



ARISE

African Research And Innovative  
Initiative For Sickle Cell Education

# Newborn Screening Pathway

Nkechi Anyanwu

Community Matron

Guy's & St Thomas'

Evelina London



This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021

# Aims and Rationale of the Newborn Screening

- Neonatal screening - universal screening program is in place in England (2004)
- Early identification of children affected by major haemoglobinopathies
- Access to specialist clinicians
- On-going family education, health advice, support and advocacy
- = Reduction of morbidity and mortality in children with Sickle Cell and
- Thalassaemia.



# Newborn Screening Process

1. Newborn blood spot taken by midwives /NICU nurses/ Health-visitors
2. Processed at 1<sup>st</sup> Line Hospital (STH); an abnormal result is processed 2<sup>nd</sup> Lab ( King's College Hospital)
3. Laboratories inform – Child Health Information Services ( CHIS) of all results and SC&T Centre for active follow-up (affected births / unconfirmed carriers)
4. Affected births – parents are informed at home visits
5. Unconfirmed carriers are informed by letters
6. Results sent to parents, GPs and CHIS and updated on IT systems
7. Health Visitors inform parents of Normal / carrier results in SE London



# Newborn Screening

Process for notifying parents – use of specially prepared letters on Carenotes WITH literature from the National Sickle Cell and Thalassaemia Screening Programme

All normal and carrier results are given by Health Visitors at the child review visit and by six weeks.

- HbAS, AC, AD, AE result letter is sent to the parents with the appropriate information leaflet which are now available electronically via the Newborn Screening programme.

<https://www.gov.uk/government/publications/baby-carries-a-gene-for-unusual-haemoglobin-description-in-brief>

<https://www.gov.uk/government/publications/your-baby-carries-a-gene-for-sickle-cell/sickle-cell-and-thalassaemia-screening-your-baby-carries-a-gene-for-sickle-cell>



# Use the NHS number everytime

The NHS number is the only reliable way to identify the baby, track the baby through the screening process, reduce delays in treatment and reduce the risk of babies being missed.

NEWBORN SCREENING BLOOD TEST

Baby's NHS No. **362 184 3976**

SURNAME: Doe  
FORENAMES: John  
HOME ADDRESS: No-whene lane  
Bendigo  
POSTCODE: AA12ZZ  
SEX (✓):  M  F  
G.P. NAME & INITIALS: Dr Know  
G.P. ADDRESS: The surgery Bendigo  
PRACTICE CODE: AA12ZZ

BABY'S D.O.B.: 01/04/08  
ETHNIC CATEGORY: A  
RANK: 1/1  
GEST: 40  
BIRTH WEIGHT (kg): 3460  
MOTHER'S FULL NAME: Jane Doe  
MOTHER'S D.O.B.: 15-07-83  
MOTHER'S NHS No.: 234 15671 8912  
BABY'S ALTERNATIVE SURNAME: John Smith

DATE OF SPECIMEN: 06/04/08  
Is this a repeat (✓): YES NO   
Has baby had a blood transfusion (✓): YES NO   
Is the date of last transfusion (✓): YES NO   
Is the baby in hospital (✓): YES NO   
If YES, Current Hospital Paediatrician  
COMMENTS (eg. drug therapy, family history, temporary address, high risk): n/a  
Name of person taking specimen: Sr LANCELOT  
This person's NHS No.: 0987 654321

Whallman GmbH  
Hahnstraße 3  
42699 Solingen  
Germany  
Authorized By: The UK Newborn Screening Laboratories Network (Ref #71259)

067213751  
NHS  
UKNSLN  
Expires September 2008  
Sumame: Doe



# Newborn Screening Lab Data

- 1402 samples received for second-line testing in 2020 from St. Thomas'.
- 50 babies were referred to the nursing centre for counselling and follow-up care
- 37 babies were seen by nurse specialist from the SE London Team



