

## **Membership of Cystic Fibrosis Guideline Committee**

The Committee will operate as an advisory Committee to NICE's Board, developing a guideline on the diagnosis and management of cystic fibrosis

The terms of reference and standing orders for the Committee can be found in [appendix D of Developing NICE guidelines: the manual](#).

The Committee has 17 members, to include 15 core members and 2 topic expert members.

## Membership list

Agreed Constituency	Name	Job Title, Organisation	Comment
<b>Chair</b>			
Cystic fibrosis physician - adult (someone working in tertiary care)	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	
<b>Core members</b>			
Cystic fibrosis specialist Psychologist (ideally with family therapy experience)	Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	
Paediatric cystic fibrosis specialist nurse	Janis Bloomer	Paediatric Nurse Specialist (Children and young people) Cystic Fibrosis, Great North Children's Hospital Royal Victoria Infirmary	
Adult cystic fibrosis specialist dietician	Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	

Committee membership list – Cystic Fibrosis Guideline Committee

Lay member	Alexander Darlington	Lay member	
Cystic fibrosis physician - paediatrician (tertiary care)	Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	
Physiotherapist with experience in caring for people with cystic fibrosis (Paediatric)	Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	
Lay member	Zoe Elliott	Lay member	
Cystic fibrosis physician - adult (tertiary care)	Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	
General paediatrician part of a shared care clinic	David Lacy	General Paediatrician Wirral University Teaching Hospital NHS Foundation Trust	
Adult cystic fibrosis specialist nurse	Nichola MacDuff	Adult Specialist Nurse, Advanced Clinical Nurse Specialist & Lead Nurse, Black Country Adult CF Centre, Royal Wolverhampton NHS Trust	
Paediatric cystic fibrosis specialist dietician	Helen McCabe	Principal Paediatric Dietitian - Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation	

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		Trust	
Physiotherapist with experience in caring for people with cystic fibrosis (Adults)	Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	
Paediatric cystic fibrosis specialist Pharmacist	Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	
Adult cystic fibrosis specialist Pharmacist	Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	
GP			No applications received
<b>Topic expert members</b>			
Adult Physician – expert witness	Stuart Elborn	Dean, School of Medicine, Dentistry and Biomedical Sciences, Queen's University, Belfast	
Microbiologist – expert witness	Stephen Holden	Consultant Medical Microbiologist Nottingham University Hospitals NHS Trust	

**Date last reviewed:** 16/03/2017

## Declaration of Interests

The effective management of conflicts of interests is an essential element in the development of the guidance and advice that NICE publishes. Please refer to the NICE website for the [Policy on Conflicts of Interest](#).

<b>Name</b>	<b>Job title, organisation</b>	<b>Declarations of Interest, date declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Member of the UK Heads of Paediatric Psychology Special Interest Group 03/03/2015	Personal non-financial, non-specific	Declare and participate
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Co-Chair of the UK Psychosocial Professionals in a Cystic Fibrosis group sponsored by Forest Pharmaceuticals 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 (term of office ending June 2014) 03/03/2015	Personal non-financial, specific	Declare and participate
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Registered stakeholders of the Clinical Reference Groups for Cystic Fibrosis 03/03/2015	Personal non-financial, specific	Declare and participate
Mandy Bryon	Consultant Clinical	Published 5 articles related to Cystic Fibrosis:	Personal non-	Declare and participate

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	<p>Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust</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, Evangelii, 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 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.</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> <p>03/03/2015</p>	<p>financial, specific</p>	<p>(none of these are covered as part of the guideline scope)</p>

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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 Play Services, Great Ormond Street Hospital Foundation Trust	Speaker at a meeting arranged by CF Ireland about psychological issues for parents of children and young people with Cystic Fibrosis. The title of the presentation was “Family Matters – finding the balance with CF”. No personal fees received but CF Ireland paid for travel and overnight expenses. 21/04/2015	Personal financial, non-specific	Declare and participate (expenses within NICE Hospitality Policy and Travel and Subsistence Policy)
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Speaker at Cystic Fibrosis conference on ‘Bridging the gap between standards of care and clinical provision of psychology’. 21/04/2015	Personal non-financial, non-specific	Declare and participate (not covered as part of the guideline scope)
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Attended dinner sponsored by Actavis pharmaceuticals at the European Cystic Fibrosis conference. No sponsorship received, just dinners out with the rest of the CF team from these pharmaceutical companies. 03/06/2015	Personal financial, non-specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Invited speaker at the UK Cystic Fibrosis conference organised by the Cystic Fibrosis Trust. This was the annual CF conference arranged by the CF Trust. My presentation was: CF adolescence is no different from non-CF adolescence. Travel and overnight expenses paid but no fees received.	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)

