Appendix C

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Multiple Technology Appraisal

Elexacaftor, tezacaftor, lumacaftor and ivacaftor for treating cystic fibrosis [ID3834]

Provisional Stakeholder list

Consultees	Commentators (no right to submit or appeal)
Company • Vertex Pharmaceuticals (elexacaftor, tezacaftor, lumcaftor and ivacaftor) Patient/carer group • Asthma and Lung UK • CF Voices • Contact • Cystic Fibrosis Care • Cystic Fibrosis Trust • Genetic Alliance • Genetic Disorders UK • Jnetics • Muslim Council of Britain • NARA – The Breathing Charity • South Asian Health Foundation • Specialised Healthcare Alliance • Together for Short Lives Professional groups • Association for Respiratory Technology and Physiology • Association of Chartered Physiotherapists in Cystic Fibrosis • Association of Genetic Nurses and Counsellors • Association of Respiratory Nurse Specialists • British Dietetic Association • British Geriatrics Society • British Inherited Metabolic Disease Group • British Paediatric Respiratory Society • British Rhinological Society • British Society for Gene and Cell Therapy • British Society for Genetic Medicine	General • All Wales Therapeutics and Toxicology Centre • Allied Health Professionals Federation • Board of Community Health Councils in Wales • British National Formulary • Care Quality Commission • Department of Health, Social Services and Public Safety for Northern Ireland • Healthcare Improvement Scotland • Medicines and Healthcare Products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Welsh Health Specialised Services Committee Possible comparator companies • Accord UK (carbocisteine) • Aspire Pharma (carbocisteine) • Aurobindo Pharma – Milpharm (carbocisteine) • Brown & Burk (carbocisteine) • Dr Reddy's (carbocisteine) • Essential Pharmaceticals (pancreatin) • Esteve Pharmaceuticals (carbocisteine) • Flamingo Pharma (carbocisteine) • Janssen-Cilag (pancreatin) • Merck Serono (pancreatin) • Mylan (pancreatin) • Pharmaxis (mannitol dry powder for inhalation)

Consultees	**Commentators (no right to submit or appeal)**
• British Society for Human Genetics • British Thoracic Society • Chartered Society of Physiotherapy • Cystic Fibrosis Nursing Association • Interstitial Lung Diseases Interdisciplinary Network (ILD-IN) • National Heart and Lung Institute • Neonatal and Paediatric Pharmacists Group (NPPG) • Primary Care Respiratory Society UK • Royal College of General Practitioners • Royal College of Nursing • Royal College of Paediatrics & Child Health • Royal College of Pathologists • Royal College of Physicians • Royal Pharmaceutical Society • Royal Society of Medicine • UK Clinical Pharmacy Association • UK Cystic Fibrosis Medical Association • UK Cystic Fibrosis Pharmacy Group • UK Genetic Testing Network • UK Psychosocial Professionals in Cystic Fibrosis Group • 4-Front <u>Others</u> • Department of Health and Social Care • Kings College Hospital • Manchester NHS Foundation Trust • Newcastle NHS Foundation Trust • NHS Enfield CCG • NHS England • NHS North Norfolk CCG • Royal Brompton Hospital • Welsh Government	• Roche Products (dornase alfa) • Roma Pharmaceuticals (carbocisteine) • Sanofi (carbocisteine) • Typharm (carbocisteine) • Zentiva (carbocisteine, pancreatin) <u>Relevant Research Groups</u> • British Association for Lung Research • CF Unite • Cochrane Airways Group • Cochrane Cystic Fibrosis and Genetic Disorders Group • Genomics England • MRC Clinical Trials Unit • National Institute for Health Research • UK Cystic Fibrosis Gene Therapy Consortium <u>Associated Public Health Groups</u> • Public Health Wales • UK Health Security Agency

NICE is committed to promoting equality, eliminating unlawful discrimination and fostering good relations between people who share a protected characteristic and those who do not. Please let us know if we have missed any important organisations from the stakeholder list, and which organisations we should include that have a particular focus on relevant equality issues.

PTO FOR DEFINITIONS OF CONSULTEES AND COMMENTATORS

Definitions:

Consultees

Organisations that accept an invitation to participate in the evaluation; the company that markets the technology; national professional organisations; national patient organisations; the Department of Health and Social Care and the Welsh Government and relevant NHS organisations in England.

The company that markets the technology is invited to make an evidence submission, respond to consultations, nominate clinical experts and has the right to appeal against the Final Draft Guidance (FDG).

All non-company consultees are invited to submit a statement[1], respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Draft Guidance (FDG).

Commentators

Organisations that engage in the evaluation process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FDG for information only, without right of appeal. These organisations are: companies that market comparator technologies; Healthcare Improvement Scotland; related research groups where appropriate (for example, the Medical Research Council [MRC], National Cancer Research Institute); other groups (for example, the NHS Confederation, NHS Alliance, and the British National Formulary).

All non-company commentators are invited to nominate clinical or patient experts.

[1] Non company consultees are invited to submit statements relevant to the group they are representing.

