

“Let’s lead not follow.

Genomics is the route in and to be applied to all territories”.

Lord Willis of Knaresborough – Independent Chair

Health Education England’s summary report from the round table discussion around strengthening the Nursing & Midwifery Contribution to Genomics that took place on the 28th June 2017.



Developing people
for health and
healthcare

Forward from Lord Willis

**Genomics has the potential to impact every nurse and midwife.
It is no longer a field just for specialists.**

I was delighted to be invited again by Professor Lisa Bayliss-Pratt, Director of Nursing at HEE, to Chair this follow up roundtable discussion.

This report gives an insight into the updates received and the discussion we had at the event on the 28th June 2017. It was a pleasure to be informed of the excellent progress that's been made since the previous meeting and the ongoing implementation of the Genomics Education Programmes (GEP) nursing and midwifery transformation strategy.

The meeting took an interactive format, with the GEP team posing questions to the members attending. This generated discussion around the current and future planned resources to support the workforce development needed.

The group also saw a preview of the new GEP animation, which highlights the work the programme is doing to educate and train staff from across all professions to gain the knowledge, skills and experience they need to embrace the extraordinary potential of genomics, and bring about lasting benefits for patients.

As demonstrated at the previous round table, an eye-catching summary of the discussion was recorded in the form of visual minutes, including the three main themes to emerge from the meeting: '**Learn, Share and Reflect**'.

The outcome of the meeting was extremely positive, with all attendees engaged and keen to share new developments in genomics with their networks.

Overall the pace of progress, in this field more than almost any other, has significant implications for our future lives. From how we understand human health and develop 'personalised' approaches to preventing and treating disease.

The GEP team now has a number of actions to begin exploring with the assistance of the group. A follow-up meeting is planned for the new year to review progress.

Finally, I would like to thank colleagues from the Genomics Education Programme as an invaluable source of information and to everyone that attended on the day for their ideas and on going support.



**Lord Willis of Knaresborough
Independent Chair**

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Introduction



Health Education England



Professor Lisa Bayliss-Pratt, Director of Nursing, Deputy Director of Education & Quality, Health Education England explains why genomic education matters to all nurses and midwives in the 21st century.

As nurses and midwives we play a key role throughout the patient journey. That journey is set to be revolutionised through advances in our understanding of DNA. We need to be ready to make the best use of this huge step forward in personalised medicine.

Imagine being able to give an individual a drug or advice to mitigate problems, or to effectively target diseased cells without affecting healthy cells. These are the possibilities of DNA based care (or genomics). Understanding how a person's DNA can affect their health will change how your patient is diagnosed and how you manage and treat the condition. Cancer and prenatal care are just two of the areas where genomics offers more personalised, precise diagnosis and treatment.

It's clear to see that the nursing, midwifery and wider workforce have a pivotal role in ensuring that we successfully embed a genomics service within the NHS. Nurses, health visitors, school nurses and midwives are a huge workforce of almost 350,000, and in a unique position to support and enhance the advances being made. Personalised medicine has the potential to greatly influence nursing practice for the benefit of our patients. We all have a role in taking this further, and bringing the benefits of genomics to provide truly person-centred care.

We have an ambitious goal: to help drive changes at both a local, national and at a global level regardless of their role or clinical specialty. Embracing genomic healthcare requires a nursing and midwifery workforce that can inform, educate and empower people.

However there is still a significant challenge ahead of us to fully understand this agenda and how it integrates into clinical practice. So let's get ready with the tools we need to communicate genomic information, understand the implications of the results and provide appropriate support. Nurses, midwives and the wider workforce have a pivotal role and it is important to seize the opportunity to enhance and bring the benefits of genomics to provide person-centred care.



Read Lisa's Bayliss-Pratt's full blog here at:

<http://bit.ly/2vIkD1S>

Co-Chairs of the round table

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



Lord Willis of Knaresborough
Independent Chair



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

HEE's Vision and Values

Health Education England (HEE) exists for one reason only: to support the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place.



- ✓ Working together for patients
- ✓ Compassion
- ✓ Respect and dignity
- ✓ Improving lives
- ✓ Commitment to quality of care
- ✓ Everyone counts

Five revised objectives for HEE

- ✓ Thinking and leading
- ✓ Analysing and influencing
- ✓ Changing and improving
- ✓ Delivering and implementing
- ✓ Focusing and tomorrow

Invitations

National leaders from the nursing and midwifery system and representatives from a range of organisations were invited back, to gain their expertise and develop our thinking in order to secure the best educational system for genomics in the future.

Participants were carefully selected as a group of individuals recognised as experts across the breath of Nursing, Midwifery, Public Health, Education & Training and Genomics.



Participants



Health Education England

The following people attended the follow up round table event:

Name	Representing	Title
Lord Willis	Independent Chair	
Lisa Bayliss – Pratt	Health Education England	Director of Nursing and Deputy Director of Education & Quality
Aditi Chowdhary-Ghandi	Nursing and Midwifery Council	Standards Development Specialist
Alison Pope	Genomics Education Programme	Genomics Education Programme Operations Manager
Dr Anneke Seller	Genomics Education Programme	Genomics Education Programme Scientific Director
Carmel McCalmont	Representing Royal College of Midwives	Head of Midwifery
Charlotte Szczepanik	Genomics Education Programme	Project Administrator – Genomics Education Programme
Dr Chris Patch	Genomics England	Clinical Lead for Genetic Counselling
Dame Professor Donna Kinnair	Royal College of Nursing	Director of Nursing
Dr Julie Green	Queen's Nursing Institute – representing DNs and GPNs	Director of post graduate studies. Senior Lead in Nursing and Award Lead for Specialist Community Nursing.
Elaine Trainor	NHS England	Project Manager Evidence and Evaluation (LCAV)
Jane Niederer	Nuffield Department of Surgical Sciences at University of Oxford	Senior Nurse Clinician
Joanne Bosanquet	Public Health England	Deputy Chief Nurse
Karen Stansfield	Institute of Health	Head of Education and Quality
Maxine Foster	Genomics Education Programme	Genomics Education Programme Director
Suma Das	Nursing and Midwifery Council	Standards Development Specialist
Sue Hatton	Health Education England	Senior Nursing Policy Manager

Agenda

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

1. Introduction

- a) Focus and updates following the last roundtable in January 2017 & feedback on roundtable report, any update on pledges and professional mobilisation
- b) NMC Pre-registration standards.

2. Presentations

- a) World Collaborating Centres
- b) Faculty of Genomic Medicine update and opportunities for the nursing and midwifery workforce
- c) Creating a nursing and midwifery specialty video
- d) Update and progress to date on the HEE Genomics Education Programme
- e) Training needs analysis.

3. Discussions

- a) Overview of GEP Resources including the genomics game for nurses and midwives
- b) Toolkit and resource webpage
- c) Genomic champions/supporters/ambassadors
- d) G2NA – update
- e) Communication and professional mobilisation going forward
- f) Genomic Medicine Centres & HEI Posters

4. Summing up

- a) Next Steps and Summing up



Focus and updates from the last Round Table in January 2017

Feedback on roundtable report, any update on pledges and professional mobilisation

After Lord Willis had welcomed senior figures from the nursing and midwifery profession to its second genomics round table discussion, he explained the importance of maintaining these conversations, that there was a need to act quickly and not to wait during these unsettling political times.

“Let’s lead not follow, Genomics is the route in and to be applied to all territories”.

Lord Willis led a dialogue around progress since the last round table meeting in January 2017 and how the group could help more in sharing their experiences. It was unanimously agreed that it is important to talk about genomics at every given opportunity, adding information about genomics to talks and presentation’s to create a social movement across the nursing and midwifery profession.

Recognising the generational differences and needs of early career nurses and midwives in the workplace, there was an acknowledgement that science lessons in schools needed to address genomics alongside traditional genetics. Enabling young people to not only understand the role of genetics in their everyday lives and future careers, but to present a realistic perspective of genetics research that will encourage some to even become scientists in the future.

It was agreed that there needs to be more information shared with the midwifery profession as there had been a missed opportunity at a recent midwifery international meeting, where there hadn’t been any reference to genomics throughout the event.



NMC Consultation on standards of proficiency for registered nurses

NMC colleagues updated everyone that genomics is included in both the [Nursing Associate Framework](#) and [NMC Standards \(Pre Reg Nurses\)](#) which are currently out for consultation till the 12th September 2017.

