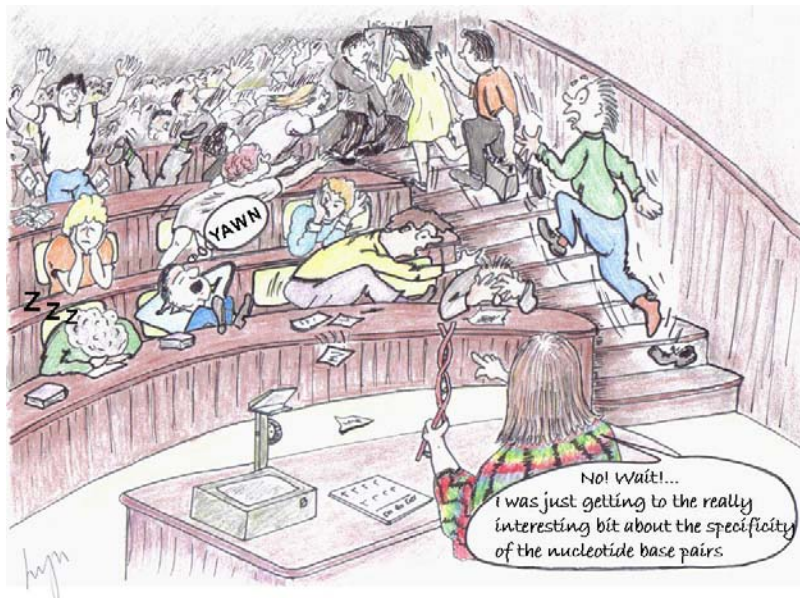


Genetics Education for Nursing Professional Groups:

Survey of practice and needs of UK educators in
delivering a genetics competence framework



Maggie Kirk
Emma Tonkin

2006

NHS

*National Genetics Education and
Development Centre*

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This report has been prepared to inform the work of the NHS National Genetics Education and Development Centre, and the associated Department of Health Steering Group

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Summary

Background and aims

The NHS National Genetics Education and Development Centre was created following the White Paper on genetics (Department of Health 2003) to facilitate the integration of genetics education into all levels of education and training for NHS health professionals. Within the Centre, the nursing professions programme for nurses, midwives and health visitors, works with stakeholders to raise awareness and build networks, and contributes to the development of education resources.

As part of this programme the authors have conducted a survey among UK educators of pre-registration nurses, midwives and health visitors, with the aim to establish:

- The breadth of provision for genetics on pre-registration courses for nurses, midwives and health visitors.
- The extent to which individual courses are helping to equip nursing professionals at pre-registration level for competent practice in genetics, as measured against the UK genetics competence framework.
- Views on how genetics competence is promoted on post-registration courses.
- What resources are used and felt to be useful in supporting genetics teaching and learning, both generally and in relation to individual competences.
- What further help respondents feel they need, both in relation to individual competences, and more generally from the Centre.

Ultimately the survey seeks to identify whether educators have needs that can be met through the activities of the Centre, and these findings will underpin the strategy of the nursing professions programme.

Approach

With over 80 higher education institutions (HEIs) across Britain, a questionnaire based approach was used for data collection. The questionnaire contained a mix of closed and open (free text) items set in three sections, and was distributed in an electronic format to members of our champions' network of educators. The genetics competence framework (Kirk *et al.* 2003) was used as a measure of how content is being translated into tangible knowledge, skills and attitudes in the student practitioner.

Findings

There remains much work to be done in order to provide a consistent level of education; currently none of the competences are achieved in full in any institution, or for any programme. However, this should not detract from the achievements of many institutions that have made significant strides to raise awareness amongst colleagues and to integrate genetics across curricula.

In order to promote competence in genetics further, the respondents identified a number of areas where support is required. These mirror in many ways the areas where they also believe the Centre can take a lead.

Areas of need:

- Access to genetics professionals
- More time within the curriculum
- Explicit demonstration of content and relevance
- Training for educators
- Opportunities for genetics placements
- Access to users
- Guidance on levels of competence

Specific help requested from the Centre through:

- Resource development
- Raising awareness
- Guidance and support (curriculum content, appropriate levels of competence and teaching genetics)
- Staff training
- Links and access to specialists
- Facilitating access to practice placements

Taking it forward

Whilst the views expressed in this study cannot be said to be entirely representative, the data collected do represent the opinions of a group of educators at half of all the eligible institutions, who are perhaps most likely to access and use resources developed by the Centre in response to the survey outcomes.

The Centre must continue in its tasks: to raise awareness about genetics, working with other healthcare and professional agencies; to act as a co-ordinating centre in disseminating information and in facilitating access to expertise and other resources; to provide guidance on teaching genetics, both 'at a distance' and via workshops or study days; to develop focused and accessible resources in a variety of formats.

This study provides a valuable baseline from which to measure future progress in developing genetic competence within nursing professional practice.

1. Introduction

It is the authors' opinion that attitudes towards genetics and its place in nursing professional education and practice are changing gradually and subtly, from 'why should we teach genetics?' to 'what should we teach?' and more recently, 'how can we best teach it?'. The establishment in 2004 of the NHS National Genetics Education and Development Centre (the Centre) is a strong indicator of the UK government view that genetics should be incorporated into the health professional toolkit. The endorsement by the Nursing & Midwifery Council (NMC) of the genetics competence framework for nurses, midwives and health visitors (Kirk *et al.* 2003) is a further indicator that the question of what should be taught is also being addressed.

This report aims to begin to answer questions about how genetics should be taught within the nursing professions, using the genetics competence framework as a basis to consider how individual establishments approach delivery of genetics education and how successful this is, what resources they use, and what resources they need. The focus primarily is on the current provision of genetics education within pre-registration nursing, midwifery and health visiting courses across the UK. The ultimate aim is to identify whether the educators have needs that can be met through the activities of the Centre.

Background

In its foreword to the genetics competence framework, the NMC stated that 'For health professionals, genetics has already become an issue they cannot observe from the sidelines' (Kirk *et al.* 2003; p4). The White Paper on genetics (Department of Health 2003) placed a strong emphasis on the importance of genetics education for health professionals:

"Over time most healthcare professionals will need to understand how a patient's family history and genetic make-up affects their likelihood of developing a disease or their response to medicines. They will need an appreciation of how genetic technology can be used in diagnosis, prevention and treatment. And they will need to be able to convey this information to patients and help them make difficult choices about whether to undergo a genetic test or to change their lifestyle in the light of information about their genetic make-up."

(Department of Health 2003;p47)

It goes on to state that educators will have to give careful thought to ensuring that genetic skills and learning needs are 'reflected, integrated and delivered within education curricula and training programmes' (p49). In order to facilitate this and to help drive and coordinate activity, the government established the NHS National Genetics Education and Development Centre in 2004.

One of the major strands of the Centre's initial programme of work focuses on the nursing professional groups (nurses, midwives and health visitors). It aims to raise awareness about the relevance and importance of genetics to nursing practice, working in partnership with other influential groups to do so, and strives to provide practical help in developing resources to promote learning. Working with educators to identify their needs is an important element in this.

Much of the work of the nursing programme builds on earlier work of the team, in particular using the genetics competence framework as a basis for further development. This framework was developed in 2003 with funding from the Department of Health, through a consensus approach using an expert panel and consultation via conference and dissemination of an interim report (Kirk et al 2003b). Through this process, a series of seven competence statements were developed to indicate the standard that all nurses, midwives and health visitors should be able to demonstrate at the point of registration (Box 1). These were set into a framework with suggested learning outcomes and practice indicators for each statement. This work had also built on earlier work which had demonstrated the patchy and insubstantial nature of provision for genetics education across pre-registration nursing curricula (Kirk 1999).

Literature Review

An extensive literature review exploring genetics education in nursing was carried out prior to the survey being conducted. This has been published separately (Burke and Kirk 2006; Appendix 1). The review, covering papers published between 1994 and 2005, found extensive agreement on the relevance of genetics for nursing professional practice. Whilst areas of good performance were revealed, many studies identified gaps in professional competence and/or education. Research on the delivery of genetics education is limited, but the role of skills-based training, the use of clinical scenarios, and the importance of assessment have all been identified as factors that can promote learning.

Project overview

The survey reported here forms part of the 'baseline' work of the nursing programme, which also incorporates the literature review and establishment of a network of educators identified through a contact list of the Council of Deans and Heads of Schools of Nursing. The survey questionnaire was distributed electronically during 2005.

Respondents were asked how they facilitate the teaching of each of the genetics competence statements and about their choice of teaching resource. They were also asked about the ways in which the Centre could support their teaching needs. The methods used to achieve this are set out in the next chapter. Chapter 3 presents the findings, which are then discussed in Chapter 4. The conclusions and recommendations are set out in the final chapter.

BOX 1

The 7 competence standard statements

All nurses, midwives and health visitors, at the point of registration, 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.

2. Methods

Establishing a Champions Network

As part of its philosophy of engaging and working with key players in health professional education, the NHS National Genetics Education and Development Centre sought to establish a Champions Network of educators of nurses, midwives and health visitors. The network would act as a means of exchanging information and best practice. As well as helping to promote and support interest in genetics, this approach also sought to facilitate more efficient contact with appropriate colleagues in the different institutions.

Members of the Council of Deans and Heads of UK University Faculties for Nursing and Health Professionals were contacted (n=85) and asked to nominate someone within their higher education establishment interested or involved in the (genetic) education of nursing professional groups. The named contact was then invited to join the network, and also to participate in the needs analysis. Eighty-four contacts were identified at 69 institutions.

Developing the questionnaire

The questionnaire sought to establish:

- The breadth of provision for genetics on pre-registration courses for nurses, midwives and health visitors.
- The extent to which individual courses are helping to equip nursing professionals at pre-registration level for competent practice in genetics, as measured against the UK genetics competence framework.
- Views on how genetics competence is promoted on post-registration courses.
- What resources are used and felt to be useful in supporting genetics teaching and learning, both generally and in relation to individual competences.
- What further help respondents feel they need, both in relation to individual competences, and more generally from the Centre.

For the purposes of the survey, 'genetics teaching' was defined as including the science of genetics and applied genetics, including screening, testing, support, discussion about genetic conditions, and ethical issues.

The questionnaire contained a mix of closed and open (free text) items set in three sections, in total covering 10 pages. Careful thought was given to the design of the questionnaire and the final version was developed through an iterative process. Content validity was checked through collaboration with colleagues at the Centre with experience and expertise in education needs analysis, and revisions were made following feedback. Face validity was checked through a pilot programme.

Pilot

The questionnaire was piloted among five academic staff (Field Leaders) at the School of Care Sciences, University of Glamorgan. Following responses to this, further alterations were made to design and content on the questionnaire, which was then re-piloted internally. Final revisions were made before the questionnaire was distributed (**Appendix 2**).

Ethics approval

Approval to conduct the survey was given by the University of Glamorgan School of Care Sciences Ethics Committee. The project was also logged with the Birmingham Women's Hospital NHS Trust Research and Development department.

No major ethical issues were anticipated. All potential respondents were sent the questionnaire with a covering email and consent to participate was deemed to have been given by the return of the completed questionnaire.

Distribution of the questionnaire

The questionnaire was distributed by email to members of the Champions network, or otherwise to contacts named on the email distribution list of the Council of Deans and Heads of UK University Faculties for Nursing and Health Professionals. Two institutions known to teach only allied health professionals were not contacted (n=83 institutions contacted in total). Information on background work (i.e. the competence framework) and on the Centre was also provided, along with appropriate PDF documents and web links attached to an electronic letter (**Appendix 3**).

In acknowledgement that the questionnaire was detailed and that for some institutions, contacts would need to liaise with other colleagues in order to complete the questionnaire, sufficient time was allowed for returns. Three reminders were sent over a five month period from August 2005.

Analysis

Individual returns were assigned a code and all data entered onto an Excel spreadsheet. From this, closed data were exported to SPSS for descriptive statistical analysis. Free text responses were entered into NVivo for thematic analysis. Websites and UCAS information were also used to identify pre-registration programmes offered by all COD members in 2005.

3. Findings

3.1 The responses

Forty-two responses, incorporating 37 completed questionnaires, were received (response rate 50.6%). Four respondents did not complete the questionnaire because they taught only post-registration nursing courses, with no identified genetics component. One replied that the institution was about to implement a new programme and so would not be able to provide current data. If these institutions are excluded from response rate calculations, along with a further three HEIs whose websites indicated that they did not teach pre-registration nursing/midwifery programmes, and who did not respond to the survey, the responses represent 37/75 eligible HEIs (49.3%). However, one institution provided separate responses for the different programmes offered and these have not been included in the quantitative analysis.

Responses pertaining to specific pre-registration programmes can be compared with programme availability identified through screening website and UCAS information to provide a further profile of response rates (Table 1). It must be acknowledged here that websites are not always accurate and so the data presented here are an indication only. However, Table 1 does indicate that responses were obtained from across the range of pre-registration nursing professional programmes.

Table 1. Response rates according to individual pre-registration programmes

Programme	Response rate % (n)
Adult branch	43.0 (31)
Child	50.9 (28)
Mental health	41.8 (28)
Learning disability	51.3 (20)
Midwifery (short course)	51.3 (19)
Midwifery (long course)	54.0 (27)
Health visiting	34.5 (10)

N.B. Percentages are rounded up to the nearest unit if 0.05 or greater throughout.

Not all questions were answered in all cases; where this occurred the respondents identified some difficulties in gathering information from colleagues for programmes for which the respondents were not directly responsible. These missing data are shown when appropriate.

3.2 Provision for genetics education on pre-registration courses

Respondents were asked whether they included genetics within any of the pre-registration programmes offered (Table 2).

