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Skirton, Heather

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**A Delphi study to determine the European core curriculum for Master
programmes in genetic counselling**

Running title: European genetic counsellor curriculum

Authors

Heather Skirton

Faculty of Health, Education and Society, Plymouth University, United Kingdom

Sivia Barnoy

Nursing Department, School of Health Professions, Tel-Aviv University, Israel

Charlotta Ingvoldstad

Department of Public Health and Caring science, Uppsala University, Sweden.

Ingrid van Kessel

Department of Clinical Genetics, Erasmus University, Rotterdam, The Netherlands

Christine Patch

Department of Clinical Genetics Guys and St Thomas' NHS Foundation Trust, Kings College London, London UK

Anita O'Connor

Faculty of Health, Education and Society, Plymouth University, United Kingdom

Clara Serra-Juhe

Unitat de Genètica, Universitat Pompeu Fabra, Barcelona, Spain.

Barbara Stayner

Department of Clinical Genetics, Churchill Hospital, Oxford, United Kingdom.

Marie-Antoinette Voelckel

Department of Medical Genetics. La Timone Children Hospital. Marseille. France

Corresponding author:

Professor Heather Skirton

Plymouth University

Wellington Road

Taunton TA1 5Yd, United Kingdom.

Telephone: +44 1823 366911

Fax: +44 1823 366901

Email: heather.skirton@plymouth.ac.uk

Abstract

Genetic counsellors have been working in some European countries for at least 30 years. While there are great disparities between the numbers, education, practice and acceptance of these professionals across Europe, it is evident that genetic counsellors and genetic nurses in Europe are working autonomously within teams to deliver patient care. The aim of this study was to use the Delphi research method to develop a core curriculum to guide the educational preparation of these professionals in Europe. The Delphi method enables the researcher to utilise the views and opinions of a group of recognised experts in the field of study; this study consisted of four phases. Phases 1 and 4 consisted of expert workshops, while data were collected in Phases 2 and 3 ($n=35$) via online surveys. All participants in the study were considered experts in the field of genetic counselling. The topics considered essential for genetic counsellor training have been organised under the following headings: 1) counselling, 2) psychological issues, 3) medical genetics, 4) human genetics, 5) ethics, law and sociology, 6) professional practice and 7) education and research. Each topic includes the knowledge, skills and attitudes required to enable genetic counsellors to develop competence. In addition, it was considered by the experts that clinical practice should comprise 50% of the educational programme. The core Master programme curriculum

will enable current courses to be assessed and inform the design of future educational programmes for European genetic counsellors.

Key words: education, curriculum, genetic counsellor, Delphi study.

Introduction

The multi-disciplinary specialist genetic healthcare team may include allied health professionals who offer direct patient care; genetic nurses and counsellors have been working in some European countries for at least 30 years within such teams¹. Both groups of practitioners require specialist training, for example, in the United Kingdom (UK) genetic counsellors have undertaken a specific Master's degree in genetic counselling, while genetic nurses are required to undertake additional training in both genetic science and counselling skills after completing their degree in nursing². However, a survey of key informants³ from 17 countries conducted in 2009 demonstrated that there were great disparities between the numbers, education, practice and acceptance of these professionals across Europe. For example, in France the genetic counselling profession is governed by a specific law, genetic counsellors must be educated via a specific Master programme and a national organisation for practitioners exists. In Italy however, there are few genetic nurses, no genetic counsellors and no educational programme for either group of practitioners. Despite these disparities, a later study of the roles and practices of genetic counsellors⁴ in 18 countries indicated that they were 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 many situations, there appeared to be flexibility within the team, with the most appropriate person (medical or non-medical) undertaking a clinical task after assessment of the needs of the particular patient.

It is evident that genetic counsellors and genetic nurses in Europe are working autonomously within teams to deliver patient care. A set of competences and educational standards for such practitioners in Europe has been agreed⁵. While Master programmes for education of genetic counsellors exist in France, Israel, Norway, Portugal, Romania, Spain and the United Kingdom, these do not conform to any specific curriculum. Currently a system of assessment of competence for national registration of genetic counsellors and nurses exists in the United Kingdom² and in the Netherlands, but no similar formalised system exists in other European countries. As for any health profession, assuring professional competence is integral to ensuring patient safety. 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. In Europe, therefore, in order to achieve and maintain safe practice for patients, provision of appropriate education and a system of assessing competence of practitioners is required. The organisation of a European certification system for genetic counsellors and genetic nurses is needed and this is being undertaken by the European Board of Medical Genetics (EBMG), under the auspices of the European Society of Human Genetics (ESHG).

