

Cystic Fibrosis: diagnosis and management

Appendices A, B & C

Main appendix document

Scope, Stakeholders and DOIs

04 May 2017

Draft for Consultation

*Developed by the National Guideline Alliance, hosted
by the Royal College of Obstetricians and
Gynaecologist*

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

© National Institute for Health and Care Excellence 2017. All rights reserved.

Contents

Appendices	5
Appendix A: Scope	5
A.1 Guideline title:.....	5
A.2 Topic	5
A.3 Who the guideline is for	5
A.4 Equality considerations.....	5
A.5 What the guideline is about	5
A.5.1 Who is the focus?	5
A.5.2 Settings.....	5
A.5.3 Activities, services or aspects of care.....	5
A.5.4 Economic aspects.....	6
A.5.5 Key issues and questions	7
A.5.6 Main outcomes	8
A.6 Links with other NICE guidance and NICE Pathways	8
A.6.1 NICE guidance.....	8
A.6.2 NICE Pathways.....	9
A.7 Context.....	9
A.7.1 Key facts and figures	9
A.7.2 Current practice	9
A.8 Further information	10
Appendix B: Stakeholders.....	10
Appendix C: Declarations of interest	15

Appendices

Appendix A: Scope

A.1 Guideline title:

Cystic Fibrosis: diagnosis and management of cystic fibrosis

A.2 Topic

The Department of Health in England has asked NICE to develop a guideline on the diagnosis and management of cystic fibrosis.

A.3 Who the guideline is for

- People with cystic fibrosis, families and carers, and the public.
- Healthcare professionals in primary care.
- Healthcare professionals in secondary care.
- Providers of cystic fibrosis services.
- Healthcare professionals and social care practitioners in cystic fibrosis

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

A.4 Equality considerations

NICE has carried out an equality impact assessment during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

A.5 What the guideline is about

A.5.1 Who is the focus?

- Groups that will be covered
- Infants, children, young people and adults with cystic fibrosis, including those who have non-classic cystic fibrosis and those who have had an organ transplant.
- Groups that will not be covered

A.5.2 Settings

- Settings that will be covered
- all settings in which NHS-commissioned healthcare is provided.

A.5.3 Activities, services or aspects of care

- Key areas that will be covered
- The following clinical issues that will be covered in this guideline:
- The clinical manifestations of cystic fibrosis at the time of diagnosis in infants, children, young people and adults.

- The complications of cystic fibrosis
- Management of chest disease:
- Routine monitoring of lung disease, including microbiological surveillance, radiological imaging and pulmonary function testing.
- Antimicrobial management in cystic fibrosis to:
 - prevent bacterial colonisation
 - treat acute pulmonary infection
 - treat chronic pulmonary infection, including clinical exacerbations and colonisation.
- Immunomodulatory management in chest disease
- Management with mucoactive or mucolytic agents.
- Chest physiotherapy.
- The role of exercise in maintaining health.
- Management of nutrition.
- Management of exocrine pancreatic insufficiency.
- Management of distal intestinal obstruction syndrome.
- Surveillance for cystic-fibrosis-related diabetes.
- Surveillance for cystic-fibrosis-related liver disease and prevention of progression.
- Surveillance for reduced bone mineral density.
- Recognising psychological and behavioural problems.
- Models for delivery of care and multidisciplinary teams.
- Provision of information and support for infants, children, young people, adults and their carers

Note that guideline recommendations will normally fall within licensed indications. Exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. This guideline will assume that prescribers will use a drug's summary of product characteristics to inform decisions made with individual patients.

- Areas that will not be covered

This guideline does not cover:

- Specialist management of cystic-fibrosis-related diabetes.
- Specialist management of cystic-fibrosis-related fertility and pregnancy problems.
- Specialist management of cystic-fibrosis-related liver disease.
- Specialist management of cystic-fibrosis-related bone disease.
- Specialist management of cystic-fibrosis-related ear, nose and throat (ENT) disorders.
- Specialist management of cystic-fibrosis-related renal disease.
- Surgical management of gastrointestinal complications.
- Referral for, and management of, transplantation.
- Management of specific psychological conditions.
- Management of specific behavioural problems.

A.5.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS perspective, as appropriate.

