

## Cystic Fibrosis Committee meeting 4

**Date:** 19/08/2015

**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 (Chair)	(Present for notes 1 – 6)
Mandy Bryon (MB)	(Present for notes 1 – 6)
Alexander Darlington (AD)	(Present for notes 1 – 6)
Sarah Popple (SP)	(Present for notes 1 – 6)
Iolo Doull (ID)	(Present for notes 1 – 6)
Sarah Collins (SC)	(Present for notes 1 – 6)
Alexander Darlington (AD)	(Present for notes 1 – 6)
Helen McCabe (HM)	(Present for notes 1 – 6)
Zoe Elliot (ZE)	(Present for notes 1 – 6)
Helen Parrott (HeP)	(Present for notes 1 – 6)
Nichola MacDuff (NM)	(Present for notes 1 – 6)
Janis Bloomer (JB)	(Present for notes 1 – 6)
Keith Thompson (KT)	(Present for notes 1 – 6)
Elaine Edwards (EE)	(Present for notes 1 – 6)

<b>In attendance:</b>		
Ben Doak (NICE)	Guidelines Commissioning Manager	(Present for notes 1 – 6)
Sarah Catchpole (NICE) SCa	Guideline Editor	(Present for notes 1 – 6)
Stephen Murphy (SM)	Clinical Director	(Present for notes 1 – 6)
Vanessa Delgado Nunes (VDN)	Guideline Lead	(Present for notes 1 – 6)
Annabel Flint (AF)	Project Manager	(Present for notes 1 – 6)
Shona Burman-Roy (SBR)	Senior Research Fellow	(Present for notes 1 – 6)

Omnia Abdulrazeg (OA)	Research Fellow	(Present for notes 1 – 6)
Gemma Villanueva (GV)	Research Fellow	(Present for notes 1 – 6)
Zosia Beckles (ZB)	Information Scientist	(Present for notes 1 – 6)
Hugo Pedder (HP)	Statistician	(Present for notes 1 – 6)
Gemma Marceniuk (GM)	Health Economist	(Present for notes 1 – 6)

**Observers:**

None.

**Apologies:**

Andrew Jones (AJ)

Committee member

David Lacy (DL)

Committee member

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

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

No members of the public asked to observe the meeting.

The Chair informed the Committee that apologies had been received from DL and AJ.

The Chair outlined the objectives of the meeting, which included: presentations of the evidence reviews on airway clearance and liver disease monitoring and a presentation on the role of the NICE Editor in the guideline development process.

**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.

<b>Name</b>	<b>Job title, organisation</b>	<b>Declarations of Interest, date declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
Sarah Collins	CF specialist dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	At the European Cystic Fibrosis meeting on Thursday 11th June she attended a hospitality event (meal) with her team from Royal Brompton hospital which was sponsored by Chiesi.	Personal financial specific	No further action necessary.
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Iolo the president of the British Paediatric Respiratory Society and a trustee for ASH Wales	Personal non-financial non-specific	No further action necessary.
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Iolo organises the annual Royal Society of Medicine CF study day. The RSM receives an unrestricted educational grant from Actavis towards this meeting.	Non-personal financial specific	No further action necessary.
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Iolo is on the audit committee for the Children's Commissioner for Wales and sits on the Cystic Fibrosis Trust Clinical Advisory Group and Registry Committee.	Non-personal non-financial specific	No further action necessary.

Elaine Edwards	Advanced Physiotherapist, Sheffield children's NHS Foundation Trust	Through the Association of Chartered Physiotherapists (ACPCF) she will help to update the Standards of care and good clinical practice for the physiotherapy management of Cystic Fibrosis. The specific section she is working on is the use of Non-invasive ventilation in Cystic Fibrosis and the use of Intermittent Positive Pressure breathing in Physiotherapy (there is no funding associated with this work).	Personal non-financial specific	No further action necessary
Zoe Elliott	Lay member	Under the anonymity of the Cystic Fibrosis Aware twitter account she has been tweeting opinions of the price of the Vertex drug Orkambi.	Personal non-financial specific	No further action necessary
Helen Parrott	Physiotherapist, Clinical Specialty Lead - Adult CF Therapies Royal Brompton	Helen attended the European CF conference in Brussels with social events sponsored by Chiesi.	Personal financial specific	No further action necessary.

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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 HeP and EE who gave a presentation on the topic of airway clearance techniques.

The Chair introduced OA, GV and GM who gave a presentation on the evidence review and health economics on the effectiveness of airway clearance techniques. The Chair then led the Committee through the process of drafting recommendations and LETRs for this topic.

The Chair introduced Sarah Ca, NICE Guideline Editor, who gave a presentation on the role of the NICE Editor in the guideline development process.

The Chair introduced HP, SBR and GM who presented the review on liver disease monitoring. Questions were taken from the Committee.

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

**5. Questions and discussion**

The Committee discussed the draft protocol for the topic of service configuration which was presented by VDN. The draft protocol was edited live on screen.

The Committee discussed the draft protocol for the topic of antimicrobial therapy which was presented by VDN. The draft protocol was edited live on screen.

**6. Any other business**

There were no other items of business. MW thanked the Committee for attending and closed the meeting.

**Date of next meeting:** 30/09/2015 and 01/10/2015

**Location of next meeting:** King's College, Guy's Campus, London and the Royal College of Obstetricians and Gynaecologists, London.