

Cystic Fibrosis Committee meeting 1

Date: 03/03/2015

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 – 5)
Mandy Bryon (MB)	(Present for notes 1 – 5)
Andrew Jones (AJ)	(Present for notes 1 – 5)
David Lacy (DL)	(Present for notes 1 – 5)
Sarah Popple (SP)	(Present for notes 1 – 5)
Iolo Doull (ID)	(Present for notes 1 – 5)
Sarah Collins (SC)	(Present for notes 1 – 5)
Alexander Darlington (AD)	(Present for notes 1 – 5)
Helen McCabe (HM)	(Present for notes 1 – 5)
Zoe Elliot (ZE)	(Present for notes 1 – 5)

In attendance:		
Ben Doak (NICE)	Guidelines Commissioning Manager	(Present for notes 1 – 5)
Alix Johnson (NICE)	Public Involvement Adviser	(Present for notes 1 – 5)
Vanessa Delgado Nunes (VDN)	Guideline Lead	(Present for notes 1 – 5)
Kate Coles (KC, covering for Annabel Flint)	Project Manager	(Present for notes 1 – 5)
Shona Burman-Roy (SBR)	Senior Research Fellow	(Present for notes 1 – 5)
Omnia Abdulrazeg (OA)	Research Fellow	(Present for notes 1 – 5)

Gemma Villanueva (GV)	Research Fellow	(Present for notes 1 – 5)
Timothy Reeves (TR – covering for Zosia Beckles)	Information Scientist	(Present for notes 1 – 5)
Paul Jacklin (PJ)	Health Economist	(Present for notes 1 – 5)

Observers:	
None.	

Apologies:	
Annabel Flint	Project Manager

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the first 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 Annabel Flint.

The Chair outlined the objectives of the meeting, which included: an introduction to guideline development, patient involvement in guideline development and a discussion on the clinical questions for the Cystic Fibrosis guideline.

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 the Committee to verbally declare any interests on appointment and since then.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric	Mandy is a member of the UK Heads of Paediatric Psychology Special interest Group.	Personal non-financial non-specific	No further action necessary

	Psychology and Play Services – Great Ormond Street Hospital Foundation Trust			
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services – Great Ormond Street Hospital Foundation Trust	<p>Mandy is Co-Chair of the UK Psychosocial Professionals in a Cystic Fibrosis group and a committee member of the Cystic Fibrosis Trust Clinical Advisory Group, the Cystic Fibrosis trust Peer review Oversight Board and the European Cystic Fibrosis Special Interest Group</p> <p>Mandy has published 5 articles related to Cystic Fibrosis in the past 2 years (detailed below):</p> <p>Bryon, M, Havermans, T, Noordhoek, J. (2012) The social life of adolescents with cystic fibrosis. Healthcare issues and Challenges in Adolescents with Cystic Fibrosis. C. Castellani, S Elborn, H Heijerman (eds).European Cystic Fibrosis Society, Karup: Denmark.</p> <p>Randlesome, K, Bryon M, Evangeli, M (2013) Developing a measure of eating attitudes and behaviours in cystic fibrosis Journal of Cystic Fibrosis 12; 15–21.</p> <p>Alan R. Smyth, Scott C. Bell, Snezana Bojcin, Mandy Bryon, Alistair Duff, Patrick Flume, Nataliya Kashirskaya, Anne Munck, Felix Ratjen, Sarah Jane Schwarzenberg, Isabelle Sermet-Gaudelus, Kevin W. Southern, Giovanni</p>	Personal non-financial specific.	No further action necessary

		<p>Taccetti, Gerald Ullrich, Sue Wolfe. (2014) European Cystic Fibrosis Society Standards of Care: Best Practice guidelines, Journal of Cystic Fibrosis 13 (2014) S23–S42.</p> <p>A Kevin Webb, Mandy Bryon (2014) The International Depression Epidemiological Study (TIDES): unfinished business? Thorax 2014; 69:1067-1068, doi: 10.1136/thoraxjnl-2014-206200.</p> <p>Bryon, M (2015) Eating Disorders and Disturbed Eating Attitudes and Behaviours Typical in CF. In Watson RR, Diet and Exercise in Cystic Fibrosis, Elsevier, San Diego, CA. p69-72.</p>		
Sarah Collins	CF specialist dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	<p>On the 5th February 2012, as a member of the Abott Advisory Panel on Pancreatic Exocrine Insufficiency, attended a one off meeting which was completed in her own time and received an honorarium and travel costs in return.</p> <p>On the 7-8th March 2014 she was an invited speaker at the Paediatric Expert Summit in Dubai, sponsored by Abbott – flights, transfers and accommodation provided and honorarium received. Completed in own time.</p>	Personal financial specific	No further action necessary
Sarah Collins	CF specialist dietician, Nutrition & Dietetic Department, Royal	Sarah is the current Chair of the UK Dieticians CF Interest group – this role is voluntary and she receives no financial contributions, she is due to stand down as chair in May	Personal non-financial specific	No further action necessary

