

Engagement Report for Service Specifications

Unique Reference Number	1648
Specification Title	DNA Nucleotide Excision Repair Disorders Service
Lead Commissioner	Sarah Watson
Clinical Reference Group	Medical Genetics
Which stakeholders were contacted to be involved in service specification development?	CRG stakeholders from Medical Genetics including expert clinicians in these conditions. Also the British Dermatological Association and Patient Support groups from both CS and XP have also been involved.
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved	<p>Discussions with following organisations:</p> <p>British Dermatological Association Clinical Genetics Society Genetic Alliance UK</p> <p>RDAG, representation from professional bodies and Royal Colleges comments has been incorporated in earlier draft of the specification.</p> <p>RCP and RCPCH have been involved as stakeholders and also through the Rare Diseases Advisory Group.</p>
Which stakeholders have actually been involved?	Amy and Friends (the patient group for CS and TTD) has been closely involved in the specification development. Information on the aims of the development of the model of care has been shared through the Cockayne Syndrome (CS) patient forum with

	CS families.
Explain reason if there is any difference from previous question	Not applicable
Identify any particular stakeholder organisations that may be key to the specification development that you have approached that have yet to be engaged. Indicate why?	Nothing further
How have stakeholders been involved? What engagement methods have been used?	The main patient groups have been involved as members of the working group and in separate discussions as the specification developed
What has happened or changed as a result of their input?	The main change as a result of stakeholder engagement has been a tightening of the commitment in the specification to work with centres to share care and provide management advice for patients who are too sick to travel as their disease progresses. This model of patient management is not unusual in highly specialised services.
How are stakeholders being kept informed of progress with specification development as a result of their input?	Email correspondence directly to the respondents where comment was needed.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	4 weeks public consultation

