Sickle Cell and Thalassaemia Screening Programme:
*References and resources by topic

**Antenatal Screening**


http://www.bcshguidelines.com/4_HAEMATOLOGY_GUIDELINES.html?dpage=8&sspage=0&ipage=0#gl


NHS Sickle Cell & Thalassaemia Screening Programme *Inheritance risk chart and carrier risk chart combined* http://cpd.screening.nhs.uk/sct


(*Correct at time of publication)
Information for parents following screening


Haemoglobinopathy Cards
Contact details for obtaining haemoglobinopathy cards.

Vulnerable Antenatal Women


National Patient Safety Agency (2005) Understanding the patient safety issues for some vulnerable groups of women known to be at higher risk of maternal death or morbidity. http://www.npsa.nhs.uk/


Care of Pregnant Women with Sickle Cell Disease & Beta Thalassaemia

Brent Sickle Cell & Thalassaemia Centre Midwives Introduction to Sickle Cell & Thalassaemia
http://www.sickle-thal.nwlh.nhs.uk/ForHealthcareProfessionals/MidwivesFocusSickleCell.aspx

Royal College of Obstetricians & Gynaecologists (2011) Sickle Cell Disease in Pregnancy, Management of.


Website Links

Antenatal Results & Choices (ARC) Information for parents http://www.arc-uk.org/for-parents/publications-2


Healthtalkonline Advising patients about their screening options
http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia/Topic/2189/

Healthtalkonline Impact of timing and delays on decision making during pregnancy
http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia/Topic/2192/


Antenatal Screening - Research Reports

**Alpha thalassaemia**


**Website Links**

Cooley’s Anaemia Foundation (CAF) [http://www.thalassemia.org/](http://www.thalassemia.org/)

Thalassaemia International Federation (TIF) [http://www.thalassaemia.org.cy/](http://www.thalassaemia.org.cy/)

United Kingdom Thalassaemia Society (UKTS) [http://ukts.org/](http://ukts.org/)
“At risk” couples


NHS Sickle Cell & Thalassaemia Screening Programme Inheritance risk chart and carrier risk chart combined [http://cpd.screening.nhs.uk/sct](http://cpd.screening.nhs.uk/sct)


West Midlands Screening Team At risk pregnancy alert form [Alert_form_at_risk_pregnancy_WM.pdf](Alert_form_at_risk_pregnancy_WM.pdf)

Website Links

Antenatal Results & Choices (ARC) Information for parents [http://www.arc.uk.org/for-parents/publications-2](http://www.arc.uk.org/for-parents/publications-2)

Sickle Cell Society (SCS) [http://sicklecellsociety.org/](http://sicklecellsociety.org/)

United Kingdom Thalassaemia Society (UKTS) [http://ukts.org/](http://ukts.org/)
**Beta thalassaemia major**

Baer K (Edited by Cioffi G & Butler C)  *A Guide to Living with Thalassaemia*  Cooley’s Anemia Foundation  [www.cooleysanemia.org](http://www.cooleysanemia.org)


**Beta Thalassaemia - UK Guidelines for Care**


United Kingdom Thalassaemia Society (2008) *Standards for the Clinical Care of Children & Adults with Thalassaemia in the UK*  [www.ukts.org](http://www.ukts.org)
**Thalassaemia Intermedia**

Martin M, Butler C *An introduction to beta thalassaemia intermedia*  Cooley’s Anemia Foundation  
[www.cooleysanemia.org](http://www.cooleysanemia.org)


**Website Links**

BioMed Central - Open Access scientific articles on thalassaemia  [http://www.biomedcentral.com/](http://www.biomedcentral.com/)


Cold Spring Harbor Perspectives in Medicine *Hemoglobin and Its Diseases*  
[http://perspectivesinmedicine.org/site/misc/hemoglobin_and_its_diseases.xhtml](http://perspectivesinmedicine.org/site/misc/hemoglobin_and_its_diseases.xhtml)

