Fit for Practice in the Genetics Era

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

Competent, capable, caring

Report to the Department of Health NHS Genetics Team

Extended Summary

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The seven competency 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.

EXECUTIVE SUMMARY

Background and aims

The new genetics knowledge and technology has the potential to bring enormous benefits for patients: more personalised prediction of risk, more accurate diagnosis, safer use of medicines and new treatment options (Department of Health 2003).

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

Objectives

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

Approach

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

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

The 38 competency statements issued by the US National Coalition for Health Professionals in Genetics (NCHPEG) were used as a template for discussion. Consensus developed over the two day structured programme and 34 competency statements were endorsed. These were validated against appropriate professional (NMC) frameworks to demonstrate that they did not reflect an extension of professionals roles but make explicit how genetics fits into current practice. They were then further refined to develop seven competence standard statements. These represent the minimum common core competencies that nurses and midwives should achieve at the point of registration, and applies to health visitors at the commencement of their training.

An interim report on the findings of the panel was used as the basis for wider consultation that included a one-day consultation conference. Support for the seven statements has been widespread and there was agreement that they demonstrate a view of professional practice 'through the genetic lens.' Although broad, they represent the minimum standard that should be achieved.

Responses were assimilated using thematic analysis. The competence standard statements were then placed in a framework with suggested learning and practice outcomes to make more explicit the scope of the competencies.

Applying the competencies

The competency standard statements are conserved across the professional groups at the three levels of practice considered, and for different areas of health care. The types of client include individuals and/or families who are either affected by genetic conditions, carry a known or suspected genetic predisposition to certain common diseases, or have a strong family history, and the increasing number of "worried well" who are concerned about genetics and health.

The level descriptors applied to the learning and practice outcomes can be used to define the depth of knowledge required so that it is appropriate to the professional role and level of responsibility. Additional learning and/or practice outcomes may also be incorporated to reflect the professional role or field of practice.

These outcomes would be achieved over the span of the training programme and over a variety of care settings. The framework should also be viewed as dynamic. In this way, the framework provides a flexible model which can be adapted to reflect changes as new initiatives are integrated into practice.

Preparing for Practice

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

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

Conclusions

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

Recommendations

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

N.B The scenarios used throughout this extended summary to stimulate discussion have been placed to make best use of space and do not necessarily relate directly to the adjacent competency statements.

THE COMMON CORE COMPETENCY FRAMEWORK

Core Standard Statement 1: The competent practitioner (i.e. the newly qualified nurse or midwife)

Domain: Care delivery

Identify clients who might benefit from genetic information and services

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

Suggested learning outcomes	Suggested practice indicators
A. Explains basic human genetics technology. B. Describes basic patterns of biological inheritance, and variation both within families and populations. C. Recognises the role of family history in assessing predisposition to disease. D. Lists the resources available to assist clients seeking genetic information or services including the types of services available. E. Describes the different professional responsibilities and roles in relation to genetics services. F. Describes a typical 'patient journey' that might be experienced in the process of genetic counselling.	1. Demonstrates ability to take an accurate three generation family history in relation to genetic health risks. 2. Identifies potentially significant information from a family history. 3. Identifies with guidance clients who might benefit from referral to genetics specialists and/or information resources. 4. Facilitates appropriate referral to genetics specialists, accurately completing the relevant documentation.

Scenario

I wasn't too surprised when Mrs Connor approached me outside the primary school. Being the local health visitor, I'm often stopped for advice, but wasn't quite prepared for the verbal attack! "I've been sent for genetic counselling," she said. "I'm really put out about it. I'd never have an abortion, but they think that just because I'm an older mother I have to go and get tested." I could see she was really upset about it. "Look," I replied, "the children will be out in a minute so there isn't time now, but I would like to explain to you what's involved in genetic counselling. I'll call round tomorrow and we'll talk about it. I'm sure once you've had it fully explained you'll feel a lot happier, but if you still don't want to go, we can talk about that too."

