Appendix C

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Proposed Single Technology Appraisal

Lumasiran for treating primary hyperoxaluria type 1 ID3765

Provisional stakeholder list of consultees and commentators

Consultees	**Commentators (no right to submit or appeal)**
Company • Alnylam (lumasiran) Patient/carer groups • Amyloidosis Research Consortium UK • Contact • Find a Cure • Genetic Alliance UK • Jnetics • Kidney Care UK • Kidney Research UK • Metabolic Support UK • Muslim Council of Britain • National Children's Bureau • National Kidney Federation • South Asian Health Foundation • Specialised Healthcare Alliance Professional groups • Association of Anaesthetists • Association of Genetic Nurses & Counsellors • Association of Renal Technologists • Association of Surgeons of Great Britain and Ireland • British Association of Paediatric Nephrology • British Association of Urological Nurses • British Association of Urological Surgeons • British Dietetic Association • British Geriatric Society • British Renal Society • British Society for Gene and Cell Therapy • British Society for Genetic Medicine	General • All Wales Therapeutics and Toxicology Centre • Allied Health Professionals Federation • Association of Renal Industries • 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 • Inherited Metabolic and Lysosomal Disease Service, Cardiff and Vale UHB • Medicines and Healthcare Products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • National Services Division • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Welsh Government • Welsh Health Specialised Services Committee • Welsh Kidney Patients Association Possible comparator companies • Essential Healthcare (pyridoxine- Vitamin B6) • Wockhardt UK (pyridoxine- Vitamin B6) Relevant research groups

Consultees	**Commentators (no right to submit or appeal)**
• British Society for Human Genetics • British Transplantation Society • NHS Blood and Transplant • Renal Association • Royal College of Anaesthetists • Royal College of General Practitioners • Royal College of Nursing • Royal College of Paediatrics and Child Health • Royal College of Pathologists • Royal College of Physicians • Royal College of Surgeons • Royal Society of Medicine • Society for DGH Nephrologists • UK Clinical Pharmacy Association • UK Genetic Testing Network • UK Renal Pharmacy Group <u>Others</u> • Addenbrooke's Inherited Metabolic Disorders Unit • Birmingham Children's Hospital NHS Foundation Trust Inherited Metabolic disease • Department of Health and Social Care • Great Ormond Street Hospital Metabolic Unit • National Hospital for Neurology and Neurosurgery Charles Dent Metabolic Unit • NHS England • Salford Royal NHS Foundation Trust Mark Holland Metabolic Unit • UCLH NHS Foundation Trust Primary Hyperoxaluria Service • Genomic Medicine, Central Manchester Foundation Trust	• Cochrane Cystic Fibrosis & Genetic Disorders Group • Cochrane Kidney and Transplant Group • Genomics England • MRC Clinical Trials Unit • National Institute for Health Research <u>Associated Public Health Groups</u> • Public Health England • Public Health Wales

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.

Definitions:

Consultees

Organisations that accept an invitation to participate in the evaluation; the manufacturer(s) or sponsor(s) of the technology; national professional organisations; national patient organisations; the Department of Health and Social Care and relevant NHS organisations in England.

The company that markets the technology is invited to prepare a submission dossier, can respond to consultations, nominate clinical experts and has the right to appeal against the Final Appraisal Document (FAD).

All non- company consultees are invited to prepare a submission dossier respond to consultations on the draft scope, the Assessment Report and the Appraisal Consultation Document. They can nominate clinical or patient experts and have the right to appeal against the Final Appraisal Document (FAD).

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 final evaluation documentation for information only, without right of appeal. These organisations are: manufacturers of comparator technologies; Healthcare Improvement Scotland; the relevant National Collaborating Centre (a group commissioned by the Institute to develop clinical guidelines); other related research groups where appropriate (for example, the Medical Research Council [MRC], other groups (for example, the NHS Confederation, NHS Alliance, and the British National Formulary*)*.

All non-company organisations can nominate clinical or patient experts to present their personal views to the Appraisal Committee.

