



## Association of Genetic Nurses and Counsellors

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A constituent group of the British Society of Human Genetics

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## Joint Committee on Genetic Counsellor Regulation

G Hall (Chair)  
M Longmuir (AGNC)  
J Walford Moore (GCRB)  
C Patch  
J Birch  
C Barnes

### What is happening about regulation for genetic counsellors?

#### Q&A document (September 2012)

#### 1. What is happening about regulation?

- Genetic counsellors currently have a voluntary register held by the Genetic Counsellor Registration Board (GCRB).
- The profession is aiming for statutory regulation but the coalition government has decided not to extend statutory regulation but develop a process of quality assured voluntary registration for health and social groups.
- The Council for Healthcare Regulatory Excellence will be renamed the "Public Standards Authority" and has been given new powers to hold quality assured voluntary registers.

#### 2. What happened to the application to the Health Professions Council (HPC)?

- The AGNC formed a working group Genetic Counsellor Statutory Regulation Steering Group (GCSRSG) to prepare an application for statutory regulation.
- This application was successfully approved by the HPC in December 2009 and we were recommended for statutory regulation to the Secretary of State.
- This recommendation has not been taken further forward since the coalition government decided not to extend statutory regulation to any further health professional groups.
- The HPC stand by their decision and assessment that genetic counsellors should be statutory regulated.



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### 3. How will the governments plans to increase voluntary registration affect the GCRB and its registrants?

- From December 2012, Voluntary Registers will be able to apply to the PSA (formerly CHRE) for accreditation. The PSA will assess the Register against agreed standards.
- If the GCRB apply for PSA accreditation, we will need to complete a risk assessment tool. If the risk assessment highlights the need for statutory regulation, the PSA intend to inform the government although the mechanism and opportunity for recommending statutory regulation for future professions remains unclear with the current decision not to extend statutory regulation.
- PSA accreditation is not government funded so the scheme must be self funding. We do not yet know what the costs of joining the PSA will be to the GCRB or the registrants. We do not know whether the GCRB will fulfil the standards required by the PSA, particularly in relation to fitness to practice.

### 4. What is the profession doing now?

- A joint committee was formed between the AGNC and GCRB and the original statutory regulation steering group (GCSRSG).
- This group is now called the Joint Committee on Genetic Counsellor Regulation (JCGCR). The members of this committee are Georgina Hall (chair), Jan Birch, Chris Patch, Chris Barnes, Jan Moore, Mark Longmuir & a representative from Genetic Alliance U.K.
- The JCGCR is exploring all the possible options for regulation of genetic counsellors. This includes the current GCRB the opportunity for becoming a Quality Assured Voluntary Register with the CHRE and the future position of statutory regulation.
- The JCGCR has worked with the CHRE to influence and understand the new Quality Assured process that we believe will be published in November 2012. While the CHRE have published proposed standards for Voluntary Registers (see consultation on CHRE website), there remain many unknowns about this new regulation process.
- The JCGCR is preparing a risk / benefit document with an options appraisal to inform decision making for the future.



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## 5. How long will all this take?

- It is impossible to answer this question
- A recent law commission document made recommendations for government to develop processes to extend statutory regulation to health professional groups in the future based on public safety. The law commission held a public consultation on these proposals and we understand the outcome of this consultation will be formally reported to government in 2014.

## 6. Who will make the decision around regulation of genetic counsellors

- Ultimately, the government and regulator will decide the appropriate form of regulation for genetic counsellors.
- Our profession will need to decide if or when to apply for CHRE quality assured registration.
- The JCGCR will consult with the membership on this decision once it has completed the risk assessment and options appraisal.

## 7. Why is a voluntary register (GCRB) important for genetic counsellors?

- The GCRB sets and monitors standards for the genetic counselling profession in the UK. It determines entry-criteria, training and competencies for voluntary registration. It also requires genetic counsellors to demonstrate continuing professional development and evidence of good practice in order to maintain their registration.
- In this way, the maintenance of a voluntary register of genetic counsellors promotes safe and competent practice.

## 8. Do I have to be registered with the GCRB?

- No, registration remains a voluntary process. The AGNC nevertheless recommends all genetic counsellors work towards registration.
- Many employers are requiring registration.
- In future, the PSA will have a role in promoting the need for healthcare staff to be on voluntary registers and this may well become a requirement for employment within the NHS.

## 9. Why should I be registered with the GCRB?



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- Registration demonstrates your ability to practice as a competent genetic counsellor with Master's level knowledge and skills.
- Registration facilitates public and professional confidence in genetic counselling practice, with defined standards and a code of conduct and ethics.
- Employers expect all new Band 7 postholders to be registered (or to be actively working towards registration).
- Registration is required for career development. All senior genetic counsellor posts above Band 7 will be expected to be registered.
- It provides a mechanism for registered nurses/midwives to obtain recognition for the additional skills and competencies required to work as a genetic counsellor.