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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 Play Services, Great Ormond Street Hospital Foundation Trust	31/09/2015 Attended meeting to discuss the desire and feasibility of establishing a Cystic Fibrosis Society for health professionals. 31/09/2015	Personal non-financial, non-specific	Declare and participate
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Invited speaker at a Cystic Fibrosis conference to present on the topic of mental health (how the impact of knowing a person has an incurable life-threatening disease might affect their mental health) and Cystic Fibrosis. No fees received. 01/03/2016	Personal, non-financial, non-specific	Declare and participate (not covered as part of the guideline scope)
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Attended a conference titled “Cystic Fibrosis Masterclass” on 20th May. Expenses for 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	Personal financial, specific	Declare and participate [as ivacaftor and lumacaftor are outside of the scope of the guideline (Vertex is the manufacturer)]
Mandy Bryon	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital	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	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality Policy)



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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Foundation Trust	received, just dinners out with the rest of the CF team from these pharmaceutical companies. No personal finance was received. 15/06/2016		
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 14th 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. 23/11/2016	Personal financial, non-specific	Advice taken from NICE - Declare and withdraw from future discussions regarding tobramycin and hypertonic saline.
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	Attended a study day at the Royal Society of Medicine on 15th November 2015 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. 11/01/2017	Non-personal financial, non-specific	Declare and participate
Mandy Byron	Consultant Clinical Psychologist and Joint Head of Paediatric	I attended a committee meeting of the UK Psychosocial professionals in Cystic Fibrosis on 18th and 19th January 2017. The	Personal financial, non-specific	Declare and participate (expenses within NICE Travel and

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Psychology and Play Services, Great Ormond Street Hospital Foundation Trust	meeting was sponsored by the pharmaceutical company Teva. Travel expenses and overnight accommodation were paid for by Teva – within the agreed limits of NICE guidance. 08/02/2017		Subsistence Policy)
Janis Bloomer	Paediatric Nurse Specialist (Children and young people) Cystic Fibrosis, Great North Children's Hospital Royal Victoria Infirmary	Current active member of UK Cystic Fibrosis Nurse Association 21/04/2015	Personal non-financial specific	Declare and participate
Janis Bloomer	Paediatric Nurse Specialist (Children and young people) Cystic Fibrosis, Great North Children's Hospital Royal Victoria Infirmary	Accepted for European CF Conference in June 2015 Presenting poster re Telephone Triage Tool for reporting respiratory problems in children with CF. 21/04/2015	Personal non-financial non-specific	Declare and participate (as intervention not covered in scope)
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	As a member of the Abbott Advisory Panel on Pancreatic Exocrine Insufficiency, attended a one off meeting which was completed in her own time. This was a multidisciplinary advisory board about PERT, it was run by Abbott who at the time manufactured Creon preparations. It was not just specific to CF but about PEI in general. Received £200. Had no influence on my decisions regarding PERT as it was It was about marketing,	Personal financial, specific	Declare and participate (this was a general panel about marketing and image of the brand and not specific to CF)

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		and image of the brand. 03/03/2015		
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Chair of the UK Dieticians CF Interest Group. Due to stand down as chair in May 2016. 03/03/2015	Personal non-financial, specific	Declare and participate
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Chair of UK Dieticians CF group who are writing a consensus document on the Nutritional management of CF This is a consensus document written by a group of professionals that has been published by the CF Trust. It covers all of the nutritional management of CF. In the document specific products are not recommended. 03/03/2015	Personal non-financial, specific	Declare and participate
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Invited speaker at Paediatric Expert Summit in Dubai, sponsored by Abbott. The presentation was titled Nutritional management of CF. flights, transfers and accommodation provided and honorarium received. Completed in own time. 03/03/2015	Personal financial, non-specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Attendance at the European Cystic Fibrosis meeting on Thursday 11th June 2015. Attended a hospitality event which was sponsored by Chiesi and Allergan. 19/08/2015	Personal financial, non-specific	Declare and participate (expenses and hospitality within NICE Hospitality Policy and Travel and Subsistence Policy)
Sarah	CF Specialist	Invited to be a member of the	Personal	Declare and

