Genomics Education Programme

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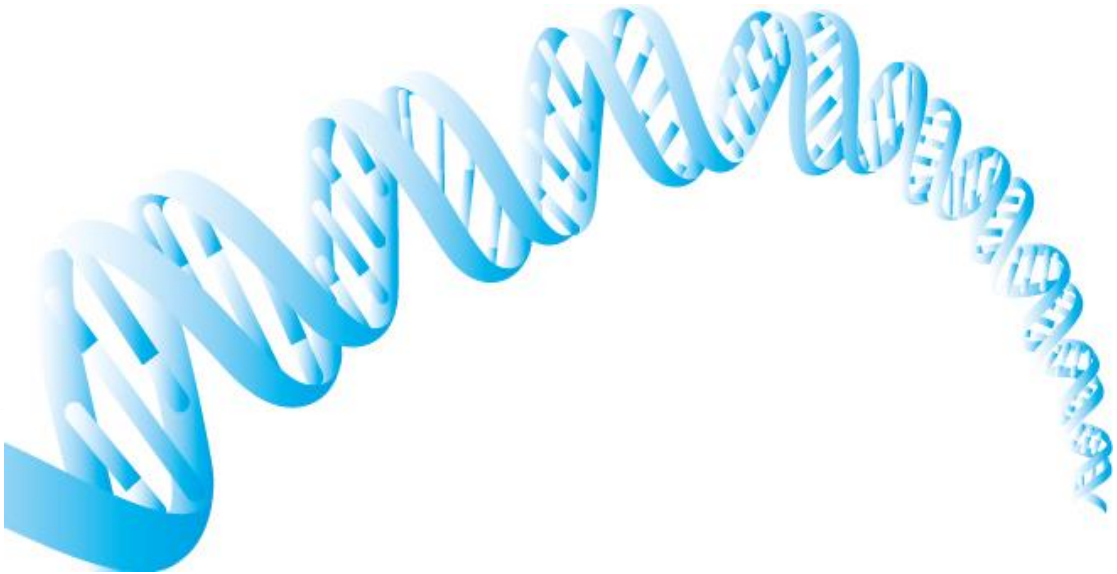
HEE Genomics Education Programme Nursing and Midwifery Round Table

28th April 2021



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	Item	Lead
1	Welcome and introductions	Lord Willis of Knaresborough Professor Mark Radford, Chief Nurse Health Education England, & Deputy Chief Nursing Officer for England
2	Update from the NHSE/I Genomics Clinical Reference Group	Lord Willis of Knaresborough
3	Update from Health Education England Chief Nurse	Professor Mark Radford, Chief Nurse Health Education England, & Deputy Chief Nursing Officer for England
4	Update from Chief Scientific Officer for England NHSE/I Genomics Unit	Professor Dame Sue Hill, Chief Scientific Officer for England, NHSE/I
5	NHSE/I Genomics Unit Transformation Project	Professor Janice Sigsworth Director of Nursing Imperial College Healthcare NHS Trust
6	Update from the Genomics Education Programme	Alison Pope, Programme Manager, Genomics Education Programme, Health Education England
7	Progress on the delivery of the University of West of England Genomics and Counselling Skills for Nurses programme	Professor Aniko Varadi, Director for Centre for Research in Biosciences University of the West of England Melanie Watson, Education and Training Lead, South West Genomic Laboratory Hub
8	Progress on developing an educator's toolkit for undergraduate nurses and a nursing competency framework	Dr Edward Miller Senior Education and Development Officer, Genomics Education Programme
9	GEP and Institute of Health Visitors collaboration to develop Good Practice Points	Sally Shillaker, Professional Development officer, Institute of Health Visiting Dr Jessica Myring, Principal Genetic Counsellor, Leicester Clinical Genetics Service
10	Summary & AOB	Lord Willis of Knaresborough and Mark Radford, Chief Nurse Health Education England, & Deputy Chief Nursing Officer for England

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Introduction

The Co-Chairs, Lord Willis of Knaresborough and Professor Mark Radford, welcomed everyone to the meeting.

Lord Willis announced his retirement as Chair from the HEE GEP Nursing and Midwifery Round Table, confirming this will be his last meeting.

Members thanked Lord Willis for all his hard work, encouragement and support over the years. His guidance and advice has been greatly appreciated, and his contribution to embedding genomics into nursing and midwifery practice incredibly helpful.

All the best for the future Lord Willis from the HEE Genomics Education Programme Nursing and Midwifery Round Table

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Update from the NHSE/I Genomics Clinical Reference Group

A paper had been circulated to provide an overview of the Genomics Clinical Reference Group (CRG).

The Genomics CRG has been convened to support the NHS England and NHS Improvement genomics programme and the implementation of the NHS Genomic Medicine Service (GMS).

The Genomics CRG advises on clinical policy and strategy for genomics, including implementation of NHS Long Term Plan commitments and future development of the NHS GMS along with other functions.

Lord Willis advised that the HEE GEP Nursing and Midwifery Round Table need to continue to link into the CRG to ensure joint working and keep nursing and midwifery on the agenda.

He also commented that the HEE GEP Nursing and Midwifery Round Table is a wonderful stakeholder group with representation from across this professional community, it is imperative this collaborative continues to develop and evolve.

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Professor Mark Radford, Director of Nursing HEE & Deputy Chief Nurse NHSE&I - National update

Professor Radford, thanked all in attendance for the hard work that has taken place during the COVID-19 pandemic. This has been an extremely challenging time for the NHS and the nursing and midwifery community has shown resilience and determination throughout.

Professor Radford highlighted how the pandemic has brought genomics to the forefront of healthcare, and its key role in the development of a vaccine within an 18-month timeframe, the fastest in history.

As Professor Radford returns to his role as Director of Nursing HEE & Deputy Chief Nurse NHSE&I, he is eager to continue to take forward the genomics agenda both within HEE, across the workforce and in the education setting. He would like to look at how we address variability in undergraduate programmes and set some ambition to measure success in the adoption of education.

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Alison Pope- update on the Genomics Education Programme

Alison Pope, GEP Programme Manager presented the work being undertaken by the Health Education England Genomics Education Programme (GEP).

Aligning to the work of NHSE/I Genomics Unit and the GMS, the GEP has three areas of focus for its 2021/22 workplan; **workforce intelligence, transformation and development.** Ensuring an integrated approach, the GEP team are working closely with the NHSE/I Genomics Unit, teams within HEE and external stakeholders. A joint Workforce Steering Group has been set up in collaboration with NHSE/I, which will be responsible for delivering on the workforce elements associated with the delivery of the GMS. Key priorities have been agreed and task and finish groups have been established.

Genome UK was published late in 2020 and sets the strategic direction for genomics in the UK for the next 10 years, building on the NHS's Long-term plan and the vision for personalised medicine. The work of the Steering Group has been mapped to the workforce recommendations in Genome UK and an implementation plan developed for the Diagnostics Workforce Board to ensure delivery of key priorities.

The GEP week of action is scheduled for 28th June 2021 – 02 July 2021. A range of activities are planned, and all were encouraged to take part to help highlight genomics in nursing and midwifery.

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Workplan for 2021/2022

- 3 areas of focus: **workforce intelligence, transformation and development**, aligning activity to the work of the NHSE/I Genomics Unit and the GMS (Hubs and Alliances).
- Established a **Joint Genomics Workforce Steering Group** with the NHSE/I Genomics Unit.
  - Membership includes representation from GLHs and GMSAs, as well as other key organisations.
- Ensure all work is **integrated and joined-up** with national initiatives:
  - Working closely with:
    - NHSE/I Genomics Unit
    - Workstreams within HEE (e.g., Cancer, NSHCS)
    - Other organisations (e.g., genomics taskforce RCOG)

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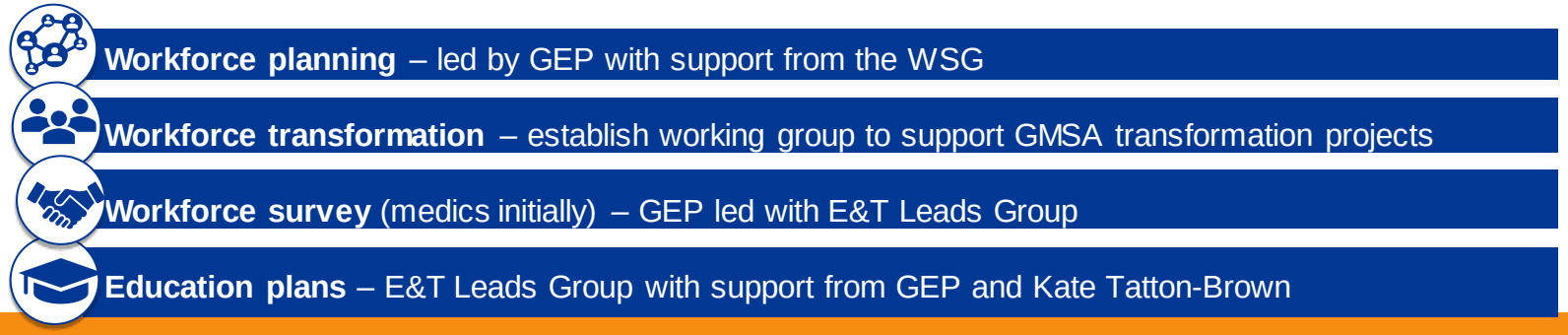
Joint Genomics Workforce Steering Group

The NHSE/I Genomics Unit, in collaboration with the Health Education England Genomics Education Programme have established a Joint Workforce Steering Group. This brings together representatives from the Genomic Laboratory Hub (GLH) and Genomic Medicine Service Alliance (GMS Alliance) regions, and other key stakeholders to:

- Focus on the workforce elements required to deliver the GMS.
- Adapt to changes in the system and take on board workforce plans and implications.
- Respond to strategic directives and policy requirements e.g. Richard's Review, NHS Long-Term Plan, Genome UK
- Develop a robust governance structure and reporting lines.
- Share best practice and shape activity for the development of the multi-professional workforce

Identified **four key pieces of work** to start in the next few months:



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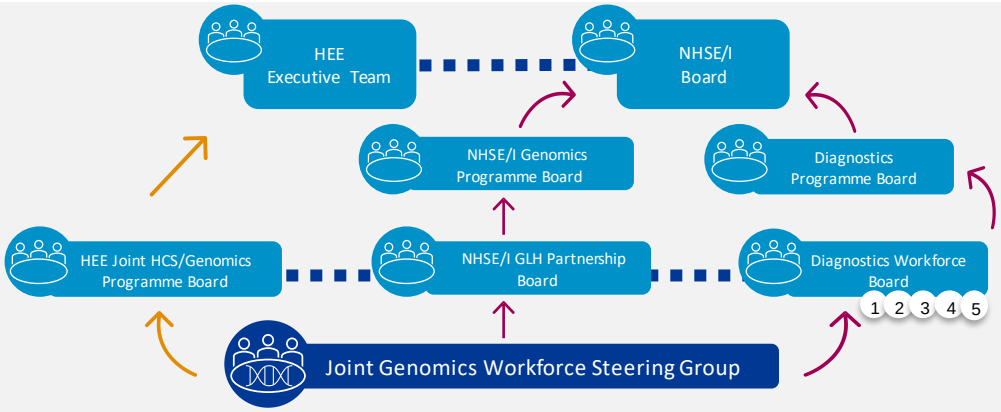
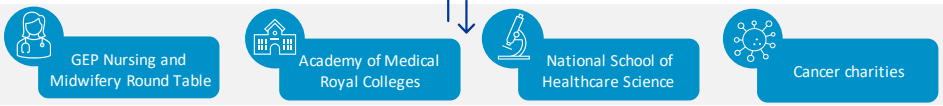
HEE NHSE/I workforce steering group

The Joint Genomics Workforce Steering Group (WSG) governance structure



Groups established to deliver on key priorities identified by WSG

Other groups who help inform the work and priorities of the WSG



The Pathology Workforce Group is one of five steering groups that feed into the Diagnostics Workforce Board

2 Pathology Workforce Group

3 Imaging Workforce Group

4 Endoscopy Workforce Group

5 Physiological Measurement Workforce Group

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Mapping our work - Genome UK & Diagnostics Workforce Board

