

## 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 Commissioning Policy Statement Abatacept for treatment of severe treatment-resistant morphea (localised scleroderma) (adults and children 2 years and over) [1921]

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

This clinical commissioning policy statement policy recommends the use of abatacept for the treatment of patients with severe, treatment-resistant localised scleroderma. This rare disease causes inflammation and thickening of skin, and in severe cases can lead to growth restriction, limb asymmetry in children and limited mobility in adults and children. The intended patient group for this policy are those who have already had treatment with a range of immune suppressive agents, yet continue to have significant symptoms impacting on quality of life.

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
<b>Age:</b> older people; middle years; early years; children and young people.	This policy statement policy aims to make abatacept available for people aged 2 years and over. Children may be more adversely impacted by	Abatacept to made be available as a treatment option for patients with severe disease aged 2 years and over who fulfil the clinical criteria.



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
	<p>localised scleroderma, given the potential for growth restriction, facial deformities and limb length discrepancy as well as psychological distress at a sense of difference to peers (Zigler et al. (2020).</p> <p>The availability of abatacept provides an additional treatment option for children with severe disease and may prevent the more severe disfigurement that can arise. The policy does limit the use of abatacept to children over the age of 2 years, due to restrictions of the licence of abatacept. This may create a disparity of access for children under 2 years, however the disease is very rarely identified in this age group.</p>	
<p><b>Disability:</b> physical, sensory and learning impairment; mental health condition; long-term conditions.</p>	<p>Localised scleroderma can result in disabling limb length discrepancies if it develops in childhood, while adults can have disabling symptoms including pain and limited mobility. The availability of abatacept would provide an additional treatment option for these patients, with potential improvement in disability.</p>	<p>Abatacept to made be available as a treatment option for patients with severe disease aged 2 years and older who fulfil the clinical criteria.</p>

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
<b>Gender Reassignment and/or people who identify as Transgender</b>	N/A	N/A
<b>Marriage &amp; Civil Partnership:</b> people married or in a civil partnership.	N/A	N/A
<b>Pregnancy and Maternity:</b> women before and after childbirth and who are breastfeeding.	The summary of product characteristics for abatacept advises to avoid this medicine in patients who are pregnant or breastfeeding, therefore this group would not be eligible for treatment on safety grounds. This is in common with many of the medical treatments for localised scleroderma.	No change can be made to the policy to mitigate this impact.
<b>Race and ethnicity<sup>1</sup></b>	N/A	N/A
<b>Religion and belief:</b> people with different religions/faiths or beliefs, or none.	N/A	N/A
<b>Sex:</b> men; women	N/A	N/A

<sup>1</sup> 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
<b>Sexual orientation:</b> 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 <sup>2</sup>	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
<b>Looked after children and young people</b>	N/A	N/A
<b>Carers of patients:</b> unpaid, family members.	It is anticipated it will have a positive impact on carers. Carers can face a significant burden in supporting the physical and emotional impact of the disease on family members and suffer work and financial pressures.	N/A
<b>Homeless people.</b> People on the street; staying temporarily with friends /family; in hostels or B&Bs.	N/A	N/A
<b>People involved in the criminal justice system:</b> offenders in prison/on probation, ex-offenders.	N/A	N/A

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

<b>Groups who face health inequalities<sup>2</sup></b>	<b>Summary explanation of the main potential positive or adverse impact of your proposal</b>	<b>Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact</b>
<b>People with addictions and/or substance misuse issues</b>	N/A	N/A
<b>People or families on a low income</b>	N/A	N/A
<b>People with poor literacy or health Literacy:</b> (e.g. poor understanding of health services poor language skills).	N/A	N/A
<b>People living in deprived areas</b>	N/A	N/A
<b>People living in remote, rural and island locations</b>	Localised scleroderma is a rare disease, often managed in specialist centres. This policy will therefore improve access to a specialist centre, with an agreed joint care pathway via regional network multidisciplinary teams (MDT).	Initial face to face review followed by annual assessment will be undertaken and provision of virtual MDT review will minimise the need for face to face visits.
<b>Refugees, asylum seekers or those experiencing modern slavery</b>	No identified positive or negative impact on this group of people.	N/A
<b>Other groups experiencing health inequalities (please describe)</b>	N/A	

**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.

<b>Yes x</b>	<b>No</b>	<b>Do Not Know</b>
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**Planned stakeholder testing**

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.

<b>Name of engagement and consultative activities undertaken</b>	<b>Summary note of the engagement or consultative activity undertaken</b>	<b>Month/Year</b>
<b>1</b> Internal Medicine NPoC Assurance Group	AG reviewed the EHIA along with policy paperwork. Some changes were recommended on groups who could positively benefit.	<b>November 2020</b>
<b>2</b> Stakeholder Testing	Completed, policy working group reviewed CRG stakeholder lists and confirmed additional patient groups had been engaged.	<b>August 2020</b>
<b>3</b> Clinical Panel	Clinical Panel reviewed the EHIA along with policy paperwork. No changes were recommended.	<b>June 2020</b>

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

<b>Evidence Type</b>	<b>Key sources of available evidence</b>	<b>Key gaps in evidence</b>
<b>Published evidence</b>	Zigler, C., Ardan, K., Hernandez, A., Caliendo, A., Magee, K., Terry, M., Mann, C. and Torok, K. (2020), Exploring the impact of paediatric localized scleroderma on health-related quality of life: focus groups with youth and	The evidence available is affected as this is rarer subgroup of a rare disease.

Evidence Type	Key sources of available evidence	Key gaps in evidence
	caregivers. Br J Dermatol. doi:10.1111/bjd.18879	
<b>Consultation and involvement findings</b>	Additional evidence and guidance identified by stakeholders.	There were gaps in evidence for use in paediatric patients. This has been supplemented by including a 2020 publication that strengthens the evidence for this cohort.
<b>Research</b>	N/A	
<b>Participant or expert knowledge</b> For example, expertise within the team or expertise drawn on external to your team	Policy working group comprised of consultant rheumatologists, a consultant dermatologist, a public health specialist, a pharmacist and patient representative.	

**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?	X	X
The proposal may support?		

Uncertain if the proposal will support?		
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**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	Not applicable	
2		
3		

**10. Summary assessment of this EHIA findings**

<p>This policy has the potential to advance equality, by providing a treatment option for a disease which has disproportionate impact on children and young people and can cause disability. The patient pathway has taken account of patients living in remote areas, by allowing for virtual MDT review to approve initiation of treatment.</p>
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**11. Contact details re this EHIA**

Team/Unit name:	Internal Medicine National Programme of Care
Division name:	Specialised commissioning
Directorate name:	Finance, Performance and Planning



Date EHIA agreed:	17 November 2020
Date EHIA published if appropriate:	July 2021