

Genetics in Primary Care

One in a series of Curriculum Statements produced by
the Royal College of General Practitioners:

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Key messages

- It has been estimated that at least one in ten of the patients seen in primary care has a disorder with a genetic component.
- Genetic knowledge, skills and attitudes are important to GPs providing support and management to patients and families with, or at risk of, genetic conditions. Consideration of the family history in, for example, cancer, cardiovascular disease and diabetes, and understanding genetic aspects of antenatal and newborn screening are particularly important.
- General Practitioners have a key role in identifying patients and families who would benefit from being referred to appropriate specialist genetic services.

[INTRODUCTION]

Rationale for this curriculum statement

The Royal College of General Practitioners in a 1998 report recognised that GPs have been involved in the detection and management of genetic diseases for many years and that this role would be likely to increase with advances in genetics². A study in general practice published in 2004 indicated that a minimum of one in ten patients seen in primary care has a disorder with a genetic component³.

Identifying those whose disorders are likely to have a major genetic component may affect management decisions, not only for the patient but also for the family. For instance, single gene disorders, although individually rare, are estimated to affect up to 5% of the population, and cause considerable ill health and premature mortality⁴. Within several common diseases, including heart disease and diabetes, there are subsets of patients whose conditions are due to a mutation in just one gene. Awareness of the inherited basis of these conditions may affect management and treatment. For instance, single gene disorders such as familial hypercholesterolaemia, Marfan syndrome and inherited cardiomyopathies and arrhythmias respond to specific forms of treatment, and may cause death if not detected.

Studies indicate that around 25-35% of some common cancers, including breast, bowel and prostate cancers, have a heritable component⁵. The identification of genes predisposing to breast, ovarian and colon cancers has led to an increase in the number of people referred to cancer genetics services⁶. In 2002, around 40% of cancer genetics referrals to clinical genetics departments came direct from GPs, and GPs dealt with an average of one or two consultations relating to family cancer a month⁷.

Many features of general practice are particularly relevant to genetics. For instance, general practitioners and their teams are skilled in counselling, screening and health promotion and have a special understanding of the impacts of health and disease on patients and families. Primary care also offers the opportunity for staged counselling – the giving and reinforcing of information over a number of consultations. The RCGP argued that general practitioners should not be expected to have extensive genetics knowledge but that it was important that they be able to recognise those with genetic conditions, referring appropriately and reassuring patients with concerns about genetic disease, where guidelines suggest their family history places them at population risk only².

Highlighting the knowledge, skills and attitudes about genetics during training is therefore likely to be of value to GPs providing support and management to patients and families with, or at risk of, genetic conditions, and to prepare for future clinical advances. This includes considering the family history in, for example, cancer, cardiovascular disease and diabetes; considering genetic aspects of antenatal and newborn screening; and ethical and social implications of genetic testing. Although regional genetic services continue to work in partnership with general practice over the care of families with Mendelian and chromosomal disorders, as genetics increasingly shifts to encompass common disorders, general practitioners are likely to deal with progressively more genetic information.

UK health priorities

Several reports have identified the impact (both realised and potential) of genetics on healthcare for the UK^{2, 8-11}. In 2003, the Secretary of State, Alan Milburn, outlined in several speeches the government's policies and investment programmes to prepare the NHS. These culminated in the publication of a White Paper, *Our inheritance, our future, realising the potential of genetics in the NHS*⁴. It demonstrated that the Department of Health recognised the current and potential benefits which genetics may bring to healthcare. This was accompanied by further investment in

service provision, education and research. It outlined a number of roles for primary care in genetics, including managing patient's concerns and expectations, identifying conditions, acting as a gatekeeper to specialist care and providing and co-ordinating long term care. The White Paper recognised that GPs are uniquely placed to help patients benefit from genetics due to: their understanding of the long term, psychosocial aspects of illness; their skills in working with individuals in the context of their families over time; their ability to identify health problems and make appropriate referrals; their skills in co-ordinating the care of the affected patient; and their role in health promotion and prevention. The White Paper also recognised the need for genetics education to be better integrated into primary care training.

The principles of identification and management of genetic disorders are recognised in several National Service Frameworks. There are specific references to the role of primary care in:

Cancer¹²: the Cancer Plan recognises that primary care teams have a key role in identifying patients at highest risk of an inherited predisposition to cancer, and that they will require clear referral guidelines to help them in this role.

