

## Engagement Report for Service Specifications

<b>Specification Reference Number</b>	A14/S(HSS)/c
<b>Specification Title</b>	Primary Ciliary Dyskinesia management service (adults)
<b>Accountable Commissioner</b>	Sarah Watson
<b>Clinical Reference Group</b>	Specialised Respiratory
What stakeholders were contacted to be involved in service specification development?	The CRG's stakeholders were consulted on the service specification, also the PCD Family Support Group have been engaged in the writing of this specification. Also clinicians from within the Highly Specialised Paediatric management service. The Royal College of Physicians and British Thoracic Society are represented on the CRG. Following a request from RDAG separate communication took place with the BTS to confirm their support for the proposal.
What stakeholders have actually been involved? State reason for any difference from previous question	As above, no difference.
How have the stakeholders been involved? What	The service specification was circulated to the CRG's stakeholders. Teleconferences and face to face meetings have been held with the patient

engagement methods have been used?	group.
What has happened or changed as a result of their input?	The service model has been written to reflect the agreed views of clinical leads and stakeholders. One change has been made to the % tolerance level in the agreed outcome measures for adult patients diagnosed with PCD managed in adult PCD specialist centres.
How are stakeholders been informed of progress with service specification development as a result of their input?	The patient group has been included in the specification development working group so has been involved in all discussions about the specification development. Contact via email and face to face meetings.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement? (see Appendix One)	4 weeks in line with standard practice for all HSS service specifications.

Draft for public consultation only

## Appendix One

### 1. When do we need to consult and how long for?

The levels below describe a consultation period and engagement activity while a consultation is live. The levels should reflect an approach that is proportionate to the needs of the policy being consulted on. The levels described are based on the assumption of a robust period of stakeholder engagement that can be well evidenced in the policy development process.

<b>Level 1</b>	minor changes – no further consultation
<b>Level 2</b>	medium changes that are broadly supported by stakeholders through prior engagement - up to 6 week consultation, limited engagement activity during the live consultation
<b>Level 3</b>	significant changes that are broadly supported by stakeholders through prior engagement - up to 10 weeks consultation to include some proactive engagement activities during the live consultation period
<b>Level 4</b>	Significant change with some contentious aspects 12 week consultation to include some proactive engagement activities during the live consultation period
<b>Level 5</b>	highly contentious/ high volume impact on numbers of stakeholders/ high levels of dissent/ high financial implications/ high media or political profile = 12 week consultation plus an extensive range of pre and during engagement activity

*NOTE: there may be exceptional operational or legal reasons that a formal consultation might be implemented outside of this framework.*

### 2. Developing criteria for what we mean by proportionate

A series of prompt questions can help to identify the length and level of public engagement:

- How significant is the change for patients?

- Are certain patient groups disproportionately impacted?
- What is the size of the population group affected?
- What is the financial impact and affordability of the proposed change?
- Will the policy change the geography of where the services are provided?
- Is the patient group very small – can they be contacted individually?
- Has an Equality and Diversity impact assessment been done? What does this say?

### 3. Calculation tool to aid decision-making about consultation periods

<i>Target audience</i>	<i>Count</i>	<i>Significance of changes</i>	<i>Count</i>
<ul style="list-style-type: none"> <li>• Public and all patients</li> </ul>	4	<ul style="list-style-type: none"> <li>• High levels of change</li> <li>• Changes are contentious</li> <li>• High public profile</li> <li>• Political interest</li> </ul>	4
<ul style="list-style-type: none"> <li>• Specialist patient groups (&lt;1000)</li> <li>• Patients experience health inequalities in relation to these changes</li> </ul>	3	<ul style="list-style-type: none"> <li>• Medium to large number of changes</li> <li>• Consensus is not likely between stakeholders</li> </ul>	3
<ul style="list-style-type: none"> <li>• Specialist patient groups (&lt;1000)</li> </ul>	2	<ul style="list-style-type: none"> <li>• Small changes</li> <li>• Consensus of support has already been established</li> </ul>	1

**Target audience + significance of change = total score.**

- A score of more than 6 indicates that a level 4 or 5 consultation should be used
- A score of 5 or 6 indicates that consideration should be given to a level 3 consultation
- A score of 4 indicates that consideration should be given to a level 2 consultation
- A score of 3 or less indicates that consideration should be given to a level 1 consultation