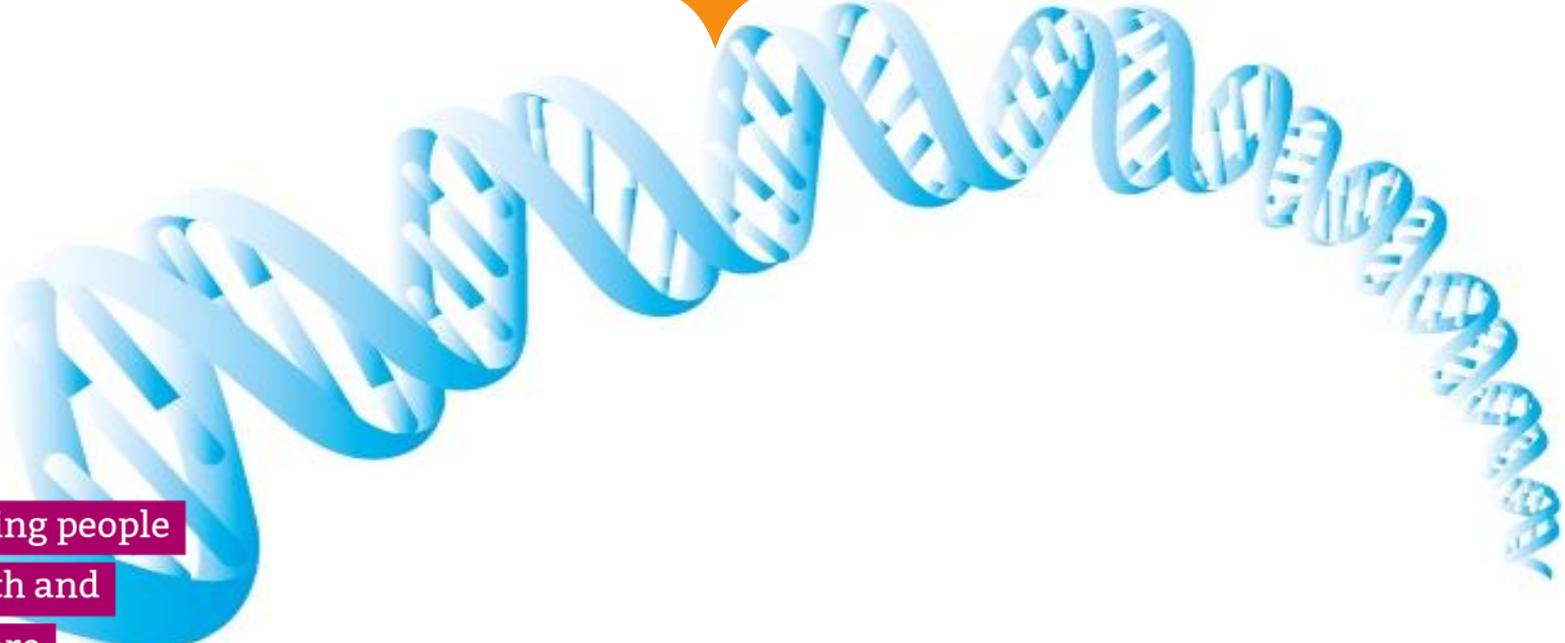


**Round table discussion:
Health Education England's Genomics Education Programme
Nursing and Midwifery Transformational Strategy
Friday 13th January 2017
Summary Report**



Developing people
for health and
healthcare

Forward from Lord Willis



Health Education England

I was delighted to accept a request from Professor Lisa Bayliss-Pratt, Director of Nursing at HEE, to Chair the Health Education England Genomics Education Programme nursing and midwifery round table event. This report gives an insight into the results of the discussion held on the 13th January 2017.

It is not intended to be a detailed account of everything that was said – rather it provides a summary of the main points that came through in the conversations. While these views may not be shared across the entire nursing and midwifery profession, they do represent the participants' opinions and thoughts at the round table.

The report's central focus is on the nursing, midwifery and the unregistered workforce. However, many of the themes raised will be equally relevant to other health and social care professionals.



Honest discussion and debate about the very real challenges so many nurses and midwives are facing today was around how we equip current and future staff for the significant changes that technology and genomic medicine brings. This is particularly at a time when the NHS is facing unprecedented pressures in the system. However, to meet the challenges that lie ahead, every individual organisation providing healthcare must ask how they can raise the bar to continue to provide a world-class health and care workforce.

Holding this extended round table conversation with many of our most senior nurse and midwifery leaders has been of enormous value in itself, but we need to take it further. This is an ambitious project with an ambitious goal: we want to drive changes at a local, national and global level.

Finally, I would like to thank Professor Sue Hill as an invaluable source of information, colleagues from the Genomics Education Programme and everyone that attended on the day for their ideas, support and pledges. This has been an invaluable learning experience for everyone involved in this ground breaking round table discussion.

Lord Willis of Knaresborough – Independent Chair

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Introduction



Health Education England

Genomics medicine is advancing rapidly and is set to accelerate the mainstreaming of genomics into routine clinical care as well as education and research practice over the next few years. The Health Education England Genomics Education Programme has listened carefully and as a result recognises there is a lot more work to do. In order to do this in an informed way, we decided to continue the engagement process by working with those with particular expertise across the nursing and midwifery fields of practice.

The NHS England “Improving Outcomes through Personalised Medicine” strategy document states that:

“Britain has the opportunity to be at the forefront of this new era of medicine, delivering 21st century healthcare. As the single biggest integrated healthcare system, combined with our world leading science base and global reputation for innovation, we have the opportunity and capability to transform the way we deliver healthcare to secure benefits for our patients, our society and our economy.”

It is recognised that nurses and midwives will be instrumental in making the significant changes required to embed genomic medicine into healthcare.



Through discussions with Professor Lisa Bayliss-Pratt it was agreed that we would bring together leaders and experts in nursing and midwifery practice to generate new ideas and explore as broadly and radically as possible what would be the best educational system to support nurses and midwives in this endeavour.

Importantly, we also understand that the nursing and midwifery education curricula will need to be reviewed and strengthened around genomics. We need to meet the demands of a constantly changing health care system, capable of developing nurses and midwives, who are both flexible and confident in all settings in the future.

The round table session was structured to present a summary of the Health Education England Genomics Education Programme and the NHS England 100,000 Genomes Project. This was followed by a full and frank discussion between the invited experts where specific themes were explored in greater detail.

Finally, Lord Willis considered the content of the discussion as a whole and reflected on key themes, opportunities and recommendations around the next steps, which were then agreed.

This summary represents the comments and thoughts of the round table discussion on the day, supported by visual minutes.

Independent Chairman



Health Education England

HEE has a national leadership role in developing the current and future workforce. A round table approach was agreed as the mechanism for bringing together a range of senior leaders and interested professional bodies across nursing and midwifery professions.

Lord Willis of Knaresborough was delighted to accept a request from Professor Lisa Bayliss-Pratt, Director of Nursing at HEE, to chair this event.



**Lord Willis of Knaresborough
Independent Chair**



**Professor Lisa Bayliss-Pratt
Director of Nursing & Deputy Director of
Education and Quality
Health Education England**

Purpose of the roundtable

HEE wanted to explore this topic as broadly and radically as possible, in the hope that bringing experts together would generate new ideas, to mobilise the professions through sharing and exploring experiences and opinions.

The overarching objectives of the discussion were to:

- Raise awareness of the key drivers, strategies and personalised medicine in genomics.
- Outline how the genomics programme will impact on the nursing and midwifery professions and patient outcomes.
- Raise the profile of the HEE Genomics Education Programme and its work in this critical area of healthcare.
- Bring together, engage and mobilise key leaders from the nursing and midwifery community and a wide range of organisations to gather their view and champion the agenda. Providing expert advice and guidance on the potential short term and longer term solutions needed to inform any further actions.
- Identify key inputs and baseline perspectives from a diverse group of nursing and midwifery leaders around how we embed genomics and personalised medicine into clinical, educational and research practice.
- Identify and take into account work already undertaken, identify differing opinions and establish a means to gain consensus.
- Ensure everyone could contribute and explore as broadly and radically as possible a variety of options during our time together.



Invitations



Health Education England

National leaders from the nursing and midwifery system and representatives from a range of organisations were invited, to gain their expertise and develop our thinking around what makes excellent practice in genomics education.

This also helped us better understand the challenges, develop new ideas through sharing and exploring together, in order to secure the best educational system for genomics in the future.



Participants



Health Education England

Name	Representing	Title
Lord Willis	Independent Chair	
Professor Lisa Bayliss – Pratt	Health Education England	Director of Nursing and Deputy Director of Education & Quality
Professor Sue Hill	NHS England	Chief Scientific Officer
Dame Professor Donna Kinnair	Royal College of Nursing	Director of Nursing
Joanne Bosanquet MBE	Public Health England	Deputy Chief Nurse
Dr Julie Green	Representing Queen's Nursing Institute	Director of Postgraduate Studies, Lecturer in Nursing and Award Lead for Specialist Community Nursing (District Nursing).
Karen Stansfield	Institute of Health Visiting	Head of Education and Quality
Philippa Jones	MacMillan	Associate Acute Oncology Nurses Advisor
Jane Niederer	Nuffield Department of Surgical Sciences at University of Oxford	Lead Research Nurse for Surgical Research Team
Carmel McCalmont	Representing RCM	Head of Midwifery - University Hospital Coventry and Warwickshire
Dr Susan Hamer	Clinical Research Network - National Institute for Health Research	Director of Nursing, Learning and Organisational Development
Anne Trotter	Nursing and Midwifery Council	Assistant Director
Zoe Scullard	Health Education England	Health Dean
Sue Hatton	Health Education England	Senior Nursing Policy Manager
Dr Anneke Seller	Genomics Education Programme	Genomics Education Programme Scientific Director
Maxine Foster	Genomics Education Programme	Genomics Education Programme Director
Alison Pope	Genomics Education Programme	Genomics Education Programme Operations Manager
Dr Ed Miller	Genomics Education Programme	Senior Education Development Officer
Charlotte Szczepanik	Genomics Education Programme	Project Administrator

Agenda

The key issues discussed during the day can be summarised as follows:

Introduction

What does HEE hope to get out of today's discussion?

Presentations

Presentation - How is genomic medicine changing service models?

Presentation - Brief background and progress to date on the HEE Genomics Education Programme.

Discussions

How nursing and midwifery practice needs to change to adapt to advances in genomic medicine?

What opportunities there are for the nursing and midwifery profession and what might be some of the workforce and education challenges?

How we mobilise and strengthen the nursing and midwifery contribution to genomic medicine?

Roles and responsibilities and how the Genomics Education Programme can support?

Summing up

Take home messages and next steps.



Background

The Genomics Education Programme is currently a Department of Health funded programme, which sits within HEE and was created to ensure the NHS becomes a world leader in genomic and precision medicine by educating and preparing the current and future workforce through:

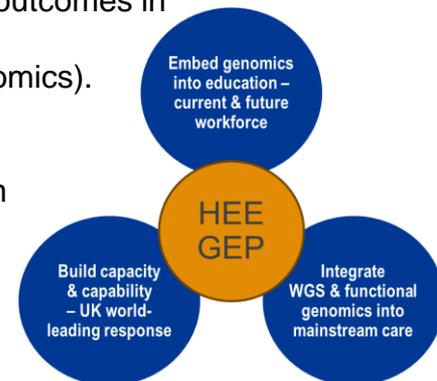
- Directly supporting healthcare professionals involved in Genomics England's 100,000 Genomes Project
- Supporting the wider transformation of services to integrate genomic technologies into healthcare
- Upskilling existing staff so they can make the most of genomic technologies in their work

The training audience

Our programme aims to reach all staff within the NHS including those in general practice and the community. We are developing resources ranging from awareness materials for patients and the public to very specific resources for specialised and the highly specialised workforce involved in the delivery of the 100,000 genomes project.

How are we achieving our aims?

- **Educational Resources** - The programme has created a variety of educational materials and has adopted a range of approaches including face to face, blended learning, and online.
- **Designing curricula and supporting the delivery of formal training** - We are funding:
 - over 550 MSc in Genomic Medicine commissions across 10 university providers in England.
 - 1,000 CPPD MSc modules to attract interest from the wider workforce. We have developed new and revised curricula for the Scientist Training Programme in Genomic Sciences (specialist outcomes in Genomics and Genomic Counselling)
 - new curricular for the Higher Specialist Scientist Training in Clinical Bioinformatics(Genomics).
- **Managing programme networks to improve delivery of genomic services to the NHS**
- **Workforce Transformation** – To support change across the system.
- **Web-based presence** - The website hosts links to the programme's online resources with a wealth of external links and resources.
- **Global Presence** - The programme is starting to raise its profile globally, working with international colleagues to learn lessons and share knowledge.



Setting the Scene

i) How is genomic medicine changing service models?

(Appendix 1- Presentation:1)

Professor Sue Hill, gave a presentation setting the context, outlining the key drivers and strategies in genomic medicine and explaining the impact of personalised medicine on the nursing and midwifery profession and patient care.

