

Core Competences in Genetics for Health Professionals in Europe

03 - Suggested core competences for health professionals who are generalists or specialising in a field other than genetics

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Suggested core competences for health professionals who are generalists or specialising in a field other than genetics

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A. Core competences in genetics for generalist healthcare professionals

This group includes all healthcare professionals who work in general settings, such as general practitioners, district nurses, physicians in general medicine or surgery, nurses working in general acute settings, general midwives and dentists.

1. Medical doctor – generalist practitioner

- **Professional background**

Medically qualified doctors trained in general practice.

- **Setting for practice**

Doctors who are working within a primary care setting, as a general practitioner or within a community or hospital setting in a non-specialist role.

| Competence | Some Proposed Learning Outcomes |
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| <p>1. Identify individuals who may have or may carry a genetic condition.</p> | <p>1.1 Knows how to take and interprets a family history.</p> <p>1.2 Understands the relevant inheritance patterns and mechanisms by which genetic disease may occur.</p> <p>1.3 Uses a family history and knowledge of inheritance patterns to identify those patients in the practice population with, or at risk of, a genetic condition.</p> <p>1.4 Demonstrates awareness that the make up of the local population may affect the prevalence of genetic conditions and attitudes towards genetic disease.</p> <p>1.5 Demonstrates an understanding of heterogeneity in genetic diseases and the principles of assessing genetic risk.</p> <p>1.6 Demonstrates awareness that reassurance is the appropriate action for patients who have been assessed as being at population risk.</p> <p>1.7 Advises patients about relevant screening programs as appropriate.</p> |

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| <p>2. Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.</p> | <p>2.1 Demonstrates awareness that genetic information may have ethical, legal and social implications.</p> <p>2.2 Demonstrates awareness that genetic information impacts not only on the patient but also on their immediate and extended family.</p> <p>2.3 Uses appropriate communication skills and demonstrates awareness of the need for confidentiality and a non-directive approach.</p> <p>2.4 Considers the patient's cultural and religious background and beliefs concerning inheritance when providing care for people with, or at risk of, genetic conditions.</p> |
| <p>3. Manage patients with genetic conditions, using accepted guidelines.</p> | <p>3.1 Demonstrates an awareness of the different uses of genetic tests (diagnostic, predictive, carrier testing) and their limitations.</p> <p>3.2 Demonstrates an awareness of the need to ensure that systems are in place to follow-up patients who have, or are at risk of, a genetic condition and have chosen to undergo regular surveillance.</p> <p>3.3 Demonstrates an awareness that preventative measures exist for some genetic conditions and advises patients of these.</p> <p>3.4 Describes the reproductive options available to those with a known genetic condition, (including: having no children; adoption; gamete donation; pre-natal diagnosis).</p> <p>3.5 Demonstrates an awareness of antenatal and other screening programmes for genetic conditions and know where to obtain information on these programmes for themselves and for patients.</p> <p>3.6 Understands and uses the national guidelines that influence healthcare provision for those with genetic conditions.</p> |
| <p>4. Obtain specialist help and advice on inherited conditions.</p> | <p>4.1 Understands the limits of his or her own genetics expertise and know when and where to seek advice.</p> <p>4.2 Understands the organisation of genetics services in his or her region or country.</p> <p>4.3 Makes appropriate referrals to genetics services.</p> |

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| 5. Co-ordinate care with other primary care professionals, geneticists and other appropriate specialists. | 5.1 Demonstrates awareness that, because genetic conditions are often multi-system disorders, comprehensive patient management is likely to involve liaison with other healthcare professionals. |
| 6. Offer appropriate psychological and social support to patients and families affected by a genetic condition. | <p>6.1 Demonstrates an awareness of the emotional impact of a genetic diagnosis on a patient and their family.</p> <p>6.2 Discusses with the patient the range of support services available, both professional and lay.</p> <p>6.3 Demonstrates an awareness of the importance of the social and psychological impact of a genetic condition on the patient and their family, dependants and employer.</p> |

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2. Nurse/midwife/allied health professional

- **Professional background**

Nurses and allied health professionals.

