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

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)[1]: Specialist Haemoglobinopathy Services (adults and children)

2. Brief summary of the proposal in a few sentences

Service specifications are intended to clearly define the standards of care expected from organisations funded by NHS England to provide specialised care.

Haemoglobinopathy Coordinating Centres (HCCs) coordinate the networked provision of healthcare by Specialist Haemoglobinopathy Teams (SHTs) and non-specialist Local Haemoglobinopathy Teams (LHTs). SHTs provide clinical services, including specialist interventions, and work with LHTs to enable equitable access for their population to high standards of care across the network.

The Specialist Haemoglobinopathy Services (adults and children) Haemoglobinopathy Coordinating Centres and Specialist Haemoglobinopathy Teams service specifications have been reviewed and updated to bring them in line with current practice and use the most up to date service specification template (published in 2022). The main changes are:

- Clarification of the roles and responsibilities of providers within the network;
- Reduction in content duplication and wording that is more concise and easier to read;
- Update and futureproofing of references.

This EHIA offers an assessment of equity across the services commissioned by NHS England (HCC, SHTs) in relation to the whole model of haemoglobinopathy services (including LHTs, which are not prescribed specialised services).

The proposed changes are not expected to impact on the way that patients access or experience care or have unallocated financial implications. Therefore, the level of change is covered by the Expanded Change process as defined in the NHS England Service Specification Methods. This EHIA covers the full service as there was no previous EHIA in place.

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[1] Proposal: We use the term proposal in the remainder of this template to cover the terms initiative, policy, proposition, proposal or programme.

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.	Sickle cell disease (SCD), thalassaemia and rare inherited anaemias are inherited conditions, therefore most children will be referred to specialist services early in their life and will need to transition to adult services for aspects of their care. Some young people receiving treatment during transition from paediatric to adult services may feel the impact of changes in care. The service specifications include a clear requirement for services to support young people who are transitioning from children to adult services.	Providers should analyse routinely collected data at regular intervals (at least annually) to consider the equity of their service arrangements by age. Inclusion of the (HEAT) tool during analysis is recommended to consider key demographic factors around of equity Services should consider the relationship of service users to other age groups in the population, additional risks and the need for other health protection measures. Adult and paediatric teams are required to work closely to ensure that older children and young people are cared for in the most appropriate setting. Providers will actively seek feedback from service users to understand patient experience, particularly of those transitioning between paediatric and adult teams. Feedback should be reviewed (at least annually) to inform service delivery.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	SCD and thalassemia are long-term conditions (LTC) and therefore considered to be a disability.	Commissioned providers should work with the patient, any carers and other relevant agencies (e.g. GP, Local Authority, charities) to understand the

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
	Chronic complications of SCD and thalassemia include a reduced life expectancy, severe associated chronic health problems and reduction in quality of life. Providing a specialist-led service will help to manage risks associated with the disease/treatment and reduce the physical and mental impact of SCD and thalassemia as LTC. People with any type of disability may be impacted by the need to travel to specialist centres to access treatment.	need for support to access specialist haemoglobinopathy services for people living with disabilities. Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. Providers should consider the need for psychology services to support patients in managing their SCD or thalassemia as a LTC.
Gender Reassignment and/or people who identify as Transgender	Gender reassignment and being transgender are not known to be risk factors for haemoglobinopathies. However, help seeking can be affected by experience of care: 40% of trans respondents who had accessed or tried to access public healthcare services reported having experienced at least one of a range of negative experiences because of their gender identity in the 12 months preceding the survey. 21% of trans respondents reported that their specific needs had been ignored or not	All patients who meet the inclusion criteria should be offered inclusive treatment. The BMA offers guidance on Inclusive care of trans and non-binary patients. Providers should be aware that patients in this group may face barriers to getting a diagnosis.

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
	taken into account, 18% had avoided treatment for fear of a negative reaction, and 18% had received inappropriate curiosity (National LGBT Survey). This service is expected to have a positive effect on the overall survival and overall outcomes of all patients who need this service, regardless of gender reassignment and being transgender.	
Marriage & Civil Partnership: people married or in a civil partnership.	Marriage or civil partnership status is not known to be a risk factor for haemoglobinopathies.	The service specification is not anticipated to positively or negatively impact people who are married or in a civil partnership.
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	Pregnancy or maternity are not known to be risk factors for haemoglobinopathies.	The service specifications state that all women of childbearing age should receive personalised pre-pregnancy and maternity care from specialist services, in line with the shared management and escalation protocols agreed by the local Maternal Medicine Network. SHTs must have access to genetic counselling and fertility services and have an important role to play in making patients aware of this information.
Race and ethnicity[2]	SCD is particularly common in people of Black African and Caribbean heritage but	Providers should collect data routinely on age, sex and ethnicity of service users and consider by

