



Association of Genetic Nurses and Counsellors

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The future role of Genetic Counsellors in Genomic Healthcare: A Statement by the Association of Genetic Nurses and Counsellors

Genomic Healthcare in 2014 and beyond

Traditionally, genetic diagnosis, testing and counselling mainly occurs in a tertiary care setting within regional genetics centres (RGCs) comprising a multidisciplinary team of clinical geneticists, genetic counsellors and nurses and clinical scientists. Historically, clinical genetics focused on disorders showing Mendelian inheritance, and on the wider implications of genetic diagnoses for the affected individual and their extended family. Whilst this will continue to be important, genetics centres also need to respond to the unprecedented changes in genetic technology and the inevitable impact of genomic medicine across the whole of healthcare.

Modern genomic tests aim to simultaneously identify multiple genomic changes specific to an individual and their disorder. Advances in technology promise to deliver this testing at the cost and volume required to enable genomic data to inform healthcare on a mass scale. The 100,000 genomes project epitomises the opportunity genomic technology presents for UK healthcare. In the future, broad genomic testing, co-ordinated through mainstream medicine, could enable more effective prediction of risk, management of disease and personalisation of treatment for both common and rare conditions. In the present, developing this new technology with the required data handling, bioinformatics, interpretation, information, consent and clinical management of patients presents a significant challenge for the NHS. However, it is envisioned that genomic testing will increasingly be initiated outside the sphere of clinical genetics and will instead be integrated into a wide range of medical specialties. Realisation of the potential benefits will require a breadth of healthcare professionals to develop knowledge and proficiency in managing and communicating genomic information within their specialty.

Partnerships between clinical genetics and mainstream medicine will be critical in realising the vision of genomic medicine. Current genetic expertise delivers interpretation and communication of complex genomic information with the provision of support and counselling for “whole person” and “whole family” care. As identified in the Human Genomics Strategy Group (HGSG) report, maintenance of this specialist workforce, both as a clinical service and as a resource to support integration of genomic technology and expertise within mainstream medicine, will be essential elements of the future genomic strategy¹. Current proficiency in the application of genetics and genomics outside of clinical genetics is variable². A combination of formal education programmes and continual reinforcement through clinical support will be required to deliver successful and sustainable training. Harnessing the genetic counselling capacity of RGCs, and embedding their specialist expertise in multidisciplinary teams, is essential in achieving the enhanced and responsive education and training required for true integration of genomics in mainstream medicine.

The Role of Genetic Counsellors

Genetic counsellors are internationally established as distinct healthcare professionals with specialist education in genetics and genomics combined with counselling skills. Genetic counsellors are essential members of multidisciplinary teams, enabling the genetic information generated to be appropriately relayed to provide education and support to individuals and families attempting to comprehend and adjust to a genetic condition. Genetic counsellors have distinct skills, qualifications, experience and expertise to support individuals and families with genetic conditions by:

