Brain tumour patient advocates and rare disease experts urge clarity on future of cross-border healthcare after Brexit

Organisations representing people affected by a brain tumour and representatives of an EU-wide network for rare and complex diseases want the Government to clarify its intentions on the status of European Reference Networks (ERNs) in the UK after Brexit.

The ERNs operate on the principle of open, cross-border healthcare and connect existing centres of excellence virtually to establish world-leading and sustainable networks of collaborating, multidisciplinary, research-intensive clinical centres. The ERNs are made up of 900 highly specialised healthcare units located in 313 hospitals in 25 EU member states. Seventy per cent of healthcare providers in the ERNs come from France, Italy, Germany, the Netherlands and the UK.

Yet, there is no guarantee that UK centres will be able to continue to participate in the initiative. That is because ERNS are supported by the European Commission and only centres within the EU and EEA are able to join, meaning that UK patients could miss out on the benefit of collective action and improved care.

Despite making up just under half of all newly diagnosed cancer cases in England, rare and less common cancers are responsible for approximately 54% of all cancer deaths.

Brain tumours are the biggest cancer killer of children and adults under 40. Like many other rare cancers they are difficult to treat and remain little understood compared with the more common cancers.

In fact, there are over 150 different types of brain tumour alone, some of which are extremely rare and complex. Patients and the specialist knowledge, expertise and interest in brain tumours are spread across Europe.

“No one country alone can make the difference in defeating rare cancers like brain tumours,” said Kathy Oliver, Chair of the International Brain Tumour Alliance (IBTA), which represents patients in the EURACAN ERN for rare adult solid tumours. “The idea of the ERNs is to equalise and improve, across the European Union, the standard of care available to patients suffering from rare diseases. By creating networks of expertise within and between EU member states, outcomes for people living with rare cancers will be improved.”

There is a specific ERN within EURACAN for brain and central nervous system tumours as well as ERNS for nine other rare cancer “families”. Brain tumour patient organisations in Great Britain are calling on the UK Government and European Commission to continue to support the work and aims of the ERNs after BREXIT by maintaining the invaluable efforts and active links which cross border cooperation provides.

A high level international EURACAN meeting in collaboration with EIT Health - taking place in Oxford, UK from 4 to 6 April - will highlight some of the challenges facing people with rare cancers and provide innovative solutions for sustainability and innovation in rare cancer management.

European Reference Networks, launched in December 2016, benefit patients in a number of ways including through the development of best clinical practice, access to second opinions and the facilitation of larger clinical studies.

Patients with rare diseases are represented on each of the ERNs by European Patient Advocacy Groups (ePAGs) who play a key role ensuring that the patient voice and values are embedded in all aspects of the ERNs' work.

1 https://docs.wixstatic.com/ugd/e22361_632a99df161844ea92afcc7ba6fd90a12.pdf
Cameron Miller, Head of Policy and Public Affairs at The Brain Tumour Charity, said: “These networks have the potential to really elevate best practice, knowledge, training and relationships between specialists across rare diseases like brain tumours. In truth we don’t know how Brexit will impact the UK’s participation in these initiatives but we do need a clear statement of intent from both sides on the negotiation.”

Carrie Hume, Head of Public Affairs and Campaigning at Brain Tumour Research, said: “As well as the uncertainty over the relationship of the ERNs with a post-Brexit UK and the impact that will have on patients with rare diseases, we need to be assured that crucial research links between the UK and the European Union will also continue to flourish.”

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Notes to editors
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