There is already a long history in the UK of genomics in practice and we need to build on that. Staffing is a fundamental issue and there is a need to extend the engagement with the nursing and midwifery professions particularly around the 100,000 Genomes Project across all areas of the NHS system.

Science and innovation provides the revolutionary change healthcare needs with opportunities to improve patient outcomes, but personalised medicine is going further than science alone. Service models will need to change at scale and pace to adapt to advances in technology and service delivery requirements. The cost of sequencing a genome has dropped significantly and by April 2018, Whole Genome Sequencing will be introduced as part of routine testing for the NHS.

As a result patients will want to have detailed conversations with nurses and midwives and we need to prepare and upskill the workforce to be actively engaged with the process. Consideration also needs to be given to the skill mix across multi-disciplinary teams e.g. where a clinical nurse specialist could be supported to concentrate on more specialist work.

This is a fast moving field and education and training approaches will need to be innovative. Nurses and midwives along the patient pathway will have different educational requirements and learning styles.

Creating and strengthening nursing leadership to drive the necessary changes around personalised treatment options is critical, supported also by moving from an illness to health focus including 'Predication', 'Prevention', 'Participation' & 'Personalised Care'.



Professor Sue Hill
Chief Scientific Officer for England,
SRO for the NHS England 100,000 Genomes Project

Setting the Scene

ii) Progress on the Genomics Education Programme (Appendix 1- Presentation: 2)

Dr Anneke Seller introduced the HEE Genomics Education Programme and explained that the overarching intention of the round table was to raise awareness and jointly discuss how we embed genomics into nursing and midwifery professional practice.

The 3 Genomics Education Programme aims are to:

1. Directly supporting those professionals involved in the 100,000 Genomes Project and Microbial Genomes work.
2. Supporting the wider transformation of services to integrate genomic technologies into healthcare.
3. Upskilling existing staff so they can make the most of genomic technologies in their work.



Dr Anneke Seller
Scientific Director, Genomics
Education Programme
Health Education England

HEI Network

- Exeter University
- Imperial College University
- St Georges – Kings Cross University
- Queens Mary University
- Sheffield University
- Manchester University
- Birmingham University
- Cambridge University
- Newcastle University
- Southampton University



The round table was updated on:

- New postgraduate curricula for Healthcare professionals
- Multi-professional Master's in Genomic Medicine
- Pump priming additional training places
- 100k GP Consent Training Days – 40+ GMC participants to date
- PLUS Resource development to support the move to more Personalised Medicine across the NHS

Setting the Scene

iii) 13 Genomic Medicine Centres and other potential networks

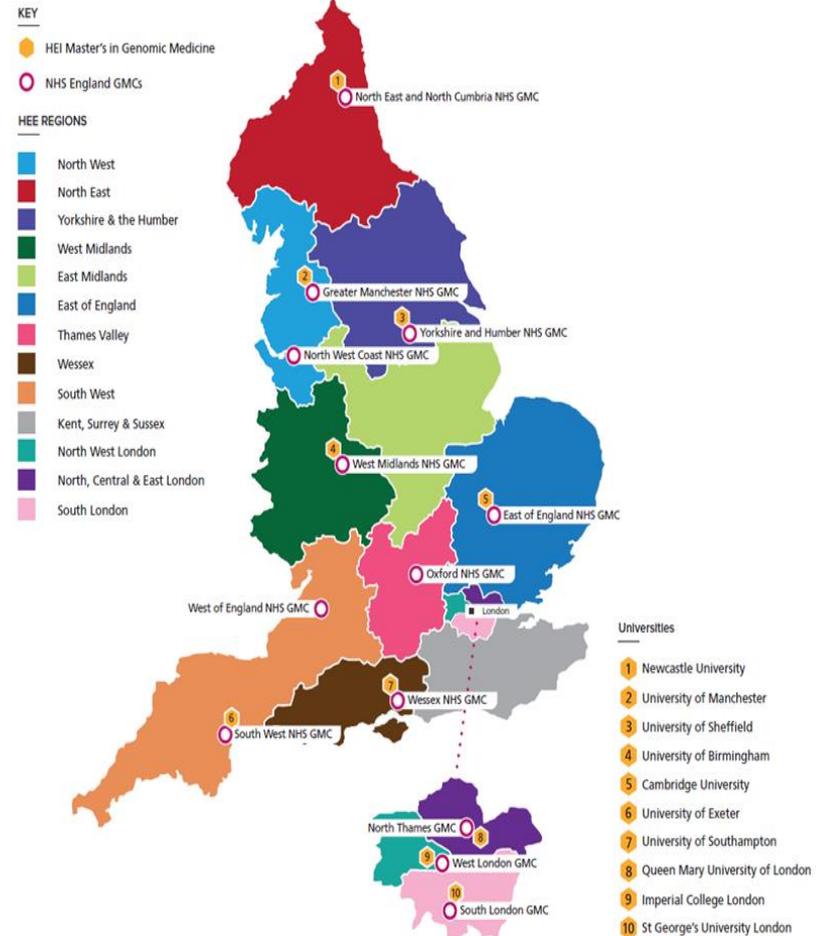
There are currently 13 Genomic Medicine Centres across the UK, each of which host an Education and Training Lead funded by the Genomics Education Programme.

These are lead organisations working with local partners to drive the delivery of the 100,000 Genomes Project and focus on the integration of the education and workforce development being led by the Genomics Education Programme.

It was widely agreed that we need to work with these existing and other potential networks to drive new partnerships and co-operation within multi-disciplinary teams.

It is also important to recognise that genomics is already making an incredible difference within healthcare and we need to build on the activity and developments that are already in place.

There is potential to create Genomic Ambassadors linking with Academic Health Science Networks who could act as multi-professional champions, spreading knowledge to others, as part of their career development. It was agreed by the round table that this would be a recommendation to take forward.



How does nursing and midwifery practice need to change to adapt to advances in genomic medicine?

Preparing the future nursing and midwifery workforce

Within this session of the round table event discussions focused on the graduate workforce in 2030 and what their requirements may be to meet advances in technology and changes in service models. It was unanimously agreed that genomics needs to be included in the nursing and midwifery pre-registration competencies and curricula, particularly now it is embedded in the Nursing Associate Framework, GCSE and A level science curricula.

It was acknowledged that nurses and midwives will have different educational requirements depending on their speciality or field of practice. A key element is managing the patient and public's expectations around 'cures' and ensuring consent, ethics and the storage of personalised data is effectively managed and communicated along the patient journey.

In addition to education and knowledge acquisition, It is important to place emphasis on changing patient pathways, to drive change and trigger intervention and improvement.

There was a recognition that within public health, sexual health nurses, PH nurses are midwives are already heavily involved in genomics through the prevention of infectious diseases in areas such as TB, Gonorrhoea and antenatal new born screening, surveillance and epidemiology.

This raised the importance of the need to use a common and consistent language to describe genomics activity. We need to think carefully about how we define this area so that it is easily identifiable as being within the genomics field.

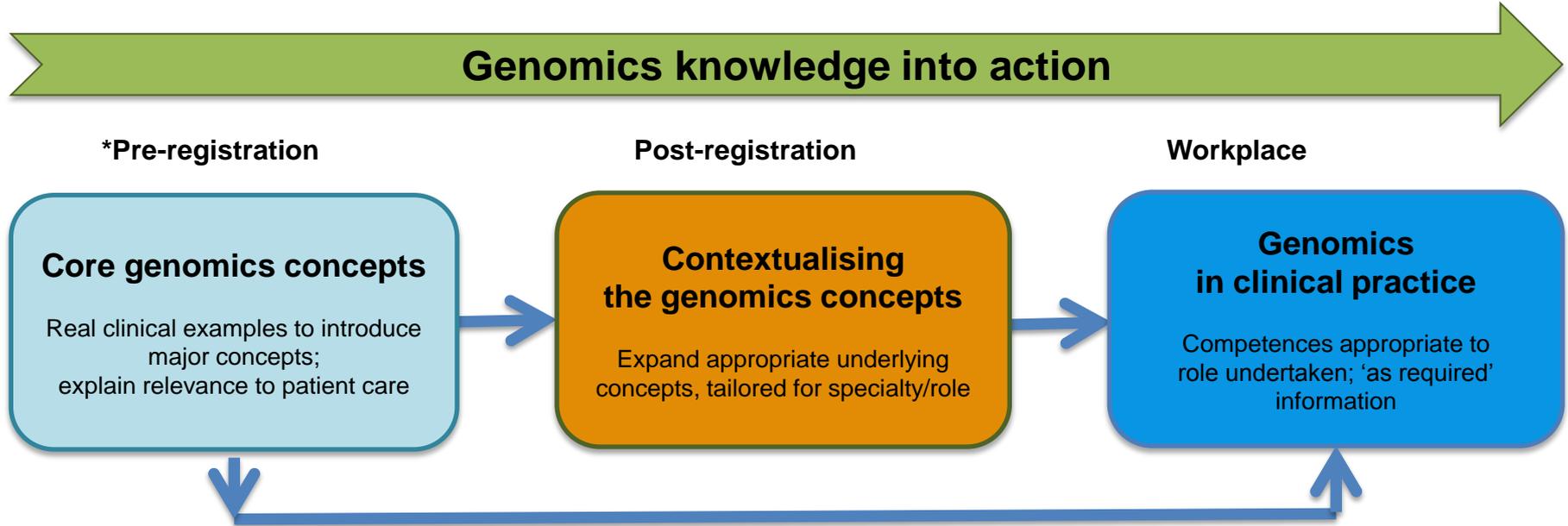
Skills already exist but the personalised medicine agenda may require a different approach.

We need to utilise experiential methods to ensure we learn from mistakes and share and develop as we go.



Genomic medicine is relevant at all stages of the education continuum

The GEP continuum of genomic medicine education



**This also covers the training undertaken by non-registered NHS staff e.g. Nursing Associates*

What is the step change and how do we make it happen?

There were a number of cross-cutting themes that emerged:

Leadership and collaboration: Nursing and midwifery

- There is a need to look at what's happening internationally and not reinvent the wheel.
- Nurse and midwifery leaders need to pick up the baton and see this as one of their priorities.

Pre-registration and post-registration education:

Clear messaging around:

- Why genomics matters to pre-registration nurses.
- What genomics means to health visitors, school nurses, general practice and district nurses and the families they care for.
- Supporting alternative placements e.g. Public Health England.
- Opportunities to strengthen knowledge within the preceptorship and other post graduate programmes.
- We need to educate the workforce before service change hits.

Utilising existing skills

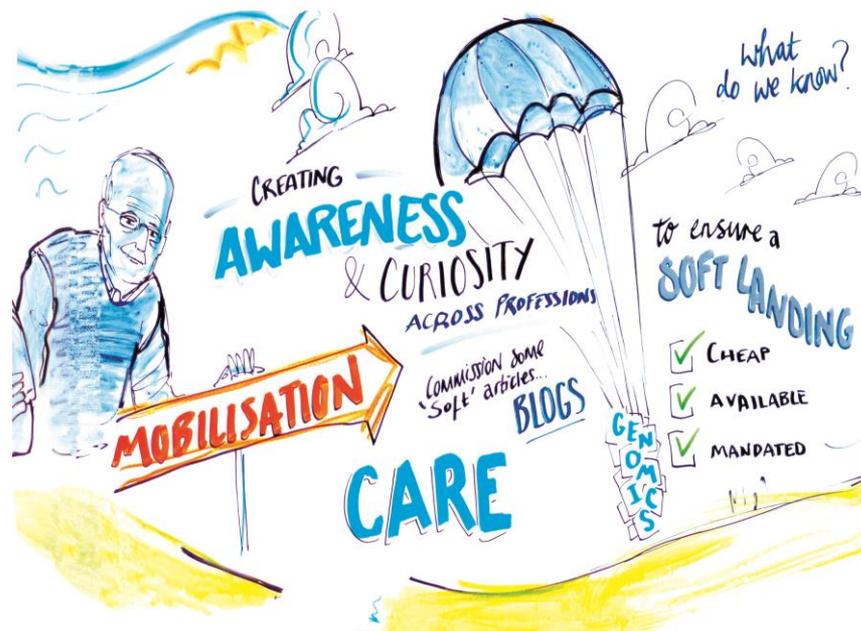
- Skills already exist within nursing and midwifery in areas such as consent and ethics, but it is the personalised care element that needs to be developed and strengthened within education programmes.
- There are specific roles and fields of practice where genomics is already present and we could learn from best practice e.g. ante-natal screening.



How do we mobilise and strengthen the nursing and midwifery contribution to genomic medicine?

Leadership and collaboration

- Be clear about who is leading the agenda- 3 principle players: the HEE Genomics Education Programme, NHS England and PHE working in partnership with a variety of Arms lengths bodies, organisations and professional bodies.
- Need to embrace what is currently happening in genomics and get our starting point right.
- Strength links and understanding where information is being produced, how it can be found and in what format enabling others such as commissioners to come on board
- Build a wider community through HEE Leads and regional communities of practice e.g. 13 GMCs.
- Review the need and membership for a HEE Nursing and Midwifery Steering Group to support the Genomics Education Programme in driving the agenda forward.
- Utilise other nursing and midwifery networks e.g. Maggie Kirk's work and global alliance.
- Explore the interest for a RCN Genomics Forum?
- Explore and develop a mechanism for individuals or organisations to sign up and pledge to be a Genomic Ambassador as part of a commitment to have 100,000 Ambassadors aligned with the 100,000 Genomics project.