It was acknowledged by NMC colleagues that it was still early days and although there hadn't been any analysis at present, overall the NMC have had positive feedback around the draft standards for future nurses, raising the profile of nursing and what is expected of them.



What do nurses think the future holds?

The draft standards of proficiency reflect what the NMC think the public will need in the future from the nurses who care for them. They are the minimum standards that a nurse will need to meet to be considered to be capable of safe and effective practice.

The full consultation - for nurses, midwives and those with a background in education or healthcare are being asked to give their views about the proposed standards of proficiency for registered nurses and the education framework: standards for education and training.

The standards of proficiency are structured under seven headings that describe key components of the roles, responsibilities and accountabilities of registered nurses.

<https://www.nmc.org.uk/education/education-consultation/registered-nurses/>

Action:

- For all members of the roundtable to keep talking about Genomics to arouse curiosity.

Presentations

Over the course of the day, there were a variety of presentations that gave an overall flavour of the discussions that needed to be explored further, to gain a consensus or to debate around some key areas to inform the developing GEP products in clinical practice.

- 2a) **World Collaborating Centres**
- 2b) **Genomics Education Programme International Collaborations**
- 2c) **Faculty of Genomic Medicine update and opportunities or the nursing and midwifery workforce**
- 2d) **Creating a nursing and midwifery specialty video**
- 2e) **Update and progress to date on the HEE Genomics Education Programme**
- 2f) **Training needs analysis**



World Collaborating Centres

Joanne Bosanquet, Deputy Director of Nursing in Public Health England (PHE), provided an update around the WHO Collaborating Centres from across the world and shared PHE's outline action plan.

The Chief Nursing Directorate at Public Health England have been designated as the first WHO Collaborating Centre for Public Health Nursing and Midwifery in November 2016. Professor Viv Bennett Chief Nurse PHE is leading on this initiative. It was also noted that there wasn't any additional finances attached to it.

3 Terms of Reference have been identified around generating evidence, defining the framework and developing a network. To date there has been two events held with a great response. PHE currently have 400 academic honorary contracts wrapped into the research. There is a concern that PHE is not in the ICN due to considerable cost involved. The RCN updated that they were aware that the ICN are currently restructuring the cost, with the desire to reunite, but obviously needs to be value for money.

During her conclusion, Joanne pledged to add some genomic slides or animations to every one of her presentations that she now gives, maximise social media and tweet using the genomics hashtag more ([#HEEGenomics](#)).

It was also noted and recognised that Professor Sue Hill was working with the G2MC around a policy positioning paper which also needed to be linked in.



Joanne Bosanquet.
Deputy Director of Nursing in Public Health England





PHE CND WHO Collaborating Centre for Public Health Nursing and Midwifery

ToR and initial outline action plan



Public Health
England

International call to action for nurses and midwives



International
Council of Nurses /
International
Council of Midwives

**Nursing and
midwifery as a
force for health
and change**



**WHO Europe
Health 2020
Strategic
Directions**

**Nurses and
midwives – a
vital resource
for health**



UK and Republic of
Ireland

**Caring for the
public's health**

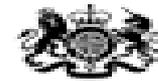
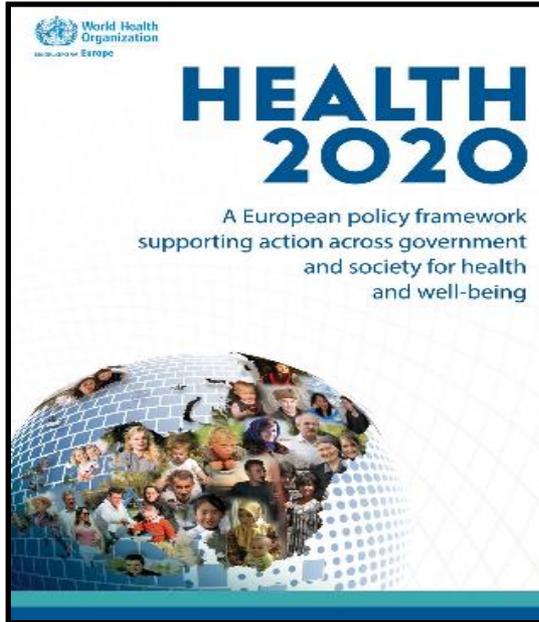
Making the vital
resource visible

Embedding and
extending the
contribution of
nurses and
midwives



Public Health
England

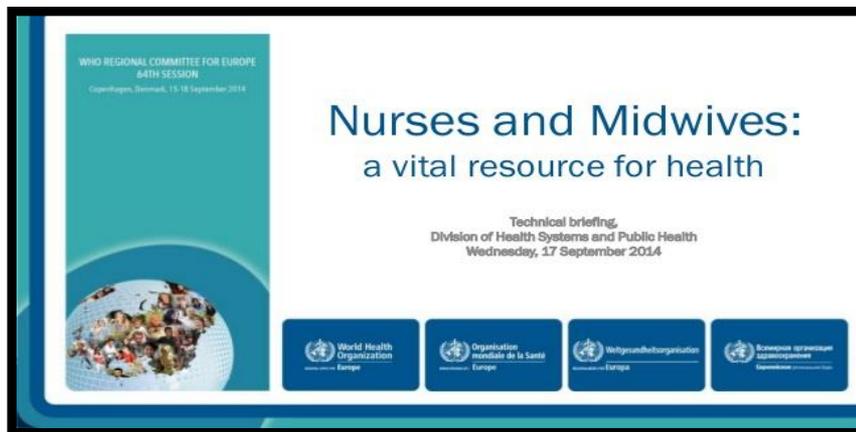
WHO Europe Health 2020



Public Health
England

**Chief Nurse Directorate
Designated first WHO
Collaborating Centre
for Public Health
Nursing and Midwifery**

Nov 2016



Prevent avoidable disease, Protect health, Promote wellbeing resilience



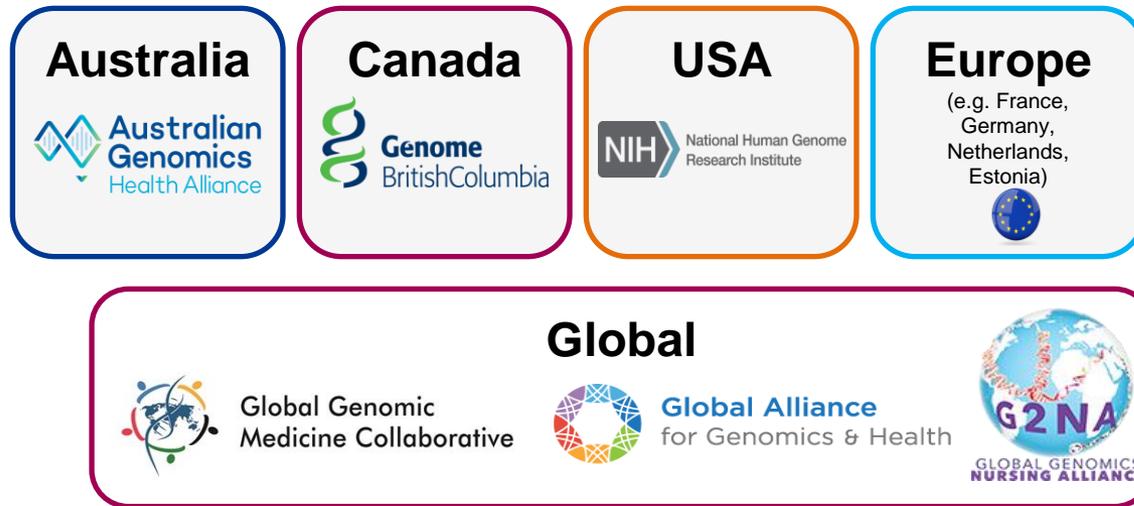
WHO Public Health Nursing and Midwifery Collaborating Centre Terms of Reference

- 1) To support WHO by generating evidence and defining frameworks of practice for nurses and midwives which prevent avoidable illness, protect health and promote wellbeing and resilience.
- 2) To support WHO by providing information about the nurses' (including health visitors) and midwives' role and impact on maternal and child health.
- 3) On request of WHO provide policy advice and technical assistance about public health nursing and midwifery to the Regional Office and Member States.

