

## **Draft paper: Assessment of competence of genetic nurses and genetic counsellors in Europe**

*NB For the purposes of this document, registration is used as the term to define the assessment and recording of competence of an individual practitioner. In some countries the terms credentialing or licensure may be used, but for ease of reading we have used one consistent term.*

### **Background**

Genetic nurses and counsellors have been working in European countries for at least 30 years. A survey of key informants<sup>1</sup> from 17 countries demonstrated that there are great disparities between the numbers, education, practice and acceptance of these professions across Europe (Table 1 and Appendix 1). However, a study of the roles and practices of genetic counsellors<sup>2</sup> in 18 countries indicated that they are undertaking key roles in the multi-disciplinary genetic healthcare team. For example, the majority of respondents were responsible for taking a family history, explaining and ordering genetic tests and disclosing test results to patients. In order to achieve and maintain safe practice for patients, appropriate education and a system of assessing competence of practitioners is needed.

Currently a system of assessment of competence for national registration of genetic counsellors and nurses exists in the United Kingdom<sup>3</sup> and in the Netherlands, but no similar formalised system exists in other European countries. Registration systems may well be introduced in other countries in the future, particularly where genetic counsellor practice has been well-established for many years. However, due to low populations and low numbers of practitioners it will not be feasible to introduce registration systems in every country. A European approach is urgently needed.

The Ad Hoc Genetic Nurse and Counsellor Accreditation Committee of the ESHG has already done considerable work on development of standards of education and Code of Professional Practice for genetic counsellors in Europe<sup>4</sup> (Appendix 2). That work has been accepted by the ESHG. It must be noted that in some countries it will be more appropriate and acceptable to utilise genetic nurses, in others genetic counsellors will be preferred. It is therefore essential to design a system that accommodates both without undue bias towards one professional group.

**Table 1. Number of genetic counsellors and genetic nurses per country and per million population**

<b>Country</b> (no of respondents from that country)	<b>Population</b>	<b>Year in which genetic counsellors/ nurses first worked in that country</b>	<b>No of Genetic Counsellors</b>	<b>No of Genetic nurses</b>	<b>Total number per million population</b>
Czech Republic (2)	10,674,947	N/A	0	0	0
Denmark (1)	5,475,791	Unknown	15	10	4.5
Finland (1)	5,279,228	Unknown	0	20	3.8
France (2)	65,800,000	2005	75	0	1.1
Germany (1)	81,820,000	N/A	0	0	0
Hungary (1)	9,999,000	N/A	0	0	0
Iceland (1)	306,694	2006	1	0	3.2
Ireland (1)	4,446,000	1998	7	2	2
Italy (3)	60,157,214	Unknown	0	37	0.6
Netherlands (2)	16,662,143	1990	65	0	3.9
Norway (1)	4,854,000	1990	17	0	3.5
Portugal (2)	11,317,192	2004	1	0	0.9
Romania (1)	22,246,862	2011	0	20	0.9
Spain (1)	46,661,950	N/A	0	0	0
Sweden (4)	9,276,509	2002	10	10	0.5

Switzerland (2)	7,785,806	2004	3	3	1.3
Turkey (1)	77,804,122	N/A	0	0	0
United Kingdom (2)	61,524,872	1980	300	20	5.2

### **Eligibility to register – Master level education**

The Committee proposes that all genetic counsellors and nurses be educated at Master level; for genetic counsellors this should be a Master degree in genetic counselling, for genetic nurses a Master degree in genetic nursing. The topics to be included in the curriculum for a Master degree in genetic counselling is included in Table 2. The course for genetic nurses should cover the same material. Only practitioners with the requisite Master degree will be eligible for European registration (see section on the Grandfather Clause below for information on arrangements for current practitioners ).

### ***Practical Placements***

The practical component of the course (placements) should account for at least 50% of the course teaching hours. A minimum of 25% of the course teaching hours (50% of the practical placement hours) must be spent by the student in a genetics centre under the mentorship of a genetic counsellor ( or where this is not possible, the mentorship of an experienced medical geneticist).

During the genetic counselling placement, it is expected that the student will progress from observation of practice (initially) to partial involvement in delivering care, through to management of cases (under supervision).

The placements in clinical genetics contexts should offer students the opportunity to:

- Develop awareness of the professional role of the genetic counsellor
- Develop communication and counselling skills
- Facilitate application of theory to practice
- Develop skills in caseload management
- Understand the roles of members of the multi-disciplinary team.

Students should have experience during the placement period in reproductive genetics, genetics related to adult onset diseases, paediatric genetics and cancer

genetics. Students working in a genetic healthcare context during the course of study may use their working hours as a practical placement.

### **Registration requirements**

A new graduate does not have the competence to work autonomously as a genetic counsellor or genetic nurse within the multi-disciplinary team. We therefore propose that a period of two years (or equivalent if the practitioner works part-time) of practice with a genetic healthcare environment should precede registration to enable practitioners to develop all the competences approved by the ESHG (Appendix 4). This practice could be undertaken in one or more departments, as long as the professional was involved in provision of genetic counselling. Figure 1. Provides information about the process.

