NHS England: Equality and Health Inequalities Impact Assessment (EHIA) template

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]: Specialist immunology services for adults with deficient immune systems

2. Brief summary of the proposal in a few sentences

Service specifications are intended to clearly define the standards of care expected from organisations funded by NHS England to provide specialised care.

Specialist immunology services include the diagnosis and management of:

- All inborn errors of immunity (IEI) in keeping with the latest International Union of Immunological Societies (IUIS) classification;
- Hereditary and acquired angioedema;
- Clinically significant secondary immunodeficiencies (excluding HIV) e.g. with recurrent infections;
- Complex autoimmune and vasculitic conditions as shared care.

The Specialised Immunology (All Ages) service specification (2013) has been reviewed and updated to reflect the Prescribed Specialised Services Manual, bring it in line with current practice and use the most up to date service specification template (published in 2022). The main changes are:

- A focus on adults only, to avoid confusion with the published Paediatric Medicine: Immunology and Infectious Diseases Service Specification
- Reduction in content duplication and wording that is more concise and easier to read
- Update and futureproofing of references

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

The proposed changes are not expected to impact on the way that patients access or experience care or have unallocated financial implications. Therefore the level of change is covered by the Expanded Change process as defined in the NHS England Service Specification Methods. This EHIA covers the full service as there was no previous EHIA in place.

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.	Many IEIs are diagnosed in early childhood. However, an increasing number of IEIs are now diagnosed in adults in later life. There may be variations in the time taken to diagnose adults, depending on the awareness of IEI as a potential diagnosis. Secondary immunodeficiencies may also be challenging to diagnose. This service specification covers adult populations only. There is a separate service specification for immunology services for children. The service specification includes a clear requirement for services to support young people who are transitioning	Providers should collect data routinely on age, sex and ethnicity of service users and consider by means of health equity audit (HEAT) whether there are any underserved populations. Service providers should consider outreach or educational activity into non-specialised services to support greater awareness of IEI/Primary Immune Deficiency (PID). Services for children are not covered within this specification, however services should consider the relationship of service users to other age groups in the population, additional risks and the need for other health protection measures. Adult immunology services are required to work closely with paediatric immunology services to ensure that older children and young people are cared for in the most appropriate setting and

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
	from children to adult services. This will have a positive impact on the care of adolescents and young adults.	transition effectively into adult services at an individually appropriate time.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	IEIs and other primary and secondary immunodeficiencies would meet the definition of disability for many adult patients, placing substantial restrictions on their ability to undertake day to day activities. Patients may have additional physical, sensory or other impairments alongside their immune deficiency. This may create barriers to physically attending treatment services, especially if long journeys are required to attend specialist centres.	Providers should ensure patients are aware of the social and economic support (for example, claiming disability-related benefits, reasonable adjustments at work) that may be available to them if their condition is defined as a disability. Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. Commissioned providers must ensure that the services provided are accessible for patients who have physical, sensory or other impairments alongside their immune deficiency. Reasonable adjustments should be made for patients who require them to access services.
Gender Reassignment and/or people who identify as Transgender	Gender reassignment and being transgender are not known to be risk factors for the conditions covered by this service specification. However, help seeking can be affected by experience of care: 40% of trans respondents who had accessed or tried to access public healthcare services reported having experienced at least one of a range of negative experiences	All patients seen by the service should be offered inclusive treatment. The BMA offers guidance on Inclusive care of trans and non-binary patients. Providers should be aware that patients in this group may face barriers to getting a diagnosis and/or may have had negative experiences with accessing healthcare services in the past.

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
	because of their gender identity in the 12 months preceding the survey. 21% of trans respondents reported that their specific needs had been ignored or not taken into account, 18% had avoided treatment for fear of a negative reaction, and 18% had received inappropriate curiosity (National LGBT Survey). This service is expected to have a positive effect on the overall survival and overall outcomes of all patients who need this service, regardless of gender reassignment and being transgender.	
Marriage & Civil Partnership: people married or in a civil partnership.	Marriage or civil partnership status is not known to be risk factor for the conditions covered by this service specification. It is not anticipated that marriage/civil partnership status are likely to pose additional barriers to patients accessing the service.	The service specification is not anticipated to positively or negatively impact people who are married or in a civil partnership.
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding.	Mallart et al (2023) conducted a retrospective study of pregnancies in women with PID/IEI.	Where a patient under the care of specialist services is or wishes to become pregnant, providers should be able to liaise with their local

