

## Cystic Fibrosis Committee meeting 16

**Date:** 08/02/2017

**Location:** RCOG London

**Minutes:** Confirmed



<b>Committee members present:</b>	
Martin Walshaw	(Present for notes 1 – 9)
Elaine Edwards	(Present for notes 1 – 9)
Iolo Doull	(Present for notes 1 – 9)
Sarah Collins	(Present for notes 1 – 9)
Alexander Darlington	(Present for notes 1 – 9)
Zoe Elliott	(Present for notes 1 – 9)
Janis Bloomer	(Present for notes 1 – 9)
David Lacy	(Present for notes 1 – 9)
Mandy Bryon	(Present for notes 1 – 9)
Andrew Jones	(Present for notes 1 – 9)
Keith Thompson	(Present for notes 1 – 9)
Sarah Popple	(Present for notes 1 – 9)
Helen Parrott	(Present for notes 1 – 9)
Nichola MacDuff	(Present for notes 1 – 9)
Helen McCabe	(Present for notes 1 – 9)
Stuart Elborn	(Present for notes 1 – 9)

<b>In attendance:</b>		
Andrew Gyton	NICE Commissioning Manager	(Present for notes 1 – 9)
James Hall	NICE Editor	(Present for notes 1 – 9)
Adam Storrow	NICE Business Analyst	(Present for notes 1 – 9)
Lisa Boardman	NGA Guideline Lead	(Present for notes 1 – 9)
Stephen Murphy	NGA Clinical Advisor	(Present for notes 1 – 9)
Fionnuala O'Brien	NGA Project Manager	(Present for notes 1 – 9)
Gemma Villanueva	NGA Systematic Reviewer	(Present for notes 1 – 7)
Gemma Marceniuk	NGA Health Economist	(Present for notes 1 – 9)
Rami Cosulich	NGA Assistant Systematic Reviewer	(Present for notes 1 – 9)
Hugo Peddar	NGA Statistician	(Present for note 4)

**Apologies:**

Alexander Darlington	Committee member
Nichola MacDuff	Committee member
Abigail Moore	NGA Assistant Systematic Reviewer

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

The Chair welcomed the Committee members and attendees to the 16<sup>th</sup> 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:

- Clinical evidence search updates
- Results of updated NMA
- Research recommendations
- Final recommendations

**2. Declarations of interest**

The Chair confirmed that, for the purpose of managing conflicts of interest, the matters under discussion were the NMA and all recommendations made to date which included hypertonic saline.

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
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	I attended a committee meeting of the UK Psychosocial professionals in Cystic Fibrosis on 18 <sup>th</sup> and 19 <sup>th</sup> January 2017. The meeting was sponsored by the pharmaceutical company Teva. Travel expenses	Personal non-financial, non-specific	Declare and participate (hospitality within NICE policy)

		and overnight accommodation were paid for by Teva – within the agreed limits of NICE guidance.		
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	<p>I am the 3rd author on a piece of work about the use of text messages to try and help nebuliser compliance that has been accepted for publication in "Patient Preference and Adherence". It was presented as an oral presentation at the ECFS conference in Basel, Switzerland in June 2016.</p> <p>It was submitted but rejected by the Journal of Cystic Fibrosis in June 2016 and the Journal of Telemedicine and Telecare in 2016.</p> <p>I have not personally and the Trust has not received any financial gain in relation to the piece of work. I have attached a copy of the abstract.</p>	Personal non-financial, non-specific	Declare and participate
Zoe Elliott	Lay member	I have been paid for the communication & marketing work I did for the James Lind Alliance Priority Setting Partnership in Cystic Fibrosis.	Personal financial, non-specific	Declare and participate

The Chair and a senior member of the Developer's team noted that previous interests declared prevent Helen Parrott and Mandy Bryon from partaking in discussions regarding Hypertonic Saline. No other interests prevented 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 who gave a presentation on outcomes of the update searches on the agreed topics. She took questions from the Committee.

The Chair introduced Gemma Marceniuk who presented the updated results of the NMA.

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

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

Gemma Villanueva lead the Committee through a discussion on the Research Recommendations and agreed on the priority ones.

Martin Walshaw, the Chair, Lisa Boardman, Guideline Lead and Stephen Murphy, Clinical Advisor, led the Committee through the recommendations made to date.

### **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:** 05/07/2017 & 06/07/2017

**Location of next meeting:** RCOG, London