Scope of professional roles within specialist genomic medicine services

On behalf of the Association of Genetic Nurses and Counsellors and Clinical Genetics Society October 2020

There are recently published documents that articulate the scope of practice of the clinical genetics workforce1 and specifically the Genetic Counsellor2 and Clinical Geneticist3 roles. This document aims to support multidisciplinary working of these professional groups highlighting within a quick-reference format, areas of shared practice and the distinctions between role profiles for a Consultant Clinical Geneticist, Principal/Consultant Genetic Counsellor and the new support role that we have termed ‘Genomic Associate’ (see AGNC career structure4).

In summary, Clinical Geneticists are medically qualified Members/Fellows of the Royal College Physicians or equivalent, where Clinical Genetics is an affiliated medical specialty. Genomic Counsellors are allied health professionals with Masters level accreditation from the Genetic Counselling Registration Board (GCRB) included in the Academy for Healthcare Science (AHCS) register; or clinical scientists (genomic counselling speciality) accredited by the Health and Care Professions Council (HCPC).

We acknowledge there is currently variability in these roles between NHS trusts and exceptions where the scope of practice for one

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-](http://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/](http://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/](http://www.agnc.org.uk/info-education/documents-websites/)

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 shared with or devolved 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.

*The colour coding provides a guide to the professional group providing each aspect of service: 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*

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|  |  | 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 |  |  |  |

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|  | 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 |  |  |  |
|  | Specific physical examination that might be considered routine with respect to  particular conditions (e.g. head measurement for a Cowden’s clinic) |  |  |  |
| 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 |  |  |  |

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|  | Routine medical investigations for specific, defined conditions, e.g. ophthalmology or audiological investigations as part of conditions involving visual and/or hearing  impairment |  |  |  |
| 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 |  |  |  |
| Making appropriate onward referrals for further psychological support |  |  |  |
| Identifying complex grief reactions and interpreting complex family dynamics |  |  |  |
|  | Specific application of genetic counselling theory to person-centred care, e.g.  application of reciprocal-engagement models and/or reflective practice models |  |  |  |
| 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 |  |  |  |

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| 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) |  |  |  |
| Referring to psychosocial research (e.g. genetic counselling or communication  research) |  |  |  |
| Leading genetic counselling research specifically on the evidence base behind  genetic counselling practice |  |  |  |
| Administration for research studies |  |  |  |
| Mainstreaming | Providing advice and support to other healthcare workers |  |  |  |

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|  | 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 |  |  |  |

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