“Raising awareness across the workforce will drive it – genomics will land more softly with everyone if they know something about it”

- Need to see the impact and get results from the 100,000 Genomes Project to see where it's making a difference by utilising case studies or profession specific information and social media.

How do we spread knowledge amongst the professions?

Communication and practical examples suggested

- We need concrete examples to communicate in ways that people can understand genetics and genomics.
- Create videos with example scenarios of how genomics is being used within certain roles with a focus on why it matters in pre and post registration education.

Levers

- Explore opportunities to mandate through the various contracts that organisations hold.

Creating a social movement and professional mobilisation

- Genomic Ambassadors were seen as one of the key initiatives to create the social movement required across the nursing and midwifery professions and wider.
- Critical mass and behaviours – if we get 1 in 6 the rest will follow e.g. Target 100,000 and reach could potentially be 600,000. Successful social movements in Dementia and HIV were acknowledged.

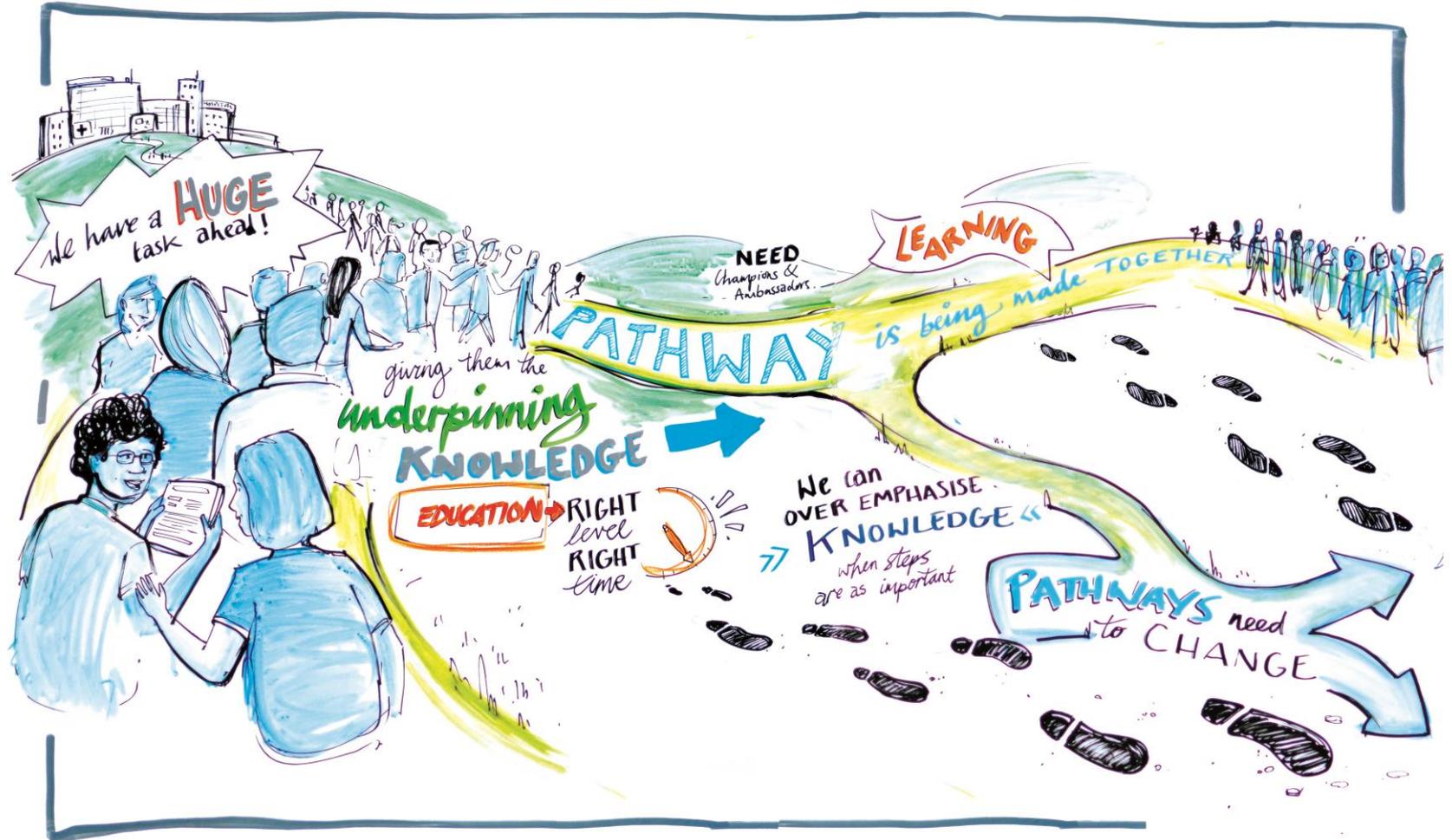
Patient Public Engagement

- Patient and public awareness was recognised as key. We need to define what genomics means to the patient/client and place them at the heart of what we do, whilst managing expectations.
- Strengthening awareness with children and young people through schools, colleges and 6th forms.
- Utilise and join up with the Genomics England engagement programme, which relates to the 100,000 Genomes Project.

Partnership Working

- Involve charities to empower staff e.g. Cancer UK, Macmillan CNS workforce.
- Recognised that private providers will be keen to be on board with the programme.





Key findings and recommendations

A number of overarching themes emerged

Of course, many of the solutions to the issues identified are the responsibility of local leaders and providers. However, there are also critical implications for national leaders and organisations. It is particularly important to ensure that we continue the debate and champion the development and implementation of the Genomic Education Programme strategy to transform and embed genomics into nursing and midwifery practice.

1. Nursing & Midwifery Leadership

It is critical that we mobilise new and existing networks to raise awareness of genomics and its impact on nursing and midwifery practice and healthcare generally. Utilising the 13 GMC Education and Training Leads within Trusts across the country we can introduce the topic more broadly, help identify and share areas of good practice and map and develop case studies currently being used in practice



We need to scope where activity is currently taking place and build a wider community through HEE, NHS England and PHE. It is important to place emphasis on changing patient pathways and putting steps in around the fundamentals of care and the process to drive change, trigger intervention and improvement, rather than focusing purely on knowledge acquisition.

2. The NMC and Council of Deans

There needs to be strong links with the NMC and Council of Deans to make sure there is a focus on understanding genomics within the undergraduate and post graduate curriculum.

This should help nursing and midwifery students to reflect on the realities of practice and the complex human interactions involved around genomics and also consider genomics in the context of treating the whole person.

3. Understanding pathways and patient touch-points

There is a need to understand where the genomics touch-points are along the patient pathway and identify education and training needs for those staff who are coming into contact with this activity.

4. Building Capacity and Capability

There is a need to build the right skills, knowledge and competencies to support NHS staff to deliver their best, working in partnership with patients and their families.

5. Genomics education

The important components are knowing how to pace the information you are giving and pitching information at the right level. We need to recognise that this isn't a 'one size fits all' approach and different people will have different requirements within a variety of roles, specialties and areas of the NHS system.

6. Communication

Raising awareness both within the nursing and midwifery profession and with patients and the public is vital to drive a social movement and change across healthcare. Communications need to be consistent and targeted at the right level using the best possible channels available to spread the word at scale and pace.

7. Language

We need to ensure we are using the right language to define activity in this area so that it is easily identifiable within the genomics arena.

8. Genomics Ambassadors

will be key and we should commit to having 100,000 nurses and midwives educated to a level where they can support others to understand what genomics is and its impact on healthcare.



Round table pledges

Organisation	A variety of pledges were made which are summarised below:
Public Health England/RCNi	PHE pledged to commission a variety of articles with RCNi, develop blogs, write peer review pieces for Cancer Nursing and Nursing Standard, work with the GEP and support 100,000 Ambassador Programme. WHO has designated the Chief Nurse Directorate at PHE as a WHO Collaborating Centre for Public Health Nursing and Midwifery, so they will look into genomic connections with WHO through the global network of Collaborating Centres.
Health Education England	HEE pledged to develop a steering group and programme of work to support the nursing and midwifery professions moving forward. Membership of the round table will be reviewed to determine if any additional partners need to be invited. Explore opportunities for a nursing and midwifery fellow enabling some dedicated time to drive the genomics programme forward across the professions in partnership with a professional body. HEE, with a dedicated communications manager within the Genomics Education Programme team will support consistent messaging to the professions. Review the HEE ACP Framework to include genomic competencies.
Royal College of Midwives	RCM pledged they will publicise the Genetics and Genomics for Midwifery Practice iLearn module.
Royal College of Nurses	RCN pledged they will develop a blog to members, develop articles in the RCN Bulletin, establish links with Maggie Kirk and request the RCN library to undertake a literature search to share with colleagues at the round table.
MacMillan	MacMillan pledged that they would determine support for Clinical Nurse Specialists and whether MacMillan can support the Ambassador Programme.
Nursing and Midwifery Council	NMC pledged to review draft competencies for pre-registration nursing and explore opportunities to include genomics within the post-registration space.
Institute of Health Visiting	IHV pledged to review the genomics competencies needed within the National Curriculum 0-19 Health Visitor/School Nurse Stakeholder Group and develop articles in IHV bulletin.
Queens Nursing Institute (represented by Dr Julie Green, Keele University School of Nursing and Midwifery)	Dr Green, as representative for the QNI, pledged to feed back the round table discussions to the QNI, link into the RCN District Nursing Forum and review the MSc ACP curriculum at Keele University. Dr Green also personally pledged to complete the MOOC on 'Whole Genome Sequencing' and encourage colleagues to do the same.
Lord Willis	Lord Willis pledged to use the visual outputs from the round table for blogs. Raise genomics at the NIHR CLAHRCs and the Association of Medical Research Charities Board to communicate with all charities.

Lord Willis closed the meeting by thanking attendees for their involvement and valuable input. He concluded that urgency is imperative and language of the utmost importance. We don't want to miss the boat!

Next steps were identified as follows:

- Distribute report outlining the round-table discussion and identifying how we take this programme of work forward, timescales etc.
- Distribute summary of the Global Nursing Alliance Retreat 23-25 January 2017
- February 2017 – round table group provide updates/progress on their pledges
- March 2017 – Steering Group Meeting
- June-July 2017 – 2nd round table planned. Date to be confirmed.



Further information

i) Genomics Education Programme Website & Infographic

www.genomicseducation.hee.nhs.uk



Home | News | Online Courses | Taught Courses | Resources | About Us



Genomics Education Programme

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. [Read more](#)

 <p>Sign Up to Our Whole Genome Sequencing Course</p>	 <p>Master's in Genomic Medicine (Fully Funded to NHS Staff)</p>	 <p>Genomic Medicine Professional Development Modules</p>
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Latest News

A genomic tool for better antenatal care
Written on Monday, 11 July 2016 10:29

French plans for a genomic healthcare future
Written on Monday, 04 July 2016 10:41

4.50 from Paddington to Genomics
Written on Monday, 27 June 2016 12:55

MSc in Genomic Medicine: Faculty Symposium
Written on Tuesday, 21 June 2016 14:59

Genomics in the battle against Zika virus
Written on Monday, 20 June 2016 11:23

And our social media...

www.facebook.com/genomicsedu

www.twitter.com/genomicsedu



Contact us ... 

genomicseducation@wm.hee.nhs.uk

The Genomics Education Programme

A funded NHS initiative that ensures healthcare professionals have the genomics knowledge they need for the future.



Training existing and future NHS healthcare professionals



Supporting and enhancing the 100,000 Genomes Project



Bringing better care and lasting benefits to patients



Genomics

- The study of an organism's complete set of genetic information.
- 'Genome' - the complete genetic information of an organism.
- The genome includes both genes and non-coding DNA.

VS



Genetics

- The study of heredity
- The study of the function and composition of single genes.
- 'Gene' - specific sequence of DNA which codes for a functional molecule.

Key partners



Department of Health



Public Health England



NHS England



NHS Health Education England



Genomics England

NHS Genomic Medicine Centres

GeCIP domains



Our educational resources



Master's in Genomic Medicine

Multidisciplinary qualifications that can be applied to research and clinical practice.



Short online courses

Engaging and interactive courses that are tailored for professional development.



Training tools

Digital training to directly support the 100,000 Genomes Project.



Multimedia

A collection of informative videos, images and animations that assist in genomics learning.



Events

Our team facilitates a series of genomics workshops and events that run alongside the education programme.



Genomics is for everybody



Highly specialised workforce

- Clinical and laboratory genetics
- Molecular pathology
- Molecular haematology
- Bioinformatics



Specialised clinical workforce

- Cancer surgery and medicine
- Cardiovascular, diabetes and neurology specialist teams



Wider clinical workforce

General practice and other healthcare professionals



Raising awareness

Managers, commissioners, patients and public

“At times it feels like we are learning a new language, but it is definitely worth it.”

