

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal

Etranacogene dezaparvovec for treating moderately severe or severe haemophilia B ID3812

Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • CSL Behring (etranacogene dezaparvovec) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Black Health Agency for Equality • Genetic Alliance UK • Gene People • Haemophilia Alliance • Haemophilia Society • South Asian Health Foundation • Specialised Healthcare Alliance <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Association of Genetic Nurses & Counsellors • British Blood Transfusion Society • British Committee for Standards in Haematology • British Geriatrics Society • British Society for Gene and Cell Therapy • British Society for Genetic Medicine • British Society for Haematology • British Society for Human Genetics • Haemophilia Nurses Association • Immunodeficiency UK • Royal College of General Practitioners • Royal College of Nursing • Royal College of Pathologists • Royal College of Physicians • Royal Pharmaceutical Society • Royal Society of Medicine • UK Clinical Pharmacy Association • UK Forum on Haemoglobin Disorders 	<p><u>General</u></p> <ul style="list-style-type: none"> • All Wales Therapeutics and Toxicology Centre • Allied Health Professionals Federation • Board of Community Health Councils in Wales • British National Formulary • Care Quality Commission • Cell and Gene Therapy Catapult • Department of Health, Social Services and Public Safety for Northern Ireland • Haemophilia Scotland • Haemophilia Wales • Healthcare Improvement Scotland • Hospital Information Services - Jehovah's Witnesses • Medicines and Healthcare products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Welsh Health Specialised Services Committee <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> • Biotest (factor IX) • Bio Products Laboratory (factor IX) • CSL Behring (albutrepenonacog alfa) • NovoNordisk (eptacog alpha, nonacog beta pegol) • Pfizer (nonacog alfa) • Swedish Orphan Biovitrum (eftrenonacog alfa)

Provisional stakeholder list for the technology appraisal of etranacogene dezaparvovec for treating moderately severe or severe haemophilia B ID3812. Issue date: January 2022

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • UK Genetic Testing Network • UK Haemophilia Centre Doctors' Organisation <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health and Social Care • NHS England • NHS South West Lincolnshire CCG • NHS Windsor, Ascot and Maidenhead CCG • Welsh Government 	<ul style="list-style-type: none"> • Takeda (nonacog gamma, factor VIII inhibitor bypassing fraction) <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Cochrane Cystic Fibrosis & Genetic Disorders Group • Cochrane UK • Genomics England • MRC Clinical Trials Unit • National Institute for Health Research <p><u>Associated Public Health groups</u></p> <ul style="list-style-type: none"> • 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.

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 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 specialists and has the right to appeal against the Final Appraisal Document (FAD).

All non-company consultees are invited to submit a statement¹, respond to consultations, nominate clinical specialists or patient experts and have the right to appeal against the Final Appraisal Document (FAD).

Commentators

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

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 the British National Formulary).

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