Moving Genomic Education Forward in the UK

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Taking a strategic approach: the NHS Genetics Education Centre nursing programme 2004-2012

- Awareness of scale of change needed
- Underpinned by analysis to identify assets, gaps, challenges
- Used the Theory of Planned Behaviour to inform a programme of research, education and development to engage nurses in genetics/ genomics.

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PROFESSIONAL ISSUES

Engaging Nurses in Genetics: The Strategic Approach of the NHS National Genetics Education and Development Centre

Maggie Kirk · Emma Tonkin · Sarah Burke

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Abstract The UK government announced the establishment of an NHS National Genetics Education and Development Centre in its Genetics White Paper. The Centre aims to lead and coordinate developments to enhance genetics literacy of health professionals. The nursing program takes a strategic approach based on Ajzen's Theory of Planned Behavior, using the UK nursing genetics competences as the platform for development. The program team uses innovative approaches to raise awareness of the relevance of genetics, working collaboratively with policy stakeholders, as key agents of change in promoting competence. Providing practical help in preparing learning and teaching resources lends further encouragement. Evaluation of the program is dependent on gathering baseline data, and the program has been informed by an education needs analysis. The challenges faced are substantial and necessitate international collaboration where expertise and resources can be shared to produce a global system of influence to facilitate the engagement of non-genetic nurses.

Keywords Nurses · Engagement · Genetics · Education · Competence

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Introduction

In the United Kingdom (UK), recognition of the imperative to engage health professionals more fully in genetics was signaled by the Genetics White Paper (Department of Health 2003). This set out the government's strategy to invest in both the service provision for genetics and the education of health professionals, to ensure that the potential benefits of genetics are realized by the National Health Service (NHS). The vehicle to drive the improvement in understanding of genetics and its role in modern healthcare among all health professionals was to be the NHS National Genetics Education and Development Centre (the Centre), and this was established in 2004 (http://www.geneticseducation.nhs.uk). The Centre works with a range of groups throughout the UK, currently focusing in particular to facilitate the integration of genetics education into all levels of education and training for doctors, nursing professionals, pharmacists and dietitians. In doing so, it aims to:

- Provide leadership in genetics education
- Help to raise awareness of genetics
- Involve patients and their families in informing all aspects of its work
- Identify the genetics knowledge, skills and attitudes useful for clinical roles
- Develop a framework for competences in genetics
- Facilitate the integration of genetics into curricula and courses
- Identify and develop resources appropriate to the needs of health professionals (and their trainers)
- Support and disseminate learning from service development initiatives in genetics.

Genetic counselors, not only as policy stakeholders in this initiative, but also as health professionals who work

Attitudes

- Raising awareness
  - Conferences, seminars, articles
- Keeping it relevant
- Encouraging reflection