### **Assessment of competence and registration process**

Assessment of competence and suitability to be placed on the European register of genetic nurses and counsellors must be made by experienced genetic nurses and genetic counsellors. Due to the different needs of each professional group, we suggest designating one part of the register for nurses and one for genetic counsellors.

Where no system exists, an assessment of the individual will have to be made. The assessment strategy below has been based on the model suggested by Miller<sup>5</sup>, which states that the level of clinical competence is shown by the ability of the practitioner to demonstrate skill in relation to clinical cases. Each section of the process below is designed to examine professional ability in relation to the competences for genetic counsellors. Assessment will be based on the applicant satisfactorily submitting all of the following:

1. A written multi-choice questionnaire (MCQ) examination to assess knowledge of genetic science and counselling theory and ability to make a genetic risk assessment. The examination will be conducted online and the applicant must be supervised during the examination by a senior colleague.
2. A case log of at least 50 cases, demonstrating the applicant's competence. The case log must be verified by the applicant's manager.
3. A minimum of two structured references. One should be from a senior colleague, either a registered genetic nurse or registered genetic counsellor, or a senior medical geneticist who has worked closely with the applicant during the two year period of preparation for registration. The first referee should have been present as an observer during at least two consultations undertaken by the counsellor and provide a short report on the counsellor's competence related to those observations.

The second should be from the applicant's line manager. Where the line manager does not work in the department with the applicant, a third reference from a senior colleague will be required. The references should address the ways in which the applicant:

- a) works within the European genetic counsellor Code of Ethics.
- b) manages a clinical caseload
- c) has access to and uses both counselling and clinical supervision
- d) maintains their professional knowledge and skills
- e) interacts with members of the multi-disciplinary team.

4. Two case studies focusing on a) use of counselling skills and b) ethical aspects of practice. These may be written in the applicant's preferred language and professionally translated into English.

5. A record of Continuing Professional Development undertaken in the previous two years. The applicant must have at least 30 hours of continuing education per year, of these hours, 10 must be taken via sources such as conferences or educational courses. The remaining hours may include: private study of journal articles (up to 5 hours), journal clubs, departmental seminars and preparation for teaching.

### **Grandfather clause**

There are a number of experienced health professionals working as genetic counsellors currently. We therefore propose that a Grandfather clause is introduced for the limited period of three years from the date of the commencement of European registration and that:

- a. Genetic counsellors who have completed a Master degree in genetic counselling and have worked as a genetic counsellor for at least two years are eligible for European registration after completing a reduced portfolio, comprising a case log of 50 cases (verified by a senior colleague) and references from two senior colleagues
- b. Genetic counsellors who have undertaken a one year course in genetic counselling and have completed three years of experience are eligible for European registration after completing a reduced portfolio, comprising a case

log of 50 cases ( verified by a senior colleague), references from two senior colleagues and two case studies

- c. Genetic counsellors who have not undertaken a specific course in genetic counselling and have completed four years of experience are eligible for European registration after completing a full portfolio.

