

Genetics/Genomics in Nursing and Midwifery



Task and Finish Group Report to the Nursing and Midwifery Professional Advisory Board

2011



About this document

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- Date:** Final March 2011
- Reporting to:** Department of Health
- Description:** The report is produced to assist the Nursing & Midwifery Professional Advisory Board in identifying issues and potential solutions concerning the future of genetics/genomics for the nursing and midwifery professional workforce.

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Summary

A task and finish group comprising ten senior nurses and midwives with interest and/or expertise in genetics/genomics was set up to consider the future of genetics/genomics in relation to nursing and midwifery. The purpose of the task and finish group was to identify key issues and potential solutions concerning the future of genetics/genomics in relation to nursing and midwifery and to provide a report to the Nursing and Midwifery Professional Advisory Board to consider and use to inform its responses and future actions.

The group conducted its review through a mix of face to face meetings, telephone discussions and email. Discussions were wide-ranging and considered the key drivers, including the scope of the science, patient expectations, the professional context, education and training and ethical considerations. Real life scenarios at different lifestyles were used to stimulate discussion.

Scientific advances in genomics are bringing unprecedented opportunities for a greater understanding of disease mechanisms across the spectrum of disease, from rare to common. They are also leading to more accurate diagnosis of disease, developments in diagnosis of genetic subtypes of common diseases and in developments of new therapies and more targeted therapies. The advances are rapid and have relevance across healthcare services, not just to specialist genetics services. Nurses and midwives represent the largest sector of the NHS professional workforce and are best placed to optimise the potential contributions of genomics for improving health. However, they face significant and complex challenges to integrating genomic healthcare into professional education and practice, in particular including:

- The scale and pace of scientific advances is complex and uncertain, but accelerating.
- The needs of patients and families affected by genetics/genomics are not being met.
- Nurses and midwives have limited competence and confidence in genetics/genomics.
- Despite the size of the workforce, there is limited capacity to develop new roles that integrate genomic healthcare in different areas of practice.
- Education provision is inconsistent and education providers may have limited awareness of the relevance of genomic healthcare to professional practice.
- Genomic healthcare and the application of genomic technologies lead to further, and more complex, ethical challenges.
- Confidence and competence in healthcare ethics related to genetics/genomics is low.
- There is a very limited evidence base for the translation of genomics advances into nursing and midwifery practice, and clinical outcomes for practice have not been established.

The task and finish group believes that all nurses and midwives at all levels of practice must be competent to deliver genomic healthcare and that professional leaders should be informing and shaping developments to incorporate genomic healthcare. Action must be taken now if they are to deliver the current and potential benefits of genomic health care for patients, families, communities and public health.

Recommendations

Policy

1. Identify the strategic leaders to take responsibility for driving improvements in genetic/genomic education and practice across the professional groups as part of a dynamic and continuing process. This leadership needs to be visible and accountable. Lines of communication must be clearly articulated.
2. Strategic leaders need to develop a UK wide implementation strategy that engages key stakeholders across all sectors and for which they are centrally and locally accountable.
3. Nursing and Midwifery leaders, including those with expert knowledge in genetics/genomics, need to have an equal voice at strategic and policy making levels.
4. The new commissioning agenda should give specific consideration to genetics/genomics that goes beyond the commissioning of specialist genetics services and should place patients' and families' experiences at the forefront of future developments.
5. New commissioning arrangements for education should give explicit consideration to genetics/genomics across all levels of training. Whilst this must be cognisant of local needs, its perspective must be national.

Education

6. The NMC standards should be expanded to reflect the integration of genetics/genomics across all areas of nursing and midwifery training with monitoring of this an integral part of the quality assurance framework.
7. The NMC, along with education commissioners and providers, should consider the model of the medical Royal Colleges in providing explicit guidance on curricula to incorporate genetics/genomics.
8. Education commissioners and providers should continue to make use of new and existing competence frameworks and resources available via the NHS National Genetics Education and Development Centre and others.
9. Education commissioners and providers should ensure that resources are up to date, accessible, relevant to present day practice, delivered by knowledgeable and confident faculty and tailored to the needs of specific groups.

Research

10. Resources need to be committed to research around the translation of scientific/clinical advances into nursing and midwifery practice that also considers ethical and psychosocial implications and impact for patients and families.
11. Resources need to be committed to research to establish the evidence base for the outcomes of genetically/genomically competent care delivered by nurses and midwives.

Professional development

12. More nurses and midwives need to be supported in their career development into the academic and clinical leads for the future to increase the diffusion of new ideas related to genomic healthcare into clinical practice and education.

Acronyms and Glossary

Genetics

Genetics is the study of heredity and variation. (In the healthcare setting this has been associated with single gene and chromosomal conditions traditionally managed in specialist genetics services.)

Genomics

Genomics is the study of the structure and function of the genome, including the interaction between genes and between genes and the environment.

Genomic healthcare

Genomic healthcare involves the use of genomic information and technologies at any stage of the healthcare continuum to determine disease risk and predisposition, diagnosis and prognosis, and the selection and prioritisation of therapeutic options. Genomic healthcare also takes into account the potential ethical, psychological and social implications of genomic information and the application of genomic technologies.

ACHD	Adult Coronary Heart Disease
CHD	Coronary Heart Disease
DTC	Direct to consumer (in the context of genetic testing)
FH	Family history
ICC	Inherited Cardiac Condition
MCADD	Medium-chain acyl-CoA dehydrogenase deficiency
MDT	Multidisciplinary team
NIPD	Non invasive prenatal diagnosis
NMC	Nursing and Midwifery Council
NGEDC	NHS National Genetics Education and Development Centre
PAB	Professional Advisory Board (for Nursing and Midwifery)
SCD	Sudden cardiac death

Background

The Nursing and Midwifery Professional Advisory Board (PAB) is responsible for providing professional oversight and advice on workforce planning and development to the Chief Nursing Officer. It seeks to develop policy to promote and improve professional development, including education, and to consider the implications of transformational developments in service provision for the nursing and midwifery workforce. In its discussions it has identified genetics as a priority area for review and thus has set up a task and finish group to consider the future of genetics in relation to nursing and midwifery. This report sets out the deliberations of that group.

Terms of reference

The purpose of the task and finish group is to:

- Identify key issues and potential solutions concerning the future of genetics/genomics in relation to nursing and midwifery
- Provide a written report with recommendations for the PAB to consider and use to inform PAB responses and future actions.

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Scope of the report

In considering the scope of this report, the task and finish group agreed that:

- Discussions would take into account the advances in genomics and genomic technology, and their implications for nursing and midwifery practice and education. The terms 'genetics' and 'genomics' are sometimes used interchangeably, particularly in the UK and it is helpful to make explicit that this report considers the implications of scientific advances in genetics and genomics.
- There is sufficient literature outlining the importance and relevance of genetics/genomics to nursing and midwifery practice to render further justification of its relevance superfluous. However, there does need to be a common awareness of the scope of genomic healthcare.
- There should be a dual focus on rare genetic disease and genomics, to include the common conditions and conditions where genomic technologies play a part in treatment/management.
- It should consider those in training and the qualified workforce. Although educating the next generation workforce is of key importance, the competence deficit in currently registered nurses and midwives, who may remain in practice for another 1-3 decades, must be recognised and addressed.
- The qualified workforce should include the clinical specialist role, both within the medical genetics services and in other healthcare settings.
- That its considerations and recommendations would pertain to the professional workforce across the UK.

Approach

The group has communicated via a mix of face to face meetings, telephone conference and email. One meeting over a 24 hour period was held at Cardiff on February 14th-15th 2011. The key drivers for change were agreed and used as a focus for debate: the scope of the science; patient expectations; professional context; education and training; ethical considerations. Each of these drivers is followed by a summary of 'What is known' and 'What needs to happen'. The barriers to progress were also considered. Real life scenarios have been used to stimulate discussion, reviewed through a lifestage approach. These were drawn from group members' own experiences and from the website *Telling Stories, Understanding Real Life Genetics* (www.tellingstories.nhs.uk). Discussions were also informed by the relevant literature. Reference to this in the outline that follows is not exhaustive, and is incorporated to provide sufficient indication of the evidence base that underpins our deliberations and the recommendations we present.

Vision for the future and for now

The task and finish group is conscious that, at a time of fiscal constraints and the need to prioritise workload and services, a strategy to address *future* healthcare needs in relation to genomic medicine where there are still uncertainties, is at risk of being overlooked. However, in preparing nurses and midwives to practise safely and effectively to incorporate genomic healthcare in the management and treatment of patients and to meet the genomic healthcare needs of patients, families and communities *today*, we must be confident and assured that the professional workforce has a firm foundation on which further knowledge and skills can be developed to integrate current and future clinical advances in genetics/genomics. The vision set out below is thus one for the here and now and which prepares a pathway to take the professions forward to embrace current and future developments in genomic healthcare.

Vision

Every nurse and midwife recognises and acts on the importance of genetics/genomics in the care they provide to people and families:

- recognising the issues of particular relevance to their area of practice;
- recognising the limits of their own competence;
- knowing where and how to seek the most appropriate help and advice.

Every nurse and midwife is competent to a minimum standard in genetics/genomics through education provision:

- in which genetics/genomics is transparent across the curriculum;
- which meets the needs of those already qualified;
- is of relevance to local providers and to local needs.

Every nurse and midwife recognises that genetics/genomics is important and relevant because of the implications:

- of the scientific advances, including the need for caution in identifying needs that cannot be met;
- for family care;
- for the significant percentage of the population who have a rare genetic disease;
- for personalised healthcare and the stratification of risk, diagnosis, treatment and the subsequent care pathway.

Why nurses and midwives?