Genome UK priority	WSG priority	Diagnostic Workforce Group: Genomics Pillar Implementation Plan outcomes	Delivery
Ensure that all new graduating doctors, nurses, midwives, pharmacists, allied health professionals, dental and relevant non-clinical staff have a level of awareness and knowledge of genomics that is relevant to their role.	Education and training plans Transformation	Consistent, comprehensive, and evidence-based education and training plans across the GMS infrastructure, including input from PPI A robust and sustainable process to support workforce transformation	Genomics Education Programme Workforce Steering Group
Ensure that the healthcare science workforce continues to have advanced genomic training and education within their programmes.	Education and training plans Transformation	Consistent, comprehensive, and evidence-based education and training plans across the GMS infrastructure, including input from PPI A robust and sustainable process to support workforce transformation	Genomics Education Programme Workforce Steering Group National School of Healthcare Science
Put in place continuing professional development programmes to ensure all relevant staff maintain an up-to-date and role-appropriate understanding of genomics.	Education and training plans Education and training resources	Consistent, comprehensive, and evidence-based education and training plans across the GMS infrastructure, including input from PPI	Genomics Education Programme Workforce Steering Group
Utilise workforce modelling data to inform investment decisions for training numbers across all professions and support workforce growth to meet the needs of the genomic medicine service particularly in specialist scientific and medical workforce areas.	Workforce planning	A clear picture of the current genomics workforce and the requirements to meet the need for the future genomic medicine service, to inform a genomics workforce plan	NHSE/I Genomics Unit Genomics Education Programme Workforce Steering Group
Establish and invest in training pipelines for in-demand occupations such as bioinformatics to build capacity within the health service and the wider sector.	Workforce planning	A clear picture of the current genomics workforce and the requirements to meet the need for the future genomic medicine service, to inform a genomics workforce plan	NHSE/I Genomics Unit Genomics Education Programme Workforce Steering Group National School of Healthcare Science
Redevelop clinical pathways and standards of care to that fully incorporate the latest genomic testing and results.	Transformation	A robust and sustainable process to support workforce transformation	NHSE/I Genomics Unit Genomics Education Programme Workforce Steering Group
Support the NHS workforce by providing simple, practical, informatics solutions for training, genomic analysis and decision-support.	Education and training resources	Consistent, comprehensive, and evidence-based education and training plans across the GMS infrastructure, including input from PPI	NHSE/I Genomics Unit Genomics Education Programme

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HEE funded workforce transformation projects 2020-2021 (HEE underspend)

- £1.4 million allocated from HEE in December 2020 for in year spending by March 31st 2021
- 33 workforce transformation/ E and T projects funded (NW=2, NT=9, East=5, SW=2, C&S=6, SE=5, NEY=4)
- Funded via their Trust Learning and Development Agreement process and aligned to HEE assurance process to measure delivery and alignment to HEE priorities.
- **Themes funded – Lynch, FH, Pathology, Informatics, Cardiology, Pharmacy, Maternity, Inherited Cardiac conditions, Leadership, Primary care, Fetal Medicine**

  Align to project submissions in 2021/22 NHSE/I funding.
- Review process in place - Feedback session took place on 14 April 2021 to examine if these regional projects have delivered, been successful and could they be rolled out nationally?
- Final reports due 30th April 2021

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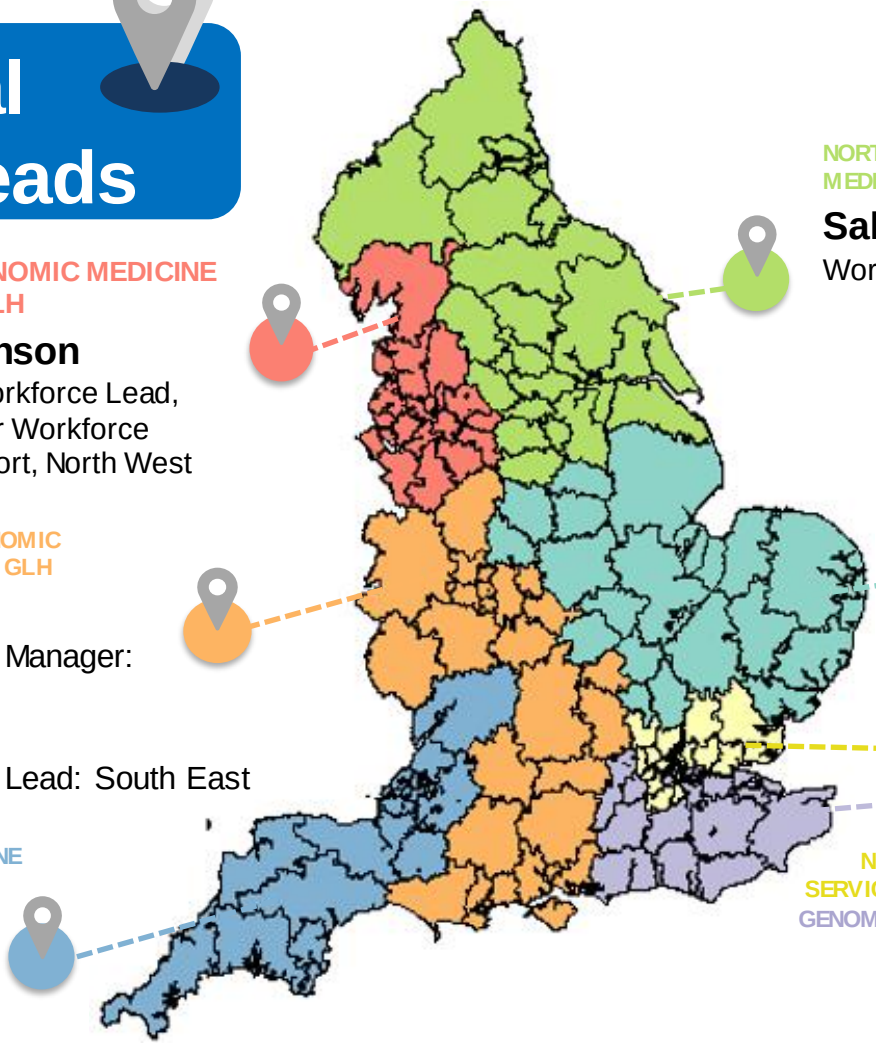
HEE Regional Genomics Leads



NORTH WEST NHS GENOMIC MEDICINE SERVICE ALLIANCE/GLH

Nick Fowler-Johnson
Healthcare Science Workforce Lead, North West and Cancer Workforce Plan Programme Support, North West

NORTHEAST &YORKSHIRE NHS GENOMIC MEDICINE SERVICE ALLIANCE / GLH

Sally Drew
Workforce Planning Lead

EAST NHS GENOMIC MEDICINE SERVICE ALLIANCE / GLH

Lucy Dennis
Workforce Transformation Manager

CENTRAL AND SOUTH NHS GENOMIC MEDICINE SERVICE ALLIANCE / GLH

Adrian Tams
Workforce Transformation Manager: Midlands

Donna Poole
Workforce Transformation Lead: South East

SOUTH WEST NHS GENOMIC MEDICINE SERVICE ALLIANCE / GLH

Mark Wilson
Workforce Transformation and Planning Manager

NORTH THAMES NHS GENOMIC MEDICINE SERVICE ALLIANCE / GLH & SOUTH EAST NHS GENOMIC MEDICINE SERVICE ALLIANCE / GLH

Sanjiv Ahluwalia
Postgraduate Dean

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Week of Action Monday 28 June – Friday 2 July 2021

Think genomics isn't relevant to you? Think again!

It may seem too complex or time-consuming to learn how genomics is shaping patient care, but the #GenomicsConversation makes it easy to get clued up

www.genomicseducation.hee.nhs.uk

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Dame Professor Sue Hill- Update on the Genomic Medicine Service (GMS)

Professor Dame Sue Hill (NHS England and Improvement) provided an update on the NHS Genomics Medicine Service (GMS).

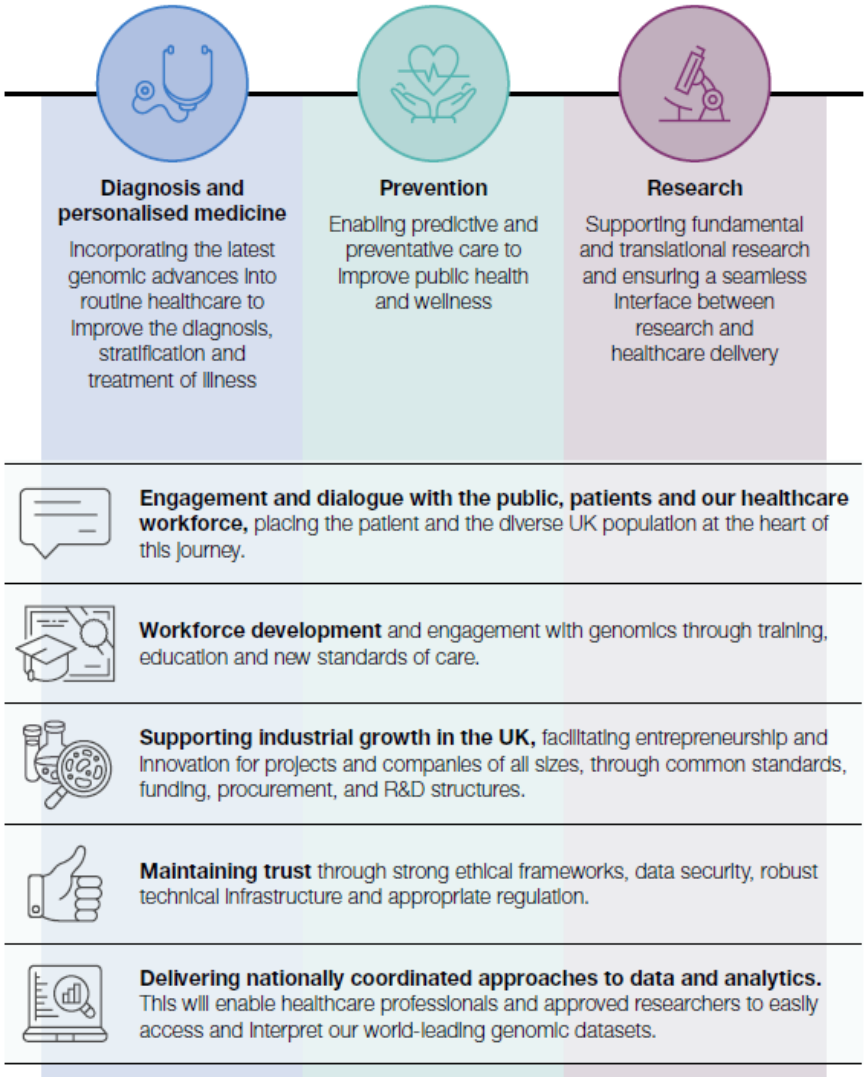
The update included details of the government's ambition over the next 10 years, outlined in Genome UK, details of the NHS GMS infrastructure to embed genomics into mainstream healthcare and the need to put patients at the centre of involvement at all parts of the GMS infrastructure.

Seven GMS Alliances have been established to cover the same geographies as the GLHs. This infrastructure will be responsible for embedding genomic medicine and testing into the NHS against a national test directory. Key deliverables have been agreed and business plans to take development forward are being produced.