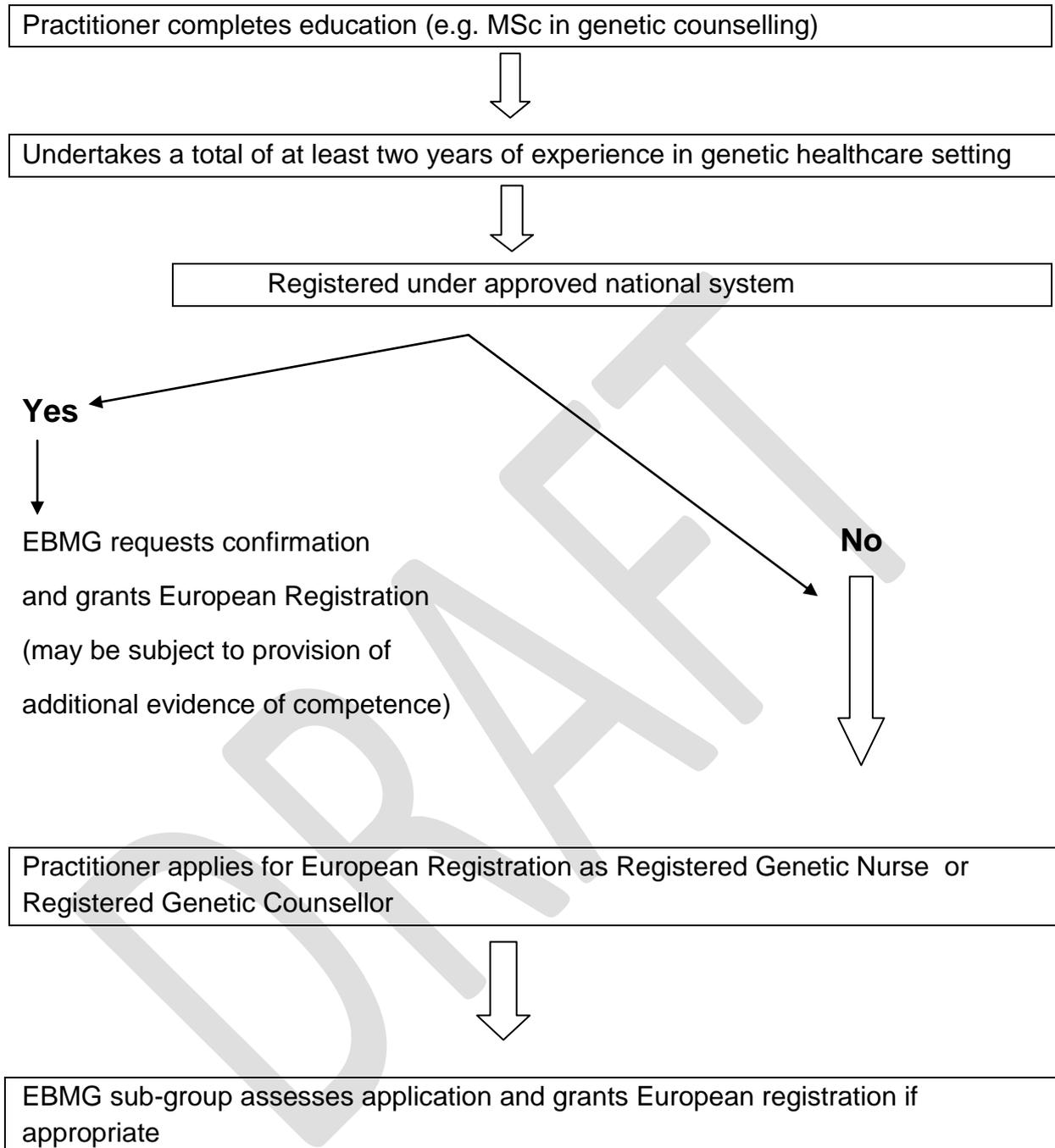
Similar arrangements for genetic nurses will exist.

### **Registration by an applicant already registered in a European Country**

Where a rigorous national system of registration exists, we propose that practitioners who are already registered could apply for entry onto the European register without the need for additional assessment. In such cases, the national registration system will be assessed and approved by the EBMG. In some cases, additional evidence of competence may be required by the European Board. Conversely, national boards may require additional evidence when registering an applicant who already has European registration. Registration at European level will not supersede local registration systems where those exist.

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**Figure 1. Flow chart demonstrating process**



**Table 2. Proposed European Curriculum for MSc Genetic Counselling**

*N.B. The number of the relevant European competence is included in brackets after each topic.*

Topic	Knowledge	Skills	Attitudes
<b>Counselling skills</b>	Enable the student to acquire knowledge on: <ul style="list-style-type: none"> <li>- philosophy of genetic counselling (including a non-directive counselling approach) (1,5,12,14)</li> <li>- relevant counselling theories (1,5,12,14)</li> <li>- core and advanced counselling skills (1,3,4,5,7,12,13,14)</li> <li>- the range of potential psychological and emotional reactions to living with a genetic condition in the family or living at risk (3,4,7)</li> </ul>	Provide adequate opportunity for students to develop the ability to: <ul style="list-style-type: none"> <li>- use of a range of appropriate communication and counselling skills (1,3,5)</li> <li>- communicate effectively with the patient and family (1,3,4,5,14)</li> <li>- assess the patient's psychological state (prior/current) (1,3,4,5,7)</li> <li>- facilitate decision-making (1,3,4,5)</li> <li>- reflect on own practice (11,12,13,14)</li> <li>- adopt a non-judgemental approach (5)</li> <li>- develop self-awareness to reflect on and inform own practice (11,12,13,14)</li> <li>- use clinical and counselling supervision (12,13,14).</li> </ul>	Provide an environment in which the student can develop: <ul style="list-style-type: none"> <li>unconditional acceptance of each individual (1,3,5,12).</li> </ul>
<b>Psychological issues</b>	Enable the student to acquire knowledge on:	Provide adequate opportunity for students to develop the ability to:	

