

Enhancing patient care by integrating genetics in clinical practice

UK Workforce Competences for Genetics in Clinical Practice for Non-Genetics Healthcare Staff

To ensure that patients have access to genetic advances now and in the future, healthcare staff may need to be able to

- identify patients with or at risk of genetic conditions
- collect family history information
- work out who is likely to be affected and to refer them accordingly
- explain the results of a test
- take into account the implications of a genetic test to other members of a patient's family

These steps form part of a patient pathway; to help support the application of genetics in the patient pathway, a large group of healthcare staff drew on their clinical experience to generate a set of skills and knowledge that may be used. These form the UK Workforce Competences for Genetics in Clinical Practice for Non-Genetics Healthcare Staff. Their application aims to improve care for patients with or at risk of genetics conditions.

This document contains all nine of the workforce competences that cover the patient pathway. Not all of the competences will be applicable to all roles.

November 2007

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UK Workforce Competences for Genetics in Clinical Practice for Non-Genetics Healthcare Staff

A framework and competences for genetics activities in patient care have been developed by the NHS National Genetics Education and Development Centre and Skills for Health working together with a wide range of health professionals.

What is a competence framework?

Competence frameworks describe the activities that cover a patient pathway, practitioner role or specialty area. Individual competences within a framework indicate how the activities are carried out (performance criteria), and the underpinning knowledge, skills and attitudes required.

How was the genetics competence framework developed?

The competence framework describes a pathway of activities involving genetics knowledge, skills and attitudes which may be carried out by non-genetics healthcare staff. The activities were identified by different healthcare staff groups considering where 'genetics' impacts on their role and the patient care they provide. Staff from Regional Genetics Centres were an integral part of the process in developing the competences.

How should the genetics competences be used?

We anticipate that the competences will be incorporated into job descriptions when a health professional's job description already includes genetic activities, where a patient pathway would benefit from genetics activities being added to an existing job role when new roles are developed.

Not all nine genetics competences will be applicable to every role; although the competences cover the whole of the pathway for a patient with, or at risk of, a genetic disorder, for any individual health professional only those genetic competences relevant to their agreed professional role should be selected and included in a job description. Some competences will be widely applicable whilst others will be relevant only to a small number of specialist healthcare professionals.

They give an overview – specific details (e.g. which genetic conditions, which pathway) need to be determined locally appropriate to the role being undertaken in a particular patient pathway.

Agreed competences can be used by individuals to develop their own knowledge, skills and performance, by education and training providers to identify learning needs, define learning outcomes and specify qualifications, and by organisations to set standards and improve the quality of services they offer.

What support will be available for the genetics competences?

The NHS National Genetics Education and Development Centre is currently consulting on the support and assessment materials required and hope to facilitate and develop these as appropriate. Details will be posted on the Centre's website (www.geneticseducation.nhs.uk).

The nine competences in the genetics framework

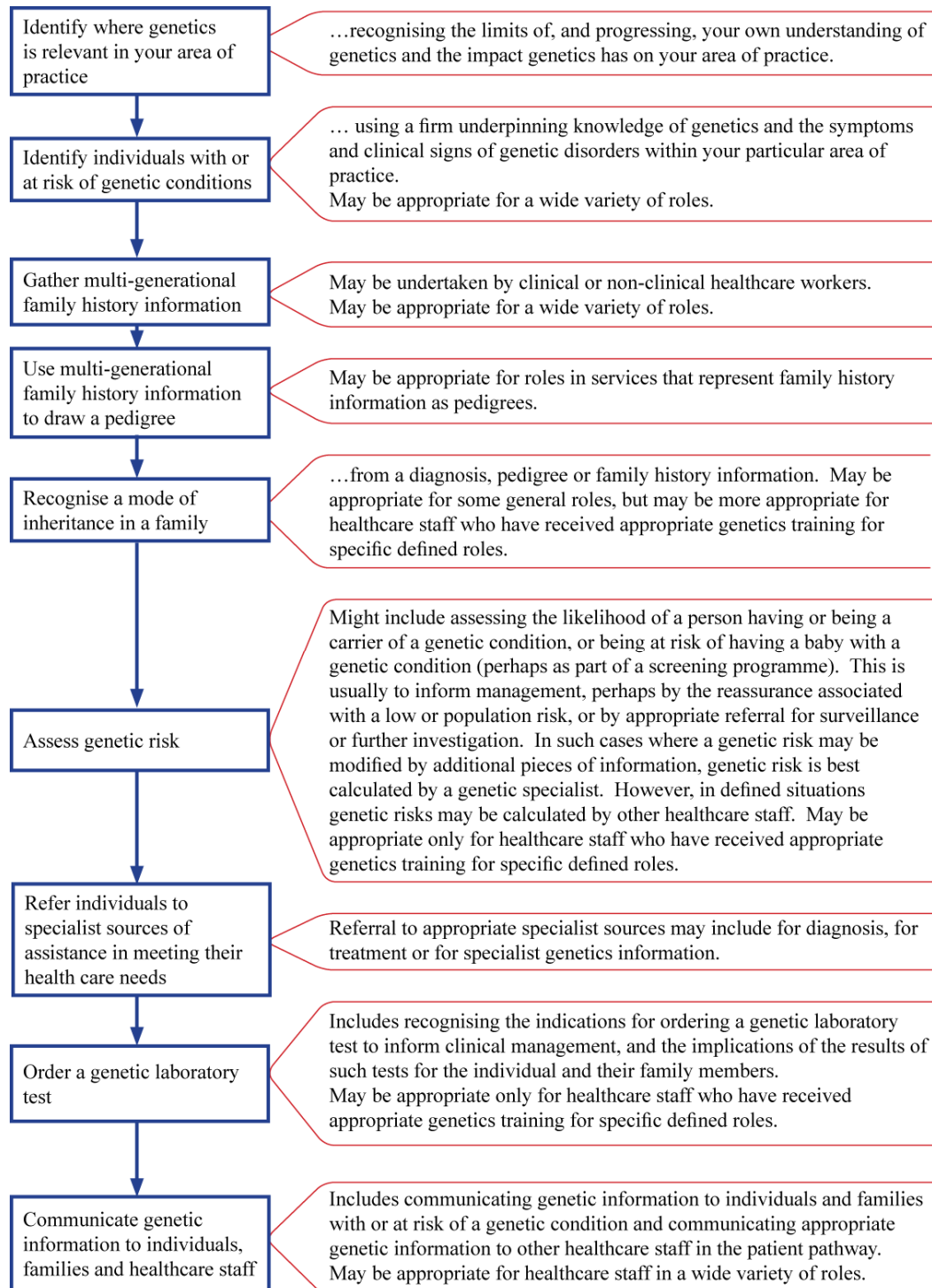
An overview of the draft framework and a very brief summary of each competence follow. Each competence is designed to address a discrete area of function and responsibility which a person working in a healthcare role may be asked to undertake.