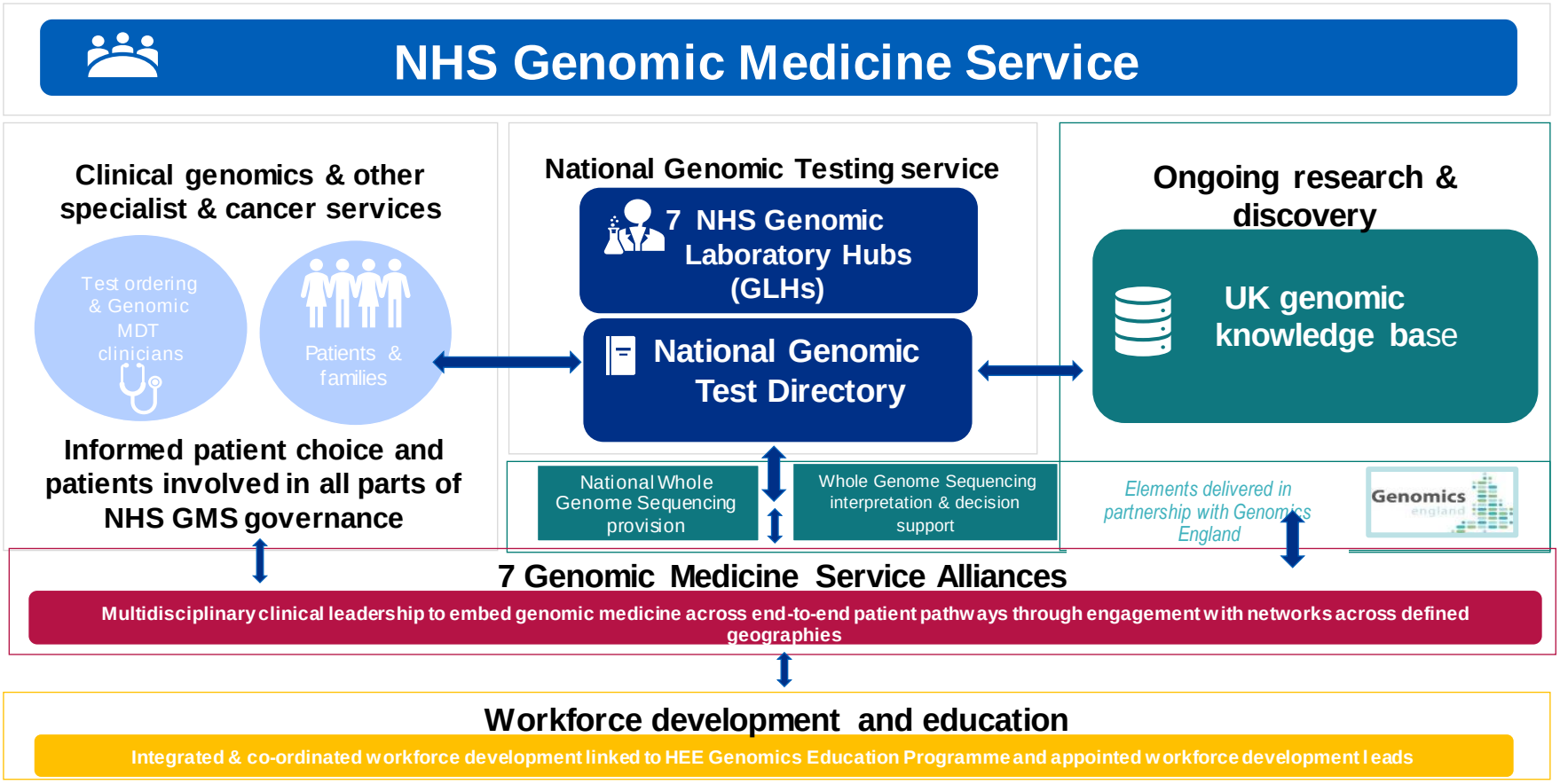
Professor Dame Hill discussed the opportunities to come over the next year including details of research collaboratives.

Genome UK – National Genomics Healthcare Strategy

- Over next 10 years Government's ambition is to create the most advanced genomic healthcare system in the world, underpinned by the latest scientific advances, to deliver better health outcomes at lower cost.
- It will incorporate the latest genomics advances into routine healthcare to improve the diagnosis, stratification and treatment of illness.
- Harness power of health data to make UK best place in the world to access genomic data responsibly, ensuring equity of and diversity of access and using this to inform all parts of a patients care.
- Includes the NHS Long Term Plan commitment to sequence 500,000 WGS and new work (led by GEL) on newborn screening, diversity and new cancer technologies including long-read
- The four UK nations will work together on delivering on the priorities through the Implementation Working Groups



NHS Genomic Medicine Service Infrastructure



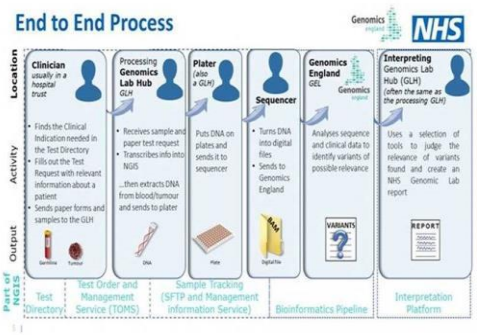
NHS GMS at the cutting edge of science

Implementation of **whole genome sequencing** as part of routine clinical care

Rapid **whole-exome testing for NICU/PICU and fetal patients**

Implementation of **NTRK gene fusion testing in partnership with industry and NICE** to support histology independent cancer treatments and **DPYD testing** for detection of adverse drug reactions

GRAIL partnership to look at early detection of cancer coverage will be piloted in 165,000 patients



BBC NEWS

Cancer: Blood test for 50 types to be trialled by NHS

CANCER RESEARCH UK

NHS to pilot blood test that could detect over 50 different cancer types

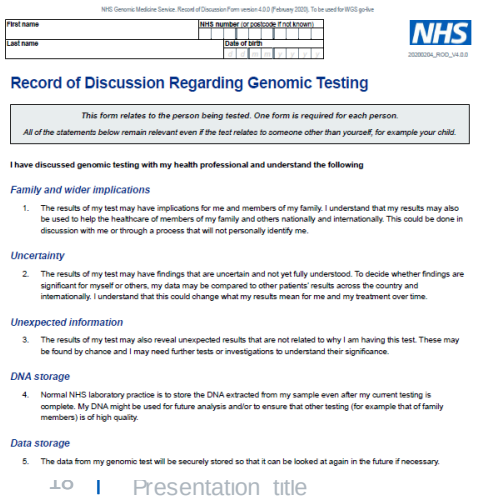
Putting patients centre stage

A **patient choice model** for WGS and non-WGS :

- All patients given a **clear and informed choice** about the tests being offered and how their data is processed
- **Information** to help understand choice and consequences
- Covers both **use of patient data within healthcare** services (e.g. clinical and administrative standards), as well as **innovative aspect of genomic care and data** use to support/develop service
- Everyone given **opportunity to participate in research**
- **Clear and distinct choice** to be part of research programme (without impact on standard of clinical care of individual)

Patient and public involvement in all aspects of NHS GMS:

- Patients as **full members** of all key governance groups at national level and in the NHS GMS Alliances
- **People and communities forum** to act as a 'critical friend' and to provide strategic advice around ethical issues and patient choice
- **Links with research** through 100K Participant Panel
- Ensures **compliance with legal duties** to involve the public in commissioning decisions – through consultation and engagement
- Working with NHS Citizen to hear **seldom heard voices** – eg BAME children and young people


NHS Genomic Medicine Service. Record of Discussion Form version 4.0.0 (February 2020). To be used for WGS go-live

First name | NHS number (or postcode if not known)

Last name | Date of birth

NHS

20200204_ROD_V4.0.0

Record of Discussion Regarding Genomic Testing

This form relates to the person being tested. One form is required for each person.

All of the statements below remain relevant even if the test relates to someone other than yourself, for example your child.

I have discussed genomic testing with my health professional and understand the following

Family and wider implications

1. The results of my test may have implications for me and members of my family. I understand that my results may also be used to help the healthcare of members of my family and others nationally and internationally. This could be done in discussion with me or through a process that will not personally identify me.

Uncertainty

2. The results of my test may have findings that are uncertain and not yet fully understood. To decide whether findings are significant for myself or others, my data may be compared to other patients' results across the country and internationally. I understand that this could change what my results mean for me and my treatment over time.

Unexpected information

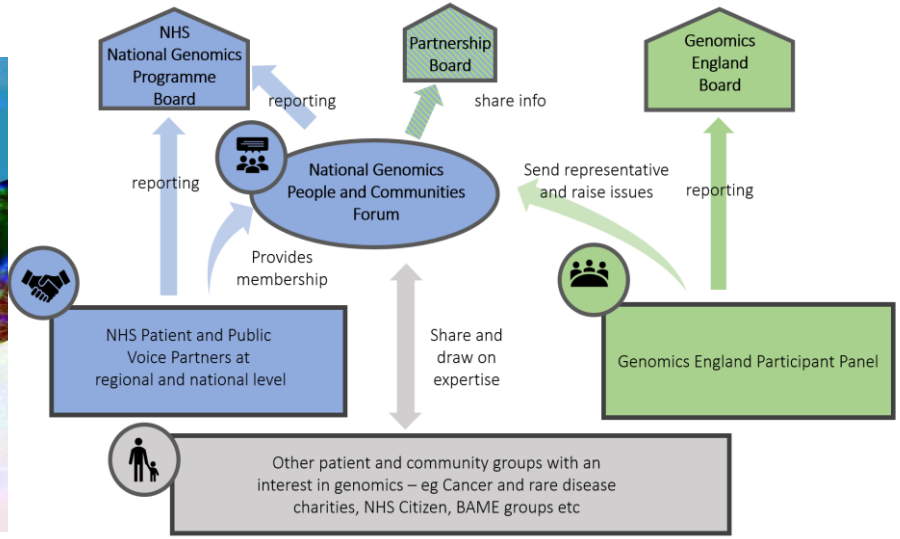
3. The results of my test may also reveal unexpected results that are not related to why I am having this test. These may be found by chance and I may need further tests or investigations to understand their significance.

DNA storage

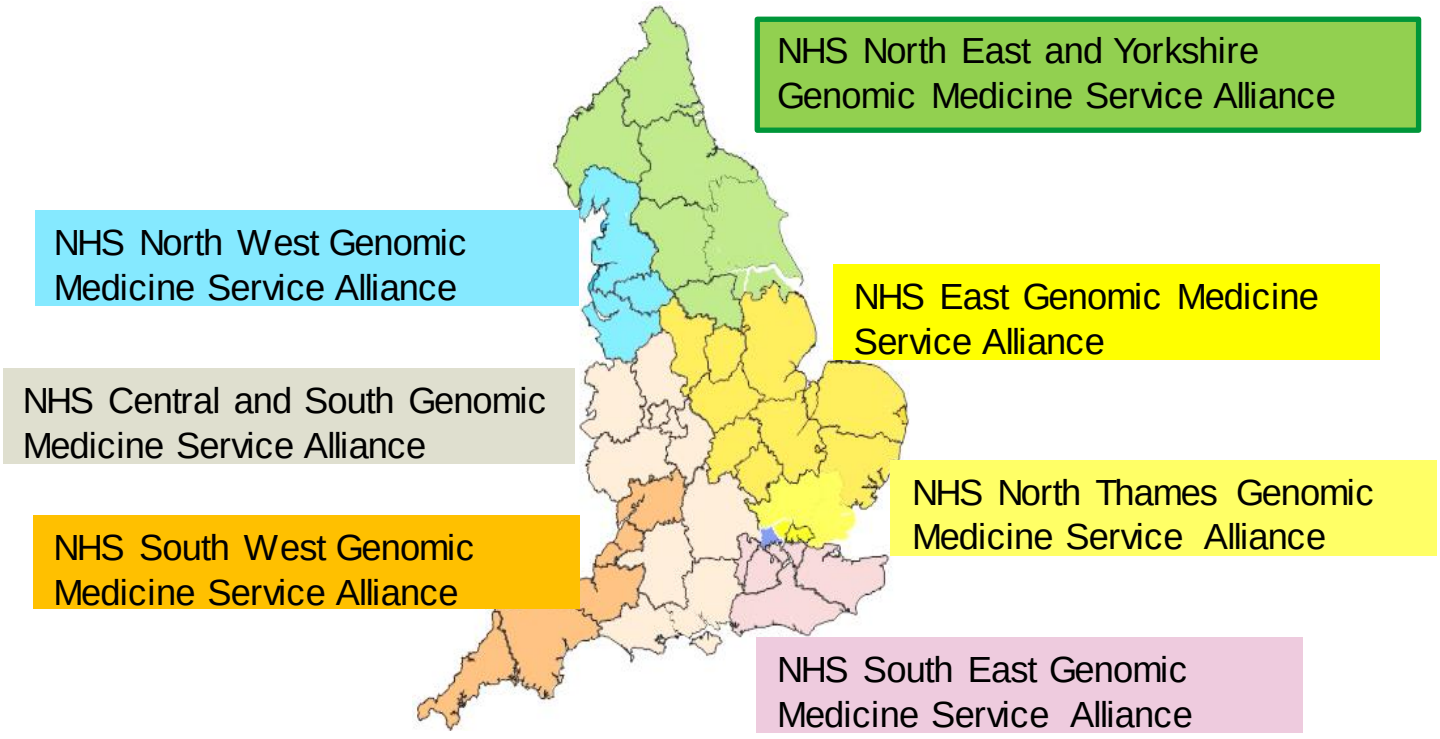
4. Normal NHS laboratory practice is to store the DNA extracted from my sample even after my current testing is complete. My DNA might be used for future analysis and/or to ensure that other testing (for example that of family members) is of high quality.

