



A competence based education framework for nurses, midwives and health visitors

Fit for Practice in the Genetics Era

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Competent, capable, caring

Final Report to the Department of Health NHS Genetics Team

Prepared by
the Genomics Policy Unit, University of Glamorgan,
and the
Medical Genetics Service for Wales, University Hospital of Wales

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Acknowledgements

This report represents the culmination of a project commissioned by the NHS Genetics Team, Department of Health, to define core competencies in genetics for all nurses, midwives and health visitors across the UK. The Project Team is grateful for their support.

The work was carried out as a collaboration between the Genomics Policy Unit, School of Care Sciences, University of Glamorgan, and the Medical Genetics Service for Wales, University Hospital of Wales. Guidance has been provided by our Steering Group, and we have appreciated their ongoing commitment and enthusiasm for the project.

The delegates at the Expert Panel also gave their time freely and the Project Team thanks them for the interest they have demonstrated. The contribution from the Turners Syndrome Society to the conference was particularly welcomed. We are also grateful to all those individuals and organisations who have contributed to this report through their participation in the consultation process.

Thanks to all

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This report can also be downloaded from the GPU web pages at
<http://www.glam.ac.uk/socs/research/gpu/FinalReport.pdf>
ISBN 1-84054-104-0

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FOREWORD

“Genetics” is a word that has quickly established itself in the language. It has moved from science books to national newspapers in only a few years. Many people feel they have some awareness of genetics without necessarily having any deep understanding. For health professionals, genetics has already become an issue they cannot observe from the sidelines.

The expansion in genetics knowledge, together with increased public awareness and demand for information about its impact on health care, are powerful motivators for change in both education and clinical practice in the 21st century. To prepare nurses, midwives and health visitors appropriately and effectively in order to integrate genetics into their everyday practice presents a significant challenge.

The NMC welcomes this report. It demonstrates and builds on a valid interpretation of the requirements for professional practice, making them relevant and applicable to the evolving genetics and health arena. The competencies described in the report, with their linked standard statements and exemplars of learning and practice outcomes, are a welcome step forward in improving what can be described as “genetic literacy” across the professions. In so doing, the report will help prepare health professionals for the increasing complexities of health care delivery.

Most importantly, implementation of the standard statements will help serve to safeguard the interests of patients and may ameliorate their concerns about genetics. For this reason alone, we would encourage nurses, midwives and health professionals to embrace these competency standards.



JONATHAN ASHBRIDGE
President
Nursing and Midwifery Council

EXECUTIVE SUMMARY

Background and aims

In its White Paper on genetics, the Department of Health (2003) emphasised that education for health professionals is vital if advances in genetics are to be translated effectively into everyday practice. To support this, an NHS Genetics Education and Development Centre will be established, with the development of competency frameworks as part of its role. Ahead of this initiative, the Department of Health commissioned the Genomics Policy Unit, in collaboration with the Medical Genetics Service for Wales, to develop such a framework for nurses, midwives and health visitors. The primary aim of this project is thus to define the knowledge, skills and attitudes in genetics that these professional groups need at different levels of practice to deliver high quality care to different client groups, in order to inform health, education and professional policies. It builds on earlier work and is complementary to the work undertaken by the Public Health Genetics Unit in developing a national strategy for genetics education for all health professional groups (Burton 2003).

Approach

A four-phase process was used overseen by a Steering Group: defining and refining the competencies; consultation; assimilation of responses; completing the framework.

Using a nominal group approach, a UK-wide Expert Panel of 40 stakeholders from relevant fields of health care, including user groups, was invited to consider the competence in genetics that these professionals need at different levels of practice and for different patient groups. Scenarios were used to stimulate discussion within a structured programme, with voting in iterative rounds. Electronic voting technology captured and tracked views. Three levels of experience were considered, from the newly-registered to the more experienced practitioner such as the ward manager. Five settings were considered: cancer care, haemoglobinopathies, paediatrics, learning disability and primary care.

Consensus developed over the two day structured programme and 34 competency statements were endorsed. These were validated against appropriate professional (NMC) frameworks and then further refined to develop seven competence standard statements. An interim report on the findings of the panel was used as the basis for wider consultation that included a one-day consultation conference. Responses were assimilated using thematic analysis. The competence standard statements were placed in a framework with proposed learning and practice outcomes.

The endorsed competencies

Support for the seven statements (below) has been widespread and there was agreement that they demonstrate a view of professional practice 'through the genetic lens.' Although broad, they represent the minimum standard that should be achieved, the learning and practice outcomes making more explicit the scope of the competencies.

The competency standard statements

At the point of registration, all nurses, midwives and health visitors should be able to:

1. Identify clients who might 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.
2. 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.
3. 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.
4. 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.
5. 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.
6. 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.
7. Obtain and communicate credible, current information about genetics, for self, clients and colleagues using information technologies effectively to do so.

Applying the competencies

The competency standard statements are conserved across the professional groups at all levels of practice considered, and for different areas of health care. The level descriptors applied to the learning and practice outcomes can be used to define the depth of knowledge required so that it is appropriate to the professional role and level of responsibility. Additional learning and/or practice outcomes may also be incorporated to reflect the professional role or field of practice. In this way, the

framework provides a flexible model which can be adapted to reflect changes as new initiatives are integrated into practice.

Preparing for Practice

There is little dispute that practitioners need to gain competence in genetics, but there are concerns over how this may be achieved. Elements identified as being crucial to success include engagement of stakeholder groups, educating the educators, addressing competing priorities within curricula, identifying appropriate and innovative approaches to teaching and learning, clinical involvement and support, and effective management of change. The report outlines nine recommendations in relation to these issues.

The financial implications of developing and providing appropriate resources, and supporting access to these, is likely to be substantial. The need for close collaboration between educators and practitioners is seen as being particularly important in making explicit the links between practice and the underpinning theory. Mentors in practice will also need adequate support to ensure they are equipped to assess students' competence.

Any preparation strategy developed to promote competence will need to consider provision for practitioners already in post and top-up schemes for those who have achieved the minimum competence standards.

The implications for higher education institutions and the NHS in promoting achievement of the genetic competencies are acknowledged to be substantial. The role of the NHS Genetics Education and Development Centre in co-ordinating and evaluating developments will be crucial to success.

Conclusions

Reaching a consensus on the framework represents an important step forward for nursing, midwifery and health visiting, providing a firm platform on which to base further developments integrating genetics into education and professional practice.

GENETIC COUNSELLING - A PERSONAL VIEW

My daughter Lowri was born one week late on 24th June 2000, after a normal pregnancy and normal birth. She weighed 5 lb 12 oz. She was a new sister for Lewis who was 6½ years old. Even though she was a small baby she was very active (constantly wriggling/moving even when asleep), slept very little, drank small amounts of milk (although she continued to gain weight this was quite low but steady).

At her 9 month check our GP stated she was rather small and a bit slower in doing some things, but not to worry we would look at this again when she was one year old. A few weeks later she had a virus and lost over 1 lb in weight, she was immediately referred to a Paediatrician at the beginning of May 2001. By the end of May she had her first appointment, she was put on high energy milk/powders which made little or no difference to her weight gain. After 3 months of blood/sweat tests we were asked if Lowri could have a chromosome test, only a small blood test. Two weeks later we had a telephone call to attend the hospital later the same day. Immediately alarm bells started ringing, why did they need to see us so soon? What was wrong ?

Strangely enough Lowri slept when we were at the hospital as if she knew we needed time with the doctor. The doctor explained that the chromosome tests had shown up a condition called Turner Syndrome and handed us a booklet, explained briefly what TS was and told us to read the booklet, adding that not all the information would apply to Lowri but we would be sent an appointment to see a growth specialist.

Armed with only the booklet we made the journey home. Why did our daughter have TS? What did I do wrong? Can this be corrected? Will she suddenly develop anything physical? Why didn't anyone else know about TS? Why did we have to read a booklet, couldn't someone talk to us about this?

Reading the book amongst the many tears was difficult (it still hurts even now) and family and close friends did not know what to say as they did not know what TS was. We contacted the Growth Foundation who gave us the telephone number for the TSSS (Turner Syndrome Support Society).

Spoke to Arlene - my life line even though she was in Scotland and I made lots of tearful calls, had lots of questions which were always answered, someone who knew what I was talking about at last. Well worth the huge phone bill. In October 2001 an appointment to see the Growth Specialist, I had waited so long, at last someone who could answer all my questions. Disappointed we did not have much time with the doctor but we were asked if we wanted Genetic Counselling - A BIG YES PLEASE. Unfortunately this appointment did not happen until October 2002.

During the wait for the appointment, I spoke to my Health Visitor who wanted to help but had not even heard of TS, our GP had heard of it but never dealt with it, again felt very alone and no support from anyone, other than TSSS. Surely I can do something to help my daughter, but who do I turn to, what problems will she have, surely as a mother I can do something to help? But what - I felt that I was useless and wanted to do something, but what? Who could help me, was there any one who could guide me?

At last the appointment with Genetics arrived and after only 10 minutes I felt that someone understood how I felt and I felt that I understood more of my daughter's condition. The Doctor explained the make-up of Lowri's chromosomes, even had a colour picture, also explained that Lowri had a Ring X chromosome which answered some questions of poor sleeping/hyperactivity/poor eating etc. Suddenly a year after her diagnosis I felt that some help was available, and things slotted into place, even my husband began to accept her condition as before this he wanted to believe it was not really happening to us, and don't worry she'll be fine, but from that day on he became more supportive and between us we were able to work together to help Lowri. I feel that during the time waiting for the appointment I wasted time worrying instead of enjoying my daughter for what she is - a lovely but very lively little girl. (Although a good night's sleep would be nice.)

I feel that the first year after diagnosis was very difficult, the feeling of loneliness trying to deal with a condition that was seldom heard of, not knowing whether I was doing right or wrong or what should I do if anything. Yes, an earlier Genetics appointment would have helped but also other professionals being more aware of genetic conditions like TS and being able to offer help/support at the earliest opportunity not waiting a year. To understand the condition fully and a pointer in the right direction would have made a difficult time a little easier.

Yes it is my daughter who has TS but my whole family are affected and I feel that this could have been made easier with earlier input and support from the professionals, who can answer your questions and be able to reassure you that yes it is OK to cry, you will ask, why me? You will be able to do things to help and not wait for things to happen, just the reassurance of knowing that there is help if you need it, would have been nice and that there is someone who understands your feelings and is aware of TS or another genetic condition.

Lynette Jones
Mother to Lowri and Lewis

1. SETTING THE SCENE

Introduction

The publication of the Genetics White Paper *Our Inheritance Our Future*, in June 2003 signalled very clearly the need for concerted action to develop and integrate genetics into health professional education and practice. The White Paper emphasises that if advances in genetics are to be translated effectively into everyday practice, genetics education for all health professionals will be vital. As part of its commitment to promoting genetics education, the Department of Health commissioned the Genomics Policy Unit, in collaboration with the Medical Genetics Service for Wales, to map out the competencies in genetics needed by nurses, midwives and health visitors. This report represents the culmination of that work.

The report is presented in four sections. In this first section we set out the background to this report, placing the work in context of other initiatives in this field. We summarise the process that has led to the compilation of this document.

In the second section, we present the common core competencies, setting them within a framework with proposed learning and practice outcomes. The implications of this framework for more experienced practitioners, for the individual professional groups, and for different healthcare settings, are considered in the third section. The final section looks at some of the issues raised in the process of consultation, and considers a way forward to promote genetic literacy for the professions.

The policy context

The advances being made in genetics and related technologies and the subsequent implications for health care have been widely discussed. There is now widespread acknowledgement that a 'genetics revolution' is underway, but there is also agreement that it will be a gradual process, and progress may be made more rapidly in some areas than others. The White Paper states:

The new genetics knowledge and technology has the potential to bring enormous benefits for patients: more personalised prediction of risk, more accurate diagnosis, safer use of medicines and new treatment options.

It sets out the government's plan for action and investment to maximise opportunities presented by these advances, outlining four key action strands that focus on building capacity within specialised genetics services, building genetics into mainstream services, further investment in genetic research and development, and investment in education and training for NHS professionals.

'Spreading knowledge across the NHS' is thus a key objective, and the paper sets out how the government will:

- invest in education and training,
- support evidence based care,
- invest in information systems, and
- support commissioners.

The major catalyst for achieving this will be the establishment of the NHS Genetics Education and Development Centre, to drive and co-ordinate activity. The remit of the centre will be to liaise with key stakeholders to promote integration of genetics into education programmes, and will help in identifying learning needs. Of most relevance to this project, it will also help in identifying skills and competency frameworks and in developing curricula for NHS staff groups.

