

Wednesday 8th November | 15Hatfields, London







### Welcome to the Genomics Conference!



8th November 2023 8am – 4pm 15Hatfields, London



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## **Chairs Opening Address**



### **Chris Sleight**

Chief Officer - Greater Manchester Imaging & Pathology Networks - Greater Manchester Provider Federation Board



### Speaking Now...



**Prof. Matt Brown** Chief Scientific Officer Genomics England



### **Panel Discussion...**

This panel debate will explore the potential benefits and risks of using genomic data in clinical decision making within the NHS. On the one hand, genomic data can provide doctors with important information about a patient's genetic makeup, which can help to tailor treatment plans and improve patient outcomes. On the other hand, there are concerns about the privacy and security of genomic data, as well as the potential for discrimination based on genetic information. The panel will discuss these issues and consider the best ways to balance the benefits and risks of using genomics in clinical care.



## Up Next...

## HURDLE



### Speaking Now...



**Toby Call, PhD** Co-Founder, Product Strategy and Operations - Hurdle



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## **Q&A Panel**



## **Morning Break**



## **Morning Break**



## **Chairs Morning Reflection**



### **Chris Sleight**

Chief Officer - Greater Manchester Imaging & Pathology Networks - Greater Manchester Provider Federation Board



### Speaking Now...



### Videha Sharma

NHS Clinician and Lecturer in Health Informatics - University of Manchester



### Speaking Now...



### **Chris Sleight**

Chief Officer - Greater Manchester Imaging & Pathology Networks - Greater Manchester Provider Federation Board



**Greater Manchester** 



**Diagnostics Network** 

The Sustainable Workforce of the Future – Do Generations Z and Alpha have the solution?

Mr Chris Sleight Chief Officer Greater Manchester Diagnostics Network Email: Chris.Sleight@nca.nhs.uk

**NVENZIS** 

Understanding Genomics in the NHS

8<sup>th</sup> November 2023





## Who am I am what is my role?

- I started my career as a Junior B MLSO (with degree in Physics & Mathematics !?!)
- Divisional Director for Diagnostics at Pennine Acute Hospitals in 2008
- Various Operation and Strategic Senior Roles in Greater Manchester member of GM PACS Collaborative Board and became SRO for the Board in 2018
- Chief Officer for the Greater Manchester Diagnostics Network
- SRO for GM Community Diagnostic Centre Programme
- Chair of GM Diagnostics Digital Board
- I have Programme Director responsibilities for GM Pharmacy programmes.....and I am a father of 4 boys



## GREATER MANCHESTER

# The Sustainable Workforce of the Future Do Generations Z and Alpha have the solution?

- Priorities for GM Imaging Network; with a focus on
  - Reducing Health Inequalities
  - Digital Enablers
  - Workforce
- Why a short-, medium-, and LONG-TERM Workforce Focus is critical now to sustain future services
  - An ageing Population
  - New Generations with different stereotypes



















Measures of deprivation and inequality in Manchester based on Indices of Deprivation (IoD) 2019



Analysis by Elvis Nyanzu and Alasdair Rae, University of Sheffield. This work was funded by the Nuffield Foundation - www.nuffieldfoundation.org Gini coefficient 0.35 This is the Gini coefficient for Manche

This is the Gin come inclusion with the area. The Gini coefficient ranges from 0 (perfect equality) to 1 (perfect inequality) so that a higher figure indicates a higher level of inequality.

### Economic imbalance

This is the 20:20 Index. It is the ratio of small areas (LSOAs) within the Local Authority that are among the 20% least (blue) or 20% most (red) deprived nationally, based on the Income Domain of the 2019 English Indices of Deprivation. It is used here as an indicator of local economic imbalance.

#### Spatial concentration



nearby areas are. Values closer to 1 indicate similar areas are clustered together. In general, values over 0.4 generally indicate that similar areas are significantly clustered.



Life expectancy at birth for Manchester residents fell by an estimated 3.1 years for men and 1.9 years for women in 2020.

42% of children under-16 in Manchester are living in poverty. Approximately two thirds of those children are in a family where at least one parent is working.

1 in 4 of Manchester's 16-19 years old are unemployed

1 in 3 Manchester children are not school-ready when they start reception

1 in 5 of all unemployed residents aren't in work due to longterm sickness

The ethnic diversity of Manchester's population is increasing. We are the only city outside London to have residents in each of the 90 listed ethnic groups in the census. Over 200 languages are spoken here.