A.5.5 Key issues and questions

While writing this scope, we have identified the following key issues, and key questions related to them:

1. Diagnosis and complications
 - What are the clinical manifestations of cystic fibrosis at the time of diagnosis in infants, children, young people and adults?
 - What are the complications of cystic fibrosis?
2. Management of pulmonary disease
 - What is the effectiveness of the following in monitoring pulmonary disease?
 - Microbiological investigation, including techniques such as bronchoscopy and lavage
 - Chest X-ray
 - Chest computed tomography (CT) scan
 - Lung function testing, including lung clearance index and forced expiratory volume in 1 second (FEV1).
 - What is the effectiveness of antimicrobial treatment:
 - To prevent bacterial colonisation
 - To treat acute pulmonary infection
 - To treat chronic pulmonary infection, including clinical exacerbations and colonisation?
 - What is the effectiveness of mucoactive or mucolytic agents, including rhDNase, nebulised saline (isotonic and hypertonic) and mannitol?
 - What is the effectiveness of immunomodulatory agents in the management of lung disease (for example, corticosteroids, azithromycin)?
 - What is the effectiveness of airway clearance techniques in people with cystic fibrosis?
3. What is the effectiveness of exercise programmes in the management of cystic fibrosis?
4. Gastrointestinal manifestations
 - What is the effectiveness of enzyme replacement in the treatment of exocrine pancreatic insufficiency?
 - What are the effective strategies for prevention and treatment of distal ileal obstruction syndrome?
5. Nutritional care
 - What is the effectiveness of nutritional interventions in cystic fibrosis?
6. Cystic Fibrosis related diabetes
 - How should people with cystic fibrosis be monitored for the onset of cystic-fibrosis-related diabetes?
7. Liver disease
 - What is the effectiveness of ultrasound scanning to detect clinically important cystic-fibrosis-related liver disease?
 - What is the effectiveness of ursodeoxycholic acid for preventing liver disease progression in people with cystic fibrosis?
8. Bone disease
 - How should monitoring be carried out to identify reduced bone mineral density?
9. Psychological and behavioural problems
 - How should people with cystic fibrosis be monitored for psychological or behavioural problems?
10. Information and support

- What information and support should be offered to people with cystic fibrosis?
- 11. Delivery of care
 - What is the most effective model for delivery of care for people with cystic fibrosis (including multidisciplinary teams of varied compositions, shared care, centre care, community care, home care and telemedicine)?
 - How can services be organised to minimise the risk of cross-infection?
 - What parts of the transition from children's to adult services are most important for young people with cystic fibrosis and their family members and carers?

A.5.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

- 12. Health-related quality of life.
- 13. Height, weight and BMI.
- 14. Survival rates.
- 15. Lung function (for example, FEV1).
- 16. Rate of acute pulmonary infections, including those needing hospitalisation.
- 17. Prevalence of infection with specific bacterial pathogens.
- 18. Patient satisfaction.

A.6 Links with other NICE guidance and NICE Pathways

A.6.1 NICE guidance

- Gastro-oesophageal reflux disease (2015) NICE guideline NG1
- Dyspepsia and gastro-oesophageal reflux disease (2014) NICE guideline CG184
- Infection: prevention and control of healthcare-associated infections in primary and community care (2012) NICE guideline CG139
- Constipation in children and young people (2010) NICE guideline CG99
- Depression in adults with a chronic physical health problem (2009) NICE guideline CG91
- Living-donor lung transplantation for end-stage lung disease (2006) NICE interventional procedure guidance 170
- NICE guidance that will be updated by this guideline

Depending on the outcome of a NICE technology appraisal review proposal this guideline will either update and replace, or incorporate, the following NICE guidance:

- Colistimethate sodium and tobramycin dry powders for inhalation for treating pseudomonas lung infection in cystic fibrosis (2013) NICE technology appraisal guidance 276
- Mannitol dry powder for inhalation for treating cystic fibrosis (2012) NICE technology appraisal guidance 266
- NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to cystic fibrosis:

- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76

A.6.2 NICE Pathways

When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

A.7 Context

A.7.1 Key facts and figures

Cystic fibrosis is a multi-system genetic disorder affecting the lungs, pancreas, liver and intestine. It can have a significant impact on life expectancy and quality of life.

Cystic fibrosis is associated with a reduced life expectancy. The current median age at death is 29 years and the median predicted survival is 36.6 years.