The work by Hilary Burton and colleagues at the Public Health Genetics Unit (PHGU) in Cambridge was commissioned jointly by the Department of Health and the Wellcome Trust to help underpin the education component of the White Paper. The final report (Burton 2003) sets out a strategy to develop genetics education for all health professionals. This encompasses three elements. The **national steering group** for genetics education will 'champion the cause', providing leadership and vision for the development and promotion of genetics education. Echoing the White Paper, Burton also recommends the establishment of a **national centre for education**. This will take forward a **formal programme** that would include:

- Raising awareness and motivation among professionals to learn
- Pursuing formal opportunities to promote genetics education in service provision
- Promoting the development of leaders and facilitators with a special interest in genetics
- Developing education programmes
- Facilitating and sharing resources
- Developing electronic resources
- Developing core competencies in genetics.

Burton's work took a multidisciplinary perspective, but it was recognised that the needs of individual professional groups should also be considered. The work set out in this report is complementary to the PHGU initiative, and will be used to inform developments that emerge from the NHS Genetics Education and Development Centre.

These projects are not happening in isolation. Other, more general changes are also underway in the NHS, including in primary care. Changes to the way that GPs work as set out by the BMA (2003) may bring significant changes to the way that services in primary care are organised and delivered. The White Paper also highlights the role that primary care can play in genetics and indicates its firm support for genetics initiatives in this field.

The modernisation of the NHS described by the government in *Agenda for Change* (Department of Health 1999) is driving a review of roles and skills within the NHS and so is of some relevance to this current project. Linked to a revised pay system, one of the aims is to 'pay fairly and equitably for work done, with career progression based on ... competence' (p6). In this way, staff who take on more responsibility and develop new skills may be rewarded appropriately. Related to this is the NHS Knowledge and Skills Framework (Department of Health 2003), which aims to identify the knowledge and skills that individuals need to apply in their post, and to support effective learning and development of individuals.

Of course, not all of these policies apply across all regions of the UK. The work of the PHGU has been UK-wide in its perspective, but the White Paper applies to England. However, the devolved administrations of Scotland, Wales and Northern Ireland are considering the implications of the White Paper for development of services in these regions.

Background to report: our earlier work

A national survey on genetics education in pre-registration nursing programmes indicated that provision was patchy and insubstantial (Kirk 1999a). Following this, an expert advisory panel on nurse education was convened to review the place of genetics in the future of pre-registration nursing education. The consensus of the panel was that nurses were not being prepared adequately in genetics to meet the existing or future needs of patients and that this needed to be addressed. The panel recommended the establishment of a national collaboration to promote awareness of genetics, to provide curriculum guidelines and to act as a central resource to support teaching and learning (Kirk 1999b).

This current work represents a significant step forward in the moves to enhance genetic literacy amongst nurses, midwives and health visitors. The first phase of the project was reported on earlier in 2003 and this final report builds on the work presented in that document (Kirk et al 2003).

Aims

The primary aim of this project is 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 client groups, in order to inform health, education and professional policies. The competencies identified are placed within a framework that may be used as the basis for further development for each of the professional groups and for different health settings.

We hope that the framework developed will inform standards of care, service organisation and education policy and will provide a foundation for integrating genetics into practice involving other professional groups across the spectrum of care.

Objectives

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.

Approach

Simply producing a list of the identified knowledge, skills and attitudes in genetics required for competent practice by the three professional groups, whilst indeed representing a first step, would be of limited benefit. Moreover, in the rapidly moving field of genetics, it would also have a limited shelf-life. We want to move beyond the defined competencies to develop a framework that can also support capability. Fraser and Greenhalgh (2001) define competence as 'what individuals know or are able to do in terms of knowledge, skills, attitude'. However, they urge that education should aim for programmes of study that also enhance capability. They define this as 'the extent to which individuals can adapt to change, generate new knowledge, and continue to improve their performance.' The framework developed endeavours to promote competence and capability for ethical practice.

We were aware from our own work and from others, that engagement of stakeholder groups would be crucial to subsequent success in implementing the framework to be developed during the course of the project. For this reason, we felt involvement in the process was important in encouraging ownership of the framework, produced by a national collaborative effort. The steps taken to achieve this are set out next.

The Process

The final competencies set out in this report have been developed through a four-phase process: (1) defining and refining the competencies, (2) consultation, (3) assimilation of responses, and (4) completing the framework. A Steering Group has overseen the process, offering guidance and expertise, and has ensured that the process has been conducted in an open and transparent fashion.

Defining and refining the competencies

After a review of the literature, we decided to use the competency statements issued by the US National Coalition for Health Professional Education in Genetics (NCHPEG) as a template for discussion and identification of competencies appropriate for nurses, midwives and health visitors practising in the UK. These comprise 35 core competencies in genetics for all health professionals categorised under knowledge, skills and attitudes, and three minimum core competencies.

These three minimum competencies are that all health professionals 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.

Using a nominal group approach, a UK-wide Expert Panel of 40 stakeholders from relevant fields of health care, including user groups, was invited to participate at a two day meeting in Cardiff in May 2003. We used a structured programme of discussion and voting in iterative rounds, to enable us to construct a series of statements about the competence in genetics that the three professional groups need at different levels of practice and for different client groups.

As the NCHPEG statements were to be used as a framework for discussion only, and it was anticipated that revised wording would be adopted, we did not overly concern ourselves with the language or phrasing.

Panellists were selected on the basis of criteria identified by the Project/Steering Group team, but all had to be acknowledged experts within the stakeholder group. Heads/ Chairs of the stakeholder organisations, if unable to attend in person, were asked to nominate an appropriate representative.

Scenarios were used to stimulate discussion. In order to provide an element of 'future proofing' for the outcome, we also asked participants to think about how the health service itself might change over the next five years, and to bear in mind the lead time required for development and revision of curricula.

Electronic voting technology provided a rapid means of capturing and assimilating data, providing instant feedback to panellists. It was decided beforehand that the threshold for agreement for inclusion of a competency statement would be set at 75%. In order to identify when agreement had reached a level that was felt to be appropriate and sufficient for inclusion, we had to make a decision about what this level should be. In doing this, we had to strike a careful balance between ensuring that we were representing the majority, and not losing (or unduly promoting) the minority view. The nominal group allows for discussion and re-rating about possibly contentious issues, and these could be noted by the project team to explore further during the consultation exercise. This approach has allowed us to 'test' any issues that were raised and about which there was a strength of feeling.

Syndicate discussion groups were used to consider issues of relevance to the specific professional groups, and the five care settings considered (cancer care, haemoglobinopathies, paediatrics, learning disability and primary care).

Consensus developed over the two days and 34 competency statements were endorsed as representing the minimum core competencies common to the three

professional groups. Many elements of the knowledge, skills and attitudes required were agreed to be common across the professional groups and for different client groups, although the setting influences the emphasis on a particular competency. It was also agreed that the depth of competence achieved should reflect increasing experience.

These 34 statements were validated against appropriate professional (NMC) requirements to demonstrate that they do not represent an extension of professional roles, but do make explicit how genetics fits into the current framework. The statements were then further refined to develop seven competence standards (see Table 1, p17). Seven additional competencies were also proposed. An interim report produced on the findings of the Panel was then used as the basis for wider consultation (Kirk et al 2003).

We believe that the process whereby we were able to formulate these competencies was rigorous and that, as one respondent said, *'the approach taken, of getting experts to validate statements in serial voting procedures seems practical and egalitarian.'*

Consultation

The consultation conference

To launch the Interim report, and as part of the consultation process, a one-day conference was held at the University of Glamorgan in July 2003. Information about the event was widely disseminated, and attendance was free of charge. Over 80 delegates attended (Appendix 1).

That day's programme (see Appendix 2) commenced with a plenary session of individual presentations, including one from a user of genetics services. A panel discussion included representatives from the NMC, GIG, the NHS, Human Genetics Commission, and higher education. In the afternoon, delegates moved into syndicate groups (nursing, midwifery and health visiting) to discuss four tabled questions. The day closed with a plenary discussion about the issues raised in the syndicate groups, with a vote on three further questions.

The syndicate questions

Delegates were asked to discuss:

1. Should the seven competencies be endorsed by the stakeholders in professional education and development?
2. 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?
3. What do you think would be the three greatest challenges to successful integration of these competencies into everyday practice?
4. 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 of Professional Conduct, by defining specific competencies?

The plenary questions

Delegates were asked to indicate by raising a colour coded card, their responses to the following:

1. Would you be willing to adopt these competencies yourself?
2. Are they 'doable' in your immediate sphere of responsibility?
3. Do you think the health services will rise to the challenge?

Wider consultation

To seek further views, the consultation document was distributed widely to individuals and stakeholder groups across the UK. The document was also published on the University of Glamorgan web site.

Assimilating the responses to the consultation exercise

We received 32 responses to the consultation document from individuals and organisations (Appendix 3). These were collated, along with notes taken during the conference, and thematic analysis was carried out to ascertain views and to assess the strength of agreement on the different issues raised. This has informed the final presentation of the competencies.

Completing the framework

The seven common core competencies were reviewed by the Steering Group in the light of the responses and minor revisions made where appropriate. These endorsed competencies were then used as the basis for a framework that incorporates outcome indicators for each competency standard statement, presented as learning outcomes and practice indicators. The final framework will be disseminated through publications, the Internet and conference and seminar presentations.

2. THE COMPETENCY FRAMEWORK

In this section we will set out the seven common core competency standards in the context of the original competency statements and then within a framework that includes suggested learning and practice outcomes for the newly-registered ('competent') and more experienced practitioner.

Table 1: The common core competency standards

<p>All nurses, midwives and health visitors, at the point of registration, should be able to:</p> <ol style="list-style-type: none">1. Identify clients who might benefit from genetic services and information<ul style="list-style-type: none">• 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.2. Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level<ul style="list-style-type: none">• recognising that ethnicity, culture, religion and ethical perspectives may influence the clients' ability to utilise these.3. Uphold the rights of all clients to informed decision making and voluntary action<ul style="list-style-type: none">• 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.4. 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.5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information<ul style="list-style-type: none">• 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.6. Recognise the limitations of one's own genetics expertise<ul style="list-style-type: none">• based on an understanding of one's professional role in the referral, provision or follow-up to genetics services.7. Obtain and communicate credible, current information about genetics, for self, clients and colleagues<ul style="list-style-type: none">• using information technologies effectively to do so.

The competency standard statements

The seven competency standard statements are presented above, in Table 1. The panellists felt that the original list of 34 statements was too cumbersome and should be further refined. In the Interim Report, once we had validated each of the original statements by mapping them against the NMC requirements for pre-registration programmes, we re-grouped those statements into seven related themes. From these, we developed an overarching competency standard statement for each group. Table 2 shows the refined statements (shaded, and labelled A-G to distinguish them from the original statements) and the statements from which they were derived.

In developing essentially seven ‘new’ statements it was important to affirm that these were a valid representation of the endorsed list of competencies. The consensus has been that they are, and that they provide a more manageable list. It is therefore these seven statements that are used to form the basis of the competency framework.

As they are quite general statements, they might be vulnerable to re-interpretation and so need to be set in the context of Table 2. However, the development of learning and practice outcomes will make more explicit the scope of the competencies.

Table 2: The competency standard statements (shaded A-G) refined from the endorsed competencies

A	Identify clients who might 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	Identify clients who would benefit from genetic services
3	Know how and when to make a referral to a genetics professional
15	Understand the basic patterns of biological inheritance and variation within families
17	The importance of family history in assessing predisposition to disease
31	Gather genetic family-history information, including an appropriate family history
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 current genetic-counselling process and the indications for referral to genetic specialists
34	Seek assistance from and refer to appropriate genetics experts and peer support resources
B	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	Appreciate the importance of sensitivity in tailoring information and services to clients’ culture, knowledge and language level
4	Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services
22	That ethnicity, culture, related health beliefs and economics influence the clients’ ability to use genetic information and services

C	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
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.
27A 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 information 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

Support for the competence standard statements

Support for the competencies has been widespread and clearly welcomed by a number of organisations, including higher education institutions (HEIs):

"We strongly support the statutory drive to guide HEIs in providing appropriate genetic education and training and endorse the efforts of the [team] in developing an informed framework to prepare the NHS workforce to meet the future genetic challenges, especially those associated with screening, diagnosis, treatment of genetic disorders."

and professional organisations:

"We believe and agree that all nurses should have a responsibility to be able to at least answer questions adequately about inherited disease or to at least have the skills to support and assist families in acquiring relevant information and referring onwards ... appropriately."

"if nurses and midwives were able to achieve these levels of competence at registration then this would improve the experience of families with concerns about genetic conditions immeasurably."

However, we would be misrepresenting the respondents if we did not make clear that the affirmation of the competencies was not without qualification. One concern was that the statements are too broad. Others, although acknowledging that this could be challenging, viewed this more positively:

"... very often broad-base guidelines, devised centrally, for local consideration with close internal supervision and monitoring may often be the most appropriate way to move the agenda ahead."

Paradoxically, there was also some concern expressed at the level of detail required, particularly for statements 4 and 5, which were thought to expect 'too much detailed knowledge of junior nurses', but that statement 6 (Recognise the limitations of one's own genetics expertise) 'took some of the burden out of this':

"if every nurse recognises the limitations of her/his expertise, they should be able to acknowledge s/he might not have all the answers about genetic tests or genetic factors, when questions arise. If the situation is handled accordingly, then patient queries can be taken seriously and channelled appropriately, without knowing many details about how exactly genetic factors might contribute to the development of particular disease, or how genetic tests for particular conditions might work."

