

Genetic Education for GP Registrars

Final Report

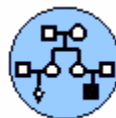
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Executive Summary

Introduction

Evidence in the published literature suggests that advances in genetics may lead to new demands on GPs. This has implications for the educational needs of GP Registrars (GPRs).

Methods

Data were collected in the West Midlands region between January and October 2003 from two main sources.

1. A postal survey of GPRs in four areas of the West Midlands Deanery (South Birmingham; North/West Birmingham; Black Country and Coventry and Warwickshire; response rate 73%, 90/123).
2. A two-round Delphi survey of genetics consultants (N=10), GP trainers (N=40) and programme directors (N=10) in the West Midlands. The overall response rates were 63% for the first round (38/60) and 67% for the second round (34/51).

Findings

Learners' Views

- Nearly half (49%) of respondents thought that genetics presents as an element of a case only rarely.
- Low levels of genetics education within GPR training were reported.
- Responses to attitude statements indicate that the majority of GPRs felt genetics was important, but felt under-prepared in this area. Many GPRs were not sure what genetics services were available in the region.
- Topics that GPRs thought were most essential were: appropriate referral; multifactorial conditions; taking and interpreting a family history; common genetic disorders; social and psychological implications for the family and patient; and how to access further information.
- Preference was expressed for face-to-face training, delivered by a geneticist and GP trainer.
- The majority of open comments stressed the importance of genetics education, but some respondents were concerned about the impact of increased genetics training on other areas of their education.

Development of Genetics Learning Topics

- The Delphi process generated a list of 37 knowledge items, 7 skills and 12 attitudes considered 'needed' or 'essential' by the majority of respondents.
- Geneticists rated some areas significantly higher than non-geneticists did, which may reflect higher expectations regarding the amount of genetics knowledge GPs require or the functions they should fulfil.
- Topics considered of highest priority were highly relevant to clinical practice. Understanding when and how to make a referral to Clinical Genetics and identifying families who would benefit from genetic referral were considered the greatest priorities.
- Open comments revealed concerns regarding the balance of genetic education with other educational needs.

Conclusions and Recommendations

1. Both trainers and trainees stressed the importance of genetics education that is highly relevant to clinical practice. Educational interventions that emphasise the clinical relevance of genetics to general practice, for example through the use of relevant scenarios and cases, is recommended.
2. GP trainers serve as important role models to their trainees. Both trainers and trainees stressed the importance of GP trainers' knowledge being up-to-date. It is recommended that ways of addressing the learning needs of trainers, for example through 'training the trainers' courses or distribution of appropriate learning materials, be explored.
3. The Delphi process developed a list of genetic knowledge, skills and attitudes relevant to general practice and identified the priority areas for genetics education. Given the existing pressures on GPRs and concerns regarding learning in other areas, it is important that genetics education focuses initially on achieving basic competency in the priority areas, listed below.

Priority areas of genetics education for GPRs

Identifying and referring patients with genetic disorders

- Understanding when and how to make a referral to Clinical Genetics
- Guidelines for referral in familial cancer
- Taking a good family history
- Recognise the basic patterns of inheritance
- Make appropriate referrals to genetics clinics

Basic knowledge of genetics

- Awareness of familial forms of common diseases

Genetic testing

- Ethical issues relating to genetic testing, particularly of children
- Ethical issues relating to presymptomatic testing for late onset disorders
- Appreciate the sensitivity of genetic information and the need for confidentiality
- Recognise that genetic information may have ethical, legal and social implications

1. Introduction

The importance of genetics education for NHS staff has been increasingly recognised in recent years. Reports by the House of Commons 'Science and Technology Committee' (1995) and the Nuffield Trust's Genetics Scenario Project (Zimmern and Cook, 2000) emphasised the importance of genetics education and training. In a keynote speech in April 2001, the former Secretary of State for Health, Mr Alan Milburn, described the vision of integrated genetics services and emphasised the challenge of equipping the NHS workforce with genetic skills.

In June 2003 the Department of Health published a White Paper, "Our Inheritance, Our Future: realising the potential of genetics in the NHS". It acknowledges the major changes in healthcare that could result from the Human Genome Project, including developments in genetic testing, pharmacogenetics, and gene therapy:

The new genetics knowledge and technology has the potential to bring enormous benefits for patients: more personalised prediction of risk, more accurate diagnosis, safer use of medicines and new treatment options (Department of Health, 2003: 22).

The White Paper recognises that a delivery strategy is necessary if the NHS is to harness these benefits and that such a strategy will include education and training for staff. Following recommendations made in the White Paper, the NHS National Genetics Education and Development Centre (NGEDC) was established in 2004 to provide a focal point for genetics education and training in the NHS. The White Paper also provided funding for the creation of 10 General Practitioner with special interest in genetics (GPwSI) posts. The purpose of these positions is to explore ways to develop the capacity and capability for providing genetic-based health care in primary care by building on routine procedures and core skills already existing in general practice. The successful GPwSI bids were announced in March 2005.

Research has identified primary care as a priority area for genetics education and recognised the need for a genetics curriculum to establish a minimum genetic competence for primary care physicians (Burton 2002; Burton 2003). It is within this context that this study has been conducted, to identify genetics learning topics for GP Registrars (GPRs). This is a collaborative project, funded by the West Midlands Deanery, between the Centre for Research in Medical and Dental Education (CRMDE) and the Centre for Education in Medical Genetics (CEMG).

This report outlines the identification of genetics learning topics for GPRs. Chapter 2 presents the methods adopted, and Chapter 3 reviews some of the key literature in this field. The findings are presented in Chapters 4 and 5, and conclusions and recommendations are presented in Chapter 6.

2. Methods

The aim of this project is the identification of genetics learning topics for GPRs. To achieve this aim data were collected in the West Midlands region between March 2003 and January 2005. Data were collected from two main sources: a questionnaire to GPRs and a Delphi survey of GP trainers, programme directors and genetics consultants. These data sources are outlined in more detail below.

2.1 Survey of GPRs

GPRs in the West Midlands were consulted regarding their experiences of genetics and genetics education, and their preferences for content and delivery of genetics training. All GPRs in four areas of the West Midlands Deanery (South Birmingham; North/West Birmingham; Black Country and Coventry and Warwickshire; N=123) were sent a postal questionnaire in June 2003, with a re-mail to non-respondents in July 2003 (Appendix 1). Ninety responses were received, a response rate of 73%.

Consultation with learners was originally planned to take place in focus group discussions. Course Organisers were contacted and asked whether focus group discussions of around 30 minutes could take place within Vocational Training Scheme (VTS) training days. However, access to training days was declined in all cases, leading to the adoption of a questionnaire as a means of consulting GPRs. The use of a questionnaire meant that group discussion of issues could not take place, but the advantages include consultation with a larger group of GPRs: 123 rather than the 40 or so who could have been involved in focus group discussions. The use of a questionnaire also meant that a less biased sample was surveyed, as focus groups would only include GPRs who attended VTS training days. The lack of access to training days contrasts with the response from a parallel study to develop genetics curricula for SpRs. In that study, all six trainers approached (three specialties across two deaneries) were willing to grant access to training days (although one group could not be consulted in this way due to the timing of the training days not fitting in with the timetable of the study).

2.2 Modified Delphi Survey

The second data source was a modified Delphi survey to GP trainers, programme directors and genetics consultants in the West Midlands (N=58). Delphi technique is one of a series of 'consensus methods', which attempt to either measure the extent

of agreement or develop consensus around a particular issue (Jones and Hunter, 1996). The original Delphi method takes place across a series of 'rounds' and continues until statistical consensus is achieved (Figure 1). The first round questionnaire is usually unstructured and allows participants relatively free scope to elaborate on the topic under investigation. Analysis of the results then provides the basis on which to construct the second and subsequent questionnaires (Powell, 2003). Advantages of this technique include its efficiency, its ability to achieve consensus in an area of uncertainty, and the way in which feedback between rounds can widen knowledge and stimulate new ideas (Powell, 2003).

Figure 1: The Delphi Method

(adapted from Jones and Hunter, 1996).

Round 1	<p>Relevant individuals are invited to provide opinions on a specific matter, based on their knowledge and experience.</p> <p>These opinions are grouped together under a limited number of heading and statements drafted for circulation to all participants on a questionnaire.</p>
Round 2	<p>Participants rank their agreement with each statement in the questionnaire.</p> <p>The rankings are summarised and included in a repeat version of the questionnaire.</p>
Round 3	<p>Participants re-rank their agreement with each statement in the questionnaire, with the opportunity to change their score in view of the group's response.</p> <p>The re-rankings are summarised and assessed for degree of consensus. If an acceptable degree of consensus is obtained the process may cease, with final results fed back to participants; if not, the third round is repeated.</p>

In this study, a modified Delphi method was adopted in which, rather than continuing to conduct rounds until statistical consensus was achieved, two rounds were conducted. This allowed for both the flexibility of an unstructured first round and the opportunity for participants to comment on and develop the results produced. A similar adapted Delphi process has previously been used to develop a family planning curriculum for general practice (Wall and Houghton, 1997).

The adapted Delphi process therefore consisted of two rounds of consultation. Firstly, participants were sent a survey (Appendix 2) which asked them to list topics or areas in clinical genetics which they thought should be included within the training for GP Registrars. Both paper-based and online versions of the survey were used to encourage a high response rate. The results from this first phase formed the basis of the second phase, where the participants were asked to comment on the list of topics that had been developed (Appendix 3).

