

Acknowledgements

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Executive summary

In the 21st century the expansion in genetics knowledge and the related technological advances, combined with increased public awareness and demand for genetic information are powerful motivators of changes in health care. Preparing health professionals adequately to integrate genetics into their everyday practice presents a significant challenge, and the need to improve genetic literacy amongst nurses in the UK is recognised by the major stakeholders in nurse education and training. What constitutes a 'basic knowledge of genetics' is open to interpretation; there is no national agreement about the knowledge and skills required by nurses, midwives or health visitors.

Using a nominal group approach, an expert panel of stakeholders from relevant fields of health care met to define the knowledge, skills and attitudes in genetics that nurses, midwives and health visitors need at different levels of practice and for different patient groups. The expert panel was invited to construct a series of statements identifying the core competencies in genetics required for nurses, midwives and health visitors. The guidelines formulated in the U.S. by the National Coalition for Health Professional Education in Genetics (NCHPEG; see appendix 1) were used as a template for discussion with electronic voting capturing and tracking both individual and group views. Five specific practice settings were considered: cancer care, haemoglobinopathies, paediatrics, learning disability and primary care.

Consensus developed over the two day structured programme, and 35 competency statements were endorsed by the panel, using a threshold for consensus of 75%. Many elements of the knowledge, skills and attitudes required are common across the professional groups and for different client groups, although the setting influences the emphasis of the specific knowledge required. Health visitors awarded consistently higher points to the competencies than nurses, and voted to include two of the competencies that otherwise failed to reach the 75% required for inclusion. The Panel agreed that the depth of competence demonstrated should reflect increasing experience.

The statements were mapped to the Code of Professional Conduct and to the requirements for the pre-registration programmes for the three professional groups.

The statements are further refined to develop seven minimum competence standards for all nurses, midwives and health visitors at the point of registration:

A. Identify clients who may benefit from genetic services

- through an understanding of the importance of family history in assessing predisposition to disease,
- seeking assistance from and referring to appropriate genetics experts and peer support resources, and
- based on an understanding of the components of the current genetic counselling process.

B. Uphold the rights of all clients to informed decision making and voluntary action

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

C. Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level

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

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

E. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information

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

F. Recognise the limitations of one's own genetics expertise

- based on an understanding of one's professional role in the referral, provision or follow-up to genetics services.

G. Obtain and communicate credible, current information about genetics, for self, clients and colleagues

- using new technologies effectively to do so.

Panellists were invited to suggest additional competencies and seven were proposed:

Knowledge

- i. All nurses, midwives and health visitors should understand the variable spectrum of severity of many genetic conditions.

Skills

All nurses, midwives and health visitors should be able to:

- ii. demonstrate facilitative discussion of genetic issues
- iii. empower clients to formulate their own genetic agenda
- iv. facilitate discussion regarding the contribution of post mortem information in making a clear diagnosis in relevant circumstances
- v. facilitate the ethical storage of DNA samples, including from patients dying or deceased from an inherited condition

Attitudes

All nurses, midwives and health visitors should:

- vi. acknowledge the importance of the client's readiness to access genetic information
- vii. recognise the importance of non-directive working in providing health promotion advice that incorporates genetic information and decision-making

The panellists represented a diversity of interests, expertise and experience yet the degree of consensus achieved was remarkable. To further validate the competencies a consensus day is being held to broaden the debate and include the franchise of a wider group of nurses, midwives and health visitors. The questions to be explored relate to the appropriateness of the competencies to all three professional groups and the addition of any further competencies.

The competencies described in this document are a first step and will be further refined in the light of this consultation. The final report (Autumn 2003) will reconsider the competencies for the three professional groups at different levels of practice and in different practice settings, and will include recommendations on performance indicators.

Responses to the issues raised in this document are invited and welcomed from all those with an interest in the place of genetics within professional preparation, development and practice.

SECTION 1 INTRODUCTION

Purpose of this report

In February 2003, the Genomics Policy Unit, University of Glamorgan and its collaborative partners at the Cancer Genetics Service for Wales (part of the Medical Genetics Service for Wales, University Hospital of Wales) were commissioned by the Department of Health to define the core competencies in genetics for nurses, midwives and health visitors working in all areas of health care. This was in response to the growing recognition that the impact of clinical advances on genetics on all areas of health care would create a major challenge to the professional preparation of practitioners faced with integrating 'new genetics' into everyday practice.

In carrying out this project, we aim to provide a first step in addressing this challenge. Working with stakeholders, we seek to define the knowledge, skills and attitudes in genetics that nurses, midwives and health visitors need at different levels of practice to deliver high quality care to different patient groups. In doing so, we aim:

1. To define the common elements of knowledge, skills and attitudes in genetics required for nurses, midwives and health visitors to meet patients' needs, irrespective of the client group;
2. To describe those elements of competence that are unique to specific professional and patient groups;
3. To ascertain the range of views across stakeholder groups so that differences of opinion may be identified and further explored.

The first phase of this project, the convening of an Expert Panel to identify core competencies, has been completed. This report sets out the findings of the Panel and invites comments in response to these during a consultation exercise, prior to the completion of a final report to the Department of Health in autumn 2003.

Other initiatives in genetics

White Paper on genetics

In a major speech at Newcastle in 2001, the then Secretary of State for Health Alan Milburn announced the government's agenda for investment in genetic services within the NHS, and the commissioning of a Green Paper. This is due to be published shortly as a White Paper and it will be UK-wide in its focus. It is anticipated that the key themes will include a vision of the possible future healthcare benefits from genetics, preparing the NHS for future genetic technologies and the engagement of the public and ethical issues. It is understood that there will be a strong focus on the preparation of the NHS, specifically on the education and training of health professionals who work outside of the medical specialty itself. Preparation will need to address:

- Raising awareness
- Education and training at undergraduate, postgraduate and post-registration levels, presenting appropriate knowledge at the right time
- Having access to good quality information at the point of use
- Good practice guidelines and clinical governance.

National Strategy Programme

The Department of Health and the Wellcome Trust has also jointly commissioned the Public Health Genetics Unit (PHGU) in Cambridge to develop a national strategy for the education and training in genetics for health professionals. The aim of this project is to ensure that the NHS workforce is equipped to integrate clinical advances in genetics for the benefit of the public health. It aims to achieve this by developing a strategy that recognises education needs across professional boundaries, and that ensures that educational programmes are efficiently and effectively developed and utilised. The key approach in addressing this is

likely to be the establishment of a national coalition representing all professional groups. This first phase of this work reported in 2002 (Burton 2002) and is now nearing completion. The work of Fit for Practice in the Genetics Era is complementary to the work of the PHGU and will inform strategy development.

National Coalition for Health Professional Education in Genetics

The National Coalition for Health Professional Education in Genetics (NCHPEG) in the United States is an interdisciplinary group that includes approximately 120 'stakeholder groups' in health care, including the American Academy of Nursing and the American Nurses Association. It represents a national effort to promote health professional education in genetics and access to relevant information. In 2000 it endorsed a series of core competencies in genetics for all health professionals, in order to encourage the integration of genetic knowledge, skills and attitudes into everyday health care, 'effectively and responsibly' (Appendix 1 and <http://www.nchpeg.org>). Thirty five competencies were identified for health professionals working outside the specialist field of genetic counselling, each representing the minimum level of knowledge (17 competencies), skills (8) and attitudes (10) required to provide patient care that involves awareness of genetic issues and concerns. A further three competencies were identified as representing the minimum level of competence:

Each health care professional should at a minimum be able to

- Appreciate limitations of his or her genetic expertise.
- Understand the social and psychological implications of genetic services.
- Know how and when to make a referral to a genetics professional.

NCHPEG emphasises that need for commitment on the part of all educators to incorporate genetic information into all levels of professional education. It acknowledges that the list is a challenging one, but stresses that it provides a direction for curriculum content and will help to prepare for 'the reality of tomorrow and not only for the needs of today'.

AGNC Education Working Group

The Association of Genetics Nurses and Counsellors (AGNC) is the professional body representing health professionals (mainly nurses) who work in the field of genetic counselling. The AGNC Education Working Group prepared a series of reports the Department of Health (Genetics Division), mainly focusing on the training of genetic counsellors and capacity building within this professional group. One of the reports however provided the basis for discussion about appropriate levels of education for practitioners working outside this field (AGNC 2002). That report was used to inform the work of this project.

Reading and responding to this report

The next section of this report sets out some of the developments in genetics to provide a background for this current work. Section 3 sets out our approach, using a nominal group method to conduct the Expert Panel that considered the competencies in genetics. In Section 4, the findings of the Panel are set out in relation to the common core competencies. Section 5 looks at these in relation to the individual professional groups, and their applicability to five different healthcare settings. The compatibility of the agreed competencies within the existing NMC frameworks for nurses, midwives and health visitors is reviewed in Section 6, where we re-define the statements. Section 7 takes us beyond these core competencies, looking at additional competencies identified by the Panel, and considering briefly the implications of the agreed competencies for practice and education.

We have used scenarios throughout the document to stimulate discussion and reflection within your own professional environment. We have also posed questions about the deliberations of the Panel, and invite you to respond to these. These questions are summarised in Section 8.

SECTION 2 SETTING THE SCENE

The developments in genetics

The expansion in genetics knowledge and the related technological advances are powerful drivers of change for health care in the 21st century. When combined with the developments in informatics and pharmaceuticals, and alongside the increased public awareness and demand for genetic information, the impetus for change becomes inexorable.

The application of knowledge from the Human Genome Project and other genomic research is making it increasingly possible to identify individuals at risk of the rarer 'single gene' conditions, and of common diseases such as cancer and cardiovascular disease. Greater understanding of the role and function of genes, of the interaction between genes and between individual genetic make-up (genotype) and the environment is leading to a paradigm shift in healthcare, with an increasing focus on individualised preventive medicine based on genetic risk, and informed by environmental risk factor assessment. The potential benefits that may accrue from this 'new genetics' were outlined by Bell (1998):

- A new disease classification, based on the molecular mechanisms that cause disease rather than the clinical manifestation e.g. the identification of the sub-types of Type 2 diabetes, particularly the MODY sub-types, based on the particular gene involved. This will go alongside a better understanding of the pathological mechanisms of disease, and of the influence of environmental factors.
- The possibility of earlier detection of disease, with an increasing range of genetic tests.
- Greater opportunities for prevention, by identifying individuals and sub-populations who might be more at risk, and identifying ways of modifying or preventing this risk.
- Better targeted and more effective treatments, using genotype to identify subtypes of populations who are more likely to display an enhanced response or increased toxicity.
- New types of treatment, with rational drug development based on an understanding of the pathogenesis, with a longer term focus on gene therapy.

Symptomatic individuals can thus expect a more specific diagnosis, with the classification of diseases based on the knowledge of their underlying molecular mechanisms. Pharmacogenomics research is making possible new treatment advances that utilise molecular specific therapies, with gene therapy being an ultimate goal (Collins and McKusick 2001).

Of course these predicted benefits do not come alone, and whilst many argue that the new genetics poses no *new* ethical challenges, there is broad agreement that the *magnitude* of the challenges that are posed – to privacy, confidentiality, discrimination – are substantial. The potential for the application of genetic technologies to health care raises hopes and expectations as well as raising anxiety. Recent high profile legal challenges have raised awareness of the ethical issues around the application of reproductive technologies. The 'therapeutic lag' between being able to identify individuals with or at risk of a genetic condition, and being able to offer effective treatment or cure is likely to be significant for the majority of conditions. Speculation on how this may affect health-seeking behaviour has led to concern about the effect on primary care of an increase in consultations from the 'worried well' (Shickle and Chadwick 1994).

Whilst the pace of change brought about by advances in genetic research and technology may be debated, the scope of its potential impact is not, a factor echoed by former Secretary of State for Health Alan Milburn in a speech in 2001, when he stated that:

Developments in genetics should allow us to eradicate much of the trial and error common in medical practice. The NHS of the future should increasingly allow us to predict and prevent the common diseases of life.

Agreeing core competencies will help us take the first step towards change.

Fit for practice: the implications of genetics for nursing, midwifery and health visiting

The implications of these developments for healthcare are far-reaching, both for the organisation and delivery of services that integrate genetics in clinical practice, and for the preparation of professionals who may need to acquire new knowledge and skills in order to do so. Medical genetics services across the UK already are struggling to cope with a growing demand for information. Referrals to the service have risen markedly in recent years; between 1991 and 1997, the workload covered by regional centres increased by between 50-100%. It has become apparent that health professionals from outside the specialist field will need to play a significant part in helping to meet the workload associated with an increasing demand for genetic services. Further, with the growing understanding of the roles that genes play in common diseases, it is no longer appropriate to consider that genetics is relevant only to health professionals working within the specialty. Nurses, midwives and health visitors could play a central role in identifying individual genetic risk, providing information about genetic testing, gene-guided diagnoses and treatment options, and developing appropriate strategies for referral.

Translated into everyday practice, this would require the practitioner to be able to recognise need, informed by the collection of an observant family history, and underpinned by a broad-based genetic awareness. Triaging patients and clients on the basis of their genetic risk would require an awareness of the available referral mechanisms. Communicating genetic information and explaining risk and possibilities for management require the application of communication skills that incorporate understanding of the benefits and limitations of genetic testing.

Supporting informed decision-making and providing on-going support for individuals with or at risk of an inherited condition would be integral components of any such role, and this would need to be underpinned by an awareness of the complexity of a family reaction to an actual or suspected genetic condition. All of these elements would need to be incorporated within an ethical framework that acknowledges the influence of other factors such as culture, values and beliefs on health-seeking behaviour and decision-making.

There are also broader professional issues that go beyond the preparation of individual practitioners. These include the need for the professional groups to contribute to policy making that incorporates new genetics, and to commission and undertake research to build the evidence base that informs practice and responds to change. However, there is as yet no consensus on what the professional roles should be in relation to genetics outside of the specialist field itself, nor is there consensus on what competencies in genetics these health professionals should demonstrate. Clearly, if the health service is to prepare itself to integrate genetics into practice, the education and training of health professional will present a major challenge.

Preparing the professionals: the challenges for nurses, midwives and health visitors

The need to improve genetic literacy amongst nurses, midwives and health visitors in the UK is recognised by the major stakeholders in professional education and training. In its report (*Fitness for Practice*), the UKCC noted that “nurses and midwives of the future will have to have a basic knowledge of genetics, at the very least” (UKCC 1999, p14). Similar sentiments are also expressed by those responsible for the future provision of health

services. For example, the National Plan for the NHS in England, and the National Assembly for Wales' Nursing Strategy document '*Realising the Potential*,' echoes these points. The Nuffield Trust (Zimmern and Cook 2000) recommends that the UK government and health services should establish and implement a strategy for the promotion of genetic literacy that includes a systematic approach to the training and education of health professionals.

Although various authors have reported deficits in knowledge of particular groups of health professionals, there has been no large scale systematic assessment of knowledge, skills or learning needs in relation to genetics for nurses at different levels of practice. Walter et al. (2001) found that only a third of practice nurses they surveyed had attended educational events about risk management of breast cancer in the previous three years. Bankhead et al. (2001) identified that 97.5% of practice nurses would find further education useful.

Concomitantly, the inadequacies of existing provision for nurse education in genetics have been identified. A survey of the status of genetics education in pre-registration courses carried out by the Genomics Policy Unit in 1997 exposed the poverty of provision (Kirk 1999a). The survey (with an 84% response rate) indicated that although genetics is taught across the UK on all but two training programmes at diploma level, provision is inadequate, with most programmes including only 10 hours or less of genetics over three years, and nearly one-third of courses providing five hours or less genetics.

