

# Equality Impact Assessment form – Public Sector Equality Duty

January 2024

# Introduction

The general equality duty that is set out in the Equality Act 2010 requires public authorities, in the exercise of their functions, to have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

The general equality duty does not specify how public authorities should analyse the effect of their existing and new policies and practices on equality, but doing so is an important part of complying with the general equality duty.

### THIS SECTION IS FOR INTERNAL USE ONLY

#### DO NOT INCLUDE THE FOLLOWING IN PUBLISHED DOCUMENTS

Please complete the form by following the instructions in each box. If you have any questions or suggestions on this form, please contact <u>rahul.patel@dhsc.gov.uk</u> or <u>david.bartlett@dhsc.gov.uk</u> in the Policy Assurance & ALB Oversight team.

Legal advisers need to clear equality impact assessments before they are sent to ministers.

The Secretary of State also has a legal duty relating to reducing health inequalities. If you have any questions about that duty, please contact the Health Disparities team at <u>healthdisparities@dhsc.gov.uk</u>.

#### **END OF SECTION**

# **Equality Impact Assessment**

Title: Equality analysis – The Public Sector Equality Duty and Family Test analysis concerning the introduction of screening for Tyrosinemia type 1 (HT1) as part of the newborn bloodspot screening programme.

What are the intended outcomes of this work? Include a brief outline of the policy and the main aims. What changes are you proposing, and why?

This equalities analysis examines the potential impact of the inclusion of Tyrosinemia type 1 (HT1) in the existing Newborn Bloodspot Screening programme in accordance with the Equality Act 2010. In addition, in respect of England, this document considers issues relevant to the Secretary of States duty to have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service, under section 1C of the National Health Service Act 2006.

The UK National Screening Committee (UK NSC) is the independent scientific committee that advises Ministers and the NHS in all four UK countries on all aspects of screening programmes. Evidence for implementing a new screening programme or amending an existing programme, first has to be reviewed by the UK NSC for a formal recommendation to be made.

In XXXX, the Government approved the UK National Screening Committee's (UK NSC) recommendation for screening for HT1 as part of the NHS Newborn Bloodspot Screening (NBS) programme. The recommendation estimated the main benefits of screening to be:

- a reduction in the number of babies with HT1 who experience severe liver disease in the early months of life

- potentially, a reduction the number of babies with HT1 who need a liver transplant in later life

- reducing uncertainty through asymptomatic diagnosis
- increasing equity in access to treatment for HT1

#### **Background on Screening**

Screening is the process of identifying people who are asymptomatic (have no symptoms) but have an increased risk of developing a disease or condition. NHS screening programmes are an efficient and proven method for early diagnosis while minimising false

positive results as much as possible. Early detection for some risk and conditions has real benefits, with individuals identified as being at greater risk of developing a condition being supported to take preventative measures to reduce their likelihood of becoming unwell. For those where a condition is detected, individuals can make better informed decisions around their treatment with early detection likely to make any required treatment more effective and therefore lead to better health outcomes. As a population screening offer is universal and there are mechanisms to monitor and quality assure the completeness of offer, the policy and associated implementation is likely to advance equality of opportunity and reduce inequality.

In England the NHS NBS screening programme, also known as the heel prick test, is offered to all newborn babies normally when they're 5 days old, either in the hospital or at home. This screening programme enables early identification, referral, and treatment of babies with nine rare but serious conditions including sickle cell disease, cystic fibrosis, congenital hypothyroidism and 6 inherited metabolic diseases including phenylketonuria (PKU). Babies who test positive for one of these conditions can be treated early to help improve health outcomes, prevent severe disability or even death.

All of the conditions screened for via the NBS test are genetic. The test itself looks for biological markers in the blood that could indicate the presence of the condition and further tests would be required for a formal diagnosis.

A positive screen for one of the nine condition is dependent on how rare the condition is, for example every year in the UK around 270 babies are born with sickle cell disease, 1 in every 2,500 babies is born with cystic fibrosis and 1 in every 2,000 to 3,000 babies has congenital hypothyroidism.<sup>1</sup>

Coverage (the proportion of the eligible population that is tested and has a result documented) is typically very high for NBS screening programme for those babies registered within the Integrated Care Board (ICB) at birth. The latest published coverage figure for this group, for the period 1 October to 31 December 2022, was 96.3% for England. However, coverage for movers in (babies eligible for NBS who have changed responsible ICB or have moved in from another UK country or abroad, in the reporting period) is lower at 78.1% for the period 1 October to 31 December 2022.