Core Standard Statement 2: The competent practitioner

Domain: Professional and ethical practice

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

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

Suggested learning outcomes	Suggested practice indicators
A. Recognises that clients' cultural, ethnicity and religious perspectives may influence their ability to use genetic information and services. B. Discusses the communication and interpersonal skills required in relation to genetic issues. C. Recognises the need to use language appropriate to the client's level of understanding.	1. Demonstrates the ability to communicate sensitively with clients to elucidate their cultural, religious and ethnic perspectives. 2. Demonstrates an awareness of the client's background in facilitating communication about genetics issues. 3. Demonstrates the ability to utilise resources to facilitate effective communication and access to genetics services. 4. Chooses language appropriate to the client's level of understanding and developmental age. 5. Uses communication skills to promote and check the client's understanding.

Scenario: The effective interface between practice and policy

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

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

Reflecting on practice

This scenario illustrates how sound policies and systems, implemented by competent practitioners able to integrate knowledge and skills into the practice environment, promote delivery of high quality care. Unfortunately, this scenario is based on a real-life situation that was almost the mirror image. Testing was not offered to the mother, despite the hospital policy, and the carrier status of her and her husband went undetected until some time after their son was born and later diagnosed with sickle cell disease. This event had a profound impact on the family, presenting them with cultural, psychological and social challenges. It also had adverse repercussions for the hospital and professionals who were responsible for Mrs Henry's care.

Core Standard Statement 3: The competent practitioner

Domain: Professional and ethical practice

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 the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias,
- recognising that personal values and beliefs may influence the care and support provided to clients during decision-making.

Suggested learning outcomes	Suggested practice indicators
A. Describes the social and psychological implications of accessing genetic services and information. B. Recognises the importance of and upholds the rights of all clients to informed decision making and voluntary action. C. Recognises the particular needs of those unable to give informed consent in relation to accessing and using genetic information. D. Discusses how personal values and beliefs in relation to ethical, social, cultural, religious and ethnic issues might influence client care. E. Identifies how an awareness of the past and potential future misuse of genetic information underpins the principle of the non-directive approach in genetic counselling.	1. Demonstrates an awareness of clients' needs, showing fairness and sensitivity when exploring with them the rationale for seeking specialist genetics advice/referral. 2. Identifies situations when one's own beliefs and values may have potential to influence the care given to clients. 3. Identifies situations where clients' own beliefs and/or values influence genetic choices. 4. Utilises communication skills to enable the client to express his or her own wishes, or to pursue a chosen course of action. 5. Displays a non-judgemental attitude at all times.

Core Standard Statement 4: The competent practitioner

Domain: Care delivery

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

Suggested learning outcomes	Suggested practice indicators
A. Describes the role of genetic factors in maintaining health and preventing disease. B. Describes the role of genetic factors in the manifestation of disease, using examples of the common inherited conditions. C. Identifies that disease expression may be influenced by the interaction between genetic and other factors, at different life stages. D. Applies basic concepts of risk to distinguish between genetic susceptibility and clinical manifestation of a disease.	1. Applies knowledge and understanding to identify potentially significant information from a family history. 2. Demonstrates the ability to use family history information to inform health education advice.

Core Standard Statement 5: The competent practitioner

Domain: Professional and ethical practice

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.

Suggested learning outcomes	Suggested practice indicators
A. Identifies the potential benefits, risks and limitations of genetic testing and accessing genetic information. B. Recognises the sensitivity of genetic information, in particular the associated ethical, legal and social issues. C. Discusses the potential impact of genetic information for individuals, family members and communities.	1. Ensures privacy when discussing genetic information. 2. Maintains confidentiality when recording genetic information. 3. Demonstrates sensitivity to the potential impact of genetic information for the individual and other family members. 4. Responds appropriately to enquiries about genetic concerns.

Scenario

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

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

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

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

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

Reflecting on practice

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

Core Standard Statement 6: The competent practitioner

Domain: Personal and professional development

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.