- Katherine, Nurse

“The programme is part of a bigger movement across the country, genomics and personalised medicine is the future.”

- Brenda, Masters Student



ii) Global Genomics Nursing Alliance



Nurses have a pivotal role in bringing the benefits of genomics to everyday healthcare. However global effort is needed to transform nursing policy, practice, education and research to be cognisant of the biopsychosocial and ethical implications of genomic technologies for individuals and societies. We want to establish the first global genomics nursing alliance to address these issues.

The Global Genomics Nursing Alliance (G2NA) project represents the culmination of concerted national and international efforts to accelerate the integration of genomics into everyday practice.

Background

Genomics advances that have evidence-based clinical utility have implications world-wide across the healthcare continuum and impact all nurses regardless of academic preparation, role or clinical specialty. Embracing genomic healthcare requires a prepared workforce that can inform, educate and empower people, addressing existing and novel ethical issues and anticipating any potential negative impact on vulnerable populations. However, this represents a significant challenge as deficits in genomic literacy in nursing and other health professions are widely acknowledged.

Aim

The primary aim of this initiative is to strategise on methods to establish a Global Genomics Nursing Alliance (G2NA) to accelerate the integration of genomics into everyday professional practice.

Accelerating integration of genomics into everyday nursing practice

Establishing the Global Genomics Nursing Alliance for knowledge mobilisation and action around developments in nursing and genomic healthcare.

Creating a G2N Roadmap that lays out how to integrate genomics into nursing education, practice and research.

Agree and prioritise the collaborative efforts needed to realise the Roadmap.

A summary will be distributed after the retreat to all members of the roundtable.

ROUND table DISCUSSION

HEALTH EDUCATION

ENGLAND'S Genomics Education Programme

JANUARY 13th 2017

Nursing & Midwifery TRANSFORMATION Strategy

the solutions are within the system, we need to take the OPPORTUNITIES

this is the FUTURE

& we need to train & educate our staff to LEAD

NURSES & MIDWIVES have a VITAL ROLE to play!

How to EMBED?

INCLUDING a Module
high quality LEARNING graduate workforce

UP SKILLING

We have a HUGE task ahead!

giving them the underpinning KNOWLEDGE

EDUCATION → RIGHT level RIGHT time

WE CAN OVER EMPHASISE KNOWLEDGE when steps are as important

PATHWAYS need to CHANGE

3 billion letters
FINDING PLANNING

100,000 Genomes Project
enabled by advances in DATA & COMPUTING

WE have been building a NETWORK!

partnerships & collaboration like we've never seen before!

LEARNING is being made TOGETHER

EMBEDDING in EDUCATION & MAINSTREAM CARE
FIRST GRADUATE COHORT
MULTI PROFESSIONAL MASTERS
ONLINE RESOURCES & COURSES

PATHWAYS need to CHANGE

Access to HEALTH PERSONALISED MEDICINE

Holistic Care
Better Characterisation
Informing Primary & Secondary Interventions
Increased diagnostic capacity

NON structural DATA
CONTROLLED ACCESS
still a challenge of CONSENT & ETHICS
esp for frontline staff

LONG TERM legacy

We can't learn in Isolation

CREATING AWARENESS & CURIOSITY ACROSS PROFESSIONS
Commission some Soft activities
BLOGS
GEMMA GALE?

MOBILISATION
Mainstream CARE
ENGAGING EVENTS
Developing COMMUNITIES OF PRACTICE Partnerships

TRAINING & EDUCATION MATERIALS
New Modules
CURRICULUM
LITERATURE SEARCH
Teaching the FRONTLINE

What are the KEY MESSAGES?
how to keep them consistent?

A COMMON LANGUAGE?
"We call it SURVEILLANCE & EPIDEMIOLOGY"

MAPPING the System
What do we know?
What are we already doing?
How are we doing it?

FUNDING?
R&D New skill sets

TO ensure a SOFT LANDING
✓ CHEAP
✓ AVAILABLE
✓ MANDATED

NEED LEADERSHIP & COLLABORATION
SPECIALISTS
Who is talking to WHO?
REGIONAL Community of practice

If the public demand it then we have to deliver

URGENCY!
we don't want to miss the BOAT!

KEEPING MOMENTUM
SHARING the KNOWLEDGE GLOBALLY
not trying to reinvent the WHEEL

100,000 Genomics Ambassadors
HOW TO SUPPORT?
Don't want to create a relay race with no one to pick up the baton...



Artwork by Creative Connection.co.uk

If you have any comments or queries?

Please contact:

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Appendices

- Presentation - How is genomic medicine changing service models?
- Presentation - Progress on the Genomics Education Programme

How is genomic medicine changing service models?

Professor Sue Hill @CSOsue

Chief Scientific Officer for England

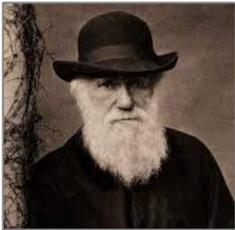
SRO, NHS Genomics Programme

13 Jan 2017



Science & innovation provides the revolutionary change health needs

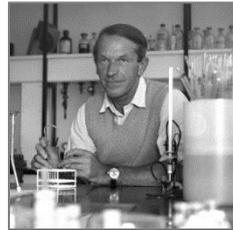
- Throughout its existence, the NHS has turned to scientific innovation to provide the step-change in practice required to keep pace with patient needs and service demands
- Genomics builds on the long history of discovery and advance in the UK



**1859: Darwin –
Origin of Species**



**1951: Watson
& Crick**



**1974: Sanger
– DNA sequencing**



**1984: Alec Jeffreys –
DNA fingerprinting**

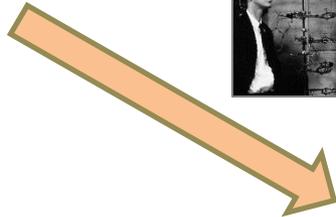


**1997: Dennis Lo –
cfDNA NIPT**

PLUS firsts in:

- Diagnostic ultrasound
- CT scanning
- IVF & PGD

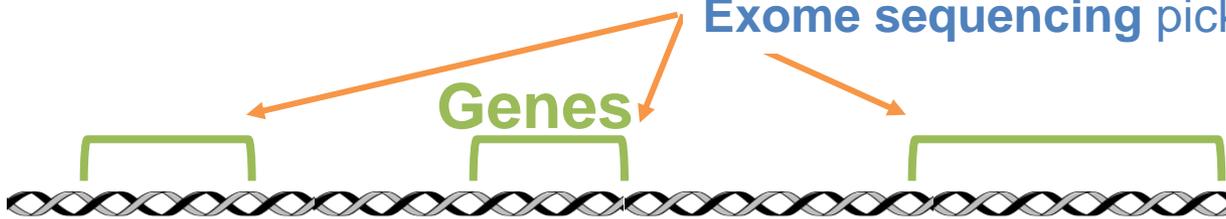
UK has fostered more than twice as many Nobel prizes for Medicine & Physiology per capita than anywhere else in the world.



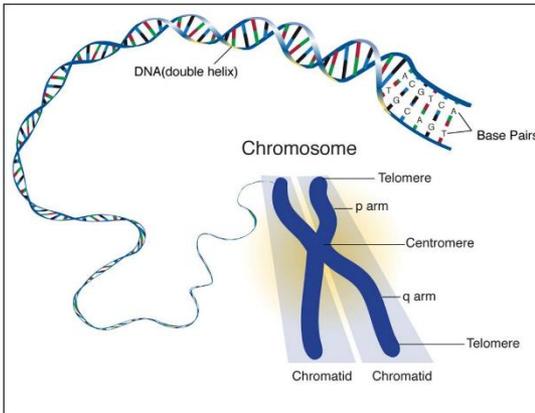
The NHS has had specialist genetic labs since the 1960s, with Next Generation Sequencing capability & UK Genetic Testing network - sponsored by NHS England - coordinating role for approval of tests/panels for routine care purposes

Exploring the human genome

Exome sequencing picks out all the genes



Genome sequencing:
examines all 3 billion DNA 'letters'

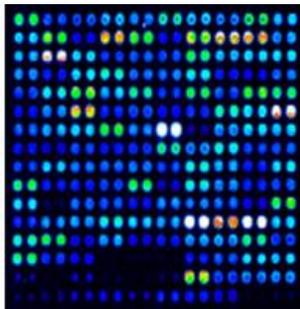


Gene – a region of DNA that encodes function
- the molecular unit of heredity

Mutation – changes in the DNA sequence of a
gene which may (*or may not*) affect the coded
product and may (*or may not*) be pathogenic

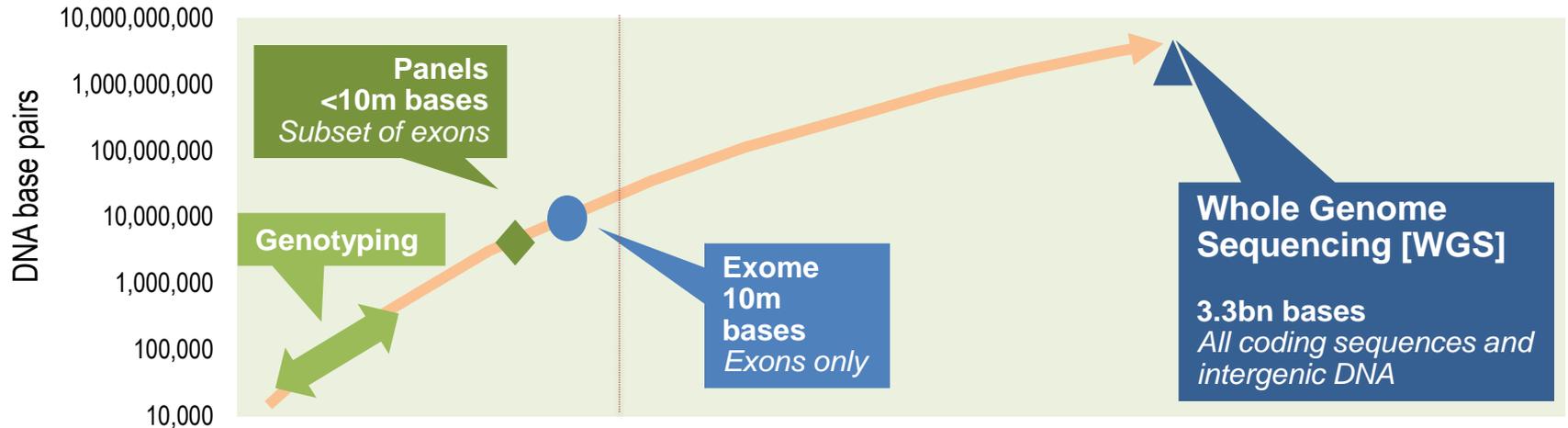
Genome – the **complete** set of genetic
material in an organism

Exome – all the coding regions of the Genome
(*only about 1.5% of the total genome in
humans*)



Panel
testing picks
out a few
genes of
interest

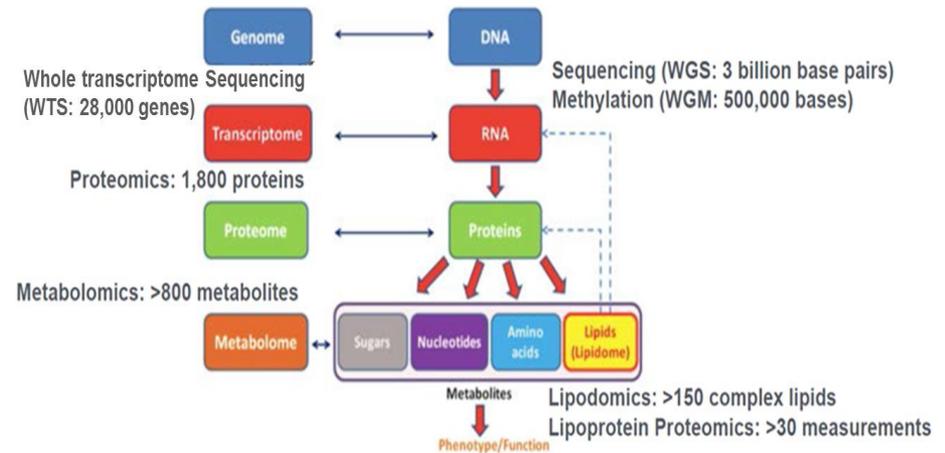
Genomic & computing advances have provided an exponential jump in diagnostic data



Existing testing

UKGTN: since 2003
 562 tests recommended, 95NGS with 231 sub-panels; 4800 genes can now be tested from clinical exome within NHS genetic laboratories - combined specialist and CCG funding
Molecular diagnostics for cancer generally provided by pathology - mainly CCG funded

Functional Genomic Pathway



Alongside WGS, information from the functional genomic pathway – the steps in translating the genetic code – provides a wealth of information and insight, with important implications for future testing

The 100,000 Genomes project - a catalyst for change combining technology & information: *Health Education England*

In 2012 PM David Cameron launches 100,000 Genomes Project made possible due to the decreasing cost of sequencing and developments in computational power and data analytics

“By unlocking the power of DNA data, the NHS will lead the global race for better tests, better drugs and above all better care.”