### **Background on Tyrosinemia**

HT1 is a very rare, genetically inherited, disorder. Babies with HT1 have inherited an abnormal gene from both parents, which is much more likely when parents are from the same family (consanguinity). It prevents the body from breaking down tyrosine which is found in food. This leads to the build-up of toxic levels of tyrosine and other harmful

<sup>&</sup>lt;sup>1</sup> Newborn blood spot test, NHS England (2021) Available online: https://www.nhs.uk/conditions/baby/newborn-screening/blood-spot-test/

metabolites in the blood. Over time, people with HT1 are at an increased risk of learning difficulties, liver cirrhosis and cancer. If left untreated, death from liver failure or liver cancer usually occurs before the age of 10 years. There is no cure for HT1, but treatment, using a special diet and the drug Nitisinone, can help prolong life.

One person in 100,000 is affected with HT1 globally, but it may be more common in some areas. It affects approximately 7 babies born each year in the UK.

Currently in the UK, there is no universal screening of newborns for HT1. Newborns with siblings living with HT1 are identified through genetic testing and others may be identified when undergoing screening for phenylketonuria (PKU). Incidental finding of newborns with HT1 through PKU screening is not ideal, as three babies a year are likely to be missed and diagnosed later in life when they present with liver disease and may then later require a liver transplant.

#### **Policy Objectives**

The model used in the UK NSC recommendation estimated that screening would increase the number of babies with HT1 who are detected before the onset of symptoms, by 3 babies a year on average. These babies could then be offered drug treatment and dietary management earlier, avoiding liver disease and the need for liver transplantation.

The model also estimated that replacing current practice with screening for HT1 would mean that 89 babies would avoid receiving an incorrect diagnosis as they do not have HT1 (referred to as false positive results). This would avoid unnecessary worry and stress for their parents.

Further discussion of the modelling used, and cost effectiveness, can be found in the Impact Assessment. [insert link]

#### Who will be affected? E.g. staff, patients, service users

Babies - all babies up to but not including their first birthday are eligible for NBS, so all parents would be offered screening for their babies for HT1.

Parents – parents (or primary care givers) will need to make the decisions about whether a baby takes part in the screening programme, the analysis and impacts will focus primarily on the likely impact on parental/care giver protected characteristics on their likelihood to participate, rather than on the baby's protected characteristics.

The NHS – the NHS will need to update laboratory protocols and train laboratory staff. The healthcare professionals involved in the NBS programme will also need training on the

addition of HT1. Genomic counsellors will need to be updated regarding the changes. There will be around 3 additional babies that will go into the treatment pathway earlier, so capacity will be needed to treat these babies effectively.

## Evidence

What evidence have you considered? List the main sources of data, research and other sources of evidence (including full references) reviewed to determine impact on each protected characteristic. This can include national research, surveys, reports, research interviews, focus groups, pilot activity evaluations etc. If there are gaps in evidence, what you will do to close them.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9387838/

Parental decision-making and acceptance of newborn bloodspot screening: an exploratory study - PubMed (nih.gov)

Should parental refusals of newborn screening be respected? - PubMed (nih.gov)

<u>Consent for newborn screening: parents' and health-care professionals' experiences of consent in practice - PMC (nih.gov)</u>

Tyrosinemia Type 1 - Symptoms, Causes, Treatment | NORD (rarediseases.org)

Ensuring pregnant trans men get equal quality care - PHE Screening (blog.gov.uk)

Addressing language as a barrier to healthcare access and quality - PubMed (nih.gov)

<u>Geographical and Ethnic Distribution of Mutations of the Fumarylacetoacetate Hydrolase</u> <u>Gene in Hereditary Tyrosinemia Type 1 - PubMed (nih.gov)</u>

Screening for tyrosinaemia type I. - PMC (nih.gov)

Sickle cell and thalassaemia screening: data report 2019 to 2020 - GOV.UK (www.gov.uk)

Sickle cell and thalassaemia screening: data report 2018 to 2019 - GOV.UK (www.gov.uk)

Psychosocial Issues Related to Newborn Screening: A Systematic Review and Synthesis (nih.gov)

Interviews with NHSE staff running NBS programmes

<u>KPIs</u>

Coverage of babies registered with ICBs at birth

The proportion of babies registered within the ICB both at birth and on the last day of the reporting period who are eligible for newborn blood spot (NBS) screening and have a conclusive result for phenylketonuria (PKU) recorded on the child health information service system (CHISS) at or before 17 days of age. This standard is to ensure that all eligible babies receive NBS screening within an effective timeframe. Coverage of ICB responsibility at birth **96.3%** for the period 1 October to 31 December 2022.

