

## **About The R-PROMS Study**

### **A feasibility study of Remote Patient-Reported Outcome measures in Mitochondrial disease and Spinocerebellar ataxias (R-PROMS)**

The R-PROMS study is a research study funded by Newcastle University (UK) and Monash University (Australia). It is managed by Newcastle University and is taking place at The Newcastle upon Tyne Hospitals NHS Foundation Trust.

This study aims to investigate whether online assessments can be used to measure the severity of ataxia (movement, balance and co-ordination difficulties) in people with Mitochondrial Disease and Spinocerebellar ataxia.

We are planning to recruit 30 adults (aged over 16) with a confirmed diagnosis of mitochondrial disease or Spinocerebellar ataxia into this study.

One in-person study visit will take place at the Clinical Ageing Research Unit (CARU) in Newcastle upon Tyne. At this visit a number of clinical assessments will be performed. Participants will then be asked to complete a number of online tasks and questionnaires every two months for a period of one year. These will be performed in the participant's home and at their own convenience. Telephone/video support by the research team will be provided if needed.

The study visit and completion of the online assessments will take approximately 2-3 hours each time. Travel expenses for the in-person study visit will be reimbursed.

Participants will need a computer with a keyboard, mouse and microphone and access to the internet in order to take part.

If you would like further information about taking part in the study, please contact the study team on **0191 208 3103** or email **nuth.mitoresearch@nhs.net**.