NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Proposed Highly Specialised Technology Programme

Intrathecal idursulfase for treating mucopolysaccharidosis type II ID1223

Provisional matrix of consultees and commentators

Consultees	**Commentators (no right to submit or appeal)**
Company • Shire Human Genetic Therapies AB (intrathecal idursulfase) Patient/carer groups • Action for Sick Children • Children living with Inherited Metabolic Diseases • Contact a Family • Findacure • Genetic Alliance UK • MPS Society • National Children's Bureau • South Asian Health Foundation • Specialised Healthcare Alliance Professional groups • Association of Genetic Nurses and Counsellors • Association of Surgeons of Great Britain and Ireland • British Inherited Metabolic Disease Group • British Society for Genetic Medicine • National Metabolic Biochemistry Network • Royal College of Anaesthetists • Royal College of General Practitioners • Royal College of Nursing • Royal College of Paediatrics & Child Health • Royal College of Pathologists • Royal College of Physicians • Royal College of Surgeons • Royal Society of Medicine • UK Clinical Pharmacy Association	General commentators • 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 • 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 Commissioning for Scotland's Health • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Welsh GovernmentWelsh Health Specialised Services Committee • Possible comparator companies • Shire Human Genetic Therapies AB (intravenous idurdulfase) Relevant research groups • Cochrane Cystic Fibrosis and Genetic Disorders Group • MRC Clinical Trials Unit • National Institute for Health Research • Society for the Study of Inborn Errors of Metabolism

Consultees	Commentators (no right to submit or appeal)
• UK Genetic Testing Network Others • Addenbrooke's Lysosomal Disorders Unit • Birmingham Children's Hospital NHS Foundation Trust Lysosomal Storage Disorders Unit • Department of Endocrinology, University Hospital Birmingham Foundation Trust • Department of Health and social care • Great Ormond Street Hospital Metabolic Unit • National Hospital for Neurology and Neurosurgery Charles Dent Metabolic Unit • NHS England • Royal Free Lysosomal Storage Disorders Unit • Salford Royal NHS Foundation Trust Mark Holland Metabolic Unit • Willink Unit, Genetic Medicine, Central Manchester Foundation Trust	Associated Public Health Groups • 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 lists in the matrix, 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 manufacturer(s) or sponsor(s) of the technology; national professional organisations; national patient organisations; the Department of Health 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 NHS Commercial Medicines Unit, and the British National Formulary*)*.

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

Evidence Review Group (ERG)

An independent academic group commissioned by the National Institute for Health Research (NIHR) Health Technology Assessment Programme (HTA Programme) to assist the HST Evaluation Committee in reviewing the company evidence submission to the Institute.