We found that the curriculum emphasis tends to be on 'traditional' genetics topics such as Mendelian inheritance, and many do not address new genetics issues such as gene testing. Nearly 30% do not cover ethics issues, and a further 55% do not look at societal issues. The predominance of genetics science in the topics covered is reflected in where genetics is placed within the curriculum – over 60% classify it solely and 30% partly within the science curriculum. Delivery is also constrained. Only a third use case studies and teaching is delivered by lecturers with no qualifications in genetics on 94% of programmes. There is also little rigorous examination of the subject; 75% of programmes do not assess students compulsorily in genetics, and of those that do, approximately half use multiple-choice questions. However, the majority of our respondents recognise the growing importance of genetics in health care and its relevance to nurses, although over 67% felt that the teaching within their departments was already appropriate to meet the health care needs of patients.

The findings from our research were considered by an Advisory Panel of nursing experts from education, clinical genetics, UKCC and National Boards, RCN and nursing practice, in a two day meeting in November 1998. The 20-strong panel was asked to consider the place of genetics in future pre-registration nurse education training programmes, and to make recommendations on how genetics education could be developed and delivered to provide a curriculum that is relevant, focused on nursing, and flexible enough to adapt to clinical advances in the fast-moving field of genetics (Kirk 1999b).

The consensus of the panel was that nurses were not being prepared adequately in genetics to meet existing or future needs of patients, and that there was an urgent need to address this. A number of obstacles to provision were identified, including the lack of awareness at organisational level (i.e. statutory and professional bodies, academics and the NHS) of the growing importance of genetics, and deficits in the expertise of teachers in terms of both subject knowledge and clinical experience. This was felt to be compounded by a lack of accessible resources, particularly those that focus on nursing, and by the lack of an appropriate infrastructure for dissemination of resources. Also noted was the lack of a national strategic framework, with informed guidelines on the content and level of genetics teaching.

Although the remit of the Panel was to focus on pre-registration programmes, concern was also expressed at the level of provision for post-registration education, which it felt also merited review. Subsequent research by Burton and Metcalfe confirms this view (Burton 2002). The need for a constructive, planned programme for nursing education was

indicated. In particular, the Panel recommended the development of guidelines for a core curriculum in genetics.

Some guidance on genetics education has been published, but this has been developed for nurses practising in the United States with the development of the competencies for all health professionals identified by NCHPEG. How many nurses in the U.S. achieve these levels of competence is unclear, but nursing in the U.K. cannot match the progress made in the U.S. Here, there is no national agreement and very limited discussion on what core competencies in genetics nurses should possess on qualifying, although the AGNC has defined standards for practice within the medical genetics specialty (Skirton et al. 1998). Clearly, there is some way to go to establishing the robust infrastructure needed to underpin the integration of genetics into practice, a point echoed in Milburn's speech (2001), when he stated that:

Mainstreaming genetic services in the NHS will also require big changes in how we educate and train health professionals.

SECTION 3 APPROACH

Professional competence: Definition of terms used

The issues of competence appears to be a complex one and there has been some debate as to its definition and assessment. Cattini and Knowles (1999) felt that there was no fully satisfactory description of competence that also reflected its dynamic aspect, and their definition is that competence is:

the ability to fulfil the nursing role effectively and/or expertly, recognising that competence possesses a complexity that increases with experience and as responsibilities become more intricate.

Fraser and Greenhalgh (2001) state simply that competence is 'what individuals know or are able to do in terms of knowledge, skills, attitude'. The expert practitioner is described as 'someone who knows how to access knowledge efficiently and judiciously and who can form conceptual links between seemingly unrelated areas'. Achieving competence then, could be said to be the process whereby the 'knowing what' is translated into 'knowing how' and understood as 'knowing why' within a particular practice context.

The NMC uses the term competence to describe the skills and ability to practise safely and effectively without the need for direct supervision (NMC 2002b). It states that at the point of registration, the nurse should be able to apply knowledge, understanding and skills when performing to the standard required in employment and 'provide the nursing care ... safely and competently'. Pre-registration nursing programmes should recognise that nursing is founded on the principle that evidence should inform practice through the integration of relevant knowledge and that the *Code of professional conduct* applies to all practice interventions.

The standards of competence

Competence is conceived as a process of professional development which may range from beginning to understand nursing science and how it relates to practice, through to advanced practice that has developed through experience and formal training. For the purposes of this report, we have delineated a hierarchy of professional development by nominating three depths of knowledge:

- 1 = Know and understand the implications for practice
- 2 = Apply the concepts to professional practice
- 3 = Teach the concepts to others

As well as identifying the core competencies in genetics for nurses, midwives and health visitors, the panellists were also asked to define what depth of knowledge should be ascribed to the competency statement for the different professional groups, at different levels of practice.

Level of practice

Being able to delineate practice through professional or clinical mastery offers a system that facilitates skill-mix organisation and career progression. For the purposes of the Expert Panel, three levels of practice in genetics for health professionals working *outside* the clinical genetics service have been defined. In doing so, the authors do not wish to preclude the work of professional organisations in defining levels of competence; we seek only to provide 'labels' that will allow us to build a matrix of competencies that indicates career progression. The three levels are:

Level 1: Competent

This equates to the newly-registered nurse or midwife working in a general or specialist area. We originally labelled this level as 'beginner', but the Panel felt this term did not

reflect the requirement by the NMC that all registrants should be competent and 'Fit for Practice'.

Level 2: Experienced

This level describes the registered nurse or midwife who has been working in a general or specialist area for more than two years since qualifying (e.g. senior staff nurse or staff midwife), or a registered health visitor. At this level of practice, the health professional is able to refine and evaluate the evidence base in the light of growing experience.

Level 3: Higher

This level represents the experienced registered nurse, midwife or health visitor who has undertaken additional post-registration training and whose role requires the exercising of higher levels of judgement and decision-making, e.g. a ward manager or clinical specialist nurse. At this level, the health professional is able to contribute to defining competence in his or her area of practice.

Levels of competence for genetic counsellors (Advanced level) have been defined by the AGNC and are outside the remit of this report.

Reaching a consensus: the Expert Panel process

Approach

This project used a nominal group approach to define and describe the depths of competencies required for different levels of practice, and for different patient groups. The nominal group technique is a method that attempts to assess the extent of agreement and to resolve disagreement through a structured programme in which panellists rate, discuss, and then re-rate a series of items.

The Panel

Experts across the UK from relevant fields of health care, including patient/user groups, were invited to meet on May 12th and 13th at Cardiff. The job of this Expert Panel was to construct a series of statements about the competence in genetics that these health professionals need at different levels of practice, from newly-qualified to higher level practitioner, for different patient groups.

The Expert Panel was recruited by various means, but all potential members had to satisfy the criteria identified by the Project/Steering Group team. All had to represent one of the eighteen stakeholder groups identified by the team, and all had to be acknowledged 'experts' within the stakeholder group, either by virtue of their professional/public role and/or position within that group. In order to provide a broad perspective on the issues under discussion, it was stressed that outside of those stakeholder groups clearly associated with genetics, expertise or experience in genetics was not a pre-requisite for panel membership. Many nominees satisfied the criteria in more than one area, for example, acknowledged academic leadership and professional leadership as members of the NMC. If the identified nominee from an organisation was unable to attend, he or she was asked to nominate another representative. The list of delegates, and the institutions and organisations they represented is presented in Appendix 2.

The Process

The fundamental question that was asked of the Expert Panel was: can you identify the knowledge, skills and attitudes essential for the health professional group, at the specified level of practice? The list of 38 competencies agreed by the National Coalition for Health Professional Education in Genetics (NCHPEG) for all health professionals in the USA, was used as a guide (three minimum competencies and the list of 35).

Each Panel member was sent a briefing pack prior to the meeting, containing relevant literature and a glossary of terms. A preliminary voting sheet was also included and panellists were asked to complete this before the meeting. This was to provide a baseline indication of views on the core competencies that all nurses and midwives should be able to

demonstrate at the point of registration, *as a minimum*. By virtue of the entry requirements for health visitor training, health visitors would automatically be included in any nursing competencies at this stage.

The two-day nominal group meeting was facilitated by Dr Marcus Longley, an expert in health strategy and policy, and an experienced facilitator. Scenarios were used throughout the discussions to illustrate issues around competent practice. These were drawn from actual or real-life situations and as such were typical of many that are encountered in practice within the field of genetics. They, and others, are reproduced in this report to re-create the stimulus for reflection. The programme is reproduced in Appendix 3.

The meeting commenced with an outline of the aims of the project and purpose of the meeting, and a revision of the terms and definitions that would be used. The developments in genetics, and the implications for healthcare were also reviewed. Vote 1 was then processed to record baseline views on which of the 38 competencies should be included or excluded from the list, for all nurses and midwives at the point of registration. Discussion followed, considering not only the common core competencies themselves, but also the standard (or depth) of competency that should be demonstrated. This was then captured in the second vote.

This first round of discussion sought to identify the common elements for the three groups of health professionals. Syndicate group discussions were initiated to identify any additional competencies that would be unique to the specific group, and to explore the appropriate standard of competency for that profession, at different levels of practice. Three levels of practice were considered for nurses and midwives, and two for health visitors. For each level, participants were asked to identify additional items, over and above those identified as the common core competencies for all three professional groups. These views were then further discussed as a plenary group, and views were captured in the third and final vote of the first day.

The second day aimed to broaden the discussion to look at different areas of health care, to identify the unique and transferable competencies. Five exemplar health settings were considered: cancer care, haemoglobinopathies, paediatrics, learning disability and primary care. The ‘condition-based’ nurses, such as the haemoglobinopathy nurse counsellors, have been practising for many years, dealing with patients and families with or at risk of one of the single gene disorders. The impact of genetics on cancer care provides an indicator of the likely effect in other areas of health care as the contribution of genetics to common conditions is elucidated.

Following syndicate group discussions, the Panel re-convened to consider the implications for the stakeholder groups of the agreed list of competencies. In the light of the all of the previous discussions, the Panel was then asked to re-vote on the standards of competency in genetics for all nurses, midwives and health visitors at the point of registration; essentially this was a repetition of the second vote.

The aim was thus to build a matrix of competencies for the three professional groups, at different levels of practice:

Nurses	Midwives	Health visitors
Level 3: Higher Defining competence Vote 3	Level 3: Higher Defining competence Vote 3	Level 3: Higher Defining competence Vote 3
Level 2: Experienced Refining competence through experience Vote 3	Level 2: Experienced Refining competence through experience Vote 3	Level 2: Experienced Refining competence through experience Vote 3
Level 1: Competent Newly-registered Votes 1,2 & 4	Level 1: Competent Newly-registered Votes 1,2 & 4	

For each cell of the matrix, the intention was then to identify the appropriate standard of competence for each of the knowledge, skills or attitudes.

Nurses	Midwives	Health visitors
Higher	Higher	Higher
Experienced	Experienced	Experienced
Competent	Competent	

	Know	Apply	Teach
Knowledge x 17			
Skills x 8			
Attitudes x 10			

The Voting

An electronic vote capturing system was used. Each Panellist was given a hand held device called a Communicator with which to vote. These communicators were about the size of a mobile phone, with a numeric keypad. This enabled Panellists to register their votes with a degree of privacy.

Each competency was projected onto a screen via an interactive PowerPoint presentation. The first slide showed the competency being considered, and the numbers that the Panellists needed to press on their communicators to register their required vote. To register that a competency should be required at depth 1, Panellists pressed “1” on their Communicators, for depth 2 they pressed “2” and for depth 3, “3”. If Panellists thought that a competency should not be included, they pressed “4”. The competency was displayed on the screen, the facilitator asked Panellists to vote, and they then had six seconds to press the relevant button. After these six seconds, the receiving computer counted the number of votes per depth, calculated a percentage for each depth, and displayed the results in a bar chart on a second slide. This feedback loop was virtually instantaneous, taking no more than three seconds from the close of voting to the result appearing on screen.

The electronic voting system was readily accepted by the Panellists, even though some of the voting sessions seemed lengthy. Vote 3 was especially demanding because it was a double vote for first the Experienced level of practice, followed immediately by the Higher level of practice, making 76 consecutive competency votes. In addition to this, Vote 3 came at the end of the long first day. Even so, Panellists were keen to ensure that their votes were registered, and if they voted incorrectly, or missed the six second voting window, they would ask for that vote to be taken again. These requests were always granted.

A six second time window may sound draconian, but in practice it was usually long enough for Panellists to register their votes. Most votes were cast in the first two to three seconds of the six second window.

The eagerness of Panellists to retake incorrect or missed votes indicates that when a Panellist did not vote on a particular competency, it was likely that this indicated a

deliberate decision to abstain. For this reason, all analyses have included missed votes in the total number of votes cast per competency.

The Steering Group

The Project Team is being advised by a Steering Group, who are meeting on a number of occasions to discuss and guide the process and progress of the project. The project membership is detailed in Appendix 4.

SECTION 4 DEFINING THE COMPETENCIES

The agreed common core competencies in genetics for nurses, midwives and health visitors

The Panel felt that the scenarios presented highlighted the complexities of delivering health care within a system that offers different points of access, involving different professional groups and where the unit of care is the family, with all of its complexities, rather than an individual. Nonetheless, the scenarios did demonstrate deficits in care that could be attributed to ‘unconscious incompetence’. Awareness of resources was felt to be an issue generally, and a common thread was identified of the failure on the part of the professional to ask the question, ‘could this be genetic?’.

Table 1: The development of consensus

The Panel expressed some concern about taking a uni-professional approach in view of the move towards multi-professional education. It was explained that the work represented a first step towards this by aiming to identify the common core competencies for the three broadly related professional groups. These commonalities can then be used as a basis for exploring the common elements for other professions.

There was clear development of consensus as the Panel met and discussed the common core competencies in genetics for the three professional groups. Table 1 shows the pattern of voting for each of the competencies for the three voting sessions that considered the practitioner at the point of registration, from Vote 1 (the baseline views) to Vote 4 (the final vote). For all of the competencies, the consensus for inclusion was higher in the final vote than in the first. For most of the competencies, a progression can be seen as consensus increases for the successive votes, although this was not apparent for nine of the statements.

The results of the final round of voting on the common core competencies for all nurses, midwives and health visitors at the point of registration are shown in Table 2. This shows the percentage of votes for the different depths of knowledge, from 1-4:

1. Know and understand the implications for practice
2. Apply the concepts to professional practice
3. Be able to teach the concepts to others
4. Should not be included

Missing items, where a vote was not registered for an individual panellist, are shown in the final column. We cannot conclude from these missing items whether the panellist chose not to vote, or failed to enter a vote within the time limit.

However, there were a number of occasions when individuals ‘missed’ the six-second voting period and requested a re-vote,

<i>Competency Ref no.</i>	% voting to include		
	Vote 1	Vote 2	Vote 4
1	97	94	97
2	88	100	100
3	91	94	100
4	74	94	100
5	100	100	100
6	76	83	95
7	82	94	100
8	74	83	97
9	59	71	100
10	100	100	100
11	88	97	95
12	97	94	100
13	85	89	92
14	97	97	97
15	71	83	100
16	56	57	90
17	71	80	100
18	82	80	97
19	62	80	97
20	59	66	100
21	29	31	71
22	56	80	100
23	59	77	97
24	21	17	47
25	59	89	92
26	56	91	92
27	29	54	84
27A			97
28	74	94	90
29	50	74	87
30	79	91	95
31	56	69	89
32	82	100	95
33	50	46	76
34	97	83	100
35	88	91	93
36	71	97	100
37	21	37	71
38	32	34	47

and appeared to be quite conscientious about this, even during a period of quite prolonged voting. It seems more likely therefore, that these missing items represent abstentions.

