

NHS England and NHS Improvement: Equality and Health Inequalities Impact Assessment (EHIA)

A completed copy of this form must be provided to the decision-makers in relation to your proposal. The decision-makers must consider the results of this assessment when they make their decision about your proposal.

1. **Name of the proposal (policy, proposition, programme, proposal or initiative):** Clinical Policy Anakinra for Haemophagocytic Lymphohistiocytosis (HLH) for adults and children in all ages [1924]

2. **Brief summary of the proposal in a few sentences**

This clinical commissioning policy recommends the use of anakinra for the treatment of patients with haemophagocytic lymphohistiocytosis (HLH) in all ages.

HLH is a rare condition and comprises a syndrome of severe, uncontrolled inflammation or hyperinflammation causing multi-organ failure with a very high mortality rate. HLH may be triggered by rheumatic disease, malignancy and infection (when it may be indistinguishable from sepsis) or by use of treatments such as CAR T cell therapy or stem cell transplant therapy.

HLH affects people of all ages.

There are two types:

- a genetic immune system defect usually identified in infants or childhood termed primary HLH (pHLH) leading to a failure of immune regulation and hyperinflammation
- resulting from a trigger from another disease process leading to uncontrolled, pathological inflammation (hyperinflammation) most commonly, this is due to cancer.

The intended patient groups for this policy are those presenting with primary or secondary HLH regardless of the cause trigger condition, requiring treatment for HLH as part of their clinical care, and in whom first line therapy with corticosteroids has not been effective or would obscure the diagnosis of the underlying condition.

3. Main potential positive or adverse impact of the proposal for protected characteristic groups summarised

Please briefly summarise the main potential impact (positive or negative) on people with the nine protected characteristics (as listed below). Please state **N/A** if your proposal will not impact adversely or positively on the protected characteristic groups listed below. Please note that these groups may also experience health inequalities.

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
Age: older people; middle years; early years; children and young people.	The policy will address that children have access now and adults currently do not.	Anakinra to be made available as a treatment option for patients in all ages fulfilling the clinical criteria.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	The policy could reduce disability caused by HLH as it can result in long term morbidity and mortality if not treated appropriately.	Anakinra to be made available as a treatment option for patients in all ages fulfilling the clinical criteria.
Gender Reassignment and/or people who identify as Transgender	N/A	N/A
Marriage & Civil Partnership: people married or in a civil partnership.	N/A	N/A
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	N/A	N/A
Race and ethnicity¹	N/A	N/A

¹ Addressing racial inequalities is about identifying any ethnic group that experiences inequalities. Race and ethnicity include people from any ethnic group incl. BME communities, non-English speakers, Gypsies, Roma and Travelers, migrants etc. who experience inequalities so includes addressing the needs of BME communities but is not limited to addressing their needs, it is equally important to recognise the needs of White groups that experience inequalities. The Equality Act 2010 also prohibits discrimination on the basis of nationality and ethnic or national origins, issues related to national origin and nationality.

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
Religion and belief: people with different religions/faiths or beliefs, or none.	N/A	N/A
Sex: men; women	N/A	N/A
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	N/A	N/A

4. Main potential positive or adverse impact for people who experience health inequalities summarised

Please briefly summarise the main potential impact (positive or negative) on people at particular risk of health inequalities (as listed below). Please state **N/A** if your proposal will not impact on patients who experience health inequalities.

Groups who face health inequalities ²	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
Looked after children and young people	N/A	N/A
Carers of patients: unpaid, family members.	The policy should reduce the burden on care givers, by reducing the impact of the disease in patients.	N/A
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	N/A	N/A

² Please note many groups who share protected characteristics have also been identified as facing health inequalities.