- **Setting for practice**

Practitioners who are working in a general setting, e.g. primary care, acute medical or surgical ward or in the community.

| Competence | Some proposed learning outcomes |
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| 1. Identify individuals who might benefit from genetic information and services. | 1.1 Explores significant family history to assess potential genetic risk of altered health states. 1.2 Obtains relevant genetic information resources necessary for practice. 1.3 Understands and informs individuals about the role of the specialist genetics services and the referral pathway for appropriate individuals. 1.4 Understands the basic inheritance patterns and mechanisms by which genetic disease may occur. |
| 2. Tailor genetic information and services to the individual's culture, knowledge and language. | 2.1 Demonstrates the use of appropriate communication skills in relation to the individual's level of understanding of genetics issues. 2.2 Appreciates the impact of culture, ethnicity and religion on a individual's potential use of genetic information and services. |
| 3. Uphold the rights of all individuals to informed decision making and voluntary action. | 3.1 Explores how personal values and beliefs in relation to ethical, cultural, religious and ethnic issues could impact on client care. 3.2 Facilitates the individual's rights to self determination through ensuring informed decision making and voluntary action. 3.3 Ensures that the particular needs of those unable to give informed consent in relation to accessing genetic information are addressed. 3.4 Is aware of situations where autonomous choice may have an adverse impact on the health of the individual or others may be adversely affected. |

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| 4. Demonstrate knowledge of the role of genetic and other factors in health and disease. | <p>4.1 Explores the role of genetic factors in disease, including the common inherited conditions.</p> <p>4.2 Understands how disease expression throughout the lifecycle may be influenced by genetic and environmental factors.</p> <p>4.3 Appreciates how family genetic history may influence health education for both individuals and populations.</p> |
| 5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information. | <p>5.1 Demonstrates confidentiality and maintains privacy when discussing and recording genetic information.</p> <p>5.2 Has an awareness of the potential risks, benefits and limitations of genetic testing and access to genetic information.</p> <p>5.3 Has an awareness of the ethical, legal and social implications of genetic information for individuals and families.</p> <p>5.4 Responds appropriately to enquiries about genetic concerns.</p> |
| 6. Recognise the limitation of one's own genetic expertise. | <p>6.1 Explains how specialist genetic services and other agencies provide appropriate patient/client care.</p> <p>6.2 Develops a collaborative approach to patient/client care in relation to genetics, with other statutory and voluntary organisations.</p> |
| 7. Obtain and communicate credible current information about genetics for self, clients and colleagues. | <p>7.1 Incorporates current genetic knowledge from reputable sources into practice.</p> <p>7.2 Utilises reliable genetic evidence when communicating with patient/clients.</p> |

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B. Core competences for health professionals who are specialists in fields other than genetics

This group includes practitioners who specialise in one area of healthcare (other than general practice) and who require specific genetics education to enable them to provide care to the specialised group of patients. Practitioners in this group would include colorectal or breast surgeons, haematologists, fetal medicine midwives, obstetricians, sickle cell disease nurses, and specialist dentists.

1. Medical doctor

- **Professional background**

The medical specialist has undertaken additional training in a particular speciality after completing basic medical training.

- **Setting for practice**

Medical specialists generally may work in public institutions, private institutions or in private practice.

| Competence | Some Proposed Learning Outcomes |
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| 1. Identify individuals with or at risk of a genetic condition. | 1.1 Knows how to take and interpret a family history. 1.2 Is able to draw a family tree. 1.3 Uses a family history and knowledge of inheritance patterns to identify those patients in the practice population with, or at risk of, a genetic condition. 1.4 Understands the relevant inheritance patterns and mechanisms by which genetic disease may occur. 1.5 Demonstrates an understanding of heterogeneity in genetic diseases and the principles of assessing genetic risk. 1.6 Demonstrates expertise in diagnosis of genetic conditions related to own speciality. 1.7 Demonstrates awareness that patients may present with a genetic condition of which there is no family history. |

