

# Fit for Practice in the Genetics/Genomics Era: a revised competence based framework with Learning Outcomes and Practice Indicators

A guide for nurse education and training

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## Acknowledgements

The project team would like to thank all those who participated in the review and development of the learning outcomes and practice indicators.

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## The new genetics/genomics education framework for nurses

In April 2010 we published a revised set of eight competency statements setting out the knowledge, skills and attitudes in genetics/genomics required by all nurses in the UK at the point of registration. It was developed through consensus and builds upon the original framework first set out in 2003 (Kirk et al.<sup>1</sup>). This updated version (see page 3) is to ensure that the patient and their family/carers remain at the centre of the care journey both now and in the future.

### Why the review?

Nurse education and training must reflect the changing face of healthcare. Recognising the pace of genetics/genomics research, the original team in 2003 recommended that a review of the framework take place within 5-10 years. In the intervening period, our knowledge and understanding of genetics and genomics has grown significantly and its translation into patient benefit continues. The Nursing and Midwifery Council has also reviewed its pre-registration education standards, published in 2010 and as such, it was felt timely to undertake this review of the genetic competences. As a result, explicit guidance in relation to genetics/genomics will be available to:

- educators as they incorporate the new NMC standards into curricula from 2010
- mentors as they develop the clinical competence of students whilst on placement
- nurses and managers as they integrate genetics/genomics into the care provided.

A separate review is being undertaken for the midwifery profession.

### The approach

The project team convened a national meeting in February 2010 involving nurses in practice and management, educators, policy makers and patient representatives. Attendees reviewed patient/carer stories illustrating a range of life-stages and practice areas. Five key themes (see Fig. 1 Key themes) were used to prompt discussion and participants considered two questions:

1. *What are the patient/client needs? (including family members and carers)*  
**and**
2. *What does the nurse need to know, think and do in order to meet those needs?*

Resulting statements were mapped to the original framework to identify gaps and areas requiring updating. Changes were made to the original competences to reflect the discussion that took place on the day and this new framework was endorsed by the meeting participants.

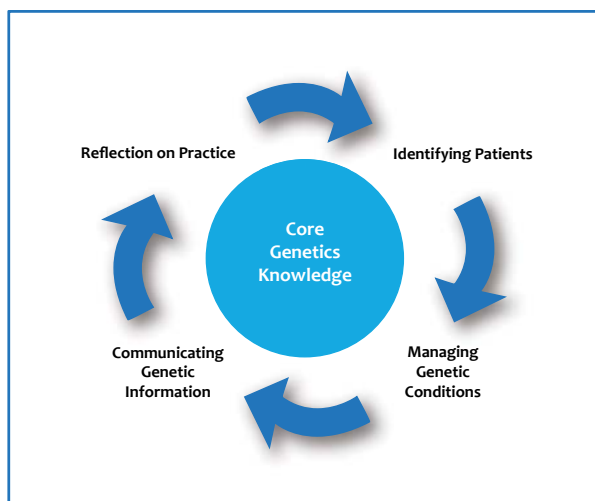


Fig.1 Key themes

<sup>1</sup> Kirk M, McDonald K, Anstey S, Longley M, (2003) Fit for Practice in the Genetics Era. A competence based education framework for nurses, midwives and health visitors. Pontypridd ISBN: 1-84054-104-0



## Outcomes of the review

A new competence (Statement 8) has been added that highlights the importance of ongoing nursing care to address the needs of both the individual and their family/carer that may change over time. Revisions were made to all of the original statements. In particular, Statement 1 now reflects the need to include family history information as part of a comprehensive nursing assessment and Statement 6 emphasises the responsibility of nurses to keep up to date in their own area of practice. The review panel were clear that many of the verbs used within the original statements should be changed to ones that were much ‘purposeful’ and which describe both the knowledge and actions that they expect from nurses today.

