

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal

Triheptanoin for treating long-chain fatty acid oxidation disorders ID3891

Provisional Stakeholder List

Provisional Consultees	Provisional Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Ultragenyx (triheptanoin) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Action on Pain • Alex – The Leukodystrophy Charity • ArchAngel MLD Trust • Gene People • Genetic Alliance UK • Metabolic Support UK • Pain Concern • Pain UK • South Asian Health Foundation • Specialised Healthcare Alliance <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> • Association of Genetic Nurses & Counsellors • British Association of Perinatal Medicine • British Geriatrics Society • British Inherited Metabolic Disease Group • British Nutrition Foundation • British Society for Paediatric Endocrinology & Diabetes • British Society of Gastroenterology • British Society for Genetic Medicine • Clinical Genetics Society • Institute of Child Health • National Metabolic Biochemistry Network (MetBio) • Nutrition Society • Primary Care Society for Gastroenterology • Royal College of General Practitioners • Royal College of Midwives 	<p><u>General</u></p> <ul style="list-style-type: none"> • All Wales Inherited Metabolic Disease Service Cardiff • 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 - Northern Ireland • Healthcare Improvement Scotland • Medicines and Healthcare products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • National Services Division • NHS Confederation • Scottish Medicines Consortium • Scottish Society of Gastroenterology • Welsh Government • Welsh Health Specialised Services Committee <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> • None <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Cochrane Metabolic & Endocrine Disorders Group • Genomics England • MRC Clinical Trials Unit • National Institute for Health Research <p><u>Associated Public Health groups</u></p> <ul style="list-style-type: none"> • Faculty of Public Health • Public Health Wales

Provisional stakeholder list for the evaluation of triheptanoin for treating long-chain fatty acid oxidation disorders ID3891

Issue date: October 2024

Provisional Consultees	Provisional Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • Royal College of Nursing • Royal College of Paediatrics and Child Health • Royal College of Pathologists • Royal College of Physicians • Royal Pharmaceutical Society • Royal Society of Medicine • UK Clinical Pharmacy Association • Society for Endocrinology <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health and Social Care • Great Ormond Street Hospital – Metabolic Medicine Department • NHS England 	<ul style="list-style-type: none"> • 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.

Definitions:

Consultee or commentator stakeholders are provisional until a signed Confidentiality Agreement & Undertaking form is submitted to NICE at the evaluation stage. Participating stakeholders will be listed on the project information page for the evaluation.

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 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 relevant to the group they are representing, 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]); other groups (for example, the NHS Confederation and the British National Formulary).

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