To note WHO have a wide understanding of PH nursing and midwifery encompassing most community care

Genomics Education Programmes

International collaborations



International Collaboration:

Around Genomics, there are currently significant global groups collaborating with the aim to share GEP knowledge and learn how they work. During the discussions a variety of actions were then identified by colleagues from around the roundtable, as it was recognised that when engaging internationally pace at scale was key. It was also important to gain the support locally to ensure that pace at scale and to spend time sharing best ideas and practice.

The round table were also asked for suggestions of contacts and organisations to link into regarding global collaboration.

Actions:

- The roundtable group to be kept updated via JB.
- The GEP needs to link in with the National Institute of Nursing Research (NINR).
- HEE to co-ordinate international links with Director of Global Health, PHE and WHO.
- To request a position statement from the ICN.
- HEE to follow up other key contacts suggested by the membership.

Faculty of Genomic Medicine update

Opportunities for the nursing and midwifery workforce



Health Education England

An updated was provided on the Faculty of Genomic Medicine which was launched in March 2017 by Sue Hill.

What is it?

In order to embed genomic medicine in mainstream healthcare a Faculty of Genomic Medicine has been created that will serve as the strategic and operational lead in this aim. The Faculty currently has 449 members.

The three key areas of activity are:

- To serve as the **centre of knowledge and expertise** about how advances thinking in genomic medicine will impact routine diagnosis, care and management of NHS and 3rd sector patients.
- To act as a professional network that **drives the spread** of this knowledge and its implementation in practice across the services of the NHS and wide health system partners.
- To inform, and be informed by, developments in genomics education and training, and research priorities in this space, **supporting innovation and change** in healthcare.

A strategic advisory group

A strategic advisory group made up of leaders in genomic medicine will determine opportunities and activities for the Faculty which will then be delivered by Faculty members, drawn from across the healthcare sector in England as well abroad.

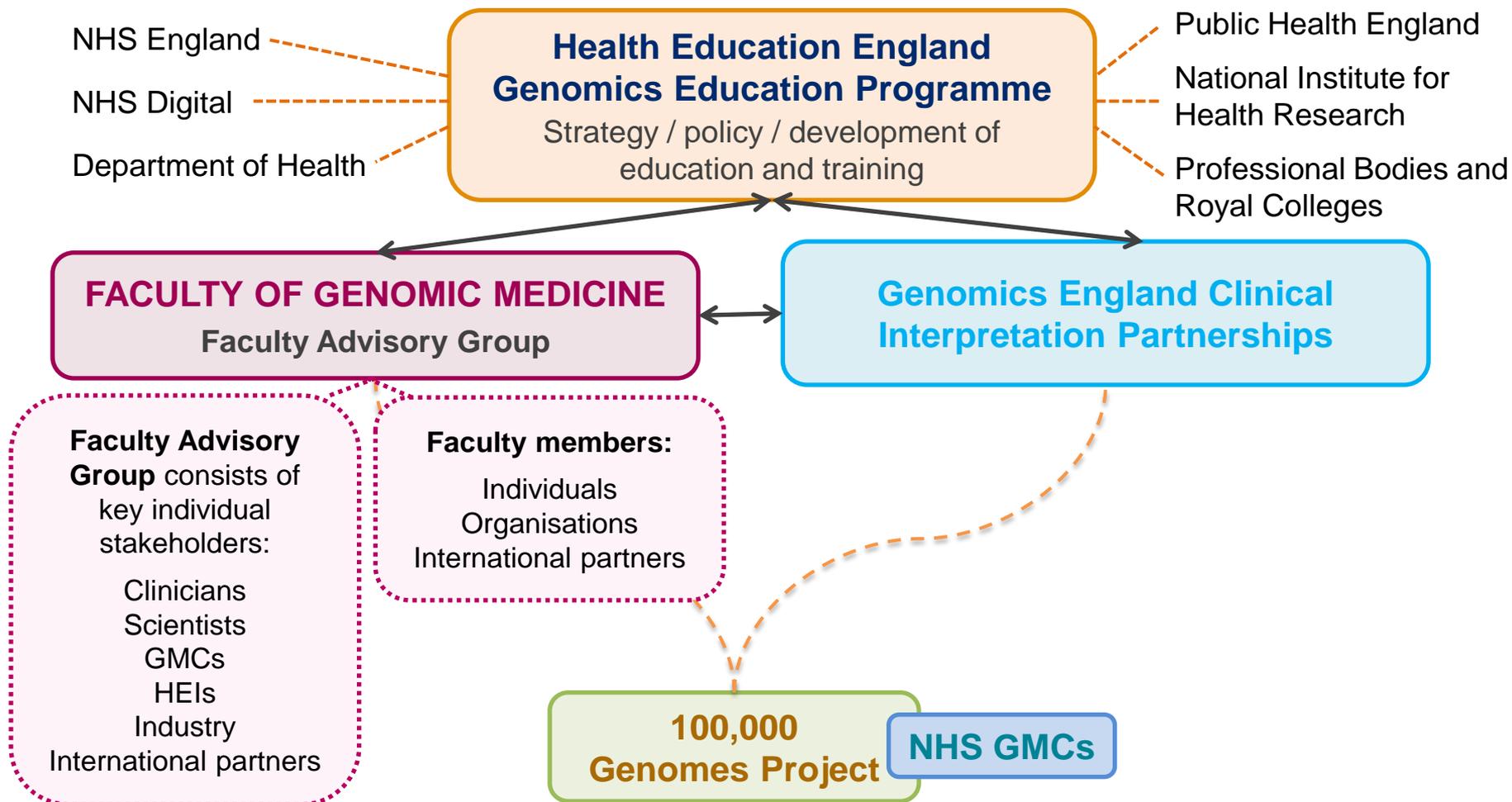
Thoughts are maturing how they can better engage with nurses and midwives going forward.

Faculty Benefits:

- Advance your career and research opportunities.
- Access webinars & lectures by experts.
- Networking - make connections and enhance relationships.
- Share and gain knowledge across clinical and scientific specialties.



Emerging operating model for GEP



Four webinars are planned per year, led by leading healthcare professionals available to Faculty members introducing them to emerging themes within genomic medicine. <https://www.youtube.com/watch?v=scr0bgYWj8Q>

Two webinars so far in 2017 looking at the role of the Faculty in genomic medicine and the impact of genomic medicine on diagnosis and treatment. Other themes for 2017 include:

- genomics and workforce transformation in England
- the genomics ‘industry’
- genomics on an international scale.
- Faculty members are also invited to submit potential themes for webinars, including presenting their own research.

The discussion focused primarily around engaging and reaching nurses and midwives and there was a strong theme around the need for the GEP communications to link into more groups and for members of the roundtable need to be speaking within their communities about Genomics.

Actions:

- Members of the round table were invited to submit potential themes for webinars relevant to nursing and midwifery and to link in with their professional communities.
- Links with Clinical Academic Careers programme to be explored.
- HEE colleagues to meet strategically to discuss how the GEP can link the programme into the WHO framework.
- GEP to link into the CLAHRC programmes, which have been extending to 2019 and looking for new ventures to build an interface and advise on how future research strategies can align and maximise opportunities around nurse led initiatives with academics are merging with other fields. GEP to send information regarding Genomics directly to the Directors so that they can communicate the work the genomics programme is doing.



Update on the HEE Genomics Education Programme

Training needs analysis of NHS Staff:

- Developed in conjunction with E&T leads from GMCs
- Cross-sectional survey with 2578 responses (covering all professional groups)
- 623 people out of 2578 that completed the training needs analysis were nurses and midwives.
- 23% (n=317) **do not feel** they have sufficient knowledge or skills in genomics to perform their **CURRENT** role
- 84.9% (n=93) feel they **need further training** in genomics

“It is imperative that going forward all nurses should be taught a basic understanding of Genomics... so that we might be better able to support our patients”

General Practice Nurse

The themes of perceived needs:

Recognition of a need to acquire new knowledge and develop new skills

“Genetics (will) influence the way we treat patients... I’m open to learning... to provide personalised care to all patients”

Nurse, pain management

Understand the relevance to their clinical role

“... how it relates to my practice, impacts on patient’s care and why I should know about it”

Nurse, anaesthetics and recovery

Did not see it as relevant

“Doesn’t apply to my specific area...”