Diagnosis is primarily made during newborn screening. The median age at diagnosis is 3 months, and 1 in every 2500 babies born in the UK has cystic fibrosis. More than 57% of people on the UK cystic fibrosis registry are aged over 16 years.

Many different mutations are responsible for cystic fibrosis. The UK registry shows 90.8% of people with cystic fibrosis have one genotype; however 8.9% of people have at least one unknown genotype.

Lung function is often reduced in cystic fibrosis. The typical measure of lung function is forced expiratory volume in 1 second (FEV1). A FEV1 of 50% and above will enable people to live relatively normal lives, and is associated with fewer difficulties in completing activities of daily living. A FEV1 above 85% indicates normal or near-normal lung function.

Lung infections are a cause of significant morbidity in cystic fibrosis. Chronic infection (for example with *Staphylococcus aureus* and *Pseudomonas aeruginosa*) may need long-term use of antibiotics.

A.7.2 Current practice

Best practice for cystic fibrosis suggests that people with the condition benefit from a multidisciplinary team approach. Such teams include physicians or paediatricians with sufficient time in their job plans allocated to the disease, supported by specialist nurses, dietitians, physiotherapists, pharmacists, social workers, clinical microbiologists and clinical psychologists.

To provide sufficient multidisciplinary team experience for the management of this complex disease, people with cystic fibrosis are grouped together into specialist centres for treatment. In these centres, outpatient care is the basis of management. Patients should be monitored at least 4 times a year by the multidisciplinary team, including annual screening to assess their progress (Service specifications 2013/14, Clinical Reference Group cystic fibrosis NHS England).

Children with cystic fibrosis may be seen in conjunction with local paediatricians and their multidisciplinary teams (a shared-care model) for the convenience of their carers. Such shared-care arrangements are not supported in the adult sector, where everyone attends specialist centres except when population density and geography make travel a problem.

For inpatient care, it is considered that all people with cystic fibrosis should be admitted to single rooms with en-suite facilities on wards run by experienced cystic fibrosis staff (Service specifications 2013/14, Clinical Reference Group cystic fibrosis NHS England). Cross-infection between people with cystic fibrosis is a serious risk, and all centres and clinics should have robust protocols in place aimed at preventing it.

There is variation both in the multidisciplinary team structures and arrangements for providing care, and in the resources available to support services. Particular problems may arise with smaller shared care clinic arrangements. In some centres, both inpatient and outpatient facilities are limited. For example, there may be problems in arranging admission to single rooms with en-suite facilities. If adequate protocols are not in place, then there is a risk of cross-infection.

By producing a robust evidence-based approach to defining best practice in cystic fibrosis care, this guideline will help improve healthcare for this highly complex condition.

A.8 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in October 2017.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.

Appendix B: Stakeholders

5 Boroughs Partnership NHS Foundation Trust

Abbott Molecular UK

Alder Hey Children's NHS Foundation Trust

Allergan Ltd UK

Allocate Software PLC

Association for Respiratory Technology and Physiology

Association of Anaesthetists of Great Britain and Ireland

Association of Chartered Physiotherapists in Cystic Fibrosis

Association of Chartered Physiotherapists in Respiratory Care

Association of Directors of Public Health

Association of Paediatric Chartered Physiotherapists

Barts Health NHS Trust

Belfast Health and Social Care Trust

Birmingham Women's NHS Foundation Trust

Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust

British Acupuncture Council

British Association for Parenteral & Enteral Nutrition

British Dietetic Association

British Infection Association
British Lung Foundation
British Medical Association
British Medical Journal
British National Formulary
British Nuclear Cardiology Society
British Paediatric Respiratory Society
British Psychological Society
British Red Cross
British Society for Disability and Oral Health
British Society of Paediatric Gastroenterology Hepatology and Nutrition
British Specialist Nutrition Association
British Thoracic Society
Caplond Services
Care Quality Commission
Central Manchester and Manchester Children's Hospital NHS Trust
Chiesi Ltd
Cochrane Cystic Fibrosis and Genetic Disorders Group
Cochrane UK
College of Occupational Therapists
College of Paramedics
Community Integrated Care
Crawley CCG and Horsham and Mid Sussex CCG
Cregagh Nursing Home
Cumbria Partnership NHS Foundation Trust
Cystic Fibrosis Clinical Reference Group
Cystic Fibrosis Pharmacists Group
Cystic Fibrosis Trust
Department of Health
Department of Health, Social Services and Public Safety Northern Ireland
Diabetes UK
East Kent Hospitals University NHS Foundation Trust
East Midlands Patient & Public Involvement Senate

