NHS
North Thames
Genomic Medicine Service

@NorthThamesGenomics

MIDWIVES IN GENOMICS

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WELCOME TO OUR

Newsletter

what's inside

welcome message

Thank you to everyone who joined the NT GMS Preconception Event this spring, and to our speakers for their insightful contributions. The event highlighted the vital role of preconception care in improving maternal and neonatal outcomes and supporting safe, personalised, and equitable maternity services.

Here are some key messages from the event:

- Many factors affecting pregnancy outcomes such as long-term health conditions, lifestyle, and genetic risk are established before conception. Early identification and optimisation can reduce complications.
- Midwives and multidisciplinary teams play a crucial role in promoting preconception health, using every contact to support informed choices. Genomics is increasingly enhancing risk assessment and personalised care.
- Reducing health inequalities remains a priority, with a focus on improving access, health literacy, and culturally appropriate care.
- Embedding preconception care across services is essential to a prevention-focused approach, ensuring healthier starts to pregnancy.

Tina & Yvonne

genetic screening for sickle cell

Written by Iyamide Thomas – Sickle Cell Society NHS Engagement Lead (Screening)

Sickle cell is a collective term that describes different but similar genetically inherited blood conditions in which a mutated form of haemoglobin causes the normally round blood cells to change to a sickle or 'half-moon' shape after giving up their oxygen, blocking their flow around the body. This results in severe pain (called 'crisis'), anaemia and long-term organ damage. Sickle cell mainly affects people who originate from Africa, The Caribbean, Middle East, Mediterranean and India as the sickle gene mutation is thought to have been a protective measure against malaria. In the United Kingdom (UK), approximately 18500 people have sickle cell. Of babies born here each year, 1 in 79 will carry one copy of the recessive sickle cell gene (and are known as 'carriers' or have the 'trait'), whereas 300 will be born with two copies and have the condition. Each time two carriers have a baby, there's a 25% chance the baby will have sickle cell, a 50% chance the baby will be a carrier and a 25% chance the baby will be unaffected and have the usual haemoglobin.

The UK has an NHS Sickle Cell and Thalassaemia (NHS SCT) Screening Programme that offers antenatal screening for sickle cell and thalassaemia to identify carriers by 10 weeks gestation, to facilitate early specialist counselling and the offer of prenatal diagnosis (PND). Early access to timely screening and the offer of PND is important for women and couples who have an increased chance of having a baby with sickle cell or thalassaemia as this gives them the opportunity to make personal informed choices. NHS SCT Screening Programme also offers newborn screening using the heel prick test to detect babies with sickle cell so they can receive prompt treatment. This process also identifies babies who are sickle cell carriers. Babies up to 12 months can also be screened as part of NHS SCT Screening Programme and this is particularly useful for those newly migrated to the country.

If a pregnant woman who has an antenatal screening blood test (this could be via a midwife, GP, an NHS SCT Screening centre etc) is found to be a carrier, the father of the baby is invited for screening too. If they are both carriers, (i.e. an 'at-risk' couple) they should be fast-tracked along the screening pathway for timely counselling and offer of PND.

Preconception testing for sickle cell is not officially part of the NHS SCT Screening Programme, however with raised awareness of the conditions by Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS), young adults are wanting to know their genotype before pregnancy. This is important especially if close family have the condition or are carriers, as this helps them make informed reproductive choices.

The NHS SCT Screening Programme commissions the SCS and UKTS to work jointly with them to deliver service provision that is user-led and addressing any inequalities. The SCS and UKTS consulted service users on their experiences of antenatal screening and the communication of screening results and produced two reports with recommendations for the NHS SCT Screening Programme. More recently SCS and UKTS spearheaded two very successful online learning sessions on the communication of antenatal and newborn screening, each attended by over 100 health professionals (HCPs) such as health visitors, midwives, QA Advisors, Antenatal and Newborn Screening Advisors from all around the country. The training sessions have helped HCPs improve their services.

