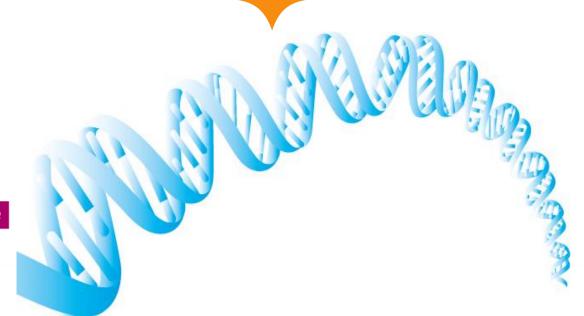




HEE Genomics Education Programme Nursing and Midwifery Round Table

Wednesday 24th January 2018 Friends House, Euston Rd, London.



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for health and

healthcare

www.hee.nhs.uk



Participants



Name	Representing	Title	
Lord Willis of Knaresborough		Independent Chair	
Professor Lisa Bayliss-Pratt	Health Education England	Director of Nursing and Deputy Director of Education and Quality	
Anne Trotter	Nursing and Midwifery Council	Assistant Director for Education and Quality Assurance	
Ethel Rodrigues	UNITE Union	Lead Professional Officer	
Professor Maggie Shepherd	Exeter University	Honorary Clinical Professor	
Dr Julie Green	Queen's Nursing Institute	Director of Postgraduate Studies, Lecturer in Nursing and Award Lead for Specialist Community Nursing (District Nursing)	
Elaine Trainor	NHS England	Programme Manager –Evidence and Evaluation	
Linda Bailey	Royal College of Nursing	Consultant in Public Health	
Karen Stansfield	Institute of Health Visiting	Head of Education and Quality	
Dany Bell	Macmillan Cancer Support	Specialist Advisor Treatment and Recovery	
Claire Meachin	Clinical Research Network	Deputy Chief Operating Officer, Guy's Hospital	
Dr Christine Patch	G2NA	Reader in Genomic Healthcare Florence Nightingale Faculty of Nursing and Midwifery, Clinical Lead for Genetic Counselling Genomics England	
Denyse King	Public Health England	Lecturer in Midwifery / Public Health Practitioner	
Josh Niderost	Council of Deans	Senior Policy and Public Affairs Officer	
Carmel Lloyd	Royal College of Midwives	Head of Education and Learning	
Bridget Hoad	Health Education England	Regional Programme Manager (Nursing Associates)	
Dr Anneke Seller	HEE Genomics Education Programme	Scientific Director and Head of Programme	
Alison Pope	HEE Genomics Education Programme	Programme Manager	
Dr Ed Miller	HEE Genomics Education Programme	Senior Education Development Officer	





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Introduction

Lord Willis of Knaresborough welcomed members to the third HEE Nursing and Midwifery Round Table meeting and thanked the group for their ongoing work, recognising the significant progress since the last meeting in July 2017.

Lord Willis remarked that he was delighted to continue his involvement in this ground-breaking programme and heard updates from each organisation represented at the meeting.

"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."



Lord Willis of Knaresborough Independent Chair





Focus and Updates



All of the Round Table members updated the group on advances in their organisations since the last meeting in July 2017. The following is an outline of the key areas of focus:

- How do we make genomics important and meaningful for the generalists?
 - The focus needs to be on appropriately layered levelling across the education continuum and all areas of nursing and midwifery. Not everyone will need specialist knowledge and training, awareness raising and some information is important for signposting to specialist services and feeling confident about having conversations with patients.
- Family history drawing with eco-map (graphical representation that shows all the systems at play in an individual's life) is incredibly important for understanding links within families and spotting potential genetic health issues. District and community nurses have a big role to play.





Focus and Updates



- Education gap for practicing nurses.
 - With genomics present in the pre-registration standards and the Nursing
 Associate Framework, trainee nurses will receive education in this area through
 the curriculum. The challenge is how we capture the existing nursing and
 midwifery workforce.
- Advance practice nurses how do we meet their training needs and embed genomics into their practice?
 - With the development of new specialist roles how do we ensure that genomics features in CPD and post-graduate training?
- NHSE have a website featuring case studies and are also considering developing a video around how genomics impacts on areas of nursing and midwifery care.





