

Genetic education and nongenetic health professionals: Educational providers and curricula in Europe

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Purpose: Advances in and diffusion of genetic technology mean that nongeneticist health professionals have an increasing need to develop and maintain genetic competencies. This has been recognized by patient support groups and the European Commission. As the first phase of the GenEd (Genetic Education for Nongenetic Health Professionals) project, we investigated health professional education at undergraduate, postgraduate, and continuing levels in terms of genetic content and delivery. **Methods:** Information was collected in the five GenEd partner countries (France, Germany, Netherlands, Sweden, and the UK) by reviewing published curricula and web sites and by directly contacting educational and regulatory organizations. Information was also requested from a further six South and East European collaborators (Greece, Hungary, Italy, Lithuania, Poland, and Spain). **Results:** Health professional education and training differed in structure with wide variation in the content and duration of genetic education provided. France and Germany have national undergraduate medical curricula but with minimal overt genetic content, mainly confined to basic science courses. In Sweden, Netherlands, and the UK, the content is largely at the discretion of individual universities. Evidence from the UK, France, and Germany indicates that genetic professionals are influencing the genetic content of medical curricula. In postgraduate training, some specialist regulators have adopted specific genetic educational requirements, but many programs lack any explicit genetics. Within each country many organizations have responsibility for setting, assessing, and delivering medical and midwifery education. **Conclusions:** Due to the multiplicity of organizations involved in the provision of genetic education, changing professional education is likely to be challenging. However, it may be that development of a multiprofessional consensus across Europe is achievable. The strategy adopted by the US National Coalition for Health Professional Education in Genetics may be helpful. *Genet Med* 2005;7(5):302–310.

Key Words: genetics, Europe, education, undergraduate, postgraduate, paramedical

Over the last decade basic scientific research has led to a greater understanding of the contribution of genes to present and future health.¹ There is a growing recognition that genetic information will need to be integrated into all aspects of health care delivery, especially primary care.^{2–4} Patient advocacy groups have lobbied to raise health professionals' awareness of genetic issues,⁵ and the need for both patients and professionals to have an appropriate level of familiarity with the new

technologies has been recognized by the European Commission.⁶

GenEd (Genetic Education for Nongenetic Health Professionals) includes social scientists, nurses, clinical geneticists, general practitioners, educationalists, and genetic patient support groups from five countries with additional collaborators from six countries. The project was funded by the European Commission 5th Framework from 2002 to 2005 following on from the Concerted Action on Genetic Services in Europe, which described specialist genetic service provision⁷ and the Confidential Enquiry into Counseling for Genetic Disorders by Nongeneticists, funded by the UK Department of Health, which examined the quality of nongenetic specialist care for genetic conditions.⁸

The current research aimed to assess education in Europe for health care providers likely to be approached by patients concerned about inherited risk. In some countries, these providers are family doctors, or general practitioners, who regulate access to other specialist services via a "gatekeeper" role. In

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Received: December 29, 2004

Accepted: March 15, 2005

DOI: 10.1097/01.GIM.0000164562.18306.71

others, it is likely that patients will directly access specialties such as pediatrics or obstetrics.

In 1990, research showed that undergraduate medical training in the UK varied in its basic genetic content and included little applied clinical genetics.⁹ Nongenetics specialist doctors with cases involving genetic issues demonstrated poor documentation, did not refer for genetic counseling, and did not consider wider implications for other family members.⁸ These findings have been supported in other countries such as Australia,¹⁰ Netherlands,^{11,12} Singapore,¹³ and USA.^{14–17} Despite this, confidence in dealing with genetic issues was relatively high among US medical students and residents (59%, $n = 85$)¹⁸ and German gynecologists (66%, $n = 172$),¹⁹ while 31% of US physicians had ordered or referred for genetic testing in the previous 12 months.²⁰ Comparison of genetic education in Europe has been complicated by the variety of health care systems, organizational structures in health professional education, and health care professionals involved at first patient contact.²¹ Recently, a pan-European policy committee has expressed concerns about the accessibility of clinical genetics services and health professional education in genetics.²²

METHODS

We examined existing policy in relation to undergraduate, postgraduate, and continuing education in 2002. Within partner countries (France, Germany, Netherlands, Sweden, and the UK), published curriculum documents were assessed by reading or electronic keyword searching (Fig. 1). Where there were no such documents, information was sought by telephone or postal questionnaire directly to the organizations responsible for setting, assessing, and implementing education (further details in Table 1). Where a questionnaire was used, this was directed to key individuals identified as being involved in curriculum development. Open questions were asked about content and structure of genetic information. Use of multiple sources, where possible, allowed for cross-verification, and information from each partner country has been independently reviewed. In countries where information concerning postgraduate education was less easily available, partners investigated primarily some specialties likely to be approached by a patient with a genetic concern, such as pediatrics, obstetrics/gynecology, and family practice. In France and Sweden, the organizational structure and diverse curricula has meant that only information relevant to a few specialist groups was available. Comparative information was supplied by expert collaborators in Greece, Hungary, Italy, Lithuania, Poland, and Spain.

