

**Title:** The perceived impact of the European Registration system for genetic counsellors and nurses

**Running title:** Perceived impact of professional registration

This is the author's accepted manuscript. The final published version of this work (the version of record) is published by Nature Publishing in the European Journal of Human Genetics (2017) available at: [10.1038/ejhg.2017.84].

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**Conflict of Interest statement:** the authors declare no conflicts of interest.

## **Abstract**

The aim of the European Board of Medical Genetics has been to develop and promote academic and professional standards necessary in order to provide competent genetic counselling services. The aim of this study was to explore the impact of the European registration system for genetic nurses and counsellors from the perspectives of those professionals who have registered. Registration system was launched in 2013. A cross-sectional, online survey was used to explore the motivations and experiences of those applying for and the effect of registration on their career. Fifty-five Genetic Nurses and Counsellors are registered till now, from them, thirty-three agreed to participate on this study. The main motivations for registering were for recognition of their work value and competence (30.3%); due to the absence of a registration system in their own country (15.2%) and the possibility of obtaining a European/international certification (27.3%), while 27.3% of respondents registered to support recognition of the genetic counselling profession. Some participants valued the registration process as an educational activity in its own right while the majority indicated the greatest impact of the registration process was on their clinical practice. The results confirm that registrants value the opportunity to both confirm their own competence and advance the genetic counselling profession in Europe.

**Keywords:** professional registration, non-medical healthcare professionals, European genetic services

## **Introduction**

In the context of healthcare, having a qualified workforce is essential to provide appropriate patient care. This requires individual health professionals to have the capacity for assimilation of and adaptation to new approaches to enable patients to benefit from innovations such as advances in diagnostic, preventative and therapeutic advances in clinical genetics<sup>1</sup>.

Traditionally a medically-led field, clinical genetics has evolved into a multidisciplinary service where other non-medical allied health professionals, such as specialised genetic nurses and genetic counsellors, are also key players in the delivery of high quality patient care<sup>2,3</sup>. This has arisen partly in response to the expansion of the need for these services<sup>4</sup>. Genetic nurses and counsellors combine expertise in medical genetics with the ability to communicate scientific information in an empathetic manner to patients and their families<sup>5</sup>.

In a young but quickly evolving field such as genetic counselling, professional registration is especially relevant. Registration is a formal process based on achievement of a set of competencies, following a periodic evaluation based on agreed standards<sup>6</sup>. While the registration system at European level was established in 2013<sup>3</sup> there are countries with a longer tradition of professional registration in the field of genetic counselling, such as the USA (since 1982), Australia (1989), Canada (1998) and the United Kingdom (2001)<sup>7</sup>. Unfortunately registration is not an option in the majority of European countries<sup>8-10</sup>.

The journey to the establishment of a European registration system has been published elsewhere<sup>3</sup>. While the process has been assessed informally, there has been no previous formal evaluation of the impact of the European registration system from the perspectives of those registered professionals. The objectives of this study were to explore: 1) the experiences of those applying for registration; 2) their motives for registering; and 3) the effect of registration on the individual's career.

## **Materials and methods**

### **Design**

We undertook a descriptive, cross-sectional online survey inviting all registered professionals (n=55) to participate. Detailed methods are included in the supplemental material.

### **Results**

Thirty-three European Registered Genetic Nurses and Counsellors responded to the survey (61.0% response rate): demographic details and information about their background and route of access for registration are presented in Table 1, 2 and Figure 1.

In an open question regarding motivation for registering, participants were asked to comment on their main motivation, 30.3% (n=10) of the respondents considered the registration would be relevant for their career development and as recognition of their work value and competence, 9 (27.3%) registered to obtain a European/international certification and for 6 (15.2%), registration was important because of the absence of a registration system in their own country. Nine (27.3%) registered to support the process and/or collaborate in the

development of the genetic counselling profession. Four (12.1%) respondents considered registration would be valuable to seek other job opportunities in another European country.