Table 2. Inclusion of genetics within pre-registration programmes

Programme	Genetics included (n) %	Genetics not included (n) %	Programme not offered (n) %	Missing data: no response (n) %
Adult	(31) 86.1%	0	0	(5) 13.9%
Child	(28) 77.8%	0	(2) 5.6%	(6) 16.7%
MH	(25) 69.4%	(3) 8.3%	(0)	(8) 22.2%
LD	(18) 50.0%	(2) 5.6%	(7) 19.4%	(9) 25.0%
Midwifery sc	(18) 50.0%	(1) 2.8%	(4) 11.1%	(13) 36.1%
Midwifery lc	(27) 75.0%	(0)	(2) 5.6%	(7) 19.4%
HV	(9) 25.0%	(1) 2.8%	(10) 27.8	(16) 44.4%

N.B: Key used throughout:

- Adult Adult nursing
- Child Children's nursing
- MH Mental health nursing
- LD Learning disability nursing
- M sc Midwifery short course (for registered nurses)
- M lc Midwifery long course (Direct entry)
- HV Health Visiting (for registered nurses)

Five respondents identified additional programmes offered by their institutions, including four for allied health professionals (two of which include genetics), one foundation programme in health science, and two programmes for community based care, one for children's nurses and one for learning disability nurses. Both of these courses include genetics.

In order to represent these data more meaningfully, Table 3 shows the percentage of programmes that do include genetics where that particular programme is offered by an institution. Genetics is included in almost all programmes (96%) of those institutions that offered a response. However, it is not included in a small number of some programmes (mental health, learning disability, midwifery and health visiting). A previous survey (Kirk 1999) found that only one adult branch and one mental health branch programme did not include genetics.

Table 3. Percentage of responding pre-registration programmes that include genetics

Programme offered	Genetics included	Genetics not included
Adult	100%	–
Child	100%	–
MH	89.3%	10.7%
LD	90.0%	10.0%
M sc	94.7%	5.3%
M lc	100%	–
HV	90.0%	10.0%

The number of programmes that incorporate assessment in genetics is comparable with previous data (Kirk 1999), with between 26–33% of nursing programmes assessing genetics content in 2005/06 (Table 4), compared with 29% in 1999. There does appear to be an increase in assessment on direct entry (long course) midwifery programmes (40% assessing), where previously only 28% of institutions assessed genetics, with 14% of these being compulsory (Kirk 2000).

Table 4. Programmes including genetics that also assess the subject

Programme	Genetics content assessed
Adult	31% 9/29
Child	26% 7/27
MH	26% 6/23
LD	33% 5/15
M sc	39% 7/18
M lc	40% 10/25
HV	38% 3/8

The format of assessments was not explored in this survey, although a few respondents commented that genetics might be incorporated into multiple choice questions or voluntarily into assignments:

... genetics as discreet units of learning are not assessed at pre-registration level but are integrated into the general assessments e.g. there may be one or two MCQ questions related to genetics but not an entire exam paper or a student may produce a case study and discuss aspects about related genetics. *CD45*

In order to ascertain how genetics content was incorporated into programmes, respondents were asked to identify whether it was delivered as a stand-alone module, and/or included in other modules (Table 5). With the exception of Child Branch programmes, the majority appear to include genetics across two or more modules, although a sizeable minority incorporate genetics into just one module. A small number of midwifery programmes include genetics more widely across the curriculum. Some respondents indicated that their programmes used problem-based learning (PBL), with genetics content being included in that approach.




Table 5. Approaches to including genetics content in nursing programmes

Programme	Stand alone module <i>1</i>	Integrated within one module <i>2</i>	Within two or more modules <i>3</i>	<i>1 + 2</i>	<i>1 + 3</i>	<i>2 + 3</i>	PBL approach
Adult	3.2%	25.8%	67.7%				3.2%
Child	24.1%	72.4%					3.4%
MH	4.2%	29.2%	62.5%				4.2%
LD		27.8%	66.7%				5.6%
M sc		21.1%	68.4%		5.3%		5.3%
M lc		20.0%	68.0%		4.0%	4.0%	4.0%
HV		44.4%	55.6%				

The results presented in this section thus indicate that genetics is included across the range of pre-registration nursing professional programmes for the great majority of HEIs responding to this survey. The extent of its inclusion varies, with the majority including genetics content in two or more modules, where the modular approach is taken. The majority still do not assess genetics content however. How the delivery of this content supports the achievement of competence in genetics as set out in the competence framework, is considered in the next section.

3.3 Achievement of competences

Rather than gathering detailed information about genetics curriculum content for all relevant programmes offered at individual institutions, or about the number of timetabled hours allocated to the subject, the authors decided to assess provision through asking how well students were equipped to achieve the competences set out in the framework, using a three-point scale where:

-  1 = our courses would not equip students to demonstrate any component of this competence
-  2 = students could achieve this competence to a limited extent
-  3 = students are able to demonstrate this competence fully on exiting from the course.

Each of the seven competences was considered in turn. A breakdown of achievement of individual competences for the different nursing professional programmes is provided in the next series of charts (figures 1–7).

Figure 1. Competence 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.

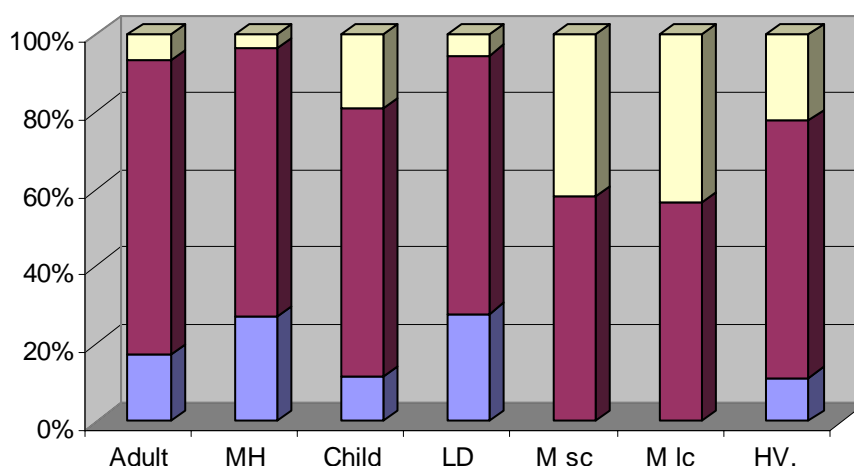


Figure 2. Competence 2

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.

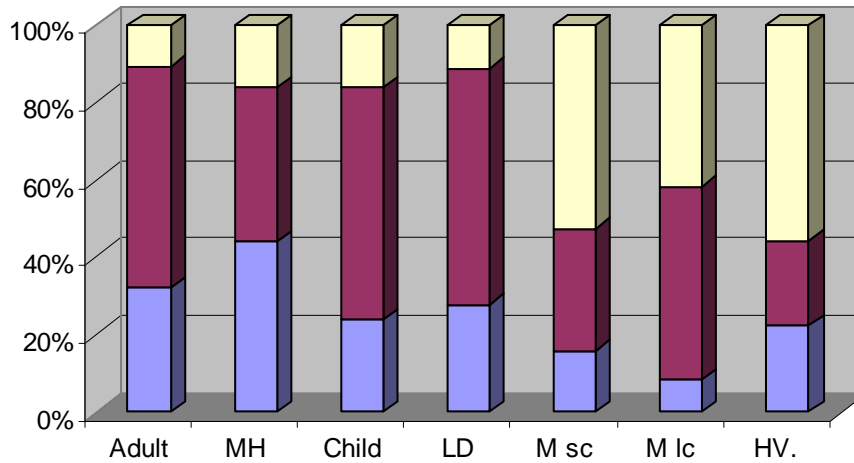


Figure 3. Competence 3

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.

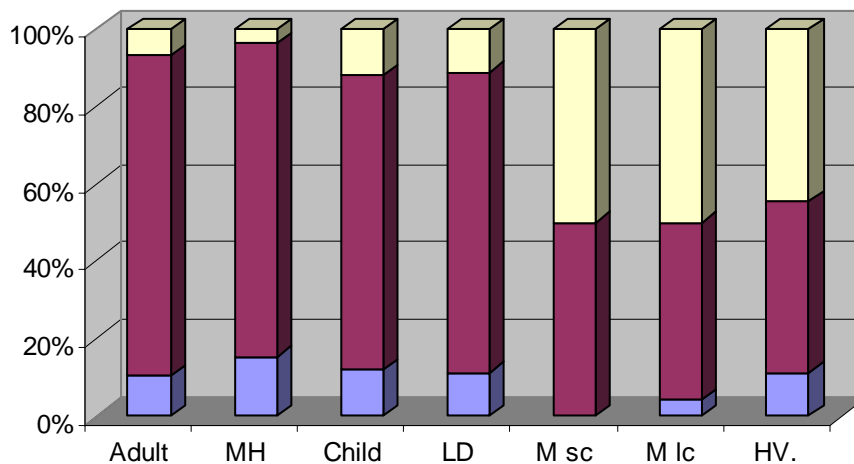


Figure 4. Competence 4

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.

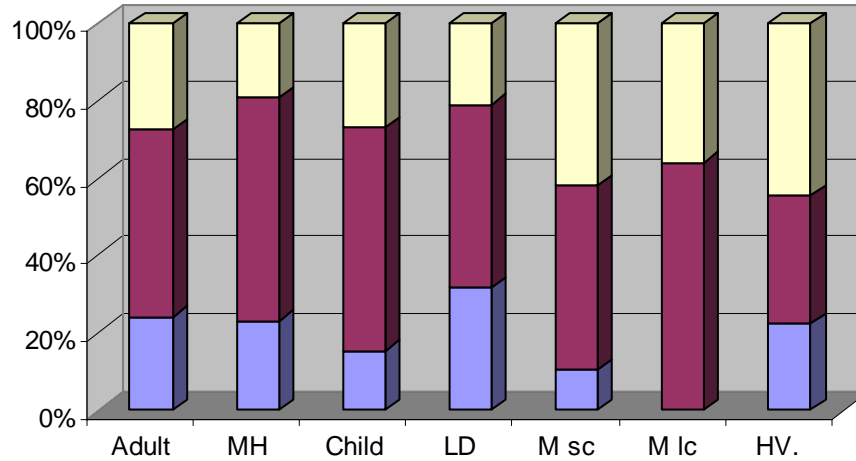


Figure 5. Competence 5

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.

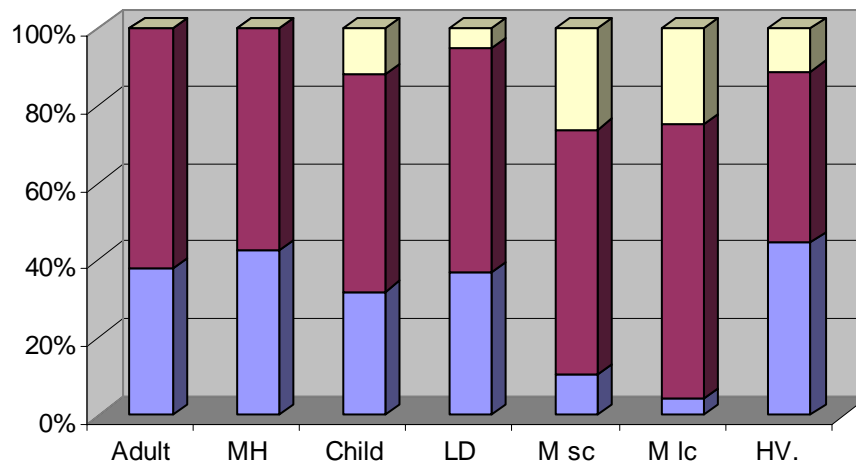


Figure 6. Competence 6

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.