Coronary Heart Disease¹³ standards 3 and 4 address preventing CHD in high risk patients. A chapter on Arrhythmias and Sudden Cardiac Death¹⁴ highlights that a good awareness in primary care of inherited conditions which can lead to sudden death is important in preventing some of these deaths.

Long-Term Conditions¹⁵ recognises the importance of referral to a geneticist for conditions that are genetic in origin, such as Huntington's disease.

Diabetes¹⁶ standards 5 and 6 recognise that maturity onset diabetes of the young (MODY) and other rare genetic disorders of insulin metabolism may be diagnosed in children and young people.

Renal Services: Part 2 Chronic Kidney Disease, Acute Renal Failure and End of Life Care¹⁷ outlines the care pathway for patients with chronic kidney disease and recommends monitoring at-risk populations, including those with a family history or genetic risk of kidney disease.

Children, Young People and Maternity Services: Key Issues for Primary Care¹⁸ identifies prospective or existing parents with a family history of a genetic disorder, and those who are concerned about familial disease or disabilities, as people who need specialist pre-conception advice, information and support.

The importance of the family history is highlighted in NICE guidelines on epilepsies¹⁹, diabetes²⁰, colorectal cancer²¹ and breast cancer²².

Guidelines from both the National Institute of Health and Clinical Excellence (NICE)²² and the Scottish Intercollegiate Guidelines Network (SIGN)²³ outline areas (particularly in familial breast and ovarian cancers) where primary care practitioners should be aware of genetic issues in their practice.

[LEARNING OUTCOMES]

The following learning objectives describe the knowledge, skills and attitudes that a general practitioner requires when relating to patients and families with genetic conditions. Due to the nature of genetic conditions, this Curriculum Statement should be read in conjunction with the other RCGP Curriculum Statements in the series. The full range of generic competencies is described in the *core* RCGP Curriculum Statement 1, *Being a General Practitioner*.

Primary care management

- Be aware that a significant minority of any practice population will include patients who have a genetic condition.
- Describe how to identify patients with a genetic condition, including those who may present with a condition of which there is no family history.
- Describe how to use family history and knowledge of inheritance patterns to identify those patients in the practice population with, or at risk of, a genetic condition.
- Describe with local and national referral guidelines and guidelines for managing patients with genetic conditions.
- Describe where to obtain specialist help and advice on inherited conditions.
- Describe the organisation of genetics services.
- Describe how to make appropriate referrals to genetics services.
- Demonstrate how to co-ordinate care with other primary care professionals, geneticists and other appropriate specialists, leading to effective and appropriate care for those with, or at risk of, inherited conditions.
- Describe the support services available for those with a genetic condition (e.g. Contact a Family).

The knowledge base

Symptoms

Patients with genetic conditions may present with a wide variety of symptoms and signs, depending upon the disease they have. Symptoms and signs of some genetic conditions, particularly autosomal dominant conditions, can vary in severity and number between affected patients, even within families (e.g. variability of expression in neurofibromatosis). Anxiety about a family history of a disease, for example breast cancer, is also a common presentation.

Common and/or important conditions

Examples of common chromosome anomalies

Down Syndrome

Turner syndrome

Klinefelter syndrome

Translocations

Examples of single gene disorders

Autosomal dominant disorders

Adult polycystic kidney disease

Neurofibromatosis

Huntington disease

Hypercholesterolemia

Recessive disorders

Cystic fibrosis

Haemoglobinopathies (Sickle cell disease, Thalassaemias)

Haemochromatosis

X-linked disorders

Duchenne and Becker Muscular Dystrophies

Haemophilia A

Fragile X

Examples of multifactorial diseases

Familial forms of common diseases (e.g. breast cancer, bowel cancer)

Disorders with a genetic component (e.g. cerebrovascular disease, cardiovascular disease, Alzheimers, asthma)

Examples of familial cancers

Breast

Colon

Examples of conditions exhibiting variable inheritance patterns

Inherited forms of deafness

Muscular dystrophies

Investigations

How to draw and interpret a family tree

How to recognise basic patterns of inheritance

Treatment/management

Treatment/management options vary depending on the individual disease but include, for example, regular surveillance or family planning options.

Basic knowledge of Genetics

DNA as genetic material and how mutations and variants contribute to human disease

Patterns of inheritance: single gene, chromosomal, multifactorial

Resources

How to access genetic information, for example from regional genetics centres and on-line (OMIM, Geneclinics).