"I would like to thank all the presenters for their very interesting contributions. Hearing from a parents' perspective will help me improve and modify my practice as an antenatal and postnatal screening midwife. Thank you" (Midwife)

In early 2026 SCS, UKTS and NHS SCT Screening Programme produced a comprehensive Screening video podcast entitled 'Pregnancy Planning and NHS Screening for Sickle Cell and Thalassaemia'. This and other resources can be found here:

- https://www.sicklecellsociety.org/the-sickle-cell-society-podcast/
- https://www.sicklecellsociety.org/screening-programme/

LEARN MORE

info@sicklecellsociety.org
www.sicklecellsociety.org

The Sickle Cell Society is the only national charity in the UK that supports and represents people affected by a sickle cell disorder to improve their overall quality of life. First set up as a registered charity in 1979, the Sickle Cell Society has been working alongside health care professionals, parents, and people living with sickle cell to raise awareness of the disorder. The Society's aim is to support those living with sickle cell, empowering them to achieve their full potential.

sickle cell disease and thalassaemia in maternity care: why early conversations matter

Written by Jennie Sule-Ejeh, Haemoglobinopathy Nurse Counsellor & Specialist Community Nurse for Sickle Cell and Thalassaemia

Drawing on my role as a Haemoglobinopathy Nurse Counsellor and Specialist Nurse for Sickle Cell and Thalassaemia, I aim to support early conversations, reproductive counselling and equitable pathways for families.

Why early conversations matter

Every booking appointment, every screening discussion and every moment of explanation is an opportunity to change the trajectory of a family's life. In haemoglobinopathy care, **conversations are clinical interventions** and when they happen too late, the consequences can be profound. The following real cases from people I encountered in my role illustrate why **making every encounter count** is essential.

Two real examples from practice

One case involved a couple who entered pregnancy without fully understanding their genetic risk. Although screened, they had not been supported to interpret their results. Key reproductive options were only discussed after birth, limiting choice and increasing distress. In another case, repeated declines of prenatal diagnosis were recorded as "informed choice". In reality, communication barriers, limited understanding and lack of support meant the woman had never been able to make a fully informed decision.

These are not cases of refusal — but of missed conversations and missed understanding.

CASE STUDY 1

When Key Conversations Happen Too Late (Sickle Cell Anaemia)

CASE STUDY 2

Repeated Declines Masking Unmet Needs (β-Thalassaemia Trait Couple)

IN ENGLAND:

1 in 79

babies is a carrier

300+

babies born each year with serious haemoglobin disorders

READ FULL BLOG

Scan the QR code to read the full blog, including the complete case studies and reflections.

r445: non-invasive prenatal testing

R445 is the clinical indicator code in the National Genomic Test Directory offering non-invasive prenatal testing (NIPT) where there is any previous pregnancy with reported full trisomy of chromosomes 13,18 or 21. We advise that you refer to the latest version of the test directory for detailed information on specific eligibility criteria.

LEARN MORE

news & events

Come to our Genomic Question Time drop in sessions! Our North Thames Education and Training Genetic Consultants & Counsellors, are happy to answer any questions you have; none too big or small!

This is a recurring event on first Thursday of the month 12:30pm-1:00pm. The next one will be held on 6 August, Thursday. Email nt-gms@gosh.nhs.uk to get the meeting link!

learning resources

For both novices and experts alike, the following links are to the educational resources for personal learning and for use ‘In the Clinic’:

