

## Cystic Fibrosis Committee meeting 12

**Date:** 12/09/2016

**NICE** National Institute for  
Health and Care Excellence

**Location:** Royal College of Obstetricians and Gynaecologists, London.

**Minutes:** Confirmed

<b>Committee members present:</b>		
Martin Walshaw		(Present for notes 1 – 6)
Elaine Edwards		(Present for notes 1 – 6)
Iolo Doull		(Present for notes 1 – 6)
Sarah Collins		(Present for notes 1 – 6)
Alexander Darlington		(Present for notes 1 – 6)
Helen McCabe		(Present for notes 1 – 6)
Janis Bloomer		(Present for notes 1 – 6)
David Lacy		(Present for notes 1 – 6)
Sarah Popple		(Present for notes 1 – 6)
Helen Parrott		(Present for notes 1 – 6)
Nichola MacDuff		(Present for notes 1 – 6)
Andrew Jones		(Present for notes 1 – 6)
Katie Perryman-Ford		(Present for notes 1 – 6)
Keith Thompson		(Present for notes 1 – 6)
Mandy Bryon		(Present for notes 1 – 6)

<b>In attendance:</b>		
Andrew Gyton	NICE Commissioning Manager	(Present for notes 1 – 6)
Vanessa Delgado Nunes	NGA Guideline Lead	(Present for notes 1 – 6)
Annabel Flint	NGA Senior Project Manager	(Present for notes 1 – 6)
Gemma Villanueva	NGA Systematic Reviewer	(Present for notes 1 – 6)
Gemma Marceniuk	NGA Health Economist	(Present for notes 1 – 6)

Maija Kallioinen	NGA Assistant Systematic Reviewer	(Present for notes 1 – 6)
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**Apologies:**

Zoe Elliot	Committee member
Stephen Murphy	NGA Clinical Advisor

**1. Welcome and objectives for the meeting**

The Chair welcomed the Committee members and attendees to the twelfth guideline committee meeting on Cystic Fibrosis. The Committee members and attendees introduced themselves.

The Chair informed the Committee that apologies had been received and these are noted above.

The Chair outlined the objectives of the meeting, which included: the presentation of the health economics for antimicrobial treatment and cross-infection, the evidence review and drafting of recommendations for psychological and behavioural assessment and nutritional interventions.

**2. Declarations of interest**

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was the diagnosis and management of Cystic Fibrosis.

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
David Lacy	General Paediatrician Wirral University Teaching Hospital NHS Foundation Trust	Attended the Cystic Fibrosis Trust “UK CF Conference” 7th September 2016. This was sponsored by Galapagos a company that are developing drugs targeting the underlying molecular defect in CF. Also attended as part of the conference a talk sponsored by Vertex that make ivacaftor and Orkambi. There were no	Non-personal non-financial, non-specific	No action needed

		specific talks that covered areas of the guideline we are developing.		
Sarah Popple	Pharmacist - Leicester Royal Infirmary Children's Hospital / De Montfort University	Attended a team building event with CF team called 'better teams together' a corporate initiative being run by Trust. Participation of team is aiming to improve communication with shared care centre. The event was sponsored by Vertex (Kalydeco/Orkambi) who gave a short presentation at the beginning and funded the room hire, refreshments and a meal.	Non-personal, non-financial, non-specific	No action needed
Zoe Elliott	Lay member	Spoke at the CF Trust conference in September. The event was sponsored by: Vertex; Mylan; Pari Medical Ltd; Raptor Pharmaceuticals; PTC Therapeutics, Inc; Gilead Sciences; Concert Pharmaceuticals; Galapagos; SPS No payment or financial inducement for speaking at the event.	Non-personal, non-financial, non-specific	No action needed
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Relevant publications RW Lord, AM Jones, A Horsley. Antibiotic treatment for Burkholderia cepacia complex in people with cystic fibrosis experiencing a pulmonary exacerbation (0144). Cochrane 2016; 20;1:CD009529. doi: 10.1002/14651858.  P Barry, AM Jones. Skin contamination leading to falsely elevated fingerprick tobramycin levels in a patient taking dry powder inhaled	Personal non-financial, specific	No further action

		<p>tobramycin J Cyst Fibros 2014; 13(6): 754</p> <p>PJ Barry, AM Jones. New and emerging therapies for cystic fibrosis. Drugs 2015; 75(11):1165-1167</p> <p>Gilchrist FJ, Belcher J, AM Jones, D Smith, AR Smyth, KW Southern, P Španěl, AK Webb, W Lenney. Exhaled breath hydrogen cyanide as a marker of early Pseudomonas aeruginosa infection. ERJ Open Research 2015; 1 (2) DOI: 10.1183/23120541.00044-2015.</p> <p>Relevant conference abstracts  HB Langman, AL Brennan, RJ Bright-Thomas, AM Jones, DW Riley, SC Johnson. Real world' introduction of tobramycin inhalation powder TIP™ in adults with cystic fibrosis. J Cyst Fibros 2015; 14suppl 1; 165.</p> <p>HB Langman, AL Brennan, RJ Bright-Thomas, AM Jones, DW Riley, SC Johnson. 'Real world' experience of introduction of Colobreathe™(Colo) in adults with cystic fibrosis. J Cyst Fibros 2015; 14suppl 1; Ws8.3.</p>		
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic	I have been invited to be a member of the NHS Specialised Respiratory Clinical Reference Group from August 2016.	Personal non-financial, specific	No further action necessary

	Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust			
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The Chair and a senior member of the Developer’s team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

**3. Minutes of last meeting**

The Chair asked the Committee whether any changes were required to the minutes of the last meeting. The Committee agreed that the minutes were a true and accurate account of the meeting.

**4. Presentations**

The Chair introduced Gemma Villanueva, Senior Research Fellow, who gave a presentation on the evidence review for the topic of psychological and behavioural assessment for people with cystic fibrosis.

Gemma Villanueva, gave a presentation on the evidence review for the topic of the nutritional interventions in cystic fibrosis.

Gemma Marceniuk, Health Economist, gave a presentation of the health economic model for cross-infection and took questions from the Committee.

Gemma Marceniuk, Health Economist, gave a presentation of the health economic model for antimicrobial treatment in cystic fibrosis.

The Committee thanked everyone for their presentations and contribution to the development of the guideline.

**5. Questions and discussion**

The Committee asked questions on the presentations and the Chair then led the Committee through the process of drafting recommendations and LETRs from the evidence reviews.

**6. Any other business**

There were no other items of business. The chair thanked the Committee for

attending and closed the meeting.

**Date of next meeting:** 19/10/16

**Location of next meeting:** Guy's Campus, Hodgkin Building