Source: Manchester City Council – Building Back Fairer - Tackling Health Inequalities in Manchester 2022–2027

## Life on the line? Differences in life expectancy across Greater Manchester

#### Female life expectancy at birth (years) OMale life expectancy at birth (years) OIMD Decile (1 most deprived; 10 least deprived)



**Tram Network:** The Metrolink tram network across Greater Manchester includes nearly 100 kilometres of track and 93 stops. In 2015 there were around 33.4 million journeys (Metrolink 2015). The average journey time between tram stops is 2 minutes, but some stops are further apart.

**Data Sources:** Office for National Statistics experimental ward level life expectancy and health living life expectancy estimates (ONS 2006) linked to selected Greater Manchester Metrolink tram stops. The selection highlights some of the biggest differences between tram stops. We also include information on socio-economic deprivation at ward level from the Index of Multiple Deprivation.

The life expectancy data is based on mortality among those living in each particular ward in 1999-2003. The estimates are not the exact number of years a baby born in the ward could actually expect to live, both because the death rates of the area are likely to change in the future, as is health care provision and because many of those people born in the ward will live elsewhere for at least some part of their lives.



## **Priority Themes for GM Diagnostics**

- Workforce,
- Workforce,
- Workforce!
- Increasing Capacity
- Improving Efficiency and Productivity
- Pathway Improvement
- Ensuring Demand is Appropriate
- Levelling Up (working as a GM system by sharing and implementing best practice & Reducing Health Inequalities)
- Communication







NHS

## WORKFORCE WORKFORCE WORKFORCE

#### Genomics Workforce Current Challenges??

The workforce in genetics spans the clinical facing service - clinical geneticists and genetic counsellors - vacancies across virtually every centre in the country for both.

- Exacerbated by retirement.
- Not enough trainee posts.
- Both professional bodies CGS and AGNC have been considering this and flagging to NHSE.

In the laboratories similar issues for both technical and clinical scientist staff.

- Increased sample throughput.
- Not enough trainees.
- Staff offered better pay and conditions by Industry and other career opportunities.

#### Overview of IMAGING Workforce and challenges in Greater Manchester



Historic Turnover and Joiner rates for diagnostic radiographers



Turnover rate Joiner rate





- High vacancy rates across all staff groups in Radiology, difficult to recruit radiologists and sonographers, national shortages.
- Total WTE diagnostic radiographers workforce has increased year on year, majority of joiners are newly qualified. International recruitment has been widely used to bring new radiographer workforce into system. Lots of initial training and lots of newly qualified/new staff in service.
- Majority of leavers are <55 years old and leaving NHS, large attrition to independent sector, especially at band 6 and 7 grade. Loss of skills and experience.
- Total WTE radiologist increased year on year, numbers coming through speciality training have increase slightly across entire NW region, however numbers of completing CCT fairly consistent year on year (approx. per year)
- Due to high vacancy rates, high use of agency/locum staff
- Limited capacity to expand training for apprenticeships and placement students
- Shortage of radiologists resulting in limited capacity to expand reporting radiographer training.
- Significant challenges in sonographer workforce, large attrition to independent sector or to trusts offering better rates of pay.



#### GM Imaging workforce strategy

in Greater Manchester

Greater Manchester NHS Provider Federation Board Part of Greater Manchester Health and Social Care Partnership

GM Pathology Network Workforce Strategy

Report to:	GM Pathology Board / GM Pathology Network Operational Managers group				
Report of:	Gareth Richardson, GM Pathology Network Workforce Development Lead				
Paper prepared by:	Gareth Richardson, GM Pathology Network Workforce Development Lead				
Date of paper:	01/03/22				
Subject:	GM Pathology Network Workforce Strategy				
	Information to note	1			
	Support				
Purpose of Report:	Accept				
Please tick 🗸	Resolution				
	Approval				
	Ratify				

Purpose:

The purpose of this paper is to provide overview of the strategic achievements and aims of the Greater Manchester Pathology workforce in 2021/22 and going forward into 2022/23.

#### GM Pathology Workforce Achievements 2021/22

#### Pathology workforce group

Pathology workforce sub group has been created and now well established to tackle to ongoing workforce issues experienced in the network. Key deliverables have been identified by the group by completing a minit gap analysis to find the areas of focus. Group has started to work collaboratively together, and become platform for sharing of best practice and ideas. Group has also created a network for distribution of information from NHSEI, HEE, IBMS and other professional bodies so pathology workforce is getting equal opportunities across the network.

#### NHSEI & HEE engagement

Good working relationships established with NHSEI and HEE colleagues, workforce lead and group now single point of contact for engagement around workforce. This has allowed for quicker decision making and rapid deployment of information and funding opportunities. Also created better equality across the network, all trusts are now being given the same opportunities. NW Pathology workforce task and finish group now established to drive forward workforce agenda across the region.

