

STANDARD OPERATING PROCEDURE I(S)PHNS - NEWBORN BLOOD SPOT SCREENING 0-19

Document Reference	SOP23-046
Version Number	1.0
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Instigated by: Date Instigated:	Rebecca Price, Heidi Fewings and Jennie Batty 17 October 2023
Date Last Reviewed:	26 October 2023
Date of Next Review:	October 2026
Consultation:	Clinical leads, Clinical team leaders, Health visitors, Nursing associates, Child health information service, Administrators
Ratified and Quality Checked by: Date Ratified:	Children and LD Clinical Governance meeting 26 October 2023
Name of Trust Strategy / Policy / Guidelines this SOP refers to:	Was Not Brought and No Engagement Policy N-072

VALIDITY – All local SOPs should be accessed via the Trust intranet

CHANGE RECORD

Version	Date	Change details
1.0	Oct 23	<i>New SOP. Approved at Children and LD Clinical Governance meeting (26 October 2023).</i>

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1. INTRODUCTION

The purpose of this document is to provide a standardised procedure across Hull and East Riding 0-19 I(S)PHN services on the delivery of newborn blood spot screening.

All health visitors or suitably qualified members of the I(S)PHN team including Child Health Information Service (CHIS) with an identified role or responsibility for the planning, undertaking or management of newborn blood spot screening are required to adhere to the requirements of this SOP.

This guidance should be used in conjunction with any documents referred to within this SOP's title page.

2. SCOPE

Newborn blood spot screening is part of the Public Health England (PHE) National screening programme. The aim is early identification of babies who have one of 9 (10*p.5) rare, but serious health conditions. Early treatment can improve health, prevent severe disability, and save lives (PHE 2017).

- All parents of babies born in Hull & East Riding of Yorkshire are offered the newborn blood spot screening for their baby between day 5 and day 8 (day of birth is day 0) by the local maternity service (this can be up to and include day 27).
- All parents of babies that are resident in Hull & East Riding who are under the age of one year, whether they were born in the UK or another country, are to be offered Newborn blood screening if they have not been previously screened or had incomplete screening for the conditions
- This screening can be delivered in a variety of settings by a health visitor or delegated to a suitably qualified member of the I(S)PHN team.

3. DUTIES AND RESPONSIBILITIES

The chief executive holds overall accountability for the adherence to this policy on behalf of Humber. This includes ensuring the organisation has the correct infrastructure and commitment to enable its implementation and application and seeks assurance through children's and learning disability divisional general manager and clinical leads.

Service manager/modern matron is responsible for:

- reviewing and updating the guidance at agreed time intervals or sooner if prompted by changes in legislation or best practice requirements.
- cascading the new revised information to all staff.
- arranging periodic audits of records to demonstrate continuous quality improvement.

Clinical team leaders are responsible for:

- ensuring staff compliance to the guidance including comprehensive training and induction.
- providing support and advice to staff as needed.
- escalating issues that cannot be managed directly by themselves - to be discussed with service manager/modern matron.
- ensuring records are reviewed in supervision, in accordance with Humber Supervision Policy.

Blood spot champion health visitors are responsible for:

- management of caseload and appropriate delegation to a suitably qualified 0-19 I(S)PHN practitioner.
- providing support and supervision to delegated practitioner including overview of record keeping.
- escalating issues that cannot be managed directly by themselves – to be discussed with the clinical team leader.
- Facilitating training and clinical supervision of staff with responsibility of undertaking blood spot sampling and newborn blood spot screening.

Child health information service (CHIS) are responsible for:

- management of new notifications of children requiring blood spot screening and timely communication with the relevant 0-19 service.

Screening Practitioners are responsible for:

- completing relevant training to ensure clinical competency prior to undertaking blood spot screening.
- undertaking the blood spot sampling as per training completed.
- entering contemporaneous record keeping and factual documentation details into the electronic care record (ECR).
- escalating issues that cannot be managed directly by themselves – to be discussed with the delegating health visitor.