GENOMICS 101

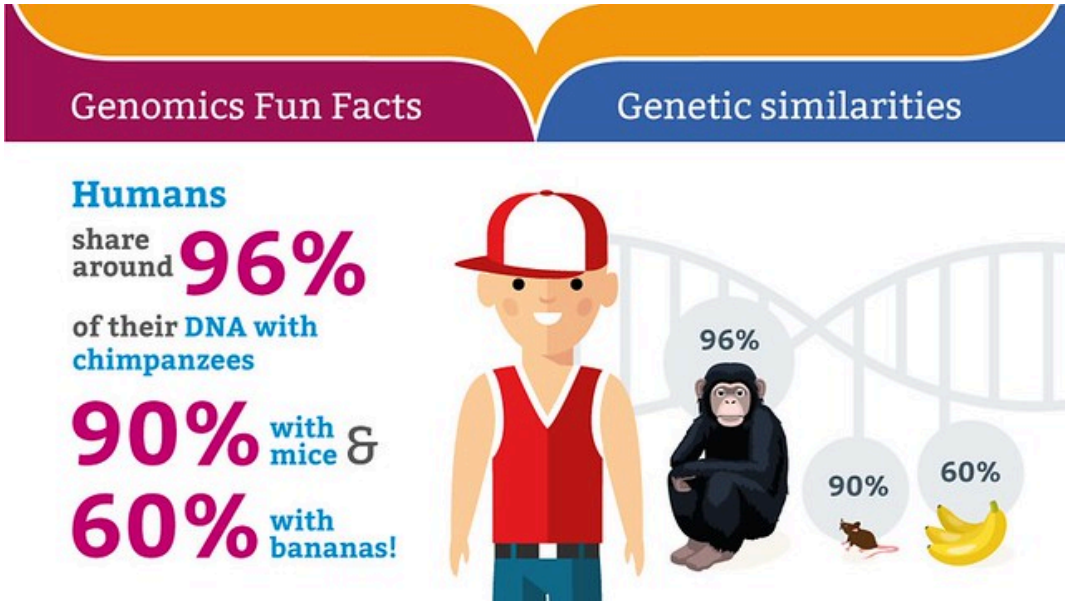
GENOTES

GENOMIC QUESTION TIME

GENOMICS EDUCATION PROGRAMME

Genomics Education Programme

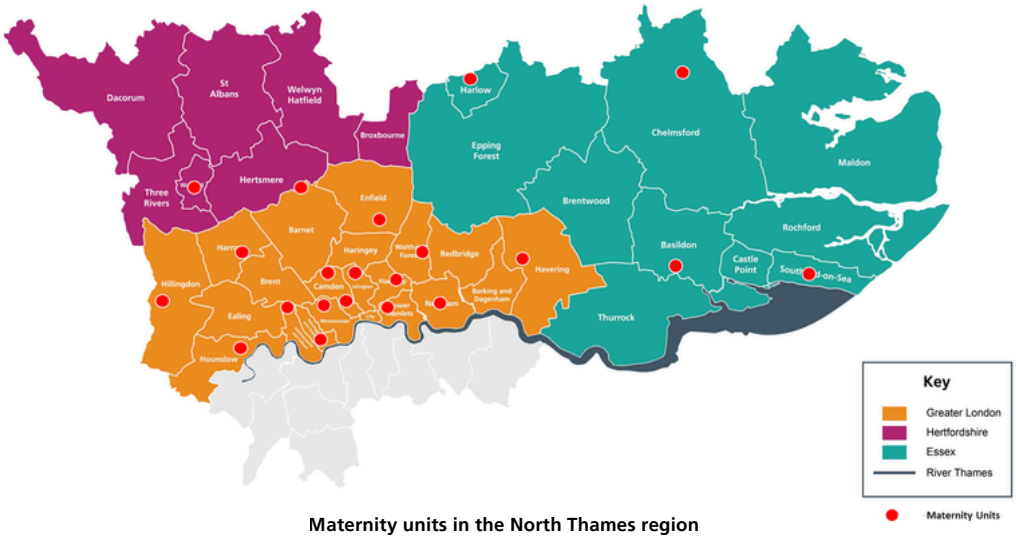
did you know?



about north thames genomic medicine service

who are we

North Thames Genomic Medicine Service (NT GMS) is one of the seven regional teams set up by the NHS Genomic Medicine Service. We work with all healthcare providers in our region, and with patients and the public to build trust in genomics and support the multi-professional workforce to use genomics safely, effectively, and efficiently, and respond to the NHS strategy for embedding genomics in the NHS.



Maternity units in the North Thames region

We want to keep this conversation going, please distribute to your colleagues and let us know your thoughts about this newsletter or if you want to contribute to a future issue. If you are interested in joining the network, please contact us: Yvonne Muwalo at yvonne.muwalo@gosh.nhs.uk or Tina Prendeville at tina.prendeville@nhs.net.

NT GMS Website:
Genomics in Nursing and Midwifery

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