

## NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Highly Specialised Technologies (HST)

## Voretigene neparvovec for treating inherited retinal dystrophies caused by RPE65 gene mutations ID1054

## Final matrix of consultees and commentators

Consultees	Commentators (no right to submit or appeal)
<p><u>Company/sponsor</u></p> <ul style="list-style-type: none"> <li>• Novartis Pharmaceuticals (UK) (voretigene neparvovec)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Eyecare Trust</li> <li>• Fight for Sight</li> <li>• Findacure</li> <li>• Genetic Alliance UK</li> <li>• Guide Dogs</li> <li>• Muslim Council of Britain</li> <li>• National Federation of the Blind of the UK</li> <li>• Organisation of Blind African Caribbeans (OBAC)</li> <li>• Olivia's Vision</li> <li>• Royal National Institute of Blind People (RNIB)</li> <li>• RP Fighting Blindness</li> <li>• SeeAbility</li> <li>• Sense</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• Thomas Pocklington Trust</li> <li>• VICTA</li> <li>• Vision UK</li> <li>• Visionary</li> </ul> <p><u>Professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of Anaesthetists</li> <li>• Association of Genetic Nurses &amp; Counsellors</li> <li>• Association of Optometrists</li> <li>• Association of Surgeons of Great Britain and Ireland</li> <li>• British and Eire Association of Vitreoretinal Surgeons</li> <li>• British and Irish Orthoptic Society</li> <li>• British Geriatrics Society</li> <li>• British Ophthalmic Anaesthesia Society</li> </ul>	<p><u>General commentators</u></p> <ul style="list-style-type: none"> <li>• All Wales Therapeutic 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>• National Services Division (specialised services in Scotland)</li> <li>• NHS Alliance</li> <li>• NHS Commercial Medicines Unit</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Uveitis Information Group (Scotland)</li> <li>• Wales Council for the Blind</li> <li>• Welsh Government</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Comparator companies</u></p> <ul style="list-style-type: none"> <li>• None</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>• British Council for Prevention of Blindness</li> <li>• Cochrane Cystic Fibrosis &amp; Genetic Disorders Group</li> <li>• Cochrane Eyes and Vision Group</li> <li>• Eye Hope</li> <li>• Genomics England</li> <li>• Institute of Ophthalmology, University College London</li> <li>• MRC Clinical Trials Unit</li> </ul>

National Institute for Health and Care Excellence  
Final matrix for the proposed technology appraisal of voretigene neparvovec for treating inherited retinal dystrophies caused by RPE65 gene mutations ID1054

<ul style="list-style-type: none"> <li>• British Society for Gene and Cell therapy</li> <li>• British Society for Genetic Medicine</li> <li>• British Society for Human Genetics</li> <li>• College of Optometrists</li> <li>• Optical Confederation</li> <li>• Oxford Eye Foundation</li> <li>• Royal College of Anaesthetists</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 College of Surgeons</li> <li>• Royal Pharmaceutical Society</li> <li>• Royal Society of Medicine</li> <li>• UK Clinical Pharmacy Association</li> <li>• UK Genetic Testing Network</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Department of Health and Social Care</li> <li>• NHS England</li> <li>• Specialised ear and ophthalmology services CRG</li> <li>• Medical genetics CRG</li> </ul>	<ul style="list-style-type: none"> <li>• National Eye Research Centre</li> <li>• National Institute for Health Research</li> <li>• UK Eye Genetics Group</li> </ul> <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> <li>• Public Health England</li> <li>• Public Health Wales</li> </ul>
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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 appraisal; the company that markets the technology; national professional organisations; national patient organisations; the Department of Health 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 specialists and has the right to appeal against the Final Appraisal Determination (FAD).

All non-company consultees are invited to submit a statement<sup>1</sup>, respond to consultations, nominate clinical specialists or patient experts and have the right to appeal against the Final Appraisal Determination (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; other 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 NHS Commercial Medicines Unit, and the British National Formulary).

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

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