Ten genetics consultants in the West Midlands were contacted by e-mail and invited to complete an online survey. Six responses were received, a response rate of 60%. From the 353 GP trainers in the West Midlands, a random sample of 40 was generated through a computer programme. These 40 were contacted by letter and invited to complete either a paper-based or online survey. In total, 23 responses were received, a response rate of 60% (only one GP trainer completed the form online, the rest completed the paper-based version). Finally, the ten programme directors in the West Midlands were also contacted by letter and invited to complete either a paper-based or online survey. Nine responses were received, a response rate of 90% (two programme directors responded online, the rest completed a paper-based survey). To summarise, 38 people were involved in the first round of the adapted Delphi process out of a sample of 60, an overall response rate of 63%.

Participants were given the option of not taking part in the second round of the Delphi process, and nine respondents indicated that they would not wish to be involved in the next phase (seven GP trainers; one programme director and one geneticist). Therefore, 51 people were contacted and invited to take part in the second round. Thirty-four responses were received (18 GP trainers, six programme directors, and ten geneticists), an overall response rate of 67%.

3. Literature Review

As outlined in Chapter 1, the importance of genetics education for NHS staff has been emphasised in a number of reports, most recently in the Government White Paper on genetics (Department of Health, 2003). This chapter will review some of the key literature on developments in genetics, the need for genetics education for healthcare professionals, and for general practitioners in particular.

3.1 Developments in Genetics

In April 2003, scientists from the Human Genome Project announced that they had sequenced the entire genetic code of a human being, to an accuracy of 99.999% (Radford, 2003). The Human Genome Project is a worldwide programme to document the entire DNA sequence of the human genome, and to analyse the relationship between gene activity and cell function (Gottweis, 2002). Advances in the Human Genome Project have had a tremendous impact on the fields of molecular genetics and biology and have significantly accelerated the rate of discovery of the genes and mutations responsible for a number of human diseases (Marian, 2000).

The Human Genome Project is likely to have a major impact on health and healthcare, through increased understanding of health and disease, and also the development of novel medical strategies to cure or prevent disease:

Our understanding and categorisation of disease will be enhanced. Drug therapy may become safer and more effective as treatments are tailored to take account of individual responses to drugs. Genetic tests will increasingly be used to predict the risk of disease and initiate preventive action. Drug development will become faster and more efficient (Zimmern, Emery and Richards, 2001).

Genetic testing is now available for many conditions, and includes predicting the risk of disease, identifying carriers, and establishing prenatal diagnosis and prognosis.

The potential scale of these developments has led to debate regarding who is best placed to meet the resulting service need. It is believed that clinical genetics departments, who have traditionally provided counselling in this area, will be unable to cope with the expected rise in demand given their existing workforce (Emery and Hayflick, 2001; Kumar and Gantley, 1999). All branches of medicine, but especially primary care, will be required to advise patients about genetic issues:

The likely increases in availability of DNA based tests and demand by patients for genetic information and advice mean that primary care practitioners will need to become genetically literate (Emery and Hayflick, 2001).

A report by the Royal College of General Practitioners in 1998 highlights the new demands that primary care will increasingly face as a result of genetic advances. It also notes that general practitioners are well placed to offer genetic screening and counselling, due to their existing involvement with screening programmes, their concern with the family as a unit, and their continued involvement with patients over time (RCGP, 1998).

There is tension between how policy makers and general practitioners view the role of primary care with regard to genetics. Emery and Hayflick (2001) write of a reluctance by primary care practitioners to adopt these new responsibilities. Kumar and Gantley (1999) conducted a grounded theory interview study with GPs who had attended a genetics course and found that all respondents thought that genetic advances would have little effect on their management of common diseases, one saying:

...the new genetics has little impact on my day to day clinical work (Kumar and Gantley, 1999: 1411).

However, they gave different reasons for this, some citing the 'therapeutic gap' between diagnosing genetic illness and the existence of effective screening technologies or treatment or prevention strategies as a reason for not raising the possibility of genetic risk with patients. Many GPs did not believe that genetic testing for susceptibility to common disorders was likely to become a routine part of their practice in the near future. All respondents also perceived the 'new genetics' as another in a series of changes imposed on general practice, expressing concern that increasing specialisation would threaten their traditional and core skills and marginalize the real substance of their work. One GP commented:

GPs are sick to death of being asked to do traditional secondary care as primary care. Where do we get the time to see our normal patients and do what GPs traditionally do? (Kumar and Gantley, 1999: 1412).

In a study by Watson et al (1999), GPs also raised concerns regarding the amount of work being placed in primary care. They saw their role as gatekeeper, deciding who should be referred on the basis of family history, but were less certain about their role in counselling the patient regarding genetic risk, one saying: "I'm not sure that avenue is actually in our area" (Watson et al, 1999: 422). A four year study of GPs' referrals of women with a family history of breast cancer, which included a questionnaire survey of participants, found that GPs did not see it as their role to

identify those from their lists who might be eligible for genetic counselling (Campbell et al, 2003). A systematic review of the literature conducted in 1998 concluded that GPs want to play only a limited role in providing genetics services, through gatekeeping, family history taking and supportive counselling (Emery et al, 1999). In a study by Watson et al (1999), most participants recognised genetics as an increasingly important area of clinical medicine in which primary care will have an important role to play, but these findings are based on a purposive sample which recruited participants on the basis of a known interest in genetics and the findings may not be generalisable.

Despite the debate about the future role of primary care in delivering on developments in genetics, primary care does already deliver genetic services. The NICE guidelines for antenatal care (NICE, 2003) outline the antenatal screening tests that should be offered and the importance of giving accurate information about tests and obtaining consent. 'The Pregnancy Book' (Department of Health, 2005) outlines the different roles of primary health care professionals involved in antenatal screening. The NHS Sickle Cell & Thalassaemia Screening Programme (2004) is currently rolling out antenatal screening for Sickle Cell and Thalassaemia Disorders in England. As part of this roll out, the PEGASUS network (PEGASUS, 2005) will facilitate training in basic genetics for the health professionals involved in this new programme. This is critical for the success of the programme, as an audit of existing thalassaemia screening programmes in 2000 found they were delivered inadequately and inequitably (Modell et al, 2000).

In addition to the long standing role of primary care in delivering antenatal genetic services, primary care has also begun to play a role in delivering cancer genetic services. The identification of genes predisposing to cancers such as breast/ovarian and colon cancers has led to an increase in the number of people referred to cancer genetics services (Lucasson et al, 2001). However, between 25% and 50% of people referred do not have a family history suggestive of an increased risk of cancer (Wonderling et al, 2001; Fraser et al, 2003). Service models have been developed to attempt to reduce the number of inappropriate referrals, including issuing guidelines (Eccles et al, 2000; Lucassen et al, 2001) and establishing triage systems (Elwyn et al, 2002) or community clinics (Campbell et al, 2003). In establishing these different models, very few studies have examined what GP's believe their role should be in managing patient concerns about cancer genetics. A cross-sectional questionnaire survey of GPs in SE Scotland found GPs believe their role encompasses: taking a

family history; deciding who to refer; providing emotional support; and discussing screening with patients, including teaching clinical screening skills such as breast self-examination (Fry et al, 1999). GPs did not feel that risk calculation comprised part of their role (Fry et al, 1999). This mirrors studies that have investigated the roles GPs envision for themselves in delivering the new genetics generally in primary care (Watson et al, 1999; Metcalfe et al, 2002).

Debate about the extent to which primary care should be involved in delivering genetic testing, screening, and counselling services continues. However, the Royal College of General Practitioners suggests that it is “unavoidable” that genetics will increasingly become a part of primary care:

...primary care will increasingly face new demands from patients with real or perceived genetics problems, and demands for genetic screening programmes. These new commitments will be unavoidable because of genuine clinical and preventive opportunities fuelled by the frenetic publicity to which patients are exposed (RCGP, 1998).

This raises questions about the knowledge and skills that GPs will need to have in order to meet these demands. Put simply: “If genetics is about to move into the mainstream of medical practice, are primary care physicians prepared?” (Collins and Guttmacher, 2001: 2323).

3.2 Education in Genetics

Kirklin (2003) suggested that even if modest predictions about the impact of genetic developments are correct, the implications for the educational needs for doctors are wide-ranging. The Department of Health (2003) White Paper on genetics stresses in particular the importance of genetics training for GPs, and a report by the Nuffield Trust stresses the importance of education in genetics for a wide range of NHS personnel, including those in primary care (Zimmern and Cook, 2000).

The need for education is supported by evidence that GPs currently lack the necessary skills. A systematic literature review concludes:

GPs appear to have a relatively limited knowledge of genetics (Emery et al, 1999: 443).

Primary care providers have indicated that they are uncomfortable with many genetics concepts, that they are not sufficiently trained to provide even basic counselling, and that they lack knowledge of genetics resources (Hayflick and Eiff, 2002). In a qualitative study of GPs’ views on genetics in the UK, participants readily admitted that they lacked knowledge and skills relevant to genetics, and hence lacked confidence in coping with an increased demand for advice, often from well-

informed patients (Watson et al, 1999). A similar study in Australia produced similar results, with GPs admitting that their knowledge of genetics was extremely poor, and expressing concern that patients often knew more than them about potential or actual genetic conditions (Metcalf et al, 2002). Even in those areas of genetics that GPs consider to be part of their role, such as family history taking and referral, GPs report that they lack confidence (Fry et al, 1999).

Emery and Hayflick (2001) suggest that genetics training for primary care should initially focus on the ascertainment of genetic risk, in particular taking, recording, and interpreting a family history (Figure 2). They suggest that this education should occur within both undergraduate and postgraduate training, but that these will depend first on the acquisition of genetic skills among all clinical teachers.

