Are we ready for the revolution in personalised medicine?

Professor Lisa Bayliss-Pratt, Director of Nursing and Deputy Director of Education and Quality at Health Education England (pictured) 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 their condition.

Cancer and prenatal care are just two of the areas where genomics offers more personalised, precise diagnosis and treatment.

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 there is huge potential in seizing this opportunity to enhance and bring the benefits of genomics to provide person-centred care.

Personalised care

Personalised medicine has the potential to greatly influence future nursing practice. Nurses, health visitors, school nurses and midwives are a huge workforce of around 350,000 and therefore have phenomenal potential.

So, let's go for it and work at the edge of our scope of practice to continue to meet the ever changing needs and wishes of those that entrust themselves and their loved ones into our care. But we need to take it further.



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. This represents a significant challenge. Personally, I am on a very exciting learning curve around this agenda to develop my own knowledge and understanding of the topic and know how it integrates into clinical practice.

The NHS aims to be a world leader in delivering personalised medicine and embedding its approach into mainstream healthcare through the 100,000 genomes project. Using genomic, lifestyle and environmental information, medicine will move away from a 'one-size-fits-all' approach towards treatment tailored to the individual.

This is ground-breaking. Let's learn together as nurses and midwives, so we can be that world leader in healthcare!

The Genomics Education Programme

All health practitioners across the NHS will need to have an awareness of genomics and its role in care, as well as developing the skills necessary to fully realise its potential. The <u>Genomics</u> <u>Education Programme (GEP)</u> was created to ensure all NHS staff have the knowledge, skills and experience necessary for the introduction of personalised medicine.

The GEP provides a range of tools, resources and courses tailored to specific needs in the nursing and midwifery workforce. Please take advantage of the free learning packages. Learning about genomics really can be fun. Look out for the fun game we are developing for student nurses and midwives too!

I hope all of these resources and others under development will be of assistance to all staff working in the NHS in responding to the healthcare needs of everyone we care for and to further develop the excellent services that many already provide. Please promote them across your teams and networks.

Ground-breaking examples of how genomics can deliver more personalised and precise diagnosis and treatment

Ground-breaking examples of how genomics can deliver more personalised and precise diagnosis and treatment for NHS patients are exciting, but they can seem very distant from day-to-day reality for most health professionals – until now.

Genetic and genomic influences are across all sectors of healthcare. Starting with preconception and prenatal testing for carrier status prior to pregnancy and new-born screening where it's a public health approach to the identification and management of health conditions identifiable in the newborn.



Figures from Rare Disease UK suggest approximately 6,000 children a year are born with an unknown condition and often these conditions will be due to changes in the individuals' DNA. The journey to diagnosis for the patient and their families is often a long one. However, genomic medicine has the potential to provide answers where there were none before.

Furthermore, it is thought that 80% of all rare diseases, such as Cystic Fibrosis are genomic in nature. With 3.5

million people in the UK alone affected by rare diseases genomics is pivotal in the diagnosis and treatment. As more data is gathered it is highly likely that the cause of more common conditions will be caused by changes to our genome and this information can be used to improve treatments and patient management.

More hereditary cancer conditions have been identified. The most common are those associated with breast, ovarian and gastrointestinal cancers. Certain tests are already used to determine which therapy will be the most effective for an individual, such as the use of Herceptin for HER2 positive cancers. Pathogen genome sequencing has also been used to track infectious diseases to identify outbreak sources, spread and susceptibility to antibiotics. MRSA and the Ebola virus have been key examples that you will be aware of.

I am always pleased to draw attention to local examples of good practice emphasising how life changing it can be.

Nurses at clinics in the <u>Royal Liverpool University Hospital</u>, <u>Warrington Hospital and the Countess of Chester Hospital</u> (right) are pioneering a genetic test to inform warfarin prescription to patients with atrial fibrillation.

They are the first frontline NHS staff to use a 45-minute saliva genotyping test to inform drug doses in a trial of clinical implementation. Results will be reported in 2017, but one patient (Paul Downie) said:



"My mum went on Warfarin eight months ago and she was back and forward to the clinic at least four times on a weekly basis before they got the dose right. I went back once, which meant I could go back to work quicker, feeling well enough to go back to normal life. I think this a win-win, for me and for the health service."

NHS England Chief Scientific Officer Professor, Sue Hill OBE, who leads the Personalised Medicine Strategy, recently said:

"This is precisely the sort of personalisation of treatment that we want to see available and delivered across the NHS."

Genomics roundtable

Lord Willis of Knaresborough and I recently held a <u>round table event</u> that was attended by leading figures from the nursing and midwifery community. Discussions centred on accelerating the integration of genomics into everyday practice, pre-registration education, and research. A variety of pledges were made to support the <u>implementation of the nursing and midwifery Genomics Education Programme transformation strategy</u>. This has been an invaluable learning experience for everyone involved in this ground breaking round table discussion.

A follow up roundtable is planned in June 2017 and a steering group has been established. In a future blog, I will describe the ongoing development of this work.

Global Genomics Nursing Alliance

Sue Hatton, Senior Nursing Policy Manager, HEE and Anneke Seller, Scientific Director, Genomics Education Programme HEE, recently attended the first global genomics nursing alliance (G2NA) to address these issues at the Wellcome campus in Cambridge.

Senior Nurse Leaders from 23 countries attended, with the primary aim to accelerate the integration of genomics into everyday professional practice by transforming nursing and midwifery policy, practice, education and research for individuals and societies. More information will follow, so keep an eye out for future blogs.

Summary of online courses, tools and resources

Introductions to genomics

- A range of links to start you off on your learning journey
- Introducing Genomics in Healthcare (8mins)
- Personalised medicine and how it will inspire the future of nursing webinar on 19 October (40mins)
- Rare disease and the 100,000 project (2mins)

Short online courses

Engaging and interactive free online courses for continuing professional development that could be used as part of your revalidation:

- Introduction to Genomics
- · Introduction to Bioinformatics
- Whole Genome Sequencing: Decoding the language of life and health this popular course will run again on Monday 24 April 2017

Training tools

Digital training to directly support the 100,000 Genomes Project, including:

- Preparing for the Consent Conversation
- Sample Processing and DNA Extraction

'Just-in-time' resources

Bitesize information on genomics for busy health professionals, for example:

- Genetics conditions information factsheets
- Genomics in mainstream medicine factsheets

Workshops, webinars and webchats

The team facilitate workshops, events and webinars for our network as well as support the education and development of the genomic workforce:

- WeNurses Webchats
- NHS Change Day Webinar

Masters and CPPD Modules

In addition to our online educational resources the GEP has developed a flexible MSc in Genomic Medicine and stand-alone CPPD modules, delivered on a part time or full time basis, through a network of 10 partner universities across England. The course is designed to assist healthcare professionals to improve their skills and support career progression and is suitable for healthcare professionals from a wide range of backgrounds.

"Genetics and genomics is not simply lab work, nor the sole remit of research staff: it is the future of healthcare. The 100,000 Genomes Project provides the opportunity for nurses to play a part in an integrated health service which looks beyond the competitive nature of acute & community trusts for the benefit of patients."

Charlotte Hitchcock RGN, West Midlands NHS GMC

Keep up to date on social media

Daily updates and tailored content is available at Twitter and Facebook.

Useful videos are also available on the <u>GEP YouTube</u> <u>channel.</u>

- What is personalised care? Nursing in the 21st Century
- What is genomics? Nursing in the 21st Century
- The power of genomics: Nursing in the 21st Century



© HEE 2017 15/03/17