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	<ul style="list-style-type: none"> <li>- relevant psychological theories including grief and loss, responses to risk, impact of event (3d, 5)</li> <li>- impact of family history on individual and family(3d, 5)</li> <li>- impact of positive and negative test results on individual and family (3d, 5)</li> <li>- potential reactions of individuals such as siblings, parents, obligate carriers to genetic risk or test results (3d, 5)</li> <li>- impact of living with disease and test result (4,5)</li> <li>- the nature of pre-symptomatic testing and differences to diagnostic testing (1,3)</li> <li>- the issues related to family communication, including the possibility of non-disclosure of information between family members (3b, 3d).</li> </ul>	<ul style="list-style-type: none"> <li>- prepare a patient for the potential outcomes of a genetic test (3b, 3c, 5)</li> <li>- make the patient aware of possible psychological responses to their situation (5)</li> <li>- support individuals to disclose genetic information to family (3c, 4)</li> <li>- facilitate decision making (5)</li> <li>- use counselling<sup>1</sup> and clinical<sup>2</sup> supervision (10,14)</li> <li>- use skills to explore patients' past and current psychosocial situation (1, 5).</li> </ul>	
<p><b>Medical Genetics</b></p>	<p>Enable the student to acquire knowledge on:</p> <ul style="list-style-type: none"> <li>- inheritance patterns (2)</li> <li>- common genetic conditions (symptoms, prevalence, penetrance, testing options, inheritance pattern,</li> </ul>	<p>Provide adequate opportunity for students to develop the ability to:</p> <ul style="list-style-type: none"> <li>- draw and interpret pedigrees (2)</li> <li>- explain inheritance and genetic concepts in patient appropriate language (3a)</li> </ul>	

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	<p>condition management), including cardiac, neurological, oncology, dysmorphology, metabolic./endocrine, haematology conditions (2, 7)</p> <ul style="list-style-type: none"> <li>- types of mutations (2)</li> <li>- interpretation of test results (2, 7)</li> <li>- technologies for testing (7)</li> <li>- different uses of testing (PST, carrier, PND, diagnostic) (3a, 3b, 7)</li> <li>- application of testing (3b, 7)</li> <li>- research methods (16)</li> <li>- embryology including normal embryology and its relationship to congenital malformations 97)</li> <li>- therapeutic technologies (3b, 13)</li> <li>- Impact of consanguinity (2, 3a) .</li> </ul>	<ul style="list-style-type: none"> <li>- access relevant medical information (2, 7)</li> <li>- Interpret test results (7,13,16)</li> <li>- prepare patients for testing and offering post-test support (3d, 4, 5)</li> <li>- assess genetic risk (2).</li> </ul>	
<p><b>Human genetics</b></p>	<p>Enable the student to acquire knowledge on:</p> <ul style="list-style-type: none"> <li>- structure of DNA, genes and chromosomes (and common terms) (7)</li> <li>- transcription, translation, protein</li> </ul>	<p>Provide adequate opportunity for students to develop the ability to:</p> <ul style="list-style-type: none"> <li>Draw and interpret a family pedigree (2, 6, 7)</li> <li>Explain genetic concepts and concepts or risk/probability to the patient in appropriate and</li> </ul>	

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	<p>synthesis (7)</p> <ul style="list-style-type: none"> <li>- mutations and their effects (7)</li> <li>- meiosis and mitosis (7)</li> <li>- gametogenesis (7)</li> <li>- recombination, non-disjunction, sister chromatic exchange (2, 7)</li> <li>- X-inactivation (2, 7)</li> <li>- inheritance patterns and mechanisms (2, 7)</li> <li>- chromosomal aberrations, structural and numerical (2, 7)</li> <li>- mitochondrial inheritance (2, 7)</li> <li>- patterns of inheritance (2, 7)</li> <li>- multifactorial disease (2, 7)</li> <li>- non-traditional types inheritance eg imprinting (2, 7).</li> <li>- techniques for detecting abnormalities (7)</li> <li>- methods of finding a disease gene (7)</li> </ul>	<p>culturally sensitive language (1, 3)</p> <p>Correlate mutations and chromosomal abnormalities to disease (2, 7).</p>	
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	- epigenetics (2, 7).		
<b>Ethics/Law Sociology</b>	<p>Enable the student to acquire knowledge on:</p> <ul style="list-style-type: none"> <li>- ethical principles for healthcare practice (12)</li> <li>- components of informed consent (1,15)</li> <li>- human rights (including those of the fetus) (12,13)</li> <li>- genetic law and guidelines (11,12,16)</li> <li>- cultural competence (3,4,5,14)</li> <li>- impact of illness and/or disability on the individual, family and society (3,4)</li> <li>- insurance, employment and discrimination issues relevant to genetic conditions (12,16).</li> </ul>	<p>Provide adequate opportunity for students to develop the ability to:</p> <ul style="list-style-type: none"> <li>- work within the ethical and legal framework relevant to their practice and national setting (12)</li> <li>- obtain and record informed consent (6, 13, 15)</li> <li>- practice in a reflective manner (13, 14, 16)</li> <li>- be aware of their own limitations and seek help or guidance when appropriate (13, 14)</li> <li>- deliver non-directive care in a supportive manner (5)</li> <li>- utilise listening skills (1, 7)</li> <li>- be sensitive to the patient's concerns and psychological needs (4, 5, 14).</li> </ul>	<p>Provide an environment in which the student can develop:</p> <ul style="list-style-type: none"> <li>- respect for the individual's culture, values and beliefs.</li> </ul>
<b>Practical preparation</b>	<p>Enable the student to acquire knowledge on:</p> <ul style="list-style-type: none"> <li>- the health service structure in the country of training (4)</li> <li>- sources of support and information for</li> </ul>	<p>Provide adequate opportunity for students to develop the ability to:</p> <ul style="list-style-type: none"> <li>- manage a genetic caseload (8)</li> <li>- develop an empathic relationship with the patient (1, 5, 14)</li> </ul>	

