

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Highly Specialised Technology

Setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome (review of HST31) [ID6598]

Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Rhythm Pharmaceuticals (setmelanotide) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Bardet-Biedl Syndrome UK • Beacon for Rare Diseases • Beat • British Obesity Society • British Obesity Surgery Patients Association • Contact a Family • Gene People • Genetic Alliance UK • National Centre for Eating Disorders • Obesity Health Alliance • Obesity UK • South Asian Health Foundation • Specialised Healthcare Alliance • Weight Concern <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Association for the Study of Obesity • Association of Genetic Nurses & Counsellors • British Association of Endocrine and Thyroid Surgeons • British Geriatrics Society • British Nutrition Foundation • British Obesity Surgery Society • British Society for Gene and Cell Therapy • British Society for Genetic Medicine 	<p><u>General</u></p> <ul style="list-style-type: none"> • 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 • 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 Confederation • NHS Wales Joint Commissioning Committee • Scottish Medicines Consortium • Welsh Government <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Cochrane Cystic Fibrosis & Genetic Disorders Group • Cochrane Metabolic & Endocrine Disorders Group • Cochrane UK • Genomics England • MRC Clinical Trials Unit

Provisional stakeholder list for the highly specialised technologies evaluation of setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome (review of HST31) [ID6598]

Issue date: November 2025

© National Institute for Health and Care Excellence 2025. All rights reserved.

Page 1 of 3

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • National Metabolic Biochemistry Network • Neonatal and Paediatric Pharmacists Group • Nutrition Society • Obesity Management Association • 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 Pharmaceutical Society • Royal Society of Medicine • Society for Endocrinology • TREND UK • UK Clinical Pharmacy Association <p><u>Others</u></p> <ul style="list-style-type: none"> • Birmingham Children's Hospital NHS Foundation Trust, Lysosomal Storage Disorders Unit • Central Manchester Foundation Trust, Willink Unit, Genetic Medicine • Department of Health and Social Care • Great Ormond Street Hospital Metabolic Unit • NHS England • Salford Royal NHS Foundation Trust Mark Holland Metabolic Unit • St Thomas' Hospital, London • University Hospital Birmingham Foundation Trust, Department of Endocrinology 	<ul style="list-style-type: none"> • National Institute for Health Research • Wellcome-MRC Institute of Metabolic Science, Addenbrookes <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> • 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.

Definitions:

Stakeholder list for the highly specialised technologies evaluation of setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome (review of HST31) [ID6598]

Issue date: November 2025

© National Institute for Health and Care Excellence 2025. All rights reserved.

Page 2 of 3

Consultees

Organisations that accept an invitation to participate in the appraisal; 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 Appraisal Document (FAD).

All non-company consultees are invited to submit a statement¹, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Appraisal Document (FAD).

Commentators

Organisations that engage in the appraisal process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FAD 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.