

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.

J Genet Counsel
DOI 10.1007/s10897-007-9127-y

PROFESSIONAL ISSUES

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

Maggie Kirk · Emma Tonkin · Sarah Burke

Received: 1 July 2007 / Accepted: 20 September 2007
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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

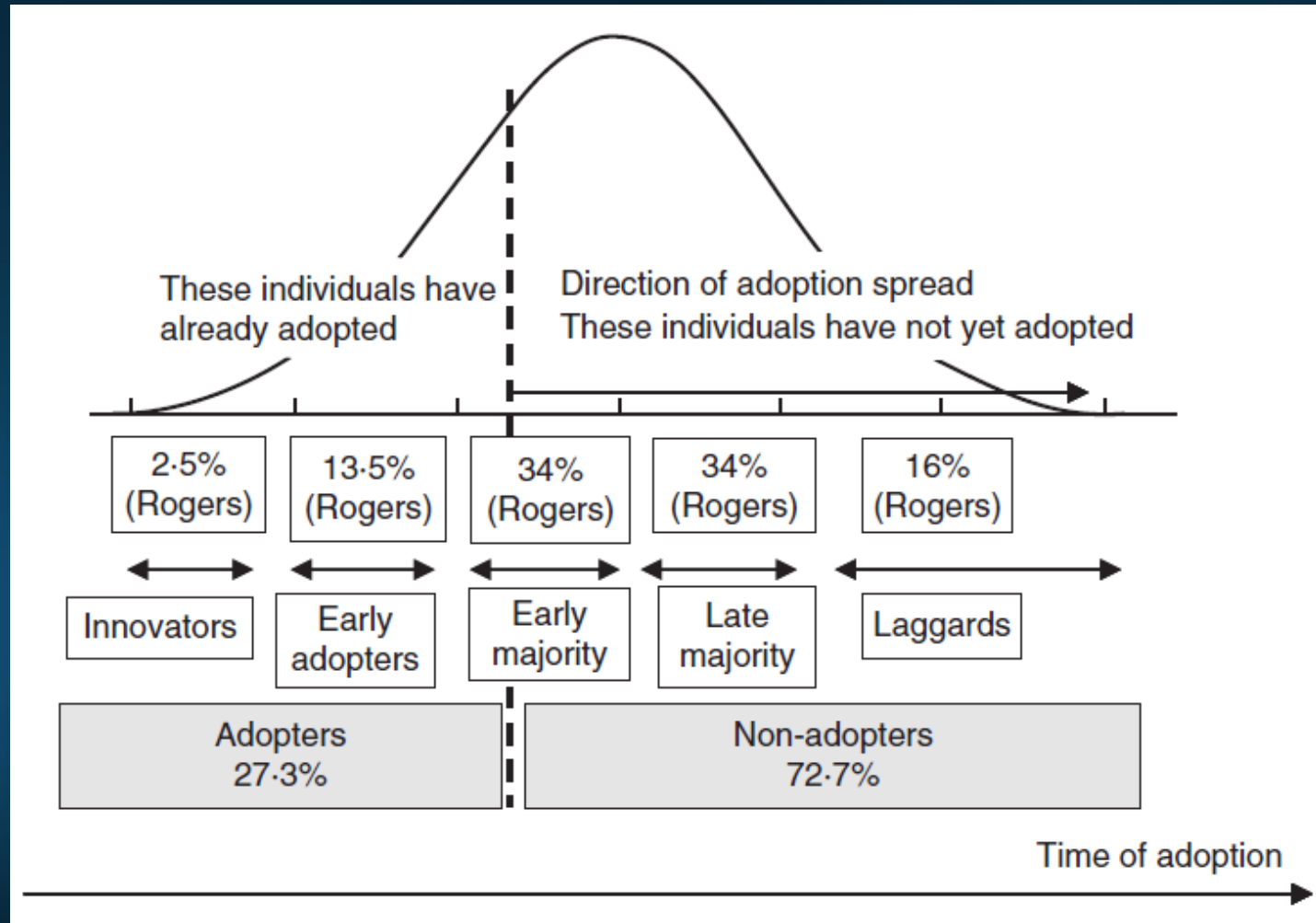
Influence of others

- 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, Lancaster & Kirk 2013



Attitudes: characteristics of adopters

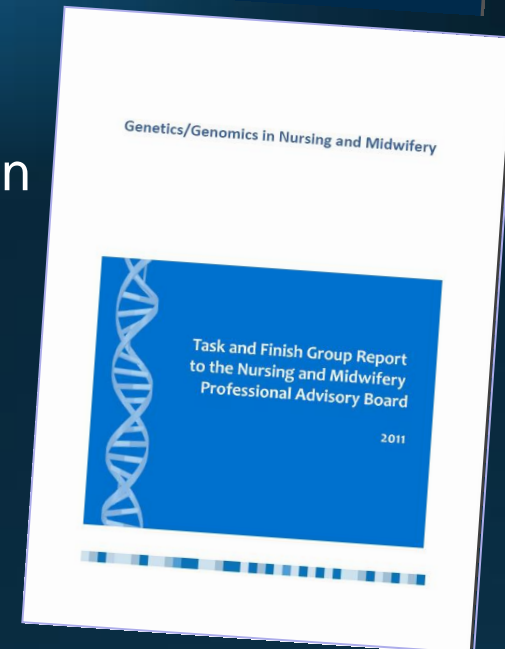
Significant distinguishing characteristics of adopters:

- 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' ...that we can build on as genomic healthcare expands.
- Leadership is an important issue ...but so is limited awareness.
- Patients and families of rare genetic conditions are under-served ...growing focus in genomic medicine and common conditions.
- Strategy is needed for all nurses and midwives, in training and qualified ...recognising the challenges in education & practice with lack of confidence and competence.