## Developing the learning outcomes and practice indicators

A second meeting was held with a smaller number of experienced nurse educators (see page 12), half of whom had been involved in the initial review meeting and competence statement development. Working with the new statements, the group has developed learning outcomes and practice indicators for each of the eight competences, providing a comprehensive framework for education and training. Using the approach taken by one of the review team previously, the accompanying learning outcomes and practice indicators have been written in a format that will allow integration into degree level nurse training programmes (see pages 5-11). Outcomes are linked to Levels 4, 5 & 6 of the QAA Framework and correspond to years 1, 2 and 3 respectively of a pre-registration undergraduate nurse training programme. Outcomes in subsequent years build on those set out in the previous year and the indicators for practice sit alongside the learning outcomes allowing a means of measuring and confirming that competence has been attained.

## Relationship to the NMC pre-registration nursing requirements

In its new standards for pre-registration nursing education, the NMC requires that “All nurses must carry out comprehensive, systematic nursing assessments that take account of relevant ... genetic and environmental factors, in partnership with service users and others through interaction, observation and measurement” (see page 18). This requirement is reflected in Statement 1 with the remaining competency statements essentially reflecting the context within which such an assessment should be carried out and acted upon in planning and implementing the care pathway for which genetic/genomic healthcare needs have been identified and are being addressed.

## Next steps

Nursing curricula are already under pressure to incorporate other content and feedback to the team indicates that guidance on where and how to incorporate genetics/genomics within teaching would be welcome. Recognising these issues, the team along with the educators involved in writing the outcomes and indicators have identified topic areas traditionally present in curricula where genetics/genomics can be taught. This guidance along with signposting to quality resources that support the teaching of these competences will be available in a separate document and via the NHS National Genetics Education and Development Centre website

[www.geneticseducation.nhs.uk](http://www.geneticseducation.nhs.uk)

<sup>2</sup> Skirton H, Gresty K, Green G, Evenden A, (2005) A proposed set of learning outcomes for genetic competency in nursing and midwifery. Educationon-line <http://www.leeds.ac.uk/educol/documents/150944.htm> (accessed August 2010).

<sup>3</sup> The Quality Assurance Agency (QAA) Framework for Higher Education in England and Wales and Northern Ireland <http://www.gaa.ac.uk/academicinfrastructure/fhcg> (accessed August 2010).

<sup>4</sup> Nursing and Midwifery Council (2010) Standards for pre-registration nursing education. NMC, London.



## Nursing competences in genetics/genomics: revised framework 2010

### **1. Identify clients who might benefit from genetic services and/or information through a comprehensive nursing assessment:**

- that recognises the importance of family history in assessing predisposition to disease, and
- recognises the key indicators of a potential genetic condition,
- taking appropriate action to seek assistance from and refer to genetics specialists and peer support resources,
- based on an understanding of the patient pathways that incorporate genetics services and information.

### **2. Demonstrate the importance of sensitivity in tailoring genetic/genomic information and services to clients' culture, knowledge, language ability and developmental stage**

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

### **3. Advocate for the rights of all clients to informed decision making and voluntary action**

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

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

### **5. Apply knowledge and understanding of the utility and limitations of genetic/genomic testing and information to underpin care and support for individuals and families prior to, during and following decision-making, that incorporates:**

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

### **6. Examine one's own competency of practice on a regular basis in order to:**

- recognise areas where professional development related to genetics/genomics would be beneficial,
- maintain awareness of clinical developments in genetics/genomics that are likely to be of most relevance to the client group, and
- based on an understanding of the boundaries of one's professional role in the referral, provision or follow-up to genetics services.

### **7. Obtain and communicate credible, current information about genetics/genomics, for self, clients and colleagues**

- using information technologies and other information sources effectively to do so, and
- applying critical appraisal skills to assess the quality of information accessed.