Data storage

5. The data from my genomic test will be securely stored so that it can be looked at again in the future if necessary.



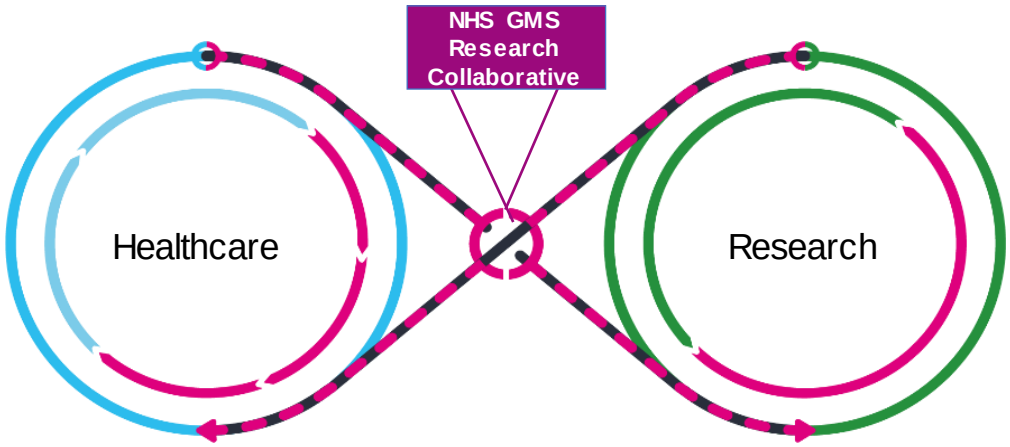
NHS Genomic Medicine Alliances



Key NHS GMS Alliance deliverables

- Completion of the 100,000 Genomes Project
- Retaining and building patient and public trust in genomics
- Strengthening partnerships across the geography and with ICSs
- Using genomics to improve health, care, productivity, quality and efficiency
- Embedding clinical leadership and supporting multi-professional workforce transformation programmes working with AoMRC
- Embedding genomics and medicines optimisation across the region
- Maximising opportunities to facilitate and participate in research and innovation
- Operating as a national network and representing the NHS Genomic Medicine Service internationally
- Participate in seven national transformation projects – DPYD, FH, Lynch, pathology, sudden cardiac death, monogenic diabetes, nursing and midwifery. Plus lead local projects

Interface with research driving clinical improvements



Making "the Loop" work as an efficient, robust and scalable system will help …

patients, as we enable dialogues on consent, diagnosis, prognosis and treatment;

healthcare teams, as we provide reliable genomic insights that are easy to request and interpret

researchers, as we accelerate research by providing data, infrastructure, insights and environment to collaborate and accelerate fundamental and translational research

Genomics england

NIHR | National Institute for Health Research

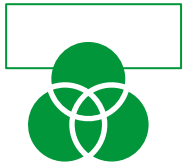
NHS GMS Research Collaborative Aims

- Map current research activity, identify unmet need and respond to emerging technologies
- Support the coordination, alignment and understanding of genomic research from a national perspective
- Increase the volume of high quality genomic research, delivered at scale and speed
- Embed research and discovery to advance clinical care for patient and societal benefit
- Review research proposals and collaborations from commercial/industry, academic, NHS and voluntary sector organisations
- Advisory committee brings together key partners including industry

Exploring new and exciting opportunities

Exploring new technologies such as Oxford Nanopore Long Read Sequencing & Functional Genomics

Working with UK Biobank on their sequencing outcomes



Implementing multi gene NGS panels and NovaSeq or high throughput testing across GLHs

LAMP – potential to utilise for pharmacogenomic testing

Roll out Whole Genome Sequencing, further expand WES and Cancer panels and rapid WGS for NICU/PICU

Considering outputs of EDS study on how polygenic risk scores could help predict and prevent disease

More equitable access and better outcomes for patients …

A revolutionary new surgery for a rare inherited retinal disease

- Lee Morris underwent Ocular Gene Therapy at Manchester University NHS Foundation Trust in one of the first gene therapy treatments undertaken by the NHS.
- Lee had vision problems from birth and at 8 years old was diagnosed with RPE65 retinal dystrophy, a rare inherited retinal condition caused by defects in one of a number of different genes.
- Other patients have been given the treatment since at other NHS hospitals and the patients are reporting that their vision is improving well.

Mail Online

'Doctors saved my sight by injecting a gene into my eye': Experts say this cutting-edge technique could one day also help many with age-related vision loss

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Professor Janice Sigsworth - Integrating genomics into nursing & midwifery practice

Professor Janice Sigsworth, Director of Nursing, Imperial College Healthcare presented an update on the nursing and midwifery transformation project being undertaken.

With the seven GMS Alliances now live, system transformation across clinical pathways via the multi-disciplinary workforce is taking place, this includes nurses and midwives.

Representation of nurses and midwives in GMS Alliances at senior levels has been agreed. Each Alliance will have one chief nurse undertaking a strategic role, plus a senior nurse and/or midwife at an operational delivery level in the core infrastructure.

One the national NHSE/I funded transformation projects being led by North East and Yorkshire GMS Alliance is nursing and midwifery and aligns and builds on the work already undertaken, for example masterclasses.

New Genomic Medicine Service Alliances

- 1st April 2021 – **7 GMS Alliances now live**
- NHS commitment – to deliver **21,000 Whole Genome Sequencing (WGS) in England** by October 2021

- Clinical programmes to **deliver system transformation** in/across clinical practice in multi-disciplinary workforce in:

- **Nursing and midwifery**
- Pharmacy
- Medical

Integrating genomics into mainstream nursing and midwifery practice

will require leadership at every level and a system-wide strategic approach using evidence based methodology to transformation projects

thinking about…

common language sharing and collaboration

systematic approach **locally owned and led**

Nursing & Midwifery - Leadership Infrastructure

- Nurses and midwives - key workforce - represented in GMS Alliances at senior levels
- Each Alliance - **one Chief Nurse –** strategic role – sits on GMS Alliance Partnership Board (all identified)
- Each Alliance – operational delivery level **senior nurse and/or midwife** in core infrastructure
- Project will be hosted by North East and Yorkshire GMS Alliance

7 NATIONAL TRANSFORMATION PROJECTS	
Monogenic diabetes	Sudden cardiac death
Familial hypercholesterolaemia	DYPD – (adverse drug reactions)
Lynch syndrome	Pathology
National Nursing and Midwifery Project	

Plus:

- Additional **projects** identified in each GMS Alliance

National Nursing and Midwifery Transformation project

- Chief Nurse Advisory Board (7 GMS Alliance CNs) – meets May ‘21
- Setting up national Nursing and Midwifery project – preparing to start
- Using tools originally developed by the Global Genomics Nursing Alliance (G2NA)
- Will enable us to **benchmark** the current state - National and by each GMS Alliance
- Build a **Roadmap** – a framework for delivering improvement/transformation across all projects and clinical pathways

In addition:

- Series of 3 webinars - target is mainstream nurses and midwives
- Offer for HEE GEP funded places on genomics course for nurses/midwives
- Provisional directory of nurses/midwives already working in genomics
- Exploring research opportunities – linking clinical practice

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Melanie Watson and Professor Aniko Varadi - Genomics and Counselling Skills for Nurses

In 2020 the HEE GEP funded a bespoke course for nurses in genomics and counselling skills. A first cohort of 30 students has already gone through the programme, and a new contract has been awarded for a further three years.

Designed for nurses with little-to-no previous knowledge of genomics, the course aims to ensure participants are competent and skilled to engage in embedding genomic literacy and understanding.

The programme has been highly successful with 100% completing the course to a very high standard.

The delivery format consists of a mixture of self-directed study, pre-recorded online presentations, scheduled interactive tutorials and group work/presentations, with the group integrating outside of the course as well.

Feedback has been fantastic from the students, and there is already evidence that this is impacting in their practice.

The course has highlighted the need to increase genomic literacy for all nurses, with one student commenting that genomics has gone '*From Niche to Necessity'.*

Progress on the delivery of the University of West of England Genomics and Counselling Skills for Nurses programme

"Nurses are the conduit between complex medical information and patient understanding. It's vital for the translator to be able to speak the language!" - from a participant on the course

UWE Bristol University of the West of England

MACMILLAN CANCER SUPPORT

NHS Health Education England Genomics Education Programme

British Heart Foundation

South West Genomic Services Educational Partnerships

NHS South West NHS Genomic Laboratory Hub

Continuing Professional development – upskilling existing staff

Clinical and Professional during training

'Socialising' the Genome- engagement and awareness raising

Supporting research projects & and honorary/clinical academic contracted staff

University of BRISTOL

UNIVERSITY OF GLOUCESTERSHIRE at Cheltenham and Gloucester

Introduction to Genomics & NHS Services

all undergraduate nurses, midwives, associate nurses, AHPs, Healthcare Scientist and medical students

UWE Bristol

EXETER

UWE Bristol

MACMILLAN CANCER SUPPORT

HEE Introduction to Genomics and Counselling for Nursing

30 Cancer and Cardiac Specialist nurses in current cohort – blended virtual learning

School and Science Festival Genomic Lego tool

UWE Bristol

HEE MSc Genomic Medicine

Co-delivery PGCert modules

Exeter continuing to offer full modular repertoire- large alumni in region

EXETER

UWE Bristol

modified from Prof Dame Sue Hill (Elizabeth Blackwell Institute Lecture 2020)

Team

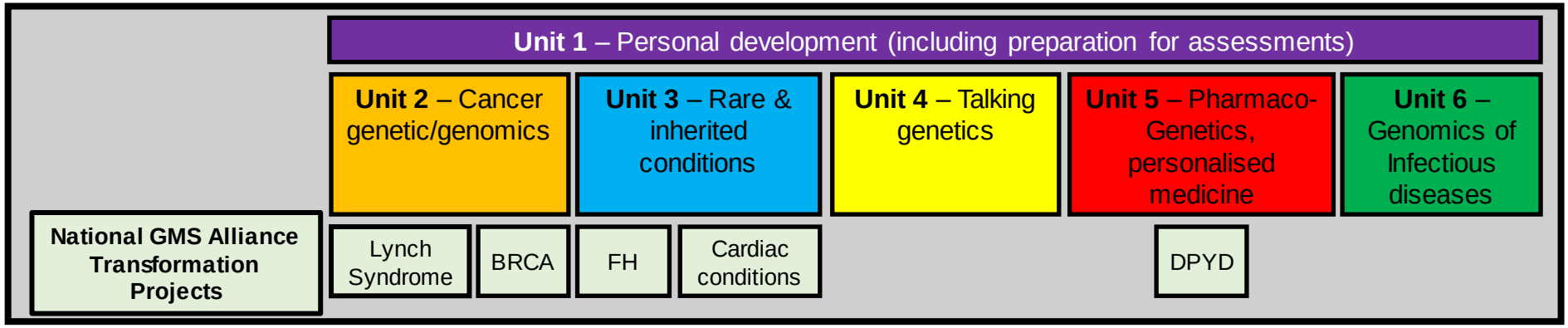
- **Catherine Carpenter-Clawson** - MSc in Genomic Medicine, West of England Genomic Medicine Centre (WEGMC)
- **Melanie Watson** - Education and Training Lead; WEGMC & SWGLH
- **Aniko Varadi** (Senior Fellow of the Higher Education Academy, UWE, Bristol)
- **Dany Bell** - Macmillan Cancer Support
- **Maureen Talbot** - British Heart Foundation
- **Alison Pope** - Health Education England (HEE)
- **Tracie Miles** - Cancer Genomic Nurse Specialist; Royal United Hospital, Bath
- **Amanda Pichini** - Lead Genomics Practitioner, University Hospitals Bristol
- **Sarah Armstrong-Klein** – Nursing and Midwifery, Genomics Unit, NHS England

