East Genomics

Making a Difference:

Genomics in Nursing and Midwifery Conference

Afternoon Midwifery Sessions

Venue Wifi:

Network: Conference

Password: Mercure24

Twitter:

#EastGenomicsNurseMidwife







Making a Difference:

Genomics in Nursing and Midwifery

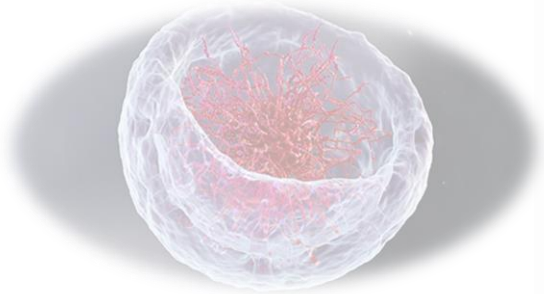
Donna Kirwan
Genomics Lead Midwife
NHS England

East GMSA - 22 November 2022

1950s

What is genomics?

The study of a person's ENTIRE DNA (genome), their genes and how they work and interact to influence the growth, development of the working of the body.



“The pace of advance in our understanding of inherited disease is rapid and accelerating. These advances are making a considerable impact on the practice of obstetrics and midwifery, as elsewhere in clinical medicine.”

Mayes’ Midwifery (1998)

“Screening is not just a test: it is a pathway that is made up of several stages.”

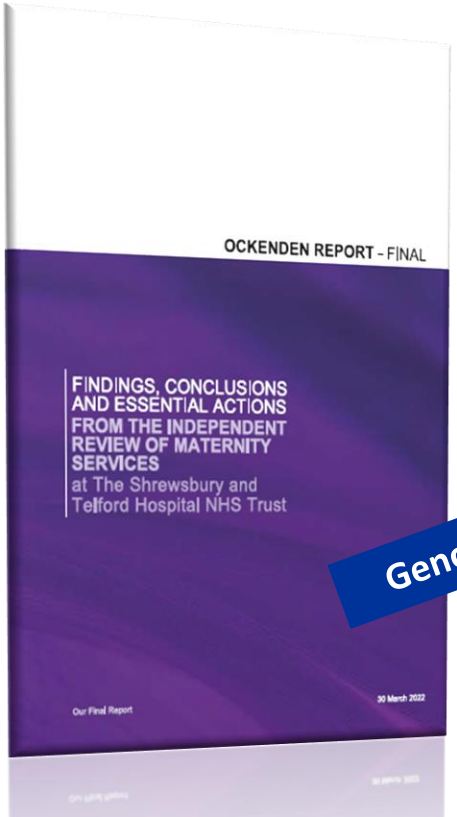
Sir Professor Muir Gray

Antenatal genomic touchpoints

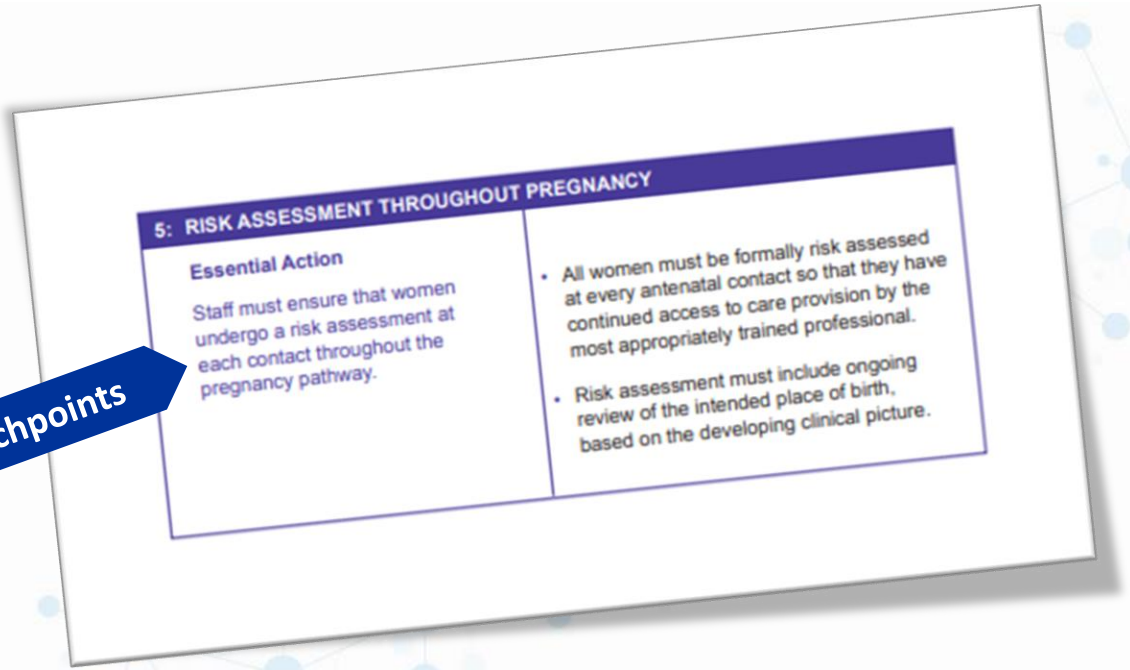
Booking history

- Sudden cardiac deaths in apparently healthy young people
- Young heart attacks, stroke, deaths in several relatives
- Diabetes (Type 1 ? MODY)
- Intellectual Disability
- Developmental Delay
- >3 pregnancy losses
- Multiple congenital anomalies, dysmorphic features
- Two or more medical conditions occurring together
- Medical problems in offspring of parents who are related by blood

Ockenden Report - FINAL



Genomic Touchpoints



5: RISK ASSESSMENT THROUGHOUT PREGNANCY

Essential Action

Staff must ensure that women undergo a risk assessment at each contact throughout the pregnancy pathway.

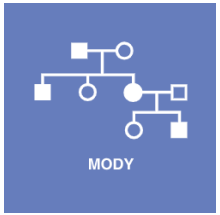
- All women must be formally risk assessed at every antenatal contact so that they have continued access to care provision by the most appropriately trained professional.
- Risk assessment must include ongoing review of the intended place of birth, based on the developing clinical picture.

SW GMSA National

Monogenic Diabetes (MODY) Transformation Project

Aims to improve the diagnosis of MODY to reduce the number of patients who are

Nationally funded training programme for midwives recognise when testing for MODY is appropriate and can benefit from it



~ 12,000 people with MODY

Runs in families

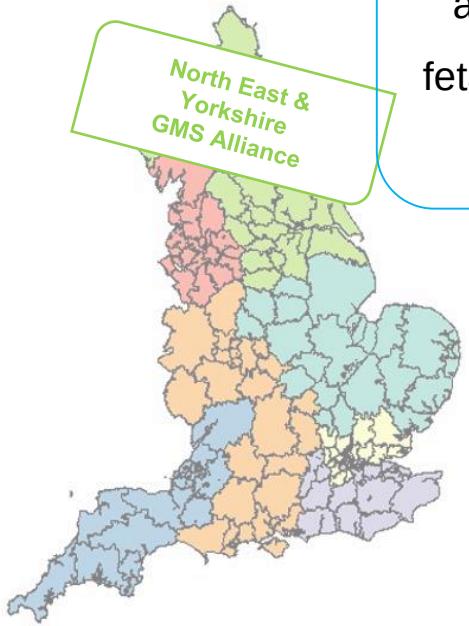
Inherited gene variant

Diagnosis can **omit the need for insulin** for oral medication

DiabetesGenes

NE&Y GMSA
Local Fetal-Maternal Project

This project is working on ways to tackle inequity of access to prenatal and postnatal genomic testing for fetal abnormalities across the North East and Yorkshire.



