Institution: University of South Wales

Unit of Assessment: UoA A3

Title of case study: Engaging the public and professionals with genetics: the impact of the Genomics Policy Unit on exploring a new age of genetic healthcare

1. Summary of the impact (indicative maximum 100 words)

The Genomics Policy Unit (GPU) has led on research into genetics and health since 1996, and has made a significant contribution to this field at both a national and international level. As one of the first Research Units in the UK to focus on the preparedness of the public and healthcare professionals for the 'new genetics', we recognised how genetic advances would radically alter how we understand health and disease. The impact of our research has been to show audiences who would not typically engage with genetics, what new opportunities are being offered to improve human health and the social and ethical issues that surround these.

The GPU was an early pioneer of new, interactive research methods, such as Citizens' Juries, to help ordinary people make their views known to policy makers. By 2003 we were engaging nurses and midwives with genetics by supporting them in developing competent practice, setting a benchmark that has influenced competency development programmes for nurses in the UK, Europe and the US. This is important because advances in genetics mean it is moving out of its specialist sphere into wider clinical practice and broader society. This case study describes the two strands of our work – professional and public engagement - and illustrates the significant impact that exposure to genetics has had on ordinary members of the public when they are given the opportunity to acquire genetic literacy and on the nursing profession by contributing to policy and education in this field.

2. Underpinning research (indicative maximum 500 words)

The GPU (Kirk, Iredale, Tonkin and McDonald, with support from Madden, Morgan and Yu) has made a significant contribution to public education, and to policy and education of health professionals, and ultimately to healthcare improvement, in the emerging era of genetics. Our approach, by adopting innovative methods, such as Citizen's Juries, mock trials and consensus techniques, aims to generate new insights into the process and outcomes of professional and public engagement and education. We publish in academic journals and reach wider audiences through publications in professional journals, also using online articles, bespoke project websites, and social media such as Facebook, YouTube, Vimeo and Twitter.

Professional competency and engagement *(led by Kirk)*

Competency in genetics is a global challenge for nursing. It has been compromised by poor education provision and resources, negative attitudes, limited awareness and lack of confidence by educators, policy-makers and practising nurses. Our programme has taken a systematic approach to address these issues at national and international levels. An early study of UK schools of nursing established that pre-registration genetics education provision was inconsistent and inadequate.[1] We put together an expert panel to consider these findings and the Department of Health responded to its ideas by commissioning us to develop a genetics education framework for nurses. We used a group problem-solving technique with stakeholders (including patients) to promote ownership of the framework developed. We used this framework as the basis for the nursing programme led by us at the NHS National Genetics Education and Development Centre from 2004-2012. It was revised in 2010, again using a consensus approach.[2] Further study identified educators' needs in delivering the framework whilst practitioners' views, practice and confidence were assessed by linking articles published simultaneously in seven specialist nursing journals to an online survey. International research in 2008 echoed the barriers and enablers to competence we had found at national level. Then, working with colleagues in the US and Japan, we used a survey and case studies to set out a model for nursing professions in other countries to locate their progress, identifying critical success factors in doing so, one of which is the existence of national guidelines such as the genetics framework.[3] A further perspective of our research is looking at how genetically competent nurses can contribute to service improvement, acting as role models and delivering new services, as genetics becomes part of the 'medical mainstream.'

Our work uses real-life stories from individuals and families to promote understanding of how genetics impacts on people's lives, helping heath professionals understand its relevance to their practice. Led by the GPU, in partnership with Skirton (Plymouth University) and Cope (Genetic

Alliance UK), the web-based education resource *Telling Stories, Understanding Real Life Genetics* was the first to apply thematic analysis to set patient/carer stories within an education framework.