Using the value of 75% as the threshold for consensus, a list of competency statements can be constructed (Table 3). On this basis, in the final vote of the proceedings, the Expert Panel endorsed (with some modification to the wording) 34 competency statements. For these statements, the Panel agreed that *as a minimum*, the practitioner should know and understand the implications of the concepts contained within the statement for his/her own area of practice, at the point of registration.

Although Statement 27 was endorsed by the Panel, with 84% agreeing that *as a minimum*, all health professionals should know and understand the implications for practice 'The indications for genetic testing and/or gene-based interventions', 16% felt it should not be included in the list. There was general agreement during discussion that this statement should be reviewed, and an alternative (27A) was proposed. This statement was felt to be more suitable (97% agreeing, none voting not to include, and one abstention) and so is substituted for Statement 27 in the ensuing discussions.

The excluded competencies

Four competency statements did not attract the 75% threshold of consensus for inclusion.

Statement 21: Professionals should understand *That ethnoculture and economics may influence the prevalence and diagnosis of genetic disease.*

This competency statement was felt to reflect more the influence of the American healthcare system. Further, the exploration of the issues implicit in the statement was thought by many to be unnecessary at the level of practice being considered, although it was felt it might be appropriate at a higher level of practice.

Statement 24: Professionals should understand *The range of genetic approaches to treatment of disease (disease prevention, pharmacogenomics/prescription of drugs to match individual genetic profiles, gene-based drugs, gene therapy).*

This statement consistently failed to reach the 75% consensus level, at all levels of practice. The potential for pharmacogenomics to influence disease management and prevention, through the development of new treatment options and genotype guided care, has been widely discussed in the literature (e.g. Bell 1998). This is therefore perhaps a surprising finding, and some panellists suggested that the competency would have to be reviewed in response to clinical developments.

Statement 37: Professionals should be able to *Educate others about client-focussed policy issues.*

This was felt to be inappropriate as a minimum core competency standard, but there was consensus for its inclusion at the higher levels of practice.

Statement 38: Professionals should be able to *Participate in professional and public education about genetics.*

This was felt to be inappropriate as a minimum core competency standard, but there was consensus for its inclusion at the higher levels of practice.

Q.1 Do you agree with the Panel that these four statements should be excluded from the list of common core competencies for professionals at the point of registration?

Q.2 Do you think they apply equally to the three professional groups?

**Table 2:
The common core competencies in genetics for nurses, midwives and health visitors: the extent of agreement amongst Panellists (Vote 4)**

Ref	Competency	% agreeing with depth ¹			
		1	2	3	4
	Each nurse, midwife and health visitor should at a minimum be able to:				
1	Appreciate limitations of his or her genetic expertise.	5	92		3*
2	Understand the social and psychological implications of accessing genetic services and information.	34	66		
3	Know how and when to make a referral to a genetics professional.	24	68	8	
	All nurses, midwives and health visitors should understand:				
14	Basic human genetics terminology	18	68	11	3*
15	The basic patterns of biological inheritance and variation within families	26	74		
16	How identification of genetic variations facilitates development of disease prevention strategies, diagnosis, and treatment options	71	16	3	11
17	The importance of family history in assessing predisposition to disease	26	68	5	
18	The role of genetic factors in maintaining health and preventing disease	29	66	3	3
19	The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation)	42	53	3	3
20	The role of behavioural, social, and environmental factors (lifestyle, socioeconomic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease	32	66	3	
21	That ethnoculture and economics may influence the prevalence and diagnosis of genetic disease	45	26		29
22	That ethnicity, culture, related health beliefs and economics influence the clients' ability to use genetic information and services	39	61		
23	The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities	34	61	3	3
24	The range of genetic approaches to treatment of disease (disease prevention, pharmacogenomics/prescription of drugs to match individual genetic profiles, gene-based drugs, gene therapy)	39	8		53
25	The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities	29	63		8
26	The components of the current genetic-counselling process and the indications for referral to genetic specialists	26	66		8

27	The indications for genetic testing and/or gene-based interventions	47	37		16
27 A	The utility and limitations of genetic testing	39	55	3	3*
28	The ethical, legal and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment)	29	61		3 8*
29	Some awareness of the history of misuse of human genetic information (eugenics)	68	16	3	8 5*
30	One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services	21	74		5
	All nurses, midwives and health visitors should be able to:				
31	Gather genetic family-history information, including an appropriate (3 generations) family history	39	47	3	8 3*
32	Identify clients who would benefit from genetic services	11	79	5	3 3*
33	Explain basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease	50	26		24
34	Seek assistance from and refer to appropriate genetics experts and peer support resources	21	79		
35	Obtain credible, current information about genetics, for self, clients and colleagues	3	89		3 5*
36	Use effectively new information technologies to obtain current information about genetics	16	84		
37	Educate others about client-focused policy issues	34	32	5	26 3*
38	Participate in professional and public education about genetics	34	13		47 5*

	All nurses, midwives and health visitors should:				
4	Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services	50	50		
5	Appreciate the sensitivity of genetic information and the need for privacy and confidentiality	5	79	16	
6	Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias	39	53	3	5
7	Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level	13	84	3	
8	Seek co-ordination and collaboration with interdisciplinary team of health professionals	24	71	3	3
9	Uphold the rights of all clients to informed decision making and voluntary action	16	68	16	
10	Recognise the limitations of their own genetics expertise		95	5	
11	Demonstrate willingness to update genetics knowledge at frequent intervals	11	82	3	5
12	Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients	16	74	11	
13	Support client-focused policies	16	68	8	8

¹ Rounding up errors mean that the figures do not always total 100% exactly.

* Missing item, shown as a percentage. These missing items are viewed as abstentions and are included in the final assessment of consensus.

Figures denoting clear consensus (>75%) are shown in bold.

Shaded statements indicate that there was no consensus for inclusion of the competency.

1 = Know and understand the implications for practice

2 = Apply the concepts to professional practice

3 = Be able to teach the concepts to others

4 = Should not be included

Refining the competencies

This list can then be further refined according to the consensus on the depth of knowledge that should be applied to each competency statement. Thus, from those endorsed competencies, we can identify:

- those where the Panellists agreed that the minimum standard required is that the practitioner should know and understand the implications for practice of that competency;
- those where the Panellists agreed that the practitioner should be able to apply the concepts contained within the competency statement to his/her own area of practice;
- those where the Panellists felt that the practitioner should know and understand the concepts contained within the competency statement to sufficient depth to be able to teach them to others.

Table 4 lists the endorsed competencies, and indicates the agreed depth of knowledge. Where consensus falls below 75%, the default depth of knowledge shown is the lower one. In other words, where opinion was divided about the depth of knowledge required (this was always between the 1st and 2nd depths of knowledge), the lower of the two levels is shown.

Table 3: Consensus for inclusion of competencies

<i>Ref</i>	Competency	% include
	Each nurse, midwife and health visitor should at a minimum be able to:	
1	Appreciate limitations of his or her genetic expertise.	97
2	Understand the social and psychological implications of accessing genetic services and information.	100
3	Know how and when to make a referral to a genetics professional.	100
	All nurses, midwives and health visitors should understand:	
14	Basic human genetics terminology	97
15	The basic patterns of biological inheritance and variation within families	100
16	How identification of genetic variations facilitates development of disease prevention strategies, diagnosis, and treatment options	90
17	The importance of family history in assessing predisposition to disease	100
18	The role of genetic factors in maintaining health and preventing disease	97
19	The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation)	97
20	The role of behavioural, social, and environmental factors (lifestyle, socioeconomic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease	100
21	That ethnoculture and economics may influence the prevalence and diagnosis of genetic disease	71
22	That ethnicity, culture, related health beliefs and economics influence the clients' ability to use genetic information and services	100
23	The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities	97
24	The range of genetic approaches to treatment of disease (disease prevention, pharmacogenomics/prescription of drugs to match individual genetic profiles, gene-based drugs, gene therapy)	47

25	The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities	92
26	The components of the current genetic-counselling process and the indications for referral to genetic specialists	92
27	The indications for genetic testing and/or gene-based interventions	84
27A	The utility and limitations of genetic testing	97
28	The ethical, legal and social issues related to genetic testing and recording of genetic information (e.g. privacy, the potential for genetic discrimination in health insurance and employment)	90
29	Some awareness of the history of misuse of human genetic information (eugenics)	87
30	One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services	95
	All nurses, midwives and health visitors should be able to:	
31	Gather genetic family-history information, including an appropriate (3 generations) family history	89
32	Identify clients who would benefit from genetic services	95
33	Explain basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease	76
34	Seek assistance from and refer to appropriate genetics experts and peer support resources	100
35	Obtain credible, current information about genetics, for self, clients and colleagues	93
36	Use effectively new information technologies to obtain current information about genetics	100
37	Educate others about client-focused policy issues	71
38	Participate in professional and public education about genetics	47
	All nurses, midwives and health visitors should:	
4	Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services	100
5	Appreciate the sensitivity of genetic information and the need for privacy and confidentiality	100
6	Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias	95
7	Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level	100
8	Seek co-ordination and collaboration with interdisciplinary team of health professionals	97
9	Uphold the rights of all clients to informed decision making and voluntary action	100
10	Recognise the limitations of their own genetics expertise	100
11	Demonstrate willingness to update genetics knowledge at frequent intervals	95
12	Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients	100
13	Support client-focused policies	92

Table 4: Consensus for *minimum* depth of competency

<i>Ref</i>	Competencies that practitioners should know and understand the implications for practice	% consensus
2	Understand the social and psychological implications of accessing genetic services and information	100
4	Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services	100
6	Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias	95
8	Seek co-ordination and collaboration with interdisciplinary team of health professionals	97
15	The basic patterns of biological inheritance and variation within families	100
16	How identification of genetic variations facilitates development of disease prevention strategies, diagnosis, and treatment options	89
17	The importance of family history in assessing predisposition to disease	100
18	The role of genetic factors in maintaining health and preventing disease	97
19	The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation)	97
20	The role of behavioural, social, and environmental factors (lifestyle, socio-economic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease	100
22	That ethnicity, culture, related health beliefs and economics influence the clients' ability to use genetic information and services	100
23	The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities	97
25	The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities	92
26	The components of the current genetic-counselling process and the indications for referral to genetic specialists	92
27A	The utility and limitations of genetic testing	97
28	The ethical, legal and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment)	89
29	Some awareness of the history of misuse of human genetic information (eugenics)	87
30	One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services	95
31	Gather genetic family-history information, including an appropriate (3 generations) family history	89
33	Explain basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease	76
	Competencies that practitioners should apply to professional practice	
1	Appreciate limitations of his or her genetic expertise.	92
3	Know how and when to make a referral to a genetics professional	76
5	Appreciate the sensitivity of genetic information and the need for privacy and confidentiality	95
7	Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level	87
9	Uphold the rights of all clients to informed decision making and voluntary action	84
10	Recognise the limitations of their own genetics expertise	100
11	Demonstrate willingness to update genetics knowledge at frequent intervals	85

12	Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients	85
13	Support client-focused policies	76
14	Basic human genetics terminology	79
32	Identify clients who would benefit from genetic services	84
34	Seek assistance from and refer to appropriate genetics experts and peer support resources	79
35	Obtain credible, current information about genetics, for self, clients and colleagues	89
36	Use effectively new information technologies to obtain current information about genetics	84

Comparisons of depths and levels across the professional groups

The Experienced and Higher levels of practice were voted on in vote 3. Vote 4 covered the Competent level of practice. Points were assigned to the genetic competencies to gauge their relative importance. Each vote for depth 1 scored 1 point, a vote for depth 2 scored 4 points and a vote for depth 3 scored 9 points. The points for each genetic competency were then totalled and divided by the number of people voting, to produce a mean points score. A high mean points score tends to suggest more people voting for depths 3 and 2 than depth 1, indicating that, for that particular genetic competency, practitioners should be required to apply the concepts and possibly teach the concepts to others, rather than just know the implications for practice. The rationale for the graded points system was to increase the variation, to allow for greater discrimination between results. It also emphasised the scoring gradient, such that a competency that required depth 3 scored more highly than one that only required depth 1.

The points for each genetic competency supported a hierarchy of levels of practice. In no case were the points at Competent level greater than those at Experienced or Higher levels. Similarly, points at the Experienced level were always below the Higher level.

The minimum and maximum differences between the levels of practice are shown below.

<i>Minimum differences</i>	Competency	Difference	Competent	Experienced	Higher
Higher - Competent	24	2.17	0.71	2.17	2.88
Experienced - Competent	1	1.20	3.74	4.94	8.23
Higher - Experienced	24	0.71	0.71	2.17	2.88
	38	0.71	0.87	4.14	4.85
<i>Maximum differences</i>	Competency	Difference	Competent	Experienced	Higher
Higher - Competent	6	5.68	2.74	4.86	8.42
Experienced - Competent	2	3.37	2.97	6.34	8.62
Higher - Experienced	6	3.56	2.74	4.86	8.42

In each case, the smaller number is subtracted from the larger, for example the maximum difference between Experienced and Competent levels of practice is $6.34 - 2.97 = 3.37$.

Competency 24, which shows the least difference between Higher and Competent and between Higher and Experienced levels of practice is the competency that the Expert Panel voted to drop at all levels.

For the Experienced level of practice, it is possible to distinguish how votes were cast dependent on which subgroup Panellists were in (i.e. Nursing, Midwifery or Health Visiting).

Originally, it was intended to perform these subgroup analyses for the Higher level of practice too, but the Panellists participating in the Health Visiting group decided that Health Visitors did not have such a hierarchical structure, so should all be classed together at the same level of practice.

Health Visitors awarded consistently higher points to the competencies than Nurses. In a ranked list of points, the top score for the Nurses (5.63 for competency 9) would be placed higher than only the bottom three competencies (1, 24 and 29) of the Health Visitors. Midwives had the greatest variation in point awarding; they awarded the most points for nine of the competencies and the least for eight of them. The maximum and minimum points by group are shown in the table below. This shows that the range of points for the Midwives (8.00) was almost double that of the Nurses (4.19) and Health Visitors (4.70). The respective mean points for Nurses, Midwives and Health Visitors were 3.75, 5.58 and 7.24. There were 16 voting members in the Nurse group, nine in the Midwives group and 10 in the Health Visitors group.

Minimum points		
<i>Group</i>	Competency Ref. No.	Points
Nurses	33	1.44
Midwives	21	0.44
Health visitors	24	3.80
Maximum points		
<i>Group</i>	Competency Ref. No.	Points
Nurses	9	5.63
Midwives	2	8.44
	32	8.44
Health visitors	22	8.50
	35	8.50
	37	8.50

At the Experienced level of practice, Health Visitors were more inclined to want practitioners to be able to teach the concepts of the competencies to others than Nurses.

SECTION 5 BUILDING THE FRAMEWORK

The practitioners

Nursing

Nurses currently play a significant role in the delivery of clinical genetics services, as specialist genetic nurses or counsellors (Appendix 5). Nurses working in other health care settings also encounter patients and clients with or at risk of the rarer genetic conditions, and as genetic advances are integrated into the care of people with common conditions, the proportion of people that nurses care for who may benefit from genetic information, or are at risk from genetic misinformation, is increasing.

