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): Lonafarnib for Hutchinson-Gilford progeria syndrome (12 months of age and over) [2402]

2. Brief summary of the proposal in a few sentences

This policy outlines whether NHS England will routinely commission lonafarnib for the treatment of patients with Hutchinson-Gilford progeria syndrome (HGPS) and if so, the commissioning criteria for accessing treatment.

Progeroid laminopathies are rare, fatal genetic conditions characterised by an appearance of accelerated aging in children. The majority of patients with progeroid laminopathies have the type HGPS. HGPS is caused by a mutation in the gene called LMNA. This genetic mutation is sporadic and occurs without family history. The LMNA gene produces the Lamin A protein, which is the structural scaffolding that holds the nucleus of a cell together. It is believed that the defective Lamin A protein makes the nucleus unstable. That cellular instability leads to the process of premature aging.

Lonafarnib is a potent and specific inhibitor of farnesyltransferase, therefore blocking the farnesylation of progerin and reducing the accumulation of progerin and progerin-like proteins in the cells. Lonafarnib is licensed for the treatment of people aged 12 months and older for Hutchinson-Gilford progeria syndrome.

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 prevalence of HGPS is estimated to be approximately 1 in 23 million (Wang et al, 2023). The incidence is approximately 1 in 4 – 8 million newborns (Hennekam 2006). HGPS is a genetic condition that becomes apparent in early childhood. Currently, the average life expectancy for patients with HGPS is approximately 14.5 years. Lonafarnib is licensed for use in those age 12 months and older. Therefore, it is expected that this policy will have a positive effect on children and young people, as they are the population in which these syndromes become apparent.	This policy states that lonafarnib is routinely commissioned for all patients age over 12 months, in line with the drug's marketing authorisation.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	HGPS is long-term conditions that results in chronic disease. Children experience the sequalae of premature aging, which manifests itself in the form of accelerated atherosclerosis, heart disease and stroke. The features of premature aging can result in long-term conditions and disability.	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 with disabilities.

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
	The aim of this policy is to improve patients' outcomes whilst on lonafarnib, potentially reducing or delaying the onset of premature aging. However, lonafarnib will need to be dispensed from specialised centres, and it is acknowledged that people living with disabilities may face increased travel costs to attend hospital appointments. This may be offset by a reduction in emergency or unscheduled care.	Prescribing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.
Gender Reassignment and/or people who identify as Transgender	As these are genetic conditions diagnosed in early childhood, gender reassignment and being transgender are not known to be risk factors for HGPS.	All patients who meet the inclusion criteria would be considered for lonafarnib. There should not be any adverse impact on this protected characteristic group through creating this policy.
Marriage & Civil Partnership: people married or in a civil partnership.	As these are genetic conditions diagnosed in early childhood, marriage status is not a risk factor for HGPS.	All patients who meet the inclusion criteria would be considered for lonafarnib. There should not be any adverse impact on this protected characteristic group through creating this policy.
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	As these are genetic conditions diagnosed in early childhood, pregnancy and maternity status are not a risk factor for HGPS. Due to the multi-organ consequences of the disease meaning that the possibility of pregnancy is exceptionally rare, it is not	All patients who meet the inclusion criteria would be considered for lonafarnib. There should not be any adverse impact on this protected characteristic group through creating this policy.

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
	expected that this policy will have a positive or negative impact on these protected characteristics.	
Race and ethnicity[1]	HGPS is not known to be more common in people of different race or ethnicity (Hennekam 2006), and this policy will promote access to lonafarnib regardless of race or ethnicity.	All patients who meet the inclusion criteria would be considered for lonafarnib. There should not be any adverse impact on this protected characteristic group through creating this policy.
Religion and belief: people with different religions/faiths or beliefs, or none.	Religion is not known to be a risk factor for HGPS. This policy will promote access to lonafarnib regardless of religion.	All patients who meet the inclusion criteria would be considered for lonafarnib. There should not be any adverse impact on this protected characteristic group through creating this policy.
Sex: men; women	No significant difference in incidence has been observed according to sex for HGPS (Hennekam 2006). This policy offers patients with HGPS lonafarnib regardless of sex.	All patients who meet the inclusion criteria would be considered for lonafarnib treatment. There should not be any adverse impact on this protected characteristic group through creating this policy.
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Sexual orientation is not known to be a risk factor for HGPS. This policy will promote access to lonafarnib regardless of sexual orientation.	All patients who meet the inclusion criteria would be considered for lonafarnib. There should not be any adverse impact on this protected characteristic group through creating this policy.

[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	This policy may have a potential adverse impact on looked after children and young people, because: 1. Looked-after children and young people may face additional barriers to accessing therapeutics. Therefore, they may have less chance of meeting the policy eligibility criteria to receive lonafarnib. 2. If eligible for treatment, looked after young people will require someone to bring them to appointments, provide consent for treatment, and guide administering of lonafarnib, which may be more difficult than for children with a permanent guardian or carer.	The adverse impact of this policy on looked after children and young people is acknowledged. Prescribing centres have responsibility to promote equity of access.