Major legacies for patients, the NHS and the UK economy by 2017

Increased discovery of pathogenic variants leading to **new treatments, devices and diagnostics**

Accelerate uptake with advanced genomic medicine practice **integrated into the NHS**

Increase **public understanding & support** for genomic medicine

Stimulate and advance UK life sciences industry and commercial activity in genomics

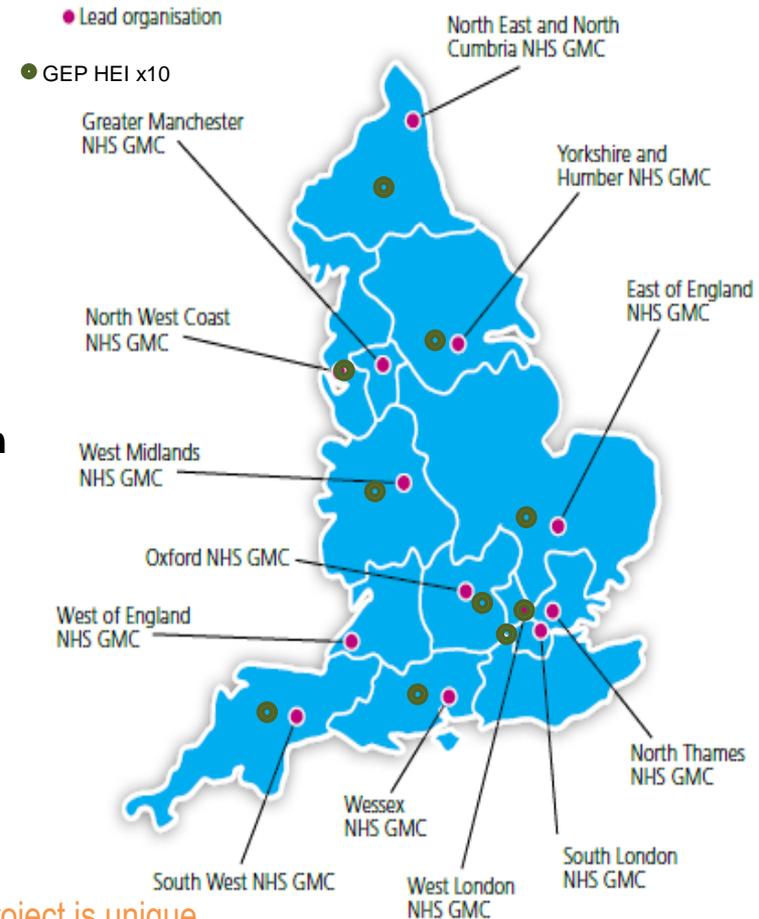
Key Principles

1. A focus on **rare inherited diseases** and **common cancers**
2. Patients to be **drawn from routine care** and **treated through routine channels**
3. All participants to provide **a fully informed consent providing for a wide range** of data and tissue capture and broad categories of use including research and industry
4. However **neither data nor tissues to go outside NHS-controlled ‘safe havens’** and all users to be properly authorised and monitored
5. A separate (*government owned*) company – Genomics England – formed to coordinate the project under an independent board, providing a **‘start-up’ mentality and drive**

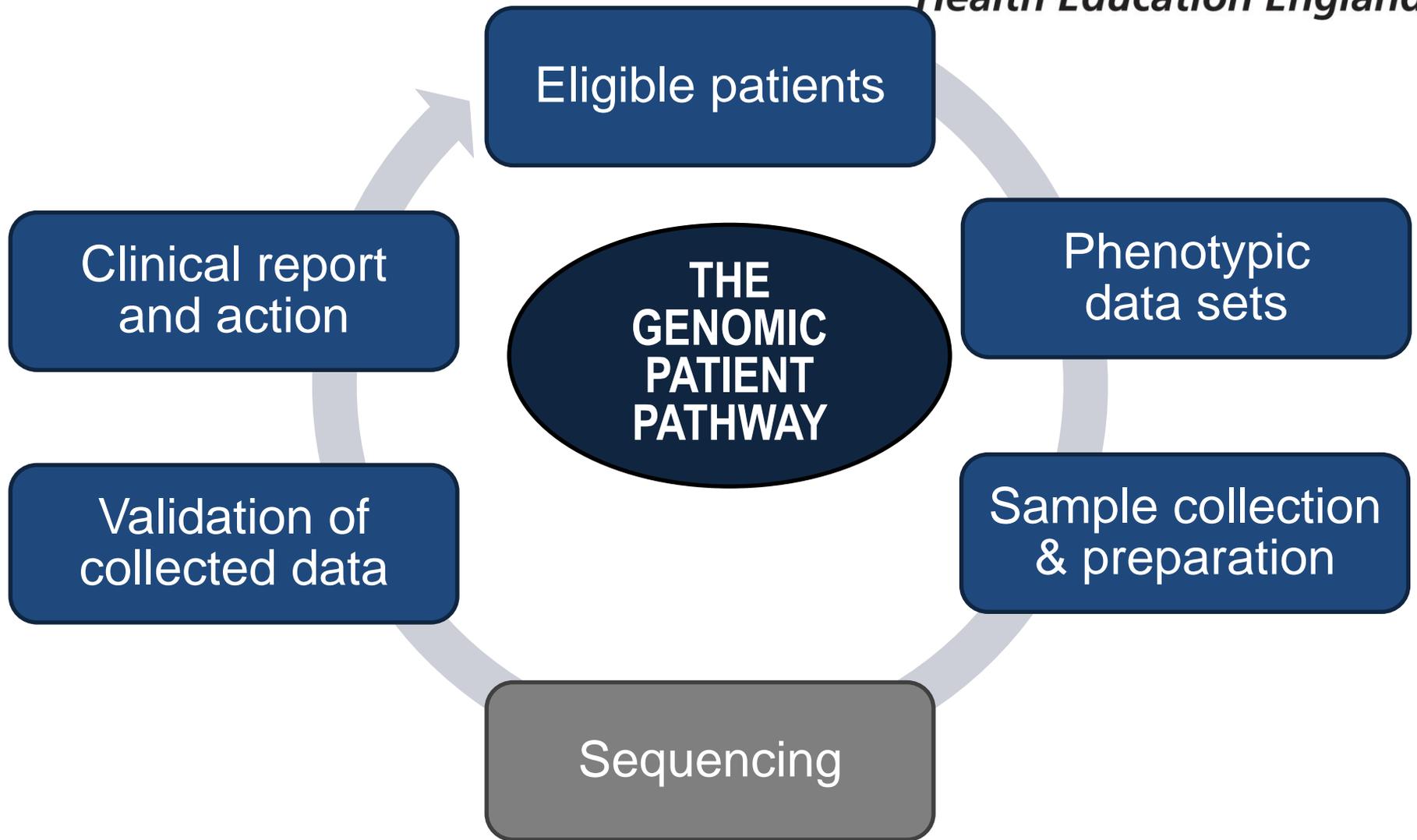
Whole genome sequencing is providing a step change in the NHS diagnostic repertoire

NHS Genomics Medicines Centres: the infrastructure for now and the future

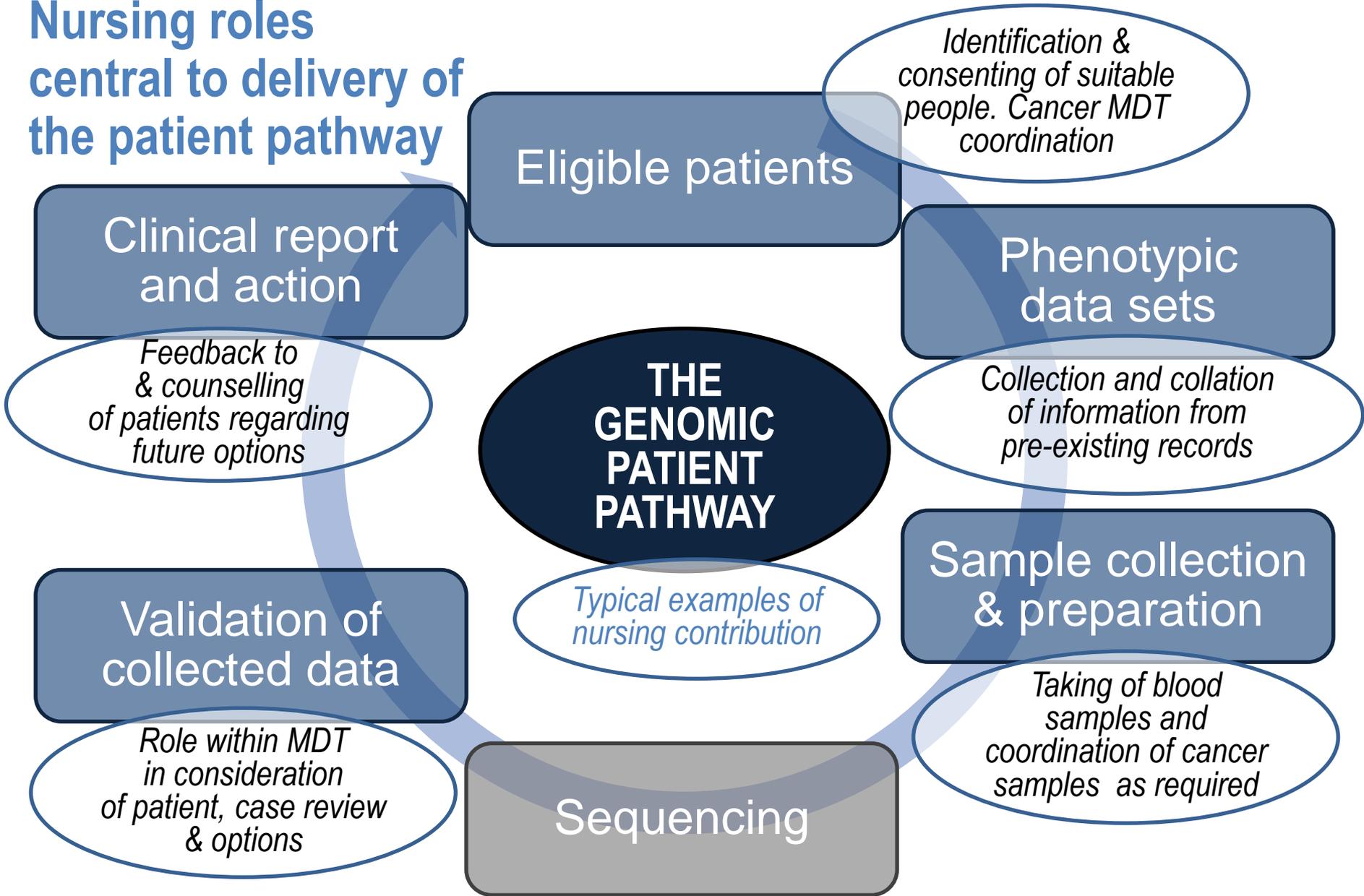
- Nationwide network of **13 NHS Genomic Medicine Centres (GMCs)** for populations of ~3- 5million recruiting participants, providing DNA and other samples and data and undertaking validation and feedback
- Lead organisations working with local delivery partners (currently **39** – 75 by March 2017)
- Clinical genetics, genetic laboratories and molecular pathology laboratories and informatics central to delivery
- Established operating models for the future driven by **focus on innovation** including:
 - Ethics, consent
 - Formalised patient participation groups
 - Standardisation and streamlined models of care
 - Data collation and handling, creation of 13 data hubs
 - Partnership and network working – e.g. partnership boards
 - Clinical Leadership for change
- Integrated with **workforce development** led by HEE Genomics Programme and underpinned by flexible HEI programme in Genomic Medicine



100,000 Genomes Project is unique
in international genomics initiatives
because of involvement of NHS



Nursing roles central to delivery of the patient pathway



Nursing also has an important strategic role supporting changes in job plans, becoming advocates, engaging with clinical teams and driving workforce transformation

The scale of the 100,000 Genomes Project



100,000 genomes



70,000 patients and family members



21 Petabytes of data.
1 Petabyte of music would take 2,000 years to play on an MP3 player.



13 Genomic Medicine Centres, and
85 NHS Trusts within them are involved in recruiting participants



1,500 NHS staff
(doctors, nurses, pathologists, laboratory staff, genetic counsellors)



2,500 researchers and trainees from around the world

Genomics - already providing answers & **NHS** changing lives for families *Health Education England*



Leslie Hedley – identified INF3 mutation cause for his lifelong high blood pressure, helping his condition as well as his daughter and granddaughter