Nurses, as members of a multi-disciplinary team, have a responsibility to be able either to answer questions about inherited conditions, or to refer patients to reliable and appropriate resources for further information and assistance, in whichever health care setting they are approached. Nurses working in secondary care, such as general medical or surgical wards, psychiatric units, or elderly care may have to respond to patients' (and relatives') questions and anxieties about their genetic risk. In these situations, nurses will need to have a level of genetic literacy sufficient to be able to refer patients appropriately.

In addition to the basic level of awareness expected of all qualified nurses, those working in specialist areas would be expected to have more in-depth knowledge about the clinical application of the relevant genetic technologies. Patients and their families will expect nurses to be able to answer questions related to inherited disease, such as about gene testing or predisposition to common diseases, or where they can obtain further information.

Nursing is a diverse and dynamic discipline. If nurses are to integrate genetics effectively and appropriately into their practice, three key strategic requirements will need to be met:

- A professional workforce of sufficient numbers and skill mix from which to draw appropriately qualified and experienced nurses to deliver care pertinent to the various roles;
- Clear delineation of roles, both within nursing and between nurses and other health professionals;
- A framework for professional development of nurses that sets out clear targets for career development, underpinned by a sound education strategy.

A 43 year old lady attends an out patient clinic for bronchial problems which she has had for many years. During the clinic she mentions to one of the nurses that she is a bit tearful today, as her nephew has just been diagnosed with a condition called Cystic Fibrosis. She asks the nurse more about this, and about any risks for her daughter, who is planning to start a family. The nurse is sympathetic to her anxiety but does not know anything about it. She knows it is a childhood condition and therefore does not think it important to mention this to the doctor taking the busy clinic.

Reflecting on practice

Cystic fibrosis is one of the commonest autosomal recessive conditions in Caucasians, and about 1 in 25 people in the UK carry the condition. It is rare for cystic fibrosis to be mild but it could be an indicator of the fact that the patient is either a carrier or is herself affected by a mild form of the disease. This information could have been helpful in her management, and the implications are of relevance to the daughter.

Reflecting on practice

Is awareness of this juvenile-onset condition relevant to the nurse's area of practice?

The syndicate group agreed that the attitudinal competency statements related very clearly to the *Code of professional conduct* (NMC 2002a), yet felt that the lack of awareness about

the place of genetics as a component of practice warranted the specific competency statements. Similarly, the other competency statements were felt to reflect the competencies in the existing pre-registration programmes, and there was some debate as to whether we needed simply to use genetic exemplars. However, it was acknowledged that given the current deficits in knowledge and skills, and the need for long-term planning to prepare for future developments, explicit statements were needed. Having identified competencies in genetics may help promote awareness and understanding, and make genetics more accessible to both practitioners and educators.

The group saw a need to demystify genetics and to demonstrate its relevance to the different areas of practice, promoting understanding of the impact that genetics has on people's lives, and also keeping it in perspective. Fundamental to this is the need to listen to what patients want, valuing all people and respecting the rights of all individuals to make their own decisions. Related to this, the group felt quite strongly that all nurses should uphold the rights of clients to informed decision-making and voluntary action (9).

It was felt that no additional competency statements that were unique to nursing were necessary for any of the levels of practice being considered, only that the depth of competence demonstrated should reflect increasing experience.

Judith Mills had just registered with the practice, and was attending the Diabetic Clinic. Just before she moved into the area, a blood test for an unrelated illness had revealed a raised fasting blood sugar. She told the practice nurse that her GP had said it was mild diabetes 'Type 2, he said', and nothing to worry about so long as she followed a healthy diet, and they kept an eye on her from time to time. However her father, who also had diabetes, had been in poor health for some years and had ended up on insulin. She wanted reassurance that she wouldn't 'go the same way' and also asked about the chances of any children she might have also developing the condition.

The practice nurse had only recently attended a study day about diabetes and genetics and knew that there were several sub-types to Type 2 diabetes, some of which could be passed from one generation to the next. It was possible that Judith had Maturity Onset Diabetes of the Young (MODY). She remembered that the most common type of this could worsen with age, and some patients had to move from tablets to insulin. In these cases, careful monitoring for complications was important. Another sub-type was 'mild', but would need careful monitoring during pregnancy. It was possible that Judith's father's poor health was not directly related to his diabetes, and had only exacerbated an otherwise mild condition.

The nurse listened to Judith's concerns carefully and agreed that she would benefit from more information and perhaps further investigation. She told Judith that she would contact the local MODY link nurse, and arrange for Judith to be seen by her.

Reflecting on practice

To what extent was this practice nurse acting within the Code of Professional Conduct?

Midwifery

The NMC states that midwifery practice "must be woman-centred and responsive to the needs of women and their families in a variety of care settings. This will be reflected in the capacity to assess the needs of women, and to determine and provide programmes of care and support for women during the pre-conception, antenatal, intrapartum and postnatal periods" (NMC 2002c). The midwife has a statutory duty of care for the mother and baby for up to 28 days after birth.

The midwife thus may often have to care for women and the fetus or baby with or at risk of genetic conditions, routinely counselling women about prenatal screening procedures such as maternal serum screening and ultrasound scanning, and postnatal screening via the

Guthrie (heel-prick) test. In all of these, midwives play a central role in identifying increased genetic risk for the woman or her baby.

This was Ella's second baby, a little boy. I'd been to see her on the 3rd day and mum and baby were doing well. On the 5th day I popped in again, and was pleased to see that her breast feeding was settling down nicely. I told her that I'd be back the day after next to do the heel prick test (Guthrie) and asked if she'd read the little leaflet about the test that we give out at antenatal clinics. Ella hadn't, and looked a bit embarrassed when she said she'd lost it. We had a laugh as I said she probably had enough to do with the baby and a toddler without searching for it, and I gave her another one.

When I went back on the 7th day, I asked Ella if she'd read the leaflet and she said yes, so I asked her to sign the consent form. I told her the tests were routine, and that the diseases were all very rare, but it helps if we pick them up early enough. I said that it took about three weeks for the labs to do the tests, and they only contact us if there's a problem, so not to worry if she didn't hear any more. The baby screamed of course when I did the heel prick – that always upsets the mums! Ella's husband Rob came home just as I was leaving, so I told him what a gorgeous son he had. I remember how proud he looked.

When the results came back to us a few weeks later, I was really shocked to hear that the baby had tested positive for Duchenne's. Something like this had never happened to me before. I went back with the health visitor to give Ella the results. I felt awful. Ella and Rob looked grey as they listened. The health visitor explained how it only affects little boys from about the age of two, and that his muscles would get gradually weaker. Ella got up and went over to the baby's carry cot and looked down at him and said "You know, I thought he wasn't kicking his legs as strongly as Sophie did when she was a baby. Do you think he's showing signs of it now then?"

It really hit me then that this test really means something. I mean, something that changes people's lives. I just felt like, well, we'd taken away the babyhood of this little boy for his family.

When we got back to the car, I just sat there and cried.

Reflecting on practice

Do you think the midwife obtained informed consent for this procedure?

The group felt that midwives hold a unique place with women, and that they value this close relationship. There was general acknowledgement that the competencies were relevant to midwifery practice, although the competencies that might be applied in some areas, such as the delivery suite, might be very different from those needed in others, such as the antenatal field. In the latter, the need to integrate genetics into education about lifestyle choices was recognised.

No additional competencies were identified, but it was agreed that statement 20 should be modified for midwives to read:

All midwives should understand the role of behavioural, social and environmental factors (lifestyle, socio-economic factors, pollutants etc.) to modify or influence the manifestation of fetal abnormality or disease.

Q.3 Do you agree?

In terms of depth of knowledge required at the different levels of practice, the view of the Panel was that at the point of registration, midwives should be able to apply all competencies to practice (=depth 2). The experienced midwife should be sufficiently competent to be able to teach the competencies.

Health visiting

The purpose of health visiting is to improve health and social well-being through identifying health needs, enabling people to improve their own health, and raising awareness about health and social well-being through influencing local policy (NMC 2002d). Thus the health visitor has to function at different levels; individual, family, social group and community. To do this effectively she or he needs to be aware of the needs and dynamics of these different 'tiers'.

Of particular relevance to genetics, the role of the health visitor includes:

- Conducting developmental screening programmes for children
- Encouraging people to achieve their potential for health
- Developing and providing health education programmes for all ages
- Identifying the health needs of the community (AGNC 2002).

David and Jane are a couple in their mid 30's. Jane has a 12 year old daughter, Melissa from her previous marriage. Jane and David also have 2 sons. Luke is 2½ years and Angus was born 10 weeks ago.

Baby Angus is already requiring treatment for milk allergy. He is fretful and Sally, the health visitor is spending a lot of time with the family offering advice and support. While at the home with Jane and the children, Sally notices that Luke is still quite clumsy when walking. He started to walk at 16 months, 'boys are always slower than girls' says Jane.

The health visitor doesn't want to add to Jane's worries but suggests that Jane ask the GP to check Luke when they are next at the surgery. She mentions to the GP her concern that Luke may have mild motor delay.

At the baby clinic, the GP examines Luke and orders a blood test. She tells Jane that she doesn't think it is anything serious but needs to check 'just to make sure'.

Luke has an elevated creatine kinase level and is referred immediately to the paediatrician. Jane phones the health visitor, very upset. She is worried that an urgent appointment may mean something serious. She has been told Luke might have a muscle problem and asks Sally for reassurance.

Luke is diagnosed with Duchenne muscular dystrophy. Jane is so shocked she doesn't take in any of the information the paediatrician gives her at the appointment. Sally visits them at home and they ask her to explain what will happen. Jane and David are now worried about Angus and ask Sally if he can be tested.

When Jane goes out of the room, Melissa asks the health visitor if she is going to get the disease and if Luke is going to die.

Reflecting on practice

How would you have responded to Melissa?

The syndicate group clearly saw much in the genetic competencies that was of relevance to the requirements set out by the NMC for pre-registration programmes (see Section 6 for further exploration of this). Panellists spoke of how health visitors are 'encouraged to look for vulnerable groups', and that 'seeking deviations from the norm' is a key function, along with a role in diagnosis and management.

The co-ordinating role of the health visitor was widely acknowledged; panellists felt that the statement should be amended to include the term 'inter-agency', thus:

All health visitors should seek co-ordination and collaboration with interdisciplinary and inter-agency teams of professionals (8).

Knowledge of genetics was considered important, and this should be at individual and population levels. There are regional differences in health visitor knowledge requirements, as some conditions are more prevalent in some areas, but it was felt that national screening programmes are to some extent lessening these regional differences. It was suggested that the revision to statement 15 for the common core competencies (the removal of the term 'and within populations') should be reversed for health visitors, thus:

All health visitors should understand the basic patterns of biological inheritance and variation, both within families and within populations (15).

Similarly, 'speaking out' was thought to be a fundamental part of the health visitor role; this phrasing implies a more pro-active role in relation to client empowerment and advocacy, and so the original wording for competency 9 was felt to be appropriate:

All health visitors should speak out on issues that undermine clients' rights to informed decision-making and voluntary action (9).

The distinction on levels of practice between Experienced and Higher was not welcomed by the group, who considered that all health visitors operate at the Higher level. Education is a fundamental part of their role, whether it involves educating individual clients or other professionals. For this reason it was felt that competencies 37 and 38 were relevant to the role and should be included in the competency list:

All health visitors should be able to:

- *Educate others about client-focused policy issues (37)*
- *Participate in professional and public education about genetics (38).*

Q.4 Do you agree that the inclusion or revisions of the competencies set out above are appropriate to the role of the health visitor?

Paul is 16 months old. He is the second child of James and Maria. He was born by ventouse extraction after a long labour.

Paul was diagnosed with cerebral palsy when he was 3 months old. Janet James, the health visitor, had noticed some muscles were hypertonic and he was diagnosed by a community paediatrician. Janet remains concerned about him and shares her worries with the GP. The parents are unwilling to hear her concerns, they can't bear any more bad news.

Paul is doing fairly well physically with physiotherapy and his parents are thinking about having another child. However, they ask the Health Visitor what the chances are of having another baby with CP. She is unsure and suggests a referral to the genetics service for discussion.

The parents are referred to the genetics clinic. The geneticist notes that Paul has some unusual physical features and his speech is delayed. He feels that Paul has a genetic condition, and tests subsequently confirm this. The parents are very upset and find it hard to accept the change in diagnosis.

Janet listens to their concerns and stays in touch, dropping around every week for a while. She contacts the genetic nurse and discusses the case with her, so she has a greater understanding of the condition. She also obtains details from the Contact a Family group in case the family ask about other affected children in the area. Gradually Paul and Maria are able to accept the new diagnosis and return to the genetics clinic for more discussion about prenatal testing in a future pregnancy.

Reflecting on practice

What competencies is this health visitor demonstrating in her practice?

From generalist to specialist: Haemoglobinopathies

There have long been nurses who work with people with or at risk of sickle cell disease or thalassaemia. The haemoglobinopathy counsellors have developed specific expertise in providing counselling, support and education for these people, their families and local communities. In 2000, the government announced that by 2004, there will be 'an effective and appropriate screening programmes for women and children including a new national linked antenatal and neonatal screening programme for haemoglobinopathy and sickle cell disease' (Department of Health 2000, Section 13.16). With the development of a national screening programme for these conditions, health professionals working outside this specialist field (particularly midwives and health visitors) will need to ensure they are sufficiently competent to deliver such a programme.

The Panel was presented with a scenario drawn from an experience within an area of high prevalence where screening is 'routine'.

Jennifer Masters is a 24 year-old bank clerk and her husband, Philip, is a 27 year-old engineer. They have been married for two years and are extremely pleased when Jennifer has a positive pregnancy test, as this baby will be the first grandchild for both families.

Philip arranges to be at home on the day that the community midwife calls to do the antenatal booking when Jennifer is 12 weeks pregnant. Jennifer and Philip classify their ethnic origin as Black British and during the taking of the family history Jennifer mentions that her mother had told her that there was 'sickle cell' in the family. The midwife asked Jennifer if she had been well throughout childhood, Jennifer replied yes, so the midwife said that it was unlikely that she had sickle cell. Philip was quick to mention that there was no history of sickle cell in his family so the midwife reassured the couple that there was no risk of the baby having a sickle cell disorder.

Jennifer's pregnancy progresses fairly well for the next few months, but at 28 weeks she notices that by the end of the day, and sometimes first thing in the morning she is experiencing mild to moderate pain in her hips and joints. She mentions this to the midwife at her next antenatal visit at the GP surgery, and is reassured when the midwife tells her about the minor ailments of pregnancy that can cause some discomfort. The midwife also takes a full blood count to check if Jennifer is anaemic, and advises Jennifer to rest when she returns home from work each day. The blood results indicate that Jennifer is mildly iron deficient, haemoglobin 10.5g/dl, so iron supplementation is prescribed.

By the time Jennifer is 32 weeks pregnant, she is not feeling any better, she was now finding it difficult to get out of bed each morning, and by the end of the day Philip would have to collect her from work and prepare the evening meal. She had intended to continue working as long as possible, but decided that she would finish work at the end of her 33rd week.

The first day of her maternity leave, Jennifer began to feel breathless and had mild pain in her chest, so made an appointment to see her GP and also mentioned the increasing pain in her hips and joints. He told her that the pains in her hips and joints were due to the extra weight associated with the pregnancy causing pressure on her joints, and stated that the pain in her ribs could be due to bruising of her ribs from foetal movements. Jennifer was given paracetamol and advised to rest.