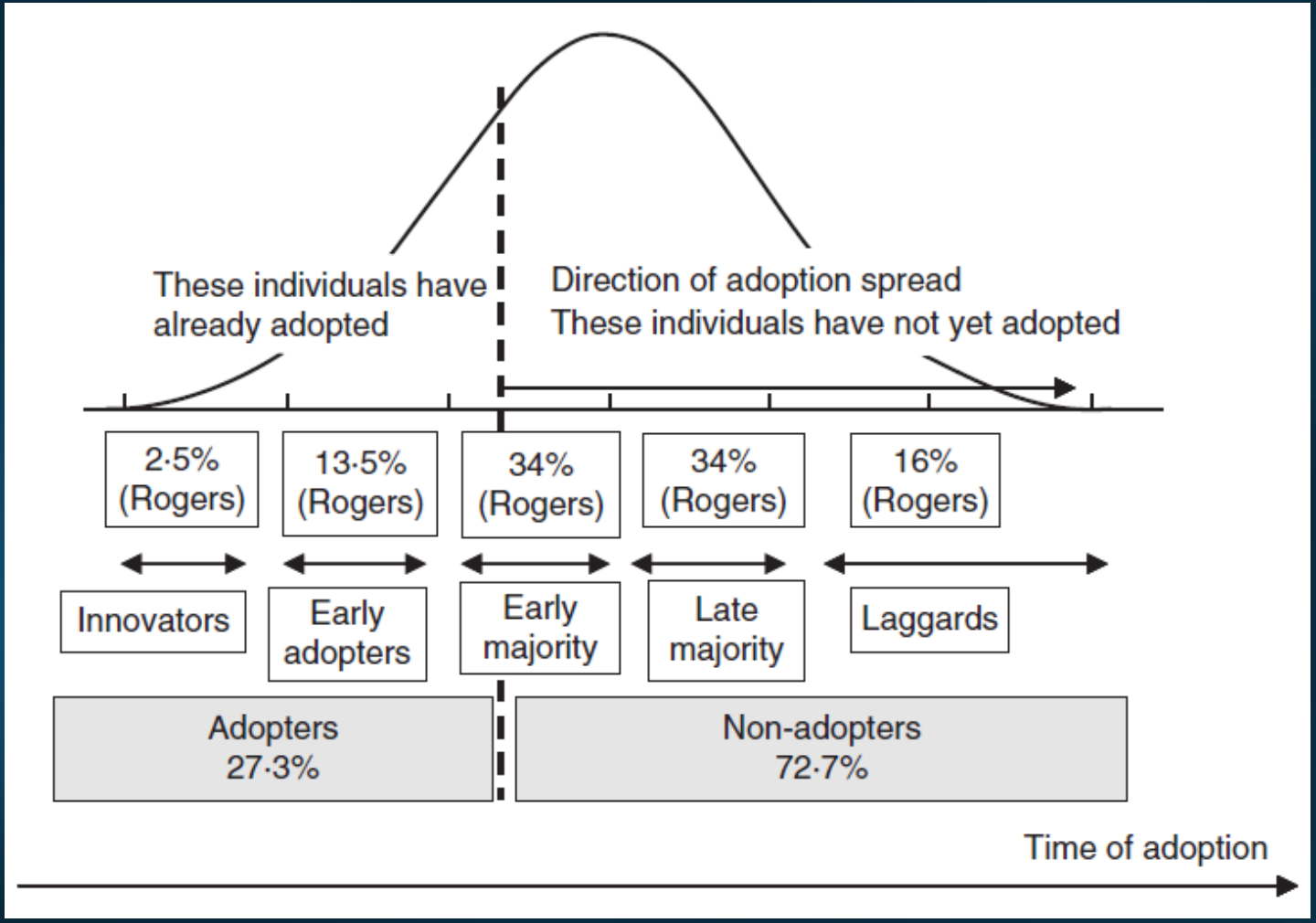
Influence of others

- Working with educators
- Working to influence policy
- Collaboration:
  - National and international
- Champions:
  - Identifying their characteristics
- Patients/ carers

Promoting doability

- FFPGGE education framework
  - Learning outcomes
  - Practice indicators
- Telling Stories online education resource
- Promoting accessible resources
- Evidence-based: needs analyses, barriers & facilitators
- Evaluating & responding to outcomes

Attitudes: the uptake of genetics in nursing practice



Andrews, Tonkin, Lancastle & Kirk 2013

Attitudes: characteristics of adopters

Significant distinguishing characteristics of adopters:

- More open to experience
- Find it easier to apply new knowledge to practice
- More likely to see genetics as relevant to their patient group
- Greater understanding of nursing care related to genetics
- More knowledgeable and confident about genetics
- More confident in talking about genetics.
- Feel patients and colleagues expect them to apply genetics

Andrews et al 2013

Influencing others

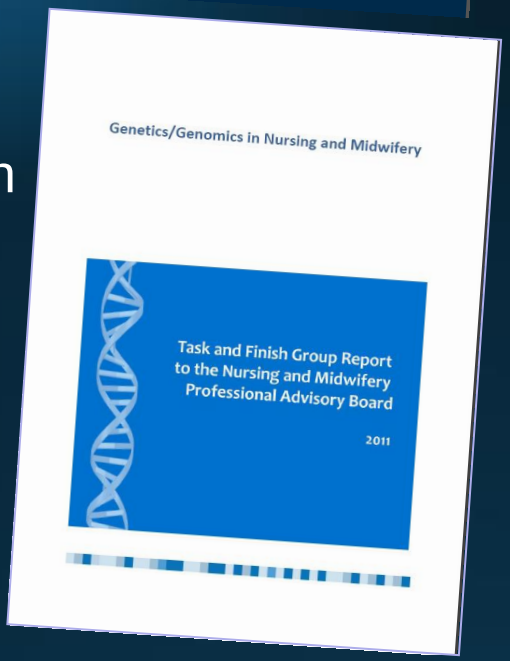
- Need a strategy for care ‘today’
- Leadership is an important issue
- Patients and families of rare genetic conditions are under-served
- Strategy is needed for all nurses and midwives, in training and qualified

...that we can build on as genomic healthcare expands.

...but so is limited awareness.

...growing focus in genomic medicine and common conditions.