Focus and Updates



- The RCM have a public health repository on their website with links to e-learning for healthcare, which is used actively. We need to ensure that midwives are not seen as a separate entity.
- Midwives possibly do not know the impact genomics will have, they
 are aware of things like genetic screening, but may not be relating it
 to genomics per se.
- Pre and post surveys very good at measuring levels and identifying gaps in knowledge.





HEE Updates



Lisa Bayliss-Pratt updated the group on developments within HEE around genomics including:

- Funding has been secured for the Genomics Education Programme for the next two years.
 - The team will remain in place in Birmingham and there will be continued investment in delivery of the MSc in Genomic Medicine amongst other key work streams. A work plan for 2018/19 is currently being developed and is expected to be signed off by the GEP Programme Board in March 2018.
- The draft HEE Workforce Strategy has been published and is currently out for consultation. Round Table members were encouraged to get involved and submit responses.





HEE Updates



- A 'big ticket' item in the genomics area would be HEEs involvement in the Topol Review around the use of digital in healthcare including Artificial Intelligence, robotics and genomics.
 - A piece of work is being led by Patrick Mitchell and 3 expert groups are being developed to advise on the way forward. These groups will focus on the following areas:
 - Digital
 - Al and Robotics
 - Genomics
- Dr Anneke Seller is linked into the genomics work stream and will be part of the genomics expert group.
- Lisa suggested that the Round Table could become a sounding board/test group for what is suggested in the report and also consider how, as part of the clinical team we get nurses and midwives involved in this area of work.





NMC Standards Updates: Anne Trotter



- Genomics is mentioned once in upcoming NMC pre-registration proficiency standards which will be published in March 2018.
- District nursing post-registration standards will be coming from the NMC.
- The apprenticeship route needs to be refreshed based on standards. Two HEIs have a graduate apprentice route but there are more in the pipeline.





Maggie Shepherd: Genetics Diabetes Nurse (GDN): an educational model.

Maggie Shepherd trained as an RGN at King's College Hospital and worked as Diabetes Specialist Nurse in Greenwich prior to joining the monogenic diabetes team in Exeter in 1995. She is a Honorary Clinical Professor at the University of Exeter Medical School, Lead Nurse for Research at the Royal Devon and Exeter NHs Foundation Trust and lead co-ordinator of the national, award winning Genetic Diabetes Nurse project.

Maggie presented to the group the work of the University of Exeter Clinical Research Facility around an educational model for the translation of genetic knowledge into clinical care. Looking at the diagnosis and treatment of monogenic diabetes and training GDNs to support delivery of this specialist service to ensure optimal outcomes for patients. Maggie presented a number of case studies where patients with an incorrect diagnosis had benefitted from genetic testing and cessation of insulin injections, replaced by more effective medication.



Exeter Clinical Research Facility



The Genetic Diabetes Nurse project: an educational model for the translation of genetic knowledge into clinical care

Maggie Shepherd RGN, PhD







The problem: clinical perspective

Monogenic diabetes accounts for 3% of UK diabetes diagnosed < 30yrs (40,000 cases)

Diabetes teams: didn't recognise 'genetic' diabetes

> 80% monogenic diabetes misdiagnosed as Type 1 or Type 2

Pre 1996 only 47 (0.1%) patients confirmed with monogenic diabetes

Referrals for genetic testing sporadic

Cases per million <10 10-20 20-30

Shields et al Diabetologia

Average of 9 years from diabetes diagnosis to molecular genetic diagnosis

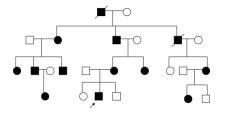
Is monogenic diabetes difficult to recognise?