	Brompton Hospital	2016. Sarah also holds the position of Chair of the UK Dieticians CF group, who are writing a consensus document on the Nutritional management of CF. This role is voluntary and she receives no financial contributions for this.		
Alexander Darlington	Lay member and PHD student.	Alexander is currently undertaking a PhD studentship as part of the Synthetic Biology Centre for Doctoral Training, joint funded by the BBSRC (Biotechnology and Biological Sciences Research Council) and EPSRC (Engineering and Physical Sciences Research Council). Additional funding for the centre itself and its infrastructure is provided by Shell Global Solutions, GlaxoSmithKline, Microsoft, DSTL (Defence Science and Technology Laboratory), Crysalin, Proctor and Gamble, DNA2 and Syngenta.	Personal non-financial non-specific	No further action necessary
Alexander Darlington	Lay member and PHD student	Alexander contributed to a manuscript that is currently in press. The work was carried out in 2012 and was funded by the CF Trust. The paper was an investigation of the non-nervous innervation of secretions in the airways. In the long term this research could inform post-transplant lung care but that is mainly conjecture – it was simply a physiological/pharmacological 'basic science' study on the airways of the sheep rather than a clinical study.	Personal non-financial specific	No further action necessary

Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	In June 2014, Iolo gave a lecture on childhood asthma for Novartis Educational. In December 2014, he gave lectures on asthma for Astra Zeneca Educational.	Personal financial non-specific	No further action necessary
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	In March 2014, he was a member of the Gilead Advisory Panel on the use of nebulised aztreonam in CF	Personal financial specific	No further action necessary
Zoe Elliott	Lay member	Zoe is a member of the Cystic Fibrosis Trust' Strategic Implementation Board, a lay advisory group for research for patient benefit trial and the Cystic Fibrosis Trust' disbanded Principle Advisory Group. Zoe is also a Lay reviewer for the Cochrane Cystic Fibrosis and Genetic Disorders group.	Personal non-financial specific	No further action necessary
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Forest Pharmaceuticals have provided sponsorship for Andrew's CF Centre's annual away day team meeting (which he helps to organise and run). Andrew participated in a multicentre project evaluating clinical outcome of use of nebulised Aztreonam - this project is sponsored by Gilead Sciences. He has also spoken at the national Irish CF Meeting – Gilead sponsor the meeting and covered the cost of return travel.	Personal non-financial specific	No further action necessary

		Andrew is a Trustee of the UK Cystic Fibrosis Trust.		
David Lacy	General Paediatrician Wirral University Teaching Hospital NHS Foundation Trust	David attended a meal paid for by Chiesi at the European CF conference in Brussels.	Personal non-financial specific	No further action necessary
Helen Parrott	Physiotherapist , Clinical Specialty Lead - Adult CF Therapies Royal Brompton Hospital	Received a consultation fee of £500 for participation on an advisory board run by Forest Pharmaceuticals on nebuliser devices	Personal financial specific	No further action necessary
Helen Parrott	Physiotherapist , Clinical Specialty Lead - Adult CF Therapies Royal Brompton Hospital	Helen annually attends a professional study day (ACPCF) which is part sponsored by Forest and part personally funded (January 2015). Helen has published work under the following titles: Clinical effects of Mannitol in adults with Cystic Fibrosis (co-author, for presentation at the European CF conference, June 2015 in Brussels), Tolerability of inhaled dry powder Mannitol – 1 year follow up (co-author) for presentation at the European CF conference (June 2015 in Brussels), Inhaled therapy in CF – agents, devices, regimens (co-author, for publication in June issue of Breathe) and 'Cystic Fibrosis' (Bilton and Bush, co-author of the physiotherapy chapter due for publication in summer	Personal non-financial specific	No further action necessary

		2015). Helen personally established and attends a CF Physiotherapy prescribers continuing professional development group which is fully funding by Forest (including speakers fees, travel, expenses and refreshments). March 2015		
Sarah Popple	Pharmacist - Leicester Royal Infirmary Children's Hospital / De Montfort University	Sarah attended Cystic Fibrosis Pharmacists Group study day sponsored by Actavis Pharmaceuticals (Forest Laboratories) manufacturer of Colomycin. She also attended an educational meeting with lunch provided. Sarah was invited to speak on Cystic Fibrosis management at parallel study day to NPPG conference for which will receive honorarium of £100 paid by Profile productions (conference organiser not the pharmaceutical company).	Personal financial specific	No further action necessary
Sarah Popple	Pharmacist - Leicester Royal Infirmary Children's Hospital / De Montfort University	Sarah has had funding approved from Abbvie pharmaceuticals (Synagis manufacturer – not of significant relevance to Cystic Fibrosis) to attend Neonatal and Paediatric Pharmacists Group Conference November 2015.	Personal financial non-specific	No further action necessary .
Martin Walshaw	Consultant Physician in General and Chest Medicine at Royal Liverpool and Broadgreen	For the last 5 years, he has provided patients for clinical trials of potential new therapies from Pharmaceutical companies including Vertex, Aptalis, AstraZeneca and	Non-personal financial specific	No further action necessary

	<p>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.</p>	<p>AlgiPharma. All remuneration was given to the Liverpool Heart and Chest Research Funds.</p>		
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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. Presentations

The Chair introduced TR, Information Scientist, who gave a presentation on Information Science in guideline development.

The Chair introduced PJ, Health Economist, who gave a presentation on Health Economics in guideline development.

The Chair introduced BD, Guidelines Commissioning Manager, who gave a presentation on how NICE guidelines are developed.

The Chair introduced AJ, Public Involvement Advisor, who gave a presentation on patient involvement in guideline development.

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

4. Questions and discussion

The Committee discussed the final scope for the NICE guideline on Cystic Fibrosis and were given the opportunity to ask questions.

OA and VDN led the Committee through an introduction to drafting protocols, reviewing evidence and an introduction to GRADE.

VDN led the Committee through a discussion on the clinical questions for the Cystic

Fibrosis guideline.

SBR led the Committee through the process of drafting the protocol for the topic of effectiveness of enzyme replacement in the treatment of exocrine pancreatic insufficiency.

5. Any other business

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

Date of next meeting: 21/04/2015

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