Nurse, surgery

Awareness raising covers two groups of health professionals:

Recognise that genomics will be relevant to their role
Unaware of potential impact to their professional Practice.





<https://youtu.be/PNtrZuPt24A?t=2m9s>

Creating a nursing and midwifery specialty video



Health Education England

Key video message:

“Genomics has the potential to impact every nurse and midwife. It is no longer a field just for specialists.”

Case studies suggested to bring in a number of different roles to ensure they demonstrate how genomics is relevant to the patient showing the nurses skill and knowledge.



- Practice nurses
- Antenatal screening teams
- Bereavement midwives
- Learning disability nurses
- Nurse consultants
- Parents from the rare diseases community, patients and members of the public.
- Videos need to be practical and relevant to the patient. Nurses need to be at the heart of the story at any point in the system and be able to start the conversation
- Video case studies could be aligned to the 4 themes from the FYFV to include mental health, cancer and primary care.
- Link to policies, Nursing Associate Framework and NMC Standards.

Awareness-raising is a key component of our programme strategy. The GEP survey conducted at RCN Congress and Primary Care Conference(n=40) showed a preference for hearing from **contemporaries** and **patients** in a video. With survey preferences in mind, the GEP are taking a ‘case study’ approach to the video based around the ‘life course’. GEP has committed to create 2 videos, one for nursing and one for Midwifery with a key theme around ‘raising awareness’.

Various questions were asked of members of the roundtable throughout the ‘life course’, who the audience would want to hear from, promote and disseminate and ensuring patient and public involvement. It was unanimously agreed how incredibly valuable these videos would be as they are vital role modules that are currently missing in this field. Antenatal screening midwives are currently developing videos of their work. It was noted that they will also contribute to the image and value of nursing and midwives.

Action:

- GEP to engage in partnership for videos and align a strategy to link with the Next steps on the NHS Five Year Forward View.
- To align with the completion of the NMC Standards consultation and new nursing students starting.
- To aim to release the video Autumn 2017.

Resources for the wider workforce

Discussions focused on an overview of GEP Resources.

WGS MOOC

- Online 'social learning' style course on FutureLearn
- Developed for health professionals with limited understanding of the sequencing process
- 13,500+ registered learners since Sep 16



Genomics 101 series

- Series of 8 short online modules aimed at health professionals with limited or no genomics knowledge.
- Designed to take the learner from genes and proteins, to genomics in clinical practice.
- Currently in development, launching late 2017



Genomics film series

Filmed interviews to raise awareness of genomics in key areas:

- Cardiology, Pathology, Cardiology, Ophthalmology, Respiratory, Primary Care
- Nursing, Midwifery, Bioinformatics
- First films to launch by autumn 2017



Genomics Game

- Board game for face-to-face interactive group learning activity
- Developed primarily for nursing workforce
- Aligned to current curricula
- Currently in testing phase, and due for release in August 2017



Also... introductory online courses, factsheets, articles, videos, animations and infographics

Resources for the wider workforce cont..

Genomics film series

- Series of 8 short online modules aimed at health professionals with limited or no genomics knowledge.
- Designed to take the learner from genes and proteins, right through to how genomics can be used in clinical practice.
- Will feature video, animation and infographics.

1. From gene to genome

2. Making a protein

3. Inheriting genetic information

4. Taking and drawing a family history

5. Classification of genetic conditions and variation

6. How genomics is used in healthcare

7. Communicating genetic and genomic information

8. How we investigate the genome

Some of the many GEP resources available



The Genomics Game



- Aimed at nursing associates and pre/post-registration nurses with little or no previous genomics knowledge.
- Designed to start the discussion and raise awareness of genomics and its application in healthcare.
- The game is a non-facilitated supplementary learning tool intended to reinforce knowledge and increase retention.
- Midwife version is in development.

HEIs sought to test new educational game

The Genomics Game, developed by Health Education England's Genomics Education Programme, is an interactive and innovative way to start a bigger conversation about genomics and its application in healthcare.

Aimed at the nursing community, the game is designed to be used as an educational tool to support learning pathways and is aligned to the Nursing Associate Curriculum Framework and the draft NMC standards, which are currently out for consultation. The GEP is currently going through user testing with Higher Education Institutes delivering nursing associate and pre-reg nursing training, with the aim to launch August 2017. If you would like further information, please contact Ed Miller at the Genomics Education Programme: genomicseducation@hee.nhs.uk

Dr Jargon is a game designed to encourage health professionals to use simple, jargon-free language when talking to patients about medical conditions, treatments and their health. GEP are looking to launch one with Genomics terminology.

Action:

- GEP to ensure that the RCN & RCM have a copy of the game for their libraries.
- To explore launching the game at the RCM on the 13th September as Heads of Midwifery from across the UK will be there.
- GEP to confirmation to roundtable members the price of the game.
- GEP to explore with Lord Willis if the game could be used as a 'Lunch and Learn opportunity' in the House of Lords.



[@GenomicsGame](https://twitter.com/GenomicsGame)



The Genomics Game

What our Trainee Associates told us

“The answers led people to generate other questions and gave a platform for developing further knowledge”

Pre-registration Nurse

“We had some useful discussions and it helped us revise what we have learnt in university”

Trainee nursing associate - TNA

“We were all able to discuss the questions once they had been answered. This added clarity to our knowledge”

Pre-registration Nurse

“Made you discuss things you were learning about” (TNA)

“This game makes learning interesting”

Pre-registration nurse

“I didn't know anything about genomes before the game” (TNA)



Q. What is a genome?

- A. A garden ornament
- B. An organism's complete genetic material
- C. An individual gene

A. B is the correct answer.

Genome describes an organism's complete genetic material, which is often referred to as DNA.

Each genome contains all the information needed to build that organism and allow it to grow and develop.

G-001

Q. Why do people want to study the genome?

- A. Scientific curiosity
- B. Specific health reasons
- C. Trace our ancestry

A. They are all correct.

The genome interests people for different reasons. In healthcare we want to improve prediction, prevention, diagnosis and treatment of disease.

For example, variations in our genome can mean we react differently to drugs and experience different side-effects.

G-013

Q. What information can a genetic family history tell us?

- A. Biological relationships
- B. Identify a genetically inherited condition
- C. Identify who else in the family is at risk

A. All 3 are correct.

Taking an individual's family history is extremely important when trying to identify whether a condition or disease runs in a family.

By documenting the genetic history of individuals and close family members it may be possible to identify patterns of inheritance, provide a diagnosis, or implement effective treatment strategies.

G-030



[@UniNhantsNews](https://twitter.com/UniNhantsNews)

Educational toolkit

Toolkit and resources webpage: The GEP education toolkit is currently in progress, the aim is to be a one-stop shop that is transferable to all professionals.

This will be a live webpage covering the whole breath of the workforce.

SESSION OUTLINE

Understanding patterns of inheritance and communicating genetic risk – A 60 minute session which builds on session 1 exploring patterns of inheritance and how individuals and families perceive chance and risk.

Aim: To develop the participants understanding of inheritance patterns and how to communicate genetic risk to individuals and families.

Objectives – At the end of the session the participants should:

- Explain the differences between the inheritance patterns associated with autosomal dominant, autosomal recessive, X-linked recessive and X-linked dominant
- Have an appreciation that some patients with a common disease (such as cancer) may have an underlying inherited cause
- Be able to explain 'chance' and how someone will inherit or be a carrier of a condition is determined
- Understand the factors involved with risk perception and ways of talking to individuals about risk

Topic	Duration	Suggested activities	Context	Possible handouts
Introduction and overview	10 mins	Refresher of session 1 and inheritance patterns.	Ensuring the participants have no misconceptions.	Short pre-test Diagram of how genes are passed through families
Understanding patterns of inheritance	20 mins	Presentation on autosomal dominant, autosomal recessive, X-linked and chromosomal abnormalities.	Understanding the different patterns of inheritance	Using family history e.g. cystic fibrosis, Marfan, DMD to explain the different modes of single gene inheritance as well as the implications of numerical and structural abnormalities. Impact of the environment and genetics on common complex conditions e.g. diabetes, obesity .
Communicating risk to families	20 mins	Explore factors which influence how families perceive risk. Discuss ways of communicating genetic information.	Understand how life experiences impact on the perception of risk and disease implications Explaining the role of language in communicating genetic information.	Using patients stories discuss how risk is perceived statistically, personal experience etc http://www.tellingstories.nhs.uk/index.asp Talking to patients about genetic risk
Conclusion and summary	10 mins	Question and answer session.	Ensure no misconceptions.	Handout
Next steps	5 mins	Suggested reading & other activities.		Reading list and urls to internet trawl.