The majority (60.6%, n= 20) of the participants agreed that the registration process was very straightforward. However 27.28% (n=9) of the participants found it laborious and time consuming. Four (12.1%) reported that the registration process was interesting and insightful and reported satisfaction in gaining an overview of their own work. The major challenge reported was time allocation for registration (18.2 %, n=6). Anonymized quotes of participants' opinion on the registration process are in the supplementary material.

As to professional status, participants felt that registration gave them credibility among colleagues and enhanced their professional visibility. Some of the participants valued the registration process as an educational activity in its own right, by reflection on their own practice and continuing professional activities, as well as consideration of ethical issues of daily practice. Some participants felt that the case log requirement of 20% cases outside of their specialty area was a challenge that allowed them to re-connect with other areas of genetics. The majority (84.4%, n= 28) had already felt an impact on their clinical practice and 66.7% (n=22) on their career development, while five (15.5%) stated the registration hadn't yet had any tangible impact on their professional activity.

As to the impact of European registration on national genetic counselling systems, 39.4% (n=13) felt European registration had an impact. While some felt that the European acknowledgement of the profession would support them to seek more recognition at national level, others stated the role of the genetic

counsellor was not yet recognized in their country. One respondent reported that they had used the EBMG registration to start a dialogue with their government. Respondents originating from countries that already had a national system of registration felt that to be register was less useful to them unless they were likely to work out of their home country, or work in a country without a pre-existing registration system.

A further indication of support for the process was the response that 78.8% (n=26) of respondents would recommend, or strongly recommend registration to their colleagues, while only one participant would not. The general feeling was one of momentum – the process would be recommended to gain a critical mass to give *‘the tools to defend our profession as recognized professionals’*.

When asked the relevance of the registration system to improving standards of genetic counselling practice in Europe, 81.8% (n=27) of respondents felt that the registration system was important or very important to improving standards, 12.1% (n=4) remained neutral, while 6.1% (n=2) felt that the registration system was unimportant to practice standards.

## **Discussion**

As the vast majority of European countries do not yet have national registration systems or guidelines advising the training and practice standards of genetic counsellors<sup>10</sup>, we believe the European registration system has made a contribution to the further development and adoption of best practice and training models. The wide range of countries from which we have received applications throughout the past three years and the enthusiastic acknowledgment of the standards and relevance of the European registration

for genetic nurses and counsellors reflects the importance it has for genetic healthcare services in Europe. However, as indicated by the results of our study, the registration process is not without considerable challenges.

One challenge attributed to the registration process was related to the request of at least 10 cases from outside applicant's areas of specialization. This requirement was set up on the light of the new areas where genetic counsellors are increasingly contributing such as cancer genetics, prenatal diagnosis, cardiac genetics, as well as diagnostic laboratories, and with the aim of ensuring registered professionals are competent to practice beyond specific specialist settings, similar systems operating in Canada, Australia and the USA<sup>11,12</sup>.

Acceptance and support of genetic counsellors' practice standards by medical geneticists can be a challenging process in countries where the establishment of the profession is at an early stage<sup>12</sup>. Further exploratory studies may contribute eliciting the views of medical geneticist colleagues about the registration process and the impact it has on local genetics healthcare services.

The competencies-based register we have developed can also contribute to future growth of genetic counselling profession in those countries through the promotion of interdisciplinary understanding, giving more visibility to the roles and added value of genetic nurses and counsellors to the teams. Within the genetic counselling context in Europe, registration additionally could mean a step towards more flexible access to European job options for registered genetic counsellors, as it seems is already the case for some participants in the present study.



## Strengths and limitations of the study

Although the response rate was good, this was a study with small numbers of respondents, due to the limited number of registrants. As a number of registered professionals did not participate in this study, we may have missed potential relevant data on the process. Professionals deciding not to participate may be those who were not satisfied with the process or felt it was unhelpful and, hypothetically, not motivated to complete the survey.

## CONCLUSIONS

Developing a registration system that addresses the needs of practitioners in countries with different educational, cultural and legal systems was a challenging task. The results of this survey have confirmed that registrants value the opportunity to both confirm their own competence and advance the genetic counselling profession in Europe.