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[2] Addressing racial inequalities is about identifying any ethnic group that experiences inequalities. Race and ethnicity includes 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

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
	cases also occur in families originating from the Middle East, parts of India, the eastern Mediterranean, and South and Central America; the common factor to this distribution is a history of malaria, or migration from a malarial area; thalassemia is mainly seen in those with an Asian and Southern Mediterranean heritage.	means of health equity audit (HEAT) whether there are any underserved populations. Commissioners should be able to monitor treatment data by detailed ethnic group and discuss with providers to ensure it is complete and that they are assured that there are no differences in outcomes and retention between different ethnic populations. Service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness. In addition, cultural competency training for staff may be considered.
Religion and belief: people with different religions/faiths or beliefs, or none.	Religion and belief are not known to be risk factors for haemoglobinopathies.	The service specification is not anticipated to positively or negatively impact people who belong to religions, faiths, belief groups or who have none. Service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness. In addition, cultural competency training for staff may be considered.
Sex: men; women	Sex is not known to be a risk factor for haemoglobinopathies.	The service specification is not anticipated to impact people whose birth assigned sex is male or female either positively or negatively. Service providers are expected to have mandatory training requirements

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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
		in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness.
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Sexual orientation is not known to be a risk factor for haemoglobinopathies.	The service specification is not anticipated to impact people who identify lesbian, gay, bisexual or heterosexual either positively or negatively. Service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness.

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[3]	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	There should be no direct negative or positive impact on young people in care or care leavers who may be better cared for in adult services. They may however need additional support to access the right services.	Adult and paediatric teams are required to work closely to ensure that older children and young people are cared for in the most appropriate setting and if necessary, transition effectively into adult services.

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

Groups who face health inequalities[3]	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
	There is no identified impact of this proposal on this group who face health inequalities although it is recognised that accessing services may be more challenging in this group.	
Carers of patients: unpaid, family members.	Being a carer is not known to be a risk factor for haemoglobinopathies. The service specification is not anticipated to positively or negatively impact people who are carers. It is acknowledged that carers may face increased travel and time costs to attend hospital for appointments or visits.	Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. In addition to providing individualised patient care, it may help to link to the family and carer's strategy or other support services available within the Trust, where this exists.
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	Being homeless is not known to be a risk factor for haemoglobinopathies. This service is not expected to impact this group differentially. It is acknowledged that homeless people may face increased difficulty in accessing specialist care and health care in general. Managing the disease requires high attention to self-care, which can be made more difficult when living in temporary accommodation and/or with limited resources.	Providers should take account of people's personal circumstances when determining the best treatment options and care plans. Providers should refer to social workers or Citizens Advice for advice on assessing eligibility for and claiming benefits. Consider referral to food banks, clothing banks or other local support if needed.

Groups who face health inequalities[3]	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.	People involved in the criminal justice system are not known to be at increased risk of haemoglobinopathies. This service is not expected to impact this group differentially. Many people within the justice system experience greater health problems than the rest of the population but have difficulty accessing care (WEPHREN). Managing the disease requires high attention to self-care, which can be made more difficult when living in places of detention, shared accommodation and/or with limited resources.	Shared care arrangements should be in place for people in custodial settings to ensure prompt care, particularly with regards to pain relief and transfer to secondary care facilities. There may be a need for closer partnership working between specialist providers and prison health care teams to optimise access to preventative measures.
People with addictions and/or substance misuse issues	People with addiction or substance misuse issues are not known to be at increased risk of haemoglobinopathies. This service is not expected to impact this group differentially.	Providers should take account of people's personal circumstances when determining the best treatment options and care plans. Where people disclose they are using substances, providers can actively signpost to specialist substance use services and offer advice on harm reduction in the context of their condition
People or families on a low income	Patients and families may be adversely affected financially by the need to travel to specialist centres to access treatment.	Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.