The rapidly changing genetics knowledge base was felt to be a further factor mitigating against too much detailed knowledge 'as this is bound to change very quickly.'

The importance of recognising the limitations of one's own genetics knowledge (statement 6) was echoed by other respondents, including one organisation who contended that this competence:

"is the statement most relevant to nurses and midwives and health visitors on point of registration. Provided this statement is understood and adhered to the other 6 are reasonable,

although they do include a considerable requirement for additional knowledge and skill that currently does not exist at this level."

This concern about the undoubted challenge to educators, service providers and practitioners in promoting achievement of these competencies was a common one, although the 'transferability' of many of the competencies was noted. One organisation captured this view when it stated:

"This is a significant education and development issue. The [organisation] believes that nurses, midwives and health visitors should be able to demonstrate the seven competencies at the point of registration, with the proviso that there should be a lead time to ensure that practitioners in the system are prepared and trained to similar standards (including those currently in training programmes and those in practice)."

Further discussion on the issues raised in relation to this is presented later (p51-56).

The additional competencies

In our Interim Report, we presented seven additional competencies proposed by the Expert Panel (Table 3).

Table 3: Additional competencies

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

Knowledge

- i. understand the variable spectrum of severity of many genetic conditions.

Skills

- 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

- 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

Consultation has indicated that opinion is divided on their appropriateness for inclusion within the list of common core competencies. The prevailing view is that they are more appropriate to the higher levels of competence, and that they could be subsumed within the other competencies. With this in mind, we have incorporated

them where appropriate into the learning and practice outcomes outlined in the next section.

Communication skills and issues around autonomy and advocacy are clearly felt to be of particular relevance and some respondents would afford these a higher profile within the competence statements. Related to these, the role of the health professional in allaying anxieties and in managing false expectations driven by the media was felt to be a valid component of competence. One respondent stated that:

“... public expectations of human genetics are often exaggerated and therefore one of the most commonly required competencies in the area of genetics will be to reassure people who are needlessly worried about conditions running in families...”.

A similar point is made by another respondent: *“The NHS is already overstretched, and we need to recognise and manage the expectations of patients/clients who may have unrealistic expectations of a ‘media hyped’ service”.*

The excluded competencies

At the Expert Panel meeting, four competency statements failed to meet the 75% threshold for inclusion:

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

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).*

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

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

There is some feeling that Statement 21 should be included as a common core competency. As one respondent argues:

“Economics will have a significant impact and importance in determining genetic developments in the UK at many different levels. This will be an important part of raising nurses’ political and economic awareness generally, in addition to making sure nurses can formulate a strong argument with a wide group of health professionals for or against the development of relevant genetic services for patients and their families.”

Another felt that this competency was *‘key to the development of accessible future genetics services, allowing health care professionals to take account of how ethnoculture and economics influence the uptake of services.’* However, the majority view was that this competency

was not appropriate for newly-registered practitioners, although it should be achieved at higher levels.

In our Interim Report, we expressed some surprise that Statement 24 was excluded from the final list of competencies, given the potential for pharmacogenetics to influence disease management and prevention. Views were clearly mixed (47% voted for its inclusion). This ambivalence has been reflected somewhat by the respondents, although the majority view is still that it is inappropriate for the newly-qualified nurse or midwife. However, its exclusion will need to be reviewed "*probably sooner than expected*" because of the advances in pharmacogenetics. This competence will be of increasing importance over time.

Following consultation, we conclude that:

- There is broad agreement that these four statements are not appropriate as minimum common core competencies.
- The four competencies should be achieved by all practitioners at higher levels of practice.
- Health visitors should demonstrate all four competencies.

Scenario: Appreciating the limitations of information

Sarah had recently qualified and was working on a general surgical ward. She was approached by Julie the sister of Melanie, one of her patients. Melanie was 34 and having a mastectomy for a diagnosis of invasive breast cancer. Julie told Sarah that she had been talking with a private plastic surgeon about having her breasts removed as she was very worried that she too might get breast cancer – she said she and Melanie always tended to have the same illnesses as children, and of course they look very much alike. Julie had found the surgeon's details from an internet search. The staff-nurse was aware that early onset breast cancer can sometimes be inherited, and so Julie might also be at risk. However, Sarah felt that what Julie was proposing was a drastic step to take without seeking further, and perhaps more independent information. She persuaded Julie to go to her GP to ask for a referral for genetic counselling before she made any further decisions about surgery.

Some time later Julie wrote to thank the staff nurse, as the genetics service were able to show that the breast cancer in her sister was due to an inherited fault in the BRCA1 gene, but that Julie had had the test and was found not to carry the faulty copy of the gene. This action by the nurse prevented Julie from having unnecessary surgery.

The common core competency framework

Context

The competency framework presented on the following pages represents the minimum standard that should be achieved by nurses and midwives at the point of registration (and by default, applies to health visitors at the commencement of their training). Each competency standard is applicable across all settings within primary, secondary and specialist health care environments. The types of client include individuals and/or families who are either affected by genetic conditions, carry a known or suspected genetic predisposition to certain common diseases, or have a strong family history, and the increasing number of “worried well” who are concerned about genetics and health.

The framework aims to support the development of academic and clinical competence by proposing possible theoretical learning outcomes and practice indicators for each standard statement. These are not meant to be exhaustive.

It is intended that these learning and practice outcomes would be achieved over the span of the training programme and over a variety of care settings. The order of the competence standards is not meant to reflect the order in which the outcomes should be achieved, and the learner may work towards achieving a variety of outcomes at the same time. The framework should also be viewed as dynamic, and outcomes may be revised to reflect developments in education, practice or policy settings.

Competence may be assessed in a number of ways. Assessment of learning outcomes may be incorporated into the existing strategy of individual institutions. Achievement of practice outcomes may be assessed through a variety of ways including:

- Direct observation and questioning of the learner within the care setting.
- Scrutiny of documentation completed by the learner.
- Feedback from other health and social care colleagues.
- Examination of a portfolio of evidence.

These standards seek to integrate the specific genetic element into the existing Nursing and Midwifery Council (NMC) pre-registration requirements for nursing and midwifery programmes. The Expert Panel agreed that the competency statements demonstrate a view of professional practice “through the genetics lens”. As such, many of the outcomes proposed are not unique to genetics and assessment of transferable knowledge and skills may be achieved within existing frameworks.

THE COMMON CORE COMPETENCY FRAMEWORK

Table 4 Core Standard Statement 1*: The competent practitioner

Domain: Care delivery	
<p>Identify clients who might benefit from genetic information and services</p> <ul style="list-style-type: none"> • 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 testing and counselling process. 	
Suggested learning outcomes	Suggested practice indicators
<ul style="list-style-type: none"> A. Explains basic human genetics technology. B. Describes basic patterns of biological inheritance, and variation both within families and populations. C. Recognises the role of family history in assessing predisposition to disease. D. Lists the resources available to assist clients seeking genetic information or services including the types of services available. E. Describes the different professional responsibilities and roles in relation to genetics services. F. Describes a typical ‘patient journey’ that might be experienced in the process of genetic counselling. 	<ul style="list-style-type: none"> 1. Demonstrates ability to take an accurate three generation family history in relation to genetic health risks. 2. Identifies potentially significant information from a family history. 3. Identifies with guidance clients who might benefit from referral to genetics specialists and/or information resources. 4. Facilitates appropriate referral to genetics specialists, accurately completing the relevant documentation.

*This represents the key common core skill that the practitioner should demonstrate as a minimum in relation to genetics.

THE COMMON CORE COMPETENCY FRAMEWORK

Table 5 Core Standard Statement 2: The competent practitioner

Domain: Professional and ethical practice	
<p>Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language</p> <ul style="list-style-type: none"> • recognising that ethnicity, culture, religion and ethical perspectives may influence clients' ability to utilise these. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. Recognises that clients' cultural, ethnicity and religious perspectives may influence their ability to use genetic information and services.</p> <p>B. Discusses the communication and interpersonal skills required in relation to genetic issues.</p> <p>C. Recognises the need to use language appropriate to the client's level of understanding.</p>	<ol style="list-style-type: none"> 1. Demonstrates the ability to communicate sensitively with clients to elucidate their cultural, religious and ethnic perspectives. 2. Demonstrates an awareness of the client's background in facilitating communication about genetics issues. 3. Demonstrates the ability to utilise resources to facilitate effective communication and access to genetics services. 4. Chooses language appropriate to the client's level of understanding and developmental age. 5. Uses communication skills to promote and check the client's understanding.

THE COMMON CORE COMPETENCY FRAMEWORK

Table 6 Core Standard Statement 3: The competent practitioner

Domain: Professional and ethical practice	
<p>Uphold the rights of all clients to informed decision making and voluntary action</p> <ul style="list-style-type: none"> • based on an awareness of the history of misuse of human genetic information and • understanding 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. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. Describes the social and psychological implications of accessing genetic services and information.</p> <p>B. Recognises the importance of and upholds the rights of all clients to informed decision making and voluntary action.</p> <p>C. Recognises the particular needs of those unable to give informed consent in relation to accessing and using genetic information.</p> <p>D. Discusses how personal values and beliefs in relation to ethical, social, cultural, religious and ethnic issues might influence client care.</p> <p>E. Identifies how an awareness of the past and potential future misuse of genetic information underpins the principle of the non-directive approach in genetic counselling.</p>	<ol style="list-style-type: none"> 1. Demonstrates an awareness of clients' needs, showing fairness and sensitivity when exploring with them the rationale for seeking specialist genetics advice/referral. 2. Identifies situations when one's own beliefs and values may have potential to influence the care given to clients. 3. Identifies situations where clients' own beliefs and/or values influence genetic choices. 4. Utilises communication skills to enable the client to express his or her own wishes, or to pursue a chosen course of action. 5. Displays a non-judgemental attitude at all times.

THE COMMON CORE COMPETENCY FRAMEWORK

Table 7 Core Standard Statement 4: The competent practitioner

Domain: Care delivery	
Demonstrate 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.	
Suggested learning outcomes	Suggested practice indicators
<ul style="list-style-type: none"> A. Describes the role of genetic factors in maintaining health and preventing disease. B. Describes the role of genetic factors in the manifestation of disease, using examples of the common inherited conditions. C. Identifies that disease expression may be influenced by the interaction between genetic and other factors, at different life stages. D. Applies basic concepts of risk to distinguish between genetic susceptibility and clinical manifestation of a disease. 	<ul style="list-style-type: none"> 1. Applies knowledge and understanding to identify potentially significant information from a family history. 2. Demonstrates the ability to use family history information to inform health education advice.

THE COMMON CORE COMPETENCY FRAMEWORK

Table 8 Core Standard Statement 5: The competent practitioner

Domain: Professional and ethical practice	
<p>Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information</p> <ul style="list-style-type: none"> • 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. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. Identifies the potential benefits, risks and limitations of genetic testing and accessing genetic information.</p> <p>B. Recognises the sensitivity of genetic information, in particular the associated ethical, legal and social issues.</p> <p>C. Discusses the potential impact of genetic information for individuals, family members and communities.</p>	<ol style="list-style-type: none"> 1. Ensures privacy when discussing genetic information. 2. Maintains confidentiality when recording genetic information. 3. Demonstrates sensitivity to the potential impact of genetic information for the individual and other family members. 4. Responds appropriately to enquiries about genetic concerns.

THE COMMON CORE COMPETENCY FRAMEWORK

Table 9 Core Standard Statement 6: The competent practitioner

Domain: Personal and professional development	
<p>Recognise the limitations of one’s own genetics expertise</p> <ul style="list-style-type: none"> • based on an understanding of one’s professional role in the referral, provision or follow-up to genetics services. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. Recognises the scope of practice as a newly-qualified health professional and acknowledges the limitations in one’s own abilities in relation to genetics.</p> <p>B. Recognises the role of specialist genetic services and other agencies in providing appropriate patient/client care.</p>	<ol style="list-style-type: none"> 1. Demonstrates appropriate care and concern for all patients/clients throughout their referral, provision and follow-up to genetics services. 2. Demonstrates awareness of the boundaries of one’s own professional practice in relation to genetics. 3. Identifies effective practice in health professionals more experienced in genetics. 4. Consults with appropriate professionals when care required is beyond one’s expertise. 5. Demonstrates an awareness of the boundaries of others involved in the provision of genetic services. 6. Actively works in a collaborative manner with health and social care colleagues (statutory and non-statutory).

THE COMMON CORE COMPETENCY FRAMEWORK

Table 10 Core Standard Statement 7: The competent practitioner

Domain: Professional and ethical practice	
<p>Obtain and communicate credible, current information about genetics, for self, clients and colleagues</p> <ul style="list-style-type: none"> • using information technologies effectively to do so. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. Recognises the importance of updating genetic knowledge at frequent intervals and the consequent benefits for self, clients and colleagues.</p> <p>B. Appreciates the limitations of information and its credibility and reliability.</p> <p>C. Critically appraises information from different sources.</p>	<ol style="list-style-type: none"> 1. Demonstrates knowledge about accessing local/regional genetics resources. 2. Actively refers to research based evidence about genetics related to patient/client care. 3. Adopts a range of interpersonal skills whilst communicating with clients and colleagues about genetics issues. 4. Takes action to meet any identified knowledge and skills deficit likely to affect the delivery of care within one's own current sphere of practice.

