NHS
North Thames
Genomic Medicine Service

@NorthThamesGenomics

MIDWIVES IN GENOMICS

ISSUE 2 | SEPTEMBER 2025

WELCOME TO OUR

Newsletter

what's inside

welcome message

Welcome to the second and summer edition of the North Thames Genomic Medicine Service's (NT GMS) newsletter for Midwives! This edition includes more interesting data from our recent survey—including the fantastic news that over 50% of you are now offering genomic tests in your practice! As promised, we are proud to continue delivering content that is tailored to your preferences and are most grateful to you for your input. For this edition we have included more maternity research and education around genetic and genomic testing for the families we care for.

The recently published "Fit for the Future: The 10-Year Health Plan for England" highlighted how genomic is central to transforming personalised care, with a strong focus on embedding genomic testing into routine NHS practice to improve early diagnosis, prevention, and treatment. This strategic direction underscores the important role midwives play in delivering equitable, cutting-edge care to families across all communities.

We look forward to keeping you informed and engaged as we move forward together in this genomic era.

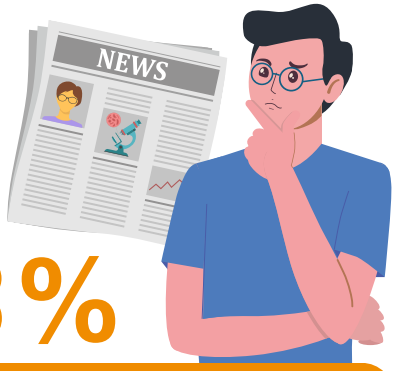
midwives in north thames survey results

Thank you for completing the survey earlier in the year telling us what you need to know about genomics. Nearly 60 of you responded to the survey and these are some of the themes from the results. We would love to share more survey highlights below:

72%

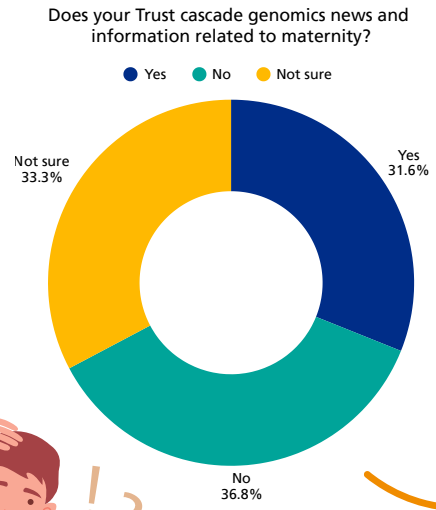
are NOT CONFIDENT speaking to patients about genomics.

On a scale of 1-10 (1 being very little and 10 being proficient), only 28% responded with 6 or above!



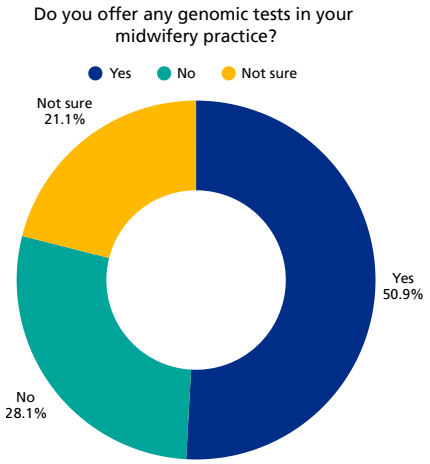
33%

are UNSURE if their Trusts cascaded news related to genomics in maternity.



21%

are UNSURE whether they offered genomic tests in their practice.



Whilst 21% of you are unsure whether your offer genomic tests in your practice, if you provide antenatal, postnatal, fetal medicine, screening care or bereavement care, you most certainly offer genomic testing. To learn more please contact Yvonne Muwalo at yvonne.muwalo@gosh.nhs.uk or Tina Prendeville at tina.prendeville@nhs.net.

jnetics

Supporting Informed Choices:
Genetic Screening for Jewish Inherited Conditions

For September's newsletter we are raising awareness of genetic screening for Jewish inherited conditions. And highlighting Jnetics a charity dedicated to the prevention and diagnosis of Jewish genetic disorders (JGDs), through awareness, testing, genetic counselling and supporting those at risk.

Each of us carries numerous genetic traits from those that determine eye colour to how our body reacts to medications. We are also all carriers of several recessive genetic conditions. These typically have no impact on an individual's health. However, if both parents are carriers of the same condition, there is a 1 in 4 chance that each child they conceive will be affected by that condition.