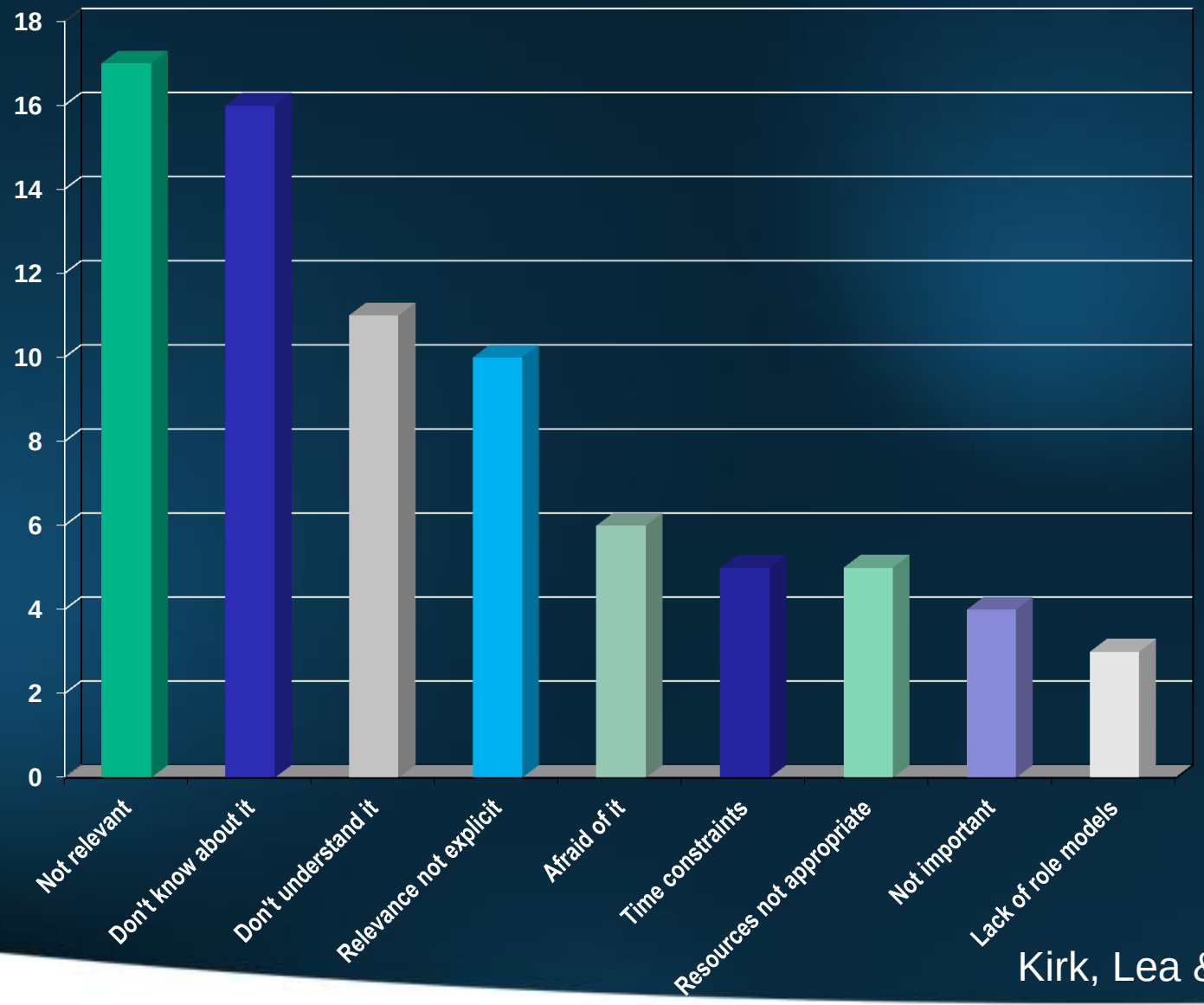
...recognising the challenges in education & practice with lack of confidence and competence.



Doability: providing education frameworks

- Original 2003 framework revised in 2010
- 8 competency statements
- Developed by consensus
- Learning outcomes
- Practice indicators
- Underpinned by accessible articles

Doability: identifying barriers



Kirk, Lea & Skirton 2008

Doability: Providing resources

NHS
National Genetics and Genomics Education Centre

Telling Stories
Understanding Real Life Genetics

HOME | ABOUT TELLING STORIES | HOW TO USE THE STORIES | SELECTING A STORY | CONTACT US | W.I.T.S.

TEXT SEARCH

Search ...

THEME SEARCH

Select a theme

AWARD FOR TELLING STORIES PROJECT!

Joint winner of the Betsi Cadwaladr Scholarship Foundation award at Chief Nursing Officer for Wales Showcase Conference.

READ MORE >

TELL US YOUR STORY

We are always looking for new stories to add to this site, and are particularly keen to hear from more practitioners. Your colleagues can learn so much from how you've dealt with situations

New Website!

Welcome to the new look Telling Stories website!

Whilst we have updated the appearance of the website, the layout and stories (and accompanying educational content) have not changed. We will also be carrying out further improvements to the site and adding some new content over the coming weeks. Please let us know if you have any questions, comments or suggestions about the new website at tellingstories@southwales.ac.uk