#### Coverage of movers in

The proportion of all babies eligible for newborn blood spot (NBS) screening who have both:

- changed responsible ICB, or have moved in from another UK country or abroad, in the reporting period

- a conclusive result for phenylketonuria (PKU) recorded on the child health information service system (CHISS) on or before 21 calendar days from notifying the child health department of movement in

Coverage of movers in was 78.1% for the period 1 October to 31 December 2022, this is below the acceptable threshold.

**Analysis of impacts.** For each protected characteristic below, and based on the evidence you have gathered, consider impacts for each of the three aims of the Public Sector Equality Duty – eliminating unlawful (direct and indirect) discrimination, advancing equality of opportunity, and fostering good relations.

Disability - attitudinal, physical and social barriers for both visible and hidden disability

Physical disabilities - Generally if the baby is no longer in hospital at 5 days old the NBS will take place at home. However, there may be follow up tests to confirm the diagnosis of a condition that take place in hospital. Parents with physical disabilities may be restricted in where they can attend for screening or follow up appointments unless there are facilities to accommodate them. If access is not facilitated this could deter individuals from getting their baby screened or attending subsequent appointments.

However contractually, providers of NHS screening services are required to make reasonable adjustments to ensure that their services are accessible to disabled people. For example, providers must ensure that their premises are suitable for the delivery of services and are sufficient to meet the needs their patients/individuals, including those with disabilities. Additionally, most newborn blood spot screening takes place at home with a midwife, ensuring NBS is more likely to be accessible to everyone. Learning disabilities - The NHS needs to secure informed consent from parents or care givers that they understand the reasons for screening. For people with learning disabilities, screening services have <u>'easy read' guides</u> developed and published to allow for equitable access to information. To ensure that people are informed and not disadvantaged the current blood spot guide will need to be updated.

#### Sex - men and women

Tyrosinemia type I affects males and females in equal numbers.<sup>2</sup>

There is no evidence to suggest that either sex may be discriminated against in the NBS programme.

#### Sexual orientation - heterosexual, homosexual or bisexual

People in same sex relationships who wish to have a child may wish to have this child by surrogate, this may impact screening for NBS as the surrogate mother's wishes take precedence over those of the intended parents. The surrogate must consent to the newborn screening programmes in order for the baby to be screened.<sup>3</sup> The Surrogate can write a letter for consent for baby to have any treatment whilst in the care of intended parents (IPs), this includes the Newborn Blood Spot screening. The IPs may be heterosexual or same sex couples in a marriage, civil partnership or living together/co habiting or a single person of any sex. Although the IP(s) may not have a direct say about whether the baby is screened – this is a broader issue about the laws surrounding surrogacy and is not specific to the NBS programme or same sex couples.

#### Race - ethnic groups, nationalities, Gypsy, Roma, Travellers, language barriers

Looking at the sickle cell data (which can be extrapolated to other newborn screening tests) there has been a steady increase in the rate of declines from 2005 – 2019 (the latest available data).<sup>4</sup> The highest rates of decline are in the "Black Caribbean" and "other" ethnic categories, it is noted that the higher rates of declines in non-White ethnicities may be related to the higher number of declines in babies that are mover-ins.<sup>5</sup>

Movers in are babies eligible for newborn blood spot (NBS) screening who have changed responsible ICB or have moved in from another UK country or abroad, in the reporting period. Coverage for movers in is substantially lower compared to the rest of the population, 78.1% for the reporting period 1 October to 31 December 2022. Parents/Care givers from this group may be unaware of services to which they are entitled, which could

<sup>&</sup>lt;sup>2</sup> Tyrosinemia Type 1 - Symptoms, Causes, Treatment | NORD (rarediseases.org)

<sup>&</sup>lt;sup>3</sup> <u>Guidelines for prophylaxis against thromboembolic disease following caesarean section</u> (leicestershospitals.nhs.uk)

<sup>&</sup>lt;sup>4</sup> Sickle cell and thalassaemia screening: data report 2019 to 2020 - GOV.UK (www.gov.uk)