To provide a foundation for setting up a certification system for genetic counsellors and genetic nurses in European countries, we needed to define the core curriculum for such practitioners. While it is possible to access curricula of individual institutions within and outside Europe, we were unable to identify any published research on the components of a Master level curriculum in genetic counselling or genetic nursing. The aim of this study was therefore to use research methods to develop a core curriculum to guide the educational preparation of these professionals in Europe.

Materials and Methods

This was a topic on which it was important to access the views of experienced health professionals in the field of genetics and to achieve consensus amongst stakeholders across a range of European countries. We therefore chose to use the Delphi research method⁶ as an appropriate way to address the research question. This method enables the researcher to utilise the views and opinions of a group of recognised experts in the field of study⁶. A Delphi study typically consists of a number of phases but there are no strict criteria for the way in which it is organised⁷; we used a four-stage mixed methods approach. Ethical approval to conduct the study was obtained from the Plymouth University Ethics Committee.

Participants

All participants in the study were considered experts in the field of genetic counselling. In terms of the Delphi approach, experts are considered those who have the requisite knowledge and experience to respond appropriately, but may also have the ability to influence policy⁸. To ensure variation in the sample, we intentionally selected participants from as many European countries as possible. We included individuals

involved in clinical practice and in professional education and those we knew were highly active in professional organisations in their own countries, for example Chairpersons of national genetic counsellor organisations. Although the number of participants in a Delphi study may vary enormously⁶, we planned to recruit between 30 and 40 respondents. As the field is still relatively small in Europe, it was not possible to recruit a large number of experts and we felt that having balanced representation across Europe was important. To be included, participants had to be experienced expert practitioners and/or educators in the field and currently working in a European country. In addition, they had to have previously declared an interest in the development of the profession in Europe (through membership of the European Network of Genetic Nurses and Counsellors). A summary of the phases and participants in each phase is included in Table 1.

Place Table 1 about here

Phase 1.

In the first phase, qualitative data on the topic area were generated⁶ for consideration by experts in the subsequent phases. During a workshop on genetics education attended by six experts in genetic healthcare from four European countries, we held a brainstorming exercise to generate ideas on the potential topics for inclusion in the Master curriculum. The topics that were generated were discussed in depth and grouped under relevant headings such as ‘genetic science’, ‘counselling skills’, ‘medical genetics’ and ‘psychosocial aspect of genetic counselling’ and identified as knowledge, skill or attitude. Following the workshop, the list of topics that had been generated was sent to the experts involved and the list was further extended. As it was important not to allow

the views of the small number of experts to determine exclusion of topics prior to the next phase, all suggested topics were included in the survey in Phase 2.

Phase 2.

In this phase we prepared a survey based on the list of potential curriculum topics. There were 109 topics in total, and each participant was asked to assign a score to each, using a five point Likert scale, where '1' indicated total disagreement with inclusion of the topic for genetic counsellor training and '5' indicated that it was essential. After each section, the participant was asked to make comments on each topic if they wished to do so and invited to suggest further topics for inclusion in the curriculum. Survey Monkey™ software was used to enable access to the survey online.

An email was sent to 40 experts from European countries where genetic nurses or counsellors were practising (n=14 countries): all participants were members of the European Network of Genetic Nurses and Counsellors and were known to be national leaders in the field. We aimed to obtain feedback from practitioners in every European country where genetic counselling was practised or developing. Every potential participant was sent a Participant Information Sheet. Those who accessed the study survey site were asked for their consent to include their responses in the study and were not able to proceed to the survey proper without recording their consent.

Phase 3

The scores from Phase 2 were examined and all topics that 70% or more participants rated as essential were deemed to be appropriate for inclusion in the curriculum. As there was substantial consensus on the topics suggested during Phase 2, we modified the Delphi survey for this phase. We reported the high degree of consensus on the relevant topics and removed them from the survey. This enabled us to shorten the survey and so

reduce the chance of ‘respondent fatigue’⁶ and increase the response rate. We then provided feedback on the Phase 2 response rates on the remaining topics and asked the respondents to decide whether they should or should not be included in the curriculum.