3. APPLYING THE COMPETENCIES

Identifying core competencies common to the three professional groups provides us with a foundation for further development of the framework according to the experience of the practitioner, the individual profession, and the clinical setting. This report is not intended to provide definitive descriptors for each of these aspects of the framework, but gives some indication of how they might be developed, based on the deliberations of the Expert Panel and subsequent consultation.

Levels of practice

Being able to describe practice through professional or clinical competence offers a system that facilitates skill-mix organisation and career progression. We have used three levels of practice in genetics for health professionals working *outside* the clinical genetics service, to allow us to build a hierarchy of competencies that places the newly-registered practitioner (nurse or midwife) on the 'first rung' of this progression. In the future, and by virtue of the entry requirements for health visiting, this professional group already would have achieved these competencies at this level. This view was endorsed by health visiting representatives attending the Expert Panel. Many midwives would also have done so, but we have included them at this 'first rung' level in order to incorporate those who enter this profession without having previously qualified as nurses (i.e. direct entry midwives).

The levels described below are felt to represent a general expectation of the professional role at that level. They should not be seen as definitive and do not claim to be so, but do offer a point of reference in the development of a hierarchy of competence. The three levels are:

Level 1: Competent

This equates to the newly-registered nurse or midwife working in a general or specialist area and who is '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.

We would anticipate that this hierarchy would be extended in the future to incorporate the role of the consultant nurse. Levels of competence for genetic counsellors have been defined by the AGNC and are outside the remit of this report (for further details see <http://www.agnc.co.uk/Registration/competencies>).

Developing competence

The competency framework (Tables 4-10) represents the minimum standard that should be achieved by newly-registered nurses and midwives. The level descriptors used for the learning and practice outcomes are based on Bloom's taxonomy of learning. Bloom (1956) developed a classification of levels of intellectual behaviour that range from simple recall or recognition of facts through increasingly complex levels to evaluation:

1. Knowledge
2. Comprehension
3. Application
4. Analysis
5. Synthesis
6. Evaluation

His seminal work is perhaps the most widely used of taxonomies to help devise learning outcomes, each level being associated with a number of words to define the level of learning achieved. The learning outcomes themselves can then be used as a tool for curriculum design.

As a *minimum*, the Panel agreed that practitioners should know and understand the implications for practice of all of the competency statements that subsequently have formed the seven standard statements, with many that should be achieved to sufficient depth that they could be applied to professional practice. The level descriptors used in this framework reflect the depth of knowledge that the Expert Panel felt would be appropriate at this career stage. It is these descriptors that can help moderate the detail required so that it is appropriate to the level of practice.

Post-registration development

It is important that this framework is not seen solely as a vehicle for the achievement of pre-registration competency; it is also integral to post-registration professional development of practitioners. As one respondent stated "*... all appropriate stakeholders should be encouraged to recognise the relevance of genetics at all stages of health care practice.*"

The framework can be adapted for more experienced practitioners by making changes to the practice indicators and learning outcomes. The level descriptors can thus be revised to reflect the greater depth of knowledge and skill required to achieve a higher level of competence. For example, whereas a newly qualified practitioner may be required only to *identify that...*, the more experienced practitioner

would be expected to *analyse how....* Similarly, the newly qualified practitioner may be required only to *'Recognise the particular needs of those unable to give informed consent...'*, demonstrating this as a learning outcome for statement 3. The experienced practitioner would be required to demonstrate in practice that s/he would be able to *'Defend the particular needs of those unable to give informed consent'*.

With this approach, the competence standard statements are conserved throughout the career progression. We do propose that in some instances, additional outcomes may be incorporated to reflect some expansion of the role with increasing experience. Examples of these are shown below for four of the competence standards for the experienced practitioner, selected specifically as these incorporate the additional competencies and those excluded at the competent level (Tables 11-14).

A similar approach may then be taken for the practitioner we describe as working at the 'higher' level. At this level, the depth of knowledge required is likely to become more specific to the specialist area. One standard statement is shown as an example for a cancer specialist nurse (Table 15). It will be important that this framework is used to map against evolving roles, such as the consultant nurses, midwives and health visitors.

It must also be recognised that many existing experienced practitioners will not have achieved the competence standards outlined for newly-qualified practitioners. Any preparation strategy developed to promote competence will need to consider provision for these post-registration practitioners, along with schemes for 'top up' of those qualified practitioners who have achieved the minimum competence standards.

APPLYING THE COMPETENCIES

Table 11 Core Standard Statement 3: Example for the experienced practitioner

Domain: Professional and ethical practice	
<p>Uphold the rights of all clients to informed decision making and voluntary action</p> <ul style="list-style-type: none"> • based on an awareness of the history of misuse of human genetic information and • understanding 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. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. <i>Analyses</i> the social and psychological implications of accessing genetic services and information.</p> <p>B. <i>Appraises</i> how personal values and beliefs in relation to ethical, social, cultural, religious and ethnic issues might influence client care.</p> <p>C. <i>Analyses</i> how an awareness of the past and potential future misuse of genetic information underpins the principle of the non-directive approach in genetic counselling.</p>	<ol style="list-style-type: none"> 1. <i>Assesses</i> clients' needs, showing fairness and sensitivity when exploring with them the rationale for seeking specialist genetics advice/referral. 2. <i>Appraises</i> situations when one's own beliefs and values may have potential to influence the care given to clients. 3. <i>Appraises</i> situations where clients' own beliefs and/or values influence genetic choices. 4. <i>Applies</i> communication skills to enable the client to express his or her own wishes, or to pursue a chosen course of action. 5. Displays a non-judgemental attitude at all times. 6. <i>Supports a non-directive approach as appropriate when delivering health education that incorporates genetic information.</i> 7. <i>Defends the importance of and upholds the rights of all clients to informed decision making and voluntary action.</i> 8. <i>Defends the particular needs of those unable to give informed consent in relation to accessing and using genetic information.</i>

N.B. Text in italics indicates new or revised outcomes

APPLYING THE COMPETENCIES

Table 12 Core Standard Statement 4: Example for the experienced practitioner

Domain: Care delivery	
Demonstrate 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.	
Suggested learning outcomes	Suggested practice indicators
<ul style="list-style-type: none"> A. <i>Discusses</i> the role of genetic factors in maintaining health and preventing disease. B. <i>Discusses the range of genetic approaches to treatment and prevention of disease.</i> C. <i>Discusses</i> the role of genetic factors in the manifestation of disease, using examples of <i>inherited conditions more commonly encountered within own sphere of practice.</i> D. <i>Analyses</i> how disease expression may be influenced by the interaction between genetic and other factors, at different life stages. E. Applies basic concepts of risk <i>to explain</i> the distinction between genetic susceptibility and clinical manifestation of a disease. 	<ul style="list-style-type: none"> 1. Applies knowledge and understanding to identify potentially significant information from a family history. 2. <i>Incorporates</i> family history information in providing health education advice.

APPLYING THE COMPETENCIES

Table 13 Core Standard Statement 5: Example for the experienced practitioner

Domain: Professional and ethical practice	
<p>Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information</p> <ul style="list-style-type: none"> • 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. 	
Suggested learning outcomes	Suggested practice indicators
<ul style="list-style-type: none"> A. <i>Analyses</i> the potential benefits, risks and limitations of genetic testing and accessing genetic information, including <i>post mortem</i> information. B. <i>Appraises</i> the sensitivity of genetic information, in particular the associated ethical, legal and social issues. C. <i>Evaluates</i> the potential impact of genetic information for individuals, family members and communities. D. <i>Discusses how</i> ethnoculture and economics may influence access to genetic information. 	<ul style="list-style-type: none"> 1. Ensures privacy when discussing genetic information. 2. Maintains <i>and defends</i> confidentiality when recording genetic information. 3. Demonstrates sensitivity to the potential impact of genetic information for the individual and other family members, <i>giving neither false reassurance nor raising undue concern</i>. 4. Responds appropriately to enquiries about genetic concerns. 5. <i>Facilitates the ethical storage of human genetic samples, including from patients dying or who have died from an inherited condition.</i>

APPLYING THE COMPETENCIES

Table 14 Core Standard Statement 7: Example for the experienced practitioner

Domain: Professional and ethical practice	
<p>Obtain and communicate credible, current information about genetics, for self, clients and colleagues</p> <ul style="list-style-type: none"> • using information technologies effectively to do so. 	
Suggested learning outcomes	Suggested practice indicators
<p>A. <i>Upholds</i> the importance of updating genetic knowledge at frequent intervals and the consequent benefits for self, clients and colleagues.</p> <p>B. <i>Evaluates information</i> in terms of its limitations, credibility and reliability.</p> <p>C. <i>Seeks</i> and critically appraises information from different sources.</p>	<ol style="list-style-type: none"> 1. <i>Teaches others</i> about accessing local/regional genetics resources. 2. Actively refers to research based evidence about genetics related to patient/client care <i>and communicates this to others</i>. 3. <i>Applies appropriate</i> interpersonal skills whilst communicating with clients and colleagues about genetics issues. 4. Takes action to meet any identified knowledge and skills deficit (<i>own and that of other colleagues</i>) likely to affect the delivery of care within one's own current sphere of practice. 5. <i>Facilitates discussion about genetics issues</i>.

APPLYING THE COMPETENCIES

Table 15 **Core Standard Statement 4: Example for the higher level practitioner**
Outcome indicators for a senior nurse working exclusively in the oncology setting

Domain: Care delivery	
Demonstrate 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.	
Suggested learning outcomes	Suggested practice indicators
<p>A. <i>Discusses</i> the role of genetic factors in maintaining health and preventing disease in particular inherited cancers</p> <p>B. <i>Discusses the current and future place of pharmacogenetics and gene therapy in the prevention and management of cancer.</i></p> <p>C. <i>Discusses</i> the role of genetic factors in the manifestation of cancer, using examples of particular cancers <i>more commonly encountered within own sphere of practice. (e.g. colorectal, breast)</i></p> <p>D. <i>Analyses</i> how cancer expression may be influenced by the interaction between genetic and other factors, at different life stages.</p> <p>E. Applies a variety of concepts of risk <i>to explain</i> the distinction between genetic susceptibility and clinical manifestation of a disease.</p>	<ol style="list-style-type: none"> 1. Applies knowledge and understanding to identify potentially significant information from a family history being aware of the difference between genetically acquired and inherited cancers 2. <i>Incorporates</i> family history information in providing health education advice. 3. <i>Facilitates and supports</i> individuals in accessing screening and health promotion initiatives, <i>presenting a balanced view of the advantages and disadvantages of these.</i> 4. <i>Demonstrates an awareness and understanding of cancers that are unlikely to have an inherited link, and of the rarer inherited cancer conditions and the consequent health promotion issues.</i>

Scenario: The clinical nurse specialist in colorectal cancer

I have a dual role working both as a research nurse and a clinical nurse specialist in colorectal cancer and sometimes the conflicting agendas cause clinical problems, especially in relation to keeping my professional knowledge up to date. This is especially relevant when I think of my involvement with Alex Lodge, a 48 year old patient of mine.

Alex is one of six brothers and sisters. Two of his brothers emigrated to Canada 30 years ago and unfortunately over time they have lost contact with each other. Two sisters (Pauline, 55 and Beverley, 63) live in Scotland but again he had not had much contact with them for several years. He was surprised when Pauline's husband telephoned to let him know that Pauline was in hospital recovering from having "lots of her bowel removed" following a diagnosis of colon cancer.

Alex visited Pauline and she told him that she had recently heard from one of her nieces that Beverley had also had colon cancer two years ago. In addition it would appear that one of their brothers had died of colon cancer at 68yrs. To their knowledge, no one else in the family had had any cancer. By coincidence Alex has just had a sigmoidoscopy as part of a research bowel screening study - which is where I had first come into contact with him. Following this we had given him the results, informing him that he had several bowel polyps but there was nothing to worry about. As part of the study he was asked to complete a questionnaire about diet, lifestyle and if any medical history. Even on reviewing his family history I did not think there was any cause for concern as it did not fulfil the risk criteria (three first degree relatives with colorectal or associated cancers, one below the age of 40).

Following his visit to see Pauline he re-contacted me, he was clearly distressed at how ill Pauline looked, worried about the risks to himself and had some new family history information in that his other brother has had polyps. I tried to reassure him but also had a nagging thought that this might be important. I agreed to try and find out more information and call him back but I do remember being a little dismissive of his concerns.