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	<p>self and patients (4, 16)</p> <ul style="list-style-type: none"> <li>- the impact of a genetic condition on individual, family and society (3)</li> <li>- effective functioning of the multi-disciplinary team (10)</li> <li>- the role of health and social care professionals involved with an individual with a genetic condition (4, 10)</li> <li>- counselling skills (1, 5)</li> <li>- communication skills, including contacting patients face to face, by telephone and in writing (1, 5).</li> </ul>	<ul style="list-style-type: none"> <li>- work collaboratively within the multi-disciplinary team (10)</li> <li>- manage cases safely and effectively (8, 14)</li> <li>- produce clear correspondence including referral letters and post-consultation summary letters (3a, 6, 7)</li> <li>- make clear and contemporaneous health records (6)</li> <li>- work within the professional code of conduct for genetic counsellors (12)</li> <li>- work safely as an autonomous practitioner (13, 14, 16)</li> <li>- gain broad experience in different relevant areas of healthcare and/or social care<sup>3</sup> (11, 16)</li> <li>- obtain broad experience in provision of genetic services (10)</li> <li>- develop counselling and communication skills (13, 14, 16)</li> <li>- understand limitations of own skills and knowledge (13).</li> </ul>	
<p><b>Education and research</b></p>	<p>Enable the student to acquire knowledge on:</p> <ul style="list-style-type: none"> <li>- a range of relevant research methods in</li> </ul>	<p>Provide adequate opportunity for students to develop the ability to:</p> <ul style="list-style-type: none"> <li>- conduct critical appraisal of relevant research</li> </ul>	<p>Provide an environment in which the student becomes a lifelong</p>

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	<p>relation to genetic counselling practice<sup>4,5</sup> (15, 16)</p> <p>- tools for use in adult education (9, 14).</p>	<p>evidence (7)</p> <p>- conduct a research study related to genetic counselling<sup>4</sup> (7)</p> <p>- provide education to patients (9)</p> <p>- provide education to other health professionals (9).</p>	<p>learner.</p>
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1. Counselling supervision is 'a contracted, professional relationship between two or more individuals engaged with counselling activities, which leads to reflection on the counselling situation and its structure'<sup>6</sup>.
2. Clinical supervision is formalised support offered within the clinical team to ensure patient safety and the development of the practitioner. It usually involves case discussion and review.
3. The purpose is to help the student understand the impact of a genetic condition on the life of the individual and family.
4. The research should be focussed on genetic counselling, and should not include laboratory research.
5. Social science research methods should be included.

## References

1. Cordier C, Lambert D, Voelckel MA, Hosterey-Ugander U, Skirton H. (2011) A profile of the genetic counsellor and genetic nurse profession in Europe. *Journal of Community Genetics*. Published online 14 December 2011. DOI 10.1007/s12687-011-0073-x.
2. Skirton H, Cordier C, Lambert D, Voelckel MA, Hosterey-Ugander U. (in preparation) Roles and responsibilities of genetic counsellors and genetic nurses in Europe. Submitted to the *European Journal of Human Genetics*.
3. Skirton H, Kerzin-Storrar L, Patch C Barnes C, Guilbert P, Dolling C, Kershaw A, Baines E, Stirling D. (2003) Genetic counsellors - a registration system to assure competence in practice in the United Kingdom. *Community Genetics* 6(3): 182-183.
4. Skirton H, Voelckel MA, Patch C. (2010) Using a community of practice to develop standards of practice and education for genetic counsellors in Europe. *Journal of Community Genetics* 1: 169-173.
5. Miller GE. (1990) The assessment of clinical skills, competence and performance. *Academic Medicine* 65: S63-S67.
6. European Association for Counselling (2012) Counselling Supervision. Accessed at <http://www.eacnet.org/index.php?Standards-and-Ethics/counselling-supervision.html> on 27 February, 2012.

## **Appendix 1. Profile of genetic nurse and counsellor practice in 17 European countries.**

### *Legal framework for genetic counsellors*

Only respondents from France and Norway reported that in their country there was a specific governing legal framework for genetic counsellors. However, in four other countries (Iceland, Sweden, Turkey and UK) the work of genetic counsellors was or would be subject to statutory regulation of a more general nature, for example by laws governing a range of healthcare professions. In contrast, the work of genetic nurses is governed by the statutory regulation of nurses in each individual country and through European law. Although only two respondents stated that working with a medical colleague was a legal requirement for genetic counsellors, a further six (54.4%) replied that this was standard practice.

Respondents from France, Netherlands, Norway, Switzerland and Turkey said it was illegal for genetic counsellors to work outside the supervision of a medical doctor in their country, while genetic counsellors from Iceland, Denmark, Ireland, Sweden and UK stated that genetic counsellors normally worked with medical doctors.