Funding

Successful in receiving funding to support upskilling of support staff to create future Biomedical scientist, total funding received for network was £68k from NHSE&I and £80k Objective 1 – to attract and retain talent in the network, to decrease vacancy and turnover rates.

Objective 2 – to create clear development opportunities for all Imaging staff to maximize staff potential and create equality in training across the network

Objective 3 – to better understand the workforce needs in Imaging and create a workforce sustainable for the future.



## World > Probabilistic Projections > Life Expectancy > Both Sexes

World



United Nations, DESA, Population Division. World Population Prospects 2022. http://population.un.org/wpp/

## UK > Probabilistic Projections > Life Expectancy > Both Sexes

100 95 median – 80% prediction interval 95% prediction interva 90 observed 60 sample trajectories 85 Years 80 75 70 1950 1960 1970 1980 1990 2000 2010 2020 2030 2040 2050 2060 2070 2080 2090 2100

United Kingdom



## So is it all great news?



## Population by age group, including UN projections, United Kingdom



Historic estimates from 1950 to 2021, and projected to 2100 based on the UN medium-fertility scenario. This is shown for various age brackets and the total population.



	<b>Generation Alpha</b>	Generation Z	Millennials	Generation X	Baby Boomers	Silent Generation
Born	2012 - 2024	1997-2012	1981-1996	1965-1980	1946-1964	1926-1945
Age	Up to 13	14-26	27-42	43-58	59-77	78+
Stereotype	Very short attention span. All information needed instantly available. Allergies, obesity and health problems related to screen time. Family Oriented. 80% dictate family activities such as holidays! Exceptional learning abilities and opportunities.	More racially and ethnically diverse than any previous generation. No memory of life before the internet. Give more voice to social causes than previous generations. Ambitious. Confident. Higher Diagnosis of mental health. Prone to anxiety. Puberty onset earlier.	Most educated generation of humans to ever exist, with around 40 percent having a university degree or higher. Ambitious, Confident, Curious, but often labelled as "Spoilt and Lazy" the "Me, Me, Me" generation.	"Latch Key" Generation - left at home alone whilst parents worked. Resourceful. Logical. Problem-Solvers.	So called because of huge increase in birth rates following end of the second World War. Committed. Self sufficient. Competitive.	Grew up during and after World War II; taught to be "seen and not heard". Disciplined. Loyal.
Communication	Social networks, and streaming services; low interest in TV. Create on line communities.	Hand held or integrated in clothing comms device / Facetime	Text / social media / on line real time text messaging /face to face	e-mail / text	Face to Face / Telephone Landlines	Speaking Face to Face / Formal letters
Major events	Covid 19	Global financial crisis 2008	Nine Eleven (2001)	Fall of Berlin wall (Nov 89)	Moon landing	World War Two
I conic Toys	Fidget Spinners Playstation 4 X Box 360	Nintendo DS Scooters Fashion Dolls (BRATZ)	Cabbage Patch Kids BMX Bike Little Tykes (Log Cabin/Cozy Coupe)	Lego Rubix Cube Chopper Bikes	Etch A Sketch Spacehopper Frisbee	Bubble Solution Roller Skates Toy Soldiers
Music	Smart Speakers	Spotify	iPod	Walkman /CDs	Audio Cassette	Record Player
Major Influences on	Internet. Tik Tok. Pandemic.	Youtubers. Internet. Parents.	Peers. Television. Internet. Parents.	Parents. Television. Books.	Parents. Newspapers. Music (e.g. Beatles). World events. Books.	World War Two. Parents /Grandparents/
## Unsure Which Generation You Are?

#### **Generation Alpha**

Samsung Galaxy Z Flip 5G

(other suppliers are available!)

**Generation Z** 

Smartphone

#### Millennials

Phone

#### **Generation X**

**Mobile Phone** 

Baby Boomers .....