All clinical and admin staff having contact with patients via the telephone are responsible for:

- entering contemporaneous record keeping and factual documentation details into the electronic care record (ECR) about appointments and telephone conversations with the parent/carer or health professional about the child.

Clinical Lead (Hull only) is responsible for:

- Review of the SOP at agreed time intervals or when process changes, and cascading the new revised information to all staff within the 0 – 19 service.
- ISPHN SPOC - Coordination and allocation of any repeat blood spot screening that is required for babies over 28 days of age, and babies that are identified by CHIS as requiring blood spot screening due to have moved into the area under one year of age (appendix 3).
- When a baby is identified with a condition, ensuring the named Health Visitor is informed, that they receive the screening results and information for the parents. (Appendix 2)
- Ensuring the results of the screening are **sent to** parents when a result letter will not be sent by CHIS (not all 9 conditions are 'not suspected' due to the baby being over 8 weeks of age at the time of screening and not screened for CF.)
- Facilitating training and clinical supervision of staff within the 0 – 19 service who are to undertake blood spot sampling.
- Facilitating training for Health visitors and students regarding Newborn blood spot screening.

4. PROCEDURES

The screening is for 9 (10*) conditions which includes:

1. sickle cell disease (SCD)
2. cystic fibrosis (CF) *only offered up to 8 weeks of age due to unreliability of results (PHE, 2017).
3. congenital hypothyroidism (CHT)
4. phenylketonuria (PKU)
5. medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
6. maple syrup urine disease (MSUD)
7. isovaleric acidaemia (IVA)
8. glutaric aciduria type 1 (GA1)
9. homocystinuria (pyridoxine unresponsive) (HCU)
10. *SCID – Severe Combine Immuno Deficiency (only those processed by Sheffield Labs)

Parents of those babies who are identified with any of the above conditions will receive an outpatient appointment and the baby will receive follow up care from the local acute Paediatric medical service, within the timeframe set out by the UK screening programme for each condition (appendix 2).

All parents of babies born in Hull & East Riding should receive the results of their babies screening before 8 weeks of age, (PHE 2018)

Only the parents of babies who have 9 (10*) 'not suspected' results from the screening will be sent a result letter by the local Child Health Service (CHS).

Newborn blood spot screening information and results are sent electronically between the local Newborn screening laboratories, CHIS and the 0 – 19 service through the Electronic Care Record (ECR) of the baby.

Parents can choose to decline all, or part of the Newborn blood spot screening (PHE 2016) – to follow the recommendations of the training undertaken.

- A. The Newborn blood spot screening procedure for all babies born in Hull: Appendix 1.
- B. The procedure for when a condition is suspected through the Newborn blood spot screening programme: Appendix 2.
- C. Blood spot screening required procedure: Appendix 3:
 - To be used for repeat samples requests due to inconclusive results or rejected samples for babies from day 28 that are identified by CHS (timeframe - 72 hours from request.)
 - To be used for movers into Hull and East Riding up to the age of one year old that are identified by CHS (timeframe - results to be recorded in the ECR by CHS before 21 calendar days from request.)

4.1. Training

During the preceptorship period all staff members identified in the SOP are required to access and read the SOP.

This SOP does not replace the requirement for training in Newborn blood spot screening and sampling - it is to be used to support staff training.

Training needs to be identified via Development Review annually or as required via supervision. Practitioners who wish to take on the role must complete newborn blood spot clinical competency assessment.

[Newborn Blood Spot Clinical Skills Competency](#)

[Newborn blood spot screening: education and training - GOV.UK \(www.gov.uk\)](#)

5. REFERENCES

Reference should be made here to any other associated relevant Trust strategies/policies/guidelines or documents.