Nurses and midwives represent the largest sector of the NHS workforce, with around 512,629 qualified staff in post. There were 395,229 qualified nursing, midwifery and health visiting staff in the NHS hospital and community health services in England as at September 2009¹ and 33,021 qualified nurses and midwives in Wales.² The majority of these (215,854 in England; 18,651 in Wales) are located in acute elderly and general services. Nurses and midwives in Scotland (68,133) comprise 40.3% of the NHS workforce (September 2010).³ There were 16,246 qualified nurses and midwives within Northern Ireland Health and Social Care workforce (March 2010).⁴ These figures do not

¹ Source: The NHS Information Centre for health and social care 2009 Non-Medical Workforce Census © 2010

² Source: StatsWales; <http://www.statswales.wales.gov.uk>

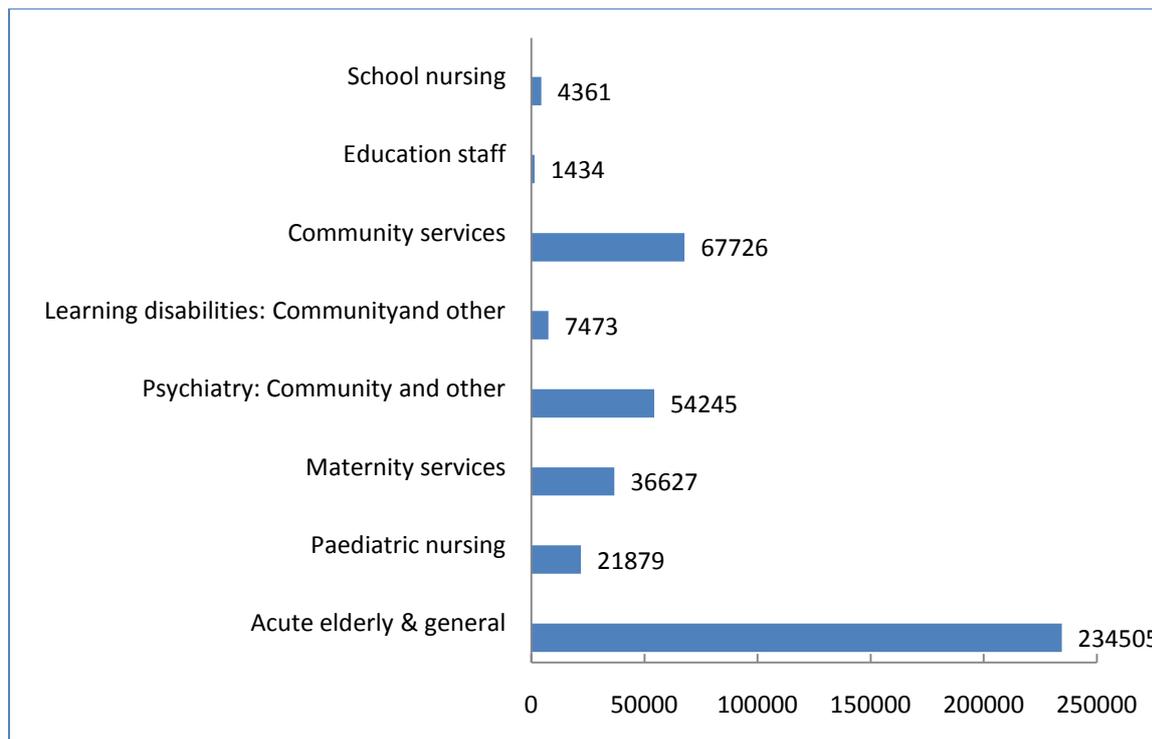
³ Source: ISD Scotland National Statistics; <http://www.isdscotland.org>

⁴ Source: Northern Ireland Information and Research Agency; <http://www.nisra.gov.uk>

include nurses located in GP practices, of which there were an estimated 21,935 in England alone in 2009.¹

Nursing and midwifery are large and diverse professions (Figure 1), even more so when specialisms within acute services are taken into account.

Figure 1 The profile of qualified NHS nursing and midwifery staff locations in England and Wales as at September 2009 (headcount)



Nurses and midwives are central to the public's health, through health promotion and prevention or amelioration of ill-health through screening programmes, early detection, targeted treatment and individualised care. They are often the first point of contact and are best placed to communicate with patients and families and to coordinate multiagency care. All these functions are also core to delivering genetic/genomic healthcare and Jenkins et al. (2011) argue that nurses play a key role in bridging the gap between genomic discoveries and their translation into clinical care, stating that:

Nurses have a tremendous responsibility and opportunity to become informed about the potential benefits and challenges of genomics discoveries for clinical care (Jenkins et al. 2011, p1).

In considering the potential for nursing to incorporate genetics/genomics in professional practice, Calzone et al. (2010) contend that "the nursing profession is a pivotal provider of quality health care services and is essential to closing the gap between research discoveries that are efficacious to health care and their successful adoption to optimise health" (p26). Nurses and midwives are well placed to embrace advances in genetics/genomics, in terms of their core skills and roles, and through the scale of the workforce. They can accept the changes brought to healthcare by genomics

as passive agents or they can be proactive in shaping and informing the transformation in their areas of practice.

Viewpoint: Midwives must be at the forefront of developments

Midwives have an opportunity to embrace and embed genetics/genomics into practice; as lead care-givers for a large proportion of pregnant women they must be competent in genetics/genomics if they are to meet the needs of patients within the context of current work streams and also in view of advancing technologies.

The booking interview is a vital aspect of risk assessment and care planning and is a missed opportunity if midwives are not competent in obtaining a family history. Information disclosed at this consultation could potentially be dismissed as irrelevant if the midwife is not genetics/genomics aware. This not only has implications for midwifery care but can have a lifelong impact for the woman and her family.

Antenatal and newborn screening is an integral part of midwifery care in the UK. Many of the current screening programmes have a genetic component. National data for 2007/08 show that 359 babies were identified with screen positive results for a clinically significant haemoglobinopathy disorder and affected infants were identified in every Strategic Health Authority (SHA) in England. Screening for cystic fibrosis and medium-chain acyl-CoA dehydrogenase deficiency (MCADD) are the newest addition to newborn bloodspot screening and means all midwives need to understand and have the ability to discuss inheritance patterns with parents.

The possibility of additional and increased testing occurring prior to and during pregnancy, the postnatal and neonatal period means that midwives need to keep abreast of technological advances, in particular the use of Non Invasive Prenatal Diagnosis (NIPD) for Down syndrome. Although NIPD requires further testing before it can be approved for implementation in the NHS, it seems feasible that at some point in the future, pregnant women could be offered a blood test that can diagnose certain genetic disorders without the need for invasive testing.

Midwives need to be at the forefront of these developments if they are to provide midwifery care that is not only appropriate and relevant in the here and now but care that meet the individual needs of patients in the future.

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Key drivers

The scope of the science

It is 10 years since the first draft of the human genome was published (International Human Genome Sequencing Consortium 2001), bringing unprecedented opportunities for understanding health and disease, developing new therapies and changes in medical practice (Green et al. 2011). Green et al. (2011) comment that the current era is characterised by the growth in understanding of the biology of disease, which in turn becomes the basis for improving health, as exemplified by Crohn's disease, type 2 diabetes and age-related macular degeneration. However, they also caution that although genomics has already begun to improve diagnosis and management for some conditions, 'profound improvements in the effectiveness of healthcare cannot realistically be expected for many years' (Green et al. 2011, p 204). Even so, technology developments, which they describe as being both revolutionary and evolutionary, will continue to drive genomics advances. They present five imperatives that will be able to capitalise on these and other opportunities afforded by the growth in understanding into disease biology over the coming decade:

1. Making genomics-based diagnostics routine.
2. Defining the genetic components of disease – from the rare Mendelian to common complex disorders such that the genetic variation underlying the full spectrum of diseases is determined.
3. Comprehensive characterisation of cancer genomes – leading to more robust diagnostic and therapeutic strategies.
4. Practical systems for clinical genomic informatics to provide readily accessible information that can be reviewed as knowledge evolves.
5. The role of the human microbiome in health and disease – to investigate how the microbiome may be manipulated as a new therapeutic approach.

Although their paper sets out an ambitious vision for the next decade, the potential advances are based on current achievements and direction and it is important not to lose sight of the fact that genomic healthcare is 'already happening'. The House of Lords Science and Technology Committee (2009) conducted a comprehensive inquiry into genomic medicine and outlined some of the key achievements in this field:

- Predictive diagnosis and single gene conditions, with genetic tests for over 1000 diseases currently available for clinical testing.
- Diagnosis of genetic subtypes of common diseases such as diabetes, Alzheimer's disease, Parkinson's disease and several types of cancer.
- Use of genetic/genomic tests to inform disease management, e.g. through tumour profiling to identify breast cancer patients who are more likely to respond to trastuzumab (Herceptin).
- Predicting individual responsiveness and side effects to certain drugs, e.g. responsiveness to warfarin, or to identify potential hypersensitivity reaction to abacavir for HIV treatment.
- Further potential to improve and rationalise management of a broad range of diseases.
- Advancing strategies for disease prevention and public health.

The Committee also noted the increase in number of private companies offering individual genetic tests or entire genomic profiles for sale directly to consumers (DTC tests). Typically, these are available through the Internet. It recommended establishing a voluntary code of practice that should include provision of information about laboratory accreditation and the evidence base for the utility of tests offered.

Pace of discovery

The 'hype' surrounding early discoveries led to some disappointment when clinical translation was not immediately realised. There remains uncertainty over the scale and pace of discovery but the accelerating pace is acknowledged by authors such as Green et al. (2011) and in the review of the Genetics White Paper (Department of Health 2008). The Royal Society (cited in DH 2008, p27) captures this succinctly:

“Increased knowledge of genetics and genomics in the long term will impact substantially on the way in which we understand and treat disease; the impact on healthcare is just beginning and will not be dramatic over a short timescale. Instead, new diagnostic treatments and new disease classifications will emerge with increasing frequency but will not change the basics of clinical care overnight.”

Implications for healthcare

Nonetheless there has been a significant impact on healthcare already, particularly in relation to increases in referral rates to specialist genetics services from primary care and other 'mainstream' services, and in care delivery in other specialisms such as cancer services and initiatives such as expanded newborn screening, and cascade testing for familial hypercholesterolaemia in Wales. Other examples are presented in this report.

It was already clear in 2001 that the NHS was unable to keep pace with this increase in activity, and that the gap between demand and delivery would grow without targeted intervention, resulting in substantial investment by the UK government (DH 2008). The implications for healthcare are indicated in that investment strategy: the need to strengthen specialist genetics services, the need to build genetics/genomics into mainstream services and the need to ensure that the healthcare workforce is knowledgeable and competent to deliver care that incorporates genetics/genomics. Understanding the science of genomics presents a particular challenge for nursing and midwifery as science teaching is regarded as 'the singularly most problematic area of the curriculum' (White and Ousey 2010).

