Scope of professional roles within specialist genomic medicine services

On behalf of the Association of Genetic Nurses and Counsellors and Clinical Genetics Society

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There are numerous published documents that articulate the scope of practice of the clinical genetics workforce[1] and specifically the genetic counsellor[2] and clinical geneticist[3] roles. This document aims to provide, within a quick-reference format, the distinctions and differences between role profiles for a consultant clinical geneticist, principal/consultant genetic counsellor and new support role that we have termed 'genomic associate' (see AGNC career structure[4]).

We acknowledge there is currently variability in these roles between NHS trusts and also exceptions where the scope of practice for one professional group exceeds what is provided below.

The roles are **deliberately forward looking**, i.e. they acknowledge that there are some areas of practice that may have traditionally been performed by one professional group, can now be handed over to other groups. Broadly speaking, the clinical geneticist leads on diagnostics and therapeutics and the genetic counsellor leads on psychosocial issues and care of the extended family. Both groups have skills and training in clinical genetics and there is much cross over between roles. The genomic associate leads on administrative support for the clinic, the patient and the clinical activities of the clinical geneticist and genetic counsellor. The genomic associate is part of the genetic counsellor career structure and has a clinical role that is different to a secretary; it is a position that has already been incorporated into the new Genomics Service Specification.

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[1] Dragojlovic, N et al. (2020) The composition and capacity of the clinical genetics workforce in high-income countries: a scoping review. Genet Med 22, 1437–1449.

[2] AGNC (2020) The Genetic Counsellor Role in the United Kingdom A statement from the Association of Genetic Nurses and Counsellors (AGNC), August 2020 Endorsed by the Genetic Counsellor Registration Board (GCRB) and Academy for Healthcare Science (AHCS) Accessed on 3rd Sept 2020 from https://www.agnc.org.uk/media/11727/the-genetic-counsellor-role-in-the-uk.pdf

[3] CGS (2020) What is Clinical Genetics? Accessed on 3rd Sept 2020 from https://www.clingensoc.org/about-us/what-is-clinical-genetics/

[4] AGNC (2020) Career structure for genetic counsellors and support roles. Accessed on 3rd Sept 2020 from https://www.agnc.org.uk/info-education/documents-websites/

AGNC
Association of Genetic Nurses & Counsellors

CGS CLINICAL GENETICS SOCIETY

The colour coding refers to a training and competency to perform the tasks:
green = routinely within the scope of practice
amber = within the scope of practice for some professionals, but not for the majority
red = outside of the scope of routine practice

		Clinical Geneticist	Genetic Counsellor	Genomic Associate
Triaging referrals	Referrals are assessed and triaged			
Advice and guidance letters for refused referrals	Letters written in response to referrals that require clinical advice, but do not meet GMS referral guidelines			
	Responsibility for responding to referrals that do not require any clinical advice nor clinical contact			
Access to the appointment	Facilitating patient access, including establishing if patient wants to be seen, supporting minority populations to access services, supporting patients with disabilities/audio/visual impairment to access services, contacting patients to explain what clinical genetics can offer, arranging interpreters			
	Acting as a chaperone in clinic			
	Arranging measurements for patients in clinic, e.g. taking patient's weight and height			
Preparation for appointment	Transcribing a written pedigree into electronic software			
	Gathering relevant medical records, pathology reports, death certificates, tumour blocks			
	Organising and obtaining familial blood or saliva samples to help confirm diagnosis in proband			
	Obtaining record of patient choice/consent (not having the full consent conversation, but recording that it has been taken)			
	Collating appropriate patient leaflets, consent forms for the clinic as determined by senior staff			

Patient/family type seen	General genetics (adult or paediatric)			
	Cancer genetics (adult or paediatric)			
	Prenatal			
Physical medical examination	Examination of a patient to make a clinical diagnosis and/or to support or stratify genetic testing			
Family history	Taking a family history			
	Evaluating a family history to determine genetic risk			
Psychosocial history	Taking a detailed psychosocial history to determine effect of genetic diagnosis on individual and wider family members			
Investigations	Medical investigations: Employ a range of tailored investigations including genetic, biochemistry, radiology, haematology etc for clinically undiagnosed patients			
	Genetic investigations: Choose appropriate genetic testing for patients with specific family history indicative of genetic risk (e.g. family history of cancer)			
	Genetic investigations: Choose appropriate genetic testing determined by a pre-existing definitive clinical diagnosis/clinical presentation (e.g. breast cancer)			
	Take samples (e.g. blood saliva) for genetic testing			
Consent	Consent a patient for genetic testing			
	Arrange and consent for cascade genetic testing amongst extended family (e.g. BRCA, Fra-X testing)			
Counselling and support	Generic genetic counselling skills e.g. disclosure of diagnosis, breaking bad news etc.			
	Supporting patients and families adjusting to a genetic diagnosis or coping without one			
	Identifying complex grief reactions and interpreting complex family dynamics and making appropriate onward referrals for further psychological support			
Genomic variant interpretation	Interpreting gene variants to determine clinical decisions, as part of a multidisciplinary team			
	Integrating the results of clinical presentation and investigation to determine whether a rare phenotype supports variant pathogenicity			
	Interpreting whether an established clinical presentation supports variant			

	pathogenicity			
	Administration to track down relatives to provide evidence in support of variant interpretation			
Management and Treatment	Reviewing and recommending peer-reviewed management guidelines. Writing, e.g. NICE guidance			
	Organising appropriate disease screening and acting as patient advocate to arrange access to services			
	Devising individual management guidelines for a rare disorder based on research evidence			
	Prescribing pharmaceuticals or molecularly targeted therapies			
	MDT coordination, collating agenda items, taking meeting minutes			
	All administration required for clinic and follow up			
	Ordering of clinic supplies, test kits, appropriate proformas, consent forms			
Follow Up	Follow up care of the nuclear family (e.g. parents and children)			
	Follow up care of the extended family (e.g. 2nd and 3rd degree relatives)			
	Monitoring/chasing outstanding records/samples/screening and any administration work needed to support the clinical geneticists and genetic counsellors			
Research	Leading or referring to research studies relating to patient's genetic diagnosis			
	Leading or being a site investigator for Clinical Trials of Investigational Medical Products			
	Finding and referring to surveillance trials (e.g. for cancer screening)			
	Leading or referring to psychosocial research (e.g. genetic counselling or communication research)			
	Administration for research studies			
Mainstreaming	Providing advice and support to other healthcare workers			
	Participation in multi-disciplinary team meetings			

	Managing and leading a specialist nurse mainstreaming team (e.g. Familial hypercholesterolemia clinic, family breast screening clinics, pre-implantation genetic diagnosis within an IVF clinic)			
Education	Patients, public, health professionals			
	Developing educational material such as leaflets, interactive infographics and decision aids			
	Liaising with patient support groups to participate in patient led events and sharing of verified information			
	Administration for education events			
Management	Running a genetic register			
	Training and mentoring colleagues from genetics services			
	Training, mentoring and supporting non-genetics healthcare colleagues			
	Acting as Clinical Lead for a clinical genetics service			
	Acting as management lead for clinical genetics service			
Leadership	Sitting on regulatory bodies for own profession			
	Designing professional competency to practice frameworks			