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 (policy, proposition, programme, proposal or initiative):

2. Brief summary of the proposal in a few sentences

Scleromyxedema is a rare, severe skin disorder, the signs and symptoms of which include abnormal accumulation of mucin (naturally occurring proteins) under the skin. Mucins are usually associated with fighting infection. This buildup of mucin (mucinosis) causes abnormal lumps within the skin. The condition is also associated with an increased production of connective tissue cells which, whilst vital for maintaining the form and function of the body and its organs, an overproduction can lead to problems with organ function.

The causes of scleromyxedema are not known.

Owing to the extremely rare nature of the condition there is a limited evidence base, and no standard therapies or treatment algorithms exist in England. Treatment options include phototherapy, and systemic immunosuppression. The proposed intervention is to prescribe human normal immunoglobulin to be given either as an addition to current treatment, or as an alternative. The treatment is administered by infusion either intravenously or under the skin (subcutaneously) (IVIg/SCIg).

If accepted, the policy would bring NHS treatment in line with European-wide practice, which already recommends human normal immunoglobulin as first line treatment.

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

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.	Scleromyxedema usually affects middle-aged adults between the ages of 30 and 80 years. However, the policy will cover adults and post pubescent children. The positive impact of the policy is that it will bring England in line with European guidelines on the use of IVIg/SCIg for the condition.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema if clinically eligible. Prior approval proformas will be required to commence and continue the treatment and the inclusion criteria will focus upon severity of the condition and not the age of the patient, as long as they are adults or post pubescent children.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	Positive impacts: Disability may be caused by or exacerbated by scleromyxedema and the proposed treatment may benefit their overall condition and ability to independently manage their activities of daily living. Untreated disease has a large impact on quality of life and function. Conditions such as scleromyxedema are often associated with mental health illness for patients suffering the disease.	All patients with a documented diagnosis of scleromyxedema will be eligible for this treatment, which has a potential positive impact of improving disability caused by or exacerbated by scleromyxedema.
Quality of life measures Gender Reassignment and/or people who identify as Transgender	Neither positive or negative: there is no identified impact of this policy on this protected characteristic.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema regardless of gender identity.
Marriage & Civil Partnership: people married or in a civil partnership.	Neither positive or negative: there is no identified impact of this policy on this protected characteristic.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema regardless of ethnicity.

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**
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	Neither positive or negative: Currently there are guidelines on the use of IVIG in pregnancy which do not include scleromyxedema. Cross over evidence suggests it is safe for use in pregnancy.	As IVIg is proven to be safe for some conditions, the policy will include women who are pregnant in the consideration for treatment, subject to individual clinical assessment of the patient.
Race and ethnicity[1]	Neither positive nor negative - there is no identified impact of this policy on this protected characteristic.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema regardless of ethnicity.
Religion and belief: people with different religions/faiths or beliefs, or none.	Neither positive nor negative. There are no demographic groups particularly associated with the condition, hence the proposed policy will be available to all patients.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema regardless of religion.
Sex: men; women	Neither positive nor negative. There are no demographic groups particularly associated with the condition, therefore the proposed policy will be available to all patients.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema regardless of sex.
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Neither positive nor negative. There are no demographic groups particularly associated with the condition, hence the proposed policy will be available to all patients.	This policy aims to make human normal immunoglobulin available for all patients with scleromyxedema regardless of sexual orientation.

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[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.

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	Potential positive impact for a small number of children and young people whose potentially long-term health and social care needs could be reduced by improving their quality of life indicators in terms of better disease management and improvement in mental health symptoms and illness. Furthermore, people from these groups often experience difficulties accessing services and accessing follow up. The use of subcutaneous Ig as proposed in the policy may be advantageous in this setting as it allows administration outside secondary care.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.
Carers of patients: unpaid, family members.	Positive impact for carers of family members with complex needs resulting from complications of scleromyxedema. The treatment aims to reduce symptoms and systemic involvement, which reduce burden of needing for travel to healthcare settings.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.

