



Public Health
England



NHS Sickle Cell and Thalassaemia (SCT) screening programme

Public Health England leads the NHS Screening Programmes

SCT Newborn Outcomes Register

In April 2017 data collections for the SCT screening programme previously held at KCL were transferred to the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Approval was given to retain the legacy data and continue to receive new cases

Data collection templates can be downloaded from Gov.UK <https://www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-outcome-data>. Completed data templates should be sent from an NHS.net email address to NCARDRS via scts.evaluation@nhs.net

Dr Moira Dick is seconded to PHE to help transition

NCARDRS patient information leaflets (in your pack) are being sent to specialist centres; for further copies of this leaflet please email ncardrs@phe.gov.uk

Please make this information freely available and accessible to parents

Any questions please email ncardrs@phe.gov.uk or telephone 0207 811 7322

SCT Newborn Outcomes Register

Through links with other data bases e.g. NHS summary care record NCARDRS are already improving the quality and completeness of the data

Dr Allison Streetly has submitted a paper for publication

We are continuing with our business case to procure a system to automate the gathering and reporting of data and links with NCARDRS and the National Haemoglobinopathy Register (NHR) and through further iterations provide visibility of the baby along the screening/treatment pathway. We also recommend that a second phase should be undertaken to conduct failsafe activities, thereby ensuring all patients receive the appropriate levels of care

More information cathy.coppinger@nhs.net

THANK YOU FOR SUPPORTING THIS WORK

We would be happy to update you at future meetings