

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

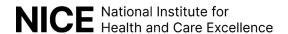
# **Single Technology Appraisal**

# Olezarsen for treating familial chylomicronaemia syndrome ID6585

### **Final Stakeholder List**

Provisional Consultees	Provisional Commentators (no right to
	submit or appeal)
<u>Company</u>	<u>General</u>
Sobi (olezarsen)	<ul> <li>All Wales Therapeutics and Toxicology Centre</li> </ul>
Patient/carer groups	<ul> <li>Allied Health Professionals Federation</li> </ul>
Action FCS	Board of Community Health Councils in
Beacon	Wales
Gene People	<ul> <li>British National Formulary</li> </ul>
Genetic Alliance UK	Care Quality Commission
Metabolic Support UK	Cell and Gene Therapy Catapult
<ul> <li>South Asian Health Foundation</li> </ul>	Department of Health - Northern Ireland
Specialised Healthcare Alliance	Healthcare Improvement Scotland
	<ul> <li>Medicines and Healthcare products</li> </ul>
Healthcare professional groups	Regulatory Agency
<ul> <li>Association of Genetic Nurses and</li> </ul>	<ul> <li>National Association of Primary Care</li> </ul>
Counsellors	<ul> <li>National Pharmacy Association</li> </ul>
British Dietetic Association	<ul> <li>National Services Division</li> </ul>
British Geriatrics Society	NHS Confederation
British Inherited Metabolic Disease	<ul> <li>NHS Wales Joint Commissioning</li> </ul>
Group	Committee
British Society for Gene and Cell	<ul> <li>Scottish Medicines Consortium</li> </ul>
Therapy	Welsh Government
British Society for Genetic Medicine	
HEART UK	<u>Comparator companies</u>
National Metabolic Biochemistry	Akcea Therapeutics (volanesorsen)
Network	Arrowhead Pharmaceuticals
Royal College of General Practitioners  Only of Name of N	(plozasiran)
Royal College of Nursing  Device College of Pathodo sing	Delevent receives
Royal College of Pathologists  Payal College of Physicians	Relevant research groups
Royal College of Physicians  Payal Physics a surfice Consists	<ul> <li>Cochrane Cystic Fibrosis and Genetic Disorders Group</li> </ul>
Royal Pharmaceutical Society      Royal Society of Madicine	Cochrane Metabolic and Endocrine
Royal Society of Medicine     Society for Endocrinology	Disorders Group
Society for Endocrinology     UK Clinical Pharmacy Association	Genomics England
UK Clinical Pharmacy Association	MRC Clinical Trials Unit
Others	National Institute for Health Research
All Wales Inherited Metabolic Disease	Society for The Study of Inborn Errors
Service	of Metabolism
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Final stakeholder list for the evaluation of olezarsen for treating familial chylomicronaemia syndrome ID6585



Provisional Consultees	Provisional Commentators (no right to
	submit or appeal)
<ul> <li>Central Manchester Foundation Trust, Willink Unit, Genetic Medicine</li> <li>Department of Health and Social Care</li> <li>Great Ormond Street Hospital Metabolic Unit</li> <li>Guys and St Thomas' NHS Trust, Adult Inherited Metabolic Diseases</li> <li>Leeds Teaching Hospitals NHS Trust, St James' Hospital, Diabetes</li> <li>NHS England</li> <li>NHS England National Programmes of Care, Internal Medicine: Hepatobiliary and Pancreas Clinical Reference Group (CRG)</li> <li>NHS Genomic Medicine Service</li> <li>Salford Royal NHS Foundation Trust Mark Holland Metabolic Unit</li> <li>Specialised Endocrinology CRG</li> <li>University Hospital Birmingham Foundation Trust, Department of Endocrinology</li> <li>University Hospitals of Bristol NHS Foundation Trust, Clinical Biochemistry</li> </ul>	Associated Public Health groups  • 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:**

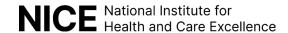
Consultee or commentator stakeholders are provisional until a signed Confidentiality Agreement & Undertaking form is submitted to NICE at the evaluation stage. Participating stakeholders will be listed on the project information page for the evaluation.

#### 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.

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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.