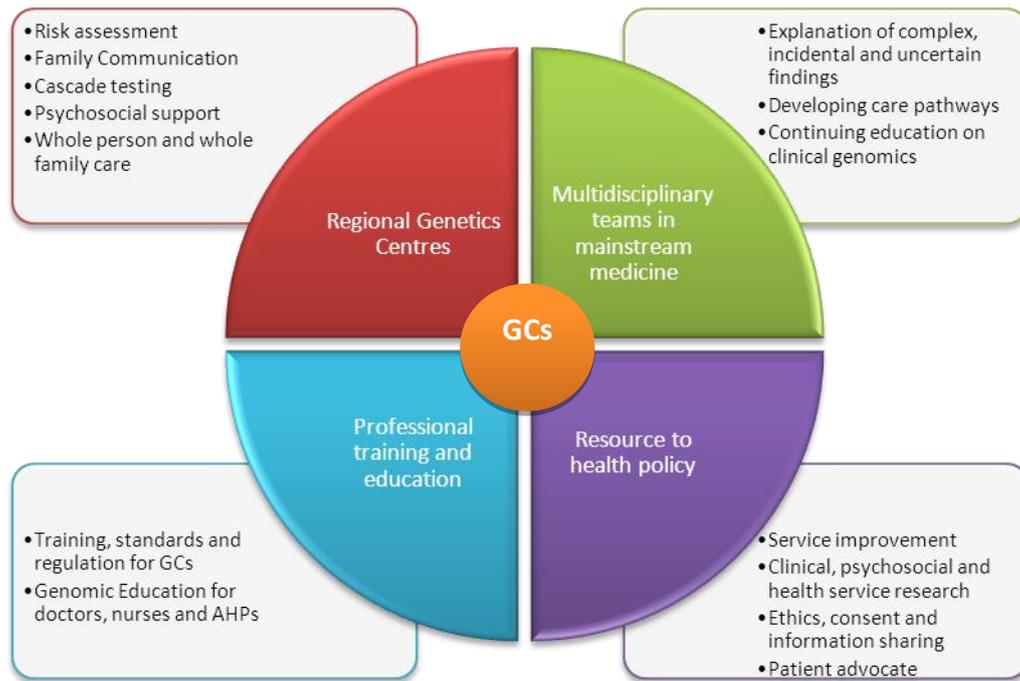
- Applying genomic information to overall future healthcare for an individual and family.
- Providing practical and psychosocial support for those with rare genetic disease.
- Navigating the ethical challenges surrounding the disclosure and sharing of genetic information.
- Interpreting and explaining complex, incidental or uncertain genomic information.
- Providing education for the wider healthcare workforce on the clinical application of genomics.

The UK has been at the forefront of developing the profession and has established the gold standard for genetic counselling which has been emulated across Europe and worldwide³. In the UK, much of the value of the unified profession is underpinned by the dual entry background: nursing and scientific. The establishment of voluntary professional registration and postgraduate training programmes for genetic counsellors in the last two decades represents significant progress. In 2009, the required minimum standards of competence for genetic counsellors were recognised by the provisional approval of Genetic Counsellors for regulation by the Health Professionals Council. The AGNC and Genetic Counsellor Registration Board (GCRB) continue to work with the Professional Standards Authority, to implement robust genetic counsellor regulation through Assured Voluntary Regulation (AVR): ultimately enhancing patient safety and professional accountability.

The future vision of Genetic Counsellors in implementation of the genomic strategy

The incorporation of genetic counsellors within specialist multidisciplinary teams utilising genomic technologies will be integral to providing safe and high quality patient care. The strength of such an integrated approach is in the combined fulfilment of clinical and educational roles in tandem. This enables genetic counsellors to contribute specialist genomics advice and education within the clinical team, while providing support and management advice for both the affected individual and the extended at-risk family members. Development of such partnerships enables specialist, condition-specific input to be provided alongside genetics expertise and establishes a solid foundation for the implementation of genomic technology in mainstream healthcare.

Genetic counsellors are ideally situated, with the skills, training and expertise, to deliver not only Genomic Healthcare in the NHS (both through regional genetic services and also through multidisciplinary working across specialities) but also to deliver training, enhance professional standards and develop health policy (see diagram). The AGNC is committed to supporting Genomic Medicine for the patient, family and world-class health service delivery.



References

1. Human Genomics Strategy Group (2012) *Building on our inheritance: genomic technology in healthcare*, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213705/dh_132382.pdf
2. *Genetics and mainstream medicine*. Burton H. PHG Foundation (2011). ISBN 978-1-907198-07-6.
3. Skirton H, Kerzin Storrar L, Barnes C, Hall G, Longmuir M, Patch C, Scott G, Walford-Moore J. Building the Genetic Counsellor Profession in the United Kingdom: Two Decades of Growth and Development. *J Genet Couns*. 2013 *J Genet Counsel* (2013) 22:902–906