NHS England: 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: Allogeneic Haematopoietic Stem Cell Transplantation (Allo-HSCT) for adult transfusion dependent thalassaemia [URN 2120]

2. Brief summary of the proposal in a few sentences

The policy is: allo-HSCT is recommended to be available as a routine commissioning treatment option for adults with transfusion dependent thalassaemia (TDT) within a set of eligibility criteria.

The policy is restricted to adults as allo-HSCT is already commissioned for a number of disorders including children aged up to 18 years with TDT.

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.	There is an existing policy for children. This policy would allow adults who had not accessed treatment as children to	Referrals will be considered for approval by the National Haemoglobinopathy Panel, with input from

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
	make the choice to access it as adults. This has the potential to benefit young adults in particular those who were unable to make their own choice about treatment as children and would now be able to.	expert transplanters taking into account evidence of safety and efficacy.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	Disability is not known to be a risk factor for Thalassemia, however people with TDT can experience moderate to severe impacts on daily life as outlined in the patient impact assessment. Allo-HSCT is currently the only curative treatment, which offers potential to reduce these impacts. There are potential adverse outcomes if the transplant is not successful, for example graft rejection or graft versus host disease. The policy is to offer patient choice in the context of being deemed fit for treatment.	The proposed pathway contains eligibility criteria based on current safety evidence and expert clinical opinion. This includes being deemed fit for treatment by a multidisciplinary team (MDT), with further scrutiny from the National Haemoglobinopathy Panel. It also includes optimisation prior to transplant. Existing improvements in supportive care and transplant conditioning have reduced some risks such as graft rejection or graft versus host disease already. These factors combined are intended to increase the likelihood of success and reduce risks of adverse outcomes.
Gender Reassignment and/or people who identify as transgender	There should be no direct negative or positive impact on this group as gender reassignment and/or people identifying as transgender has not been identified as a high-risk group.	Specific counselling for patients who have undergone gender reassignment to ensure that there are no interactions/any interactions are mitigated between hormone blocking therapies and optimisation regimens.

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	There may be an interaction between hormone blockers and optimisation regimens. There is no specific data exploring this interaction though the Policy Working Group consider it is a manageable interaction.	
Marriage & Civil Partnership: people married or in a civil partnership.	There should be no direct negative or positive impact on this group as marriage/civil partnership has not been identified as a high risk group.	Not applicable.
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	Although many people who have TDT will have reduced fertility, some can, with appropriate care, get pregnant and deliver healthy term babies (see for example: Fertility and Pregnancy in Women with Transfusion-Dependent Thalassemia - ScienceDirect and TIF-2021-Guidelines-for-Mgmt-of-TDT.pdf (thalassemia.org)) In addition to the condition (TDT) itself, the conditioning regime for stem-cell transplant can negatively affect fertility. However, some people can, again with appropriate care, get pregnant and deliver healthy term babies (see for example Pregnancy outcome following hematopoietic cell transplantation for thalassemia major | Bone Marrow Transplantation (nature.com)).	The policy would include exclusion criteria related to current pregnancy and breastfeeding. It is recommended that the pathway include offer for referral to existing counselling for patients to consider options for fertility. To include guidance on pregnancy planning around allo-HSCT.

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	The proposed treatment does introduce a new risk to fertility, however, remaining un-treated also carries risks. The evidence base is insufficient to allow direct comparison across populations. Rather, this is noted and referral to existing fertility counselling should be considered as part of the pathway.	
Race and ethnicity[1]	The prevalence of thalassaemia is higher amongst people of Mediterranean, South Asian, South East Asian and Middle Eastern origin. In the UK, the highest prevalence is in ethnic minority populations, the largest groups in the latest NHR reports are Indian, Pakistani, Bangladeshi, 'other Asian' 'other White' 'other ethnic group' and 'not stated.' (NHR 2019/20). This treatment would be offered equally to all therefore we do not anticipate this treatment having an effect on inequalities	Not applicable.

[1] 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 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
	within people eligible. The numbers are small but any positive health impacts from this treatment would be likely to reduce rather than increase overall inequalities.	
Religion and belief: people with different religions/faiths or beliefs, or none.	Although the transplant service states that major UK religions support blood and organ donation and transplantation, people whose faith prohibits accepting blood products such as those following the Jehovah's Witness faith may refuse the treatment. Although standard care involves blood transfusion, which would also be likely to be refused, this issue is important to highlight and could have an adverse impact.	The policy does not create any additional adverse impact on this group of patients as the current standard of care is lifelong transfusion. It is important to counsel patients following the Jehovah's Witness faith on the different treatment options and pursue the option they feel is most suitable for them.
Sex: men; women	There should be no direct negative or positive impact because sex has not been identified as risk factor.	Not applicable.
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	There should be no direct negative or positive impact on this group as there are no known risk factors for the condition or treatment associated with sexual orientation.	Not applicable.

