

# HEE Genomics Education Programme Nursing and Midwifery Round Table

**Wednesday 01st May 2019 - Radisson Blu Edwardian,  
Kenilworth, London.**

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## Introduction

Lord Willis of Knaresborough welcomed everyone to the meeting. He spoke about his ongoing involvement in this area of work and the vital role nurses and midwives play in both supporting patients and embedding genomics into healthcare practice.

He also highlighted his involvement in the new NMC Standards of Proficiency. The inclusion of genomics in the standards will influence the development of curricula and education and training for pre and post-registration nurses moving forward.

Lord Willis complimented the Genomics Education Programme on the amount of work that had been taken forward since the last meeting.



# Professor Lisa Bayliss-Pratt (HEE)

## National update

Professor Lisa Bayliss-Pratt (HEE) updated the group on the work that is currently being undertaken within HEE around nursing and midwifery.

The shortage of nurses globally and in the UK is a big consideration for HEE. A target has been set to increase nurse recruitment by 3% (6,000 individuals) each year to ensure the NHS gets the workforce required, based on the current model of care.

The new Trainee Nursing Associate (TNA) programme is proving to be a success with 7000 on programme. The students not only bridge the gap between support workers and registered nurses but are also changing the dynamics of the healthcare system.

There is a challenging aspiration to recruit a further 7500 by the end of 2019.

The interim People Plan, which was outlined in the NHS Long-Term Plan and led by Baroness Dido Harding is expected to be released in the next two weeks.



# Professor Lisa Bayliss-Pratt (HEE)

## National update

A RePAIR (**R**educing **P**re-registration **A**ttention and **I**mproving **R**etention) report has recently been published by HEE. The report includes resources aimed at supporting the NHS and higher education providers in reducing the level of student attrition and improving nurse retention.

The research has shown that the experience students' have on placement makes a significant difference to their early career choices and the report details how changes can be made. RePAIR also found that preceptorship programmes must be bespoke and offer a range of rotational experiences. Opportunities to be involved in genomics could be included during the preceptorship period to spark curiosity.

The development of the new NMC standards started in 2017, in January 2019 the standards went live and from September 2020 only programmes approved against the new standards will be able to accept students.

# Professor Lisa Bayliss-Pratt (HEE)

## Things to consider:

- Future nurses will be very different to today's and genomics should be an enabler to providing better person-centred care.
- Sparking interest and curiosity in genomics could support retention.
- The need for genomic champions within nursing and midwifery to drive forward change.



# Health Education England update

**Professor Lisa Bayliss-Pratt**  
**Chief Nurse, Health Education England**



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# The nursing workforce challenge



- Global significance
- Long term plan
- Interim People Plan



# Nursing associates



The nursing associate is not a stand-alone project – it forms a key part of the agenda focusing on developing the nursing workforce.

Shape of Caring review in 2015 highlighted the need for bridging role between support workers and registered nurses.

*“HEE should explore with others the need to develop a defined care role that would act as a bridge between the unregulated care assistant workforce and the registered nursing workforce”*



## Raising the Bar

Shape of Caring: A Review of the Future Education and Training of Registered Nurses and Care Assistants

Lord Willis, Independent Chair - Shape of Caring review  
Health Education England





Since then, the role has flourished at pace.

2000 trainee nursing associates (TNAs) began their programme in January 2017 and an additional 5000 were recruited in 2018.

By the end of 2019 we will have recruited an additional 7500 TNAs.

# Key findings from the evaluation: what's helped and hindered progress



## Academic

- ✓ Integrated learning
- ✓ Blended learning
- ✓ Lecturers and teachers who are close to practice
- ✓ Support from personal tutors



## Home

- ✓ Strong support networks
- ✓ Supported learning opportunities within the numbers
- ✓ Protected learning time



## Placement

- ✓ Optimising the sequence of placements
- ✓ Placement preparation and support
- ✓ Exposure to breadth of experiences

- 
- ✗ Heavy workload e.g. bottlenecks, duplication
  - ✗ Insufficient qualifications

- ✗ Lack of protected learning time
- ✗ Limited support due to workforce challenges
- ✗ Limited understanding of TNA role and remit

- ✗ Utilised as an HCA
- ✗ Lack of protected learning time
- ✗ Placement length too short
- ✗ Limited understanding of TNA role and remit

# Current topics of discussion

- Celebrating where we are and what we have achieved
- Transition into workforce and preceptorship
- Developing the nursing associate to registered nurse pathway

## Royal Star & Garter @Staran...

Earlier this month Surbiton Health Care Assistants Karen, Leena and Fiona started their two-year trainee #Nursing Associate course. They said: "We give so much of ourselves emotionally and physically, so it's nice when that hard work is recognised." [bit.ly/RSGH-NA](https://bit.ly/RSGH-NA)



## Gill East @YorkGillyGilly

Super proud of our very own Helen Snowden(W14) on her invite to The House of Commons! A celebratory event held by @LordWillisg in honour of the first Nursing Associates to join the NMC register. Lucky Helen #verywelldeserved #futureworkforce @wrightgNHS @hey\_helhey71 @Bgearyyork



suewaddecar @s... · 15/01/2019 ✓

University of Bolton Trainee  
Nursing Associate Celebration



University of Bolton Trainee  
Nursing Associate Celebration...  
[alliance-scotland.org.uk](https://alliance-scotland.org.uk)



Nicky Burns-Muir @nicolaburnsmuir · 3h

So proud of our Lee Pockett off to **Nursing Times Awards** nominated for **Nursing Associate** Trainee of Year @MKHospital @JoeHMK @KateBurkeNHS @MichaelaTait8 @SandhamMatt @MarshNadean @ClaireJelly Go get the award #soproudalreadyawinnerdorus 🎉



# RePAIR (reducing pre-registration attrition and improving retention)



**RePAIR**



# Purpose of the RePAIR study

HEE has recently published the **RePAIR** report and set of resources aimed at supporting the NHS and higher education providers in reducing the level of student attrition and improving nurse retention.

**Scope:**

- Nursing
- Midwifery
- Therapeutic Radiography

The **RePAIR** project was established to deliver an aspect of the Department of Health's HEE 2015 refreshed Mandate.



**“ RePAIR has enabled  
us to rekindle the  
discussion.”**

### **Understanding indicators of attrition**

- ♦ Definitions
- ♦ National baseline attrition data
- ♦ Completion trends

### **Insight into the stakeholders' experience**

- ♦ National student survey (3447)
- ♦ Focus groups with students (155) and newly qualified practitioners (25)
- ♦ Discussions with academics (67) and clinical educators (63)

### **In-depth enquiry into improving retention**

- ♦ Case study sites

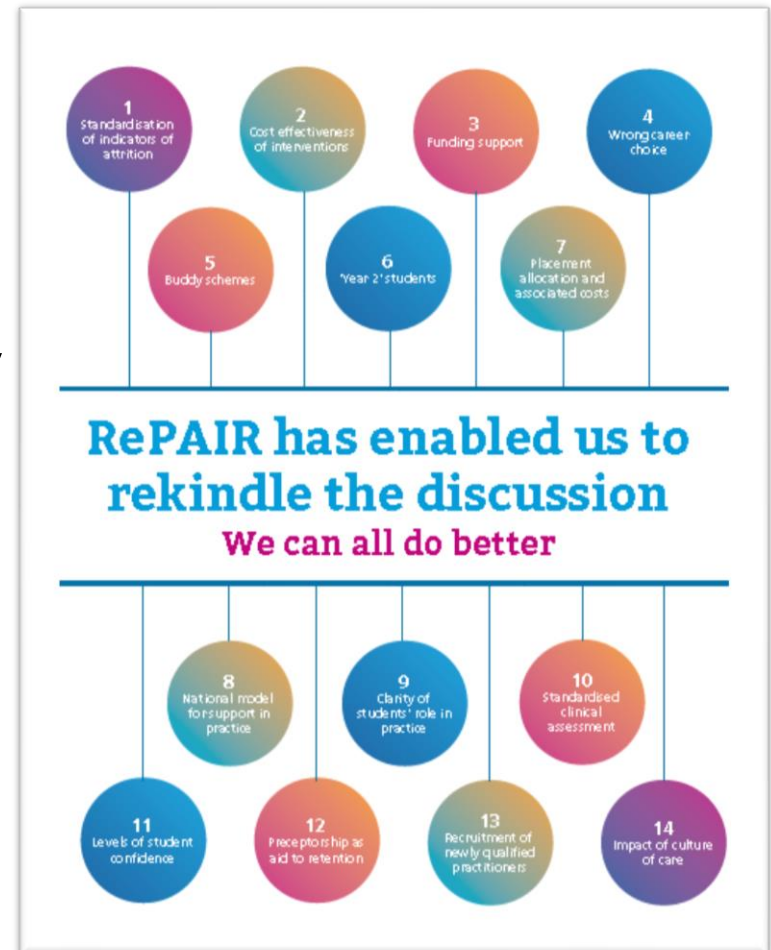
**RePAIR** research has shown that the experience students have on placement makes a significant difference as to students' early career choices. Improving the practice learning experience has two effects:

- it reduces attrition from pre-registration programmes
- it influences early career choices and is most likely to ensure they stay in the profession and within the NHS.

We have seen that second year students use the combination of good placement experience alongside the perceived preceptorship offer in deciding where their first post will be.

**RePAIR** also found that preceptorship programmes must be bespoke to the individual and ideally offer a range of rotational experiences, perhaps taking newly qualified nurses (NQNs) across employers within an integrated care system.

The duration of the preceptorship period should be flexible and meet need of the NQN.



The next phase of **RePAIR** Implementation focuses on 4 core elements:

- Improve the practice learning experience for students
- Support the system to provide the highest quality supervision in clinical practice
- Develop a Preceptorship toolkit that employers and NQNs can dip in and out of to draw down the component parts that they need
- Build on the proof of concept developed by UWL to provide an online platform that supports both students and clinical supervisors in the practice learning setting.

Six legacy projects are looking at insights from **RePAIR** findings in greater depth:

- Valuing Year 2 students (recommendation 6)
- The Impact of the Culture of Care on the learning environment (recommendation 14)
- Transition shock and levels of self-doubt (recommendation 11)
- Early career choices
- Late and end of career choices
- Clinical training capacity (qualitative only).



# New standards for education



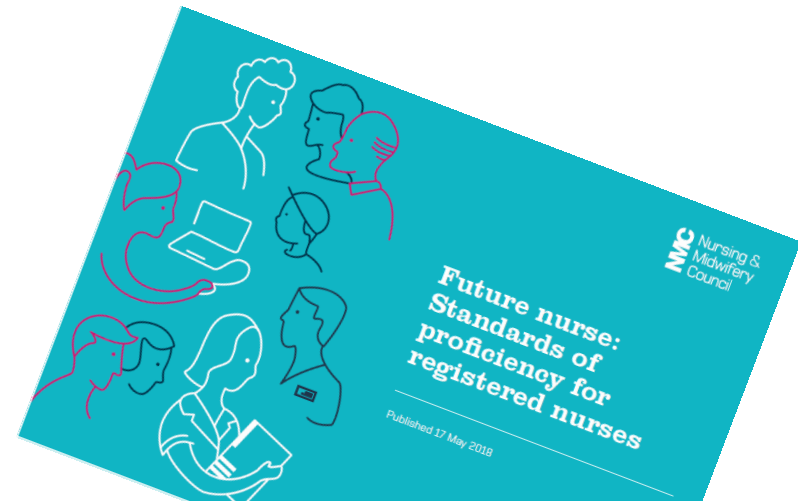
# NMC: timeline for the new standards

- **2017** - Developed with input from stakeholders and feedback from the consultation held.
- **17<sup>th</sup> May 2018** - New standards published
- **28<sup>th</sup> January 2019** - Standards went live. All NMC programme approvals will now be against the new standards
- **After 1<sup>st</sup> September 2020** - only programmes approved against the new standards will be able to accept new students.

# Future nurse: standards of proficiency for registered nurses

The proficiencies are grouped under seven platforms:

- representing the **knowledge, skills and attributes** that all registered nurses must demonstrate when caring for people of all ages and across all care settings.
- reflecting what the public can expect nurses to know and be able to do in order to deliver **safe, compassionate and effective** nursing care.
- providing a **benchmark** for nurses from the EEA, EU and **overseas** wishing to join the register.
- providing a benchmark for those who plan to **return to practice** after a period of absence.