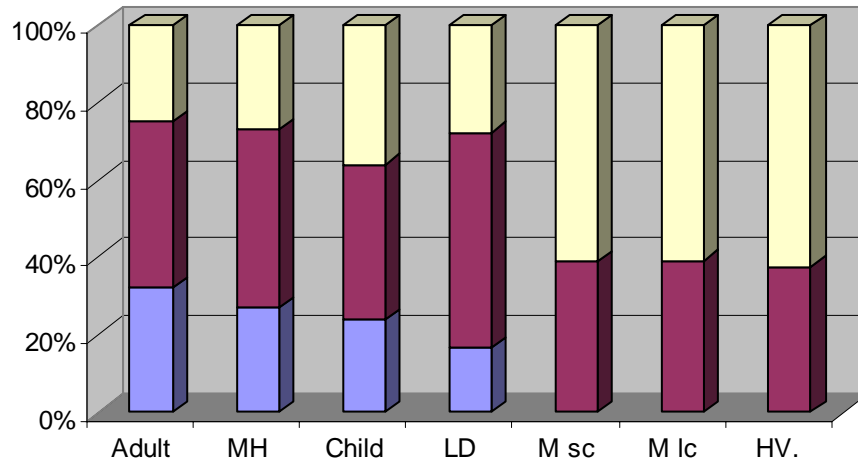
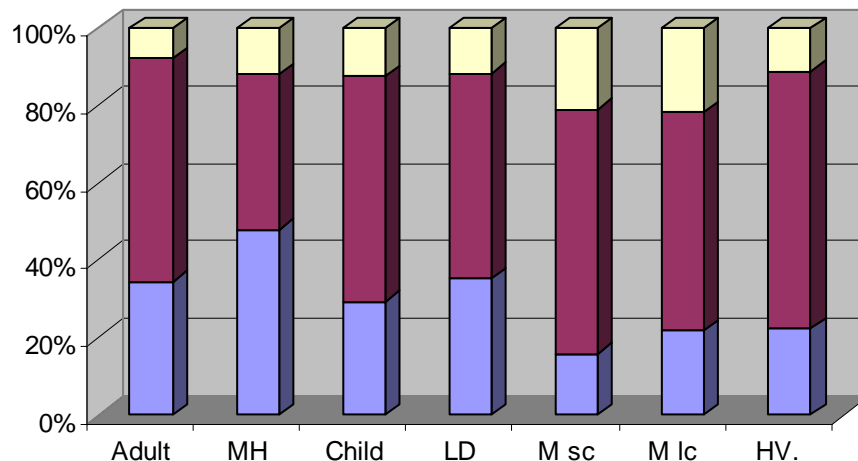


Figure 7. Competence 7

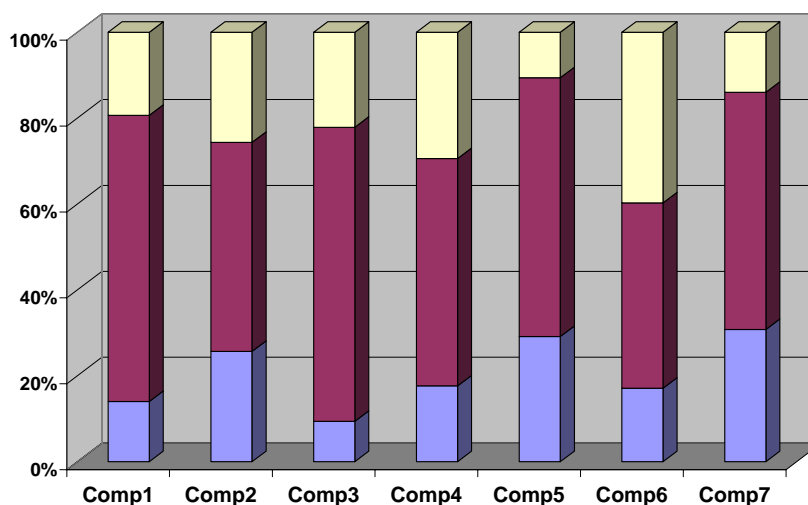
Obtain and communicate credible, current information about genetics, for self, clients and colleagues

- using information technologies effectively to do so.



The series of charts indicate that there are quite wide discrepancies in genetics education as assessed against the competence framework, both in terms of the professional programmes and achievement of competence for the individual competence statements. Figure 8 indicates how well individual competences are achieved across all courses.

Figure 8. Achieving competences across all courses



If scores are assigned to the three categories (Do not equip = 0; Limited extent = 1; Fully equipped = 2) the competences can be ranked according to achievement across all programmes (Table 6). To allow for the differences in the numbers of responses received for each competence, the percentage of the total response for each competence was used for the calculation rather than the absolute number of responses. This indicates that Competence 6 (Recognising the limitations of one’s own genetics expertise) is most commonly achieved. Students are least likely to achieve Competence 5 (Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information).

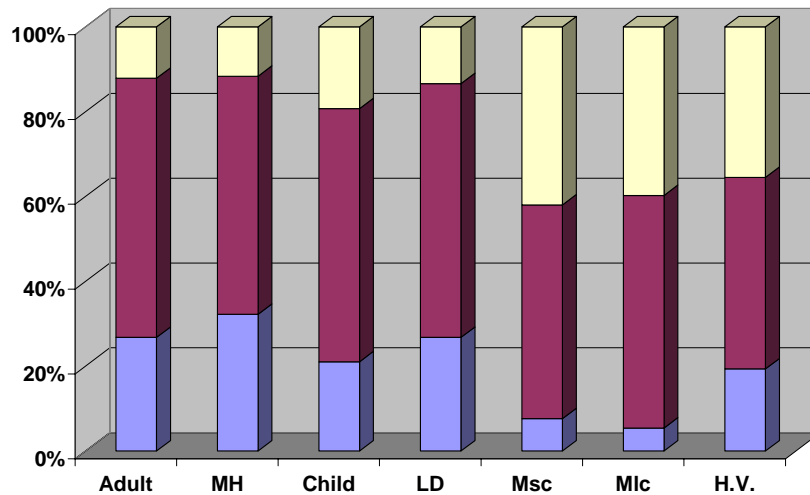
Table 6. Rank order of achievement of competence across all courses

Competence No.	Brief competence descriptor	Score	Rank
6	Limitations of own expertise	123	1
3	Uphold rights	113	2
4	Genetics knowledge to underpin practice	112	3
1	Identify clients	105	4
2	Appreciate sensitivity	100	5
7	Obtain & communicate information	83	6
5	Utility & limitations of testing	81	7

When achievement of competence is considered according to programme offered (Figure 9), midwifery programmes appear to equip students to a greater extent compared with others. Approximately 41% of midwifery courses were identified as fully equipping

students to achieve competence in genetics. Mental health programmes fare the least well, with approximately 32% failing to equip students with genetics competence, although just over half (56.1%) identify limited achievement of competence, and 11.7% full achievement. Midwifery and health visiting programmes appear consistently to 'out perform' other courses.

Figure 9. All seven competences by programme



Consistency of provision

Respondents were invited to comment on whether provision for genetics was consistent across all relevant programmes offered by individual HEIs. Twenty-two comments were received, half of which indicated that the respondents were uncertain. For some, this was as a result of the number of programmes offered and the difficulty of one person having an overview on genetics provision across all of these courses. One respondent's comments highlighted the varying expertise of the lecturers as a factor in consistency:

I have no idea. As all programmes are taught via Enquiry-Based Learning the content depends very much on the quality of the facilitator. Even within a programme the quality of the coverage will vary according to the facilitation group and the facilitator. Nearly all, if not all, have no expertise (or interest) in the area.... *CD27*

Another respondent felt that their provision was consistent across all programmes, but clearly felt there was some disadvantage in comparison with other HEIs where there are opportunities for links with the regional genetics centres:

Exposure of students is generally equitable at [University]. This is not the case when comparisons are made with other universities delivering pre registration courses who have access to medical genetic departments and appropriately qualified professionals. *CD57*

Others felt that there were discrepancies, for different reasons:

There is variation across programmes. The School is in the process of revalidating a number of nursing and midwifery programmes and genetics as a theme based on the national framework is being incorporated into the developments with greater emphasis. It is recognised that genetics as a topic is not addressed as fully as it could be within the present curricula. *CD45*

Whilst acknowledging the importance of the competencies, several Course Leaders commented on the difficulties of balancing the competing priorities within their curricula, given the limited time available. *CD40*

There is a great variation in the achievement across pre-registration courses partly due to time issues and variations in perceived benefits and needs. *CD69*

There was also scope for variations within a programme, depending on the assessment strategy within individual modules:

For assessment purposes, students choose cases that are of particular relevance to them, so the genetic aspects of functioning and practice may or may not be assessed for a particular student undertaking such a module. (For each module, whether or not the genetics is always assessed depends on the learning outcomes of the module.) *CD40*

There was also a view that some programmes had a greater focus on genetics than others, in particular children's nursing and learning disability nursing from the nursing programmes:

Nursing – One resource session (lecture) in year 1. The learning package ... is all on a very basic level. Midwifery – At present this is not explicitly expressed in either of our courses, but we may be stronger on some areas than others. *CD27*

Midwifery content is more specifically related to competencies. LD and Child branches have some specific sessions and content related to competencies. *CD13*

That health visiting programmes and other post-qualifying courses might have different genetics content was also acknowledged:

Pre-registration health visitors/specialist community public health nurses have specific standards of proficiency and requirements and as a post qualifying award, assumptions are made about the level of knowledge and of common issues relating to genetics, testing counselling etc. *CD75*

One respondent commented on the developments taking place within the pre-registration nursing programme that would help promote consistency:

As a result of the genetics project it is now aimed that the competencies will be covered for all nurses in the common foundation programme. A Learning disability nursing lecturer is going to lead the LD team in addressing how the competencies are to be best included in LD branch, and significant change is envisaged here. *CD38*

Perhaps the final word should go to the respondent who sounded a note of caution:

I feel a similar limited level is achieved consistently across courses; the problem is the limited level to which it is achieved. *CD84*

3.4 Post-registration courses

The extent to which genetics is included in post-registration courses is unclear and many respondents felt unable to comment on this. Six said that no provision existed within their institutions, but 16 were able to identify some content on a range of courses other than pre-registration midwifery or health visiting. Most commonly, genetics is integrated into specific modules, particularly cancer care, chronic disease management and heart disease. One respondent commented that some post-qualifying provision was being developed:

Students are also encouraged to avail of local study days on the topic. Plans exist to incorporate a full study day around the competency statements. *CD84*

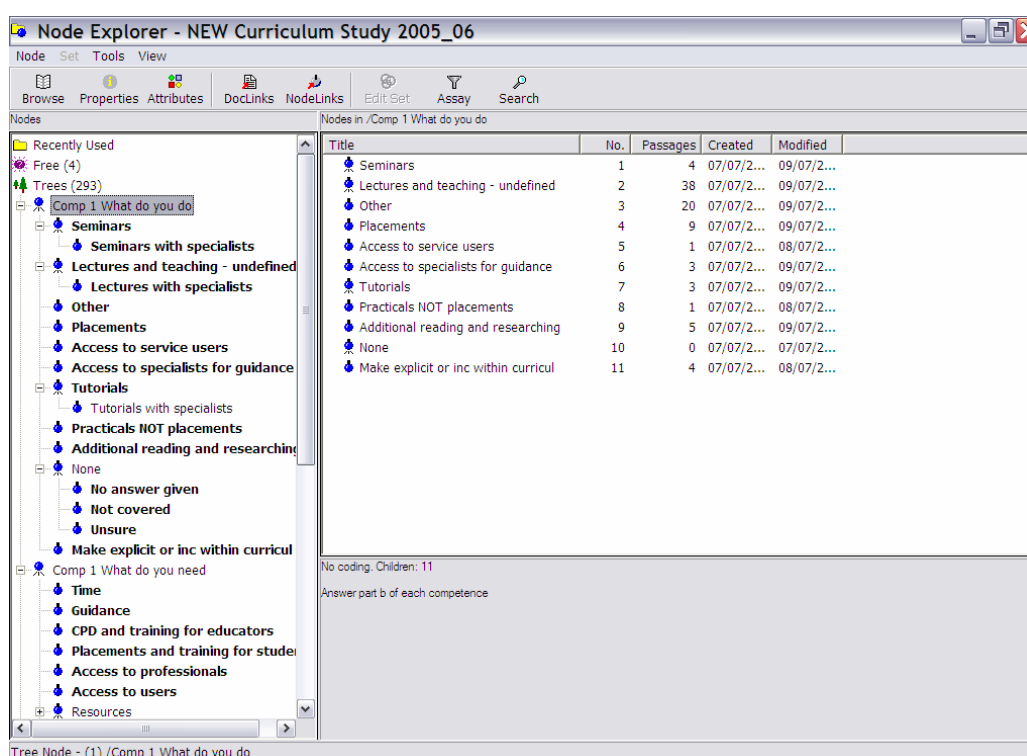
Two respondents commented that they had some provision at Master's level, but in one case, the course had not run recently, and in the other, had not been requested by service providers or practitioners. The issue of funding as a key factor in provision was also identified by one respondent:

Due to financial difficulties [within NHS trusts] all post-registration courses have been cancelled until further notice by the NHS trusts. Local service providers do not wish (and are not prepared to pay for) any stand alone units. Genetics has to be incorporated, where appropriate, into existing units. *CD27*

3.5 Facilitating achievement of competence

Respondents were invited to comment on how individual HEIs facilitated the achievement of each competence. A number of themes emerged during analysis using NVivo (Figure 10 right hand window) and these tended to be applicable across all competences, with none specific to an individual competence statement. A range of approaches was noted, but the majority identified the use of seminars, lectures and tutorials to facilitate the competences (28–45 passages identified). Only a few mentioned specific resources, or approaches other than these – e.g. clinic visits, use of interactive sessions, involvement with screening experts, use of videos and debates.

Figure 10. Facilitating competence: Identified themes using NVivo



A common element to many of the responses was that the competences were often addressed through the general curriculum because of the transferable nature of knowledge and skills needed to underpin the competences. Thus whilst many respondents felt that the competences were covered to an extent, a common limiting feature was that genetics was seldom the focus of such approaches. In some cases, respondents were unable to comment as facilitation of competence was very limited:

The current level of teaching genetics is very basic and none of the above competencies can be met with what is currently taught to all of the above courses. *CD14*

The approaches used to facilitate achieving each individual competence are presented next, with the brief statement descriptor as an aide-memoir.

