

Ministerial Statement of Intent - Genome UK: Shared Commitments Update

In recent years, great strides have been made in the field of genomic medicine, transforming healthcare and vastly improving our understanding of cancer, rare disease and infectious diseases. The UK is a global leader in genomics and in September 2020, the four UK nations published *Genome UK – the Future of Healthcare*, which sets out a 10-year strategy to create the most advanced genomic healthcare system in the world.

Here in Northern Ireland, genomic and molecular diagnostic service developments have facilitated a major step forward in our own diagnostic capability. Much progress has been made in recent years, with notable highlights including Northern Ireland's participation in the 100,000 Genomes Project, the establishment of a Regional Molecular Diagnostic Service, the Pathogen Genome Sequencing response to the COVID-19 pandemic, and developments in both HSC workforce and IT infrastructure to better support and deliver genomic services in NI.

Genomics is one of the fastest growing fields in modern medicine and in order to keep pace with advancements on an international scale, it is imperative that we work closely with our neighbours across the UK and Ireland to harness the potential of genomics for the benefit of our patients and our health service. In recognition of this, in March I co-published *Genome UK: Shared Commitments* alongside my fellow Health Ministers in Scotland and Wales and the Minister for Technology, Innovation and Life Sciences in England. The *Shared Commitments* are a series of joint, UK-wide, high-level commitments to work together across the UK to realise the ambitions of Genome UK.

To facilitate this ambition, I set out my plans to establish a Genomics Partnership for Northern Ireland, which would bring together delivery partners from across government and the HSC, public health, industry, research and academia, with patient input, working to deliver an integrated genomics service for the health, wealth and prosperity of the region. The Partnership would be responsible for setting policy, strategic direction, vision and priorities for genomics in Northern Ireland and would be a key stepping stone to the development and publication of a Shared Commitments Implementation Plan for Northern Ireland by the end of the year.

But I also noted that investment would be needed to ensure that we can deliver on these *Shared Commitments* and that the establishment of a Genomics Partnership would be necessary for genomics to develop and thrive in Northern Ireland. Back in March, it was almost inconceivable that we would find ourselves in this position, 7 months on, with no Executive. The consequent lack of an agreed Health budget has had a severe impact on my ability to plan strategically and invest in our Health Services in the ways in which I had hoped. Unfortunately, genomics is one such area that has suffered because of these budgetary constraints and it has not been possible to progress the work at the pace we had anticipated. Without a Genomics Partnership in place, my Department is not able to deliver on its commitment to produce a meaningful Shared Commitments Implementation Plan by December 2022. Furthermore, without future sustained investment in our genomics workforce and supporting IT infrastructure, our Regional Molecular Diagnostic Service will simply not have the resources to provide an equitable genomic testing service for our patients in line with the rest of the UK, leading to delayed diagnoses and treatment for rare disease and cancer patients, with poorer patient outcomes. This is the reality we are facing as a direct result of the political impasse in which we find ourselves.

However, I want to take this opportunity to reiterate my Department's commitment to working to deliver on *Genome UK: Shared Commitments* and to progressing the Genomics agenda in Northern Ireland as soon as resources allow; that is, a commitment to providing strategic governance in the form of a Genomics Partnership and a fit for purpose Implementation Plan for Northern Ireland, and also a commitment to develop and cultivate our genomics service, in line with service development across the UK. This approach will also support our other key strategic priorities such as the Cancer Strategy, which includes a commitment to deliver genetic and genomic testing in cancer pathways in line with NICE recommendations, and also in public health, where rapid genome sequencing of pathogens has proven so vital in our current and future pandemic preparedness.

Despite the lack of new funding in this current mandate, staff in the Regional Molecular Diagnostic Service, across our Universities and in Public Health, continue to provide

a much appreciated and valued genomic testing service for our population under challenging circumstances and I thank them wholeheartedly for that.

In my Department, officials continue to work closely with genomic policy colleagues across the other UK nations to identify areas of mutual benefit and opportunities for UK-wide collaboration in the spirit of the *Shared Commitments*. Links have been made to explore opportunities on an all-island basis. Work has been ongoing to further refine and strengthen our Genomic governance plans for the region so that a Genomics Partnership for Northern Ireland can be established as quickly as possible once funding has been secured.

In closing, I want to highlight the huge significance that genomic medicine has for the future and the very real and exciting prospects that it offers for healthcare here: preventative medicine, faster diagnosis, personalised, better treatment for patients. This potential should not be underestimated; investment is needed now to develop resilience in our genomics service and build our workforce to guarantee future progress in this fast-moving field, to allow Northern Ireland to keep step with genomic testing advancements and to ensure that our patients are offered a first-class homegrown genomic medicines service.