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Newborn Genomes Programme

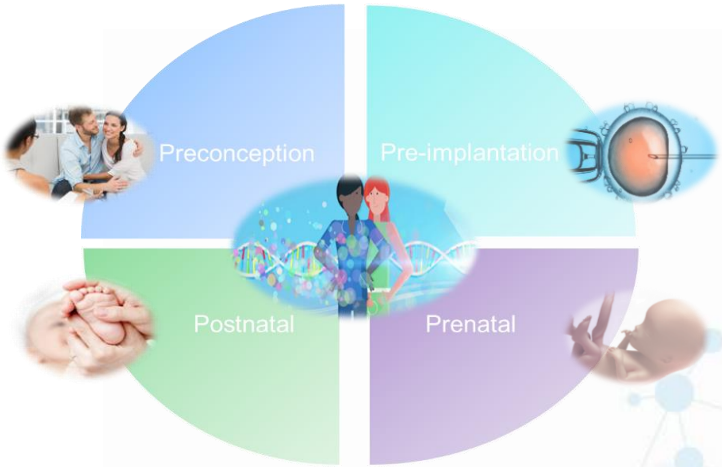
- Evaluating the utility and feasibility of **screening newborns for a larger number of childhood-onset rare genetic conditions** in the NHS using whole genome sequencing
- Understanding **how babies' genomic data could be used for discovery research**, focusing on developing new treatments and diagnostics for NHS patients
- Exploring the potential risks, benefits, and broader implications of **storing a baby's genome over their lifetime**

Pilot start 2023

Transgenerational genomics

World-first national genetic testing service for babies and children

Rapid NICU/PICU
Whole Genome Sequencing



~ 20 Fetal Genomic Tests

Non-Invasive Prenatal Diagnosis

(NIPD)

Non-Invasive Prenatal Testing

(NIPT)

Microarray

QF-PCR

Rapid Prenatal Exome

Sequencing

Transforming care for patients

1 in 500 babies have a genetic change which predisposes to **complete irreversible hearing loss** when given **gentamicin.**

PALOH

The simple genetic test for newborns that can prevent profound deafness and save the NHS millions every year

HEE Genomics Education Programme

- Genomics 101
- Genomics in Nursing
- Genomics in Midwifery
- Webinars
- Fact Sheets
- Podcasts
- Competency Frameworks
- Clinical Pathway Initiative
- Glossary

Further reading

“The term genomic medicine will soon disappear. It will just be called medicine and in all branches of our work”

Professor Sir John Burn

Ex Professor of Clinical Genetics at Newcastle University

Life Scientific: BBC Radio 4 (2018)

Thank You

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NHS
North East and Yorkshire
Genomic Medicine Service

NEY Fetal Genomic Transformation Project

Denise Barnes – Lead Midwife for Genomics in North East & Yorkshire.

Jenni Petrie – Fetal Medicine & Screening midwife and Genomics Midwife, Leeds.

NHS
North East and Yorkshire
Genomic Medicine Service

Problem Statement

"Women and families do not have equitable access to genomics services related to pregnancy across the North East and Yorkshire"

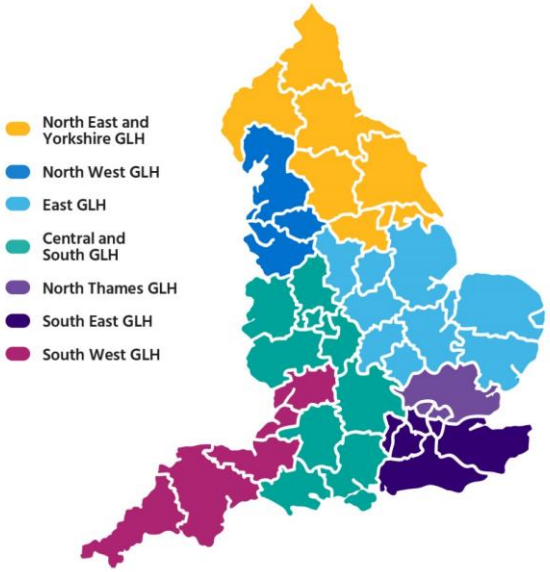
Programme Aims

- To reduce the inequity of access to prenatal and postnatal genomic testing within the NEY GMSA
- To develop end–to-end clinical pathways for ongoing pregnancies and for pregnancy losses, after fetal anomalies are identified
- To create a multi-professional network of healthcare providers to embed genomics in to maternity care and deliver culturally competent services
- To contribute to transformation projects in nursing and midwifery.

The Fetal Genomics Transformation Project.

NHS
North East and Yorkshire
Genomic Medicine Service

- NEY GMSA
- Project leads
  - Clinical genetics – Jen Campbell
  - Fetal medicine – Kelly Cohen
  - Midwifery lead – Denise Barnes
  - Project Managers – Mark Hurrell & Simanjay
  - Data Lead – Andrew Michaelson