# Genetic/Newborn Screening Preliminary Result for Sickle Cell Disorder

Preliminary  
result  
received  
from  
Newborn  
Screening  
Lab

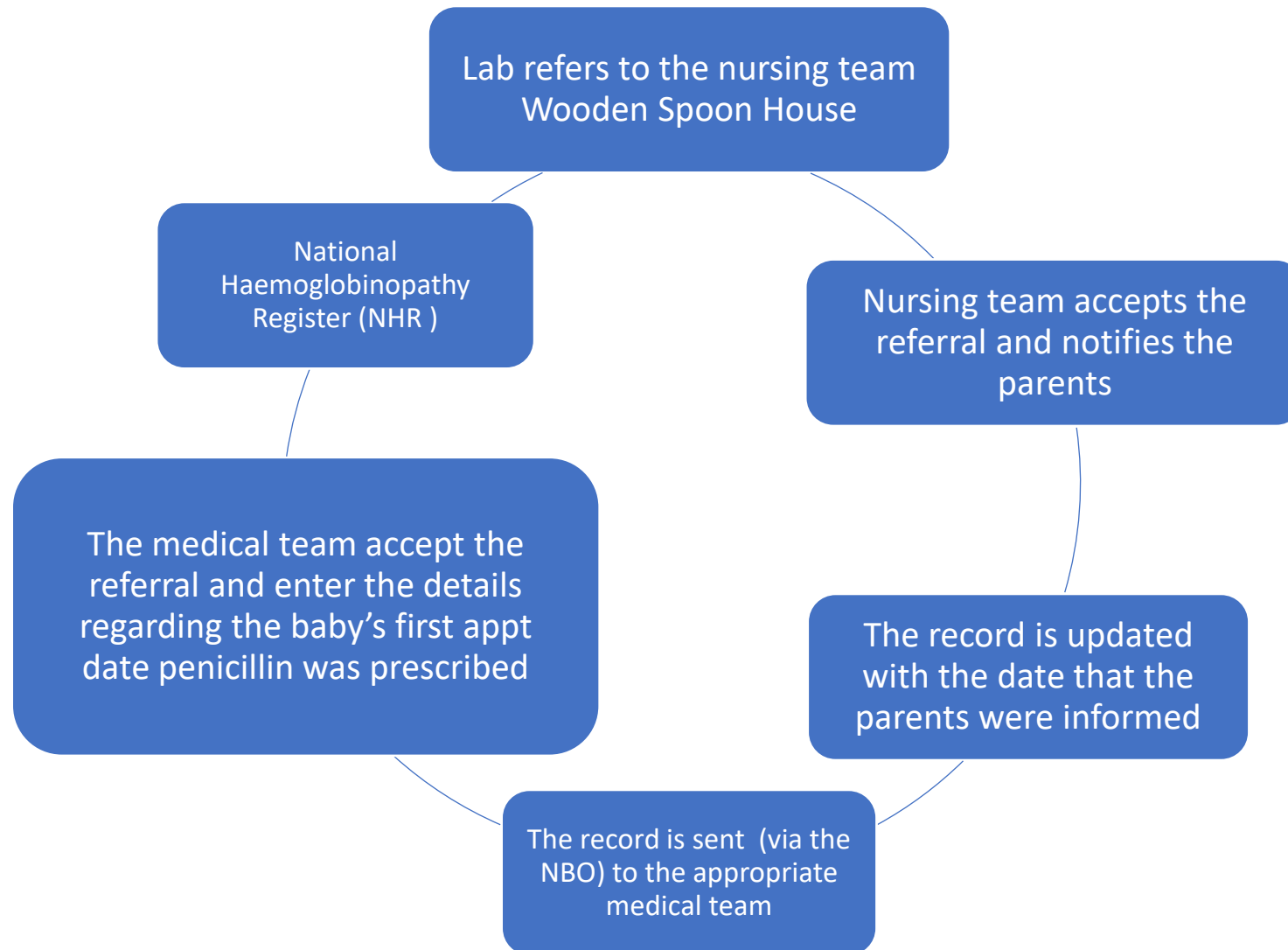
Send  
appointment  
letter to  
mother for  
home visit by  
genetic  
counsellor  
within 5 days

Visit mother  
at home to  
convey and  
explain  
preliminary  
result

Refer to  
consultant for  
paediatric  
follow-up care



# Newborn Outcome Pathway





# THANK YOU

FOR ALL YOU DO





ARISE

African Research And Innovative  
Initiative For Sickle Cell Education

This presentation reflects only the author(s)'s view and the EU Research Executive Agency (REA) is not responsible for any use that may be made of the information it contains.



This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021