Person-centred care

- Demonstrate a patient-centred consultation model, being aware that genetic information may have ethical, legal and social implications.
- Communicate information about genetics in an understandable, comprehensible way, helping patients to make informed decisions and choices about their care.
- Describe how genetic information impacts not only on the patient but also on their immediate and extended family.

Specific problem-solving skills

- Demonstrate appropriate communication skills with particular awareness of the need:
 - for confidentiality when information received from or about one individual can be used in a predictive manner for another family member in the same practice

- to remain non-directive
- Describe how to take and interpret a family history. This involves:
 - knowledge of relevant questions,
 - knowledge of basic inheritance patterns.
- Demonstrate an awareness of the different uses of genetic tests (diagnostic, predictive, carrier testing) and their limitations.
- Demonstrate an awareness of the genetic aspects of antenatal and newborn screening programmes (e.g. Down syndrome, Sickle Cell and Thalassaemia) and know their indications, uses and limitations.
- Demonstrate an awareness of the heterogeneity in genetic diseases and understand the principles of assessing genetic risk, e.g.
 - principles of risk estimates for family members of patients with Mendelian diseases
 - principles of recurrence risks for simple chromosome anomalies, e.g. trisomies
 - ability to use on-line risk assessment tools as they become available
- Demonstrate awareness that reassurance is the appropriate action for patients at population risk.

A comprehensive approach

- Demonstrate awareness that, because genetic conditions are often multi-system disorders, comprehensive patient management is likely to involve liaison with other healthcare professionals.
- Demonstrate 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 (for example: imaging for breast cancer and adult polycystic kidney disease, endoscopy for colon cancer.)
- Demonstrate an awareness that preventative measures exist for some genetic conditions (for example lifestyle interventions; mastectomy and/or oophorectomy for BRCA1/2 mutation carriers; colectomy for APC mutation carriers; Statin use for familial hypercholesterolaemia; venesection for haemochromatosis)
- Describe the reproductive options available to those with a known genetic condition, (including: having no children; adoption; gamete donation; pre-natal diagnosis)
- Demonstrate 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.

Community orientation

- Demonstrate awareness that the make up of the local population may affect the prevalence of genetic conditions and attitudes towards genetic disease.

A holistic approach

- Demonstrate 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. An example of a belief concerning inheritance is that a particular genetic disease in a family is linked with a particular physical appearance.
- Demonstrate an awareness of the importance of the social and psychological impact of a genetic condition on the patient and their family, dependants and employer.
- Demonstrate an awareness that it is not always possible to determine the:
 - cause of a condition (e.g. learning disability) that may be genetic in origin

- the mutation responsible for a genetic condition.

Contextual aspects

- Demonstrate awareness that consultations involving the giving and discussion of genetic information may require more time.
- Describe the national guidelines that influence healthcare provision for those with genetic conditions.
- Demonstrate an awareness that a genetic diagnosis in an individual may have implications for the management of other family members who may ask for a consultation

Attitudinal aspects

- Demonstrate an awareness of their professional limits in regard to managing genetic conditions and know when and where to seek advice.
- Describe the ethical aspects of managing patients/families with genetic conditions being aware of:
 - the different views towards genetic information patients/families may have,
 - the issues involved in genetic testing, such as confidentiality, testing children, and pre-symptomatic testing.
- Demonstrate an ability to discuss genetic conditions in a non-directive, non-judgemental manner,
 - being aware that people have different attitudes and beliefs about inheritance
 - ensuring that a doctors' own beliefs do not influence the content of the consultation and the management options offered to a patient.
- Demonstrate an awareness of the emotional impact of a genetic diagnosis on a patient and their family, particularly associated with guilt about 'passing on' a condition.

