

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Multiple Technology Appraisal

Nusinersen and risdiplam for treating spinal muscular atrophy (review of TA588 and TA755) ID6195

Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Biogen (nusinersen) • Roche (risdiplam) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Ally Cadence Trust for Spinal Muscular Atrophy • Annabelle Rose Foundation for Spinal Muscular Atrophy • Arthritis and Musculoskeletal Alliance • Brain and Spine Foundation • Brain Charity • Gene People • Genetic Alliance UK • Jnetics • Muscular Dystrophy UK • Neurological Alliance • South Asian Health Foundation • Specialised Healthcare Alliance • Spinal Muscular Atrophy UK • TREAT-SMA <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> • Adult SMA Reach • Association of Anaesthetists • Association of British Neurologists • Association of Genetic Nurses and Counsellors • Association of Surgeons of Great Britain and Ireland • British Dietetic Association • British Geriatrics Society • British Myology Society • British Neuropathological Society • British Orthopaedic Association 	<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 • Cell and Gene Therapy Catapult • 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 • Neurological Alliance of Scotland • NHS Confederation • Scottish Medicines Consortium • Wales Neurological Alliance • Welsh Government • Welsh Health Specialised Services Committee <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> • Novartis Gene Therapies, Inc. (onasemnogene abeparvovec) <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Bone Research Society • Brain Research UK • Chronic Pain Policy Coalition • Cochrane Musculoskeletal Group • Cochrane UK • Genomics England

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Issue date: July 2023

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • British Paediatric Neurology Association • British Society for Children's Orthopaedic Surgery • British Society for Gene and Cell Therapy • British Society for Genetic Medicine • British Society for Rheumatology • British Society of Physical and Rehabilitation Medicine • Chartered Society of Physiotherapy • Institute of Neurology • National Neuroscience Advisory Group • Neonatal and Paediatric Pharmacists Group • Primary Care and Community Neurology Society • 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 Pharmaceutical Society • Royal Society of Medicine • SMA Reach UK • Society for Endocrinology • Treat-NMD • UK Clinical Pharmacy Association <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health and Social Care • NHS England 	<ul style="list-style-type: none"> • John Walton Muscular Dystrophy Research Centre • MRC Centre for Neuromuscular Diseases • MRC Clinical Trials Unit • National Hospital for Neurology and Neurosurgery • National Institute for Health Research • Orthopaedic Research UK <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:

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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 statement¹, 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.