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	There should be no direct negative or positive impact on this group as there are no known risk factors for the condition or treatment relevant to children & young people who are looked after.	Not applicable.
Carers of patients: unpaid, family members.	For patients who decide to take up this treatment if it is commissioned, there may be short-term impact on carers in terms of additional support required around preparation and supportive care following transplant, however, this would be expected to be balanced out by reduced support needed in the longer term since the patient impact assessment highlights the fluctuating needs that are partly connected to transfusion cycle. This is expected to reduce any longer term impact on carers, should a successful transplant be undertaken, reducing the level of support required from carers.	The policy recommends that the suitability of Allo-HSCT as an intervention is assessed by the MDT team. This includes considering the support and care mechanisms a patient would require undergoing the intervention.
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	It is not anticipated that there would be high numbers in this cohort as	The policy recommends for anyone eligible who may benefit from the intervention.

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

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	homelessness is not a known risk factor for TDT. There may be increased difficulties in optimising prior to transplant and ensuring suitable follow-on care for homeless people as their housing situation may lead to increased risk of infection.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risk for homeless patients.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	It is not anticipated that there would be high numbers in this cohort as being in the criminal justice system is not a known risk factor for TDT. There may be increased difficulties in optimising prior to transplant and ensuring suitable follow-on care for people in the criminal justice system as their housing situation may lead to increased risk of infection.	The policy recommends for anyone eligible who may benefit from the intervention. Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risk for people in the criminal justice system.
People with addictions and/or substance misuse issues	It is not anticipated that there would be high numbers in this cohort as addictions and/or substance misuse is not a known risk factor for TDT. There may be increased difficulties in optimising prior to transplant and ensuring suitable follow-on care for people with addictions and/or substance	The policy recommends for anyone eligible who may benefit from the intervention. Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risk for people with addictions and/or substance misuse issues.

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	misuse issues as the substances used may lead to increased risks and interactions with optimisation regime.	
People or families on a low income	Successful transplantation has the potential to reduce requirement for travel to hospital for transfusions, which may benefit people on a low income.	Not applicable.
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).	This group may find it hard to understand their condition and the benefits and risks associated with different treatment options. For people for whom English is not their first language, there may also be additional requirements to ensure they are able to understand the benefits and risks of treatment, through use of interpreting services etc.	Shared decision making should be used as best practice so clinicians will need to ensure that patients are well informed, this can be through various mediums including verbal as well as written shared decision-making tools, translated and Easy Read materials. It is proposed that a holistic MDT assessment of an individual is undertaken to assess their suitability for treatment.
People living in deprived areas	A national commissioning policy aims to ensure there is equal access to treatment regardless of location. Therefore no identified impact.	Not applicable.
People living in remote, rural and island locations	A national commissioning policy aims to ensure there is equal access to treatment regardless of location. Therefore no identified impact.	Not applicable.

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
Refugees, asylum seekers or those experiencing modern slavery	There is no known association with increased risk of the condition for this group. People who are refugees, seeking asylum or experiencing modern slavery may be less likely to access treatment due to lower access to healthcare. Optimising prior to treatment may be more difficult if their environment puts them at increased risk of infection.	The policy recommends the development of the policy for anyone eligible who may benefit from the intervention. Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risk for people who are refugees, seeking asylum or experiencing modern slavery.
Other groups experiencing health inequalities (please describe)		

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	**Stakeholder testing**	There was a 2-week stakeholder engagement period with key stakeholders as per NHS England's standard methods.	**27th March-14th April**
2	**Public consultation**	Not formally required	
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 external review of available clinical evidence was undertaken to inform this policy.	Limited evidence comparing overall Quality of Life or Healthy Life Expectancy between adults receiving standard care (transfusions) and people who had allo-HSCT and were transplanted as adults.
Consultation and involvement findings		
Research		
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	A Policy Working Group was assembled which includes Thalassemia specialists, a public health specialist and patient and public voice representatives.	

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?			
The proposal may 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?		
The proposal may 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	N/A	
2	N/A	
3		

10. Summary assessment of this EHIA findings

Adoption of this policy would be likely to reduce inequalities in access to health services through offering patients over the age of 19 years to access treatment that was previously not available. Although the published evidence is limited on quality of life comparisons, the patient impact assessment demonstrates the negative impacts on functioning that people can experience in current treatment and offering this potentially curative treatment would give increased patient choice in the context of being deemed fit for treatment. There is limited evidence to assess health outcomes, but it is expected that this policy would have a neutral or marginally positive impact on reducing inequalities in health outcomes.

11. Contact details re this EHIA

Team/Unit name:	Specialised commissioning
Division name:	Blood and Infection Programme of Care
Directorate name:	Finance

Date EHIA agreed:	
Date EHIA published if appropriate:	