Public engagement *(led by Iredale)*

Our research involving public engagement has been characterised by using fresh ways of involving the public in policy and in engaging hard-to-reach communities. Iredale led the first Citizens' Jury in the UK on genetic testing within the NHS in 1998 and the first young persons' Citizens' Jury on Designer Babies in 2006.[4] The expertise we gained from these studies was disseminated widely and our methods replicated by others. These approaches have also spread into other policy areas, such as deciding on the use of genetic information for insurance purposes.

Much of the research into the public understanding of genetics has been quantitative and short-term, using traditional social scientific methods of inquiry. These studies have often reported that the public's understanding of genetics is poor. By using highly interactive research approaches, we have demonstrated that 'ordinary people' can hold and discuss complex social and ethical views about genetics. One outcome of a study seeking to engage young people in exploring the relation between genes and cancer (with 20 12-13 year old schoolchildren) was the production of their own genetics rap (Let's talk about genes; www.youtube.com/genomicspolicyunit).

Globally, research with young people concerning genetics has been limited, particularly involving those who are not in education, employment or training, including. young offenders. Our innovative research with the Designer Baby Citizens' Jury, the GAMY project[5] and the National DNA Database on Trial project[6] demonstrates that research with young people is both necessary and can be successful, and that young people have sophisticated, multi-layered understandings of the concepts and issues surrounding genetics which they can express in a variety of ways, using a variety of media. In partnership with them, we have also created a legacy of resources.

3. References to the research (indicative maximum of six references)

[1] Kirk M (1999) Preparing for the future: the status of genetics education in diploma-level training courses for nurses in the UK. *Nurse Education Today* 19(2):107-15 doi:10.1054/nedt.1999.0617.

[2] Kirk M, Tonkin E, Skirton H (2013) An iterative consensus-building approach to revising a genetics/genomics competency framework for nurse education in the United Kingdom. *Journal of Advanced Nursing* doi:10.1111/jan.12207. (Also listed in REF 2.)

[3] Kirk M, Calzone K, Arimori N, Tonkin E (2011) Genetics-genomics competencies and nursing regulation. *Journal of Nursing Scholarship*. 43(2):107-16. (Also listed in REF 2.)

[4] Iredale R, Longley M, Thomas C, Shaw A (2006) What choices should we be able to make about designer babies? A Citizens' Jury of young people in South Wales. *Health Expectations* 9:207-217 doi:10.1111/j.1369-7625.2006.00387.x

[5] Iredale R, Madden K, Taverner N, Yu J, McDonald K (2010) The GAMY Project: young people's attitudes to genetics in the South Wales valleys. *The HUGO Journal* 4(1-4):49-60. doi:10.1007/s11568-010-9148-8

[6] Stackhouse R, Anderson C, Shaw AM, Iredale R (2010) Avoiding the "usual suspects": young people's views of the National DNA Database. *New Genetics and Society* 29 (2):149-166 doi:10.1080/14636778.2010.484234

Related income has been from a variety of peer-reviewed sources, including:
Iredale: Wellcome Trust 2008-09 £27,914 The National DNA database on trial; Wellcome Trust 2008-09 £129,030 Genetic Literacy and family history (The GAMY project); Beacons for Wales 2010-11 £14,109 Having fun with science; Tenovus 2012 £28,844 Let's Talk about Genes.
Kirk: British Heart Foundation 2008-11 £109,000 Cardiac Genetics Nurse Initiative; Department of Health/Welsh Government 2004-12 c£200,000 Nursing Programme (NHS National Genetics Education & Development Centre); Wellcome Trust 2005-07 £28,000 Telling Stories.

Evidence of the quality of research is reflected through awards including: 2013 International Award, Best of *Journal of Nursing Scholarship* – Clinical Scholarship Award (paper 3); The Designer Baby Citizens' Jury Project was used as an exemplar of good practice by the Wellcome Trust in their Annual Report 2006 (paper 4).The GAMY Project rap: Judges' Choice winner of The Scientist Labbies 2010 (paper 5). Other indicators of the quality of research include: Royal College of Nursing 2013 (Fellowship in recognition of outstanding contribution to nursing); Association of Healthcare Communicators 2009 (Best use of new media award); International Society of Nurses in Genetics Founders' Award 2006 (outstanding contribution to education).