1. [Being an accountable professional](#)
2. [Promoting health and preventing ill health](#)
3. [Assessing needs and planning care](#)
4. [Providing and evaluating care](#)
5. [Leading and managing nursing care and working in teams](#)
6. [Improving safety and quality of care](#)
7. [Coordinating care](#)

# Future Nurse Oversight Board

*‘To provide strategic leadership and direction across the health and care system in order to assure system preparedness and responsiveness to the implementation and implications of the Future Nurse standards across England’.*

- Established in October 2018 by HEE with system-wide representation.
- HEE invited Professor Dame Jill Macleod Clark to be independent chair.
- Role is to influence key decisions, strategy and policy and to support future changes to the profession.
- Identification of objectives, work plans and interdependencies is underway.
- Four expert sub-groups are being established to cover specific areas of challenge around system readiness and preparedness.



# Genomics Education Programme



[linkedin.com/in/lisa-bayliss-pratt](https://www.linkedin.com/in/lisa-bayliss-pratt)



@hee\_lisaBP

# Dr Anneke Seller - update on the Genomics Education Programme

Dr Anneke Seller (HEE GEP) presented the work being undertaken by the Genomics Education Programme.

The aim of the programme is to provide coordinated national direction and oversight for education and training in genomics and is currently funded to 31st March 2020.



## **Key areas of focus are:**

- Ensuring the NHS workforce is able to deliver the new GMS
- Supporting the completion of the 100,000 Genomes Project
- Developing innovative approaches to delivery of genomic education
- Establishing international collaborations

# Dr Anneke Seller - update on the HEE Genomics Education Programme

Anneke highlighted the importance of collaboration and working with key partners.

A competency framework to support clinicians consenting patients for any type of genomic testing is being developed. The framework is evidence based and has been developed using a consensus approach involving feedback from experts in the field. It is also cross-professional, which aims to encourage multi-disciplinary engagement within and between clinical teams to enhance delivery of genomic medicine.

A nurse educators toolkit to support the delivery of genomics education based on the current NMC Standards of Proficiency is planned to be released in September 2019. Anyone wishing to contribute to shaping the learning outcomes and the content of the toolkit should contact Ed Miller in the GEP.



# Anneke Seller - update on the Genomics Education Programme

A Genomics 101 series is being launched. Four short e-learning modules are live on the e-Learning for Healthcare platform and a further four will be released by the end of 2019. (<https://www.e-lfh.org.uk/programmes/genomics-education-programme/>)

Other resources available via the GEP website include a film, Nursing in the Genomics Era. A midwifery film will follow. The Genomics Game has been distributed and feedback has been positive. A midwifery version is also coming soon.

The second GEP Genomics Conversation Week of Action ran in March 2019, the aim being to spark conversations among health professionals on social media. Statistics demonstrate a marked increase in numbers involved from the WoA in 2018. A successful patient panel event was held, podcasts were published and GEP resources and tools promoted. Another week is being planned for 2020.

# Anneke Seller - update on the Genomics Education Programme

Challenges for the programme include securing GEP funding beyond March 2020, understanding the impact of the Genomic Medicine Service on the health service and the workforce, undertaking accurate workforce planning and ensuring effective workforce transformation.

Lord Willis acknowledged the achievements of the programme and significant progress since the last meeting. He highlighted the need to educate the existing workforce as well as the new trainees coming through the system. This is a concern particularly as the NHS is already stretched and achieving the required change will be difficult.

Consistency across the system is important particularly within the Genomic Laboratory Hubs (GLHs) and Genomic Medicine Centres (GMCs) who will be facilitating the mainstreaming of genomic care.

# Anneke Seller - update on the Genomics Education Programme

Professional bodies and Royal Colleges need to endorse the importance of genomics and influence developments in curricula and workforce development. There needs to be wider engagement with Integrated Care Systems (ICSs), Sustainability and Transformation Partnerships (STPs) and Local Workforce Action Boards (LWABs) to raise awareness of genomics and ensure it is highlighted as a priority area for care. Embedding standards into practice is critical and will help ensure a consistency.

The question of how we achieve consistency in genomics education across those HEIs delivering nursing programmes was also raised.

It is imperative nurse leaders and Trusts are on board, raising that initial awareness to spark further interest in healthcare staff.

# Dr Anneke Seller

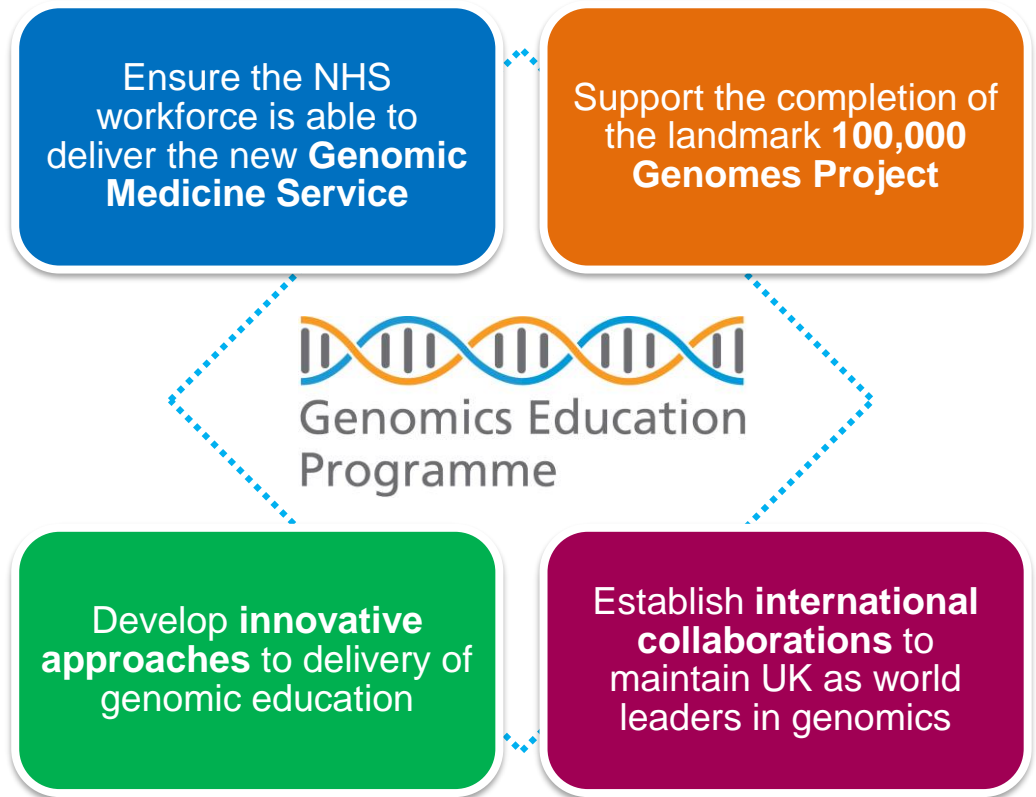
## Things to consider:

- Learning lessons from the HEE dementia awareness campaign.
- Working through already established nursing networks e.g. Macmillan nurses.
- Nurse leaders championing genomics and spreading the word – need to select leaders to educate and train.
- Nurse educators and faculties of healthcare within universities need to see the importance of genomics.

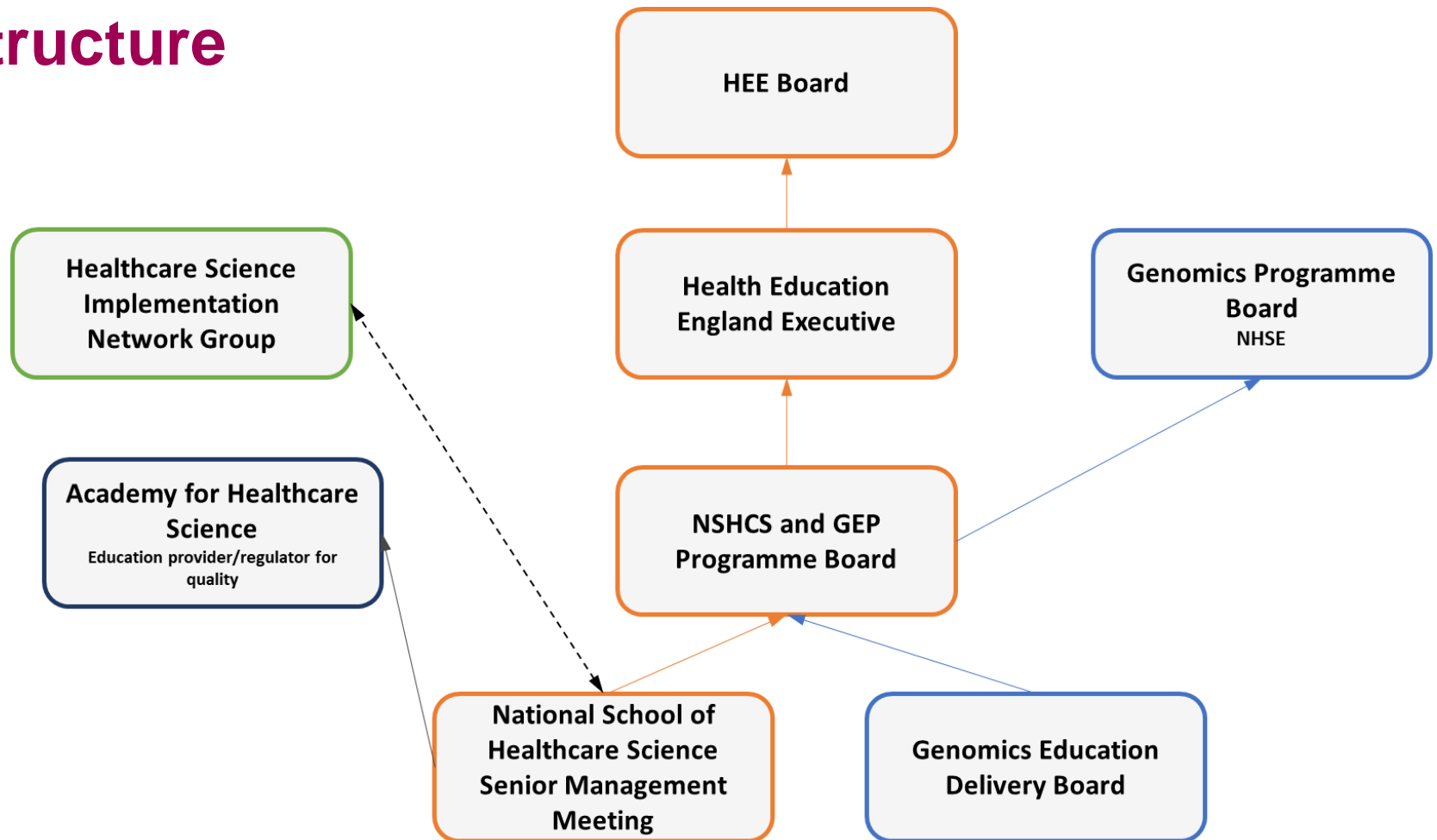


# The GEP 2018 – 2020 (2 year plan)

Programme funding until March 2020 to provide coordinated national direction and oversight of education and training in genomics, with four key areas of focus:



# How the GEP sits within HEE: Governance Structure





# Key priorities for 2019/20



## **Workforce planning**

As part of the Workforce Implementation Plan outlined in the Long-Term Plan the GEP is working with NHS Improvement and NHS England to scope and understand the numbers and skill mix required to deliver the Genomic Medicine Service (GMS) and the wider workforce implications including looking at alternative roles and new ways of working.



## **Workforce development**

The GEP is continuing its co-ordinated and integrated approach to workforce development, aligning its output to the evolving needs of the specialist and wider workforce as the GMS is established, and supporting the genomic aspects of the NHS Long Term Plan.



## **Topol Review**

Involved in the expert panel who gathered evidence on how genomics and related technologies are likely to impact on patients, clinicians and the NHS over the next 5, 10 and 20 years. Final report due 11 February 2019, and the GEP will be instrumental in delivering its recommendations.

# Supporting Workforce Planning

- Involvement in the HCS and genomics working group, chaired by Professor Dame Sue Hill, established as part of the work being led by Baroness Dido Harding to develop a Workforce Implementation Plan as outlined in the Long-Term Plan.
- GEP undertaking a review of the current genomics workforce, looking at numbers and skill mix required to deliver the GMS. Collecting workforce data from GLHs, GMCs and clinical genetics departments. Triangulating with ESR data and interviews with department leads.
- A first phase report produced draft 31<sup>st</sup> March 2019- work is ongoing

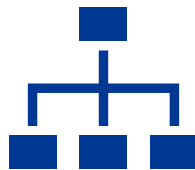


# Supporting the Genomic Medicine Service

- In collaboration with NHS England and Genomics England, the GEP is scoping the education and training needs of staff involved in the new Genomic Medicine Service.
- We are developing a wide range of educational resources across these key themes:



**Patient choice**



**Patient pathways**



**NGIS**  
(National Genomics  
Informatics System)



**Feedback  
of results**

- First resources due to be published in June 2019.