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<b>Name</b>	<b>Job title, organisation</b>	<b>Declarations of Interest, date declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
Collins	Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	James Lind Alliance's Cystic Fibrosis Priority Setting Partnership (PSP) Steering Group, which is jointly funded by the UK CF Trust, the University of Nottingham and Nottingham Hospital NHS Trust Charity. 01/03/2016	non-financial, specific	participate
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Awarded a NIHR/HEE-ICA Clinical Doctoral Research Fellowship, based at Royal Brompton Hospital, registration for PhD at King's College, London. Will be undertaking a training and research programme to obtain PhD, in addition to a clinical commitment. 26/04/2016	Non-personal financial, non-specific	Declare and participate
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 financial, non-specific	Declare and participate (hospitality within NICE Hospitality Policy and Travel and Subsistence Policy)
Sarah Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	I spoke at the RSM CF meeting on 15th November 2016. My talk was entitled the Nutritional Management of CF. I did not receive any financial reimbursement for this. 23/11/2016	Personal non-financial, specific	Declare and participate
Alexander Darlington	Lay member	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	Non-personal financial, non-specific	Declare and participate

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		Council). Additional funding for the centre itself and its infrastructure is provided by Shell Global Solutions, GlaxoSmithKline, Microsoft, DSTL (Defence Science and Technology Laboratory), Crystallin, Proctor and Gamble, DNA2 and Syngenta. 03/03/2015		
Alexander Darlington	Lay member	Contributed to a paper due to be published in June 2015. 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. 03/03/2015	Non-personal financial, specific	Declare and participate
Iolo Doull	Consultant Respiratory Paediatrician, Children’s Hospital for Wales, Cardiff	Lecture on childhood asthma for Novartis Educational. 03/03/2015	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	Member of Gilead Advisory Panel (March 2014) to consider data on the use of nebulised aztreonam in CF. Honorarium was paid. 03/03/2015	Personal financial, specific	Declare and participate (beyond 12 months before meeting where aztreonam was discussed)
Iolo Doull	Consultant Respiratory Paediatrician,	President of the British Paediatric Respiratory Society	Personal non-financial,	Declare and participate

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<b>Name</b>	<b>Job title, organisation</b>	<b>Declarations of Interest, date declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
	Children's Hospital for Wales, Cardiff	19/08/2015	non-specific	
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Trustee for ASH Wales 19/08/2015	Personal non-financial, non-specific	Declare and participate
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Organises the annual Royal Society of Medicine CF study day. The RSM receives an unrestricted educational grant from Actavis towards this meeting. 19/08/2015	Non-personal financial, specific	Declare and participate
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Member of the audit committee for the Children's Commissioner for Wales and sits on the Cystic Fibrosis Trust Clinical Advisory Group and Registry Committee. 19/08/2015	Personal non-financial, specific	Declare and participate
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Educational lectures on asthma for Astra Zeneca Educational. 19/08/2015	Personal financial, non-specific	Declare and participate (Asthma not discussed in this review)
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Authored a paper that was considered and excluded as part of the Guideline review on models of care in CF - Full, shared and hybrid paediatric care for cystic fibrosis in South and Mid Wales. Doull I, Evans H; South and Mid Wales Paediatric Cystic Fibrosis Network. Arch Dis Child. 2012 Jan;97(1):17-20 26/04/2016	Personal non-financial, specific	Declare and participate (This was published in 2012; therefore more than 12 months before he joined the committee)
Iolo Doull	Consultant Respiratory Paediatrician,	Attended a meal funded by Actavis.	Personal financial, specific	Declare and participate (hospitality

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	Children's Hospital for Wales, Cardiff	15/06/2016		within NICE Hospitality 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
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	Gave a talk to GPs about asthma which was sponsored by Astrazeneca. Was paid directly. Astrazeneca do not manufacture any products discussed in this guideline or for the treatment of CF. 19.10.2016	Personal financial, non-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 23/11/2016	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. 23/11/2016	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 23/11/2016	Personal non-financial, non-specific	Declare and participate (Asthma is not discussed in this guideline)
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	Through the Association of Chartered Physiotherapists (ACPCF) contributed to the update of the Standards of care and good clinical practice for the physiotherapy management of Cystic Fibrosis, specifically the use of Non-invasive ventilation in Cystic Fibrosis and the use of	Personal non-financial, specific	Declare and participate

