February 2021

Mainstreaming Genomics – the role of Genetic Counsellors

Genetic counsellors are healthcare professionals, with specialized training and experience in managing genomic risk and genomic testing. They support individuals and families to understand their risk and healthcare choices; to make informed decisions about genomic testing and related options; to communicate information within the family including to their children; and to adapt psychologically to living with a genomic diagnosis. More information about the Genetic Counsellor role in the UK can be found at https://www.agnc.org.uk/info-education/documents-websites/.

Genetic Counsellors are expert clinical specialists who work with patients and families, especially for more complex cases. With this expertise, they are also ideally placed to support mainstreaming of genomic risk assessment and testing for more straightforward cases, and already have extensive experience of doing so. They can provide education and support to colleagues providing genomic risk assessment and testing; lead or advise on pathway development; advise about complex or uncertain genomic test results; manage complex cases; and liaise with clinical scientist colleagues, clinical geneticist colleagues and specialist healthcare providers for timely and seamless care for patients and at-risk relatives.

Genetic Counsellors (GCs) are currently involved in supporting mainstreaming genomics, and have already developed networks, skills and expertise. Current practice uses a variety of different models, some of which are outlined below.

Leading a service provided by other healthcare professionals (HCPs)

A GC leads a service (for example clinics within secondary care such as a family history oncology clinic or cardiac genetics clinic) where the majority of appointments, genetic risk assessment, appropriate genomic testing and onward referrals for management are carried out by other HCPs such as nurses. The GC is responsible for leading the service; education and support of the other HCPs; pathway development; and managing complex cases, which need more specialist input.

Supporting HCPs to provide genomic risk assessment and testing

GCs provide training and education for HCPs in other specialties who will be carrying out genomic risk assessment and offering genomic testing, using the criteria specified in the National Genomic Test Directory. GC led training programs enable gradual upskilling and mentoring of mainstream colleagues. The HCPs observe the GC's clinic sessions as part of their learning, and the GC observes their initial consenting and testing clinics. HCPs contact the GC directly with queries about eligibility, process and results, and refer on complex cases for the GC to manage. This model exists within many services, including cardiology, ophthalmology, neurology and cancer risk assessment services in secondary care.

GCs develop competency frameworks to support HCPs to upskill in the areas needed to provide genomic medicine, for example around consenting for genomic testing, and support HCPs to develop these

competences in their practice. They work with particular professions (such as Health Visitors) to outline key Good Practice Points, which the profession can use to develop their competence.

Pathway development

GCs develop networks with HCPs in other specialties to adapt/develop pathways to ensure that genetic risk assessment and genomic testing is offered where appropriate. They bring their expertise to pathway development to promote equity of access and ensure that the impact of this process is managed appropriately. They also signpost to (or provide) education for the HCPs, and ensure that the pathway includes the process of onward referral to clinical genetics services, where appropriate.

Working within and alongside other clinical specialties

GCs are employed by other services (such as oncology, cardiology, ophthalmology, reproductive medicine, primary care) to provide genetic risk assessment, genomic testing and genomic counselling to patients accessing the service. They contribute their expertise to MDT discussions, education and support of colleagues, and pathway development.

GCs are also seconded from their local genetics service to provide genetic counselling clinics (e.g. for presymptomatic testing clinics) within mainstream services.

Alternatively, GCs are employed by or seconded to a particular trust/hospital to support mainstreaming, by providing clinics, providing support and training to colleagues, and helping with pathway development.

Whether working within a particular service or a particular trust, GCs act as a wider resource by liaising with patient support groups, identifying information platforms when needed and ensuring the timely engagement of the mainstream HCPs to maintain patient support.

MDTs

GCs chair MDT meetings (often online) for HCPs working in other specialties to bring cases for advice and discussion. This includes cases where they are querying eligibility for testing, asking for guidance with uncertain or complex results, or discussing management of the patient and family. These MDT meetings are usually for a particular specialty, but may also be open for any HCP who wishes to bring a case related to genetics/genomics. The GC has administrative support to manage the MDT meeting.

Regional Specialty Forums/Networks

GCs assemble networks and run regular regional forums for HCPs working in other specialties, creating an interface to convey a uniform regional message/communication opportunity between Clinical Genetics Services and clinicians in other specialties, or between Genomic Laboratory Hubs and mainstream clinicians. Such forums enable Clinical Genetics Services and Genomic Laboratory Hubs to be responsive to service user needs, and enable mainstream clinicians to provide appropriate genomic care, including interacting with the Test Directory effectively. The GC has administrative support to manage the forum and network.

Test Directory Development

GCs monitor the Test Directory and submit relevant amendments where they will aid mainstreaming activity and pathway development. This includes applications to ensure particular clinicians (such as those in primary care) are eligible to request certain genomic tests, and to add groups of patients (such as those with a history of a pregnancy affected by trisomy) to eligibility indications for particular tests.

Leading a team of educators

HCPs working in other specialties require education and training to be able to provide genomic risk assessment and testing. GCs are the education and training leads for some regions, ensuring that this is provided appropriately to these HCPs. GCs support and train educators who provide this training by helping to develop content for education, signposting to resources already available, and supporting the educators to deliver the training.

Strategic Transformation and Quality Improvement

GCs working within or alongside mainstream services are ideally positioned to develop and implement transformation initiatives that aim to enhance key deliverables relevant to that specialty, pathway or HCP group. For example, this may involve building digital solutions, infrastructure or education, based on need. By measuring outputs and generating an evidence base, this can be used to enhance patient care and open up research avenues. For example, GCs can use their expertise in communicating with and working with diverse communities to develop and implement initiatives to enhance equity of access to genomics, a core aim of the genomic medicine service.

Patient and Public Engagement and Involvement

GCs are expert communicators in genomics, so lead on efforts to engage with the public around the genomic medicine service and facilitate involvement of patients in service design and delivery. They are skilled in working with diverse communities, and routinely employ a range of health belief models and counselling practices, which help to engage and involve patients. This expertise is also used to help create scalable resources such as patient information leaflets and web materials.

Research and service evaluation

GCs are involved in a range of genomics research, and lead research within a mainstream setting, to ensure that the genomic medicine service is based on evidence-based practice. They connect the outputs of mainstreaming initiatives to a relevant research platform, to promote good quality research and drive forward knowledge and understanding. They have particular expertise in assessing patient and HCP attitudes, key components in the success of providing genomic medicine to all.