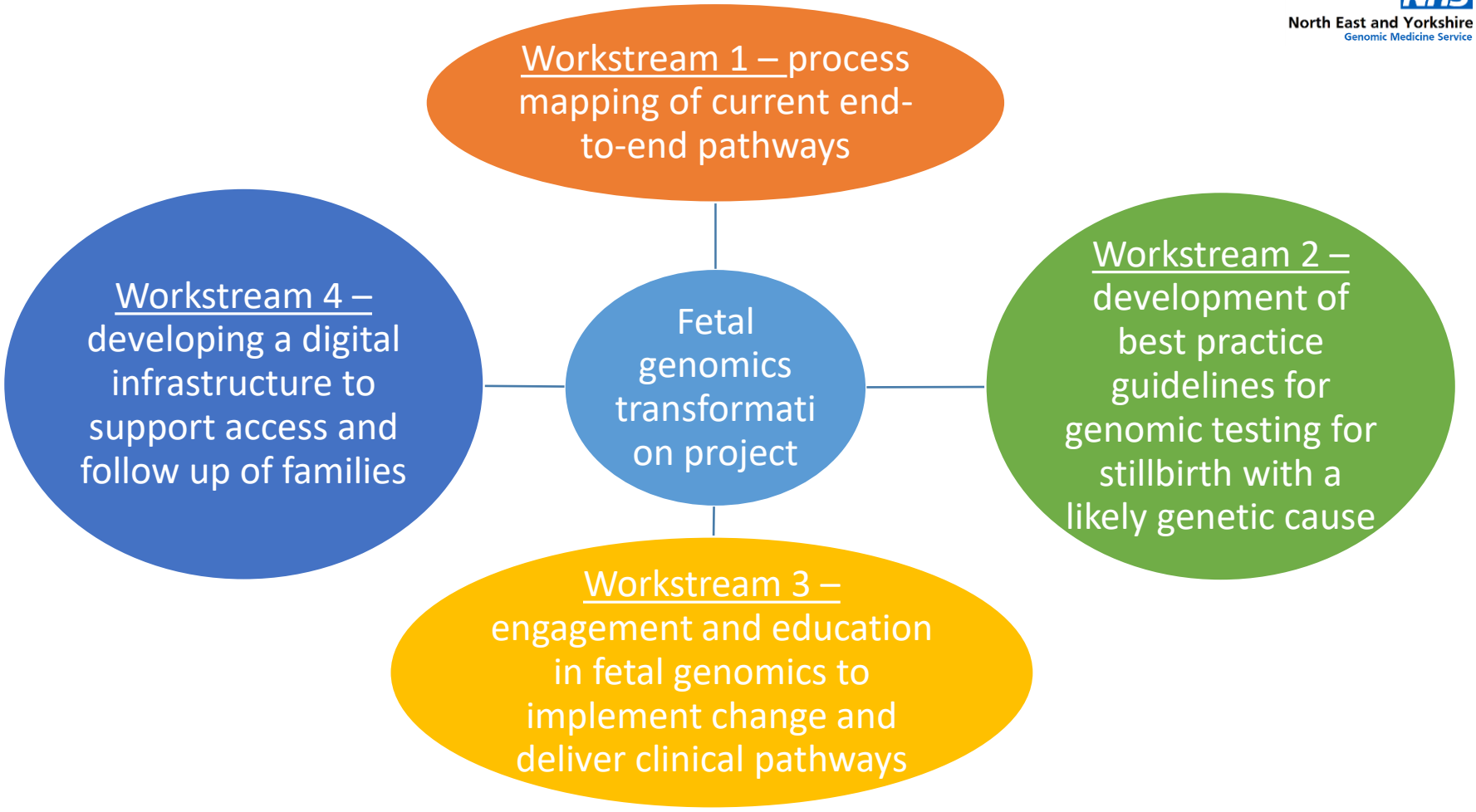


- Sheffield: Julie Walsh ,Alison Stewart, Richard Sayers
- Newcastle: Angela Lightfoot, Marta Bertoli, Lesley Walker.
- Leeds: Jenni Petrie & Emily Fadipe, Steph Hart, Saghira Malik, Debbie Gray
- Clinical fellows: Jess Woods, Abby Hyland

NHS
Sheffield Teaching Hospitals
NHS Foundation Trust

NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust

The Leeds Teaching Hospitals NHS
NHS Trust


Workstream 1 – process mapping of current end-to-end pathways
Workstream 4 – developing a digital infrastructure to support access and follow up of families
Fetal genomics transformation project
Workstream 2 – development of best practice guidelines for genomic testing for stillbirth with a likely genetic cause
Workstream 3 – engagement and education in fetal genomics to implement change and deliver clinical pathways

Workstream 1 : Pathway mapping

- Current pregnancy with fetal anomaly
- Pregnancy loss with fetal anomaly
- Family history of genetic condition

Clinical Pathway Mapping Themes

North East and Yorkshire Genomic Medicine Service

External/ Internal

Define who completes referral, when and how. .

Type of Appointment

Telephone, F2F, Tele Med etc.

How Communicated.

Who communicates results, when are they given, how are they given. Consider pregnancy loss.

Referral → Triage → Appointment → Tests → Results

Method of Triage

Who triages, via what format, and how communicated back to referrer

What, who and when.

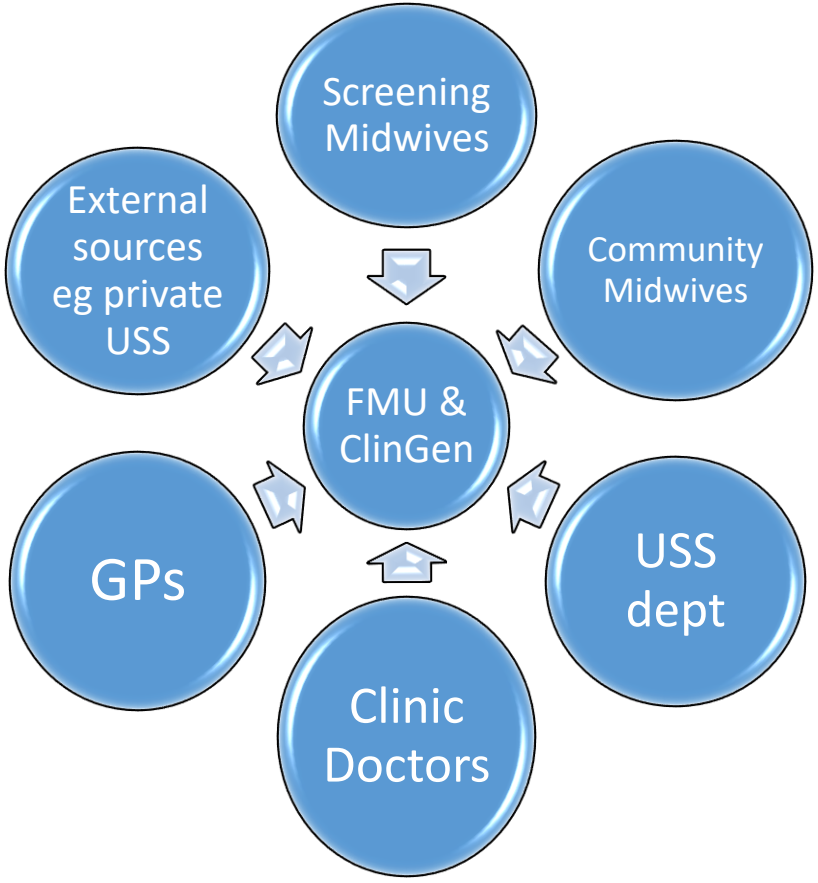
MDT discussion of tests performed for fetal anomaly?

Communication to MDT of tests performed/required.

Internal Referral pathway for Leeds, Newcastle and Sheffield

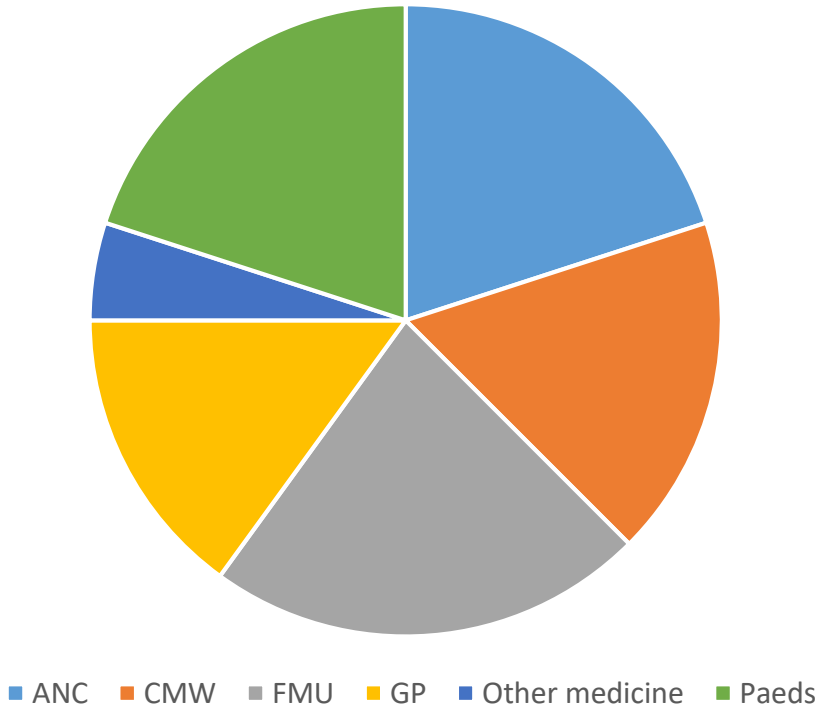
- Point of referral
- Method of referral
- Criteria for referral
- Timeframe.