What is known

- Scientific advances are rapid and the importance of genetics and genomics will grow steadily as research progresses.
- Advances in genomics have relevance across healthcare services and not just to specialist genetics services.
- Services have limited capacity in their ability to respond to scientific advances in a timely manner
- Increasing availability and range of tests.
- Capacity to diagnose via genetic testing currently is outstripping our ability to interpret and treat.
- Increase in clinical indication for testing.
- Typically patients present through mainstream services and are fully assessed in specialist genetics services.
- Increasing capability to identify population sub-groups who are at increased risk where there is opportunity for primary and secondary prevention.
- Targeted therapies are already being applied, with potential for more.
- Increase in demand for and expectations of, testing and genetic health services.
- Private sector and DTC providers for genetic testing are on the increase.

- The full potential of genomics is unclear.

What needs to happen

- Healthcare commissioners, providers and practitioners need to understand the relevance of genomic science to *current* healthcare practice and to recognise its future potential in delivering more effective healthcare.
- Researchers in genomic healthcare need to ensure that the clinical relevance of new discoveries is explicit and realistic.

Patient expectations and concerns

The influence of the expectations of patients and families in shaping healthcare that incorporate genetics/genomics may be considered from two perspectives. First, there are the raised expectations or concerns associated with new genomic discoveries. The announcements of these in the media, which happen on a regular basis, may lead an individual to question if they or their family may be at risk of a condition they had not previously thought of as being inherited. News of genomic discoveries may be surrounded by 'hype' in the popular media and lead to unrealistic expectations for potential treatments or even cures across the spectrum of disease, from single gene or chromosomal to multifactorial conditions. Responding to individuals' and families' concerns about this typically falls to primary care in the first instance and puts pressure on health professionals to keep abreast of developments and to interpret and communicate new findings (Cooley 2008). How uptake of direct to consumer testing in the UK may impact on this is uncertain at present.

Secondly there are the patients and families already affected by or at risk of an inherited condition whose expectations are modest. There have been several UK studies that have aimed to capture what it is such families want from health services. These highlight common experiences and deficits in care alongside relatively simple needs and a low level of expectations. Three such studies will be outlined briefly to illustrate the issues raised.

Burke et al. (2007) explored the experiences and preferences of people with or at risk of genetic conditions and parents of children affected by a genetic condition (n=27) with regard to receiving genetic information from health professionals outside the genetics specialty. They outlined three common issues from their interviews:

1. *Greater awareness*

Most believed that there is a need for greater awareness of the genetic aspects of conditions amongst healthcare professionals, who should be more willing to consider the possibility of a genetic condition, take the concerns of patients and families seriously and refer patients appropriately.

2. *Communicating information*

Most wanted healthcare professionals to provide genetic information without judgement and with sensitivity, being mindful of the potential emotional impact on individuals and wider family. They also wanted professionals to tailor the information to individual preferences and to direct people to further information.

3. *Professional role*

Most saw the GP's role as referring patients appropriately and providing ongoing support and co-ordination. They felt consultants in different medical specialties could play a greater role in providing genetic information. More support from healthcare professionals in gaining access to appropriate genetic information would be welcomed.

The Genetic Interest Group (GIG; now Genetic Alliance UK) also considered patient needs as part of their Family Route Map project (GIG 2008). Their key findings supported those highlighted by Burke et al (2007), echoing the importance of communication of accurate and up to date information by knowledgeable health professionals. The report made a number of recommendations in response to the issues identified, including that:

- Up to date training and education in genetics for all healthcare professionals should be a requirement for their continuing professional development.
- Better communication between patients and professionals and between professionals involved in their care would support patients in make informed decisions.
- Clearer guidelines for treatment and surveillance of rare genetic conditions are required.
- Coordinated care within a multidisciplinary team approach would help counter fragmentation across organisational boundaries.
- Practice nurses could be a resource for reliable sources of information for patients and families and provide continuity of care with much needed psychological support.

In developing its strategic vision, Rare Disease UK undertook a wide range of activities with a broad range of stakeholders. They included focus groups, a survey of patients' and families' experiences (n=600), a series of working groups and a consultation exercise, to articulate the current situation for people with rare disease. In its report, Rare Disease UK emphasised that although individually rare, collectively such conditions are numerous with over 6000 being identified; 1 in 17 people in the UK are affected by a rare disease at some point in their lives and 80% have a genetic origin. These include for example, muscular dystrophy, Huntington's disease, Tay-Sachs, Marfan syndrome and cystic fibrosis. However, there is a lack of awareness of rare conditions amongst healthcare professionals that often results in a delayed diagnosis or misdiagnosis. Patients' needs are often not met even after diagnosis and their experiences highlight common issues. Again, these centre on the provision and communication of reliable and accurate information, coordination of multi-professional and multi-agency care and ongoing holistic support. The recommendations set out in its report (Rare Disease UK 2011) include:

1. Patients should be provided with ongoing, reliable information on their condition, management and treatment options, and accessing the support they need.
2. Information should be made available in various formats and at various levels of scientific and medical knowledge.
3. Psychological support for the whole family should be considered an integral part of the care package.
4. Social support for those affected by rare diseases should be a fundamental part of the patient's care package.

Rare Disease UK calls for the development of a UK wide strategy for rare diseases, developed in partnership with key stakeholder groups, including patients and voluntary organisations.

What is known

- Needs of patients and families affected by genetics/genomics are not being met.
- Patient groups are consistent in articulating what they need for 'genetic healthcare'.
- Ongoing media interest in genomic discoveries will continue to raise awareness (and expectations) about the relationship of genetics/genomics to health and ill-health.

What needs to happen

- Greater emphasis is required by policymakers to ensure patients' and families' experiences are at the forefront of developing care models relating to genetic conditions.
- Nursing and midwifery education providers need to ensure that their training courses place sufficient emphasis on the impact of genomic healthcare on the individual and family, through an understanding of their experiences.
- Education provision for nurses and midwives needs also to equip them with the necessary knowledge and skills to manage patient/family expectations in relation to genomic healthcare.
- Nurses and midwives must play their part in educating and empowering patients, families and voluntary organisations to be able to understand, influence and contribute to care and service developments that meet genomic healthcare needs and the policies underpinning these. One approach to this is through establishing clear lines of communication to nursing and midwifery 'power houses'.

Viewpoint: A view from the British Heart Foundation

There are estimated to be around 340,000 people in the UK with Inherited Cardiovascular Conditions (ICCs) – cardiac diseases that are caused by a single gene defect.¹ These include arrhythmia syndromes, cardiomyopathies, arteriopathies, muscular dystrophies and disorders of lipid metabolism. ICCs are a cause of sudden and unexpected cardiac death.

Recent advances in genetics have paved the way for genetic testing in affected families to identify family members who are carrying a gene defect. Access to genetic testing is needed to identify people at risk so they can be supported to modify their lifestyle or receive appropriate medical management to prevent or modify disease progression, and to facilitate access to genetic counselling. Genetic testing also reassures family members who do not carry a mutation and do not require long-term medical follow up. High quality education for the multidisciplinary ICC team is crucial to deliver these specialised services.

Over the last few years, the BHF has increased its investment in the provision of services for people with ICCs. Since 2006 we have invested in Arrhythmia nurses, Familial Hypercholesterolaemia nurses, a Genetic Information service² for affected families, and the provision of patient information. An ongoing evaluation of our recently funded nine Cardiac Genetics nurses is showing that they improve the quality of the patient experience, empower patients through education and advocacy, and enhance existing services. We have also invested substantial sums in research into ICCs.

The BHF will continue to innovate in response to fast-moving developments in genetics and genomics to help ensure access to appropriate education and support for healthcare professionals, and high quality testing and care for all affected families.

British Heart Foundation

¹ www.phgfoundation.org/reports/4986/

² For more information, please visit: www.bhf.org.uk/heart-health/how-we-help/support/genetic-information-service.aspx

Professional context

Paradoxically, the scientific and technological advances that characterise genomics and its application to healthcare brings to the fore the importance and centrality of the nursing and midwifery roles in 'caring for' patients and families throughout their healthcare journey. To do so effectively within the current context of healthcare requires a professional workforce that is open to change.

Good quality nursing has been described as meaning 'a good experience for patients' and the National Nursing Research Unit (NNRU 2008) has identified six core elements to this:

1. A holistic and patient-centred approach to continuous care.
2. Efficiency and effectiveness combined with humanity and compassion.
3. Professional, high quality evidence-based practice.
4. Safe, effective and prompt nursing interventions.
5. Patient empowerment, support and advocacy.
6. Seamless care through effective multidisciplinary teamwork.

The NNRU (2008) also considers how the role of the nurse is changing in response to changes in nurse-patient relationships and the environments for education and practice. Some of the influences on changing roles it identifies include:

- New roles and autonomy for community nurses.
- Greater focus on health and prevention of ill health.
- Independent nurse prescribing.
- Increased nurse specialist, consultant and practitioner roles.
- Increased interdisciplinary teamwork and multiprofessional care.

All of the elements for quality care could be interpreted 'through the genomics lens' and the influences for change are particularly pertinent to nurses and midwives as they incorporate genomic healthcare into practice.

Nurses have played an important role in delivering specialist genetics services for many decades. To do so effectively they and their specialist medical colleagues rely on health professionals in 'mainstream' healthcare (i.e. outside specialist genetics services) to make timely and appropriate referrals, and to provide ongoing support and continuing care to patients and families accessing the specialist service. However as will be outlined later, many nurses and midwives lack confidence and competence in genetics/genomics and the surveys of patient experience noted above appear to support this. Thus there are already deficits in care and there will be limited capacity to develop new roles and incorporate new knowledge and skills as genomics impacts on other specialisms, including primary care and public health, without a concerted effort to address deficits in competence.

