

HIPS/21/13 – Development and validation of a patient-reported measure (PRM) of treatment burden in stroke.

Many treatments are recommended after discharge from hospital with a stroke e.g. medications or physiotherapy and this can have considerable impact on an individual's life. We define the workload of healthcare and the impact on wellbeing for people with long-term conditions as treatment burden. Treatment burden can arise from having a lot of tasks to do for example take multiple medications or attend numerous appointments, or it can arise from deficiencies in the way care is provided, for example difficulties accessing care when it is needed. We need to be able to measure treatment burden to test ways of lessening it, but currently there are no good measurement tools for use with people who have experienced a stroke. We aim to test a new self-reported questionnaire that measures treatment burden after stroke (PETS-stroke). We have developed questions for PETS-stroke by amending a questionnaire used in non-stroke patients (PETS) using knowledge gained from our previous research involving stroke survivors. We then conducted interviews with stroke survivors to evaluate if PETS-stroke is understandable and relevant to them. We now plan to test PETS-stroke in a large group of stroke survivors living at home to test if it measures treatment burden accurately and reliably using statistical methods. This involves giving out survey packs to stroke survivors that are completed at home and sent back to the research team. In future we plan to use PETS-stroke to measure how treatment burden affects outcomes such as quality-of-life and develop and test new ways of providing healthcare that lessen treatment burden.