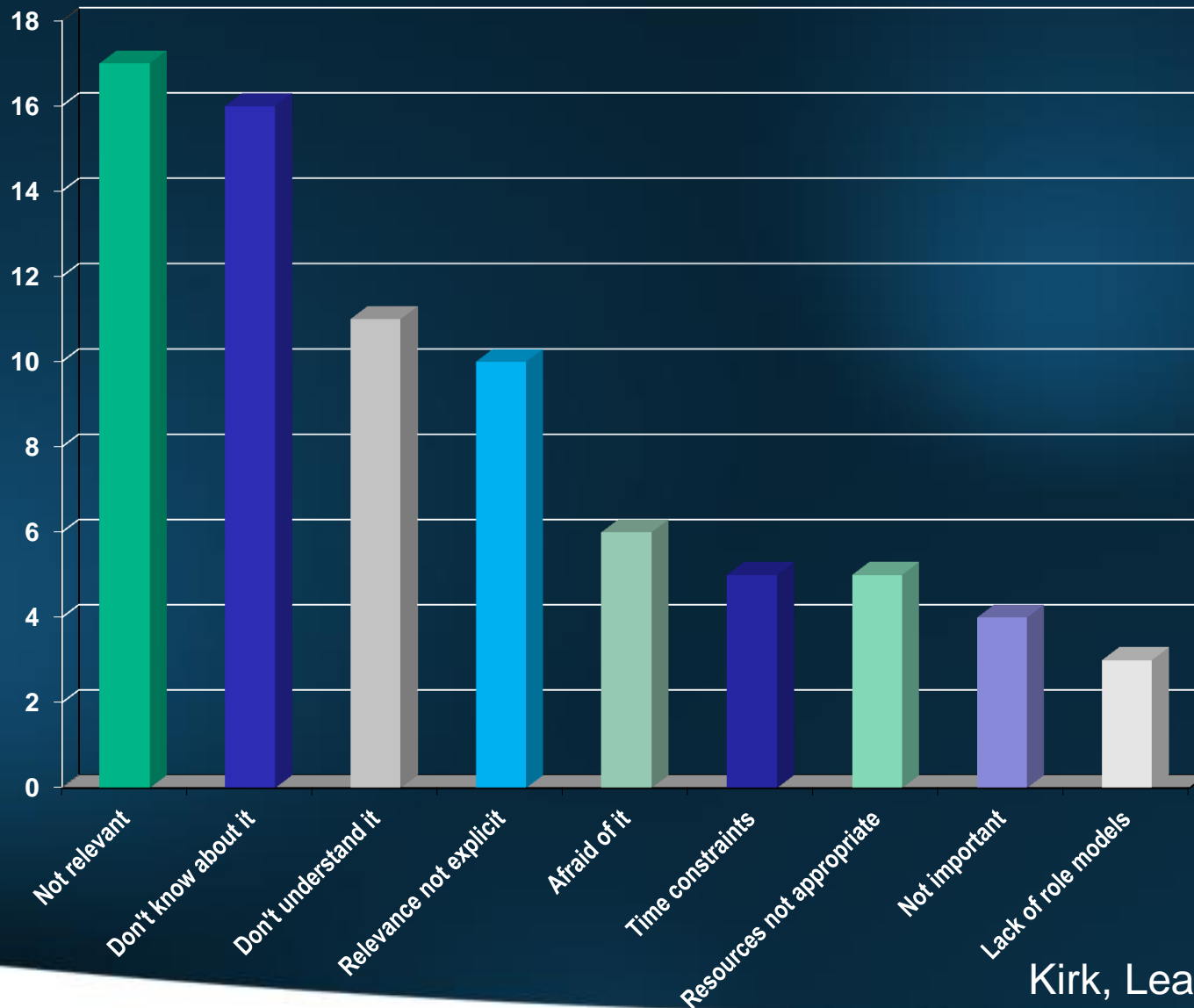


Doability: providing education frameworks


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




Doability: identifying barriers




Doability: Providing resources






National Genetics and Genomics
Education Centre



Telling Stories
Understanding Real
Life Genetics

