Response to the Scottish Genomic Medicine Strategy

The British Society for Genetic Medicine and the Association of Genetic Nurses and Counsellors, following discussion with our Scottish members and colleagues welcome the publication of the first Scottish Genomic Medicine Strategy as we hope this will increase access to testing and improve care for our patients.

We are glad to note that there is a plan to develop a robust multi-disciplinary whole-system workforce model in order to inform the investment, capacity, staffing levels and skills required to meet the needs of current and future genomics services.

Workforce planning

However, it is disappointing that the year one aims of the strategy do not specifically mention workforce planning for Clinical Geneticists, Genetic Counsellors or Genetic Nurses. This new Scottish Genomic Medicine Strategy , similar to England's genomic strategy, recognise the downstream impact of increased genomic and genetic testing on Clinical Genetics services, and the need to maintain and develop the workforce in order to meet this increased demand and this recognition should be followed by concrete workforce planning to avoid patient harm due to peaked capacity of testing.

The SSNGM has also said it will support the design of a flexible career framework including opportunities for career development, advancement and collaboration on research, development and innovation. The strategy states that this will be supported by training infrastructure and underpinned by robust education programmes and educational resources to enable a sustainable, flexible and future-proofed healthcare genomic workforce.

It is worth noting that the complexity of genomic healthcare is such that genetic counselling is not just offered to patients in need of a genetic test, but to families at risk of genetic disease and therefore while having a strategy based on genetic test uptake may work for the clinical laboratories, a more holistic view is needed when considering the genomic health professional workforce.

We hope planning for all clinical roles will be covered by the '*Development of a national workforce development and training plan for staff supporting genomic medicine in conjunction with other workforce training developments in Scotland*' which is planned to be initiated in 2024-2025.

In 2024, the Association of Genetic Nurse and Counsellors (AGNC) for the UK and Ireland updated the '*Career Structure for Genetic Counsellors and Support Roles'* which will be timely to support workforce development for healthcare science genetic specialist roles Bands 3-8. As a relevant stakeholder for these professional

groups, we would advocate that the AGNC Career Working group is a participant in the workforce planning enabling previous expertise to be equally implemented.

Regarding training infrastructure, it is important to point out that there is currently no Genetic Counsellor training programme in Scotland. This contrasts with England, Wales and Northern Ireland which commissions STP Clinical Scientist Genomic Counsellor training posts. This means that in Scotland, all genetic counsellor training posts are filled through substantive post vacancies. The AGNC membership has voiced the feeling that the increased burden of training new GCs has fallen onto the small number of experienced GCs currently in practice, in addition to our increasing clinical workload as genomic testing increases. This additional pressure currently means that Genomic Medicine Services struggle to have a correct balance of skills and experience to deliver services, train staff or succession plan.

The unsustainable pressures for the associated Scottish Clinical Genetic Services, and particularly having insufficient Principal Genetic Counsellor level staff to undertake training and supervision heavily contributed to the closure of the MSc in Genomic Counselling at Glasgow University. This course formed part of the Scientific Training programme for Genetic/Genomic counsellors and graduates from this course have filled many of the vacancies in Scotland since it began in 2016.

Similarly, the demand of clinical scientists and bioinformaticians surpasses supply given the growth of genomics in clinical, academic and industry has been extensive. We recognise this is a wider issue affecting all nations and we would support a UK wide effort to ensure there is adequate workforce for the delivery and sustainability of this strategy.

Clinical Pathways

The strategy is focused in ensuring genetic testing is offered at the right time to patients who can benefit and disseminated appropriately, which we thoroughly support. While genetic testing is a key element of genomic medicine, it can often be a small part of a patient's and family's journey. A genetic diagnosis is life long and often involves regular surveillance, management, family planning support. These elements are expected to have a significant pathway and workforce requirement. A recent study by Genetic Alliance UK, '*Rare Conditions: The Stories Behind the Stats*' has shown inconsistencies in how the most common rare diseases are managed. We want to ensure that patients not only get the right diagnosis but also the right treatment throughout their lives. Without this element, the health system would struggle with a large volume of test results and little clinical benefit over time.

Data and Digital Infrastructure

We applaud NHS Scotland for their efforts to provide data transfer between labs as well as the computing and storage facilities required to process vast amounts of data. We would also add the importance of digital genomic test ordering and reporting in an end to end pathway, ensuring that data from clinic flows into the lab and back seamlessly, efficiently and safely. Current practices include paper test requests which would not fit into clinical governance frameworks.

Genomic data returns and building a robust evidence base
Plans to ensure genomic results will directly benefit patients through central database development would be key to the delivery of long term support for patients and families. Genomic data is often relevant to the individual patient and their family. It may also contain sensitive information about relationships and/or future risks of disease. We recommend that the national minimum dataset is developed with consideration of the sensitivity of genetic data in mind and with rigorous data security measures.

Whole System Workforce and Education
Finally, within the strategy aims, the BSGM and AGNC are encouraged by the support offered by the SSNGM for the provision of information, resources and training packages that improve access to and use of genomic testing by non-specialist clinical staff. However, it does not mention what support they will give and who these training packages will be delivered by. At present, any training of non-genetics staff falls on Clinical Genetics departments (primarily Clinical Geneticists and Genetic Counsellors) who are already over-stretched and under-staffed. We hope that the work and investment being placed on the growth of the Genomic Training Academy – as a resource for all nation in the UK, will continue to strengthen training and support opportunities.

We applaud the significant amount of thought and effort that has gone into creating a solid framework, and appreciate this work. We, as professional societies and the SSNGM have a shared vision of advancing genomic medicine and believe there are areas where we can collaborate to refine and enhance certain aspects to ensure the best outcomes. We would welcome the opportunity to continue engaging on this and work together towards achieving our shared objectives.