Using stories in group work

Meriel's story: having a child with Down syndrome Learning about the implications of a chromosome imbalance to a daughter's development	Biological Issues	Psychological Issues	Social Issues
1. Having a child that has *Down Syndrome* (DS) was a shock. I became pregnant for the first time at age 32, and had not had any *screening tests* as my husband and I did not agree with termination. I probably naively thought that nothing would happen, but we also felt on another level that we would accept what we got. I had no problems during my pregnancy and the baby was very active. My daughter was born full term. It was a surprisingly quick labour, and due to drugs given late on, I was not very aware of what was going on. When she was born, I just remember the room being surprisingly silent. When I first saw my daughter I commented that her eyes looked slightly oriental in shape. The medical staff said nothing. Looking back this was as it should have been. I was able to meet my daughter, and spend the night with her. It was not till mid morning the next day that a nurse came and told me what they suspected. I will always be grateful that I had the chance to know my daughter, before being told that there was something different.	• Down Syndrome • Extra copy of chromsome 21	• stress • shock • guilt • uncertainty of the first year • ashamed • frustration on lack of medical treatment • worried about chance of having another child with down syndrome. • Arguing with mother about telling family members about the down syndrome.	• Struggling to cope with long term condition • Don't tell people about the DS as parents worry child will be discriminated against • Isolated as very few knew she had the condition • Pity from GP • Knowing she has down syndrome will affect the way people treat her and what they expect of her.
2. My daughter has changed my life completely - as any child would have. I have no other child to compare her with. The first couple of months were very difficult. It all seems a daze now. We were overcome with love for her, but also distraught that she had a disorder that it seemed we could do little about, and with not much hope for the future. In those early days, we relied on what the medical profession told us - which was not much and not very positive. We were told she was at greater risk of *heart defects*, hearing problems, eye problems, *learning difficulties*, would probably be short and delayed in her development. Rather dismal! We asked them how she would personally be affected and they told us they really could not say and we would have some idea at 1 year old. The uncertainty has been there from the start and still remains. I was amazed that with all the medical advances we have, there was not one drug treatment we could use.	Possible problems • Heart defects • Hearing problems • Eye problems • Learning difficulties • No real drug treatment		
3. I spent the first 8 weeks frantically searching for information. I have a background of Psychology and extensive research experience - both in health and psychology. We found a lot on the internet - positive and negative. After researching it, we started our daughter on supplements specifically designed to try and counteract the effects of the extra genetic material. These consist of vitamins, minerals and *amino acids*. There's no definite proof, but many parents have found it useful - as we have. Having an extra copy of *chromosome 21* results in a chemical imbalance which increases cell damage. The supplements try to balance the *metabolic* difference and improve growth and the *immune system*. I also believe that a health diet, mainly organic, is a good basis, plus *omega 3* and 6 oils and the occasional *probiotic*. We have become used to integrating all this into her everyday food. This seemed a very conservative level of intervention and we are still frustrated at the lack to medical treatment.	• However certain supplement specifically designed to try & counteract effects of the extra genetic material • Extra copy of chromsome 21 results in a chemical imbalance which increases cell damage. • Healthy diet - mainly organic		
4. Later on we saw a genetic counsellor. It was really useful, but also raised more questions. She told us about our slightly increased chances of having another child with a chromosomal disorder. We do plan to have other children, but now feel that we could not cope with another child with DS. We might not be so lucky to have a child who is mildly affected, and			

Drama in education: Unfolding case studies using stories

Initiation

Preparation/ underpinning knowledge/ skills

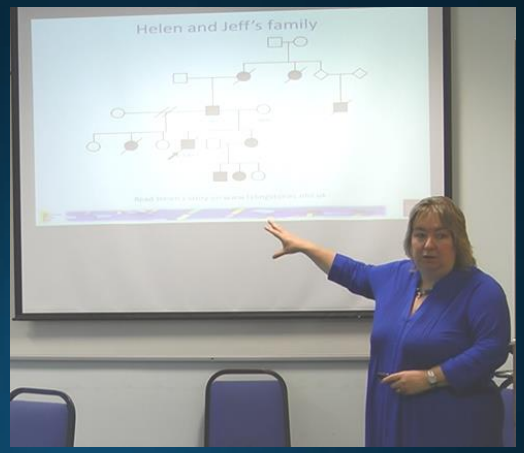
Experience scenario event

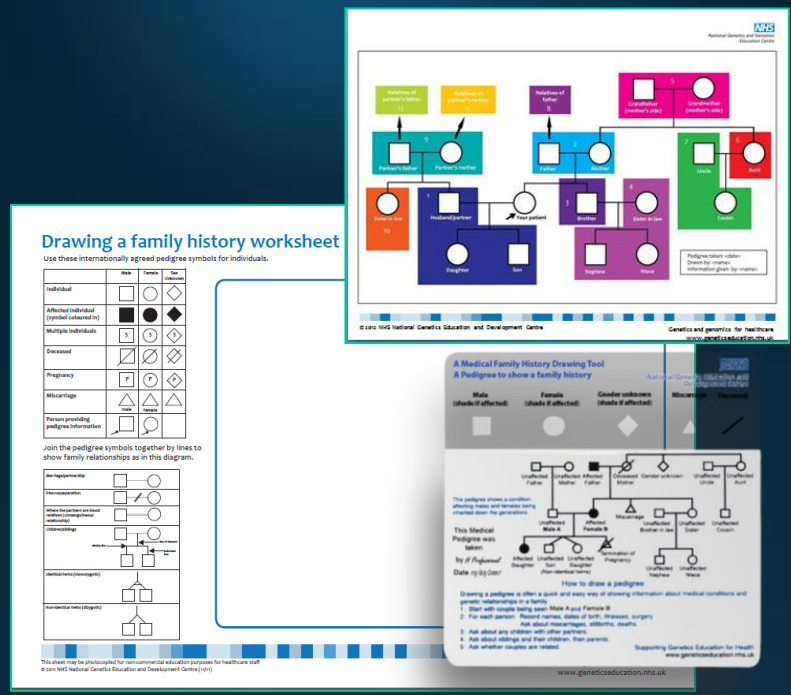
Reflection

Evaluation

Scaffolding the case study

- Intersperse with brief teaching moments and further interactive activities
- Utilise HEE resources
- Provide ‘real’ information – patient information leaflets
- Reflect at key points as the case study unfolds
- Back up with information on a VLE
- Evaluate