Cooley’s Anaemia Foundation (CAF)  [http://www.thalassemia.org/](http://www.thalassemia.org/)

Thalassaemia International Federation (TIF)  [http://www.thalassaemia.org.cy/](http://www.thalassaemia.org.cy/)

United Kingdom Thalassaemia Society (UKTS)  [http://ukts.org/](http://ukts.org/)

NHS Choices  *Thalassaemia*  [http://www.nhs.uk/Conditions/Thalassaemia/Pages/Introduction.aspx](http://www.nhs.uk/Conditions/Thalassaemia/Pages/Introduction.aspx)

NHS England *Expert Patients Programme*
Birthrate


Website Links

Office for National Statistics Births & Fertility

Consent


Commissioning Services for Patients with Haemoglobinopathies


Disability & Pregnancy

Ethnicity, Diversity & Equality

Ethnicity


Equality


Website Links

Ethnicity Online Website Cultural Awareness in Healthcare http://www.ethnicityonline.net/

http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia/Topic/2190/

Healthtalkonline Screening for sickle cell and thalassaemia
http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia/Topic/2191/

NHS Choices Black & Minority Ethnic Groups

NSC Interpreter Guidelines
Fathers & Families

NHS Sickle Cell & Thalassaemia Screening Programme (2012) Tests for dads leaflet


Information to help professionals with accessing fathers for screening


Public Health England Contacting men for sickle cell and thalassaemia screening

Royal College of Midwives Reaching Out: Involving Fathers in Maternity Care
https://www.rcm.org.uk/sites/default/files/Father%27s%20Guides%20A4_3_0.pdf


Website Links

Men’s Health Forum; http://www.menshealthforum.org.uk/

Men’s health on NHS Choices
http://www.nhs.uk/Livewell/men1839/Pages/Menshealthweek.aspx
Genetics


Website Links

British Society for Genetic Medicine  http://www.bsgm.org.uk/


Genetic Alliance UK Information for the Public & Professionals about Genetic Conditions http://www.geneticalliance.org.uk/


Healthtalkonline Explaining genetics and risk http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia/Topic/2187/
Haemoglobinopathies


Ryan, Kate; Bain, Barbara J; Worthington, David; James, Jacky; Plews, Dianne; Mason, Anthony; Roper, David; Rees, David C; De La Salle, Barbara; Streetly, Allison; on behalf of the British Committee for Standards in Haematology (2010) *Significant haemoglobinopathies: guidelines for screening and diagnosis*. Blackwell Publishing Ltd British Journal of Haematology149, 35-49 http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2141.2009.08054.x/epdf


**Website Links**

Huisman THJ et al A database of Human Hemoglobin Variants and Thalassemias http://globin.bx.psu.edu/cgi-bin/hbvar/counter

UK Forum for Haemoglobin Disorders http://www.haemoglobin.org.uk/
Haemoglobinopathy Cards

Contact details for obtaining haemoglobinopathy cards.

Language


Website Links

Ethnologue Website  *Languages of the world.*  http://www.ethnologue.com

Linkage

Chris Lambert on behalf of NHS Sickle Cell & Thalassaemia Screening Programme

*Summary of Linkage*

NHS Sickle Cell & Thalassaemia Screening Programme  *Linkage between antenatal and newborn screening*  
**Literacy**


NHS Sickle Cell & Thalassaemia Screening Programme (2007) *Accessible Information to Support Antenatal and Newborn Screening Programmes.* Executive Summary. PDF document


Newborn Bloodspot Screening

Newborn Bloodspot Screening Programme (2013) *Standards for newborn blood spot screening. Version 1.0*  


Newborn Bloodspot Screening Programme - *Status Codes*  

Newborn Blood Spot Programme (2015) *Procedures for Newborn Bloodspot Screening for Babies Under 1 year of age, for whom screening results are not available*  


