

JOINT COMMITTEE on GENETIC COUNSELLING REGULATION (JGCR):
REGULATION INFORMATION UPDATE
02.12.16

The quest for Regulation: a brief history of how we got to where we are now!

- In 2002, after a prolonged period of discussion and development by a working group of the AGNC, the Genetic Counselling profession in the UK began a voluntary register under the auspices of the Genetic Counsellor Registration Board (GCRB).
- In 2006, the Genetic Counsellor Statutory Regulation Steering Group (GCSRSG) was formed. This working group was set up on behalf of genetic counsellors by the AGNC. The aim of the group was to put together an application for statutory regulation to the then Health Professions Council (HPC). The group comprised of experienced genetic counsellors and included representatives from both the GCRB and AGNC Committee.
- In December 2009, the GCSRSG submitted an application for statutory regulation to the HPC. This application was successful. As a result, the HPC (now renamed 'the Health and Care Professions Council', HCPC) recommended to the then Labour government that genetic counsellors be statutorily regulated.
- In 2010, the newly elected coalition government decided not to extend statutory regulation but to develop a process of accredited voluntary registration (AVR) for health and social groups. The organisation tasked with developing and managing the AVR process was the Council for Healthcare Regulatory Excellence, now renamed the Public Standards Authority for Health and Social Care (PSA). As well as holding accredited voluntary registers (now called Accredited Registers) for health and social care groups, the PSA oversee statutory bodies that regulate health and social care professionals in the UK (such as the GMC and NMC).
- In 2011, a new working group, the Joint Committee on Genetic Counsellor Regulation (JGCR) was formed. This group, tasked to address the subject of regulation in the light of the current situation, was formed between the original GCSRSG, the AGNC and the GCRB. The JGCR also had lay representation from Genetic Alliance.
- The JGCR began exploring the 3 options available for the regulation of genetic counsellors:
 - continue voluntary regulation with the GCRB for the foreseeable future
 - explore the possibility of becoming an Accredited Register with the PSA
 - await the possible extension of statutory regulation via the HCPC sometime in the future
- After in-depth discussions about the pros and cons of these options over a number of months, the JGCR began consultations with the PSA in preparations for an application to become an Accredited Register (AR). This decision was based on the consideration of several factors, mainly:
 - the maintenance of a voluntary register of genetic counsellors promotes safe and competent practice, and the AR scheme offers currently the best and most secure framework for such practice.
 - the preferred option of the JGGR would be statutory regulation. However, this was not currently available.
 - if the PSA thought that statutory regulation for genetic counsellors was necessary because of the levels of risk involved in unsafe practice, then they would make this clear to the government and recommend statutory regulation via the HCPC

- In mid-2014, the GCRB/JCGCR jointly submitted a draft application for AR to the PSA, in order to obtain their feedback and comments. Detailed and encouraging feedback was provided by the PSA, who invited the GCRB/JCGCR to submit a formal application as soon as possible.
- At this point, Registered Genetic Counsellors were asked to vote on whether a formal application for AR should now be made. Of those who voted, 96% were in favour of an application being made. The application fee of £12,000 was raised by generous donations from the AGNC and a number of NHS Trusts who supported such a venture.
- The formal AR application to the PSA was made in June 2015. The PSA Accredited Registers Programme Panel met on 26th April 2016 to consider the application and concluded that the GCRB register met the Standards for Accredited Registers. The GCRB Register now has the PSA 'Quality Mark', and is one of 23 health and care organisations to have achieved AR through this process.

What Accredited Regulation has achieved

According to the PSA website, when a member of the public uses a practitioner on an Accredited Register, they know that:

- the practitioner is part of a government-backed scheme to protect the public
- the organisation holding an Accredited Register has been rigorously assessed by the PSA and awarded its quality mark
- the PSA ensure that the organisation handle complaints fairly and robustly
- if a practitioner is struck off an Accredited Register they are not allowed to join another Accredited Register
- practitioners who are committed to high standards choose to join an Accredited Register.
- responsible employers and commissioners choose practitioners on Accredited Registers.

The PSA recommends that the public ONLY see practitioners on an Accredited or Statutory Register.

Regulation: current and future challenges

It is not mandatory to join an Accredited Register in order to be a genetic counsellor in the UK. This remains a concern, particularly as the number of genetic (and genomic) counsellors in private practice looks set to increase. Also, if someone is removed from an Accredited Register, that alone does not prevent him or her from being able to work in that profession or use the title 'genetic counsellor'. However, now the GCRB Register is accredited by the PSA, the reasonable expectation is that all new non-trainee genetic counsellor posts in the NHS will be held by a genetic counsellor on the GCRB Accredited Register.

Further questions around regulation have arisen with the new Scientific Training Programme (STP) in Genomic Counselling. The new Masters training programme in Genomic Counselling started in September 2016 and forms part of the Scientific Training Programme under the National School of Healthcare Science (NSHCS) and provides a funded training scheme for genetic counselling. The 3-year STP programme will combine an MSc in Genomic Counselling with work-based training in a Regional Genetics Centre supporting families with a range of genetic and genomic conditions. It is designed to provide the education in the science of genomics and relevant counselling theory, alongside the experience required to practice as a Genetic Counsellor and to obtain professional registration. There are currently 15 funded training places. Graduates from this programme are likely to have the option to register as Clinical Scientists with the HCPC and be statutorily regulated with the HCPC.

The JCGCR is continuing to work to understand the best frameworks for regulation for genetic counsellors. We are working with the Professional Standards Authority, Health Education England and Genetic Alliance to develop an options appraisal for regulation of future genetic counsellors that delivers the best framework for patient and public safety. If you have any queries around regulation developments, you are welcome to contact the members of the JCGCR.

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