

Cystic Fibrosis Committee meeting 9

Date: 15/06/2016



Location: Royal College of Obstetricians and Gynaecologists, London.

Minutes: Confirmed

Committee members present:	
Martin Walshaw	(Present for notes 1 – 6)
Mandy Bryon	(Present for notes 1 – 6)
Iolo Doull	(Present for notes 1 – 6)
Sarah Collins	(Present for notes 1 – 6)
Alexander Darlington	(Present for notes 1 – 6)
Zoe Elliot	(Present for notes 1 – 6)
Helen McCabe	(Present for notes 1 – 6)
Andrew Jones	(Present for notes 1 – 6)
Keith Thompson	(Present for notes 1 – 6)
Janis Bloomer	(Present for notes 1 – 6)
David Lacy	(Present for notes 1 – 6)
Sarah Popple	(Present for notes 1 – 6)
Helen Parrott	(Present for notes 1 – 6)
Nichola MacDuff	(Present for notes 1 – 6)

In attendance:		
Shona Burman-Roy	Senior Research Fellow	(Present for notes 1 – 6)
Vanessa Delgado Nunes	Senior Research Fellow and Guideline Lead	(Present for notes 1 – 6)
Annabel Flint	Project Manager	(Present for notes 1 – 6)
Gemma Villanueva	Research Fellow	(Present for notes 4 – 6)
Hugo Pedder	Statistician	(Present for notes 1 – 6)
Gemma Marceniuk	Health Economist	(Present for notes 1 – 6)
Rami Cosulich	Research Assistant	(Present for notes 1 – 6)
Katie Perryman-Ford	NICE Guideline	(Present for notes 1 – 6)

	Commissioning Manager	
Stephen Holden	Co-opted member	(Present for notes 1 – 6)
Stuart Elborn	Co-opted member	(Present for notes 1 – 6)

Observers:	
None.	

Apologies:	
Stephen Murphy	Clinical Director
Alexander Darlington	Committee member
Elaine Edwards	Committee member

1. Welcome and objectives for the meeting
<p>The Chair welcomed the Committee members and attendees to the tenth guideline committee meeting on Cystic Fibrosis. The Committee members and attendees introduced themselves.</p> <p>The Chair informed the Committee that apologies had been received and these are noted above.</p> <p>The Chair outlined the objectives of the meeting, which included: the presentation of the health economics for chronic antimicrobial treatment, the evidence review for cross infection and drafting the protocol for complications of cystic fibrosis.</p>

2. Declarations of interest
<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>

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and	Attended a conference titled "Cystic Fibrosis Masterclass" on 20th May. Expenses for	Personal financial, specific	Declare and participate [as ivacaftor and lumacaftor are outside of the scope of the guideline

	Play Services, Great Ormond Street Hospital Foundation Trust	travel and overnight expenses, dinner and time spent on slide preparation sponsored by Vertex as an invited speaker. The topic of the presentation was "The psychological and developmental complexities that make adherence so challenging" 15/06/2016		(Vertex is the manufacturer)]
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Attended the European CF conference from 8th – 11th June. Attended two dinners with CF team and other CF teams from the UK. One meal was sponsored by Acativs Allergan and one sponsored by Chiesi. No personal sponsorship received, just dinners out with the rest of the CF team from these pharmaceutical companies. No personal finance was received. 15/06/2016	Personal non-financial, specific	Declare and participate (expenses within NICE policy)
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Attendance at the European Cystic Fibrosis meeting in June 2016. Attended a hospitality event which was sponsored by Chiesi and Allergan. 15/06/2016	Personal non-financial, non-specific The hospitality was within the NICE policy and therefore not considered financial, the meeting was	Declare and participate (expenses within NICE policy)

			general and not directly related to the content of the guideline = non-specific	
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Attended a meal funded by Actavis. 15/06/2016	Personal financial, specific	Declare and participate (expenses within NICE policy)
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Organised a meeting to establish a British Cystic Fibrosis Society at the European CF Society meeting. Actavis supplied funding for the room hire. 15/06/2016	Non-personal financial, specific	Declare and participate (expenses within NICE policy)
Stuart Elborn	Dean, School of Medicine, Dentistry and Biomedical Sciences, Queen's University, Belfast	Provide ongoing consultancy on clinical trial design and leadership for Vertex, Novartis, Gilead, Celtaxsys, Abbvie/Galapagos. All drugs are in development so there is no overlap with this guideline. 15/06/2016	Personal financial, specific	Declare and participate (is a co-opted expert to the guideline and there is no overlap between the content of the guideline and the consultancy provided)
Stuart Elborn	Dean, School of Medicine, Dentistry and Biomedical Sciences, Queen's University, Belfast	Lead for clinical trials with Vertex, Novartis and Celtaxsys, ProQr and Flatley Laboratories. This is ongoing. 15/06/2016	Personal non-financial, specific	Declare and participate (is a co-opted expert to the guideline)
Martin Walshaw	Consultant Physician in General and Chest Medicine at Royal Liverpool and Broadgreen	Attended several non-promotional pharmaceutical company sponsored evening meals at the European CF	Personal non-financial, specific	Declare and participate(hospitality within NICE policy)

	University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust	Conference in Basel, as part of large groups of UK CF healthcare professionals. 15/06/2016		
<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>3. Minutes of last meeting</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>4. Presentations</p>				
<p>The Chair introduced Gemma Villanueva, Senior Research Fellow, and Rami Cosulich, Research Assistant, who gave a presentation on the evidence review for the topic of cross infection. The Chair then led the committee through the process of drafting recommendations and LETRs for this topic.</p> <p>Vanessa Delgado Nunes, Senior Research Fellow and Guideline Lead led the Committee through the process of drafting the protocol for the topic of complications of cystic fibrosis.</p> <p>Gemma Marceniuk gave a presentation of the health economic model for chronic antimicrobials and took questions from the Committee.</p> <p>The Committee thanked everyone for their presentations and contribution to the development of the guideline.</p>				
<p>5. Questions and discussion</p>				
<p>6. Any other business</p>				
<p>There were no other items of business. MW thanked the Committee for attending and closed the meeting.</p>				

Date of next meeting: 20/07/16

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