# Supporting the implementation of a Genomic Medicine Service (GMS)

- Genomic testing is increasingly taking place outside of specialist genetics clinics
- NHS England is implementing a Genomic Medicine Service (GMS) including a National Genomic Test Directory
- Testing will include a 'patient choice' model of consent which covers both the clinical implications of a test as well as a research offer within the clinical pathway, initially for whole genome sequencing indications only
- The Genomics Education Programme is leading on the development of a framework and other resources to support the workforce who will be having conversations about genomic testing with patients

# A competency framework for consent to genomic testing

- Identifies core competencies to facilitate consent for genomic testing, based on an evidence-based, consensus approach
- Designed as a guide for best practice for healthcare professionals offering various genomic tests, incorporating professional judgement
- Competencies benchmarked against four broad categories of healthcare professionals based on training and experience with genomics
- Aims to provide a comprehensive and consistent foundation for training to ensure the choice to undergo genomic testing is discussed in a safe and effective manner across specialities
- Encourages multi-disciplinary engagement to enhance the delivery of genomic medicine

# How can this framework be used?

- By individuals in clinical and/or training leadership roles, to consider how competencies fit within the education and training needs of their specific workforce group or specialism
  - Used by genetic counsellors supporting training for clinical nurse specialists that will be starting to order diagnostic testing in their patient pathway (i.e. inherited cardiac conditions, neuromuscular disorders, oncology)
  - Used to develop agenda for specialty-specific training or study
- By individual healthcare professionals to identify learning needs as part of ongoing reflective practice
- By medical and other professional colleges, adopted and/or accredited for use in development of undergraduate and postgraduate training
- To guide the development of future tools and resources made by the GEP

# Resources for ‘patient choice’

Workforce Development task-and-finish group as part of bi-weekly national Patient Choice WebEx meetings have provided feedback on resources and identified priorities for further resource development, including:

- Two clinician guides for requesting whole genome sequencing, covering cancer and rare diseases
- Supplementary information document to provide further detail and resources about key points in the guides
- Short videos outlining the patient choice conversation including the research offer (in development)



# Supporting the nursing workforce

## ► Nurse Educators toolkit

- An aid to support the delivery of genomics education based on the current NMC standards of proficiency
- It will include, but not limited to:
  - tangible learning objectives
  - lesson plans and facilitator notes
  - presentations to support teaching
  - links to resources and supporting e-learning
- Currently in development, in collaboration with:

# Supporting the workforce

## ► Genomics 101 series

- Series of 8 short e-learning modules aimed at health professionals with limited or no genomics knowledge.
- Designed to take the learner from genes and proteins, to genomics in clinical practice.
- Currently live :
  - Genomics in Healthcare
  - Taking and Drawing a Genetic Family History
  - Genes to Genome
  - Inheriting Genomic Information



### Coming soon:

- Making a protein
- Talking Genomics
- Investigating the Genome
- Classifying Genomics Conditions

# Supporting the nursing workforce

## ► film series

- Out now: Nursing in the Genomics Era
- Launching in 2019: Midwifery in the Genomics era



## ► Genomics Game

- **400** distributed to NHS, Trusts and HEIs up to January 2019
- Midwifery version launching this year



# Week of Action 2019

Monday 4<sup>th</sup> March saw the GEP launching their second week of action.



The aim of the week was to...

***“to spark a conversation among health professionals and increase familiarity with the word ‘genomics’ so they feel more comfortable discussing genomic testing with their patients as well as signposting to relevant information and services.”***



# Week of Action 4<sup>th</sup> – 8<sup>th</sup> March 2019

During the week various free activities took place, including:

- A successful panel event '[Talking Genomics with Patients](#)', on Tuesday 5 March in Birmingham with 50 attendees. Facilitated by Dr Christine Patch, the panel comprised of patients who had been through the genomic testing process. **71% of attendees rated the event excellent.**
- Launched a new [podcast](#) (a special co-branded podcast with Genetics Unzipped - **245 direct hits to the podcast**)
- Highlighted online [courses](#) and educational [resources](#).

# Week of Action 4<sup>th</sup> – 8<sup>th</sup> March 2019

## Social Media Stats

	2018	2019
<u>#GenomicsConversation Webpage views</u>	664	976
<u>Uses of Genomics Conversation Hashtag</u>	601	837
<u>Reach of Genomics Conversation Hashtag*</u>	1,000,000	640,000
<u>Hashtag impressions</u>	4,143,960	2,620,562
<u>Top Tweet during the week</u>	<u>26 re-tweets</u>	<u>32 re-tweets</u>

## Website Stats (Visitors to the #GenomicsConversation Webpage)

	2018	2019
<u>Unique users</u>	<u>4017</u>	<u>7167</u>
<u>New users</u>	3488	6453
<u>Page views</u>	<u>11796</u>	<u>13782</u>
<u>Views to Genomics Conversation Blog Article</u>	<u>73</u>	<u>147</u>

# Future challenges



## Securing GEP **funding** beyond March 2020

The pressing need to build workforce capacity and capability in genomics will only grow as the NHS Genomic Medicine Service (GMS) is rolled out and fulfils the government's commitment to sequence 500,000+ whole genomes over the next five years.



## Accurate, future-proof **workforce planning**

This significant piece of work requires high-level expertise to predict how the GMS will operate before it has been fully established. Understanding the impact on the wider health service is vital so we can anticipate the required workforce numbers and skills mix.



## Effective **workforce transformation**

Our ability to commission the education and training needed to transform the workforce hinges on both the commitment to continue to fund the programme and our understanding of the workforce requirements to deliver the GMS.



# **Sarah Harriman & Kelly Western – Nursing Associate Foundation Degree Programme**

Sarah Harriman & Kelly Western, students currently undertaking the LLR Nursing Associate Programme in Leicestershire attended the meeting and shared their experiences.

This is a unique programme in Leicestershire, validated by De Montfort University and delivered at the Leicestershire School of Nursing Associates, based on the Glenfield Hospital site.

The two-year apprenticeship programme, combines both academic and work-based learning in the physical, psychological and public health aspects of care from pre-conception to end of life.



# **Sarah Harriman & Kelly Western – Nursing Associate Foundation Degree Programme**

The programme is structured around a number of clinical placements which can include:

- Adult, Mental Health, Child and Learning Disability
- At home, close to home and within the hospital

The University costs for the programme are fully funded, and successful completion of the programme leads to a Foundation Degree as a Nursing Associate.

It was highlighted that the Nursing Associate is a stand-alone role providing support but not substituting registered nurses.

# **Sarah Harriman & Kelly Western – Nursing Associate Foundation Degree Programme**



Genomics has been incorporated as part of teaching using the Genomics Game at a workshop. It was noted that the informality of this learning increased its success. The game sparked interest leading Sarah and Kelly to undertake further research on the subject and also to get involved in the redevelopment of the GEP website.

Sarah and Kelly highlighted the need for everyone in the NHS to have some awareness of genomics, as a patient may not ask their consultant questions, some feel more comfortable around other members of staff. The TNA is often the person supporting families who have questions or who know little on the subject matter.

# Sarah Harriman & Kelly Western

## Things to consider:

- Genomics shouldn't be a tick box exercise for staff, if they have a personal interest and can see how it affects the work they do, the patients and their families, knowing about genomics or where to sign post people will help in their roles.
- It was agreed that patient stories help engage and ease the fear of genomics making it understandable. The GEP has several films available and continues to develop more resources including patient stories.
- Engagement with staff, patients and families needn't be formal, there are many ways to engage including social media, cafes and an array of forums across the country.
- Could the Genomics Game be converted into an App?

Following the presentation Professor Dame Sue Hill's advised the Genomics Implementation Team in NHS England could arrange for the TNAs to meet the genomics team at Leicester.



# Genomics Education within the Nursing Associate Foundation Degree Programme.

Sarah Harriman – Leicestershire  
School of Nursing Associates  
Wednesday 1<sup>st</sup> May 2019



# The Trainee Nursing Associate programme in Leicester, Leicestershire and Rutland (LLR).

- The Foundation Degree for Nursing Associates is a two year apprenticeship programme validated by De Montfort University and delivered at the Leicestershire School of Nursing Associates.
- The Nursing Associate is regulated in England by the Nursing and Midwifery Council (NMC), and is intended to address a skills gap between health care assistants and registered nurses.
- The Nursing Associate is a stand-alone role. We will support, not substitute, registered nurses.



- The two-year apprenticeship programme, incorporates both academic and work-based learning in the physical, psychological and public health aspects of care throughout the patients full life course.
- As trainee Nursing Associates we work clinically for 80% of our contracted hours per week in our own base area and attend classroom teaching one day per week.
- The programme is structured around a number of clinical placements which may include: Adult, Mental Health, Child and Learning Disability. This enables us as trainee's to gain insight into areas we may not have previously experienced, enhancing our personal development and building up our underpinning knowledge required for the role.

# Why makes Leicester unique.....

- The LLR Nursing Associate Training programme is being constantly developed and taught by the clinical staff from a wide range of different NHS, independent and private organisations across Leicestershire. This gives us as trainees access to invaluable specialist clinical knowledge held by each of our trainers, our mentors and personal tutors that is not only valuable to our learning and development but enriches it in a way no text book can. Their knowledge comes alongside many years of experience that they are never too busy to share, broadening our knowledge base and shaping us into Leicestershire's finest Nursing Associates

# Genetics and Genomics Education within the LLR Nursing Associate programme.



- During our programme, along with my cohort I have participated in playing The Genomics Game. We played the game at a workshop learning day. The game is played in two in two teams. My team's aim was to be the first to collect the five coloured discs in order to cover up the word "GENES." In order to win the discs my team had to correctly answer a series of questions based on genetics and genomics asked by the opposing team.

# A Board Game to aid learning??

- The board game was an interactive learning tool that we could engage with together as a group.
- It didn't feel like "formal" learning.
- The game led to my team having conversations regarding genetics and genomics that I feel we all gained extra knowledge from. These conversations wouldn't have been initiated had we not been playing the game.

- My awareness of genetics and genomics prior to the genomics game was limited.
- The genomics game not only broadened my underpinning knowledge but also allowed me to engage with my peers and discuss how genetics and genomics plays a valuable role in healthcare.
- The game led to me personally reading around the subject of genetics and genomics in order to widen my knowledge and understand better the role it plays in the changing clinical practice that as a Nursing Associate I will be involved in.

# Where the game led....

- In September 2018, I was involved as a tester for the new genomics education programme website. I was consulted on my opinion regarding the design and layout of the website alongside if the website was Nursing Associate friendly!
- I believe the website is a very useful platform that informs the user of what the education programme is and how it can help you as a user to learn more about genomics. It also provides credible, evidence based information on genomics that individuals such as myself can incorporate into their daily clinical practice, whilst enriching their personal learning and development.



# Where next.....

- Genomics is constantly advancing and each development may have an impact upon all primary care areas.
- As a Nursing Associate on the front line any future advances will undoubtedly affect some of my patients and their families at some point.
- Incorporating the genomic education website into my future learning will positively aid my practice, ensuring I able to care for individuals in a holistic person centred manner and assist with any questions they may have regarding genomics.
- As a Nursing Associate I will hopefully go on to mentor future trainee Nursing Associates, I will be recommending they play the genomics game to gain confidence and knowledge in the area of genomics alongside using the website to further develop their learning and keep up to date with advances within the area of genomics.

