

Cystic Fibrosis Committee meeting 3

Date: 03/06/2015

NICE National Institute for
Health and Care Excellence

Location: Royal College of Obstetricians and Gynaecologists, London.

Minutes: Confirmed

Committee members present:		
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)
Keith Thompson (KT)		(Present for notes 1 – 6)
Elaine Edwards (EE)		(Present for notes 1 – 6)

In attendance:		
Ben Doak (NICE)	Guidelines Commissioning Manager	(Present for notes 1 – 6)
Stephen Murphy	Clinical Director	(Present for notes 1 – 6)
Vanessa Delgado Nunes (VDN)	Guideline Lead	(Present for notes 1 – 6)
Anne Carty (AC, Covering for	Project Manager	(Present for notes 1 – 6)

Annabel Flint)		
Ronke Fawehinmi (RF)	Interim 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)
Alex Bates (AB)	Health Economist	(Present for notes 1 – 6)
Hugo Pedder (HP)	Statistician	(Present for notes 1 – 6)
Paul Jacklin (PJ)	Health Economist	(Present for notes 1 – 6)

Observers:

None.

Apologies:

Annabel Flint	Project Manager
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Alexander Darlington	Committee member
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1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the third guideline committee meeting on Cystic Fibrosis. The Committee members and attendees introduced themselves.

No members of the public asked to observe the meeting.

The Chair informed the Committee that apologies had been received from AD and AF.

The Chair outlined the objectives of the meeting, which included: the discussion of the draft protocols for monitoring pulmonary disease; the effectiveness of chest physiotherapy techniques; the effectiveness of immunomodulatory agents; the effectiveness of antimicrobial therapy; effectiveness of mucolytic therapy and monitoring for liver disease. The primary treatment and secondary prevention of

distal ileal obstruction syndrome evidence review was also to be discussed.

2. Declarations of interest

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 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
Janis Bloomer	Paediatric Nurse Specialist (Children and young people) Cystic Fibrosis, Great North Children's Hospital Royal Victoria Infirmary	Janis will be attending the European Cystic Fibrosis meeting in Brussels and received sponsorship towards expenses of £250 from Chiesi and £50 from Forest to help towards the cost of attending said event in June 2015.	Personal financial specific	No further action necessary.
Mandy Byron	Consultant Clinical Psychologist - Joint Head of Paediatric Psychology and Play Services – Great Ormond Street Hospital Foundation Trust	Mandy will be attending the European Cystic Fibrosis meeting in Brussels, where she will receive evening hospitality from Pharmaceutical firms (Chiesi, Umedica and Novartis, who make CF antibiotics). These evenings are non-promotional. She has also received	Personal financial specific	No further action necessary.

		sponsorship regarding expenses only from Chiesi.		
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Andrew was invited by the Cystic Fibrosis Foundation Therapeutics Development Network Data Safety Monitoring Board to conduct the Data Safety Monitoring of a Phase 2 study on the investigation of a product which is an anti-inflammatory product produced by Corbus – who are not involved with the study (he is not receiving any payment for this work).	Personal non-financial non-specific	No further action necessary.
David Lacy	General Paediatrician Wirral University Teaching Hospital NHS Foundation Trust	David will be attending the European Cystic Fibrosis meeting in Brussels, where he will receive evening hospitality from Pharmaceutical firms (Chiesi, Umedica and Novartis, who make antibiotics used in the treatment of Cystic Fibrosis). These evenings are non-promotional.	Personal financial specific	No further action necessary

Helen McCabe	Principal Paediatric Dietitian - Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust	Helen will be attending the European CF meeting in Brussels, where her team will receive evening hospitality from Pharmaceutical firms (Chiesi, Umedica and Novartis, who make antibiotics used in the treatment of Cystic Fibrosis). These evenings are non-promotional.	Personal financial specific	No further action necessary
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Currently preparing a manuscript for a service development project on the use of inhaled antibiotics (namely aztreonam lysine in combination with another agent - tobramycin or colomycin) in people with CF, prescribed within the UK commissioning policy. This work has not been commercially sponsored but he has had access to an independent economic consultant who has been remunerated by	Personal non-financial specific	No further action necessary.

		Gilead Sciences Inc.		
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 (formerly The Cardiothoracic Centre – Liverpool NHS Trust), with a special interest in Adult Cystic Fibrosis and Lung Cancer.	Martin will be attending the European CF meeting in Brussels, taking 14 other people from his MDT where they will receive evening hospitality from Pharmaceutical firms (Chiesi, Umedica and Novartis, who make antibiotics used in the treatment of Cystic Fibrosis). These evenings are non-promotional.	Personal financial specific	No further action necessary.

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 GV, Research Fellow, who gave a presentation on the primary treatment and secondary prevention of distal ileal obstruction syndrome. GV took questions from the group.

The Committee discussed the evidence and drafting recommendations for treatment

and secondary prevention of distal ileal obstruction syndrome. Notes were made live on screen.

The Committee thanked GV for the presentation and contribution to the development of the guideline.

5. Questions and discussion

The committee discussed the draft protocol for monitoring pulmonary disease presented by SBR. The draft protocol was edited live on screen.

The committee discussed the draft protocol for the effectiveness of chest physiotherapy techniques presented by OA. The draft protocol was edited live on screen.

The committee discussed the draft protocol for the effectiveness of immunomodulatory agents presented by OA. The draft protocol was edited live on screen.

The committee discussed the draft protocols for antimicrobial therapy agents presented by OA. The draft protocol was edited live on screen.

The committee discussed the draft protocol for monitoring liver disease which was presented by SBR. The draft protocol was edited live on screen.

6. Any other business

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

Date of next meeting: 19/08/2015

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