I decided I needed some expert advice so I contacted one of my colleagues working in the Cancer Genetics Team. He recalled that a relatively new condition Autosomal Recessive Colorectal cancer (MYH) had been identified where the colon cancers occur at an older age, there is an association with bowel polyps, and parents are unaffected. This is in contrast to presentation of FAP or HNPCC, inherited conditions known to cause colorectal cancer, where one parent is affected (dominant inheritance). This rang alarm bells for me in relation to Alex's family history.

Feeling very guilty and concerned by my apparent lack of knowledge I called Alex back, explained a little of what I had discovered and offered to refer him on to my colleagues in Genetics. He seemed a little surprised by the mention of the word genetics and said that he did not want to be experimented on. I tried to reassure him that it was all about trying to help determine whether his family history was a problem and to offer him some support and surveillance.

I sorted out the referral and am now much more aware of how important it is to keep up to date and to avoid at all costs giving false reassurance.

Professional Groups

In the US, the approach taken by NCHPEG was to develop genetic competencies as a multidisciplinary initiative, and in doing so, 38 competency statements were produced for all health professionals. Given the differences between the health care systems in the US and UK and the health professional groups, we felt that identifying the common and unique elements of competence required across the professional groups of nursing, midwifery and health visiting would be an appropriate first step. Indeed, given the diversity of these professionals roles, this approach may not be as narrow in focus as it might seem. That we have been able to demonstrate a remarkable degree of consensus, with the professions having far more in common than not, bodes well for further work that takes a broader multidisciplinary perspective to develop a common health professionals framework.

Of course, we may not have achieved this consensus had the competencies been particularly narrow in focus. Some may view their broad terms as being vulnerable to re-interpretation, but this also provides some flexibility in adapting them to different professional groups and different healthcare settings. Thus they may be used as a framework for further development. Some indication of how this may be applied to the different professional groups is presented below.

Nursing

For nursing, the application of the competency framework to the professional role is perhaps less of an issue than its implementation. Feedback from the consultation indicates general support for the framework and the individual standard statements; that it is *'broadly acceptable and mindful of future needs.'* The standard statements are also felt to be appropriate to the professional role and reflect general nursing competencies and practice, simply applied to the area of genetics. No additional competencies have been proposed.

There is some concern about the extent to which statement 1 (Identify clients who might benefit from genetic information and services) could be achieved at the point of registration. Achieving the other competencies will be challenging, and it is felt that in-depth knowledge may be inappropriate for the newly qualified nurse. Statements 4 (Demonstrate knowledge and understanding of the role of genetic and other factors in maintaining health ...) and 5 (Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information) have generated most concern in this regard. The pace of advancement of genetics knowledge may render *'any hard and fast facts quickly out of date'*. The role of inter-professional communication is particularly pertinent to statement 7 (Obtain and communicate credible, current information about genetics for self, clients and colleagues) and some respondents felt this should be emphasised.

The transferability of many elements of the competency standard statements has been a recurring comment. These elements should be highlighted when applying the framework to current nurse education programmes and nursing practice. However, in doing so, the emphasis should be on integration. A number of respondents commented that genetics should not be viewed in isolation, and that nursing needed to build up an evidence base for its integration into professional practice.

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” (NMC 2002c, p4). 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 and postnatal screening. In all of these, midwives play a central role in identifying increased genetic risk for the woman or her baby. This role is highlighted in the genetics White Paper where it states that by 2004/5 “all pregnant women will be offered antenatal screening for Down’s syndrome and counselled by midwives to help them make an informed choice” (p42). The development of antenatal and newborn screening programmes for sickle cell and thalassaemia within a similar timescale is also outlined.

Generally there is agreement that the competencies are appropriate for midwives but a commonly raised concern is that the competencies are too broad. Although there may be some advantage to this, it could be difficult to interpret them accurately. As one organisation stated:

“the competencies are too general and miss many of the specific needs of midwives in advising, supporting and caring for women from the antenatal period through to postnatal screening processes.”

However, there was also concern expressed that in adapting the competencies for midwifery practice, further detail would be added to an overburdened curriculum, although again, the transferability of the competencies was acknowledged:

“The idea of a minimum number of competencies is good, and many of those outlined will take account of transferable skills, rather than new additions to the packed curriculum, e.g. informed consent, using current evidence based practice, tailoring information to meet cultural, religious and ethical perspectives.”

The implications for midwifery practice in incorporating these competencies was commented upon by one respondent, particularly in relation to statement 3 (Uphold the rights of all clients to informed decision making and voluntary action):

“All aspects of health care currently have concerns about the validity and reliability of real informed choice/consent. Concerns exist about ‘paying lip service’ to the amount/ quantity/ quality of information provided – the competencies hope to rectify this situation, but as a

midwife, I would be concerned about adding more information to an already overloading antenatal screening process."

In adapting the competencies for midwifery practice, there was strong support for the inclusion of a statement that addresses 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'. We therefore propose a modification to statement 4:

Demonstrate knowledge and understanding of the role of genetic and other factors:

- **in maintaining maternal and fetal health,**
- **in the manifestation, modification and prevention of disease expression in the mother, and**
- **in the modification and manifestation of fetal abnormality or disease to underpin effective practice.**

Whilst this is aimed at midwifery practice, there was some feeling that this would be also relevant to other professional groups.

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).

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).

Health visitors participating in the consultation process have commented that they feel their role deals very much with the 'real side' of genetics, dealing with families on a long term basis. This involves working increasingly with vulnerable families, and this may develop to working with fewer families but with a greater depth of involvement. The emphasis in discussions has been on the overall philosophy of working in partnership with clients. One point raised in relation to this was that not all clients may chose referral to genetics services and this uncertainty should be reflected in the wording of statement 1 (Identify clients who *might* benefit from genetics services and information).

There is general support for the statements themselves but a point that has been made consistently is that the issue for health visitors focuses more on the level of competence that should be demonstrated rather than the appropriateness of the

competence itself. There was a strong feeling at the Expert Panel meeting that health visitors should be able to apply the competencies to practice, and the depth of knowledge should support the teaching function of this professional group. In particular, it is felt that:

All health visitors should be able to:

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

Although some concern was expressed about the extent to which newly qualified health visitors would be prepared to undertake this role, one professional organisation felt strongly that these two competencies are *'appropriate and fundamental to the role of the health visitor at the point of registration.'*

Suggested development work:

The competency framework should be used as a basis for further development for the individual professional groups, identifying any specific learning and practice outcomes.

Specialist areas

At our initial Expert Panel meeting, we used five fields of health care (cancer care, haemoglobinopathies, paediatrics, learning disabilities and primary care) to explore the common and unique elements of the competencies. In doing so, we aimed to see how a competency framework might be applied and adapted for different fields. The five settings selected were felt to represent areas where competence in genetics might be thought to have particular relevance. We sought views on whether the achievement of competence may be more urgently required in particular areas, as well as on the applicability of the competence statements to all areas of health care.

There was agreement amongst respondents that the five fields identified do represent areas where genetics competence is of particular relevance to practitioners. However, there was also a very firm view that the competencies have to apply to all areas of care, and that genetics is becoming increasingly relevant to all areas. One response indicated that it is *"risky to assume that some client groups beyond the obvious acute areas are more or less of a priority."*

Although there was a wider range of views on the other areas where there is significant relevance, elderly care, diabetes and cardiothoracic care, and areas pertaining to women's health were identified by a number of correspondents. The White Paper notes the increasing relevance of genetics to diseases such as cancer, heart disease, and diabetes, all priority clinical areas. Its influence in other conditions such as asthma, osteoporosis and mental illness is also being explored. Although one respondent felt mental health may be a lower priority, this view was not reflected in

other responses, with several indicating that it too is an important area. As one respondent said:

“In mental health, there are currently controversial studies examining the genetic basis of personality disorders. Many patients feel concerned and nurses need to be able to discuss with patients about the genetics versus environmental factors involved in mental health the same as they are applied to physical health.”

Comments pertaining to the five specialist areas are outlined below.

Cancer

At the consultation day, it was emphasised that cancer genetics provides a model for how services will cope, and how genetics may be integrated into other specialties as its contribution to the manifestation of other common conditions is elucidated. The White Paper outlines a service model developed in collaboration with Macmillan Cancer Relief, for people at risk of, or concerned about familial cancer. This will offer a continuum of advice and care involving primary care, local cancer services and specialised genetic and cancer services. It includes:

- The provision of consistent, accurate and appropriate information for service users
- Risk assessment according to an agreed national framework
- Streamlined referral according to agreed pathways
- Consistent management of people in the appropriate setting according to their level of risk.

Senior clinical nurses working exclusively in a cancer setting, or site specific clinical nurses (e.g. breast or colorectal) have regular contact with individuals experiencing a life threatening diagnosis. The clinical skills involve supporting and managing cancer patients from the point of diagnosis, through treatment towards cure and rehabilitation and/or palliative care. The broad consensus is that at this level of practice, the Cancer Nurse would be expected to explain the basic concepts of probability and disease susceptibility. The ability to communicate risk has been identified as being of particular relevance in risk management for a disease of multifactorial aetiology such as cancer and genetic information will need to be set within this context. However, some felt that it may be more appropriate for the more experienced practitioner:

“... all HCP’s [Health Care Professionals] working in cancer care should be able to identify individuals that may be potentially at risk of having a genetic predisposition to cancers and at the same time be able to allay fears and concerns of those at a low risk by explaining the genetic inheritance of cancer and disease development.”

For more junior staff, the ability to recognise cancers with a known genetic link through the family history and an awareness of specialist resources to aid them in their care of patients is important.

Haemoglobinopathies

Haemoglobinopathy counsellors have a long history of integrating specialist genetics knowledge into the delivery of care. The implementation of a newborn screening programme for sickle cell disease by the end of 2004, and a targeted antenatal screening programme will bring awareness of these conditions to the forefront of practice for other health professional groups outside the specialist field. The role of practice nurses and family planning nurses in screening was identified as being of particular potential benefit in helping clients to make informed choices before conceiving a child.

The need to practise in a multi-cultured way was emphasised and this is underpinned by statements 2 (Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language) and 3 (Uphold the rights of clients to informed decision making and voluntary action), but the requirement to do so is already explicit in the Code of Professional Conduct (NMC 2002a).

Scenario: The effective interface between practice and policy

When Mrs Henry attended antenatal clinic at her local NHS hospital, in line with the Trust's established haemoglobinopathy screening programme, she was offered screening. She consented to the test. The new student midwife attending asked her mentor afterwards why haemoglobinopathy screening had been offered. The staff midwife explained that the hospital policy was to offer screening to all women regardless of their ethnicity, although in this instance Mrs Henry's ethnic background was one associated with a high risk of sickle cell disease. "We don't make assumptions" she said.

The next time Mrs Henry attended, it was to receive her results. They revealed that she was a healthy carrier of sickle cell disease. Her husband accompanied her, and subsequent testing revealed that he too was a carrier. Prenatal tests showed that the baby was positive for sickle cell disease. Mr and Mrs Henry made the very painful decision to opt for termination of pregnancy. Although very distressed, they felt it was the best decision for them, and the midwife supported them during the decision-making period and afterwards.

Reflecting on practice

This scenario illustrates how sound policies and systems, implemented by competent practitioners able to integrate knowledge and skills into the practice environment, promote delivery of high quality care.

Unfortunately, this scenario is based on a real-life situation that was almost the mirror image. Testing was not offered to the mother, despite the hospital policy, and the carrier status of her and her husband went undetected until some time after their son was born and later diagnosed with sickle cell disease. This event had a profound impact on the family, presenting them with cultural, psychological and social challenges. It also had adverse repercussions for the hospital and professionals who were responsible for Mrs Henry's care.

Paediatrics

There was broad agreement that the competencies are of relevance to practitioners who work with children. One participant commented that much of what we were considering could be included under the remit of child protection '*focusing on the best interests of children and their future health.*' As with other specialist groups, the competencies were endorsed, but it was felt that there may need to be greater emphasis given to specific areas of competence – for example informed consent for tests that have genetic implications such as creatine kinase tests and the implications of this for the diagnosis of Duchenne muscular dystrophy.

Enhanced emphasis on communication was noted by some respondents, in particular in relation to the advocacy role of the practitioner and in tailoring language appropriately to the child as an individual.

The Expert Panel identified that one challenge facing practitioners is how to integrate genetics into care, helping parents to incorporate information into parenting without labelling the child. There was firm agreement that this is an important issue, but not one that is necessarily unique to genetics or to those working with children, but that genetics may be used as an example to raise awareness about this, which is a societal issue as much as a health care one.

Learning disabilities

Respondents agreed that the competencies indicated are of particular importance for health professionals working in the field of learning disabilities, but again, the issue was raised that they are also of importance to all professional groups. One respondent stressed the need for midwives to have some understanding of learning disabilities in order to:

- a) *Care for women and their partners who become pregnant, and who may have learning disabilities;*
- b) *Provide appropriate information/referral for women who may have children with learning disabilities.*

This latter point was felt more appropriate for the more experienced practitioner and was not a minimum core competency. 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.

There was general agreement that this was relevant, although it was not felt to be exclusive to health professionals working in this field. One organisation commented that:

“health professionals working with people and their families with learning disabilities should be able to demonstrate an understanding of the frameworks that they journey through and where the seeking and provision of genetic information fits into this process. People with learning disabilities may require an advocate in this area, and a nurse should be knowledgeable and skilled in the manner prescribed by this competency.”