At the end of this week, Jennifer, now 34 weeks pregnant, had attended her GP's surgery three times, with increasing breathlessness and chest pain, and was referred to the Obstetrician at the local hospital, where a pulmonary embolism was diagnosed. Her haemoglobin was 6.3 g/dl and haemoglobin electrophoresis revealed that Jennifer had Haemoglobin SC Disease. Three days later she had an emergency caesarean section and delivered a live boy in good condition, but only weighing 1.67kg.

Haemoglobinopathy screening was requested for the baby, and a diagnosis of Sickle Cell Disease was made (Hb SS). It transpired that Philip was a carrier of the sickle cell gene (Hb AS).

Reflecting on practice

Would you have approached the antenatal booking appointment any differently as a midwife? Given that Jennifer had not been identified as being at risk of sickle cell disease, is it reasonable to expect that the symptoms of joint pain and the anaemia might have alerted the midwife or GP to re-consider a possible link with sickle cell disease?

The Panel felt that the scenario illustrated an attitudinal problem of unconscious incompetence, with the situation being compounded by poor co-ordination and communication between the different health professionals involved in caring for the couple. The importance of family history in assessing predisposition to genetic conditions (17) was acknowledged, but panellists stressed that the more complex family structures, and smaller families, mean that non-informative family histories can be problematic in ascertainment of risk. Integrating the family history into practice so that it remains current, rather than being 'filed and forgotten' was also seen as an issue.

The issues raised by the scenario did not appear to be unique to the needs of clients within this specialist area. More general discussion about the client group did focus on the need to practice in a multi-cultured way. Some panellists felt that reluctance to ask questions to do with ethnic background as part of family history-gathering might reflect anxieties about political correctness. There needs to be a balance between asking questions sensitively and ensuring that clients will still receive the health care they need. For this reason, it could be argued that, for this specialist area of care, practitioners should in particular:

Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients (12).

However, this attitude is also implicit in the *Code of professional conduct* and thus the scenario presented, and the particular client group involved, could be seen as exemplars of how the principle to 'Respect the patient or client as an individual' may be applied to caring for people with or at risk of an inherited condition.

Cancer Care

The impact of genetics on cancer care provides an indicator of the likely effect in other areas of health care as the contribution of genetics to common conditions is elucidated. Skirton and Patch (2000) suggest that cancer genetics services represent the mid-point between the traditional genetics services that have focused on the rarer single gene disorders, and a future where genetics is integrated into all areas of health care, and case identification and screening using genetics become part of the medical toolkit. The Panel was told about the escalating volume of referrals to the cancer genetics services, many of which are for people at low risk and are inappropriate based on family history.

Although the expansion of genetics into 'the medical mainstream' is used as the rationale for improving genetic literacy in health professionals, the feeling of the Panel was that "if we can't get it right for the single gene disorders, we won't get the rest right." This is compounded when the levels of knowledge and skills within the particular specialty, such as cancer, are also poor.

The scenario presented illustrated the importance of the cancer nurse:

- Recognising the importance of family history in assessing predisposition to disease;
- Identifying clients who may benefit from genetic services;
- Understanding the potential limitations of genetic information – that identification of a genetic mutation does not necessarily lead to manifestation of the disease.

It was felt that one important focus for cancer nurses is to be able to identify people who may be at risk and who may benefit from genetics services. The estimation of risk, based on clinical guidelines was felt to be an area of growing significance, as well as having an awareness of the management of different levels of risk. The ability to communicate risk is of particular relevance in risk management for a disease of multifactorial aetiology such as cancer, and one panellist stressed the need to be able conceptualise genetics as 'another risk factor'.

Putting genetic risk into context in such circumstances requires that the professional understands the basic concepts of probability and thus competence 33:

All health professionals working in cancer care should be able to explain the basic concepts of probability and disease susceptibility and the influence of genetic factors in the maintenance of health and development of disease

may be seen as being of particular relevance to this specialty.

Q.5 Do you agree that this skill is important for professionals working in cancer care?

If such a skill is to be demonstrated, it would need to be underpinned by an understanding of the relationship between genotype and disease expression, in other words:

All health professionals working in cancer care should understand the difference between clinical diagnosis of a disease and the identification of genetic predisposition of disease (19).

Sarah is 49 years old and was diagnosed with bowel cancer at the age of 45 years. She has developed widespread metastases and is currently an inpatient on Ward C1 in the Oncology Unit, undergoing palliative chemotherapy.

Her sister Margaret has come to visit her and, on her way out, asks to speak to the Staff Nurse about Sarah's condition. She is tearful and worried about her own risk of developing the disease, and any risk for her children, now in their late teens. Margaret feels guilty that she is worrying about herself when her sister is so poorly. She discusses her concerns with Staff Nurse Davies, who is recently qualified, and asks if he thinks she or her children may

be at risk. Staff Nurse Davies asks if anyone else in the family has had cancer. Margaret tells him that their father died from bowel cancer, after a number of years of illness, and that her paternal grandmother also died of cancer. However, she is sure that her grandmother didn't have bowel cancer, and that it was 'probably cancer of the womb'. She says to Staff Nurse Davies that she knows bowel cancer is very common, and her father was in his sixties when he died, so 'there probably isn't a link'.

Staff Davies is busy and uncertain, but he is aware that some bowel cancers can be inherited and feels the family history may be suspicious. He tells Margaret that he isn't quite sure about any family link and asks her to speak to the Charge Nurse the following day; he will make a note in the diary.

Margaret is subsequently seen by the Charge Nurse who, on closer questioning, feels there is sufficient concern to warrant referral to the cancer genetics service. He explains what this will involve, and tells Margaret that even *if* she is found to have a mutation that is associated with bowel cancer, it doesn't automatically mean she will develop the disease. It transpires that Sarah and Margaret's father had initially been diagnosed with bowel cancer in his late forties, and their grandmother had died from endometrial cancer in her early fifties. Sarah is found to have HNPCC (hereditary non-polyposis colorectal cancer). Margaret is tested for this dominantly inherited mutation but is found to be negative (clear). Although very relieved, the guilt that Margaret feels is exacerbated by this outcome.

Reflecting on practice

What competencies is this Staff Nurse demonstrating in his practice?

Paediatrics

Paediatric nurses and health visitors work across a range of settings, at primary, secondary and tertiary levels of care. They deliver child-centred care whilst maintaining and supporting family involvement. Skirton et al. (AGNC Education Working Group 2002) outline the situations in which practitioners in this specialty need to use genetic information:

- to provide supportive, informed communication at the time of diagnosis or receipt of definitive results
- to ensure the nurse can act as a trusted and informed carer for children growing up with genetic conditions (such as muscular dystrophy or cystic fibrosis), as they may be probing increasingly for information about the condition, its prognosis and effect on life plans
- to help parents deal with feelings of anger, guilt or blame as they acknowledge their own genetic contribution to the child's illness or consider prenatal diagnosis in a future pregnancy
- to enhance awareness of conditions which may mimic non-accidental injury or abuse, such as osteogenesis imperfecta or conditions that result in failure to thrive
- to facilitate referral to local genetic services when appropriate.

The scenario presented to the syndicate discussion group related to a failure in the process of care for a mother and her baby born with sickle cell disease. The mother was attending for maternity services at an NHS Trust, in an area of high prevalence for this condition, with an established universal antenatal and neonatal screening programme for sickle cell disease. The mother was not offered screening. The birth of the affected baby had a profound impact on the family, and adverse consequences for the professionals involved. The event resulted in financial costs against the Trust.

The Panel felt that the scenario highlighted two issues central to the delivery of effective health care: the importance of competence on the part of the individual practitioner, and

the implementation of effective and efficient systems within organisations. To be competent, the practitioner must also be aware of these systems and how they operate.

At the Baby Clinic in the local Health Centre, the practice nurse is approached by Marie, whose son is receiving his first MMR injection. She is concerned and asks the significance of the six pale coffee coloured birthmarks her son has on his body. The nurse asks if they are painful, unsightly or cause her son problems, and Marie replies that they don't seem to. The nurse then tells her not to worry.

One year later Marie has a daughter who is born with a limb deformity and who has learning difficulties at school and a brain tumour in later life. The nurse missed the significance of the birthmarks being part of a dominant genetic condition called neurofibromatosis type 1 (a variable condition affecting boys and girls) which can be mild with birthmarks known as café-au-lait patches, and can also include nodules on the nerves, brain tumours, limb abnormalities and learning disabilities.

If the nurse had responded with a question such as, "Does anyone else in the family have them?" she would have been told that the father had them along with multiple unsightly lumps, many of which he had had removed, and he had had difficulties at school. If she had asked further about the wider family, or taken a family history, she would have seen that other members of the father's family had similar lumps, and maybe then seen the need to refer the family for specialist information and treatment for the child.

Reflecting on practice

There are thousands of conditions that have a significant genetic component, the great majority of which most health professionals will never encounter in their everyday practice, but of course some are more common. It is unrealistic to expect such professionals to know about all of these conditions, but adopting the approach of always asking yourself 'could this be genetic?' may help avoid a situation like that described above.

Do you agree?

Several key points emerged from a more general discussion on the role of the health professional working with children and their families. That the care of the child should be paramount is axiomatic, but was felt to be particularly relevant in relation to genetic testing. The ethical and legal issues around consent and the rights of the child, and around confidentiality, were acknowledged to be complex, with the potential for further difficulty when children with a genetic condition are fostered or adopted. Related to this, competence in acting as advocates for children or their parents was felt to be important, including in contributing to policy developments.

Psychosocial issues are also seen as being of relevance. Family dynamics can be seriously affected when a child has a genetic condition, and this is exacerbated by feelings of guilt or blame. The Panel expressed concern about the potential for discrimination against parents or children with a genetic condition; this was felt likely to become more of an issue with the increasing availability of information offered by the new genetics. One challenge facing practitioners is thus how to integrate new genetics into care, helping parents to incorporate information into parenting, without 'labelling' the child.

Q.6 Do you agree that integrating genetics into care, without labelling the child with or at risk of a genetic condition is a significant challenge facing health professionals who work with children? If so, to what extent would demonstration of the competencies set out in Table 10 help to address this challenge?

The Panel noted that competence in multidisciplinary working would require not only effective communication and co-ordination between health and social care professionals, but also between other professional groups, including teachers.

The issue of education is multi-dimensional. As part of the National Curriculum, children today are likely to have a better understanding about genetics, and many will have the skills to access information from the internet but will lack the critical skills to evaluate this. They will therefore need to be able to obtain honest, accurate and reliable information from health professionals in response to their questions. School nurses are seen as playing a key role in providing this information, including incorporating awareness about genetics and the implications of knowing one's own genetic make-up for informing lifestyle choices and reproductive decision-making into personal and social education programmes.

Q.7 Are the competencies identified in this document relevant to practitioners who work with children? Are there any additional competencies that you feel have been omitted?

Learning Disability

The learning disability nurse is specifically educated to care for people with learning disabilities and their involvement largely focuses on:

- Enabling people with learning disabilities and their families to be fully included and valued within society
- Promoting and maintaining physical and mental health of people with learning disabilities
- Assisting people with learning disabilities to develop skills to promote and maintain independence, empowerment and choice to a level at which each person with learning disabilities is able
- Providing direct nursing care and undertaking clinical activities for people with complex health needs
- Facilitating self advocacy for people with learning disabilities and when necessary acting as an advocate for people with learning disabilities with a particular focus on access to high quality services that promote and maintain health.

The contribution of inheritance to conditions associated with learning disabilities is well known. Members of the syndicate group acknowledged that more diagnoses would follow as a result of the 'new' genetics, and that old contacts would be reactivated as family links are explored in the light of new knowledge and clinical developments.

Learning disability nurses require a genetic knowledge base in order to:

- provide support to parents and people with learning disabilities who are referred for genetic investigation
- provide support and clarify information provided at the time of diagnosis of a confirmed genetic condition in one or more children
- assist parents work through the process of adaptation to the presence of learning disabilities which has a confirmed genetic cause in young and older children / adults
- plan and implement future care related to the presence of specific genetic conditions in relation to people with learning disabilities in order to promote health and limit complications
- working with parents who have learning disabilities who are planning to have children or are pregnant
- providing prompt and accurate information about access to genetic services to siblings and other relatives of people with learning disabilities who may ask about their personal genetic risks
- support people with learning disabilities who may develop any of the other genetic based conditions not associated with learning disabilities e.g. cancer, Huntington disease
- facilitate access to services and assist in the gaining of informed consent for genetic investigation in a range of other settings (Barr 2002).

Siobhan is nine years old and has a history of developmental delay since early childhood. She has had many appointments with a range of doctors, over a period of 4 years. No confirmed diagnosis was made. Mum attended most of the appointments, had kept regular contact with the local Health Visitor at the time, and made use of the General Practitioner when she felt this was necessary. Siobhan is well cared for at home and the family adapted around her abilities and needs. Following educational statementing, Siobhan has been attending a special school for children with severe learning difficulties for four years.

At nine years old Siobhan's behaviour became more difficult to manage at home and Mum became concerned about Siobhan eating inedible objects on a regular basis, such as plastic, wood, paper and blu-tac. This heightened concerns about Siobhan's future, how they would continue to care for her, and if her school placement would be changed.

The GP suggested a referral to the Paediatrician at the Area Hospital. Mum did not contact the Health Visitor as by then she did not have ongoing contact with her and felt from past experience she had little to offer in relation to managing Siobhan's behaviour. Mum was not aware of the local learning disability services.

The Paediatrician suggested an appointment to see a geneticist, as Siobhan had a number of physical features that would suggest the possibility of a genetic condition. On questioning by Mum as to what features were present the doctor is reported as listing small stature, small hands and limited wrist movement, awkward gait when walking, small head, small mouth and a high roof of mouth, adding this is similar to children with Down syndrome. Mum concluded that her child had been referred to see a geneticist because the doctor thought Siobhan might be 'slightly Down syndrome'.

Four months later Mum received an appointment to attend the Regional Genetic Service. During that time Mum had no contact with the GP, Health Visitor or Regional Genetic Service. Mum was becoming increasingly concerned about what would happen at the appointment and how Siobhan would behave. She was in the local health centre and 'bumped into' the Health Visitor, who told her that the Geneticist would want to examine Siobhan, take blood, ask some questions and maybe do some other tests. This heightened Mum's concerns, but the Health Visitor told her not to worry it would be fine, and she may find out what caused Siobhan's condition after all.

Mum and Dad reported feeling very unprepared for the appointment, particularly worried about how Siobhan would behave and also increasingly concerned about what if the doctor confirmed a condition and was able to say if it was someone's fault. On attending the appointment both parents found the Geneticist very welcoming and able to gain Siobhan's co-operation for a physical examination which both parents felt had been carried out with respect and dignity for Siobhan. The Geneticist was not specific but felt it was likely a genetic condition did exist, but wanted to do some more tests, such as x-rays.

When I spoke with the parents six weeks after their appointment, the x-rays had been taken they had received a written summary of their appointment and were waiting for another appointment with the Geneticist. They had no contact with local primary care services, but thought the Health Visitor may still get in touch.

Reflecting on practice

What genetic knowledge, skills and attitudes might have helped this health visitor to offer greater support to this family?