Cohort I – Oct. 2020- Feb. 2021; 30 professionals

Course structure & content

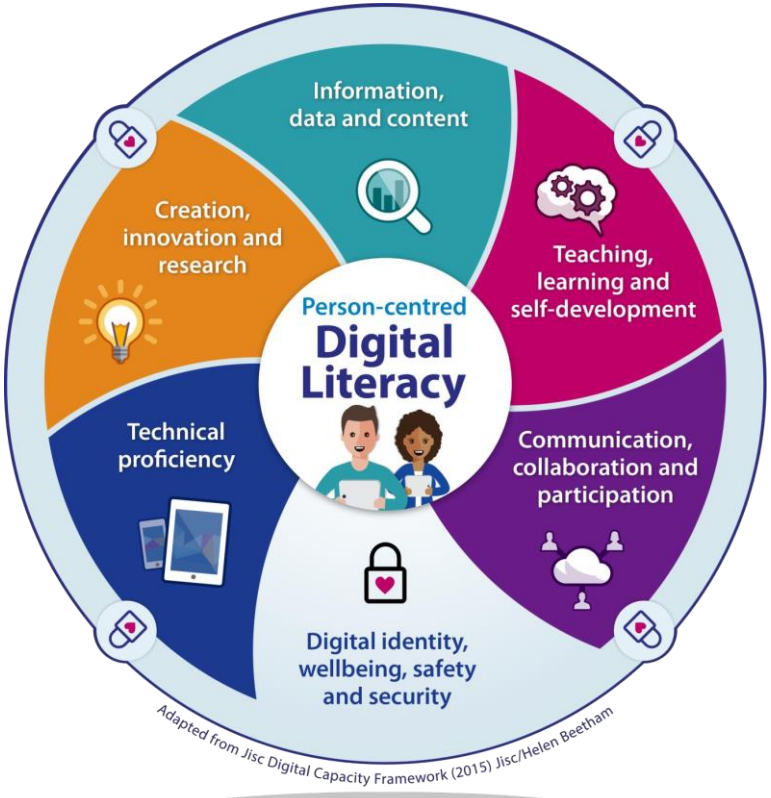
Key learning outcomes:

- Demonstrate an understanding of the relationship of genetics and genomics to health, prevention, screening, and diagnostics
- Develop **basic genetic counselling skills and ability of taking consent**, **and feedback of results in a genomic setting** either in cancer or rare & common conditions
- Understand the **Genomic Medicine Service (GMS) Alliance structure** including **support networks**, and up to date information about the **Test Directory, patient choice, confidentiality and data storage**



"The expertise available to students on this course is invaluable!" – from a participant

Digital skills training



Jisc (2020) Learning and teaching reimagined: Leadership survey data. jisc.ac.uk/reports/learning-and-teaching-reimagined-survey-synthesis

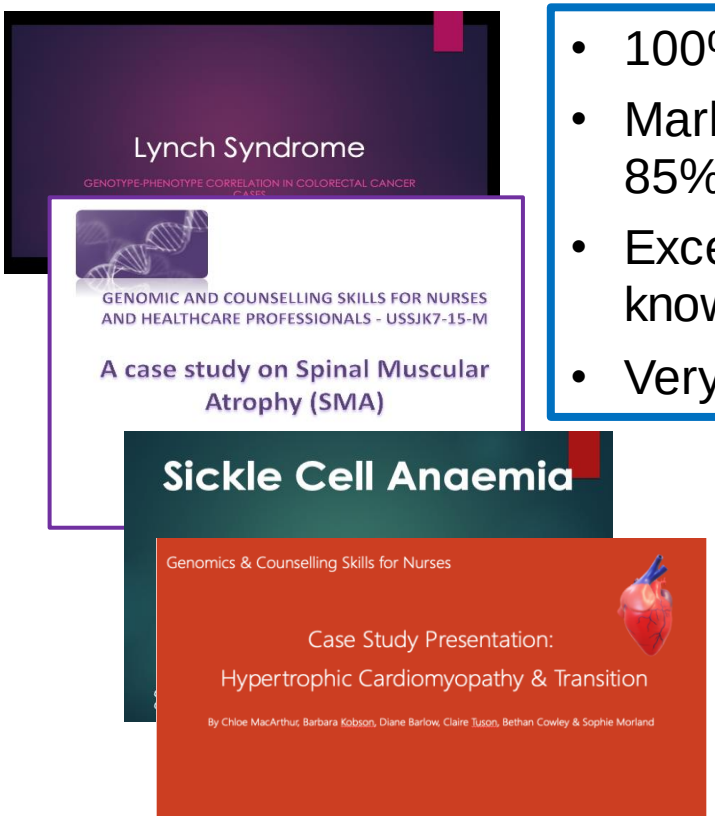
Blended learning

- Prerecorded online lectures (40h, *Blackboard*)
- Online live tutorials (30h, *Blackboard Collaborate Ultra*)
- Online discussion forums (*Blackboard*)
- Small group online live tutorials (*Blackboard Collaborate Ultra*)
- Online live group presentations (*Blackboard Collaborate Ultra*)
- File sharing (*OneDrive*)
- Assessment submission (*MyUWE*)
- Group networking (*WhatsApp; FutureNHS)*

100% of participants reported good or excellent digital technology support

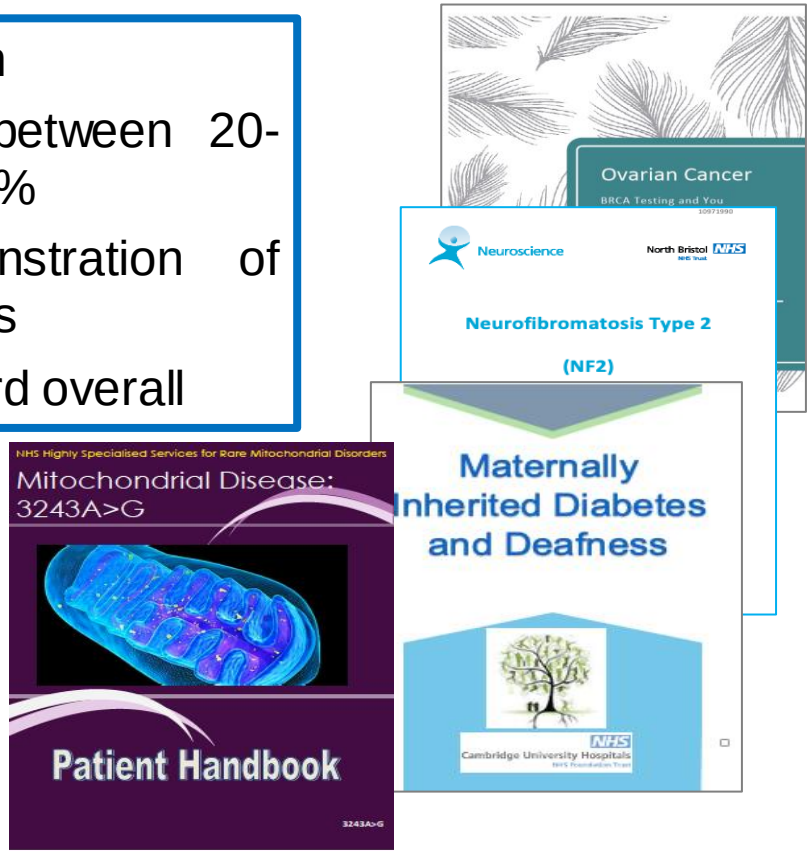
Assessments

Group oral presentations



- 100% submission
- Marks ranging between 20-85%, average 69%
- Excellent demonstration of knowledge & skills
- Very high standard overall

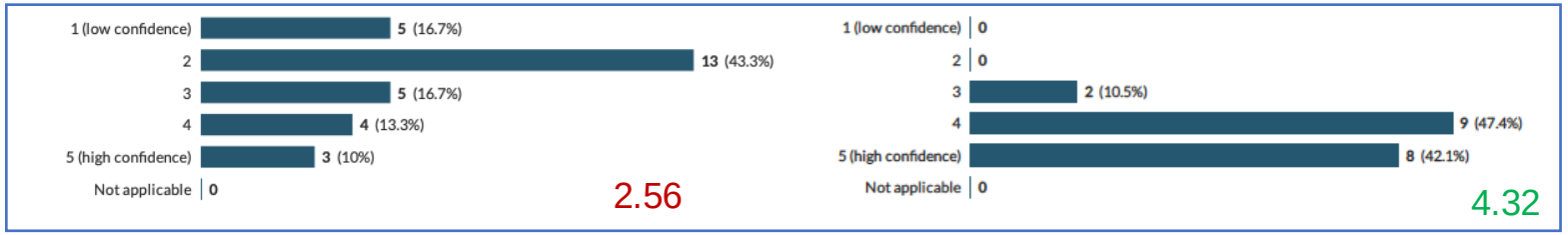
Individual information leaflets



Impact of the course

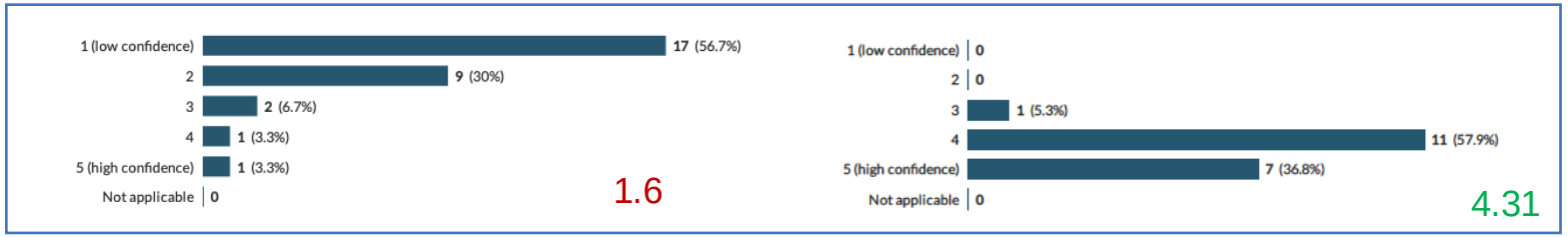
BEFORE **AFTER**

Q1 Understanding of the basic scientific concepts of inheritance, genetics and genomics



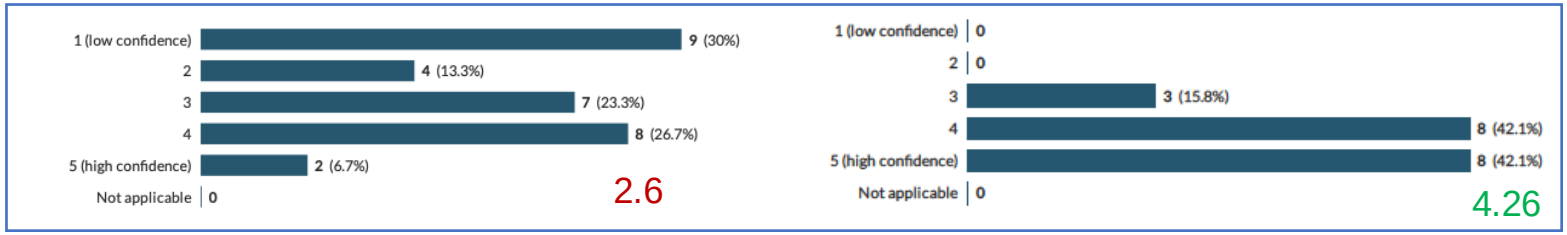
Low ↓ High

Q2 Understanding of the difference between the germline and somatic (tumour) genome and clinical implications associated with germline or somatic genetic variants



Low ↓ High

Q3 Understand what local genetic testing services are available and how to refer patients



Low ↓ High

Impact of the course – on Participants

"it doesn't scare me now! Its so interesting and I want to know more. "

"I now feel I have the understanding, which empowers me to make a potential difference for my patients."