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		Intermittent Positive Pressure breathing in Physiotherapy. 19/08/2015		
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	Works on the Cystic Fibrosis unit at Sheffield Children's Hospital and has recruited patients to the following two studies (she is not active in either study and will only see patients in professional capacity): PEOteKT – phase 11a, randomised controlled open label trial of Rosuvastatin for the prevention of Aminoglycoside-induced kidney toxicity in children with Cystic Fibrosis. Vertex study. A phase 3 randomized double blind placebo controlled, parallel group study to evaluate the efficacy and safety of VX-661 in combination with Ivacaftor in subjects aged 12 years and older with CF, homozygous for the F508del-CFTR mutation. 31/09/2015	Non-personal financial, specific	Declare and participate
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	Attended the Association of Physiotherapists in Cystic Fibrosis (ACPCF) annual study days. Travel fees were reimbursed by Actavis UK Ltd 01/03/2016	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	Helped organise, but not teach, a course on 'Paediatric respiratory assessment and treatment for physiotherapists' held by the Respiratory Physiotherapy team at Sheffield Children's Hospital sponsored by Hill-Rom and B&D Electromedical (paid for lunch and	Non-personal financial, specific	Declare and participate.



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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		consumables for course participants). Did not receive any personal financial gain. 20/07/2016		
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 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. 11/01/2017	Non-personal financial, non-specific	Declare and participate
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	I am the 3rd author on a piece of work about the use of text messages to try and help nebuliser compliance that has been accepted for publication in "Patient Preference and Adherence". It was presented as an oral presentation at the ECFS conference in Basel, Switzerland in June 2016. It was submitted but rejected by the Journal of Cystic Fibrosis in June 2016 and the Journal of Telemedicine and Telecare in 2016. I have not personally and the Trust has not received any financial gain in relation to the piece of work. I have attached a copy of the abstract. 08/0/2017	Personal non-financial, non-specific	Declare and participate
Stuart Elborn	Dean, School of Medicine, Dentistry and Biomedical	Provide ongoing consultancy on clinical trial design and leadership for Vertex, Novartis, Gilead, Celtaxsys,	Personal financial, specific	Declare and participate (is a co-opted expert to the

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Sciences, Queen's University, Belfast	Abbvie/Galapagos. All drugs are in development so there is no overlap with this guideline. 15/06/2016		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)
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. 23/11/2016	Personal non-financial, specific	Declare and participate – (as a co-opted member)
Zoe Elliott	Lay member	Member of the Cystic Fibrosis Trust's Strategic Implementation Board, a lay advisory group for research for patient benefit trial and the Cystic Fibrosis Trust's disbanded Principle Advisory Group.  No payment for any of the roles received. The research for patient benefit trial is trialling a hearing test for those on IV aminoglycosides which doesn't finish for at least another two years and isn't an area covered by the guideline. My role on the Strategy Implementation Board has me giving my opinion on proposed research to be funded by the trust. The	Personal non-financial, specific	Declare and participate

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		executive then decide whether to fund. I have no further involvement in that research. 03/03/2015		
Zoe Elliott	Lay member	Lay reviewer for the Cochrane Cystic Fibrosis and Genetic Disorders group. 03/03/2015	Personal non-financial, specific	Declare and participate
Zoe Elliott	Lay member	Using the anonymity of the Cystic Fibrosis Aware twitter account tweeting opinions of the price of the Vertex drug Orkambi. 19/08/2015	Personal non-financial, specific	Declare and participate
Zoe Elliott	Lay member	Attendance at a dinner with the CF Trust. 31/09/2015	Personal financial, non-specific	Declare and participate (hospitality within NICE Hospitality Policy, CF Trust is not a commercial body)
Zoe Elliott	Lay member	Parent member of the James Lind Alliance Priority Setting Partnership in CF Steering Committee. I receive no payment for this. The steering committee is overseeing the project to ensure that as many community members as possible get involved and have their say over what they feel should be researched about the treatment and management of the condition. The end of the project will see the ten most popular questions being published, these may or may not become actual research projects in the future.	Personal non-financial, specific	Declare and participate
Zoe Elliott	Lay member	Spoke at the CF Trust	Non-	Declare and