Recognising patterns of inheritance quiz

Which of the modes of inheritance is the most likely based on the pattern of people with the condition in this family?

a. Chromosomal translocation
b. Autosomal dominant
c. X-linked dominant
d. Mitochondrial
e. Autosomal recessive

www.genomiceducation.hee.nhs.uk @genomicedu #genomes100k

Understanding patterns of inheritance: Prompt questions if you require them

Here are some questions you may want to raise with the students at the end of session 1. They can be used as a summary if you don't get any questions from the students.

1. Why do you see genetic variations between parents and children?
2. What are the three main classifications of single gene conditions?
3. In autosomal dominant conditions what is the percentage probability for each child inheriting the condition?
4. In autosomal recessive conditions (where both parents carry the gene alteration) what is the percentage probability for each child inheriting the condition?

Further information

i) Genomics Education Programme Website & Infographic

www.genomicseducation.hee.nhs.uk



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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](#)

 <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@hee.nhs.uk

Genomics Champions/Supporters/Ambassadors



Health Education England

It was acknowledged that 'Genomics ambassadors' were an action that arose from the previous meeting in January.

The discussion that took place focused around the following questions:

When should we launch?

Suggested that we could launch in September when new nursing students start.

Institutions could become Genomics Champions with their members being Genomics Ambassadors.

Also need to have resources that nurses and midwives can use.

Suggested that we could link with the nurses day.

What should they be called?

The round table was invited in its advisory capacity to make a decision and it was agreed for them to be called 'Genomic Champions'.

How to promote and disseminate?

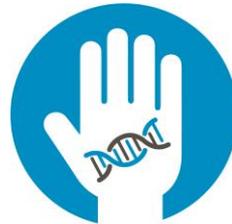
A variety of suggestions were discussed and actions agreed.

How to encourage uptake?

Need to incentivise individuals to become members and celebrate what people have achieved.

Actions:

- GEP to develop a briefing for Jane Cummings following the CMO report on the 4th July.
- GEP to review time table to get resources ready and then pick a day to launch with the appropriate communications materials and maximising opportunities at major conferences throughout the year to obtain organisational sign up. Chief Medical Officer to be asked to promote.
- GEP to explore a bracelet, badge, digital badge to be used on emails and social media, awards etc. to encourage take up.
- GEP to contact PHE re. Antibiotic Guardians model and lessons learnt.
- GEP to explore badges with scouts, guides, cubs and brownie groups around a genomics badge.



Key themes and recommendations

Lord Willis again noted the progress since the last roundtable. A number of overarching themes emerged from the discussion

1. Nursing & Midwifery Leadership

National leadership and from organisations represented at the roundtable continued to be seen as vitally important to continue the debate and champion the development and implementation of the GEP strategy to transform and embed genomics into nursing and midwifery practice. A key action for roundtable members was for us all to keep talking and promoting across our organisations about Genomics and promote at every opportunity to create a curiosity.

2. Building Capacity and Capability

There is a need to think about nursing and midwifery in the next 20 years and what the expectations will be to ensure that the workforce of today and tomorrow has the right skills, knowledge and competencies.

Ideas focused around having shorter express training – similar to primer day but for those who are already involved in Genomics. The importance of nurses and midwives ‘grabbing’ and accessing information when and where it is needed and applying it to their clinical practice.

3. The NMC and Council of Deans

To continue links with the NMC and forge links with the Council of Deans to make sure there is a stronger focus and understanding around genomics within the undergraduate/postgraduate curriculum and to identify what additional support is required from the GEP to support education establishments.

4. Utilising existing professional networks

It was seen as critical that we mobilise new and existing networks to raise awareness of genomics and its impact on nursing, 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 where genomics is currently being used in practice to develop the set of case studies.

5. Genomic Champions

Was seen as a key initiative to sign up individuals and organisations where they can support others to understand what genomics is and its impact on healthcare especially across the nursing and midwifery.



Key Findings and Recommendations

6. Communications and utilising social media

It was unanimously agreed around the importance to talk about genomics at all given opportunities, adding information about genomics to talks and presentation's to create a social movement across the nursing and midwifery professions.

The new GEP animation and filmed case studies suggested to bring in a number of different roles to ensure they demonstrate how genomics is relevant to the patient showing nurses and midwives at the heart of the story aligned to the Five Year Forward, Nest Steps around mental health, cancer and primary care linking into policies and new NMC Standards.

A need to strengthen and target communications to ensure engagement to highlight access to learning that's profession appropriate. When you increase the number of people who see that genomics is relevant, then more individuals will engage highlighting the sense of urgency.

Key is around utilising existing communication avenues through PHE, iHV, RCN, RCM and other organisations around the roundtable to ensure consistent and targeted messages at pace and scale.

7. 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.

8. Global Collaborations

There are currently significant global groups collaborating with the aim to share GEP knowledge and learn how they work. When engaging internationally pace at scale was key, as important to gain the support locally, ensure pace at scale and to spend time sharing best ideas and practice. It was agreed that the GEP would establish stronger links with PHE Collaborating Centre.

9. Faculty of Genomic Medicine

In order to embed genomic medicine in mainstream healthcare, the Faculty of Genomic Medicine has been created that will serve as the strategic and operational lead in this aim that roundtable members were asked to promote across their networks.



Next Steps: Learn Share and Reflect

Lord Willis closed the meeting by thanking attendees for their involvement and valuable input. He highlighted the success of the Nursing and Midwifery round table and celebrated the work that is being done around the country.

During the summing up he praised that huge step change in activity and conversations since the previous meeting in January and offered his continued support at the round table, his continued involvement around signposting to information and resources.



If you have any comments or queries?

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Appendix 1. Genomic Medicine Centres and HEI's posters

There is lot of activity taking place at the local GMC centres.



Personalised medicine in the NHS

Translating and embedding genomics in Y&H

Julie Atkey, The Yorkshire and Humber NHS GMC

Education at North Thames GMC

100k Genomes Project & workforce transformation

Masuma Harrison and Danielle Stevenson



ABOUT US

The Yorkshire & Humber Genomic (YHGM) is a joint collaboration between Sheffield Teaching Hospitals' Trusts, together with 11 local delivery partners, comprising 20 other regional hospitals. It serves a population of 5.2 million. Our aim is Y&H to:

- collect samples from 4,700 participants
- create a lasting legacy to bring personalised medicine to NHS patients in our region.

The team picked up the baton in the Great Exam of Adoption and delivered a number of the Yorkshire and Humber Academic Health Science Network's innovation, improvement & impact awards.

"Genomics is key to the future of medicine and the formation of the Y&H NHS Genomic Medicine Centre will be a catalyst for the transformation of care".
Andrew Jack, Clinical Director for YHGM

SPOTLIGHT ON BEST PRACTICE

YHGM has a very active PPI group, with members involved in every aspect of the project.

"The YHGM GMC serves a large metropolitan population with whom many PPI activities have to be adapted. I expect to continue expanding the number of our PPI activities and will continue to work with our delivery partners to ensure we have maximum representation in our GMC panel".
Michelle Brown, PPI Lead

Sharing information, H&C Week - Learning what about the varied uses of H&C and our work in the 100,000 Genomes Project for H&C week

Cancer MDT 'vib' sheets

PARTNERSHIP WORKING

Working in partnership with HEE and HEIs to ensure workforce transformation in line with the broader agenda.

Collaboration with Prof Anne Kerr, Head of School, Sociology, University of Leeds, Wellcome Trust award in Society and Ethics (2015-2020), researching how patienthood is changing in the post-genomic era, focusing in particular on cancer.