RESULTS

Tables 2 (partner countries) and 3 (observer countries) show demographics of undergraduate, postgraduate, and continuing education relating to genetics. The countries are listed alphabetically within each table.

Medical undergraduate education

In France, professors of genetics are responsible for undergraduate training. The number of hours devoted to genetics is variable and at the discretion of each medical faculty, whereas the professor of genetics decides particular topics covered. Assessment is at the end of each year, usually by multiple-choice examination and short questions about knowledge or clinical management. Until 2004, students also took an “internat,” a competitive examination, in their 6th year if they wished to become specialists. The internat addressed eight specific medical genetic issues, but preparation was variable, at the initiative of the university, and focused mainly on scientific genetic principles. Since 2004, a national examination has been taken in the 6th year including three wide-ranging extended essay questions. The genetic content is more specific but includes only trisomy 21, cystic fibrosis, and fragile X to highlight different modes of inheritance. Due to this, the Pedagogic working group of the National College of Genetic Practitioners produced unofficial guidance specifying the medical genetics issues about which undergraduate students should be knowledgeable.²³

In the German written curriculum (Catalogue of Teaching Objectives; Gegenstandskatalog), the most commonly found keywords relevant to genetics were in courses on basic biology (45/125 topics; 36%) and orthopedics (30/293 topics; 12%). In most subjects, including gynecology/obstetrics, neurology, and surgery, < 6% of the curriculum was relevant to genetics. In 2002, a new set of regulations came into force allowing individual universities more flexibility, although the first doctors following this new syllabus will not qualify until 2014.

In the Netherlands, curricula vary but universities share a general scheme of examinations and a framework of 328 problems. All doctors should have encountered these problems during training and know how to react appropriately to them. Five problems are relevant to medical genetics (request for reproductive genetic evaluation, suspicion of genetic or congenital anomaly, positive screening result, request for preventive evaluation, and request for information) but recognizing a genetic problem or genetic problem solving are not included. In most universities, genetics is integrated within other courses (reproduction, sense organs, or developmental disorders) and comprises only a small proportion of the total course if included at all (1 to 21%, mean 8%).

In Sweden, there are national goals for medical education but these contain no overt genetics and each medical school has flexibility in how it fulfils them. The cell and molecular biology course includes many elements of basic genetics and constitutes most of the first semester curriculum in all medical schools. The involvement of clinical geneticists in education varies between universities. Some schools have no separately defined medical genetics courses.

The General Medical Council (GMC) Education Committee formally regulates undergraduate medical education in the UK and has recommended an emphasis on problem-based learning rather than knowledge-based curricula.²⁴ In practice,