	Generation Alpha	Generation Z	Millennials	Generation X	Baby Boomers	Silent Generation
Attitude to Γechnology	They don't just use technology; they intuitively understand it. Navigating digital spaces, for them, is as natural as breathing. "Technoholics". Totally dependent on IT - have no grasp of alternatives. More digitally savvy than any previous generation. Will not understand and will become quickly irritated by previous generations "lack of understanding" of modern technology.	Totally dependent on IT - (born with a smartphone and a tablet) - very limited grasp of alternatives.	Digital natives - technology is part of their everyday lives. Activities mediated by a screen. Don't need to be problem solvers as internet does it for them.	Digital immigrants. Technology was growing fast but in its infancy. Understand the importance of digital and non-digital.	Early adopters. Extremely cautious and sceptical. Seen as a luxury.	Largely disengaged. Lack of understanding or interest.
Attitude to Work	No constraints on geography; massively influenced on climate change and saving the planet. Like Generation Z, but moreso, they will have jobs that do not exist in today's world. Extremely curious – will want to learn new things. As yet unknown when they will want to retire – theories on this are diverse.	Career "multitaskers" - will move between employers and job roles. Very low limitation on geography. Want to retire early.	Digitally driven. Work "with" an employer rather than "for". Diminished geography constraint. Want to retire early.	Professionally loyal (not necessarily to employer). Geography constrained. Expect to retire at 65 or earlier. "Workaholics"	Organisational loyalty. High dependence on geography. Expect to retire at 65 or return to work.	Jobs are for Life. Totally dependant on geography.
Aspiration	Predicted to be the wealthiest generation ever, financial savvy and will demand financial stability.	Security and Stability (due to global economic turbulence in formative years)	Freedom and Flexibility	Work Life Balance	Job Security	Home Ownership





#### So are Generation Alpha the answer?

Permanently connected – such is their attention to technology.

Video doorbells, facial recognition, streaming services, and 3D printing aren't novelties to them; they're the norm. They are the most tech-savvy generation. They don't just use technology; they intuitively understand it. Navigating digital spaces, for them, is as natural as breathing.

They have a very heightened self-awareness, coupled with a strong social and environmental consciousness. They will "save the planet" because they understand they need to.

Realistic and practical – shaped by the pandemic and global upheaval financial stability is a genuine aspiration. They understand savings, investments and financial planning.

They're not just looking for success; they seek fulfilment.

Extremely curious – wanting to learn and do new things. This may mean they actually want to have longer careers than previous generations....

#### Exploring Generation Alpha A Look into the Future







- To build a sustainable health services to meet the needs of our growing population we need a workforce that meets not only the needs of our patients, but the needs of our future workforce... "Generation Z" have very different career aspirations to previous generations. And there are less of them to look after a growing and aging population.
- By 2030 Generation Alpha predicted to be 13% of the workforce; by 2040 could be 50%.
- We have to adapt now!!



This means asking ourselves some very difficult questions; for example -

- Do we need develop new roles perhaps even working across "traditional professional boundaries?"
- Are we as "attractive" as we can be to meet the needs and aspirations of our future workforce? (Opportunities for Career Change, Cutting Edge Technology, Financial Reward?)
- Do we need to take more control of ensuring demand on services is appropriate and making a difference to patient care?
- Is "Generation X" able to design a strategy to meet the aspirations of "Generations Z and Alpha"?





IN SUMMARY - We need to do things differently, and we need to act now to tackle the long-term workforce challenges.

We can't focus all our energy on the short term workforce issues – as crucial as it is we address these.

"State of the Art" digital systems and AI in healthcare have never been so important, not just for our patients, managing increasing demand and improving productivity and quality, but because our future workforce will expect it – they will only be attracted to careers using high performance technology.

We must create new roles that are attractive to new generations, well remunerated, and which allow for their curiosity and need to learn.

Genomics will remain increasingly critical to the health of our population, and we all have a responsibility to ensure we provide an inspirational and rewarding career for our current and future workforce.



![](_page_44_Picture_1.jpeg)

![](_page_44_Picture_2.jpeg)

# Thank you for listening, any questions?

Diagnostics Network Twitter: @GM Imaging

Diagnostics Network LinkedIn: @GMImagingandPathologyNetworks

Visit our Website https://greatermanchesterdiagnostics.nhs.uk/

# Or you can even send me a written letter <sup>©</sup>

![](_page_45_Picture_0.jpeg)

### Speaking Now...

![](_page_45_Picture_2.jpeg)

#### **Dr Tootie Bueser**

Director of Nursing & Midwifery/Chief Nurse - South East Genomic Medicine Service Alliance/North Thames Genomic Medicine Service Alliance

# The Transformation of Nursing & Midwifery Practice through Genomics

Tootie (Teofila) Bueser, RN F

@2tbueser

Director for Nursing & Midwifery, SEGMSA, Guy's & St Thomas' Hospital

Chief Nurse, NTGMSA, hosted by GOSH

tootie.bueser@nhs.net

# Why do nurses & midwives need to know about genomics?

- It's in our NMC proficiency standards
- We are the largest section of the NHS workforce and are best placed to optimise the contribution of genomics to improving health
- Many are already involved in genomics in specialised roles but general awareness/genomics mindset needed for all
- We need more nurses & midwives to lead in this field and ensure equity of care