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TEXT SEARCH

THEME SEARCH


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

AWARD FOR TELLING STORIES PROJECT!

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

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New Website!

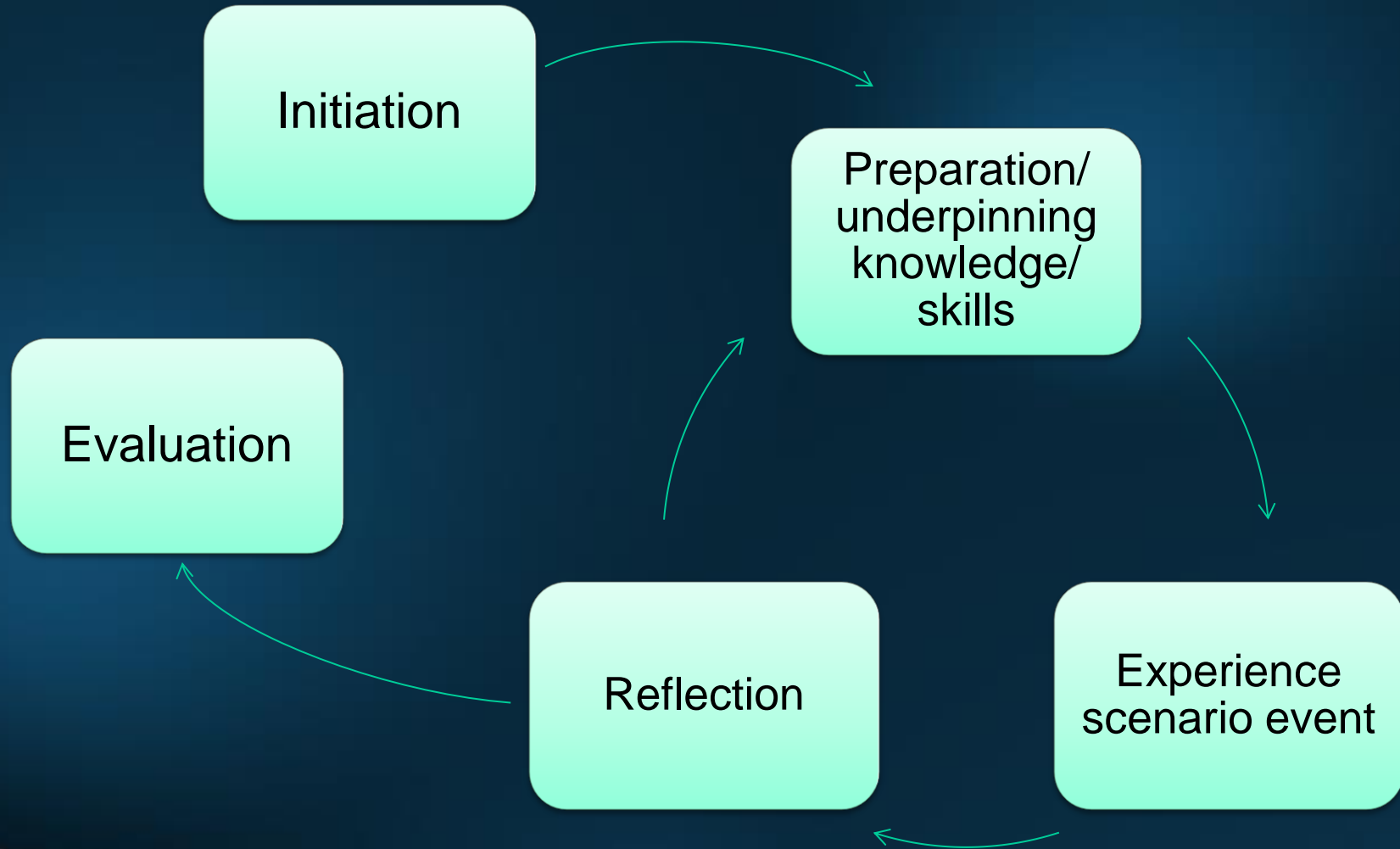
Welcome to the new look Telling Stories website!

