



Building awareness on genetic counselling: the launch of Italian Association of Genetic Counsellors (AIGeCo)

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Dear Editor,

“Genetic counseling is the process through which knowledge about the genetic aspects of illnesses is shared by trained professionals with those who are at an increased risk or either having a heritable disorder or of passing it on to their unborn offspring” (WHO). Genetic counsellors (GC) are practicing all over the world, especially in the USA and the UK, with a common background for providing “patient-oriented” support for those persons, and their families, dealing with a genetic condition, providing information on the inheritance, recurrence risks, sharing the concerns of patients and their healthcare providers. In Europe a joint activity between EUROAGENTEST network and the European Society of Human Genetics strongly supported the evidence that the key element in improving the quality of genetic testing services in Europe is the provision of appropriate genetic education for health professionals Coviello et al. (2007), and the

Education Committee of ESHG, in 2010, published the core competences to support preparation of health professionals in Europe Skirton et al. (2010). As the use of genomic technologies in DNA testing is now being greatly extended to a wide range of medical specialties, possibly generating an excess of information, there is a higher demand for genetic counselling to patients and their families Cordier et al. (2018), and GC are now active in more than 11 European countries Abacan et al. (2019).

Genetic counselling around the world

The profession of genetic counsellor was born about 50 years ago in the USA. It is estimated that, actually, there are in 28 countries about 7000 people who work as genetic counsellor Abacan et al. (2019). Actually there are some countries in Europe (and beyond) where the genetic counsellor has a recognized profession (e.g., the UK, Spain, France, the USA, or Australia), but unfortunately, this is not a reality in all Europe. Due to the different regulatory system (healthcare system) and educational path, it was thought in Europe to guarantee an educational standard in different European countries and advance in genetic counselling Paneque et al. (2017). The European Board of Medical Genetics has been established to develop and promote academic and professional standards needed to provide competent genetic counselling services to guarantee an adequate professional level through the European registration system.

The perspective of genetic counselling in Italy and AIGeCo

To date, genetic counsellor is not a fully recognized profession by the Italian NHS, despite the fact that the GC is already part of the course within the hospital in case of patient with

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hereditary pathology. The “Associazione Italiana di Genetic Counsellors” (AIGeCo) was established in 2019 as a “network” of people appropriately trained and already involved in GC services or projects. AIGeCo was launched with the overall intention of improving genetic health and to facilitate the mutual interoperability of a multidisciplinary approach (clinical, psychological, social, scientific, technological, etc.) needed for the most appropriate care of people affected by genetic diseases. AIGeCo is engaged to advocate for the role of genetic counsellors in Italy and to “call to acknowledge” that GC should be employed in the daily clinical practice of health facilities. Indeed, GC may have a pivotal role in helping patients to become more autonomous in making decisions regarding their genetic health Madlensky et al. (2017). In Italy, while some healthcare providers support having patients (and families) more capable of using genetic information autonomously, and making appropriate decisions on their own, others are less supportive. As these scientific debates and discussions abound, Italian genetic counsellors, in strictly collaboration with other genetic services in clinics, homes, or other local social settings, would help patients to receive the appropriate “tools” to modify their lifestyle based on their personal genetic risk and to facilitate the understanding of complex medical information and the personal decision-making process. Many members of AIGeCo are operating in public hospitals located in different regions, mostly from northern Italy. AIGeCo is now committed to build a body of knowledge of GC, through collaborative research projects (both at national and international level) and publications in magazines, conferences, social media, etc. We will also put pressure on the public authorities to strengthen the practice of GC in order to provide the best assistance to people with genetic diseases. For more information, please contact the authors of this letter at direttivo@aigeco.care.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants performed by any of the authors.

References

- Abacan M, Alsubaie L, Barlow-Stewart K, Caanen B, Cordier C, Courtney E, Davoine E, Edwards J, Elackatt NJ, Gardiner K, Guan Y, Huang LH, Malmgren CI, Kejriwal S, Kim HJ, Lambert D, Lantigua-Cruz PA, Lee JMH, Lodahl M, Lunde Å, Macaulay S, Macciocca I, Margarit S, Middleton A, Moldovan R, Ngeow J, Obregon-Tito AJ, Ormond KE, Paneque M, Powell K, Sanghavi K, Scotcher D, Scott J, Juhé CS, Shkedi-Rafid S, Wessels TM, Yoon SY, Wicklund C (2019) The global state of the genetic counseling profession. *Eur J Hum Genet* 27(2):183–197. <https://doi.org/10.1038/s41431-018-0252-x>
- Cordier C, McAllister M, Serra-Juhe C, Bengoa J, Pasalodos S, Bjørnevoll I, Feroce I, Moldovan R, Paneque M, Lambert D (2018) The recognition of the profession of genetic counsellors in Europe. *Eur J Hum Genet* 26(12):1719–1720. <https://doi.org/10.1038/s41431-018-0260-x>
- Coviello DA, Skirton H, Ceratto N, Lewis C, Kent A (2007) Genetic testing and counselling in Europe: health professional current educational provision, needs assessment and potential strategies for the future. *Eur J Hum Genet* 15(12):1203–1204. <https://doi.org/10.1038/sj.ejhg.5201927>
- Madlensky L, Trepanier AM, Cragun D, Lerner B, Shannon KM, Zierhut H (2017) A rapid systematic review of outcomes studies in genetic counseling. *J Genet Couns* 26(3):361–378. <https://doi.org/10.1007/s10897-017-0067-x>
- Paneque M, Moldovan R, Cordier C, Serra-Juhé C, Feroce I, Pasalodos S, Haquet E, Lambert D, Bjørnevoll I, Skirton H (2017) The perceived impact of the European registration system for genetic counselor and nurses. *Eur J Hum Genet* 25(9):1075–1077. <https://doi.org/10.1038/ejhg.2017.84>
- Skirton H, Lewis C, Kent A, Coviello DA (2010) Genetic education and the challenge of genomic medicine: development of core competences to support preparation of health professionals in Europe. *Eur J Hum Genet* 18(9):972–977. <https://doi.org/10.1038/ejhg.2010.64>

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