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[2] Please note many groups who share protected characteristics have also been identified as facing 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**
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	Potential positive impact for people whose health and social care needs may be reduced by management of the disease and subsequent complications. For example, improved mobility.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	Neither wholly positive or negative. Better symptom management should support an improvement in overall health. However, people from this group often experience difficulties accessing services and accessing follow up.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.
People with addictions and/or substance misuse issues	Positive impact for a small number of people whose health and social care needs may be reduced by management of the disease and subsequent complications. For example, improved mobility.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.
People or families on a low income	Positive impact for people whose health and social care needs may be reduced by better management of the disease and subsequent complications.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group./A
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).	Positive impact for people whose health and social care needs may be reduced by better management of the disease and subsequent complications. However, people from this group often experience difficulties accessing services and accessing follow up.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group. Clinicians will need to ensure that patients are well informed when discussing and consenting for this treatment. Communication with those with poorer language skills or literacy can be through various mediums for example by adapting verbal communication style, using written shared decision-making tools, and accessing Easy Read materials.

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
People living in deprived areas	Neither wholly positive or negative. Better symptom management should support an improvement in overall health. For example, improved mobility. However, people from this group often experience difficulties accessing services and accessing follow up.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.
People living in remote, rural and island locations	Neither wholly positive or negative. Better symptom management should support an improvement in overall health, which may reduce need for travel for admissions for patients and families living in remote locations. However, people from this group often experience difficulties accessing services and accessing follow up. The use of subcutaneous Ig as proposed in the policy may be advantageous in this setting as it allows administration outside secondary care.	Treatment should be available locally, which should reduce requirement for long travel to specialist centres, once initial diagnosis and treatment decisions have been made through the specialized centres. Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme
Refugees, asylum seekers or those experiencing modern slavery	Neither wholly positive or negative. Better symptom management should support an improvement in overall health. However, people from this group often experience difficulties accessing services and accessing follow up. The use of subcutaneous Ig as proposed in the policy may be advantageous in this setting as it allows administration outside secondary care.	Commissioned providers should work with the patient and other relevant agencies (e.g. GP, Local Authority, charities) to mitigate the risks for this group.
Other groups experiencing health inequalities (please describe)	N/A	N/A

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 engagement completed using the listed rheumatology and Dermatology services stakeholder list provided by NHS England.	Further public consultation is not considered to be required.	**August 2023**
2			
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	Knobler, R., Moinzadeh, P., Hunzelmann, N, et al. (2017) European dermatology forum S1-guideline on the diagnosis and treatment of sclerosing diseases of the skin. Part 2: scleromyxedema, scleredema and nephrogenic	

Evidence Type	Key sources of available evidence	Key gaps in evidence
	systemic fibrosis J Eur Acad Dermatol Venereol, 31(10), pp. 1581-1594 Kennemer C, Pavlidakey P, Sami N. (2017) Successful treatment with IVIg therapy of diabetes-associated scleredema severe progressive case and review of the literature. Dermatol Ther, 30(4), e12504	
Consultation and involvement findings	Stakeholder engagement will be completed using the listed rheumatology and dermatology services stakeholder list provided by NHS England.	
Research	It is accepted that the evidence base for treatment is limited with this disease, mainly owing to the rarity of the condition not wholly supporting many randomized controlled trials. However European evidence has been used as reference evidence along with clinical expert opinion and real-world use of the treatment.	
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	The Policy Working Group includes clinicians from Dermatology and Rheumatology who are clinical experts within connective tissue disorders.	

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
The proposal may support?	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	Assessing effectiveness from a patient perspective on activities of daily living.	Refinement of the policy following stakeholder engagement.
2		
3		

10. Summary assessment of this EHIA findings

Successful treatment of the condition will undoubtably improve the health and well being of patients by improving symptom control that can impede patient independence. Treatment may also reduce deterioration in organ dysfunction such as cardiovascular and respiratory disease which on occasions can be life threatening. The condition also has a degree of skin disfigurement which patients may also find distressing.

This potential improvement will have an overall positive impact upon a patient’s health and well being across a number of protected characteristics and perceived health inequality situations that may improve other aspects of inequalities experienced by the patient.

11. Contact details re this EHIA

Team/Unit name:	Specialised Rheumatology CRG / Internal Medicine Programme of Care
Division name:	Specialised Commissioning
Directorate name:	Chief Finance Office
Date EHIA agreed:	April 2024
Date EHIA published if appropriate:	5 November 2024