Point of referral



Internal referrals to Clinical Genetics

Referrals to clinical genetics Q3 21/22



In October to Dec 2021, one third of referrals to CG from maternity services came from an obstetrician in ANC. On investigation 75% of these patients were seen by a midwife in Community where an earlier referral could have been made.

Case Study

Jess attended her booking appointment and obstetric history was noted

Previous baby affected with Dravet's Syndrome in 2019

Jess was anxious and wishing for genetic testing

Community Midwife referral to Genetics

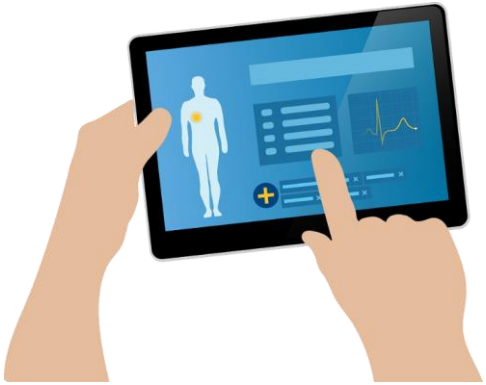
Jess was referred to ANC for review

Consultant in ANC referred to Genetics

What could have been done differently?

How do we make a difference?

Focus group – Continuity of Care team of 6 midwives. Aimed to establish understanding of care pathways. Observed booking appointments.



Explored genomic history questions within the electronic maternity systems.

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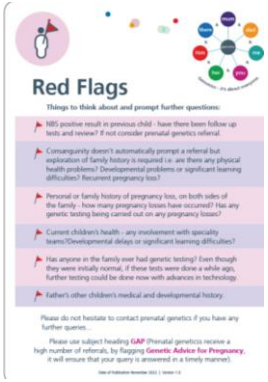
North East and Yorkshire
Genomic Medicine Service

Education Package

- Community midwife education sessions
- Flashcard/Quick reference guide
- Educational poster
- Staff education videos



What does this mean for me?

- Consider your role in your local clinical and pregnant person pathways
- Resources available to expand your expertise (Health Education England – GEP)
- Share cases with your colleagues through collaboration.

Thank you

Any questions?

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Lead midwife for fetal transformation project, Leeds.

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Lead Midwife Genomics NEY

Newborn Genomes Programme

Genomics in Nursing and Midwifery Conference

Sally Shillaker

Clinical Content Developer

22 November 2022

Current NHS Newborn Blood Spot (NBS) Screening Programme

Newborns can currently be screened for nine conditions via a bloodspot test.

There is a 97% uptake of newborns screening in the UK.

> "There is a clear potential for genomics in the testing for many of the conditions currently included in the blood spot test."
>
> Generation Genome

- Sickle cell disease
- Cystic fibrosis
- Congenital hypothyroidism
- Phenylketonuria
- Medium-chain acyl-CoA dehydrogenase deficiency
- Maple syrup urine disease
- Glutaric aciduria type 1
- Homocystinuria

NHS screening currently only looks for these conditions, rather than screening the baby's genome. We are testing a broader approach.

Our research study's focus

Three parts | All subject to ethics committee approval

** **Key point**: not just **how** each might be implemented, but **whether** they should be implemented.**

01 Evaluating the utility and feasibility of **screening newborns for a larger number of childhood-onset rare genetic conditions** in the NHS using whole genome sequencing

02 Understanding **how babies' genomic data could be used for discovery research**, focusing on developing new treatments and diagnostics for NHS patients

03 Exploring the potential risks, benefits, and broader implications of **storing a baby's genome over their lifetime**

How we work

Core in-house team

Expert working groups established, focusing on:

- Conditions the research study should screen for
- Recruitment
- Ethics
- Evaluation
- Education and training

- NHS Steering Group – designed to support and develop the research study
- Co-design with parents and healthcare professionals
- Engagement programme to work with stakeholders – including members of the public
- Participant panel

Designing the service

We need to establish 6 design elements – each linked, and co-dependent:

01

A process for establishing the conditions we will screen for

02

How, where (i.e., which NHS trusts), and when we will recruit newborns to the research study

03

A process for asking parents to consent for their newborns' inclusion in the research study

04

Identifying the best way to take samples from newborns, and sequence those samples

05

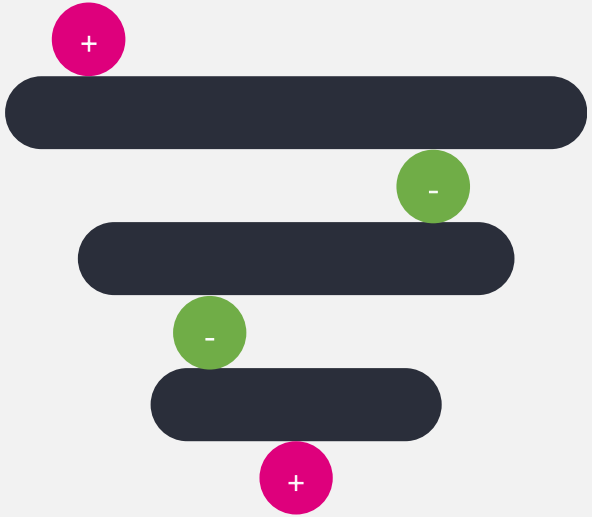
Establishing systems to return results to parents: the role of bioinformatics

06

Ensuring there are care and treatment pathways and support in place where positive results returned – e.g., through establishing a network of treating clinicians

Choosing which conditions to screen for

- The challenge: there are hundreds of conditions that *could* be detected through whole genome sequencing – but we may not want to look for all of them
- The programme will only screen for a specific set of conditions, genes, and variants
- Principles and criteria for screening already exist – we are taking a bespoke approach in the context of a UK-based research programme



Principles

Overview

- Principle A: variants cause the condition (with a confirmatory test available)
- Principle B: the condition is highly penetrant and significantly impacts quality of life
- Principle C: early/pre-symptomatic intervention improves outcomes in children
- Principle D: the intervention is equitably accessible to all (based on NHS input)

Parents' views

Co-design with parents

- Ongoing ad-hoc discussions with small groups of parents as issues arise
- Early 2022: first set of discussions involved 8 parents – focused on best approach to informing parents about the research study – e.g., design and language
- Next – asking parents about the research and consent aspects of the research study

The screening experience and expectations of new, and expectant, parents

- Interviews with 60 parent / expectant parents, carried out by Revealing Realities
- Understanding current pregnancy experiences
- Gathering views on how invitation leaflets should be written / presented

Workforce input

- Workshop with midwives (April 2022)
- Engaging with genetic counsellors (led by in-house genetic counsellor)
- Working with clinicians across a range of specialisms to establish how the research study would affect clinical care (led by in-house clinical advisor)

- Discussing the research study with nurses – e.g., via Children's Hospital Alliance
  - To understand the approach the research study should take to care and treatment pathways given resource issues.
  - Talking to the workforce to make sure we can adopt an optimal approach and take its concerns into account.