Neonatal Diabetes: diagnosed <6 months of age

Previously considered / treated as Type 1 diabetes



- Maturity Onset Diabetes of the Young (MODY):
- i) Diabetes diagnosed below 25 years of age
- ii) Non insulin dependent
- iii) Autosomal dominant inheritance



Typically misdiagnosed as Type 1 diabetes (or Type 2 in those diagnosed older / with higher BMI)

Syndromic diabetes: Diabetes plus eg DIDMOAD (Wolfram)

May have been recognised as being different - genetic cause not always identified

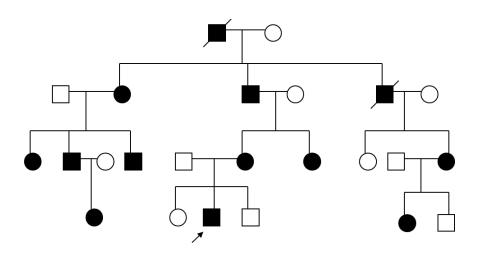
Dan's story: Lack of knowledge reduced access to genetic testing



Diabetes diagnosed at 16 years of age

On insulin x 4 daily

'We'd taken in a drawn up family tree, but they didn't do anything about it, they just said 'He's Type 1'



'We asked for genetic testing many times and they said 'We'll never take him off insulin so what's the point?'

Journal of Diabetes Nursing, 2008, Vol 12, No 1, pages 14-18

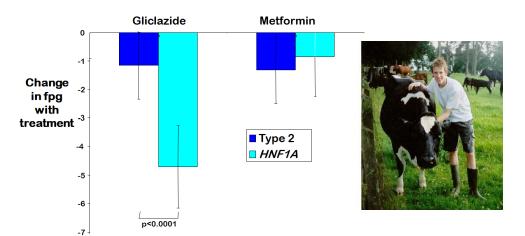
Impact of misdiagnosis in HNF1A diabetes: A case study

Maggie Shepher

Why does this matter?

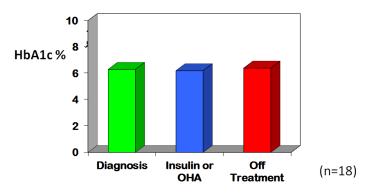
Different types of MODY need different treatment / management

Sulphonylurea sensitivity in HNF1A



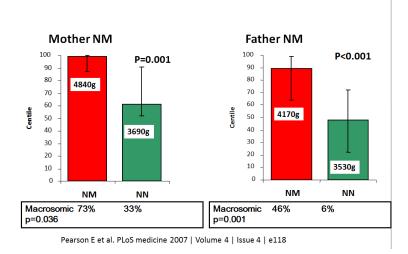
Pearson et al Lancet 2003

GCK MODY patients do not need treatment: HbA1c unaltered



(Stride, Diabetologia 2014)

Birthweight increased in babies with HNF4A mutation



HNF1B: Renal cysts and diabetes (RCAD)

Renal involvement:

Renal cysts frequent

Renal abnormalities may be seen in utero

Variable renal histology eg single / horseshoe kidney

Renal function ranges from normal - dialysis

Some patients have had renal transplants

Diabetes:

Typically develops after renal disease

Age at diagnosis variable

Beta cell dysfunction

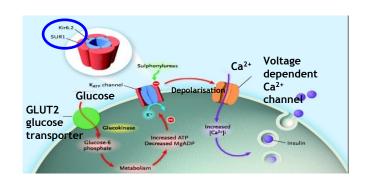
Usually require insulin

Not all family members affected (50% of cases spontaneous mutations)

Other features: uterine malformations and gout

Most patients with Katp channel neonatal diabetes can stop insulin

K^{ATP} channel genes identified in 2004



13 12 - 11 - 10 - 10 - 9 - 4 - On insulin On sulphonylurea

Pearson et al NEJM 2006

Jack



BW 2.0kg at 38 weeks gestation
No FH
Diagnosed at 3 wks
BG 58 mmol/l, vomiting, DKA
Started insulin
Learning difficulties

Genetic testing confirmed Katp channel mutation

The solution:

National Genetic Diabetes Nurse (GDN) project

Initial DH funding in 2002

DH White Paper:

Realising the potential of genetics in the NHS. Building genetics into mainstream services.



Why Diabetes Specialist Nurses?