The full competence statements are available on the NHS National Genetics Education and Development Centre website:

<http://www.geneticseducation.nhs.uk/develop/index.asp?id=44>

UK Workforce Competences for Genetics in Clinical Practice for Non-Genetics Healthcare Staff- The Patient Pathway

Nine workforce competences cover the pathway for a patient with, or at risk of, a genetic disorder



Not all genetics competences will be applicable to every role; only those relevant to an individual's agreed role should be selected and included in a job description. Some competences will be relevant only to a small number of specialist healthcare professionals. The competences give a broad overview – specific details (e.g. which genetic conditions, how a service operates) appropriate to the role being undertaken in a particular patient pathway need to be determined and agreed locally.

1. Identify where genetics is relevant in your area of practice

About this workforce competence

This competence is about recognising the limits of, and progressing, your own understanding of genetics and identifying the impact genetics has on your area of practice.

Advances in genetics are beginning to affect or impact the patient pathway in many clinical areas. There is a need for practitioners to be aware of genetics and to keep up-to-date with the application of genetics within their clinical field.

This is a competence which may be generally applicable to healthcare staff in a wide variety of roles.

Performance criteria

You need to:

- 1) identify how **genetics** impacts on
 - a. your own role
 - b. an individual's clinical pathway
 - c. their family's health and well-being
- 2) recognise the level of genetic knowledge and skills required for your job role and your own limitations
- 3) take responsibility for identifying and addressing your own **learning needs** related to genetic activities through relevant training
- 4) **access information** about genetics that is current and reliable
- 5) keep your genetic knowledge up-to-date and act on the implications this has for your area of work
- 6) make sure any genetic information you give to others is within the limits of your role, responsibility, knowledge and experience

Knowledge and understanding

You need to apply:

- K1. an in-depth understanding of your own limitations in practice regarding genetics
- K2. a basic awareness of genetic conditions that may occur within your clinical area
- K3. a working knowledge of population groups most at risk of genetic conditions in your area of practice
- K4. a basic understanding of the indications for and implications of genetic screening and testing relevant to your area of practice
- K5. a basic awareness of ethical issues associated with genetics
- K6. a working knowledge of how and where to access accurate up-to-date genetic information
- K7. a working knowledge of genetics national guidelines relevant to your area of practice
- K8. an in-depth understanding of how to determine your personal training needs in genetics
- K9. a working knowledge of the responsibility you hold for imparting accurate information to others

Links

This competence links with the following dimensions and levels within the NHS Knowledge and Skills Framework Working (October 2004)

Dimension: Core 2 Personal and People Development

Level: 3

Searchable key words

Personal, professional development, genetics, learning

Origin

This workforce competence was developed by Skills for Health with the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|----------------|--|
| Genetic | Involving, resulting from, or relating to genetic material (genes and/or chromosomes). |
|----------------|--|

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|---------------------------|---|
| Access information | <p>May include:</p> <ul style="list-style-type: none"> a) genetics clinical meetings b) media c) specialised courses d) websites e) other personal development |
| Learning needs | <p>May include:</p> <ul style="list-style-type: none"> a) action learning sets b) on the job training c) ongoing work d) research e) specialised courses |

2. Identify individuals with or at risk of genetic conditions

About this workforce competence

This competence is about identifying individuals with or at risk of genetic conditions, using a firm underpinning knowledge of genetics and the symptoms and clinical signs of genetic disorders within your area of practice.

This is in order to meet the healthcare needs of the individual including surveillance for potential complications and to make the offer of genetic information where appropriate.

This is a competence which may be generally applicable to healthcare staff in a wide variety of roles.

