Associated Public Health Group – commentator'	NICE Secretariat		Moved	This organisation has been re-classified as 'Associated Public Health Group – commentator'

	<p>We would like to request that aHUS Action be moved from the list of 'Commentators' to the list of 'Consultees'.</p> <p>aHUS Action should be classified as a 'consultee' under 'Professional Groups' as we are a coalition of leading clinical experts who are campaigning for better NHS care for patients with atypical haemolytic uremic syndrome (aHUS) in England.</p> <p>aHUS Action's Executive Committee are all leading clinicians specialising in aHUS or complement and represent leading clinical opinion in the field.</p> <p>We are calling for a national specialised service for the diagnosis and treatment of aHUS, and to ensure that new therapies are available to all patients who need them.</p>	aHUS Action	Moved	aHUS action has been moved to the list of consultees after consideration of its comments.
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	<p>A number of patient/carer and professional groups listed in the provisional matrix (Appendix C) do not have a vested interest (direct or indirect) in the diagnosis or treatment of aHUS and therefore should be removed from the list. These groups include the following:</p> <p>Afiya Trust</p>	Alexion Pharmaceuticals	None	Afiya Trust meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove British Liver Trust	Alexion Pharmaceuticals	None	British Liver Trust meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove Children's Liver Disease Foundation	Alexion Pharmaceuticals	None	Children's Liver Disease Foundation meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove Addenbrookes Liver Transplant Association	Alexion Pharmaceuticals	None	Addenbrookes Liver Transplant Association meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove British Association for Services to the Elderly	Alexion Pharmaceuticals	None	British Association for Services to the Elderly meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.

	Remove British Association of Urological Nurses	Alexion Pharmaceuticals		None	British Association of Urological Nurses meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove British Association of Urological Surgeons	Alexion Pharmaceuticals		None	British Association of Urological Surgeons meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove British Geriatrics Society	Alexion Pharmaceuticals		None	British Geriatrics Society meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove Royal College of Anaesthetists	Alexion Pharmaceuticals		None	Royal College of Anaesthetists meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove Urology Foundation	Alexion Pharmaceuticals		None	Urology Foundation meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove Welsh Urological Society	Alexion Pharmaceuticals		None	Welsh Urological Society meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.
	Remove Research Institute for the Care of Older People.	Alexion Pharmaceuticals		None	Research Institute for the Care of Older People meets the inclusion criteria and has a close interest in this evaluation topic therefore this organisation will remain on the matrix.

	In addition, there are no other manufacturers of eculizumab other than Alexion so there are no possible comparator manufacturers to contact.	Alexion Pharmaceuticals	Updated	There are currently no comparator manufacturers for this technology therefore the comparator manufacturers section has been updated to 'None'.
	As this is such a rare condition there should be no barriers for nurses who have primary experience of caring for these patients being able to comment on the scoping exercise because the professional organisation they belong to is not on the consultees list	Royal College of Nursing	None	Stakeholders are selected following the interim process based on the Single Technology Appraisal process, therefore individuals are asked to submit their comments through relevant stakeholder organisations that meet the inclusion criteria and with a close interest to the evaluation.