

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	A01X01
Policy Title	Ivacaftor for children aged 2-5 years with cystic fibrosis (named mutations)
Accountable Commissioner	Sue Sawyer
Clinical Reference Group	Cystic Fibrosis
Which stakeholders were contacted to be involved in policy development?	Cystic Fibrosis CRG membership and all registered stakeholders
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
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

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<p>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>	<p>None</p>
<p>How have the stakeholders been involved? What engagement methods have been used?</p>	<p>The draft policy 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. 8 stakeholders responded. The majority of comments were expressing support for the policy proposition and the evidence presented. A few minor modifications to the criteria for commissioning were proposed, to add further details for this specific age group of patients.</p>
<p>What has happened or changed as a result of their input?</p>	<p>Stakeholders were invited to comment. The policy proposition has been updated to detail criteria for commissioning in this specific age group, including initiation, monitoring, stopping and exclusion criteria. An additional sentence on adverse effects was added to the evidence review.</p>
<p>How are stakeholders being kept informed of progress with policy development as a result of their input?</p>	<p>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.</p>
<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>