Suggested learning outcomes	Suggested practice indicators
A. Recognises the scope of practice as a newly qualified health professional and acknowledges the limitations in one's own abilities in relation to genetics. B. Recognises the role of specialist genetic services and other agencies in providing appropriate patient/client care.	1. Demonstrates appropriate care and concern for all patients/clients throughout their referral, provision and follow-up to genetics services. 2. Demonstrates awareness of the boundaries of one's own professional practice in relation to genetics. 3. Identifies effective practice in health professionals more experienced in genetics. 4. Consults with appropriate professionals when care required is beyond one's expertise. 5. Demonstrates an awareness of the boundaries of others involved in the provision of genetic services. 6. Actively works in a collaborative manner with health and social care colleagues (statutory and non-statutory).

Scenario: Appreciating the limitations of information

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

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

Core Standard Statement 7: The competent practitioner

Domain: Professional and ethical practice

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

- using information technologies effectively to do so.

Suggested learning outcomes	Suggested practice indicators
A. Recognises the importance of updating genetic knowledge at frequent intervals and the consequent benefits for self, clients and colleagues. B. Appreciates the limitations of information and its credibility and reliability. C. Critically appraises information from different sources.	1. Demonstrates knowledge about accessing local/regional genetics resources. 2. Actively refers to research based evidence about genetics related to patient/client care. 3. Adopts a range of interpersonal skills whilst communicating with clients and colleagues about genetics issues. 4. Takes action to meet any identified knowledge and skills deficit likely to affect the delivery of care within one's own current sphere of practice.

Scenario

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

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

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

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

Reflecting on practice

This scenario highlights the need to see genetics as only part of the picture and as part of the client's 'journey'. *If the nurse had found that Tony's notes actually confirmed Fragile X (as well as indicating the social issues), should she have then referred Jason for genetic counselling?*

APPLYING THE COMPETENCIES

Examples for the experienced practitioner

This level describes the registered nurse or midwife who has been working in a general or specialist area for more than two years since qualifying (e.g. senior staff nurse or staff midwife), or a registered health visitor. At this level of practice, the health professional is able to refine and evaluate the evidence base in the light of growing experience. N.B. Text in italics indicates outcomes that are new or revised compared with those for the competent practitioner.

Domain: Professional and ethical practice

Core Standard Statement 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 the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias,
- recognising that personal values and beliefs may influence the care and support provided to clients during decision-making.

Suggested learning outcomes	Suggested practice indicators
A. *Analyses* the social and psychological implications of accessing genetic services and information. B. *Appraises* how personal values and beliefs in relation to ethical, social, cultural, religious and ethnic issues might influence client care. C. *Analyses* how an awareness of the past and potential future misuse of genetic information underpins the principle of the non-directive approach in genetic counselling.	1. *Assesses* clients' needs, showing fairness and sensitivity when exploring with them the rationale for seeking specialist genetics advice/referral. 2. *Appraises* situations when one's own beliefs and values may have potential to influence the care given to clients. 3. *Appraises* situations where clients' own beliefs and/or values influence genetic choices. 4. *Applies* communication skills to enable the client to express his or her own wishes, or to pursue a chosen course of action. 5. Displays a non-judgemental attitude at all times. 6. *Supports a non-directive approach as appropriate when delivering health education that incorporates genetic information.* 7. *Defends the importance of and upholds the rights of all clients to informed decision making and voluntary action.* 8. *Defends the particular needs of those unable to give informed consent in relation to accessing and using genetic information.*

Scenario

Ten year old Amy often seems to be at home when I call these days and I suspect that mum keeps her home to help look after her little brother Ben, who was born two years ago with Down syndrome. He's quite a handful and mum is finding it hard to cope. A lot of responsibility for Amy too though. Today, she said she was home with a sore throat. As I was going, Amy saw me to the door. She looked a bit unsure of herself. As she handed me my coat, she asked, 'If I have babies when I'm older will they be like Ben too?'

Reflecting on practice

How would you deal with Amy's question? What would you need to know to inform your response?