<sup>&</sup>lt;sup>5</sup> Sickle cell and thalassaemia screening: data report 2019 to 2020 - GOV.UK (www.gov.uk)

create an obstacle to their uptake of screening services. This group may include asylum seekers, who are often not registered with a GP and particularly hard to track. If the mother and baby are not registered with a GP then they won't be offered screening. Movers in normally have contact with the health system through Health Visitors who provide the offer of newborn screening, rather than the general newborn population who are screened by midwives. Movers in babies may also be a lot older when they are screened, as they can be screened up to one year old, older babies are reported to be harder to perform the newborn bloodspot on as they are a lot more mobile. Health visitors therefore may have a training gap, as a lot of the training for newborn bloodspot is for babies that are 5 days old, not several months. Additionally, there needs to be adequate training for health visitors to explain the offer of screening to the movers in. The health visitors need to explain that the screening on offer may include conditions not included in the country of origin where the baby was born, and additionally the UK labs are UKAS accredited and screening is recommended even if the baby has been screened abroad.

Babies who are screened later than 5 days may have reduced health benefits from screening for HT1 as Nitisinone treatment is most effective when started early before symptoms appear.

Roma, Gypsy, and Traveller people – although these are distinct populations, there is some cross over in health inequalities for these groups as part of their nomadic lifestyle. Gypsy and Traveller people have poor access to healthcare generally, with difficulty in registering with GPs and poor access to services as a result, including health screening, home visits and access to secondary health care. For example, in 2016 to 2017, Gypsy or Irish Traveller people aged 65 and over had the lowest health-related quality of life of all ethnic groups.<sup>6</sup> There have been reports of breaches in equality laws as Gypsy, Roma and Traveller community members were refused care by British GP practices. Some reports of lack of trust in health services<sup>7</sup> – this could mean these populations are more likely to decline screening. Experience of discrimination with healthcare workers might also deter travellers from accessing healthcare around pregnancy and not accessing or declining screening. Specifically with regards to NBS, a lack of continuity of care could mean that these groups do not receive adequate informed choice around screening during pregnancy. Possible mitigations would need to be broader than screening. Existing mitigations include specialist health visitors and midwives with training and awareness of Gypsy and traveller culture.

Language - Groups who do not speak English as their first language may also be less able to access health services due to language barriers. Evidence shows that there are several ways in which access to primary care may be challenging for people with limited spoken English. People who do not speak English report greater barriers accessing primary care

<sup>&</sup>lt;sup>6</sup> <u>Gypsy, Roma and Irish Traveller ethnicity summary - GOV.UK Ethnicity facts and figures (ethnicity-facts-figures.service.gov.uk)</u>

<sup>&</sup>lt;sup>7</sup> Gypsies' and Travellers' lived experiences, health, England and Wales - Office for National Statistics (ons.gov.uk)

than those who do not, have a poorer patient experience and are more likely to be in poor health.<sup>8</sup> Language barriers may impact people's ability to make an informed choice about taking up the screening offer, as well as accurately relaying information needed to clinicians and affect their ability to ask questions about the programme. To help people to make an informed choice in the current NHS screening programmes, information leaflets and videos in <u>12 other languages are available</u>, and will be updated for the new testing.

Pakistani population in west midlands - there is a higher incidence of HT1 in the Pakistani population in the West Midlands predominantly in Birmingham. <sup>9,10</sup> A study showed that of 44 patients from the West Midlands with HT1, 30 (68%) were of Pakistani origin. This is over 22-fold higher than the frequency of people of Pakistani origin in other regions. This mutation was not detected in patients from any other close-by region suggesting a founder effect from the region of origin of this population. So, this ethnic minority in this specific region would see greater levels of benefit from HT1 screening than other groups.

In some communities, fear of stigma may cause parents to decline NBS for their babies. A study reported that parents of varied demographic backgrounds expressed concerns about potential societal stigma and discrimination associated with the diagnostic labels of "cystic fibrosis" and "sickle cell disease" or being "carriers" of genetic mutations for either of these conditions.<sup>11</sup>

#### Age - age ranges, old and young

There is a lack of evidence relating to age and uptake for the NBS programme in England.

#### Gender reassignment (including transgender) - transgender and transsexual people

It is possible in some circumstances for trans men to become pregnant and have babies. It is known that the LGBT community are less engaged with screening. Therefore, it is possible that trans men might be less likely to engage with NBS.