Located within diabetes team

Patient caseload

Rapid integration into clinical practice

Journal of Diabetes Nursing, 2003, Vol 7, No 8, pages 289–292

Integrating genetics into diabetes care: a new role for DSNs

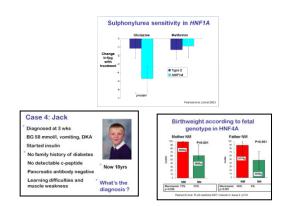
Maggie Shepherd, Amanda Stride, Sian Ellard, Andrew Hattersley



GDN role

Experienced DSNs identified, seconded 3.5 hrs/week

- Presentations to health care professionals across region to raise awareness
- Identify / refer possible patients
- Guide treatment change
- Organise family follow up



On-going training for GDNs

Training: Initial 2 days (core skills)

- non genetic tests aiding differential diagnosis
- MODY probability calculator
- drawing family trees
- basic genetics
- causes and characteristics of MODY
- neonatal diabetes
- impact of transfer from insulin to SUs



Ongoing training: x 3 per year (extended skills)

Identifying patients with likely monogenic diabetes, clinical management of monogenic diabetes, communicating genetic information

Additional training encouraged:

Genetic counselling, MOOC / MSc in Genomic Medicine

GDNS trained across the UK

Trained 66 GDNs (12 intakes since 2002)

77 study days

24 GDN's currently in post

Funding:

SUPPORTED BY





Genomics Education Health Education England



Programme



Methods to evaluate GDN project

Dissemination of knowledge via presentations to healthcare professionals

Development of services / support for families

Initiation of monogenic clinics

Support of patients during genetic testing

Patients changing treatment

Assessment of performance through: cases discussed, monthly activity, 1:1 reviews, number and quality of referrals

Referrals for genetic testing

Appropriateness of referrals

Positive test results

Numbers of affected family members tested

Ten years of the national genetic diabetes nurse network:

a model for the translation of genetic information into clinical care

Authors: M Shepherd, A K Colclough, B S Ellard, C and AT Hattersley

Dissemination of knowledge via presentations to healthcare professionals

935 presentations to >12,950 professionals 99% rated excellent / very good



'I have given >60 presentations throughout my region to >1000 professionals who now refer possible patients to me'

Development of services / support for families

10 monogenic clinics

Support of patients during genetic testing: liaison with local teams / Exeter >1250 patients changed treatment as consequence of genetic testing



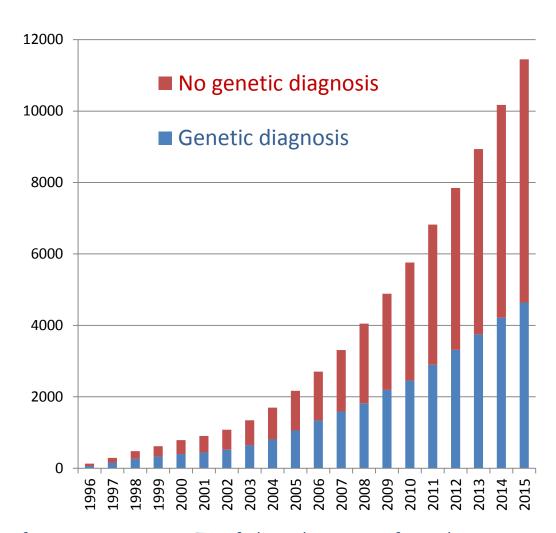
'In 2005 there were no MODY patients in Brighton, we now have >70 confirmed MODY patients in the area, resulting in significant changes to treatment, including transfer of 17 patients from long term insulin to sulphonylureas, our monogenic clinic is held fortnightly and is well attended'.

Increased referrals for genetic testing

GDNs helped increase referral rates for genetic testing

Higher positive pick up rate by GDNs than patients referred by others (255/710, 36% v 661/2935, 23%,p<0.0001)

Increased referrals of family members for genetic testing by GDNs than others (165/255 (65%) v 345/661(52%),p<0.0001)





'I have referred 162 patients for genetic testing, 78 of these have a confirmed genetic diagnosis, which has allowed transfer to the most appropriate treatment and follow up of family members'