Examples for the experienced practitioner

Domain: Care delivery

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

Suggested learning outcomes	Suggested practice indicators
A. *Discusses* the role of genetic factors in maintaining health and preventing disease. B. *Discusses the range of genetic approaches to treatment and prevention of disease.* C. Discusses the role of genetic factors in the manifestation of disease, using examples of *inherited conditions more commonly encountered within own sphere of practice.* D. *Analyses* how disease expression may be influenced by the interaction between genetic and other factors, at different life stages. E. Applies basic concepts of risk *to explain* the distinction between genetic susceptibility and clinical manifestation of a disease.	1. Applies knowledge and understanding to identify potentially significant information from a family history. 2. *Incorporates* family history information in providing health education advice.

Scenario

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

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

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

Reflecting on practice

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

Examples for the experienced practitioner

Domain: Professional and ethical practice

Core Standard Statement 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.

Suggested learning outcomes	Suggested practice indicators
A. *Analyses* the potential benefits, risks and limitations of genetic testing and accessing genetic information, *including post mortem information*. B. *Appraises* the sensitivity of genetic information, in particular the associated ethical, legal and social issues. C. Evaluates the potential impact of genetic information for individuals, family members and communities. D. *Discusses how ethnoculture and economics may influence access to genetic information.*	1. Ensures privacy when discussing genetic information. 2. Maintains *and defends* confidentiality when recording genetic information. 3. Demonstrates sensitivity to the potential impact of genetic information for the individual and other family members, *giving neither false reassurance nor raising undue concern.* 4. Responds appropriately to enquiries about genetic concerns. 5. *Facilitates the ethical storage of human genetic samples, including from patients dying or who have died from an inherited condition.*

Domain: Professional and ethical practice

Core Standard Statement 7
Obtain and communicate credible, current information about genetics, for self, clients and colleagues
- using information technologies effectively to do so.

Suggested learning outcome	Suggested practice indicators
A. *Upholds* the importance of updating genetic knowledge at frequent intervals and the consequent benefits for self, clients and colleagues. B. *Evaluates information* in terms of its limitations, credibility and reliability. C. *Seeks* and critically appraises information from different sources.	1. *Teaches others* about accessing local/regional genetics resources. 2. Actively refers to research based evidence about genetics related to patient/client care *and communicates this to others.* 3. *Applies appropriate* interpersonal skills whilst communicating with clients and colleagues about genetics issues. 4. Takes action to meet any identified knowledge and skills deficit (*own and that of other colleagues*) likely to affect the delivery of care within one's own current sphere of practice. 5. *Facilitates discussion about genetics issues.*

Scenario: Communicating within an ethical framework

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

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

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

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

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

What should happen next?

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

Reflecting on practice

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

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

APPLYING THE COMPETENCIES

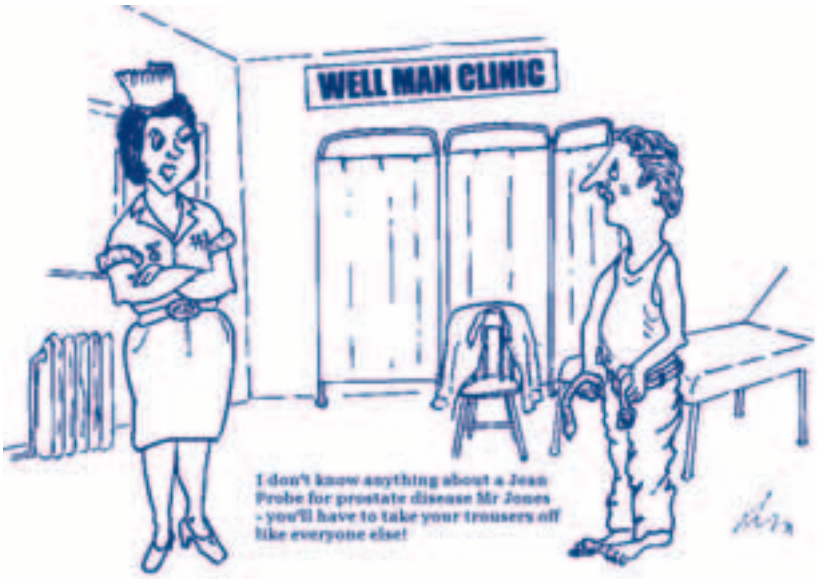
Example for the higher level practitioner