Performance criteria

You need to:

- 1) identify individuals with, or at risk of, a **genetic** condition using combinations of:
 - a. a known diagnosis of a genetic condition either in the individual or a family member
 - b. clustering of a condition within a family
 - c. knowledge of the genetic component of clinical conditions
 - d. screening programmes
- 2) ask relevant **questions** of the individual to confirm initial identification and inform your **next actions**
- 3) act within the limits of your role, responsibility, knowledge and genetic experience

Knowledge and understanding

You need to apply:

- K1. a working knowledge of the genetic components of specific conditions in your clinical area of practice
- K2. a working knowledge of symptoms and clinical signs of genetic disorders within your area of practice
- K3. a working knowledge of patterns of affected people associated with modes of inheritance relevant to the genetic conditions in your area of practice
- K4. a working knowledge of UK genetic screening programmes
- K5. a working knowledge of where to obtain further information and support for individuals affected by, or at risk of, a genetic condition
- K6. an in-depth understanding of your own limitations in practice regarding genetics
- K7. an in-depth understanding of use of effective communication skills and strategies consistent with the level of understanding, background, culture and preferred ways of communicating of the person giving the information

Links

This competence links with the following dimensions and levels within the NHS Knowledge and Skills Framework Working (October 2004).

Dimension: HWB2 Assessment and care planning to meet health and well-being needs

Level: 4

Searchable Keywords

Genetic risk, Sickle cell, cystic fibrosis, cancer, Downs syndrome, renal, heart, births, pregnancies

Origin

This workforce competence was developed by Skills for Health with the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|----------------|--|
| Genetic | Involving, resulting from, or relating to genetic material (genes and/or chromosomes). |
|----------------|--|

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|---------------------|---|
| Questions | Questioning may cover a variety of subjects including: <ul style="list-style-type: none"> a) symptoms and clinical signs, including age of onset b) known medical conditions c) family history d) psychosocial aspects |
| Next actions | May include: <ul style="list-style-type: none"> a) taking a multi-generation family history b) drawing a family pedigree c) consideration of genetic testing d) confirm diagnosis if appropriate e) referral to specialist source of assistance in meeting relevant healthcare needs, including genetics clinics |

3. Gather multi-generational family history information

About this workforce competence

This workforce competence is about gathering accurate family history information and may be undertaken by clinical or non-clinical healthcare workers.

You will need to manage information gathering with great care and sensitivity as some parts of the family history may evoke strong emotions. You may need to probe gently and ask questions that cover a range of subjects and you may need to ask individuals to find out further information from other sources.

As information is revealed, individuals may start to theorise about their health and you need to be prepared to deal with a situation that at this point has no confirmed outcome.

This is a competence which may be generally applicable to healthcare staff in a wide variety of roles.

Performance criteria

You need to:

- 1) allocate sufficient time for the discussion to be completed
- 2) explain the **purpose** of taking the family history
- 3) seek agreement to take the family history and share it (and/or a pedigree drawn from it) with relatives and health professionals if appropriate
- 4) respect the individual's rights and wishes relating to their privacy, beliefs and dignity
- 5) use appropriate **questions** to gather relevant multi-generation family history information
- 6) encourage the individual to ask questions throughout the consultation
- 7) recognise and adapt to the **stresses and barriers of communication** that result from the questions asked and the answers being given
- 8) make sure sufficient information is taken so that a pedigree can be drawn if relevant
- 9) record the information in an appropriate format
- 10) explain to the individual the next stages following the consultation
- 11) make sure any **genetic** information you give to the individual is within the limits of your role, responsibility, knowledge and experience
- 12) signpost the individual to sources of further genetic information if requested
- 13) maintain the chain of confidentiality when passing information to other healthcare professionals

Knowledge and understanding

You need to apply:

Multi-Generational family history

- K1. a working knowledge of the stages of gathering multi-generational family history information
- K2. a working knowledge of the types of questions which elicit the required multi-generational family history information
- K3. a working knowledge of the extent of the multi-generational family history required
- K4. a basic awareness of the value, use, advantages and limitations of multi-generational family history information and how this changes/informs future practice and treatment
- K5. a basic awareness of social, psychological, emotional, cultural, linguistic factors which may emerge when taking a multi-generational family history

Communication

- K6. an in-depth understanding of use of effective communication skills and strategies consistent with the level of understanding, background, culture and preferred ways of communicating of the person giving the information
- K7. an in-depth understanding of how to discuss sensitive issues with individuals
- K8. an in-depth understanding of family issues that may emerge as a result of taking multi-generational information
- K9. a working knowledge of appropriate environments in which to capture and discuss confidential information

Records and Documentation

- K10. a working knowledge of the information that should be recorded
- K11. a working knowledge of record keeping practices and procedures in relation to gathering and recording multi-generational family history information
- K12. a working knowledge of consent and confidentiality guidelines particularly relating to genetics

Links

This workforce competence has indicative links with the following dimensions and levels within the NHS Knowledge and Skills Framework (October 2004).