![](_page_47_Picture_5.jpeg)

Future midwife: Standards of proficiency for midwives

DRAFT-January 2019

![](_page_47_Picture_8.jpeg)

www.nmc.org.uk

![](_page_47_Picture_10.jpeg)

# **Accelerating Genomic Medicine**

Our vision is that the power of genomics in **predicting**, **preventing and diagnosing disease**, **and targeting treatment** is accessible to all as part of **routine care in the NHS** 

![](_page_48_Figure_2.jpeg)

![](_page_48_Picture_3.jpeg)

Slide from NHSE

![](_page_48_Picture_5.jpeg)

# The benefits of embedding genomics

![](_page_49_Figure_1.jpeg)

**NHS** South East Genomic Medicine Service Alliance

![](_page_49_Picture_3.jpeg)

# The National Genomic Test Directory

The test directory contains:

- Tests available in the NHS in England
- Rare and inherited disorders
- Cancer
- Technology platform by which each test is delivered
- Clinical eligibility
- Funding

**Genomic Medicine Service Alliance** 

NHS

#### https://www.england.nhs.uk/publication/national-genomic-test-directories

![](_page_50_Picture_9.jpeg)

![](_page_50_Picture_10.jpeg)

![](_page_51_Figure_0.jpeg)

#### The Genomic Medicine Service Alliances (GMSAs)

- Support the systematic • embedding of genomics into routine clinical care
- Facilitate rapid adoption of • scientific advances
- Collaborative partnership ٠ working across disciplines and geographies

South East Genomic Medicine Service Alliance

# Genomics is for all but is it accessible to all?

- Cardiomyopathies (1:200-1:500)
- Polycystic kidney disease (1:400-1000)

![](_page_52_Picture_3.jpeg)

- Lynch syndrome: ~40% eligible relatives not tested (Seppala et al EJHG 2017)
- Familial hypercholesterolaemia: 1:250 less than 8% are currently identified (NHSE 2020)
- A proportion of African American breast cancer patients who meet criteria for genetic testing do not receive it as part of routine care. In women who do not meet testing guidelines, nearly 5% have a known deleterious mutation associated with breast cancer Ademuwiya et al (2019)

In a sample of unexplained stillbirths, 8.5% could be attributed to genetic disease variants (Stanley et al 2020)
North Thames Genomic Medicine Service Alliance
NHS Genomic Medicine Service Alliance

# Supporting equitable access to genomic services & care excellence

![](_page_53_Figure_1.jpeg)

NHS South East Genomic Medicine Service Alliance North Thames NHS Genomic Medicine Service Alliance

#### Nursing & Midwifery-National Transformation Project 2022-2023

![](_page_54_Figure_1.jpeg)

# Initial outputs

![](_page_55_Figure_1.jpeg)

#### COULD YOUR PATIENT HAVE GENETIC EPILEPSY?

Does your patient have epileptic seizures PLUS ANY of the following

![](_page_55_Figure_4.jpeg)

# **Nurse-led Genomic Innovations**

![](_page_56_Picture_1.jpeg)

![](_page_56_Picture_2.jpeg)

### Lynch Syndrome Project: Infrastructure Development

**Building Capacity** 

**Upskilling the Workforce** 

**Expert Networks** 

2 7 National Clinical Leads Regional Clinical Leads

2 10 National Lynch Nurses Regional Lynch Nurses

236/248 (95%)

MDT Lynch Champions appointed Across all CRC and Gynae MDTs

#### Genomic Practitioners, Lynch CNS roles, Expert Network Coordinators

Cancer Alliances supporting additional expertise & pathway resource

1400+ participants

**425** Completed **standardised online training** packages for cancer teams, pathology & primary care

300 Attended MDT team national workshops

350 Attended Pathology national workshops

**250** Attended **Nursing** national workshops supported by industry partnerships

**10 Regional Lynch Nurses** participating in comprehensive Lynch education, mainstreaming skills, and peer support programme. 'Train the Trainer' model to achieve onward dissemination to MDT CNS roles.