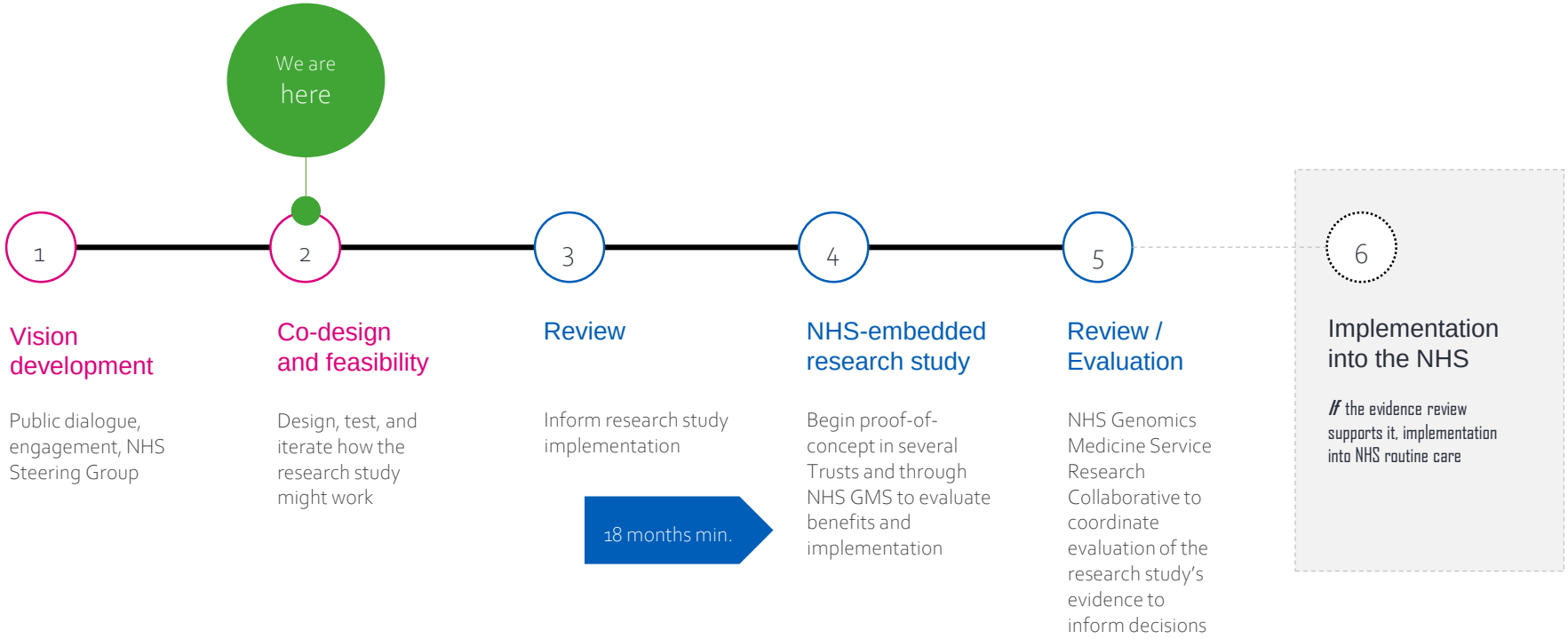
Care and treatment pathways

"Considering existing pressures in healthcare, the programme must understand the services and resources required to support children and families, and education and training needs for the workforce to provide high quality care."

* The above steps may not be needed for each condition, and the order of those steps may vary

Although the total number of screen-positive babies in the lifetime of the research study is expected to be 500 - 1,000. Each baby needs a structured care and treatment pathway in place before we begin.

Where are we?


We are here
1
2
3
4
5
6
Vision development
Public dialogue, engagement, NHS Steering Group
Co-design and feasibility
Design, test, and iterate how the research study might work
Review
Inform research study implementation
18 months min.
NHS-embedded research study
Begin proof-of-concept in several Trusts and through NHS GMS to evaluate benefits and implementation
Review / Evaluation
NHS Genomics Medicine Service Research Collaborative to coordinate evaluation of the research study's evidence to inform decisions
Implementation into the NHS
If the evidence review supports it, implementation into NHS routine care

Thank you

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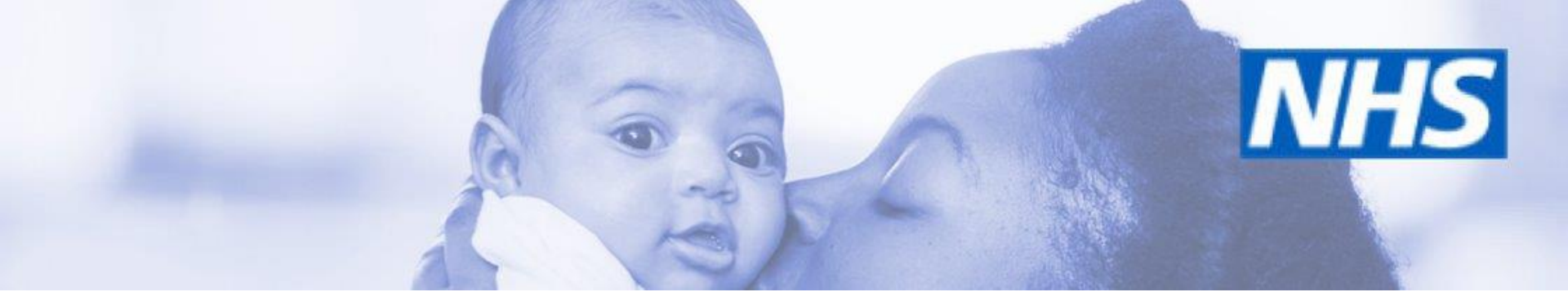
www.genomicsengland.co.uk/newborns

@GenomicsEngland

The Genomics England newborns core team:

- **Dr David Bick**, Consultant Clinical Geneticist & Clinical Advisor
- **David Bowen**, Enterprise Architect
- **Dasha Deen,** Genome Data Scientist
- **Sally Donovan**, Delivery Manager
- **Frankie Edwards,** Integrated Designer
- **Harriet Etheredge**, Ethics Lead
- **Edyta Jaworek**, Product Designer
- **Sofia Garcia Noriega**, Service Designer
- **Kate Harvey,** Engagement Manager
- **Mathilde Leblond,** Human-Centred Design Researcher
- **Christella Matoko**, Delivery Coordinator
- **Amanda Pichini**, Clinical Lead for Genetic Counselling
- **Jonathan Roberts**, Clinical Content Developer
- **Dr Richard Scott**, Chief Medical Officer (senior sponsor)
- **Sally Shillaker**, Clinical Content Developer
- **Katrina Stone**, Clinical Fellow in Genomics
- **Alice Tuff-Lacey**, Programme Lead
- **Chantal Wood**, Programme Manager
- **Joanna Ziff**, Delivery Manager