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**Table 1.** Socio-demographic characteristics of the sample (n=33)

<b>Demographics</b>		<b>n</b>	<b>%</b>
Gender	Male	3	9.1
	Female	30	90.9
Age	20-25	0	0
	26-30	4	12.1
	31-35	12	36.4
	36-40	6	18.2
	41-45	2	6.1
	46-50	3	9.1
	51-55	2	6.1
	56-60	4	12.1
	Over 60	0	0
Place of work (multiple responses permitted)	Hospital	28	84.8
	Research centre	5	15.2
	Private institute	3	9.1
	Laboratory	1	3
	Other	2	6.1
Professional qualifications (multiple responses permitted)	Bachelor degree in science or genetics	9	27.3
	Bachelor degree in nursing or midwifery	1	3
	Other bachelor degree	1	3

	Master degree in genetic counselling	25	75.8
	Master degree in genetic nursing	0	0
	Other master degree	8	24.2
	PhD	10	30.3
	Professional registration in nursing or midwifery	5	15.2
Occupation (multiple responses permitted)	Genetic counsellor	28	84.8
	Genetic nurse	3	9.1
	Other (e.g., lecturer, project manager)	6	18.2
Number of years working as a genetic nurse or counsellor	Less than 1 year	0	0
	1 year	0	0
	2 years	0	0
	3 years	3	9.1
	4 years	2	6.1
	5 years	5	15.2
	Between 6 and 10 years	14	42.4
	Between 11 and 15 years	5	15.2
	Between 16 and 20 years	0	0
	Between 21 and 25 years	1	3
	Between 26 and 30 years	3	9.1
	Over than 30 years	0	0

**Table 2.** Route of access to the registration and countries of origin of the sample (n=33)

<b>Countries</b>	<b>Do not remember</b>	<b>Prior National Registration Route</b>	<b>Grandfather Clause A</b>	<b>Grandfather Clause B</b>	<b>Grandfather Clause C</b>
<b>Belgium</b>					1
<b>France</b>	1		10		
<b>Greece</b>				1	
<b>Ireland</b>		2			
<b>Norway</b>	1			1	
<b>Portugal</b>				1	
<b>Romania</b>				1	
<b>Spain</b>	1		3	1	2
<b>Sweden</b>			1		
<b>Switzerland</b>			1		
<b>United Kingdom</b>		4	1		

## **Supplementary online material**

### **Materials and Methods**

Ethical approval for the study was obtained from the Babes-Bolyai University Ethics Committee (Romania).

### **Data collection**

A survey comprising 28 questions was developed by the Genetic Nurses and Genetic Counsellors (GNGC) Professional Branch of the EBMG. Multiple choice questions and several requiring free-text responses were included (Supplemental table 1). We first identified topics of interest and formulated questions using an iterative process to refine the wording. Due to the wide geographical area in which potential respondents were located, we used an online survey tool, Google Drive®, to maximise ease of data collection and therefore enhance numbers of responses.

### **Procedures**

All European registered genetic nurses and genetic counsellors (n=55) were sent a link to the survey, with an invitation letter, by the GNGC group email, so that they could then complete the survey in their own time. A reminder was sent to all registrants a month after sending the initial invitation. Those who

completed the survey could not be identified from their responses. All participants gave consent for the anonymised data they contributed to be published. Registrants were free to decline to be involved by simply ignoring the invitation. Respondents could leave the survey at any time before submitting their answers.

### **Data analysis**

The data were analysed using descriptive statistics. The open questions were analyzed using thematic analysis<sup>16</sup>. Lists of the themes were compiled. Sub-themes that clustered together to form a major theme were tabulated together. Five experienced researchers (CS, HS, MP, RM, IB) analysed each the answers to open ended questions, as per the method described previously. Results are presented using relevant quotations followed by the participant number.