Newborn Bloodspot Screening Programme – *Newborn blood spot screening: results to parents template letter*  

Research Reports


www.marchofdimes.org

Website Links

Newborn Bloodspot Screening Programme: *Supporting Publications*  
Newborn Screening for Sickle Cell Disease


Brent Sickle Cell & Thalassaemia Centre (2010) Newborn Screening and Counselling Form.
http://sickle-thal.nwlh.nhs.uk/


NHS Sickle Cell & Thalassaemia Screening Programme Template letter for parents of babies who are carriers WORD Document

NHS Sickle Cell & Thalassaemia Screening Programme Core competencies in genetics for sickle cell and thalassaemia counselling


DNA for Transfused Babies


NHS Sickle Cell & Thalassaemia Screening Programme (2010) Follow up and counselling for transfused babies who have been screened by DNA https://www.gov.uk/government/publications/dna-tests-for-transfused-babies-sickle-cell-and-thalassaemia-screening

Website Links

NHS Sickle Cell & Thalassaemia Screening Programme Supporting Publications https://www.gov.uk/search?q=nhs+sickle+cell+and+thalassaemia+screening+supporting+publications


National Haemoglobinopathy Register http://www.nhr.nhs.uk/

Royal College of Paediatrics and Child Health http://www.rcpch.ac.uk/child-health

Sickle Cell Society (SCS) http://sicklecellsociety.org/
NHS Sickle Cell & Thalassaemia Screening Programme

Antenatal & Newborn Screening Policy


Standards & Guidelines


Research Reports


Information Resources


Website Links


Non-Paternity


Patient Information


Website Links

Antenatal Results & Choices (ARC) Information for parents http://www.arc-uk.org/for-parents/publications-2


NHS Choices Thalassaemia http://www.nhs.uk/Conditions/Thalassaemia/Pages/Introduction.aspx


Sickle Cell Society (SCS) [http://sicklecellsociety.org/](http://sicklecellsociety.org/)

United Kingdom Thalassaemia Society (UKTS) [http://ukts.org/](http://ukts.org/)
Prenatal Diagnosis (CVS & Amniocentesis) & Termination of Pregnancy

CVS & Amniocentesis


Referral for Prenatal Diagnosis


Termination of Pregnancy


Website Links

Pre-Implantation Genetic Diagnosis


Website Links

Genetic Alliance About PGD http://www.geneticalliance.org.uk/aboutpgd.htm

Guy’ & St Thomas’s Hospital PGD website http://www.pgd.org.uk/home.aspx


Human Fertilisation and Embryology Authority PGD Conditions Licensed http://guide.hfea.gov.uk/pgd/

Medscape Website PGD Overview http://emedicine.medscape.com/article/273415-overview
Quality Assurance & Quality Standards

Antenatal Screening

http://guidance.nice.org.uk/qs22

NHS Sickle Cell & Thalassaemia Screening Programme (2011) Antenatal Screening Failsafe Procedures


Newborn Screening

Newborn Bloodspot Screening Programme Failsafe arrangements

NHS Sickle Cell & Thalassaemia Screening Programme Newborn Outcomes Project (2015)
https://www.gov.uk/newborn-outcomes-project-definition-and-implementation


Data Reports


Public Health England Key Performance Indicators for Screening- Data Reports

Website Links

NHS England Serious Incident Framework
www.england.nhs.uk/ourwork/patientsafety/serious-incident/

Public Health England Managing Safety Incidents in NHS Screening Programmes


Public Health England Screening Incident Management Training Resource
http://cpd.screening.nhs.uk/incident-resource
Religion & Spirituality

Royal College of Nursing (2011) *Spirituality in Nursing Care.*
http://www2.rcn.org.uk/development/publications/publicationsA-Z#S

