

Engagement Report for Specialised Commissioning Policies

Unique Reference Number and NICE ID	170093P ID001
Policy Title	Everolimus for adjunctive treatment of refractory partial-onset seizures caused by tuberous sclerosis in people aged 2 years and over
Accountable Commissioner	██████████
Clinical Lead	██████████
Clinical Reference Group	Paediatric Neurosciences
Which stakeholders were contacted to be involved in policy development?	Paediatric Neurosciences CRG and registered stakeholders Tuberous Sclerosis Association The Daisy Garland Charity Epilepsy Research UK Epilepsy Society Young Epilepsy
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	The Tuberous Sclerosis Association has participated as a member of the policy working group
Which stakeholders have actually been involved?	Tuberous Sclerosis Association Paediatric Neurosciences CRG and registered stakeholders
Explain reason if there is any difference from	Organisations declined the offer to participate in the development of the policy

previous question	
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?	None, the main patient and carer representative organisation (Tuberous Sclerosis Association) was involved throughout the development of the draft policy proposition.
How have stakeholders been involved? What engagement methods have been used?	Policy working group meeting and subsequent contact for policy development. Stakeholder engagement process. 14 day email engagement exercise with registered stakeholders.
What has happened or changed as a result of their input?	One minor change has been made as a result of their input. The proposed criteria for commissioning have been modified to include the term “designated Children’s Epilepsy Surgery Service” in the bullet which discusses previous consideration for surgical resection.
How are stakeholders being kept informed of progress with policy development as a result of their input?	Stakeholders will be kept informed of the policy’s progress through NHS England’s consultation portal website.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	Not all stakeholders made a recommendation. Those that did selected: 1 - changes that could reasonably be expected to be broadly supported by stakeholders - up to 6 week consultation.