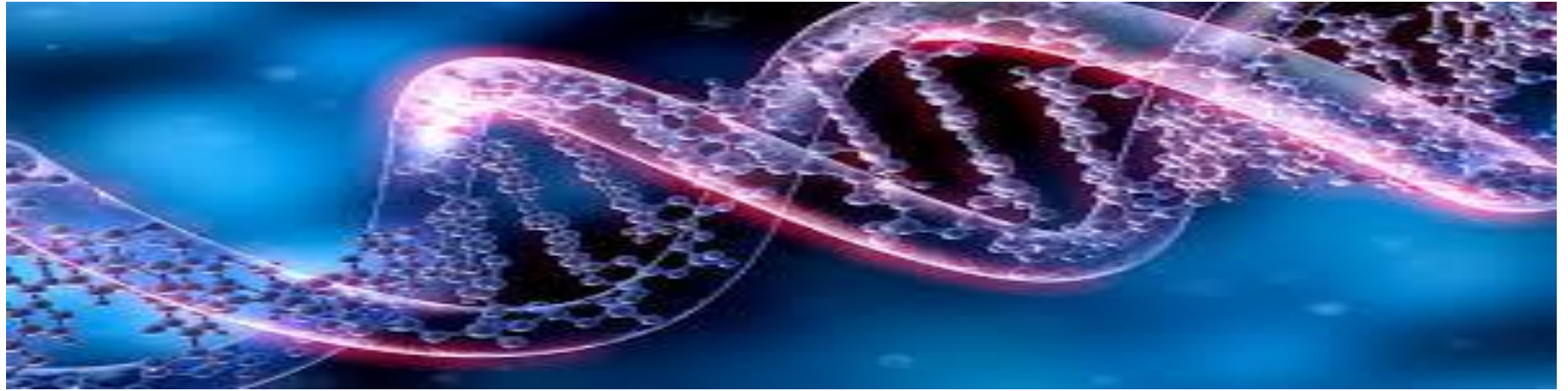
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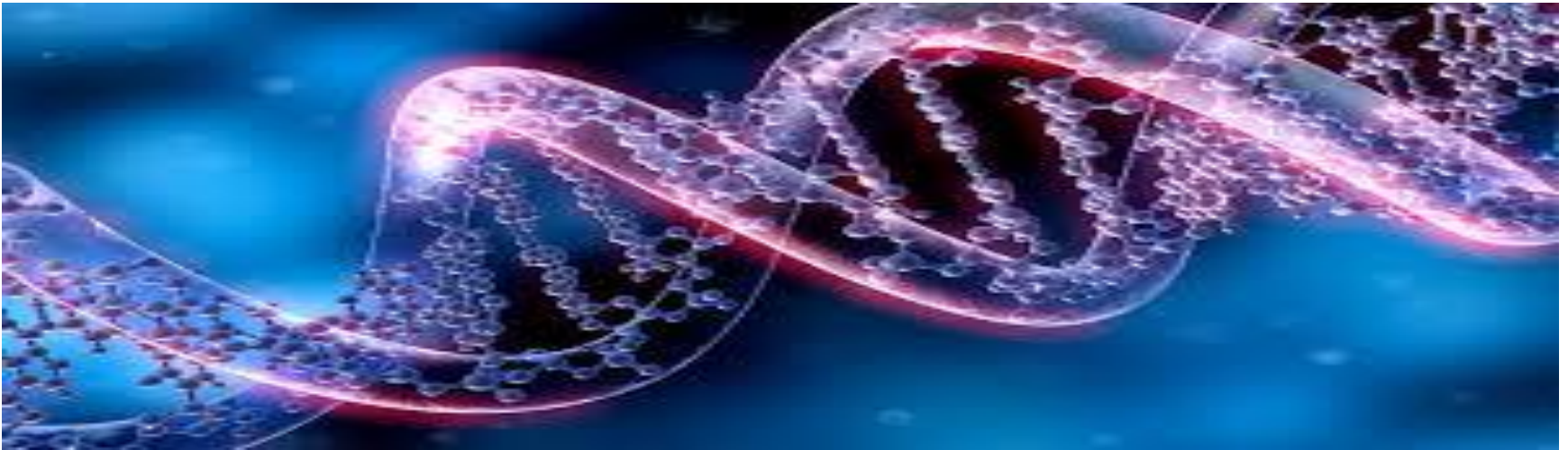
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Thank you all for listening



# **Dame Prof Sue Hill- Update on the Genomic Medicine Service (GMS) and Long-Term Plan**

Professor Dame Sue Hill (NHS England) joined the meeting and provided an update on the Genomics Medicine Service (GMS). The NHS Long term plan acknowledges the need to change the model of care and harness new technology. Using genomics to transform the healthcare system in clinical priority areas is recognised throughout the report.



To deliver quality genomic medicine the pathways for delivery need to be redesigned. There are a number of interlinking professionals and services to be provided through a complex system. Early findings from the 100,000 Genomes Project have already demonstrated significant patient benefits of whole genome sequencing.

# **Dame Prof Sue Hill- Update on the Genomic Medicine Service (GMS) and Long-Term Plan**

For some patients, involvement in the 100,000 Genomes Project has brought an end to the diagnostic odyssey, reducing ongoing and unproductive testing. It has identified simple and more cost-effective treatments for other patients (such as dietary changes) and has identified actionable mutations in 50%+ of cancer patients – providing eligibility for clinical trials.

There will be an 18-month transition period to develop and establish the GMS across seven Genomic Laboratory Hubs (GLHs) and Genomics Medicine Centres (GMCs). The service will set clear and informed choice about use of the NHS GMS and genomic tests to patients, provide information to help patients understand the choice and consequences and give patients the opportunity to participate in research.

Nurses and midwives will form a critical part of shaping the service.

# Genomics: A strategic priority for improving outcomes

**Professor Dame Sue Hill** @CSOsue  
Chief Scientific Officer for England

May 2018

NHS England and NHS Improvement



# Definitions:

## What is genomics?

*World Health Organisation definition:*

**Genetics** is the study of heredity.

### Genomics

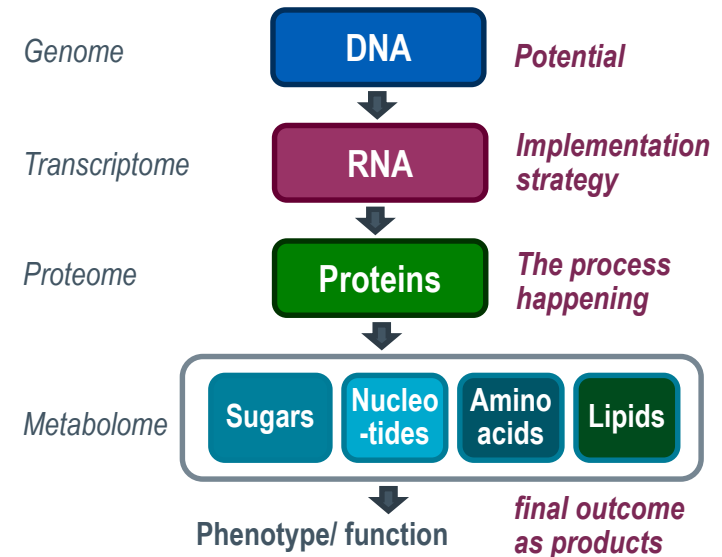
is defined as the study of genes and their functions, and related techniques.

*i.e. Genes & their influence on growth, development and working of the body (e.g. all cancers develop because something has gone wrong with one or more genes)*

**- NHS Genomics encompasses everything from single genes to whole genome sequencing, and will stretch beyond DNA**



### Beyond DNA: Functional genomics

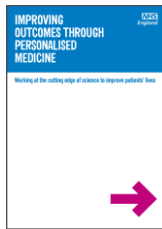




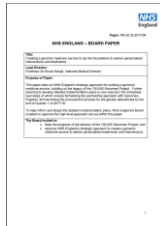
# A new model of care: The time is now



**Five Year Forward View (2014)** – harnessing technology to address the ‘three gaps’ – care quality; inequalities; sustainability



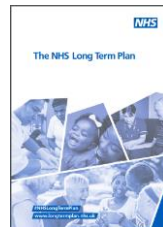
**Improving Outcomes through Personalised Medicine (2016)** – using advances in genomic technology to improve health through better treatment selection, more tailored to individual patients



**Creating a Genomic Medicine Service (NHS England Board, 2017)**  
A strategic nationwide approach to provide the infrastructure to provide more comprehensive testing and embed genomic medicine into day-to-day care



**Government plan for genomics (2019)**  
Funding 1million genome sequences over next 5 years (500k through NHS) with ‘bold aspiration’ of 5million genomic analyses



**NHS Long Term Plan (2019)**  
Recognises the central role of genomic medicine in delivering high quality care and making people healthier – particularly in NHS priority areas

# Genomics delivering NHS Long Term Plan priorities



The future direction and clinical priorities for the NHS is set out in the 10-year **NHS Long Term Plan**. The power and potential of genomics to transform healthcare – particularly in clinical priority areas – is recognised throughout, particularly when coupled with ‘big data’ analysis techniques



## Technology

Targeted investment in areas of innovation that we believe will be transformative, particularly genomics



NHS Genomic Medicine Service will sequence 500,000 whole genomes by 2023/24.

Improving recruitment to clinical trials

## Children & Young people

A strong start in life for children and young people



All children with cancer to be offered WGS  
Seriously-ill children likely to have genetic disorder to be offered WGS

## Cancer

Rapid Diagnostic Centres  
Access to personalised care  
Stratified follow-up pathways  
Earlier diagnosis



Extended access to molecular diagnostics  
Genomic testing routinely offered to all people with cancer  
(*>100k people per year*)

## Cardiovascular

Early detection and treatment  
Rapid identification of high-risk conditions

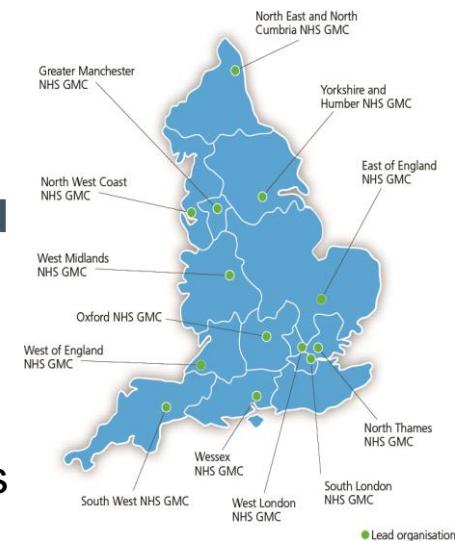


Expanding access to genomic testing for Familial Hypercholesterolaemia

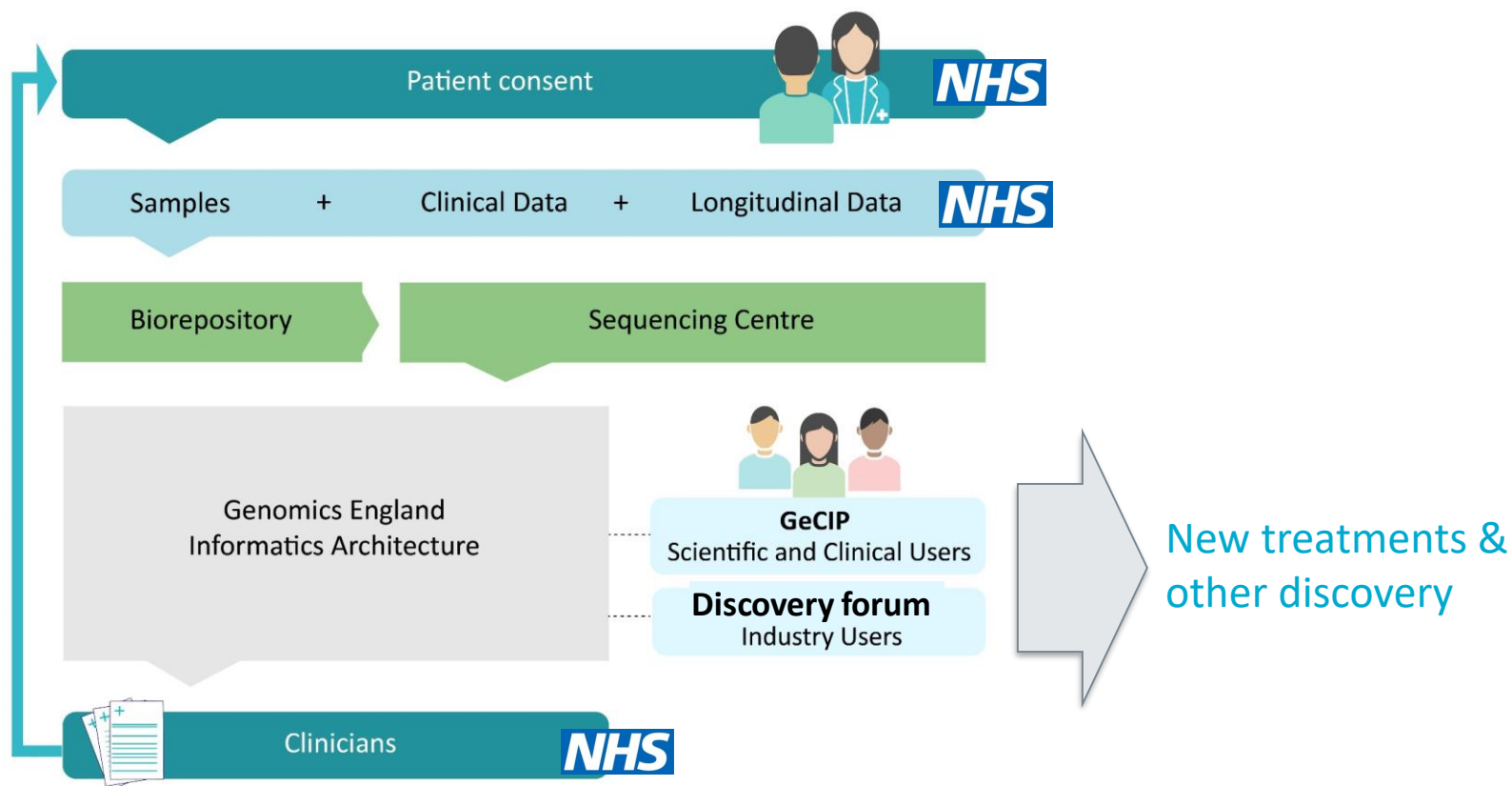
# The 100,000 Genomes Project – infrastructure for the future