### *Preparation for the role*

There are specific educational programmes for genetic counsellors in seven countries; France, Netherlands, Norway, Portugal, Romania, Turkey, United Kingdom. The number of graduates of these programmes varied from only 2-3 per year in the Netherlands to between 6-18 per year in France, 10-15 per year in Sweden and 5-18 per year in the UK. In Sweden, a one year Master course was previously offered but is no longer running: a new Nordic Master course is planned but has not yet been formally established.

The educational background and professional preparation for the role differed enormously between countries. For example, in France where there is legal governance of genetic counselling, only graduates of a specialised Master course (established after the legislation was introduced) may practice as a genetic counsellor. This was only the case in France; in all other countries where genetic counsellors worked they had a range of professional backgrounds. In Denmark, for example, it was reported that nurses, medical laboratory technologists, midwives and secretaries were all working in a role described as genetic counselling.

### *Professional organisations*

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Organisations created specifically for genetic counsellors and/or genetic nurses now exist in six countries. These are the Norwegian National Association of Genetic Counsellors, French Association of Genetic Counsellors (Association Française des Conseillers en Génétique), Association of Genetic Nurses and Counsellors (UK), Swedish Association of Genetic Counsellors (Svenska föreningen för genetiska vägledare) the Dutch Society of Genetic Counsellors (Nederlandse Vereniging Genetisch Consulenten) and the Spanish Society of Genetic Counsellors (Sociedad Española de Asesoramiento Genético-SEAGen). In several other countries (such as Finland, Italy, Iceland and France), genetic counsellors and/or genetic nurses were members of the national genetics society.

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## **Appendix 2. Professional and educational standards for genetic counsellors in Europe**

This document has been prepared by the members of the European Network of Genetic Nurses and Counsellors, under the auspices of the Ad Hoc Genetic Nurse and Counsellor Accreditation Committee of the European Society of Human Genetics (ESHG). It refers to health professionals working as genetic counsellors. We propose that the professional title 'genetic counsellor' becomes a protected title in Europe to ensure those using this title are appropriately educated and competent in this specialised field of practice.

### **Definition of the profession of genetic counsellor in Europe**

It is important to make a distinction between the activity of genetic counselling, which may be undertaken by a range of health professionals in specific contexts, and the profession of genetic counsellor.

A genetic counsellor is a health professional who has undertaken a period of education and training at Master level to enable them to develop the necessary competences to fulfil the role, as described below. It is envisaged that in the future (by 2020) the standard training and education for a genetic counsellor will be the Master degree in genetic counselling. However, practitioners who have been formally assessed as having the necessary competences at Master level and are accredited legally as genetic counsellors in their own country will also be eligible to use the title 'genetic counsellor' in Europe.

### **Role of the genetic counsellor**

The role of the genetic counsellor includes:

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- To identify the needs of the individual or family and use an empathic, client-centred approach to the provision of genetic counselling
- To collect, select, interpret, confirm and analyse information (including family and medical history, pedigree, laboratory results and literature) relevant to the delivery of genetic counselling for individuals or families
- To help people understand and adapt to the medical, psychological, social and familial implications of genetic contributions to disease
- To assess the chance of disease occurrence or recurrence
- To provide diagnostic information to clients based on family and/or medical history and/or genetic testing
- To provide education about inheritance, testing, management, prevention, resources and research to relevant individuals or families and other healthcare professionals
- To promote informed choices and psychological adaptation to the condition or risk of the condition
- To apply expert knowledge to facilitate the individual or family to access the appropriate healthcare resources, including a medical diagnosis and resources for management of the condition.

### **Setting for practice**

The specialist genetic counsellor works in collaboration with other members of a multi-disciplinary team that includes specialist medical staff. The setting in which the counsellor works may be focussed on a specific disease or genetic setting (such as oncology or prenatal). In general, genetic counsellors will work with families with a pre-established diagnosis or in a general setting under the supervision of a clinical doctor. The genetic counsellor will not be responsible for undertaking clinical examinations as part of the diagnostic process, but is required to have the requisite skills and knowledge to make or confirm a genetic diagnosis based on family or medical history or genetic test results. Genetic counsellors will generally play a larger role in preparing the client for genetic testing, facilitating decision-making and supporting the client psychologically (prior to and after the genetic test or genetic diagnosis) than other members of the multi-disciplinary team.

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Genetic counselling practice (which may include delegation of roles by medical practitioners) must be organised appropriately according to the legal system and health service in each country.

The Ad Hoc Genetic Nurse and Counsellor Committee of the ESHG welcomes the acceptance of medical genetics as a speciality in Europe and regards this step as important to the process of accreditation for genetic counsellors.

### **Competences**

Genetic counsellors are required to have the competences described by the European Society of Human Genetics for genetic counsellors (see Core Competences document). In order to acquire those competences, the practitioner is required to undergo a period of specialised education and practical training. The standard training and education for a genetic counsellor will be the Master of Science degree in genetic counselling.