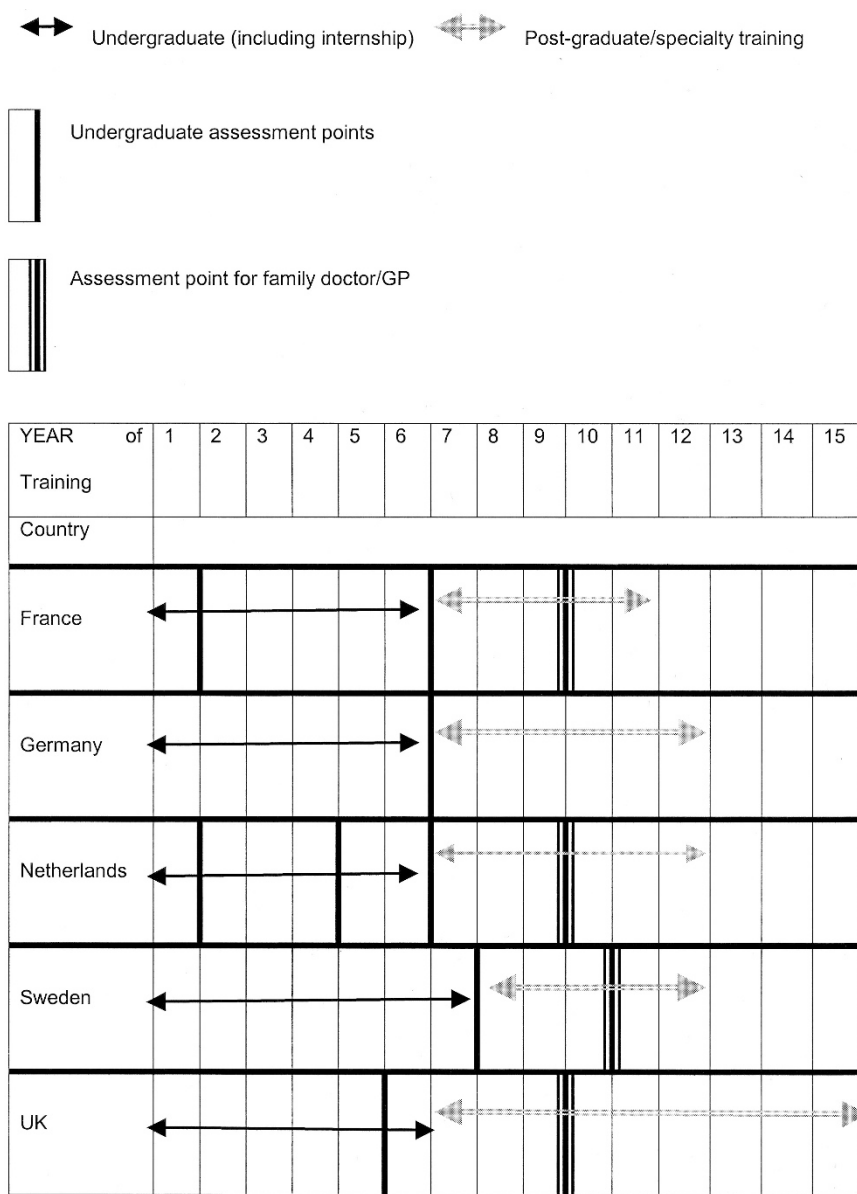


Fig. 1. Comparative table of structure of medical education in five European countries. Black arrows, Undergraduate (including internship). Gray arrows, Postgraduate/specialty training.

universities have reasonable autonomy to define their own courses. Various bodies including the Royal College of Physicians of London and the British Society for Human Genetics^{9,25} have recommended core basic science and clinical curricula for the teaching of medical genetics to medical students, but these are not compulsory.

Table 3 provides further information relating to undergraduate education in the additional countries.

Medical postgraduate education

In France, future medical specialists train for a specialist diploma (DES) and can then train further for a complementary diploma (DESC). Specialty professors at each of the 43 universities autonomously organize the content of specialist training,

making collection of accurate data regarding curriculum content impossible. There are some inter-regional agreements between medical universities about the organization of programs, including topics to be taught. In some specialties, there is a national college responsible for setting topics and for the organization of training. There is no standardization of genetic education between different specialties. Twelve universities offer DESCs related to medical genetics [chromosomal abnormalities (4 universities), molecular cytogenetics (3 universities), congenital malformations, genetics in hematology and oncology, development and heredity, biostatistics and genetics, and cancer genetics and adult genetic diseases].

In Germany, postgraduate guidelines define the extent to which any item needs to be taught. From these it appears that

Table 1
Sources of information

Undergraduate medical education		
France	Medical faculties	www.medsyn.fr/fmc3.htm
		www.b3e.jussieu.fr
		www.fac.med.univ-rennes1.fr
		www.univ-paris12.fr
	Ministry of education	www.timone.univ-mrs.fr/medecine/enseignement/censeignement.htm
		www.education.gouv.fr/botexte/bo020523/MENS0201196A.htm
		www.education.gouv.fr/presse/2002/santedp.htm
		www.education.gouv.fr/botexte/bo990422/MENS9900752A.htm
		www.education.gouv.fr/botexte/bo981112/MENS9802810A.htm
		www.sante.gouv.fr/adm/dagpb/bo2002/02-15/a0151374.htm
Ministry of health	www.sante.gouv.fr/adm/dagpb/bo2002/02-15/a0151374.htm	
	Internet	www.avisantpharma.fr/main/0,1003,FR-FR-31027-49242--,00.html www.laconferencehippocrate.com/conhipp/libpro.asp (now out of use)
	National College of Genetic Practitioners	http://college-genetique.igh.cnrs.fr/enseign.html
Germany	Gegenstandskatalog	www.impp.de/lmppGk.html
Netherlands	University curricula	Checked with the genetic educationalist at each medical school
Sweden	Departments of Clinical Genetics	Direct contact
UK	Genetics teaching leads	Open University survey ³⁴
Postgraduate medical education		
France	Syllabi	University of Marseilles ^{35,36}
Germany	Bundesärztekammer	www.bundesaeztekammer.de
Netherlands	Curricula	www.knmg.nl
Sweden	Education book (curricula)	www.slf.se
UK	Curricula	Via www.sta-mrc.org.uk
	Questionnaire	Educational lead in each specialty
Continuing medical education		
France	University	www.fmc-marseille.com
	GP training	www.medsyn.fr/formation/organismes.htm
	Journal	www.quotimed.com
	Questionnaire	Clinical genetics professors
Germany	Journal	www.aertzeblatt.de
Netherlands		No systematic overview available
Sweden	Specialty organisations	Personal contact
UK	GMC	www.gmc-uk.org
	Royal Colleges and Specialty organisations	Via www.sta-mrc.org.uk
Nursing and midwifery		
France	Regulations	www.sante.gouv.fr/hm/pointsur/metier_sante/paramedicale/3para.htm www.sante.gouv.fr/hm/pointsur/metier_sante/medicale/4medicale.htm
	Questionnaire	Heads of nursing and midwifery schools in Provence
Germany	Not studied	
Netherlands	Midwifery schools	Direct request for information
Sweden	Nursing schools	Mail contact with telephone followup
UK	Nursing and midwifery council	www.nmc-uk.org

