



BREXIT AND BRAIN TUMOURS

A statement from BNOS

the British Neuro-Oncology Society

with support from

The Brain Tumour Charity, Brain Tumour Research, brainstrust, Brain Tumour Action, Brain Tumour Support, Brain Tumour Research and Support Across Yorkshire, and the International Brain Tumour Alliance (IBTA)

The British Neuro-Oncology Society (BNOS) is the UK national learned society for all disciplines within the field of brain and CNS tumours. In accordance with our goals of providing the very best research, care and support for people affected by brain and CNS tumours - many of which are rare cancers - we ask the UK Government to urgently clarify their intentions on the status of European Reference Networks (ERNs) in the UK, post-Brexit, and what progress has been made in relation to this specifically since the publication of the “Collaboration on science and innovation: a future partnership paper”.

We also urge the European Commission to clarify their intentions on the status of European Reference Networks in the UK, post-Brexit.

There are over 150 types of brain tumours, a substantial number of which are very rare. Action on rare cancers has been prioritised by the EU and numerous Member States but there remains a long way to go in terms of the knowledge, understanding and capacity required to diagnose, treat and care for people affected. Unfortunately, brain and CNS tumours remain one of the most intransigent of all cancers and our patient community faces great unmet need in terms of durable treatments to sustain survival.

As experts in brain and CNS tumours and cognizant of the need for international collaboration in this field for the benefit of the patients and families we serve, we support continued cross border access to treatment for UK citizens affected by a rare cancer after the UK leaves the EU.

The principle of open, cross borders in delivering world class care, access to clinical trials and improved patient outcomes must remain intact to ensure that the interests of patients with rare cancers continue to come first. Patients, knowledge, expertise and capacity regarding rare cancers, like brain and CNS tumours,

are dispersed across Europe. Consequently, pan-European co-operation and collaboration are now inherent in the field of rare cancers as a result of open borders.

ERNs were established under the EU Directive on cross border healthcare. Each ERN aims to establish a world-leading, patient-centric and sustainable network of multidisciplinary research-intensive clinical centres. ERNs are virtual and connect existing centres of excellence from across 25 EU Member States.

In reality relatively few patients from the UK physically travel across borders to receive healthcare subsidised by the UK National Health Service (NHS). But collectively, EU Member States harness a great wealth of information, experience and capacity in the field of rare cancers which can be used to help treat and research these rare cases. The exchange of these assets is made easier by harmonized regulation, free movement and joint funding initiatives.

ERNs have the potential to improve treatment and care in numerous ways. For example, clinicians can more easily seek counsel on patient data and get a second opinion or seek suggestions for treatment protocols where the relevant expertise does not exist in their own country. Patient advocacy organisations from across the EU can more easily disseminate educational tools to advance clinicians' and the public's understanding of the patient journey. And clinical practice guidelines can be continually reviewed and developed across Europe to better reflect best practice and thus result in fewer disparities regarding treatment.

Researchers conducting pre-clinical and clinical trials also benefit from access to reliable patient data through commonly established procedures between ERNs and Member States that can reduce delay, bureaucracy and maximise the impact of research and funding grants.

The engagement of sufficient cohorts of brain tumour researchers and disparate patient groups such as those with a specific type of brain tumour or children, teenagers and young adults (CTYA) is vital to progress. The UK Government recognises that ERNs are integral to the delivery of its commitments in the UK Strategy for Rare Diseases¹ but has failed to offer a definitive assurance to UK brain and CNS tumour patients, researchers and healthcare professionals that ERNs will be able to continue to operate as designed across UK and EU Member State borders². We also urge the EU to provide clarity on this point.

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¹ <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/01/ern-guidance-provider-application.pdf>

² <https://www.gov.uk/government/publications/collaboration-on-science-and-innovation-a-future-partnership-paper>