As set out in the blog <u>Ensuring pregnant trans men get equal quality care - PHE Screening</u> (blog.gov.uk), a mitigation would be for all maternity departments to review their own policies to make sure they're inclusive of trans people at every step, and not to wait until the first trans person books for maternity care to check the system works.

<sup>&</sup>lt;sup>8</sup> Addressing language as a barrier to healthcare access and quality, British Journal of General Practice, 72, 714, 4-5 (2022) K L Whitaker, D Krystallidou, E D Williams, G Black, C Vindrola-Padros, S Braun and P Gill

<sup>&</sup>lt;sup>9</sup> Geographical and Ethnic Distribution of Mutations of the Fumarylacetoacetate Hydrolase Gene in Hereditary Tyrosinemia Type 1

Francesca Angileri,

<sup>2015</sup> 

<sup>&</sup>lt;sup>10</sup> Hutchesson et al. 1998).

<sup>&</sup>lt;sup>11</sup> Psychosocial Issues Related to Newborn Screening: A Systematic Review and Synthesis - PMC (nih.gov)

### Religion or belief - people with different religions, beliefs, or no belief

Results from a study showed that parents who declined NBS were more actively religious and more often indicated that alternative medicine/lifestyle is important to them when compared to participating parents.<sup>12</sup> Moreover, more than half of the parents that declined NBS indicated that they were not planning to vaccinate their child for childhood infectious diseases. Declining both the NBS and the vaccination program might therefore also be representative decisions for a way of life. Mitigation would involve ensuing that parents or care givers have all the necessary facts and information, but then ensuring the right to choose – The national screening programme is based on informed choice.

# **Pregnancy and maternity** - working arrangements, part time working, infant caring responsibilities

There is no evidence to suggest that working arrangements or caring responsibilities impacts on uptake of NBS.

#### Marriage and civil partnership - married couples, civil partnerships

There is no evidence that marriage or civil partnership of the parents/ care givers has an impact on uptake of NBS for babies.

#### Other identified groups

#### Education level/ socio economic background/ deprivation

Mothers with lower incomes were almost four times less likely to receive information prenatally about NBS and more likely to be informed during the suboptimal postpartum time than their higher income counterparts.<sup>13</sup>

Respondents who participated in NBS made a more undisputed choice to participate (p < .001), while NBS nonparticipants indicated having more doubt (p < .001). From the study of all respondents who participated in NBS, respondents with a high educational level had more knowledge about NBS (difference of 0.75, p<0.001) and a more positive attitude towards NBS (difference of 0.46, p<0.001), compared to respondents with a low/middle educational level.

**Unassisted birth or "free birth**" (When a person chooses to give birth at home or somewhere else without the help of a healthcare professional such as a midwife.) - Unassisted birth is a choice and is not the same as giving birth at home before a planned midwife has time to arrive. If you have an unassisted birth, you must 'notify' the birth of

<sup>&</sup>lt;sup>12</sup> Parents' views on accepting, declining, and expanding NBS - PMC (nih.gov)

<sup>&</sup>lt;sup>13</sup> Tluczek, A.; Orland, K.M.; Nick, S.W.; Brown, R.L. Newborn screening: An appeal for improved parent education. J. Périnat. Neonatal Nurs. 2009, 23, 326–334.

your baby to a relevant public body within 36 hours. Once the birth has been notified, you should be given an NHS number for your baby. There is very little research on unassisted/freebirth. The number of freebirths in the UK and the outcome of these births are unknown. This is because women often disguise their choice of a freebirths as Born Before Arrivals (or BBAs where a baby is born before a pregnant person has time to get to the hospital). Consequently, we do not have reliable and accurate quantitative research (research that relies on numbers and statistics) that focuses on freebirth. It is possible that some people don't register their babies and so aren't offered NBS, or once they are offered NBS they decline. Mitigation would involve ensuring that parents or care givers have all the necessary facts and information, but then ensuring the right to choose – The national screening programme is based on informed choice.

Antivaxers/antiscreeners – similarly there are some people that are generally anti-medical care/ anti vaxer/ anti screener. It is their choice to decline screening for their baby – but again mitigation would involve ensuing that parents or care givers have all the necessary facts and information, but then ensuring the right to choose – The national screening programme is based on informed choice.