Dimension: HWB2 Assessment and care planning to meet health and well-being needs

Level: 4

Dimension: Core 1 Communication

Level: 3

Searchable Keywords

Multi-generation, family history, births, deaths, cystic fibrosis, sickle cell, cancer, renal, heart disease, donor

Origin

This workforce competence has been developed by Skills for Health with the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|--|--|
| Genetic | Involving, resulting from, or relating to genetic material (genes and/or chromosomes). |
| Multi-generational family history | Usually encompasses three generations. However, for certain genetic conditions a different number of generations may be appropriate. |

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|---|--|
| Questions | <p>Questioning may cover a variety of subjects including:</p> <ul style="list-style-type: none"> a) how people are related to each other b) births, pregnancy losses and deaths c) medical conditions within the family and their ages of onset d) environmental and lifestyle factors |
| Immediate and extended family | <p>Will include:</p> <ul style="list-style-type: none"> a) blood relatives b) non-blood relatives c) relatives from second or successive partnerships <p>and will encompass all age ranges</p> <ul style="list-style-type: none"> a) alive b) deceased |
| Purpose | <p>The information gathered may be used to:</p> <ul style="list-style-type: none"> a) draw a pedigree b) recognise inheritance patterns c) identify genetic risk d) assess genetic risk |
| Stresses and barriers to communication | <p>May include:</p> <ul style="list-style-type: none"> a) culture b) disability c) emotions d) English is not individual's first language e) familial implications of genetic information f) subject sensitivity g) unwillingness to disclose information |

4. Use multi-generational family history information to draw a pedigree

About this workforce competence

This workforce competence is about drawing an accurate pedigree from multi-generational family history information.

The pedigree will form part of the individual's clinical record.

This is a competence which may be generally applicable to healthcare staff in a wide variety of roles.

Performance criteria

You need to:

- 1) make sure sufficient and appropriate **multi-generational family history** is available so that you can draw the **pedigree** in as much detail as required
- 2) if the need arises, clarify family history details with the individual who gave the information or others, ensuring that appropriate consent has been obtained
- 3) use the standard convention for laying out a pedigree
- 4) use appropriate symbols and notations for **drawing**:
 - a. the relationship of **individuals** to the person seeking information
 - b. gender
 - c. alive or deceased
 - d. their disease status
- 5) provide a key for each of the different **symbols**
- 6) add personal information as appropriate (e.g. names, dates of birth, medical information)
- 7) make sure the drawing is legible
- 8) write your name legibly, sign and date pedigree
- 9) maintain the chain of confidentiality of records when using or passing on the pedigree

Knowledge and understanding

You need to apply:

Pedigrees

- K1. a working knowledge of how to translate family history information into a pedigree
- K2. a working knowledge of internationally recognised pedigree symbols and their relationship to each other
- K3. a working knowledge of the standard convention of laying out a pedigree
- K4. a working knowledge of the role of the pedigree as a means of representing multi-generational family history information
- K5. a working knowledge of best practice guidelines relevant to pedigrees

Records and Documentation

- K6. a working knowledge of record keeping practices and procedures in relation to drawing a pedigree
- K7. a working knowledge of consent and confidentiality in relation to an individual's clinical records

Links

This workforce competence has indicative links with the following dimensions and levels within the NHS Knowledge and Skills Framework (October 2004).

Dimension: HWB2 Assessment and care planning to meet health and well-being needs

Level: 4

Dimension: IK2 Information collection and analysis

Level: 2

Searchable key words

Genes, genetic, family history, medical history, pedigree, chromosomes, family tree.

Origin

This workforce competence has been developed by Skills for Health with the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|--|---|
| Multi-generational Family history | Encompasses three generations of family history, however, where there are existing indications of a particular genetic condition this may be targeted more specifically. |
| Individuals | Any adult, child or baby - alive or deceased. In the context of this competence pregnancies and pregnancy losses would also be relevant. |
| Pedigree | A graphical representation of genetic relationships and medical conditions in a family. |
| Symbols | Best practice recommends that the symbols drawn are those recognised by the Pedigree Standardisation Task Force, however, your organisation may utilise other symbols or methodologies. |

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|----------------|--|
| Drawing | May include using: <ul style="list-style-type: none"> a) free-hand b) stencil template c) pre-printed materials d) computer software |
|----------------|--|

5. Recognise a mode of inheritance in a family

About this workforce competence

This competence is about recognising a mode of inheritance in a family from a diagnosis, pedigree or family history information.

Disorders which appear to run in families may be genetic, environmental or caused by a combination of genetic and environmental factors. Recognising a mode of inheritance in a family involves considering:

- Who is affected in the family
- How they are related
- The underlying genetic mechanism
- The possibility of the same condition being caused by different modes of inheritance

This is in order to meet the healthcare needs of the individual and their family, including surveillance for potential complications and to make the offer of genetic information where appropriate.