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	They emphasise the importance of expert surveillance and tailored prophylaxis to increase the probability of a successful pregnancy and birth. Nevertheless, with this in place, most women in the study were able to become pregnant and have a successful birth at similar rates to the general population.	maternity service provider to give advice and support during the pregnancy and birth. For patients who wish to become pregnant, providers should be able to offer pre-conception advice and support. Providers should be able to refer patients to specialist genetic counselling where they wish to become pregnant and are concerned about the risk of their child inheriting an immune deficiency disorder.
Race and ethnicity[2]	IEIs are a varied and fast expanding group of disorders. There is no evidence of differential rates of primary antibody disorders by ethnicity (Krishna et al, 2020). However, some rare immunodeficiencies such as severe combined immunodeficiency (SCID), which follow an autosomal recessive pattern of inheritance are more prevalent in populations where consanguineous marriage is common.	Providers should collect data routinely on age, sex and ethnicity of service users and consider by means of health equity audit (HEAT) whether there are any underserved populations. Commissioners should be able to monitor treatment data by ethnicity and discuss with providers to ensure it is complete and that they are assured that there are no differences in outcomes and retention between different ethnic populations.

[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
	In the UK these families are usually of BAME and particularly Pakistani or Bangladeshi heritage (Krishna et al, 2020). In broad terms, BAME patients are more likely than white British patients to experience a range of barriers in seeking and receiving help, ranging from a lack of confidence in approaching health services to conscious or unconscious bias from the medical professionals diagnosing and treating them. If a patient has a first language other than English this may present barriers to effective communication and delay diagnosis or treatment.	Providers and commissioners should work together to explore and address any under-representation of BAME patients in services. Service providers should have translated materials and translation support available for patients whose first language is not English and/or who do not communicate comfortably in English. Providers should be able to refer patients to specialist genetic counselling if they have an inherited immune deficiency. In addition, service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness.
Religion and belief: people with different religions/faiths or beliefs, or none.	Religion and belief are not known to be risk factors for the conditions covered by this service specification. However, patients may experience barriers to accessing services, or less positive outcomes from treatment, if needs relating to their religion/belief are not met, or if they experience	The service specification is not anticipated to positively or negatively impact people who belong to religions, faiths, belief groups or who have none. Service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness.

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
	discrimination in relation to their religion/ belief. Some patients, mainly Jehovah's Witnesses, who have a religious objection to receiving blood or blood products may have concerns about the use of immunoglobulin. The acceptance of blood fractions such as immunoglobulin is considered acceptable by some Jehovah's Witnesses but not all, so it is generally a matter for individual consideration by the patient.	Shared decision making to support informed patient consent, with reference to any existing Trust policies for the treatment of patients who refuse blood products. Trusts often have a Jehovah's Witness hospital liaison committee who may offer advice and support. When developing commissioning policies, considering how alternative treatments to immunoglobulin can be supported if available, for patients who refuse blood products.
Sex: men; women	IEIs are a heterogeneous group of disorders, of which a small number are 'X-linked', which means that only men will have symptomatic disease. Women will be carriers. However across the full range of IEIs, prevalence of IEIs in men and women is very similar (The United Kingdom Primary Immune Deficiency (UKPID) registry 2012 to 2017 - PMC (nih.gov)) Secondary immunodeficiencies also have similar prevalence across the sexes.	The service specification is not anticipated to impact people whose birth assigned sex is male or female either positively or negatively. Service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness.

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
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Sexual orientation is not known to be a risk factor for the conditions covered by this service specification. However, help seeking and the outcomes of care can be affected by experience of care and, conscious or unconscious bias or discrimination by healthcare providers on the basis of sexual orientation.	The service specification is not anticipated to impact people who identify lesbian, gay, bisexual or heterosexual either positively or negatively. Service providers are expected to have mandatory training requirements in place for all staff to ensure compliance with Equality, Diversity and Inclusion awareness.