- The 100,000 Genomes Project was set up to **establish the proof of concept for genomic medicine** pathways and key elements of infrastructure
- Focus on **cancer & rare disease** – unmet clinical need
- 13 NHS Genomic Medicine Centres provide **population-based networks** covering between 3-7million people.
- Focus on **innovation, service transformation, clinical engagement & workforce upskilling** from the frontline up
- Regional genetic labs, clinical genetic services & pathology were **core teams** who worked with other services & specialities
- NHS GMCs operated to **define and refine the genomic medicine service model** for their locality as part of end-to-end care pathways – *from new ways of gaining consent through sample handling and processing to validation & return of results*
- Nursing teams have been a key part of delivery across the NHS GMCs

The 13 NHS Genomic Medicine Centres



# 100,000 Genomes: samples & data flows

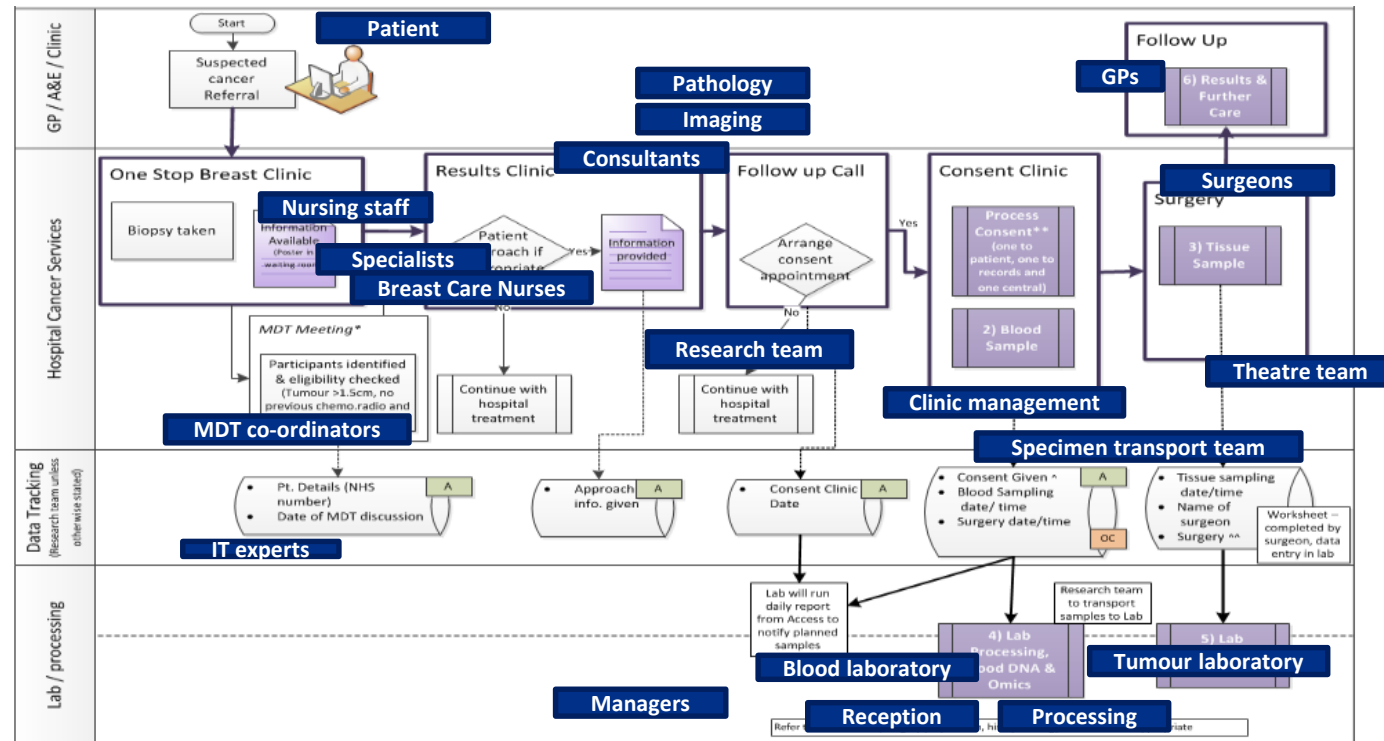


# The complexity of re-engineering pathways to delivery quality genomic medicine

Tremendous achievements have been made in re-engineering clinical pathways given the complexity of the task and the number of interlinking professionals and services

Significant clinical engagement has been delivered throughout this process

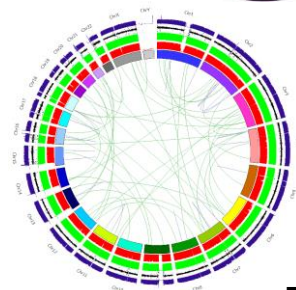
Typical breast cancer pathway



# Delivering clear patient benefit

Early findings from the 100,000 Genomes Project has already demonstrated significant patient benefits of whole genome sequencing:

- Typical **diagnostic yield of 25%** for rare & inherited disease (*above standard of care*) – up to 50-60% in some conditions
- Brought an **end to diagnostic odyssey** for patients – sometimes stretching into decades – reducing ongoing & unproductive testing
- Has identified **simple & cheap** treatments for some patients – inc. dietary changes or vitamin supplementation
- Has identified **actionable mutations in 50%+** of cancer patients – providing eligibility for clinical trials



# Continuing 100,000 Genomes Project Activity

## Validation & Reporting of findings

Can be a complex process requiring triangulation against targeted testing and functional analyses, particularly where pathogenicity of variants isn't well documented

## Return of results to participants

Multiprofessional process where patients not only receive results but can discuss short & longer term option for their care & potential implications for family members. Not always 'black & white' answers

## Supporting pharmacogenomics & additional looked-for findings

Additional looked for findings and pharmacogenomic profiles incorporating 43 high impact gene-drug pairs will be returned later this year– need to determine integration into existing care pathways

## Understanding the impact on NHS Services

Further analysis of the short and longer-term effect of all genomic information on clinical pathways, patient flows and individual decision-making

*Patient support an important part of delivery*



# How the NHS harnessed the Project to shape the future of genomics

Made clinical & economic case for WGS in routine care - securing new funding for genomics ( WGS and non WGS)



Focused consolidation of labs & clinical services  
– new models of care (*post 2012 HGSG report*)



Established principle of single national approach, protocols, standards & scrutiny *inc National Genomics Test Directory*



Cancer: highlighted problems with inequity of provision, variable approach & pathology issues



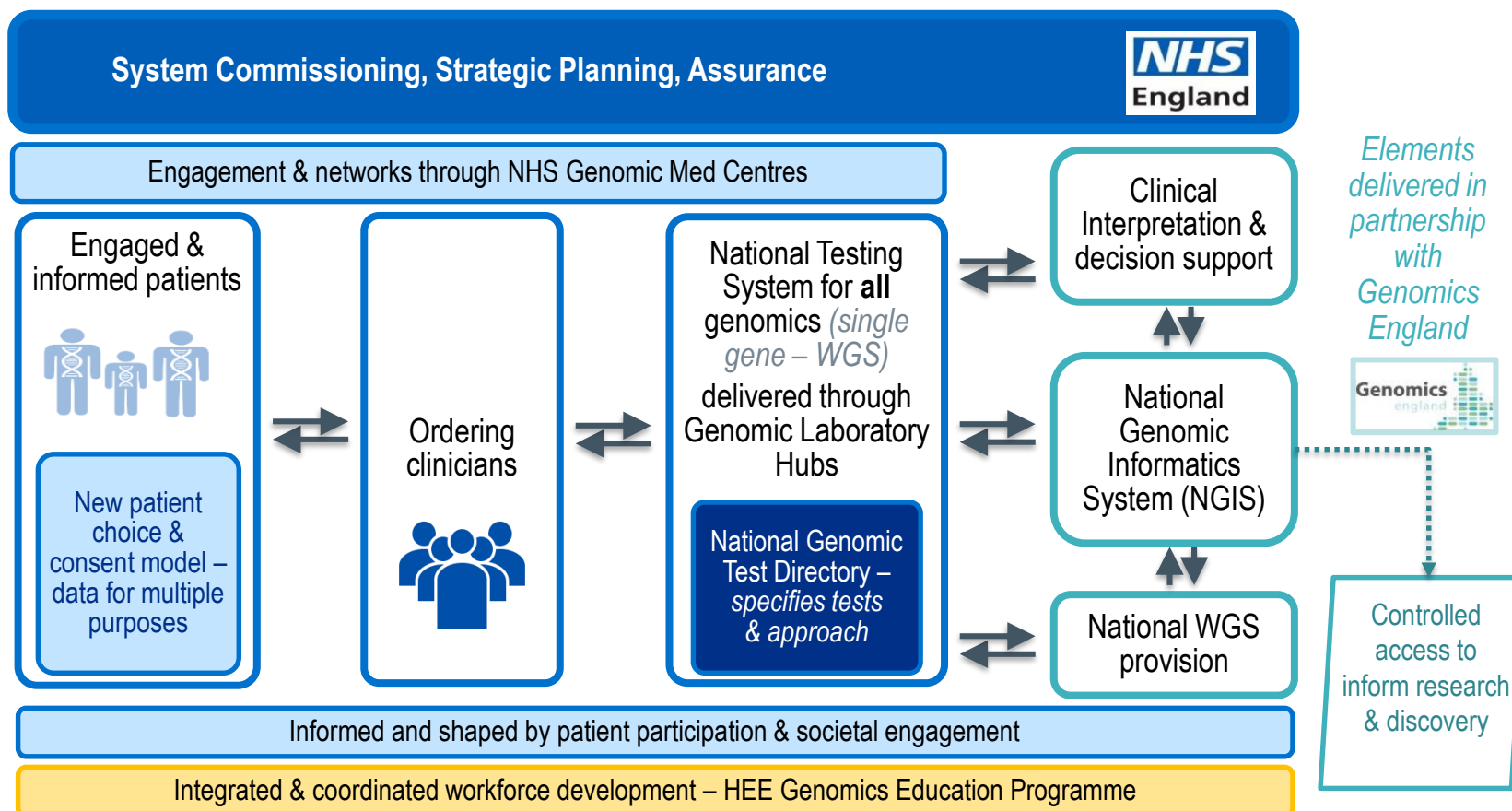
Supporting improved personalisation of care esp. medicines optimisation (£17bn pa & rising) & tackling adverse reactions



