Parliamentary and Scientific Committee

Bringing Science and Parliament together

Established 1939

Non-Malignant Cancers, Precision Medicine and Genome Mapping

In the UK, someone is diagnosed with cancer every 2 minutes and one in two people will face this diagnosis in their lifetime. Most of us are informed when it comes to the more common cancers, such as breast or bowel, but we may not have such an awareness of the rarer cancers. This meeting's topic was all about non-malignant tumours, precision medicine and genome mapping, however the resulting discussion and Q&A centred mainly around blood cancers, specifically myeloma.

Late diagnosis of cancer can have a negative effect on survival rates and chances of recovery. Blood and non-malignant cancers, especially myeloma, have a high rate of late of diagnoses; but there are many factors that contribute to this. A particular issue highlighted was the lack of GP knowledge surrounding these rarer cancers. In comparison to some more common cancers, such as breast or lung cancer, the symptoms are relatively non-specific, therefore further education for GPs is incredibly important. Once the Doctors have the knowledge, the next step is the availability of testing.

If early genomic testing and diagnosis is the key to increasing survival rates, why are we not doing mass screening? The simple answer is the current lack of funding and resources. Looking forward, a strategy could be implemented in which at risk groups are targeted for mass testing initially. Age, gender, ethnicity and more can all affect the likely hood of developing some diseases or illnesses; something that has been highlighted recently by Covid-19 data. Funding is imperative to increase testing levels, however it is equally important that research into precursor states, such as monoclonal gammopathy, is invested in.

Results from genomic testing can cause huge amounts of stress and anxiety on individuals, which makes the regulations surrounding private testing incredibly important. A lack of support and advice following from test results could not only be damaging for the individual's mental health but could also lead to further strain on the NHS. There are currently European regulations, in which the UK is part of, stating that all genetic testing must be followed up with counselling, however outside of the EU and online testing this much harder control.

Sharing data is vital for the advance in genomic research, precision medicine and non-malignant cancers, however accessing global data has been found to be difficult. Data should be shared freely within the scientific community globally all the while protecting and preventing the misuse of data. Although results from genomic testing have a high level of anonymity, making it virtually impossible to trace back to the individual, it's important to remember that many who have contributed to this data have sadly lost their lives in the hope of helping others. This is one of the reasons why maintaining strong legislations and regulations surrounding data sharing is of high priority.

This meeting highlighted some important next steps to be further discussed, including introducing blood cancers to the Genomics England Screening Program, increasing research funding and to improving data sharing and protection. In the last 10 years the survival rates for blood cancer have increased dramatically, however there is still a long way to go in the fight against blood cancer.

Charlotte Hall

P&SC Discussion Meeting, 'Non-Malignant Cancers, Precision Medicine and Genome Mapping', 14th September 2020