Competence 1 – Identify clients

A range of approaches was identified, with delivery mainly through lectures, seminars and tutorials. For many, the focus was not specific to genetics although genetics was clearly integrated within other content:

[Public Health Nursing]: Recognition of the need for referral is the main area and identification of appropriate referral pathways. General teaching in relation to holistic family assessment, communication skills and ethics of healthcare. *CD34*

This is achieved largely through the foundation programme (year 1 all branches) which includes detailed history and assessment taking and also communication skills which deal with the delivering of bad news [and] clinical investigation skills. *CD52*

The importance of good history taking, including family history is included in teaching sessions for example, antenatal booking history. The principles of genetic inheritance are taught in the anatomy and physiology sessions and genetic disorders and their inheritance/ management and prevention are taught in modules. Use of genograms to aid risk assessment and also integrated in sessions around health assessment, health protection, health promotion and skills of health visiting. *CD75*

A few identified more specific genetic content such as visits to genetics clinics or other initiatives:

Interactive sessions creating karyotypes, reading karyotypes. *CD29*

Access to antenatal screening co-ordinator – follow ladies through with abnormal results. *CD57*

In order to achieve this in midwifery, we have linked with the regional and national co-ordinators for antenatal and newborn screening. This has been very positive and has really helped to move us on in ensuring a stronger focus within the midwifery curriculum. *CD11*

Competence 2 – Appreciate sensitivity

Many respondents commented that this competence represented a core value and the knowledge and skills needed to underpin it were addressed at several levels throughout different programmes. However, many also identified that genetics might not be an explicit element in the various sessions. Nonetheless, this also provides some indication

about how genetics might be integrated more fully into curricula without necessarily increasing curriculum time:

Discussions within sessions on ethnicity, culture and religion – impact of genetics touched on but not necessarily the only focus. *CD45*

We have links with many minority groups and together we facilitate workshops with students although to date the issues of genetics have been the focus of these sessions. Several sessions, discussions and seminars. *CD52*

2nd year Midwifery students: workshops/scenarios looking at knowledge and skills and sensitivity associated with assessment and referrals. *CD62*

Midwifery: [What we teach is] not specifically related to genetic information but more in relation to the way all information at booking is related to an individual. This will include things about screening for genetic abnormalities. Students are encouraged to think about appropriate language and knowledge. Probably not the cultural aspects. *CD27*

Some respondents did identify specific approaches to facilitating this competence:

I believe that our ongoing work with members of the local, regional and national screening task force will be of benefit in moving this work on within our own pre and post registration midwifery curriculum... In considering the issues of genetic screening and culture, students are encouraged to make known their own understanding and insights into cultural barriers and imperatives. The teacher then helps them to refine or redefine these insights and apply them to a theoretical practice situation. *CD11*

[Child branch]: through a scenario based PBL programme. [Learning Disability nursing]: Engendering in the student an understanding of various partnership approaches and effective means of communicating with people who demonstrate a range of abilities. [Midwifery]: Scenario PBL and placing an emphasis on women's choices and cultural diversity throughout the programme. *CD34*

Competence 3 – Uphold rights

Again, many emphasised that this competence was addressed as a transferable skill throughout the programme:

Midwifery (long and short): The rights of the woman are implicit throughout the course. Also specific sessions on: consent legal and ethical viewpoints; autonomy; assertiveness. *CD18*

Through enquiry based learning, group discussion and story telling, such issues are addressed within the curriculum. Although this would not apply to every

student, I am reasonably confident that a majority of our students would recognise that personal values and beliefs may influence the care and support that midwives provide to women during decision-making. *CD17*

As such, the genetics element may be integrated within other content:

[Midwifery]: This is covered within congenital abnormalities. We mention the link between the offer of antenatal screening tests and the information provided for informed choice for parents. *CD27*

However, some identified that specific application to genetics might not be covered:

Informed decision making in general would be covered but not really applied to genetics in particular. Not in this depth. *CD19*

Some approaches included the use of student-led debates or role play:

Try to raise awareness that as a person the practitioner will have their own opinion and they need to be aware of it and why they feel this way. They must allow the information to be given in a way that allows the patient to decide that is right for THEM even if it is not what the practitioner thinks is right. Use of case studies and role play. *CD32*

One respondent drew attention to the importance of addressing this competence:

More worked examples which outline the issues that may need to be considered and demonstrate the complex interactions that may occur in 'offering' genetic investigations. In particular attention needs to be given to the risks of presenting tests as 'routine'. *CD84*

Competence 4 – Genetics knowledge to underpin practice

Generally a little more detail was given on how this competence might be addressed through specific content, and through integration with other modules:

Inheritance and disease are taught in the 1st year in the anatomy and physiology element of the prenatal care module. Genetic disorders are taught from a neonatal and maternal perspective in year 3 / part 2. Inheritance, disease and genetic disorders are taught in the anatomy and physiology element of the nursing modules across the three years of the awards as appropriate to the chosen branch of nursing. In the Health Visiting awards there are two key modules that explore these issues in some depth. *CD75*

Role of genetic influences on common multifactorial disorders is covered in a number of modules. General sessions on genetic influences on health in first year to students in adult, child, mental health and learning disabilities pathways.

Subsequent sessions focus on specific disorders, e.g. heart disease, diabetes mellitus, cancer, causes of LD syndromes. Midwives have a session on pre-conception care, foetal abnormalities and birth defects. *CD82*

Promoting public health role of midwifery and nursing. Addressing some of the aetiological factors that predispose to disease and the role that genetics play e.g. diabetes, cancers, Promotion of Health Belief Model in reducing risk. *CD29*

Lectures / tutorials on conditions with genetic bases and sessions on interaction between environment and genetic predisposition. *CD45*

Some limitations were also noted:

With the exception of our midwifery students, most of our pre-reg nursing programmes/branches would touch upon the role of genetic factors in causation of ill health but wouldn't really address issues of modification and prevention. *CD89*

Specific approaches such as visits, use of specific resources, web sites, debate, and workshops, were included:

[Child branch]: through a scenario based PBL programme. [Learning disability nursing]: Teacher led clinical genetics workshop. Multiple choice pre and post module self assessment "quiz". [Midwifery]: PBL and clinical practice. [Public Health Nursing]: Included as part of a theoretical session on Children with Special Needs, delivered by an external expert. All aspects are included within practice placements but this will vary depending on the available experiences. *CD34*

2nd year students practice based modules considering implications of inherited genetic disorders: seminars. 2nd year Midwifery students workshops/scenarios looking at knowledge and skills associated with assessment and referrals. *CD62*

Websites like *Headstartinbiology* and *GeneSense*. *CD80*

The need to put genetics into context was also identified:

Try to contextualise genetics not just about disease but normal function – it is only when it goes wrong that it can cause disease. *CD32*

Competence 5 – Utility & limitations of testing

There was little identified in the way of specific approaches to promoting this competence and teaching was most commonly incorporated with ethics:

Core module on ethical issues in nursing incorporating some genetic based scenarios – nursing. *CD13*

Lecture and seminar delivered in students' 1st year, seminar focusing upon potential physical and/or psychosocial effects of genetic information. Midwifery students have more input in their second year looking at the impact on patients and families [using] seminar: case studies/scenarios. *CD62*

Sessions devoted specifically to cytogenetics related to practice using relevant case studies and another session for molecular genetics with clinical applications. Need to review the understanding of one before embarking on the other!! *CD32*

Monitor the achievement of students' personal developmental learning goals in working in early pregnancy units, working with counsellors in Fetal medicine and participating in neonatal screening. *CD29*

Midwives, for example cover antenatal screening and some of the issues. Genetic testing not widely covered on other programmes, though testing in general would be. *CD19*

Competence 6 – Limitations of own expertise

Many respondents stressed that this was a fundamental requirement of all nurses, midwives and health visitors:

Students are guided by the NMC code of practice and therefore should not undertake work for which they are not prepared. *CD52*

As a common core competence it is developed throughout the programme, as one respondent commented:

To reiterate and reinforce the partnership role that the student midwife has in knowing professional scope and limitations. To enable the student to know when and how to refer to other members of the multidisciplinary team. *CD29*

Preparation includes a variety of education approaches, such as role play, portfolio development and others:

Students are expected to develop action plans for future learning based around awareness of limits of competence. Whilst genetics is not a specific element of all action plans it could be part of that reflective process. *CD75*

Use of self awareness which develops via theoretical and clinical exposure each year of the 3 year programme. Use of reflection as the practice assessment tool. Use of enquiry based learning and inter professional learning. *CD57*

A few respondents did refer to more explicit genetics content:

Module focusing upon professional practice/role. Lecture and seminar [on] what is the role of genetics services in the NHS. *CD62*

Talk about what they can do and what they might want further advice about. Use case studies from area of specialty for them to work through. Educate them about the structure of the clinical genetics service, how they can contact their local [Clinical Nurse Specialist/ Genetic Counsellor]. *CD32*

Some of the comments raised some interesting issues about the nature of competence, being aware of one's limitations, and about the possibility of 'unconscious incompetence':

Most students would acknowledge their limitations, but may be unclear about referral although taught session includes this. *CD22*

Students are aware of their limitations related to genetic expertise because there is very little input into their course. They often say they find the topic difficult or complicated although some also say that the first year workshop is very informative. *CD82*

Students seem aware of their limitations, in fact this can be a major obstacle to learning as genetics is all too often presented in terms of science and biologically focused. *CD84*

A hard one to answer. Our nursing students appreciate the general duty to recognise their own limitations but they probably lack the specific knowledge of genetics to fully recognise these. *CD89*

Competence 7 – Obtain & communicate information

Many stressed that this competence would be delivered as part of general communication skills teaching:

[Midwifery]: communication skills, searching and retrieving information and analysis of material is embedded into the course. Adult [branch]: introduction of use of internet, use of health related sites such as NELH and encouragement to use [in] preparation of assignments etc. Child [branch]: encouragement of development of IT skills throughout programme and use in preparation for workshops and presentations. *CD64*

[Public Health Nursing] There would be an expectation that on completion of the programme practitioners would be able to retrieve/ direct clients to IT resources about any condition. They would not be expected to communicate information to clients unless diagnosis and advice had already been given. *CD34*

To help students use transferable skills in using information technology to a) retrieve information, b) develop skills of critical analysis in reading information, c) to develop health education/ promote teaching resources for their clients. *CD29*

However, some specific genetics content was noted:

Give them web addresses, demonstrate sites and have a sentence about what the site info is geared towards. Often ask them to go to two nominated web sites to let them see the pitfalls of using the web and the importance of knowing the source. *CD32*

The first year genetics workshop is well referenced to relevant sources of information especially websites. An effort was made to run the genetics workshops in the computer labs but not all groups could be accommodated (out of an intake of 300 students). *CD82*

Two respondents mentioned some difficulties that could be encountered in achieving this competence:

All of our students should have acquired good search skills but, with the exception of the midwives, they probably lack the understanding to appraise any literature they find. *CD89*

Although students are taught literature searching skills a lack of awareness of specific resources can create problems. *CD20*

One respondent identified the development of IT literacy among staff via IT (ECDL) training as a means of promoting this competence.

3.6 Engagement in related activities

The survey asked about any developments or initiatives within the individual's institution that were helping to promote competence in genetics. Approximately half of all respondents replied that they were either uncertain of any initiatives, or stated that there were no initiatives currently in progress. In two cases, there had been discussion about potential development, but with very little progress being achieved so far.

Responses from twelve institutions provided information on more specific developments. Several related to the identification of a named lecturer with responsibility for genetics and its development across curricula, and a few referred to their role within the Champions Network:

Yes [name] Senior Lecturer Midwifery represented the Faculty at the Genetics in Health Education Consultation... and has attended genetics workshops and has fed back to the teams and some of the issues from her feedback are included in genetics sessions. *CD75*

Six respondents indicated that they were involved in module or curriculum reviews, with one stating that this had been completed:

The 7 competencies have been integrated into the 'rewrite' of our curriculum. *CD88*

Other HEIs are also clearly proactive in promoting genetics competence, and specific activities were identified:

I have provided in-service education to midwives on the new screening for haemoglobinopathies as a rolling programme, to enable all midwives working in the community to enhance their knowledge base and to facilitate their ability to educate clients when seeking informed consent for neonatal screening. I have also developed a study package for e-learning on understanding haemoglobin and haemoglobinopathies for health professionals. *CD29*

The first genetics workshop was reinstated after DoH White Paper *Our Inheritance Our Future* in 2003. Previously it had been a one hour lecture – it is now a 3 hour workshop. I also do the workshop for the Foundation Degree in Health Care Sciences. *CD82*

Yes, we have set up a GeneSense website to support learners and professionals across the health professions – www.genesense.org.uk. I have co-authored two textbooks for use by health professionals. *CD64*

We have a Genetic Interest Group (members from Hospital Trusts, genetic counsellors, user/ carer/ lecturers, practitioners from PCTs, student representatives) which meets on a monthly basis... We are at present developing a genetics programme by way of Road Shows across our Trusts. The first Road Show is on [date] 2006. We have also developed a website with several links on genetics for lecturers, students and practitioners to access. *CD60*

3.7 Use and usefulness of resources

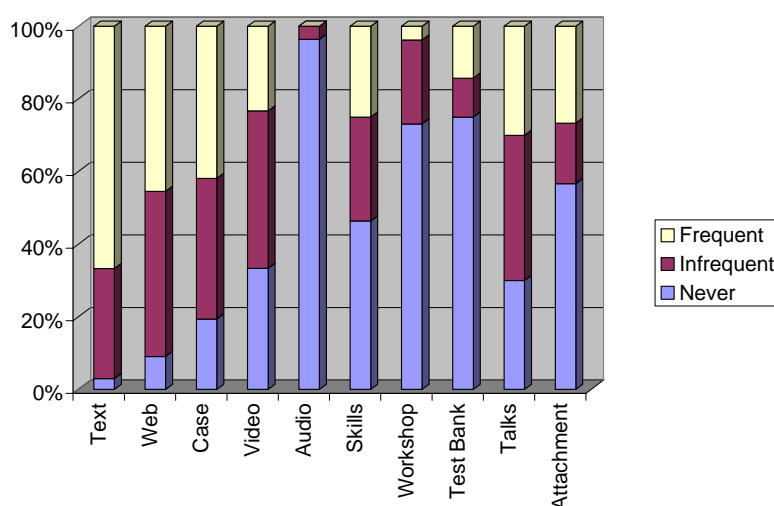
Facilitating access to high quality teaching and learning material is fundamental to the Centre's role of supporting education. The nursing programme asked respondents about their current preferences for ten teaching resource formats; how often different formats are used and how useful they are. As some resource types may not be available at every HEI, respondents were also asked to include how useful they thought a resource could be even if they weren't currently using it. Identifying the formats that work well in teaching will help direct the Centre in the development of future resources.