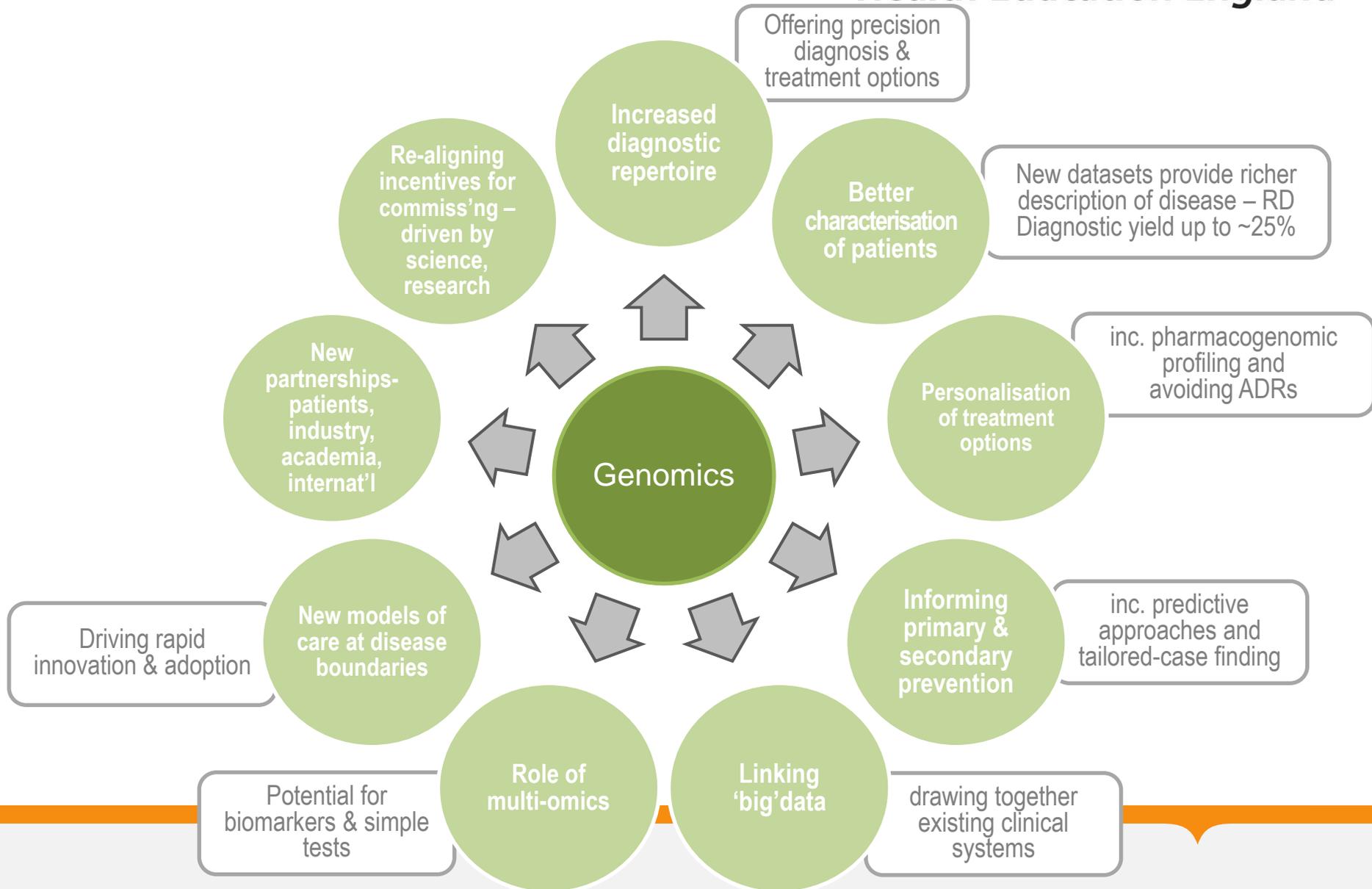
Jessica Wright (*with Mum and Dad*) – diagnosis provided answers for the family and identified that a special diet could help her epilepsy & improve quality of life

~18,000 genomes sequenced to date – building database for insight

Taking the NHS into the future of care



Health Education England



Moving from illness to health

By moving away from a 'one size fits all' approach to one which uses emergent approaches to target therapies, healthcare can achieve a shift from a focus on illness to focusing on health

ILLNESS

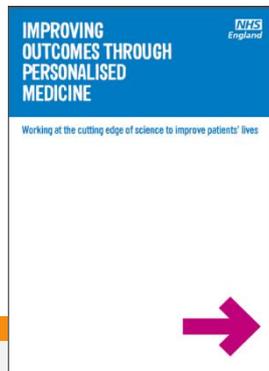
- Delayed diagnosis
- Late stage disease
- Multiple conditions
- Restricted treatment & management options
- Poorer outcomes & patient experience



HEALTH

Using emergent techniques to improve outcomes and health through

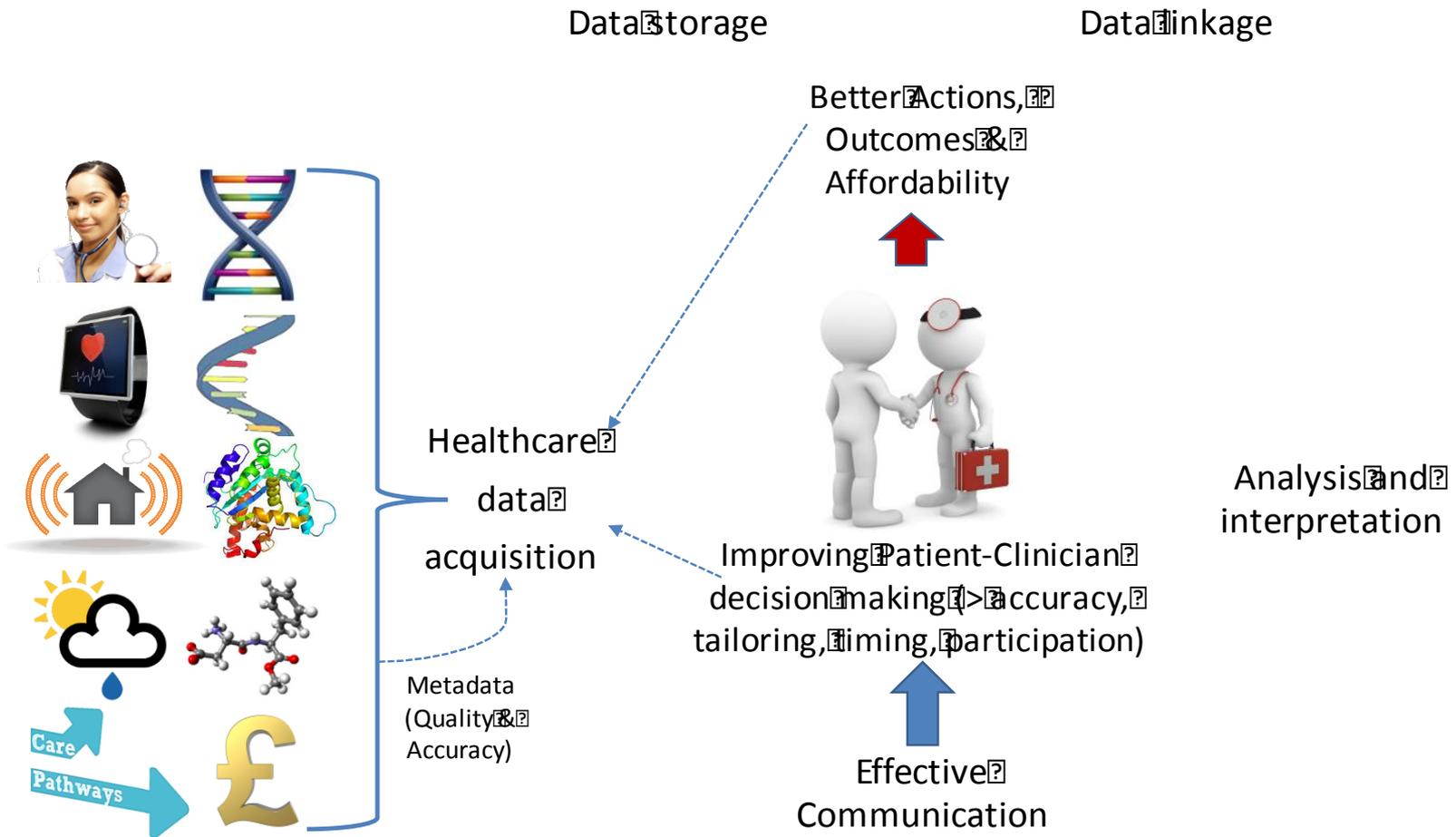
- Prognosis
- Earlier disease identification offering more & more effective treatment options
- Influencing lifestyle factors and population health
- Stratified medicine
- This will deliver the 4 Ps of:
 - **P**rediction (& prevention) of disease,
 - more **P**recise diagnoses,
 - **P**ersonalised and targeted interventions
 - with a more **P**articipatory role for patients



Personalised Medicine & Health- *What do we mean?*



Health Education England



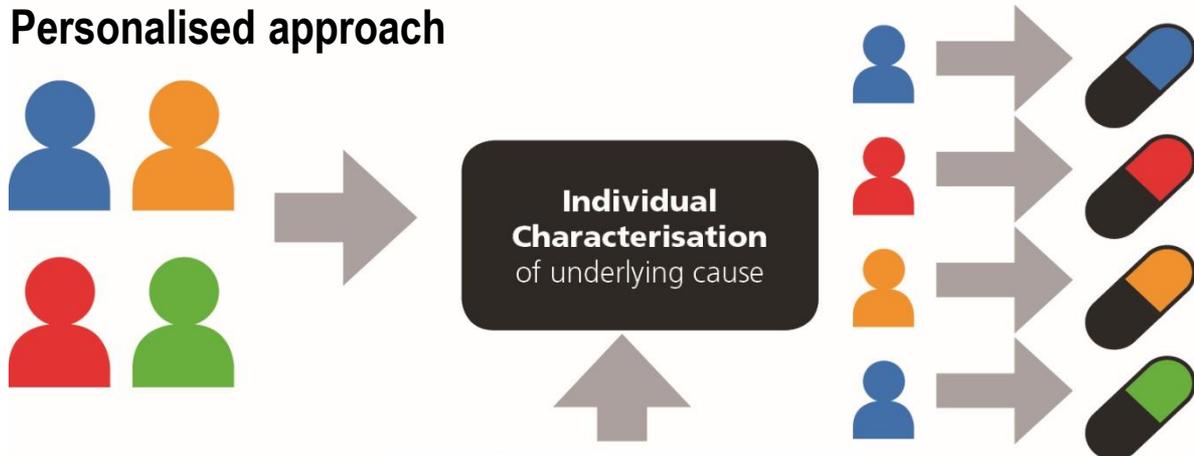
Using this knowledge: The end of the 'one size fits all' era of medicine

Traditional approach



Everybody receives the same medicine –
typically only 30-60% effective

Personalised approach



Tailored treatment to match an individual's makeup & response –
more effective and fewer side-effects

Early opportunities for personalised medicine underpinned by genomics



Development of personalised medicine is a multi-dimensional activity:

- Evidence base for utility/cost effectiveness
- Responsiveness & turnaround time for results
- Evolution of Informatics and analytical platforms
- Integrated and coordinated genomic testing and other functional diagnostics
- Whole pathway approach
- Prioritising key clinical priority areas: cancer; diabetes & obesity; mental health & dementia; CVD inc stroke

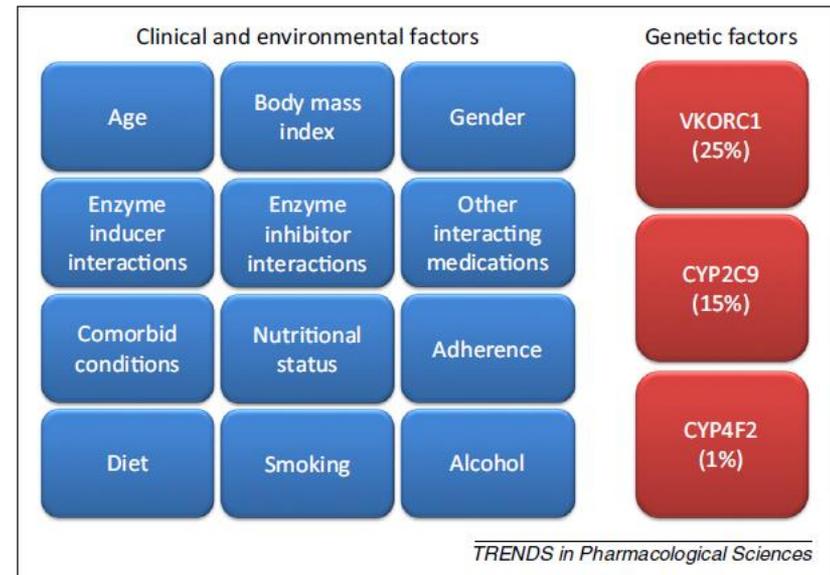
At home

Spectrum of delivery across all the NHS

Specialist Care

Transforming Warfarin management through genomics

- 600,000 Warfarin users in UK
- Massive variability in individual response – 40x variability in dose
- Major cause of adverse reactions
- Established methodology – ‘trial and error’ via INR clinics
- Have identified the genetics that accounts for significant element of variation in response
- Research has established genotype guiding protocols – allowing clinicians to get to the right dose sooner, with fewer adverse effects
- Improves patient outcomes and patient experience