Three key issues emerged from the discussion that followed the scenario presentation:

- The importance of the client journey and the part that accessing genetics services plays in this;
- The value base of practice in learning disabilities;

- The importance of inter-agency collaboration.

The client journey

Clients accessing genetic services in the field of learning disabilities have often been searching for a diagnosis for some time, and genetics may be seen as representing (potentially) the end of that quest. Where a diagnosis is available, a more informed prognosis can be offered, and it was thought also that being able to attach a 'medical label' could be helpful in mobilising and accessing resources for support. It was also felt that this label could alter the client's ability to cope with the condition, helping understanding and the implications for other family members. It also can affect the responses of others, particularly where there are associated behavioural problems.

However, for many clients in the learning disability field, a diagnosis is not available. It was felt that this likelihood was not always appreciated by clients, and the importance of explaining the purpose of referral – in many instances it is so that genetics can be ruled out – and outlining what to expect from the referral, was emphasised. Even though the outcome may not be a diagnosis, being able to close that route in the quest for understanding, can help in providing some form of closure.

It was felt that for these reasons, the competencies that related to accessing genetics services were of particular importance to health professionals working in the field of learning disabilities:

- Identify clients who would benefit from genetic services (32)
- The components of the current genetic-counselling process and the indications for referral to genetic specialists (26)
- One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services (30)
- The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities (23)

Q.8 Do you agree that these are of particular importance for this client group?

An additional competency was also proposed:

All nurses and health visitors should understand the frameworks of adaptation that parents of children with disabilities journey through and where the seeking and provision of genetic information may fit into this process.

Q.9 Do you agree that health professionals working with people and their families with learning disabilities should demonstrate this competency?

The value base

The value base of learning disability nursing is rooted very much in viewing the client as an equal, with a right to access the same quality of information and services as is available to other groups. The issue of the quality of pre-conceptual care and advice for people with a learning disability was cited as an example of where inequity can occur.

One panellist emphasised that the place of genetics in learning disability should be seen as profoundly different because of the 'thin line' between genetics and eugenics. For this reason, there was strong feeling that the original wording of some of the competencies that referred to 'prevention' was inappropriate, and should be replaced by 'prevention of disease'.

There was strong support for the competencies that addressed the empowering and advocacy role of the health professional working with clients with learning disabilities, and their families. It was felt that all professional groups should be able to apply such competencies in their everyday practice. These were:

- Uphold the rights of all clients to informed decision making and voluntary action (9)
- Support client-focused policies (13)

- Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients (12)
- Some awareness of the history of misuse of human genetic information (eugenics) (29)

Q.10 Do you agree that health professionals working in the field of learning disabilities should be able to apply these competencies to their practice?

The importance of inter-agency collaboration

The client journey is often not a linear one as services can be accessed at different points, and different services accessed at the same or different times. The issues emerging from the scenario highlighted the role of inter-agency care and the need for co-ordination and collaboration for effective and efficient care and support. This competency was thus viewed as being of particular relevance.

I was surprised when Jason came to collect his younger half brother Anthony from the day centre. Anthony has learning difficulties and his behaviour can be disruptive and antisocial - he set fire to the local community centre last year. Jason doesn't normally collect Anthony as their mother usually does so, but he wanted to speak to the nurse at the centre. He asked me if he could be tested for Fragile X because he was thinking about his future. He told me that he wouldn't want a child like his brother. I'd only just started at the day centre at the time, and I wasn't absolutely clear about Anthony's medical history, but of course I knew that if he had Fragile X, then Jason also would have a 50% chance of inheriting the mutation.

I sat down with Jason and listened to his worries and as he talked, I became more and more concerned about his motivation for testing. He told me that his father and step-mother with whom he is currently living say he is 'just like his brother' and he wants to prove them wrong. He says 'I know I'm thick like him but I'm not bad'.

I told Jason that I would need to check Anthony's notes and asked him to call back. I said we could put him in touch with the genetics service if needs be, and they will be able to help - I've got to know their specialist nurses quite well over the years.

When I checked Anthony's notes, I found that although Fragile X was queried along with other possibilities a number of years ago, the tests were clear. No definitive diagnosis had been ascertained, but the notes highlighted the difficult social situation and it was felt that the home environment had not helped Anthony's behavioural problems. I realised then that that the issues confronting Jason didn't indicate the need for referral to the genetics service, but there are clearly problems there, and they're affecting his self-esteem. I might have a chat with the social worker instead.

Reflecting on practice

This scenario highlights the need to see genetics as only part of the picture and as part of the client's 'journey'.

If the nurse had found that Anthony's notes actually confirmed Fragile X (as well as indicating the social issues), should she have then referred Jason for genetic counselling?

Primary Care

In primary care where the majority of patients will be seen, the pattern of care will alter, as new services take the place of existing ones: more genetic screening alongside more specialist genetic counselling; more regular check-ups; more help for people to give up smoking not just advice that they should; more exercise on prescription alongside drugs on prescription, tailored to the individual's personal genetic profile.

Milburn 2001

In the debates which have followed the realisation of the need for change, the potential for primary care to play a more prominent part has been much discussed. Many authors have written enthusiastically about expanding the role of the primary health care team to include basic genetics services, supporting their arguments with research studies demonstrating the feasibility of this (e.g. Boulton et al. 1996; Rose et al. 1999). Primary care nurses have featured strongly in the provision of such services, particularly in relation to gathering family history or running family history clinics, and participating in screening initiatives. Skirton et al. (AGNC 2002) outline a number of clinical situations where genetics education would be relevant for nurses in primary care:

- offering pre-conception care
- caring for a child with developmental delay
- advising clients on the relevance of family history for conditions such as cancer, diabetes or heart disease
- contributing to the development of local policy guidelines for screening.

While calling into the well women clinic for a repeat prescription for the pill, Susan, a 36 year old woman, mentioned to the nurse that she had just found out that two of her father's sisters had had breast cancer. The nurse was not concerned and did not ask any further questions; she was aware that some breast cancer could be inherited but presumed her client's aunts were elderly and that inheritance of "female" cancers does not come from the male side. Susan was told not to worry.

At the age of 39, Susan then presented to her GP with stage 3 breast cancer. If the nurse had been aware that some breast cancer can be inherited as an autosomal dominant gene mutation, she would have been aware that her patient was at risk - even though it was the father's relatives who had been affected. If the nurse had asked further about the aunts, she would have been told that this information had only come to light as Susan had made contact with her father's side after many years, and in fact the cancers were diagnosed when the aunts were 36 and 40 years old. If the nurse had taken a three generation family tree she would have found that Susan's grandmother died at 60 from ovarian cancer.

If this patient's risk had been recognised then she could have been offered early surveillance by mammography and encouraged to report any breast concerns earlier than she did.

Reflecting on practice

What knowledge, skills and attitudes would have helped this nurse to practise from an evidence base?

The potential role for primary care health professionals was acknowledged by the syndicate group to be substantial and there was broad agreement that it was likely to be the focus for the 'new genetics'. As such, the competencies were felt to be relevant to primary care practitioners.

Concern was expressed about the burden of increased workload for the practice nurse in particular, and the inevitable expectation that nurses and health visitors would take on extended roles to meet increased demand. The need for additional training to support these roles, for new and existing staff was widely acknowledged. This should include training in the use of technology to access information, and to store, manage and integrate information such as that gathered from family history. The role of technology to support co-ordination and continuity of care was felt to be important.

Communicating effectively about risk was also felt to be a key issue, including the need to do so in a non-directive way, which might be contrary to the approach adopted in the more general approach to offering health education and advice. Related to this, raising awareness about avoiding inappropriate reassurance was felt to be an issue that has its roots in the fundamental ethos in nursing of wanting to reassure patients and 'make things better'.

Genetics competence in specialist areas

In selecting these five specialist areas for discussion (haemoglobinopathies, cancer, learning disabilities, paediatrics and primary care), the intention was to identify those elements of competence in genetics that are common, and to describe those that are unique. This would enable us then to create a framework of competencies that could be adapted to other areas of healthcare. The syndicate groups all recognise the place and relevance of genetics within these areas of practice. Of the common core competencies endorsed by the Panel, none was felt to be irrelevant to any of the specialist areas, and in some cases, it was felt that the minimum standard of a specific competency needed to be raised for a particular area.

- Q.11 Do you think these five specialist fields are areas where genetics competence is of greater relevance to practitioners?**
- Q.12 In which other areas do you think genetics competence has a particular relevance?**
- Q.13 Are there areas of care, for example, mental health or ITU, where you think competence in genetics should be of lower priority?**

SECTION 6 VALIDATING AND REFINING THE COMPETENCIES

Competence: The NMC framework

Where do these competencies fit into the existing frameworks set out by the NMC?

They can be mapped in two ways:

1. In relation to the Code of Professional Conduct (NMC 2002a)
2. In relation to the Requirements for pre-registration programmes for each of the professional groups (NMC 2002b, NMC 2002c, NMC 2002d).

The Code of Professional Conduct for nurses, midwives and health visitors (NMC 2002a) provides the foundation for the competencies set out in each of the core documents on competencies for the three professional groups (NMC 2002b, NMC 2002c, NMC 2002d). The NMC stipulates that adherence to the Code of Professional Conduct is an 'essential condition of entry to the profession', and its principles 'must be reflected at all stages of programmes of preparation'.

Table 5 shows where the three minimum competency standards (1-3) and the ten attitudinal statements can be aligned to the Code. Tables 6,7 and 8 respectively demonstrate where the competencies can be aligned to those set out in the nursing, midwifery and health visitor documents respectively.

Tables 6 and 7 outline both the domains and the related competency statements set out in the NMC's requirements for pre-registration programmes for nurses and midwives.

The Code of Professional Conduct

As a registered nurse, midwife or health visitor, you are personally accountable for your practice. In caring for patients and clients you must:

1. Respect the patient or client as an individual.
2. Obtain consent before you give any treatment or care
3. Protect confidential information
4. Co-operate with others in the team
5. Maintain your professional knowledge and competence
6. Be trustworthy
7. Act to identify and minimise risk to patients and clients.
(NMC 2002a)

Health visitors take a slightly different approach, basing the competencies on the principles of health visiting. Domains are outlined under each of the four principles, and competencies then described for these domains. The guiding principles are stated as:

1. Search for health needs (7 domains)
2. Stimulation of awareness of health needs (3 domains)
3. Influence on policies affecting health (5 domains)
4. Facilitation of health enhancing activities (6 domains)

Table 5: The NMC *Code of professional conduct* and related genetic competencies

Principle	Ref. no.	Related genetic competency
<i>Respect the patient or client as an individual</i>	2 4 7 9 12	Understand the social and psychological implications of accessing genetic services Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level Speak out on issues that undermine clients' rights to informed decision making and voluntary action Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients
<i>Obtain consent before you give any treatment or care</i>	6	Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias
<i>Protect confidential information</i>	5	Appreciate the sensitivity of genetic information and the need for privacy and confidentiality
<i>Co-operate with others in the team</i>	8	Seek co-ordination and collaboration with interdisciplinary team of health professionals
<i>Maintain your professional knowledge and competence</i>	1 3 10 11	Appreciate limitations of his or her genetic expertise Know how and when to make a referral to a genetics professional Recognise the limitations of their own genetics expertise Demonstrate willingness to update genetics knowledge at frequent intervals
<i>Be trustworthy</i>		
<i>Act to identify and minimise risk to patients and clients</i>	13	Support client-focused policies

Table 6: Pre-registration requirements for nursing programmes (NMC 2002b)

Domain	Competencies	Related genetic competency no.
Professional and ethical practice	Manage oneself, one's practice and that of others, in accordance with the UKCC's Code of professional conduct, recognising one's own abilities and limitations	1;3;4;5;6;7; 10;12
	Practise in accordance with an ethical and legal framework which ensures the primacy of patient and client interest and well-being and respects confidentiality	5;6;13;28;29
	Practise in a fair and anti-discriminatory way; acknowledging the differences in beliefs and cultural practices of individuals or groups	4;7;9;12;22
Care delivery	Engage in, develop and disengage from therapeutic relationships through the use of appropriate communication and interpersonal skills	2
	Create and utilise opportunities to promote the health and well-being of patients, clients and groups	33;34;35; (37;38)
	Undertake and document a comprehensive, systematic and accurate nursing assessment of the physical, psychological, social and spiritual needs of patients, clients and communities	3;17;31;32
	Contribute to the planning of nursing care, involving patients and clients and, where possible, their carers, demonstrating an understanding of helping patients and clients to make informed decisions	3;9;26;32;33
	Contribute to the implementation of a programme of nursing care, designed and supervised by registered practitioners	
	Demonstrate evidence of a developing knowledge base which underpins safe nursing practice	14;15;16;18; 19;20
	Demonstrate a range of essential nursing skills, under the supervision of a registered nurse, to meet individuals' needs which include (<i>inter alia</i>) maintaining dignity, privacy and confidentiality; effective communications and observational skills, including listening and taking physiological measurements	3;5;7;32
	Formulate and document a plan of nursing care, where possible in partnership with patients, clients, their carers and family and friends, within a framework of informed consent	
	Based on the best available evidence, apply knowledge and an appropriate repertoire of skills indicative of safe nursing practice	11,35,33; 36
	Contribute to the evaluation of the appropriateness of nursing care delivered	
Recognise situations in which agreed plans of nursing care no longer appear appropriate and refer these to an appropriate accountable practitioner		

	Provide a rationale for the nursing care delivered which takes account of social, cultural, spiritual, legal, political and economic influences	2;4;6;20;22
	Evaluate and document the outcomes of nursing and other interventions	30
	Demonstrate sound clinical judgement across a range of differing professional and care delivery contexts	
Care management	Contribute to public protection by creating and maintaining a safe environment of care through the use of quality assurance and risk management strategies	23;27A
	Demonstrate knowledge of effective inter-professional working practices which respect and utilise the contributions of members of the health and social care team	8;25;30
	Delegate duties to others, as appropriate, ensuring that they are supervised and monitored	8
	Demonstrate key skills	36
Personal and professional development	Demonstrate a commitment to the need for continuing professional development and personal supervision activities in order to enhance knowledge, skills, values and attitudes needed for safe and effective nursing practice	11
	Enhance the professional development and safe practice of others through peer support, leadership, supervision and teaching	35

Table 7: Pre-registration requirements for midwifery programmes (NMC 2002c)

Domain	Competencies	Related genetic competency no.
Effective midwifery practice	Communicate effectively with women and their families throughout the pre-conception, antenatal, intrapartum and postnatal stages	2;9;7;33
	Diagnose pregnancy, assess and monitor women holistically throughout the pre-conception, intrapartum and postnatal stages through the use of a range of assessment methods and reach valid, reliable and comprehensive conclusions	17;18;20;23;31;32
	Determine and provide programmes of care and support for women which are appropriate to the needs, contexts, culture and choices of the women, babies and their families; are made in partnership with women; are ethical; are based on best evidence and clinical judgement; involve other practitioners when this will improve health outcomes	3;7;9;32;34;35
	Provide seamless care and interventions in partnership with women and other care providers during the antenatal period which are appropriate for women's assessed needs, context and culture; promote their continuing health and well-being; are evidence-based; are consistent with the management of risk; draw upon the skills of others to optimise health outcomes and resource use	1;2;3;7;8;10;23;25;34;35
	Refer women who would benefit from the skills and knowledge of other individuals	3;10;32;34
	Care for, monitor and support women during labour and monitor the condition of the fetus and conduct spontaneous deliveries	
	Undertake appropriate emergency procedures to meet the health needs of women and babies	
	Examine and care for babies immediately following birth	
	Work in partnership with women and other care providers during the postnatal period to provide seamless care and interventions	2;3;5;8;26;27A;32;33;34
	Examine and care for babies with specific health or social needs and refer to other professionals or agencies as appropriate	3;32
	Care for and monitor women during the puerperium, offering the necessary evidence-based advice and support on the baby and self-care	2;23;27A;32
	Select, acquire and safely administer a range of permitted drugs consistent with legislation, applying knowledge and skills to the situation which pertains at the time	
	Complete, store and retain records of practice	31
	Actively monitor and evaluate the effectiveness of programmes of care and modify them to improve the outcomes for women, babies and their families	30
	Contribute to enhancing the health and social well-being of individuals and their communities	13;32