### **Aim of education and training**

The aim of the education and training for genetic counsellors is to:

1. Ensure that genetic counsellors have the relevant competences to practice appropriately in relevant clinical settings
2. Enable genetic counsellors to develop skills in critical appraisal of evidence that will inform service provision
3. Provide genetic counsellors with an appropriate scientific and research training to facilitate the development of a body of research evidence in the field.

### **Multi-disciplinary education and training**

Genetic counsellors work in a multi-disciplinary environment and the education and training should reflect the involvement of many disciplines required for the development of competence and effective professional working. The primary teachers and mentors will

be qualified and experienced genetic counsellors (preferably with a teaching qualification). In addition, practical and theoretical contributions should be sought from: medical doctors (including clinical geneticists and other specialist and primary care physicians), scientists (in molecular genetics, cytogenetics and embryology), counsellors, psychologists, ethicists, lawyers, social workers, sociologists and epidemiologists. The involvement of service users and patient support groups will also be vital to the training of genetic counsellors.

In turn, it is expected that genetic counsellors will make a substantive contribution to the education of other health care professionals working with clients or patients affected by or at risk of genetic conditions.

### **Content of the education and training**

The Master degree in genetic counselling should include:

- Human genetics (Mendelian and non-Mendelian genetics, cytogenetics, basis knowledge of molecular and biochemical principles, genetic risk determination)
- Medical genetics and clinical aspects of human genetic disease, for example metabolic disorders, congenital malformations, cancer syndromes, multifactorial disorders and mental retardation
- Counselling skills training, including theoretical models to underpin counselling practice, practical skills development and exercises to enhance awareness of the impact of the counsellor's personal history on the counselling process
- Preparation for working in a range of clinical areas, including prenatal, paediatric and adult services in both hospital and community settings
- Psychosocial issues, including the impact of genetic conditions and genetic testing on the individual and family
- Ethics/law/sociology as relevant to genetic counselling practice.

The educational program must include substantial practical experience in a clinical genetics and other relevant settings and research training.

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### **Code of professional practice for genetic counsellors in Europe**

The genetic counsellor will:

1. Respect the human rights of the client, in accordance with the recommendations of the World Health Organisation.
2. Work in accordance with the legal and ethical requirements of the setting and country in which he or she practices.
3. Enable equality of access to services, without discrimination on the basis of ethnicity, religion, belief, gender, disability, age or sexual orientation.
4. Protect confidential information obtained in the course of professional practice and obtain the client's consent to disclose information to other professionals and/or family members.
5. Offer accurate information on the range of options available to clients, while respecting the right of the client to make decisions based on their own beliefs and values.
6. Enable clients to make informed decisions, free from coercion.
7. Avoid any abuse of the professional relationship with clients.
8. Maintain clear, contemporaneous (concurrent) and accurate medical records.
9. Collaborate and co-operate with colleagues to achieve standards of good clinical practice.
10. Act as an advocate for service users, as appropriate.
11. Act appropriately to report concerns about the safety of clients and/or quality of care.
12. Be aware of his or her physical, mental and emotional health and take action to prevent adverse impact on practice.
13. Participate in clinical and counselling supervision.

14. Be aware of his or her personal beliefs and limitations of expertise and refer clients as appropriate to ensure they have access to the full range of services and decision options.
15. Maintain his or her knowledge and skills through continuing professional education.

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**Appendix 3 Core competences for genetic counsellors (Approved by European Society of Human Genetics)**

<b>Competence</b>	<b>Learning outcomes</b>
1. Establish relationship and clarify clients' concerns and expectations.	1.1 Establishes an environment which facilitates client to expression of feelings, anxieties, beliefs, and expectations and considers clients' experiences. 1.2 Identifies client needs. 1.3 Enables clients to make informed choices about the implications of their family history. 1.4 Takes appropriate action to meet identified needs with the agreement of the client.
2. Make appropriate and accurate genetic risk assessment.	2.1 Ascertains sufficient medical, family and personal information from the client to make appropriate genetic risk assessment. 2.2 Ascertains medical information from other sources to confirm family information and diagnosis. 2.3 Acts to ensure the genetic counselling provide to the client is based upon an accurate diagnosis. 2.4 Understands the patterns of inheritance and the underlying mechanisms by which genetic disease may occur.
3. a. Convey clinical and genetic information to clients, appropriate to their individual	3.1 Provides information about the genetic disorder appropriate to the client's assessed needs, reflecting their values, religious and cultural beliefs and preferences. 3.2 Provides information based upon appropriate interpretation of genetic and clinical knowledge.