Figure 2: Genetic skills and knowledge required in primary care

Taking, recording, and interpreting family history

- Recognition of common patterns of inheritance
- Awareness of the importance of ethnicity in determining risk and specific cancer clusters
- Communication of risk and counselling in a non-directive manner
- Understanding of the limitations of genetic testing, including the implications of testing for insurance

(Source: Emery and Hayflick, 2001, compiled through literature review)

The Royal College of General Practitioners (1998) highlights the need for trainers, course organisers and general practice tutors to be aware of developments in genetics, to understand basic clinical skills, and to be able to help people learn and refine these skills. They suggest knowledge, skills and professional values which GPs should possess, extracts of which are shown in Figure 3.

Figure 3: Education and training in genetics

Knowledge

- Sufficient knowledge of genetic disease to understand the different inheritance patterns, laboratory tests, and unusual appearances associated with genetic disorders.
- Sufficient understanding of disease and test results to be able to put into perspective the risk of genetic illness and advise concerned patient or parents appropriately.
- Familiarity with the secondary and tertiary services available, and the existing resource limitations in such providers.

Skills

- Sufficient counselling skills to be able to place the likelihood of inherited disease into a meaningful comparison for a particular patient.
- Be able to explain the meaning of positive and negative results of diagnostic tests and use their consultation and communication skills to respond to the patient's concerns and fears.
- Be sufficiently familiar with secondary care to be able to alert patients to the tests which they are likely to encounter at the hospital.
- Be familiar with the essentials of screening, including the pros and cons, ethical implications, and possibly future developments for pregnancy, family and population screening.
- Team working skills, including the ability to negotiate and delegate, to work to others' strengths and support them through difficult situations.
- Skills in critical evaluation and the ability to minimise and manage risk.

Professional Values

- Includes issues such as the importance of informed consent before genetic testing, confidentiality of genetic information, and the GP acting as the patient's advocate as well as seeking equity in access to care and avoiding harm.
- Keeping abreast of new developments, being aware of one's own clinical limitations and knowing when to seek expert advice.

(Source: extracts selected from RCGP, 1998, compiled by a Genetics Group)

A review of education in genetics for health professionals (Burton, 2002) found that the level of educational work in genetics was low, that initiatives were piecemeal, and that very few resources had been provided to support educational initiatives. This report highlights the need for education to be based on core competencies in genetics:

An educational programme in genetics must be based firmly on an understanding of what health professionals need to know. This should encompass both expressed needs (what the professionals say they need) and what “experts” think they need (Burton, 2002: 54).

The importance of such curriculum development being driven by trainees’ needs has been recognised (Hayflick and Eiff, 2002).

In addition to the competencies identified by Emery and Hayflick (2001) and the RCGP (1998), attempts have been made to define the core competencies in genetics. In the USA the National Coalition for Health Professional Education in Genetics (NCHPEG, 2001) developed a list of core competencies through a consensus process which drew on current programmes, articles and draft educational materials submitted to and refined by a multi-disciplinary working group. These competencies represented the minimum knowledge, skills and attitudes necessary for health professionals from all disciplines. The American Society of Human Genetics (ASHG, 1995) has developed a core curriculum in genetics for medical schools, which is complemented by a further list of objectives in clinical genetics for medical schools developed by the Association of Professors of Human or Medical Genetics (Friedman et al, 1998). In the UK, a list of core medical genetics topics for undergraduate medical teaching was agreed by the Joint Committee on Medical Genetics and British Society of Human Genetics in 2003 (Haite, 2003). This was informed by a survey of 240 clinicians and other medical teachers in 1988, a ranking of the topics by medical schools in 1996, and by discussions by a multi-disciplinary group of some 30 experts including senior lecturers and professors from UK and European genetics departments (Harris et al, 1990; Burton 2002; Haite, 2003).

Within primary care, a Royal College of General Practitioners Virtual Genetics Group, set up in September 2001, agreed at its inaugural meeting that a genetics curriculum is required in order to establish a minimum genetic competence for primary care physicians (RCGP, 2001). However, no agreement has yet been reached on such a genetics curriculum in the UK. The American Academy of Family Physicians (1999) has developed a medical genetics curriculum in cooperation with the American

College of Medical Genetics, the Association of Professors of Human and Medical Genetics, the Association of Departments of Family Medicine, the Association of Family Practice Residency Doctors and the Society of Teachers of Family Medicine, although no detail is provided on the methods used to develop this curriculum.

Research conducted into current undergraduate teaching of genetics in the UK shows that aspects of genetics are present in all medical curricula but that this provision is varied and patchy (Jones et al, 2003). In a study of the genetic education needs of non-genetics specialist registrars (SpRs), the SpRs interviewed felt that their genetics training at undergraduate level had been adequate, but more training was required at the postgraduate level because that knowledge had either been forgotten or was out of date (Burke et al, 2005).

Some research has been conducted to develop new teaching materials in genetics. For example, a case-based genetics syllabus for primary care has been developed in the USA (Burke, Fryer-Edwards and Pinsky, 2001). However, there is a general lack of research into the effectiveness of these teaching materials. There is also lack of consensus regarding the best forms of delivery for genetics education. Grant (2002) highlights the complexity of learning in a profession such as medicine, where learning is integrated with practice and arises from it, warning:

The search for the one best or 'right' way of learning is a hopeless task (Grant, 2002: 159).

Other authors have also argued that a range of teaching methods can prove effective:

Medical genetics can be taught effectively by a variety of different methods and in various formats (ASHG Information Committee, 1995).

However, a study of the genetic education needs of GPs in Australia found that most GPs and GP educators preferred a case-based approach, where the content is made relevant to their day-to-day practice (Metcalf et al, 2002).

3.3 Summary

To summarise, advances in genetics may lead to new demands on GPs, who may increasingly be involved in genetic testing, screening and counselling. Research suggests that GPs currently have relatively limited knowledge of genetics and low levels of confidence in this area and a training need is therefore evident. Some work has been conducted to define the core competencies required, but there has been little development within primary care and the methods used to develop such

curricula are undisclosed. There is also a lack of consensus regarding effective forms of educational delivery.

4. Results: Learners' Views

In order to explore learners' views, GPRs were consulted regarding their experiences of genetics and genetics education and their preferences for the content and delivery of genetics training. GPRs in four areas of the West Midlands Deanery (South Birmingham; North/West Birmingham; Black Country and Coventry and Warwickshire; N=123) were sent a postal questionnaire. In total, 90 responses were received, a response rate of 73%. The breakdown of responses by area was: South Birmingham 69% (22/32); North/West Birmingham 63% (10/16); Black Country 70% (28/40); and Coventry and Warwick 83% (29/35)¹.

4.1 Personal Experiences of Genetics and Genetics Education

The GPRs were asked a series of questions about their personal experiences of genetics. First, they were asked to indicate how often in their clinical work genetics presents as an element in a case. As shown in Table 1, nearly half of the respondents (49%) stated that genetics presents as an element in a case only rarely, and only a quarter (26%) thought that it presents more than once a week. Whether this reflects the true nature of presenting cases in general practice, or whether GPRs are unaware of the genetic elements within cases, remains unknown.

Table 1: How often does genetics present as an element in a case?

	<i>Frequency</i>	<i>Percentage²</i>
At least once a day	5	6
At least once a week	18	20
At least once a month	23	26
Only rarely	44	49

GPRs were then asked, in an open question, what genetics topics they could remember being taught at undergraduate level, and 86 respondents provided answers which are summarised in Table 2 (respondents could identify more than one topic and thus percentages sum more than 100%). The most commonly identified topic which respondents could remember being taught in their undergraduate training was single gene disorders, identified by 65% of respondents. Some respondents listed particular disorders that they had learned about and in total 16 disorders were

¹ The area for one respondent could not be determined

² Valid percentages (percentage of respondents to that question) are shown. Percentages may not sum 100% due to rounding

identified, most commonly: cystic fibrosis (18 respondents); haemoglobinopathies (14); Down syndrome (11); Huntington's disease (10); and haemophilia (6). Fifty-eight per cent of respondents remembered being taught about modes of inheritance, and examples given included Mendelian, mitochondrial and chromosomal inheritance. Nearly half (45%) recalled training in chromosomal abnormalities, and 43% indicated that they had learned about 'basic molecular genetics', with responses under this latter category including DNA and chromosomes. One respondent indicated that they received no undergraduate training in genetics, and 'other' comments included, "long way back to remember".

Table 2: Genetics topics taught in undergraduate training

	<i>Frequency</i>	<i>Percentage</i>
Single gene disorders	56	65
Modes of inheritance	50	58
Chromosomal abnormalities	39	45
Basic molecular genetics	37	43
Genetics of cancer	13	15
'Genetic testing' / screening	8	9
Genetic counselling	6	7
Constructing a pedigree	5	6
Gene therapy	4	5
Risk assessment	3	3
Insurance / legal issues	2	2
None	1	1
Other	3	3

Respondents were asked to estimate the amount of time allocated to genetics in their undergraduate training. In total, 86 respondents provided answers to this question, summarised in Table 3. Six respondents indicated that there was no time allocated to genetics in their undergraduate training, and a further 12 had either 'very little' or a few hours of genetics training. Thirty-four respondents (40%) provided answers between a day and a week, and four estimated that two weeks was devoted to genetics. Twenty respondents provided 'other' answers, the majority of which were answers from which it was impossible to determine the total time, such as "one year course", or "1 hour a week". Ten respondents could not remember the time devoted to genetics in their undergraduate training, an unsurprising finding given that it may have been several years ago.

Table 3: Time allocated to genetics in undergraduate training

	<i>Frequency</i>	<i>Percentage</i>
None	6	7
Very little	2	2
1-4 hours	10	12
A day	8	9
2-3 days	8	9
A week	18	21
2 weeks	4	5
Other	20	23
Can't remember	10	12

The survey then asked, in an open question, what genetics topics had been covered in the respondent's GP Registrar training so far. Eighty-five respondents answered this question, and the responses are summarised in Table 4 (respondents could indicate more than one topic). The large majority of respondents (78%) indicated that they had covered no genetics topics during their GPR training so far. The most commonly cited areas were cancer, including family history of cancer (identified by 5 respondents), and ad hoc discussion of genetic issues (also identified by 5 respondents).