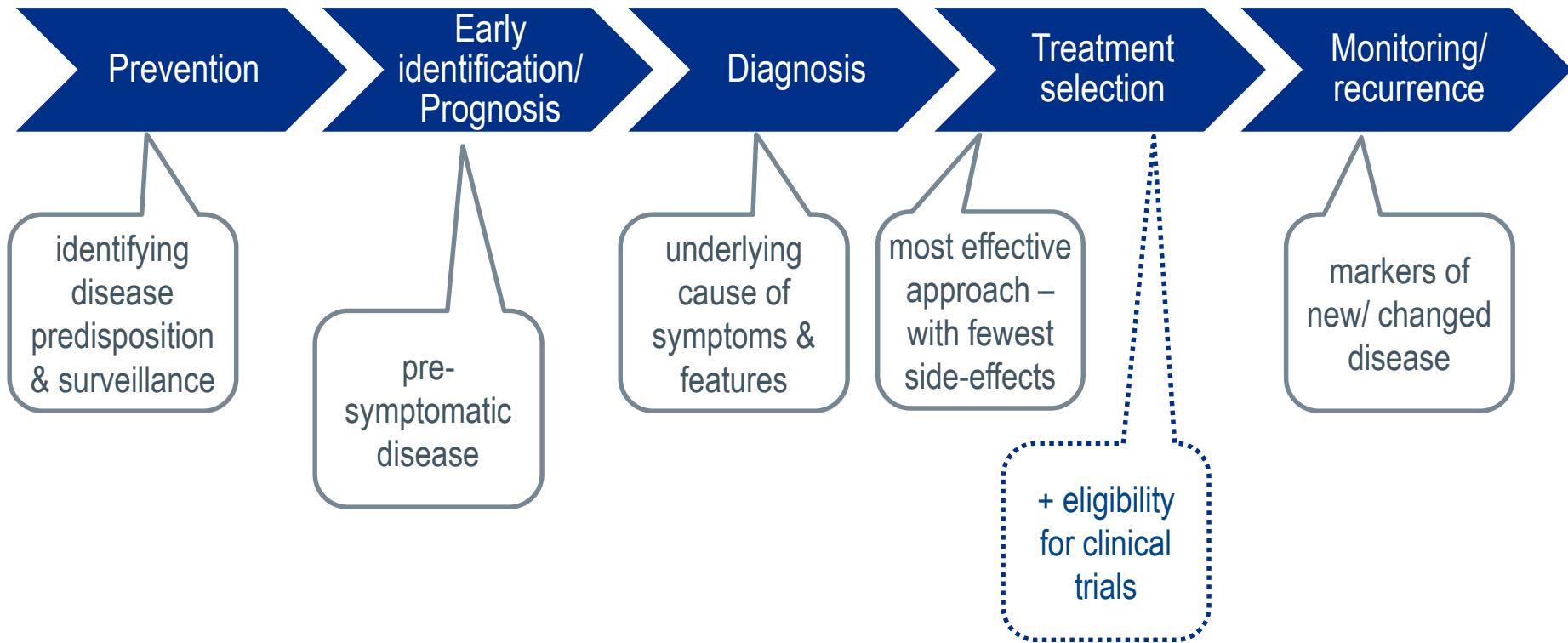
Highlighted the importance of local-level coordination though NHS Genomic Medicine Centres



# The new national genomic infrastructure



# Genomics: understanding patients better at all stages of care



# Supporting patients across the spectrum of testing approaches

The breadth of testing within the NHS Genomic Medicine Service (*WGS – single gene*) will call upon a broad range of skills of support as patients go through their journey

Whole Genome Sequencing

Ensuring effective understanding & consent, given the breadth of information identified – inc additional findings

Rapid Exome  
(NICU/PICU)

Supporting parents through testing and feedback at a challenging time

Cancer

Enhanced support for somatic and germline findings

Familial  
Hypercholesterolemia

Coordinating cascade testing & familial consequences

Tumour disposition

Managing the uncertainties of prognostic testing & implications for others

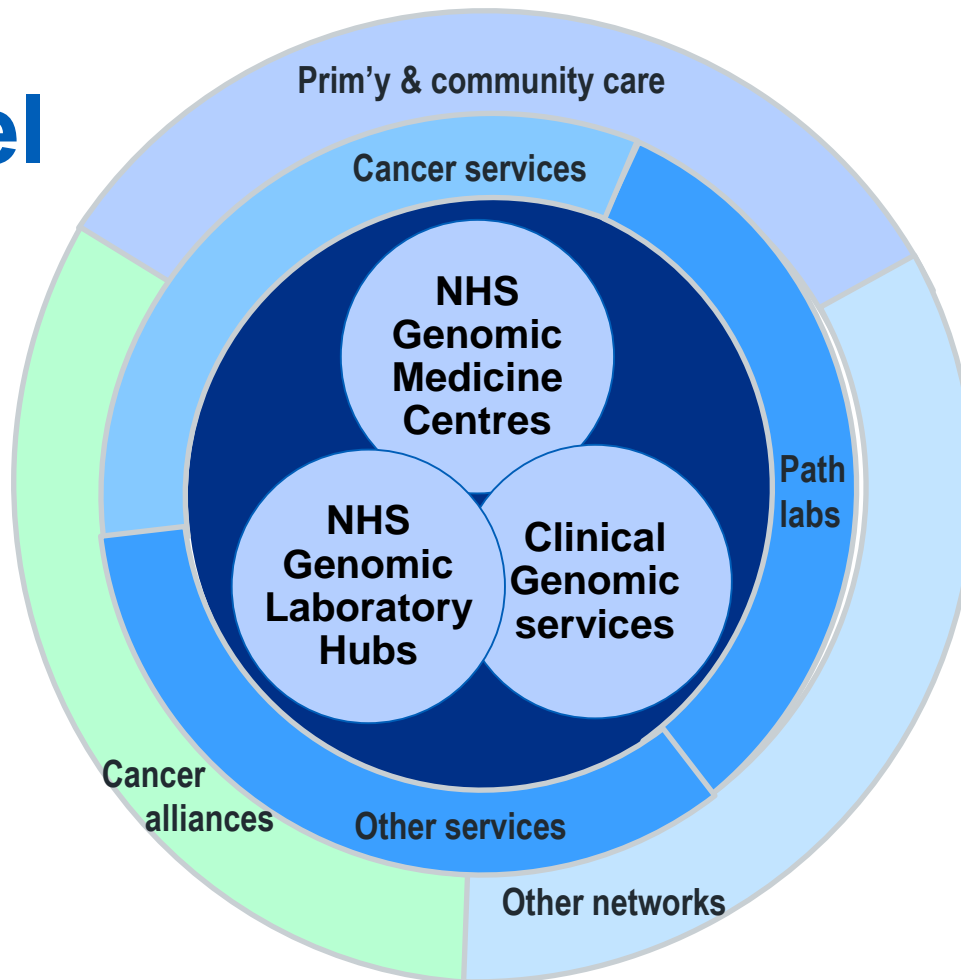
Pharmacogenomics

Helping patients (& clinicians) to make sense of the practical consequences of pharmacogenomic results

Polygenic risk scores

Supporting people to understand risk and implications

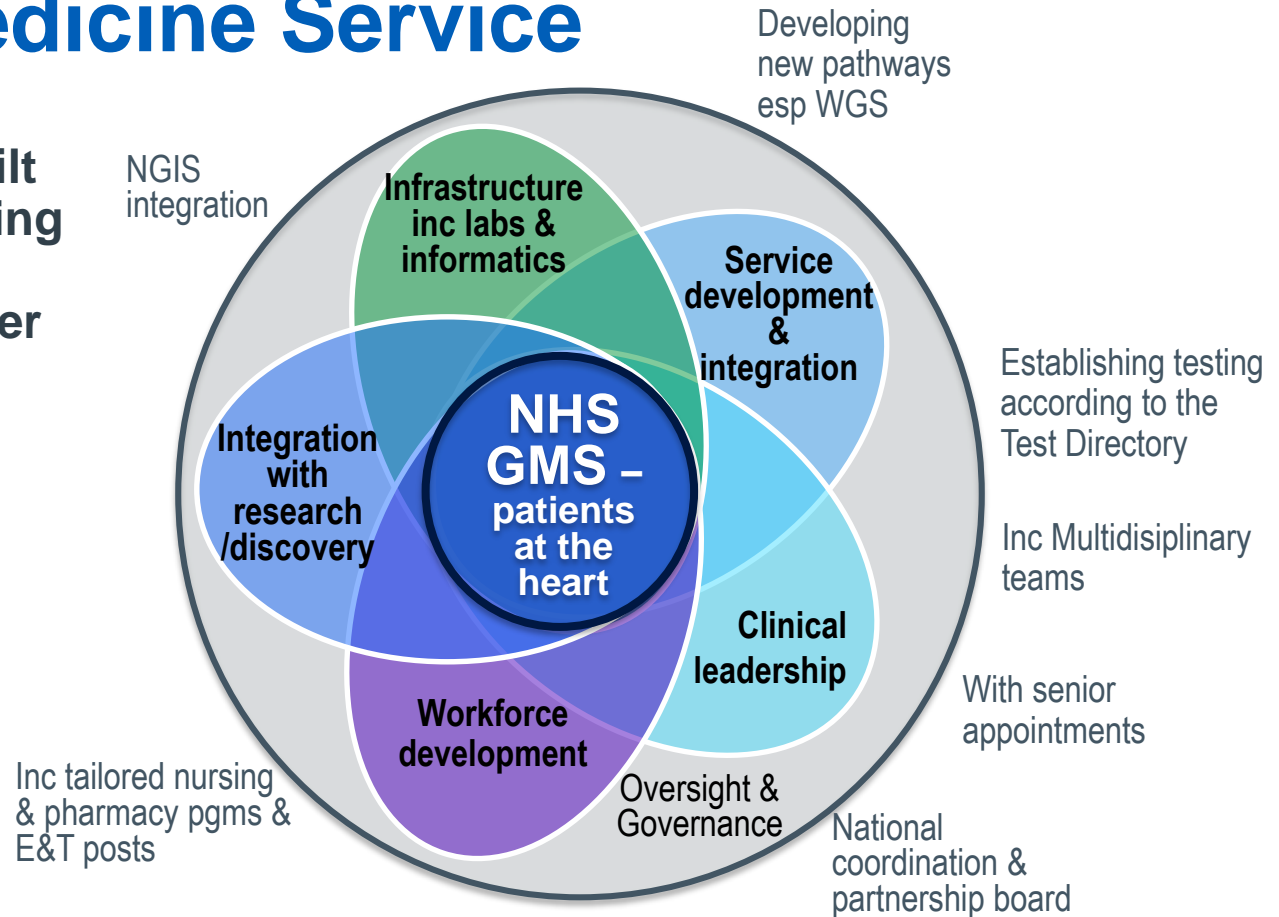
# Model of care



The NHS Genomic Medicine Service is on a journey to establish its reach across the system – with an 18 month transition period to ensure provision remains robust and clinically safe as new pathways and approaches are established

# Building the Genomic Medicine Service

The NHS Genomic Medicine Service is built upon a set of interlocking and co-dependent elements which together deliver improved care and outcomes

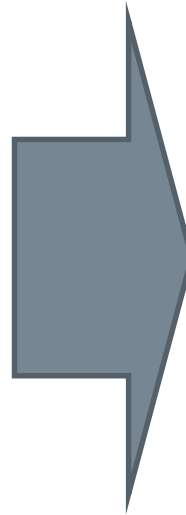


# Evolving the commissioning approach for genomics

The commissioning of genomic medicine is being fundamentally changed from the organic, ad-hoc arrangements that have grown up over years to a single nationally-coordinated model that provides greater clarity, quality and equity

## Pre-existing

- **Multiple funding routes** (CCG/ Specialised/Provider-Provider)
- **Significant variation** in delivery & access & across country
- Genomic services often **buried** within broader service tariff (e.g. *cancer*)
- **No clear understanding** of what is actually delivered
- **Hard to commission** for quality, particularly when within broader tariff



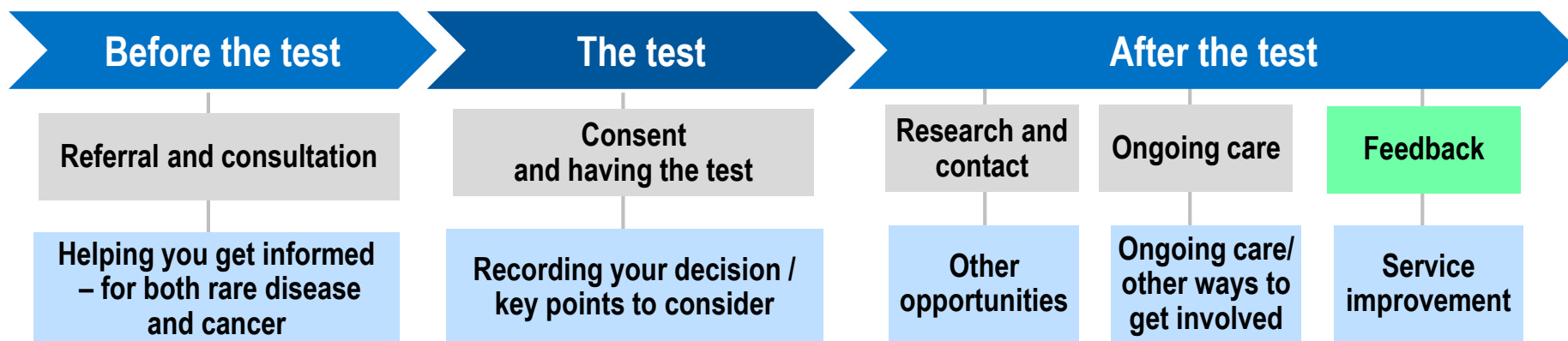
## New model

- Single integrated (&enhanced) budget to cover genomic testing in National Genomic Test Directory
- Commissioned & managed centrally - testing currently being unbundled from cancer tariff
- National commissioning of clinical genetic services to new service specification
- Driven by quality & value for money. Clear metrics & performance management
- Integrated where appropriate into commissioning of other services