Benefits for patients

'When I got diagnosed wrongly as type 2 it was the scariest time of my life. Since I have met my local Genetic Diabetes Nurse I have someone who understands how I feel. The most amazing care was advice on the best way to treat my type of diabetes. This change in medication has made me feel so much better and is giving me more consistent blood sugar levels. To have access to this level of support is life changing for me - I do not feel like a number, I feel like an understood informed individual. I cannot thank the Genetic Diabetes Nurses enough' (Joanne)





After reading a newspaper article about MODY and contacting Exeter, I was put in touch with my local Genetic Diabetes Nurse who arranged blood tests for me and supported me when I was confirmed as having MODY. Having been on insulin for 25 years, it was a relief to talk to someone who understood and who could help me with the transformation to tablets. The Genetic Diabetes Nurse was also interested in assessing my daughter who had a diagnosis of 'Type 1 diabetes' and was injecting daily. My daughter is also now taking Gliclazide which has impacted positively on her life. It is very supportive to have the occasional phone call from the Genetic Diabetes Nurse to follow up the diagnosis and to ensure all is well.

(Janette)

Benefits for GDNS



After 20 years of working as a DSN it's the first time in a long time that I have felt truly excited and clinically challenged by diabetes. It's so wonderful to be active in an area of diabetes care that is so innovative and exciting! It has brought the 'buzz' back into clinical practice

Being part of the GDN project has been both exciting and stimulating, and has changed practice not only for myself but the whole team who are now always on the look out for possible patients





With 25 years' experience as a DSN I thought I knew a bit about diabetes and its management. Since starting as a GDN I have gained a new perspective about diagnosing and finding the best available treatment options for all patients with diabetes.

Winner national diabetes awards 2015: 'Best innovation in integrated care model'







GDNs also involved with:

Neonatal diabetes family days



Monogenic Diabetes Symposium

"Right diagnosis, right treatment"
Wednesday 10 – Thursday 11 February 2016
The Rougemont Hotel, Queen Street
Exeter, Devon, UK, EX4 3SP

Diabetes Diagnostics App





Promoting c/peptide / antibody testing





Journal of Diabetes Nursing, 2011, Vol 15, No 4, pages 149-151

Importance of genetic testing and recognition of neonatal diabetes: A case report

Agnieszka Graja, Jane Young, Maggie Shepherd, Sian Ellard, Jeremy Fletcher

Journal of Diabetes Nursing, 2013, Vol 17, No 7, pages 250-254

Improving awareness of monogenic diabetes through a specialist genetic diabetes nurse

Kate Morel, Kevin Colclough, Nick Vaughan, Maggie Shepherd

Practice*Nursing*

Reassessing people diagnosed with diabetes under age 25 years Julie Cropper, Maggie Shepherd (Feb 2011)

Journal of Diabetes Nursing, 2005, Vol 9, No 1, pages 7–10

MODY link nurses: pushing the boundaries of diabetes nursing

Sandra Dudding, Heather McMahon, Maggie Shepherd



Practical **DIABETES**

Neonatal diabetes is more than just a paediatric problem: 57 years of diabetes from a Kir6.2 mutation

H John, SE Flanagan, R Corrall, AT Hattersley, S Ellard, M Shepherd

Home > The 100,000 Genomes Project

What are the challenges?

Costs are modest (~£5.5k/per GDN/year) but obtaining continued funding is challenging

NI and Wales under discussion

Aim for 1 GDN per 1 million population

Identifying GDNs: in certain geographical areas, of required calibre

Time consuming – but benefits outweigh

Discussion: could this work in other areas?

Developing skills of specialist nurses is cost effective and successful means of rapidly increasing genetic knowledge into clinical care

Health Education England used GDN project as a model for the translation of genetics into clinical care in disease areas

Readily transferrable to other specialities: particularly suited when:

- Genetic testing can guide patient diagnosis and management within speciality
- There is not a tradition of genetic training in the speciality
- There are experienced specialist nurses / other healthcare professionals with high level of core subject knowledge without specific training in genetics
- There is an appropriate centre of expertise in the subject area to provide training and support

Discussion: could this work in other areas?