Close-relative marriage and genetic risk

Naz Khan

Clinical Lead Equality, Ethnicity & Genetics, NHSE

Registered Genetic Counsellor Manchester Genomic Medicine

Close relative marriage & genetic risk

- *Background*
- *Why is this a healthcare issue?*
- *The National Strategy*

Diversity in the UK

- UK- ethnically diverse society
- Asian/British Asian second largest ethnic group in the UK
- UK national average 4.9% (Pakistani Indian Bangladeshi)
- North West 10.4%
  - Manchester 15.2%
  - Oldham 22.5%
  - Blackburn 28%
- 17.7% Muslim
  - 4.8% average in UK

Clarity

The term 'South Asian' is broad

‘South Asian’ covers a large, ethnically diverse population of South Asia

Includes: Afghanistan; India; Pakistan; Bangladesh; Sri Lanka; Nepal; Bhutan and the Maldives as the constituent countries

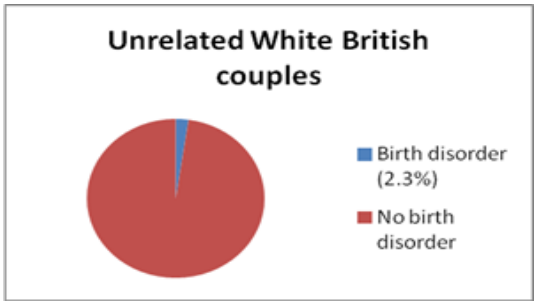
‘Lumping together’ can lead to confusion and can cause offense

British Pakistanis

UK Pakistani population

- 2nd largest ethnic group in UK 1.17 million (2011 census)
- Pakistan is huge country (3.3 times bigger than the UK)
- 70% of Pakistani's originate from Mirpur/Azad Kashmir/Jhelum
  - Rural/conservative area of Pakistan
  - Rigid Hierarchy
  - Close knit families
  - 90% consanguinity
- Remainder from Punjab and Pashtuns (Khyber district of Pakistan)
  - More prosperous part of Pakistan

Risks of genetic disorders in different populations



Sheridan et al 2013; The Lancet

- Risks of infant death & disability higher among communities practising close relative marriage.
- All Asian British/Pakistani heritage children were over-represented in both mortality and chronic morbidity categories (MBRRACE-UK 2020, PHE, CDOP)
- Congenital abnormalities are the leading cause of death for Pakistani infants (Li et al 2018)
- Family-level clustering
- Over 90% of babies born to cousin couples are healthy.

Close relative marriage

- Consanguineous marriage = marriage between blood relatives
- Benefits and risks recognized for centuries
- Close relative marriage is widely practised globally with recognized benefits to couples and their families.
- 20% of world's population live in communities that favour consanguineous marriage
- 8.5% of all births are to parents who are consanguineous
- Associated with Islam but neither encouraged nor discouraged by Islam
- However, the level of increased risk has often been exaggerated and this marriage pattern has been stigmatised in the UK

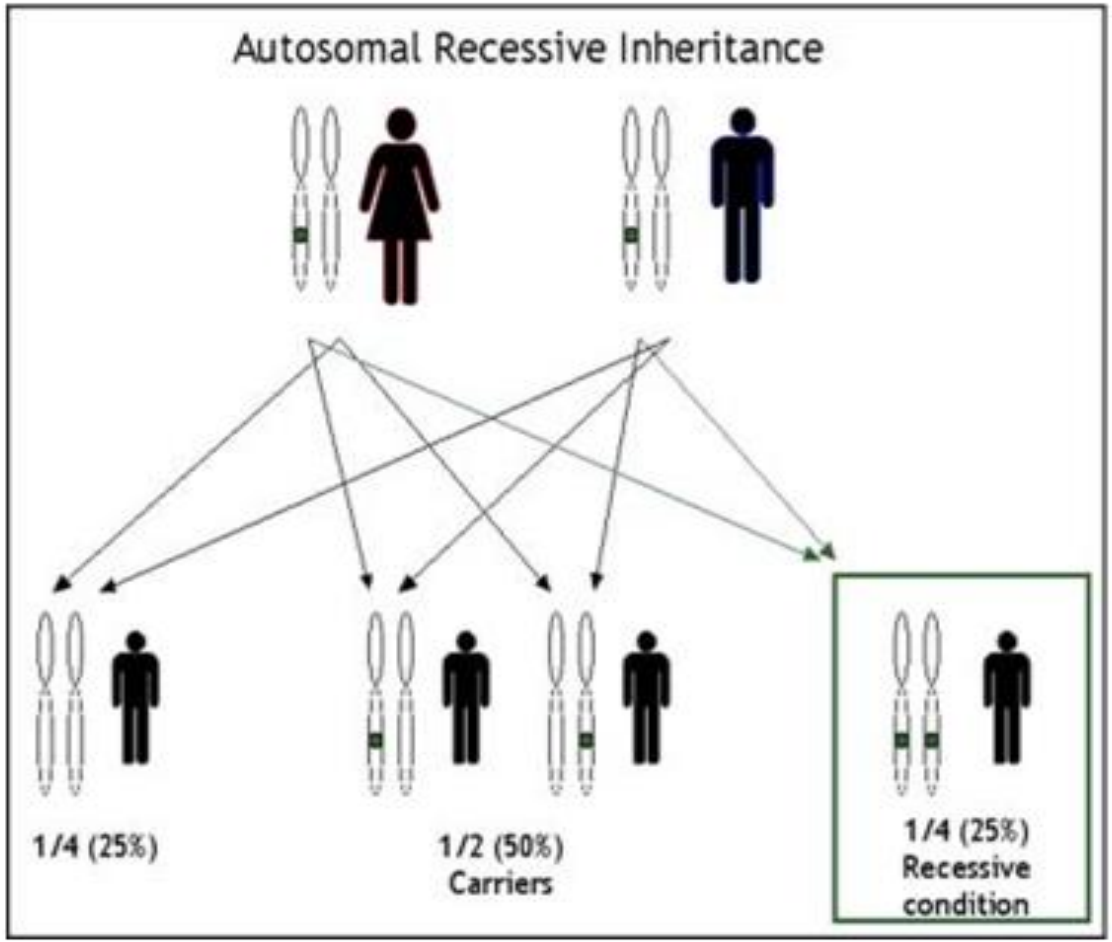
UK patterns of close relative marriage

- Born In Bradford study (2007-2011)
  - 12,453 women
  - 50% identified as South Asian
  - 49.9% non South Asian
- Pakistani mothers
  - 37% married to a first cousin,
  - 21% to other blood relative and
  - 42% to non-relative
- Also common in other ethnic groups, but lack of data

Genetics

- An autosomal ***recessive*** genetic condition occurs when both copies of the SAME gene happen to be faulty
- Recessive genetic conditions occur in all population groups
- Some recessive conditions are quite common
- Partners in a consanguineous relationship are not more likely than other individuals to carry faults in their genes
- But, because they share more of their genetic material than unrelated partners, they are more likely to carry the same faulty gene as their partner
- Children of related partners have a higher risk of inheriting two copies of the same faulty gene for a recessive genetic condition than children of unrelated partners