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

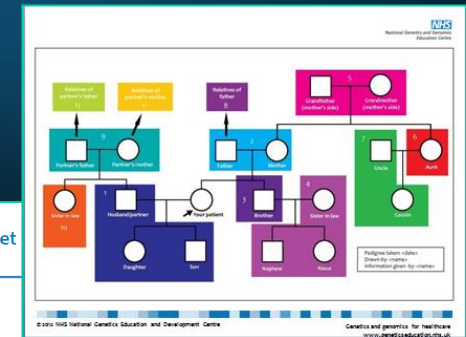
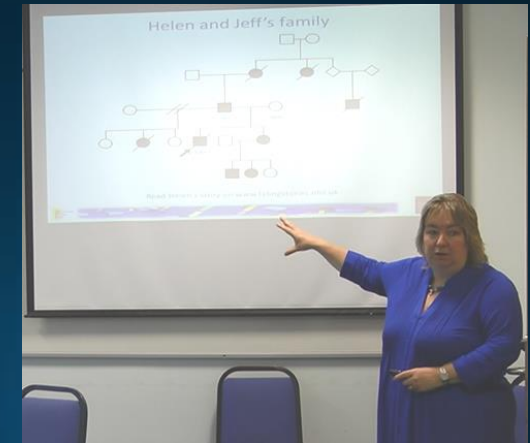
Meriel's story: having a child with Down syndrome Learning about the implications of a chromosome imbalance to a daughter's development	Biological Issues	Psychological Issues	Social Issues
<p>1. Having a child that has Down Syndrome (DS) was a shock. I became pregnant for the first time at age 32, and 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.</p> <p>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.</p> <p>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.</p> <p>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</p>	<ul style="list-style-type: none"> • Down Syndrome • Extra copy of chromosome 21 <p><u>Possible problems</u></p> <ul style="list-style-type: none"> • Heart defects • Hearing problems • Eye problems • Learning difficulties • No real drug treatment. <ul style="list-style-type: none"> • However certain supplement specifically designed to try to counteract effects of the extra genetic material. • Extra copy of chromosome 21 results in a chemical imbalance which increases cell damage. • Healthy diet - mainly organic 	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • 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.

Drama in education: Unfolding case studies using stories



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



Drawing a family history worksheet

Use these internationally agreed pedigree symbols for individuals.

