

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Highly Specialised Technology Evaluation

### Afamelanotide for treating erythropoietic protoporphyria [ID927]

#### Matrix of consultees and commentators

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• Clinuvel UK (afamelanotide)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• British Porphyria Association</li> <li>• Genetic Alliance UK</li> <li>• Muslim Council of Britain</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> </ul> <p><u>Professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of Genetic Nurses and Counsellors</li> <li>• British Association of Dermatologists</li> <li>• British Dermatological Nursing Group</li> <li>• British Inherited Metabolic Disease Group</li> <li>• British and Irish Porphyria Network</li> <li>• British Skin Foundation</li> <li>• British Society for Genetic Medicine</li> <li>• Primary Care Dermatology Society</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> <li>• Royal Society of Medicine</li> <li>• Mark Holland Metabolic Unit</li> <li>• UK Genetic Testing Network</li> <li>• UK Clinical Pharmacy Association</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Department of Health</li> <li>• Kings College Hospital NHS Foundation Trust</li> <li>• NHS Ealing CCG</li> <li>• NHS England</li> <li>• NHS South Cheshire CCG</li> <li>• Welsh Government</li> </ul>	<p><u>General</u></p> <ul style="list-style-type: none"> <li>• Allied Health Professionals Federation</li> <li>• Board of Community Health Councils in Wales</li> <li>• British National Formulary</li> <li>• Cardiff porphyria service</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 Alliance</li> <li>• NHS Commercial Medicines Unit</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Comparator manufacturers</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>• Cochrane Cystic Fibrosis and Genetic Disorders Group</li> <li>• European Porphyria Network</li> <li>• MRC Clinical Trials Unit</li> <li>• National Institute for Health Research</li> <li>• Society for the Study of Inborn Errors of Metabolism</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>

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.

***PTO FOR DEFINITIONS OF CONSULTEES AND COMMENTATORS***

## **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 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 recommendations.

All non-company/sponsor consultees are invited to make an evidence submission or submit a statement<sup>1</sup>, respond to consultations, nominate clinical specialists or patient experts and have the right to appeal against the recommendations.

### 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 final evaluation documentation 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], other groups (for example, the NHS Confederation, NHS Alliance and NHS Commercial Medicines Unit, and the British National Formulary).

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

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