"I was complete novice….I do actually understand some of those words now and it kind of makes sense."

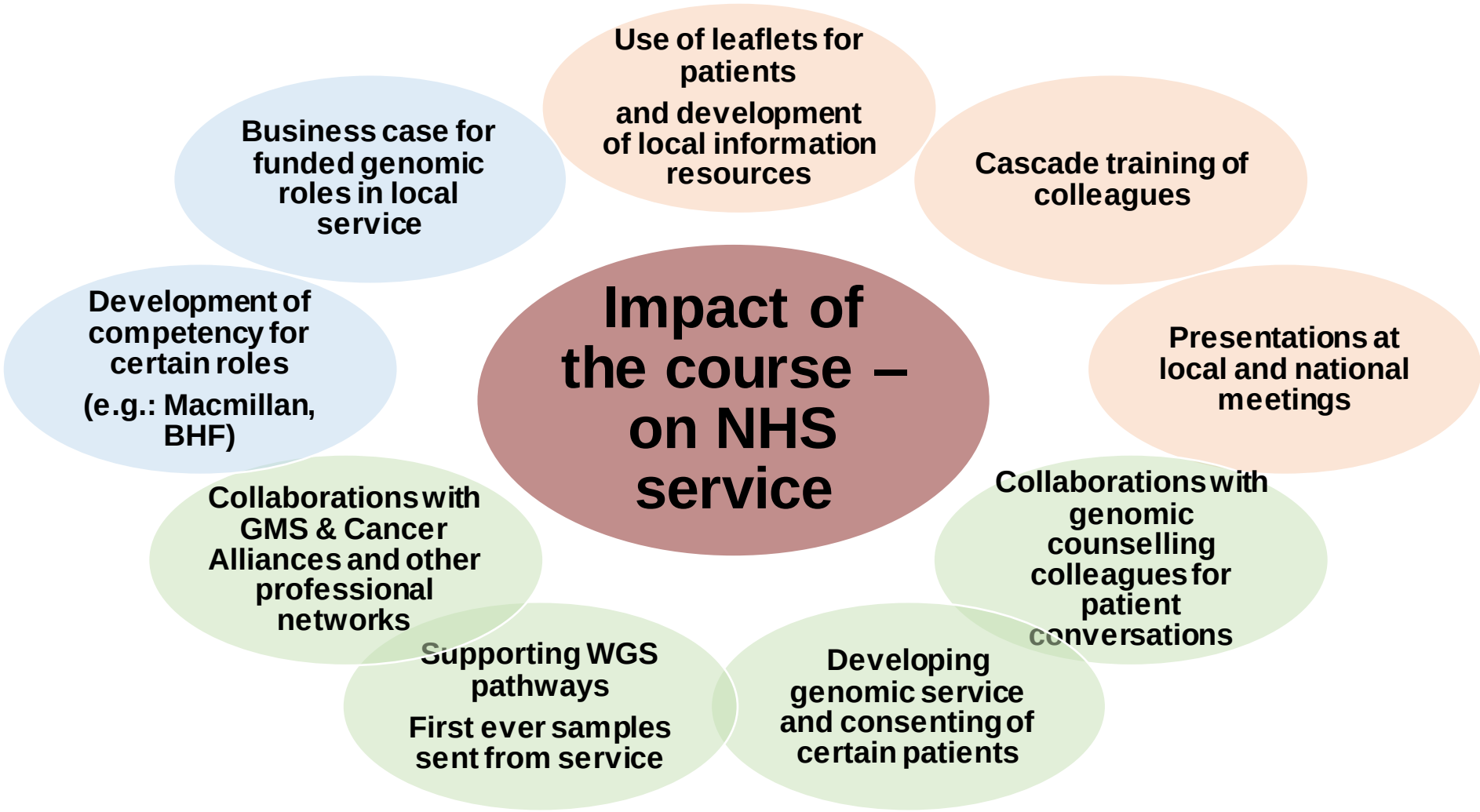
"I have increased my genomic literacy and gained greater confidence in talking genomics with colleagues, patients and their families."

"I find myself listening and understanding when the pathologists talk in MDT!!"

"it re-energized me, trying to support those families in a better way. There's got to be a better way of doing it for me. So, thank you."

"The course has given me more confidence in myself and my abilities."

"I feel more confident and understand the jargons …"


Impact of the course – on NHS service
Use of leaflets for patients
and development of local information resources
Business case for funded genomic roles in local service
Cascade training of colleagues
Development of competency for certain roles
(e.g.: Macmillan, BHF)
Presentations at local and national meetings
Collaborations with GMS & Cancer Alliances and other professional networks
Collaborations with genomic counselling colleagues for patient conversations
Supporting WGS pathways
First ever samples sent from service
Developing genomic service and consenting of certain patients

Importance of future training

"I hope that genomics courses that extend and develop from this one might be available in the near future. Nurses are often overlooked as professionals, academically patronised and socially undervalued. ***It is so refreshing to undertake a course like this, one that finally 'sees' us, challenges us and celebrates our role as essential navigators on the patient's pathway towards the future of better, personalised healthcare.***" from a participant on the course

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Dr Edward Miller - Genomics for Undergraduate and Nursing Competencies

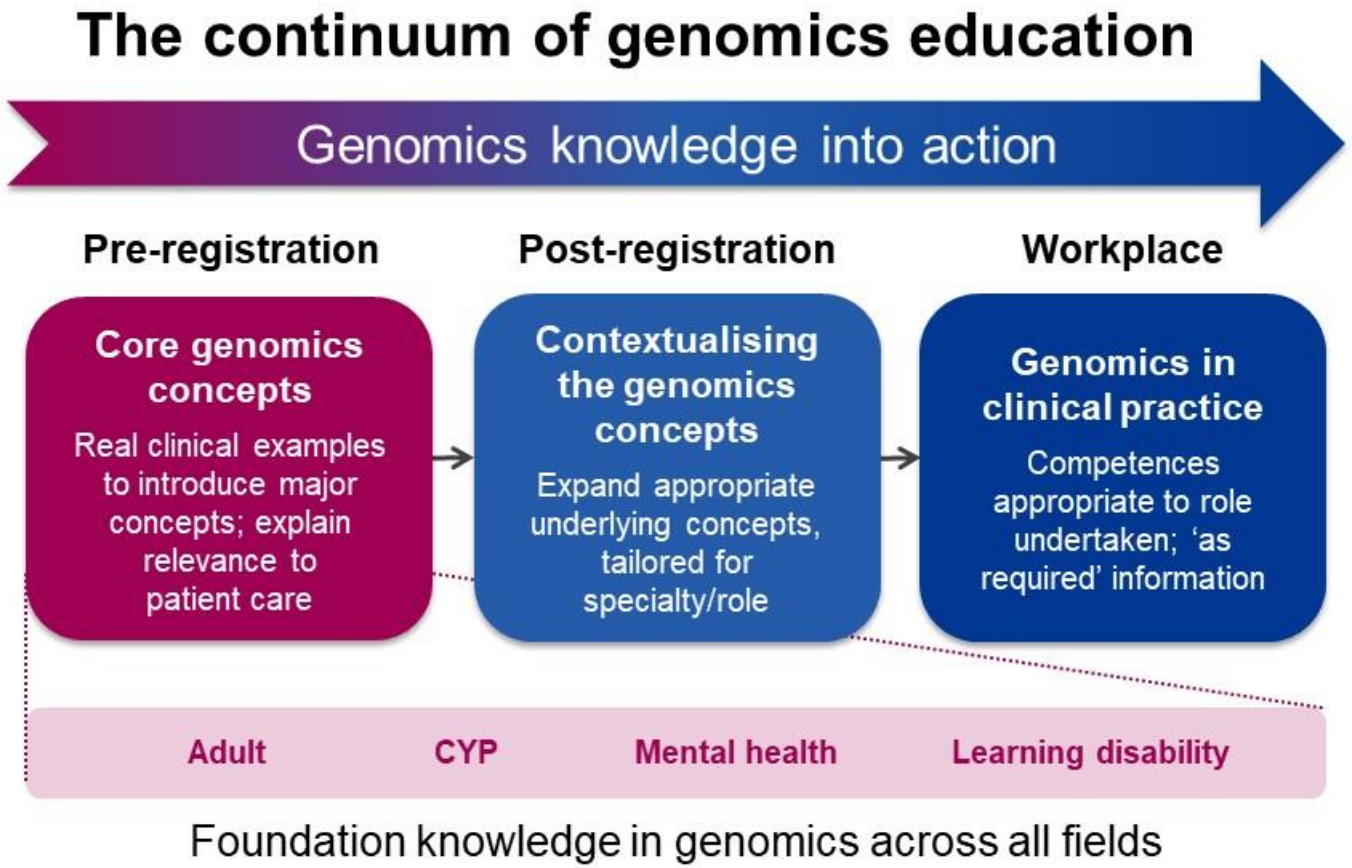
Dr Edward Miller presented on the nursing and midwifery work being undertaken by the HEE GEP.

All aspects of nursing and midwifery training have been taken into consideration within this workstream from pre-registration to post-registration and into practice, ensuring a good foundation knowledge across all fields. The work is focusing on core genomic concepts, contextualising these concepts and looking at how genomics can be embedded in clinical practice.

To support undergraduate genomic education, Dr Miller demonstrated the educator's toolkit which is currently being developed on the GEP website. Members were invited to make contact if they were interested in being involved in this project.

A competency framework for current and future workforce is also being developed by a steering group with representatives from nursing policy, practice and education.

Recognising where genomics is relevant



Undergraduate nurses: Educator's Toolkit

- To support educators with the delivery of genomics in pre-registration nursing and beyond

- Designed to be intuitive, flexible and adaptable to different curricula and teaching styles

- The toolkit aims to demonstrate that genomics:
  - is not a standalone subject;
  - can be knitted throughout curricula;
  - is applicable to different levels of teaching, nursing fields and areas of practice.
- Planned 2 phase approach with the toolkit evolving to include more resources e.g. lesson plans etc

Educator's toolkit

- Case-study based, categorised by
  - Nursing field
  - Nursing activities e.g Identification, communication, management
  - Area of practice e.g rare disease, cancer
  - NMC platform

- Each case study will be supported by additional teaching guidance and supporting information where needed
- Light review of approach from nurse educators Feb 2021 with a more in-depth evaluation once live
- (DEMO)