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	This service specification is for adults only. There should be no direct negative or positive impact on young people in care or care leavers who may be better cared for in adult services. They may however need additional support to access the right services.	Adult immunology services are required to work closely with paediatric immunology services to ensure that older children and young people are cared for in the most appropriate setting and transition effectively into adult services at an individually appropriate time. Service providers should consider how they can work sensitively with young adults who are care-

[3] Please note many groups who share protected characteristics have also been identified as facing 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
	Young adults who are care-experienced are likely to have low trust in health services and limited confidence in communicating with professionals. This may make it difficult for young adults not previously diagnosed to seek or receive a diagnosis and subsequent treatment. The NHS Long Term Plan identifies care leavers as a group at high risk of health inequalities and exclusion.	experienced, to support their engagement in diagnosis or treatment.
Carers of patients: unpaid, family members.	Being a carer is not known to be a risk factor for the conditions covered by this service specification. However, as described above, many patients who are cared for by specialist services will have significant disabilities and hence will receive substantial support from unpaid carers and family members. Carers tend to be at particular risk of poor health outcomes because they may have little time to attend to their own physical health (e.g. by attending screening appointments, or seeking	Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. Service providers should ask about unpaid care and be able to signpost family and other unpaid carers to sources of support (e.g. local carers' support organisation, guidance about claiming Carers' Allowance, carers' assessment through their local authority). Service providers should be able to signpost families to relevant patient support organisations where these exist.

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
	healthcare), and their mental wellbeing may suffer from the stress of caring. The service specification is not anticipated to positively or negatively impact people who are carers, although an effective service which improves patients' health and quality of life will also reduce the burden on unpaid carers. Unpaid caring reduces the resources available to a family, so the economic burden of attending appointments at a specialist service will be greater and may present barriers to diagnosis or treatment.	
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.	Being homeless is not known to be a risk factor for the conditions covered by this service specification. The service specification is not anticipated to positively or negatively impact people who are homeless. Someone who is homeless and has an IEI or secondary immunodeficiency will face very significant barriers to accessing and engaging in specialist treatment.	Providers should take account of people's personal circumstances when determining the best treatment options and care plans. Service providers should liaise with adult social care, supported housing providers, VCSE organisations or any other service involved in supporting a homeless patient to create a care plan which gives the patient the best opportunity to receive care and treatment.

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
		Service providers should be willing to liaise with local authorities to provide evidence and support where the patient's condition may give rise to a case for higher priority in re-housing.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	The conditions covered by this service specification do not disproportionately impact people involved in the criminal justice system positively or negatively. However, people in contact with the criminal justice system who have an IEI or secondary immunodeficiency are likely to face very significant barriers to accessing specialist treatment, or to being diagnosed if symptoms arise in adulthood.	Service providers should liaise with the justice system for incarcerated patients, and with other supporting agencies where the patient is in the community, to create a care plan which gives the patient the best opportunity to receive care and treatment.
People with addictions and/or substance misuse issues	The conditions covered by this service specification do not disproportionately impact people with addictions and/or substance misuse issues positively or negatively. However, people with addictions and substance misuse issues who have an IEI or secondary immunodeficiency typically face very significant barriers to accessing specialist treatment and are likely to find it more difficult to adhere to treatment plans.	Service providers should liaise with any specialist substance misuse agencies that are supporting the patient, to ensure that they are helped to attend treatment and to develop a self-management plan for their condition.

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
People or families on a low income	Patients and families may be adversely affected financially by the need to travel to specialist centres to access treatment. Patients may be adversely impacted by loss of earnings due to admission or attendance at hospital. Patients on a low income may struggle with paying for childcare or may depend on unpaid care.	Providing centres need to ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. Providing centres should consider the potential to offer appointments in different modalities where viable (e.g. phone, virtual or outreach locations) to limit travel costs. Providers should consider how the booking of appointments or treatment times may disadvantage patients on a low income, e.g. if patients have to make long journeys on public transport, travel at peak times or take time off work. Where possible, providers should work with patients to agree appointment times that limit financial hardship and take childcare and work commitments into account. Providers should refer/signpost to social workers, Citizens Advice Bureau and local support organisations in their area for advice on assessing eligibility for and claiming benefits. Consider referral to food banks or other local support if needed.
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).	A 2015 OECD survey estimated that 1 in 6 adults in the UK have 'very poor' literacy skills, limited to reading very	Shared decision making should be used using appropriate mediums including verbal, written shared decision-making tools, translated, and Easy Read materials. The NHS has produced a