4. Details of the impact (indicative maximum 750 words)

Professional competence and engagement

The genetics education framework for nursing/midwifery we developed in 2003 (revised 2010) addressed an identified need in the Government's drive to improve genetic literacy in the NHS workforce. It set a benchmark that has influenced similar competency development programmes in the US and in Europe and formed the basis of the NHS National Genetics Education & Development Centre nursing programme we led from 2004-2012. The RCN and UK National Screening Programme adopted it when developing competency frameworks for sickle cell and thalassaemia (SCAT) nurses in 2011 and for specialist SCAT counsellors in 2013.

Our work has helped to raise awareness of genetic healthcare and its relevance to good quality nursing care, nationally and internationally, and has helped give nursing a voice in informing policy. This is highly significant in a profession where there is still resistance to embracing genetics although it is increasingly part of mainstream healthcare. In 2009, Kirk was invited to give evidence to the House of Lords Science and Technology Committee's review of Genomic Medicine. Her comments were reflected in the recommendations made by the Committee to the Nursing and Midwifery Council, who, in 2010 for the first time included a reference to genetics in the revised pre-registration requirements. In 2010, Kirk was invited to chair and convene a Task and Finish Group to consider the implications of genetics/genomics for nursing and midwifery, for the Department of Health Nursing & Midwifery Professional Advisory Board. The recommendations were subsequently endorsed in the report by the Human Genomics Strategy Group, a government-appointed body to develop the vision for genomics in the NHS.

We enhance our impact by providing practical help for educators, practitioners and others, publishing accessible articles and web resources. Over 64,300 people from 173 countries have visited the Telling Stories resource since 2009. An evaluation in 2008 showed it was well regarded by educators (http://www.tellingstories.nhs.uk/Preliminary_report.pdf). The numbers of visitors coming to the site from links on over 500 patient support websites indicate that the resource has wider impact than just health professionals and the American Museum of Natural History is currently our top referring site. It has also had an impact on our 100+ storytellers whom we regard as partners. They have reported their involvement as a positive and even cathartic experience, in the words of one story teller: "*I think that for me, it was a form of therapy. I needed to 'shout out' and it's taken me 24 years! Thanks for giving me that release!"*

Public engagement

One of the most important things a person can do to promote their own and their family's health is to gain genetic literacy. Our research has empowered many people to contribute to debates about genetics. Young people are the generation for which genetic and reproductive technologies are most relevant in the 21st century and this group has been a particular focus of our work. There has been a clear trajectory from the earliest research 15 years ago, with young people exploring their views on gene therapy in a series of reconvened interviews, through to Citizens' Juries, Mock Trial as well as long term projects with teenagers. The GAMY Project Rap has attracted more than 76,000 views on You Tube.

Government consultations on genetics issues have used results from our public involvement projects. Participants have been invited to visit the Welsh Government, the Human Genetics Commission and the Human Fertilisation and Embryology Authority to put forward their views to policy makers in Wales and England making delicate decisions about genetics services in the UK. On one occasion 12 young people were supported to visit London for this purpose. This also has wider significance in terms of engaging young people in 'citizenship'.

The Let's Talk about Genes project directly involved twenty 12-13 year olds (and their teachers) in learning about genes, family history and cancer. One commented that *I learnt that only 5% of cancers are passed down through genes...I enjoyed the session because we learnt everything in a fun way.* The video the children produced has already attracted over 3,800 views. YouTube analytics indicates viewers are aged from 13-65 years and older, with 13-17 year olds accounting for 30% of views. We are thus reaching a broad range of ages.