Table 2
Education in partner countries

	France	Germany	Netherlands	Sweden	UK
Undergraduate medical education					
No. of institutions providing education (per million population) ³⁷	43 (0.74)	36 (< 0.5)	8 (0.52)	6 (0.67)	26 (< 0.5)
Length	6 y	6 y	6 y	5.5 y + 1.5 y internship	5 y + 1 y internship
National curriculum	Themes but not specifics	Detailed	List of 328 issues to be addressed	Themes 'National Goals'	No
Problem-based learning	Not possible to assess	Not possible to assess	To some extent	To some extent	Predominant method
'Genetics' in undergraduate medical education	3 diseases as exemplars	1 clinical genetics course	5/328 issues had genetic elements	No genetics mentioned	Difficult to assess
Organization responsible for licensing to practice as a medical doctor	Conseil de l'ordre des medecins	State chambers under state law	Ministry of Health, Welfare and Sports	"Socialstyrelsen" National Board of Health and Welfare	General Medical Council
Medical postgraduate education					
No. of specialties including medical/clinical genetics (duration of specialist training)	36	40	27 hospital specialties (4–6 y) General practice (3 y) Nursing home MD (2 y) Social medicine MD (4 y) MD for the mentally handicapped (4 y)	62 plus subspecialties (5 y)	54 (2–3 y general plus 4–6 y higher specialist)
'Genetics' in nongenetic specialist curricula	Not possible to assess	12/39 mentioned genetics knowledge (31%).	4/31 programs mentioned genetics	9/17 curricula (53%) Only 17/62 assessed	47/53 mention genetics (89%)
Recognition of clinical/medical genetics as a specialty	Yes	Yes	Yes	Yes	Yes
Organization responsible for regulation of training	Conseils Nationaux de Formation Medicale Continue	Bundesarztekkammer of each specialty Chamber. Regulated by state law.	Medische Specialisten Registratie Commissie, national committees for GPs, social medicine, nursing home MDs and MDs for the mentally handicapped	Socialstyrelsen sets a framework based on suggestions by the professional organization	Medical Royal Colleges
Specialty curricula available at a national level	No	Yes	Guidelines	Yes	Yes
Existence of primary care/family doctor/ GP as specialty	Created in 2004	Family doctors are specialists in general or internal medicine	Yes	Yes	Yes
Continuing medical education (CME)					
Compulsory CME	No	Yes, but unregulated	Yes	No	Newly compulsory
Amount of genetics	Not possible to assess	'5.7% of articles in a popular medical journal throughout 2001'	'Very little'	'Very little'	Not possible to assess
Nursing and midwifery					
Duration of nursing/midwifery training	3 y/5 y	Information not collected as nurses/midwives have no independent role in healthcare provision	4 y (midwives)	3 y/1.5 y once registered nurse	3 y/3 y or 1.5 y if registered nurse
Institutions providing nurse training	Specific schools		Not assessed as no independent role	Universities, University Colleges, Colleges of Health	Universities, University Colleges
Institutions providing midwifery training	First year with medical students, then outside university		4 non-university institutions	Universities	Universities, University Colleges

^aThis term (Genetics) was applied loosely by most countries and assessment methods varied to take into account differing educational systems and access to documentation. It is used in this table to represent any reference to clinical/medical/applied human genetics found in the curriculum.