Groups who face health inequalities[3]	**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**
	Patients may be adversely impacted by loss of earnings due to admission or attendance at hospital. Managing the disease requires high attention to self-care, which can be made more difficult when living with limited resources.	Providers could ask families how best to support their attendance at appointments in a way that minimises impact on low-income households. The NHS advice on digital inclusion may be of use. Providers should refer to social workers or Citizens Advice for advice on assessing eligibility for and claiming benefits. Consider referral to food banks, clothing banks or other local support if needed.
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).	This group may find it harder to understand their condition and the benefits and risks associated with different treatment options. This might impact on their ability to access treatment or maintain involvement in a treatment regime. Principle 4 of the NHS Constitution states that 'Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment'. NICE acknowledge that health literacy is a fundamental component of shared decision making. People with lower levels of literacy may not derive the same benefit from treatment as others.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to ensure adequate referral access and attendance support for people living poor literacy or health literacy. Shared decision making should be used using appropriate mediums including verbal, written shared decision-making tools, translated, and Easy Read materials. The NHS has produced a Health Literacy Toolkit (2nd Edition, 2023) that providers should use to ensure that all patients are able to participate in their care and get the best out of the treatments offered to them equitably. Treatment should be provided in a way to assist those with poor health or literacy skills. A holistic assessment of an individual should be undertaken to assess their suitability and understanding in relation to any barriers for treatment.

Groups who face health inequalities[3]	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 living in deprived areas	Deprivation alone is not known to be an independent risk factor for haemoglobinopathies but high-risk groups from certain ethnic backgrounds are more likely to be over-represented in deprived populations. Managing the disease requires high attention to self-care, which can be made more difficult with limited resources.	A national service specification sets out the minimum standards for the delivery of equitable care across England, regardless of location. Providers should refer to social workers or Citizens Advice for advice on assessing eligibility for and claiming benefits. Consider referral to food banks, clothing banks or other local support if needed.
People living in remote, rural and island locations	People people living in remote, rural and island locations are not known to be at increased risk of haemoglobinopathies. However, access to prompt treatment may be affected by remote locations.	Providing centres should ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. The model of care described in the service specifications is designed to facilitate expert led care closer to home.
Refugees, asylum seekers or those experiencing modern slavery	As SCD is most common in people of Black African and Caribbean heritage, those from the Middle East, parts of India, the eastern Mediterranean, and South and Central America, there may be a correlation with people who are more likely to seek asylum. In addition, living with haemoglobinopathies as a refugee, asylum seeker or those experiencing modern slavery may be especially challenging:	Service providers may need to link patients to specific advice on eligibility for secondary care services for people who have migrated to this country (including those who are refugees and asylum seekers) NHS entitlements: migrant health guide - GOV.UK (www.gov.uk) Visitors who do not need to pay for NHS treatment - NHS (www.nhs.uk)

Groups who face health inequalities[3]	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
	• there may be difficulty accessing appropriate healthcare in an unfamiliar system • there may be uncertainty relating to entitlement to care • managing the disease requires high attention to self-care, which can be made more difficult when living in temporary accommodation and/or with limited resources	Consider the need for interpretation or other support services that can help bridge cultural aspects of self-care. Providers should refer to social workers or Citizens Advice for advice on assessing eligibility for and claiming benefits. Consider referral to food banks, clothing banks or other local support if needed.
Other groups experiencing health inequalities (please describe)	Not applicable	Not applicable

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 x	**No**	**Do Not Know**

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	Service specification working group and Haemoglobinopathies Clinical Reference Group	Review of draft service specification	April 2024

2	Informal stakeholder testing	Draft service specification shared widely for informal stakeholder feedback	June-July 2024

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	NICE Clinical Knowledge Summary: Sickle Cell Disease / Tuo, Yuanyuan et al. Global, regional, and national burden of thalassemia, 1990–2021: a systematic analysis for the global burden of disease study 2021. eClinicalMedicine, Volume 72, 102619 National LGBT Survey, Government Equalities Office. July 2017.	Not applicable
Consultation and involvement findings	Informal stakeholder testing with patient organisations, HCC networks and regional commissioners.	Not applicable
Research	Not applicable	Not applicable
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	Clinical expertise and patient input through the service specification working group.	Not applicable

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	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
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		

10. Summary assessment of this EHIA findings

The updated service specification will make a contribution to reducing health inequalities by setting clear standards of patient care for all specialist haemoglobinopathy services.

No adverse impacts have been identified.

11. Contact details re this EHIA

Team/Unit name:	Blood and Infection Programme of Care
Division name:	Specialised Commissioning
Directorate name:	CFO
Date EHIA agreed:	2024
Date EHIA published if appropriate:	2025