Scientific aspects

- Demonstrate an awareness that genetics is a rapidly evolving area and it is therefore important to keep up-to-date with clinical advances and their implications on ethical debate and service planning

[FURTHER READING]

Examples of relevant texts and references

General texts

- Kingston HM. ABC of Clinical Genetics London: BMJ Books, 2002
- Rose P and Lucassen A Practical Genetics for Primary Care Oxford: Oxford University Press, 1999
- Turnpenny P and Ellard S. Emery's Elements of Medical Genetics London: Elsevier Churchill Livingstone, 2005

Specific texts

- Harper PS. Practical Genetic Counselling London: Arnold, 2004
- Hodgson SV and Maher ER. A practical guide to human cancer genetics Cambridge: Cambridge University Press, 1999
- Department of Health. Concordat and Moratorium on Genetics and Insurance, March 2005
- The Royal College of General Practitioners. Genetics in Primary Care: a report from the North West England Faculty Genetics Group - Occasional Paper 77 July 1998 ISBN: 0850842441

Web resources

Genetics in Practice

Family history

The Clinical Genetics Society (CGS) guidance document for pedigree drawing

<http://www.clingensoc.org/Docs/Standards/CGSPedigree.pdf>

Availability of genetic tests

UK Genetic Testing Network

<http://www.ukgtn.nhs.uk>

Accessing specialist genetics services

Directory of UK Genetics Centres

http://www.bshg.org.uk/genetic_centres/uk_genetic_centres.htm

Databases of genetic conditions

GeneTests. This National Institute of Health (NIH - USA) funded site has a GeneReviews section which gives information on specific diseases and an illustrated glossary in its Educational Resources section. GeneTests also has an international directory of genetic testing laboratories and clinics.

www.geneclinics.org/

OMIM - On-line Mendelian inheritance in man This is a catalogue of all Mendelian disorders in humans, instigated by Dr Victor McKusick, Johns Hopkins Hospital
www3.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM

Orphanet is a database of rare diseases (90% caused by genetic factors) and orphan drugs. It includes peer-reviewed information on these diseases and a directory of current services
www.orpha.net/

Genetics Education for primary care physicians

The NHS National Genetics Education and Development Centre website provides information on resources and learning support materials for healthcare professionals learning genetics, teaching genetics, developing genetics services, and applying genetics in practice.
www.geneticseducation.nhs.uk/

NeLH - Clinical Genetics The National Electronic Libraries for Health aim to provide clinicians with access to the best current know-how and knowledge to support healthcare-related decisions.
libraries.nelh.nhs.uk/genepool/

The Genetics File - a GP resource provides information for GPs on a number of topics that Australian GPs identified as most relevant to their practice, including familial cancers and conditions such as haemochromatosis and thalassaemias.
www.mcrci.edu.au/GF/pages/GeneticsFile.asp

Genetics in Primary Care (GPC) Training Program Curriculum Materials. These American modules are a series of teaching cases designed to demonstrate genetics issues and principles relevant to primary care.
http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm

Cancer Genetics

National Cancer Institute USA This website provides information for healthcare professionals on prevention, genetics and causes of a number of different types of cancers
<http://cancernet.nci.nih.gov/Templates/doc.aspx?viewid=580BE4B7-D4B8-4194-AB95-C95A258B67C1>

Screening

NeLH - Screening The National Electronic Libraries for Health aim to provide clinicians with access to the best current know-how and knowledge to support healthcare-related decisions.
<http://libraries.nelh.nhs.uk/screening/>

PEGASUS, commissioned by the NHS Sickle Cell and Thalassaemia Screening Programme, aims to facilitate training in basic genetics for health professionals involved in antenatal and newborn screening in England.
www.pegasus.nhs.uk/

UK National Screening Committee
www.nsc.nhs.uk/

Policy and Guidance Websites

Department of Health Genetics Policy

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Genetics/fs/en

National Institute for Health and Clinical Excellence (NICE) published guidelines and cancer service guidance

www.nice.org.uk/page.aspx?o=guidelines.completed

UK Human Genetics Commission

www.hgc.gov.uk/

Interesting papers

These papers provide a background to the role of genetics in primary care

- Burke W, Emery J. Genetics education for primary-care providers. *Nature Reviews in Genetics* 2002; 3: 561-6
- Donnai D, Elles R. Integrated regional genetic services: current and future provision. *BMJ* 2001; 322: 1048-1052
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- Fry A, Campbell H, Gudmundsdottir H, Rush R, Porteous M, Gorman D, Cull A. GPs' views on their role in cancer genetics services and current practice. *Family Practice* 1999; 16: 468-474
- Kumar S, Gantley M. Tensions between policy makers and general practitioners in implementing new genetics: grounded theory interview study. *BMJ* 1999; 319: 1410-1413
- Metcalfe S, Hurworth R, Newstead J, Robins R. Needs assessment study of genetics education for general practitioners in Australia. *Genetics in Medicine* 2002; 4: 71-7
- Qureshi N, Armstrong S, Modell B. GPs' opinions of their role in prenatal genetic services: a cross-sectional survey. *Family Practice* 2005 doi: 16115832
- Qureshi N, Modell B, Modell M. Timeline: Raising the profile of genetics in primary care. *Nature Reviews in Genetics* 2004; 5: 783-90
- Watson EK, Shickle D, Qureshi N, Emery J, Austoker J. The 'new genetics' and primary care: GPs' views on their role and their educational needs. *Family Practice* 1999; 16: 420-425