Table 3
Education in observer countries

	Greece	Hungary	Italy	Lithuania	Poland	Spain
Undergraduate medical education						
No. of institutions providing education	7	4	39	2	11	26
Length	6 y	6 y	6 y	6 y	6 y	6 y
National Curriculum	None	Broad—Committee for Under- and Postgraduate Education for Health Science	Detailed—Ministry of Universities and Research	None	Detailed—Ministry of Health	Detailed—Ministerio de educación, cultura y deporte
Problem-based learning	To some extent	Hardly at all	To some extent	Predominant	To some extent	To some extent
Genetics ^a	Single course (40 h)	14–28 h clinical genetics per semester in 5th y, also in cell biology & biochemistry	3 courses (70 h)	2 courses (88 h)	2 30-h clinical genetics courses with 10 h of genetics in biology	7 of 378 total credits
Licensing to practice as a medical doctor	Local medical associations	National	National	National	National	National
Medical postgraduate education						
No. of specialties including medical/clinical genetics (duration of specialist training)	38 (4–7 y)	33 (6–8 y)	56 (4–5 y)	46 (4–6 y)	30 specialties plus 31 subspecialties (5–7 y)	48 (4–5 y)
Recognition of clinical/medical genetics as a specialty	No	Yes	Yes	Yes	Yes	No
Specialty curricula available at a national level	Yes	Yes	Yes	Yes	Yes	Yes
Existence of primary care/family doctor/GP as specialty	Yes, but few in practice	Yes	No	Yes	Yes	Yes
Continuing medical education (CME)						
Compulsory CME	No	Necessary for reregistration	Yes, assessed by credits	Yes, regulated by health ministry	No	No
Amount of genetics	Not possible to assess	Not possible to assess	Not possible to assess	Classes of 72 or 160 hours	“Poor”	Not possible to assess

^aThis term (Genetics) was applied loosely by most countries and assessment methods varied to take into account differing educational systems and access to documentation. It is used in this table to represent any reference to clinical/medical/applied human genetics found in the curriculum.

the majority of specialist trainees require no explicit knowledge of medical genetics. The only specialties in which genetics is stipulated are gynecology/obstetrics, where “20 cases of application of the principles of human genetics for family planning” are required, and pediatrics, where “200 indications for biochemical screening and classifying the disease pattern” have

to be documented. A survey of specialist examinations in internal medicine, gynecology and obstetrics, pediatrics, and general medicine in 2001 suggested that genetic knowledge plays little role.

In the Netherlands, only specialist training in obstetrics/gynecology, neurology, and pediatrics included formal genetic

education, but the format of this is not specified. General Practitioner training is organized through institutes at the eight universities that provide medical undergraduate education. Several institutes spend some time on genetic education in their training program, but there are no formal regulations. MDs for the mentally handicapped are expected through training to be familiar enough with clinical genetics to be able to refer appropriately.

In Sweden, each specialty has a defined curriculum set by the National Board of Health and Welfare (Socialstyrelsen) in conjunction with the professional organizations. We found phrases referring to genetic knowledge in the curricula for general practice, endocrinology, gynecologic oncology, neurology, obstetrics and gynecology, oncology, pediatric medicine, pediatric psychiatry, and pediatric neurology. Genetic conditions for which the trainee is expected to demonstrate competence in management are defined, but the format of training is not.

In the UK, postgraduate training is supervised by the Medical Royal Colleges. It is regulated and assessed regionally and is monitored by regional representatives of the relevant Royal College. Published curricula included theoretical knowledge of genetics in anesthesia, chemical pathology, histopathology, toxicology, neonatology, allergy medicine, cardiology, endocrinology, gastroenterology, hematology, immunology, medical oncology, neurophysiology, palliative medicine, rehabilitation, renal medicine, respiratory medicine, all psychiatric specialties, clinical oncology (radiotherapy), general surgery, orthopedics, urology, and pediatric (endocrinology, gastroenterology, nephrology, neurology, rheumatology, and surgery). Demonstrable skills are required for the following: obstetrics/gynecology, medical and surgical ophthalmology, audiological medicine, dermatology, neurology, metabolic medicine, child and adolescent psychiatry, endocrine surgery, and oral and maxillofacial surgery. A few specialties require attendance at genetic specialist clinics but mostly training relevant to genetics is self-directed and self-assessed on the part of the trainee.

See Table 3 for information on postgraduate medical education in additional countries.

Continuing medical education

In France, after an annual "call for proposals," Sécurité Sociale regional centers announce priority topics then select session organizers from private pharmaceutical industries, professors of medicine, or professional educational associations. Many specialists join physician societies who also provide continuing education courses, but these are not organized nationally. In 2002, 14 such organizations existed. It is difficult to be precise about the role of medical genetics in continuing medical education because of the number of organizations involved.

