Cystic Fibrosis Committee meeting 15

Date: 11/01/2017

Location: Broadway House, EEF Venues London

Minutes: Confirmed



Committee members present:	
Martin Walshaw	(Present for notes 1 – 10)
Elaine Edwards	(Present for notes $1 - 10$)
lolo Doull	(Present for notes $1 - 10$)
Sarah Collins	(Present for notes $1 - 10$)
Alexander Darlington	(Present for notes $1 - 10$)
Zoe Elliott	(Present for notes $1 - 10$)
Janis Bloomer	(Present for notes $1 - 10$)
David Lacy	(Present for notes $1 - 10$)
Mandy Bryon	(Present for notes $1 - 10$)
Andrew Jones	(Present for notes $1 - 10$)
Keith Thompson	(Present for notes $1 - 10$)
Sarah Popple	(Present for notes $1 - 10$)
Helen Parrott	(Present for notes $1 - 10$)
Nichola MacDuff	(Present for notes $1 - 10$)
Helen McCabe	(Present for notes $1 - 10$)

In attendance:		
Andrew Gyton	NICE Commissioning Manager	(Present for notes 6 – 10)
Alex Bates	NGA Guideline Lead	(Present for notes $1 - 10$)
Lisa Boardman	NGA Guideline Lead	(Present for notes $1-9$)
Stephen Murphy	NGA Clinical Advisor	(Present for notes $1 - 10$)
Fionnuala O'Brien	NGA Project Manager	(Present for notes $1 - 10$)
Gemma Villanueva	NGA Systematic Reviewer	(Present for notes 5 – 10)
Gemma Marceniuk	NGA Health Economist	(Present for notes $1 - 10$)
Rami Cosulich	NGA Assistant Systematic Reviewer	(Present for notes $5 - 10$)

Apologies:

Abigail Moore

NGA Assistant Systematic Reviewer

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the 15th 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:

- Evidence review and draft recommendations for cystic fibrosis related diabetes
- Update on the evidence review of complications of CF and confirm recommendations
- Review recommendations

2. Declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was CFRD, Complications of CF and recommendations 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
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	British Thoracic Society Winter Meeting Dec 2016 has abstract submitted as a poster with my name as an author which is a survey on the role of the physiotherapy for the CF patient in ITU	Personal non- financial, specific	Declare and participate
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric	Attended a study day at the Royal Society of Medicine on 15 th November 2015	Non-personal financial, non- specific	Declare and participate

	Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	on Cystic Fibrosis in children and adults. I was not a speaker and received no fees or expenses for attending but the fee to attend the day was subsidised for all attendees by an unrestricted educational grant to the RSM from Teva pharmaceuticals.		
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Wrote a manuscript entitled 'Conventional therapies and emergent precision medicines for cystic fibrosis: challenges and opportunities' which was published in the Clinical Pharmacist journal (Nov 2016). This was commissioned by the publisher – there was no sponsorship from the pharmaceutical industry, nor remuneration received for the piece. The manuscript was based on published information already in the public domain, and was based on current UK practice and guidance. There was no disclosure of information discussed in the NICE GDG	Personal non- financial, non- specific	Declare and participate

Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	meetings, the main topic (precision medicine) is outside the scope of the current guideline, and the guideline does not reference the manuscript. A delegate at the UK CF Microbiology Consortium held in Liverpool on 25th November 2016. This meeting received sponsorship from Teva Pharmaceuticals Ltd. I did not receive	Personal non- financial, non- specific	Declare and participate (hospitality within NICE Policy)
		any personal financial or other incentive in relation to this meeting.	2	
Martin Walshaw	Consultant 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	Was a delegate at the UK CF Microbiology Consortium held in Liverpool on 25th November 2016. This meeting received sponsorship from Teva Pharmaceuticals Ltd. Chaired a meeting during this consortium but the content did not relate to any topics covered in this guideline. No personal financial or other incentive in relation to this meet received.	Personal non- financial, non- specific	Declare and participate.
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	On the 21/9/16 attended a network meeting for the hospitals that form the	Personal non- financial, non- specific	Declare and participate (hospitality within NICE Policy)

network for Sheffield Children's Foundation Hospital Cystic Fibrosis service. The venue and lunch was paid for using sponsorship from the drug company Vertex. None of the company's representatives were present during the meeting times and they had no input into the agenda items discussed.
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The Chair and a senior member of the Developer's team noted that the interests declared by Helen Parrott and Mandy Bryon have resulted in them withdrawing from 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 James Hall, NICE Editor, who gave a presentation on the NICE editing process and took questions from the committee.

The Chair introduced Gemma Villanueva who gave a presentation on the clinical evidence of cystic fibrosis related diabetes and took questions from the Committee.

Alex Bates, Guideline Lead, led the Committee through the process of drafting recommendations for the topic of CF related diabetes.

The Chair introduced Rami Cosulich who gave an update presentation on the complications of CF.

Alex Bates, Guideline Lead, led the Committee through the process of drafting recommendations for complications of CF.

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.

Martin Walshaw, the Chair, Alex Bates, 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: 08/02/2017

Location of next meeting: RCOG, London