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| <p>2. Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.</p> | <p>2.1 Demonstrates awareness that genetic information may have ethical, legal and social implications.</p> <p>2.2 Demonstrates awareness that genetic information impacts not only on the patient but also on their immediate and extended family.</p> <p>2.3 Uses appropriate communication skills and demonstrates awareness of the need for confidentiality and a non-directive approach.</p> <p>2.4 Is able to explain potential options for treatment or prophylaxis of conditions within own speciality.</p> <p>2.5 Demonstrates an awareness that a patient's cultural and religious background and beliefs concerning inheritance are important to consider in providing care for people with, or at risk of, genetic conditions.</p> |
| <p>3. Be familiar with the uses and limitations of genetic testing and be able to use genetic testing appropriately</p> | <p>3.1 Knows the differences and similarities between diagnostic, predictive and carrier genetic testing.</p> <p>3.2 Understands the limitations of genetic tests, particularly in relation to his or her own speciality.</p> <p>3.3 Knows the clinical indications for ordering genetic tests</p> <p>3.4 Knows how to organise genetic testing, including how to access help via the local clinical genetics service.</p> <p>3.5 Is aware of the ethical issues involved in genetic testing, such as confidentiality, testing children, and pre-symptomatic testing.</p> <p>3.6 Is able to understand and interpret the laboratory report in the context of the care of the patient and family.</p> |
| <p>4. Manage patients with genetic conditions, using accepted guidelines.</p> | <p>4.1 Ensures that systems are in place to manage and follow-up patients and family members who have, or are at risk of, a genetic condition related to his or her speciality.</p> <p>4.2 Demonstrates an awareness of preventative measures for genetic conditions related to his or her speciality.</p> <p>4.3 Practises within the national guidelines that influence healthcare provision for those with genetic conditions related to his or her speciality.</p> |

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| 5. Obtain specialist help and advice on inherited conditions, as appropriate. | <p>5.1 Understands the limits of his or her own genetics expertise and know when and where to seek advice.</p> <p>5.2 Understands the organisation of genetics services in his or her region or country.</p> <p>5.3 Recognises the need to offer appropriate referral for comprehensive genetic counselling.</p> <p>5.4 Makes appropriate referrals to genetics services.</p> |
| 6. Co-ordinate care with primary care professionals, geneticists and other appropriate specialists. | <p>6.1 Liaises appropriately with other healthcare professionals.</p> <p>6.2 Acts as a specialist resource to other health professionals (including the genetics team) in relation to genetic conditions related to his or her specialty.</p> |
| 7. Offer appropriate psychological and social support to patients and families affected by a genetic condition. | <p>7.1 Demonstrates an awareness of the emotional impact of a genetic diagnosis on a patient and their family.</p> <p>7.2 Demonstrates awareness of the range of support services available, both professional and lay.</p> <p>7.3 Demonstrates an awareness of the importance of the social and psychological impact of a genetic condition on the patient and their family, dependants and employer.</p> <p>7.4 Makes appropriate referrals to lay and other support groups.</p> |

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2. Midwife or nurse working in a specialist field

- **Professional background**

Nurses and midwives may develop specialist expertise with one client group (e.g. children, pregnant women) or in one area of health care (e.g. cancer care, neurology). Specialist nurses and midwives generally have post – registration or post graduate education in their field of specialisation.

- **Setting for practice**

Specialist nurses and midwives practice in both acute and community health services that may be publicly or privately funded. Exceptionally, specialist nurses or midwives may be self-employed.

| Competence | Some proposed learning outcomes |
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| 1. Identify individuals who might benefit from genetic information and services. | 1.1 Explores significant family history to assess potential risk of genetic conditions, especially in relation to own area of specialisation. 1.2 Obtains relevant genetic information resources necessary for specialist practice. 1.3 Understands and informs individuals concerning the roles of the specialist genetics services and the referral pathway for appropriate individuals. 1.4 Understands the relevant inheritance patterns and mechanisms by which genetic disease may occur. |
| 2. Tailor genetic information and services to the individual's culture, knowledge and language. | 2.1 Demonstrates the use of appropriate communication skills in relation to the individual's level of understanding of genetics issues. 2.2 Appreciates the impact of culture, ethnicity and religion on an individual's potential use of genetic information and services. |
| 3. Uphold the rights of all individuals to informed decision making and voluntary action. | 3.1 Explores how personal values and beliefs in relation to ethical, cultural, religious and ethnic issues could impact on client care. 3.2 Facilitates the individual's rights to self determination through ensuring informed decision making and voluntary action, including obtaining informed consent for testing. 3.3 Ensures that the particular needs of those unable to give informed consent (for example children) in relation to accessing genetic information are addressed. 3.4 Be aware of situations where autonomous choice may have an adverse impact on the health of the individual or others may be adversely affected. |