In Germany, continuing medical education (CME) requirements are often met by reading suitable educational material. In 2001, "Deutsches Ärzteblatt," a weekly journal read by about 75% of physicians, contained 6% (8/141) of articles with even peripheral genetic relevance.

In the Netherlands, registration as a specialist is required every 5 years. Each specialty is responsible for accreditation of courses and decides the number of hours of CME required annually. Courses relevant to genetics have been offered in pediatrics and obstetrics, but these are infrequent and specialists are free to choose between accredited courses; currently few opt for continuing genetic education.

CME in Sweden has until recently been sponsored mostly by the pharmaceutical industry. Recently, there have been more incentives to undertake education, but there is little evidence that progress has been made in any specialty. Of 12 specialty organizations surveyed (9 responses), three offered CME in genetics during 2002 (obstetrics and gynecology in cancer and fetal diagnostic courses, oncology via one lecture in a 10-day course biennially and at most conferences, and an annual 1-day course in pediatrics).

In the UK, the GMC is responsible for assessment and revalidation of specialists, whereas the medical Royal Colleges approve particular events and courses. The Colleges of Psychiatrists, Pediatrics and Child Health, and Obstetrics and Gynaecology have formal publications about CME; none of these specifically addresses genetics.

See Table 3 for information on continuing medical education in additional countries.

Midwifery and nursing

French midwives study genetics for on average 30 hours including modes of inheritance, prenatal diagnosis, and chromosomal anomalies. Continuing education is optional and providers did not mention training in genetics. Within nurse training, genetics occurred during the first and second years (1 to 6 hours according to the school). The official program involves "screening, congenital malformations, and genetic diseases" although some schools added "prenatal diagnosis and genetic counseling."

In the Netherlands, 1 week in the first year of midwifery training and 2 weeks in the third year are spent on genetics. Some institutions also offer 2 weeks of practical genetic education in the fourth year. Continuing education is organized by one agency, and in 1997, the majority of practicing midwives attended courses on clinical genetics.

In Sweden, there is no national nursing curriculum and universities vary in curricula and examinations. Registered nurses can enter 1-year programs to become specialized nurses or may enter courses to become registered midwives. In our survey, most schools stated that specific education in medical/clinical genetics was missing. Genetic aspects were considered in basic cell biology, or as part of teaching about various disorders, ethics, or pharmacology. The most common topics were basic Mendelian and molecular genetics with between 2 to 6 hours of teaching time, mostly lectures but also including seminars and project work. However, genetic specialists were not used as teachers.

The UK Nursing and Midwifery Council (NMC) publishes requirements for nursing and midwifery programs; these do not include any specific mention of genetics. Required mid-

wifery competencies include the following: enabling women to make informed choices, referring women who would benefit, and examination and care of babies with specific health or social needs (including congenital disorders). A survey found that most nursing schools offered < 10 hours of genetics, and most had no assessment of genetic learning.²⁶ Similar competencies exist for registration as a health visitor, which requires a further degree after qualification as a nurse or midwife. A separate group examining genetics in postgraduate nursing education found that half of postgraduate nursing or midwifery curricula included no genetics.²⁷ Core genetic competencies for nurses and midwives in the UK have recently been published and recognized by the NMC.²⁸

DISCUSSION

We experienced major difficulties in attempting to elicit details of the genetic education content of medical and midwifery training programs in the 11 GenEd countries because of great variability of health care systems and associated wide disparity in health professional education and in the duration and content of genetic education.

In France and Germany, the national medical undergraduate curricula contained little genetics and this was mainly confined to basic molecular genetics or cell biology courses. In the Netherlands, Sweden, and the UK, individual universities decide undergraduate curricula and detailed analysis was beyond the capacity of this study. Within undergraduate medical education, genetic theory and competence seem to be relatively neglected. This does not appear to be associated with any particular type of educational or health service structures, although assessment has been hampered by lack of clarity and structure in curricula, particularly in systems where educational policy allows individual faculties or schools great autonomy.

Although improving education in genetics for health care professionals has been recognized as necessary by a European Commission expert committee,⁶ achieving this will be difficult because of the multiplicity of systems and organizations that must be influenced. Curricula are being modified in France and Germany and two curricula are running concurrently. In France and the UK, national professional organizations have been actively trying to increase the relevance and quality of genetic education at undergraduate level.^{23,25} It is encouraging to find that a number of regulators of specialist curricula have identified specific requirements in genetic training for specialization, but many specialist disciplines remain without any required study in clinical genetic topics. There are many differences between the five countries in the curricular content of the same specialty. In general practice/family medicine, Sweden and Germany have a nationally regulated curriculum, which includes no formal genetic education. In France, the Netherlands, and the UK, there is less regulation and the content varies between universities.

