

Cystic Fibrosis Committee meeting 14

Date: 23/11/2016

Location: Hodgkin Building, Guy's Campus.

Minutes: Confirmed

NICE National Institute for
Health and Care Excellence

Committee members present:		
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)
Helen McCabe		(Present for notes 1 – 9)
Helen Parrott		(Present for notes 1 – 9)
Stuart Elborn		(Present for notes 1 – 9)
Sarah Popple		(Present for notes 1 – 9)

In attendance:		
Andrew Gyton	NICE Commissioning Manager	(Present for notes 1 – 9)
Andrew Storrow	NICE Business Analyst	(Present for notes 1 – 9)
Alex Bates	NGA Guideline Lead	(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 – 9)
Gemma Marceniuk	NGA Health Economist	(Present for notes 1 – 5)
Rami Cosulich	NGA Assistant Systematic Reviewer	(Present for notes 1 – 9)
Bishal Bhandari	NGA Assistant Systematic Reviewer	(Present for notes 1 – 4)

Apologies:	
Keith Thompson	Committee member
Nichola MacDuff	Committee member
Thomas Feist	NICE Guideline Co-ordinator
Stephen Murphy	NGA Clinical Advisor
Abigail Moore	NGA Assistant Systematic Reviewer

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the thirteenth 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:

- The presentation on the complications of CF
- Transition from children to adult services
- Update on the rhDNase economic model

2. Declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matters under discussion were transition from children's to adults services, complications of CF, re-cap on rhDNase economic evidence and resource impact.

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
Sarah Pople	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Attended a joint meeting between paediatric and adult CF service in Leicester. Meeting venue and refreshments were sponsored by Actavis pharmaceuticals (pulmozyme) followed by a meal	Personal non-financial, specific	Declare and participate

		afterwards. There was no promotional content to the meeting and nothing specific to this guideline was discussed.		
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Attended the Cystic Fibrosis Pharmacist Group study day in Birmingham Jurys Inn – Day was sponsored by Actavis pharmaceuticals (pulmozyme). The meeting venue and lunch was provided by the sponsors.	Personal non-financial, specific	Declare and participate
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Invited speaker at Neonatal and Paediatric Pharmacists Group Conference (NPPG) Introduction to Paediatric Pharmaceutical Care study day. Delivered a teaching session on cystic fibrosis to pharmacists new to paediatrics. Organised by profile productions and the conference has various pharmaceutical industry stands but none were relevant to cystic fibrosis. Will receive an honorarium for this.	Personal financial, non-specific	Declare and participate
Sarah	Pharmacist,	Facilitated a	Personal non-	Declare and

Popple	Leicester Royal Infirmary Children's Hospital / De Montfort University	roundtable at the NPPG conference above on 'New treatments in CF and funding issues in Shared Care'. It covered recent developments in CF care, newly licensed drugs and those still in clinical trials. It did not focus on any one new treatment or any one pharmaceutical company. Nothing sensitive to this guideline was discussed. For this I received one night's accommodation at the conference venue funded by profile productions.	financial, specific	participate (expenses within NICE Policy)
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Received sponsorship from Abbvie pharmaceuticals for registration and accommodation for one night at the Neonatal and Paediatric Pharmacists Group conference. Abbvie have no CF interest relevant to this guideline.	Personal financial, non-specific	Declare and participate (no relevance to the topics discussed within the CF guideline)
Stuart Elborn	Dean, School of Medicine, Dentistry and Biomedical Sciences, Queen's University, Belfast	BBC interview on new data on Orkambi. No financial transaction involved.	Personal non-financial, specific	Declare and participate – (as a co-opted member)
Andy Jones	Consultant and Honorary Reader in Respiratory	Attended North American CF Conference in	Personal non-financial, specific	Declare and participate (hospitality was

	Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	October 2016 including a non-promotional event for a large group of CF healthcare professionals sponsored by Chiesi		not classed as excessive or extravagant and so within the NICE Policy)
Andy Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Attended the Royal Society Medical Meeting (as a delegate) in November 2016. The meeting received an unrestricted educational grant from TEVA.	Non-personal financial, non-specific	Declare and participate.
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	I spoke at the RSM CF meeting on 15 th November 2016. My talk was entitled the Nutritional Management of CF. I did not receive any financial reimbursement for this.	Personal non-financial, specific	Declare and participate
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	I received payment from Astra Zeneca to give a lecture on Asthma in Childhood	Personal financial, non-specific	Declare and participate (Asthma is not discussed in this guideline)
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	I received payment to attend a meeting on asthma in childhood from Bohringer Ingelheim	Personal financial, non-specific	Declare and participate (Asthma is not discussed in this guideline)
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	I attended a meeting on asthma in childhood where my meal was paid for by GSK	Personal non-financial, non-specific	Declare and participate (Asthma is not discussed in this guideline)
Helen Parrott	Physiotherapist, Clinical	Advisory board on 'Adherence'	Personal financial, non-	Advice taken from NICE -

	Specialty Lead, Adult CF Therapies Royal Brompton Hospital	run by Hammell Communications for Chiesi (no conversations regarding drugs or topics relevant to the guideline were discussed) – consultancy fee of £350 received (14/11/16)	specific	Declare and withdraw from any discussion regarding hypertonic saline or Tobramycin
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Attended an advisory group on 14 th November 2016 to advise on the development of an adherence training programme for CF professionals. The training programme is being developed by Hammel, behaviour change consultants but the meeting was sponsored by Chiesi. I was given an attendance fee but not travel or other expenses. Advice from NICE was sought before attending this meeting and their guidance was followed. I am prepared to sit out of any future meeting where drugs produced by Chiesi are discussed.	Personal financial, non-specific	Advice taken from NICE - Declare and withdraw from any discussion regarding hypertonic saline or Tobramycin

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 Bishal Bhandari who gave a presentation titled “Transition from Children’s services to Adult Services”.

The Chair introduced Rami Cosulich who gave a presentation titled “Complications of CF”.

The Chair introduced Andrew Storrow who gave a presentation on resource impact of the recommendations in the guideline.

The Chair introduced Gemma Marceniuk who gave a presentation titled “Health Economics Recap on daily vs alternate dornase alpha (rDNase)”.

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.

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: Broadway House, Tothill Street, SW1H 9NQ