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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:

- 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
- 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.

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 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 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 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 own 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 own knowledge and skills through continuing professional education.

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

a. Genetic counsellor - Professional background

The genetic counsellor has typically completed a relevant first degree (e.g. in nursing, genetics, biology, psychology or social work), followed by a Master's degree in genetic counselling which includes human genetics and counselling skills training.

- **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.

N.B. In some countries, specialist genetic nurses may work in genetics clinics. We suggest the competences for specialist genetic nurses, where these exist, are based on those for genetic counsellors.

Competence	Learning outcomes
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 needs. 3. b. Explain options available to	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.

the client, including the risks, benefits and limitations. 3. c. Evaluate the understanding of the individual related to the topics being discussed. 3. d. Acknowledge the implications of individual and family experiences, beliefs, values and culture for the genetic counselling process.	3.3. Communicates with respect to the genetic risk assessment and possible options. 3.4 Supports dissemination of information about the genetic disorder to at risk relatives by the client. 3.5 Ensures clients receive appropriate follow-up care and support in respect of the genetic diagnosis and/or test results.
4. Make an assessment of clients' needs and resources and provide support, ensuring referral to other agencies as appropriate.	4.1 Ascertains psychological and social needs of the individual or family. 4.2 Respecting clients' preferences, provides support and makes referrals to other agencies (such as psychologist or patient support groups). 4.3 Identify and support clients' access to local, regional and national resources and services. 4.4 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.

5. Use of a range of counselling skills to facilitate clients' adjustment and decision-making.	5.1 Uses safe, effective and appropriate counselling skills to support clients to make adjustments and decisions.
6. Document information including case notes and correspondence in an appropriate manner.	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.
7. Find and utilise relevant medical, genetic and psychosocial information for use in genetic counselling.	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 professional development. 7.3 Disseminates evidence of good practice and service improvement through verbal and written media.
8. Demonstrate ability to organise and prioritise a case load.	8.1 Addresses client needs in a sensitive and fair manner making best use of resources available 8.2 Prioritises according to patient need.
9. Plan, organise and deliver professional and public education	9.1 Facilitates understanding of how genetics impacts on affected individuals, their families, partners and carers. 9.2 Seeks to raise awareness of available services and resources related to genetic healthcare.

	9.3 Acts as a resource for other professionals and lay groups.
10. Establish effective working relationships to function within a multi-disciplinary team and as part of the wider health and social care network.	10.1 Promotes patient-centred care in partnership with the client, their family, and appropriate care providers. 10.2 Facilitates communication via a strong multidisciplinary network of professional and lay colleagues. 10.3 As appropriate, co-ordinates patient and family care. 10.4 Using expert knowledge, contributes to the development of management guidelines or care pathways and implements these, as appropriate.
11. Contribute to the development and organisation of genetic services.	11.1 Evaluates own practice and that of others in the light of new evidence and modifies practice appropriately. 11.2 Uses skills of critical appraisal to consider how new evidence may contribute to the improvement of service organisation and delivery. 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. 11.4 Actively seeks opportunities to collaborate with colleagues in audit and research that has the ultimate aim of improving client care
12. Practice in accordance with an appropriate code of ethical conduct.	12.1 Upholds professional standards of safe and ethical practice at all times. 12.2 Uses professional standards of practice to evaluate own and others' performance.

	12.3 Recognises the duty to seek professional advice if standards of care are threatened. 12.4 Contributes to the debate on ethical challenges in genetic practice. 12.5 In normal circumstances discloses information about individuals to appropriate third parties only with the client's permission.
13. Recognise and maintain professional boundaries and limitations of own practice.	13.1 Recognises practice limitations and demonstrates referrals to other health professionals when appropriate. 13.2 Consults other health professionals when the client's needs fall outside the scope of genetic practice. 13.3 Refers clients to colleagues when necessary.
14. Demonstrate reflective skills and personal awareness for the safety of individuals and families.	14.1 Demonstrates reflective practice, which informs future clinical interactions. 14.2 Utilises clinical supervision to underpin and enhance practice 14.3 Accesses regular counselling supervision to ensure appropriate quality of genetic counselling services.
15. Present opportunities for clients to participate in research projects in a manner that facilitates informed choice.	15.1 Enables clients to make an informed choice on whether to participate in a research project or not.
16. Demonstrate continuing professional	16.1 Actively seeks opportunities to update knowledge and skills, and reflects on the implications of these for own practice

development as an individual practitioner and for the development of the profession.	and that of professional colleagues.

References

Association of Genetic Nurses and Counsellors (2006) Registration. Available a: [http://www.agnc.org.uk/Registration/registration.htm] Accessed 22.11.2006

Greco K, Prows CA, Skirton H, Williams J, Jones S, Middelton L, Lewis J, Bickford C, Humes YD, Seiler M, Carson-Smith M. (2006) Genetics/Genomics Nursing: Scope and Standards of Practice International Society of Nurses in Genetics and American Nurses Association. ISBN- 13: 978-1-55810-234-7.

Skirton H et al (2003) Genetic counsellors - a registration system to assure competence in practice in the United Kingdom. Community Genetics 6(3):182-183.

Skirton H, Lewis C, Kent A, Coviello D. (2010) Genetic education and the challenge of genomic medicine: development of core competences to support preparation of health professionals in Europe. European Journal of Human Genetics http://www.nature.com/doifinder/10.1038/ejhg.2010.64.