Phase 4

A face to face two day workshop of eight European genetic nurse or counsellor leaders was convened to finalise the curriculum. The scores from both Phase 2 and Phase 3 of the study were presented to all attendees, along with any comments made by study participants in the particular topics. All topics were discussed and using the Delphi results as the guide, the curriculum was finalised. Each curriculum topic was mapped to the European core competences⁹ to ensure the educational programmes facilitated development of all the necessary competences.

Results

Profile of respondents

In Table 1 we provide an overview of the number and type of participants in each phase. The 35 participants who responded to either or both Phases 2 and 3 were drawn from 17 European countries (Figure 1). The demographic characteristics of respondents for Phases 2 and 3 are presented in Table 2; in Phase 2, 73.3% described themselves as genetic counsellors, and 75.8% had worked as either a genetic counsellor or genetic nurse for five years or more.

In Table 3 we present the data on the number of respondents who responded in Phase 2 that the specific topic was essential to genetic counsellor education. In Phase 3, respondents were asked to consider whether those topics considered by less than 70% as essential in Phase 2 (P2) should be included in the curriculum. Phase 3 (P3) responses

(where relevant) are also presented in Table 3. In accordance with the results, in Phase 4 the following topics were omitted from the final curriculum: 1) pedagogic theory relevant to patient and health professional education (P2 score 48.1%, P3 score 60%), 2) theoretical constructs of disability (P2 score 22.2%, P3 score 69.6%), 3) performing venesection (P2 score 25.9%, P3 score 25%), 4) adult educational practice and theory (P2 score 34.6%, P3 score 60%), and 5) gaining broad experience in health and social care settings (P2 score 63%, P3 score 65.2%). However, as one of the descriptors of a Master level programme is to enable students to develop an ability to critique research and this is an essential skill for those using evidence based practice, the participants of the workshop strongly believed that it was not possible to omit the topics on ability to critique research, knowledge of relevant research methods (particularly social science methods) and conduct of a research study. They did emphasise however that the study should be related to genetic counselling practice to maximise relevance to the clinical role.

Finally, during Phase 4 we mapped the topics to the European core competences⁹ for genetic counsellors to ensure all topics were relevant and all competences were covered by the curriculum. The final curriculum, as completed during Phase 4, and relevant core competences for each topic is presented in Table 3. In addition, the requirements for the practical component of the Master course (Figure 2) were elucidated by the participants of Phase 4, who believed that the considerable supervised practical experience was a key component of the Master degree course, to prepare the individual to work in a range of clinical areas in hospital and community settings and to provide a service for families in differing clinical scenarios, for example prenatal diagnosis and presymptomatic or carrier testing. It was considered that the practical component of the

Master programme should comprise approximately 50% of the learning hours. With respect to the term ‘supervision’ used in the curriculum, 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’¹⁰. This type of supervision should be provided by an experienced, trained counsellor or psychologist who is skilled in enabling practitioners to explore the impact of their own personal beliefs and issues on their professional relationships with clients. Counselling supervision may be offered individually or in a group. Clinical supervision is formalised support offered within the clinical team by a senior practitioner, to ensure patient safety and the development of the practitioner. It usually involves case discussion and review.

Discussion

As far as we could ascertain, this is the first core curriculum for genetic counsellors that is based on data collected using a validated and appropriate research method. The Delphi method has been used in many other situations to determine the views of experts and we considered that the establishment of a core curriculum for Europe required input from those who were actually working in the field. The use of online methods of data collection enabled us to elicit the views of practitioners across a wide range of countries, while the face to face workshops facilitated deep discussion on key points. It may have been helpful to widen the survey in Phases 2 and 3 to include more practitioners, but we were focussing on the views of professional leaders and those with extensive experience in each country. One weakness was the lack of input from several countries where genetic counsellors practise, including Ireland and Cyprus.

In keeping with other health professions such as medicine¹¹ and nursing¹², there is a clear need for clinical placements to be incorporated into the educational pathway to professional practice. The recommendation that 50% of the programme should be based in practice is consistent with educational programmes in nursing¹³, but there are of course financial implications of such a programme for both institutions and students. Due to the need for extensive practical experience as well as theoretical preparation, the Master programme will usually require two years or more to complete. In addition, placing students in suitable clinical environments can be challenging, especially in countries where the profession is not firmly established. Where there are few senior experienced genetic counsellors, clinical supervision will of necessity fall to colleagues from other disciplines, mainly medicine and counselling psychology. As genetic counsellors work in multi-disciplinary teams, this should not be to the detriment of the training, however it is important that mentoring in the professional role is a key component of the training and should be chiefly undertaken by an experienced genetic counsellor wherever possible.