Respondents were not asked to provide details on resources for individual programmes, rather they were asked to provide an overview of use across all the programmes taught.

Frequency of resource use

Three possible response options (never, infrequently and frequently) were provided for each resource format. Figure 11 illustrates the distribution of responses received.

Figure 11. Resource use across all programmes



The three response options were weighted by assigning a numerical value (never = 0; infrequently = 1; frequently = 2). These were then used to calculate an 'overall score' for each resource format. The percentage of each response for each format was used in the calculation to allow for variations in the number of completed responses for this question. Using the total 'score' the resources can be ranked in order of frequency of use (Table 7) with 1 being the most frequently used and 10 least used. This indicates that text books are the most frequently used teaching resource with audio tapes least favoured.

Table 7. Rank order of resources used across all courses

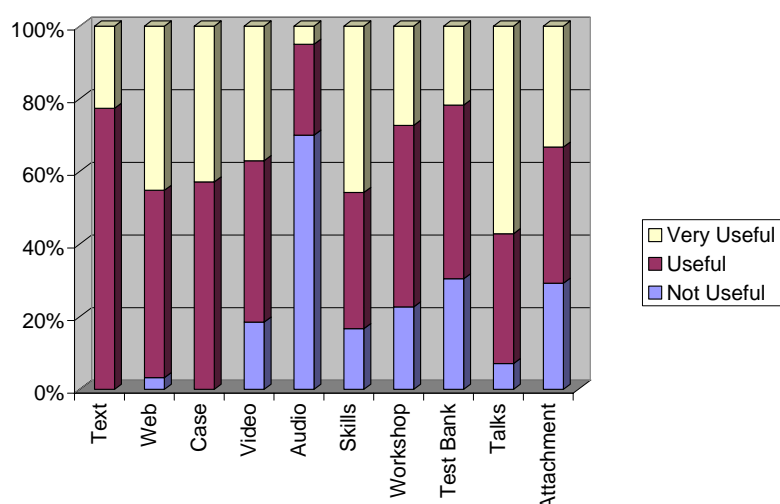
Rank	Resource	Score
1	Text books	164
2	Web sites	137
3	Annotated scenarios and case studies	123
4	Access to users or providers of genetic services willing to visit and talk with student groups	100
5	Videos / CDs / DVDs	90
6	Skills practice (e.g. family history workshop)	79
7	Attachment to medical genetics service (e.g. for observation) or other relevant centres e.g. fetal medicine or haemoglobinopathies centres	70
8	Test Bank for assessment purposes	40
9	Access to workshops for educators on skills practice.	31
10	Audio tapes	4

One respondent (*CD26*) suggested haemoglobinopathies, congenital abnormalities, PKU and Down syndrome as topics for educator workshops. Although this HEI does not use workshops currently, the respondent felt that it might be useful.

Usefulness of resource

Three possible response options (not useful, useful and very useful) were provided for each resource format. Figure 12 illustrates the distribution of responses received.

Figure 12. Usefulness of different resource formats across all courses



An estimation of the perceived usefulness of each resource type was determined in the same way as frequency of use. Numerical values were assigned to each of the three response options (not useful = 0; useful = 1; very useful = 2) and used to calculate an overall score for the resource using the percentage of each response received. Resource type was ranked according to usefulness with 1 = most useful and 10 = least useful (Table 8). Although most frequently used, text books rank in fifth place out of the 10

formats in terms of usefulness in teaching. Talks by users or providers of genetic services are found to be most useful, and audio tapes least useful.

Table 8. Rank order of the usefulness of resources across all courses

Rank	Resource	Score
1	Access to users or providers of genetic services willing to visit and talk with student groups	150
2	Annotated scenarios and case studies	143
3	Web sites	142
4	Skills practice (e.g. family history workshop)	129
5	Text books	123
6	Videos / CDs / DVDs	118
7	Access to workshops for educators on skills practice.	105
8	Attachment to medical genetics service (e.g. for observation) or other relevant centres e.g. fetal medicine or haemoglobinopathies centres	104
9	Test Bank for assessment purposes	91
10	Audio tapes	35

Respondents were able to list additional types of resources they use and to comment on how frequently they are utilised and how useful they have been found to be. Responses included:

Some student midwives have chosen haemoglobinopathy screening centres for their 'elective' study (local and international). Useful. *CD29*

Debate. Infrequently used. Not useful. *CD32*

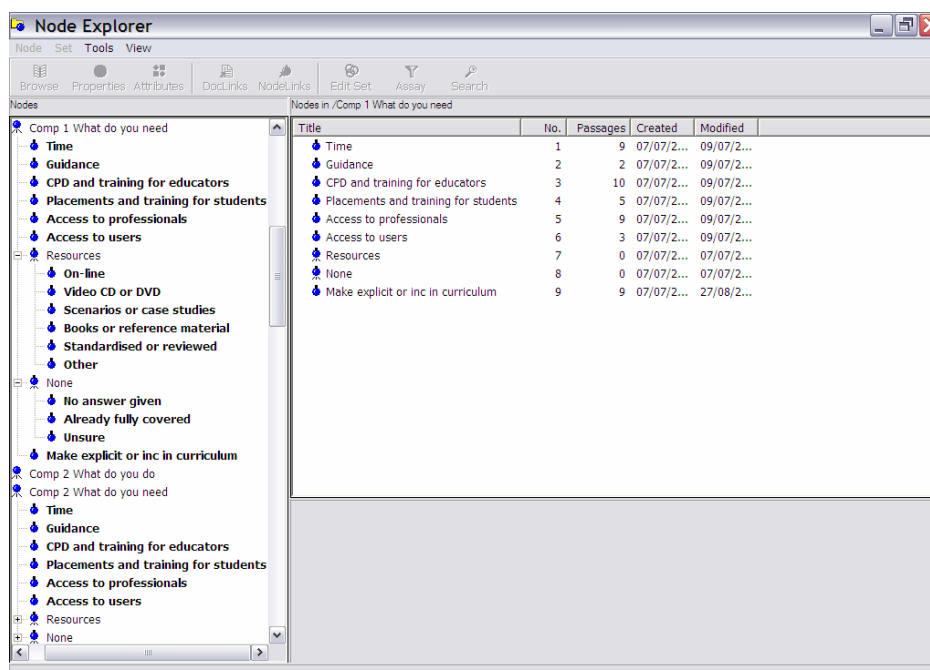
Student midwives have a placement in antenatal clinics with a registered midwife for practice supervision. History taking in the clinical setting with a registered midwife / GP / obstetrician is frequently used and very useful. *CD63*

Clinical practice with children and families who may have been referred for genetic counselling or whose children have genetic conditions. Frequently used. Very useful. *CD88 (Child branch)*

3.8 Identified needs to promote competences

Educators were asked what they most needed to help them to integrate the individual competences into their curricula. Passages were identified for each competence (Figure 11) and seven main categories emerged from this thematic analysis (Table 9).

Figure 11. Help needed to promote competence: Identified themes using NVivo



Three institutions indicated that some (four or more) competences were sufficiently integrated into their curricula, for midwifery, learning disability or public health nursing, although one respondent did state that these ‘could be made more explicit in relation to genetics issues’ (CD4). Many comments were reiterated against the individual competences, although some comments were specific to a particular competence. As a crude analysis, if the number of occurrences of passages identified for each of these themes is added up for each of the competences, some indication of priority of these needs may be obtained (Table 9).

Table 9. Ranking of themes for help needed according to number of passages identified.

Rank	Theme	No. of passages
1	Access to genetics professionals	48
2	More time within the curriculum	39
3	Explicit demonstration of content and relevance	35
4	Training for educators	33
5	Opportunities for genetics placements	23
6	Access to users	20
7	Guidance on levels of competence	17

Some of the needs identified against each of these themes will be described below.

Access to genetics professionals

It was clear that the opportunity to link with genetics services and practitioners from the specialty was seen as important by respondents, and was valued where this was already occurring. It was felt that 'actual practitioners' would be helpful in demonstrating the relevance of genetics, and this was highlighted for mental health and learning disability fields in particular. They could also play a role in explaining such things as 'differences in drug responses, management etc.' (CD64), and in sharing expertise in relation to the history of genetics, of particular relevance for competence 3 (Uphold rights):

We do not equip our students with an awareness of misuse of human genetic info. This would need to come from a specialist in the field. *CD18*

The benefits of closer working with genetics professionals were also identified in relation to keeping up to date with clinical developments:

Partnership working with genetics services/agencies to explore opportunities available to develop knowledge, skill and attitude related to genetics competency and looking at ways in which this can be integrated into the curriculum... Increased collaborative working with genetics services to ensure that the curriculum reflects current developments in genetics science and health care practice. *CD62*

The means of linking with specialist services most often identified was via visiting lecturers, although the establishment of a network was also mentioned by some respondents. Involvement of other professionals was included in the latter, such as 'Access to interpreters and link community workers' (CD57) for competence 2 (Appreciate sensitivity).

More time within the curriculum

Curriculum time to cover the genetics competences was a common concern, and several respondents mentioned the tensions from competing priorities. One respondent commented that 'To cover this topic in any more depth a longer course would be needed' (CD75). However, another indicated that the issue might be 'better timetabling' (CD82).

Explicit demonstration of content and relevance

There was evident support for the need both to continue to demonstrate the relevance of genetics to different areas of practice, and to make more explicit the genetics content across curricula:

Appreciation of relevance and importance of basic genetic information to nursing. *CD13*

The role of other tutors in integrating genetics into the curriculum and in collaborating with others was also raised:

A greater understanding by other tutors about genetics and the relevance to practice. *CD32*

Widening participation into branch programmes and facilitating other tutors to teach aspects of genetic in relation to their own subject... To develop collaborative links with special nurses, health visitors, to promote shared learning/ teaching approaches across pre-registration curricula. *CD29*

Training for educators

Linked to the above theme, further engagement and education of teaching staff was identified as a common need across all competences:

Staff development may be needed as some may see genetics as a specialism, rather than with relevance to all health professionals. *CD19*

Staff training: Further staff education in this area, in the absence of staff educated around the competency areas it will be difficult to provide a holistic education in relation to genetics as envisaged in the competencies. The risk is that the focus will remain on the biological aspects. *CD84*

In relation to competence 7 specifically (Obtain and communicate information), the need to develop IT and e-learning skills was highlighted by two respondents.

Opportunities for genetics placements

Although fewer comments were received in relation to this theme, there was clearly some support for opportunities for students to have access to relevant practice areas and to specialist services. However, one respondent expressed concern that 'Adult and mental health nursing may have less opportunity to attend genetic counselling' (*CD21*). The role of mentors in relation to this was identified by one respondent. This would involve having sufficient trained practitioners able to demonstrate the links between genetics and the particular sphere of practice. To support this, one respondent suggested:

Mapping of clinical placements to identify where students can see the integration of theory and practice so that genetics education is applied to the practice setting. *CD62*

However, another respondent, in commenting on the need for practitioners to recognise the limits of their expertise (Competence 6), appeared less certain about developing genetics skills in 'non-genetic' practitioners:

All too willing to acknowledge their limitations in genetics. Could probably do more in their practice but leave it to the 'specialists'. Uncertain about how this could be addressed, some of this is a cultural issue. I would rather they be cautious having dealt with over enthusiastic practitioners in the past. *CD32*

Access to users

A small number of respondents felt that access to 'users and carers willing to discuss their needs with nurses' (CD18) would be of help, along with involvement of patients and carers in curriculum planning. In relation to competence 2 (Appreciate sensitivity), one respondent requested:

[A] bank of written accounts of service users' experience of care and how ethnically sensitive it has been. *CD80*

For help with promoting competence 5 (Utility and limitations of testing), another suggested:

Engaging the help and input from affected families and support groups to impress upon students the impact of physical/ psychosocial consequences of genetic screening. *CD29*

Guidance on levels of competence

Linked to comments on the need for access to genetics professionals, there were a small number of comments about the need for guidance on the 'application and delivery of knowledge and skills relating to genetics education' (CD62) and:

Clear guidance on the level to which this subject should be incorporated within the pre-registration programmes. *CD63*

One respondent felt that 'de-mystifying' genetics would also be helpful:

Clearer statements, such as these competencies on what nurses need to know and how genetics relates to their work. With more focus on what nurses need to know for practice and practical examples I believe nurses will be more realistic and less frightened about what they need to know. *CD64*

3.9 Specific help from the Centre

In addition to the 'general' needs outlined in the above section, respondents were also asked how the Centre could help with any initiatives in planning or underway in promoting competence in genetics amongst health professional groups. Eight respondents did not identify any specific needs and three responses indicated that help might be needed, but there was uncertainty about what form this could take. Responses from the remainder were grouped into themes, with 20 respondents providing

comments on the need for resource development. These and other comments will be outlined below.

Resource development

There were numerous helpful comments on the range and type of resources that would be of value. One common sub-theme in this was for help generally in producing a range of resources that for example could be incorporated into problem-based learning approaches, or could be focused for a specific area of practice such as children's nursing. Several made the suggestion that more general information could be provided in the form of regular updates:

Continued development and awareness aided by perhaps an organisation such as the [Centre] who could send out short updates to non specialist lecturing staff.
CD38

Up to date statistics with regard to incidence of genetic influenced illness, perhaps as a regular bulletin. A resource guide, with particular regard to the real efficacy of new genetic testing. Informed comment of the progress of genetic screening.
CD20

As well as producing resources, the Centre's role in acting as a central focus for the co-ordination and dissemination of resources was noted. One respondent suggested the production of a 'catalogue' would be useful.