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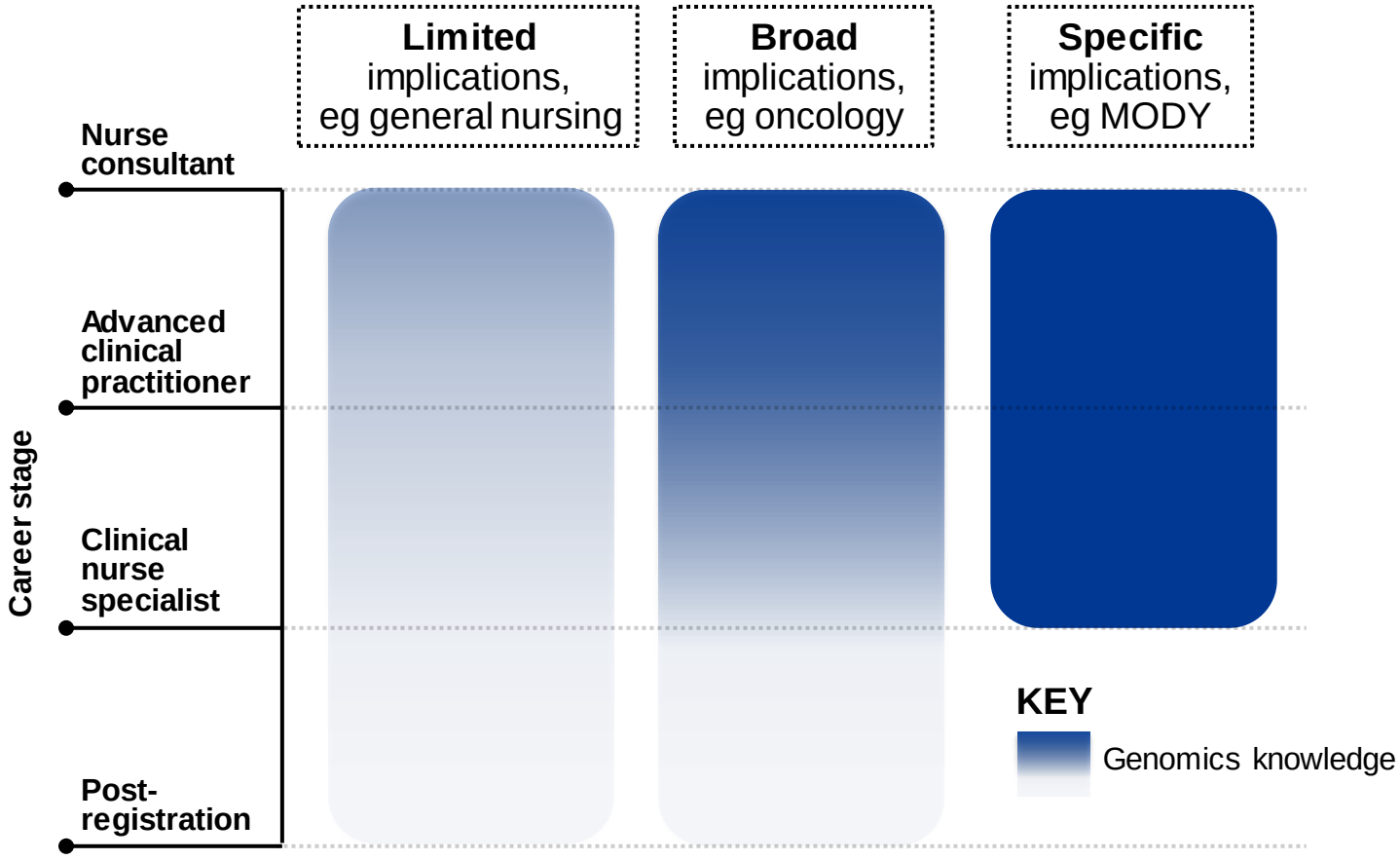
Nursing in genomics: knowledge map



Competency frameworks

- Building on previous work by Kirk et al 2014
- For current and future workforce reflecting a modern genomics medicine service.
- Framework covering three aspects:
  - Undergraduate nurses
  - General nursing workforce
  - Specialist nursing workforce e.g. Advanced nurse practitioners
- Developed with steering group with representatives from nursing policy, practice and education

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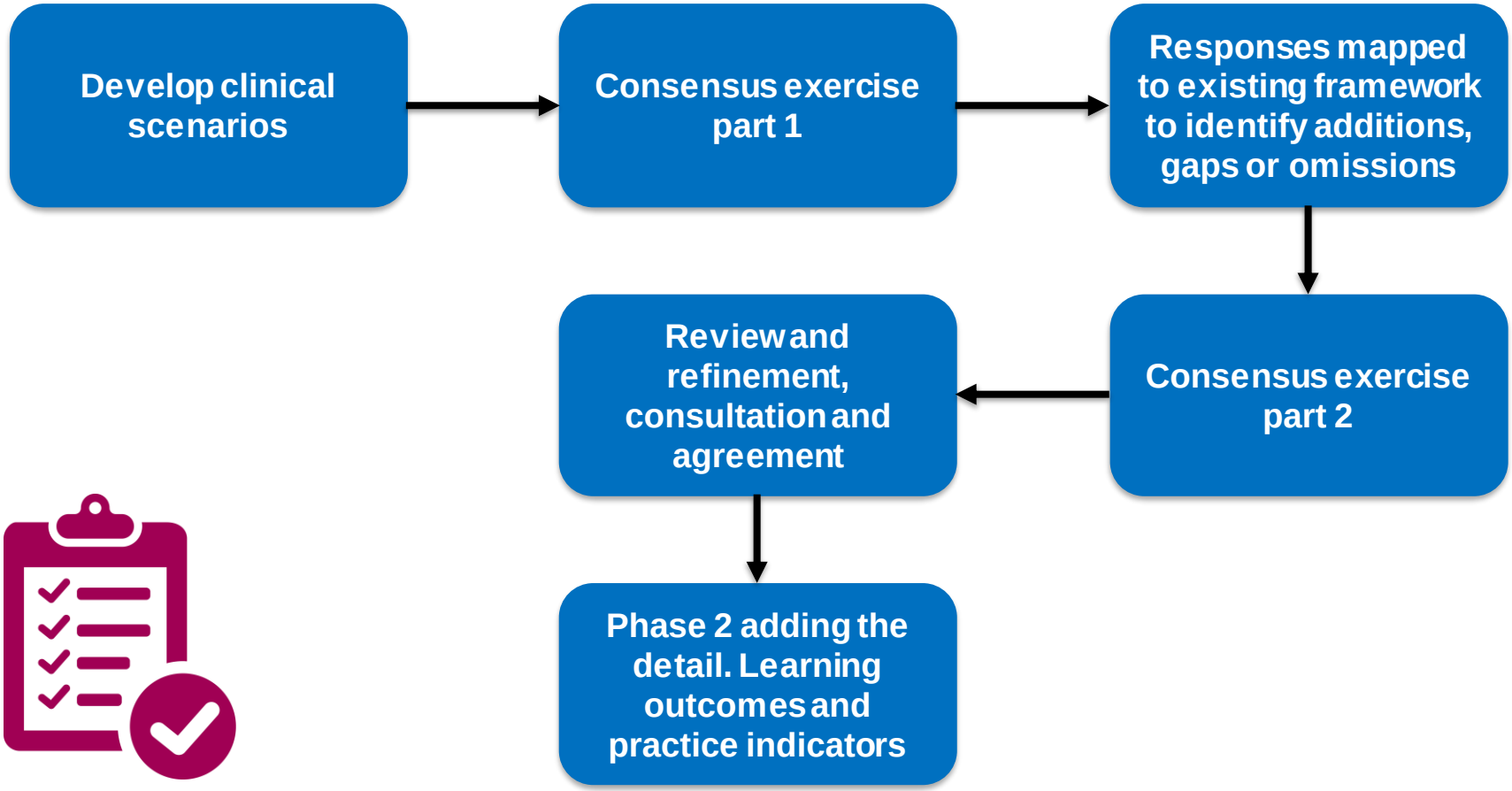
Competency framework: consensus approach



Competency framework: a pilot (impact of pandemic)

- Select 3-4 competency from existing framework, representing absolute must knows
- Will need some revising to reflect current workforce and service
- Trial in a local trust via ESR aligned to appropriate learning resources
- If successful look at using this model to role out nationally

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Like to get involved?

- Educator's Toolkit
  - Trial the toolkit within teaching
  - Participate in detailed review
  - Provide case studies
- Competency Framework
  - Participate in consensus work
  - Support the implementation by using the framework in education and training

Edward.miller@hee.nhs.uk

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Dr Jessica Myring and Sally Shillaker - GEP and Institute of Health Visitors Good Practice Points

At a previous Nursing and Midwifery Round Table the need for genomics education for health visitors had been highlighted . The HEE GEP and Institute for Health Vistors (iHV) have been working in collaboration with Dr Jess Myring to respond to this need.

Resources have been developed using existing mechanisms within the profession known as Good Practice Points (GPPs).

A team of experts worked together, with Jess as the subject matter expert.

Five genomics GPPs have been created and these were presented.

An evaluation is planned where iHV members will be given the opportunity to complete pre and post questionnaire to assess knowledge change following use of the GPPs. A focus groups with HVs will also be arranged to elicit views, and access statistics will also be monitored.

Genomics Good Practice Points (GPPs): making genomics accessible for health visitors (HVs)

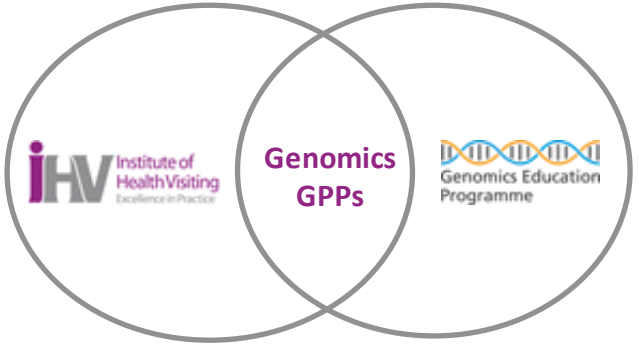
Leicester Clinical Genetics Service
Dr Jessica Myring

Institute of Health Visiting
Sally Shillaker

Genomics Education Programme
Ben Armstrong,
Dr Michelle Bishop
Alison Pope

Project drivers: bridging the gap

Genomics GPPs: a collaborative project to **bridge the gap** between **genomics** and **health visiting** clinical practice.



Institute of Health Visiting (iHV) strategy:

- Identification of potential gap in health visitors' knowledge regarding application of genomics in practice.

Genomics Education Programme (GEP) collaborative approach:

- Use established education and training methods recognised by the profession.
- Co-production with input from key members of the profession.
- Embed genomics knowledge into known infrastructure of given clinical practice.

"Hearing from genomic experts about what needs to be said and hearing from health visitors about how this can be best conveyed."

- Sally Shillaker, health visitor professional expert

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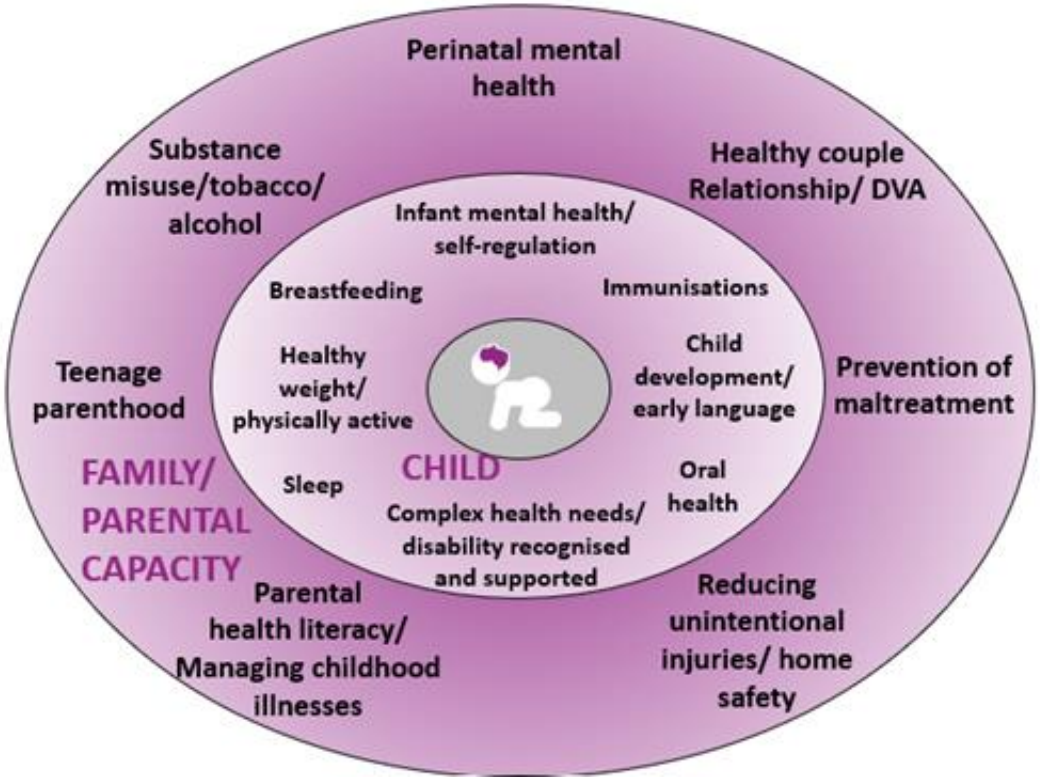
NHS Trust

What does a health visitor do?

Prevention → Early identification → Engaging families- recruitment/ retention → **Intervention** → Safety net for all children → Improved outcomes



Based on Bronfenbrenner's Ecological Systems Theory

What is the Institute of Health Visiting or iHV?