Ferrer Internacional S.A
Freshwinds
Frimley Park Hospital NHS Foundation Trust
Genetic Alliance UK
Gilead Sciences Ltd
Gloucestershire Hospitals NHS Foundation Trust
Great Ormond Street Hospital
Health and Care Professions Council
Healthcare Improvement Scotland
Healthcare Quality Improvement Partnership
Healthwatch Bristol
Healthwatch Darlington
Healthwatch Salford
HQT Diagnostics
Hywel Dda University Health Board
Intermedical
JT Healing
King's College Hospital NHS Foundation Trust
laughter ball yoga
Leeds Adult Cystic Fibrosis
Leeds Regional Paediatric Cystic Fibrosis Network
Leeds Teaching Hospitals NHS Trust
Liverpool Heart and Chest Hospital NHS Trust HQ
Liverpool University
MAP BioPharma Limited
Mastercall Healthcare
Medical Directorate Services
Medicines and Healthcare Products Regulatory Agency
Milton Keynes Hospital NHS Foundation Trust
Ministry of Defence
Morecambe Bay Hospitals NHS Trust
MRSA Action UK
Muslim Doctors and Dentists Association

Mylan UK

National Collaborating Centre for Cancer

National Collaborating Centre for Mental Health

National Collaborating Centre for Women's and Children's Health

National Deaf Children's Society

National Guideline Alliance

National Guideline Centre

National Institute for Health Research

National Paediatric Respiratory and Allergy Nurses Group

Neonatal & Paediatric Pharmacists Group

Newcastle upon Tyne Hospitals NHS Foundation Trust

NHS Choices

NHS Chorley and South Ribble CCG

NHS Digital

NHS England

NHS Health at Work

NHS Mid Essex CCG

NHS Sheffield CCG

NHS Somerset CCG

NHS Tayside

NHS West Cheshire CCG

NHSCC

NIHR CCRN ENT Specialty Group

Nordic Pharma

Northern Health and Social Care Trust

Northumbria Healthcare NHS Foundation Trust

Nottingham University Hospital NHS Trust

Nottinghamshire Healthcare NHS Foundation Trust

Novartis Pharmaceuticals

Nursing and Midwifery Council

Nutricia Advanced Medical Nutrition

Oxford Adult Cystic Fibrosis Centre

Papworth Hospital NHS Foundation Trust

Pari Medical
Perspectum Diagnostics Ltd
Profile Pharma
PTC Therapeutics
Public Health England
Raptor Pharmaceuticals
Roald Dahl's Marvellous Children's Charity
Roche Products
Royal Brompton Hospital & Harefield NHS Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Nursing
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Speech and Language Therapists
Royal College of Surgeons of Edinburgh
Royal College of Surgeons of England
Royal Cornwall Hospitals NHS Trust
Royal Devon and Exeter NHS Foundation Trust
Royal Pharmaceutical Society
Royal Wolverhampton Hospitals NHS Trust
Sandoz Ltd
Scottish Intercollegiate Guidelines Network
Sheffield Children's NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust
Social Care Institute for Excellence
Society for Cardiothoracic Surgery in Great Britain and Ireland

South Eastern Health and Social Care Trust
South Somerset Partnership School
South West Yorkshire Partnership NHS Foundation Trust
Southern Health & Social Care Trust
Staffordshire and Stoke on Trent Partnership NHS Trust
States of Jersey
Teva UK
The British In Vitro Diagnostics Association
The Project Surgery
UK Clinical Pharmacy Association
UK Dietitians' cystic fibrosis Interest Group
UK NSC
UK Psychosocial Professionals in Cystic Fibrosis
uMotif Digital Health
University Hospital Birmingham NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
University Hospitals of Leicester NHS Trust
University Hospitals of Morecambe Bay
University of Manchester
Vertex Pharmaceuticals
Warrington Health Plus
Welsh Government
Welsh Health Specialised Services Committee
Welsh Scientific Advisory Committee
Western Health and Social Care Trust
Wrightington, Wigan and Leigh NHS Foundation Trust

Appendix C: Declarations of interest

All Committee members' interests were recorded on declaration forms provided by NICE. The form covered personal, non-personal, specific or non-specific and non-financial or financial declarations. Committee members' declarations of interests are listed in this section. No conflicts were identified that required a Committee member to be asked not to participate in the relevant discussions. Details are available from the Committee minutes available on the NICE website where the policy can also be accessed (see <https://www.nice.org.uk/about/who-we-are/policies-and-procedures>).

