ARTICLE

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

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Genetic counsellors have been working in some European countries for at least 30 years. Although 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, whereas 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.

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INTRODUCTION

The multidisciplinary specialist genetic health-care 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 teams.¹ 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 nursing.² 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 important roles in the

multidisciplinary genetic health-care 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 agreed.⁵ While Master programmes for education of genetic counsellors exist in France, Israel, Norway, Portugal, Romania, Spain and the UK, 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 UK² 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, because of low populations and

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low numbers of practitioners, it will not be feasible to introduce registration systems in every country. In Europe, therefore, 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 among 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 study.⁶ A Delphi study typically consists of a number of phases, but there are no strict criteria for the way in which it is organised;⁷ 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 policy.⁸ 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 enormously,⁶ 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.

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 health care 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 before the next phase, all suggested topics were included in the survey in Phase 2 (P2).

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 (Palo Alto, CA, USA) 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 P2 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 P2, 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 P2 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 2-day workshop of eight European genetic nurse or counsellor leaders was convened to finalise the curriculum. The scores from both P2 and Phase 3 (P3) 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 P2 and P3 were drawn from 17 European countries (Figure 1). The demographic characteristics of respondents for P2 and P3 are presented in Table 2; in P2, 73.3% described themselves as genetic counsellors, and 75.8% had worked as either a genetic counsellor or genetic nurse for 5 years or more.

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

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 health care 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	Forty 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 <i>vice versa</i>
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 health-care professionals

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

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

Table 2 Demographic characteristics of respondents to Phases 2 and 3

Demographic characteristics	Phase 2 % (n = 30)	Phase 3 % (n = 26)
<i>Professional title</i>		
Genetic nurse	13.3 (4)	11.5 (3)
Genetic counsellor	73.3 (22)	50.0 (13)
Other	13.3 (4)	38.5 (10)
<i>Years working as a genetic nurse or genetic counsellor</i>		
< 1 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

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.

Table 3 Data from Phases 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 ^a % Of respondents who rated the topic 'required for GC training'	European core competence to which topic relates (see Supplementary information 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 and 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 presymptomatic 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 information to family	81.5		3c, 4
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 and 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

Table 3 (Continued)

Topic	Phase 2 % Of respondents who rated the topic 'essential for GC training'	Phase 3 ^a % Of respondents who rated the topic 'required for GC training'	European core competence to which topic relates (see Supplementary information for a list of the competences)
<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	7, 13, 16
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 and 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 and 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, for example, 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 health-care practice	88.9		12
Components of informed consent	85.2		1, 15
Human rights (including those of the foetus)	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

Table 3 (Continued)

Topic	Phase 2 % Of respondents who rated the topic 'essential for GC training'	Phase 3 ^a % Of respondents who rated the topic 'required for GC training'	European core competence to which topic relates (see Supplementary information for a list of the competences)
<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 multidisciplinary	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 multidisciplinary 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	10
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

^aOnly those topics where <70% respondents considered it essential in Phase 2 were included in the Phase 3 round.

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, whereas the face-to-face workshops facilitated deep discussion on important points. It may have been helpful to widen the survey in P2 and P3 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 nursing,¹² 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 nursing,¹³ but there are of course financial implications of such a programme for both institutions and students. Owing to the need for extensive practical experience as well as theoretical preparation, the Master programme will usually require 2 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 multidisciplinary teams, this should not be to the detriment of the training; however, it is important that mentoring in the professional

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.

Figure 2 Requirements for practical placements.

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 Europe.⁹ 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.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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