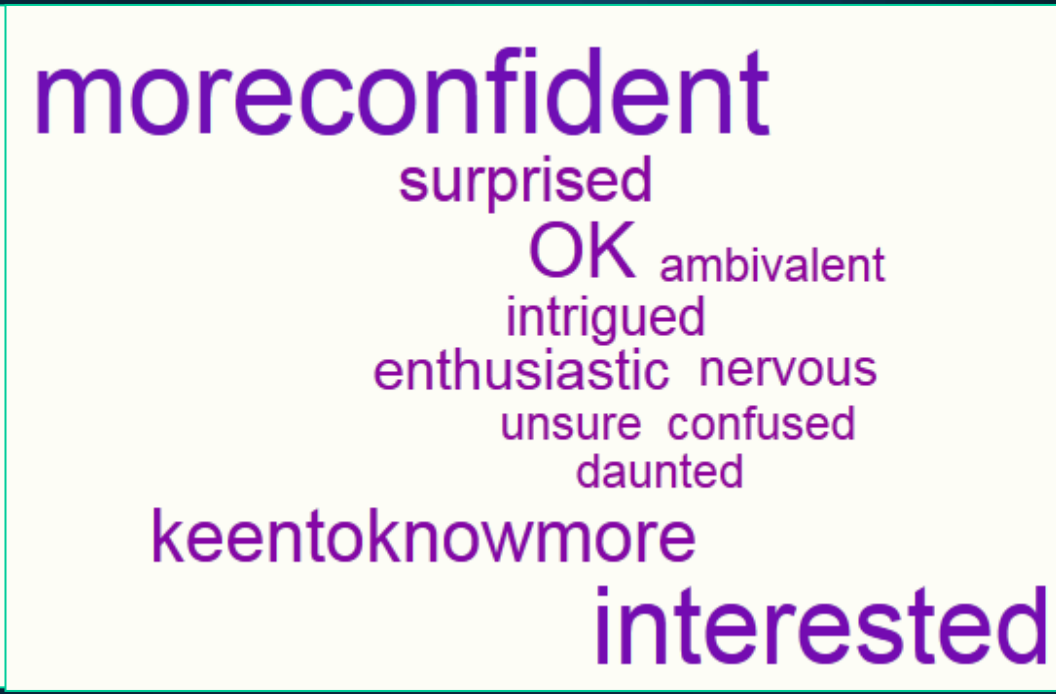




What works?: Post-registration nurses Word Cloud evaluation

1. Before

2. After



What works & challenges

- Making genetics/ genomics accessible
- Making it relevant: tailoring to professional role and experience
- Make clinical links explicit
- Don’t assume prior knowledge – & have a CPD strategy
- Sharing ideas and resources
- Value of critical mass and collaboration

- Attitudes
- Leadership from policy-makers
- Limited awareness
- Limited evidence of patient benefit
- Nursing being side-lined
- Limited science background of some nurses
- Limited confidence
- Limited role models/ reinforcement
- Competing priorities

International collaboration

- Identifying education resources (Tonkin et al 2011)
- Identifying critical success factors (Kirk, Calzone & Arimori 2011)
- Identifying global strategies (Williams et al 2011)

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GENETICS AND GENOMICS SERIES

Genomic Education Resources for Nursing Faculty

Emma Tonkin, PhD, BSc(Hons)[1], Kathleen Calzone, MSN, RN, APNG, FAAN[2], Jean Jenkins, PhD, RN, FAAN[3], Dale Lea, MPH, RN, CGC, FAAN[4], & Cynthia Prows, CNS, RN, FAAN[5]

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Genetics-Genomics Competencies and Nursing Regulation

Maggie Kirk, PhD, BSc (Hons), DipN, RGN[1], Kathleen Calzone, MSN, RN, APNG, FAAN[2], Naoko Arimori, PhD, RN, RMW, PHN[3], & Emma Tonkin, PhD, BSc (Hons)[4]

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Strategies to Prepare Faculty to Integrate Genomics Into Nursing Education Programs

Janet K. Williams, PhD, RN, FAAN[1], Cynthia A. Prows, MSN, CNS, FAAN[2], Yvette P. Conley, PhD[3], Julie Eggert, PhD, APRN-BC, GNP, AOCN®[4], Maggie Kirk, PhD, BSc(Hons), DipN, RGN[5], & Francine Nichols, PhD, RN[6]