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		conference in September. The event was sponsored by: Vertex; Mylan; Pari Medical Ltd; Raptor Pharmaceuticals; PTC Therapeutics, Inc; Gilead Sciences; Concert Pharmaceuticals; Galapagos; SPS No payment or financial inducement for speaking at the event. 12/09/2016	personal, non-financial, non-specific	participate
Zoe Elliott	Lay member	I have been paid for the communication & marketing work I did for the James Lind Alliance Priority Setting Partnership in Cystic Fibrosis. 08/02/2017	Personal financial, non-specific	Declare and participate
Stephen Holden	Consultant Medical Microbiologist Nottingham University Hospitals NHS Trust	Received a one-off payment from Astellas Pharma for chairing an education meeting relating to Clostridium difficile infection. 31/09/2015	Personal financial, non-specific	Declare and participate (co-opted expert) Declare and participate
Stephen Holden	Consultant Medical Microbiologist Nottingham University Hospitals NHS Trust	Ongoing consultancy with Profile Pharma. Advisory role limited to matters relating to the introduction of a UK licensed formulation of oral fosfomycin for the treatment of uncomplicated urinary tract infection. Profile Pharma also market Promixin for intravenous and nebulised use – these drugs are used in the management of cystic fibrosis but the work for the company does not relate to these products. 31/09/2015	Personal financial, non-specific	Declare and participate (co-opted expert)
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis,	Sponsorship from Forest Pharmaceuticals (Actavis) for CF Centre's annual away day team meeting and annual meeting with paediatric teams. Forrest hired the room	Non-personal financial, specific	Declare and participate

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Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	for the meeting, this was done directly by Forrest (Actavis) and the conference facility and included basic refreshments for all participants, no other payment was received either by myself or the department. 03/03/2015		
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Participated in a multicentre project (2013-2015) evaluating clinical outcome of use of nebulised Aztreonam - this project is sponsored by Gilead Sciences. Gilead sponsored meeting venues and travel to meetings. 03/03/2015	Personal financial, specific	Declare and participate (expenses within NICE Hospitality Policy; held more than 12 months before meeting where Aztreonam was discussed)
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Speaker at the National Irish CF Meeting sponsored by Novartis. Travel expenses and accommodation were covered by Novartis who provide an unrestricted educational grant to sponsor the meeting, all my travel and accommodation was arranged by the meeting organisers, no other payment was received either by myself or the department. It was a general CF educational meeting. 03/03/2015	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West	Trustee of the UK Cystic Fibrosis Trust. 03/03/2015	Personal non-financial, specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Lung Centre, University Hospitals South Manchester NHS Foundation Trust			
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	On behalf of the Cystic Fibrosis Foundation Therapeutics Development Network Data Safety Monitoring Board, conducted the Data Safety Monitoring of a Phase 2 study on the investigation of an anti-inflammatory product produced by Corbus. 03/06/2015	Personal non-financial, specific	Declare and participate (not part of scope of guideline)
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Delegate at the regional Transpennine CF Club meeting held on 25th February 2016. This meeting received sponsorship from Actavis UK Ltd. It was a free to attend educational meeting sponsored by Actavis. 19/08/2015	Non-personal financial, 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	Member of Cystic Fibrosis Trust Research Strategy Implementation Board (2013-January 2015). There are no areas of overlap between this role and the work on the guideline. 04/11/2015	Personal non-financial, specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Foundation Trust			
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Chair (2004-) of the Cystic Fibrosis Trust Infection Control Committee. This committee has published national recommendations for the prevention and control of Pseudomonas aeruginosa infection (2001 and 2004), Burkholderia cepacia complex infection (2004), MRSA (2010) and (M. abscessus 2013) in people with cystic fibrosis 04/11/2015	Personal non-financial, specific	Declare and participate (all topics discussed were 12 months before joining the committee)
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Vertex Pharmaceuticals have provided an unrestricted educational grant to department to fund a one day Cystic Fibrosis meeting in 2016. 04/11/2015	Non-personal financial, specific	Declare and participate
Andrew Jones	Adult Physician, Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Invited to Chair the CF Trust Infection Control Group 01/03/2016	Personal non-financial, specific	Declare and participate
Andrew Jones	Consultant and Honorary	Invited to be a member of the Study Steering Committee of	Personal non-	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	“The cystic fibrosis (CF) anti-staphylococcal antibiotic prophylaxis trial (CF START); a randomised registry trial to assess the safety and efficacy of flucloxacillin as a long term prophylaxis agent for infants with CF”. CF START is a national UK study that has been funded by the HTA. 26/04/2016	financial, specific	
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Relevant publications RW Lord, AM Jones, A Horsley. Antibiotic treatment for Burkholderia cepacia complex in people with cystic fibrosis experiencing a pulmonary exacerbation (0144). Cochrane 2016; 20;1:CD009529. doi: 10.1002/14651858. P Barry, AM Jones. Skin contamination leading to falsely elevated fingerprick tobramycin levels in a patient taking dry powder inhaled tobramycin J Cyst Fibros 2014; 13(6): 754 PJ Barry, AM Jones. New and emerging therapies for cystic fibrosis. Drugs 2015; 75(11):1165-1167 Gilchrist FJ, Belcher J, AM Jones, D Smith, AR Smyth, KW Southern, P Španěl, AK Webb, W Lenney. Exhaled breath hydrogen cyanide as a marker of early Pseudomonas aeruginosa infection. ERJ Open Research 2015; 1 (2) DOI: 10.1183/23120541.00044-2015. Relevant conference abstracts	Personal non-financial, specific	Declare and participate



Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>HB Langman, AL Brennan, RJ Bright-Thomas, AM Jones, DW Riley, SC Johnson. Real world' introduction of tobramycin inhalation powder TIP™ in adults with cystic fibrosis. J Cyst Fibros 2015; 14suppl 1; 165.</p> <p>HB Langman, AL Brennan, RJ Bright-Thomas, AM Jones, DW Riley, SC Johnson. 'Real world' experience of introduction of Colobreathe™(Colo) in adults with cystic fibrosis. J Cyst Fibros 2015; 14suppl 1; Ws8.3.</p> <p>12/09/2016</p>		
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Invited to be a member of the NHS Specialised Respiratory Clinical Reference Group from August 2016. There is no overlap between this guideline and the work on the reference group. 12/09/2016	Personal non-financial, 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	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 any personal financial or other incentive in relation to this meeting. 11/01/2017	Non-personal financial, non-specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Andy Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Attended North American CF Conference in October 2016 including a non-promotional event for a large group of CF healthcare professionals sponsored by Chiesi. 23/11/2016	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality 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. 23/11/2016	Non-personal financial, non-specific	Declare and participate.
David Lacy	General Paediatrician Wirral University Teaching Hospital NHS Foundation Trust	Attended a meal paid for by Chiesi at the European CF conference in Brussels. This was a meal out with my CF team and teams from all over the UK. There was no promotional talk or activity during the meal.  At the rest of the conference there were scientific talks on many different products- these were not sponsored in any way by the drug companies. However I did go to a lunch time talk sponsored by vertex where lunch was provided – Vertex make Ivacaftor which is not being considered in the guideline.	Personal financial, non-specific	Declare and participate (expenses within NICE Hospitality Policy)