This appendix includes all interests declared between the start of development and submission on 16 March 2017.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS 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	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS 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	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	Registered stakeholders of the Clinical Reference Groups for Cystic Fibrosis 03/03/2015	Personal non- financial, specific	Declare and participate
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	Published 5 articles related to Cystic Fibrosis: 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. 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. Alan R. Smyth, Scott C. Bell, Snezana Bojcin, Mandy Bryon, Alistair Duff, Patrick Flume, Nataliya Kashirskaya, Anne Munck, Felix Ratjen, Sarah Jane Schwarzenberg, Isabelle	Personal non- financial, specific	Declare and participate (none of these are covered as part of the guideline scope)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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>		
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	<p>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.</p> <p>21/04/2015</p>	Personal financial, non-specific	Declare and participate (expenses within NICE Hospitality Policy and Travel and Subsistence Policy)
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	<p>Speaker at Cystic Fibrosis conference on ‘Bridging the gap between standards of care and clinical provision of psychology’.</p> <p>21/04/2015</p>	Personal non-financial, non-specific	Declare and participate (not covered as part of the guideline scope)
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	<p>Attended dinner sponsored by Actavis pharmaceuticals at the European Cystic Fibrosis conference.</p> <p>No sponsorship received, just dinners out with the rest of the CF team from these pharmaceutical companies.</p> <p>03/06/2015</p>	Personal financial, non-specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS 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. 31/09/2015	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Mandy Bryon	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	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	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS 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	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS 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	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	Attended the European CF conference from 8th – 11th June. Attended two dinners with CF team and other CF teams from the UK. One meal was sponsored by Acatis Allergan and one sponsored by Chiesi. No personal sponsorship	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality Policy)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>received, just dinners out with the rest of the CF team from these pharmaceutical companies.</p> <p>No personal finance was received.</p> <p>15/06/2016</p>		
Mandy Byron	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	<p>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.</p> <p>23/11/2016</p>	Personal financial, non-specific	Advice taken from NICE - Declare and withdraw from future discussions regarding tobramycin and hypertonic saline.
Mandy Byron	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	<p>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.</p> <p>11/01/2017</p>	Non-personal financial, non-specific	Declare and participate
Mandy Byron	Senior Consultant Clinical Psychologist Head of Psychological Services, Great Ormond Street Hospital for Children NHS Trust	<p>I attended a committee meeting of the UK Psychosocial professionals in Cystic Fibrosis on 18th and 19th January 2017. The meeting was sponsored by the pharmaceutical company Teva. Travel expenses and overnight</p>	Personal financial, non-specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		accommodation were paid for by Teva – within the agreed limits of NICE guidance. 08/02/2017		
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 Abott 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, and image of the brand. 03/03/2015	Personal financial, specific	Declare and participate (this was a general panel about marketing and image of the brand and not specific to CF)
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	Personal non-financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		management of CF. In the document specific products are not recommended. 03/03/2015		
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 Collins	CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton Hospital	Invited to be a member of the 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	Personal non-financial, specific	Declare and 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	CF Specialist Dietician,	I spoke at the RSM CF	Personal	Declare and

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Collins	Nutrition & Dietetic Department, Royal Brompton Hospital	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	non-financial, specific	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 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. 03/03/2015	Non-personal financial, non-specific	Declare and participate
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,	Member of Gilead Advisory Panel (March 2014) to consider data on	Personal financial, specific	Declare and participate (beyond 12 months before

