



*UK National
Screening Committee*



Screening Programmes

Quality Assurance

Newborn Outcomes Project UK Haemoglobinopathy Forum

14 May 2014

Presentation subheading set in 20pt Arial

Part of Public Health England



Aims of the project

- Do babies see a doctor by three months of age?
- Are babies prescribed penicillin by three months of age?
- Review any babies who have died
- Review the mothers antenatal screening

To assess these aims needs:

- Named data on all babies with sickle cell disease and thalassaemia
- With support of the Sickle Cell Society and UKTS the programme applied to Ethics and Confidentiality Committee of National Information Governance Board
 - Received Approval from the NIGB in April 2010
 - Approval reviewed annually

Number of babies

- Pilot/Main Study 1215
- Clinically insignificant cases 44
- Born before September 2013 1002

Babies with no screen result (n=3)

NB Lab	ID	Blood Spot Result	Comments
Leeds	NB05/528CN	Declined screening	Seen in clinic
Birmingham	NB01/706CN	Tested in India	Confirmed diagnosis β thalassaemia major; seen in clinic
London CMX	NB07/1059CN	Born in Indonesia	Needs further investigation

Babies Confirmed Results: consistency with screen result

Babies Result	N	% of Total
Blood Spot	1212	99.8
Confirmed Diagnosis	698	57.5
Screen & Confirmed Diagnosis	695	57.3

Inconsistent screen and diagnostic result (n=2)

Baby's Screening Result	Baby's Confirmed Diagnosis	Comments
FA	β Thal Major	Needs further investigation
FSC Hb SC	Hb CC	Needs further investigation

Comparison with Antenatal Results

	N	% of Total
Mother's Results	855	70.5
Confirmed Diagnosis	698	57.5
Antenatal Result & Confirmed Diagnosis	673	55.4

Inconsistent Mother & Baby Results (n=3)

Mother's Result	Baby's Confirmed Diagnosis	Comments
HPFH	β Thal Major	Needs further investigation
Hb AC	Hb SS	Needs further investigation
Hb AS	Hb E- β Thal	Needs further investigation

Babies who have Died (n=9)

Age at Death (days)	Cause of Death	Reported by ONS
17	Necrotizing enterocolitis with perforation, prematurity, sepsis, lactic acidosis, hypertension, IVH III renal failure, IUGR foetus intermittent absent EDF.	Yes
291	Prematurity and very sick. Cause of death unknown.	Yes
351	Death caused by cardiac, awaiting post mortem results.	Yes
78	Unknown cause found at post mortem. SIDS as per SCTC, not sickle related.	Yes
66	Extreme prematurity (27-28 weeks) and multiple complications. Unknown cause, awaiting post mortem results.	Yes
16	Severe IUGR, bilateral grade 4 intraventricular haemorrhage; born 31 weeks gestation.	Yes
250	Extreme prematurity, cerebral palsy, chronic lung disease, SID after coryzal illness.	Yes
39	Cause of death unknown and not sickle related as per CMX and Carshalton labs.	Yes
18	Surgical complications of necrotising enterocolitis, unrelated to the incidental Hb E disease.	No

Time Seen in Clinic

	N	% of Total
Seen < 3 months	561	56.0
Seen > 3 months	147	14.7
Missing Data	294	29.3
Total	1002	100

Babies seen in clinic born before Sept 2013, (n = 1002)

Time Penicillin Prescribed

	N	% of Total
Prescribed < 3 months	446	44.5
Prescribed > 3 months	118	11.8
Missing Data	337	33.6

Time Penicillin prescribed in babies born before Sept 2013 (n = 1002)

Non Reporting of Data from the Lab

- 19 screen positive babies
- Identified through data chasing process
- Followed up in clinic and prescribed the standard treatment

Next steps

- Continue Data collection and follow up
 - Please note: Some support available
- Report results
- Feedback by centre

Thank You

A big thank you to all those involved who have supported this project.

Please continue to support us.

<http://sct.screening.nhs.uk/evaluation>