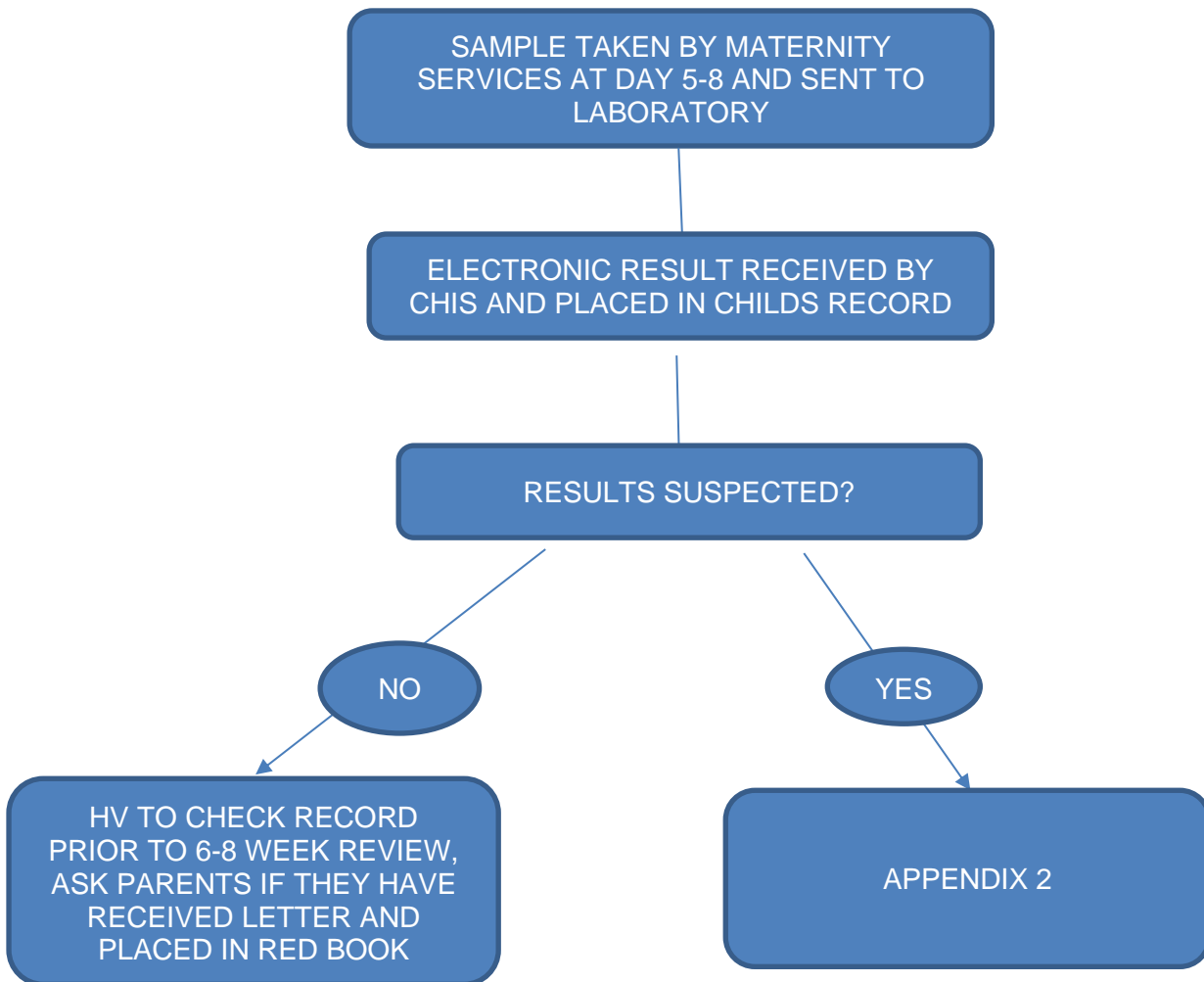
Public Health England (2016) *Guidelines for Newborn Blood Spot Sampling*. Available at: [Newborn blood spot sampling guidelines: quick reference guide - GOV.UK \(www.gov.uk\)](#)