Even so, there are examples of where nurses and midwives are demonstrating leadership, working within multidisciplinary teams to develop new or enhancing existing services that incorporate genomic healthcare, for example in offering family history clinics in primary care, the development of cancer, cardiac and renal genetics services, and the development of a new referral pathway for haemochromatosis. Many of the roles require the nurse or midwife to work across organisational boundaries – even across different hospitals. The fact that genetics/genomics crosses all boundaries (i.e. geographical, life stage, diseases, services and specialisms) brings an additional and significant challenge at service level. Some of these initiatives have been evaluated (Martin et al. 2009) and the challenges identified will be noted later.

It remains to be seen how the Department of Health White Paper (DH 2010) might impact on healthcare and services in England as it pertains to the development of genomic healthcare. Its intention to involve patients in decision-making, provide greater access to information and to strengthen the collective voice of patients and public (*Putting patients and public first*) would be a positive development, particularly for those with (rarer) genetic conditions. It also announces that the new system will focus on personalised care and encourage strong, joint arrangements and local partnerships. These are core themes in developing genomic healthcare but we would urge caution whilst there is limited awareness of the relevance of genetics/genomics to inform commissioners and providers of local needs at local level. There is also limited competence in being able to interpret genetic/genomic information at local level to support patients and families in their decision-making. This brings to the forefront the need for appropriate education and training in genetics and genomics.

What is known

- The roles of nurses and midwives are changing in response to changes in nurse-patient relationships and the environments for education and practice.
- The nursing role in specialist genetics services is well established.
- Nurses and midwives are demonstrating leadership in developing new services that incorporate genetics/genomics but this needs to be reinforced at organisational and senior professional levels.
- Nurses and midwives have limited confidence and competence in genetics/genomics.
- Clinical outcomes for practice that incorporates genetics/genomics are not established.

What needs to happen

- Nurse and midwifery leaders need to be proactive in promoting engagement at all levels across the professions.
- Networks need to be strengthened so that others may learn from new initiatives in nursing or midwifery care that incorporate genetics/genomics.
- There needs to be a clear articulation of the networks of influence in order to bring about change in professional practice.
- Concerted efforts are needed to promote clinical competence in genetics/genomics.
- Need to promote research to develop the evidence base for interventions that utilise knowledge and skills in genetics/genomics, to promote continuous improvement in care and service delivery, and to inform commissioning of services.

Viewpoint: Specialist nurses working to improve care in diabetes

The Genetic Diabetes Nurse (GDN) project (formally known as the MODY link nurse project) was established in 2002 with initial funding from the Department of Health and was highlighted in the Genetics White Paper (DH, 2003) as a means of building genetics into mainstream services. The GDN project may be considered a potential model for the translation of genetic information into clinical care.

This project was developed to increase knowledge and awareness of monogenic diabetes amongst healthcare professionals across the UK and provide support to families undergoing genetic testing. This was designed to meet an identified need as 90% of patients with monogenic diabetes are initially misdiagnosed as having Type 1 or Type 2 diabetes and started on inappropriate treatment.

The project provides ongoing training for experienced Diabetes Specialist Nurses (DSNs) about monogenic diabetes, genetics and genetic counselling. They continue to work as DSNs but are seconded to the GDN project for 3.5hrs per week. This enables them to raise awareness of the condition through presentations to healthcare professionals within their region, aid recognition of individuals likely to be affected, ensure appropriate referral for genetic testing and establish family follow up when a positive molecular genetic diagnosis is confirmed. They also liaise with local diabetes teams and other healthcare providers and support patients transferring from long term insulin injections to sulphonylurea tablets where appropriate. The GDNs also collaborate with local clinical genetics services in cases where families request predictive genetic testing in those under 18 years of age.

This project has increased appropriate referrals for genetic testing and improved rates of family follow up. GDNs have given presentations on monogenic diabetes to over 5000 healthcare professionals and 36 GDNs have been seconded to the project since its inception. Training diabetes specialist nurses has proved an effective means of increasing awareness of monogenic diabetes and providing support for families. This is an efficient, cost effective use of resources and has aided the recognition of cases which were not previously considered to have a genetic cause, thereby improving the care of families with monogenic diabetes.

Dr Maggie Shepherd
Specialist in diabetes nursing & genetics

Education and training

Genetics education for nurses and midwives in the UK has varied widely between university providers, often with a lack of consensus on what should be taught, although with a tendency to focus on the bioscience component (Kirk & Tonkin 2006; Metcalfe & Burton 2003). Generally, there is often a limited recognition by education providers and clinical practitioners of how genetics/genomics is influencing medicine and consequently the healthcare in which they are involved in delivering. For education, this means that provision is inconsistent and often dependent on local interest and there may be no firm foundation of knowledge and understanding provided at pre-registration level on which post-registration development can be built.

Genetics often appears quite remote to many nurses and midwives, viewed as a specialist area only within the realms of medicine (Metcalf et al. 2010). Recent surveys of nurses' and midwives' views about the role and importance of genetics used everyday scenarios that the nurses or midwives were likely to encounter in practice and then explored the genetics related activities that might be involved in those scenarios (Metcalf 2010; 2009; 2008; 2007). The overwhelming majority of respondents recognised these areas of activity as important to their practice but they reported limited competency to deliver the genetics related care.

Too often, many families are receiving limited care from nurses and midwives who are not sufficiently conversant with genetics to understand the needs of the individual affected and the psychological welfare of other family members (Metcalf et al. 2011; Plumridge et al. 2011a; b). From antenatal care through to end of life, there is a need for nurses and midwives to be knowledgeable about genetics. This knowledge should not be focusing around genetic testing but in understanding the implications of an inherited condition and what that means for the individual affected and their family members. In the questionnaire survey of midwives (Metcalf et al. 2007), many were initially sceptical about their need to know about genetics, until they were asked about how they dealt with 'everyday activities' where they had not realised genetics played an important role. Similarly, in hospice settings, many nurses reported they had not comprehended the effects of a genetic diagnosis on families (Metcalf et al. 2010, 2009, 2008), despite the increased likelihood of early death and multiple deaths within a family (Lillie et al. 2011), which are important factors in causing complex grief reactions (Metcalf & Clifford 2011, in press).

The NHS National Genetics Education Development Centre (the Centre) was established in 2004 to support educators and practitioners as they look to integrate genomic healthcare into professional practice. The Centre takes a strategic approach to raise awareness, establish and maintain networks, identify teaching and learning needs and provide practical support in developing resources, of which the *Telling Stories* website forms a part (www.tellingstories.nhs.uk). The competence based genetics education framework for nurses and midwives (Kirk et al. 2003) has recently been revised to provide two separate frameworks. The nursing framework now sets out detailed learning outcomes against 8 competence statements for genetics and genomics to provide guidelines for undergraduate training (Kirk et al. 2011). These learning outcomes are based on those developed by Skirton et al. (2006), showing progression through educational levels 4-6 and which were used to inform the development of an e-learning resource for nurses and midwives (GeneSense) that takes a lifestage approach as a framework to present its content (Gresty et al. 2007).

A similar document to the revised nursing framework is being prepared by the Centre for midwifery. In addition, the National Screening Committee has mapped education and training resources to the NMC midwifery pre-registration standards (see <http://cpd.screening.nhs.uk/competency-tool>).

Despite these and other commendable developments, there has been only limited traction with the nursing and midwifery communities in recognising the importance of genetics/genomics to clinical practice. In its evidence to the House of Lords Science and Technology Committee, the Centre cautioned that the challenge to prepare the nursing/midwifery workforce in genomic healthcare was substantial and would require sustained effort, with still some way to go in changing attitudes. Even the Nursing and Midwifery Council (NMC) does not appear to have recognised the impact of genomics on healthcare, from changing disease taxonomy and diagnosis, the personalisation of treatments or the impact of risk communication in families for even the most common of diseases. In its new Standards for pre-registration nursing education (NMC 2010) it makes a single limited reference to genetics (and none at all to genomics), and this is in relation to nursing assessment:

All nurses must carry out comprehensive, systematic nursing assessments that take account of relevant physical, social, cultural, psychological, spiritual, genetic and environmental factors, in partnership with service users and others through interaction, observation and measurement.

A similar pattern is seen in the standards for pre registration midwifery education (NMC 2009). Whilst some of the NMC midwifery standards have an implicit genetic component, there is no explicit reference to genetics or genomics. Although there is an expectation that a student midwife should be confident in sharing information about common antenatal screening tests, there is no reference to the underlying genetics of the conditions for which screening is being carried out.

Without further clarification on what 'genetic' means in the context of a nursing assessment, the standards are open to variation in interpretation and other important elements of genomic healthcare (as set out in the Centre's revised competence framework) may be overlooked. In its report on Genomic Medicine, the House of Lords Science and Technology Committee (2009) urges the NMC to set detailed standards for genetics/genomics across the curriculum at pre- and post-registration levels. In this regard, it may be that the approach adopted by the medical Royal Colleges could provide a useful model for consideration.

Education about genetics/genomics is essential from the undergraduate to the post-registered nurse or midwife. Educating the educators is a priority with cascaded teaching to the clinical groups. There is a tremendous opportunity with the move to an all-graduate profession in England when many nurses with diplomas will want to study for degree level qualifications. Including genetics/genomics as a core requirement of that educational process to develop nurses to this graduate standard might be an excellent opportunity to begin the evolutionary process of recognising the NMC's Standard (2010) to ensure nurses carry out a holistic assessment including the 'genetic' component of health. However, efforts are needed across the other nations of the UK where graduate entry is already established to ensure that qualified nurses and midwives also receive the necessary education and training in genomic healthcare.

The White Paper on the NHS reforms (DH 2010) also proposes significant changes to education commissioning in England (DH 2010b). The implications of these will be discussed later.

What is known

- Education provision is inconsistent and often dependent on local interest.
- Education providers may have limited awareness of the relevance of genomic healthcare, and may lack confidence in teaching about it.
- Generally, pre-registration education does not provide a sound foundation of knowledge and understanding in genetics/genomics on which to build at post-registration levels.
- Nurses and midwives lack competence and confidence in genetics/genomics.
- Limited competence amongst qualified staff restricts the role models available to students.
- Currently there is very limited capacity to develop new roles and incorporate new knowledge and skills as there is no sound foundation of genetics/genomics knowledge on which to build at post-registration levels.
- NMC standards for pre-registration nurses and midwives make limited reference to genetics and none at all to genomics and do not indicate how genetics/genomics should form part of competent practice.
- The model of curriculum and standards setting by the medical Royal Colleges has no equivalent in nursing and midwifery and consequently the response of education providers

to NMC standards that incorporate genetics is variable, with a risk that genomics is overlooked.