The dissemination and development of web-based resources was highlighted by nine respondents. A few approaches were suggested:

Yes – if you have ideas and resources that we can put on Blackboard, the students can then access these themselves and work through some of the issues on their own. It can form part of their guided study or Blackboard sessions.
CD26

... need for more videotaped examples relating genetics to everyday healthcare, I believe those would be useful.
CD64

Most useful would be some film clips on-line that can be downloaded into PowerPoint presentations showing clinical scenarios of a variety of situations. In addition, a library of photos to show some of the unique features of some of these cases would be useful.
CD80

Although electronic resources were clearly popular, the use of other formats was also acknowledged to be useful, in particular for paper-based resources to be available alongside electronic formats. Text based resources 'on their own' were also requested:

Slim accessible text which focuses on genetics applications in health care.
CD86

One respondent suggested the development of packages of resources for blended teaching approaches:

Possibly reference material for example short booklets on inheritance, the methodology of genetics testing and tracing family tree contacts. Some simple, easily utilised web based resources that would provide guidance to the teacher, or materials that could be used in their entirety for teaching purposes. *CD75*

Raising awareness

Six respondents commented on the role of the Centre in raising awareness about the competence framework, and its work generally, to promote the role of genetics in health care to other educators and practitioners. One reply suggested that the Centre could play a role to 'enlighten senior nurses [purchasers] enabling them to recognise that this is important' (CD27). Its role in disseminating examples of best practice was also noted. Related to this, other respondents indicated the role of the Centre in collaborating with other professional agencies in promoting genetics competence:

It may be difficult to make progress unless the competencies are in the learning outcomes of each programme and would then be built into the assessment. The involvement of the professional bodies would certainly be very helpful. *CD19*

My colleagues and myself believe that as long as the NMC does not give clear direction as to what should be included in Nursing and Midwifery programmes in relation to genetics, progress will be very slow. *CD60*

In raising awareness about genetics, the role of the Centre in providing a balanced commentary was also suggested:

A more open appraisal of the limitations of genetic investigation and the limitations of the projects such as the HGP. Students and the media all too often get caught up in the 'genohype' and fail to recognise the timescales for potential developments and the limitations of what may be achieved. *CD84*

Guidelines/support

There were several comments about the Centre providing support and guidance on curriculum content, about appropriate levels of competence, and about teaching genetics. The Centre has a key role to play in providing guidance and co-ordinating support and other resources. One respondent's comments encapsulated this well:

Guidance about how to support educators and practitioners to facilitate the teaching and learning of genetics in the classroom and clinical environment. Provide information on institutions with particular experience/expertise in delivering genetics education to pre-reg. health care practitioners. Suggest useful texts that could be considered to help develop competency in genetics. *CD62*

Staff training

Help from the Centre in staff development and training was felt to be particularly important by some; that motivation should be included in this was indicated by another. Study days or short courses were suggested by one respondent, and another expanded on this idea:

Structured and accredited staff training: Further staff education in this area, in the absence of staff educated around the competency areas it will be difficult to provide a holistic education in relation to genetics as envisaged in the competences. The risk is that the focus will remain on the biological aspects.
CD84

Links and access to specialists

Several responses asked that the Centre play a role in facilitating access to visiting lecturers and other institutions with expertise in relevant areas of genetics.

Facilitate access to practice placements

One respondent requested that the Centre assist in finding practice placements for their students, as there were none in the area.

Although responses were grouped into themes, these are clearly inter-related and indicate the matrix of functions that the Centre has to undertake, as indicated by one response:

Your work has prompted us to think about how we can develop our curricula to meet the seven standards. Clearly there is considerable work to do. We are fortunate in now having [a centre of excellence] housed in the department and this is a repository of considerable expertise. Colleagues from the unit have started to have lecturing input in our programmes and there may be scope to build on this. We hope to identify colleagues to lead on genetics for each of the branches and we may well come back to you to seek advice on resources, examples of best practice etc. *CD89*

What has emerged from the responses to this section is that the Centre must continue in its tasks: to raise awareness about genetics, working with other healthcare and professional agencies; to act as a co-ordinating centre in disseminating information and in facilitating access to expertise and other resources; to provide guidance on teaching genetics, both 'at a distance' and via workshops or study days; to develop focused and accessible resources in a variety of formats.

4. Further discussion

It was identified at the outset that the ultimate aim of the survey was to identify whether educators in the UK have needs that can be met through the activities of the Centre. Part of our strategy in striving to develop genetic literacy is to work with those most willing to 'champion' the initiative to integrate genetics more fully into nursing professional education and practice. This survey has tested that willingness both through the lengthy questionnaire and because of the difficulties a number of respondents expressed in being able to answer questions across the range of pre-registration programmes. For some, this necessitated collating responses from other colleagues. Thus although the needs identified and views expressed cannot be said to be representative of the larger sample, the data collected do represent the views of a group of educators (49.3% of all eligible institutions) who are perhaps most likely to access and use resources developed by the Centre in response to the survey outcomes.

The survey sought to establish:

- The breadth of provision for genetics on pre-registration courses for nurses, midwives and health visitors.
- The extent to which individual courses are helping to equip nursing professionals at pre-registration level for competent practice in genetics, as measured against the UK genetics competence framework.
- Views on how genetics competence is promoted on post-registration courses.
- What resources are used and felt to be useful in supporting genetics teaching and learning, both generally and in relation to individual competences.
- What further help respondents feel they need, both in relation to individual competences, and more generally from the Centre.

Breadth of provision

Although it must be acknowledged that the sample responding to this survey might reflect a bias towards genetics, the picture that emerges is similar to that found previously with regard to the breadth of provision and assessment (Kirk 1999; n=201, 84% response rate for pre-registration nursing). Then, although the majority of institutions identified that they did include genetics in their pre-registration nursing programmes, the extent of that provision was variable, and less than 30% included any form of assessment.

It appears on the face of it that little may have changed, but there are indicators of a shift in attitude. In 1999, 67.6% felt that genetics teaching within their department was appropriate, with 18.3% neutral, and only 11.3% disagreeing with this statement. Metcalfe and Burton (2003), in their survey of 38 HEIs in 2002, found that many course leaders felt that genetics topics needed to be further developed in the curriculum, but that the majority felt that the importance and relevance of genetics was not recognised by more senior colleagues. This resulted in less priority being allocated to genetics. In

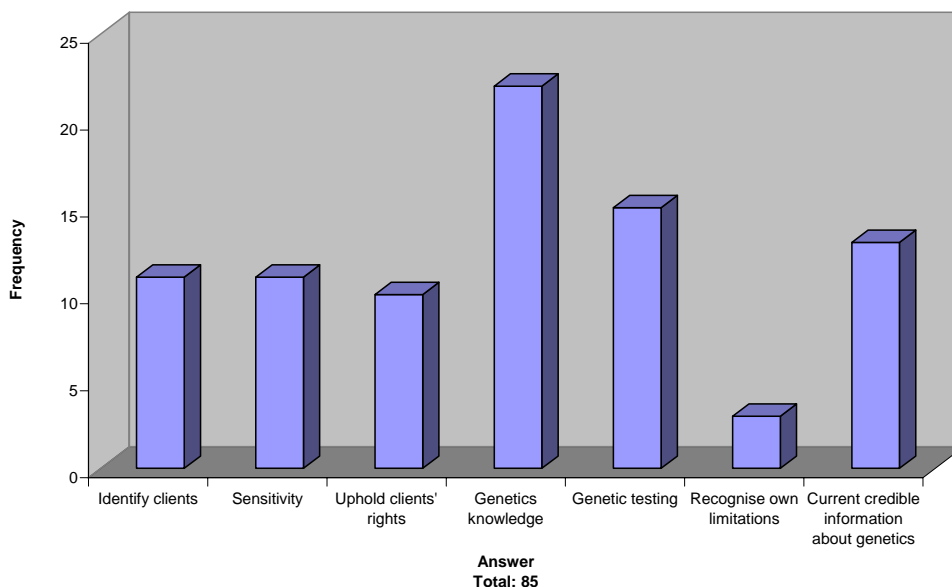
this current survey, just over a third of respondents indicated that developments in relation to genetics had either been completed, or were ongoing, or planned. These included the provision of roadshows, curriculum revisions and development of specific resources, including websites and textbooks. The identification of named individuals with responsibility for genetics provision across nursing and related programmes within institutions is also seen as a positive step and one that the authors welcome.

Achievement of competences

Whilst the scope of provision remains broad, with some genetics content in most pre-registration programmes, it is the depth of knowledge, skills and attitudes acquired by the students on exiting the programme that is most crucial to good quality patient care. As the majority of programmes do not assess genetics, it is difficult to identify an objective measure of success in this regard. Asking educators to make a judgement on how well their institutions equip students to achieve the seven competence standards, we believe, provides a useful baseline against which future progress may be measured. The frequency with which 'do not equip' was selected against all competences and for all programmes is testimony to the candid nature of the responses.

The findings reveal that individual competences are achieved to varying degrees (Figure 8; p20) and that none of the competences are achieved in full in any institution, or for any programme (Figure 9; p21). The rank order of achievement of competences is set out in Table 6 (p20) and it is interesting to compare these findings with a survey conducted at the launch of the genetics competence framework in 2004. Delegates (representing a range of stakeholder groups from across the nursing professions, n=85) were invited to vote on which competence they felt nurses were furthest away from achieving (Kirk and McDonald, unpublished). The results are shown in Figure 12.

Figure 12. Which competence are we furthest from achieving?



(Kirk and McDonald 2004, unpublished)

A comparison of the two reveals some consistency in the views expressed, but also some discrepancy, particularly in relation to competence 4 (Genetics knowledge to underpin practice) (Table 10). Competence 5 (Utility & limitations of genetic testing) is clearly felt to be challenging, and it is interesting to note that genetic testing was identified as one of three priority areas for education for non-genetic specialist registrars (Burke *et al.* 2005). These current findings provide some indication of where resources might best be focused in supporting educators.

Table 10. Comparison of achievement of competence

Rank order of competences achieved 2006 (Most fully achieved first)	Rank order of competences most difficult to achieve 2004 (Least difficult first)
6	6
3	3
4	2
1	1
2	7
7	5
5	4

Performance against individual programmes also revealed quite wide variation, with midwifery and health visiting programmes performing best. Although midwifery (short course) and health visiting are post-qualifying pre-registration programmes (i.e. for qualified nurses), the midwifery (long course) is a pre-qualifying course yet performance is comparable. If post-qualifying programmes build upon a foundation of knowledge, skills and attitudes established in pre-registration programmes, it might be anticipated that performance would be further developed in comparison than appears to be the case here. Recent surveys of qualified nursing professionals about their confidence and competence in genetics tend not to support this. McGregor (2005) found low levels of knowledge of basic genetics principles amongst 605 qualified practice nurses, midwives and health visitors in Wales.

Barr and McConkey (2006) conducted a survey of health visitors in Northern Ireland and found that the majority of respondents (n=194; 56.2% response rate) supported the need for further education in genetics. Over 70% of respondents identified that they needed to acquire knowledge and skills related to six of the competence statements. Just over half felt they needed further education in relation to Competence 1 (Identify clients). The greatest knowledge deficit (93.3% agreeing) was in knowing what resources were available to assist clients seeking genetics information and services.

Bennett *et al.* (2004) conducted a survey of midwives in the West Midlands to assess their views on the importance of genetics and their self-assessment of their own

competence. They found that midwives (n=416; response rate 51%) rated genetics as important but rated their confidence in their own competence as low or fairly low. Most midwives (89%) were interested in undertaking a course in genetics and 41% specified that they needed more knowledge of genetics to make appropriate referrals and provide support for their patients.

The broader picture in relation to post-registration provision is not clear but again, there are indications of increase in provision, with 16 respondents able to identify genetics inclusion across a range of courses other than the pre-qualifying midwifery and health visiting programmes. Metcalfe and Burton (2003) found that 19 out of 38 institutions did not include genetics in post-registration curricula. Post-registration provision and uptake is particularly important if student health professionals are to receive mentorship from qualified staff who are able to demonstrate the links between theory and practice, and who can promote achievement of competence.

Use and development of resources

Although a range of resource formats was identified when respondents were asked about approaches to facilitate development of competence, for the majority, the emphasis remains on traditional resources, via lectures and seminars and using text-based resources. There were very few resources that appeared to be specific to individual competences.

Figure 13. The traditional approach to genetics?



The extent to which selection of resources was by choice can be considered by a comparison of the ranking of both the use of resources (Table 7) and the usefulness of resources (Table 8). Table 11 shows that although text-based resources are most often used, they are ranked 5th in terms of usefulness, with access to users or genetics service

providers being most useful. Web sites and annotated case studies show some consistency in both their use and their utility. Audio tapes are least often used and also ranked the least useful in promoting competence.

Table 11. Use of resources and identified usefulness

Rank Use	Resource	Rank Usefulness
1	Text books	5
2	Web sites	3
3	Annotated scenarios and case studies	2
4	Access to users or providers of genetic services willing to visit and talk with student groups	1
5	Videos / CDs / DVDs	6
6	Skills practice (e.g. family history workshop)	4
7	Attachment to medical genetics service (e.g. for observation) or other relevant centres e.g. fetal medicine or haemoglobinopathies centres	8
8	Test Bank for assessment purposes	9
9	Access to workshops for educators on skills practice.	7
10	Audio tapes	10

This provides some indication of the formats in which resources should be produced if they are to be acceptable to educators. Although web-based resources do feature highly, perhaps they should not be developed to the exclusion of paper-based resources. The inconsistencies that are apparent may be more reflective of accessibility of resources rather than choice. Access to web sites depends on IT resources within the teaching environment as well as the compatibility of downloadable resources with existing virtual learning environments such as Blackboard. Access to users and service providers may well be limited by distance from a regional centre, or otherwise may depend on the network of links between genetics services in the locality and individuals in HEIs.