Public Health England (2017) *NHS Newborn Blood Spot Screening Programme Standards*. Available at: [Newborn blood spot screening: standards - GOV.UK \(www.gov.uk\)](#)

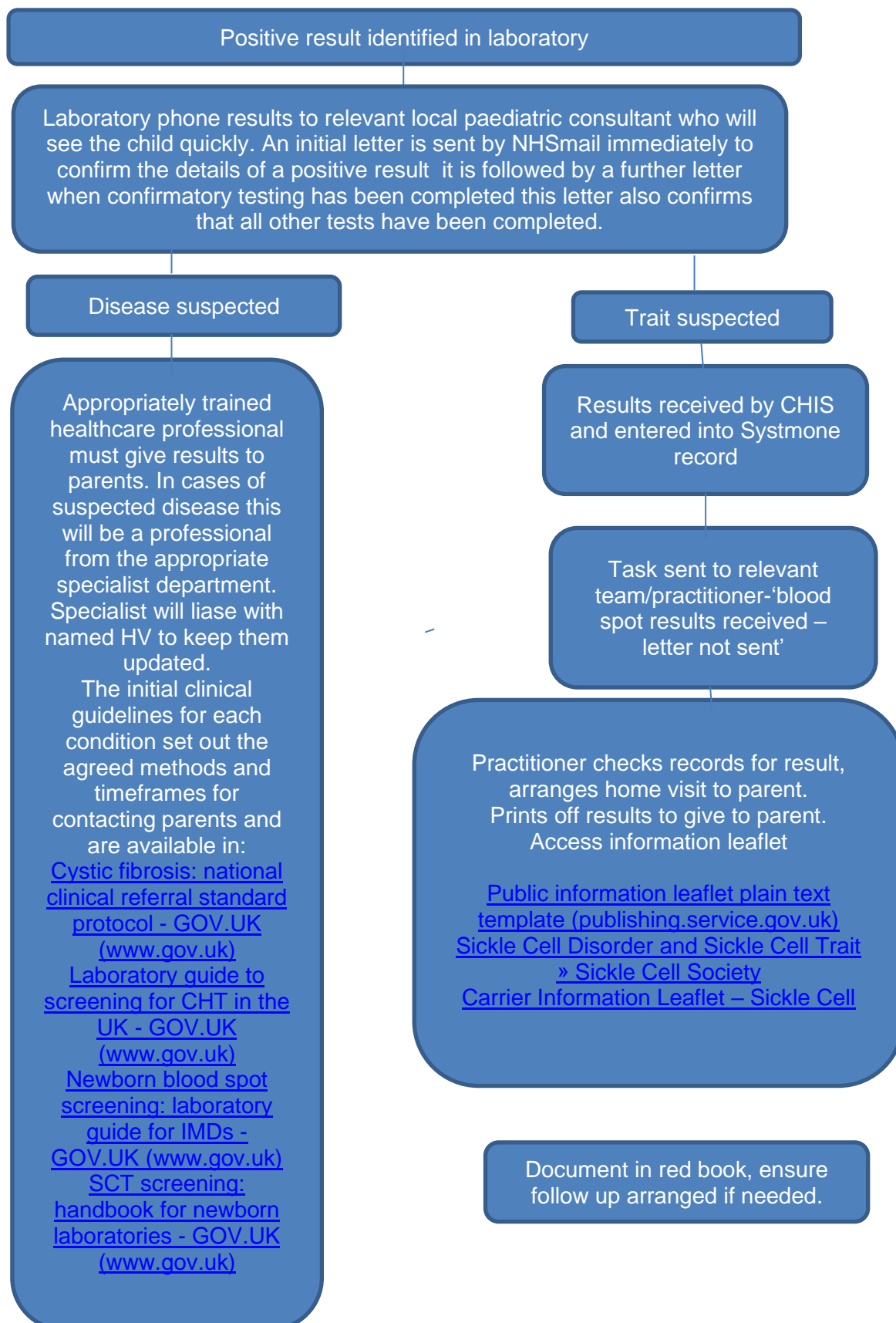
Public Health England (updated 2018) *Guidelines Newborn Blood Spot Screening: Movers in with no available Records*. Available at: <https://www.gov.uk/government/publications/movers-in-screening-babies-with-no-available-records/>

