REVEALS: Registry of Endpoints and Validated Experiences in ALS

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Respiratory function in Amyotrophic Lateral Sclerosis (ALS) declines rapidly, necessitating regular assessment to facilitate timely intervention (NICE 2016). However, the relationships between commonly used respiratory measurements (SNIP/FVC/SVC) and respiratory morbidity and symptoms require investigation. The purpose of this study is to address this question by comparing real world experience to clinical measurements of respiratory function by evaluating (1) the impact of declining respiratory function on symptoms and secretion management and (2) the frequency and impact of respiratory tract infection.
A Prospective Multi-Centre Longitudinal Study examining respiratory decline, mortality and morbidity in spinal and bulbar onset ALS commenced in March 2018. Six TRICALS centres are involved. Inclusion criteria include patients who are Kings stage 2 or 3 and without a significant respiratory history or FTD. The aim is to recruit 300 patients and to conduct serial 3 monthly respiratory assessments with detailed logging of symptoms, respiratory infections and care needs over 18 months. To date 101 patients have been recruited. Baseline data indicate that these patients have early respiratory involvement with a low burden of respiratory morbidity.
This study has the potential to provide a rich database of respiratory function and decline as well as the real-life impact of this decline in ALS.

NICE (2016). Motor neurone disease: assessment and management. . Clinical Guideline NG42. . N. I. f. H. a. C. Excellence. London:, NICE.