Sheffield T1 research day looking at differences in patients

ABOUT US

- Great Ormond Street Hospital
- Bar's Health
- London North West Healthcare
- Moorfields Eye Hospital
- Royal Free London
- University College London Hospitals

As well as all other hospitals in the geography of the UCLPartners AHSN

MEASURING SUCCESS

APP	Type of activity	Reached in next 12 months
GP VTS training	11 (1st session)	400
GP VTS training	14 (2nd session)	710
GP VTS training	14 (3rd session)	80
GP VTS training	14 (4th session)	1,000

GP VTS training - average score (average number of 12 months after training)

Specialist and generic training evaluation - average score (average number of 12 months after training)

Short training session evaluation - average score (average number of 12 months after training)

SPOTLIGHT ON BEST PRACTICE

Embedding programme into yearly training cycles to maximise trainees over time and to ensure sustainability: GP VTS trainees / SpRs / nurses / medical students

PARTNERSHIP WORKING

- Close links with local HEE office - funded 1718 posts
- GMC embedded with Academic Health Science Network
- Training programme directors
- For 1718, education co-ordinator post also PPI lead / comms lead / and part programme manager, resulting in better joined-up workstreams across the GMC
- Recent pan-London group established

KEY CHALLENGES

data, engagement, money, time, communication, attitudes, change, workload, evaluation

MEASURING SUCCESS

Master's programme "What does it mean, what would we expect to see?"

H&C week profile: Key note by Carolyn Leng (An Expert Practitioner in Diagnostic Research Lead)

The most visited space on our website: education!

Develop and utilize effective evaluation and feedback approaches

Engage with Faculty of Genomic Medicine, develop a regional network to address gaps

Second training needs analysis (TNA) planned to evaluate uptake and engagement

TOP PRIORITIES

- Begin to address outcomes from TNA, eg. interpathologists focus day
- Increase wider awareness across region
- Help increase cancer recruitment
- Address the needs of new recruiting loans and LDPs
- Identify local genomics improvement / innovation challenges
- Engage nursing staff, junior doctors and primary care

KEY CHALLENGES

Embedding programme beyond current funding cycles

2016/2017 Clinical geneticist: 2 PAs
Genetic counsellor: 0.8wte
Co-ordinator: 0.8wte
2017/2018 Clinical geneticists: 2 x 1PA
Geneticist: 0.5wte
Co-ordinator (also programme manager / communication lead / PPI lead): 0.8wte - (6 months only)

TOP PRIORITIES

- Improving cancer recruitment - further cancer education programme
- Training all SpRs
- Further work with GPs

ABOUT US

- North West Coast NHS Genomic Medicine Centre covers Merseyside, Cheshire, Lancashire & South Cumbria.
- We are based in Liverpool Women's Hospital.
- Currently we have recruited over 1,000 samples into the project.
- We recruited an Education & Training Project Manager in August 2016.

SPOTLIGHT ON BEST PRACTICE

- Taking 100,000 Genomes Project to Cumbria.
- Delivering Pharmacogenomic module for MSc Programme.
- Structure of NWC Genomic Alliance with educational subgroup for all stakeholders in our patch.
- Comprehensive programme of workshops being run with UoL & NWC GMC.
- Local marketing tools being produced and used widely.
- Social media used regularly inc. WhatsApp / Twitter / Instagram to raise our public profile.

PARTNERSHIP WORKING

- Taking the 100,000 Genomes Project to Cumbria with Newcastle GMC.
- Providing training with University of Liverpool (UoL).
- Running modules with UoL and University of Manchester.
- Running joint workshops with Liverpool Health Partners in 'Infection Education' and 'Genomics & Oncology'.
- Part of the Northern Genomics Alliance with other Northern GMCs - regular sharing of materials and ideas.

KEY CHALLENGES

- Logistics: South Cumbria is over 90 miles away from our base.
- Accessing GP practices and engaging with them to assess their needs.
- Engaging across the UK for attendees to our Prenatal Micro-array Workshop at Alder Hey Children's Hospital in June.
- Turning our successful training needs analysis into manageable useful data to improve education and training for all NHS staff.

MEASURING SUCCESS

- Since the E&T Project Manager has been appointed (Aug 2016) there has been an increase of 35% in recruitment.
- Interest from outside private companies, e.g. Astra Zeneca, wanting to work with us.
- Increase in public approaching our hospital stands due to increased awareness of the 100,000 Genomes Project, especially after our Community Roadshow in Liverpool City Centre.

TOP PRIORITIES

- Improve primary care and GP involvement.
- Improve Cumbria's involvement.
- Improve training and regularity of training to all clinical staff.
- Improve local knowledge of the study by involving community groups and charities.
- Transfer successful workshops to online programmes for other GMCs and their staff.
- Create a mainstream workshop model to distribute information.



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Appendix 1. Genomic Medicine Centres and HEI's posters

There is lot of activity taking place at the local GMC centres.

West Midlands Genomics Education
Health Education England

West Midlands Genomics Education
A transformative approach to embed genomics in healthcare
Education Team, West Midlands Genomic Medicine Centre

ABOUT US

The West Midlands is the largest NHS Genomic Medicine Centre (WM GMC) comprising a consortium of 18 Local Delivery Partner (LDP) Trusts.

We have taken a different approach to most GMCs by focusing on **transformation**, including recruitment across the entire region and outside of clinical genetics.

In collaboration with the West Midlands Academic Health Science Network, the WM GMC has appointed three geographically based **Genomics Ambassadors** to support this transformative process, and the spread and adoption of genomics and genomics education across the LDPs.

A suite of educational programmes has been developed to underpin the delivery of the project and to ensure the current and future workforce is equipped to understand how genomics medicine might impact on their role.

SPOTLIGHT ON BEST PRACTICE

Personalising medicine and mainstreaming genomics: this masterclass hosted by the WM GMC, and attended by 84 people, looked at the impact of genomics on patient care and a patient who presented her story. This will be rolled out as a regional roadshow.

A flexible 4th Year medical student elective in genomics has been piloted with the University of Birmingham (UoB) giving 40 students the opportunity to shadow clinical staff and assist with project duties.

MEASURING SUCCESS

Numbers trained (Aug 15 - Jan 17)

- Genomics course completed: 55 staff
- Consent & recruitment: 57 staff
- Consent & recruitment training: 320 staff
- Baseline genomics training: 808 staff (Sep 16 - Jan 17)

PARTNERSHIP WORKING

Partnership working with the regional healthcare science workforce has led to the completion of a training needs analysis.

It has also enabled the promotion of genomics at public engagement and schools events.

New work experience opportunities in genetic counselling and genomics at HSC and J-level have been designed in partnership with HealthTec.

A Central Region Genomics Education and Training Network has been established, enabling collaborative working, including a workshop for General Practice Nurses in March 2017.

University of Birmingham Master's uptake exceeds original target at 75 places.

KEY CHALLENGES

We have identified the following challenges:

- Reaching out to so many clinical staff across the health sector; getting the messages right so that they understand the impact of genomics for their role and for their patients
- Mainstreaming genomics education across current and new education programmes to ensure a sustainable model in future.

TOP PRIORITIES

We have identified the following training and education priority areas:

The validation of results and delivery of results to patients and their families

Ensuring that genomics is made accessible for clinical staff, by linking to case studies and the impact of personalised medicine on the management of patient conditions and pathways.

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West Midlands Genomics Education

Dawn of precision medicine in Wessex
Health Education England

Dawn of precision medicine in Wessex
Educating and preparing our workforce
Dr Catherine Mercer, Wessex GMC

ABOUT US

Working in partnership with trusts from across the south, NHS is the lead organisation of the Wessex NHS Genomic Medicine Centre (GMC). The Wessex NHS GMC is one of 13 centres involved in the delivery of the 100,000 Genomes Project and serves 1.3 million people from Dorset, Wiltshire, Hampshire, Isle of Wight and parts of Somerset, Surrey and Sussex.

The education team has been working in three main areas. First to promote the uptake of the Genomic Medicine MSc by NHS staff. Interest in the course and recruitment figures have remained strong, student feedback has been excellent. Secondly, we work with all specialties in the hospital and active patient groups to identify patients who could benefit from participating in the 100,000 Genomes Project. We also run workshops and awareness-raising seminars to train individuals in the current processes. In addition, we are running a comprehensive, pan-regional education programme designed to reach so many healthcare professionals as possible.

To celebrate the successes of the 100,000 Genomes Project so far and to engage with those who will be involved in the further transformation process, we have organised an event aimed at NHS staff across Wessex.