- There are nationally coordinated efforts to support education and educators through the provision of guidelines, resources and other activities but the limitations of these have been acknowledged.
- As well as a growing collection of 'reusable' learning resources to support genetic/genomic education for nurses, midwives and other health professionals, different groups want resources tailored to their particular specialism, such as haemophilia nurses (Burke et al. 2011) and hospice nurses (Metcalfe et al. 2010).

What needs to happen

- Greater recognition is required of how genetics/genomics may affect individuals and families at different stages of their lives, so that clinicians provide better care and educators fully prepare their students.
- Need strategic and coordinated effort, with policy makers and education providers working together to develop competence in nurses and midwives at all levels of practice through education and training.
- Education curricula should be informed by local needs but follow nationally agreed standards for genetics/genomics.
- Local skills networks, health education commissioners and education providers need to recognise the potential of genomics in delivering more effective healthcare and optimise its uptake.
- Clinical relevance must be explicit and realistic in the development of education resources, and tailored to the requirements of individual groups as appropriate.
- Need to identify and use champions across all sectors.
- There should be a strong steer in England to incorporate genetics/genomics into post-registration graduate training for nurses with diplomas seeking graduate status.

Viewpoint: US efforts to embed genetics/genomics into nursing curricula and the importance of engagement of regulators

In the United States (U.S.), essential genetic/genomic nursing competencies, curricular guidelines and outcome indicators have been created, endorsed, and now provide the foundation for education of all nurses.¹ This competency document was used as the basis for the integration of genetics and genomics into the revision to the American Association Colleges of Nursing (AACN) Essentials of Baccalaureate Education for Professional Nursing Practice.² The AACN Essentials form the basis for the *Commission on Collegiate Nursing Education nursing program accreditation standards*. As such, in 2010 accreditation reviews included an assessment that assures genetics/genomics has been included in the Baccalaureate curriculum.

We conducted a survey to assess the impact of this regulatory development, using a stages of change framework to assess the intention of nursing faculty intention to integrate genetic and genomic curriculum content into entry level nursing education. Seventy one percent (n=161) rated their own personal genetics/genomics knowledge as low or very low. However, despite self reports of low levels of personal genetics/genomics knowledge, 83% agreed that preparing nurses to use genetic/genomic information was an important role for nurse educators and 85% of respondents agreed or strongly agreed that now was the time to start teaching genetics and genomics. The majority of faculty were found to be in the *contemplation stage* with 35% planning to adopt curriculum changes within the next 6 months. Four percent had plans to make changes within the next 30 days so were in the *preparation stage*. Some faculty were already in the *action stage* with 9% already reporting curriculum changes that included genetics/genomics for less than six months and 10% in *maintenance stage* with curriculum changes that included genetics/genomics for greater than six months.

This single regulatory action thus stimulated appreciation of the value of genetics/genomics for nursing education. In addition, more than half of respondents were in some phase of action all aimed at meeting CCNE accreditation requirements. In light of this success, the U.S. Genetic/Genomic Nursing Competency Initiative has continued to focus efforts towards the regulatory environment where the impact can be immediate and the outcome readily measured.

Kathleen Calzone

Co-director, US Genetic/Genomic Nursing Competency Initiative

¹Consensus Panel on Genetic/Genomic Nursing Competencies. *Essentials of genetic and genomic nursing: Competencies and curricula guidelines and outcome indicators*. 2nd ed. Silver Spring, MD: American Nurses Association; 2009.

²American Association of Colleges of Nursing (AACN). *Essentials of baccalaureate nursing education for professional nursing practice*. Washington DC, 2008.

Ethical considerations

The nature of genetic information and its relevance to members of a family other than the individual who might be seeking or given that information, its potential psychosocial impact and its potential for misuse, has long required consideration of surrounding ethical issues in healthcare practice. The generation and application of genomics discoveries and new technologies to healthcare also present ethical challenges. These may be outlined as follows:

- Issues around genetic testing
 - Confidentiality, privacy and disclosure of information for the benefit of other family members.
 - Limitations of testing, such as where confirmation of a gene mutation does not predict with certainty that a condition will develop, or predict its severity or age of onset.
 - Inappropriate applications of testing, such as gender selection for 'family balancing' purposes.
- The potential for discrimination
 - On the basis of genetic predisposition to illness.
- Setting the boundaries for the application of genetic technologies
 - That recognises and respects the beliefs and values of people involved in decision-making.
 - In relation to human enhancement and reproductive cloning.
- Wider societal issues, including
 - Equity of access to genetics services and genomic healthcare.
 - The safety of gene therapy.
 - The utility of DTC tests.
 - The use and storage of DNA on forensic and other databases.

There are clear implications for nurses and midwives in ensuring that their practice is 'ethically competent' and in promoting public confidence in genomic healthcare. This requires knowledge and awareness of genomic science and the potential ethical issues surrounding the use and misuse of genetic information and technologies. They also need to be skilled in supporting informed decision-making, not just in relation to healthcare but also in relation to participation in research. However, competence related to the utility and limitations of genetic testing and its associated ethical issues is least well achieved through education provision (Kirk and Tonkin 2006) and is viewed with least confidence and importance by practitioners (Kirk et al. 2007). The need for more education in healthcare ethics has been highlighted as particularly important (DH 2008).

What is known

- Ethical issues related to genetic services remain significant.
- Genomic healthcare and the application of genomic technologies lead to further, and more complex, ethical challenges.
- Confidence and competence in healthcare ethics related to genetics/genomics is low.

What needs to happen

- The profile of ethics in genomic healthcare needs to be raised in nursing and midwifery education at pre- and post-registration levels.
- Nurses and midwives must be supported in developing skills in supporting informed decision-making specifically as it applies to genomic healthcare.

Issues in integrating genomic healthcare into nursing and midwifery education and practice

Many of the challenges and issues to establishing and expanding a midwifery and nursing workforce competent and confident in delivering genomic healthcare have been indicated in the preceding sections. They will be summarised here in a framework that considers genomic healthcare itself and

its 'presentation'; the individual healthcare professional; the context and setting for education and practice that incorporates genomic healthcare.

Genomic healthcare itself

- The Public Health Genetics Foundation (PHG 2010) captures several broad barriers:
 - Complexity of the science.
 - Lack of clarity about what can be achieved in relation to genomic healthcare.
 - Its limited success in delivering effective clinical interventions.
 - Uncertain timeframe in relation to this (but technological advances are accelerating).
 - Variation in capacity and capability for effective translation of genomic science into clinical practice.
- Paucity of the evidence base for specific outcomes associated with genetically/genomically competent nursing practice (Calzone 2010).
- Effective dissemination of new interventions and services to raise awareness of 'what is possible and relevant'.
- Several studies and commentaries have highlighted the importance of accessible information about genomics advances and their relevance to healthcare, and the need to ensure that the ethical and psychosocial aspects are captured alongside the biological. More education in healthcare ethics is felt to be particularly important (DH 2008).

The individual healthcare professional

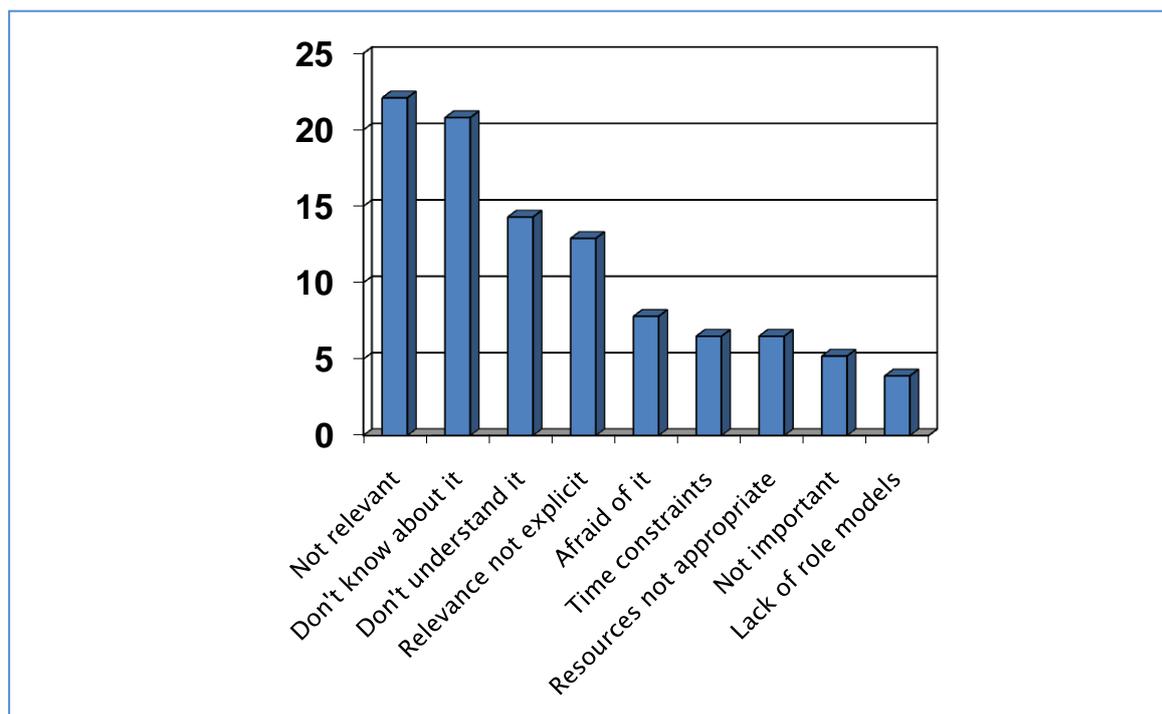
- Numerous studies highlight the lack of confidence and competence of UK nurses and midwives in relation to genetics and genomics, its perceived lack of importance to some and its relevance to clinical practice (e.g. Kirk et al. 2007; Metcalfe et al. 2008, 2009, 2010).
- Lack of experienced nurses who are interested in developing their skills in 'clinical genetics' (Sleightholme et al. 2009).