The *Having fun with science* project aimed to promote genetic literacy across a variety of audiences. We developed a series of games and teaching resources disseminated via our links with Techniquest, the Wales Gene Park and the Teachers' Genetics Network, to improve understanding of the role that family history plays in health and disease. The games have been showcased around Wales and are easily accessible to all sectors of the public. This research has also been disseminated via interactive road shows and community festivals in deprived areas of the South Wales valleys, such as the Green Man Festival in 2011 (where 105 visitors aged 4-65 also responded to a survey).

One of the positive outcomes from our work has been its broader reach, fostering new collaborations with the local police, the *Magistrates in the Community* scheme, the probation service and Funky Dragon (young people's organisation in Wales), i.e. those who are not usually involved in this sort of public engagement with science initiative.

The beneficiaries of our public engagement work go beyond the immediate participants. One of the outcomes of our research, the DVD *Cheek to Court*, was used by the National DNA Database Manager and the Home Office for staff training. The 15 minute video itself has attracted over 275 views since being uploaded to YouTube last year.

We facilitate young people's understanding of genetics issues in ways that make personal sense to them and which are located in their own particular environments or communities, because we help them engage with the issues over an extended period.

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. Reference to the incorporation of the genetics framework into the European competencies: Skirton H, Lewis C, Kent A & Coviello D (2010) Genetic education and the challenge of genomic medicine: development of core competencies to support preparation of health professionals in Europe. *European Journal of Human Genetics* 18, 972-977. HTML available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2987423/
2. US Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf Kirk's contribution to the development of the US nursing competencies referenced on p3 & p9.
3. House of Lords Science and Technology Committee (2009) Genomic Medicine Volume I. See p74 for evidence given to committee by Kirk. Available to download at http://www.publications.parliament.uk/pa/ld200809/ldselect/ldsctech/107/107i.pdf
4. Evidence of impact of the report by the Task and Finish Group to Department of Health Nursing & Midwifery Professional Advisory Board (Genetics/Genomics in Nursing and Midwifery) can be found in *Building on our inheritance: Genomic technology in healthcare. A report by the Human Genomics Strategy Group* (2012). "We endorse the recommendations of this report" (p66). See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132369 .
5. Contribution of the genetics framework to sickle cell and thalassaemia nursing and counselling: RCN Competencies: Caring for people with sickle cell disease and thalassaemia syndromes. A framework for nursing staff. Background available at http://sct.screening.nhs.uk/nursing-framework and to download: http://www.rcn.org.uk/__data/assets/pdf_file/0004/372991/003874.pdf. Genetics framework identified as a contextual factor p11. Kirk listed as a major contributor p34. Development of core competencies for sickle cell and thalassaemia counsellors; Kirk and Tonkin named contributors; see Introduction, p5. http://sct.screening.nhs.uk/genetic-competences
6. Telling Stories: www.tellingstories.nhs.uk: Google Analytics™ data: over 16,600 visits are from referring sites. The American Society of Human Genetics (nearly 8,000 members) has highlighted a link to the resource from its education front page (http://www.ashg.org/education/) and the Director of Education for ASHG has endorsed the value of the resource (in an email). Testimonials from other organisations and storytellers further support this view (in emails).
7. The DNA Database on Trial project is referenced by the Nuffield Council on Bioethics in their discussions with the Home Office on the use of genetic information in criminal justice (p7): http://www.nuffieldbioethics.org/sites/default/files/files/Home%20Office%20NDNAD%20consultation%20July%2009.pdf.
8. Presentation of DNA database on trial findings by youngsters involved to Welsh Government (3/12/2008) and Human Genetics Commission (9/12/2008) (emails and agenda).
9. *Let's talk about genes* rap (https://www.youtube.com/watch?v=oMNHUFmLOsc) shows number of views.
10. Other outputs from public involvement work include 'Cheek to Court' video (http://www.youtube.com/watch?v=A9-2OIdn3AE), a 7ft DNA model and a DNA tapestry made by twenty young offenders at Parc Prison, South Wales (available to view at USW).