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

Domain: Care delivery

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

Suggested learning outcomes	Suggested practice indicators
A. *Discusses* the role of genetic factors in maintaining health and preventing disease in particular inherited cancers B. *Discusses the current and future place of pharmacogenetics and gene therapy in the prevention and management of cancer.* C. *Discusses* the role of genetic factors in the manifestation of cancer, using examples of particular cancers *more commonly encountered within own sphere of practice. (e.g. colorectal, breast)* D. *Analyses* how cancer expression may be influenced by the interaction between genetic and other factors, at different life stages. E. Applies a variety of concepts of risk *to explain* the distinction between genetic susceptibility and clinical manifestation of a disease.	1. Applies knowledge and understanding to identify potentially significant information from a family history being aware of the difference between genetically acquired and inherited cancers 2. *Incorporates* family history information in providing health education advice. 3. *Facilitates and supports individuals in accessing screening and health promotion initiatives, presenting a balanced view of the advantages and disadvantages of these.* 4. *Demonstrates an awareness and understanding of cancers that are unlikely to have an inherited link, and of the rarer inherited cancer conditions and the consequent health promotion issues.*



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Scenario: The clinical nurse specialist in colorectal cancer

I have a dual role working both as a research nurse and a clinical nurse specialist in colorectal cancer and sometimes the conflicting agendas cause clinical problems, especially in relation to keeping my professional knowledge up to date. Alex is one of six brothers and sisters. Two of his brothers emigrated to Canada 30 years ago and unfortunately over time they have lost contact with each other. Two sisters (Pauline, 55 and Beverley, 63) live in Scotland but again he had not had much contact with them for several years. He was surprised when Pauline's husband telephoned to let him know that Pauline was in hospital recovering from having "lots of her bowel removed" following a diagnosis of colon cancer.

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

Following his visit to see Pauline he re-contacted me, he was clearly distressed at how ill Pauline looked, worried about the risks to himself and had some new family history information in that his other brother has had polyps. I tried to reassure him but also had a nagging thought that this might be important. I agreed to try and find out more information and call him back but I do remember being a little dismissive of his concerns. I decided I needed some expert advice so I contacted one of my colleagues working in the Cancer Genetics Team. He recalled that a relatively new condition Autosomal Recessive Colorectal cancer (MYH) had been identified where the colon cancers occur at an older age, there is an association with bowel polyps, and parents are unaffected. This is in contrast to presentation of FAP or HNPCC, inherited conditions known to cause colorectal cancer, where one parent is affected (dominant inheritance). This rang alarm bells for me in relation to Alex's family history.

Feeling very guilty and concerned by my apparent lack of knowledge I called Alex back, explained a little of what I had discovered and offered to refer him on to my colleagues in Genetics. He seemed a little surprised by the mention of the word genetics and said that he did not want to be experimented on. I tried to reassure him that it was all about trying to help determine whether his family history was a problem and to offer him some support and surveillance. I sorted out the referral and am now much more aware of how important it is to keep up to date and to avoid at all costs giving false reassurance.

References and Resources

Policy documents and relevant academic papers

Association of Genetics Nurses and Counsellors Education Working Group (2002) *Reports for the Genetics Policy Unit, Department of Health.* (Convenor H Skirton)

Burton H (2003) *Addressing Genetics Delivering Health. A strategy for advancing the dissemination and application of genetics knowledge throughout our health professions.* Cambridge: Public Health Genetics Unit.

Department of Health (1999) *Agenda for Change. Modernising the NHS pay system.* London: Department of Health.

Department of Health (2003) *The NHS Knowledge and Skills Framework and related development review.* London: The Stationery Office.

