

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	E09X03
Policy Title	Sodium oxybate for symptom control of narcolepsy with cataplexy (children)
Accountable Commissioner	Penelope Gray
Clinical Reference Group	Paediatric neurosciences
Which stakeholders were contacted to be involved in policy development?	<p>All CRG members and registered stakeholders British Academy of Childhood Disability British Paediatric Neurology Association British Paediatric Neurosurgery Group British Sleep Association Cauldwell Children's Society Cerebra Challenging Behaviour Foundation Child Brain Injury Trust Contact a family Council for Disabled Children Mencap MIND UK Muscular Dystrophy UK Narcolepsy UK National Network of Parent Carer Forums (NNPCF) Neurological Alliance Rethink Royal College of Psychiatrists Royal College of Physicians Royal College of Paediatricians Society of British Neurological Surgeons Together for shorter lives Young Minds</p>
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	Representatives of relevant Royal College or Professional Societies were contacted for Stakeholder Testing as part of the CRG.

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Which stakeholders have actually been involved?	All of the key stakeholders listed above were invited to comment.
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?	None
How have the stakeholders been involved? What engagement methods have been used?	<p>The draft policy proposition and evidence review was circulated to the full membership of the CRG and registered stakeholders for one week for their views, both to establish whether any amendments to the policy are required, and to understand from their perspective what the key questions to ask at consultation might be.</p> <p>Five responses were received – all from CRG members (including one patient group).</p> <p>The responses are summarised as follows:</p> <ol style="list-style-type: none"> 1. A high volume of comments were received regarding the lack of equity of access between those children receiving sodium oxybate by Department of Health instruction (as a result of a suspicion that the 2009/10 swine flu vaccination might have triggered their narcolepsy with cataplexy) and those whose disease is inborn. 2. Many CRG members argued that in instances like this where there is paucity of high-quality evidence for children, the adult evidence should be used and extrapolated. Specifically, it was argued that the biological characteristics of the sub-group (post-pubertal children weighing >40kg) were similar to the adult population. 3. Moreover, some CRG members noted that all interventions currently prescribed to children with this disease are done so off-label. 4. Many CRG members stated that sodium oxybate was an important treatment option for a small highly-select group of patients resistant to, or with unacceptable side effects from, first and second line medication options.
What has happened or changed as a result of their input?	The Policy Working Group (PWG) reviewed the feedback and felt that legitimate questions had been raised about the evidence base of the policy proposition, and recommended that another evidence review be commissioned that included adult evidence. This was supported by NHS England who commissioned Solutions for Public Health (SPH) to undertake a new evidence review to include adults. The new evidence review formed the basis for a re-submission of an updated policy proposition to Clinical Panel.
How are stakeholders been informed of progress with policy development as a result of their input?	This engagement report, along with the updated policy proposition will be circulated as part of the public consultation. Stakeholders will be notified and invited to comment further.

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<p>What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?</p>	<p>Public consultation for a period of 30 days as supported by stakeholders.</p>
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