Table 4: Genetics topics taught in GPR training

	<i>Frequency</i>	<i>Percentage</i>
None	66	78
Cancer	5	6
Ad hoc discussion	5	6
Thalassaemia	2	2
Chromosomal abnormalities	1	1
Inheritance	1	1
Neurodevelopment	1	1
Multifactorial conditions	1	1
Single gene disorders	1	1
Huntingtons	1	1
Downs syndrome	1	1
Cystic fibrosis	1	1
Ethical / legal / social issues	1	1

The GPRs were asked to estimate the amount of time allocated to genetics in their GP Registrar training so far. In total, 87 respondents provided answers to this question, shown in Table 5. Notably, the large majority of respondents (85%) indicated that no time had been allocated to genetics within their postgraduate training. Eleven respondents had received either 'very little' or a few hours of training, and the most time allocated to genetics was one day.

Table 5: Time allocated to genetics in postgraduate training

	<i>Frequency</i>	<i>Percentage</i>
None	74	85
Very little	3	3
1-4 hours	8	9
A day	2	2

The survey asked GPRs what, in their undergraduate and postgraduate education, was the main way in which they have learned about genetics. As shown in Table 6, 32% had mainly learned through lectures, 27% through self-directed learning, and the largest group, 42%, had learned through a combination of methods. Of the 37 respondents who had mainly learnt through a combination of methods, 36 provided further details. The most commonly cited combination, listed by 27 respondents, was lectures and some form of self-directed learning.

Table 6: Main forms of learning

	<i>Frequency</i>	<i>Percentage</i>
Lectures	28	32
Self-directed learning	24	27
Combination of methods	37	42
Other	0	0

4.2 Suggested Curriculum

The survey presented a list of topics related to genetics (originating from the first Delphi survey to GP trainers, programme directors and genetics consultants, see Chapter 5) and asked GPRs to indicate how important they thought each topic was for their work and when they thought it should be taught. The results are presented in Tables 7 and 8 (percentages are shown in brackets).

Looking first at Table 7, appropriate referral to genetics services was rated essential by 86% of respondents, and none rated this 'not useful'. Over three quarters of respondents also rated the following topics essential: multifactorial conditions (82%); taking and interpreting a family history (79%); common genetic disorders (79%); social and psychological implications for family and patient (78%); and how to access further information (77%). Use of genetics in therapy was rated essential by only 18% of respondents, and 15% considered this 'not useful', perhaps reflecting the limited impact that gene therapy currently has on patient care.

Table 7: Perceived importance of genetics topics for GPRs' work

	<i>Not useful for my work</i>	<i>Useful but not essential</i>	<i>Essential</i>	<i>Don't know</i>
Basic science of genetics	0 (0)	25 (28)	65 (72)	0 (0)
Taking and interpreting a family history	0 (0)	18 (20)	71 (79)	1 (1)
Common genetic conditions	1 (1)	18 (20)	71 (79)	0 (0)
Non-directive genetic counselling	4 (4)	51 (57)	27 (30)	8 (9)
Screening for genetic conditions	3 (3)	27 (31)	58 (66)	0 (0)
Cancer genetics	4 (5)	34 (38)	51 (57)	0 (0)
How to access further information	0 (0)	19 (21)	69 (77)	2 (2)
Multifactorial conditions	1 (1)	15 (17)	72 (82)	0 (0)
Use of genetics in therapy	13 (15)	57 (64)	16 (18)	3 (3)
Legal Issues	1 (1)	22 (25)	66 (74)	0 (0)
Appropriate referral to genetics services	0 (0)	13 (14)	77 (86)	0 (0)
Ethical, philosophical and cultural perspectives	0 (0)	37 (41)	52 (58)	1 (1)
Social and psychological implications for patient and family	1 (1)	19 (21)	70 (78)	0 (0)

Table 8 shows that, with the exception of one topic, the majority of respondents believe that these topics are appropriate for their GPR training, either for the first time or to revise and extend undergraduate training. The exception is basic science of genetics, for which 77% indicated that this should be taught only at undergraduate level. Particularly high percentages are shown for appropriate referral to genetics services; ethical philosophical and cultural perspectives; and social and psychological implications, for which over 95% indicated that GPR training was appropriate. Split results are shown for taking and interpreting a family history and common genetic conditions, for which roughly half of respondents think they should

be taught only at undergraduate level and half that they should be taught in both undergraduate and GPR training.

Table 8: When genetics topics should be taught

	<i>Undergraduate</i>	<i>GPR training</i>	<i>Both</i>
Basic science of genetics	68 (77)	0 (0)	20 (22)
Taking and interpreting a family history	38 (44)	8 (9)	41 (47)
Common genetic conditions	41 (47)	4 (5)	43 (49)
Non-directive genetic counselling	12 (14)	54 (63)	20 (23)
Screening for genetic conditions	20 (23)	28 (32)	39 (45)
Cancer genetics	24 (27)	23 (26)	41 (47)
How to access further information	7 (8)	42 (48)	38 (44)
Multifactorial conditions	13 (15)	8 (9)	66 (76)
Use of genetics in therapy	29 (34)	19 (22)	37 (44)
Legal Issues	4 (5)	59 (67)	25 (28)
Appropriate referral to genetics services	1 (1)	71 (81)	16 (18)
Ethical, philosophical and cultural perspectives	8 (9)	28 (32)	52 (59)
Social and psychological implications for patient and family	4 (5)	32 (36)	52 (59)

Respondents were invited to indicate other genetic areas that they felt should be included in their GPR training, and 30 provided answers, summarised in Table 9. The most common response was 'none', suggesting that the list given in the questionnaire was sufficient. This is supported by the fact that, of the 14 topics listed in response to this question, 11 already appear on the list provided. The exceptions, which were listed by only one respondent in each case, were neurodegenerative disorders, mitochondrial disorders, and careers in genetics.

Table 9: Other genetic areas that should be covered in GPR training

	<i>Frequency</i>	<i>Percentage</i>
None	10	33
Information on access to services and other information	3	10
Common genetic disorders	2	7
Antenatal screening	2	7
Cancer and genetics	2	7
The law and ethics	2	7
Psychological and social aspects to patient and family	2	7
Taking a family history	1	3
Genetic counselling	1	3
Chronic disease / multifactorial genetics	1	3
Neurodegenerative disorders	1	3
Mitochondrial disorders	1	3
Careers in genetics	1	3
Gene therapy	1	3
Basic science	1	3

Five respondents provided comments on the list provided. One suggested that there is a need to know more about genetics, and another that it is an important subject which should receive dedicated training in the GPR training year. One suggested that GPRs need to be able to recognise when genetics is important, another stated that the basic science should be taught as an undergraduate. Finally, one respondent suggested that there is a lack of exposure to genetic problems in general practice so it is difficult to build up a knowledge base.

4.3 Views of genetics education

The survey presented a series of value statements about genetics, and asked the GPRs to indicate on a five point Likert scale the degree to which they agreed with each one. The results are shown in Table 10 (percentages are shown in brackets).

Table 10 shows that the vast majority of respondents (92%) believed that learning about genetics was a productive use of their time, and 90% agreed that genetics was increasingly important and should be given more time within the training. Only 10% thought they knew all they need to know about genetics for their job, and only 19% thought that their training in genetics had sufficiently prepared them for work as a GP. Finally, 50% thought that genetic testing would become a routine part of their practice, with only 35% thinking it would not become a routine part of their practice, and 15% indicated that they did not know.

Table 10: Value statements about genetics education

<i>Statement</i>	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>	<i>Don't know</i>
Learning about genetics is not a productive use of my time	0 (0)	3 (3)	67 (74)	16 (18)	4 (4)
Genetics is increasingly important and must be given more attention in my training	9 (10)	72 (80)	6 (7)	0 (0)	3 (3)
I feel I know all I need to know about genetics for my job	0 (0)	9 (10)	53 (59)	22 (24)	6 (7)
The training that I have received in genetics has been sufficient to prepare me for work as a GP	0 (0)	17 (19)	49 (54)	15 (17)	9 (10)
I don't see genetic testing becoming a routine part of my practice	1 (1)	30 (34)	36 (40)	9 (10)	13 (15)

The GPRs were also asked to select from a list to indicate how much time should be devoted to genetics within the GPR training. Table 11 shows that only one respondent thought that there should be no genetics training, with the majority of respondents (74%) indicating that there should be a day or more of training.

Table 11: Time that should be devoted to genetics in GPR training

	<i>Frequency</i>	<i>Percentage</i>
None	1	1
An hour	0	0
Half a day	22	25
A day	39	44
More than a day	26	30

4.4 Who should deliver training?

The survey ended with a series of open questions. First, GPRs were asked who they thought should deliver genetics training, and why. In total, 87 respondents provided answers, which are summarised in Table 12. The most popular option, raised by 41% of respondents, was for genetics training to be delivered by a combination of a geneticist and a GP trainer. Fourteen respondents provided reasons why this combination would be best, and all noted that the different trainers could offer different and useful perspectives. For example, it was suggested that the geneticist

would know more about the science, rare conditions, future developments in screening, appropriate referral, and would generally have more in-depth, up-to-date knowledge. In contrast, the GP trainer could discuss the practical application of genetics within the general practice setting, thereby making the training more relevant to primary care.

Table 12: Who should deliver genetics training?