Department of Health (2003) *Our Inheritance, Our Future. Realising the potential of genetics in the NHS.* London: The Stationery Office.

Kirk M (1999a) Preparing for the future: the status of genetics education in diploma-level training courses for nurses in the United Kingdom. *Nurse Education Today* 19(2): 107-115.

Kirk M (1999b) *Nurse education and the new genetics: Preparing the practitioners of the future. A report of an Expert Advisory Panel.* Pontypridd: University of Glamorgan.

Kirk M (2000) Genetics, ethics and education: considering the issues for nurses and midwives. *Nursing Ethics* 7(3): 215-226.

Kirk M, McDonald K, Longley M, Anstey S et al. (2003) *Fit for Practice in the Genetics Era: Defining what nurses, midwives and health visitors should know and be able to do in relation to genetics.* Pontypridd: University of Glamorgan.

Web sites

1. *National Coalition for Health Professional Education in Genetics*
   http://www.nchpeg.org
2. *Essentially an on-line text book on genetics:*
   http://www.usd.edu/med/som/genetics/curriculum/TableofContents.htm
3. *Public Health Genetics Unit, Cambridge: a good all-round resource with a regular 'round up' of current papers and events*
   http://www.medinfo.cam.ac.uk/phgu
4. *An interactive web site with some useful teaching and learning resources*
   http://gslc.genetics.utah.edu/
5. *The Genetics Observatory website has short articles exploring genetics and ethics*
   http://www.ircm.qc.ca/bioethique/obsgenetique/
6. *The GeneTests website offers detailed information about particular conditions and tests with an illustrated glossary*
   http://www.geneclinics.org
7. *This Genetics Home Reference site provides clear information and a good glossary*
   http://ghr.nlm.nih.gov/

Text books

Abramsky L 2003 *Prenatal Diagnosis, the Human Side.* Nelson Thornes

British Medical Association (1998) *Human Genetics: Choice and Responsibility.* Oxford University Press, Oxford.

Harper PS (1998) *Practical Genetic Counselling.* 5th edition. Butterworth Heinemann, Oxford.

Harper PS and Clarke A (1997) *Genetics, society and clinical practice.* Bios, Oxford.

Lea DH, Jenkins JF, Francomano CA (1998) *Genetics in Clinical Practice. New directions for nursing and health care.* Jones and Bartlett, Massachusetts.

Marteaux T. and Richards M. (1996) Eds. *The Troubled Helix: social and psychological implications of the new human genetics.* Cambridge University Press, Cambridge.

Rose P and Lucassen A (1999) *Practical genetics for primary care.* Oxford University Press, Oxford.

Skirton H and Patch C (2002) *Genetics for healthcare professionals.* Bios, Oxford.

Regional Genetic Centres

Mothercare Unit of Clinical Genetics &
Fetal Medicine
Institute of Child Health
30 Guilford Street
London WC1N 1EH
Tel: 020 7242 9789

Kennedy Galton Centre for Clinical Genetics
Level 8V
Northwick Park Hospital
Harrow HA1 3UJ
Tel: 020 8869 2795

Regional Clinical Genetics Service
Department of Paediatrics
Moston Lodge
Countess of Chester Hospital
Chester CH2 1UL
Tel: 01244 364754

Mersey & Cheshire Clinical Genetics Service
Alder Hey Children's Hospital
Eaton Road, West Derby
Liverpool L12 2AP
Tel: 0151 252 5238

Regional Genetics Service
St Mary's Hospital
Hathersage Road
Manchester M13 0JH
Tel: 0161 276 6264

Regional Department of Clinical Genetics
Manchester Children's Hospital NHS Trust
Pendlebury
Manchester M27 4HA
Tel: 0161 727 2335

Northern Genetics Service
International Centre for Life
Central Parkway
Newcastle upon Tyne NE1 3BZ
Tel: 0191 241 8600

Yorkshire Regional Genetics Service
Ashley Wing
St James's University Hospital
Beckett Street
Leeds LS9 7TF
Tel: 0113 206 5143/5