Curricula are frequently devised in institutional settings, albeit by academics who have some experience of the field. This curriculum has been grounded in practice, not only because it was developed by a wide range of experienced practitioners, but also through alignment with the core competences developed for genetic counsellors and nurses in Europe⁹. The core curriculum can now be used to inform the design of new courses, while further work is now required to assess the curricula for existing Master level courses to determine whether they are compatible with these recommendations.

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References

1. Skirton H, Barnes C, Curtis G, Walford Moore J: The role and practice of the genetic nurse: Report of the AGNC working party. *J Med Genet* 1997; **34**: 141-147.
2. Skirton H, Kerzin-Storrar L, Patch C *et al*: Genetic counsellors: a registration system to assure competence in practice in the United kingdom. *Community Genetics* 2003; **6**: 182-183.
3. Cordier C, Lambert D, Voelckel M-A, Hosterey-Ugander U, Skirton H: A profile of the genetic counsellor and genetic nurse profession in European countries. *Journal of Community Genetics* 2012; **3**: 19-24.
4. Skirton H CC, Lambert D, Hosterey-Ugander U, Voelckel MA, O'Connor A,: A study of the practice of individual genetic counsellors and genetic nurses in Europe. *Journal of Community Genetics* In review.
5. Skirton H, Patch C, Voelckel M-A: Using a community of practice to develop standards of practice and education for genetic counsellors in Europe. *Journal of Community Genetics* 2010; **1**: 169-173.
6. Keeney S, Hasson F, McKenna H: Consulting the oracle: ten lessons from using the Delphi technique in nursing research. *Journal of Advanced Nursing* 2006; **53**: 205-212.
7. Mead D, L. M: The use of the Delphi as a research approach *Nurse Researcher* 2001; **8**: 4-23.
8. Baker J, Lovell K, Harris N: How expert are the experts? An exploration of the concept of 'expert' within Delphi panel techniques. *Nurse Researcher* 2006; **14**: 59-70.
9. Skirton H, Lewis C, Kent A, Coviello DA, Members of Eurogentest U, Committee EE: Genetic education and the challenge of genomic medicine: development of core competences to support preparation of health professionals in Europe. *Eur J Hum Genet* 2010; **18**: 972-977.

10. European Association for Counselling: Counselling Supervision. Accessed at <http://wwwweacnetorg/indexphp?/Standards-and-Ethics/counselling-supervisionhtml> on 27 February, 2012
11. Bleakley A: The curriculum is dead! Long live the curriculum! Designing an undergraduate medicine and surgery curriculum for the future. *Medical Teacher* 2012; **34**: 543-547.
12. Courtney-Pratt H, FitzGerald M, Ford K, Marsden K, Marlow A: Quality clinical placements for undergraduate nursing students: a cross-sectional survey of undergraduates and supervising nurses. *Journal of Advanced Nursing* 2012; **68**: 1380-1390.
13. Nursing and Midwifery Council: Pre-registration nursing education in the UK 2010.

Table 1. Summary of Delphi study phases and participants

| Phase number and description | Participants | Number of participants | Notes |
|-------------------------------------|---|-------------------------------|--|
| Phase 1. Face to face workshop | Experts in genetic healthcare from four European countries | 6 | Three participants were experienced educators in the field of health genetics as well as being genetic counsellors, two were health genetics educators and the remaining person was an experienced genetic counsellor |
| Phase 2. First survey round | Members of the European Network of Genetic Nurses and Counsellors, all considered national leaders in the field | 33 | 40 potential participants from 14 European countries were sent an invitation (82% response rate) |
| Phase 3. Second survey round | As Phase 2. | 27 | As Phase 2. However, some of those who failed to respond in Phase 2 responded in Phase 3, and vice versa |
| Phase 4. Face to face workshop | European genetic nurse or counsellor leaders | 8 | The participants were from six countries. Two had attended the initial workshop in Phase 1. Six of the eight participants were actively involved in delivering Master level education to genetics healthcare professionals |