SPOTLIGHT ON BEST PRACTICE

- Taking advantage of existing forums such as Grand Round, MDTs, research meetings, educational rolling half days.
- Using every educational occasion to advertise resources, eg Master's.
- Appointment of a Genomic Nurse Specialist (Barrie ward sister)
- Weekly meetings for those involved in delivering the project: rare disease, cancer, IT, education, laboratory
- Involve ment of medical students, informing clinicians in clinical setting, consulting patients
- Public engagement events across Wessex, from school age children to LGA.

MEASURING SUCCESS

KEY CHALLENGES

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Genomic Education Activity
Health Education England

Genomic Education Activity
North East & North Cumbria NHS GMC
Hayley Lucas, Genomic Training Co-ordinator

ABOUT US

The North East and North Cumbria NHS GMC is based at the Northern Genetics Service, within the International Centre for Life in Newcastle upon Tyne.

NENC Genomic Education Team

Project Clinical Lead	Dr Paul Brennan
Project Manager	Jan Stacey
Genomic Education & Training Co-ordinator	Hayley Lucas
Healthcare Science Lead, Life and Physiological Sciences (HLS)	Gill Crosswell
Genomics Research Nurse	Manda Mathison-Howard

SPOTLIGHT ON BEST PRACTICE

Collaboration and sharing of resources

The NENC GMC education team has produced a number of resources and regularly share these on Genomics Connect.

Patient and public involvement

We are part of the Genomic Medicine Advisory Working Group, which consists of rare disease patients and carers, NENC NHS GMC and Newcastle University.

Working with NENC North and their valuable resource of STEM ambassadors to develop lesson plans for each key stage of compulsory education.

Primary care

We have produced a general practice information pack, which is being distributed to every practice in our region.

PARTNERSHIP WORKING

- Partnership working with the North Region Core Group
- 100,000 Genomes Project
- General Information Pack
- We have formed the NENC Genomic Education Steering Group; we work closely with local universities, other trusts in the region, AHSN and many more.

KEY CHALLENGES

We are a small team and have been through a lot of staff changes in the last few months. This has created challenges such as:

- Cancer: We have been working hard to increase cancer recruitment but have found that for many eligible cancers there are multiple pathways and one size does not fit all.
- Geography: Our GMC covers vast rural areas (Cumbria) and we have found working collaboratively with NENC GMC is the only way to tackle this.
- Engagement with CCGs: Due to a number of reasons this is a slow process. Our aims are to work closely with all CCGs in the region to disseminate information.

MEASURING SUCCESS

- Evaluation of appropriate education events using Survey Monkey questionnaires.
- Developed our own Twitter page – engagement activity is monitored.
- Use of hit by links – we can monitor visits to our websites and interest in events.

TOP PRIORITIES

To focus on:

- Hospital engagement and staff education – increasing recruitment to the cancer strand of the project.
- Increased engagement in primary care especially in more rural areas.
- Patient and public engagement in the 100,000 Genomes Project throughout the region.
- Supporting and informing the school curriculum and educating the future workforce.

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Appendix 1. Genomic Medicine Centres and HEI's posters



Health Education England

There is lot of activity taking place at the local GMC centres.



Training and Education Oxford NHS Genomic Medicine Centre Jen Whitfield, Training and Education Lead

South London Genomics Education Delivering high-quality education and training South London NHS Genomic Medicine Centre

Workforce transformation Building the leg of the 100,000 Genomes Project Melanie Watson, Eileen Roberts and Aniko Varadi, West of England NHS GMC

ABOUT US

Lead organisation:
Oxford University Hospital Foundation Trust

5 local delivery partners (LDPs):
Great Western (for rare disease), Milton Keynes, Frimley Health, Royal Berkshire, Berkshire Healthcare (and 4 other smaller local trusts in scope)

Population size: ~3 million

SPOTLIGHT ON BEST PRACTICE

School and careers events

- Exhibits and activities developed for older school children to educate, inspire and highlight career opportunities in genomics (from winners of Bucks Skills Show 2016)
- Collaboration with HEE-TV has expanded our network of contacts and led to new events.

Patient and public engagement

- Attracting patient days allowed us to highlight the 100,000 GP and the progress being made toward personalised medicine.
- Cafe Scientifique** stretched our creativity with technology-free presenting and a diverse audience (yes, you can explain genomics with ribbons and fuzzy felt), but also created a lively debate and led to further invitations to give talks.

PARTNERSHIP WORKING

HEE-Thames Valley

- Working with local schools to demonstrate genomics in practice and potential career routes to the next generation.
- Engagement with health dean, interim GP dean, and genomic champion, who have agreed to help raise the profile of genomics.

Other GMCs

- Oxford GMC, HMGMC and EESMC jointly ran a workshop on genomics at the General Practice Nursing Conference (March 2017), and also ran a stand with information on genomic education opportunities.

Oxford Academic Health Science Network

- Slow to engage, but key relationships recently established with potential to exploit existing networks.

Centre for Personalised Medicine

- The Oxford CPM has expressed interest in collaborating and has experience of running events for GPs, one of our hard-to-reach groups.

ABOUT US

Delivering high-quality and accessible education and training to healthcare workers throughout South London, Kent, Surrey and Sussex*

Our genomics education programme is embedded in the South London NHS Genomic Medicine Centre and is responsible for delivering education across:

- 4 NHS Trusts in South London
- 12 NHS Trusts in Kent, Surrey and Sussex (KSS)
- 3 higher education institutions (HEIs)

SPOTLIGHT ON BEST PRACTICE

- Website development**
- Online resources**
- Face-to-face teaching**
- MSc Genomic Medicine**
- Raising awareness**
- Building a legacy**

PARTNERSHIP WORKING

- We work collaboratively across the South London and KSS regions. Representatives from the South London Trusts and KSS are members of the South London Genomics Education and Training Working Group.
- We are actively engaged with the South London LECTB (HESU) and have regular meetings with the postgraduate dean and his team.
- We have presented at the Confederation of South London Lead Providers (COSL) to garner wider support of genomics.
- We are members of a recently established pan-London/Southeastern genomics education and training network.

KEY CHALLENGES

Engagement with primary care

- Routes to effective communication unclear.
- GPs in practice especially hard to reach (geographically dispersed and time-poor).
- Established collaboration with HEE-TV GP Deas to improve appraising of information and training opportunities.
- Training afternoon planned for early April.

No local HEI for HEE Master's

- 33 people with funding approved following extensive and persistent advertising
- Practical support with study leave/voluntary expenses available and culture of continuous professional development in our organisation

Reaching nurses

- Training needs analysis: 46% of nurses feel they have insufficient knowledge of genomics
- Time poor and unlikely to take up non-mandatory training.
- Training approach and delivery must be aligned with their limited time and focus on specific needs.

LDP engagement

- Peer-to-peer contact effective, and clinical training at all LDPs for rare disease, but further engagement at chief executive level needed to provide message to rest of training across partner Trusts.

MEASURING SUCCESS

Training uptake: Despite not having a local HEI for the Master's, 33 healthcare professionals have confirmed funding to undertake the course.

Funding: An RCPPath award was granted for outreach work that is providing equipment for genomic activities in schools.

Engagement: Month-on-month increase in people attending training sessions (866 in February 2017 across all GMC activities).

Referrals: Effective clinical engagement has led to increasing RD referral rates over successive quarters, largely from non-genetics departments.

TOP PRIORITIES

Training delivery

- Follow up requirements identified through training needs analysis, especially the development and implementation of training for nurses.
- Exploit links through AHSN, Oxford CPM and HEE-TV to extend training to hard-to-reach groups such as primary care.
- Develop a **variant interpretation package** to support healthcare students and genetic counsellors.

Local delivery partners

- Extend training needs analysis to LDPs and begin engagement through local training and communications officers, including genomics café events at each site.
- Hold an **LDP onboarding event** to bring LDP and clinical clinicians together to encourage engagement and celebrate progress to date.

KEY CHALLENGES

"There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don't know. But there are also unknown unknowns. These are things we don't know we don't know." Donald Rumsfeld

- Large numbers of healthcare workers, Trusts and HEIs in our sector.**
- Manpower:** We have limited numbers of specialists capable of delivering high-quality genomics education and training.
- Awareness:** Many healthcare workers are not aware of the importance of genomics for future diagnosis and management.
- Pacing:** Many healthcare workers are busy with conflicting demands on their time.
- Motivation and meaningfulness:** Many healthcare workers have not yet seen genomics in their practice and so do not understand the relevance of the training and education.