[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
Carers of patients: unpaid, family members.	Carers may be indirectly positively affected by this policy. This policy may benefit carers who support patients with HGPS by reducing their associated co-morbidities.	The availability of lonafarnib will provide a treatment option for patients, potentially reducing carer burden. Prescribing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	Being homeless is not a risk factor for developing HGPS. The lack of a permanent base for which follow-up appointments could be co-ordinated may be challenging in this cohort of patients. Those who are homeless could be at risk of adverse outcomes due to lack of access to services and/or incomplete follow up.	Consideration needs to be given to groups that face inequalities, including homeless people, to ensure that access to the service is enabled/supported.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	There are no identified potential positive or adverse impacts of this policy on this group.	Consideration needs to be given to groups that face inequalities, including people involved in the criminal justice system, to ensure that access to the service is enabled/supported.
People with addictions and/or substance misuse issues	There are no identified potential positive or adverse impacts of this policy on this group.	Consideration needs to be given to groups that face inequalities, including people with addiction and/or substance misuse issues, to ensure that access to the service is enabled/supported.

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 or families on a low income	Chronic disease is known to have a financial impact on patients and many people are affected by financial difficulties.	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 of families on a low income. Prescribing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).	Individuals with poor literacy/health literacy may not have access to the same information and resources as those more literate. This may limit their agency and ability to access lonafarnib.	Consideration needs to be given to groups that face inequalities, including people with poor literacy or health literacy, to ensure access to the service is enabled/supported. Prescribing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.
People living in deprived areas	Deprivation is not known to be a risk factor for HGPS, however, it may be a factor for delayed diagnosis.	Consideration needs to be given to groups that face inequalities, including people living in deprived areas, to ensure that access to the service is enabled/supported. Prescribing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.
People living in remote, rural and island locations	Living in a remote, rural or island location is not known to be a risk factor for HGPS. However, it may mean that patients have difficulty reaching prescribing centres to begin treatment.	Consideration needs to be given to groups that face inequalities, including people living in remote, rural or island locations, to ensure that access to the service is enabled/supported.

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
		Prescribing 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	Being a refugee, asylum seeker or experiencing modern slavery are not known to be risk factors for HGPS. However, it may mean that patients have difficulty reaching prescribing centres to begin treatment.	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 refugees, asylum seeker or experiencing modern slavery. Prescribing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme.
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 testing	This took place in May/June 2025 and involved clinical staff, professional groups, patients, patient groups and industry groups who have expressed an interest in this topic area. 3 responses were received which were supportive of the policy to routinely commission lonafarnib for the population outlined. One stakeholder was unsure whether they supported the policy, but no further information was provided.	2025
2	Policy working group	This involved input from a range of clinical staff who have experience in treating patients with HGPS.	2025

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	A full evidence review has been undertaken by SPH.	No evidence was identified for cost effectiveness or subgroups of patients.
Consultation and involvement findings	Stakeholder testing took place in May/June 2025. 3 responses were received which were supportive of the policy to routinely commission lonafarnib for the population outlined. One stakeholder was unsure whether they supported the policy, but no further information was provided.	N/A
Research	No pending research is known.	N/A
Participant or expert knowledge	Through the Women and Children Programme of Care and its Clinical Reference Group structures supporting the	N/A

Evidence Type	Key sources of available evidence	Key gaps in evidence
For example, expertise within the team or expertise drawn on external to your team	policy working group with its expert knowledge regarding the epidemiology and treatment of HGPS.	

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	
The proposal may support?			
Uncertain whether the proposal will support?	x		x

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 noted	N/A
2		
3		

10. Summary assessment of this EHIA findings

This assessment should summarise whether the findings are that this policy will or will not make a contribution to advancing equality of opportunity and/or reducing health inequalities, if no impact is identified please summarise why below. This policy aims to make lonafarnib available for all patients with HGPS if clinically eligible. HGPS is a genetic condition that becomes apparent in early childhood. Currently, the average life expectancy for patients with HGPS is approximately 14.5 years. Lonafarnib is licensed for use in those age 12 months and older. Therefore, it is expected that this policy will have a positive effect on children and young people, as they are the population in which these syndromes become apparent. The aim of this policy is to improve patients' outcomes whilst on lonafarnib, potentially reducing or delaying the onset of premature aging. No adverse impacts of this policy have been identified.

11. Contact details re this EHIA

Team/Unit name:	Women and Children Programme of Care
Division name:	Specialised Commissioning
Directorate name:	System Development Group
Date EHIA agreed:	May 2025
Date EHIA published	June 2026