Table 2. Demographic characteristics of respondents to Phases 2 and 3

| Demographic Characteristics | Phase 2 | Phase 3 |
|---|-----------------|-----------------|
| Professional Title | % (n=30) | % (n=26) |
| Genetic Nurse | 13.3 (4) | 11.5 (3) |
| Genetic Counsellor | 73.3 (22) | 50.0 (13) |
| Other | 13.3 (4) | 38.5 (10) |
| Years working as a Genetic Nurse or Genetic Counsellor | % (n=33) | % (n=27) |
| Less than one year | 12.1 (4) | 14.8 (4) |
| Between 1 and 3 years | 6.1 (2) | 7.4 (2) |
| Between 3 and 5 years | 6.1 (2) | 11.1 (3) |
| Between 5 and 10 years | 36.4 (12) | 33.3 (9) |
| Between 10 and 15 years | 21.2 (7) | 11.1 (3) |
| Between 15 and 20 years | 15.2 (5) | 18.5 (5) |
| Between 20 and 25 years | 3.0 (1) | 3.7 (1) |
| Over 25 years | 0 | 0 |

Table 3. Data from Phase 2 and 3 showing percentage scores for each topic and relation to core competences

| Topic | Phase 2 % of respondents who rated the topic 'essential for GC training' | Phase 3 * % of respondents who rated the topic 'required for GC training' | European core competence to which topic relates (see Supplemental file 1 for a list of the competences) |
|---|---|--|--|
| <i>Counselling Knowledge</i> | | | |
| Relevant counselling theories | 70.4 | | 1,5,12,14 |
| Core and advanced counselling skills | 92.6 | | 1,3,4,5,7,12,13,14 |
| The range of potential psychological and emotional reactions to living with a genetic condition in the family or living at risk | 85.2 | | 3,4,7 |
| Appropriate use of a non-directive counselling approach | 77.8 | | 1,5,12,14 |
| <i>Counselling Skills</i> | | | |
| Use a range of appropriate communication and counselling skills | 92.6 | | 1,3,5 |
| Communicate effectively with the patient and family | 92.6 | | 1,3,4,5,14 |
| Assess the patient's psychological state (prior/current) | 76.9 | | 1,3,4,5,7 |
| Facilitate decision-making | 92.6 | | 1,3,4,5 |
| Reflect on own practice | 66.7 | 92.0 | 11,12,13,14 |
| Adopt a non-judgemental approach | 74.1 | | 5 |
| Develop self-awareness to reflect on and inform own practice | 74.1 | | 11,12,13,14 |

| | | |
|---|------|----------|
| Use clinical and counselling supervision | 74.1 | 12,13,14 |
| <i>Counselling Attitudes</i> | | |
| Develop unconditional acceptance of each individual | 77.8 | 1,3,5,12 |

| <i>Psychosocial Knowledge</i> | | |
|---|------|-----------|
| Relevant psychological theories including grief and loss, responses to risk, impact of event | 70.4 | 3d, 5 |
| Impact of family history on individual and family | 81.5 | 3d, 5 |
| Impact of positive and negative test results on individual and family | 80.8 | 3d, 5 |
| Potential reactions of individuals such as siblings, parents, obligate carriers to genetic risk or test results | 70.4 | 3d, 5 |
| Impact of living with disease and test result | 81.5 | 4,5 |
| The nature of pre-symptomatic testing and differences to diagnostic testing | 77.8 | 1,3 |
| Possibility of non-disclosure among family members | 70.4 | 3b, 3d |
| <i>Psychosocial Skills</i> | | |
| Prepare a patient for both outcomes of a genetic test | 96.3 | 3b, 3c, 5 |
| Make the patient aware of possible psychological responses to their situation (normalise) | 81.5 | 5 |
| Support individuals to disclose genetic | 81.5 | 3c, 4 |

| | | |
|--|------|--------------|
| information to family | | |
| Facilitate decision making | 85.2 | 5 |
| Use counselling and clinical supervision | 70.4 | 10, 14 |
| Use tools to explore patients' past and current psychosocial situation | 59.3 | 79.2 1, 5 |