	<i>Frequency</i>	<i>Percentage</i>
Geneticist and GP trainer	36	41
Geneticist	29	33
Geneticist or GP with special interest	11	13
GP trainer	8	9
Other	3	3

Twenty-nine respondents (33%) thought that a geneticist should deliver genetics training, and 11 provided reasons why. The most commonly cited reason, raised by six respondents, was that GP trainers do not know enough to deliver training in this area. Comments included: “I’m not convinced that other doctors have the skills and knowledge to deliver such training”; “not all GP trainers have the knowledge base”; and “GP trainers don’t know enough”. The other responses stressed the positive qualities of geneticists: that they are up-to-date specialists who are able to provide advice on appropriate referral and common conditions.

The concerns raised about GP trainers are reflected in the fact that only eight respondents (9%) thought that a GP trainer was the best person to deliver genetics training. Of these, five gave written reasons for their choice, and four suggested that training by a GP trainer would be more relevant and focused on genetic problems within primary care. One wrote:

A clinical geneticist may dwell too long on abstraction/theory, but a GP trainer is more likely to be pragmatic (GPR).

The other respondent stated that it is the role of the GP trainer to provide training to the GPR.

Eleven respondents suggested that genetics training should be delivered either by a geneticist with a special interest in primary care or a GP with a special interest in genetics, and four provided written reasons. One suggested that either specialist with a special interest would provide training that was more relevant for day-to-day work. Another suggested that a geneticist with a special interest in primary care

would have their “feet on ground and head out of clouds”. Two suggested that a GP with special interest (GPSI) in genetics would be preferable, one writing that the training would be more practical and relevant, the other suggesting that a GPSI would be:

Able to bring the required solutions for the problems of the diseases and understanding GPs attitudes and problems in looking after these at primary level” (GPR).

4.5 What format should training take?

The GPRs were asked in an open question (with suggestions) what format they thought training should take, and why. In total 89 respondents provided answers, summarised in Table 13.

Table 13: What format should training take?

	<i>Frequency</i>	<i>Percentage</i>
Face to face	40	45
Face to face and reference materials	16	18
Face to face and electronic	11	12
Face to face, electronic, and reference materials	8	9
Multiple methods	6	7
Interactive learning (face to face or electronic)	3	3
Electronic	2	2
Reference materials	2	2
Format doesn't matter	1	1

The most popular format of training is face to face, preferred by 45% of respondents. Eleven of these respondents provided reasons for their choice, five writing that it is easier to ask questions, five that it is easier to learn in this format, and three that more information is absorbed (some respondents provided multiple reasons). One respondent suggested that face to face learning should include the use of actors for genetic counselling. Sixteen respondents (18%) preferred face to face teaching combined with reference materials, one elaborating that confusing issues could be addressed during the face to face teaching, then reference materials could be easily checked later on. Another wrote:

A short time spent on face to face training would be useful to find out when and how genetics would be relevant, but there are many competing topics to cover in general practice. Access to reference materials as required would be the most useful for clinical practice (GPR).

Twelve per cent of respondents would prefer face to face teaching combined with electronic learning, and 9% wanted a combination of face to face teaching, reference materials and electronic learning. Electronic learning alone, or reference materials alone were less popular formats, each preferred by only 2% of respondents. Seven

per cent preferred multiple methods of teaching, but did not state which formats this should include. Reasons given for preferring multiple methods were to “maintain attention”, to “learn better”, and “to aid learning of different aspects of educational needs”. Finally, three respondents would prefer learning to be interactive, whether it be face to face or electronic, and one respondent thought that the format does not matter.

4.6 Learning with other professional groups

The survey asked whether there were any other professional groups with whom it would be productive to learn about genetics, and 56 people responded to this question. The results are summarised in Table 14 (some respondents listed more than one group). Seven respondents (13%) indicated that there were no other professional groups with whom it would be productive to learn about genetics, one writing: “Information about genetics should be tailored to our needs as GPs”. A quarter of respondents (25%) thought that learning with geneticists or genetics counsellors would be appropriate, and 13% thought it would be appropriate to learn with nurses. Five respondents wrote patient self-help groups or societies for particular genetics conditions, although it is unclear whether they expected to learn with these groups or from them. A number of other professional groups are listed by small numbers of respondents.

Table 14: Learning with other professional groups

	<i>Frequency</i>	<i>Percentage</i>
Geneticists / genetics counsellors	14	25
Nurses (practice nurse, nurse practitioners)	7	13
Patient self-help groups / societies	5	9
Paediatricians	4	7
Obstetricians / gynaecologists	3	5
Primary Care Team	2	4
Midwives	1	2
Oncologists	1	2
Physiotherapists	1	2
All physicians	1	2
Undergraduate BSc genetics students	1	2
Other	4	7
No other professional groups	7	13
Don't know	8	14

4.7 Services in the region

Respondents were asked to indicate in an open question what services they were aware of in the health region to give advice on genetic cases, and 76 people

provided answers to this question, summarised in Table 15 (some indicated more than one service and there is overlap between the categories identified).

Table 15: Genetics services identified as available in the West Midlands

	<i>Frequency</i>	<i>Percentage</i>
Genetics service at Birmingham Women's Hospital	8	11
Referral to secondary care	6	8
Genetics service at Queen Elizabeth Hospital	5	7
Genetics service at Birmingham Children's Hospital	4	5
Genetics counsellors	4	5
Area geneticist	4	5
Internet sites	4	5
Specialist family history clinics	3	4
Geneticist in Birmingham	3	4
Genetics clinic in Birmingham	3	4
Haemoglobinopathy group	1	1
Breast cancer clinics	1	1
Various societies	1	1
West Midlands Deanery	1	1
The Handbook	1	1
None	22	29
Not sure	9	12
Would find out if needed	6	8

Of the 76 respondents, 22 (29%) indicated that they knew of no services in the region, and a further 9 (12%) were not sure what services were available. Six respondents wrote that they would find out what services were available if they needed to know for a particular patient. The most commonly identified service was the genetics service at Birmingham Women's Hospital, although services at the Queen Elizabeth Hospital and Birmingham Children's Hospital were also listed, and referral to secondary care was considered a source of advice. A number of the suggestions were vague, such as "geneticist in Birmingham", or "various societies".

4.8 Final comments

Thirty-three respondents provided final comments. Of these, 15 (45%) stated that they needed to know more about genetics, and some of those comments are listed below:

Generally have very poor knowledge base of available resources and appropriateness of referrals.

Better education is vital before patients teach/correct us.

I feel it would be very beneficial to know more about the work of the genetics service so I can guide patients when they enquire about referral.

Twelve respondents emphasised the importance of training in genetics, with comments such as:

It will become increasingly important, especially in view of the Government announcement this week.

It is very important to know about genetics as it is the future for some parts of the preventative medicine.

In this period of time genetic knowledge is becoming very important. Particularly in Primary care, which is first service patients come with every problem.

Genetics and genetic testing is going to be a massive part of patient requests. Look at the white paper! Only 10 doctors to be trained for all of the country! I think the demand from patients will be explosive.

Five respondents stated that little attention is currently given to genetics within their training, one describing it as: “a neglected part of the curriculum”, another as: “an area which I believe was covered poorly at an undergraduate level and hasn’t been addressed at all at postgraduate level. Three respondents noted that trainers know little about genetics, one recounting a patient request for a paternity test which was particularly difficult because neither the trainer nor the other partners know about the legal or ethical issues or the practical process involved. The trainee concludes: “Thankfully there were instructions enclosed”. Another wrote: “My personal experience shows that the trainers know less about the genetics than the Registrars themselves”. Three respondents suggested topics for further training, one suggested that genetics would be a useful topic at the half day release course, and another suggested that an introductory session to show trainees where to go for further information would be helpful.

In contrast, five trainees suggested that there were more important topics than genetics to learn about during their GPR training, describing it as “of limited use” and “not high on my list of priorities”. Two respondents thought that genetics was the realm of specialists and therefore of limited relevance to their practice, and two expressed concern that learning about genetics would detract from learning in other areas, stating, “If we are going to learn more about this, then at the cost of what else?” and “There may be more important subjects to cover within the year”.

4.9 Summary

- Nearly half (49%) of respondents thought that genetics presents as an element of a case only rarely.
- Low levels of genetics education within GPR training were reported.
- Responses to attitude statements indicate that the majority of GPRs felt genetics was important, but felt under-prepared in this area. Many GPRs were not sure what genetics services were available in the region.
- Topics that GPRs thought were most essential were: appropriate referral; multifactorial conditions; taking and interpreting a family history; common genetic disorders; social and psychological implications for the family and patient; and how to access further information.
- Preference was expressed for face-to-face training, delivered by a geneticist and GP trainer.
- The majority of open comments stressed the importance of genetic education, but some respondents were concerned about the impact of increased genetics training on other areas of their education.

5. Results: Modified Delphi Survey

Chapter 4 indicated that GPRs feel genetics is an important topic and presented GPRs views on whether particular broad topics were essential for their work. This Chapter presents findings from a modified Delphi Survey, which was designed to identify and expand learning topics for GPRs. In the first round, a sample of GP trainers (N=40), programme directors (N=10) and genetics consultants (N=10) were asked on the form in Appendix 2 to list topics or areas in clinical genetics which they thought should be included within the training for GP Registrars (response rate 63%). In the second round, they were asked to rank the importance of the items identified (response rate 67%).

5.1 First Round Delphi

The first round of the Delphi process generated a long list of items, which were collated using NVivo software and coded into the categories knowledge, skills and attitudes. The majority of items generated (70%) were knowledge items, with skills and attitudes forming only 20% and 10% respectively. As might be expected, geneticists generated more items per respondent (9.7) than GP trainers (5.3) and programme directors (5.2).

5.2 Second Round Delphi

The list of topics generated in the first Delphi round was checked and amended by Dr Stone and Professor Farndon, who removed repetitions and grouped similar items together. The resulting list was used as the basis of the second round of the Delphi process, where participants were asked to rank the importance of the items listed (as shown in Appendix 3). Some items were broad topics whilst other were specific teaching points.