Genetics


Autosomal Recessive Inheritance
1/4 (25%)
1/2 (50%)
Carriers
1/4 (25%)
Recessive
condition

Pakistani population

Data from: research; Child Death Overview Panels; and clinical experience (midwives, genetics, health visitors and social care); Audit; PPI

- Repeated unexpected affected births (and deaths) to couples and across extended families
- Significant number attributed to recurrence in same family
- More than 50% of families with a likely AR condition are not referred to Genomic service
- Can lack the confidence to seek services and rely on referrals by healthcare practitioners
- Are sometimes refused referrals by GPs and others
- Have mixed experiences of genomic services, with some leaving without a good grasp of information & choices
- May struggle to share information with family members, but can be supported to do so
- Persistent unmet need for information and support
- Positive outcomes where services are better

Previous and current approaches

Period	General English policy approach	Outcome
Pre-2003	Some focused clinical research; Calls to ‘stamp out’ cousin marriage; political and media sensationalism; some	• harmful, alienating
2003-2008	DH Genetics White Paper (2003); two genetics-led ‘pilot’ projects (2005-) Bradford and Blackburn/Manchester	• promising, but limited evaluation, not scaled-up
2008-2018	National Support Team for Infant Mortality (2008-11) Several local public health-led initiatives; some multi-professional work; Child Death Overview Panel attention	• some good local learning • patchy, mainly focused at community level • inappropriate and unrealistic goals; many short-lived
2018-present	Multi-professional, national level work; plus some promising ongoing local initiatives. Formal Delphi exercise undertaken confirmed need for more coordinated approach	• Opportunity to share learning • Aiming for consistent and sustained approach

National steering group

- University of Sheffield. First steering group meeting Jan 2019 (group chaired by Sarah Salway and Naz Khan)
- Membership of steering group
- Work plan agreed based around Delphi consensus statements
- Twin aims:
  - equity of access
  - informed reproductive decision making
- Many statements agreed regarding service model
- 2019-2020 consultation exercises with patient/public groups to sense-check Delphi findings

How should health policy and practice respond to the increased genetic risk associated with close relative marriage? results of a UK Delphi consensus building exercise Salway, S., Yazici, E., **Khan, N.,** Ali, P., Elmslie, F., Thompson, J., & Qureshi, N. *BMJ open, 9(7), e028928* 2019.

Aim

- To reduce unmet need for genetic counselling and testing
- To increase informed reproductive decision making (within existing unions and future unions)
- Strengthen access and ensure cultural competence
- Identify families with an affected member
- Cascade information and support wider family members

Culturally competent genetics services: 4 strands

- Community-led
- Raise awareness of genetic risk
- Improve access to services
- Empower and build trust
- Varied, accessible format
- Reduce stigma and fear
- Local, multi-agency working group established
- *Nationally-provided health promotion materials*

1. Raise genetic literacy at community level

2. Educate & equip healthcare professionals

- Close relative marriage midwife "champion" 0.4WTE band 6
- Added value - health visitor champion (not required)
- Promote the e-learning module
- *e-learning for healthcare 'close relative marriage' modules*
- *National webinar post training*

All four strands must be applied to gain best results

- Develop and improve care pathways from primary & secondary care – improve access for underserved groups
- *Genomics associates (nationally funded) in clinical genetics services to support access, follow up non-attenders & support family conversations*

3. Improve access to genetics services for underserved groups

4. National support

- Oversight: national steering group
- National communities of practice for close relative marriage midwives, genomics associates & public health teams
- Progress reports & share learning
- Metrics with analytics advice
- Evaluation
- Funding: ongoing & start up

Key:
National support offer

Close relative marriage midwife

- Band 6, 0.4 WTE per each of the 9 areas of high need
- Not a specialist role per se, raise the profile of and embed work on genetic risk
- E-learning for Healthcare training module, HEE
- Enhance identification, empowered decision making and appropriate referral to genomic services
- Champion or manage caseload of families at increased genetic risk associated with close relative marriage

Genomic associate

- Based in regional genomic service
- Training and support available from NHSE
- Enhance journey and engagement with genetic services
- Aid understanding of genetic information
- Contact post genetic clinic
- Cascade screening extended family
- Point of contact between genetic literacy/close relative marriage midwife

Genomic literacy

Complement midwife role and enhance referral pathways

Improve genetic literacy in communities

Improve referral and identification of families in the community

Opportunity to share practice across all areas

Ongoing support from NHSE

Feedback from health professionals

We deal with the coughs & colds, check they are under a paediatrician and don't think about a referral to genetics (GP)

I was not aware of the issues; how to refer or who to refer. (GP)

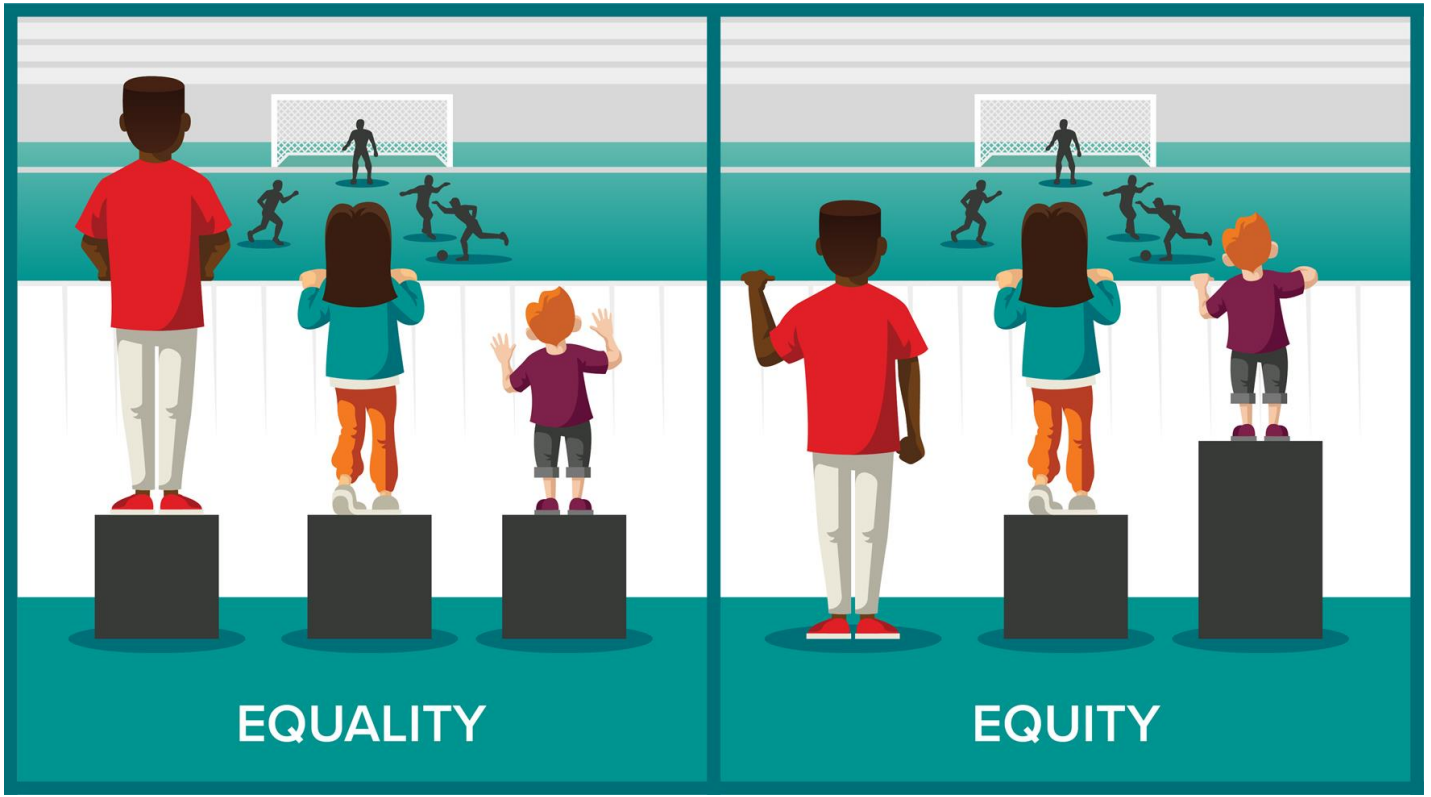
If you ask the questions the families are forthcoming. I did not know how to ask the question before the training. I was worried about offending them (midwife)