Primary care

Primary care is widely acknowledged as being a priority area for implementing initiatives in genetic education (Burton 2003). The White Paper outlines the roles that practice nurses and other primary care practitioners could offer to help their patients benefit from genetics and its applications:

- Managing patients’ concerns and expectations
- Identifying genetic conditions
- Assessing risk
- Managing risk
- Screening
- Testing
- Providing and co-ordinating long-term care
- Gate-keeping to specialist care

Cancer genetics is an area that has already produced a significant impact on primary care. The role of primary care practitioners in working with cancer teams and cancer networks for the management of people at low, medium and high risk has already been identified. Competence in effective communication about genetic risk will be particularly relevant here, but it is also felt to be an important factor in giving health education advice more generally. Placing risk into context, giving appropriate reassurance (including avoiding false reassurance) and the advocacy role of primary care professionals are all felt to be important elements to be considered in integrating genetics into practice.

Conclusion

The consensus is that the competencies should apply to all areas, but there is acknowledgement that in particular areas, there may be a greater urgency for the achievement of competence. One professional organisation captures the general view:

“As genetic approaches are expected to become increasingly prominent in the prevention and treatment of disease and are set to have a huge impact on all aspects of health care we feel that genetic competence is becoming increasingly relevant to all health professionals. Thus, we believe that the level of competence should relate to the level of practice rather than the area of practice.”

Scenario: Communicating within an ethical framework

As a charge nurse working in an Emergency Admissions Unit mental health setting, I quite frequently see families with Huntington's disease (HD) and am often quite unsettled by some of the issues. It's a very distressing disease and must be so difficult for relatives who come to visit. Those at high risk themselves could be thinking 'is this what I could be like?' and of course, people who've had a test and been given the all clear can still feel guilty that they are OK.

John had come to see his dad Terry. Terry is in his early 50's and has been affected with Huntington's disease since his mid 40's. John was only 14 when Terry started showing symptoms - not an easy situation to have to deal with when you're a teenager. Terry developed paranoia suddenly and was admitted to our unit a week ago.

After visiting time John approached me and asked if he could talk about things; he was clearly distressed and agitated. He said that prior to his dad's recent admission, he had been thinking about predictive testing as he is keen to marry his long term girlfriend Sophie and wants to know about the risks to any children. John told me a little about how he felt at seeing his dad in his present condition. He wanted to know if I had seen many people with HD. We talked for a little while and I told him about some of the problems commonly experienced - I tried to be honest without making things worse, and when he left, he seemed to be a bit calmer.

Two days later, John came back to see me again. He requested that our conversation be confidential. I explained that I could assure him of confidentiality but that there were boundaries to this and if I thought any issues raised were beyond my professional role, I might have to ask for more specialist help, but would discuss this with him first. This is an approach I always use. I think he heard this but I am not sure if it registered with him.

John stated that he was going ahead with the predictive test. He was having real difficulties coping with the changes the disease had caused in his father and had made plans. If the result was positive, then once he started to get symptoms he would "end it all" and commit suicide. He seemed to have thought this out quite carefully. I wasn't shocked at this, but I did worry that perhaps I had given him too much information a few days previously.

What should happen next?

After discussing and agreeing with John, the charge nurse arranged for him to be referred to the clinical psychologist.

Reflecting on practice

In 'setting the scene' for conversations it is important to set boundaries for the interaction and acknowledge that confidentiality will be respected but may need to be broken in certain circumstances.

Should the charge nurse have been more reassuring in telling John about the burden associated with this condition?

4. PREPARING TO PRACTISE IN THE GENETICS ERA: THE WAY FORWARD

In carrying out this work we have been involved in a great deal of discussion and heard a variety of views, during the Expert Panel meeting, at the consultation conference, and in the course of receiving feedback through the consultation period. There appears to be little dispute that health professionals need to become more competent in genetics, but there is concern about how this will be achieved, and about the extent to which stakeholder groups are yet fully prepared to meet the inevitable challenges. Some of the issues and concerns raised are set out below.

Issues and challenges

Does genetics merit special treatment in education?

In our Interim Report, we mapped all of the original 34 competencies endorsed by the panel against the NMC competency frameworks for each of the professional groups. This demonstrated that the genetics competencies did not represent an extension of the professional role but offered a view of these requirements ‘through the genetic lens’, making explicit how genetics competencies may be integrated into professional practice. We felt that this was an important exercise given the issue of competing priorities within both professional practice and education. The consultation sought views on this, asking if specific competencies should be defined, and if this was the best approach to promote competence in genetics.

The majority view is that competence in genetics does need to be promoted and specific competencies *‘help ensure a degree of parity and standardisation, in order that all practitioners educated in the UK are able to provide a similar high level of care.’* Furthermore, defining competencies was felt to be important because of the acknowledged deficits in education; *‘identifying specific competencies helps in the planning for training and in the identification of potential areas of weakness which can then be addressed.’* However, there was disagreement, some commenting that every speciality should be mapped against the NMC requirements, and one stating that competence should be promoted more by integration into achieving the NMC competencies.

The prerequisites for success

We asked about the most important factors that would need to be in place to promote the achievement of these competencies by the three professional groups. Responses to this question generated over 50 items that were grouped into categories by the project team, and then ranked according to the number of participants who identified the item. We then asked about the major challenges to successful integration of the competencies into practice. These responses were analysed in the same way. The responses to both questions that were identified by more than one respondent are outlined below, in rank order.

Table 16 Rank order of items identified as pre-requisites and as challenges to successful integration of genetics into professional practice

What needs to be in place?	What are the challenges?
Engagement	Engagement
Educating the educators	Competing priorities
Curriculum issues	Support from and for practitioners
Team approach to teaching and learning	Educating the educators
Resources for teaching and learning	Effective management
Education provision	Provision of resources
Clinical links and support	Keeping up to date
Effective management	

It is interesting to note that many of the pre-requisites are also identified as presenting the greatest challenge to successful integration of genetics into practice. That said, the majority of delegates at the consultation seminar agreed that achieving competence was 'doable'.

Engagement

Raising awareness, commitment and engagement of stakeholders at individual, professional and organisational levels was identified as the top priority for success. Professional leadership and support from the key stakeholder groups is fundamental to effecting change. This echoes the views of the earlier expert advisory panel on nurse education (Kirk 1999b) and is also highlighted in Burton's work. She identifies that 'ownership' of the strategy she sets out will be gained only gradually through inclusion, involvement and effective communication. Our respondents reflect this, but also indicate that the challenges being faced are not insurmountable:

"Assessment of present knowledge and skills of practitioners and raising awareness of genetics could be an awesome task. However, with the probable implementation of 'Agenda for Change' in the autumn of 2004 there could be a rare opportunity to include the competencies when roles are being profiled."

The NHS Knowledge and Skills Framework (KSF) is designed to identify the knowledge and skills that individuals need to apply in their post and help guide the development of individuals. The KSF will be able to be used and linked with current and emerging competence frameworks. Should these competencies be endorsed, the KSF process could be a significant factor that will promote the achievement of these competencies by all nurses."

Another noted that acceptance of the competencies 'within a crowded policy agenda and already full education programmes' represented a significant challenge, but proposed a more succinct approach:

"The trick will be to encourage the view that the competencies aren't new, they are all an endorsement of what should have been happening."

Educating the educators

The need to 'educate the educators' was the second most common theme to emerge from the consultation, in terms of both raising awareness about the relevance of genetics, and in developing expertise in delivering education programmes that incorporate genetics. As one respondent stated: *"There is a need to educate the educators, help them recognise the importance of genetics and how it can be integrated into their curricula without significant additional work"*. The implications of this for staff time for preparation and study was noted:

"It seems to me that expertise in this field – at advanced levels such as Master's degree, is thin on the ground and will require substantial investment."

The limited availability of nursing and midwifery lecturers with both subject knowledge and relevant clinical expertise was noted by Kirk (2000) following earlier surveys of pre-registration diploma level nursing and midwifery (direct entry) programmes. Burton (2003) reported that a survey of post-registration courses for nurses, midwives and health visitors also indicated that many schools did not have confidence in their ability to teach genetics 'across the full curriculum' (Metcalf, unpublished). She noted the suggestion that a group of teachers should be purposefully developed and supported. This notion of developing 'genetics champions' as a first step was raised by one of our participants.

The task of developing appropriate expertise amongst educators does indeed represent a significant challenge and one which will require a sustained and well-supported effort. The role of the NHS Genetics Education and Development Centre will be crucial in co-ordinating programmes to develop confidence and skill in teaching genetics effectively and facilitating integration into practice.

Competing priorities: curriculum

Concern about competing priorities has been a common thread throughout this work, both for health professionals working in a busy practice setting, and for educators. The curriculum issues generated most comment.

Tensions over competition for curriculum space have been noted for some time and were reflected by a number of participants. One concern generally expressed was that the 'already overcrowded curriculum' would mean that genetics is given a low priority:

"Students need time for reading, thinking and reflection if the competencies are to be achieved and it may be difficult to find that space."

However, one participant countered this argument:

"On the perennial fight between subjects for curriculum time, when I talk to students around the country they don't see a shortage of time on the course for important things... for important things time can and must be found."

The possible ways in which some time can be found are considered below.

Approaches to teaching and learning

There was clear support for multidisciplinary teaching and learning, involving teaching teams with complementary areas of expertise and experience, and where students with common ground can share learning experiences. Teaching teams would need to include genetics specialists and relevant healthcare professionals.

A number of respondents identified problem based learning as one approach that might be particularly suited to integrating genetics within the curriculum:

“... problem-based learning using case studies is ideally suited to this type of work. Students will need time to think and reflect and will need to proceed at their own pace. A combination of resource based case studies followed up by group work and discussions would be ideal. There may be a role for web-board discussion groups and other forms of e learning.”

It was also felt that problem-based learning would help raise awareness that genetics is a cross-curricular subject, and although it should be taught alongside ‘robust’ biological sciences, it should not be presented as ‘a separate subject divorced from mainstream activities.’

However, this approach was not without some caveats:

“The [Interim Report] perhaps fashionably, suggest that problem based learning may provide the medium for the integration and deep learning necessary. Whilst in principle I agree, this is dependent upon motivated learners, able and knowledgeable facilitators and excellent and easily available learning resources.”

The need for careful planning in integrating genetics within the curriculum, perhaps with a designated curriculum co-ordinator, was also requested:

“Gaining confidence and competence in genetics requires consideration of a sequence of concepts that can build towards understanding and application. Where this is threaded through a number of modules throughout a programme, careful planning will be necessary to ensure coherence. This is particularly true where students are drawn from different professional programmes.”

Resources

There is clearly a need for the provision of, and access to, resources that support the achievement of competency for professionals in training, for continuing professional development of practitioners and for their teachers. The financial implications of this are likely to be substantial. Educators will need time to prepare programmes of study, in collaboration with clinical colleagues, time to develop learning materials, and time to develop their own expertise. Practitioners will need time and financial support to access courses. Updating knowledge and skills will also be a factor in this.

The importance of providing learning resources that are relevant to practice was emphasised by a number of participants. There is a dearth of learning resources that focus on nurses, midwives and health visitors. This is compounded by the number of educators with appropriate clinical experience and expertise in genetics, and by the limited exposure to role models in the practice setting. Re-creating clinical exposure will present a challenge for both educators and practitioners. Client and patient-based scenarios were identified as being a particularly useful approach to doing this.

Development of resources has to be underpinned by an assessment of needs for both teaching and learning. Burton (2003) identifies that this is 'the first critical step in continuing professional development and is the process through which an individual or organisation recognises a learning need'. We propose that the competence framework set out here is used as the basis to assess these educational needs, in order to further inform strategy and resource development.

Education provision

As well as educating the educators and the challenges around integrating genetics into pre-registration programmes, access to and availability of post-registration training and continuing professional development is also an issue. This is particularly pertinent given the rapid pace of change in genetics. Being able to keep up with these developments, and being able to access education programmes that deliver the 'right knowledge at the right time' will certainly present a challenge to education providers. This is compromised by the current level of genetics literacy amongst health professionals generally, which is acknowledged to form a poor platform on which to build.

In addition to providing education programmes, consideration will also have to be given about evaluating the success of these:

"There is little point producing competence statements or standards unless, by some suitably professional and fair mechanism, we assess people against them, both at the point of entry to practice at the various levels and subsequently."

The mechanisms adopted for assessment, as well as being rigorous, should also be 'modern' in their approach.

Clinical involvement and support

Strong clinical leadership and support for achievement of competence in genetics are pre-requisites for success. As in education, practitioners are faced with competing demands on their time and resources, and leadership is necessary to help prioritise those demands. The need for robust systems and structures at organisational level to underpin competent practice has been highlighted, along with the development and dissemination of clear policy guidelines. The involvement of clinicians and practitioners as part of the multidisciplinary teaching team is also important in helping to make explicit the links between practice and the underpinning theory,

emphasising the process of care bound up in the competencies, and contributing to the development of clinical guidelines.