Groups who face health inequalities²	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	N/A	N/A
People with addictions and/or substance misuse issues	N/A	N/A
People or families on a low income	N/A	N/A
People with poor literacy or health Literacy: (e.g., poor understanding of health services poor language skills).	N/A	N/A
People living in deprived areas	N/A	N/A
People living in remote, rural and island locations	HLH is a rare disease, often managed in specialist centres. The patient pathway proposes the treatment is approved by a regional network MDT, with a review that can be virtual.	Provision of virtual MDT review to facilitate decision-making, potentially widening access to specialist care. The Histo UK Haemophagocytic Lymphohistiocytosis across specialty collaboration (HASC) website will be updated to improve access to HLH specialist advice.
Refugees, asylum seekers or those experiencing modern slavery	N/A	N/A
Other groups experiencing health inequalities (please describe)	HLH often can affect families where English is spoken as a second language.	The information available to patients should be readily available for those who speak English as a second language.

5. Engagement and consultation

a. Have any key engagement or consultative activities been undertaken that considered how to address equalities issues or reduce health inequalities? Please place an x in the appropriate box below.

Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Do Not Know <input type="checkbox"/>
---	-----------------------------	--------------------------------------

b. If yes, please briefly list up the top 3 most important engagement or consultation activities undertaken, the main findings and when the engagement and consultative activities were undertaken.

Name of engagement and consultative activities undertaken		Summary note of the engagement or consultative activity undertaken	Month/Year
1	Policy Working Group	The Policy Working Group reviewed the CRG stakeholder lists and advised on additional patient groups to be consulted and invited a patient representative onto the group.	December 2020
2	Stakeholder testing	The Policy Working Group undertook stakeholder testing of the policy over 3 weeks.	February 2021
3			

6. What key sources of evidence have informed your impact assessment and are there key gaps in the evidence?

Evidence Type	Key sources of available evidence	Key gaps in evidence
Published evidence	An evidence report was compiled from the published evidence in peer reviewed journals which will be published on the NHS England website after policy approval. This was supplemented by a report by the Public Health member on additional evidence identified during stakeholder testing.	Rarity of the condition limits the evidence base

Evidence Type	Key sources of available evidence	Key gaps in evidence
Consultation and involvement findings	20 of the 22 respondents supported the draft Equality Health Impact Assessment (EHIA) and agreed that the Patient Impact Assessment (PIA) represented patient and carers lived experience of this condition. The other two responses felt that the PIA may underestimate the impact on patients and carers and highlighted that predominantly children are affected, and that children of consanguineous families and cultures where English is a second language are affected too. This has been noted in the EHIA. Respondents supported the policy. Some changes relating to clinical use were included as clarifications.	
Research	N/A	
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	The Policy Working Group comprised of consultant rheumatologists, a consultant haematologist, and a public health specialist. A patient member was included in the Policy Working Group after stakeholder testing. Stakeholder testing resulted in contributions from professional societies, patient groups, NHS trust clinical teams and individuals.	

7. Is your assessment that your proposal will support compliance with the Public Sector Equality Duty? Please add an x to the relevant box below.

	Tackling discrimination	Advancing equality of opportunity	Fostering good relations
The proposal will support?	x	x	
The proposal may support?			x
Uncertain whether the proposal will support?			

8. Is your assessment that your proposal will support reducing health inequalities faced by patients? Please add an x to the relevant box below.

	Reducing inequalities in access to health care	Reducing inequalities in health outcomes
The proposal will support?	x	x
The proposal may support?		
Uncertain if the proposal will support?		

9. Outstanding key issues/questions that may require further consultation, research or additional evidence. Please list your top 3 in order of priority or state N/A

Key issue or question to be answered		Type of consultation, research or other evidence that would address the issue and/or answer the question
1	None identified.	
2		
3		

10. Summary assessment of this EHIA findings

This policy has the potential to advance equality, by providing a treatment option for a rare disease which can cause significant disability and mortality. The patient pathway has taken account of patients living in remote areas, by allowing for virtual MDT review to approve initiation of treatment.

11. Contact details re this EHIA

Team/Unit name:	Clinical Programmes
Division name:	Specialised Commissioning
Directorate name:	Finance, Performance and Planning
Date EHIA agreed:	21 October 2020
Date EHIA published if appropriate:	September 2021