

Engagement Report for Clinical Commissioning Policy Statements

Unique Reference Number	1805
Policy Title	Allogenic Mesenchymal Stromal Cell Infusion Therapy for Children with Severe Generalised Recessive Dystrophic Epidermolysis Bullosa
Clinical Reference Group	Specialised Dermatology
Which stakeholders were contacted to be involved in policy development?	<p>The Specialised Dermatology CRG.</p> <p>The stakeholders registered with the Specialised Dermatology CRG.</p> <p>DebRA the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB).</p>
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	The British Association of Dermatology who have 2 representatives on the CRG.
Which stakeholders have actually been involved?	All of the above.
Explain reason if there is any difference from previous question	Not applicable.
Identify any particular stakeholder organisations that may be key to the policy development that you have approached that have yet to be engaged. Indicate why?	<p>DebRA the national charity was emailed and directly approached to comment during stakeholder testing on the policy but have declined to do so.</p> <p>A meeting with representatives of DebRA was held in November 2018 to explain why a research approach was being taken forward and the intention that the treatment would not be commissioned in the interim. This is in the context that when the policy proposal was submitted it was recognised by Clinical Panel that there was a lack of evidence to form a policy and the topic still required research on safety and efficacy. Hence NHS England has been working with the clinical proposer to support</p>

	development of a research proposal with NIHR. The research proposal is still being developed.
How have stakeholders been involved? What engagement methods have been used?	After Clinical Panel had requested some changes this version was emailed to the Specialised Dermatology CRG, CRG stakeholders and the DebRA charity and asked to comment during a two week period in November 2018. "DebRA" was also contacted directly after the engagement period had closed by the Highly Specialised Commissioner.
What has happened or changed as a result of their input?	The policy statement is to provide clarity on the commissioning position to support clinicians and commissioners in the interim. No responses received. No changes made.
How are stakeholders being kept informed of progress with policy development as a result of their input?	The Lead Commissioner is ensuring the CRG and CRG Stakeholders are kept informed. The Highly Specialised team commissioning manager is in contact with "DebRA" the key patient group for this condition and they will be updated about the outcome of this engagement.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	This is a policy statement and no further Public Consultation is proposed given the context for developing this "Not for Routine Commissioning" policy statement in parallel with an NIHR research proposal.