| <i>Medical Genetics Knowledge</i> | | | |
|---|------|-------|-----------|
| Traditional and non-traditional inheritance patterns | 88.9 | | 2 |
| Common genetic conditions (symptoms, prevalence, penetrance, testing options), including cardiac, neurological, oncology, dysmorphology, metabolic/endocrine, haematology | 81.5 | | 2,7 |
| Types of mutations | 59.3 | 100.0 | 2 |
| Interpretation of test results | 70.4 | | 2,7 |
| Technologies for testing | 33.3 | 84.0 | 7 |
| Different uses of testing (presymptomatic, prenatal, carrier, diagnostic) | 74.1 | | 3a, 3b, 7 |
| Applications of testing | 55.6 | 84.0 | 3b, 7 |
| Research methods | 33.3 | 76.0 | 16 |
| Embryology including normal embryology and its relationship to congenital malformations | 25.9 | 80.0 | 7 |
| Therapeutic technologies | 29.6 | 72.0 | 3b, 13 |
| Impact of consanguinity | 59.3 | 95.8 | 2,3a |
| <i>Medical Genetics Skills</i> | | | |
| Draw and interpret pedigrees | 88.9 | | 2 |

| | | |
|--|------|----------|
| Explain inheritance and genetic concepts in patient appropriate language | 88.9 | 3a |
| Access relevant medical information | 77.8 | 2,7 |
| Interpret test results | 66.7 | 73.9 |
| Prepare patients for testing and offering post-test support | 81.5 | 3d, 4, 5 |
| Assess genetic risk | 77.8 | 2 |

| <i>Human Genetics Knowledge</i> | | | |
|--|------|-------|------|
| Structure of DNA, genes and chromosomes (and common terms) | 85.2 | 7 | |
| Transcription, translation, protein synthesis | 51.9 | 83.3 | 7 |
| Mutations and their effects | 66.7 | 96.0 | 7 |
| Meiosis and mitosis | 44.4 | 92.0 | 7 |
| Gametogenesis | 37.0 | 84.0 | 7 |
| Recombination, non-disjunction, sister chromatid exchange | 55.6 | 96.0 | 2, 7 |
| X-inactivation | 48.1 | 100.0 | 2, 7 |
| Inheritance patterns and mechanisms | 88.9 | | 2, 7 |
| Chromosomal aberrations, structural and numerical | 81.5 | | 2, 7 |
| Patterns of inheritance | 92.6 | | 2, 7 |
| Mitochondrial inheritance | 70.4 | | 2, 7 |
| Multifactorial disease | 74.1 | | 2, 7 |
| Non-traditional types inheritance eg imprinting | 61.5 | 100.0 | 2, 7 |
| Techniques for detecting abnormalities | 44.4 | 91.7 | 7 |
| Methods of finding a disease gene | 40.7 | 78.3 | 7 |
| Epigenetics | 42.3 | 91.7 | 2, 7 |

| <i>Human Genetics Skills</i> | | |
|---|------|---------|
| Draw and interpret a family pedigree | 92.6 | 2, 6, 7 |
| Explain genetic concepts and concepts or risk/probability to the patient in appropriate and culturally sensitive language | 85.2 | 1, 3 |
| Correlate mutations and chromosomal abnormalities to disease | 74.1 | 2, 7 |

| <i>Ethics, legal and social issues knowledge</i> | | |
|---|------|---------------------|
| Ethical principles for healthcare practice | 88.9 | 12 |
| Components of informed consent | 85.2 | 1, 15 |
| Human rights (including those of the fetus) | 59.3 | 87.5 12, 13 |
| Genetic law and guidelines | 66.7 | 96.0 11, 12, 16 |
| Cultural competence | 61.5 | 83.3 3, 4, 5, 14 |
| Impact of illness and/or disability on the individual, family and society | 74.1 | 3, 4 |
| Discrimination issues | 44.4 | 78.3 12, 16 |
| Insurance and employment issues relevant to genetic conditions | 44.4 | 92.0 12, 16 |

| <i>Ethics, legal and social issues skills</i> | | |
|---|------|------------|
| Work within the ethical and legal framework relevant to their practice and national setting | 84.6 | 12 |
| Obtain and record informed consent | 92.3 | 6, 13, 15 |
| Practice in a reflective manner | 88.5 | 13, 14, 16 |
| Be aware of their own limitations and seek help or guidance when appropriate | 88.5 | 13, 14 |
| Deliver non-directive care in a supportive manner | 88.5 | 5 |
| Utilise listening skills | 92.3 | 1, 7 |