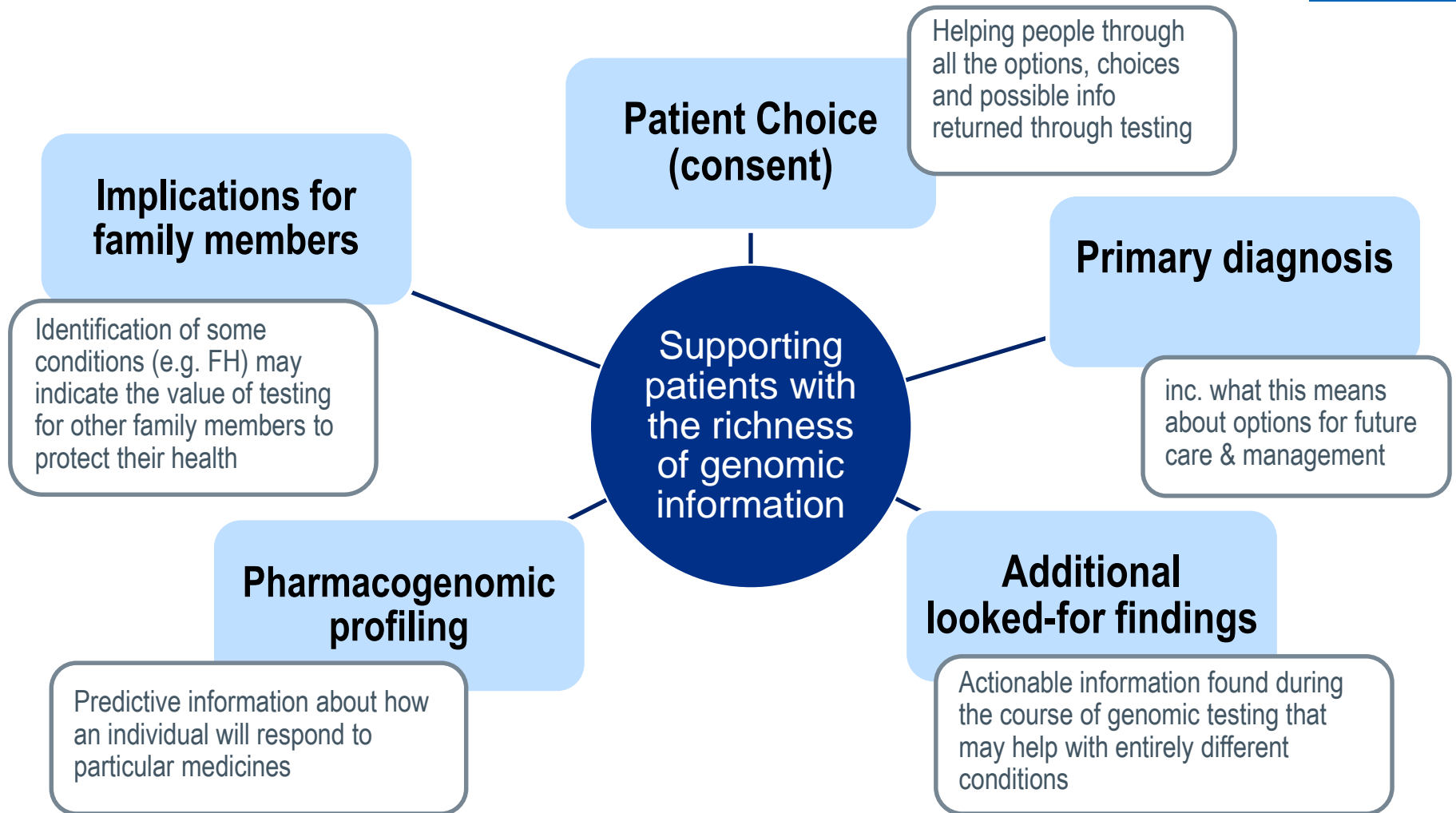
# Patient choice: informing throughout the journey

## EXEMPLAR PATHWAY:



## KEY ASPECTS OF APPROACH

- Aim to set **clear and informed choice** about use of NHS GMS and Genomic Tests to patients
- Choice **supported by plenty of information** to help patients understand the choice and consequences
- Will cover **both usual use of patient data** within healthcare services as well as **innovative aspect of genomic care and data** use to support/develop service
- All patients to be given the **opportunity to participate in research**
- **Clear and distinct choice to be part of research** programme (without impact on standard of clinical care of individual)



# Delivering the genomic ambition for the NHS and broader society

- Established a **world-leading Genomic Medicine Service** encompassing all genomic testing to improve patient outcomes & experience through greater personalisation of care
- Made value case for **significantly increased NHS investment**
- **Accelerating sequencing pace**: from 100k WGS in 4 years to 500k NHS WGS in 5 years (as part of Gov't 1 million WGS commitment)
- Underpinned by **ongoing and unique partnership with Genomics England**
- Contributing to and supporting Government's **broader genomic ambition** of 5million analyses and **Life Sciences Industrial Strategy** initiatives such as Accelerating Detection of Disease Project
- Informing the **UK Genomic Healthcare Strategy**

# Embedding genomics into nursing & midwifery workforce plans to underpin the GMS

Professor Janice Sigsworth, Director of Nursing, Imperial College Healthcare and Sarah Armstrong-Klein from NHS England presented their proposal for a collaborative to operationalise and embed genomics into nursing and midwifery practice.

They acknowledged nursing and midwifery teams are the largest part of the NHS workforce and can optimise the contribution of genomics into the service.



The team are planning to develop a nurse-led genomic collaborative programme over a 12-18-month period to support embedding adapted and new practices into workforce plans and everyday clinical practice.

# Embedding genomics into nursing & midwifery workforce plans to underpin the GMS

A full communications plan is being developed with stakeholder mapping and discussions with Royal Colleges and other key partners. It will be important to include those involved in both undergraduate and post-graduate teaching.

A Directors of Nursing & Directors of Midwifery “masterclass” is being planned with support from GEP on 10<sup>th</sup> July 2019 in London.

Work with pilot sites across the seven GLH geographies with local leads will also begin, with the plan to have 3-5 workstreams per pilot site.

Lord Willis highlighted a requirement for good governance to avoid duplication and parallel working. The GEP/HEE have developed a lot of material, resources and teaching tools and should be involved in overseeing the education and training of the nursing and midwifery workforce to ensure consistency.

# Embedding genomics into nursing & midwifery workforce plans to underpin the GMS

He acknowledged this is an opportunity to have excellent teaching materials and resources which could form one package of learning to meet requirements across the nursing and midwifery professions.

It was suggested that the GEP could kite mark or accredit new resources to highlight the quality of the material being produced.

The plan for the collaborative work is to have a portal for nurses and midwives which would provide both information and access or sign-post to relevant educational resources.



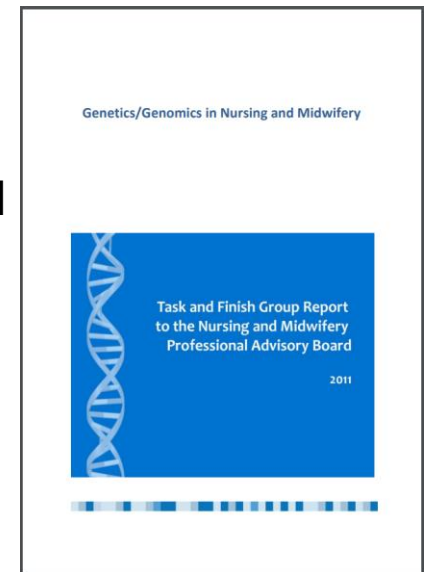
# Background:

## Nursing - central to continuity of care and patient support



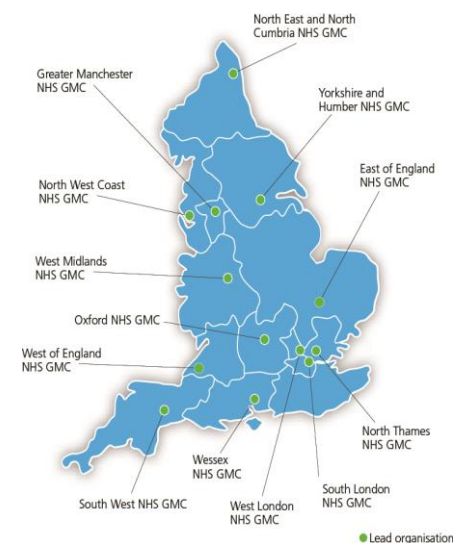
Nursing & Midwifery Professional Advisory Board recognised importance of nursing to delivering potential of genomics (2011) - through their central role in continuity of care & providing informed advice, support and guidance to patients & families:

- Nurses & midwives - central to public's health through health promotion & prevention and amelioration of ill-health
- Often first point of contact for patients
- Best placed to communicate with patients & families
- Best placed to coordinate multiple services & agencies involved
- Essential to closing gaps between research discoveries and their adoption in practice – shaping and informing transformation in their areas of practice



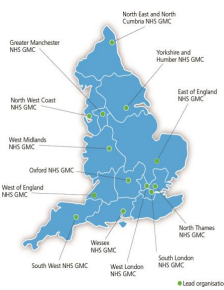


**Nursing individuals and teams –  
have been a **key part of delivery** for  
100K Genomes project across the  
NHS GMCs**



13 GMCs

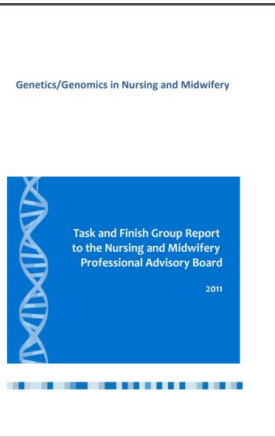
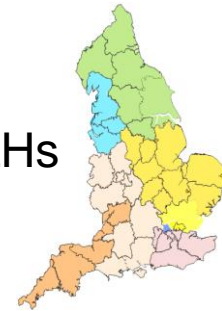
# Nursing: central to continuity of care and patient support



13 GMCs



7 GLHs



2011



**100KG Project**

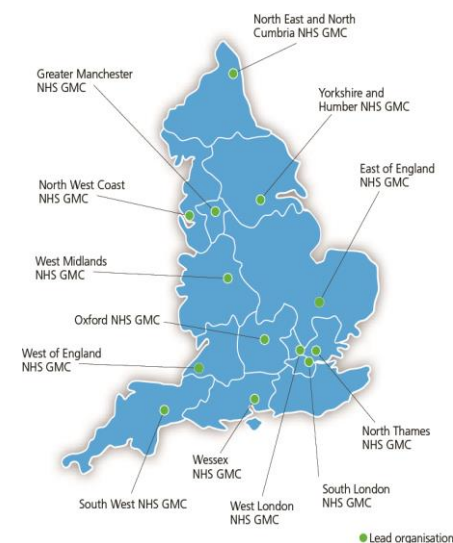
2012 – 2019/20



**GMS - mainstream**

2019 - future

We now need to embed into workforce plans in a **systematic & sustainable way** so that many **more patients can benefit** from genomic medicine