Performance criteria

You need to:

- 1) make sure you have sufficient information about the grouping of symptoms and clinical signs, or of known conditions in the family
- 2) clarify with the appropriate person any information that is missing or about which you are unsure
- 3) determine the likely **mode of inheritance** in the family using your knowledge of a) the disorder's usual mode of inheritance or b) the **patterns of affected people** seen in **genetic** conditions, comparing these with the **pattern** seen in the family
- 4) where a specific condition can be inherited in different ways, consider whether the pattern shown in the family would be compatible with each of the known modes of inheritance for that condition
- 5) determine whether any action is required to confirm the mode of inheritance and refer appropriately if required
- 6) act within the limits of your role, responsibility, knowledge and experience, seeking further advice if the pattern of affected people seen in the family does not fit an expected mode of inheritance

Knowledge and understanding

You need to apply:

- K1. a working knowledge of the patterns of affected people associated with each mode of inheritance
- K2. a working knowledge of the information required to identify a mode of inheritance in a family
- K3. a working knowledge of symptoms and clinical signs of genetic disorders within your area of practice
- K4. a working knowledge of how to read a pedigree
- K5. a critical understanding of the value, use, advantages and limitations of genetic information and how this changes/informs future practice and treatment

Links

This workforce competence has indicative links with the following dimensions and levels within the NHS Knowledge and Skills Framework (October 2004)

Dimension: HWB2 Assessment and care planning to meet health and well-being needs

Level: 4

Searchable key words

Genetic, family history, medical history, pedigree, inheritance patterns, Downs syndrome, cystic fibrosis. Sickle cell

Origin

This workforce competence has been developed by Skills for Health with the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|----------------------------|---|
| Genetic | Involving, resulting from, or relating to genetic material (genes and/or chromosomes). |
| Mode of inheritance | The way in which a specific genetic characteristic or disorder is passed from one generation to the next e.g. autosomal dominant. |

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|---|---|
| The mode of inheritance | The mode of inheritance is identified in order to: <ul style="list-style-type: none"> a) Decide whether an individual or family members might benefit from genetic risk calculation, surveillance, screening or testing b) Answer an individual's questions such as 'am I at risk', 'am I a carrier' or 'are my children at risk?' c) Refer individuals appropriately for surveillance, treatment or further information |
| A pattern of affected people in a family | Interpreting the pattern of affected people in a family may suggest a mode of inheritance. These include: <ul style="list-style-type: none"> a) Autosomal dominant b) Autosomal recessive c) X-linked d) Chromosomal e) Mitochondrial f) Multi-factorial |

6. Assess genetic risk

About this workforce competence

This competence is about assessing genetic risk. This might include assessing the likelihood of a person having a genetic condition or a genetic predisposition to a condition, being a carrier of a genetic condition or being at risk of having a baby with a genetic condition. This is usually used to inform clinical management, perhaps by the reassurance associated with a low or population risk, or by appropriate referral for surveillance or further investigation.

Sometimes it is only possible to assign a broad risk, whilst in other cases a very precise risk may be calculated using additional information. In such cases where a genetic risk may be modified by additional pieces of information, genetic risk is best calculated by a genetics specialist. However, in defined situations genetic risks may be calculated by other healthcare staff.

Performance criteria

You need to:

- 1) ensure that you have received appropriate training and are competent to assess genetic risks relevant to your area of practice
- 2) confirm the diagnosis of the condition in the family
- 3) confirm the disease status of the person whose risk is being assessed
- 4) ensure that adequate pedigree or family history information is available
- 5) confirm the usual modes of inheritance for the condition
- 6) assess the likely **mode of inheritance** from the pattern of affected people in the family
- 7) identify the relationship of the individual to the closest affected family member
- 8) determine the appropriate **risk assessment method**
- 9) assess the risk of the genetic condition for an individual using recognised **risk assessment methods**
- 10) use appropriate protocols and guidelines where available to assist in assessment of genetic risk
- 11) determine the appropriate further action based on the **assessment of genetic risk**
- 12) act within the limits of your role, responsibility, knowledge and experience, seeking further advice if a pedigree pattern does not fit an expected mode of inheritance

Knowledge and understanding

You need to apply:

- K1. a critical understanding of the factors which determine an individual's genetic risk
- K2. a critical understanding of genetic conditions, symptoms and clinical signs and inheritance patterns relevant to your area of practice
- K3. a critical understanding of methods of assessment of genetic risk relevant to your area of practice
- K4. a critical understanding of the mendelian patterns of inheritance for conditions in your area of practice and how specific risks are calculated
- K5. an in-depth understanding of how to use tables of empiric risk data for conditions relevant to your area of practice
- K6. a working knowledge of the use of protocols and guidelines for management of individuals in your area of practice following genetic risk assessment
- K7. a critical understanding of the concepts of probability, burden and risk, and the different ways of presenting probability information

Links

This workforce competence has indicative links with the following dimensions and levels within the NHS Knowledge and Skills Framework (October 2004).

Dimension: HWB2 Assessment and care planning to meet health and well-being needs

Level: 4

Searchable Keywords

Genetic, risk, empirical, Mendelian, Downs syndrome, cystic fibrosis, sickle cell

Origin

This workforce competence has been developed by Skills for Health and the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|-------------------------------|---|
| Genetic | Involving, resulting from, or relating to genetic material (genes and/or chromosomes). |
| Risk assessment method | The method of assessing an individual's risk of a specified genetic disorder. |
| Mode of inheritance | The way in which a specific genetic characteristic or disorder is passed from one generation to the next e.g. autosomal dominant. |