Symbol	Sex	Status	Notes
□	Male	Individual	
○	Female	Individual	
◻	Male	Affected individual (shaded)	
◌	Female	Affected individual (shaded)	
◻◌	Male	Multiple individuals	
◌◻	Female	Multiple individuals	
◻◌	Male	Deceased	
◌◻	Female	Deceased	
◻◌	Male	Pregnancy	
◌◻	Female	Pregnancy	
◻◌	Male	Miscarriage	
◌◻	Female	Miscarriage	
◻◌	Male	Person providing pedigree information	
◌◻	Female	Person providing pedigree information	

Join the pedigree symbols together by lines to show family relationships as in this diagram.

Relationships

- Horizontal line: Mating
- Vertical line: Offspring
- Diagonal line: Consanguinity
- Double horizontal line: Consanguinity
- Double vertical line: Consanguinity
- Double diagonal line: Consanguinity
- Horizontal line with a vertical line ending in a diagonal line: Adoption
- Vertical line with a horizontal line ending in a diagonal line: Adoption
- Diagonal line with a horizontal line ending in a diagonal line: Adoption
- Diagonal line with a vertical line ending in a diagonal line: Adoption

This leaflet may be photocopied for non-commercial educational purposes for healthcare staff © 2010 NICE National Genetics Education and Development Centre (NICE)

A Medical Family History Drawing Tool

A Pedigree to show a family history

Male (shaded if affected) **Female (shaded if affected)** **Gender unknown (shaded if affected)** **Miscarriage** **Deceased**

This pedigree shows a condition affecting males and females being inherited from the grandparents.

This Medical Pedigree was taken by [Name] on [Date] at [Location].

How to draw a pedigree

- Start with simple family units. Make A and B.
- For each person: Record names, dates of birth, illnesses, surgery. Ask about miscarriages, stillbirths, deaths.
- Ask about any children with other partners.
- Ask about siblings and their siblings, their parents.
- Ask whether couples are related.

Supporting Genetics Education for Health www.geneticseducation.nhs.uk

What works?: Post-registration nurses Word Cloud evaluation

1. Before

daunted
nervous
can't see the point
keen
OK
uninterested
intrigued
interested
enthusiastic

2. After

more confident
surprised
OK
ambivalent
intrigued
enthusiastic
nervous
uninterested
confused
daunted
keen to know more
interested



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)

Genomic Education Resources for Nursing Faculty

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The increasing recognition regarding the relevance of genomics to the scope of nursing bedside practice has resulted in the drive to appropriate genomic knowledge and skills into nurse education and in this final article of the series Genetics-Genomics and Nursing Education we will look at genetic and genomic education resources and the factors

Genetics-Genomics Competencies and Nursing Regulation

Maggie Kirk, PhD, BSc (Hons), DipN, RGN¹, Kathleen Calzone, MSN, RN, APNG, FAAN², Naoko Arimori, PhD, RN, RMW, PHN³, & Emma Tonkin, PhD, BSc (Hons)⁴

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Key words

Genetics, genomics, competence, regulation, nursing education, nursing licensure

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Accepted January 1, 2011

doi:10.1111/j.1547-5069.2011.01388.x

Abstract

Purpose: The aim of this integration of genetics-genomics regulatory standards. By taking aim to develop a framework international genetics-genomics. We focus our attention on the progress, achievement relation to the integration exemplars from three of the findings. Analysis of the themes that play a critical nursing education and practicing themes: nursing education at an appropriate current standards for registration. Strong leadership a critical role in defining of nursing professionals and institutions is essential if offered by genomic health Clinical Relevance: Safe needs of those with, at risk as well as those who might be in the diagnosis and management of patients. Professional practicing nurses should d

Regulation of the nursing profession, encompassing the key pillars of governance, discipline, and education, is fundamental to the identity, structure, and type of services a nurse can offer (International Council of Nurses [ICN], <http://www.icn.ch/pillarsprograms/regulation/>). Affair Registration, incorporating licensure, is an important aspect of regulation and provides the route of entry to

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Journal of Nursing Scholarship, 2011, 42(2), 231-238.
No derivative US government works

Strategies to Prepare Faculty to Integrate Genomics Into Nursing Education Programs