In contrast to the UK, Sweden, and France, nurses in Germany have no independent role in delivering health care ser-

vices to families. In the Netherlands, midwives have an active role in providing genetic education to families. However, genetic education for both nurses and midwives is generally minimal; the provision for Dutch midwives is notably greater. Genetics is present in the prequalification nursing and midwifery curricula in Sweden. The UK lacks a defined undergraduate nursing curriculum, but core competencies have been defined for nursing and midwifery training.²⁸

Where centralized curricula exist, as in France and Germany, changing the national framework would potentially lead to changes at the university level. However, in the absence of a centralized curriculum and where individual universities have more autonomy, a consensus framework of competencies might prove more useful. The publication by genetic professional groups in France and the UK of recommended core competencies in genetics similar to those of wide general relevance from the US National Coalition for Health Professional Education in Genetics (NCHPEG)²⁹ is welcome. Others published are relevant to individual professional groups,³⁰ while a recent UK report³¹ recommends a national genetics education strategy and establishment of a National Health Service Genetics Education and Development Centre, which is now running (<http://www.geneticseducation.nhs.uk>). A "training the trainer" approach has been shown to have some success,³² whereas for patients at-risk for colorectal cancer, direct patient education was as effective as education of their physician.³³

Whatever is published we believe that enhancing health professional education in genetics will require that professionals themselves should recognize the importance of genetic competencies in providing appropriate and timely care to their patients. Accordingly, the second phase of GenEd is surveying pediatricians, obstetrician/gynecologists, general practitioners, and midwives to explore awareness of genetics in their practice and to ascertain their priorities for genetic education and competencies.

In the present report, we provide information that we believe will be helpful to health service planners, specialists, and patient advocacy groups enabling them favorably to influence curricula in genetics for nongenetic health care professionals.

ACKNOWLEDGMENTS

On behalf of the GenEd (Genetic Education for Nongenetic Health Professionals) research group: Participating investigators: Sandrine Arnaud (Marseilles), Marieke J.H. Baars (Amsterdam), Frits A. Beemer (Utrecht), Lina Florentin (Athens), Karin Henriksson (Lund), György Kosztolányi (Pécs), Vaidutis Kučinskas (Vilnius), Giovanni Neri (Rome), Yasmin Paul (Hannover), Anne Marie C. Plass (Amsterdam), Maria Ramos-Arroyo (Pamplona), Jacek Zaremba (Warsaw). Collaborators: Elizabeth Anionwu (London), Wolfgang Holzgreve (Basel), Alistair Kent (London), Ysbrand Poortman (Leuven).