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		03/03/2015		
David Lacy	General Paediatrician Wirral University Teaching Hospital NHS Foundation Trust	Attended the Cystic Fibrosis Trust “UK CF Conference” 7th September 2016. This was sponsored by Galapagos a company that are developing drugs targeting the underlying molecular defect in CF. Also attended as part of the conference a talk sponsored by Vertex that make ivacaftor and Orkambi. There were no specific talks that covered areas of the guideline we are developing. 12/09/2016	Non-personal financial, non-specific	Declare and participate
Nichola MacDuff	Adult Specialist Nurse, Advanced Clinical Nurse Specialist & Lead Nurse, Black Country Adult CF Centre, Royal Wolverhampton NHS Trust	Husband is a shareholder in the following companies: GlaxoSmithKline and Lidco. 21/04/2015	Personal financial, non-specific	Declare and participate
Nichola MacDuff	Adult Specialist Nurse, Advanced Clinical Nurse Specialist & Lead Nurse, Black Country Adult CF Centre, Royal Wolverhampton NHS Trust	Teaching to GPs on inhaler devices and COPD guidelines sponsored by Astra Zeneca 01/03/2016	Personal financial, non-specific	Declare and participate (COPD is not within the scope of the guideline)
Nichola MacDuff	Adult Specialist Nurse, Advanced Clinical Nurse Specialist & Lead Nurse, Black Country	Attended a Chiesi sponsored dinner while at the European CF Conference in Basel, Switzerland. 26/04/2016	Personal financial, non-specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Adult CF Centre, Royal Wolverhampton NHS Trust			
Helen McCabe	Principal Paediatric Dietitian - Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust	Attendance at the European CF meeting in Brussels, received evening hospitality from Pharmaceutical firms (Chiesi, Umedica and Novartis, who make antibiotics used in the treatment of Cystic Fibrosis). 03/06/2015	Personal financial, non-specific	Declare and participate (hospitality within NICE Hospitality Policy)
Helen McCabe	Principal Paediatric Dietitian - Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust	Contributed to a meeting by Nutricia Advanced Medical Care to discuss paediatric products/ developments. 31/09/2015	Non-personal financial, specific	Declare and participate
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	Participated in an advisory board run by Forest Pharmaceuticals on nebuliser devices in 2012. 03/03/2015	Personal financial, specific	Declare and participate (this occurred more than 12 months before appointment to the committee)
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	Annually attends a professional study day (ACPCF) which is partly sponsored by Forest Laboratories. 03/03/2015	Non-personal financial, specific	Declare and participate
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal	Published articles: Clinical effects of Mannitol in adults with Cystic Fibrosis (co-author, for presentation at the European CF conference, June 2015 in Brussels),	Personal non-financial, specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Brompton Hospital	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 2015). 03/03/2015		
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	Established and attends a CF Physiotherapy prescribers continuing professional development group which is fully funding by Forest Laboratories. 03/03/2015	Non-personal financial, specific	Declare and participate
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	Chair of a meeting related to Cystic Fibrosis and the medicines used to treat the condition. Expenses and refreshments were paid for by Forest Laboratories. 21/04/2015	Non-personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	Attendance at the European CF conference in Brussels with social events sponsored by Chiesi. 19/08/2015	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality Policy)
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal	Invited to be involved in an expert panel at the Clinical Advances in CF conference on palliative care for late stage CF. No speaker fee or travel expenses received.	Personal non-financial, specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Brompton Hospital	19/08/2015		
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	Advisory board on 'Adherence' run by Hammell Communications for Chiesi (no conversations regarding drugs or topics relevant to the guideline were discussed) – consultancy fee of £350 received. 23/11/2016	Personal financial, non-specific	Advice taken from NICE - Declare and withdraw from future discussions regarding tobramycin and hypertonic saline.
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. 11/01/2017	Personal non-financial, specific	Declare and participate
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Attended Cystic Fibrosis Pharmacists Group study day and educational meeting sponsored by Actavis Pharmaceuticals (Forest Laboratories) manufacturer of Colomycin, which included an educational meeting with lunch provided. 03/03/2015	Non-personal financial, specific	Declare and participate
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Invited speaker on Cystic Fibrosis management at parallel study day to NPPG conference for which will receive honorarium paid by Profile Productions. Profile productions are not a Pharma company, they are a corporate company who manage events and organise the NPPG conference. It is a different company to profile who produce promixin. Conference input was general	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>to cystic fibrosis reaching junior pharmacists and those new to paediatrics about cystic fibrosis in a broad sense and covers all medications used.</p> <p>There was no particular focus on any drug other than to discuss current practice.</p> <p>03/03/2015</p>		
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	<p>Funding approved from AbbVie pharmaceuticals (Synagis manufacturer – not of significant relevance to Cystic Fibrosis) to attend Neonatal and Paediatric Pharmacists Group Conference November 2015. AbbVie are not relevant to this guideline.</p> <p>31/09/2015</p>	Personal financial, non-specific	Declare and participate
Sarah Popple	Pharmacist - Leicester Royal Infirmary Children's Hospital / De Montfort University	<p>Attended a team building event with CF team called 'better teams together' a corporate initiative being run by Trust. Participation of team is aiming to improve communication with shared care centre.</p> <p>The event was sponsored by Vertex (Kalydeco/Orkambi) who gave a short presentation at the beginning and funded the room hire, refreshments and a meal.</p> <p>12/09/2016</p>	Non-personal, financial, non-specific	Declare and participate
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	<p>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 afterwards. There was</p>	Non-personal financial, specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		no promotional content to the meeting and nothing specific to this guideline was discussed. 23/11/2016		
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. 23/11/2016	Non-personal 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. 23/11/2016	Personal financial, non-specific	Declare and participate
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	Facilitated a 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	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)



Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>guideline was discussed. For this I received one night's accommodation at the conference venue funded by profile productions. 23/11/2016</p>		
Sarah Popple	Pharmacist, Leicester Royal Infirmary Children's Hospital / De Montfort University	<p>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. 23/11/2016</p>	Personal financial, non-specific	Declare and participate (no relevance to the topics discussed within the CF guideline)
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	<p>Manuscript for a service development project on the use of inhaled antibiotics (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 Gilead Sciences Inc. Not personally remunerated for this work which was subsequently not published. It was discussed at European CF Conference in May 2015 (Pharmacy meeting only), but has not been referenced in the meeting discussions 03/06/2015</p>	Personal non-financial, specific	Declare and participate.
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and	Reimbursed by Gilead for expenses (Conference fees and accommodation paid directly; travel was reimbursed for personal out	Personal financial, specific	Declare and participate (expenses within NICE Travel and