NHS England *Public Health Commissioning*, service specification (No 19). Available at: www.england.nhs.uk/commissioning/pub-hlth-res/

Appendix 1 - The Newborn blood spot screening procedure for all babies born in Hull

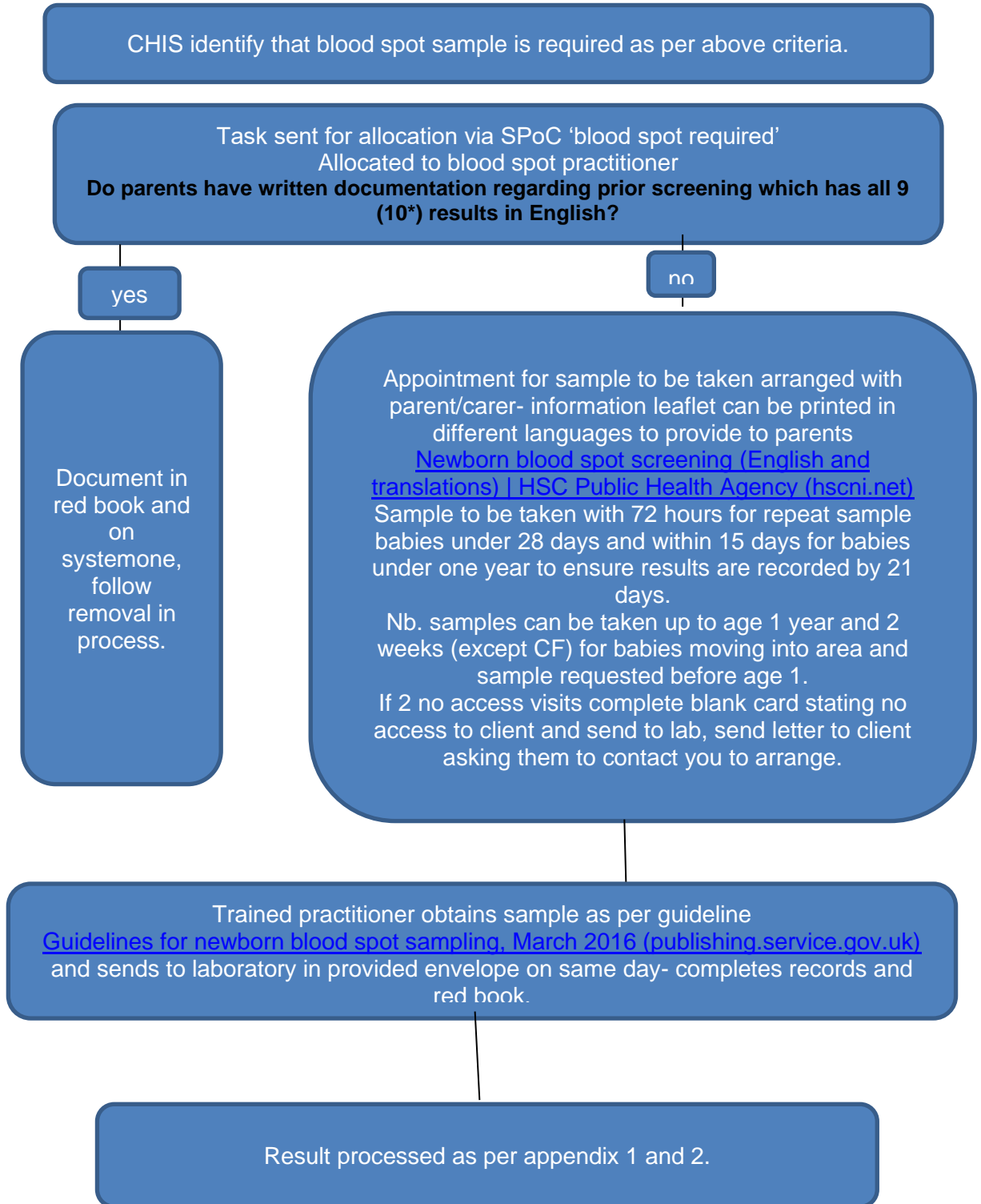


Appendix 2 - The procedure for when a condition is suspected through the Newborn blood spot screening programme



Appendix 3 - Blood spot screening required procedure

- To be used for repeat samples requests due to inconclusive results or rejected samples for babies from day 28 that are identified by CHS (timeframe - 72 hours from request.)
- To be used for movers into Hull and East Riding up to the age of one year old that are identified by CHS (timeframe - results to be recorded in the ECR by CHS before 21 calendar days from request.)



Appendix 4 - Equality Impact Assessment

For strategies, policies, procedures, processes, guidelines, protocols, tenders, services

1. Document or Process or Service Name: I(S)PHNS - Newborn Blood Spot Screening 0-19
2. EIA Reviewer (name, job title, base and contact details): Rebecca Price, modern matron (IPHN)
3. Is it a Policy, Strategy, Procedure, Process, Tender, Service or Other? SOP

<p>Main Aims of the Document, Process or Service</p> <p>The purpose of this document is to provide a standardised procedure across Hull and East Riding 0-19 I(S)PHN services on the delivery of newborn blood spot screening.</p>
<p>Please indicate in the table that follows whether the document or process has the potential to impact adversely, intentionally or unwittingly on the equality target groups contained in the pro forma</p>

<p>Equality Target Group</p> <ol style="list-style-type: none"> 1. Age 2. Disability 3. Sex 4. Marriage/Civil Partnership 5. Pregnancy/Maternity 6. Race 7. Religion/Belief 8. Sexual Orientation 9. Gender re-assignment 	<p>Is the document or process likely to have a potential or actual differential impact with regards to the equality target groups listed?