While around 1 in 300 people in the general population are carriers for Tay-Sachs Disease (TSD), a severe, progressive neurological disorder with which very few children would survive past the age of five, 1 in 25 Ashkenazi Jews carry a gene fault for this. Thanks to screening, TSD is now more often diagnosed in non-Jewish children, however it is vital that referral is offered to NHS Genetic Counselling services to families of Ashkenazi Jewish heritage for discussion on TSD, even with no family history. Jnetics offers comprehensive carrier screening for 49 genetic conditions that are prevalent in people of Jewish ancestry. However, it is not just TSD and not just Ashkenazi jews. Among Indian Jews, for example, 1 in 27 are carriers for Fanconi Anaemia (Group A), a serious condition affecting DNA replication and repair, reducing the blood cell count. Nearly 40% of people Jnetics screen are found to be carriers for at least one severe JGD.

When couples know they are both carriers for the same condition, they can make informed reproductive choices, which makes preconception screening ideal. Options include preimplantation genetic testing or prenatal testing (ideally before 20 weeks), making testing as early as possible vital. One couple's story can be viewed here.

To learn more please contact Jnetics
by emailing screening@jnetics.org or visiting www.jnetics.org.

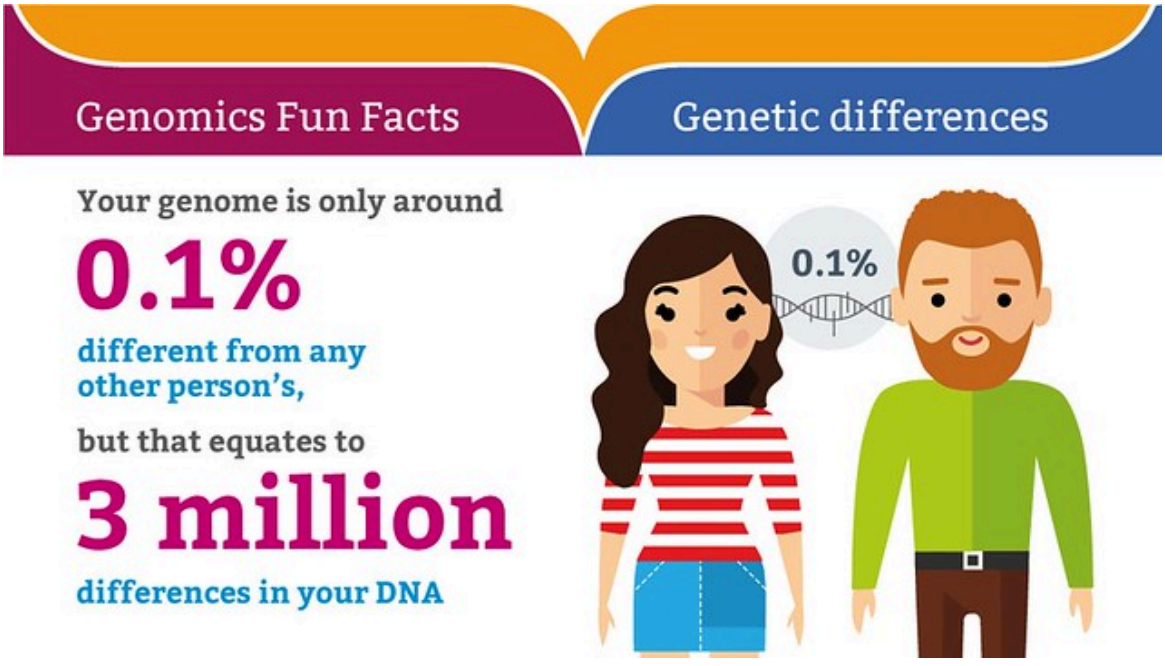
midwives genomics passport

Genomics is now a key part of midwifery practice and is included in the NMC's standards. While midwives are expected to discuss genomics confidently, many need additional training. To support this, a specialist working group created the Genomics Learning Passport for Midwives, which offers a structured pathway from basic to advanced knowledge. It also helps midwives track their learning for revalidation.

Genomics Education Programme

LEARN MORE

did you know?



research spotlight

Diverse Genomes, Shared Risk: A Whole Genomic Sequencing Study of spontaneous PTB in the UK

PRESTIGE-PTB

PRESTIGE-PTB stands for Preterm Birth Genomic Investigation using Whole Genome Sequencing. It's a nationwide multicentre cohort study using Whole Genome Sequencing (WGS) to identify genetic determinants of spontaneous preterm birth (sPTB).

The study is sponsored by Imperial College London and funded by the Tommy's charity, with support from Genomics England Ltd. The Chief Investigator for this study is Professor Catherine Williamson, who is the director of the Tommy's National Centre for Preterm Birth.