Getting diagnosis and intervention right

- neonatal diabetes

Health Education England

- mutations in >25 different genes cause neonatal diabetes –often mistaken for Type 1
- Patient pathway that combines traditional diagnostics with genomic technology has identified 5 new genetic subtypes which inform therapy



KCNJ11 p.V59M

Permanent diabetes & developmental delay

Sulphonylurea therapy

EIF2AK3 p.E371*

Wolcott Rallison Syndrome

Liver Transplant

FOXP3 c.227delT

IPEX syndrome

Bone Marrow Transplant

GATA6 c.1448-1455del

Syndromic pancreatic agenesis

Insulin and exocrine supplements

STAT3 p.T716M

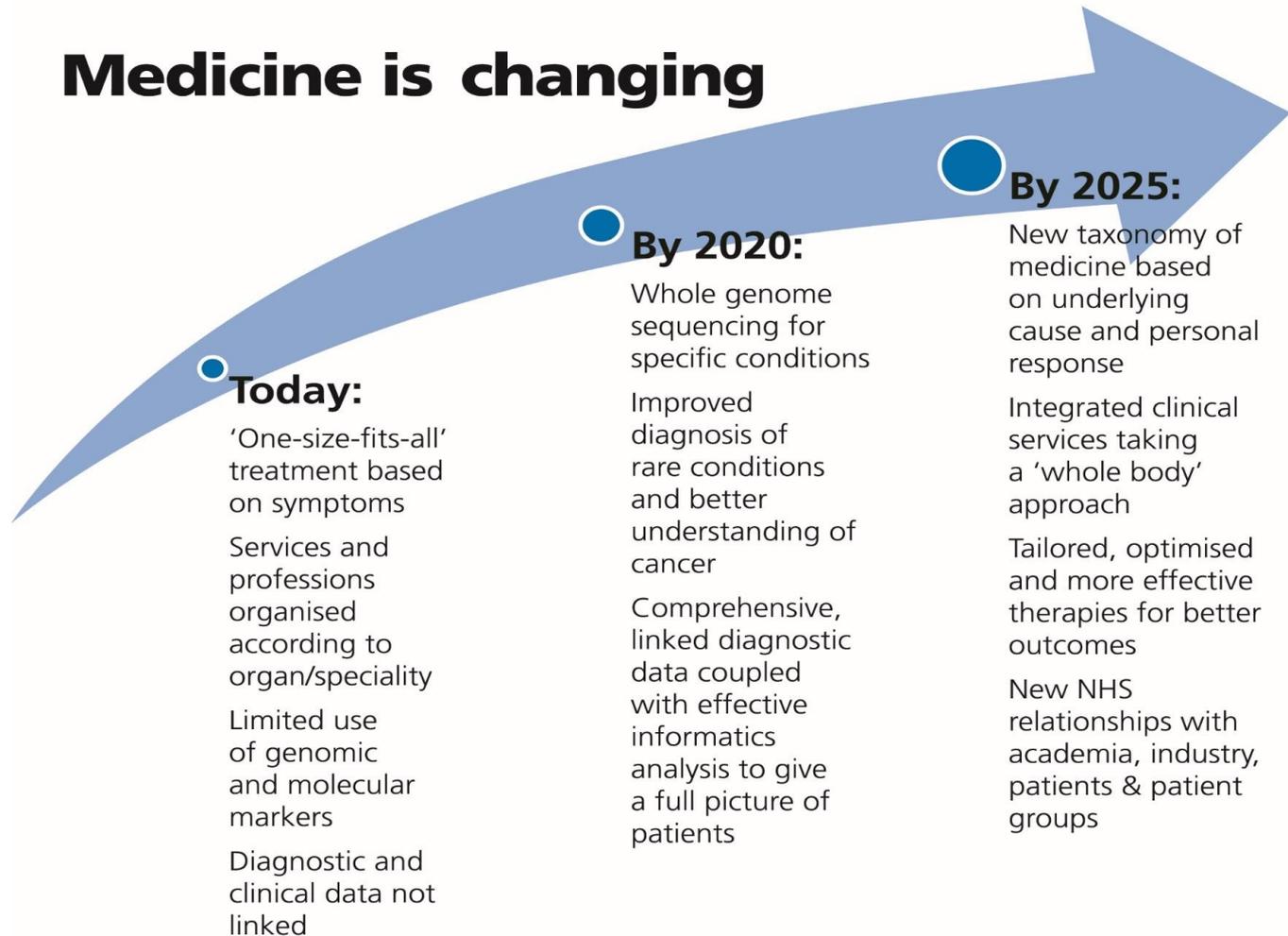
Multi-organ autoimmune disease

? STAT3 inhibitor

Five babies; five different treatments

The personalisation journey over the next decade

Medicine is changing



Importance of professional engagement



- Step-change in genomic knowledge needed across clinical professions - far beyond the highly specialised workforce.
- The HEE Genomics Education Programme set up to support transformation in knowledge and understanding at all levels of the NHS workforce – with a wide range of resources to support current NHS staff
- The GEP Masters in Genomic Medicine provides a truly multiprofessional approach to developing genomic knowledge – alongside many other GEP resources to support teams

Broader strategy for nursing: Meeting the *Health Education England* 'Closing the Gaps' commitments

The developments around genomics and personalisation are designed to meet the transformational aims of the 'closing the gaps' commitments

1. We will promote a culture where improving the population's health is a core component of the practice of all nursing, midwifery and care staff
2. We will increase the visibility of nursing and midwifery leadership and input in prevention
3. We will work with individuals, families and communities to equip them to make informed choices and manage their own health
4. We will be centred on individuals experiencing high value care
5. We will work in partnership with individuals, their families, carers and others important to them
6. We will actively respond to what matters most to our staff and colleagues
7. We will lead and drive research to evidence the impact of what we do
8. We will have the right education, training and development to enhance our skills, knowledge and understanding
9. We will have the right staff in the right places and at the right time
10. We will champion the use of technology and informatics to improve practice, address unwarranted variations and enhance outcomes



Genetics and genomics is not simply lab work nor the sole remit of research staff: it is the future of healthcare.

The 100,000 Genomes Project provides the opportunity for nurses to play a part in an integrated health service which looks beyond the competitive nature of acute & community trusts for the benefit of patients.

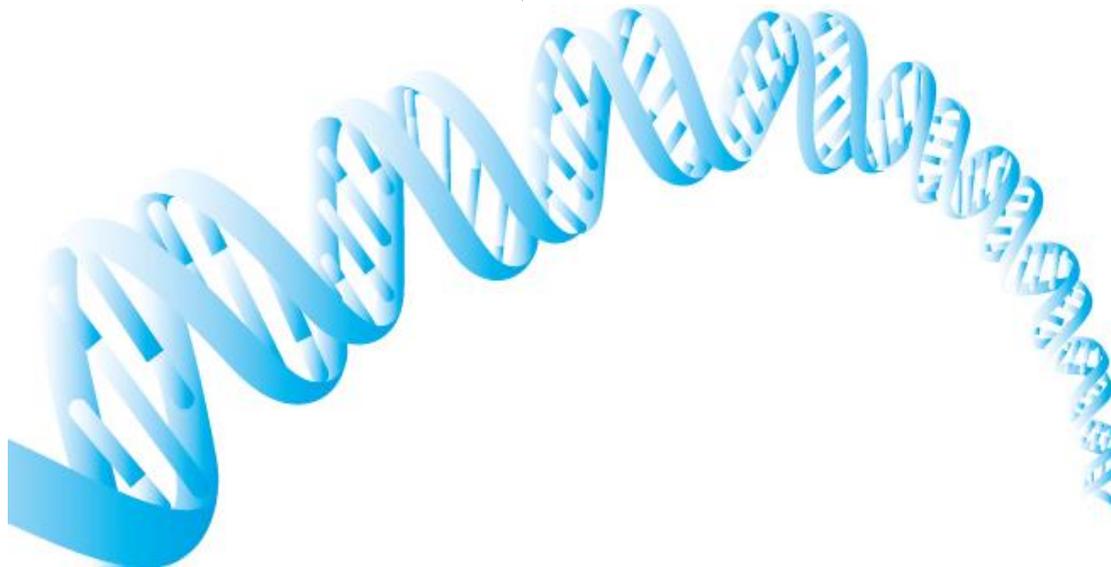
Charlotte Hitchcock RGN
Genomics Ambassador
West Midlands NHS Genomic Medicine Centre

Supporting the workforce to deliver Genomics and Personalised Medicine

Dr Anneke Seller Scientific Director, HEE GEP

Developing people
for health and
healthcare

www.hee.nhs.uk



Purpose of the Round Table Discussion

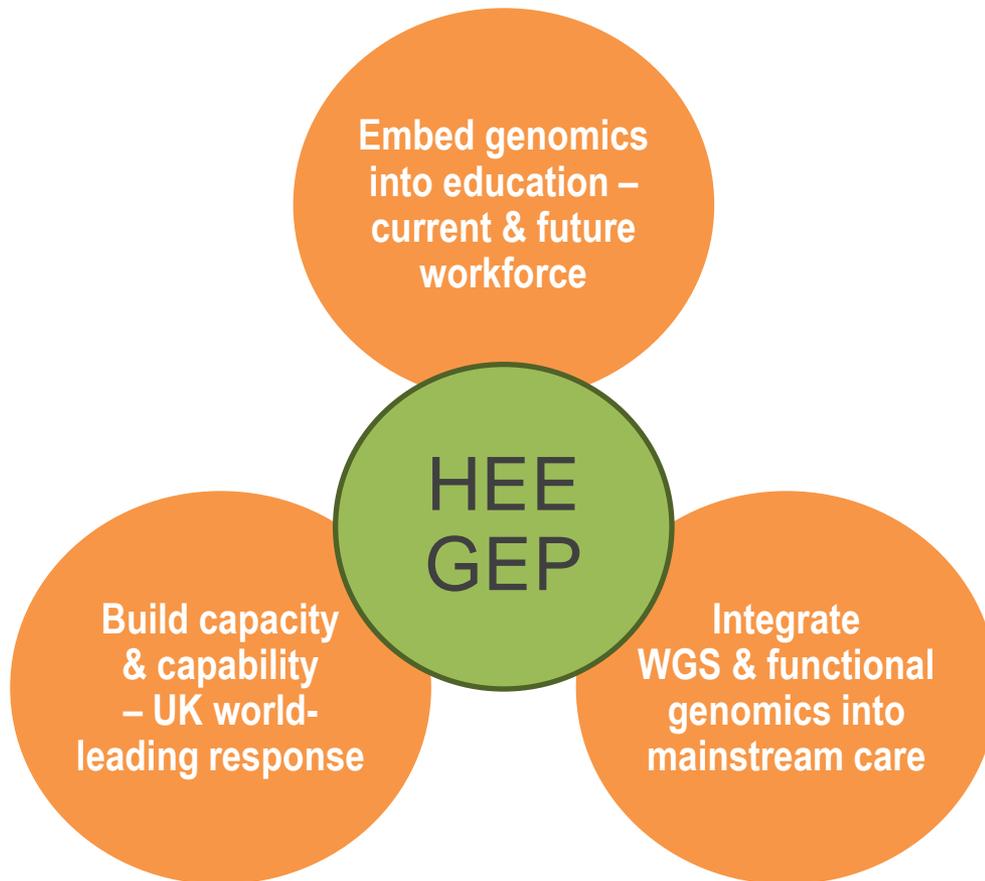
- To engage with key stakeholders from the nursing and midwifery community on the implementation of genomic medicine in the NHS
- To demonstrate leadership in genomics education
- To consider:
 - the application of genomics in the job roles nurses and midwives undertake, and the associated education requirement
 - the alignment of the Genomics Education Programme (GEP) with the Global Nursing Alliance retreat next week
- Inform the GEP transformation and workforce developments for nursing and midwifery

Why the HEE GEP is necessary

To ensure that the health and care workforce of today and tomorrow has the right numbers, skills, values and behaviours **to harness the potential of genomic medicine through the mainstream adoption & use of genomic technologies & practice**