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Cardiff	the use of nebulised aztreonam in CF. Honorarium was paid. 03/03/2015		meeting where aztreonam was discussed)
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff	President of the British Paediatric Respiratory Society 19/08/2015	Personal non-financial, non-specific	Declare and participate
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, Children's Hospital for Wales, Cardiff	Attended a meal funded by Actavis. 15/06/2016	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality Policy)
Iolo Doull	Consultant Respiratory Paediatrician, Children's Hospital for Wales,	Organised a meeting to establish a British Cystic Fibrosis Society at the	Non-personal financial,	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Cardiff	European CF Society meeting. Actavis supplied funding for the room hire. 15/06/2016	specific	
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 Intermittent Positive Pressure breathing in Physiotherapy. 19/08/2015	Personal non-financial, specific	Declare and participate
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	Non-personal financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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</p>		
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	<p>Attended the Association of Physiotherapists in Cystic Fibrosis (ACPCF) annual study days. Travel fees were reimbursed by Actavis UK Ltd 01/03/2016</p>	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	<p>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 consumables for course participants). Did not receive any personal financial gain. 20/07/2016</p>	Non-personal financial, specific	Declare and participate.
Elaine Edwards	Advanced Physiotherapist, Sheffield Children's NHS Foundation Trust	<p>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</p>	Non-personal financial, non-specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		times and they had no input into the agenda items discussed. 11/01/2017		
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 Sciences, Queen's University, Belfast	Provide ongoing consultancy on clinical trial design and leadership for Vertex, Novartis, Gilead, Celtaxsys, Abbvie/Galapagos. All drugs are in development so there is no overlap with this guideline. 15/06/2016	Personal financial, specific	Declare and participate (is a co-opted expert to the guideline and there is no overlap between the content of the guideline and the consultancy provided)
Stuart Elborn	Dean, School of Medicine, Dentistry and Biomedical Sciences, Queen's University, Belfast	Lead for clinical trials with Vertex, Novartis and Celtaxsys, ProQr and Flatley Laboratories. This is ongoing. 15/06/2016	Personal non-financial, specific	Declare and participate (is a co-opted expert to the guideline)
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	Personal non-financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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 executive then decide whether to fund. I have no further involvement in that research.</p> <p>03/03/2015</p>		
Zoe Elliott	Lay member	<p>Lay reviewer for the Cochrane Cystic Fibrosis and Genetic Disorders group.</p> <p>03/03/2015</p>	Personal non-financial, specific	Declare and participate
Zoe Elliott	Lay member	<p>Using the anonymity of the Cystic Fibrosis Aware twitter account tweeting opinions of the price of the Vertex drug Orkambi.</p> <p>19/08/2015</p>	Personal non-financial, specific	Declare and participate
Zoe Elliott	Lay member	<p>Attendance at a dinner with the CF Trust.</p> <p>31/09/2015</p>	Personal financial, non-specific	Declare and participate (hospitality within NICE Hospitality Policy, CF Trust is not a commercial body)
Zoe Elliott	Lay member	<p>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</p>	Personal non-financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		project will see the ten most popular questions being published, these may or may not become actual research projects in the future.		
Zoe Elliott	Lay member	Spoke at the CF Trust 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	Non-personal, non-financial, non-specific	Declare and 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
Zoe Elliott	Lay Member	Accepted for European CF Conference June 2017 Presenting posters: #questionCF - The use of social media to engage the CF community in research Question CF: A James Lind Alliance Priority Setting Partnership in Cystic Fibrosis 31/03/2017	Personal non-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	Personal financial, non-specific	Declare and participate (co-opted expert)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		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		
Andrew Jones	Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	Sponsorship from Forest Pharmaceuticals (Actavis) for CF Centre’s annual away day team meeting and annual meeting with paediatric teams. Forrest hired the room 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	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 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.	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		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	Trustee of the UK Cystic Fibrosis Trust. 03/03/2015	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	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 Foundation Trust	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
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)

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
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 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 Study Steering Committee of "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	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	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	Personal non-financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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.</p> <p>Relevant conference abstracts</p> <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. 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
Andy Jones	Consultant and Honorary Reader in Respiratory Medicine	Attended North American CF Conference in October 2016 including a non-	Personal financial, specific	Declare and participate (hospitality within

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust	promotional event for a large group of CF healthcare professionals sponsored by Chiesi. 23/11/2016		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. 03/03/2015	Personal financial, non-specific	Declare and participate (expenses within NICE Hospitality Policy)
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	Non-personal financial, non-specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		are developing. 12/09/2016		
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 Adult CF Centre, Royal Wolverhampton NHS Trust	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)
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 Brompton Hospital	Published articles: Clinical effects of Mannitol in adults with Cystic Fibrosis (co-author, for	Personal non-financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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 2015). 03/03/2015</p>		
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	<p>Established and attends a CF Physiotherapy prescribers continuing professional development group which is fully funding by Forest Laboratories. 03/03/2015</p>	Non-personal financial, specific	Declare and participate
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	<p>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</p>	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	<p>Attendance at the European CF conference in Brussels with social events sponsored by Chiesi. 19/08/2015</p>	Personal financial, specific	Declare and participate (hospitality within NICE Hospitality Policy)
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	<p>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. 19/08/2015</p>	Personal non-financial, specific	Declare and participate
Helen Parrott	Physiotherapist, Clinical Specialty Lead, Adult CF Therapies Royal Brompton Hospital	<p>Advisory board on ‘Adherence’ run by Hammell Communications for Chiesi (no conversations regarding</p>	Personal financial, non-specific	Advice taken from NICE - Declare and withdraw from future discussions regarding