13 GMCs

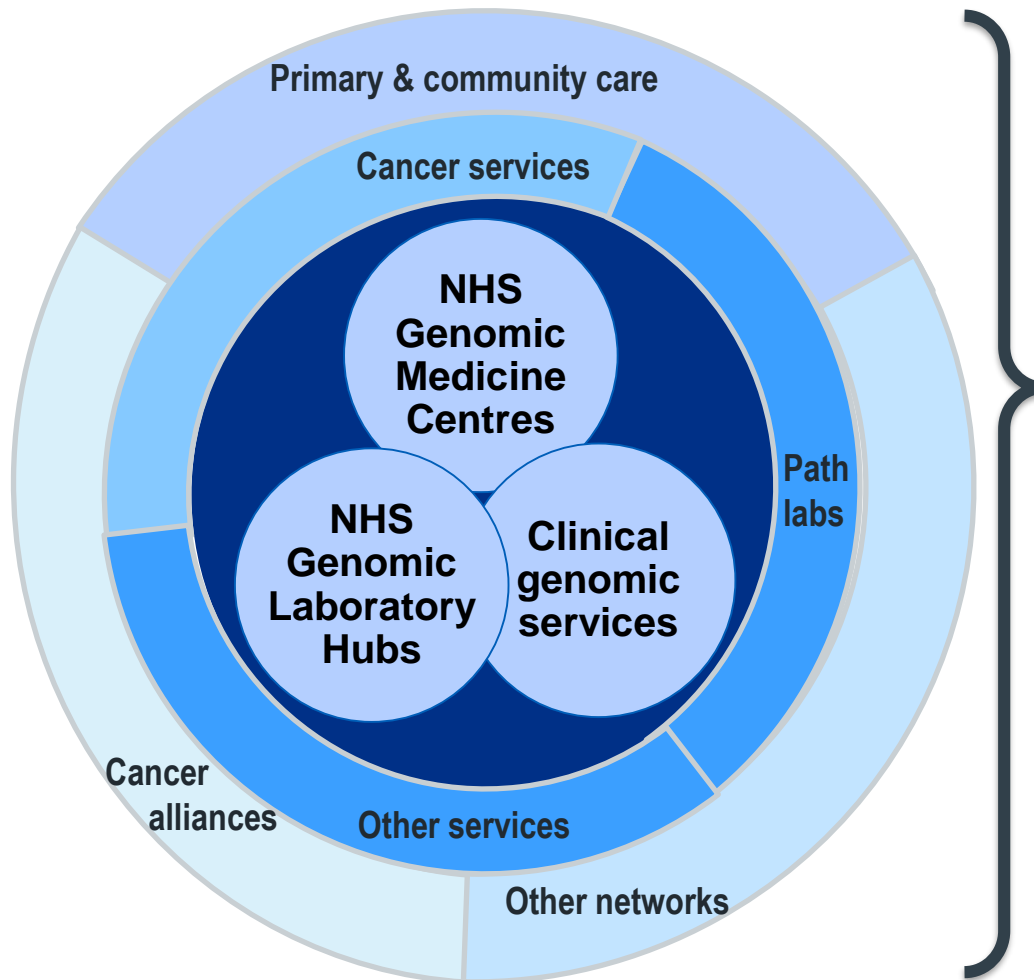
# New Genomics Medical Service

- **Requires new ways of working** to deliver its full potential for patients and service
- **Nursing, Midwifery & care staff** - the largest NHS workforce & best placed to optimise the contribution of genomics to improving health
- **Senior leadership** of these professions, in steering the nursing workforce, will be critical to the success of the NHS GMS
- **Building from the experience** of the staff in those organisations already heavily engaged in genomics will provide the platform for a system-wide strategy to maximise the nursing contribution



7 GLHs

# Model of care



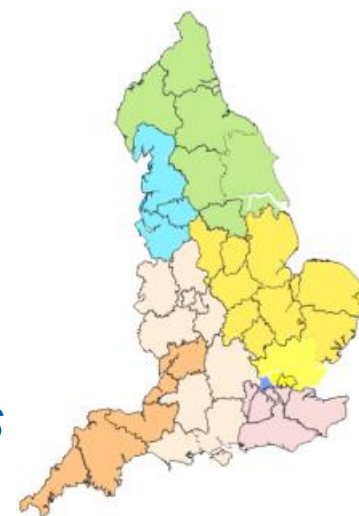
Significant Nursing involvement across all key areas of Model of Care

Secured agreement from Ruth May for genomic medicine to be one of her CNO priorities

*(Janice Sigsworth to be NHS lead)*

# Developing a Nurse-Led Genomics Collaborative programme

**12-18 month** programme of work *within the service* to look at the *service need (workforce)* aiming to *embed genomics into workforce plans*



7 GLHs

# Embedding Genomics into the nursing & Midwifery Workforce



- To deliver - we have engaged with experts, clinicians, front-line staff and academics to test the approach, refine thinking & our approach to implementation

***Overarching framework*** to be delivered under a ***3-strand approach***:

## **1. Nurse-led Genomics Collaborative Programme**

*Practical application to test & deliver the service need*

## **2. Building capacity & capability**

*Building knowledge and skills frameworks to underpin practice*

## **3. Large-scale change**

*Embedding sustainable changes in workforce across the system*

with some cross-cutting themes



## Embedding Genomics into Nursing & Midwifery workforce



### Nurse-led Collaborative

- 7 pilot sites across 7 GLHs
- Selection criteria and process
- Information pack
  - Expectations & support
- Preparation of Collaborative
  - Detail & information
  - Timescales & workshops dates
  - Reporting & measures
- Select sites – GLHs to nominate
- Pre-work with Sites
  - Agree teams & site Team Lead
    - Agree workstreams
    - Process maps & baseline
    - Identify skills gaps
    - Site work plans to test/ implement change ideas
    - Risk assessments
    - Measures & reporting
- Deliver work in the Collaborative programme over 12-18 months

### Building Capability & Capacity

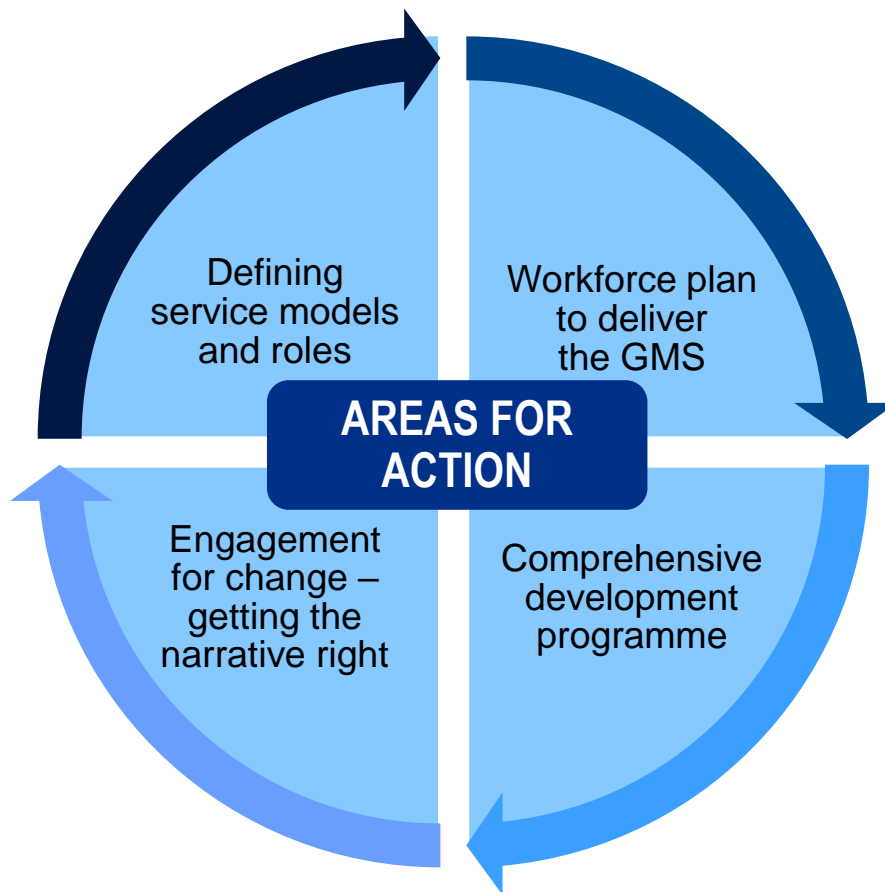
- Masterclasses – pilot sites & wider audiences
- Faculty for nurses & midwives
- Identify essential skill sets
  - Generic &
    - required in specialty
    - Identify skills gaps
- Build improvement expertise
  - with essential skills for service delivery & timescales
- Implementation plan to develop teams
- Competencies to support clinical practice
- Utilise & signpost HEE GeP (& other) resources
- Links with pre-reg curriculum

### Large-scale Change

- Comms strategy
  - Stakeholders map
  - Social Media strategy
- Exposure
  - Speaking at conferences
  - Stands at events
  - Publications
- Involve Royal Colleges & statutory bodies
- Genomics standards for Nursing & Midwifery
- Work with academics & experts
- Networks:
  - Links with G2NA & AGNC
  - Build on Clinical Champions network
    - Forge links with other networks
- Identify new roles
- Embed genomics into workforce plans

**Cross cutting themes:** Consistency and relevance of language & narrative, use relevant patient stories to area of practice, case studies and best practice examples for sharing widely

# Collaborative programme focus:



**Objectives**

# Summary plan of work...

- 12-18 month programme
- Leadership & governance
- 7 pilot sites (7 GLH geographies) & local Leads
- 3-5 workstreams at each pilot site
- Central QI Leads to support teams
- Advice from subject-matter experts (ERG)
- Measurement for improvement
- 4 action- based workshops
- Sharing & learning – celebratory event



## What we are doing...

- Expert focus group – 26<sup>th</sup> Feb
- Directors of Nursing & Directors of Midwifery
  - ‘Masterclass’ with HEE - 10<sup>th</sup> July London
- Communications strategy for engagement at all levels

### Planned for pilot site teams - ‘Baseline’ introduction to genomics

- ‘**why**’ should I do it and ‘**what**’ do I need to do
- Identify **skillset** required to deliver the service in **my** area of practice
- Identify the gap for service delivery
- Implement programme to equip staff with ‘just-in-time’ skills for service delivery
- Test change ideas & measurement for improvement
- Embed into practice & workforce plans



# Leadership & Governance:

- **Leadership**
- Nurse-Led Genomics Collaborative Programme – locally owned, nationally spread
  - Professor Janice Sigsworth NHS National Clinical Nursing Lead
- **Governance**
  - Sites to work under their GLH & Partnership Board governance structures in their own regions.
  - Project oversight group (*Chair: Prof Janice Sigsworth*)
  - Central coordination and support from NHS England Genomics Unit
  - Shelford Group Directors of Nursing to act as a professional reference group
  - Expert Reference Group – experts for subject matter
- **Networking and roll-out**
  - Pilot site lead organisations work with others & in their geographies throughout the process
  - GLHs and partnership boards to support spread plans locally



# Outputs for the Collaborative:

- **Strategy/framework** for nurses and midwives
- Agreed set of **key principles**
- Set of **tools and resources**
  - produced during the life of the programme and signposting to existing resources
- **Case studies** and examples of **best practice**

**Embedded into workforce plans**

# Aspirations for the future

- **Nurses** at the forefront - **leading their own improvements** in genomic medicine arena, ensuring patient pathways are optimised (from a nursing perspective)
- Nurses/ midwives at every level will be developed/upskilled in the process on both genomics and how to apply it in their *specific work* area
- Patients - better informed through more productive conversations - supported by a more prepared & knowledgeable workforce
- Possible new roles/ joint roles & responsibilities for nurses emerging (e.g. genomics counsellor roles; nursing with research or consent roles)
- New knowledge shared - case studies and best practice for benefit of patients, families & the professions



# Summary

Lord Willis of Knaresborough thanked everyone for attending the day and the contributions to discussions.

The offers of help and numbers attending the day show the enthusiasm for genomics and the importance in the healthcare system.

Communication is key, the NHS needs to promote the success stories and the excellent work that takes place daily.

Educating the existing workforce will be a challenge but imperative.

Genomics is not the province of a single group of people, it is up to everyone to promote it.



# Actions and next steps

- NHSE Genomics Implementation Unit to organise a visit for TNAs to the laboratories at Leicester
- Explore potential to add genomics into preceptorship programmes
- Contact Ed if wish to be involved in the development of the educator's toolkit
- Explore how we capture patient stories and how these can be disseminated via the GEP website and links to other platforms
- Align work to the collaborative to ensure consistency of education and training, could include stories in the portal
- Encourage DoNs/DoMs to attend masterclass on the 10<sup>th</sup> July
- GEP to run an awareness raising campaign, learning lessons from the HEE dementia programme
- GEP to continue the work that is already being taken forward with Macmillan and the other cancer charities
- Round Table membership to be kept up-to-date re. the collaborative work being led by Janice Sigsworth and NHSE to ensure consistency and joined up working.



# Round Table Participants

Name	Representing	Email
Lord Willis of Knaresborough	Independent Chair	
Professor Lisa Bayliss-Pratt	Health Education England	
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Dr Anneke Seller	Genomics Education Programme, Health Education England	Anneke.Seller@hee.nhs.uk
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Cara Evan	Royal College of Midwives	
Carmel Lloyd	Royal College of Midwives	Carmel.Lloyd@rcm.org.uk
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Denyse King	Bournemouth University	dking@bournemouth.ac.uk

# Round Table Participants

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The programme has been set up to ensure staff in the health and care system have the knowledge skills and experience to keep this country a world leader in genomic and precision medicine.


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20 April 2018

Monday 5th March 2018 was the start of our first annual #GenomicsConversation, the Genomics Education Programme's (GEP) week of action for nurses and midwives. Here's a summary of our achievements...

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# HEE Genomics Education Programme

## NURSING and MIDWIFERY ROUND TABLE

