

## A no-deal Brexit will be detrimental to people with rare diseases

We wish to emphasise the detrimental health implications of a no-deal Brexit for the one in 17 UK citizens who are diagnosed with a rare disease. No deal will result in the exclusion of the UK from the 24 European Reference Networks (ERNs) that were established to improve the care of the patients bearing the lifelong burden of these conditions, which require highly specialised diagnosis and treatment.

Rare diseases are rare, but experts are rarer still. With an estimated 6000–8000 rare diseases, ERNs were set up because no single country has the expertise or resources to cover them all. Thus far, ERNs have had a pivotal role in harnessing the collective knowledge across Europe and developing sustainable health care for these conditions.

The UK has been at the forefront of the creation and development of these networks, six of which were led from the UK, and we are now reaping the benefits of closer collaboration with experts and patient advocates throughout Europe. The ERNs have made it much easier to develop guidelines, create disease registries, build research collaborations, and create new education and training programmes. Above all, they have directly improved patient care by establishing a pan-European platform that brings international experts together to advise on complex problems that are specific to the patient and therapeutic options, where insufficient expertise exists in one country alone.

Leaving the EU without an agreement on UK participation in ERNs negates years of progress made by UK clinicians, researchers, and patient advocates, while also reducing access to clinical trials and funding. Most importantly, a no-deal Brexit will diminish our ability to provide the best

care for the millions of children and adults with rare diseases and complex conditions in the future.

We declare no competing interests. BP works for The Congenital Diaphragmatic Hernia Charity, which is a registered charity in England and Wales.

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See Online for appendix

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