5.2.1 *Essential topics*

In the second round of the Delphi process, participants were first asked to indicate, for each item listed on the questionnaire, whether they thought it need not be included in the GPR curriculum (1), was useful for inclusion in the curriculum (2), needs to be included in the curriculum (3), or was essential for inclusion in the curriculum (4). The knowledge, skills and attitudes rated 3 (needed) or 4 (essential) by more than 50% of respondents are shown in Tables 16 to 18.

Table 16: Knowledge considered 'essential' or 'needed'

<i>Topic</i>	<i>% rating 3 or 4</i>
Organisation and role of NHS Clinical Genetics Services	
Understanding when and how to make a referral to Clinical Genetics	92
Roles of the clinical geneticist, genetics counsellors and other members of the genetics team	71
Basic knowledge of genetics	
<u>Nature of the genetic material</u>	
DNA as genetic material	56
<u>Chromosomal basis of inheritance</u>	
Types of chromosome anomalies	60
Common chromosome anomalies – Down syndrome, Turner syndrome, Klinefelter syndrome, translocations	74
How to suspect a chromosome anomaly from the clinical phenotype or pedigree	65
Principles of recurrence risks for chromosome anomalies	53
<u>Single genes and their inheritance patterns</u>	
Patterns of inheritance	67
Autosomal dominant disorders (Adult polycystic kidney disease, neurofibromatosis type 1, Huntington's disease, hypercholesterolaemia)	74
Variable expression in dominant disorders	53
Reduced penetrance in dominant disorders	51
New mutation causing a dominant or X-linked disorder	51
Recessive disorders (cystic fibrosis, haemoglobinopathies, haemochromatosis)	67
X-linked disorders (DMD, haemophilia A)	67
Principles of derivation of risk estimates for family members	53
<u>Multifactorial Inheritance</u>	
Pedigree patterns of multifactorial inheritance	51
Awareness of familial forms of common diseases (e.g. breast cancer, bowel cancer)	82
Knowledge of disorders with a genetic component (e.g. cerebrovascular disease, Alzheimers, asthma)	67
Knowledge of the role of genetics in familial cancer	
The genetic basis of susceptibility to specific cancers	73
Guidelines for referral	91
The management of low / moderate / high risk patients	74
DNA testing in clinical practice	
Uses and limitations of DNA diagnostic tests	60
Issues surrounding genetic testing	
The differences and similarities between diagnostic, predictive and carrier genetic testing	63
Ethical issues relating to genetic testing particularly of children	82
Ethical issues relating to other presymptomatic testing for late onset disorders	81
Societal and other issues	
Genetic test results and insurance	65
Ethnic and cultural factors in genetic disease	62
Clinical Service Applications	
Taking a family history	82
Analysing pedigrees to establish mode of inheritance	54
A genetic test may be a clinical examination or investigation rather than a DNA test	55
Principles of Genetic Counselling	54
Reproductive options, i.e. the fact that there is more to offer than PND	62
Principles of prenatal diagnosis	66
Screening	
The difference between 'testing' and 'screening'	78
Ethical problems involved in screening / testing	66
Screening prenatally – indications, the importance of prompt referral, types of testing	72
National screening programmes for genetic conditions e.g. cystic fibrosis, haemoglobinopathies	75

In total 37 knowledge items were rated 'needed' or 'essential' by more than 50% of respondents (Table 16). Particularly high percentages (over 80%) rated the following

topics as important: understanding when and how to make a referral to Clinical Genetics; guidelines for referral (familial cancer); awareness of familial forms of common diseases (e.g. breast cancer, bowel cancer); ethical issues relating to genetic testing particularly of children; taking a family history; and ethical issues relating to other presymptomatic testing for late onset disorders. Items are grouped under broad headings, which show that the largest groups of knowledge items relate to basic knowledge of genetics (16 items), clinical service applications (6) and screening (4). In open comments, three GP trainers wrote that many of the topics were too specialised and that a broad knowledge of the essential issues would be sufficient. One GP Trainer asked whether an update would be available for trainers and two programme directors noted that much of the genetics knowledge should have been covered in the undergraduate curriculum.

Table 17 lists the seven skills considered 'needed' or 'essential' by the majority of respondents. These items relate to identifying families with genetic disorders (5 items) and information sources (2). Particularly high percentages (88%) rated the following topics as important: recognise the basic patterns of inheritance; identify families who would benefit from referral to the genetics services; access the services of the local genetics centre; and make appropriate referrals to genetics clinics. In open comments, three respondents (2 geneticists and 1 GP trainer) noted that GPRs already received training in generic communication skills. Four respondents (2 geneticists and 2 GP trainers) stated that advanced communication skills were not universally required as GPs do not need to know how to communicate genetic information themselves.

Table 17: Skills considered 'essential' or 'needed'

<i>Topic</i>	<i>% rating 3 or 4</i>
Identifying families with genetic disorders	
How to draw and interpret a family tree	79
Recognise the basic patterns of inheritance	88
Identify families who would benefit from referral to the genetics services	88
Access the services of the local genetics centre	88
Make appropriate referrals to genetics clinics	88
Information sources	
Access sources of information other than the internet about genetic conditions	54
Access online genetic information and databases (including OMIM, Geneclinics)	61

Table 18: Attitudes considered 'essential' or 'needed'

<i>Topic</i>	<i>% rating 3 or 4</i>
Philosophy of Genetic Counselling	
Recognise that genetic counselling (including the communication of risks and discussion of options) is an information giving process	60
Recognise that genetic counselling is practised in a non directive manner	57
Recognise the need to offer referral to clinical genetic services for genetic counselling where appropriate	82
Adopt a non-judgemental approach over reproductive choice and prenatal testing	66
Appreciate that sufficient clinic time should be set aside for genetic counselling	59
Testing	
Appreciate the principles of, issues around, and differences between predictive (presymptomatic) testing and diagnostic testing	63
Recognise that genetic information may have ethical, legal and social implications (e.g. for insurance)	82
Appreciate the impact of genetic diagnosis on the extended family and the approach to at risk relatives who are not consultands	78
Appreciate the sensitivity of genetic information and the need for confidentiality	85
Understand the complexity of genetic disease and the pitfalls of determining genetic risks	68
Accept that patients may have different views towards genetic risks and genetic testing (including prenatal diagnosis) and that they also have a right not / to know	72
Appreciate the social and psychological implications of genetic information for the patient and their extended family, including employment and paternity issues	75

Twelve attitudes were rated 'needed' or 'essential' by the majority of respondents, relating to testing (7 items) and the philosophy of genetic counselling (5). Particularly high percentages (over 80%) are shown for: appreciate the sensitivity of genetic information and the need for confidentiality; and recognise that genetic information may have ethical, legal and social implications (e.g. for insurance). One GP trainer noted in an open comment that attitudes have a large influence on when and how to refer.

5.2.2 Levels of Consensus

In order to explore levels of consensus between groups, the mean and standard deviation (S.D.) of scores given by geneticists were compared with those given by non-geneticists (programme directors and GP trainers). Table 19 shows the results, collated under broad topic headings (p values were calculated using the Mann-Whitney U test. T-tests were not used because the Shapiro-Wilk test indicated that results for 7 of the 14 topic areas were not normally distributed).

The mean scores in Table 19 indicate three broad areas with low mean ratings (below 2.5) from both geneticists and non-geneticists: societal and other issues; future advances; and communication skills. Areas with high mean ratings (above 2.6) from both geneticists and non-geneticists were: organisation and role of NHS

Clinical Genetics Services; issues surrounding genetic testing; screening; identifying families with genetic disorders; philosophy of genetic counselling; and testing.

Table 19: Levels of consensus

<i>Topic Area</i>	<i>Geneticists</i>		<i>Non-geneticists</i>		<i>p</i>
	<i>Mean</i>	<i>S.D.</i>	<i>Mean</i>	<i>S.D.</i>	
Knowledge					
Organisation/role of NHS Clinical Genetics Services	3.4	0.3	3.2	0.7	0.595
Basic knowledge of genetics	2.9	0.5	2.4	0.8	0.039
Knowledge of the role of genetics in familial cancer	3.0	0.3	2.7	0.6	0.075
DNA testing in clinical practice	2.6	0.5	1.8	0.6	0.002
Issues surrounding genetic testing	3.7	0.4	2.7	0.8	0.001
Societal and other issues	2.4	0.4	2.2	0.6	0.551
Clinical Service Applications	3.3	0.4	2.6	0.9	0.012
Screening	3.1	0.4	2.7	0.8	0.194
Future advances	2.1	0.4	1.9	0.6	0.242
Skills					
Identifying families with genetic disorders	3.4	0.2	2.9	0.8	0.033
Information sources	2.8	0.9	2.6	0.9	0.477
Communication skills	2.4	0.5	2.3	1.0	0.407
Attitudes					
Philosophy of genetic counselling	3.4	0.4	2.7	0.9	0.019
Testing	3.4	0.3	2.8	0.7	0.010

In some areas there was a significant difference between the responses from geneticists and non-geneticists (in each case geneticists giving higher ratings). In two areas, DNA testing in clinical practice and issues surrounding genetic testing, differences were highly significant ($p < 0.01$). Exploration of the specific topics within those areas reveals large differences in mean ratings (over 1) for the following topics:

- scanning a gene to detect an unknown mutation: indications and practicalities;
- testing for a specific or known mutation: direct DNA diagnosis;
- uses and limitations of DNA diagnostic tests; and
- the differences and similarities between diagnostic, predictive and carrier genetic testing.