### **8. Provide ongoing nursing care and support to patients, carers and families with genomic healthcare needs**

- being responsive to changing needs through the life-stages,
- demonstrating awareness about how an inherited condition, and its implications for family members, might impact on family dynamics,
- working in partnership with family members and other agencies in the management of conditions,
- recognising the expertise of patients and carers with enduring genomic healthcare needs that develops over time and with experience.

## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

<b>Competence 1</b>			
<b>Identify clients who might benefit from genetic services and/or information through a comprehensive nursing assessment:</b>			
<ul style="list-style-type: none"> <li>• that recognises the importance of family history in assessing predisposition to disease, and</li> <li>• recognises the key indicators of a potential genetic condition,</li> <li>• taking appropriate action to seek assistance from and refer to genetics specialists and peer support resources,</li> <li>• based on an understanding of the patient pathways that incorporate genetics services and information.</li> </ul>			
<b>Level 4 Learning Outcomes (Year 1)</b>	<b>Level 5 Learning Outcomes (Year 2)</b>	<b>Level 6 Learning Outcomes (Year 3)</b>	<b>Practice Indicators</b>
<p>1.1.1 Outline the relevance of a multi-generational family history in relation to assessing genetic health risk.</p> <p>1.1.3 Describe basic patterns of biological inheritance and their variations in families and populations.</p> <p>1.1.4 List resources available for clients and professionals seeking genetic information.</p> <p>1.1.5 Identify the different types of services and other agencies which can support individuals and families with or at risk of a genetic condition.</p>	<p>1.2.1 Acquire and record accurate information for the construction of a multi-generational family history to assess genetic health risk.</p> <p>1.2.2 Explore significant family history to recognise genetic risk of altered health states.</p> <p>1.2.3 Distinguish patterns of biological inheritance and their variation in families and populations.</p> <p>1.2.4 Utilise relevant genetic/genomic information resources to inform practice.</p> <p>1.2.5 Describe the roles of specialist genetic practitioners and the range of services they provide.</p>	<p>1.3.1 Construct a multi-generational family history for the process of assessing genetic health risk.</p> <p>1.3.2 Interpret significant family history to assess genetic risk of altered health states.</p> <p>1.3.3 Differentiate patterns of biological inheritance and explain how these may vary in families and populations.</p> <p>1.3.4 Use and evaluate relevant genetic/genomic information resources to inform practice.</p> <p>1.3.5 Appraise the role of specialist genetic services and other agencies in the provision of appropriate patient/client care.</p> <p>1.3.6 Describe a typical patient pathway which incorporates genetic services and information.</p>	<p>Demonstrate the ability to collect information as part of a comprehensive nursing assessment and use the information to draw a family history using standard symbols.</p> <p>Recognise and document potentially significant genetic/genomic information from a family history.</p> <p>Apply knowledge of local and regional referral pathways to explain to patients the services that are available.</p> <p>Facilitate referral to genetic services and other agencies when appropriate.</p>

## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

Competence 2			
Demonstrate the importance of sensitivity in tailoring genetic/genomic information and services to clients' culture, knowledge, language ability and developmental stage			
<ul style="list-style-type: none"> <li>recognising that ethnicity, culture, religion, ethical perspectives and developmental stage may influence the clients' ability to utilise these.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 2)	Practice Indicators
<p>2.1.1 Recognise how communication of genetic/genomic issues should take into account the client's level of understanding.</p> <p>2.1.2 Outline how a client's ethnicity, culture, religion and ethical perspectives may influence their understanding and use of genetic/genomic information and services.</p>	<p>2.2.1 Demonstrate the use of appropriate communication skills in relation to the client's level of understanding of genetic/genomic issues.</p> <p>2.2.2 Discuss the impact of ethnicity, culture, religion and ethical perspectives on a client's potential use of genetic/genomic information and services.</p>	<p>2.3.1 Effectively communicate genetic/genomic issues at a client's level of understanding.</p> <p>2.3.2 Critically evaluate the significance of ethnicity, culture, religion and ethical perspectives on a client's potential use of genetic/genomic information and services.</p>	<p>Demonstrate the ability to communicate sensitively with clients to elucidate their ethnic, cultural, religious and ethical perspectives.</p> <p>Demonstrate sensitive and effective communication of genetic/genomic issues.</p> <p>Tailor genetic/genomic information to meet individual needs taking into account the cultural, ethnic, religious and ethical perspectives as well as developmental stage, and using resources to facilitate effective communication as appropriate.</p> <p>Identify and assess an individual's understanding of genetic/genomic information.</p> <p>Describe how the impact of information is influenced by individual factors.</p>

## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

<b>Competence 3</b>			
<b>Advocate for the rights of all clients to informed decision making and voluntary action</b>			
<ul style="list-style-type: none"> <li>• based on an awareness of the potential for misuse of human genetic/genomic information, and</li> <li>• understanding the importance of delivering genetic/genomic education and counselling fairly, accurately and without coercion or personal bias,</li> <li>• recognising that personal values and beliefs of self and client may influence the care and support provided during decision-making.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
<p>3.1.1 Explain how one’s own beliefs and values can influence client care.</p> <p>3.1.2 Identify past and potential future misuse of genetic/genomic information.</p> <p>3.1.3 Recognise the rights of all individuals to informed decision making and voluntary action.</p>	<p>3.2.1 Explore how personal values and beliefs in relation to ethical, cultural, religious and ethnic issues could impact on client care.</p> <p>3.2.2 Discuss how the misuse of genetic/genomic information could potentially influence a client’s ability to make an informed decision and act voluntarily.</p> <p>3.2.3 Facilitate clients’ rights to self determination through ensuring informed decision making and voluntary action.</p> <p>3.2.4 Ensure that the particular needs of those unable to give informed consent in relation to accessing genetic/genomic information are addressed.</p>	<p>3.3.1 Critically evaluate the significance of personal values and beliefs in relation to ethical, cultural, religious and ethnic issues in the context of client care.</p> <p>3.3.2 Appraise the impact of genetic/genomic information misuse on a client’s ability to make an informed decision and take voluntary action.</p> <p>3.3.3 Uphold clients’ rights to self determination through ensuring informed decision making and voluntary action.</p> <p>3.3.4 Advocate the particular needs of those unable to give informed consent in relation to accessing genetic/genomic information.</p> <p>3.3.5 Analyse how the principle of a non-directive approach underpins the process of genetic counselling, in facilitating client autonomy and empowerment.</p>	<p>Articulate situations where people’s values and beliefs might impact on care.</p> <p>Identify situations where patients/clients may be vulnerable to coercion and involuntary action.</p> <p>Assess patient’s ability to make informed decisions and triggers best interest process.</p> <p>Where or when appropriate, act as an advocate or work with advocacy agencies.</p>



### Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

Competence 4			
Demonstrate a knowledge and understanding of the role of genetic/genomic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
<p>4.1.1 Discuss how genetic and genomic factors affect health and disease.</p> <p>4.1.2 Outline how disease expression throughout the life-cycle is affected by both genetic and genomic factors.</p>	<p>4.2.1 Explore the role of genetic and genomic factors in altered health states using examples of common inherited conditions.</p> <p>4.2.2 Explain with examples, how disease expression throughout the life-cycle may be influenced by genetic and genomic factors.</p>	<p>4.3.1 Apply knowledge of genetic and genomic factors within the human health-disease continuum, including in the context of public health.</p> <p>4.3.2 Critically analyse the impact of genotype and environment throughout the human life-cycle.</p> <p>4.3.4 Distinguish between genetic susceptibility and clinical manifestation of disease using basic concepts of risk.</p>	<p>Explain the genetic component contributing to the manifestation of disorders within their sphere of practice.</p> <p>Provide appropriate lifestyle advice based on knowledge of gene-environment interactions.</p> <p>Demonstrate ability to distinguish between individuals at high, medium and low risk of complex conditions.</p>

## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

Competence 5			
Apply knowledge and understanding of the utility and limitations of genetic/genomic testing and information to underpin care and support for individuals and families prior to, during and following decision-making, that incorporates:			
<ul style="list-style-type: none"> <li>• awareness of the ethical, legal and social issues related to testing and recording of genetic/genomic information,</li> <li>• awareness of the potential physical, psychological and social consequences of genetic/genomic information for individuals, family members and communities.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
<p>5.1.1 Explain the need for and maintain privacy and confidentiality when discussing and recording genetic/genomic information.</p> <p>5.1.2 Demonstrate awareness of the process of genetic/genomic testing and its limitations.</p> <p>5.1.3 Demonstrate awareness that individuals and families may have ongoing needs for support in relation to the genetic condition.</p>	<p>5.2.1 Demonstrate confidentiality and maintain privacy when discussing and recording genetic/genomic information.</p> <p>5.2.2 Explore potential risks, benefits and limitations of genetic/genomic testing and access to genetic/genomic information.</p> <p>5.2.3 Debate the psychological, ethical, legal and social implications of genetic/genomic information for individuals and families.</p>	<p>5.3.1 Ensure confidentiality and privacy when discussing and recording genetic/genomic information.</p> <p>5.3.2 Evaluate potential risks, benefits and limitations of genetic/genomic testing and access to genetic/genomic information.</p> <p>5.3.3 Critically appraise the psychological, ethical, legal and social implications of genetic/genomic information for individuals and families.</p> <p>5.3.4 Respond appropriately and effectively to enquires about genetic/genomic concerns recognising the limitations of one's own knowledge.</p> <p>5.3.5 Recognises individuals and families who have needs for ongoing support in relation to the genetic condition.</p>	<p>Ensure genetic/genomic information is discussed in an appropriate environment.</p> <p>Obtain consent to share information with other professionals and with other family members as appropriate.</p> <p>Demonstrate awareness of the potential psychological effects of accepting or declining genetic/genomic testing on the individual and family.</p> <p>Evaluate the appropriateness of genetic/genomic information for individuals.</p> <p>Communicate information in an appropriate and sensitive way, involving appropriate health professional(s) as necessary.</p> <p>Where appropriate, provides ongoing support to individuals and families.</p>

## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

Competence 6			
<p><b>Examine one’s own competency of practice on a regular basis in order to:</b></p> <ul style="list-style-type: none"> <li>recognise areas where professional development related to genetics/genomics would be beneficial,</li> <li>maintain awareness of clinical developments in genetics/genomics that are likely to be of most relevance to the client group, and</li> <li>based on an understanding of the boundaries of one’s professional role in the referral, provision or follow-up to genetics services.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
<p>6.1.1 Recognise the opportunities for learning related to genetics/genomics knowledge and practice.</p> <p>6.1.2 Recognise the limitations of your role in the referral, provision or follow-up to genetic services.</p>	<p>6.2.1 Utilise learning resources to improve genetic/genomic knowledge and practice.</p> <p>6.2.2 Develop a collaborative approach to patient/client care in relation to genetics, within a multidisciplinary team including other statutory and voluntary organisations.</p>	<p>6.3.1 Maintain contemporaneous knowledge of genetic/genomic developments and the implications for your practice.</p> <p>6.3.2 Promote a collaborative approach to enhance patient/client care in relation to genetics/genomics with other statutory and voluntary organisations.</p>	<p>Demonstrate ongoing professional development in genetics/genomics within portfolio.</p> <p>Demonstrate an awareness of the boundaries of self and others involved in the provision of genetic/genomic care.</p> <p>Enhance patient care through working collaboratively with other service providers.</p>



## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

Competence 7			
Obtain and communicate credible, current information about genetics/genomics, for self, clients and colleagues			
<ul style="list-style-type: none"> <li>using information technologies and other information sources effectively to do so, and</li> <li>applying critical appraisal skills to assess the quality of information accessed.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
7.1.1 Employ a range of appropriate genetic/genomic information resources to inform practice.	7.2.1 Evaluate a range of appropriate genetic/genomic information resources to inform practice.	7.3.1 Critically evaluate information and evidence from a range of reliable sources.	Demonstrate ability to select reliable and appropriate genetic/genomic information.
7.1.2 Recognise the importance of regularly updating genetics/genomics knowledge from reputable sources.	7.2.2 Evaluate and incorporate current genetic/genomic knowledge from reputable sources into practice.	7.3.2 Critically evaluate and incorporate current reputable genetic/genomic information into own practice.	Demonstrate ability to utilise reliable and appropriate genetic/genomic information.
7.1.3 Display an ability to use information technology to retrieve relevant and reliable genetic/genomic information.	7.2.3 Utilise reliable genetic/genomic evidence when communicating with patients/clients.	7.3.3 Develop effective communication strategies to inform clients and colleagues of relevant genetic/genomic information.	Demonstrate effective communication skills when discussing genetic/genomic information with clients and colleagues.



## Learning outcomes and practice indicators for each nursing competence in genetics/genomics: a framework for education and training

<b>Competence 8</b>			
<b>Provide ongoing nursing care and support to patients, carers and families with genomic healthcare needs</b>			
<ul style="list-style-type: none"> <li>• being responsive to changing needs through the life-stages,</li> <li>• demonstrating awareness about how an inherited condition, and its implications for family members, might impact on family dynamics,</li> <li>• working in partnership with family members and other agencies in the management of conditions,</li> <li>• recognising the expertise of patients and carers with enduring genomic healthcare needs that develops over time and with experience.</li> </ul>			
<b>Level 4 Learning Outcomes (Year 1)</b>	<b>Level 5 Learning Outcomes (Year 2)</b>	<b>Level 6 Learning Outcomes (Year 3)</b>	<b>Practice Indicators</b>
8.1.1 Describe the key life-stages where a genetic diagnosis or condition may have an impact.	8.2.1 Explain how a genetic condition may impact at different life-stages within a family.	8.3.1 Apply knowledge and understanding of impact of genetic conditions at different life-stages to plan care and anticipate family needs.	Demonstrate knowledge and understanding of genetics and genomics appropriate to life-stages, when carrying out a nursing assessment and care delivery.
8.1.2 Describe basic patterns of biological inheritance and their variation in families. (1.1.3)	8.2.2 Apply knowledge of inheritance patterns to identify members within a family who might have or be at risk of a genetic condition.	8.3.2 Integrate understanding of inheritance risk with knowledge of potential bio-psychosocial consequences of genetic/genomic information, to outline potential impact on family dynamics.	Incorporate knowledge of inheritance risk and impact on family dynamics to anticipate potential issues when planning care.
8.1.3 Describe the roles of key members of multi-agency teams involved in the care of people with enduring genomic healthcare needs.	8.2.3 Discuss how a multi-agency team might interact in providing ongoing care.	8.3.3 Promote effective interaction within a multidisciplinary team to coordinate care.	Recognise own role and contribute effectively within a team. Contribute to the co-ordination of an individual's care, demonstrating leadership as appropriate.
8.1.4 Recognise that an individual and/or family member may have expertise about a particular genetic condition.	8.2.4 Discuss how expertise within the family can inform ongoing care.	8.3.4 Promote a partnership approach with the individual and/or family members as appropriate to ensure optimal care.	Actively seek advice from the individual or family members to address care needs.
		8.3.5 Utilise the expertise of the individual and/or family members to gain knowledge and understanding of a particular genetic condition for self and others.	Demonstrate ability to work in partnership with families.

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## Learning Outcome and Practice Indicator Development

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