The context and setting for genomic healthcare

- In education, several barriers have been consistently highlighted, including competing priorities within curricula, engagement of educators in genetics/genomics, training for educators and access to relevant resources:
"There is a great variation in the achievement across pre-registration courses partly due to time issues and variations in perceived benefits and needs." CD69 (Kirk & Tonkin 2006, p22).
- The limited response of the NMC to genomic healthcare:
"My colleagues and myself believe that as long as the NMC does not give clear direction as to what should be included in Nursing and Midwifery programmes in relation to genetics, progress will be very slow." CD60 (Kirk & Tonkin 2006, p22).
- In practice, PHG (2010) note the failure to use existing knowledge and expertise effectively to improve the health of families who might benefit.
- Challenges of cross-speciality working (e.g. Martin et al. 2009; Sleightholme et al. 2009).
- Attitudes of senior nurses and midwives have a significant impact in encouraging and supporting staff to engage in genetics/genomics (Kirk et al. 2007; Metcalfe et al. 2008).
- Martin et al. (2009), evaluating the 'mainstreaming pilots' funded by DH, note tensions between different commissioning arrangements, including those related to knowledge around genetics, and service structures that rendered genetics a peripheral concern. They highlight the need for 'considerably more support from policy-makers and local managers alike'.

A survey amongst international genetics nurses (n=77) indicated that the issues in relation to integration of genetics/genomics into nursing practice are common across several countries (Kirk et al. 2008). Barriers were identified across all three of the categories outlined above, with awareness of, and attitude towards genetics/genomics being most often cited. These are shown ranked in order of percentage of votes cast (Figure 2). Whilst it is disappointing that these issues are so widespread, the collective voice of nurses and midwives in this field can be powerful and international collaborative efforts to raise awareness about genomic healthcare are valuable.

Figure 2 Barriers to the integration of genomics into nursing practice.



Viewpoint: Genetics Mainstreaming and Liaison Initiative

In 2005 Consultant Geneticist Dr Ian Ellis at the Cheshire and Merseyside Clinical Genetic Service, part of the Liverpool Women's NHS Foundation Trust, secured funding for a 2-year pilot project which involved a liaison genetic counsellor providing education and support to practitioners in three settings (fetal medicine in a DGH, a Cardiology Service and a Haematology service). The project incorporated back fill funding to encourage nursing leaders to release staff for training. The project evaluation led to the continued funding of the role, together with an ongoing session of Consultant time and clerical support. The remit is to liaise with other specialties and to develop different approaches to collaborative working for the benefit of patients.

The current post has been split between two Genetic Counsellors, with one day allocated to cardiology and the remaining four days allocated to a variety of specialties.

The objectives of the Mainstreaming and liaison post are:

- Improve Networking and Liaison
- Development of Pathways and Protocols
- Development of Educational Packages
- Benchmarking/ Evaluation

The other specialties include haemoglobinopathies (Cheshire and Merseyside are low prevalence areas), haematology and cancer families in primary care. Midwives and nurses were very keen to develop their skills for the benefit of their patients, but the continuation of liaison funding did not incorporate the back fill monies of the original project and nursing leaders are reluctant to release staff. As a result there has been minimal involvement of the role with familial hypercholesterolaemia, renal medicine, fetal medicine, reproductive medicine and the early pregnancy unit.

Our experiences so far have shown how genetics/genomics is relevant across all of the specialties with whom we currently liaise. To enable the contribution from nurses, midwives, health visitors, and Nurse Specialists to make a real difference to the experiences of patients, they need to be able to access up to date training on new genetic tests and technologies (perhaps through Regional Centres/laboratories). Effective and efficient communication and cooperation is vital between the different branches of our profession to ensure the best possible outcome. After evaluation, the concept of the Liaison Genetic Counsellor has evolved, and due to financial pressures expectations have had to be readjusted. However, our initiative has shown that with appropriate resources and the commitment of staff, positive outcomes can be achieved.

Gail Mannion
Lead Genetic Counsellor
Cheshire and Merseyside Clinical Genetics Service

Further considerations

The discussions around the key drivers and associated issues outlined above, and the common issues that were identified as a consequence of these (Appendix 1) and through discussions using the scenarios at different lifestages (Appendix 2) have been wide-ranging. We believe this is indicative of the scale and complexity of the challenge to integrating genomic healthcare into professional education and practice in order to optimise its benefits for individuals, families and wider population. The nature of the challenge is characterised by complexity, blurred boundaries, ethical issues, limited knowledge and understanding, limited engagement at several levels, and uncertainties. When this is placed in the wider context of nursing and midwifery education reform (i.e. graduate entry in England and new NMC standards) and the reforms for health services and professional workforce development in England set out in the White paper (DH2010), there is even further scope for complexity and uncertainty. However, it could provide an opportunity for genomic healthcare to become integrated into new policies and arrangements for education and practice.

Education continues to be core but there remain significant barriers to the issues we have set out, including inequities in provision and lack of awareness in relation to genetics/genomics. The consultation report on workforce development (DH 2010b) sets out a number of principles and proposals which resonate with the issues raised in this report in relation to genomic healthcare. The emphasis on development of skills of the existing NHS workforce is welcomed as is the acknowledgement of the importance of clinical leadership in raising the standards of education and training.

The reforms proposed also seek to be responsive to patient needs and we would agree that healthcare providers should consult with patients and local communities about how the local workforce should be developed. In doing so, they should ensure that the collective voice of those with rare diseases is heard and responded to.

There is a strong focus on locally commissioned education. For genetics/genomics, we would suggest that this needs to be an 'additive' model based on nationally agreed standards and minimum curriculum content. Whilst local demographics may influence the profile of inherited conditions these may fluctuate with family migration. Furthermore, in a field where there is limited awareness of the prevalence of genetic conditions and of the relevance of genomic healthcare across specialisms, there is always a risk of 'commissioning what you know'.

The proposals outline the intention to establish local skills networks which would also include educational expertise. We are concerned that access to expertise in genetics and genomics may not be readily available (or even identified as necessary), especially if skills networks fall outside the immediate local boundaries of a regional genetics centre.

One of the underpinning design principles set out in the document is 'doing at national level only what is best done at national level' (DH 2010b; p18). However, it recognises the importance of national oversight and leadership, particularly in relation to commissioning education and training for specialist skills, assuring a UK-wide approach where this is relevant. We welcome this proposal and would argue firmly that genetics/genomics education needs to fall into this category.

The 'case for' nurses and midwives to engage in genetics/genomics through education, policy, practice and research has been rehearsed for many years. It is time to move on from this and our recommendations for progress are set out in the next section.

Viewpoint: Addressing the expertise gap in genomic healthcare

To date, genetics in health care has been located within NHS funded specialist genetic services. There is a history of multidisciplinary working with all centres employing a mixture of medically qualified staff, scientists, and genetic counsellors, some of whom have nursing backgrounds. However in the main we have seen families with rare inherited disorders and syndromes requiring specialist genetic knowledge and expertise. Despite seeing mainly rare disorders the number of referrals has increased year on year. As outlined in this report, with advances in genomic medicine the impact of genomics across specialities and life stages is increasing. Today we have the need for increasing specialist nursing input into specific disorders, for example inherited cancers and cardiac conditions.

In my experience as a clinical manager the quality of service is increased by having the specialist genetic services working alongside and in partnership with other specialities. What is clear however is that those specialist nurses today need more education and preparation for practice in terms of genetic expertise. Very soon genetic tests will form part of routine management of patients, informing prescribing and treatment decisions, for example in cancer or diabetes. There will also be increased choices for patients in terms of decisions around pregnancy or managing future risk of disease.

Nurses, midwives and health visitors should be in a position as trusted health professionals to help patients and families navigate this new landscape of genomic healthcare. However in order to do that they need better education and preparation for practice. This report in making specific recommendations to be taken forward is a welcome first step in addressing this expertise gap.

Dr Christine Patch

Consultant Genetic Counsellor and Manager, Clinical Genetics, Guy's Hospital

Recommendations

We believe that nurses and midwives should be informing and shaping care and services to incorporate genomic healthcare. Furthermore, all nurses and midwives at all levels of practice must be competent to deliver effective health care that incorporates genetics/genomics. It is imperative that action is taken now if nurses and midwives are to deliver the current and potential benefits of genomic health care for patients, families, communities and public health. In order for this to happen, the following recommendations are made.

Policy

1. Identify the strategic leaders to take responsibility for driving improvements in genetic/genomic education and practice across the professional groups as part of a dynamic and continuing process. This leadership needs to be visible and accountable. Lines of communication must be clearly articulated.
2. Strategic leaders need to develop a UK wide implementation strategy that engages key stakeholders across all sectors and for which they are centrally and locally accountable.

These first two recommendations are pre-requisites for the remaining recommendations.

3. Nursing and Midwifery leaders, including those with expert knowledge in genetics/genomics, need to have an equal voice at strategic and policy making levels.
4. The new commissioning agenda should give specific consideration to genetics/genomics that goes beyond the commissioning of specialist genetics services and should place patients' and families' experiences at the forefront of future developments.
5. New commissioning arrangements for education should give explicit consideration to genetics/genomics across all levels of training. Whilst this must be cognisant of local needs, its perspective must be national.

Education

6. The NMC standards should be expanded to reflect the integration of genetics/genomics across all areas of nursing and midwifery training with monitoring of this an integral part of the quality assurance framework.
7. The NMC, along with education commissioners and providers, should consider the model of the medical Royal Colleges in providing explicit guidance on curricula to incorporate genetics/genomics.
8. Education commissioners and providers should continue to make use of new and existing competence frameworks and resources available via the NHS National Genetics Education and Development Centre and others.
9. Education commissioners and providers should ensure that resources are up to date, accessible, relevant to present day practice, delivered by knowledgeable and confident faculty and tailored to the needs of specific groups.

Research

10. Resources need to be committed to research around the translation of scientific/clinical advances into nursing and midwifery practice that also considers ethical and psychosocial implications and impact for patients and families.

11. Resources need to be committed to research to establish the evidence base for the outcomes of genetically/genomically competent care delivered by nurses and midwives.