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
	simple texts. This will vary by region across the UK (PIAAC | OECD). Principle 4 of the NHS Constitution states that 'Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment'. NICE acknowledge that health literacy is a fundamental component of shared decision making. People with lower levels of literacy are likely to also have a lower degree of 'health literacy' (understanding of health services in general and their condition in particular). People with lower literacy and health literacy skills will find it harder to understand their condition and the benefits and risks associated with different treatment options, especially if they are given written material well beyond their reading ability. This might impact on their ability to access treatment or maintain involvement in a treatment regime.	Health Literacy Toolkit (2nd Edition, 2023) that providers should use to ensure that all patients are able to participate in their care and get the best out of the treatments offered to them equitably. Providers should review written material provided to patients and ensure that it can be understood by people with lower reading ages. Various 'readability checker' tools are available to support this. Treatment should be tailored to the needs of those with poor health or literacy skills. A holistic assessment of an individual should be undertaken to assess their suitability and understanding in relation to any barriers for treatment. If individuals have poor literacy or health literacy, they should have the option to be supported by a family member, friend or advocate where possible. 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 who have poor literacy or health literacy.

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
People living in deprived areas	The conditions covered by this service specification do not disproportionately impact people living in deprived areas either positively or negatively. However, people living in more deprived areas are proportionately much more likely to experience all the health inequalities described above in relation to low income, poor literacy and health literacy, caring responsibilities, homelessness and housing insecurity. All of the above are strongly related to overall deprivation.	A national service specification sets out the minimum standards for the delivery of equitable care across England, regardless of location. As specialist services serve a large catchment population, they will normally see patients from a wide geographical area, rather than serving specific communities living in more deprived areas. However, providers should be mindful that patients living in areas of greater deprivation are likely to experience a number of the disadvantages and barriers described and should consider ways of addressing these as discussed above.
People living in remote, rural and island locations	The conditions covered by this service specification do not disproportionately impact people living in remote, rural and island locations positively or negatively. The service specification includes the requirement for both face to face and remote outpatient clinics for assessment and follow-up, which may reduce the need to travel for hospital appointments.	Providing centres should ensure eligible patients and carers are aware of the NHS Healthcare Travel Costs Scheme. Providing centres should consider the potential to offer appointments in different modalities where viable (e.g. phone, virtual or outreach locations) to limit travel costs and make it as easy as possible for people living in remote locations to receive treatment.

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
Refugees, asylum seekers or those experiencing modern slavery	The conditions covered by this service specification do not disproportionately impact refugees, asylum seekers or those experiencing modern slavery positively or negatively. However, someone who is a refugee, asylum seeker or has experienced modern slavery and has an IEI or secondary immunodeficiency will face very significant barriers to accessing specialist treatment, or to being diagnosed in adulthood.	Service providers should consider how they can liaise with organisations supporting refugees and asylum seekers, to create a care plan which gives the patient the best opportunity to receive care and treatment. In particular, service providers should consider the translation of materials into the patients' first language and/or the availability of translation support for appointments and treatment.
Other groups experiencing health inequalities (please describe)	People from gypsy and traveller communities typically experience significant health inequalities. However, the conditions covered by this service specification do not disproportionately impact gypsy and traveller communities.	Service providers should consider how they can liaise with organisations supporting gypsy and traveller communities, to create a care plan which gives the patient the best opportunity to receive care and treatment. In particular providers should be mindful that people from gypsy and traveller communities often have poor literacy and health literacy and should consider the recommendations for this group above.

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	Service specification working group and Specialised Immunology & Allergy Clinical Reference Group	Review of draft service specification	March 2024
2	Informal stakeholder testing	The BSI-CIPN Steering Group was contacted for informal stakeholder feedback in the first instance, followed by wider stakeholder engagement.	Apr-Sept 2024

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	Not applicable	Not applicable
Consultation and involvement findings	Informal stakeholder testing with patient organisations, professional network and regional commissioners.	Not applicable
Research	Not applicable	Not applicable

Evidence Type	Key sources of available evidence	Key gaps in evidence
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	Clinical expertise and patient input through the service specification working group.	Not applicable

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	
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		
2		
3		

10. Summary assessment of this EHIA findings

The updated service specification will make a contribution to reducing health inequalities by setting clear standards of patient care for all specialised immunology centres.

11. Contact details re this EHIA

Team/Unit name:	Blood and Infection Programme of Care
Division name:	Specialised Commissioning
Directorate name:	CFO
Date EHIA agreed:	
Date EHIA published if appropriate:	