

**NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

**Single Technology Appraisal**

**Pitolisant for treating narcolepsy in children and young people 6 to 17 years  
ID6353**

**Provisional Stakeholder List**

<b>Consultees</b>	<b>Commentators (no right to submit or appeal)</b>
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• Bioprojet UK (Pitolisant)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Narcolepsy UK</li> <li>• Neurological Alliance</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• The Brain Charity</li> <li>• The Sleep Council</li> </ul> <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> <li>• Association for Respiratory Technology &amp; Physiology</li> <li>• Association of British Neurologists</li> <li>• Association of Respiratory Nurse Specialists</li> <li>• British Association of Neuroscience Nurses</li> <li>• British Geriatrics Society</li> <li>• British Neuropathological Society</li> <li>• British Neuropsychiatry Association</li> <li>• British Sleep Society</li> <li>• British Society of Dental Sleep Medicine</li> <li>• British Thoracic Society</li> <li>• Institute of Neurology</li> <li>• National Heart and Lung Institute</li> <li>• Primary Care and Community Neurology Society</li> <li>• Primary Care Respiratory Society UK</li> <li>• Royal College of General Practitioners</li> <li>• Royal College of Nursing</li> <li>• Royal College of Pathologists</li> <li>• Royal College of Physicians</li> <li>• Royal Pharmaceutical Society</li> </ul>	<p><u>General</u></p> <ul style="list-style-type: none"> <li>• All Wales Therapeutics and Toxicology Centre</li> <li>• Allied Health Professionals Federation</li> <li>• Board of Community Health Councils in Wales</li> <li>• British National Formulary</li> <li>• Care Quality Commission</li> <li>• Department of Health, Social Services and Public Safety for Northern Ireland</li> <li>• Healthcare Improvement Scotland</li> <li>• Medicines and Healthcare products Regulatory Agency</li> <li>• National Association of Primary Care</li> <li>• National Pharmacy Association</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Welsh Government</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> <li>• Aristo Pharma (sodium oxybate)</li> <li>• AS Kaleks (sodium oxybate)</li> <li>• Aspire Pharma (atomoxetine)</li> <li>• Atnahs Pharma UK (solriamfetol)</li> <li>• Aurobindo Pharma – Milpharm (atomoxetine, modafinil)</li> <li>• Brown &amp; Burk UK (dexamfetamine)</li> <li>• Dr. Reddy’s Laboratories (atomoxetine)</li> <li>• Eli Lilly (atomoxetine)</li> <li>• Flynn Pharma (methylphenidate)</li> <li>• Genus Pharmaceuticals (atomoxetine)</li> <li>• Glenmark Pharmaceuticals Europe (atomoxetine)</li> <li>• Janssen-Cilag (methylphenidate)</li> </ul>

Provisional stakeholder list for the evaluation of pitolisant for treating narcolepsy in children and young people 6 to 17 years ID6353  
Issue date: April 2024

<b>Consultees</b>	<b>Commentators (no right to submit or appeal)</b>
<ul style="list-style-type: none"> <li>• Royal Society of Medicine – Sleep Specialists</li> <li>• UK Clinical Pharmacy Association</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Department of Health and Social Care</li> <li>• Guy’s and St Thomas’ Hospital</li> <li>• Imperial College Healthcare Sleep Centre</li> <li>• King’s College Hospital</li> <li>• National Hospital for Neurology and Neurosurgery</li> <li>• NHS England</li> <li>• Royal Brompton Centre for Sleep</li> <li>• The Evelina Children’s Hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Martindale Pharma (methylphenidate)</li> <li>• Medice (dexamfetamine, methylphenidate)</li> <li>• Mylan (methylphenidate)</li> <li>• Neuraxpharm UK (atomoxetine, sodium oxybate)</li> <li>• Rosemont Pharmaceuticals (dexamfetamine)</li> <li>• Sandoz (atomoxetine, methylphenidate)</li> <li>• Sovereign Medical (dexamfetamine)</li> <li>• Takeda (lisdexamfetamine, methylphenidate)</li> <li>• Teva Pharma (modafinil)</li> <li>• UCB Pharma (sodium oxybate)</li> <li>• Zentiva (methylphenidate)</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>• Brain Research UK</li> <li>• British Association for Lung Research</li> <li>• Cochrane Common Mental Disorders Group Cochrane UK</li> <li>• Genomics England</li> <li>• MRC Clinical Trials Unit</li> <li>• National Institute for Health Research</li> </ul> <p><u>Associated Public Health groups</u></p> <ul style="list-style-type: none"> <li>• Public Health Wales</li> <li>• UK Health Security Agency</li> </ul>

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 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.