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Standing up in Multiple Sclerosis (SUMS): Protocol for a multi-centre randomised controlled trial evaluating the clinical and cost effectiveness of a home-based self-management standing frame programme in people with progressive multiple sclerosis.

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Background:

Multiple sclerosis (MS) is an incurable, unpredictable but typically progressive neurological condition. Within 15 years of diagnosis, approximately 50% of people are unable to walk unaided, and over time an estimated 25% depend on a wheelchair. Those who are more severely impaired spend much of their day sitting, often with limited ability to change position. In response, secondary complications can occur including: muscle wasting and weakness, pain, reduced skin integrity, spasms, stiffness, constipation, and associated psychosocial problems such as depression. Effective self-management strategies, which can be implemented relatively easily and cheaply are needed to improve mobility and reduce sedentary behaviour. This is challenging, particularly in the latter stages of disease. Regular supported standing is one potential option.

Methods/Design: SUMS is a pragmatic multi-centre randomised controlled trial evaluating use of Oswestry standing frames with blinded outcome assessment and full economic evaluation. Participants are randomly allocated (1:1) to either a home-based, self-management standing programme (with advice and support) along with their usual care or to usual care alone. The intervention group participants are asked to stand for 30 minutes three times weekly over 20 weeks. Participants are followed-

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up at 20 and 36 weeks post baseline. The primary clinical outcome is motor function (Amended Motor Club Assessment) and primary economic endpoint is quality-adjusted life years. Secondary outcomes include measures of explanatory physical impairments, key clinical outcomes, and health-related quality of life. An embedded qualitative component explores participant's and carer's experiences of the standing programme.

Discussion: This is the first powered multi-centre trial to assess the clinical and cost effectiveness of a home based standing frame programme for people severely impaired by MS. If demonstrated to be effective this evidence will be used to develop recommendations for a health service delivery model which could be implemented across the UK.

Trial Registration: ISRCTN69614598