Significant differences ($p < 0.05$) are shown for the following areas: basic knowledge of genetics; clinical service applications; identifying families with genetic disorders; philosophy of genetic counselling; and testing. Within those areas, large differences in mean ratings (over 1) were shown for the following topics:

- differences between cytogenetics and molecular genetics;
- patterns of inheritance;
- pedigree patterns of multifactorial inheritance; and
- analysing pedigrees to establish mode of inheritance.

In all cases of significant difference, geneticists gave higher ratings. This suggests that geneticists may have higher expectations regarding the amount of genetics knowledge GPs require or the functions they should fulfil (such as genetic counselling).

5.2.3 Teaching Priorities

The Delphi survey also asked respondents to choose their top five priorities for the curriculum and list them in order, one being the most important. In the analysis process ratings were inverted which allowed calculation of an 'importance rating' for each topic, based on the sum of all ratings given for that topic, with a higher score indicating greater perceived importance. The results are shown in Table 20.

Topics receiving the highest priority ratings were: understanding when and how to make a referral to Clinical Genetics; identifying families who would benefit from genetic referral; taking a good family history; and awareness of familial forms of common disease. It is notable that the topics listed in Table 20 are highly relevant to clinical practice, such as identifying families for referral, knowledge of referral processes, guidelines and the services available, and having appropriate communication skills. Scientific knowledge that is prioritised focuses on basic concepts, such as patterns of inheritance or awareness of familial forms of common disease.

Table 20: Topics of highest priority

<i>Topic</i>	<i>Rating*</i>
Understanding when and how to make a referral to Clinical Genetics	54
Identify families who would benefit from genetic referral	34
Taking a good family history	30
Awareness of familial forms of common disease	29
Ethical issues of genetic testing	27
Appropriate consultation / counselling skills	23
Basic understanding of genetics and inheritance patterns	22
Make appropriate referrals to genetics clinics	18
Concepts of screening	16
Appreciate the social and psychological implications of genetic information for the patient and their extended family	15
Recognise that genetic information may have ethical, legal and social implications	13
Awareness of options for genetic testing	12
Knowledge of services available	12
Guidelines for referral (familial cancer)	12
How to draw and interpret a family tree	10
How to access genetic information	8
Organisation of genetics services	7
How to access genetic counselling services	7
Appreciate the sensitivity of genetic information and the need for confidentiality	5
Appreciate the impact of genetic diagnosis on the extended family and the approach to at risk relatives who are not consultands	4
Difference between testing and screening	3
Philosophy of genetic counselling	3
Understanding the limitations of genetic testing	3
Assessing genetic risk	2
The future	2

*The sum of inverted ratings; a high score indicates high priority

Nine respondents made open comments. One respondent noted that genetics education needs to be balanced with other curriculum needs and another wrote:

In modern training there are probably more important areas to be dealt with in depth than genetics.

Another respondent stressed the importance of focusing on areas which are needed in practice, rather than complex theoretical information. One geneticist commented that it was difficult to assess the content of training without an indication of the time that would be available to deliver it. One respondent felt that all GPs would benefit from training in some areas and another suggested that an update for trainers was needed. Two respondents criticised the length of the questionnaire, but another praised the approach taken.

5.3 Summary

- The Delphi process generated a list of 37 knowledge items, seven skills and 12 attitudes considered 'needed' or 'essential' by the majority of respondents.
- Geneticists rated some areas significantly higher than non-geneticists did, which may reflect higher expectations regarding the amount of genetics knowledge GPs require or the functions they should fulfil.
- Topics considered of highest priority were highly relevant to clinical practice. Understanding when and how to make a referral to Clinical Genetics and identifying families who would benefit from genetic referral were considered the greatest priorities.
- Open comments revealed concerns regarding the need to balance genetic education with other educational needs.

6. Conclusions and Recommendations

This report has presented findings from a project conducted between March 2003 and January 2005 to develop a genetics curriculum for GP Registrars (GPRs). The project drew on two main data sources: a survey to GPRs and a modified Delphi survey to genetics consultants, GP trainers and programme directors. This chapter considers the findings as a whole, drawing out the key issues that have emerged and making recommendations for future developments. Firstly, strengths and limitations of the project are explored.

6.1 Project strengths and limitations

This project was designed to explore many aspects of genetics education: views on current genetics teaching; perceptions of learning need; preferred styles of learning; genetics topics to be covered; and learning priorities. It has therefore provided a wide range of information from which educational interventions can be planned. The project involved a range of stakeholders: learners, trainers, programme directors and geneticists. The involvement of geneticists was vital in order to access their specialist genetics knowledge, evidenced by the fact that the geneticists produced more detailed topic lists in the first Delphi round. The involvement of GP trainers and programme directors ensured that the lists developed were relevant to general practice and also encouraged engagement and ownership by these groups to help promote genetics education in the future.

There are, however, methodological constraints to this study. Exploration of current genetics education relied on learners' recollections of undergraduate and postgraduate training. Respondents may have forgotten much of the genetics training they received at medical school and therefore under-represented the amount received. It is arguably of more interest to explore the subjects remembered rather than the subjects taught, although recall may have been greater if respondents had been prompted with a list of topics. The timing of the questionnaire may have had an effect on responses regarding levels of genetics within GP training as some trainees were only part-way through their full training period and may have received genetics education at a later date. Interviews with trainers may have provided more information regarding levels and forms of delivery of current genetics training. The modified Delphi process enabled involvement of participants from across the West

Midlands region but proved time consuming, both for the participants and in administration and analysis.

6.2 Conclusions and Recommendations

1. Review of the literature suggests that advances in genetics will lead to new demands on GPs, who will need education to cope with those changes. In this study, responses to attitude statements by GPRs indicate that they recognise the importance of genetics but feel under-prepared in this area, a result supported by the inability of 41% of respondents to identify any genetic services in the region. However, some GPRs expressed concern that increased genetic education would mean less time for training in other areas, and nearly half (49%) thought that genetics presents as an element of a case only rarely. Both trainers and trainees prioritised genetic topics that were highly relevant to clinical practice, and education that emphasises the clinical relevance of genetics to general practice may address trainees' concerns that genetics is "of limited use".

We recommend that educational interventions emphasise the clinical relevance of genetics to general practice, for example through the use of relevant scenarios and cases, and the inclusion of practical elements such as referral to local genetics services.

2. GPRs reported low levels of genetics training: 78% stated that they had covered no genetics topics during their specialty training. Open comments by three GPRs suggested that trainers know little about genetics, and two Delphi respondents indicated that an educational update for trainers was needed. GP trainers serve as important role models to their trainees and their views will influence trainees' perceptions. It is therefore that a strategy for genetics education in general practice addresses the learning needs of both trainers and GPRs.

It is recommended that ways of addressing the learning needs of trainers, for example through 'training the trainers' courses or distribution of appropriate learning materials, be explored.

3. The Delphi process developed a list of genetic knowledge, skills and attitudes relevant to general practice and identified the priority areas for genetic education (Figure 4). Geneticists rated some areas significantly higher than non-geneticists did, which may reflect higher expectations regarding the future role of GPs, for example in delivering genetic counselling. Given the existing pressures on GPRs

and concerns regarding learning in other areas, it is important that genetics education focuses initially on achieving basic competency in the priority areas.

It is recommended that educational interventions focus on priority genetics topics.

Figure 4: Priority areas of genetics education

Identifying and referring patients with genetic disorders

- Understanding when and how to make a referral to Clinical Genetics
- Guidelines for referral in familial cancer
- Taking a good family history
- Recognise the basic patterns of inheritance
- Identify families who would benefit from referral to the genetics services
- Access the services of the local genetics centre
- Make appropriate referrals to genetics clinics

Basic knowledge of genetics

- Awareness of familial forms of common diseases

Genetic testing

- Ethical issues relating to genetic testing, particularly of children
- Ethical issues relating to presymptomatic testing for late onset disorders
- Appreciate the sensitivity of genetic information and the need for confidentiality
- Recognise that genetic information may have ethical, legal and social implications

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APPENDIX 1
Questionnaire to GPRs



Genetics Education for GP Registrars

Thank you for agreeing to participate in our survey to help us develop genetics education for GP Registrars. We would appreciate your frank response and so guarantee that your responses will remain anonymous and confidential.

Your Personal Experience of Genetics Education

1. How often in your clinical work does genetics present as an element in a case?
Please tick answer closest to your experience

- At least once a day
- At least once a week
- At least once a month
- Only rarely

2. What genetics topics can you remember being taught at undergraduate level?

3. How much time in the curriculum was allocated to genetics in your undergraduate training? *Please state approximate amount, e.g. none, an hour, a day, a week*

.....

4. In your GP Registrar training so far, what genetics topics have been covered, if any?

5. In your GP Registrar training so far, how much time has been allocated to genetics training? *Please state approximate amount, e.g. none, an hour, a day, a week*

.....

6. In your undergraduate and postgraduate education, what is the main way in which you have learned about genetics?

- Lectures
- Self directed learning
- Combination of methods (please state)
- Other (please state).....

Suggested Curriculum

7. The topics listed in the central panel of the table below have been suggested as areas which a GPR should know by the end of their training.
- Please go down the left hand side of the table, and mark how important you feel each item is.
 - Then go down the right hand side and indicate whether you think this topic should be taught at undergraduate level, in GPR training, or in both undergraduate and GPR training.

a) How important is it? (please tick one response per line)				Items	b) When should it be taught? (please tick one response per line)		
Not useful for my work	Useful but not essential	Essential	Don't know		Undergraduate	GPR training	Both
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Basic science of genetics (e.g. DNA, genes, inheritance patterns)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Taking and interpreting a family history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Common genetic conditions (e.g. neurofibromatosis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Non-directive genetic counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Screening for genetic conditions (e.g. Thalassaemia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Cancer genetics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	How to access further resources and information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Multifactorial conditions (e.g. diabetes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Use of genetics in therapy (e.g. gene therapy, pharmacogenomics)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Legal issues (e.g. insurance, confidentiality)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Appropriate referral to genetics services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ethical, philosophical and cultural perspectives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Social and psychological implications for patient and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Are there any other genetic areas that you feel should be included in your GPR training, or any comments on the above list?