Training Specialist Nurses in genetics could be effective across range of specialist areas eg: Cardiology, Oncology, Paediatrics, Neurology, Nephrology, Ophthalmology, Endocrinology, Audiology, Hepatology

Key component: national centres of excellence in discrete specialist areas who could identify national champions (nurses or other health professionals) to lead and develop the training

National champions can identify specialist nurses who could undertake these specialist roles e.g. Genetic Cancer Nurses, Genetic Cardiac Nurses etc.

This model of training *guarantees training* for a wide range of health care professionals, as opposed to 'assumed' knowledge with lack of *targeted* training

Conclusions: GDN project effective

Increased awareness of monogenic diabetes across the UK leading to better care, more appropriate treatment and considerable cost savings for the NHS

Widespread support received from diabetes teams across the UK

Provide local expertise in monogenic diabetes and provide excellent service for patients and diabetes teams

Recruited and trained highly motivated GDN workforce

Leading education of monogenic diabetes across UK



www.diabetesgenes.org

Acknowledgements

Previous funders of GDN project



Diabetes Foundation Current funders of GDN project

SUPPORTED BY









Key points that were raised as part of the Round Table discussion

Following Maggie's presentation a range of points were raised by the group including:

- The use of case studies is extremely important for capturing interest and demonstrating benefit.
- Is there a case for specialist diabetes midwives? The GDNs are already speaking to and are encouraged to link into colleagues in obstetric teams to impart knowledge and information.
- Could this model influence NICE guidelines for treatment of diabetes? Currently NICE guidelines focus on Type 1 and Type 2.
 We need to consider how monogenic diabetes could be included.
 NICE require ongoing evidence and research to support a change to the guidelines.





Key points that were raised as part of the Round Table discussion

- How can we grow this network and how many specialist diabetic nurses are required to meet the needs of the population? We need to consider this as part of HEEs remit around workforce planning and supply. We need to move away from ad-hoc planning based on previous year's figures. This could feed into responses to the draft Workforce Strategy.
- This model could be replicated for other specialist nurses. However, it appears that there is currently no consistent approach to specialist nurse training across the system. The consistency and quality of training is also dependent on the knowledge and expertise of the person delivering it and we need to consider a requirement to ensure equity and standardisation across providers.





Key points that were raised as part of the Round Table discussion

- The new laboratory structure which is being developed to support the implementation of an NHS genomic service in October 2018 may produce centres of excellence that could nurture specialist nurses.
- Is there a call for a competency framework for this kind of specialist training e.g. mental health training model?
- Undertaking a gap analysis would be helpful where provision could be mapped against population health.







Anneke Seller-update on the Genomics Education Programme

Dr Anneke Seller, Scientific Director and Head of the GEP updated the group on developments within the GEP since the last Round Table meeting in July 2017.

Funding has been agreed to take the programme forward for another two years and a work plan is being developed to outline key priorities for the GEP. This will reflect HEE priorities around workforce planning and development with more of a focus on supporting providers and employers. Clinical academic careers will also be key to promoting innovation and research in the workplace.





Future of the GEP post March 2018

- HEE commitment to continue to fund the GEP team until March 2020
- Work plan for 2018/19 in development for sign off at end of February 2018
- Working closely with NHSE Genomics Implementation unit and HEE to ensure the co-ordinated approach and alignment to:
 - HEE cancer workforce plan
 - HEE workforce plan
 - Life Science Industry strategy
 - Generation Genome
 - NHSE Genomic Medicine







Future of the GEP post March 2018

Three strategic aims:

- Strategic leadership and advisory role
- Building the future genomics leaders
- Educating and developing the current and future workforce







Week of Action 5th – 9th March 2018

- The aim of the GEP Week of Action is to start a bigger conversation about genomics and its application in nursing and midwifery practice.
- Nurses and midwives will be encouraged to get involved in a week long social media driven event.
- Resources are being developed to support activity e.g. nurses video, Genomics 101
- During the week participants will be asked to Tweet their pledges and commit to actively engaging with genomics





Week of Action – Planned Activities

- Thunderclap
- Twitter Take-over
- Blogs
- Podcasts
- Game Day
- Twitter Chats







Nursing Video

- With contacts from our Round Table and other key stakeholders e.g.
 GMCs we have scoped the content of a video aimed at nurses
- Focus is to raise awareness of genomics and highlight the important role nurses play in the delivery of personalised medicine
- Filming took place on the 15th January 2018 with a nurse clinical educator on site to advise
- The video will be released as part of the Week of Action activity