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<p>needs.</p> <p>3. b. Explain options available to the client, including the risks, benefits and limitations.</p> <p>3. c. Evaluate the understanding of the individual related to the topics being discussed.</p> <p>3. d. Acknowledge the implications of individual and family experiences, beliefs, values and culture for the genetic counselling process.</p>	<p>3.3. Communicates with respect to the genetic risk assessment and possible options.</p> <p>3.4 Supports dissemination of information about the genetic disorder to at risk relatives by the client.</p> <p>3.5 Ensures clients receive appropriate follow-up care and support in respect of the genetic diagnosis and/or test results.</p>
<p>4. Make an assessment of clients' needs and resources and</p>	<p>4.1 Ascertain psychological and social needs of the individual or family.</p> <p>4.2 Respecting clients' preferences, provides support and makes referrals to other agencies (such as psychologist or</p>

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<p>provide support, ensuring referral to other agencies as appropriate.</p>	<p>patient support groups).                      4.3 Identify and support clients' access to local, regional and national resources and services.                      4.4 Applies expert knowledge to facilitate the individual or family to access the appropriate healthcare resources, including a medical diagnosis and resources for management of the condition.</p>
<p>5. Use of a range of counselling skills to facilitate clients' adjustment and decision-making.</p>	<p>5.1 Uses safe, effective and appropriate counselling skills to support clients to make adjustments and decisions.</p>
<p>6. Document information including case notes and correspondence in an appropriate manner.</p>	<p>6.1 Uses a systematic approach to collecting and maintaining comprehensive and accurate records that detail the rationale underpinning any interventions.                      6.2 Maintains confidentiality and security of written and verbal information.</p>
<p>7. Find and utilise relevant medical, genetic and psychosocial information for use in genetic</p>	<p>7.1 Collects, evaluates and uses relevant information about the genetic disorder in question, including psychological and social implications of the disorder and/or genetic testing.                      7.2 Uses a range of psychological and social information to provide psychosocial adjustment and decision-making.                      7.2 Critically appraises current evidence to inform practice and</p>

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counselling.	<p>professional development.</p> <p>7.3 Disseminates evidence of good practice and service improvement through verbal and written media.</p>
8. Demonstrate ability to organise and prioritise a case load.	<p>8.1 Addresses client needs in a sensitive and fair manner , making best use of resources available.</p> <p>8.2 Prioritises according to patient need.</p>
9. Plan, organise and deliver professional and public education	<p>9.1 Facilitates understanding of how genetics impacts on affected individuals, their families, partners and carers.</p> <p>9.2 Seeks to raise awareness of available services and resources related to genetic healthcare.</p> <p>9.3 Acts as a resource for other professionals and lay groups.</p>
10. Establish effective working relationships to function within a multi-disciplinary team and as part of the wider health and social care network.	<p>10.1 Promotes patient-centred care in partnership with the client, their family, and appropriate care providers.</p> <p>10.2 Facilitates communication via a strong multidisciplinary network of professional and lay colleagues.</p> <p>10.3 As appropriate, co-ordinates patient and family care.</p> <p>10.4 Using expert knowledge, contributes to the development of management guidelines or care pathways and implements these, as appropriate.</p>
11. Contribute to the development	<p>11.1 Evaluates own practice and that of others in the light of new evidence and modifies practice appropriately.</p>

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<p>and organisation of genetic services.</p>	<p>11.2 Uses skills of critical appraisal to consider how new evidence may contribute to the improvement of service organisation and delivery.</p> <p>11.3 Actively seeks opportunities to meet with colleagues to discuss professional issues and innovations in care, in order to disseminate best practice and improve standards of care.</p> <p>11.4 Actively seeks opportunities to collaborate with colleagues in audit and research that has the ultimate aim of improving client care</p>
<p>12. Practice in accordance with an appropriate code of ethical conduct.</p>	<p>12.1 Upholds professional standards of safe and ethical practice at all times.</p> <p>12.2 Uses professional standards of practice to evaluate own and others' performance.</p> <p>12.3 Recognises the duty to seek professional advice if standards of care are threatened.</p> <p>12.4 Contributes to the debate on ethical challenges in genetic practice.</p> <p>12.5 In normal circumstances discloses information about individuals to appropriate third parties only with the client's permission.</p>
<p>13. Recognise and maintain professional boundaries and limitations of own</p>	<p>13.1 Recognises practice limitations and demonstrates referrals to other health professionals when appropriate.</p> <p>13.2 Consults other health professionals when the client's needs fall outside the scope of genetic practice.</p> <p>13.3 Refers clients to colleagues when necessary.</p>

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practice.	
14. Demonstrate reflective skills and personal awareness for the safety of individuals and families.	<p>14.1 Demonstrates reflective practice, which informs future clinical interactions.</p> <p>14.2 Utilises clinical supervision to underpin and enhance practice.</p> <p>14.3 Accesses regular counselling supervision to ensure appropriate quality of genetic counselling services.</p>
15. Present opportunities for clients to participate in research projects in a manner that facilitates informed choice.	<p>15.1 Enables clients to make an informed choice on whether to participate in a research project or not.</p>
16. Demonstrate continuing professional development as an individual practitioner and for the development of the profession.	<p>16.1 Actively seeks opportunities to update knowledge and skills, and reflects on the implications of these for own practice and that of professional colleagues.</p>

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