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| 4. Demonstrate knowledge of the role of genetic and other factors in health and disease. | <p>4.1. Explores the role of genetic factors in health and disease, especially in relation to own area of specialisation.</p> <p>4.2 Educates other health professionals in relation to genetics and his or her own speciality.</p> <p>4.3 Acts as a specialist resource to other health professionals (including the genetics team) in relation to genetic conditions related to his or her speciality.</p> <p>4.4 Demonstrates an awareness of preventative measures for genetic conditions related to his or her speciality.</p> |
| 5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information. | <p>5.1 Demonstrates confidentiality and maintain privacy when discussing and recording genetic information.</p> <p>5.2 Has an awareness of the potential risks, benefits and limitations of genetic testing and access to genetic information for the patient, the family and others.</p> <p>5.3 Responds appropriately to enquiries about genetic concerns.</p> |
| 6. Recognise the limitation of one's own genetic expertise. | <p>6.1 Explores own strengths and weaknesses in genetic knowledge and practice.</p> <p>6.2 Works collaboratively with other statutory and voluntary organisations.</p> |
| 7. Obtain and communicate credible current information about genetics for self, clients and colleagues. | <p>7.1 Employs a range of appropriate genetic information resources to inform practice.</p> <p>7.2 Incorporates current genetic knowledge from reputable sources into practice.</p> <p>7.3 Utilises reliable genetic evidence when communicating with patient/clients.</p> <p>7.4 Engages in continuing professional education.</p> |

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3. Specialist Dentist

- **Professional background**

The dental specialist has undertaken additional training in a particular speciality after completing basic dental training (paediatric dentist, special needs dentist, periodontologists, orthodontists). As dentists are not trained as medical practitioners, specialist dentists are included here in a specific section.

- **Setting for practice**

Dental specialists generally may work in public institutions, private institutions or in private practice.

| Competence | Some Proposed Learning Outcomes |
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| 1. Identify patients with a genetic condition. | 1.1 Takes and interprets a family, medical and dental history. 1.2 Uses a family history and knowledge of inheritance patterns to identify those patients in the practice population with, or at risk of, a genetic condition. 1.3 Demonstrates awareness that the make up of the local population may affect the prevalence of genetic conditions and attitudes towards genetic disease. 1.4 Demonstrates an understanding of heterogeneity in genetic diseases and the principles of assessing genetic risk. 1.5 Recognises dental/orofacial anomalies and their genetic basis. 1.6 Recognises that the dental problem may be part of or a trigger sign for a general genetic disease. |
| 2. Communicate | 2.1 Demonstrates awareness that genetic information may |

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| <p>information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.</p> | <p>have ethical, legal and social implications.</p> <p>2.2 Demonstrates awareness that genetic information impacts not only on the patient but also on their immediate and extended family.</p> <p>2.3 Uses appropriate communication skills and demonstrates awareness of the need for confidentiality and a non-directive approach.</p> <p>2.4 Explains potential options for treatment or prophylaxis of conditions within own speciality.</p> <p>2.5 Demonstrates an awareness that a patient's cultural and religious background and beliefs concerning inheritance are important to consider in providing care for people with, or at risk of, genetic conditions.</p> <p>2.6 Demonstrates an awareness of the importance of the social and psychological impact of a genetic condition on the patient and their family, dependants and employer.</p> |
| <p>3. Manage patients with genetic conditions, using accepted guidelines.</p> | <p>3.1 Appropriately uses a range of genetic tests in collaboration with the geneticist.</p> <p>3.2 Understand the limitations of genetic tests, particularly in relation to his or her own speciality.</p> <p>3.3 Ensures that systems are in place to follow-up patients who have, or are at risk of, a genetic condition related to his or her area of specialisation.</p> <p>3.4 Make the appropriate diagnosis through differential diagnosis.</p> <p>3.5 Explains the dental/orofacial component of the disease to the patient as well as treatment options.</p> <p>3.6 Practises within the national guidelines that influence healthcare provision for those with genetic conditions related to his or her specialty.</p> |
| <p>4. Obtain</p> | <p>4.1 Understands the organisation of genetics services and</p> |

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| specialist help and advice on inherited conditions, as appropriate. | reference centres in his or her region or country. 4.2 Makes appropriate referrals to genetics services and reference centres. |
| 5. Co-ordinate care with primary care professionals, geneticists and other appropriate specialists. | 5.1 Liaises appropriately with other healthcare professionals. 5.2 Acts as a specialist resource to other health professionals (including the genetics team) in relation to genetic conditions related to his or her specialty. |
| 6. Offer appropriate psychological and social support to patients and families affected by a genetic condition. | 6.1 Demonstrates an awareness of the emotional impact of a genetic diagnosis on a patient and their family. 6.2 Demonstrates awareness of the range of support services available, both professional and lay. |

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