

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health Technology Evaluation

Equality impact assessment – Scoping

Olezarsen for treating familial chylomicronaemia syndrome [ID6585]

The impact on equality has been assessed during this evaluation according to the principles of the NICE Equality scheme.

1. Have any potential equality issues been identified during the scoping process (draft scope consultation and scoping workshop discussion), and, if so, what are they?

Yes, at scoping stakeholders raised the following potential equality issues:

- **Ethnicity:** There is a higher incidence of FCS in people from South Asian backgrounds. People from these backgrounds:
 - are at greater risk of developing type 2 diabetes, which compounds the burden of disease, dietary restrictions, and health risks
 - may have more difficulty adhering to the strict dietary requirements of current treatment, as traditional South Asian diets often include foods that are particularly challenging to restrict
 - may have more difficulty adhering to strict monitoring requirements for volanesorsen, as many people maintain strong family links in South Asia and travel abroad regularly. Anecdotal evidence also suggests that the additional monitoring may be stigmatised within tightknit communities
- **Access to care:** There are practical concerns around regional access to genetic testing, lipid clinics and dietetic support.
- **Route of administration:** Self-injection favours people better able to self-manage; hospital injection may favour those better able to travel. There is a need to ensure arrangements for home administration or shared care is available, where appropriate.
- **Pregnancy:** FCS may impact people's decision on whether to have children, or how many children to have. There are also difficulties managing the condition during pregnancy – the rise in triglyceride levels during pregnancy raises the risk of pancreatitis which is potentially life-threatening for both mother

and unborn child and can result in premature birth. This leads to substantial stress, as well as the need for plasmapheresis, which is a time-consuming, draining and very short-term intervention. The impact of gestational diabetes can be very negative and add huge amounts of stress to the pregnancy as high blood glucose leads to higher triglycerides.

2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?

The committee will consider the potential equality issues raised during the appraisal process. Differences in incidence and prevalence cannot be addressed in a technology appraisal.

3. Has any change to the draft scope been agreed to highlight potential equality issues?

Yes – pregnancy has been added as a subgroup.

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4. Have any additional stakeholders related to potential equality issues been identified during the scoping process, and, if so, have changes to the stakeholder list been made?

No

Approved by Associate Director (name):Richard Diaz

Date: 3 Nov 2025