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|--------------------------------|--|
| Assessing genetic risk | <p>May involve:</p> <ul style="list-style-type: none"> a) determining level of risk from a combination of a known diagnosis and family history information in order to determine appropriate further action b) the interpretation of risk information presented on laboratory reports to determine appropriate further action c) calculating precise genetic risk. d) the use of computer applications and genetic risk assessment tools |
| Risk assessment methods | <p>These include:</p> <ul style="list-style-type: none"> a) for a known single gene disorder e.g. cystic fibrosis, sickle cell disorder: confirmation of pattern of inheritance; confirmation of relationship of individual to closest affected relative; application of mendelian principles to determine risk b) for risks determined from empiric risk tables e.g. trisomy 21 Down syndrome: confirmation of relationship of individual to closest affected relative; use of empiric risk tables to determine risk c) for other familial conditions with complex patterns of inheritance e.g. familial breast cancer: confirmation of family history information; use of relevant protocols and guidelines to determine level of risk and appropriate further action d) for risks associated with inherited chromosome disorders, use relevant empiric risk figures or calculate specific figures from a knowledge of the breakpoints or from diagrams of meiosis involving the abnormal segments |

7. Refer individuals to specialist sources of assistance in meeting their health care needs (CHS151)

About this workforce competence

This workforce competence is about referring individuals to specialist sources of assistance in the process of meeting their relevant health care needs.

Users of this competence will need to ensure that practice reflects up to date information and policies.

Performance criteria

You need to:

- 1) discuss the possibility of referral with the individual and significant others in a positive, honest and respectful manner, including the benefits and risks
- 2) identify the range of specialist services with features that meet the individual's needs and preferences
- 3) discuss with the individual and significant others, the available options for referral, including their advantages and disadvantages
- 4) agree with the individual which specialist service(s) they will be referred to and obtain the necessary consent for the referral
- 5) refer individuals to suitable specialist services following agreed referral arrangements and provide the necessary referral information
- 6) identify the priority of the individual's requirements in the referral information
- 7) provide the individual, and significant others where appropriate, with the opportunity to discuss any queries they have regarding their referral and/or the service provider(s) to which they are being referred
- 8) enable individuals to overcome any problems they may have in accessing specialist services
- 9) produce records and reports that are clear, comprehensive and accurate, and share information only with those who have the right and need to know

Knowledge and understanding

You need to apply:

Legal, professional, and organisational requirements

- K1. a working knowledge of the legislation which relates to your work including: health and safety, confidentiality and information sharing, the provision of services, the rights of individuals, anti-discriminatory practice, and informed consent
- K2. a working knowledge of the professional standards and codes of practice for your area of work and how to interpret and apply these
- K3. a working knowledge of the nature, extent and boundaries of your work role and its relationship to others in the organisation
- K4. a working knowledge of the roles of other health and social care practitioners and how they relate between and across agencies
- K5. a working knowledge of the principle of informed consent, and how to obtain informed consent from individuals
- K6. a working knowledge of the importance of confidentiality and how to ensure personal data are kept confidential whilst being shared with other agencies

Communication and relationships

- K7. a working knowledge of how to communicate effectively with individuals
- K8. a working knowledge of the importance of working in a facilitative and enabling way and how to do this

- K9. a working knowledge of how to present information in ways which are appropriate for different people
- K10.a working knowledge of the ways in which communication can be modified and altered for different needs, contexts and beliefs
- K11. a working knowledge of the rights of people to make decisions for themselves and to take risks in the context of their own lives

Health and well-being

- K12.a working knowledge of the main issues, debates, and policies relating to modifiable risks to health and well-being
- K13.a working knowledge of the guidance that is available for your own practice, and the sources of the guidance
- K14.a working knowledge of evidence based practice, and its role in improving services
- K15.a working knowledge of how factors in people's lifestyles can affect their risk of developing health problems

Services

- K16.a working knowledge of how to identify when individuals should be referred to specialist services that may help them to promote their health and well-being and reduce health risks
- K17.a working knowledge of the range of specialist services available locally and nationally to help promote health and well-being and reduce health risks
- K18.a working knowledge of the nature, strengths and limitations of these services
- K19.a working knowledge of the different features services must have to meet individuals' gender, culture, language or other needs
- K20.a working knowledge of the arrangements for referring people to specialist services

Record keeping

- K21.a working knowledge of how to complete and structure records and reports so that they contain all of the essential information and are suitable for others to use
- K22.a working knowledge of the importance of effective record keeping in accordance with professional guidelines and local policy, and the procedures relating to this.

Links

This workforce competence has indicative links with the following dimensions and levels within the NHS Knowledge and Skills Framework (October 2004)

Dimension: HWB2 Assessment and care planning

Level: 3

Dimension HWB6 Assessment and treatment planning

Level 3

Searchable key words

Referral, refer patients, patient referral.

Origin

This workforce competence was developed by Skills for Health. Final version approved March 2007

Scope

This section provides guidance on possible areas to be covered in this unit.

| | |
|-----------------|--|
| Features | <p>May include:</p> <ul style="list-style-type: none"> a) geographical location b) access hours c) method of delivery d) those determined by the gender, culture, language or special needs of individuals |
| Priority | <p>May include:</p> <ul style="list-style-type: none"> a) potential risks and difficulties for those caring for the individual b) the extent of the individual's needs c) the likelihood of the individual's condition deteriorating d) the risks to the individual e) urgent needs or emergency actions required |
| Problems | <p>May include:</p> <ul style="list-style-type: none"> a) availability and requirements of the services b) the policies and priorities of the services c) physical arrangements within the environment d) appointment time e) cost f) availability of funding g) others who need to be present h) transport. |

8. Order a genetic laboratory test

About this workforce competence

This competence is about recognising the indications for ordering a genetic laboratory test to inform clinical management, and the implications of the results of such tests for the individual and their family members.