Your opinion about genetics education

9. For each statement below please tick the box that best corresponds with your views

Statement	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
Learning about genetics is not a productive use of my time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetics is increasingly important and must be given more attention in my training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel I know all I need to know about genetics for my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The training that I have received in genetics has been sufficient to prepare me for work as a GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't see genetic testing becoming a routine part of my practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. How much time do you think should be devoted to genetics in your GPR training?

None An hour Half a day A day More than a day

11. Who do you think should deliver genetics training, and why?
(e.g. geneticist, GP trainer, other)

12. What format would you like training to take, and why?
(e.g. face to face, electronic, reference materials)

13. Are there other professional groups with whom it would be productive for you to learn about genetics?

14. What services are you aware of in the region to give you advice on genetic cases?

15. Any other comments?

MANY THANKS FOR COMPLETING THIS QUESTIONNAIRE

Please return within 2 weeks using the FREEPOST envelope to Dr Alison Bullock, CRMDE,
School of Education, University of Birmingham, B15 2TT

APPENDIX 2
Delphi Survey: Round 1



THE UNIVERSITY
OF BIRMINGHAM

DEVELOPING A GENETICS CURRICULUM FOR GP REGISTRARS

Please take a few minutes to complete this form, in which we ask you to list topics or areas in clinical genetics which you feel should be included within the training for GP Registrars. All responses are confidential and anonymous.

Please tick this box if you would **not** like to be involved in the next phase of the study (in which we will ask you to comment on the draft curriculum, synthesised from your responses to this survey).

Please list the topics or areas you feel should be included in a genetics curriculum for GP Registrars. In doing this you might like to think about the genetic knowledge, skills and attitudes a GP Registrar needs to acquire.

Please use space overleaf if necessary.

MANY THANKS FOR COMPLETING THIS QUESTIONNAIRE

Please return by 30th May using the FREEPOST envelope to Dr Alison Bullock, CRMDE,
School of Education, University of Birmingham, B15 2TT

APPENDIX 3
Delphi Survey: Round 2



DEVELOPING A GENETICS CURRICULUM FOR GP REGISTRARS

1. The table below lists core knowledge, skills and attitudes. For each item, please indicate the extent to which you think they should be included in the GPR curriculum (space for comments is provided).

CORE KNOWLEDGE	To what extent is it important that these items be included in the GPR curriculum? <i>Please tick one circle per line</i>			
	Need not be included in curriculum	Useful for inclusion in curriculum	Needs to be included in curriculum	Essential for inclusion in curriculum
ORGANISATION AND ROLE OF NHS CLINICAL GENETICS SERVICES				
Understanding when and how to make a referral to Clinical Genetics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Roles of the clinical geneticist, genetic counsellors and other members of the genetics team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BASIC KNOWLEDGE OF GENETICS				
Nature of the genetic material				
DNA as genetic material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Structure and function of genes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Replication, transcription and translation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organisation of the genome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chromosomal basis of inheritance				
Chromosome structure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell division: meiosis and mitosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Types of chromosome anomalies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Common chromosome anomalies – Down syndrome, Turner syndrome, Klinefelter syndrome, translocations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to suspect a chromosome anomaly from the clinical phenotype or pedigree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Principles of recurrence risks for chromosome anomalies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difference between cytogenetics and molecular genetics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Single genes and their inheritance patterns				
Patterns of inheritance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autosomal dominant disorders (Adult polycystic kidney disease, neurofibromatosis type 1, Huntington's disease, hypercholesterolaemia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Variable expression in dominant disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reduced penetrance in dominant disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New mutation causing a dominant or X-linked disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recessive disorders (cystic fibrosis, haemoglobinopathies, haemochromatosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
X-linked disorders (DMD, haemophilia A)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic heterogeneity (locus and allele)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Principles of derivation of risk estimates for family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multifactorial Inheritance				
Pedigree patterns of multifactorial inheritance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How effects at more than one locus may summate or interact to produce common disease phenotypes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The role of environmental factors in multifactorial diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Awareness of familial forms of common diseases (e.g. breast cancer, bowel cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledge of disorders with a genetic component (e.g. cerebrovascular disease, Alzheimers, asthma)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An awareness of other mechanisms such as:				
Mitochondrial inheritance, Mosaicism, Triplet repeats, X inactivation, imprinting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	To what extent is it important that these items be included in the GPR curriculum? <i>Please tick one circle per line</i>			
	Need not be included in curriculum	Useful for inclusion in curriculum	Needs to be included in curriculum	Essential for inclusion in curriculum
KNOWLEDGE OF THE ROLE OF GENETICS IN FAMILIAL CANCER				
The genetic basis of susceptibility to specific cancers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other factors influencing the progression to cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Knudson (two-hit) hypothesis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Guidelines for referral	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The management of low / moderate / high risk patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DNA TESTING IN CLINICAL PRACTICE				
The types of mutations – missense, nonsense – and how they cause their clinical effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The importance of distinguishing normal variants from pathogenic mutations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Following a gene through a family using DNA polymorphic markers being inherited with the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scanning a gene to detect an unknown mutation: indications and practicalities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Testing for a specific or known mutation: direct DNA diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uses and limitations of DNA diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISSUES SURROUNDING GENETIC TESTING				
The differences and similarities between diagnostic, predictive and carrier genetic testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ethical issues relating to genetic testing particularly of children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ethical issues relating to presymptomatic testing for late onset disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SOCIETAL AND OTHER ISSUES				
History of eugenics movement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic test results and insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ethnic and cultural factors in genetic disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The human genome project and what it achieved in understanding the diseases in each medical specialty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLINICAL SERVICE APPLICATIONS				
Taking a family history	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Analysing pedigrees to establish mode of inheritance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A genetic test may be a clinical examination or investigation rather than a DNA test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Principles of Genetic Counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reproductive options, i.e. the fact that there is more to offer than PND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Principles of prenatal diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SCREENING				
The difference between 'testing' and 'screening'	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gene frequencies of common recessive mutations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Principles governing population genetic screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ethical problems involved in screening / testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Screening prenatally – indications, the importance of prompt referral, types of testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
National screening programmes for genetic conditions e.g. cystic fibrosis, haemoglobinopathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
FUTURE ADVANCES				
Current applications of pharmacogenetics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The potential of genetic polymorphism testing in prescribing practice (pharmacogenetics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Future possibilities of gene therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In vitro fertilisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Preimplantation genetic diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Myths about cloning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you have any comments on the knowledge items listed above?

CORE SKILLS	To what extent is it important that these items be included in the GPR curriculum? <i>Please tick one circle per line</i>			
	Need not be included in curriculum	Useful for inclusion in curriculum	Needs to be included in curriculum	Essential for inclusion in curriculum
IDENTIFYING FAMILIES WITH GENETIC DISORDERS				
How to draw and interpret a family tree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognise basic patterns of inheritance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess genetic risks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Calculate the risks of individuals suffering from mendelian disorders where the genetics is straightforward	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identify families who would benefit from referral to the genetics services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access the services of the local genetics centre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make appropriate referrals to genetic clinics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
INFORMATION SOURCES				
Access sources of information other than the internet about genetic conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access online genetic information and databases (including OMIM, Geneclinics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COMMUNICATION SKILLS				
Genetic counselling skills (may involve diagnostic work, counselling a specific individual or couple or extended family studies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arrange that sufficient time is set aside for this to be possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicate genetic information and risk in a clear and understandable way both verbally and by letter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicate genetic information in a non-judgemental way without prejudice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you have any comments on the skills items listed above?

CORE ATTITUDES	To what extent is it important that these items be included in the GPR curriculum? <i>Please tick one circle per line</i>			
	Need not be included in curriculum	Useful for inclusion in curriculum	Needs to be included in curriculum	Essential for inclusion in curriculum
PHILOSOPHY OF GENETIC COUNSELLING				
Recognise that genetic counselling (including the communication of risks and discussion of options) is an information giving process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognise that genetic counselling is practised in a non directive manner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognise the need to offer referral to clinical genetic services for genetic counselling where appropriate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adopt a non-judgemental approach over reproductive choice and prenatal testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appreciate that sufficient clinic time should be set aside for genetic counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To what extent is it important that these items be included in the GPR curriculum? <i>Please tick one circle per line</i>				
	Need not be included in curriculum	Useful for inclusion in curriculum	Needs to be included in curriculum	Essential for inclusion in curriculum
TESTING				
Appreciate the principles of, issues around, and differences between predictive (presymptomatic) testing and diagnostic testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognise that genetic information may have ethical, legal and social implications (e.g. for insurance)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appreciate the impact of genetic diagnosis on the extended family and the approach to at risk relatives who are not consultands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appreciate the sensitivity of genetic information and the need for confidentiality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understand the complexity of genetic disease and the pitfalls of determining genetic risks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accept that patients may have different views towards genetic risks and genetic testing (including prenatal diagnosis) and that they also have a right not / to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appreciate the social and psychological implications of genetic information for the patient and their extended family, including employment and paternity issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you have any comments on the attitudes items listed above?

2. Looking at the full list above (knowledge, skills and attitudes), please choose the top 5 items that you think should be included in the curriculum, and list them below, with 1 being the most important.

1.
2.
3.
4.
5.

3. Are there any other comments you would like to make?

MANY THANKS FOR COMPLETING THIS QUESTIONNAIRE
Please return within two weeks using the FREEPOST envelope to Dr Alison Bullock,
CRMDE, School of Education, University of Birmingham, B15 2TT