| | | |
|--|------|----------|
| Be sensitive to the patient's concerns and psychological needs | 88.5 | 4, 5, 14 |
| <i>Ethics, legal and social issues attitudes</i> | | |
| Develop respect for the individual's culture, values and beliefs | 96.3 | 4, 5, 10 |

| <i>Professional Practice - Knowledge</i> | | |
|---|------|----------|
| The health service structure in the country of training | 70.4 | 4 |
| Sources of support and information for self and patients | 77.8 | 4, 16 |
| Impact of a genetic condition on individual, family and society | 81.5 | 3 |
| Effective functioning of the multi-disciplinary | 74.1 | 10 |
| The role of health and social care professionals involved with an individual with a genetic condition | 70.4 | 4, 10 |
| Counselling skills | 92.6 | 1, 5 |
| Communication skills, including contacting patients face to face, by telephone and in writing | 88.9 | 1, 5 |
| <i>Professional Practice - Skills</i> | | |
| Manage a genetic caseload | 74.1 | 8 |
| Develop an empathic relationship with the patient | 92.6 | 1, 5, 14 |
| Work collaboratively within the multi-disciplinary team | 85.2 | 10 |
| Manage cases safely and effectively | 85.2 | 8, 14 |

| | | |
|---|------|------------|
| Produce clear correspondence including referral letters and post-consultation summary letters | 85.2 | 3a, 6, 7 |
| Make clear and contemporaneous health records | 70.4 | 6 |
| Work within the professional code of conduct for genetic counsellors | 85.2 | 12 |
| Work safely as an autonomous practitioner | 81.5 | 13, 14, 16 |
| Obtain broad experience in provision of genetic services | 66.7 | 96.0 |
| Develop counselling and communication skills | 92.6 | 13, 14, 16 |
| Understand limitations of own skills and knowledge | 88.9 | 13 |

| <i>Education and research - knowledge</i> | | | |
|---|------|-------------|---------------|
| A range of relevant research methods relevant to genetic counselling practice | 48.1 | 68.2 | 15, 16 |
| <i>Education and research - skills</i> | | | |
| Conduct critical appraisal of relevant research evidence | 59.3 | 68.0 | 7 |
| Conduct a research study | 33.3 | 62.5 | 7 |
| Provide education to patients | 59.3 | 84.0 | 9 |
| Provide education to other health professionals | 55.6 | 88.0 | 9 |
| <i>Education and research - attitudes</i> | | | |
| Become a lifelong learner | 81.5 | 7,9,13,16 | |

Table 3 Legend

*** Only those topics where less than 70% respondents considered it essential in Phase 2 were included in the Phase 3 round**