The need for support for existing practitioners to access education programmes and thereafter to update knowledge has already been identified. This has to be facilitated by access to learning resources 'off campus'. The contribution of technology to gaining access to information is acknowledged as being significant, but the very limited access of many community nurses to these facilities will compromise this.

Registered practitioners need to attain competence in genetics, not only to deliver high quality care, but also to facilitate education in practice of student nurses, midwives and health visitors. Mentors in practice will need adequate support to ensure that they are equipped to assess students' competence.

Management of change

Although this theme was given less priority, the need for a systematic approach to the development of education and training was noted. The implications for higher education institutions for providing and delivering genetics education at pre- and post-registration levels are significant. Likewise, the requirement for education of qualified professionals 'already in the system' will be substantial and the implications of this for workforce planning and resources are considerable. Corporate responsibility in this respect was noted, but individual responsibility to seek to improve and promote competence in genetics is also important.

Although issues around effective management of change and of implementation of an education strategy were given less priority by many participants, perhaps, like funding to support further developments, this has to be a 'given'. The issues that have been raised are inter-linked and cannot be developed or promoted in isolation. The role of the national strategic group proposed by Burton, and the NHS Genetics Education and Development Centre will be crucial in co-ordinating developments in education and practice, and in evaluating the effectiveness of new initiatives.

Recommendations

The challenges that have been identified here are not necessarily new, echoing the findings of our earlier work (Kirk 1999) and those of Burton (2003). However, it has been a valuable exercise to ascertain the range of views, and from these have emerged the recommendations outlined below.

1. The White Paper pertains only to England, yet the professional requirements to register to practise as a nurse, midwife or health visitor are determined by a national body, the NMC. In reality therefore, a UK-wide approach has to be taken. The devolved regional governments, in their considerations of the implications of the White Paper, are urged to take a collaborative approach to supporting the establishment of the NHS Genetics Education and Development

Centre so that agreed standards of genetic competence can be upheld across the UK.

2. The integration of genetic knowledge and health care across the NHS has to take place within the context of other policies. ‘Dovetailing’ with other initiatives such as the Knowledge and Skills Framework, and National Service Frameworks, may have a synergistic effect.
3. NHS employers need to consider ways in which support may be offered to practitioners through continuing professional development programmes, not only to promote and maintain effective patient care and personal career development, but also to help promote the development of clinical mentors.
4. Promotion of genetics competence has to be underpinned by clear and robust policies and systems at organisational level, and service leaders have a clear role to play in this.
5. Programmes to ‘educate the educators’ should be given an early priority.
6. Educators need to continue to work collaboratively with practitioners from all fields of health care, include medical genetics, to develop education programmes that address the needs of learners and practitioners. In particular, there is a need to devise ways of re-creating clinical exposure to help promote capability in dealing with real-life situations. Collaboration should also extend beyond the health care arena to reflect the cross-curricula nature of genetics, involving colleagues from disciplines such as philosophy and social sciences.
7. Any preparation strategy to promote competence will need to consider provision for practitioners already in post, along with ‘top-up’ schemes for those who have achieved the minimum competence standards.
8. Professional organisations need to demonstrate strong leadership in order to build further on this competence framework, and should be at the forefront of initiatives to raise awareness about genetics.
9. Effective management of change is axiomatic, and must include evaluation. In determining how this competency framework may have influenced the care of individuals with an actual or potential genetic condition, over a five year period we would hope to see:
 - That healthcare professionals can demonstrate improved levels of genetic literacy.
 - That pre-registration curricula can demonstrate the integration of the genetics competencies.
 - That training is supported by appropriate and knowledgeable mentorship during clinical placements.
 - Health Service organisations demonstrate an active inclusion of genetics in the job profiles of relevant posts.
 - Post-registration practitioners whose clinical activity has either an implicit or explicit links to genetics, have genetics clearly identified in their personal development plans.

Finally, we would like to endorse the comment made by a user group representative in the course of this work, that ‘knowledge on its own is not enough’. Effective communication is crucial between all stakeholder groups.

Conclusions

Our remit in preparing this report was to set out a competency framework for the three professional groups that could be adapted for different levels of experience and for different fields of health care. The framework we have developed is based on seven agreed competency standard statements that we believe will promote practice that is competent, capable and caring in delivering genetic health care.

The statements themselves are conserved for different levels of experience across the three professional groups, and across a range of fields of practice. It is the learning and practice outcomes that may be adapted to provide the flexibility required to reflect different professional roles, and to integrate new developments within the dynamic context of genetics research and health care.

Two core strands have been evident throughout this work – the need for engagement by stakeholders, and the need for high quality resources that address learning and teaching needs. The proposed NHS Genetics Education and Development Centre, informed by Burton’s strategy, will seek to address both of these issues, and act as a catalyst to further developments. However, this can be successful only by working in close collaboration with colleagues from all health professional groups, from the fields of practice, education and research. Nurses, midwives and health visitors have demonstrated here what can be achieved through commitment and collaboration.

This has been a national collaborative project involving stakeholder groups from across the UK, representing diverse interests, but all with a commitment to the delivery of high quality care to individuals and families. With that central shared value it may not be surprising that a consensus was reached to the extent that it has been, but nonetheless we have been delighted by this.

Reaching a consensus on the framework represents an important step forward for nursing, midwifery and health visiting. It provides us with a firm platform on which to base further developments as the professional groups integrate genetics into education and practice. At the same time, it makes a significant early contribution to implementing the strategy for health professional education developed by Burton and colleagues (Burton 2003), and to the action plan for investment in education and training for NHS professionals set out in the genetics White Paper.

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NMC (2002d) *Requirements for pre-registration health visitor programmes*. London: NMC

APPENDICES

Appendix 1: Participants at the consultation day

(including Steering Group members in attendance)

Delegate	Position	Institution
Mrs Maria Andrade	Lecturer	School of Health Science, University of Wales Swansea
Professor Elizabeth Anionwu	Head	The Mary Seacole Centre for Nursing Practice, Thames Valley University
Mr Owen Barr	Lecturer in Nursing - Learning Disabilities	School of Nursing, University of Ulster
Ms Jenny Barrell	South Gwent Area Midwifery Manager	Royal Gwent Hospital
Mrs Amanda Barry	Genetic Nurse Counsellor	Coventry Primary Care Trust
Dr Caroline Benjamin	Macmillan Genetic Associate	Merseyside and Cheshire Clinical Genetics Service, Royal Liverpool Children's Hospital
Dr Catherine Bennett	R&D Specialist in Education for Medical Genetics	Centre for Education in Medical Genetics, Birmingham Women's Hospital
Mr Peter Bentley	Lecturer in Applied Biological Sciences	City University
Dr Tony Blackett	Senior Lecturer	School of Nursing and Midwifery, University of Sheffield
Miss Sally Bridger	Macmillan Breast Care Nurse	The Brodey Centre, The Horton Hospital, The Oxford Radcliffe Trust
Ms Adele Bruce	Student Midwife	School of Care Sciences, University of Glamorgan
Ms Lucy Burgess	Macmillan Cancer Genetic Counsellor	Clinical Genetics Unit, Birmingham Women's Hospital
Mrs Angela Burgess	Education Officer	The Wales Gene Park, Techniquet
Ms Sarah Buston	Genetic Counselling Student	
Mr Martin Christensen	Lecturer	The Institute of Health and Community Studies, University of Bournemouth
Mrs Ailsa Clarke	Lecturer in Biosciences	European Institute of Health and Medical Sciences, University of Surrey
Mr Richard Currie	Senior Lecturer	Department of Nursing, University of Central Lancashire
Miss Gina Dolan	Associate Lecturer	School of Care Sciences, University of Glamorgan
Mrs Claire Dolling	Genetic Counsellor	Clinical Genetics, St Michael's Hospital

Delegate	Position	Institution
Miss Sarah Emerton	Student Nurse	School of Care Sciences, University of Glamorgan
Sister Alexina Fantato	Departmental Sister	Oxford Eye Hospital, Oxford Radcliffe Hospitals NHS Trust
Mr Antoine Paul Farine	Health Lecturer	School of Nursing, University of Nottingham
Mr Jeremy Felvus		Pfizer Pharmaceuticals
Mr Mick Fisher	Professional Adviser	Health Professions Wales
Mrs Susan Fleming	Deputy Director of Health Studies and Nursing Services	Guernsey Board of Health, Castel Hospital
Mrs Liz France	Senior Genetic Nurse Counsellor	Institute of Medical Genetics, University Hospital Wales
Miss Ruth Gammon	Senior Lecturer	School of Health, Staffordshire University
Mrs Miriam Gaston	Lecturer	School of Nursing, University of Salford
Dr Jonathon Gray	Consultant in Clinical Genetics	Institute of Medical Genetics, University Hospital Wales
Mrs Gill Green	Senior Lecturer/Clinical Genetics Nurse Counsellor	Institute of Health Studies, University of Plymouth
Dr Susan Green		School of Nursing and Midwifery, University of Southampton
Mrs Jenny Hall	Midwifery Lecturer	University of the West of England
Ms Toni Harper	Genetic Counsellor	Birmingham Women's Hospital
Ms Jo Haydon	Specialist Nurse in Genetic Education	Clinical Genetics Unit, Birmingham Women's Hospital
Dr Jackie Hewitt-Taylor		
Dr Rachel Iredale	Senior Lecturer	Genomics Policy Research Unit, University of Glamorgan
Mrs Margaret James	Genetic Nurse Counsellor	Clinical Genetics Department, Mulgrove Park Hospital
Professor Martin Johnson		School of Nursing, University of Salford
Mrs Rosemary Johnson	Wales Antenatal Screening Co-ordinator	Antenatal Screening Project
Miss Gail Johnson	Senior Lecturer	School of Health Studies, Homerton College
Mrs Lynnette Jones		
Miss Linda Jones	Specialist Genetic Nurse	Carmarthenshire NHS Trust
Ms Dianne Kennard	Team Leader, NHS Genetics	Genetics, Embryology and Assisted Conception Branch, Department of Health
Professor Paul Lewis	Academic Head of Midwifery	The Institute of Health and Community Studies, University of Bournemouth

Delegate	Position	Institution
Ms Tanya Lewis	Staff Midwife	Swansea NHS Trust
Mrs Jacqueline Lovstrom	Midwife	Prenatal Diagnosis, John Radcliffe Hospital
Sister Wendy Maher	Midwifery Sister	Swansea NHS Trust
Mrs Sally McGregor	PhD Student	School of Care Sciences, University of Glamorgan
Mrs Annete McHugh	Antenatal Care and Screening Co-ordinator	Antenatal Clinic, Royal Gwent Hospital
Dr Alison Metcalfe	Research Fellow	University of Birmingham
Mrs Trish Millard	Research Secretary	School of Care Sciences, University of Glamorgan
Mrs Nan Morse	Senior Lecturer	School of Care Sciences, University of Glamorgan
Ms Valerie Musson	Deputy Dean	School of Health Studies, Homerton College
Ms Sian Nisbet	Genetic Counselling Student	
Ms Ann Owen	Professional Officer	Community Practitioners and Health Visitors' Association
Mrs Emer Parker	Clinical Nurse Specialist - Genetics	The Children's Centre, Royal Glamorgan Hospital
Dr Chris Patch	Genetic Counsellor/Specialist Nurse	Southampton General Hospital
Mrs Lorna Potter	National Lead for Nurses	NHS Alliance
Miss Lyndsay Procter	Lecturer	School of Nursing, University of Salford
Ms Charlotte Riddick	Genetic Counselling Student	
Ms Laura Riley	Communications Officer	Progress Educational Trust
Mrs Anne Roberts	Head Genetic Counsellor	The Department of Clinical Genetics, The Churchill
Mrs Karen Roberts	Research Administrator	School of Care Sciences, University of Glamorgan
Ms Fiona Robson	Manager Genetic Counsellors	Yorkshire Regional Genetic Service, St James's University Hospital
Dr Anita Shaw		The Wales Gene Park, Techniquet
Dr Maggie Shepherd	Post-Doctoral Research Fellow	Department of Diabetes and Vascular Medicine, University of Exeter
Dr Heather Skirton	Nurse Consultant in Genetics	Clinical Genetics, Taunton and Somerset NHS Trust
Mr Peter Stansbie	Director of Operations	Skills for Health
Ms Sally Taffinder	Genetic Counsellor	Department of Clinical Genetics, Great Ormond Street Hospital
Mr Christian Thomas	Research Fellow	The Wales Gene Park, Techniquet
Ms Juliet Tizzard	Director	Progress Educational Trust
Mr Mike Tonkin	Nursing Officer	Office of Chief Nursing Officer, National Assembly for Wales
Ms Susan Tully	Tutor	The Education Centre, Bournemouth University