Professional and ethical practice	Practise in accordance with the NMC's Code of professional conduct, within the limitations of the individual's own competence, knowledge and sphere of professional practice, consistent with the legislation relating to midwifery practice	1;3;4;5;6;7;9;10;12
	Practise in a way which respects and promotes individuals' rights, interests, preferences, beliefs and cultures	4;6;7;9;12;22
	Practise in accordance with relevant legislation	28;29
	Maintain the confidentiality of information	5;28
	Interact with other practitioners and agencies	8;34
	Manage and prioritise competing demands	3
	Support the creation and maintenance of environments which promote the health, safety and well-being of women, babies and others	
	Contribute to the development and evaluation of guidelines and policies and make recommendations for change in the interests of women, babies and their families	9;13;30 (38)
Developing the individual midwife and others	Review, develop and enhance the midwife's own knowledge, skills and fitness to practise	11 (38)
	Demonstrate effective working across professional boundaries and develop professional networks	8;34
Achieving quality care through evaluation and research	Apply relevant knowledge to the midwife's own practice in structured ways which are capable of evaluation	14;15;16;19
	Inform and develop the midwife's own practice and the practice of others through using the best available evidence and reflecting on practice	35 (37)
	Manage and develop care utilising the most appropriate information technology systems	36
	Contribute to the audit of practice to review and optimise the care of women, babies and their families	30

Table 8: Pre-registration requirements for health visiting programmes (NMC 2002d)

Principles of health visiting	Domains	Related genetic competency no.
Search for health needs	Develop and sustain relationships with groups and individuals within those groups with the aim of improving health and social well-being	5;6;7;9
	Monitor and identify the health and social well-being and related needs of groups and individuals within those groups	22
	Identify groups and individuals who are at risk or in need of further support	3;25;26;32;34
	Identify and evaluate service provision and support networks in the local area	30
	Collect, collate and analyse data related to improving health and social well-being	16;17;18;20;31;32
	Profile the health and social well-being of a community's population and its related needs based on an analysis of existing data relating to groups	16;18;19;20
	Prioritise work and the focus of activities	
Stimulation of awareness of health needs	Raise awareness about health and social well-being and related factors and services and resources	7;23;33 (37)
	Raise awareness about the actions that individuals, groups and communities can take to improve their health and social well-being	23;25
	Work with groups to encourage and enable them to identify services, benefits and community resources that will improve their health and social well-being	
Influences on policies affecting health	Identify the need to change policies and influence the change process	
	Work with others to change policies that do not improve health and social well-being	13
	Work with others to develop services and community resources based on the identification of needs related to health and social well-being	9
	Develop, implement, evaluate and improve one's own practice on the basis of research, evidence and evaluation	1;4;5;6;9;10;11;12;14;15;28;35
	Contribute to the development, implementation, evaluation and improvement of practice on the basis of research, evidence and evaluation	35 (37)

Facilitation of health enhancing activities	Lead individual practitioners in improving health and social well-being	9
	Work effectively with other practitioners and agencies to improve health and social well-being	1;8;10;30;36
	Enable groups and individuals to develop their knowledge, skills, confidence and resources about health and social well-being	4;7;9;33;35;36
	Plan, deliver and evaluate programmes to improve the health and social well-being of groups	8;32
	Contribute to the protection of groups and individuals whose health and social well-being is at risk	2;27A;28;29
	Develop partnerships with others to improve the health and social well-being of groups and individuals	8;30

What this demonstrates is that the competencies endorsed by the Expert Panel are effectively an interpretation of these documents 'through the genetic lens'. They do not represent an extension of the professional role, but they do make explicit how genetics competencies should fit into professional practice.

With this in mind, you might feel that the *Code of professional conduct*, and the *Requirements for pre-registration nursing/ midwifery/ health visiting programmes* are sufficient; that it is up to educators and trainers to ensure that the interpretation of the different competency statements contained within these documents includes genetics. Indeed, in the document *Requirements for pre-registration midwifery programmes*, it is stated that the specific examples of outcomes listed against each competency statement 'are intended to illustrate the intent of the competency and are not an exhaustive list' (NMC 2002c p7). On the other hand you may think that although competence in genetics is an implicit part of these documents, practitioners are not being prepared adequately to integrate genetics and that this can and does adversely effect client care. Thus you may feel that this deficit in competence needs to be addressed, and making explicit the genetics competencies is essential element of doing so.

Q.14 Should genetics be treated differently from any other specialty in interpreting the NMC's requirements for pre-registration programmes and the application of the Code, by defining specific competencies?

Q.15 If you agree that competence in genetics for these health professional groups does need to be promoted, do you think that identifying specific competencies is the best approach?

Refining and re-defining the competencies

Although the panellists endorsed the majority of the competence statements, there was a feeling that the list as it stood was unwieldy and could be further refined. In particular, although the statements were sub-divided into list pertaining to knowledge, skills and attitudes, the competencies generally were predicated on the demonstration of others; that they demonstrated a progression of competence. Thus, in order to demonstrate a particular skill effectively and efficiently, the practitioner would need also to have acquired specific related knowledge, underpinned by the appropriate attitude(s).

One example of this is the minimum competency statement that the practitioner should *Know how and when to refer* (3) and the related Skills statement that they should be able to *Identify clients who would benefit from genetic services* (32). To be able to achieve this competency effectively, the practitioner would need an understanding of how the family history may indicate increased genetic risk, and this would have to be underpinned by an understanding of the patterns of inheritance within families. Further, the practitioner would need to be aware of the current provision of genetic counselling services in order to appreciate how the client may benefit.

Table 9 shows how the list of competency statements have been re-grouped into seven related 'themes'. For each of these themes, a competency statement has been developed to reflect the issues contained in the individual statements.

Table 9: Redefining the competencies

A	Identify clients who may benefit from genetic services and information through an understanding of the importance of family history in assessing predisposition to disease, seeking assistance from and referring to appropriate genetics experts and peer support resources, and based on an understanding of the components of the current genetic counselling process.
32 3 15 17 31 25 26 34	Identify clients who would benefit from genetic services Know how and when to make a referral to a genetics professional Understand the basic patterns of biological inheritance and variation within families The importance of family history in assessing predisposition to disease Gather genetic family-history information, including an appropriate family history The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities The components of the current genetic-counselling process and the indications for referral to genetic specialists Seek assistance from and refer to appropriate genetics experts and peer support resources
B	Uphold the rights of all clients to informed decision making and voluntary action, based on an awareness of the history of misuse of human genetic information and understanding of the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias, recognising that personal values and beliefs may influence the care and support provided to clients during decision-making.
9 13 29 6 12	Uphold the rights of all clients to informed decision making and voluntary action Support client-focused policies Some awareness of the history of misuse of human genetic information (eugenics) Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients
C	Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level, recognising that ethnicity, culture, religion and ethical perspectives may influence the clients' ability to utilise these.
7 4 22	Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services That ethnicity, culture, related health beliefs and economics influence the clients' ability to use genetic information and services
D	Demonstrate a knowledge and understanding of the role of genetic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.
14 16 18 19 20 33	An understanding of basic human genetics terminology Understand how identification of genetic variations facilitates development of disease prevention strategies, diagnosis, and treatment options The role of genetic factors in maintaining health and preventing disease The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation) The role of behavioural, social, and environmental factors (lifestyle, socio-economic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease Know about basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease

E	Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information, including the ethical, legal and social issues related to testing and recording of genetic information and the potential physical and/or psychosocial consequences of genetic information for individuals, family members, and communities.
27 A 28 5 2 23	The utility and limitations of genetic testing The ethical, legal and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment) Appreciate the sensitivity of genetic information and the need for privacy and confidentiality Understand the social and psychological implications of accessing genetic services and information The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities
F	Recognise the limitations of one's own genetics expertise based on an understanding of one's professional role in the referral, provision or follow-up to genetics services.
1 10 30 8	Appreciate limitations of his or her genetic expertise Recognise the limitations of their own genetics expertise One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services Seek co-ordination and collaboration with interdisciplinary team of health professionals
G	Obtain and communicate credible, current information about genetics, for self, clients and colleagues, using new technologies effectively to do so.
35 36 11	Obtain credible, current information about genetics, for self, clients and colleagues Use effectively new information technologies to obtain current information about genetics Demonstrate willingness to update genetics knowledge at frequent intervals

These seven statements are not themselves mutually exclusive, and could be seen to have a common thread running through them. If competency statement A represents the key common core skill that represents what the practitioner should be able to do as a minimum in relation to genetics, then statements B and C could be seen as outlining the way in which this competency should be delivered. Statements D-G then reflect the supporting knowledge, skills and attitudes needed to deliver the key competency.

Q.16 Do you think these seven competency statements are an appropriate representation of the endorsed list of 34 competencies?

Q.17 Do you think all nurses, midwives and health visitors should be able to demonstrate these seven competencies at the point of registration?

Table 10: The redefined competencies

All nurses, midwives and health visitors, at the point of registration, should be able to:

A. Identify clients who may benefit from genetic services and information

- through an understanding of the importance of family history in assessing predisposition to disease,
- seeking assistance from and referring to appropriate genetics experts and peer support resources, and
- based on an understanding of the components of the current genetic counselling process.

B. Uphold the rights of all clients to informed decision making and voluntary action

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

C. Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level

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

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

E. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information

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

F. Recognise the limitations of one's own genetics expertise

- based on an understanding of one's professional role in the referral, provision or follow-up to genetics services.

G. Obtain and communicate credible, current information about genetics, for self, clients and colleagues

- using new technologies effectively to do so.

SECTION 7 BEYOND THE FRAMEWORK

Additional competencies

Panellists were invited to suggest competencies they thought should be additional to those on the voting sheets. In some cases these represented a clarification of the original wording, and these revisions were adopted. Other statements are specific in their genetics focus and suggest an extension of knowledge, skills or attitudes:

Knowledge

- i. All nurses, midwives and health visitors should understand the variable spectrum of severity of many genetic conditions.

Skills

All nurses, midwives and health visitors should be able to:

- ii. demonstrate facilitative discussion of genetic issues
- iii. empower clients to formulate their own genetic agenda
- iv. facilitate discussion regarding the contribution of post mortem information in making a clear diagnosis in relevant circumstances
- v. facilitate the ethical storage of DNA samples, including from patients dying or deceased from an inherited condition

Attitudes

All nurses, midwives and health visitors should:

- vi. acknowledge the importance of the client's readiness to access genetic information
- vii. recognise the importance of non-directive working in providing health promotion advice that incorporates genetic information and decision-making

Q.18 Which of these, if any, do you agree with? Are they applicable to all three professional groups? Are there any other competencies you feel have been omitted?

Implications for policy, practice and education

The Panel felt that the 'new agenda' being driven by developments in genetics challenges established systems, and perhaps in doing so, offers an opportunity to re-assess these. The point was reiterated that professional competence has to be supported by effective systems within and between organisations.

One panellist commented on the discrepancy between the agreed level of competence and the reality of practice, with genetics being given a low priority. It was felt that if competence is not given a higher priority at organisational level, and in education, this gap would only widen. At the same time, a sense of perspective has to be maintained in prioritising service needs. A balance has to be struck between prioritising need and the risk of doing nothing.

The place of genetics in health policy needs to be recognised, and the influence of the National Service Frameworks (NSFs) in raising awareness was emphasised as presenting a key way forward. However, the Panel felt that being able to influence policies such as the NSFs in this way presented a significant challenge, but acknowledged that rising public interest in genetics could provide a stimulus for change.

In taking forward the competency statements, panellists emphasised the need to demonstrate the 'added value' for practice of gaining such competence. Appropriate performance indicators and related learning outcomes will need to make explicit how the practitioner will 'come back changed' from a course of study. The programmes of study

themselves will also need to demystify genetics, and to demonstrate its relevance to practice.

The major challenge is to education, both at the level of the individual institution incorporating genetics into programmes of study, and nationally. Professional education has undergone a number of reforms in recent years since the major upheaval of the 1990's with the introduction of Project 2000. Educating for competence in genetics would undoubtedly create tensions with other competing priorities, but the Panel felt that the problem-based learning approach may be one answer, taking an integrated approach rather than delivering genetics teaching as a discrete module. Any further education developments also have to take place within the context of others, such as multi-professional education and the strategies to develop an ethos of life-long learning.

If these developments in genetics education are to take place at all on a meaningful scale, the endorsement of the stakeholder groups is essential. The synthesis of this work with the development of a national education strategy (Burton 2002) will also be fundamental to success.

Q.19 Should these competencies be endorsed by the stakeholder groups in health professional education and development?

Q.20 If they were to be endorsed, what do you think would be the three most important factors that would need to be in place to promote the achievement of these competencies by the three professional groups?

Q.21 What do you think would be the three greatest challenges to successful integration of these competencies into everyday practice?

Conclusion

The Panel represented a diversity of interests, expertise and experience, yet the degree of consensus that was achieved in considering a long list of competency statements was, on the face of it, remarkable. When these statements are aligned to the individual professional requirements, and the *Code of professional conduct* that is shared by the three professional groups, it is perhaps less remarkable. What the statements demonstrate is a view of professional practice 'through the genetics lens'. In the light of the acknowledged deficits in the current provision for the development of competence, the arguments for sustaining a specific focus on genetics and its integration into everyday practice for nurses, midwives and health visitors is a strong one

Next steps

The competencies set out in this document are only a first step, and these will be further refined in the light of this consultation. A final report will be prepared in the autumn which will reconsider the competencies in genetics for nurse, midwives and health visitors at different levels of practice and in different practice settings. Recommendations for the appropriate performance indicators to accompany the competency statements will be issued in this report. The implications of integrating the competencies into practice for the stakeholder groups will also be considered. Comments on this and responses to the issues raised in this document are invited from all those with an interest in the place of genetics within professional preparation, development and practice.

The document in its present form will be placed on the University of Glamorgan website at <http://www.glam.ac.uk/socs/research/gpu/InterimReport.pdf>

Please send your comments on *Fit for Practice in the Genetics Era* to:

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by August 31st 2003.

SECTION 8 SUMMARY OF QUESTIONS

Q.1 Do you agree with the Panel that the four statements identified by the Expert Panel (21, 24, 37, 38) should be excluded from the list of common core competencies for professionals at the point of registration?

Q.2 Do you think the exclusion should apply equally to the three professional groups?

Q.3 It was agreed that statement 20 should be modified for midwives to read:
All midwives should understand the role of behavioural, social and environmental factors (lifestyle, socio-economic factors, pollutants etc.) to modify or influence the manifestation of fetal abnormality or disease.

Do you agree?

Q.4 *All health visitors should be able to:*

- *Educate others about client-focused policy issues (37)*
- *Participate in professional and public education about genetics (38).*

Do you agree that the inclusion or revisions of the competencies set out above are appropriate to the role of the health visitor?