Action From the Round Table

- GEP will need to ensure Round Table members are contacted prior to the Week of Action (WoA).
- The Council of Deans will circulate information to all members. Josh to ask Katarina to write a blog post.
- Lord Willis to tweet during the Week of Action to increase trending on twitter.
- All Round Table members to tweet, or blog
- The nursing video to be shown at RCN congress on the screens and any other conferences taking place at that time.





Resources for the wider workforce

► 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.
- 3 modules currently with our developers
 - Genomics in Healthcare
 - Genes to Genome
 - Taking and Drawing a Genetic Family History
- Aiming to launch Spring 2018 to coincide with the Week of Action

► Family History Videos



Series of 6 videos that can be used as educational tools:

- 3 videos show the conversation of collecting family history information to allow individuals to practice drawing a family tree
- 3 videos showing a family tree being drawn

▶ Genomics Game

- 100 generic versions of the game distributed – positive feedback
- Midwifery version currently being tested
- Dr Jargon still in development







Educators toolkit

- Meeting held on 29th November 2017 with members from the Round Table
- Discussion focused on:
 - who the toolkit was aimed at suggested it should be for educators (lecturers, mentors, assessors) in the first instance
 - What could be in the toolkit a package that allows educators to build their own learning activities e.g. learning outcomes, lesson plans, suggestions for how genomics can be incorporated into assessment
 - How to get stakeholder buy-in and key contacts from relevant organisations







Educators toolkit – next steps

- Investigate how assessments are set and how we can influence it.
- Confirm what is appearing in the standards
- Review the skills annexe and how to influence the practice document
- Review learning outcomes across year 1,2,3 and level 4,5,6,7.
- Explore closed Facebook group when toolkit launched in addition to pre-cursor webinar.
- Comms strategy is needed in conjunction with stakeholder mapping.

Anything we've missed?







Action From the Round Table

- Should the Educator's toolkit be developed as a generic resource with off shoots covering the key professions? There is a danger that nursing could get siloed.
- Council of Deans to scope which HEIs would have best by-in and could act as test beds for the toolkit.







G2NA Update: Dr Christine Patch

- A retreat was held last year with 25 attendees. The purpose of the meeting
 was to set out a roadmap for embedding genomics into nursing practice
 across the international landscape and to develop a maturity matrix.
 Sustainable funding needs to be identified for activity and a web presence.
- International confederation of midwives very influential. Nurses confederation not so much.
- Patient groups in the UK are very powerful.







Discussion and next steps

- Working with the devolved nations. There are political challenges but conversations continue.
- Do we need to review and extend the membership of the Round Table to include AHPs, public health professionals for example? This could include genetic counsellors and clinical scientists, bioinformaticians, dietitians, pharmacy.
- Do we need to consider the social care perspective as well? Social workers involved in doing family trees.
- Specialist nurse role. Post grad and CPPD training need to be a focus.







Final Actions

- GEP to share more information and social media pack for the WoA with the Round Table membership.
- Members to promote the WoA through their networks via social media, blogs and involvement in podcasts.
- GEP to write out to those who have agreed to be involved in WoA activity to create podcast and collate blog content
- GEP to share links to the public health masterclass and the family history taking films.
- GEP to make contact with Professor Chris Whitty at NIHR to discuss where current research would benefit from a connection with genomics.
- GEP to make contact with Mark Radford, Director of Nursing for Improvement at NHS Improvement to discuss ACP connections.



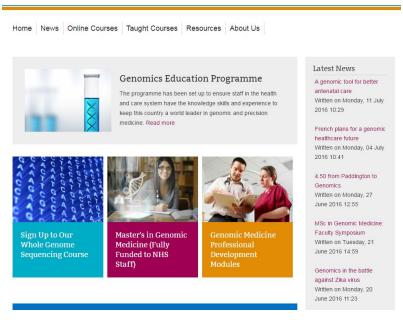


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