*Based on 2017 LDPs in Kent, Surrey and Sussex. Data: Prof. Julian Ball, Gen Practice, GA

MEASURING SUCCESS

Measuring the success of a programme can be difficult. Possibly the easiest quantitative measure of success is through the levels of engagement. These are shown below:

- Online over our three courses:**
 Jones + 41,800
 Learners + 15,737
 Active learners + 11,920
- MSc Genomic Medicine:**
 Total number enrolled in MSc/PGDip/PGCert = 71
- Face-to-face teaching:**
 We have now taught 2,350 people through face-to-face sessions.

We usually request pre- and post-course evaluation forms are completed to improve quality for future teaching sessions.

TOP PRIORITIES

Building a legacy

The top priority of the South London GMC genomics education programme is to build an infrastructure of education and training resources that will be available once active funding of the programme has stopped. We are achieving this legacy through the following:

- Building a genomics education faculty locally.** This is achieved through:
 - A postgraduate teaching skills course which is offered as part of the MSc Genomic Medicine.
 - We are applying for funding support for a genomics teaching fellow.
- Building a repository of educational resources** through the website, signposting to HEE resources, the MSc programme and online courses.
- Establishing an ongoing training needs analysis** (through the website) so new resource can be developed and targeted.

ABOUT US

The West of England NHS GMC (WEGMC) was designated as a centre in December 2015 and serves a population of 2.8 million. The WEGMC consortium is composed of five Trust partners:

In collaboration with:

- Clinical Commissioning Groups
- Health Education England South (West)
- Avon and Wiltshire Mental Health Partnership NHS Trust,
- West of England Clinical Research Network
- West of England AHSN

SPOTLIGHT ON BEST PRACTICE

- Education strategy built on vision of mainstreaming
- Seven multidisciplinary **Genomic Champions** recruited: specialist and research nurses, a GP, a consultant surgeon, a junior doctor, a genetics clinical fellow and a pharmacist
- Outreach strategy: school and public engagement with LEGO® Protobots
- Use of **public contributors** – at development and evaluation stages of educational activity
- HEI advisory capacity – UWE and Universities of Bristol, Gloucestershire & Bath

PARTNERSHIP WORKING

- Workforce Group members are multiprofessional and cross organisation, reflecting the key stakeholder voice in the West of England community
- HEE South West member of stakeholder group with links to sustainability and transformation plan workforce advisory boards and community education provider networks
- Charitable organisation links through public contributors

KEY CHALLENGES

- Funding:** finding innovative approaches by partnering with other education stakeholders
- Fully understanding the gaps in education in existing workforce**
- Ensuring primary care links across the whole WEGMC geography**
- There is a risk that appropriate mainstreaming will not be delivered in the timescale**

MEASURING SUCCESS

- Locally developed objectives for workforce and education work stream scrutinised by WEGMC partnership board
- Media interest in outreach work and planned formal evaluation & publication

TOP PRIORITIES

- Achieving a competent and resilient workforce at all delivery partners for delivering project now and embedding for business as usual
- Applications for funding to expand outreach project work
- Aligning to other workforce transformation networks: STPs and C&Pns
- Collaboration and dissemination of work with other NHS GMCs
- Evaluation of interventions linked to TNA recommendation

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There is lot of activity taking place at the local GMC centres.



Genomics in West London

The Story So Far

Joselyn King - West London NHS Genomics Medicine Centre

ABOUT US

The West London NHS Genomics Medicine Centre comprises Imperial College Healthcare NHS Trust as lead host, along with:

- Chelsea and Westminster NHS Foundation Trust
- The Royal Marsden NHS Foundation Trust
- The Royal Brompton and Harefield NHS Foundation Trust.

SPOTLIGHT ON BEST PRACTICE

- Members of the GMC are invited to attend sessions for the Master's in Genomic Medicine
- GMC Cancer and RD MDTs are used as hubs to exchange knowledge
- Cross specialty, multidisciplinary genomics training, engaging a wide range of professions as below:

PARTNERSHIP WORKING

- ICH Healthcare Scientists for Healthcare Science Week: 100K stalls across three of the LDP hospital sites to raise awareness of education and training opportunities
- NHRC Research Nurses: to provide consent training for cancer nurses
- Imperial Lead Provider: 'Genomics in Clinical Practice' training day
- Medical Education: working with clinical skills tutors to arrange consent training for medical students

KEY CHALLENGES

- West London NHS Genomics Medicine Centre not having a regional clinical genetics centre
- The clinical pressures limiting the clinicians' capacity to engage in informal training or networking
- Similarly, engaging nursing staff to participate in the educational and training opportunities available
- Working to revise the curriculum for nurses and trainees to include genomic medicine

MEASURING SUCCESS

- By using evaluation forms such as those for the 'Genomics in Clinical Practice' training day
- By the numbers enrolling into the Master's programme in Genomic Medicine
- By the number of staff members across the GMC who are providing contact information for education and training opportunities

TOP PRIORITIES

- Education needs analysis
- Map and connect local specialist skills
- Develop local resources
- Facilitate specialist training
- Engaging nurses, medical students, consultants and GPs across the GMC for greater participation in the 100K project
- Embedding genomics as business as usual for transformation

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Training and Education

Greater Manchester NHS Genomic Medicine Centre

Dr Glenda Beaman, Education and Training Lead

ABOUT US

- Greater Manchester is one of the 13 NHS Genomic Medicine Centres (GMCs) across England.
- It is a large multidisciplinary genomic medicine unit providing integrated clinical and laboratory genomics services to a population of more than 4 million and an international programme in discovery genomics and health services research.
- The genomic medicine service provides diagnostic, counselling and support services to individuals and their families with a genetic disorder affecting any body system at any age.
- We provide comprehensive services for prenatal genetics, developmental disorders, neurological genetics, metabolic genetics, orthotics and hearing loss genetics, cardiac genetics and cancer genetics. Outreach clinics are provided throughout the North West of England.
- The unit is a major training centre for specialist registrars, scientists, overseas fellows and for professionals from other disciplines. The Scientist Training Program (STP) for laboratory scientists and genetic scientists is led by the Centre with the University of Manchester. We have a number of major international partnerships, notably with Peking University Health Science Center, Beijing.

SPOTLIGHT ON BEST PRACTICE

Embedded genomics into the FY1 dedicated teaching programme within all north and east Manchester Trusts.

Holding regular patient participant days to keep them informed about the '100,000 Genomes Project' and when results will be available.

Genomic cafe events at all North Manchester Trusts – engaging with all healthcare professionals.

Engaging with patients in the RMCH on Rare Disease Day.

KEY CHALLENGES

- Sustainability of education and training within North Manchester.
- Establish a training and educational legacy in genomics.
- Maintain the momentum ensuring awareness and education in Genomics continues after the 100,000 Genome Project is completed.

MEASURING SUCCESS

- "Very interesting session. Enlightening to see the care that we can provide – and I think it is important to be made aware of such services so that we can consider all options when we treat patients with such rare diseases. Instead of mere symptomatic control that we usually do, the session showed that a diagnosis is 'so important, because even though it won't cure the patient, it can change the management plan very radically depending on the specific gene deletion'."
- "Discovering mutations in a patient's gene sequence can identify the cause of a disease. This can then be used to help other family relatives by providing specific 'treatment or bringing in treatment earlier.'"
- "Understanding about improved genomic medicine. The '100,000 Genomes Project that is being undertaken. Understanding the global scale of advancing technology and wider application of science.'"

PARTNERSHIP WORKING

- February 2015 established a North Region Education and Training Core Group Meeting – Greater Manchester, North West Coast, Yorks and Humber, Newcastle.
- Partnership with the Royal College of General Practitioners.
- Part of the Advanced Clinical Practitioners Working Group.

TOP PRIORITIES

- Cancer: increase awareness of the 100,000 Genomes Project to all cancer specialists and increase recruitment of cancer patients.
- To establish engagement with all nursing professionals.
- To embed genomics into undergraduate medical education.

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Appendix 2: The GEP team



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