Clinical Pathway Initiative completed for Lynch pathway

Supporting all regions to develop expert networks, supported by regional expert centres and the national Lvnch forum Local specialist clinics **GENERALLY ORDER** SIMPLER TESTS, WITH SUPPORT AROUND **RESULTS GIVEIN** Specialist subregional clinics DEVELOP EXPERTISE OVER TIME TERTIARY SPECIALIST GENETIC CLINIC (May be aligned to GLH/GMC) MANY TESTS ORDERED / COMPLEX TESTS FUNDED TO PROVIDE SUPPORT ROLE LEAD MDTS

![](_page_57_Picture_19.jpeg)

### Regional Lynch Syndrome Nurses

![](_page_58_Picture_1.jpeg)

**NHS** South East Genomic Medicine Service Alliance North West

![](_page_58_Picture_4.jpeg)

Mandy Darbyshire Miranda.Darbyshire@mft.nhs.uk

#### North East and Yorkshire

![](_page_58_Picture_7.jpeg)

**North Thames** 

![](_page_58_Picture_8.jpeg)

Amy SandersonKaren Westwayamy.sanderson5@nhs.netk.westaway@nhs.net

Rebecca Foster

Rebecca Foster rebecca.foster26@nhs.net

East

Central

![](_page_58_Picture_13.jpeg)

Felicity Blair Felicity.Blair@uhb.nhs.uk

#### South West

![](_page_58_Picture_16.jpeg)

Tracie Miles Associate Director of Nursing & Midwifery SWGMSA tracie.miles@nhs.net

![](_page_58_Picture_18.jpeg)

Laura Monje-Garcia

National Lead Nurse

Laura.Monje-Garcia@nhs.net

Sarah John Sarah.John@nbt.nhs.uk

![](_page_58_Picture_20.jpeg)

Anna Koziel

Anna.Koziel@nhs.net

Siobhan John siobhan.john@nhs.net

![](_page_58_Picture_22.jpeg)

Melissa Cambell-kelly melissa.cambellkelly@nnuh.nhs.uk

#### South East

![](_page_58_Picture_25.jpeg)

Aela Limbu Aela.Limbu@gstt.nhs.uk North Thames NHS Genomic Medicine Service Alliance

# Lynch Syndrome Nurses

Å
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Improve access to the Lynch syndrome diagnosis

![](_page_59_Picture_3.jpeg)

Training and Support Lynch champions

Mainstream Gene testing for Lynch Syndrome

Improve access to personalised oncological & surgical care

Open access	Original research
BMJ Oncology	The English National Lynch Syndrome transformation project: an NHS Genomic Medicine Service Alliance (GMSA) programme

Fiona Lalloo, <sup>13,14</sup> Sally Lane, <sup>15</sup> Frank D McDermott, <sup>16</sup> Tracie Miles, <sup>17</sup> Steven A Hardy, <sup>18</sup> Adele Tyson, <sup>19,20</sup> Valerie Ya Wen Wang,<sup>21,22</sup> Anna Kim,<sup>21</sup> Simone Gelinas, 23,24 Francesca Faravelli, 25 Frances Elmslie, 24,26 Adam C Shaw 23,24

https://bmjoncology.bmj.com/content/bmjonc/2/1/e000 124.full.pdf

![](_page_59_Picture_11.jpeg)

# Sudden Cardiac Death Pilot Project

![](_page_60_Figure_1.jpeg)

NHS

South East

Genomic Medicine Service Alliance

Concerns with current pathway:

- Pathologist may not store fresh spleen sample
- If taken, spleen sample may not be stored correctly or may be destroyed prior to genetic testing
- Family may not be aware that sample is available for genetic testing
- Coroners Officer may not have the knowledge to discuss importance of spleen retention
- CO may not explain importance of genetic testing/screening
- GP may not refer to specialist centre/to genetic

![](_page_60_Picture_9.jpeg)

### The SCD Coordinator Role and Making Change

![](_page_61_Figure_1.jpeg)

North

NHS Genomic Medicine Service Alliance

South East Genomic Medicine Service Alliance

# Embedding genomic testing in memory clinics and intellectual disability services

![](_page_62_Picture_1.jpeg)

Jana Mikova Senior Nurse Practitioner, Tower Hamlets Diagnostic Memory Clinic

![](_page_62_Picture_3.jpeg)

R58 (Adult-onset neurodegenerative disorder) requests from mental health services: 2021-2022 660 tests done 0/10

- Mapping mental health and genomic medicine working in North Thames region.
- Consultation on improving access to and ensuring equity in genomic investigation
- Co-creation of model genomic testing pathways
- Trial of virtual MDT
- Creation of educational modules for genomic testing in intellectual disability and dementia

![](_page_62_Picture_10.jpeg)

# **Genomics in Community paediatric nursing**

![](_page_63_Picture_1.jpeg)

Jennie Sule-Ejeh Nurse Practitioner, Community Paeds, Newham

![](_page_63_Picture_3.jpeg)

**Objectives:** 

- Provide a standardized approach to genomic nursing care in the community setting.
- Support the Paediatrician in the clinic by providing support and education to the patients while obtaining consent and testing for Whole Genome Sequencing (WGS).
- Provide information to support patients and their families in making an informed decision.
- Ensure that patients receive evidence-based, patientcentred genomic nursing care.
- Promote the integration of genomic information into patient care plans.
- Improve patient outcomes using genomic information.

