Proposed clinical commissioning policy:

Anakinra for Haemophagocytic Lymphohistiocytosis (HLH) for adults and children in all ages [1924].

This is a new policy proposal that has been developed by NHS England and NHS Improvement.

Below is the proposed policy and other supporting documents:
- Clinical commissioning policy proposal
- Clinical evidence review
- Patient impact form
- Equality and health inequalities impact assessment
- Stakeholder Testing Response Form

A final decision as to whether Anakinra for HLH will be routinely commissioned will made by NHS England and NHS Improvement following a recommendation from the Clinical Priorities Advisory Group. The proposal is: Anakinra is recommended to be available as a bridging treatment option for adults and children in all ages through routine commissioning for HLH within the criteria set out in the policy document.

About haemophagocytic lymphohistiocytosis

Haemophagocytic lymphohistiocytosis (HLH) happens when the body’s immune system responds abnormally to illness or some treatments which target the immune system. The illnesses include infection, cancer (particularly blood cancers) and some rheumatology conditions and treatments which can trigger HLH are some of those for blood cancers. Alternatively, HLH can be caused by an inherited genetic condition meaning the immune system cannot switch itself off once triggered.

In HLH the body makes too many activated immune cells causing severe inflammation (known as hyperinflammation) throughout the body. This causes fever, damage to organs (including the liver, spleen brain and heart), and destroys blood-producing cells in the bone marrow. HLH can make people more at risk of infection. Without treatment many people die. With treatment, particularly if HLH is recognised and treated early, the outlook is much better. In addition to treating the HLH, the trigger needs to be found and treated too.

Treatment will usually include medicines that reduce the body’s immune response such as steroid and immunosuppressants. Anakinra is medicine which is given either by injection under the skin or as an infusion through a drip. It works by blocking the main driver of the hyperinflammation, interleukin1 (IL1). Anakinra is usually only needed for a short period in HLH, for 3-14 days on average. Although anakinra is licensed in the UK for other illnesses, it is not licensed for the treatment of HLH.