Figure 1. Number of respondents in Phases 2 and 3 by country

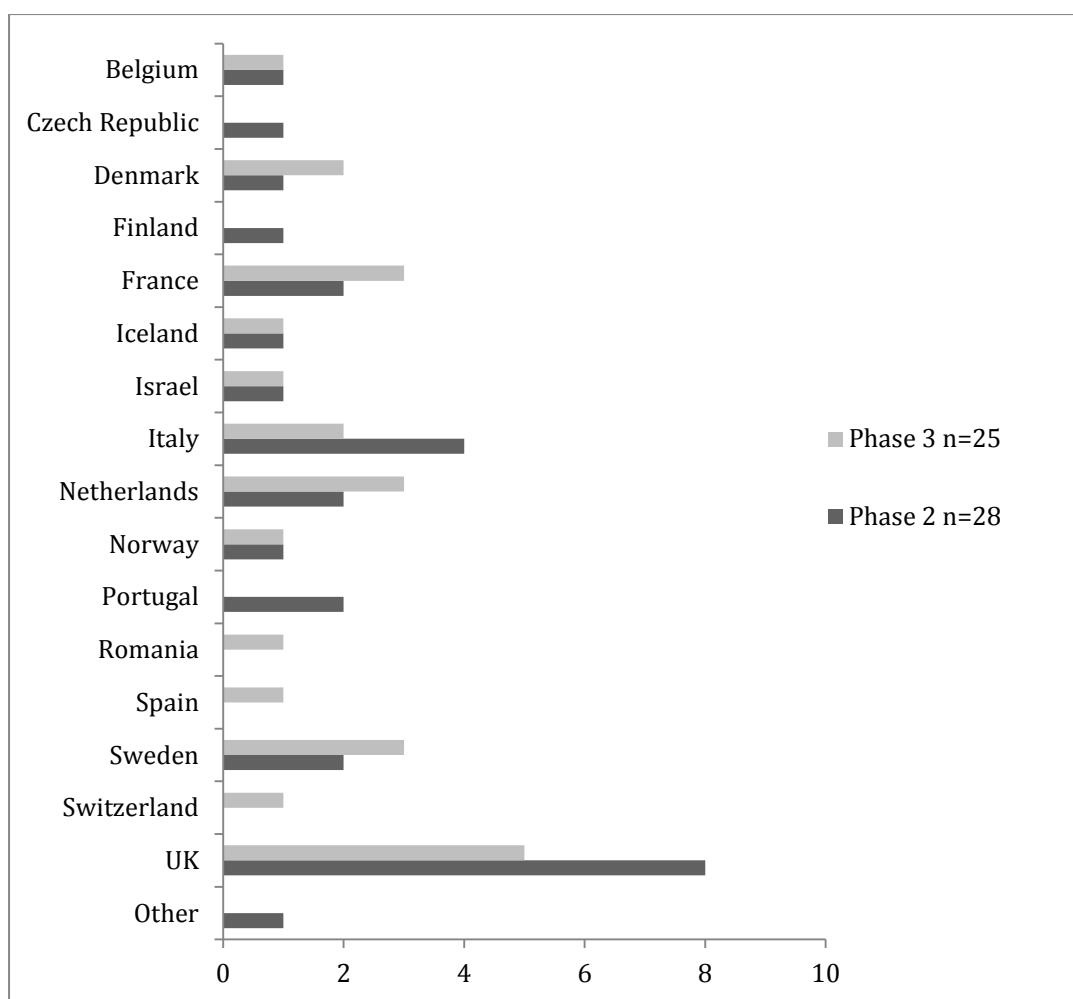


Figure 2. Requirements for practical placements

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.

Supplemental file 1: Core competences for genetic counsellors⁹

| Competence | Learning outcomes |
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| 1. Establish relationship and clarify clients' concerns and expectations. | <p>1.1 Establishes an environment which facilitates client to expression of feelings, anxieties, beliefs, and expectations and considers clients' experiences.</p> <p>1.2 Identifies client needs.</p> <p>1.3 Enables clients to make informed choices about the implications of their family history.</p> <p>1.4 Takes appropriate action to meet identified needs with the agreement of the client.</p> |
| 2. Make appropriate and accurate genetic risk assessment. | <p>2.1 Ascertains sufficient medical, family and personal information from the client to make appropriate genetic risk assessment.</p> <p>2.2 Ascertains medical information from other sources to confirm family information and diagnosis.</p> <p>2.3 Acts to ensure the genetic counselling provided to the client is based upon an accurate diagnosis.</p> <p>2.4 Understands the patterns of inheritance and the underlying mechanisms by which genetic disease may occur.</p> |
| 3. a. Convey clinical and genetic information to clients, appropriate to their individual needs. 3. b. Explain options available to 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. | <p>3.1 Provides information about the genetic disorder appropriate to the client's assessed needs, reflecting their values, religious and cultural beliefs and preferences.</p> <p>3.2 Provides information based upon appropriate interpretation of genetic and clinical knowledge.</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> |
| 4. Make an assessment of clients' needs and resources and provide support, | <p>4.1 Ascertains 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 patient support groups).</p> |

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| ensuring referral to other agencies as appropriate. | <p>4.3 Identify and support clients' access to local, regional and national resources and services.</p> <p>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> |
| 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. | <p>6.1 Uses a systematic approach to collecting and maintaining comprehensive and accurate records that detail the rationale underpinning any interventions.</p> <p>6.2 Maintains confidentiality and security of written and verbal information.</p> |
| 7. Find and utilise relevant medical, genetic and psychosocial information for use in genetic counselling. | <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.</p> <p>7.2 Uses a range of psychological and social information to provide psychosocial adjustment and decision-making.</p> <p>7.2 Critically appraises current evidence to inform practice and 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> |

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| 11. Contribute to the development and organisation of genetic services. | <p>11.1 Evaluates own practice and that of others in the light of new evidence and modifies practice appropriately.</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> |
| 12. Practice in accordance with an appropriate code of ethical conduct. | <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> |
| 13. Recognise and maintain professional boundaries and limitations of own practice. | <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> |
| 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 | <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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