Sickle cell disease


Brent Sickle Cell & Thalassaemia Centre Midwife Focus on Sickle Cell http://www.sickle-thal.nwlh.nhs.uk/ForHealthcareProfessionals/MidwivesFocusSickleCell.aspx North West London Hospitals Trust


Guidelines and Standards


Sickle Cell Society (2008) *Standards for the clinical care of adults with Sickle Cell Disease in the UK.*
[www.sicklecellsociety.org](http://www.sicklecellsociety.org)


West Midlands Quality Review Service & UK Forum on Haemoglobin Disorders (2014) *Quality Standards. Health Services for People with Haemoglobin Disorders*

**Website Links**

Cold Spring Harbor Laboratory DNA Learning Centre *Disease and Mutation 3D Animation of sickle cell anaemia* [https://www.dnalc.org/resources/3d/17-sickle-cell.html](https://www.dnalc.org/resources/3d/17-sickle-cell.html)

National Haemoglobinopathy Register [www.nhr.nhs.uk](http://www.nhr.nhs.uk)

Royal College of Paediatrics and Child Health [http://www.rcpch.ac.uk](http://www.rcpch.ac.uk)


Sickle Cell Information Centre (SCINFO) [http://scinfo.org/](http://scinfo.org/)

Sickle Cell Information Centre (SCINFO) *Tutorials* [http://scinfo.org/world-wide-resources/power-point-presentations](http://scinfo.org/world-wide-resources/power-point-presentations)

Sickle Cell Society (SCS) [http://sicklecellsociety.org/](http://sicklecellsociety.org/)

Thalassaemia International Federation (TIF) [www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)

Unit for the Social Study of Thalassaemia and Sickle Cell (TASC) [http://www.tascunit.com/](http://www.tascunit.com/)
Training Courses
Kings College London - Genetic risk assessment and counselling course (2 courses offered)
http://www.kcl.ac.uk/teares/nmvc/external/prospectus/course_info.php?code=118

Public Health England Online Training Resources
Continuing Professional Development for Screening  http://cpd.screening.nhs.uk/

Warwick Health Screening Module
http://cpd.screening.nhs.uk/warwick-module

Training Tools
Sickle Cell Society Family Legacy DVD http://sicklecellsociety.org/resources/

Related Websites
Antenatal Results & Choices (ARC) www.arc-uk.org/
British Committee for Standards in Haematology www.bcs-hguidelines.com/
British Society for Haematology www.b-s-h.org.uk
Brent Sickle Cell & Thalassaemia Centre http://sickle-thal.nwlh.nhs.uk/
Cooley’s Anemia Foundation http://www.thalassemia.org/
Department of Health https://www.gov.uk/government/organisations/department-of-health
Healthtalkonline (DIPEX) http://www.healthtalk.org/
National Haemoglobinopathy Register www.nhr.nhs.uk
Newborn Bloodspot Screening Programme https://www.gov.uk/topic/population-screening-programmes/newborn-blood-spot
NHS Choices http://www.nhs.uk/Pages/HomePage.aspx
Office for national statistics www.ons.gov.uk
Royal College of Midwives https://www.rcm.org.uk/
Royal College of Nursing http://www.rcn.org.uk/
Royal College of Obstetricians & Gynaecologists https://www.rcog.org.uk/
Royal College of Paediatrics and Child Health http://www.rcpch.ac.uk/
Royal College of Obstetricians & Gynaecologists https://www.rcog.org.uk/
Royal College of Pathologists http://www.rcpath.org/
Unit for the Social Study of Thalassaemia and Sickle Cell (TASC) http://www.tascunit.com/
Sickle Cell Information Centre (SCINFO) http://scinfo.org/
Sickle Cell Society http://sicklecellsociety.org/
Sickle Cell & Thalassaemia Screening Programme Centre www.sct.screening.nhs.uk
Thalassaemia International Federation (TIF) http://www.thalassaemia.org.cy/
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UK Thalassaemia Society http://ukts.org/