

ERN on neuromuscular diseases (ERN EURO-NMD)

Neuromuscular diseases (NMDs) occur from early childhood to late adulthood and are characterised by muscle weakness and wasting, but may be associated with other symptoms, including fatigue, pain, numbness, blindness, swallowing difficulties, breathing difficulties and heart disease. Most NMDs are progressive and debilitating, with reduced lifespan and quality of life.

There are significant gaps and disparities in access to diagnostics and treatment across Europe. Major challenges in improving outcomes include the delay in referral from primary care to a specialist centre, and managing the transition from paediatric to adult services.

ERN EURO-NMD unites Europe's leading experts to provide patients with access to specialist care through virtual and in-person consultations. The network aims to reduce time to diagnosis by 40% in its first 5 years, to improve diagnostic yield by 15% and to increase access to appropriate care pathways.



The network aims to reduce time to diagnosis by 40% in its first 5 years, to improve diagnostic yield by 15% and to increase access to appropriate care pathways.

In addition, ERN EURO-NMD will develop new guidelines and provide healthcare professionals and patients with disease-specific best-practice information. The knowledge generated and curated by the network will be widely available through eHealth tools. Building on a strong legacy of cooperation, the network will also foster collaborations with the potential to drive research and therapy development to address unmet patient needs.

NETWORK COORDINATOR

Professor Kate Bushby

*The Newcastle upon Tyne Hospitals
NHS Foundation Trust, United Kingdom*