

## Cystic Fibrosis Committee meeting 2

**Date:** 21/04/2015

**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)
Andrew Jones (AJ)	(Present for notes 1 – 6)
David Lacy (DL)	(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)

<b>In attendance:</b>		
Ben Doak (NICE)	Guidelines Commissioning Manager	(Present for notes 1 – 6)
Vanessa Delgado Nunes (VDN)	Guideline Lead	(Present for notes 1 – 6)
Justine Reader (JR)	Programme Manager	(Present for notes 1 – 6)
Anne Carty (AC, covering for Annabel Flint)	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)
Paul Jacklin (PJ)	Health Economist	(Present for notes 1 – 6)
Hugo Pedder (HP)	Statistician	(Present for notes 1 – 6)
Ebenezer Ademoisoye (EA)	Health Economist	(Present for notes 1 – 6)

<b>Observers:</b>	
None.	

<b>Apologies:</b>	
Annabel Flint	Project Manager

<b>1. Welcome and objectives for the meeting</b>
<p>The Chair welcomed the Committee members and attendees to the second 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 Annabel Flint.</p> <p>The Chair outlined the objectives of the meeting, which included: a presentation on minimally important differences when making guideline recommendations, a presentation of evidence and the drafting of recommendations relating to the subjects of exocrine pancreatic insufficiency and; the drafting of protocols for ultrasound scanning to detect related liver disease and strategies for prevention and treatment of distal ileal obstruction syndrome.</p>
<b>2. Declarations of interest</b>

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 the Committee 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
Mandy Byron	Consultant Clinical Psychologist - Joint Head of Paediatric Psychology and Play Services – Great Ormond Street Hospital Foundation Trust	<p>Mandy spoke at a meeting arranged by CF Ireland (an Irish charity for patients and family) about psychological issues for parents of children and young people with Cystic Fibrosis.</p> <p>Mandy also spoke at Cystic Fibrosis conference for which usual expenses were covered but she received no personal fee. The title of the speech given was 'Bridging the gap between standards of care and clinical provision of psychology'.</p>	Personal financial non-specific	No further action necessary
Nichola MacDuff	Adult Specialist Nurse, Advanced Clinical Nurse Specialist & Lead Nurse, Black Country Adult CF Centre, Royal Wolverhampton NHS Trust	Nicola's husband is a shareholder in the following companies: GlaxoSmithKline (169 shares) and Lidco (2000 shares).	Personal financial non-specific	No further action necessary
Helen Parrott	Physiotherapist, Clinical Specialty Lead - Adult CF Therapies Royal Brompton Hospital	Helen chaired a meeting where the expenses and refreshments had been paid for by Forest Lab, the content related to Cystic Fibrosis and the medicines used to treat the condition.	Personal financial specific	No further action necessary
Martin	Consultant	Martin was a speaker at All	Personal	No further

Walshaw	Physician in General and Chest Medicine at Royal Liverpool and Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust (formerly The Cardiothoracic Centre – Liverpool NHS Trust), with a special interest in Adult Cystic Fibrosis and Lung Cancer.	Wales conference on Cystic Fibrosis which was sponsored by Avartis but for which he received no personal remuneration.	financial non-specific	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 VDN, Guideline Lead, who gave a presentation on minimally important differences in guideline development.

VDN took questions from the group.

OA presented results of the evidence review on effectiveness of ursodeoxycholic acid for preventing liver disease. The Committee discussed the findings of the review effectiveness of ursodeoxycholic acid for preventing liver disease, drafted recommendations and notes were taken.

SBR and GV presented the results of the evidence review on pancreatic enzymes for

exocrine pancreatic insufficiency. The Committee discussed the review pancreatic enzymes for exocrine pancreatic insufficiency, drafted recommendations and notes were taken.

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

#### **5. Questions and discussion**

The Committee discussed the draft protocol for strategies for prevention and treatment of distal ileal obstruction syndrome which was presented by SBR, Senior Research Fellow. Comments and suggestions were made by the Committee and the protocol was edited on screen and agreed by attendees.

The Committee discussed the draft protocol for ultrasound scanning to detect related liver disease which was presented by OA. Comments and suggestions were made by the Committee and the protocol was edited on screen and agreed by the Committee.

#### **6. Any other business**

VDN raised the issue of clinical questions to be added to the next meeting's agenda. There were no other items of business. MW thanked the Committee for attending and closed the meeting.

**Date of next meeting:** 03/06/2015

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