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		drugs or topics relevant to the guideline were discussed) – consultancy fee of £350 received. 23/11/2016		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 to cystic fibrosis reaching junior pharmacists and those new to paediatrics about cystic fibrosis in a broad sense and covers all medications used. There was no particular focus on any drug other than to discuss current practice. 03/03/2015	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence Policy)
Sarah	Pharmacist, Leicester	Funding approved from	Personal	Declare and

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Popple	Royal Infirmary Children's Hospital / De Montfort University	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. 31/09/2015	financial, non-specific	participate
Sarah Popple	Pharmacist - Leicester Royal Infirmary Children's Hospital / De Montfort University	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. 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. 12/09/2016	Non-personal, financial, non-specific	Declare and participate
Sarah Popple	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 afterwards. There was no promotional content to the meeting and nothing specific to this guideline was discussed. 23/11/2016	Non-personal financial, specific	Declare and participate
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	Invited speaker at Neonatal and Paediatric	Personal financial,	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Children's Hospital / De Montfort University	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	non-specific	
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 guideline was discussed. For this I received one night's accommodation at the conference venue funded by profile productions. 23/11/2016	Personal financial, specific	Declare and participate (expenses within NICE Travel and Subsistence 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. 23/11/2016	Personal financial, non-specific	Declare and participate (no relevance to the topics discussed within the CF guideline)
Keith Thomps on	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	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	Personal non-financial, specific	Declare and participate.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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.</p> <p>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</p> <p>03/06/2015</p>		
Keith Thompson	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	<p>Reimbursed by Gilead for expenses (Conference fees and accommodation paid directly; travel was reimbursed for personal out of pocket travel expense [£97.50 Eurostar return standard class ticket])</p> <p>incurred in the attendance of the May 2015 European Cystic Fibrosis conference. Hospitality at said conference from Chiesi Ltd.</p>	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	<p>Attendance at annual UKCF Pharmacist Group Steering Committee meeting and study day sponsored by Allergan-Actavis the manufacturer of Colomycin® and Colobreathe®.</p> <p>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.</p>	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	Personal non-financial, specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		industry representation or sponsorship. This project will seek to prioritise research questions in CF in conjunction with the 'CF community'		
Keith Thomps on	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 Thomps on	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Invitation accepted to update a 'tab' entitled 'Approved and 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. Chapter was published; not referenced in guideline; no personal financial interest (honorarium was not offered or accepted). 26/04/2016	Personal financial, specific	Declare and participate. (Kalydeco® and Orkambi® do not fall within the scope of this guideline)
Keith Thomps on	Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust	Wrote a manuscript entitled 'Conventional therapies and emergent precision medicines for cystic fibrosis: challenges and opportunities' which	Personal non-financial, non-specific	Declare and participate

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
		<p>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 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	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>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>	Non-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	<p>Speaker at All Wales conference on Cystic Fibrosis sponsored by Avartis.</p> <p>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. 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>	Personal non-financial, non-specific	Declare and participate (cross infection covered in guideline, but this was general overview of the evidence landscape, particularly for NTM)
Martin Walshaw	Consultant Physician in General and Chest Medicine at Royal Liverpool and	Attendance at the European CF meeting in Brussels, evening hospitality from	Personal non-financial, specific	Declare and participate (hospitality within NICE Hospitality

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
	Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust	Pharmaceutical firms (Chiesi, Eumedita and Avartis. 03/06/2015		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 Liverpool and Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust	Attended several non-promotional pharmaceutical company sponsored evening meals at the European CF Conference in Basel, as part of large groups of UK CF healthcare professionals. 15/06/2016	Personal financial, specific	Declare and participate (hospitality 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	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.