Delegate	Position	Institution
Dr Jill Turner	Lecturer in Sociology & Social Policy	School of Nursing and Midwifery, Queens University Belfast
Mrs Margaretha van Mourik	Genetic Counsellor / Genetic Liaison Manager	Institute of Medical Genetics, Yorkhill NHS Trust
Ms Kate Wall		CLIMB
Ms Lynne Watson	Specialist Health Visitor for Children with Special Needs	Teddington, Twickenham and The Hampton PCT
Ms Greta Westwood	Genetic Nurse Counsellor	Wessex Clinical Genetics Service, Princess Anne Hospital
Mrs Rosie Wilkinson	Adviser in Nursing Practice	Royal College of Nursing of the United Kingdom
Mrs Lynda Williams	Student Midwife	School of Care Sciences, University of Glamorgan
Ms Melissa Winter	External Communications and Membership Engagement Officer	Genetic Interest Group

Appendix 2: Conference programme

Fit for Practice in the Genetics Era

Wednesday 9th July 2003

Glamorgan Business Centre, University of Glamorgan

9:30	Coffee and registration	
10:00	Welcome	Dr Jonathon Gray Dianne Kennard
10:15	Why integrate genetics into healthcare	Dr Heather Skirton Maggie Shepherd Lynette Jones
11:00	Review: The findings of the Expert Panel	Dr Maggie Kirk
11:30	Panel discussion with representatives from:	
	Nursing and Midwifery Council	Professor Paul Lewis
	Patient organisations	Melissa Winter
	The NHS	Lorna Potter
	Professional Education	Professor Martin Johnson
	Human Genetics Commission	Professor Elizabeth Anionwu
12:30	LUNCH	
13:30	Syndicate discussion groups	
	Health visiting	Lynne Watson
	Midwifery	Professor Paul Lewis
	Nursing 1	Professor Sue Proctor
	Nursing 2	Professor Martin Johnson
14:30	Rapporteurs	Marcus Longley
15:10	Review and discussion: implementation	Sally Anstey
15:40	Summing up and vote	Marcus Longley
16:00	Tea and close	

Appendix 3: Written responses

Responses from organisations and institutions:

Association of Genetic Nurses and Counsellors
CancerBACUP
Commission for Health Improvement
Commission for Patient and Public Involvement in Health*
Community Practitioners' and Health Visitors' Association (CPHVA)
Edge Hill Faculty of Health, Edge Hill College of Higher Education
Faculty of Health and Human Sciences, Thames Valley University
Faculty of Health Studies, Buckinghamshire Chilterns University College
General Medical Council
Joint Committee on Medical Genetics
Macmillan Cancer Relief
NHS Sickle Cell & Thalassaemia Screening Programme
NHSU*
Nursing and Midwifery Council
Nursing and Midwifery Research Unit, University of East Anglia
Office of the Chief Nursing Officer, Northern Ireland*
Office of the Chief Nursing Officer, Welsh Assembly Government
Royal College of General Practitioners
Royal College of Midwives
School of Acute & Continuing Care Nursing, Napier University
School of Health and Social Care, University of Greenwich
School of Health Science, University of Wales Swansea
School of Nursing and Midwifery Studies, University of Wales College of Medicine
School of Nursing and Midwifery, Chester College of Higher Education
School of Nursing and Midwifery, The Robert Gordon University
School of Nursing and Midwifery, University of Dundee
Sector Skills Council for Health

*Limited responses only

Responses from individuals:

Mandy Barry, Genetic Counsellor
Tony Blackett, Dept. of Midwifery & Children's Nursing, University of Sheffield
Alison Metcalfe, School of Health Sciences (Nursing), University of Birmingham
Jane Richardson and Pat James, Physiology Division, University of Central England
Surrendra Singh, Wolverhampton University

Appendix 4: Glossary

<p>Association of Genetics Nurses and Counsellors (AGNC) Membership is comprised of nurses, midwives, health visitors and others who have received specific training in genetic counselling in order to deliver genetic counselling services. The AGNC is currently seeking formal professional status for its genetic counsellors and has established a professional Registration Board.</p>
<p>Clinical Genetics Services Services are provided in every UK region by teams comprising medical geneticists (consultants and trainees) and non-medical genetic counsellors (usually nurses or graduates of a Master's programme in genetic counselling).</p> <p>The aim of genetic services is to assist people at risk of developing or carrying a genetic disease to live and reproduce as normally as possible. This involves making accurate diagnoses, a discussion of appropriate options for testing or reproduction, and offering psychosocial support to families using the service (AGNC 2002).</p>
<p>Competence The quality of being adequately or well qualified physically or intellectually. The NMC uses the term competence to describe the skills and ability to practise safely and effectively without the need for direct supervision. A simpler definition of competence is that it is what individuals know or are able to do in terms of knowledge, skills, attitude.</p>
<p>Dominant inheritance A dominantly inherited condition requires only one mutated gene to be passed on from parent to child for the person to be affected by the condition. There is a 1 in 2 (50%) chance that an affected parent will pass on the mutated gene to the offspring.</p>
<p>Duchenne muscular dystrophy A disorder that is due to a mutation in the dystrophin gene on the X chromosome. It usually affects only males, but in very rare cases, girls can be affected. The condition is transmitted through healthy females who carry the mutated gene on one of their X chromosomes, the other being unaffected. Affected boys are generally late in walking and there is a gradual reduction in mobility as the muscles deteriorate, usually with death in the late teens or early twenties. Greatly increased serum creatine kinase levels are a feature of the disease.</p>
<p>Eugenics Eugenics is the study and practice of using genetics principles to improve the quality of the human species, especially through controlling reproduction (selective breeding). It was widely adopted as official policy in several countries in the early part of the 20th century. There were two types of eugenics - positive and negative. Positive eugenics aimed at encouraging parents with characteristics or traits deemed laudable by society to produce more children, whereas negative eugenics attempted to minimise transmission to</p>

future generations of traits that were life-threatening, harmful or of no civic worth.

World War Two and its aftermath and the public revulsion and reaction against the Nazi regime led to a collapse in support for eugenic ideals.

Gene

The unit of inheritance, composed of a sequence of DNA. It is estimated that we have about 34,000 genes, which direct the development, growth and function of every cell in the body, its tissues and organ systems. The contribution of genes to health and ill-health occurs along a continuum, ranging from those conditions that are caused wholly by an error within a gene (gene mutation), to those where genetic make-up plays a very small part and environmental factors are the key causative agents. The common conditions such as cancer, heart disease and diabetes are thought to lie about mid-way along this continuum, where there is an interaction between genetic make-up (possibly with several genes playing a part) and environmental factors.

Genetic Counselling

Delivery of genetic counselling is based on a belief that individuals have an inherent right to be properly informed about the genetic risks and reproductive options, and that they should be supported during any decision-making process.

Genetic Counsellor

A person whose main professional role is to offer information and support to clients who are concerned about a condition that may have a genetic basis.

Genetic Interest Group

GIG is a national alliance of organisations which support children, families and individuals affected by genetic disorders or diseases.

Genetic screening

The systematic application of a genetic test to identify asymptomatic disease or those who are at special risk amongst large populations.

Genetic testing

The analysis of a specific gene, its product or function, or other DNA and chromosome analysis to detect or exclude an alteration likely to be associated with a genetic disorder. (Harper and Clarke 1997)

Genome

All of the genetic material in an individual's chromosomes. The normal human genome comprises 23 pairs of chromosomes.

Genotype

Genetic constitution of an individual.

<p>Haemoglobinopathies</p> <p>A group of genetic conditions (sickle cell disease and thalassaemias) that affect the structure of the haemoglobin molecule within the red blood cells, to cause different types of anaemia.</p>
<p>Health Visitor</p> <p>A qualified nurse who has undergone a further period of training. The NMC describes the overall purpose of health visiting as being to improve health and social well-being. A practising health visitor must be registered with the NMC.</p>
<p>Human Genetics Commission</p> <p>The HGC provides advice to the Government in the human genetics field.</p>
<p>Human Genome Project</p> <p>The Human Genome Project (HGP) represents a multi-billion dollar, international effort to map and sequence the entire human genome, aiming to decipher all of the genes that make up the human blueprint. The first phase was completed in 2000, five years ahead of target. In the present phase, the locations of individual genes are being mapped, and their functions identified. We still have to discover how these genes interact with each other and with the environment, in order to fully understand how genes contribute to health and illness.</p>
<p>Huntington's disease</p> <p>An inherited disorder of the central nervous system characterised by uncontrollable irregular jerky movements, with progressive dementia. It is inherited as a dominant condition that although present at birth, does not usually manifest itself until adulthood. It is invariably fatal.</p>
<p>Medical genetics services</p> <p>See Clinical Genetic Services, above.</p>
<p>Midwife</p> <p>A health professional involved in the care of pregnant women and neonates (new born babies). A practising midwife must be registered with the NMC.</p>
<p>NCHPEG</p> <p>The National Coalition for Health Professional Education in Genetics (NCHPEG) is an interdisciplinary group comprising leaders from over 120 health professional organisations, consumer and voluntary groups across the USA. It was established in 1997 and represents a national effort to promote health professional education and access to information about advances in human genetics, to improve the nation's health.</p>
<p>Nurse</p> <p>A health professional involved in the care of patients of all ages. Nurses are registered with the NMC in one or more of four branches: Adult, Child, Learning Disabilities and Mental Health. A practising nurse must be registered with the NMC.</p>

Nursing and Midwifery Council (NMC)

This statutory body maintains a register of practising nurses, midwives and health visitors across the UK. The NMC has the power to refuse, suspend or revoke a registration, if such action can be justified.

Pharmacogenetics

The study of how different people respond to drugs due to their genetic makeup, in order to identify new, more specific and more effective drug targets with fewer side-effects.

Pre-registration training

Education occurring before a student is eligible for inclusion on the NMC register of qualified professionals.

For nurses, the pre-registration curriculum consists of 12 months Common Foundation Programme, followed by 24 months in Branch studies. The four branch areas are Adult, Child, Learning Disability and Mental Health nursing.

Midwives can either pursue a three year direct entry course, or qualify as a nurse first, then take an 18 month conversion course leading to the additional qualification of RM.

Health visitors must first be registered nurses before embarking on a 12-month (minimum 32 weeks) training programme.

Recessive inheritance

A recessively inherited condition requires two copies of a mutated gene to be present in the offspring (one from each parent) for that person to be affected by that condition. People with only one copy of the mutated gene are referred to as carriers, are usually unaffected by the condition, and can pass on the mutated copy to their children. Parents who are both carrier for the same mutated gene have a statistical chance of 1 in 4 (25%) of having a child affected by the condition.

Turner syndrome (TS)

A condition affecting girls, where the second sex chromosome (X) is missing and so they have only 45 chromosomes. Such girls are usually small in stature and are infertile, because of inadequate development of the ovaries. Although the majority can deal with mainstream education, some do experience learning problems.

Sources:

- Association of Genetics Nurses and Counsellors Education Working Group (2002) *Reports for the Genetics Policy Unit, Department of Health*. (Convenor H Skirton)
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- Royal College of Nursing (2002) *Defining nursing*. RCN, London.
- Skirton H and Patch C (2002) *Genetics for healthcare professionals*. Bios, Oxford.

Appendix 5: Team Membership

The project team	
Maggie Kirk BSc, PhD, RGN, Dip N, Cert Couns	Associate Head of School of Care Sciences/ Leader Genomics Policy Unit, University of Glamorgan
Kevin McDonald BA, MSc, PGCert	Senior Lecturer, Genomics Policy Unit, University of Glamorgan
Sally Anstey RGN, MSc, DipN, Cert Ed (FE), Dip Ethics	Practice Development Co-ordinator, Cancer Genetics Service for Wales, Cardiff
Marcus Longley MA, Cert, MSc, PhD	Assistant Director, Welsh Institute for Health & Social Care, University of Glamorgan
Steering Group	
Elizabeth Anionwu RGN, HVT, PhD, CBE	Head, Mary Seacole Centre for Nursing Practice, Thames Valley University; member Human Genetics Commission
Caroline Benjamin BSc, MSc, PhD, RGN	Macmillan Genetic Associate and Research Training Fellow, Liverpool Women's Hospital Trust and Liverpool University
Sally Davies MA, MSc, FRCP, MRCP	Consultant in Genetics, Institute of Medical Genetics, Cardiff
Jane Denton RGN, RM	Director, Multiple Births Foundation, Queen Charlotte's Hospital, London; member HFEA
Elizabeth France RGN, HV Cert, MSc, Dip Couns	Senior Nurse, Cancer Genetics Service for Wales, Cardiff
Jonathon Gray BMSc, MB, ChB, PhD, MRCP	Director, Cancer Genetics Service for Wales; Clinical Director, Institute of Medical Genetics, Cardiff
Penny Guilbert RGN, Dip N, FETC	Senior Nurse, Clinical Genetics Service, Nottingham City Hospital
Rachel Iredale BSocSc, MA, PhD	Genomics Policy Unit, University of Glamorgan
Heather Skirton MSc, PhD, RGN, RM, Dip Couns	Nurse Consultant in Genetics, Taunton and Somerset NHS Trust; Lecturer, Institute of Medical Genetics, UWCM, Cardiff

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