

## **Specialised Healthcare Alliance position statement on European Reference Networks (ERNs) following Brexit**

The SHCA believes that continued UK involvement in European Reference Networks (ERNs) is vital to driving forward improvements in rare disease care in both the UK and European Union.

We are therefore calling on the UK Government and European Commission to work together to ensure the UK is able to contribute to ERNs following Brexit, in the interests of patients with rare diseases across Europe.

### **About ERNs**

ERNs are virtual networks of medical specialists across Europe. They facilitate discussions on complex or rare diseases and conditions that require highly specialised treatment. As such they are an essential resource for the 30 million rare disease patients in Europe.

ERNs convene virtual advisory panels to review patients' diagnosis and treatment. In doing so they ensure patients can benefit from the cumulative medical expertise across the EU. For many rare diseases, country-level specialist knowledge may be scarce due to low patient numbers. The cross-country collaboration and sharing of expertise enabled by ERNs is therefore hugely valuable for patients with rare diseases.

Beyond individual patient diagnosis and treatment, ERNs also support the:

- development of guidelines, training and knowledge exchange
- facilitation of large clinical studies to improve understanding of diseases
- development of new drugs and medical devices by gathering patient data
- development of new care models, e-health solutions and tools

### **UK involvement in ERNs to date**

The UK has been heavily involved in ERNs since their inception in 2017.<sup>i</sup> The UK participates in 23 of the first 24 ERNs, leading a quarter, more than any other member state.<sup>ii</sup> 129 UK healthcare professionals and 35 UK hospitals are involved in this work.<sup>iii</sup> It is estimated that the UK facilitates care for approximately 150,000 patients through ERNs.<sup>iv</sup>

As noted in the second progress report for the UK Strategy for Rare Diseases, ERNs have been a key vehicle for delivering a number of the Strategy's commitments. ERNs improve access to highly specialised services and support European co-operation on highly specialised healthcare, knowledge sharing and improved diagnosis and care.<sup>v</sup>

### **UK involvement post-Brexit**

Due to the UK's withdrawal from the EU, continued UK participation in ERNs is uncertain beyond March 2019. There is a clear consensus across patient organisations and the clinical community of the need for the UK to maintain its involvement in ERNs.

The UK Government has also stated its ambition for continued involvement, noting “the UK should seek to participate in specific policies and networks which benefit [...] patients across the UK and the EU, including: the European Reference Networks, which support European cooperation and knowledge sharing related to clinical care and research on rare diseases.”<sup>vi</sup>

However, at present, ERNs are only open to EU Member States and EEA members, meaning that there is a clear risk that the UK will no longer be able to participate following Brexit, unless agreement is reached on a new arrangement.

SHCA, February 2019

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<sup>i</sup> UK Rare Disease Policy Board. The UK strategy for rare diseases: second progress report. February 2018. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/684461/Rare\\_Disease\\_Policy\\_Board\\_-\\_Second\\_Progress\\_Report\\_2016-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/684461/Rare_Disease_Policy_Board_-_Second_Progress_Report_2016-2018.pdf)

<sup>ii</sup> UK Rare Disease Policy Board. The UK strategy for rare diseases: second progress report. February 2018. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/684461/Rare\\_Disease\\_Policy\\_Board\\_-\\_Second\\_Progress\\_Report\\_2016-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/684461/Rare_Disease_Policy_Board_-_Second_Progress_Report_2016-2018.pdf)

<sup>iii</sup> Professor Maurizio Scarpa, MetabERN Coordinator. Speech at APPG on Rare, Genetic and Undiagnosed Conditions meeting on ERNs. 9 July 2018. Available at: <https://metab.ern-net.eu/wp-content/uploads/2018/07/Ladies-Gentlemen-Scarpa-talk-1.pdf>

<sup>iv</sup> Professor Maurizio Scarpa, MetabERN Coordinator. Speech at APPG on Rare, Genetic and Undiagnosed Conditions meeting on ERNs. 9 July 2018. Available at: <https://metab.ern-net.eu/wp-content/uploads/2018/07/Ladies-Gentlemen-Scarpa-talk-1.pdf>

<sup>v</sup> UK Rare Disease Policy Board. The UK strategy for rare diseases: second progress report. February 2018. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/684461/Rare\\_Disease\\_Policy\\_Board\\_-\\_Second\\_Progress\\_Report\\_2016-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/684461/Rare_Disease_Policy_Board_-_Second_Progress_Report_2016-2018.pdf)

<sup>vi</sup> HM Government. The future relationship between the United Kingdom and the European Union. July 2018 Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/725288/The\\_future\\_relationship\\_between\\_the\\_United\\_Kingdom\\_and\\_the\\_European\\_Union.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/725288/The_future_relationship_between_the_United_Kingdom_and_the_European_Union.pdf)