

## NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

### Single Technology Appraisal

#### Vutrisiran for treating hereditary transthyretin-related amyloidosis ID5074

#### Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• Alnylam Pharmaceuticals (vutrisiran)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Action on Pain</li> <li>• Addenbrookes Liver Transplant Association</li> <li>• Beacon</li> <li>• Bladder and Bowel Community</li> <li>• Brain and Spine Foundation</li> <li>• Brain Charity</li> <li>• British Liver Trust</li> <li>• Cardiomyopathy UK</li> <li>• Gene People</li> <li>• Genetic Alliance UK</li> <li>• GUTS UK</li> <li>• Kidney Care UK</li> <li>• Kidney Research UK</li> <li>• Liver4Life</li> <li>• Myeloma UK</li> <li>• National Kidney Federation</li> <li>• Neurological Alliance</li> <li>• Pain Concern</li> <li>• Pain Relief Foundation</li> <li>• Pain UK</li> <li>• Polycystic Kidney Disease Charity</li> <li>• Sense</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• UK ATTR Amyloidosis Patients Association</li> </ul> <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of British Neurologists</li> <li>• Association of Coloproctology of Great Britain and Ireland</li> <li>• Association of Genetic Nurses and</li> </ul>	<p><u>General commentators</u></p> <ul style="list-style-type: none"> <li>• All Wales Inherited Disease Service</li> <li>• All Wales Therapeutics and Toxicology Centre</li> <li>• Allied Health Professionals Federation</li> <li>• Association of Renal Industries</li> <li>• Board of Community Health Councils in Wales</li> <li>• British National Formulary</li> <li>• Care Quality Commission</li> <li>• Cell and Gene Therapy Catapult</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>• National Services Division</li> <li>• Neurological Alliance of Scotland</li> <li>• NHS Alliance</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Scottish Society of Gastroenterology</li> <li>• Wales Neurological Alliance</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> <li>• Alnylam Pharmaceuticals (patisiran)</li> <li>• Ionis Pharmaceuticals (inotersen)</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>• Brain Research UK</li> <li>• Cochrane Cystic Fibrosis &amp; Genetic Disorders Group</li> <li>• Cochrane Neuromuscular</li> </ul>

Provisional stakeholder list for the evaluation of vutrisiran for treating hereditary transthyretin amyloidosis ID5074

Issue date: July 2022

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<b>Consultees</b>	<b>Commentators (no right to submit or appeal)</b>
<p>Counsellors</p> <ul style="list-style-type: none"> <li>• Association of Renal Technologists</li> <li>• British Association for the Study of the Liver</li> <li>• British Association of Paediatric Nephrology</li> <li>• British Association of Urological Nurses</li> <li>• British Association of Urological Surgeons</li> <li>• British Cardiovascular Society</li> <li>• British Geriatrics Society</li> <li>• British Neuropathological Society</li> <li>• British Paediatric Neurology Association</li> <li>• British Pain Society</li> <li>• British Renal Society</li> <li>• British Society for Gene and Cell Therapy</li> <li>• British Society for Genetic Medicine</li> <li>• British Society of Gastroenterology</li> <li>• British Society of Paediatric Gastroenterology, Hepatology and Nutrition</li> <li>• Institute of Neurology</li> <li>• National Heart and Lung Institute</li> <li>• National Neuroscience Advisory Group</li> <li>• Primary Care and Community Neurology Society</li> <li>• Primary Care Cardiovascular Society</li> <li>• Primary Care Society for Gastroenterology</li> <li>• Royal College of General Practitioners</li> <li>• Royal College of Nursing</li> <li>• Royal College of Ophthalmologists</li> <li>• Royal College of Pathologists</li> <li>• Royal College of Physicians</li> <li>• Royal Pharmaceutical Society</li> <li>• Royal Society of Medicine</li> <li>• Society for DGH Nephrologists</li> <li>• UK Clinical Pharmacy Association</li> </ul>	<ul style="list-style-type: none"> <li>• Cochrane UK</li> <li>• Foundation for Liver Research</li> <li>• MRC Clinical Trials Unit</li> <li>• National Centre for Cardiovascular Preventions and Outcomes</li> <li>• National Hospital for Neurology and Neurosurgery</li> <li>• National Institute for Health Research</li> <li>• Pain Relief Foundation</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>

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> <li>• UK Genetic Testing Network</li> <li>• UK Kidney Association</li> <li>• UK Renal Pharmacy Group</li> <li>• Vascular Society of Great Britain and Ireland</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Department of Health</li> <li>• National Amyloidosis Centre, at UCL</li> <li>• NHS England</li> <li>• NHS Southport and Formby CCG</li> <li>• NHS Stockport CCG</li> <li>• Welsh Government</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 lists in the matrix, 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 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 statement<sup>1</sup>, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Draft Guidance (FDG).

#### Commentators

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<sup>1</sup> Non company consultees are invited to submit statements relevant to the group they are representing.

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.