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Harefield NHS Foundation Trust	of pocket travel expense [£97.50 Eurostar return standard class ticket]) incurred in the attendance of the May 2015 European Cystic Fibrosis conference. Hospitality at said conference from Chiesi Ltd.		Subsistence Policy)
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Attendance at annual UKCF Pharmacist Group Steering Committee meeting and study day sponsored by Allergan-Actavis the manufacturer of Colomycin® and Colobreathe®. Standard class travel reimbursed as out of pocket expense (£45.45); overnight accommodation and evening meal in hotel restaurant (without alcohol) covered directly between sponsor and hotel.	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Member of the steering group for the James Lind Alliance Priority Setting Partnership in CF, which has no pharmaceutical industry representation or sponsorship. This project will seek to prioritise research questions in CF in conjunction with the 'CF community'	Personal non-financial, specific	Declare and participate
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	As chair of UK CF Pharmacist Group, oversan an update of the CF Trust document 'Pharmacy Standards of Care' for CF centres which is a document referred to in the NHS England Service Specification for CF. 26/04/2016	Personal non-financial, specific	Declare and participate
Keith Thompson	Senior Respiratory	Invitation accepted to update a 'tab' entitled 'Approved and	Personal financial,	Declare and participate.

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	<p>Off-Label drugs for the management of CF in the EU' in the Hospital Pharmacy Europe Pocket Guide to CF (the previous edition was published in 2013). This contains information on a number of drugs used in CF which will be discussed in the NICE CF guideline, but is limited to collation of information on drug doses taken from manufacturers' data or relevant literature, rather than review or recommendation. Support for the editorial development of the project was provided by Vertex, manufacturer of Kalydeco® and Orkambi® which are licensed for the treatment of CF but do not fall within the scope of this guideline.</p> <p>Chapter was published; not referenced in guideline; no personal financial interest (honorarium was not offered or accepted).</p> <p>26/04/2016</p>	specific	(Kalydeco® and Orkambi® do not fall within the scope of this guideline)
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	<p>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</p>	Personal non-financial, non-specific	Declare and participate

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>based on current UK practice and guidance. There was no disclosure of information discussed in the NICE GDG meetings, the main topic (precision medicine) is outside the scope of the current guideline, and the guideline does not reference the manuscript.</p> <p>11/01/2017</p>		
Martin Walshaw	<p>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</p>	<p>For the last 5 years, provided patients for clinical trials of potential new therapies from pharmaceutical companies including Vertex, Aptalis, AstraZeneca and AlgiPharma.</p> <p>03/03/2015</p>	<p>Non-personal non-financial, specific</p>	<p>Declare and participate</p>
Martin Walshaw	<p>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</p>	<p>Speaker at All Wales conference on Cystic Fibrosis sponsored by Avartis. The title of talk was “Cross-infection in CF – Fact and Fantasy” which was an overview of the evidence/lack of evidence for cross infection (mainly for NTM) and gave the options currently available.</p> <p>Avartis sponsored the meeting non-promotionally, but I did not receive any support for travel or speakers fees from them.</p> <p>21/04/2015</p>	<p>Personal non-financial, non-specific</p>	<p>Declare and participate (cross infection covered in guideline, but this was general overview of the evidence landscape, particularly for NTM)</p>
Martin Walshaw	<p>Consultant Physician in General and</p>	<p>Attendance at the European CF meeting in Brussels, evening hospitality from</p>	<p>Personal non-financial,</p>	<p>Declare and participate (hospitality</p>

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Chest Medicine at Royal Liverpool and Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust	Pharmaceutical firms (Chiesi, Eumedica and Avartis). 03/06/2015	specific	within NICE Hospitality Policy)
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	Ongoing role in shaping CF care in England by representing the Mersey Senate area on the Clinical Reference Group. Meeting on – 23/11/15. 26/04/2016	Personal non-financial, specific	Declare and participate
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	Former member of the (now defunct) CF CRG that advised NHSE on CF service specifications including those for the formation of clinical services. 26/04/2016	Personal non-financial, specific	Declare and participate
Martin Walshaw	Consultant Physician in General and Chest Medicine at Royal	Attended several non-promotional pharmaceutical company sponsored evening meals at the European CF Conference in Basel, as part	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality

Committee membership list – Cystic Fibrosis Guideline Committee

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Liverpool and Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust	of large groups of UK CF healthcare professionals. 15/06/2016		Policy)
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. 11/01/2017	Personal non-financial, non-specific	Declare and participate.

**Date last reviewed:** 16/03/2017