Professional development

12. More nurses and midwives need to be supported in their career development into the academic and clinical leads for the future to increase the diffusion of new ideas related to genomic healthcare into clinical practice and education.

Conclusion

There is strong evidence that genetics/genomics is having, and will continue to have, a significant impact on health care and on the lives of patients and families affected by genetics/genomics conditions and/or therapies that utilise genomic technologies. There is also good evidence that patients and families are underserved by health professionals involved in their care who are not competent in genetics/genomics. We need now to move forward from having to justify the relevance of genetics/genomics to 21st century health care to articulating how best it should be incorporated.

Nurses and midwives represent the largest sector of the NHS professional workforce and are best placed to optimise the potential contributions of genomics for improving health. However, to do so successfully requires a change in practice and education and most of all, in mindset. Paradoxically, the size of the workforce also has a bearing on the rate and scale of achievement of change. There remains a significant challenge to engage nurses and midwives at all levels in genetics/genomics so that they are competent to deliver appropriate care today and so that they may remain at the forefront of delivery of clinical advances, alongside other professional groups. To achieve this, the professional workforce must be adequately prepared to deliver safe and effective care that incorporates genetics/genomics. This must be supported by the development of an appropriate evidence base. Although progress is being made, it is likely to be piecemeal and patchy without strong and sustained leadership and support at senior levels in policy, management, education, professional regulation and practice.

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Appendix 1. Common issues spanning the lifestages, professional groups and specialties: Discussion points

Issues	Examples	Potential consequences	Implications for nursing & midwifery
State of the science and clinical advances	<p>Changing status of knowledge.</p> <p>Changing status of management and treatment options.</p> <p>Increasing number and range of tests.</p> <p>Identifying needs that cannot be met.</p>	<p>Dynamic nature and lag between interpretation of new knowledge and discoveries means that the future is unclear.</p> <p>Genetic testing identifies increased risk of conditions with no/limited treatment options, raising anxiety.</p> <p>More difficult, choices.</p> <p>More accurate diagnosis.</p> <p>Better, more targeted treatment, also reducing potential side effects.</p> <p>Better targeted surveillance increases scope for earlier detection and prevention.</p> <p>Genetic profiling may relieve people from unnecessary (and potentially invasive) surveillance.</p>	<p>Opportunity to take proactive role in translating genomic advances into effective health care.</p> <p>Need to keep abreast of developments in own specialist area, including the psychological, social and ethical implications.</p> <p>Nurses and midwives need a secure knowledge and understanding of underpinning basic scientific principles in order to develop competence as new findings emerge.</p>
Family implications of inherited conditions	<p>Communication within families.</p> <p>Implications of testing for other family members and reproductive/lifestyle choices.</p> <p>Family structures themselves are complex.</p>	<p>Benefits of family history taking</p> <p>Focus shifts to the family and not just individual</p> <p>Impact on family dynamics</p>	<p>FH taking integral to assessment – and acted upon.</p> <p>Need to communicate across organisational and geographical boundaries.</p> <p>Role of nurses and midwives as partners in care.</p>
Complex nature of conditions where genetics/genomics	<p>Multiple pathologies, across all body systems and across all life stages.</p> <p><i>The professions must recognise that it is</i></p>	<p>Fragmentation of care.</p> <p>Importance of transition care.</p> <p>Communication between and</p>	<p>Relevant to all areas of professional practice.</p> <p>Coordinating role.</p>

plays a part	<i>not just one condition that a person can have. You can have several at one time unfortunately. [Alan]</i>	coordination across specialties.	Importance of MDT membership. Leadership role.
Accessing and appraising information	<i>We had to research it all on the internet, which sometimes led us to complex research papers...so if nurses and doctors could spend time, even just half an hour, taking us through the basics of what causes the genetic disease and the current state of research that would help.[Parent]</i>	Burgeoning of information sources without critical evaluation of accuracy, swamping patients and professionals alike. Ill-informed patients (and staff) may be reluctant to shift their perspective when given more accurate and reliable information.	Nurses and midwives need to have well developed skills in critical appraisal, alongside IT skills to be able to access and appraise new information sources.
Management of expectations underpinned by understanding of science and technology	<i>Anne explained that Gefitinib will only be of benefit to those people whose tumours are shown in the laboratory to have particular genetic mutations (within the EGFR-TK domain). [Case study]</i>	Media 'hype' around new discoveries will raise expectations about the short and medium term consequences for clinical care. Patients/families may not understand the principles underpinning targeted treatment.	Nurses and midwives need to have sufficient understanding of genetics/genomics to offer clear, basic explanations, and to be able to demystify the science.
Clinical exposure to/ experience of managing rarer conditions	<i>You can go to any GP and most GPs have never heard of the problem and although a lot more people in the medical profession now are becoming aware of it... But I can understand their situation. They are seeing so many thousand patients and yet probably once every four or five years someone walks in with this condition.[Philip]</i>	Individual voices of those with rare conditions are overlooked; needs unmet. Health professionals may not appreciate the common challenges and needs of those with rare conditions. Rarity may be used as an excuse for poor quality care.	Recognise and accept that nurses and midwives cannot be expected to 'know all' but also accept the importance of being proactive in seeking appropriate information and advice.
Need to see 'whole	<i>Although I am being seen by various</i>	Identification of multiple pathologies	Nurses and midwives are trained to

person'	<i>departments for specific areas of my body affected by VHL, it is clear they do not understand what I am going through emotionally as they are not fully aware of my whole condition – just the bit that interests their department. [Rob]</i>	increase as genetic testing/more accurate diagnosis increases. Psychosocial impact on individual and family not fully appreciated.	think holistically and should be proactive in coordinating holistic care.
Education provision	<i>I would like to see more education in nursing schools about different conditions like this. And perhaps more emphasis placed on genetics, because I often feel that perhaps genetics is near the bottom of the level of the learning curve. [Eleanor]</i>	Awareness of relevance of genetics low and not integrated meaningfully in curriculum. Knowledge and skills deficit continues to grow as science advances. Nurses and midwives are not competent to address genetic/genomic needs of patients and families. Limited role models for pre-registration students.	Role of nursing and midwifery regulatory body and education providers to provide clear steer of how competence in genetics/genomics must be achieved and sustained. Role of education commissioners. Role of NGEDC and others in developing clinically relevant education resources. Role of practitioners in addressing deficits in knowledge and skills. Role of practitioners as educators themselves.
Inequities in care	<i>It very, very much depends on where people live. In some areas you can access services very, very easily and especially if you've got a child diagnosed with a terminal illness, people go out of their way to help. [Ruth]</i>	Local needs are not met.	Role in coordinating multiagency care and mobilising resources to meet local needs.
Limited number of specialists	<i>At the moment though the neurologist that I deal with is dealing with 300,000 people in the area and he openly admits</i>	Access to specialists; consultation time available to patients/families.	Skill mix to support specialist role. Service models involving nurse- or midwifery-led clinics.

	<i>he shouldn't be seeing more than 100,000. [Ruth]</i>		
Limited resources for services	<i>But we all realised that cost does come in to all kind of NHS care and it is easy to know what you would like done but someone else has to find money and resources. [Nancy]</i>	Allocation of resources lead to inequities in care ('those who shout loudest') – may be a particular issue for those with rare conditions where full impact not appreciated by professionals.	Nurses and midwives to contribute to policy on allocation of resources that is informed by understanding of the needs to those affected by genetics/genomics. Advocacy role of nurses and midwives.
Limited funding for research and the need to develop the evidence base for nursing & midwifery	<i>Unfortunately very little money has been spent on researching how to treat DS. [Meriel]</i>	Evidence base for effective care limited.	Limited evidence base for impact of care that incorporates genetics/genomics needs to be addressed through funded research programmes.

Appendix 2. Notes on discussion of implications and issues raised by genetics/genomics at different life stages

Real life scenarios were used to prompt discussion about the issues to consider for nursing and midwifery practice, policy and education in relation genetics/genomics. There are several themes/issues common across all lifestages. We also acknowledge the role of the multidisciplinary / multiagency team throughout the scenarios

Lifestage: preconception

“When a genetic condition is known to exist in a family, well informed knowledge of the condition is essential when considering having children. When I was born and my life expectancy was no more than seven years of suffering, there were many occasions when I wished I had never been born. After well informed counselling we were advised to have children if we so wished.”[Richard]

Who's involved	Key implications of genetics	Practice	Policy	Education
Fertility nurses Midwives Family planning nurses Gynae nurses Practice nurses Health visitors Specialist nurses	Changing status of knowledge. Different choices. Familial conditions. Changing treatment and management options. Increasing testing for carrier status to influence pre-conceptual & prenatal choices. Managing expectations underpinned by understanding of science and technology.	Integration into existing practice. Development of local clinical protocols and guidelines. Testing and Diagnosis. Supporting choices. Onward referral in light of identified needs.	No coordinated pre-conceptual care. Commissioning services – policy has not translated into commissioning. Location of services? Whose responsibility? Incorporation into patient pathways.	In the absence of coordinated services, there is very limited opportunity for teaching. Benefit of family history taking in facilitating decision-making and management.

Lifestage: antenatal

“We had to find out all our information from the internet, and that gave us a very, very, very scary view of CF ...I know that CF is fairly rare in the grand scheme of life, I'd never even heard of it before they said my daughter might have it at 22 weeks pregnant, so I know it's unreasonable to expect every doctor and nurse to know lots about it, but it would have made things so much easier if midwives knew more...” [Rachel]

Who's involved	Key implications of genetics	Practice	Policy	Education
Midwives Gynae nurses Practice nurses Health visitors Specialist nurses Specialist midwives, e.g. midwife sonographers	Changing status of knowledge. Communication of risk. Difficult choices. Familial conditions. Changing treatment and management options. Increasing testing for carrier status to influence prenatal choices. Managing expectations underpinned by understanding of science and technology. Management of pregnant women with rare conditions. Accessing and appraising information.	Integration into existing practice. Development of local clinical protocols and guidelines that complement national screening programme. Testing and Diagnosis. Supporting choices – including the choice of doing nothing and knowing nothing. Onward referral in light of identified needs. Tension re routinisation of screening programmes and need to recognise the limitations of screening in detecting conditions that fall outside this. Routinisation of screening. Holistic care for woman and family.	Incorporation into patient pathways. Standardisation of implementation of national policies for screening. Clear, standardised approach for validating and implementing in new screening tests clinical care – inequities and inconsistencies. Involvement of nurses and midwives in commissioning decisions – scope of practice re leadership. Exploration of issues around co-payment of care.	Keeping abreast of developments. Benefit of family history taking in facilitating decision-making and management. Education to strengthen leadership and management programmes (strategic influencing). Skills in communicating complex information.

