

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)¹: 1640 - 230801 Cystinosis Service (all ages)**
- 2. Brief summary of the proposal in a few sentences**

Cystinosis is a very rare inherited lysosomal storage disease presenting in infancy (95% of cases) with severe kidney disease but subsequently involving multiple organs (eyes, thyroid, liver, diabetes, muscle deterioration).

A dedicated specialist service has recently been commissioned in England. Current care is fragmented with major geographical variability in care quality. Early initiation of cysteamine therapy can significantly postpone, or even prevent complications of the disease. Poorly coordinated care results in patients attending multiple clinics on different days at different sites. Since the use of cysteamine and the introduction of renal replacement therapy in paediatric populations, patients with cystinosis are increasingly surviving into adulthood. However, there are few transition services from childhood to adult clinics and limited adult services. Clinical inexperience compromises care especially within adult services. Better recognition and treatment of late-term complications in adulthood will improve long-term outcomes in patients. A multidisciplinary clinical team offers the best and most comprehensive management and treatment of cystinosis.

The current published service specification sets out a new service model for this patient group to provide an integrated one stop service between multiple specialities and paediatric and adult services to ensure consistent and quality service delivered. The changes being presented via the Expanded Change process are not material and focus on transferring the content of the existing

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

specification into the new NHSE (NHS England) service specification template and updating the clinical outcomes and quality metrics.

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 service is for all ages so would positively impact the care of patients of any age The age of onset, symptoms, and severity of cystinosis can vary greatly and at age of presentation, can present in infancy.	Early initiation of cysteamine therapy can significantly postpone, or even prevent complications of the disease.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	Patients will suffer a range of symptoms depending on diagnosis, age of onset and management cystinosis is a multi-symptom disorder with a range of disabling consequences including loss of vision. Better recognition and treatment of late-term complications in adulthood will improve long-term outcomes in patients	This specification outlines the most appropriate pathway for patients considering their long-term condition through a multi-disciplinary team (MDT) and shared care approach.

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
	and so will have a positive impact on patients.	
Gender Reassignment and/or people who identify as Transgender	Cystinosis is a long-term condition so the service will potentially benefit any patient.	The service will positively impact the care of all patients with cystinosis
Marriage & Civil Partnership: people married or in a civil partnership.	Cystinosis is a long-term condition so the service will potentially benefit any patient.	The service will positively impact the care of all patients with cystinosis
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	Women with cystinosis need access to obstetricians experienced in the management of medical problems in pregnant patients.	Expertise will be made available as part of the MDT as needed.
Race and ethnicity²	The disorder is estimated to occur in 1 in 100,000-200,000 people in the general population. Cystinosis has been reported worldwide, in all ethnic groups.	The service will positively impact the care of all patients with cystinosis

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 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
Religion and belief: people with different religions/faiths or beliefs, or none.	Cystinosis is a long-term condition so the service will potentially benefit any patient.	The service will positively impact the care of all patients with cystinosis
Sex: men; women	As above. Cystinosis affects males and females in equal numbers.	The service will positively impact the care of all patients with cystinosis
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Cystinosis is a long-term condition so the service will potentially benefit any patient.	The service will positively impact the care of all patients with cystinosis

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	The service is an all-ages service specification, cystinosis is often diagnosed at a young age. Access to expertise will improve management of all patients including looked after children and young people.	Children and young people should be offered expert management of their cystinosis by the HSS service providers

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

Groups who face health inequalities³	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.	Better patient management with clear plans and expert advice would have a positive impact on carers of children and adults with cystinosis	The service will enable access for all patients who meet the inclusion criteria. The HSS and local renal centre should work together and where needed with other bodies including charities to support access to patients who may otherwise not have access to expertise and treatment.
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	There should be no direct negative or positive impact on this group as it has not been identified as a high-risk group	
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	There should be no direct negative or positive impact on this group as it has not been identified as a high-risk group	
People with addictions and/or substance misuse issues	There should be no direct negative or positive impact on this group as it has not been identified as a high-risk group	
People or families on a low income	Early initiation of therapies can significantly postpone, or even prevent complications of the disease improving outcomes for patients. Centralisation of services can result in some inequity of access for families of low income.	The highly specialised service and the patient's local renal centre will work together to support the care of patients thus minimising travel to the Cystinosis centre whilst benefitting from the expertise available.
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).	Early initiation of therapies can significantly postpone, or even prevent complications of the disease improving outcomes for patients.	The service will enable access for all patients who meet the inclusion criteria. The HSS and local renal centre should work together and where needed with other bodies including charities to support access to patients who may otherwise not have access to expertise and treatment.

Groups who face health inequalities³	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	Early initiation of therapies can significantly postpone, or even prevent complications of the disease improving outcomes for patients.	The service will enable access for all patients who meet the inclusion criteria. The HSS and local renal centre should work together and where needed with other bodies including charities to support access to patients who may otherwise not have access to expertise and treatment.
People living in remote, rural and island locations	Early initiation of therapies can significantly postpone, or even prevent complications of the disease improving outcomes for patients.	Establishing effective hub and spoke arrangements
Refugees, asylum seekers or those experiencing modern slavery	Early initiation of therapies can significantly postpone, or even prevent complications of the disease improving outcomes for patients.	The service will enable access for all patients who meet the inclusion criteria. The HSS and local renal centre should work together and where needed with other bodies including charities to support access to patients who may otherwise not have access to expertise and treatment.
Other groups experiencing health inequalities (please describe)	Early initiation of therapies can significantly postpone, or even prevent complications of the disease improving outcomes for patients.	The service will enable access for all patients who meet the inclusion criteria. The HSS and local renal centre should work together and where needed with other bodies including charities to support access to patients who may otherwise not have access to expertise and treatment.

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 <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Do Not Know <input type="checkbox"/>
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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	Relevant CRGs: Renal, Paediatric Medicine CRGs engaged as well as professional bodies and a patient organisation. A Cystinosis Patient Study Day was held in January 2019 and patients were updated on the proposal.	January 2019
2	Public Consultation	The service specification was posted on the NHS England website in accordance with the published Methods and stakeholders were notified of the opportunity to comment. Responses received included those from clinicians, patient group and patients.	Feb/March 2020
3	Provider centres were involved in rewriting of service specification into the new template	Meetings with provider centres and circulation of redrafted specification for input. Circulation to PPV member from patient charity involved in service procurement. Separate discussions and engagement with centres and QNT to agree revisions to clinical outcomes	Nov/Dec 2022

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	The development of the service specification has been formed from the synthesis of a range of clinical guidelines, international consensus documents and NICE guidance as detailed in the specification.	Some of the evidence is not specific to Cystinosis patients but broader renal guidelines
Consultation and involvement findings	Supportive of the proposal	
Research		
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	The specification working group membership was drawn from a range of disciplines with adult and paediatric expertise in treating patients with Cystinosis	

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	It will be important to continually assess the impact of the service [if agreed] to add to the evidence base	This would be by a variety of approaches including publishing of outcomes, audit and research involving patient groups.
2		
3		

10. Summary assessment of this EHIA findings

This assessment should summarise whether the findings are that this proposal 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 proposal should advance equality of opportunity for all patients with cystinosis to support improved health outcomes.

11. Contact details re this EHIA

Team/Unit name:	Highly Specialised Team
Division name:	Highly Specialised Team
Directorate name:	Specialised Commissioning
Date EHIA agreed:	June 2023
Date EHIA published if appropriate:	August 2023