**Homeless people** - Although to access medical care including antenatal and postnatal care it is not necessary to have a home or proof of address, 8% of homeless people are not registered with a GP<sup>14</sup>. However, generally most homeless people will give birth in hospital. There is lack of information about whether uptake of the NBS offered at home when a baby is 5 days old is impacted. Mitigation would be to offer the NBS before discharging patients who are known to be homeless.

**Prison** - Women and babies in prison are entitled to receive the same care and support during pregnancy and birth as women in the community. Pregnant women in secure settings are offered antenatal and newborn screening as part of standard NHS care. Newborn blood spot screening should be taken on day 5 by the community midwife visiting the secure setting. The baby will have a GP outside the secure setting who is responsible for their care. The baby will not be the responsibility of the prison primary care service.

## **Engagement and involvement**

How have you engaged stakeholders in gathering evidence or testing the evidence available? For each engagement activity, please state who was involved, how and when they were engaged and the key outputs

The NHSE have equality and diversity leads both centrally and at a local level. These individuals were consulted on the content of this assessment.

<sup>&</sup>lt;sup>14</sup> Guidance on registering and referring homeless patients in your practice | Practice Business

Due to the exceptionally high coverage of NBS (over 95%) it is difficult to identify and engage decliners. The evidence presented above includes evidence provided by teams that have engaged with decliners at local level and used their Joint Strategic Needs assessments to identify and address community needs.

How have you engaged stakeholders in shaping the policy or programme proposals? For each engagement activity, please state who was involved, how and when they were engaged and the key outputs

### Consultation

A three-month consultation was hosted on the UK NSC website regarding the suggested addition of Tyrosinemia to the NBS programme. Direct emails were sent to 19 stakeholders. The initial public consultation closed in March 2022. This was extended until 2 May 2022 because of the low response rate. The total number of consultation responses received was 5. The consultation comments received from the following stakeholders:

- British Association for the Study of the Liver (B A S L)
- Royal College of Paediatrics and Child Health
- Royal College of General Practitioners
- Genetic Alliance UK
- Metabolic Support UK

The Tyrosinemia programme would be an addition to the existing NBS programme. As such stakeholders are more often engaged on the overall programme and not necessarily specifically this new condition.

NHS laboratories have been engaged to ensure that the correct tests are available and implemented. Work will also be undertaken to ensure that changes to the patient information leaflets and informed consent documentation are tested before publication.

The expert sub groups (which include user reps) are shaping the programme and will consider wider training and information resources.

## Summary of analysis

Considering the evidence and engagement activity you listed above, please summarise the impact of your work.

Coverage of NBS is very high (96%). Of those that decline, the numbers are so small that it is difficult to draw any significant conclusions and therefore make appropriate plans to mitigate.

There is some evidence that declining could be to do with confusion about what is being screened for. NBS is a universal offer – open to all babies. In terms of it being fair and equal – it must ensure that all parents are offered screening for their babies. Information leaflets, and training for staff focuses on ensuring parents/care givers are fully informed so that they can make an informed choice about screening for their child.

'Movers in' it is less high (76%) than the overall coverage. Therefore, extra focus should be placed on identifying and offering NBS to this group

Generally, those who decline NBS decline it in totality. People don't refuse specific tests. The decliners of NBS are so low it is hard to draw robust conclusions from such small populations. A lot of it is best guesses based on the information available.

What is the overall impact? Consider whether there are different levels of access experienced, needs or experiences, whether there are barriers to engagement, are there regional variations and what is the combined impact.

Before HT1 was introduced to the NBS, families with a history of HT1 could eek screening, while those without would only discover their child had HT1 when they developed symptoms, by which time the treatment Nitisinone is less effective. Adding HT1 to the NBS creates a more equitable offer as all parents will have early access to screening and therefore the necessary treatment where needed.

As HT1 only impacts around 7 babies a year, and coverage is at around 96%, the likelihood of a baby with HT1 being born to a declining family is slim.

Addressing the impact on equalities - Give an outline of what broad action you or any other bodies are taking to address any negative impacts identified through the evidence

The NHS monitors uptake of NBS and implements appropriate mitigations on a localised basis where necessary.

**Monitoring and evaluation** - *Give an outline of what processes will be put in place to monitor the policy, including the impacts set out in this assessment, once it is implemented* 

The NHS will continue to monitor uptake and coverage for NBS and report data publicly.

## For the record

Name of person who carried out this assessment: Ray Smith

Date assessment completed: 17/01/2024

Name of responsible Director / Director General: Jonathan Marron

Date assessment was signed: 23/02/24