### **Sociodemographics and general information of participants**

Respondents included participants from each year since the European system was launched (12 were registered in 2014; 11 in 2015 and 10 in 2016). About half (48.5%, n=16) registered using via the “grandfather clause A” (having qualified through an accredited MSc program as background and at least three years’ experience), 18.2% (n=6) used their prior national registration route, 15.1% (n=5) registered via the “grandfather clause B” (having non accredited training in genetic counselling and at least four years of experience) and 9.1% (n=3) via the “grandfather clause C” (who have not undertaken a specific course in genetic counselling and who have completed five years of experience full

time). The remaining 9.1% (n=3) could not remember the registration route they used.

### **Anonymized quotes of participants' opinion on the registration process**

Participants were also asked their opinion on the registration progress. The majority of the participants agreed that the process was very straightforward and the steps were easy to follow.

*"I think it is quite easy and clear if you follow the instructions on the website." (participant n° 17)*

Participants found the registration process somewhat laborious and time consuming.

*"It is a great thing but it is a little time-consuming and it may be difficult to do it in parallel of our daily work." (participant n° 13)*

Some reported that the registration process was very interesting and insightful and mentioned feeling very satisfied to get an overview of their activity.

*"Challenging but also satisfying" (participant n° 19)*

When looking at the registration process itself, we wanted to know whether and to what extent respondents found it difficult. Only 18.2 % (n=6) found it rather challenging. The vast majority of the respondents that mentioned having difficulties said the most challenging thing was the time they needed to allocate for this process.



*“What was really difficult was to go back to every patient files and remember every course and meetings I had. It took a really long time.”*

*(participant n° 14)*

*“Finding 10 cases where all 10 clinical skills were present. It took time to choose the cases. I thought I used all clinical skills more regularly.”*

*(participant n° 25)*

When questioned whether the registration process had helped them as professionals, participants shared their experiences mainly focusing two core domains: the professional standing it had represented and as an educational process. Registered genetic counsellors and nurses referred to how the credential gave them credibility among colleagues and enhanced their professional visibility.

*“It’s a recognition of my education and experience as a genetic counsellor” (participant n° 15)*

*“Proof of what I have learned and accomplished in my years of working as genetic counsellor” (participant n° 16)*

Some of the participants valued the registration process as an educational activity in its own right. They mentioned how they valued the need to reflect on their own practice while preparing case studies, to think about the ethical issues of daily practice as well as the impact of continuing educational activities on their professional training. Some participants highlighted how the case log requirement of at least 10 cases in general settings of counselling allowed them to re-connect with other areas of genetics and the challenge this was.

*“It highlights the importance of continuing education, and maintaining registration database of the cases” (participant n° 15)*

*“I think it is an opportunity to reflect on different issues of your own practice. Although self-reflection is very important in our profession, sometimes the daily work (make it) difficult to stop and think about it. For the registration you have to revise all your cases as a whole (usually you revise case by case) as well as your Continuing Professional Development activities” (participant n° 17)*

Additionally, the majority of participants indicated the greatest impact of the registration process was for their clinical practice (84.4%, n=28) or for their career development (66.7%, n=22). Five participants (15.5%) stated the registration hadn't yet any tangible impact on their professional activity.

Among the reasons for this positive feedback on their registration as genetic counsellors or nurses, participants mentioned how it facilitated accreditation in other countries for job mobility, how it provided recognition at national level (in countries where there is no professional registration), and as a support for career development and confirmation of competence.

*“It has been an important milestone and something to be proud of... for me, for my colleagues and my boss.” (participant n° 17)*

When asked about the impact of the registration system in their countries, 39.4% (n=13) felt it had an impact, while 30.3% (n=10) said it had not and an equal number were unsure.

Some respondents explained that because the role of the genetic counsellor was not recognized or even familiar in their country, the registration system had not been helpful.

*'It doesn't have an impact yet, as the genetic counsellor job positions do not officially exist....' (participant n° 15)*

However, conversely, others felt that the European acknowledgement of the profession would support them to seek more recognition at national level.

*'It will help supporting the professional recognition of the GC title' (participant n° 7)*

One respondent reported that they had used the EBMG registration to start a dialogue with their government, while others felt that they could use the standards set by the EBMG.