Here we use the term “genetic laboratory test” to involve the direct analysis of genetic material (nucleic acid (DNA/RNA) or chromosomes) or the analysis of biochemical parameters, such as the concentration of metabolites or the activity of enzymes, to diagnose a genetic condition or make predictions about the genetic makeup of a person. Genetic information can also be obtained from clinical examination, imaging and family history. For instance, a renal ultrasound scan in persons at risk of adult polycystic kidney disease could be defined as a genetic test in that it gives “genetic information”, but this competence is restricted to genetic laboratory tests as defined above.

A genetic laboratory test should be ordered only to assist a specifically identified aspect of management. It may not be clinically necessary to offer a genetic test to every individual with a given condition.

This is a competence which is likely to be applicable only to healthcare staff in specific defined roles who have received appropriate genetics training.

Performance criteria

You need to:

- 1) identify, by using reliable information, whether a genetic laboratory test will inform clinical management for an individual
- 2) ensure the indications in each case meet the testing criteria for the particular genetic laboratory test
- 3) adhere to local and national protocols for genetic testing
- 4) adhere to consensus guidelines with respect to testing children, asymptomatic individuals and adults with incapacity
- 5) ensure any genetic information you give to the individual is within the limits of your role, responsibility, knowledge and experience
- 6) explain to the individual the purpose and process of the genetic testing including realistic timescales, familial implications and possible unexpected results
- 7) discuss any ethical, legal and social implications relating to the genetic testing
- 8) encourage the individual to ask questions and voice any concerns
- 9) respect the individual’s rights and wishes relating to their privacy, beliefs, and dignity
- 10) obtain informed consent from the individual before ordering the genetic laboratory test
- 11) agree with the individual the method of informing them of the results of the genetic test e.g. phone call, appointment
- 12) seek agreement for the storage and/or the sharing of sample and test results for the benefit of other family members if appropriate
- 13) organise appropriate genetic testing
- 14) complete all documentation ensuring all relevant information is passed on to the laboratory when ordering the genetic test
- 15) ensure the result is reported to the individual and to others (if appropriate) as agreed with the individual
- 16) maintain the chain of confidentiality when passing information to other healthcare professionals

Knowledge and understanding

You need to apply:

Genetic testing

- K1. a working knowledge of genetic conditions relevant to your area of practice, their symptoms, clinical signs and modes of inheritance
- K2. a working knowledge of services for individuals with or at risk of genetic conditions in your area of practice, including specialist genetic services
- K3. an in-depth knowledge of the potential benefits, limitations and implications of genetic testing
- K4. a working knowledge of the local and national guidelines governing genetic testing
- K5. a working knowledge of the current guidelines for genetic testing in children
- K6. an in-depth knowledge of the purpose of genetic laboratory tests relevant to your area of practice
- K7. an in-depth knowledge of the indications for genetic testing for conditions relevant to your area of practice
- K8. a working knowledge of the samples required by the laboratory for genetic testing
- K9. a working knowledge of the timescales involved in the genetic testing process
- K10. an in-depth understanding that genetic information impacts not only on the individual but also on their immediate and extended family
- K11. a working knowledge of cultural, ethical, legal and psychosocial issues relating to genetic information
- K12. a working knowledge of consent and confidentiality guidelines, including consent with regard to the sharing of genetic information with other family members for their benefit
- K13. a working knowledge about the storage of clinical samples and their use for quality assurance, audit, education and training
- K14. working knowledge of where to access accurate up-to-date genetic information
- K15. a working knowledge of where to obtain information and support for individuals affected by, or at risk of, a genetic condition

Communication

- K16. a working knowledge of how to present genetic information in ways appropriate for different individuals
- K17. a working knowledge of use of effective communication skills and strategies consistent with the level of understanding, background, culture and preferred ways of communicating of the person with whom you are communicating
- K18. a working knowledge of appropriate environments in which to obtain and discuss confidential information

Links

This competence links with the following dimensions and levels within the NHS Knowledge and Skills Framework Working (October 2004).

Dimension: HWB 2 Assessment and care planning to meet health and wellbeing needs

Level: 4

Searchable Keywords

Tests, genetics, DNA, RNA, chromosomes, Downs syndrome, cystic fibrosis, sickle cell

Origin

This workforce competence was developed by Skills for Health and the NHS National Genetics Education and Development Centre October 2006.