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Key words

Genetics, genomics, nursing education

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Accepted March 5, 2011

doi:10.1111/j.1547-5069.2011.01401.x

Abstract

Purpose: Faculty knowledge of genomics, learner competencies, and program requirements for nursing education are described to assist educators in introducing genomic information into nursing undergraduate, graduate, postgraduate, and continuing education programs regardless of geographic location. Selected programs in the United States and the United Kingdom are described to illustrate successful approaches used by nursing faculty to enhance their genomic knowledge in order to increase application of genetic and genomic content within nursing education curricula.
Organizing Construct: Nursing education guidelines and nursing competencies provide benchmarks for educators in planning genetic and genomic curriculum content and expected learner outcomes.
Methods: Elements within competencies from the United States and the United Kingdom are reviewed to provide the framework for faculty knowledge. Strategies to address development of faculty knowledge and expertise are suggested. Continuing education faculty development programs and strategies to develop doctorally prepared nurse scientists who will educate future students in the profession are described.
Conclusions: Multiple faculty who are prepared to implement education on genetic and genomic topics are needed at all levels of nursing education. Faculty networking and application of genomic principles to nursing are key elements for sustaining nursing education to produce a nursing workforce that can apply essential genomic knowledge.
Clinical Relevance: There is an urgent need to offer genomics in accessible and effective education for nursing practice to optimize health outcomes regardless of geographic location.

Genomics, the study of all genes in the human genome, their interactions with the environment, and other psychosocial and cultural influences, is an essential component of nursing education. The ability to use knowledge of genomic aspects of health and disease is an expectation of the nursing profession in implementing

each component of professional nursing roles (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009; Kirk, McDonald, Anstey, & Longley 2003). The recognition of genomics as a component of the scientific foundation for nursing was supported in the United States (US) in the 1980s, when federally funded workshops

Moving Genomic Education Forward Through International Collaborations

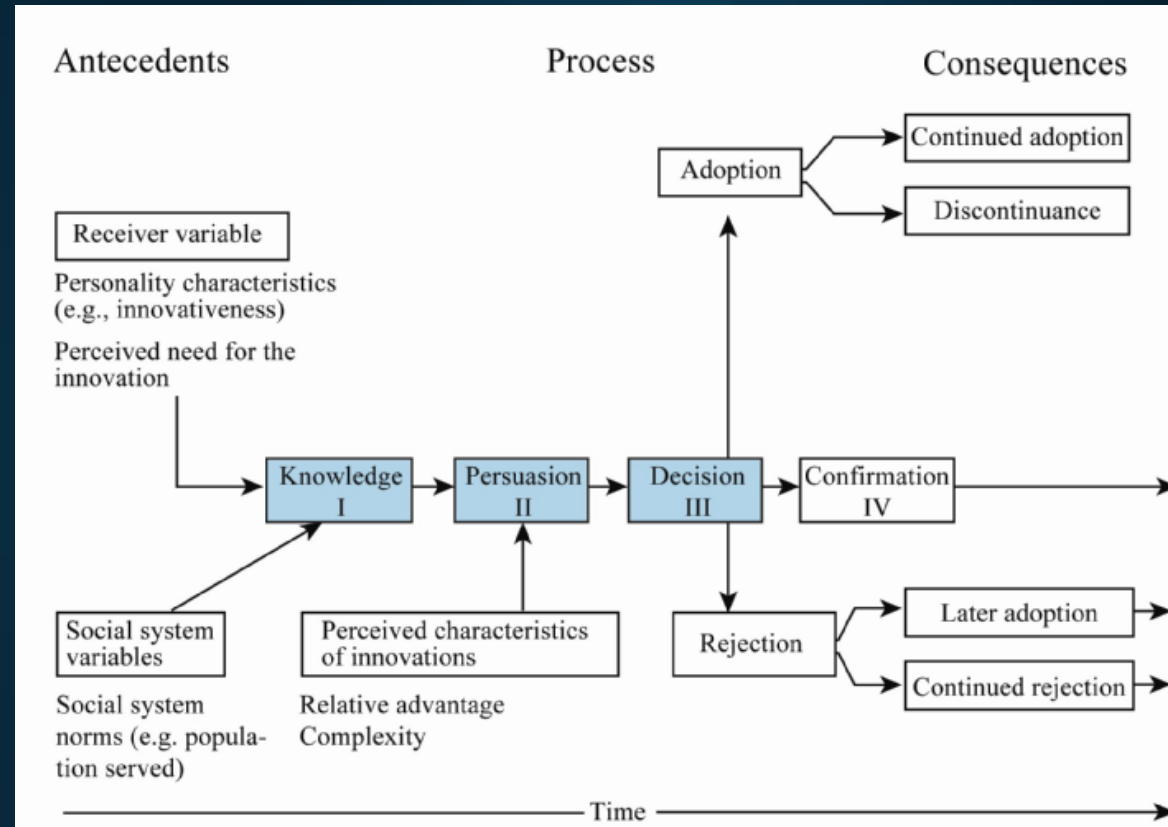
Kathleen Calzone, PhD, RN, APNG, FAAN
Center for Cancer Research,
Genetics Branch
National Cancer Institute