[PROMOTING LEARNING ABOUT GENETICS IN PRIMARY CARE]

Work-based learning – in primary care

Primary care is the ideal place for GP Registrars to learn about genetics because of the family based focus.

Learning opportunities include how to recognise conditions with a genetic component; the appropriate management of the genetic implications for the individual and the family, particularly where there are ethical, social and legal issues; referring patients appropriately to specialist services. As many common conditions seen in primary care are multifactorial, with a genetic component – including cancer, diabetes and heart disease – these can contribute to a developing awareness of how genetic components can affect disease.

The general practitioner is often the first professional consulted by patients at risk of, or worried about, an inherited predisposition to cancer. The impact in general practice of the results from antenatal or neonatal screening programmes for conditions such as cystic fibrosis, sickle cell disease and Thalassaemia may present diagnostic and genetic testing implications not only for the person tested but also for the extended family.

Work-based learning – in secondary care

Placements in a secondary care specialty will provide trainees with the opportunity to learn about the diagnosis, including molecular genetic testing where available, and management of genetic conditions seen in that specialty.

GP Registrars with a particular interest in genetics may also wish to take up the opportunity to learn from consultant geneticists and genetic counsellors working in regional specialist genetics services. This should include developing an understanding of the genetic counselling process, diagnosis and management of genetic conditions, and reproductive options including prenatal diagnosis for at-risk couples.

Non work-based learning

A number of providers run courses on different aspects of genetics in medicine, including Universities, Clinical Genetics Services, Genetics Knowledge Parks and some NHS Trusts.

The NHS National Genetics Education and Development Centre provide a searchable course database on its website. See 'Learning Genetics > Courses' at www.geneticseducation.nhs.uk. In addition, there are a small number of GPs with a special interest in genetics, providing registrars and those organising training schemes with another opportunity to promote learning about genetics in primary care.

Learning with other health care professionals

Genetic conditions frequently necessitate multidisciplinary management, involving individuals from the primary care team, the genetics team, other medical specialists, nursing professionals, allied healthcare professionals and others. Midwives, practice nurses, health visitors and other nursing and allied health professionals have an important and increasing role in providing care for those with genetic conditions. Exploration and discussion of the roles of different professional and non-professional groups are important for learning and for delivering best patient care, not only in medical management but also in ethical and social aspects of genetic disorders.

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- ¹²Department of Health The National Service Framework for Cancer London: HMSO, 2000
- ¹³Department of Health The National Service Framework for Coronary Heart Disease London: HMSO, 2000
- ¹⁴Department of Health The National Service Framework for Coronary Heart Disease Chapter 8: Arrhythmias and Sudden Cardiac Death London: HMSO, 2005
- ¹⁵Department of Health The National Service Framework for Long-Term Conditions London: HMSO, 2005
- ¹⁶Department of Health The National Service Framework for Diabetes London: HMSO, 2001
- ¹⁷Department of Health The National Service Framework for Renal Services: Part 2 Chronic Kidney Disease, Acute Renal Failure and End of Life Care London: HMSO, 2005
- ¹⁸Department of Health The National Service Framework for Children, Young People and Maternity Services: Key Issues for Primary Care London: HMSO, 2004
- ¹⁹National Institute for Clinical Excellence (NICE) the epilepsies, Clinical Guideline 20, 2004
- ²⁰National Institute for Clinical Excellence (NICE) type 1 diabetes, Clinical Guideline 15, 2004
- ²¹National Institute for Clinical Excellence (NICE) cancer services: improving outcomes in colorectal cancers, manual update, 2004
- ²²National Institute for Clinical Excellence (NICE) familial breast cancer, Clinical Guideline 14, 2004
- ²³Scottish Intercollegiate Guidelines Network (SIGN) epithelial ovarian cancer, Guideline 75, 2003