Around 1 in 13 babies are born prematurely in the UK and preterm birth is the leading cause of infant mortality globally. Significant evidence exists for a role for genetic variation in the aetiology of sPTB, but there is a lack of data relating to susceptibility to sPTB in women of non-European ancestry. The study aims to use the power of WGS within the diverse UK population to understand the genetic factors among individuals affected by sPTB from varied ancestries. Women and birthing people with a history of sPTB and/or preterm birth following preterm prelabour rupture of membranes are invited to have a single venous sample collected for WGS.

There are 34 NHS Trusts running the study in England and over 2,000 participants have been enrolled to date.

LEARN MORE

IMPERIAL

Tommy's
The pregnancy and baby charity

hot topics

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

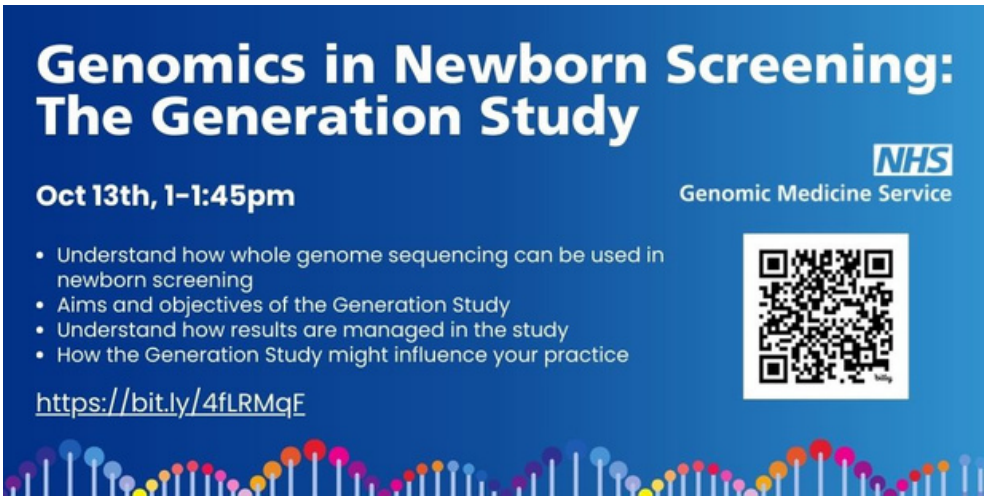
Genomics Education Programme

news & events

Antenatal Results & Choices

Antenatal Results and Choices (ARC) is the only national charity helping parents and healthcare professionals through antenatal screening and its consequences. ARC is comitted to supporting all health professionals in the field of antenatal screening and fetal medicine as such they have developed a network of midwives working in these areas. If you wihs to join this network please email info@arc-uk.org with subject line ‘Fetal Medicine Network’.

news & events



Spotlight on common aneuploidy testing: Update on R445 and QF-PCR explained

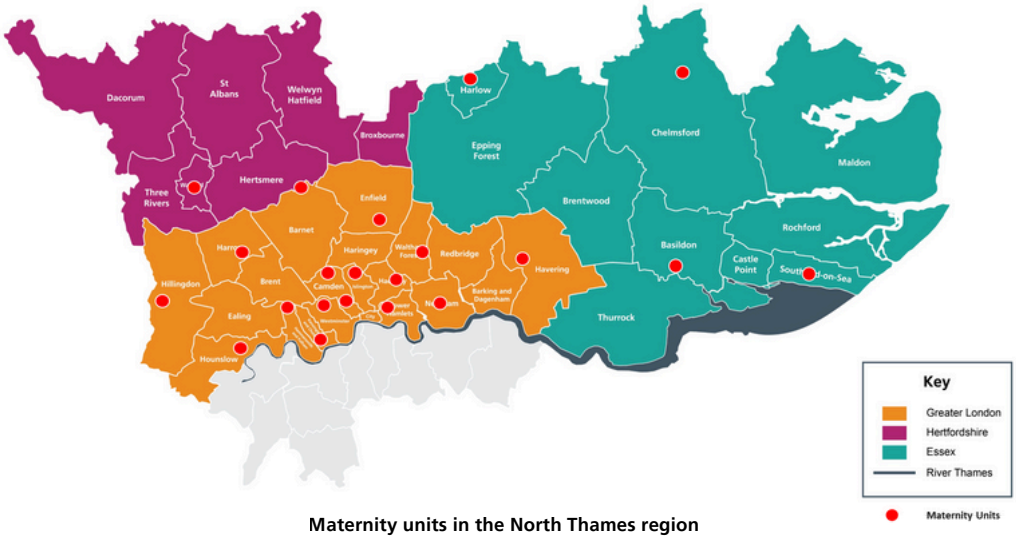
Wed 10 Sep 2025 11:00 AM - 12:00 PM BST
Online, Microsoft Teams

Please register to attend webinar on common Aneuploidy Testing which aims to explore the R445 data from the first year post implementation and QF-PCR with your professional networks.

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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