</p> <p>Equality Impact Score Low = Little or No evidence or concern (Green) Medium = some evidence or concern (Amber) High = significant evidence or concern (Red)</p>	<p>How have you arrived at the equality impact score?</p> <ol style="list-style-type: none"> a) who have you consulted with b) what have they said c) what information or data have you used d) where are the gaps in your analysis e) how will your document/process or service promote equality and diversity good practice
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Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
Age	<p>Including specific ages and age groups:</p> <p>Older people Young people Children Early years</p>	Low	Offered to all eligible children
Disability	<p>Where the impairment has a substantial and long term adverse effect on the ability of the person to carry out their day to day activities:</p> <p>Sensory Physical Learning Mental health</p> <p>(including cancer, HIV, multiple sclerosis)</p>	Low	Offered to all eligible children
Sex	<p>Men/Male Women/Female</p>	Low	Offered to all eligible children
Marriage/Civil Partnership		NA	
Pregnancy/Maternity		NA	
Race	<p>Colour Nationality Ethnic/national origins</p>	Low	Offered to all eligible children
Religion or Belief	<p>All religions Including lack of religion or belief and where belief includes any religious or philosophical belief</p>	Low	Offered to all eligible children
Sexual Orientation	<p>Lesbian Gay men Bisexual</p>	Low	Offered to all eligible children

Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
Gender Reassignment	Where people are proposing to undergo, or have undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other attribute of sex	NA	Only offered until 1 year of age

Summary

Please describe the main points/actions arising from your assessment that supports your decision.	
EIA Reviewer: Rebecca Price	
Date completed: 17/10/23	Signature: R. Price