Q.5 *All health professionals working in cancer care should be able to explain the basic concepts of probability and disease susceptibility and the influence of genetic factors in the maintenance of health and development of disease*

Do you agree that this skill is important for professionals working in cancer care?

Q.6 Do you agree that integrating genetics into care, without labelling the child with or at risk of a genetic condition is a significant challenge facing health professionals who work with children? If so, to what extent would demonstration of the competencies set out in Table 10 help to address this challenge?

Q.7 Are the competencies identified in this document relevant to practitioners who work with children? Are there any additional competencies that you feel have been omitted?

Q.8 It was felt that the competencies that related to accessing genetics services were of particular importance to health professionals working in the field of learning disabilities:

- Identify clients who would benefit from genetic services (32)
- The components of the current genetic-counselling process and the indications for referral to genetic specialists (26)
- One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services (30)
- The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities (23)

Do you agree that these are of particular importance for this client group?

Q.9 An additional competency was also proposed:
All nurses and health visitors should understand the frameworks of adaptation that parents of children with disabilities journey through and where the seeking and provision of genetic information may fit into this process.

Do you agree that health professionals working with people and their families with learning disabilities should demonstrate this competency?

- Q.10 There was strong support for the competencies that addressed the empowering and advocacy role of the health professional working with clients with learning disabilities, and their families. It was felt that all professional groups should be able to apply such competencies in their everyday practice. These were:
- Uphold the rights of all clients to informed decision making and voluntary action (9)
 - Support client-focused policies (13)
 - Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients (12)
 - Some awareness of the history of misuse of human genetic information (eugenics) (29)

Do you agree that health professionals working in the field of learning disabilities should be able to apply these competencies to their practice?

- Q.11 Do you think the five specialist fields (haemoglobinopathies, cancer, learning disabilities, paediatrics and primary care) are areas where genetics competence is of greater relevance to practitioners?
- Q.12 In which other areas do you think genetics competence has a particular relevance?
- Q.13 Are there areas of care, for example, mental health or ITU, where you think competence in genetics should be of lower priority?
- Q.14 Should genetics be treated differently from any other specialty in interpreting the NMC's requirements for pre-registration programmes and the application of the Code, by defining specific competencies?
- Q.15 If you agree that competence in genetics for these health professional groups does need to be promoted, do you think that identifying specific competencies is the best approach?
- Q.16 Do you think the seven competency statements A-G are an appropriate representation of the endorsed list of 34 competencies?
- Q.17 Do you think all nurses, midwives and health visitors should be able to demonstrate these seven competencies at the point of registration?
- Q.18 Which, if any, of the additional competencies presented, do you agree with? Are they applicable to all three professional groups? Are there any other competencies you feel have been omitted?
- Q.19 Should the seven competencies (A-G) be endorsed by the stakeholder groups in health professional education and development?
- Q.20 If they were to be endorsed, what do you think would be the three most important factors that would need to be in place to promote the achievement of these competencies by the three professional groups?
- Q.21 What do you think would be the three greatest challenges to successful integration of these competencies into everyday practice?

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SECTION 10

APPENDICES

Appendix 1

The NCHPEG competency statements

MINIMUM

Each nurse, midwife and health visitor should at a minimum be able to:

Ref. Competency

1	Appreciate limitations of his or her genetic expertise.
2	Understand the social and psychological implications of genetic services.
3	Know how and when to make a referral to a genetics professional.

KNOWLEDGE

All nurses, midwives and health visitors should understand:

14	Basic human genetics terminology
15	The basic patterns of biological inheritance and variation, both within families and within populations
16	How identification of disease-associated genetic variations facilitates development of prevention, diagnosis, and treatment options
17	The importance of family history (minimum three generations) in assessing predisposition to disease
18	The role of genetic factors in maintaining health and preventing disease
19	The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation)
20	The role of behavioural, social, and environmental factors (lifestyle, socioeconomic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease
21	The influence of ethnoculture and economics in the prevalence and diagnosis of genetic disease
22	The influence of ethnicity, culture, related health beliefs and economics in the clients' ability to use genetic information and services
23	The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities
24	The range of genetic approaches to treatment of disease (prevention, pharmacogenomics/prescription of drugs to match individual genetic profiles, gene-based drugs, gene therapy)
25	The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities
26	The components of the genetic-counselling process and the indications for referral to genetic specialists
27	The indications for genetic testing and/or gene-based interventions
28	The ethical, legal and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment)
29	The history of misuse of human genetic information (eugenics)
30	One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services

SKILLS

All nurses, midwives and health visitors should be able to:

31	Gather genetic family-history information, including an appropriate (3 generations) family history
32	Identify clients who would benefit from genetic services

33	Explain basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease
34	Seek assistance from and refer to appropriate genetics experts and peer support resources
35	Obtain credible, current information about genetics, for self, clients and colleagues
36	Use effectively new information technologies to obtain current information about genetics
37	Educate others about client-focused policy issues
38	Participate in professional and public education about genetics

ATTITUDES

All nurses, midwives and health visitors should:

4	Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services
5	Appreciate the sensitivity of genetic information and the need for privacy and confidentiality
6	Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias
7	Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level
8	Seek co-ordination and collaboration with interdisciplinary team of health professionals
9	Speak out on issues that undermine clients' rights to informed decision making and voluntary action
10	Recognise the limitations of their own genetics expertise
11	Demonstrate willingness to update genetics knowledge at frequent intervals
12	Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients
13	Support client-focused policies

Genetic counselling

Skills 39-46 delineate the components of the genetic-counselling process and are expected of all health-care professionals who provide genetic counselling services to their clients. However, health professionals should be able to facilitate the genetic-counselling process and prepare clients and families for what to expect, communicate relevant information to the genetics team, and follow up with the client after genetics services have been provided.

39	<i>Educate clients about availability of genetic testing and/or treatment for conditions seen frequently in practice</i>
40	<i>Provide appropriate information about the potential risks, benefits, and limitations of genetic testing</i>
41	<i>Provide clients with an appropriate informed consent process to facilitate decision making related to genetic testing</i>
42	<i>Provide, and encourage use of, culturally appropriate, user-friendly resources to convey information about genetic concepts</i>
43	<i>Educate clients about the range of emotional effects they and/or family members may experience as a result of receiving genetic information</i>
44	<i>Explain potential physical and psychosocial benefits and limitations of gene-based therapeutics for clients</i>
45	<i>Safeguard privacy and confidentiality of genetic information of clients to the extent possible</i>
46	<i>Inform clients of potential limitations to maintaining privacy and confidentiality of genetic information</i>

Appendix 2 Stakeholder groups and delegate list

Field	Name
Clinical genetics	Dr Heather Skirton , Nurse Consultant and Chair JCMG, Chair of AGNC Education Working Group Liz France , Senior Genetic Nurse Counsellor, Cardiff, Member AGNC Professional Board Greta Westwood , Senior Genetic Nurse Counsellor, Southampton Penny Guilbert , Clinical Genetics Service Manager/Senior Genetic Counsellor, Nottingham, Chair AGNC Professional Board Dr Sally Davies , Consultant in Medical Genetics, Cardiff
Human Genetics Commission	Chris Patch , Genetic Counsellor/Specialist Nurse, Southampton
Department of Health	Dr Alison Hill , Medical Adviser to NHS Genetics Unit, Genetics Division
Regional Nursing Divisions	Karen Lockhart , Nursing Officer (Education & Regulation) Scottish Executive Health Department Rosemary Johnson , Nursing Officer, Welsh Assembly Government
Nursing Education	Helen Langton , Associate Dean, Coventry University (Council of Deans) Marianne Moutray , Associate Head of School, Queen's University Belfast Dr Maggie Kirk , Associate Head of School, University of Glamorgan, Associate Member AGNC Professional Board
NHS	Lorna Potter , National Lead for Nurses, NHS Alliance/NHSU Sue Fleming , Deputy Director of Health Studies and Nursing Services, Guernsey (Nursing Directors Association)
Nursing and Midwifery Council	3 representatives
Patient/user groups	Alistair Kent , Director Genetic Interest Group Sherlene Rudder , Sickle Cell UK & Thalassaemia Society
Royal College of Midwives	Sally Boxall , Consultant Nurse, Southampton
Royal College of Nurses	Jane Denton , Director Multiple Births Foundation Rosie Wilkinson , Adviser in Nursing Practice, RCN Professional Officer
Sector Skills Council for Health	Peter Stansbie , Director of Operations
Midwifery	Prof. Paul Lewis , Academic Head of Midwifery, Bournemouth University (also NMC) Mary Vance , Lecturer Midwifery & Health, Robert Gordon University, (also NMC) Jenny Fraser , Lead Midwife, Norwich
Health visiting	Maureen Williams , NMC Professional Adviser for Health Visiting Dr Pauline Pearson , Senior Lecturer in Primary Care, Newcastle, (former Chair CPHVA) Lynne Watson , HV for children with special needs, Twickenham
Cancer	Dame Gill Oliver , Director of Service Development, Macmillan Cancer Relief Sally Anstey , Genetic Counsellor, Project Team, Cardiff
Haemoglobinopathies	Glenda Augustine , Specialist Midwife Antenatal Haemoglobinopathy Screening, Birmingham Lorna Bennett , Clinical Services Manager Haemoglobinopathies, Camden & Islington Centre
Paediatrics	Dr Annette Dearmun , Principal Lecturer/Practitioner, Oxford Brookes University Prof. Bernie Carter , Professor of Children's Nursing, University of Central Lancashire

	Dr Faith Gibson , Lecturer, Great Ormond Street Hospital, RCN advisor
Learning disability	Owen Barr , Lecturer, University of Ulster Prof. Bob Gates , Professor of Learning Disabilities, Thames Valley University
Primary care	Prof. Ros Bryar , Professor of Community and Primary Care Nursing, City University Prof. Brenda Poulton , Professor of Community Health Nursing, University of Ulster Sara Richards , Chair Practice Nurses Association Grethe Ridgway , Director of Nursing Practice and Executive Director, Southampton PCT, Vice-Chair of DoH Standing Nursing and Midwifery Advisory Committee

Appendix 3 Expert Panel programme

Day 1		Monday 12th May 2003	
<i>Registration</i>			8.45
<i>Session 1</i>	Welcome and introductions Defining terms: competence, depth of competence and consensus Genetics and healthcare VOTE 1: Baseline views		9:00
<i>Coffee</i>			10:15
<i>Session 2</i>	The roles of health professionals in genetics: scenarios Common core competencies for newly-registered nurses and midwives		10:30
<i>Lunch</i>			12:30
<i>Session 3</i>	Common core competencies: depths of competence for newly-registered nurses and midwives Discussion VOTE 2: Depths of competency		13:30
<i>Tea</i>			15:00
<i>Session 4</i>	Syndicate groups: Discussing depth of competence, levels of practice and additional competencies for the three professional groups <i>Nursing Discussion Group</i> <i>Midwifery Discussion Group</i> <i>Health visiting Discussion Group</i>		15:15
<i>Session 5</i>	Reconvene for voting and discussion VOTE 3: Depths of competence at different levels of practice		16:15
Close			17:15

Day 2	Tuesday 13 th May 2003
<p>Session 6</p> <p>Recap: yesterday's votes Plenary discussion: two exemplars of health professional practice incorporating 'traditional' and 'new' genetics</p> <ol style="list-style-type: none"> 1. Identifying additional competencies and depths of competence in genetics for health professionals working in the haemoglobinopathies specialty 2. Identifying additional competencies and levels of competence in genetics for health professionals working in cancer care 	9:00
<p>Coffee</p>	10:30
<p>Session 7</p> <p>Syndicate groups: Discussing competence in three further areas of health care</p> <ul style="list-style-type: none"> <i>Paediatrics Discussion Group</i> <i>Learning Disability Discussion Group</i> <i>Primary Care Discussion Group</i> 	10:45
<p>Lunch</p>	12:00
<p>Session 8</p> <p>Discussion: What needs to be put in place to enable nurses, midwives and health visitors to achieve the required standards of competence?</p>	13:00
<p>Session 9</p> <p>Summary VOTE 4: Reconsidering the depth of competence for all nurses, midwives and health visitors at the point of registration</p>	15:00
<p>Tea and close</p>	15:30

Appendix 4

Team Membership

The project team

Dr Maggie Kirk (Project leader)
Mr Kevin McDonald

Ms Sally Anstey

Dr Marcus Longley

Genomics Policy Unit, University of Glamorgan
Research Assistant, Genomics Policy Unit, University of Glamorgan

Practice Development Co-ordinator, Cancer Genetics Service for Wales, Cardiff

Assistant Director, Wales Institute for Health & Social Care, University of Glamorgan

Steering Group

Professor Elizabeth Anionwu

Ms Caroline Benjamin

Dr Sally Davies

Ms Jane Denton

Ms Elizabeth France

Dr Jonathon Gray

Ms Penny Guilbert

Dr Rachel Iredale
Dr Heather Skirton

Head, Mary Seacole Centre for Nursing Practice, Thames Valley University; member Human Genetics Commission

Macmillan Genetic Associate and Research Training Fellow, Liverpool Women's Hospital Trust and Liverpool University

Consultant in Genetics, Institute of Medical Genetics, Cardiff

Director, Multiple Births Foundation, Queen Charlotte's Hospital, London; member HFEA

Senior Nurse, Cancer Genetics Service for Wales, Cardiff

Director, Cancer Genetics Service for Wales; Clinical Director, Institute of Medical Genetics, Cardiff

Senior Nurse, Clinical Genetics Service, Nottingham City Hospital

Genomics Policy Unit, University of Glamorgan

Nurse Consultant in Genetics, Taunton and Somerset NHS Trust; Lecturer, Institute of Medical Genetics, UWCM, Cardiff

Current service provision

In the UK, medical genetics is defined by the Department of Health as a specialised service. Provision has developed largely as local centres of expertise delivered through Regional Centres, of which there are 25, serving populations of between 1 and 5 million. Consultant clinical geneticists are based at each centre, supported by specialist registrars and genetics associates. The regional centres usually also include, or are closely affiliated with, the laboratories that offer cytogenetics and molecular genetics services. Links with secondary and tertiary specialists are established, and the larger centres may include other specialisms such as fetal medicine units.

Staffing levels of two consultant clinical geneticists and four genetics associates per million population are now regarded as the minimum for provision of a satisfactory service (Royal College of Physicians 1996). The genetics associate may be a health professional with a qualification in nursing, midwifery and/or health visiting, or may have been appointed through the more recent pathway after graduating with a master's degree in genetic counselling, with or without a health professional background.

In addition to offering general genetics services, centres may offer additional expertise on specific (often rare) conditions, and run specialist clinics accordingly. A few places have developed expertise in cancer genetics and established Cancer Genetics Centres.

The services offered by individual centres are delivered as an out-patient specialty, and although they may differ a little according to the specialisms of the consultants, each centre is broadly similar and the core services incorporate:

- Diagnosis of genetic conditions;
- Evaluation and communication of risk;
- Counselling;
- Follow-up and on-going support for families with or at risk of a genetic condition;
- An expert resource for education, advice and information for professionals, affected families and the public on various aspects of genetic disorders;
- Maintenance of genetic registers for specific major genetic conditions;
- Participation in research;
- Local or district services held at regular intervals, according to demand.

Referrals to genetics centres come from a variety of routes, most commonly from GPs and paediatricians, but also including surgeons and obstetricians, amongst others.