Educators' needs and the role of the Centre

There was a clear link between the categories of support identified from educators' needs and the help that respondents felt the Centre might be able to offer. From Table 11, it can be seen that educators want greater **access to genetics professionals** and would welcome support from the Centre in this. Related to this, although indicated by fewer respondents, access to genetics service users and opportunities for genetics placements are also seen as useful in promoting competence. The Centre can consider how it can support these needs from two perspectives: by providing direct links to professionals and patients, and by providing 'clinical substitutes' through resource development.

Competing priorities and restricted curriculum time have been well documented as limiting factors in the successful integration of genetics into curricula. Although curriculum time for genetics is outside of the Centre's control, it does have a role to play in disseminating best practice where interventions have addressed this issue, if only in part, and in providing guidance on how curriculum time can be used effectively to incorporate genetics. Cragun *et al.* (2005) reported on the use of a web-based tutorial to surmount the issue of the limited flexibility to expand the curriculum for nursing and allied health professionals in the US. Although outcomes and evaluation of the tutorial were positive, the authors acknowledged that the tutorial alone was insufficient to promote proficiency in genetics.

The findings in this survey indicate that genetics is integrated within at least two modules for approximately two-thirds of programmes. Greater integration of genetics into curricula is important given the ongoing concern about competing priorities and providing sufficient time for additional genetics content. Haga (2006) discusses the concept of the horizontal approach to developing and integrating genetics across curricula which she says 'would not require new classes or units, but take advantage of existing classes that are relevant to genetics' (p226). The vertical approach then allows students to build on knowledge gained from previous units, reducing the likelihood of repeated exposure to the same learning material.

The Centre's role in acting as a catalyst in **raising awareness** and demonstrating the relevance of genetics to mainstream healthcare practice has also been highlighted. The ongoing challenge in this regard should not be underestimated. The frustration felt by some was apparent in a few replies:

Some people with an interest do raise these issues e.g. at revalidation meetings but not much overall progress made. *CD19*

The course director adult nursing could not tell me whether and how genetics is covered... I have had no reply from child, mental health and learning disability branches. Nobody I asked was aware of the competency framework. I am really sorry about this unsatisfactory reply but there is little I can do. As far as I know the indifference in the school reflects quite accurately the position of most local nurses in practice. *CD27*

Training for educators can serve a dual purpose in this regard, and the Centre has an important role in facilitating this. Training sessions can raise awareness about genetics as well as helping to develop further knowledge and skills in relation to teaching genetics.

The role of the Centre in raising awareness about genetics among senior nurses was also commented upon. This is interesting in the light of the small-scale study by Pfeil and Chi-Meih (2005) where they assessed the views of 17 senior nurses from local NHS trusts. Although five felt that nurses should receive genetics education from pre-

registration to post-registration levels, seven thought it should be confined to post-registration provision, mainly as part of other study days, and two felt genetics education was not needed. Generally, the respondents did not seem to feel that genetics was an issue that needed to be addressed urgently, except for one respondent from a trust that provides genetics services, and which the authors noted were 'actively involved in applying the competency standard statements in nurse education' (Pfeil and Chi-Meih 2005; p1130).

All of this underscores the role of the Centre in raising awareness through continuing to demonstrate the relevance and importance of genetics to non-genetic healthcare practitioners. In their needs analysis of genetics education for non-genetics specialist registrars, Burke *et al.* (2005) concluded that for educational developments to be successful, they need to emphasise the relevance of genetics to everyday practice. They also saw the need for resources to be developed in partnership between geneticists and specialists.

International collaboration can also play a part in raising awareness. Lewis *et al.* (2006) report on the US initiative to develop specific nursing competences in genetics, based on the original NCHPEG competences for all health professionals, and informed by the UK nursing framework. The authors of this report are continuing to collaborate with the team involved in the US initiative, sharing expertise and best practice in developing a strategy to promote competence.

The identification, sharing, and where appropriate, development of **resources** is a major aspect of the Centre's work and this survey has provided some useful indicators of the nature and scope of these that educators would find most useful. That they must be current, accessible and flexible is axiomatic, but they must also continue to demonstrate relevance to practice, and set within a context that provides **guidance** on their use. Where opportunities for access to genetics services are limited, they must also serve another function – that of providing a 'clinical substitution'. One respondent provides an indicator of one possible approach:

Mapping of clinical placements to identify where students can see the integration of theory and practice so that genetics education is applied to the practice setting. *CD62*

The numerous comments made by educators about the resources they felt would be most useful, and about the guidance needed in accessing, interpreting and integrating these into curricula highlight the role of the Centre, not only in developing new resources and evaluating existing ones, but also in facilitating their use. All of these factors need to be taken into account in planning the Centre's programme for nursing and other healthcare professionals.

5. Conclusion and next steps

This survey of educators' views on provision for genetics education for pre-registration nursing groups has provided useful insight into the issues they feel are important, and provides a useful snapshot in monitoring the development of genetic competence. It also plays an important role in informing the direction and planning of the NHS National Genetics Education and Development Centre, helping to ensure the Centre remains focused on the identified needs of educators in providing practical support to them.

The survey indicates that genetics provision remains at a low level, although the breadth of provision is broad. Although approximately one third of respondents indicated that this situation was not static with current or future initiatives in curriculum development, it is important to consider that two-thirds did not identify any plans for development. However, the comments gathered across all responses on the whole indicated an awareness of the deficits in provision and of the resources needed to address these, along with a willingness to support the development of genetics competence. That they saw a clear role for the Centre in facilitating this was also evident.

Conducting this survey of educators' needs represents one step in taking this role forward. A survey of the learning needs of practitioners is currently underway, working in partnership with RCN Publishing Ltd to take a novel approach to do this. Short articles and questionnaires are being published in seven specialist nursing journals to survey a wide range of nursing settings and functions. The analysis of this will provide a vital adjunct to this survey of educators' needs.

Raising awareness is an ongoing strand of the Centre's work and we will continue to work with others at national and international levels in order to promote this. The need for established networks to facilitate communication between educators and genetics professionals has been highlighted in this survey and we must seek ways of further promoting this.

In addressing the need for links with professionals and genetics service users, the Centre can offer a further perspective. Patients with or at risk of developing a genetic condition do not only use genetics services. Part of the driving force behind the whole initiative of improving competence in genetics is that genetics is integral to health and people with 'genetics needs' form part of mainstream health services. As stated in the genetics White Paper, 'six out of ten people are likely to develop a disease that is at least partially genetically determined by the age of 60' (DoH 2003; p7). Thus student health professionals do not necessarily have to attend a regional genetics centre to have the opportunity to care for people with genetics needs. What they may need is guidance on the inherited conditions they are most likely to encounter in caring for patients in specific areas of health care. As part of a longer-term plan, we have identified two initiatives.

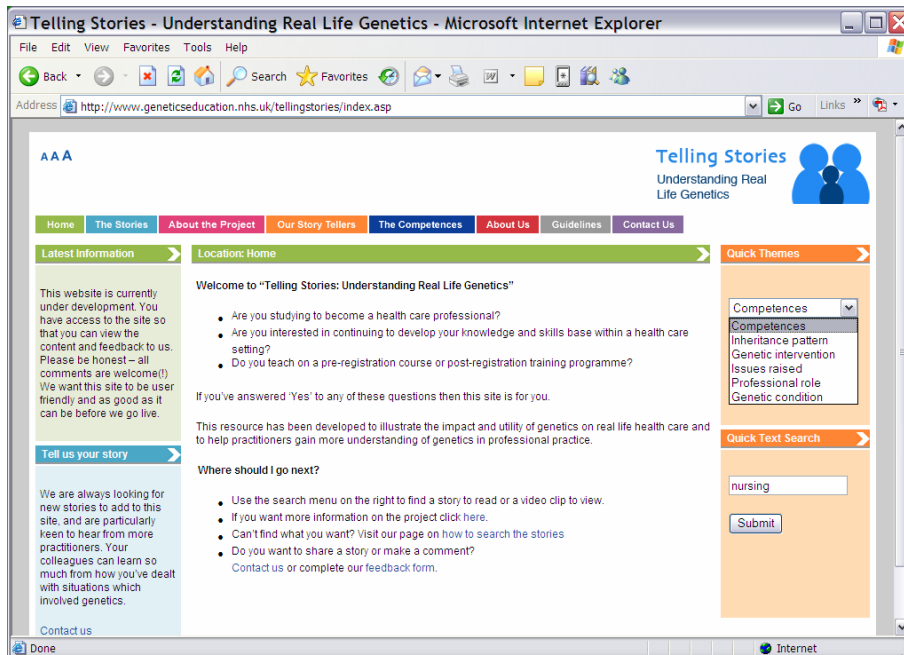
The training of students through placements is integral to the nurse education process, and provides a key opportunity for demonstrating genetics within everyday practice. In order to identify ways in which more genetics can be taught through placements the current systems of placement based mentoring and training needs to be reviewed, along with any training material currently supplied to those involved. The information obtained would be used to inform work in 2008/09 to:

- Develop a set of Placement Portfolios for Understanding Genetics for use during training placements in different clinical and community settings. A portfolio for students could provide information on conditions, genetic tests etc more commonly associated with the placement type, as well as space for reflection, activities and notes. A portfolio guide for mentors would support health care staff in providing genetics education within the context of the placement.
- Develop short guides for practitioners as 'Genetics Reference for Areas of Specialist Practice'. Guides will provide information including: why genetics is relevant within a particular specialty; where and how to identify the best sources of information and ethical/cultural/social considerations.

The Centre's role in the identification, sharing and development of resources is clearly important. Although greater focus can now be placed on the competences least well achieved so far, it is clear that all need support, and consideration will be given on how best to achieve this. The resources themselves also need to represent a range of formats, including 'at a glance' summaries and brief updates, as well as web-based reusable learning objects, all making explicit the links between theory and its application to practice. Training workshops also fall into this category and programmes for these that will address the issues raised during this survey, are already being planned.

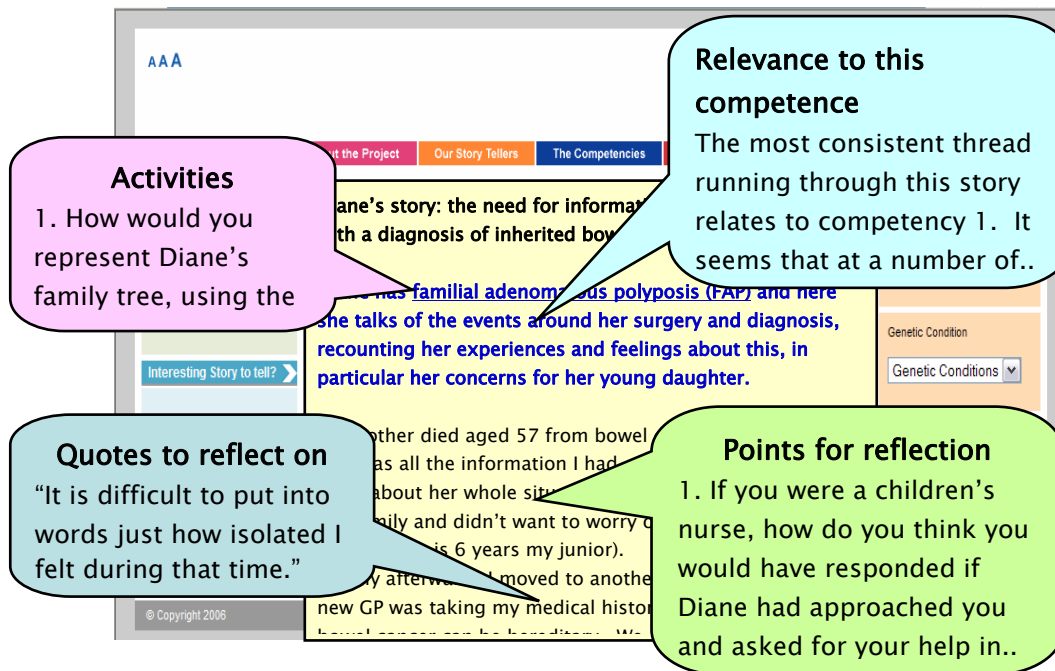
A key vehicle being developed to meet many of the identified resource and teaching needs is *Telling Stories Understanding Real Life Genetics* (www.geneticseducation.nhs.uk/tellingstories). This is a collaborative project involving the Universities of Glamorgan and Plymouth, Genetic Interest Group (at the Wales Gene Park) and the NHS National Genetics Education and Development Centre. A multi-media web-based resource is being created for healthcare professionals which will encourage the understanding of genetics, its impact on people's lives, and relevance within non-genetic specialties. To date, this Wellcome Trust project has gathered over 80 stories from clients, families and practitioners. Designed to be used by both educators and learners, the resource will be searchable and will provide structured teaching and learning objectives. The website is currently in its pilot phase (Figure 14).

Figure 14. Telling Stories home page



Each story contains links to additional information which may include notes for further explanation; points for reflection and discussion; implications for professional practice; suggested activities to help the reader develop competence; and contact details of relevant support groups (Figure 15).

Figure 15. The telling Stories: the supporting resources



This resource has tremendous potential for development, for use by other health professional groups and in widening the scope of the stories themselves. There is also the potential for international development, to promote awareness of cultural and other issues across the 'global clinic'. The educators who participated in this survey will be invited to evaluate the resource and further development will come from their responses to this.

As one of the respondents commented 'Clearly there is considerable work to do'. What this survey has shown is that there is a willingness to engage in this work, and we must continue to foster this in driving forward the development of competence in genetics.

