

## Cystic Fibrosis Committee meeting 5 day 1

**Date:** 31/09/2015

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

**Location:** King's College, Guy's Campus, London Bridge, 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)
Stephen Holden (SH)		(Present for notes 1 – 6)

<b>In attendance:</b>		
Stephen Murphy (SM)	Clinical Director	(Present for notes 1 – 6)
Vanessa Delgado Nunes (VDN)	Senior Research Fellow and Guideline Lead	(Present for notes 1 – 6)
Annabel Flint (AF)	Project Manager	(Present for notes 1 – 6)
Melanie Powell (MP)	Assistant 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 Marцениuk (GM)	Health Economist	(Present for notes 1 – 6)

<b>Observers:</b>	
None.	

<b>Apologies:</b>	
Ben Doak	Guidelines Commissioning Manager

<b>1. Welcome and objectives for the meeting</b>				
<p>The Chair welcomed the Committee members and attendees to day 1 of the fifth guideline committee meeting on Cystic Fibrosis. The Committee members and attendees introduced themselves.</p> <p>No members of the public asked to observe the meeting.</p> <p>The Chair informed the Committee that apologies had been received from Ben Doak.</p> <p>The Chair outlined the objectives of the meeting, which included: a presentation on the microbiological investigations in Cystic Fibrosis, the evidence review on the topics of monitoring pulmonary disease and the drafting of recommendations relating to this topic and, the drafting of protocols for Cystic Fibrosis related diabetes and the effectiveness of different programmes of exercise.</p>				
<b>2. Declarations of interest</b>				
<p>The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was the diagnosis and management of Cystic Fibrosis.</p> <p>The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.</p>				
<b>Name</b>	<b>Job title,</b>	<b>Declarations of Interest, date</b>	<b>Type of</b>	<b>Decision taken</b>

	<b>organisation</b>	<b>declared</b>	<b>interest</b>	
Mandy Byron	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	<p>Mandy has been invited as a speaker at the UK Cystic Fibrosis conference organised by the Cystic Fibrosis Trust.</p> <p>Mandy also attended a meeting to discuss the desire and feasibility of establishing a Cystic Fibrosis Society for health professionals</p>	Personal non-financial specific interests	No further action necessary.
Elaine Edwards	Advanced Physiotherapist, Sheffield children's NHS Foundation Trust	<p>Elaine works on the Cystic Fibrosis unit at Sheffield Children's Hospital and has recruited patients to the following two studies (she is not active in either study and will only see patients in professional capacity):</p> <p>PEOteKT – phase 11a, randomised controlled open label trial of Rosuvastatin for the prevention of Aminoglycoside-induced kidney toxicity in children with Cystic Fibrosis.</p>	Non-personal financial specific interest	No further action necessary

		Vertex study. A phase 3 randomized double blind placebo controlled, parallel group study to evaluate the efficacy and safety of VX-661 in combination with Ivacaftor in subjects aged 12 years and older with CF, homozygous for the F508del-CFTR mutation.		
Zoe Elliott	Lay member	Zoe attended a dinner with the CF Trust.	Personal non-financial non-specific	No further action necessary.
Stephen Holden	Consultant Medical Microbiologist Nottingham University Hospitals NHS Trust	<p>Stephen received a one-off payment from Astellas Pharma for chairing an education meeting relating to Clostridium difficile infection.</p> <p>Stephen performs ongoing consultancy with Profile Pharma. Advisory role limited to matters relating to the introduction of a UK licensed formulation of oral fosfomycin for the treatment of uncomplicated urinary tract infection. Profile Pharma also</p>	Personal financial non-specific	No further action necessary.

		market Promixin for intravenous and nebulised use – these drugs are used in the management of cystic fibrosis but my work for the company does not relate to these products.		
Helen McCabe	Principal Paediatric Dietitian - Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust	Helen has been invited by Nutricia Advanced Medical Care to be part of a meeting to discuss paediatric products/developments.	Personal non-financial specific interest	No further action necessary.
Helen Parrott	Physiotherapist, Clinical Specialty Lead - Adult CF Therapies Royal Brompton Hospital	Helen received an invitation to be involved in an expert panel at the Clinical Advances in CF conference on palliative care for late stage CF.	Non-personal non-financial specific	No further action necessary.
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Keith has been recently reimbursed by Gilead for expenses incurred in the attendance of the 2015 European Cystic Fibrosis conference. Hospitality at said conference from Chiesi Ltd. He also attended annual UKCF Pharmacist Group Steering	Personal financial specific	No further action necessary.

		Committee meeting and study day sponsored by Allergan-Actavis.		
<p>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.</p>				
<p><b>3. Minutes of last meeting</b></p>				
<p>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.</p>				
<p><b>4. Presentations</b></p>				
<p>The Chair introduced SBR, Senior Research Fellow, who gave a presentation on the evidence reviewed for liver disease monitoring among those with cystic fibrosis. The Chair then led the committee through the process of drafting recommendations and LETRs for this topic.</p> <p>The Chair introduced Stephen Holden, co-opted expert member and Consultant medical Microbiologist, who gave a presentation on microbiological investigations in CF.</p> <p>The Chair introduced OA, GV and GM who gave a presentation on the evidence review and health economics on the topic of monitoring pulmonary disease. The Chair then led the committee through the process of drafting recommendations and LETRs for this topic.</p> <p>The Committee thanked everyone for their presentations and contribution to the development of the guideline.</p>				
<p><b>5. Questions and discussion</b></p>				
<p>The committee discussed the draft protocol for the topic of Cystic Fibrosis related diabetes which was presented by SBR. The draft protocol was edited live on screen.</p> <p>The committee discussed the draft protocol for the topic of effectiveness of exercise programmes in CF which was presented by VDN. The draft protocol was edited live on screen.</p>				
<p><b>6. Any other business</b></p>				

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

**Date of next meeting:** 04/11/15

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