Recognition of the value of registration was confirmed by the fact that 69.7% of respondents reported that they knew of colleagues in their countries who were planning to apply within the next 2-3 years. A further indication of support for the process was the response that 78.8% (n=26) of respondents would recommend, or strongly recommend registration to their colleagues while only one participant would not. Around 2/3 of respondents provided more detail, with the majority describing 'development', 'patient safety', 'regulation' and 'recognition' as reasons for recommending registration to colleagues.

*'...this should be used to set a standard for whom should provide genetic counselling - as a measure of quality control for other medical colleagues and patients seeking care.' (participant n° 16)*

The general feeling was one of momentum – the process would be recommended to gain a critical mass to give ‘*the tools to defend our profession as recognized professionals*’:

*‘The point of being registered will be clear to everyone in the field, once many of us will be registered’. (participant n° 33)*

## **Feedback on the process of European Registration for Genetic Counsellors and Genetic Nurses: the survey**

\* Required

### **INFORMED CONSENT**

*STUDY NAME Feedback on the process of European Registration for Genetic Counsellors*  
*AIM This project is aimed at exploring the feedback of registered genetic counsellors on the European Registration process. Thank you for agreeing to complete this survey. You were invited to participate in this study because you are a registered Genetic Counsellor or Genetic Nurse. Participation in this study is completely voluntary. Your answers to all questions are confidential. The answers will help us improve the process of European Registration for Genetic Counsellors and Genetic Nurses. Thank you for your help!*

I understand my answers will be anonymous \*  
Mark only one oval.

- Yes
- No

I consent to be involved in this study \*  
Mark only one oval.

- Yes
- No

### **Demographics**

1a. Gender \*  
Mark only one oval.

- Female
- Male

1b. Age \*

Mark only one oval.

- 20-25 years
- 26-30 years
- 31-35 years
- 36-40 years
- 41-45 years
- 46-50 years
- 51-55 years
- 56-60 years
- over 60 years

1c. Country \*

Mark only one oval.

- Belgium
- Republic of Cyprus
- France
- Iceland
- Ireland
- Italy
- Norway
- Portugal
- Romania
- Spain
- Sweden
- Switzerland
- United Kingdom
- Greece

1d. Place of work (tick all that apply) \*

Check all that apply.

- Hospital
- Research centre
- Private institution
- Laboratory
- Other:

1e. Qualification/Degree (tick all that apply) \*

Check all that apply.

- Bachelor degree in science or genetics
- Bachelor degree in nursing or midwifery
- Other Bachelor degree
- Master degree in genetic counselling

- Master degree in genetic nursing
- Other Master degree
- PhD
- Professional registration in nursing or midwifery

1f. You working as ... \*

Check all that apply.

- a genetic counsellor
- a genetic nurse
- Other:

1g. What is your job title / current position ? \*

1h. How many years of experience do you have in genetic counselling or genetic nursing ? \*

Mark only one oval.

- less than 1 year
- 1 year
- 2 years
- 3 years
- 4 years
- 5 years
- 6-10 years
- 11-15 years
- 16-20 years
- 21-25 years
- 26-30 years
- over than 30 years

### **Programme and Registration system**

2 - Is there a Master degree in genetic counselling programme available in your country ? \*

Mark only one oval.

- Yes
- No
- I don't know

3 - Is there a Master degree in genetic nursing programme available in your country ? \*

Mark only one oval.

- Yes
- No
- I don't know

4 - Is there a registration system for genetic counsellors or genetic nurses in your country ? \*







11d. To your knowledge, is there any other genetic counsellor or genetic nurse colleague in your country planning to apply for registration in the next 2-3 years ? \*

Mark only one oval.

- Yes
- No
- I don't know

11e. To what extent would you recommend the registration to other colleagues ? \*

Mark only one oval.

1 2 3 4 5

not relevant at all

very relevant

Could you explain your answer ?

11f. In your opinion, how relevant has been the development of the European registration system in improving standards of genetic counsellor or genetic nurse practice generally in Europe ? \*

Mark only one oval.

1 2 3 4 5

not relevant at all

very relevant

12. Please, give us your general comments

**We would like to thank you for supporting the process of professional regulation of genetic counselling in Europe**