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APPENDIX 1

The literature review

Burke S and Kirk M (2006) Genetics education in the nursing profession: literature review. *Journal of Advanced Nursing* 54 (2): 228–237

Genetics education in the nursing profession: literature review

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BURKE S. & KIRK M. (2006) *Journal of Advanced Nursing* 54(2), 228–237

Genetics education in the nursing profession: literature review

Aim. This paper reports a literature review exploring genetics education for nursing professionals. The aim was to contribute to the debate about the future direction of such education.

Background. Advances in genetics science and technology have profound implications for health care and the growing importance and relevance of genetics for everyday nursing practice is increasingly recognized.

Method. A search was conducted in February 2005 using the CINAHL and Google Scholar databases and the keywords *nurse, midwife, health visitor, education and genetics*. Papers were included if they were published in English between 1994 and 2005 and included empirical data about genetics education in nursing. In addition, attempts were made to access the grey literature, with requests for information on research, for example, to members of the Association of Genetic Nurses and Counsellors and searches of relevant websites.

Findings. Agreement on the relevance of genetics for nursing practice is extensive. Empirical evidence of the learning needs of practitioners highlights widespread deficits in knowledge and skills, and low confidence levels. Provision of nursing education in genetics is patchy and insubstantial across a number of countries, further hampered by lack of strategic development. Significant progress has been made in the identification of learning outcomes for nurses. Research on the delivery of genetics education is limited, but the role of skills-based training, use of clinical scenarios, and importance of assessment have all been identified as factors that can promote learning.

Conclusion. Whilst areas of good performance were revealed, many studies identified gaps in professional competence and/or education. New initiatives are underway to support genetics education and its integration into professional practice, but further research is needed on the most effective forms of educational delivery, and an international collaborative approach to this should be considered.

Keywords: curriculum development, genetics, literature review, nurse education

APPENDIX 2: The questionnaire

For office use only.



Genetics Education for Nursing Professional Groups: Needs Analysis

Answering the questions below will help us to identify areas we need to focus on to help educators promote competency in genetics for all nurses, midwives and health visitors. Your answers will also help us establish a baseline against which we can evaluate the effectiveness of our programme over the next three years. For the purposes of this needs analysis, ‘genetics teaching’ is deemed to include the *science* of genetics, and *applied* genetics e.g. screening, testing, support, discussion about conditions and ethical issues.

Please be assured that we will keep your replies confidential and no institution will be identified in any publications that arise from this work. A number has been assigned to this questionnaire for tracking purposes only.

SECTION ONE

- Q1** For each course listed below, if your institution offers this course, please would you indicate:
- a) If the course includes genetics.
 - b) How you assign time to genetics – as a ‘stand alone’ block of study, as part of one module or study block, or incorporated into more than one module/block.
 - c) Whether the genetics component is specifically assessed.

If you do not offer the course, please indicate N/A alongside the course name

Please would you also add any other **pre-registration** courses you offer for health professionals (all areas) that include a focus on genetics.

Course leading to qualification as:	b			c
	a	Stand-alone module	Integrated within a module	
Genetics included? Y or N				Is genetics assessed? Y or N
RN (Adult)				
RN (Mental health)				
RN (Child)				
RN (Learning disabilities)				
Registered midwife (short course)				
Registered midwife (long course)				
Registered health visitor				
Other:				

Q2 Please provide **two answers** for each of the resource types listed below. First, how often are the resources listed used to support genetics teaching? Please tick either Never, Infrequently or Frequently for each resource. Then, please indicate (with a tick) how useful you feel each resource is in supporting the teaching of genetics at your institution? For the resources you don't currently use please indicate how useful you feel they could be.

How often do you use a resource?			Resource	How useful is the resource?		
Never	Infrequently	Frequently		Not Useful	Useful	Very Useful
			Text books			
			Web sites			
			Annotated scenarios and case studies			
			Videos / CDs / DVDs			
			Audio tapes			
			Skills practice (e.g. via family history workshop)			
			Access to workshops for educators on skills practice. Please indicate any specific area, e.g. family history taking			
			Test bank for assessment purposes			
			Access to users or providers of genetics services willing to visit and talk with student groups			
			Attachment to medical genetics service (e.g. for observation) or other relevant centres, e.g. fetal medicine, haemoglobinopathies centres.			
			Other (please give details)			

SECTION TWO

The competence-based education framework for genetics sets out seven standards statements that all nurses, midwives and health visitors should be able to demonstrate at the point of qualifying (Kirk et al. 2003). In this second section, we would very much like to know how you feel about your **pre-registration** courses in relation to each competency statement – the extent to which you feel students are able to demonstrate each competence at the end of their course, what approaches you utilise in teaching and learning to facilitate this, and what would be most helpful for you in helping to promote achievement of each competency.

Please answer the questions set out under each competency statement.

Part **a.** For each pre-registration course your institution provides, please choose the sentence which best describes the current position for your institution, and put the number alongside.

For example: *RN Adult* 2 *RN Child* 3 *Midwife (short course)* 2 etc

For parts **b.** and **c.** please answer in **general terms** for all the courses taught at your institution (please focus on pre-registration courses). We don't expect you to comment separately on each course for every competency. However, please comment if there is a branch or strand that you feel deserves a specific mention.

Please answer part **c.** of each question in this section even if you are not currently working to integrate the competency in to your course(s). This information is important to us as this questionnaire is primarily a needs assessment.

<p>Competency 1 Identify clients who might benefit from genetic services and information</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 counselling process. 		
<p>a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from 1= our courses would not equip students to demonstrate any component of this competency 2= students could achieve this competency to a limited extent 3= students are able to demonstrate this competency fully on exiting from the course.</p>		
<i>RN Adult</i> ___	<i>RN Learning Disabilities</i> ___	<i>Registered Health Visitor</i> ___
<i>RN Mental Health</i> ___	<i>Midwife (short course)</i> ___	<i>Other:</i> ___
<i>RN Child</i> ___	<i>Midwife (long course)</i> ___	<i>Other:</i> ___
<p>b. What do you do to facilitate achievement of this competency? (e.g. teaching sessions, reference materials)</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div>		
<p>c. What do you most need to help you to integrate this competency into your curricula?</p> <div style="border: 1px solid black; height: 60px; width: 100%;"></div>		

Competency 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.

a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from

1= our courses would not equip students to demonstrate any component of this competency

2= students could achieve this competency to a limited extent

3= students are able to demonstrate this competency fully on exiting from the course.

RN Adult ___ RN Learning Disabilities ___ Registered Health Visitor ___

RN Mental Health ___ Midwife (short course) ___ Other: ___

RN Child ___ Midwife (long course) ___ Other: ___

b. What do you do to facilitate achievement of this competency?**c. What do you most need to help you to integrate this competency into your curricula?****Competency 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.

a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from

1= our courses would not equip students to demonstrate any component of this competency

2= students could achieve this competency to a limited extent

3= students are able to demonstrate this competency fully on exiting from the course.

RN Adult ___ RN Learning Disabilities ___ Registered Health Visitor ___

RN Mental Health ___ Midwife (short course) ___ Other: ___

RN Child ___ Midwife (long course) ___ Other: ___

b. What do you do to facilitate achievement of this competency?**c. What do you most need to help you to integrate this competency into your curricula?**

Competency 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.

a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from

1= our courses would not equip students to demonstrate any component of this competency

2= students could achieve this competency to a limited extent

3= students are able to demonstrate this competency fully on exiting from the course.

<i>RN Adult</i>	___	<i>RN Learning Disabilities</i>	___	<i>Registered Health Visitor</i>	___
<i>RN Mental Health</i>	___	<i>Midwife (short course)</i>	___	<i>Other:</i>	___
<i>RN Child</i>	___	<i>Midwife (long course)</i>	___	<i>Other:</i>	___

b. What do you do to facilitate achievement of this competency?

c. What do you most need to help you to integrate this competency into your curricula?

Competency 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.

a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from

1= our courses would not equip students to demonstrate any component of this competency

2= students could achieve this competency to a limited extent

3= students are able to demonstrate this competency fully on exiting from the course.

<i>RN Adult</i>	___	<i>RN Learning Disabilities</i>	___	<i>Registered Health Visitor</i>	___
<i>RN Mental Health</i>	___	<i>Midwife (short course)</i>	___	<i>Other:</i>	___
<i>RN Child</i>	___	<i>Midwife (long course)</i>	___	<i>Other:</i>	___

b. What do you do to facilitate achievement of this competency?

c. What do you most need to help you to integrate this competency into your curricula?

Competency 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.

a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from

1= our courses would not equip students to demonstrate any component of this competency

2= students could achieve this competency to a limited extent

3= students are able to demonstrate this competency fully on exiting from the course.

<i>RN Adult</i>	___	<i>RN Learning Disabilities</i>	___	<i>Registered Health Visitor</i>	___
<i>RN Mental Health</i>	___	<i>Midwife (short course)</i>	___	<i>Other:</i>	___
<i>RN Child</i>	___	<i>Midwife (long course)</i>	___	<i>Other:</i>	___

b. What do you do to facilitate achievement of this competency?**c. What do you most need to help you to integrate this competency into your curricula?****Competency 7****Obtain and communicate credible, current information about genetics, for self, clients and colleagues**

- using information technologies effectively to do so.

a. How well do you think the pre-registration courses you offer equip students to achieve this competency? Please rank from

1= our courses would not equip students to demonstrate any component of this competency

2= students could achieve this competency to a limited extent

3= students are able to demonstrate this competency fully on exiting from the course.

<i>RN Adult</i>	___	<i>RN Learning Disabilities</i>	___	<i>Registered Health Visitor</i>	___
<i>RN Mental Health</i>	___	<i>Midwife (short course)</i>	___	<i>Other:</i>	___
<i>RN Child</i>	___	<i>Midwife (long course)</i>	___	<i>Other:</i>	___

b. What do you do to facilitate achievement of this competency?**c. What do you most need to help you to integrate this competency into your curricula?**

SECTION 3

Q3 In terms of the overall provision to help students achieve these competencies within your educational establishment, to what extent do you feel that a similar level is achieved across all **pre**-registration courses?

Q4 Is genetics incorporated into any **post**-registration courses? If so, please give brief details. For example, how you assign time to genetics – as a ‘stand alone’ block of study, or incorporated into one or more module/block and whether the genetics component is specifically assessed.

Q5 a) Are you, or is anyone in your institution, currently engaged in any initiatives to help promote competency in genetics amongst health professional groups, either as ‘stand alone’ units or incorporated alongside other topics? Please give brief details.

b) Is there anything the National Genetics Education and Development Centre could provide that might be of particular help in achieving this?

May we contact you to discuss any aspect of this questionnaire further?

Yes No

Please give contact details if different to the ones we already hold

Many thanks for helping us by completing this questionnaire. Please return by email or by post to:

Dr. Emma Tonkin

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APPENDIX 3

Information letter



**National Genetics Education and
Development Centre**

Dear *****,

Professor Maggie Kirk and I are delighted to have you as the nominated network member for ***** University and we do hope that, with time, you will benefit from the work of the National Genetics Education Centre (the Centre). Please remember that we are here to facilitate genetics education, working with network members to support your teaching needs. If you have questions to ask about our work, or issues to raise about genetics education please do not hesitate to get in contact.

The Centre has been established to provide a focal point for genetics education and training throughout the NHS. The Centre aims to facilitate health professionals' knowledge and understanding of genetics, enabling them to keep pace with the rapidly expanding field of medical genetics.

In addition to our programme supporting both pre- and post- registration nurses, midwives and health visitors, there are also active programmes for Medicine, Pharmacy, Dietetics, Service Development and GPs with a special interest in genetics.

The initial work for the Nursing Professions core team has focused on establishing an advisory group, developing a detailed plan for specific projects, and prioritising our activities. With well over 600,000 registered practitioners, we know we face challenges! However, over the next 12-18 months our activities will include:

- The ongoing campaign to raise awareness among stakeholder groups of the relevance of genetics to professional practice
- Educational needs analysis
- Further development of the Core Competence framework **
- Development of learning and teaching resources
- Establishing Champions Networks for practitioners and educators
- Training the trainers' workshops.

** For those who may not have seen the report to the DOH 'Fit for Practice in the Genetics Era: A competence based education framework for nurses, midwives and health visitors', I have attached within this email a PDF of the Extended Summary. The full report can be accessed at

<http://www.glam.ac.uk/socs/research/gpu/FinalReport.pdf>

Our first project is directed towards pre-registration teaching. We are asking all our network members about how, genetics is taught and assessed on pre-registration

courses and more specifically whether the content is equipping students to achieve the core competences. In addition, we are interested in what sorts of resources are being used during the teaching process and whether there is anything your institution requires that could be provided through the National Centre. The questionnaire attached can either be filled in and returned electronically, or printed out and sent to the Freepost address below. We ask that only one questionnaire is returned from each institution. If you have any problems with the attachment the questionnaire will be accessible via the Centre web site (I'll be in touch shortly when the link has been confirmed).

We recognise that for some network members, completing this questionnaire on behalf of multiple pre-reg courses will be difficult. We do hope that you will be able to draw on the knowledge of other colleagues and be able to find the time to answer as comprehensively as possible. For those working at HEIs providing only post-registration courses we are still interested in what is being taught and what your educational needs might be.

This piece of work is of prime importance in directing our future activities and we thank you in anticipation of your involvement in this. We would appreciate receiving your replies by *****DATE*****.

Further information can be obtained from the Centre's web site at <http://www.geneticseducation.nhs.uk/> It will be re-launched later this year with a new format highlighting the teaching learning and service development aspects of our work.

Once again, if you have any questions regarding the questionnaire or the Centre's work please do not hesitate to contact me.

With very best wishes,

Emma

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