References

1. Guttmacher A, Collins F. Genomic medicine: A primer. *N Engl J Med* 2002;347:1512-1520.

2. Harris R, Harris H. Primary care for patients at genetic risk. *BMJ* 1995;311:579–580.
3. Department of Health. Our inheritance, our future. London: Department of Health, 2003.
4. Greendale K, Pyeritz R. Empowering primary care health professionals in medical genetics: How soon? How fast? How far? *Am J Med Genet* 2001;106:223–232.
5. World Alliance of Organizations for the Prevention of Birth Defects. Prevention of birth defects: A task for a world alliance. 2004.
6. McNally E, Cambon-Thomsen A, on behalf of EC expert group. 25 Recommendations on the ethical, legal and social implications of genetic testing. Brussels: European Commission, 2004.
7. Harris R, Reid M, Florentin L, editors. Genetic services in Europe: a comparative study of 31 countries by the Concerted Action on Genetic Services in Europe. *Eur J Hum Genet* 1997; 5(suppl 2):1–220.
8. Harris R, Lane B, Harris H, Williamson P, Dodge J, Modell B et al. National Confidential Enquiry into counselling for genetic disorders by non-geneticists: general recommendations and specific standards for improving care. *Br J Obs Gynaecol* 1999; 106:658–663.
9. Harris R, Johnston A, Harris H, Young I. Teaching genetics to medical students. *J Roy Coll Phys Lond* 1990;24:80–84.
10. Tyzack K, Wallace E. Down syndrome screening: What do health professionals know? *Aust NZ J Obstet Gynaecol* 2003;43:217–221.
11. Van Langen I, Birnie E, Leschot N, Bonsel G, Wilde A. Genetic knowledge and counselling skills of Dutch cardiologists: Sufficient for the genomics era? *Eur Heart J* 2003;24:560–566.
12. Baars MJH, De Smit DJ, Langendam MW, Ader HJ, Ten Kate LP. Comparison of activities and attitudes of general practitioners concerning genetic counseling over a 10-year time-span. *Patient Educ Couns* 2003;50:145–149.
13. Yong M, Zhou X, Lee S. The importance of paternal family history in hereditary breast cancer is underappreciated by health care professionals. *Oncology* 2003;64: 220–226.
14. Taylor M. A survey of chairpersons of departments of medicine about the current and future roles of clinical genetics in internal medicine. *Genet Med* 2003;5:328–331.
15. Schroy Pr, Barrison A, Ling B, Wilson S, Geller A. Family history and colorectal cancer screening: a survey of physician knowledge and practice patterns. *Am J Gastroenterol* 2002;97:1031–1036.
16. Batra S, Valdimarsdottir H, McGovern M, Itzkowitz S, Brown K. Awareness of genetic testing for colorectal cancer predisposition among specialists in gastroenterology. *Am J Gastroenterol* 2002;97:729–733.
17. Barrison A, Smith C, Oviedo J, Heeren T, Schroy Pr. Colorectal cancer screening and familial risk: A survey of internal medicine residents' knowledge and practice patterns. *Am J Gastroenterol* 2003;98:1410–1416.
18. Ormond K, Gill C, Semik P, Kirschner K. Attitudes of health care trainees about genetics and disability: Issues of access, health care communication, and decision making. *J Genet Couns* 2003;12:333–349.
19. Mehnert A, Bergelt C, Koch U. Knowledge and attitudes of gynecologists regarding genetic counseling for hereditary breast and ovarian cancer. *Patient Educ Couns* 2003;49:183–188.
20. Wideroff L, Freedman A, Olson L, et al. Physician use of genetic testing for cancer susceptibility: results of a national survey. *Cancer Epidemiol Biomarkers Prev* 2003; 12:295–303.
21. Harris R, Reid M. Medical genetic services in 31 countries: An overview. *Eur J Hum Genet* 1997;5(suppl 2):3–21.
22. Godard B, Kaariainen H, Kristoffersson U, Tranebjaerg L, Coviello D, Ayme S. Provision of genetic services in Europe: current practices and issues. *Eur J Hum Genet* 2003;11(Suppl 2):S13–S48.
23. Jeanpierre M, Leporrier N, Moraine C, Stoll C. Objectifs pédagogiques de l'enseignement de Génétique. La commission pédagogique du Collège national des généticiens, 2001.
24. GMC. Tomorrow's Doctors. London: General Medical Council, 2003.
25. British Society for Human Genetics. Teaching medical genetics to undergraduate medical students. British Society for Human Genetics, 2003.
26. Kirk M. Preparing for the future: the status of genetics education in diploma-level training courses for nurses in the UK. *Nurse Educ Today* 1999;19:107–115.
27. Metcalfe A, Burton H. Postregistration genetics education provision for nurses, midwives and health visitors in the UK. *J Adv Nurs* 2003;44:350–359.
28. Kirk M, McDonald K, Longley M, et al. Fit for practice in the genetics era: a competence based education framework for nurses, midwives and health visitors. Pontypridd: University of Glamorgan, 2003.
29. Core Competency Working Group of the National Coalition for Health Professional Education in Genetics. Recommendations of core competencies in genetics essential for all health professionals. *Genet Med* 2001;3:155–159.
30. Calzone K, Jenkins J, Masny A. Core competencies in cancer genetics for advanced practice oncology nurses. *Oncol Nurs Forum* 2002;29:1327–1333.
31. Burton H. Addressing genetics delivering health: Report to the Wellcome Trust and the Department of Health. Cambridge: Public Health Genetics Unit, 2003.
32. Prows C, Hetteberg C, Johnson N, Latta K, Lovell A, Saal HM et al. Outcomes of a genetics education program for nursing faculty. *Nurs Educ Perspect* 2003;24:81–85.
33. Loader S, Shields C, Levenkron J, Fishel R, Rowley P. Patient vs. physician as the target of educational outreach about screening for an inherited susceptibility to colorectal cancer. *Genet Test* 2002;6:281–290.
34. Jones H, Owen H, Grant J Survey of genetics teaching leads in medical schools. Milton Keynes: Open University Centre for Education in Medicine, 2003.
35. Filière chirurgie. Diplômes d'études spécialisées (D.E.S) année universitaire 2000–2001. Marseille: Université de la Méditerranée, 2000.
36. Filière médecine. Diplômes d'études spécialisées (D.E.S) année universitaire 2000–2001. Marseille: Université de la Méditerranée, 2000.
37. wordIQ.com. Available at: http://www.wordiq.com/definition/Area_and_population_of_European_countries. 2004. Accessed February 20 2004.