Glossary

This section provides explanations and definitions of the terms used in this workforce competence. In competences, it is quite common to find words or phrases used which you will be familiar with, but which, in the detail of the competence, may be used in a very particular way.

| | |
|---------------------------------|--|
| Genetic | Involving, resulting from, or relating to genetic material (genes and/or chromosomes). |
| Genetic laboratory test | The analysis of human DNA, RNA, chromosomes, proteins or metabolites undertaken to detect changes related to a genetic disorder. |
| Molecular genetic test | Test for a genetic condition that involves testing nucleic acid (DNA or RNA). |
| Cytogenetic test | Test for anomalies of the number or structure of chromosomes |
| Biochemical genetic test | Test to study enzymes, proteins or metabolites which may be altered by a genetic condition |
| Testing criteria | Define the conditions that should be met for a genetic test to be appropriate. They define the clinical appropriateness of a genetic test referral such as the criteria set out in the <i>Gene Dossier</i> approved by the UKGTN and GenCAG for molecular genetic testing. |
| Screening | A public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications. |
| Diagnostic test | A test that aims to give a definitive answer about diagnosis. |
| Predictive test | The use of a genetic test in an asymptomatic person to predict the risk of disease in the future. |
| Carrier | Unaffected person who has one normal and one altered form of the same gene - called a heterozygote. Also applies to an unaffected individual who has a structural rearrangement of chromosomes where there has been no gain or loss of chromosomal material (e.g. a balanced translocation). |

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|--------------------------------|---|
| Laboratory genetic test | <p>The assay may be:</p> <ul style="list-style-type: none"> a) molecular b) cytogenetic c) biochemical <p>Please refer to glossary for definitions</p> |
|--------------------------------|---|

| | |
|------------------------------------|--|
| <p>Reliable information</p> | <p>May come from a combination of:</p> <ul style="list-style-type: none"> a) existing diagnosis in the individual or family members b) family history c) pedigree d) knowledge of genetic conditions |
| <p>Purpose</p> | <p>The purpose of genetic testing may include:</p> <ul style="list-style-type: none"> a) Diagnosis b) predictive testing c) testing for carrier status d) screening e) prenatal diagnosis f) pharmacogenetic tests (predict response to therapy) |

9. Communicate genetic information to individuals, families and other healthcare staff

About this workforce competence

This competence is about communicating genetic information to individuals and families with or at risk of a genetic condition and communicating appropriate genetic information to other healthcare staff in the patient pathway.

There exists a variety of beliefs and understanding around genetic concepts. Some languages may not have specific words for genetic terms. It is important that your communication skills take account of background, language and level of understanding.

This is a competence which may be generally applicable to healthcare staff in a wide variety of roles.

Performance criteria

You need to:

- 1) ensure sufficient time is available for the consultation
- 2) identify the specific needs of the individual including preferred language, method of communication and any translation services needed
- 3) ensure relevant **resources** are available if required
- 4) assess the individual's current level of understanding of the genetic condition and their expectations regarding the implications for themselves and the family
- 5) communicate **information** about a **genetic** condition in an understandable non-directive manner, being aware of the impact genetic information may have on an individual / family
- 6) appreciate the importance of sensitivity in tailoring genetic information and services to the individual's culture, knowledge and language levels
- 7) ensure any genetic information you give to the individual is within the limits of your role, responsibility, knowledge and experience
- 8) encourage the individual to ask questions throughout the consultation
- 9) provide sources of information and support to individuals and others following the identification of genetic conditions
- 10) discuss any ethical, legal and social implications of a genetic diagnosis
- 11) respect the confidentiality of individuals and their families
- 12) communicate appropriate genetic information to other healthcare staff in the patient pathway as required

Knowledge and understanding

You need to apply:

Genetics

- K1. a working knowledge of genetic conditions, symptoms and clinical signs and modes of inheritance
- K2. a working knowledge of the psychological and social implications of genetic information for individuals and families
- K3. a working knowledge of specialist genetics services
- K4. a working knowledge of where to obtain information and support for individuals affected by, or at risk of, a genetic condition
- K5. a working knowledge of cultural, ethical and legal implications of genetic information

Communication Skills

- K6. a working knowledge of how to assess an individual’s level of understanding, prior knowledge and misconceptions
- K7. a critical understanding of how to present information in ways appropriate for different individuals
- K8. an in-depth understanding of effective communicative skills and strategies consistent with levels of understanding, background, culture and preferred ways of communicating, including working with interpreters
- K9. an in-depth understanding of how to discuss sensitive issues with individuals
- K10.a working knowledge of how to access support services, for example interpreters, before consultation
- K11.an in-depth understanding that genetic information impacts not only on the individual but also on their immediate and extended family
- K12.an in-depth understanding that genetic consultations should be non-directive in supporting the individual to make informed choices
- K13.a working knowledge of how to ask questions, listen carefully and summarise back

Organisational

- K14.a working knowledge of consent and confidentiality guidelines

Links

This competence links with the following dimensions and levels within the NHS Knowledge and Skills Framework Working (October 2004).

Dimension: HWB 2 Assessment and care planning to meet health and wellbeing needs

Level: 4

Dimension: Core 1 Communication

Level: 4

Searchable Keywords

Communication, genetics, information, Downs syndrome, cystic fibrosis, sickle cell

Origin

This workforce competence was developed by Skills for Health October with the NHS National Genetics Education and Development Centre October 2006.

Scope

This section provides guidance on possible areas to be covered in this workforce competence.

| | |
|----------------------------|--|
| Genetic Information | <p>Involving, resulting from, or relating to genetic material (genes and/or chromosomes)and may include:</p> <ul style="list-style-type: none"> a) causes of genetic conditions b) modes of inheritance c) implications for other family members d) future reproductive implications and options e) genetic testing |
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| Resources | May include: <ul style="list-style-type: none">a) communication aidsb) individual supportc) test resultsd) translator/interpreter |
|------------------|--|