	Non Invasive Prenatal Diagnosis for Down Syndrome screening	Post DTC testing 'mop up' by midwives. Managing outcomes.	Increasing testing being offered outside NHS: no current policy on how to deal with this. NHS Fetal Anomaly Screening Programme will consider results in detail to understand implications for screening practice.	
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Lifestage: neonatal

“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.” [Meriel]

Who's involved	Key implications of genetics	Practice	Policy	Education
Midwives Neonatal nurses Children's nurses inc. Community outreach Health visitors Specialist nurses	Changing status of knowledge. Familial implications. Changing treatment and management options. Managing expectations underpinned by understanding of science and technology. Uncertainty around prognosis. Implications of diagnosis. Lag of information available via technological advances and its interpretation. Psychosocial implications. Earlier diagnosis positive in mobilising resources, reducing uncertainty where there is a diagnosis, informing future reproductive choices.	Integration into existing practice. Development of local clinical protocols and guidelines re access to information. Testing and Diagnosis. Onward referral in light of identified needs. Multiagency support including voluntary sector. Long term/ongoing and seamless care of child and family. Transfer of care. Holistic care – psychosocial/spiritual.	NSF – care pathways? Policy to articulate care pathway. Role of HV currently being examined.	Communicating complex and difficult information in timely manner to meet family needs. MDT working to ensure coordinated care.

Lifestage: child

"I now realise there is a 50% risk that my 7 year old daughter has inherited the faulty gene. I am very anxious about her future. I am not convinced anyone at our local hospital will take my concerns seriously when the time comes to begin her screening (if that is what she chooses to do)...It would be wonderful to have someone qualified to speak to her as I am concerned I will make her worry and panic if I go about it the wrong way.... I can only hope that there is more support available to us as a family when the time comes for her to decide if she wants to be tested." [Diane]

Stephanie is being cared for at the hospice because her physical and mental health is deteriorating rapidly due to an unknown cause – Stephanie's parents have been told that her problems may be genetic but they are undecided whether they should consent to any genetic tests.

Who's involved	Key implications of genetics	Practice	Policy	Education
Children's nurses Practice nurses Health visitors School nurses Specialist nurses	Consent and assent implications for testing. Supporting family communication. Changing status of knowledge. Different and difficult choices. Familial conditions. Changing treatment and management options. Managing expectations underpinned by understanding of science and technology.	Integration into existing practice. Development of local clinical protocols and guidelines. Testing and Diagnosis. Supporting choices. Onward referral in light of identified needs. Facilitating communication. Respect for autonomy. Coordinated care. Transitional care. Psychosocial implications.	Incorporation into patient pathways. Review of tertiary provision: ? impact	Understanding of key Child policies from the genetics perspective. Benefit of family history taking in facilitating decision-making and management.
Hospice nurses Children's nurses Learning Disability nurses	Multi systems involvement. Implications of testing for other family members/future reproductive choices.	Managing death and dying and familial implications. Multiagency integration. Supporting decision-making	Scenario also highlights issue of consent to obtain tissue samples (e.g. SCD) – role of nurses in developing policy.	Ethicolegal issues around genetic testing. Palliative care through the genetic lens.

Specialist nurses HV School nurses Community nurses Practice nurses		around genetic testing. Understanding importance of wider implications of a genetic diagnosis for other family members (re obtaining samples).		Leadership.
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Many life-limiting conditions of childhood are genetic – 45% of children in hospice care are affected by genetic conditions

Lifestage: Adolescent

“Our then 16 year old son, who was well in himself apart from being thirsty and having sugar in his urine, was diagnosed as Type 1. No tests were run on him first – he was started on insulin immediately. We gave the consultant at the hospital a copy of our family tree, and explained I was Type 2 and my father was Type 1 and asked for genetic testing. We were told it was impossible for us to be different types, but were denied further investigation. It was as if they had a plan of care for a teenager who presented with some symptoms, but wouldn’t deviate from it or think out of the box. After our son spent months on insulin and became more and more ill to the point of regular unconsciousness, both he and I were genetically tested and found to have MODY 3 diabetes. ...Within a day or two of stopping the insulin we had our healthy teenager back.” [Jenny]

Who’s involved	Key implications of genetics	Practice	Policy	Education
Practice nurses Secondary care School nurse Specialist nurses Child and Adolescent Mental Health Nurses	Changing status of knowledge. Familial conditions. Changing treatment and management options. Managing expectations underpinned by understanding of science and technology. Life-long conditions – transition of care. Consent/assent for testing. Access to testing.	Integration into existing practice. Development of local clinical protocols and guidelines. Testing and Diagnosis. Supporting choices. Onward referral in light of identified needs. Transition of care. Reproductive health. Individualised care (giving the young person a voice).	Incorporation into patient pathways. Access to testing. issue of consent to obtain tissue samples (e.g. SCD) – role of nurses in developing policy.	Benefit of family history taking in facilitating decision-making and management. Contraception advice/reproductive health. Listening to families: patient as expert.

Lifestage: adult

“The condition is sufficiently common, 1 in 500, every practice will have a several of these patients. They may not know it but they almost certainly do. I think there needs to be an awareness in practice nurses... The thing about [familial hypercholesterolaemia] is that it is a condition which is very amenable to treatment, and it is more amenable to treatment now than it was five years ago because the understanding is better and the treatments are better...” [Bill]

Stephen sounded upset when he phoned Anne, his Lung Cancer Clinical Nurse Specialist. He had just heard that Mala, another member of the Lung Cancer Support group, had been started on Gefitinib. He had heard a lot in the media about people being denied new cancer drugs because of financial constraints in the NHS. He was worried he was a victim of the "cuts".

Anne explained that Gefitinib will only be of benefit to those people whose tumours are shown in the laboratory to have particular genetic mutations (within the EGFR-TK domain). She reassured Stephen that his treatment was that which research had indicated to be the most likely to be of most benefit to him. She offered him the chance to discuss this further with his oncologist but he was satisfied with her explanation.

Who's involved	Key implications of genetics	Practice	Policy	Education
Secondary care Practice nurses Occupational Health Specialist nurses Public health nurses School nurses	Changing status of knowledge. Familial conditions and implications. Changing treatment and management options. Effective treatment options. Prophylaxis. Tertiary care. Familial hypercholesterolaemia cascade screening. Importance of family history. Genetics/environment interaction – public health implications.	Integration into existing practice. Development of local clinical protocols and guidelines. Testing and Diagnosis. Onward referral in light of identified needs. Taking family history. Family communication (for cascade screening).	Incorporation into patient pathways. Policy-implementation gap. Commissioning the pathway – and who pays for testing. Role of voluntary sector. Referral guidelines.	Training for specialist nurses – access to education. Increased awareness – prevalence, treatable. Red flags.
Community nurses	Managing expectations underpinned	Support for patients	Responsive commissioning	Difference between germ

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<p>Specialist (e.g. palliative care) and advanced practice nurses</p>	<p>by understanding of science and technology. Stratified diagnosis and targeted treatment – not linked to inherited condition (tumour mutation). Stratified diagnosis will inform trajectory of care. Recognition of inherited condition at point of diagnosis in common conditions. Changing landscape of testing.</p>	<p>according to treatment available – those eligible for specific treatment regimes and those not. Appreciating familial and psychosocial implications. MDT decision making acknowledging evidence base for test.</p>	<p>pathology tests in a dynamic landscape. Availability of treatment. Equity of access to testing and treatment.</p>	<p>line and somatic mutations. Understanding pharmacogenetics. Appreciating the here and now.</p>
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Appendix 3. Nursing competences in genetics/genomics: revised framework 2010

1. Identify clients who might benefit from genetic services and/or information through a comprehensive nursing assessment:

- that recognises the importance of family history in assessing predisposition to disease, and
- recognises the key indicators of a potential genetic condition,
- taking appropriate action to seek assistance from and refer to genetics specialists and peer support resources,
- based on an understanding of the patient pathways that incorporate genetics services and information.

2. Demonstrate the importance of sensitivity in tailoring genetic/genomic information and services to clients' culture, knowledge, language ability and developmental stage

- recognising that ethnicity, culture, religion, ethical perspectives and developmental stage may influence the clients' ability to utilise these.

3. Advocate for the rights of all clients to informed decision making and voluntary action

- based on an awareness of the potential for misuse of human genetic/genomic information and
- understanding the importance of delivering genetic/genomic education and counselling fairly, accurately and without coercion or personal bias,
- recognising that personal values and beliefs of self and client may influence the care and support provided during decision-making.

4. Demonstrate a knowledge and understanding of the role of genetic/genomic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.

5. Apply knowledge and understanding of the utility and limitations of genetic/genomic testing and information to underpin care and support for individuals and families prior to, during and following decision-making, that incorporates:

- awareness of the ethical, legal and social issues related to testing and recording of genetic/genomic information,
- awareness of the potential physical, psychological and social consequences of genetic/genomic information for individuals, family members, and communities.

6. Examine one's own competency of practice on a regular basis in order to:

- recognise areas where professional development related to genetics/genomics would be beneficial,
- maintain awareness of clinical developments in genetics/genomics that are likely to be of most relevance to the client group, and
- based on an understanding of the boundaries of one's professional role in the referral, provision or follow-up to genetics services.

7. Obtain and communicate credible, current information about genetics/genomics, for self, clients and colleagues

- using information technologies and other information sources effectively to do so, and
- applying critical appraisal skills to assess the quality of information accessed.

8. Provide ongoing nursing care and support to patients, carers and families with genomic healthcare needs

- being responsive to changing needs through the lifestages,
- demonstrating awareness about how an inherited condition, and its implications for family members, might impact on family dynamics,
- working in partnership with family members and other agencies in the management of conditions,
- recognising the expertise of patients and carers with enduring genomic healthcare needs that develops over time and with experience.