It has changed how I obtain family history. Now I ask if they have children with health problems rather than 'is there any genetic condition in your family?' It had never occurred to me before that they wold not know a diagnosis (Obstetrician)

Recognize challenges

- Complex patterns of risk at population and individual level; family cascading of information crucial
- Connected to the highly personal and emotional (marriage and reproduction; culture and difference)
- Unmet need concentrated among individuals and communities who commonly experience discrimination within services and wider society
- History and persistence of institutional racism

Danger of doing more harm than good

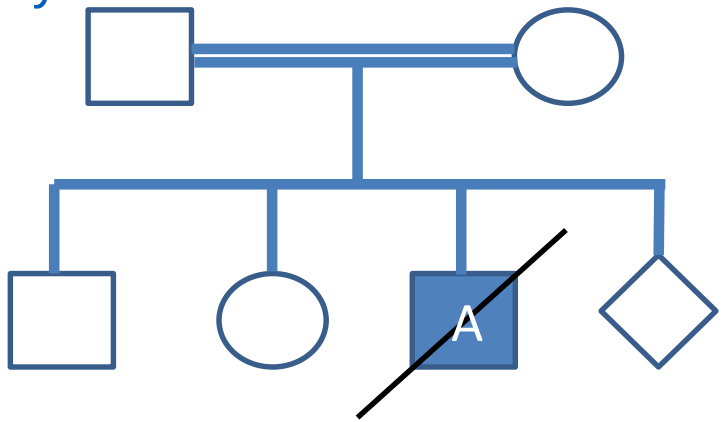

EQUALITY
EQUITY

Family A: background

- Baby died at 2 months of epidermolysis bullosa (EB) in NICU
- No referral to genetics
- In subsequent pregnancy mum concerned re potential risks
- GP appointment at 7 weeks, mum asked about prenatal diagnosis (PND) but was told the treatment was not available and routine antenatal care advised
- Mum persistent – rang EB nurse in Birmingham who referred her to genetics (NK)

Family A: genetics journey

- Confirmed parental carrier status
- Arranged PND (unaffected)
- Arranged carrier testing in extended highly consanguineous family
- Further carrier couple identified and informed of the possibility of PND in future pregnancy



Family B: background

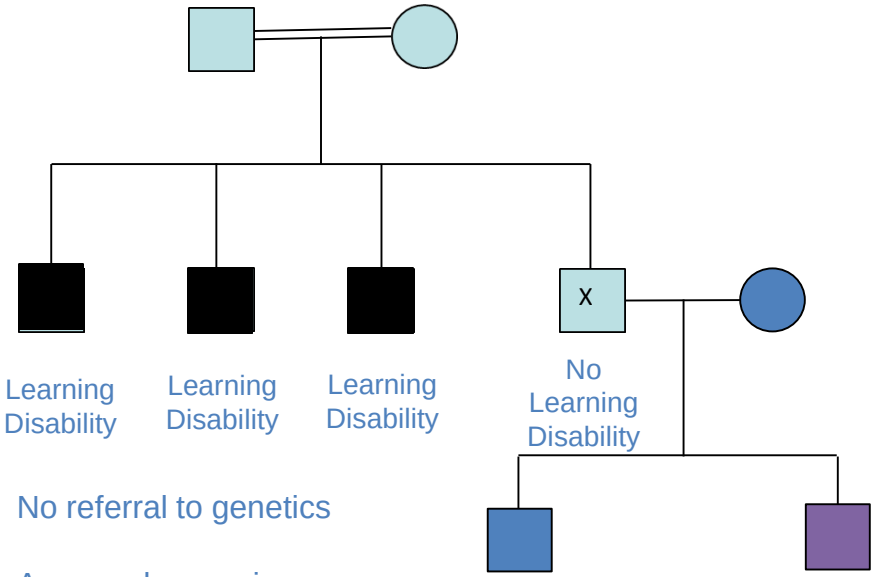
- Fatima: 10 weeks pregnant. Married to first cousin.
- Booking appt informs midwife; sister affected Factor X deficiency
- Midwife referred to Consultant Obstetrician ~16 weeks gestation
- Obstetrician referred to joint haematology/obstetric clinic tertiary centre
- High risk pregnancy ‘cared for as baby affected’
- Anxiety for family ~ 20 plus weeks gestation
- No referral to genetics
- Another family member (cousin) referred by obstetrician at 16 weeks to genetics
- Seen by NK: Genetic Counselling

Family B: genetics journey

- GC appointment (cousin 16 weeks)
  - Family History
  - AR inheritance
  - Carrier testing
  - 1 in 4 if both parents carriers
  - PND/birth plan if required
  - Implications for other family members

- Requested GP refer Fatima to Genetics to clarify risk
- Fatima seen in the genetic clinic at 26 weeks
- Lessons: early appropriate referral equates
  - early informed reproductive choices
  - reduces anxiety/stress for woman and family
  - NHS resources
  - Genetic input in the past

Family C



No referral to genetics

Assumed recessive

X assumed low risk as not related to partner

Second son affected by Wolf Hirschhorn Syndrome Chromosome imbalance (not recessive)
X carrier of balanced chromosome translocation
Brothers all affected by same condition

Lessons learnt

- Don't assume that genetic conditions are as a result of close relative marriage (are autosomal recessive)
- Important to get genetics input

Feedback from families

We didn't know it was genetic. We thought genetics was about cousin marriage

I had no idea about implications for me or my future children. Nobody said anything 'inherited' or 'genetic'

It is better to stop it once you know about problems but we didn't know about prenatal diagnosis before, never mind how to get it.

It is up to the doctors to refer us, we never heard of genetics or what it was but it has helped us so much. How can we ask for something we do not know exists?

ANY QUESTIONS?

Break and networking

Reconvene in King’s Hall in 20 mins