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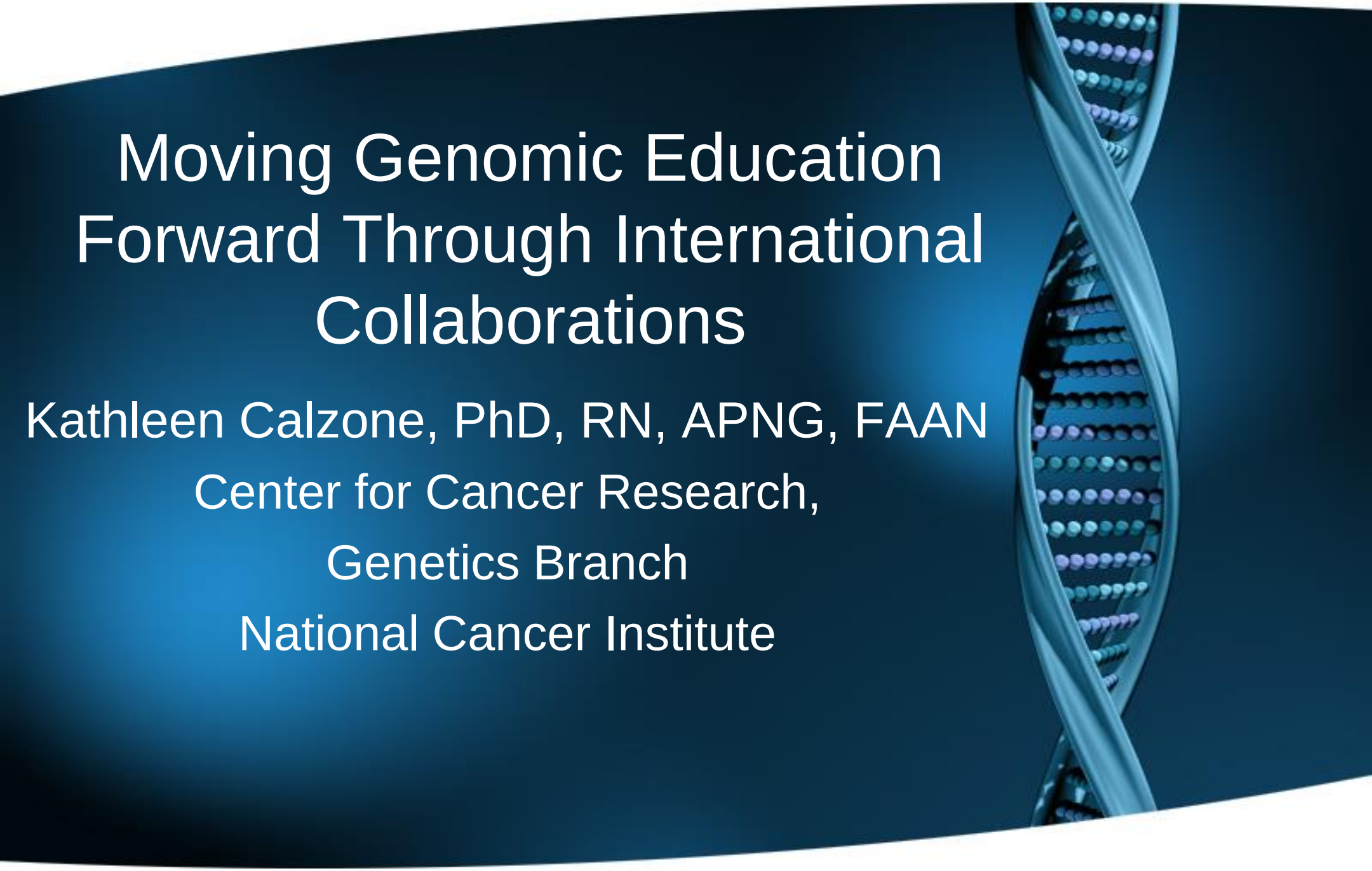
Moving Genomic Education Forward Through International Collaborations