![](_page_63_Picture_11.jpeg)

![](_page_63_Picture_12.jpeg)

# **Neurogenetics Project**

![](_page_64_Picture_1.jpeg)

Mark Mencias Neurogenetics CNS

![](_page_64_Picture_3.jpeg)

**Dr. Emma Matthews** Consultant Neurologist

![](_page_64_Picture_5.jpeg)

Dr. Elizabeth Caruana-Galizia Consultant Neurologist

![](_page_64_Picture_7.jpeg)

Dr. Meriel McEntagart Consultant Clinical Geneticist

![](_page_64_Picture_9.jpeg)

Dr. Frances Elmslie Consultant Clinical Geneticist

![](_page_64_Picture_11.jpeg)

**Dr. Nayana Lahiri** Consultant Clinical Geneticist

![](_page_64_Picture_13.jpeg)

![](_page_64_Picture_14.jpeg)

![](_page_64_Picture_15.jpeg)

# **Milestones Achieved**

As of 17th March 2023

- 310 Referrals to the neurogenetics nurse
- 235 offered genomic/genetic testing.
- 76% participated in research through NGRL.
- Results from nurse clinic
  - 15 identified genetic cause (positive)
  - 5 no identified genetic cause (negative)
- Opened SGH as a site capable of offering Tofersen for SOD1 positive MND patients.
- More clinical research studies opened in SGH.

• Steering committee membership

![](_page_65_Picture_11.jpeg)

- Increased engagement across medical and nursing colleagues.
- Upskilling of nursing and midwifery workforce (e.g. Neuroscience CNS).
- Presentations/Participation in conferences and symposia

![](_page_65_Picture_15.jpeg)

![](_page_65_Picture_16.jpeg)

![](_page_65_Picture_17.jpeg)

# Darzi Fellowship-focus on non-small cell lung cancer (NSCLC)

![](_page_66_Figure_1.jpeg)

NHS South East

Genomic Medicine Service Alliance

## Why do our patients need to wait for so long for their pathology results?

Who consents our patients for their biomarker tests?

What is Genomics?

Why is this field of study relevant to lung cancer patients when you can't inherit it?

(or can you...?)

Tracey Cole Lung Cancer Lead Nurse University College London Hospital

![](_page_66_Picture_8.jpeg)

# 4. Promote equality & diversity, challenge discrimination ....

2022 survey of patients within EGFR +ve UK = 92% of patients are White British

![](_page_67_Figure_2.jpeg)

# Familial Hypercholesterolaemia Project

![](_page_68_Picture_1.jpeg)

Dominic Studart FH Project Nurse, NTGMSA Lead Nurse, SEGMSA & NTGMSA

South East

**Genomic Medicine Service Alliance** 

#### **Nurse Led Primary Care Screening – UCLP FH Screening Framework**

![](_page_68_Figure_4.jpeg)

![](_page_68_Picture_5.jpeg)

# Familial Hypercholesterolaemia Project

PCN	No. of <30 (TC>7.5mmol/L)	No. of >30 (TC>9mmol/L)	No. of Coded FH	PCN Total	No. Excluded	No. Coded FH Already Tested	No. Identified for Testing	No. Tested	No. Positive FH Test	No. Negative FH Test
PCN1	20	132	80	232	198	13	21	8	4	4
PCN2	23	176	68	267	222	6	39	17	12	5
Total	43	308	148	499	420	19	60	25	16	9

![](_page_69_Picture_2.jpeg)

![](_page_69_Picture_3.jpeg)

# **Renal Genomics Project**

![](_page_70_Picture_1.jpeg)

Eduardo Lee Renal Genomics CNS Guy's & St Thomas' Hospital

2023 British Journal of Nursing Renal Nurse of the Year

![](_page_70_Picture_4.jpeg)

![](_page_70_Picture_5.jpeg)

# South East GLH: Renal WGS Data

![](_page_71_Figure_1.jpeg)

![](_page_71_Figure_2.jpeg)

Genomic Medicine Service Alliance

![](_page_71_Figure_4.jpeg)

Overall increase in uptake of genetic testing in kidney disease across SE Thames (14.6 million people ~ 1 million with kidney disease) up by 101% as a result of implementing "think DNA think Genetics" renal initiative