The iHV was launched in 2012 with the aim to raise standards in health visiting practice, so improving public health outcomes for all children, families and communities.

The iHV is:

- **working** to improve quality and consistency in health visiting practice by acting as a Centre of Excellence and setting professional standards for continuing professional development;
- **building** leadership in health visiting;
- **providing** targeted professional development to address capability gaps for example, Good Practice Points (GPP's), "Champions" training and e-learning;
- **developing** new effective ways to get key public health information to families, both directly, and through the health visiting service; and
- **creating** a strengthened research base for health visiting

The benefits of GPPs

GPPs:

- are short, succinct, evidence based documents covering a breadth of issues relating to health visiting practice;
- offer ongoing professional development and learning for members;
- conclude with specific points for health visitors to apply to practice; and
- are one of the most valued resources cited by iHV members (from feedback).

The iHV is always looking for new areas to write relevant GPP's.

Project goals:

- To **increase equity of access** to genomics for children and families by embedding genomics knowledge into HV practice.
- To **empower HVs to feel confident** using genomics, and realise its potential
- To **create genomics resources** for HVs based on iHV model of good practice points (GPPs)

Achieving project goals: our team

January 2020 - a group of experts from relevant disciplines begin working together.

Core team:

- **Subject matter expert** (clinical genetic counsellor)
- **Profession expert** (iHV representative, GPP production)
- **GEP team** (provision of editorial, educational and strategic support)

Double blind peer review process

Three independent peer reviewers, all health visitors;

- An academic who trains health visitors
- Health visitors with a background:
  - a) in paediatric nursing.
  - b) with experience in genomics.

Peer review from the clinical genetics team, Leicester

Including consultant clinical geneticists and genetic counsellors.

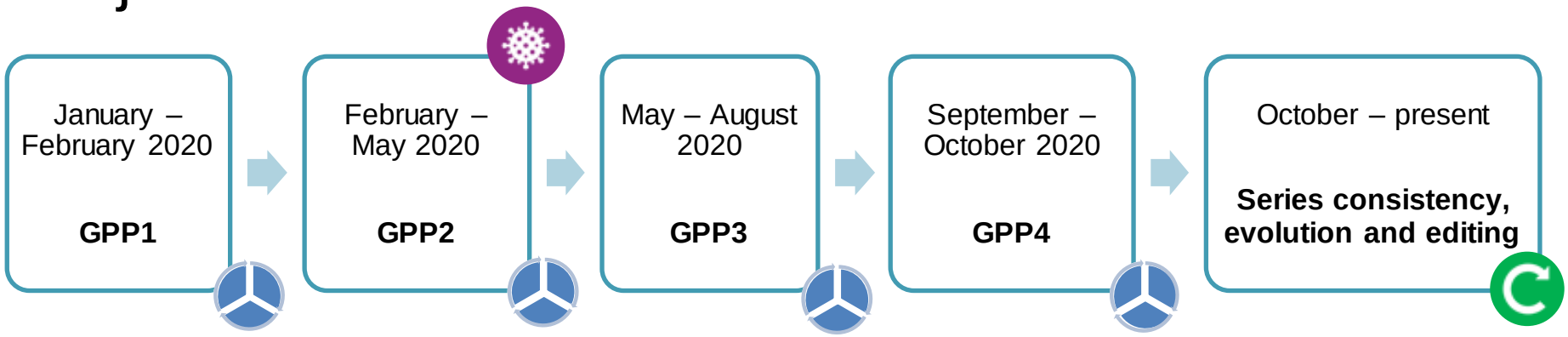
Achieving project goals: our imperatives

- Strong focus on *utility* of document
- Direct relation to practice
- Accessible
- Aspirational, empowering HVs to see their role in genomics
- Emphasis on cross-specialism reciprocal support and multidisciplinary practice
- Ultimately useful and transferable to other education/transformation genomics projects

Our approach

- Creative approach, developing new ideas and **responding dynamically** to the evolution of a new product
- Importance of **collaboration** - bringing together the knowledge of each **expert**, as well as **peers**.
- Working within limitations and **overcoming setbacks** caused by Covid-19 pandemic

Project timeline



Four Genomics GPPs:

GPP1: Introduction to genomics

Introduces basic concepts in genomics and highlights the benefits of genomics to patients, families and HV practice.

GPP2: The role of the specialist genomic medicine service

Introduces the teams involved, and explains how HVs can widen their role, get support and help families to access services

GPP3: Supporting a family through the 'diagnostic odyssey'

Explains concept of rare genetic diseases, the 'red flags' that can indicate them and how to start a conversation about this with families

GPP4: Communication around genomics for health visitors

Explains the types of conversations that HVs might have with families throughout the diagnostic odyssey

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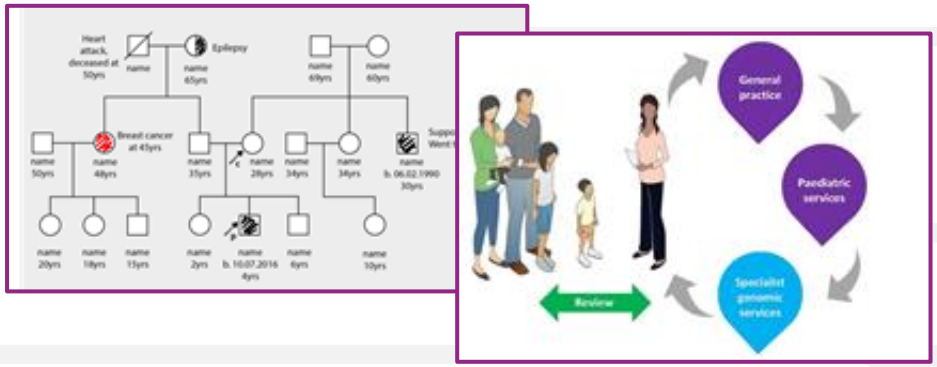
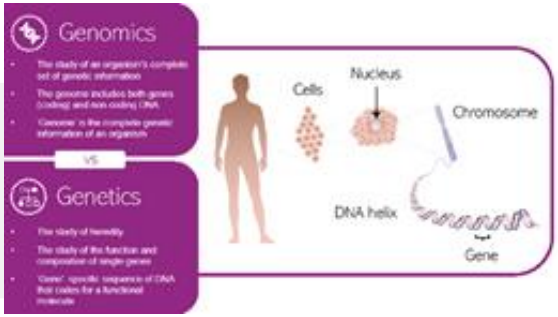
Six icons used consistently through all four documents to highlight and reinforce good practice points



Approachable, bold and peer-reviewed figures and case studies to help health visitors to understand and apply genomics in their practice

Genomics diagrams and infographics to illustrate important concepts



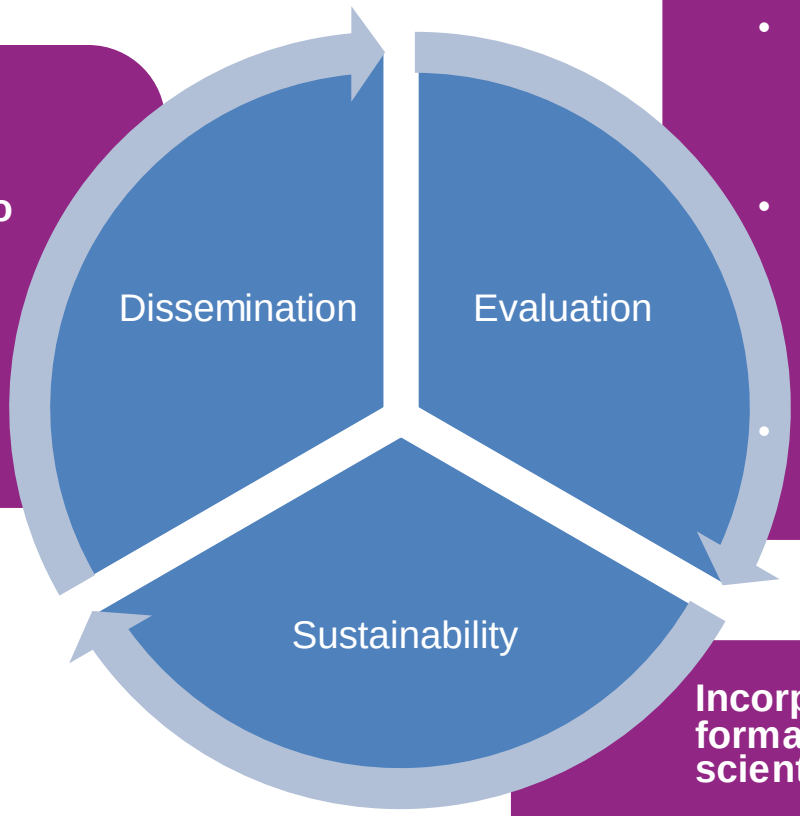
Wide signposting to other educational resources and sources of help to encourage further reading and provide support

GPPs: a success story for integrating genomics into existing educational frameworks

- Work with leadership within the profession and experts from all parties.
- Peer review from all professional groups.
- Allow for dynamic evolution of the project from multiple experts.
- Learn from iHV members and peer reviewer feedback in order to evolve the model further.

Next steps

Shared through iHV website (summer 2021), on Twitter and directly to iHV members via newsletter, iHV evidence-based conference September 2021.



GEP and iHV April-July 2021. Including:

- **Pre and post questionnaires to assess change in knowledge**
- **Focus Groups planned for May-June to inform a dissemination plan and ensure most effective use.**
- **Evaluation of the design process e.g. lessons learned.**

Incorporating user feedback, formal evaluation and new scientific information.

Biennial review with intention to address any required changes before then if required.

Future projects: community genomics

- Who else would you consider to be working as part of the community genomics family?
- What other professions might benefit from this approach to resource development?

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Actions and next steps

- Round Table membership encouraged to take part in the GEP Week of Action from the 28th June 2021, which will again focus on the nursing and midwifery professions.
- Professor Radford is keen to ensure genomics is included in curricula and setting metrics to measure success of adoption in education.
- Any organisations keen to be involved in the educator's toolkit or competency framework projects to contact Dr Miller – Edward.miller@hee.nhs.uk
- The iHV GPPs to be discussed with NHSE/I and HEE around relevant transformation projects especially within community paediatrics.

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Health Education England

Round Table Participants

Name	Representing
Lord Willis of Knaresborough	Independent Chair
Professor Mark Radford	NHS England and Improvement & Health Education England
Alison Pope	Genomics Education Programme, Health Education England
Agnes Hibbert	Health Education England
Aniko Varadi	University of the West of England
Anne Trotter	Nursing and Midwifery Council
Alison Morton	Institute of Health Visiting
Ben Armstrong	Genomics Education Programme, Health Education England
Carmel Bagness	Royal College of Nursing
Dr Christine Patch	Genomics England
Dany Bell	Macmillan Cancer Support
Deborah Porter	NHS England and Improvement
Donna Kirwan	NHS England and Improvement
Dr Edward Miller	Genomics Education Programme, Health Education England
Dr Emma Tonkin	University of South Wales
Ethel Rodrigues	Unite Union
Gill Moss	NHS England and Improvement
Professor Janice Sigsworth	Imperial College Healthcare NHS Trust /NHS England and Improvement

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Round Table Participants

Name	Representing
Jane Niederer	Nuffield Department of Surgical Sciences
Jamie Waterall	Public Health England
Jess Myring	Leicester Clinical Genetics Service
Kat Lynch	Genomics Education Programme, Health Education England
Jennifer Allison	National Institute for Health Research (NIHR)
Mel Watson	South West Genomic Laboratory Hub
Maggie Clarke	SAPHNA
Marie Batey	NHS England and Improvement
Michelle Lyne	Royal College of Midwives
Natalie Percival	North Thames GMS Alliance
Nicola Trotter	Nursing and Midwifery Council
Nigel Harrison	Anglia Ruskin University
Paul Driscoll-Evans	University of Suffolk
Sarah Armstrong-Klein	NHS England and Improvement
Sally Shillaker	Leicester Clinical Genetics Service
Sue Boran	Queen's Nursing Institute
Professor Dame Sue Hill	NHS England and Improvement
Vicky Cuthill	London North West University Healthcare NHS Trust