Kathleen Calzone, PhD, RN, APNG, FAAN

Center for Cancer Research,

Genetics Branch

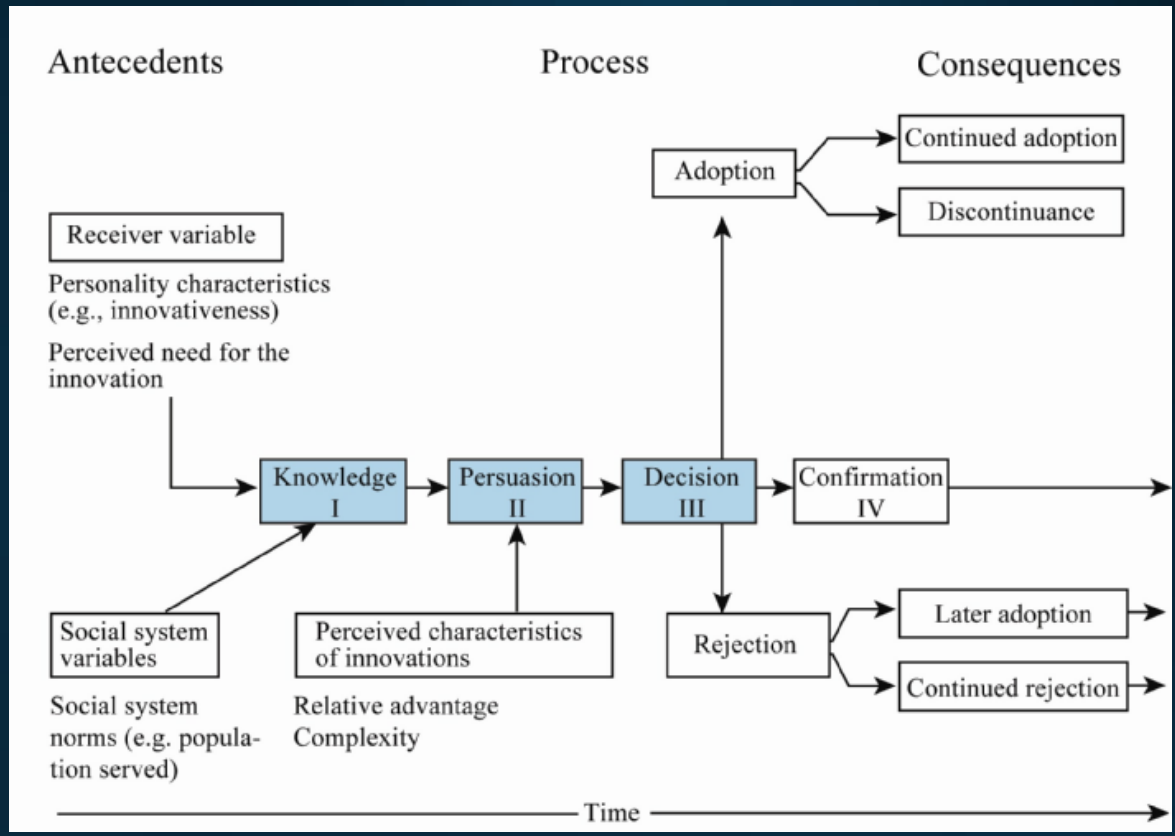
National Cancer Institute



Diffusion of Innovations

The process which an individual moves through after first hearing about an innovation to final adoption

- Diffusion
  - Within society and/or group
- Adoption
  - Individual



Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

Knowledge

- Competencies
  - Core and Advanced
- GGNPS
- G2C2
- G3C

Persuasion

- NCLEX
  - Nursing Science Blueprint
- AACN Essential Series
- Stakeholder Engagement
- Champions
  - Faculty
  - Clinicians

Decision

- Publication Series
  - JNS
    - Education
    - Clinical
- MINC Website
- OSEN Website
- Point of Care Decision Support

Adoption

- Sustainability Strategic Plan (2014-2020)
  - Infrastructure
  - Workforce Competency
  - Regulation
  - Clinical Service Delivery Infrastructure
  - Quality Outcomes
    - Outcome Indicators
- Patient, Family, Public Engagement
- Evidence Generation
- Leadership Persuasion
- Pathways of Influence

Method for Integrating a New Competency into Practice (MINC)

- Develop, implement and evaluate a year-long genomic education program to train, support, and supervise institution administrator and educator dyads to increase nursing capacity to integrate genomics
  - Expand the Global Genetics and Genomics Community to support education initiatives
- Evaluate institutional nursing workforce attitudes, practices, receptivity, confidence and competency in genomics of common disease and utilization of family history
  - Establish GGNPS reliability using test/retest methods to further refine the instrument
- Describe the impact of study participation on policies that support genomic integration including privacy/confidentiality, research, and electronic health records

Methods

- Institution administrator and educator dyads
  - Baseline education content
  - Ongoing education and support
  - Institutional Action Plans
  - Virtual site visits and quarterly action plan reports

Population

Intervention Group

- 21 Magnet Recognition Program® Designated Hospitals from 18 States (N=25,630)
- Number of nurses employed ranged from 80-3382

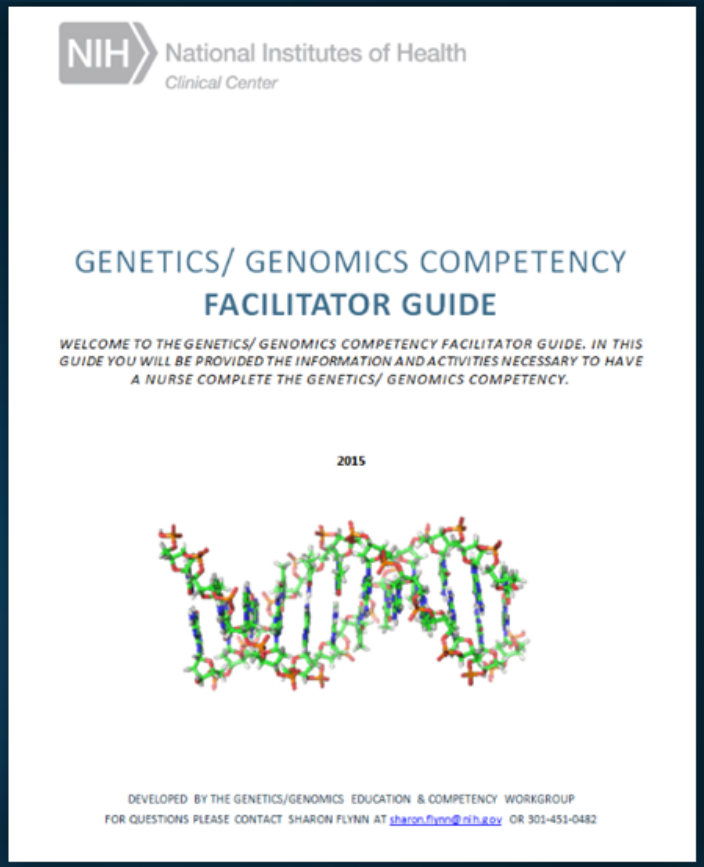
Control Group

- 2 Magnet Recognition Program® Hospitals

MINC Outcomes

- Awareness of genomics has increased
- Scope of interventions influenced degree of knowledge gain
- No change in adoption domains
- Increased educational intent
- Nursing workforce is clearer that nursing leadership values genomics
- Genomic education in school or post licensure appears to increase capacity to achieve genomic competency
- Complex competency and one year is insufficient