NI Regional Genetics Centre
Clinical Genetics Service
Belfast City Hospital Trust
Lisburn Road
Belfast BT9 7AB
Tel: 028 9032 9241 ext 2323

East Anglian Medical Genetics Service
Department of Medical Genetics
Box 134, Addenbrooke's Hospital
Hills Road
Cambridge CB2 2QQ
Tel: 01223 216446

Department of Clinical Genetics
The Churchill
John Radcliffe NHS Trust
Old Road, Headington
Oxford OX3 7LJ
Tel: 01865 226026

N of Scotland Regional Genetics Service
Department of Medical Genetics
Medical School
Foresterhill
Aberdeen AB9 2ZD
Tel: 01224 552120

Regional Genetics Services
Human Genetics Laboratories
Department of Pathology
Ninewells Hospital and Medical School
Dundee DD1 9SY
Tel: 01382 632680

Regional Cytogenetics Services
Southmead Hospital
Bristol BS10 5NB
Tel: 0117 959 5570

W of Scotland Regional Genetics Service
Institute of Medical Genetics
Yorkhill Academic Campus
Glasgow G3 8SJ
Tel: 0141 201 0365 /0361/0000

S Thames (East) Regional Genetics Centre
8th Floor, Guy's Tower
Guy's Hospital
London SE1 9RT
Tel: 020 7955 4648/9

South West Thames Genetics Service
Department of Clinical Genetics
St Georges Hospital Medical School
Cranmer Terrace
London SW17 0RE
Tel: 020 8725 5304/5335

SE Scotland Clinical Genetics Service
Department of Clinical Genetics
Western General Hospital
Crewe Road South
Edinburgh EH4 2XU
Tel: 0131 651 1012

Clinical Genetics Department
Royal Hospital for Sick Children
St Michaels Hill
Bristol BS5 5BJ
Tel: 0117 928 5652

Clinical Genetics Department
Royal Devon & Exeter Hospital
Barrack Road
Exeter EX2 5DW
Tel: 01392 403151

Wessex Clinical Genetics Service
Level G
Princess Anne Hospital
Coxford Road
Southampton SO16 5YA
Tel: 023 8079 6166

Department of Clinical Genetics
Leicester Royal Infirmary
Leicester LE1 5WW
Tel: 0116 258 5736

Department of Clinical Genetics
City Hospital
Hucknall Road
Nottingham NG5 1PB
Tel: 0115 962 7728

Department of Clinical Genetics
Sheffield Children's Hospital
Sheffield S10 2TH
Tel: 0114 271 7025

Medical Genetics Service for Wales
Institute of Medical Genetics
University Hospital of Wales
Heath Park
Cardiff CF14 4XN
Tel: 029 2074 4028

West Midlands Regional Clinical Genetics Service
Clinical Genetics Unit
Birmingham Women's Hospital
Edgbaston, Birmingham B15 2TG
Tel: 0121 627 2630

Gene Knowledge Parks

Cambridge Genetics Knowledge Park
Public Health Genetics Unit
Strangeways Research Laboratory
Worts Causeway
Cambridge CB1 8RN
Tel: 01223 740200
www.cgkp.org.uk

London IDEAS Genetics Knowledge Park
First Floor, Institute of Child Health
30 Guilford Street
London WC1N 1EH
Tel: 020 7905 2221
www.londonideas.org

Oxford Genetics Knowledge Park
The Churchill
John Radcliffe NHS Trust
Old Road, Headington
Oxford OX3 7LJ

Life Knowledge Park
Institute of Human Genetics
International Centre for Life
Central Parkway
Newcastle upon Tyne NE1 3BZ
http://www.centreforlife.co.uk/ngkp/index.php

Nowgen - NW Genetics Knowledge Park
7th Floor, St Mary's Hospital
Hathersage Road
Manchester M13 0JH
Tel: 0161 276 6147
www.nowgen.org.uk

Wales Gene Park
The Medicentre, Heath Park
Cardiff CF14 4UJ
Tel: 029 2075 7744
www.walesgenepark.com