**NHS Genomic Medicine Service Alliance**
## NHS Genomic Networks of Excellence

- A multidisciplinary group with a shared area of focus and subject matter expertise
- Brings together the NHS GMS, academia, third sector organisations, industry, and other partners
- These partners form networks aiming to develop models of adoption and the creation of evidence in support of the innovation pathways
- Aims to inform the future strategic direction and commissioning intentions of the NHS GMS.
- Will inform an NHS Industry partnership framework for rapid adoption of technologies and ongoing collaborative working





### **Research Opportunities**

- Education
- Research delivery
- Psychological impact and patient & family outcomes
- Clinical practice & communication
- Big data
- Equity of access to research



EDITORIAL ! Free Access

#### Genomic research: The landscape for nursing

Tootie Bueser ", Amanda Skinner, Layla Bolton Saghdaoui, Calvin Moorley

First published: 27 July 2022 | https://doi.org/10.1111/jan.15396

Editorial note: Editorials are opinion pieces. This piece has not been subject to peer review and the opinions expressed are those of the authors. None of the authors has relevant political or other a! liations to declare.



North Thames NHS Genomic Medicine Service Alliance

#### https://onlinelibrary.wiley.com/doi/full/1 0.1111/jan.15396

# Our Ask - Think about where genomics applies to your practice & research interest









#### Take part in genomics training & education National Genomics Education



#### **Education and training: supporting clinicians**

**—** 

**+** 

#### Pharmacy programme

Creating national networks and a systematic approach to workforce development of the role of pharmacists in genomics and driving personalised medicine.

Nurse & Midwifery led Genomics Collaborative

Working with Chief Nurses across England to systematically and sustainably embed genomics into nursing and midwifery roles and responsibilities



#### **Medical Programme**

J.

Working with the Academy of Medical Royal Colleges to support the systematic roll out of genomic medicine within clinical pathways and to ensure clinicians have access to the right education and information at the right point

## Resources for Genomics for Nurses and Midwives

#### **National Resources**

- Genomics in Midwifery Genomics Education Programme (hee.nhs.uk)
- <u>Genomics in Nursing Genomics Education Programme (hee.nhs.uk)</u>
- Genomics 101
- GeNotes (coming soon) <u>https://www.genomicseducation.hee.nhs.uk/abou</u> us/genotes-genomic-notes-for-clinicians/

#### Post graduate courses

- Master's in Genomic Medicine Genomics Education Programme (hee.nhs.uk)
- <u>Genomics course for nurses and midwives: funded places now available-</u> <u>Conomics Education Programme (hee.nhs.uk)</u>





## **Genomic Lunch and Learns**

Virtual event every 4<sup>th</sup> Friday of the month at 13:00-14:00

Bringing awareness of genomics to nurses and midwives. <u>www.genomicseducation.hee.nhs.uk</u>

To inform on current patient eligibility to genomic testing <u>NHS</u> <u>England » National Genomic Test Directory</u>

To learn about the genomics behind specific conditions

To ask yourself where does genomics fit into practice for my patients



Lunch and Learn Library



## Be or Nominate a Genomic Ambassador

- At least 1 nurse and 1 midwife from each trust/site
- Supported by the Chief Nurse and Director of Midwifery
- Ambassador masterclass and/or additional training provided
- Regular network meetings
- Professional development opportunities
- Publication and research opportunities



NHS Genomic Medicine Service Alliance

**NHS** South East Genomic Medicine Service Alliance

## Find more resources and get in touch!

#### https://southeastgenomics.nhs.uk/





#### https://www.norththamesglh.nhs.uk/ NHS North Thames Genomic Laboratory Hub Bringing genomic research and testing together 100,000 Genomes About Healthcare Patients and Education & News and Research Contact Professiona Resources Project Events We are the North Thames **Genomic Laboratory Hub** One of seven genomic laboratory hubs in England responsible for providing genomic and genetic testing, including the start of whole genome sequencing as part of the new genomic medicine service in the NHS. Find out more



@NorthThamesGLH





### Talk to our teams

If you;

- Want to share your good practice & get involved in our projects
- Have any questions
- Would like to be involved in bringing genomics into your hospital and specialties
- Would like to request tailored local training for your region

North Thames norththamesglh@nhs.net

South East gst-tr.southeastglh@nhs.net







South East Genomic Medicine Service Alliance NFS North Thames NHS Genomic Medicine Service Alliance

## Thank you!

For more information please contact:

North Thames: norththamesglh@nhs.net

South East: gst-tr.southeastglh@nhs.net



## **Q&A Panel**



#### Slido

Please scan the QR Code on the screen. This will take you through to Slido, where you can interact with us.





## Lunch & Networking



#### Thank you for attending the Genomics Conference!