MINC Model:
NIH Clinical Center Exemplar



NIH National Institutes of Health
Clinical Center

GENETICS/ GENOMICS COMPETENCY
FACILITATOR GUIDE

WELCOME TO THE GENETICS/ GENOMICS COMPETENCY FACILITATOR GUIDE. IN THIS GUIDE YOU WILL BE PROVIDED THE INFORMATION AND ACTIVITIES NECESSARY TO HAVE A NURSE COMPLETE THE GENETICS/ GENOMICS COMPETENCY.

2015

DEVELOPED BY THE GENETICS/GENOMICS EDUCATION & COMPETENCY WORKGROUP
FOR QUESTIONS PLEASE CONTACT SHARON FLYNN AT sharon.flynn@nih.gov OR 301-451-0482

NIH CLINICAL CENTER NURSING DEPARTMENT
CRN COMPETENCY VALIDATION

Name: _____ Manager or Designee: _____
Work Area: _____ Hire Date: _____ Competency Date: Met _____ Not Met: _____
Reason for validation: ☐ Orientation ☐ Re-validation ☐ PI Follow-up ☐ Other _____

Key: 1 = No knowledge/Experience; 2 = Knowledge/No experience; 3 = Knowledge/Done with assistance; 4 = Knowledge/Done independently
Method used for validation: D = Demonstration; T = Test/Quiz; DR = Documentation Review; O = Activity in Class; V = Verbalization

Competency: Genetics/ Genomics – Integration of genetics/ genomics into the Nursing Professional Practice Domain related to nursing assessment, education, care and support.

Behavioral Indicators	Self-Evaluation	Assessment Method	Validator's Initials/Date: Met	Validator's Initials/Date: Not Met*	Comments
BEGINNER LEVEL (All CRNs/Research Nurses)					
1. Demonstrates ability to define basic genetics and genomics terminology.	1 2 3 4	T			
2. Recognizes one's own attitudes and values related to genetic and genomic science and how it may affect care provided to clients.	1 2 3 4	V			
3. Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening and diagnostics.	1 2 3 4	T, O			
4. Demonstrates the ability: a. To elicit a minimum of a three-generation family health history information. b. Constructs pedigree from collected family history information using basic standardized symbols and terminology.	1 2 3 4	O			
5. Demonstrates ability to recognize how to maintain privacy and confidentiality when discussing genetic and genomic information.	1 2 3 4	T, V			
6. Discuss scope of legislative protections and possible limitations a. GINA (Genetic Information Nondiscrimination Act) b. State laws c. ADA	1 2 3 4	T			

Key: 1 = No knowledge/Experience; 2 = Knowledge/No experience; 3 = Knowledge/Done with assistance; 4 = Knowledge/Done independently
Circle method used for validation: D = Demonstration; T = Test/Quiz; DR = Documentation Review; O = Other (specify); V = Verbalization

Competency: Genetics/ Genomics – Integration of genetics/ genomics into the Nursing Professional Practice Domain related to nursing assessment, education, care and support.

Cusack, G., et al. (2015). Igniting Genetic/Genomic Education and Competency at a Research Facility: Successes and Challenges. Proceedings of ISONG.

Global Genomics Nursing Alliance (G2NA)

- Establish G2NA for knowledge mobilization and action through sharing ideas, expertise, and resources
- Create a G2NA Roadmap that lays out how to integrate genomics into nursing education, practice and research
  - Benchmark progress between nursing communities, recognising real-world constraints and enablers.
- Agree and prioritize collaborative efforts needed to realise each dimension of the G2NA Roadmap

ROADMAP to guide and benchmark progress to accelerate integration of genomics into everyday healthcare practice

Maturity Matrix

"What does effective and ethical nursing which promotes global health outcomes in genomics look like?"

For each Domain of the MM:

Stages of Maturity

Outcome descriptors

Indicators

Level of indicator at Stage 1

Level of indicator at Stage 2

Level of indicator at Stage 3

Actions needed and timescale

Barriers and facilitators

Who can action this?

Who else should be involved?

Resources to support achievement in each MM Domain: people, curriculum guidelines, education resources etc.

Gaps in resources: what, who, when, how?

Priorities for action

Graphic Facilitator

G2NA Retreat

- January 23-25, 2017 at Hinxton Hall, Cambridge, UK
- Countries Represented
  - Australia, Brazil, Canada, China, Columbia, Germany, Israel, Japan, Jordan, Mexico, Netherlands, Nigeria, Pakistan, South Africa, South Korea, Switzerland, Taiwan, UK, USA
- International Organizations Represented
  - International Council of Nurses, International Society of Nurses in Genetics, Sigma Theta Tau
- Other Representation
  - European Board of Medical Genetics

Questions/Discussion

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