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

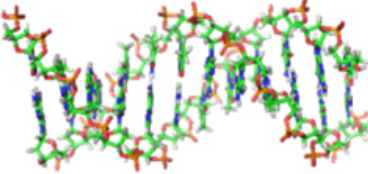
MINC Model: NIH Clinical Center Exemplar

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 Designer: _____				
Work Area: _____			Hire Date: _____		Competency Date: Met _____ Not Met _____				
Reason for validation: <input type="checkbox"/> Orientation <input type="checkbox"/> Re-validation <input type="checkbox"/> PI Follow-up <input type="checkbox"/> 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 DR = Documentation Review V = Verbalization T = Test/Quiz O = Activity in Class					
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		Comments	
						Met Not Met*			
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 DR = Documentation Review V = Verbalization T = Test/Quiz O = Other (specify)					
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

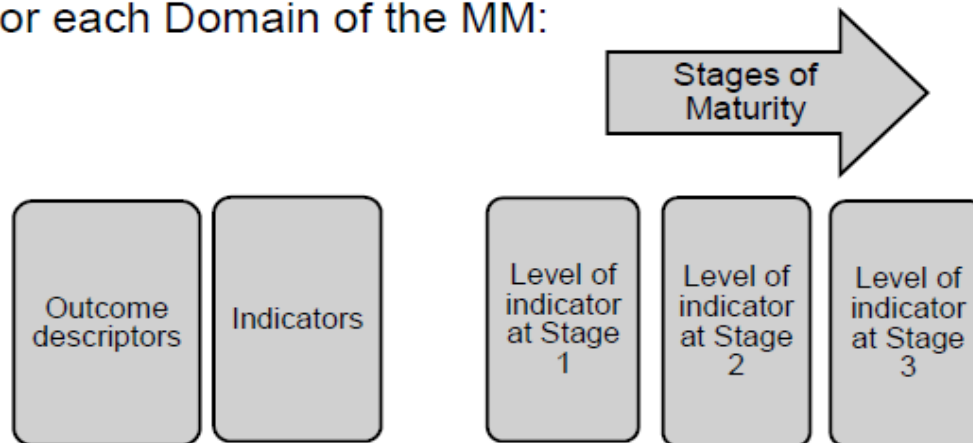


ROADMAP to guide and benchmark progress to accelerate integration of genomics into everyday healthcare practice

Maturity Matrix

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

For each Domain of the MM:



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

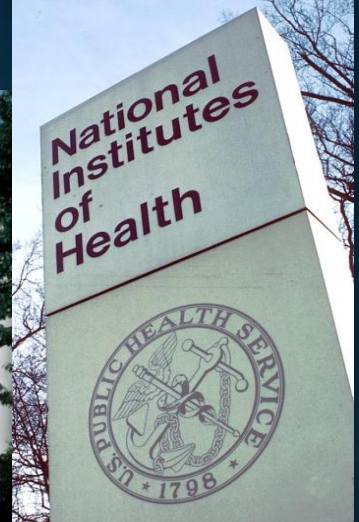




G2NA Retreat

- 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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