## 10. Should I maintain my registration as a nurse?

- Registered genetic counsellors who are also Registered Nurses and/or Midwives frequently ask if they should be 'dual' registered.
- If you are not yet GCRB-registered and are a graduate nurse and/or midwife without a accredited MSc in Genetic Counselling, you must maintain your NMC registration to be eligible for GCRB registration.
- If GCRB registration becomes statutory, then there would be no need to maintain dual registration.
- While GCRB registration remains voluntary, some nurses/midwives will continue to maintain their NMC registration, but this will be a matter of individual choice. However, nurses/midwives must check the conditions of their employment as their employing authority may require NMC registration. If nurses are considering letting their NMC registration lapse either now or in the future, they would be advised to check that this will not affect their NHS pension arrangements (e.g. special classes status).

## 11. What might happen if the GCRB became an assured voluntary register under the CHRE (PSA)?

- A genetic counsellor would register through the GCRB in the same way as now, agreeing to meet the standards set by the GCRB.



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- A registered genetic counsellor would agree to behave in accordance with the GCRB Code of Ethics. If they do not, they can be struck off the GCRB register and this information made public. This means that employers, patients and the public can check whether a person is on the register and is meeting its standards.
- It is similar to statutory regulation but there are two important differences. Firstly, it is not mandatory to register in order to practise. Secondly, if someone is struck off a voluntary register, that alone does not prevent him or her from being able to work in that profession.
- The PSA will publish a list of accredited registers and carry out periodic reviews of the operation of the registers accredited.

## 12. What will it cost?

- The PSA Assured Voluntary Register scheme will be self-funding, operating on a “not for profit” basis.
- However, the fees have not yet been determined.

## 13. Where can I find out more about how genetic counsellor regulation might affect me?

- **Your Employer:** It is important to familiarise yourself with the detail of your own current individual job description, contract and Terms and Conditions of Employment. If you do not have a copy of these documents, you can ask your Line Manager or your employing Trust's Department of Human Resources. If you have any specific questions you can raise them through these channels and/or through your trade union (see below)
- **GCRB:** Check the GCRB website which will be updated regularly, and watch out for briefing papers, updates in BSHG Magazine and presentations at the GCRB AGM
- **AGNC:** Check the AGNC website which will be updated regularly, and watch out for briefing papers, updates in BSHG Magazine and presentations at the AGNC AGM. Information updates will also be cascaded through the AGNC Regional Representatives
- **Trade Union:** If you are a member of a Trade Union (and remember, the AGNC is not a Trade Union) you can ask for advice on any specific personal concerns, ask any general questions or look for guidance through the organisations standard channels of communication and support (e.g. local Accredited Work Place Representative, local Staff Side meetings, union website)



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### **14. If I am not GCRB registered, what will happen if the profession becomes statutory regulated or Quality Assured Voluntary registration becomes a pre-requisite for NHS employment?**

- If Quality Assured Voluntary registration becomes a condition of employment for NHS Genetic Counsellor posts and you are not registered, this will have implications for your future career progression as any GC jobs subsequently advertised will have to list registration as an essential criteria for the post. If you are already in an existing genetic counsellor post, you would need to discuss your individual situation with your employer as to how they would plan to manage your post in the interim, i.e. in the period of time between when Quality Assured Registration begins and the date when you achieve the required GC registration in order to practice in that role.
- Ultimately, if the profession becomes statutory regulated Registration will be mandatory for anyone to practice or to be employed as a Genetic Counsellor or to use the title which will be protected in law.

### **15. How do I express my views about Genetic Counsellor regulation?**

- By writing to or emailing the chair of the JCGCR
- By taking part in the JCGCR Survey via the link on the AGNC website
- By contacting your AGNC Regional Representative
- By contacting the Council for Healthcare Regulatory Excellence (Public Standards Authority)

### **16. What do managers, commissioners and medical colleagues think about genetic counsellor regulation?**

- Like genetic counsellors, colleagues and managers have a lot of questions and uncertainty around the impact of voluntary registration versus statutory regulation for genetic counsellors.
- Our current consultation demonstrates a lot of support around the risks of genetic counselling work and the need for regulation.

*“The registration process is very stringent and ensures that only clinically competent counsellors practice as key members of a clinical multidisciplinary team. It is pivotal for the registration scheme to be mandatory and a statutory component of clinical practice akin to that for all Doctors rather than a voluntary scheme in order to protect patients from inappropriate practice.” (UKGTN)*



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### 17. What do patients think about regulation of genetic counsellors?

- Genetic Alliance have considered the need for regulation for the protection of patients seeking genetic counsellors. In their response to the CHRE they wrote:

*“we believe that genetic nurse counsellors are close in public and patient perception to doctors and to nurses and other statutorily regulated allied health professionals. Indeed we believe that the majority of patients would be surprised to discover that genetic nurse counsellors are not regulated in the same way as these statutorily regulated health professionals.”*

*“Genetic Alliance UK believes that a compulsory register of genetic nurse counsellors supported by appropriate regulation should be the long term aim for the profession. We believe the GCRB to be capable of managing such a system.”*