Genomic Education Programme aims

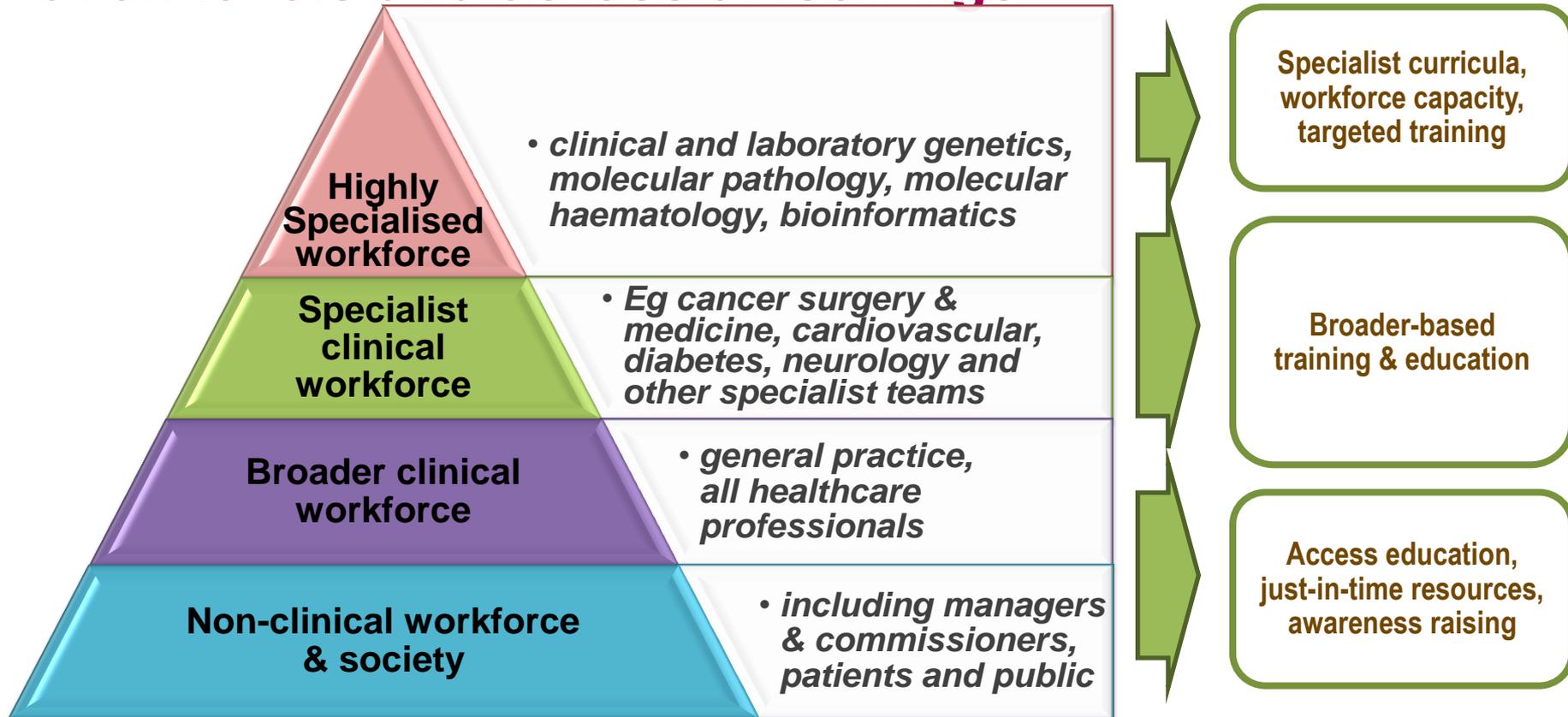


Providing a long-term legacy of the 100,000 Genomes Project – embedded in the healthcare system

Our approach

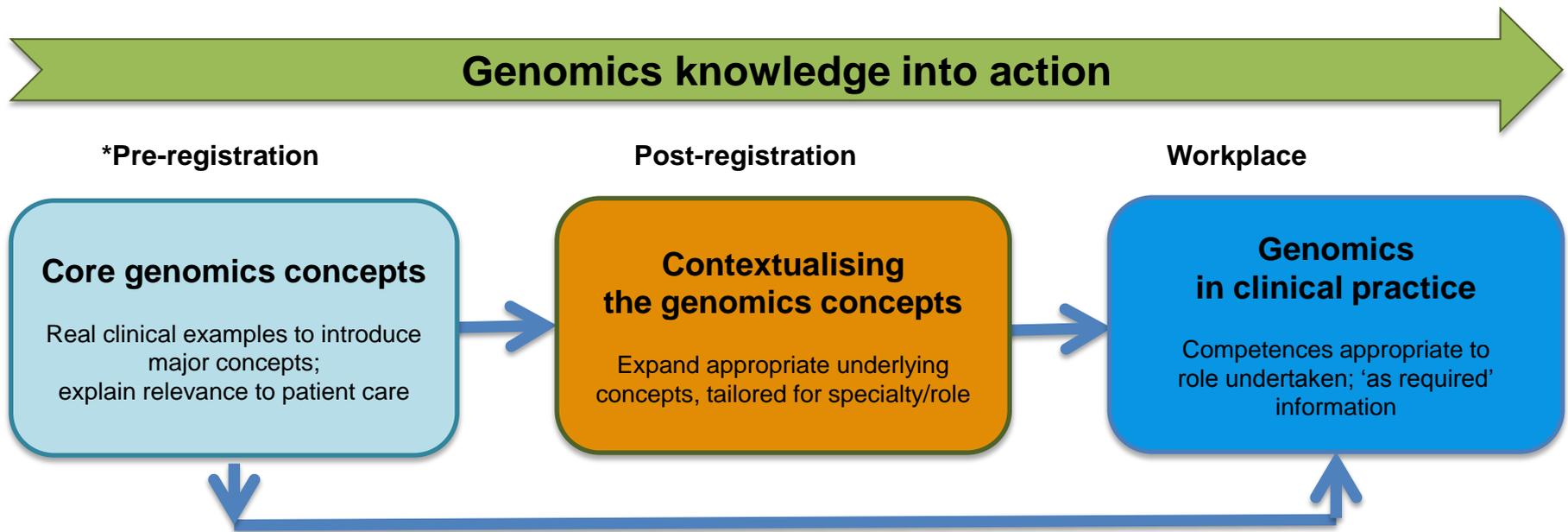
- To reach the parts that other education & training doesn't reach
 - Stressing the importance of multiprofessional & multidisciplinary working across the broader workforce
 - Identifying gaps and supplementing the areas already well-served by existing initiatives

Interventions to support workforce transformation at all levels and across all settings



Incorporating relevant genomic medicine at all stages of the education continuum

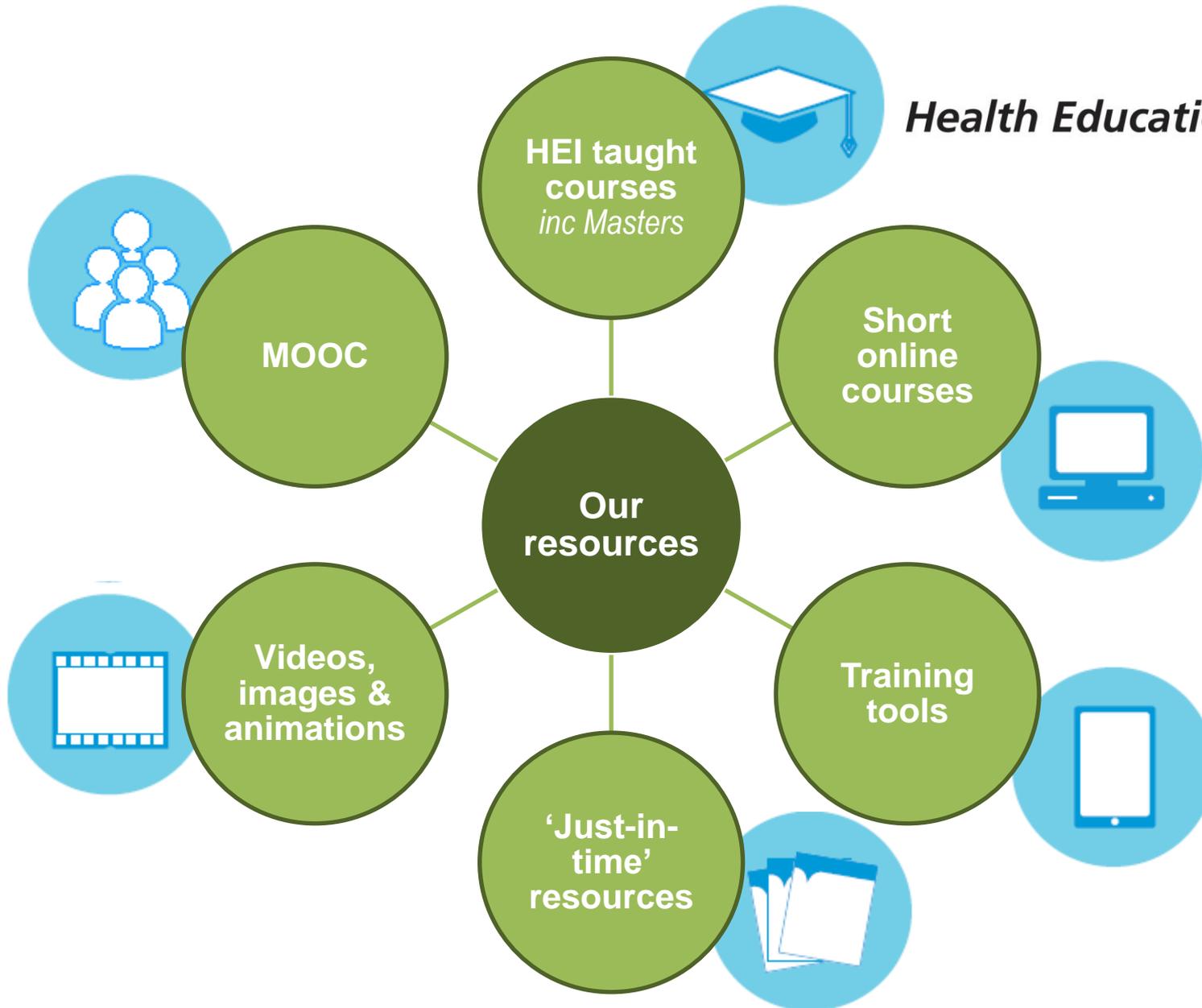
The GEP continuum of genomic medicine education



**This also covers the training undertaken by non-registered NHS staff e.g. Nursing Associates*

Building Capacity and Capability

- New postgraduate curricula for Healthcare professionals
- Multiprofessional Master's in Genomic Medicine
- Pump priming additional training places
- 100k GP Consent Training Days – 40+ GMC participants to date
- **PLUS** Resource development to support the move to more Personalised Medicine across the NHS



HEE GEP

Direct team

GMC E+T leads network

Education & Training GeCIP

HEI provider network

- Support staff in GMCs to deliver 100,000 Genomes Project
- Increase workforce capacity and capability in genomic medicine and bioinformatics
- Funding Research and Innovation projects
- Legacy and transformation

- One lead in each GMC
- Local HEE leads
- Support 100,000 Genomes Project + wider workforce development
- Sustainability and transformation

- Co-ordinating Group
- Education & Training leads from all GeCIP domains
- Crucial to the Legacy
- International network
- Membership open to others via submission of online form

(www.genomicsengland.co.uk/join-a-gecip-domain/)

- Deliver the commissions for masters and CPPD
- Collaborate to maximise the benefits to the NHS & exploit institutional expertise
- Partnership with the NHS/GMCs to support research and excellence in genomic medicine

Mind the gap...

- Key aspect of GEP is to identify interventions to address gaps in knowledge, skills and competencies for the delivery of current and future care
- Informed by NHS GMC local training needs assessments
- Close working with professional bodies and organisations including:
 - Royal College of Nursing
 - Council of Medical Deans - undergraduate medical curricula
 - Medical Royal Colleges (e.g. RC Physicians, RC General Practice) - Postgrad curricula and CPD
 - HEE National School of Healthcare Science – esp. postgrad & doctoral scientist curricula
 - Royal Pharmaceutical Society



Reaching out across the professions

- GEP has developed a training model with specialist diabetes nurses - looking to refine and roll out this model with other specialist groups
- Nursing Associate curriculum framework has genetic and genomic competencies.
- GEP has shared competencies with the NMC to develop new standards for the future graduate registered nurse.
- WeNurses webinar
- RCM detailed 2 hour module for midwifery practice from NGEDC.
- Techniques and interventions for N&Ms/ AHPs /Public Health will require further development to ensure relevance & effectiveness



Upcoming initiatives for Nurses & Midwives

- Follow up work continuing following WeNurses webinar/chat for NHS Change Day
- Working group to look into development of Genomics ACP role
- Global Genomics Nursing Alliance end of January 2107.
- Development of a 'Genomics Game' to support Pre-registration education

Long term role for the HEE GEP



GEP is aligning to a number of other HEE programmes including:

- Technology Enhanced Learning (TEL)
- Cancer workforce project
- Diagnostic Programme
- Prevention and Public Health
- Primary and Community Care
- Sustain, Transformation Plans, New Care Models
- Advanced Clinical Practice (ACP)
- Apprenticeships – Talent for Care
- Shape of Caring Programme

Finding out more: Genomics Education Programme Website

www.genomicseducation.hee.nhs.uk



And our social media...

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Genomics Education Programme

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. [Read more](#)

Latest News

A genomic tool for better antenatal care
Written on Monday, 11 July 2016 10:29

French plans for a genomic healthcare future
Written on Monday, 04 July 2016 10:41

4.50 from Paddington to Genomics
Written on Monday, 27 June 2016 12:55

MSc in Genomic Medicine: Faculty Symposium
Written on Tuesday, 21 June 2016 14:59

Genomics in the battle against Zika virus
Written on Monday, 20 June 2016 11:23

Sign Up to Our Whole Genome Sequencing Course

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Genomic Medicine Professional Development Modules



Contact us ...



genomicseducation@wm.hee.nhs.uk