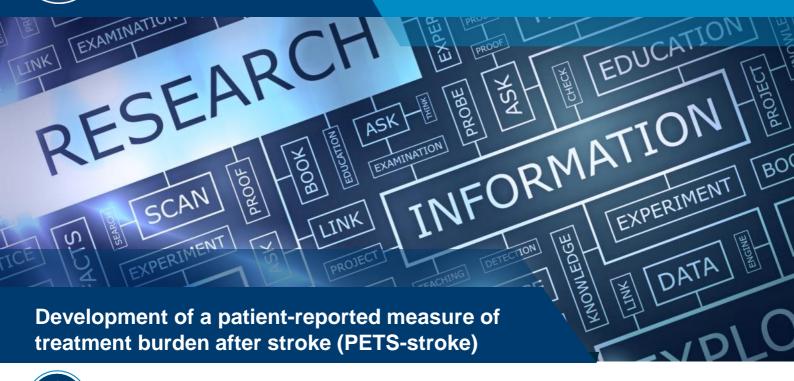# Development of a patient-reported measure of treatment burden after stroke (PETS-stroke)

AIMS

Treatment burden is defined as the workload of healthcare and the impact on wellbeing. It has previously been under recognised by clinicians, researchers and policy makers. Our aims were:

- To develop a questionnaire that measures the burden of treatment experienced after stroke from the patient's perspective.

- To test if the developed questionnaire is accurate, reliable and easy to use.

KEY FINDINGS

- The questionnaire developed and tested in this study is called the PETS-Stroke (Patient Experience of Treatments and Self-Management - Stroke).

- PETS-stroke has 34 questions or items that each ask about a different aspect of treatment burden.

- Our results suggest that PETS-stroke measures treatment burden accurately, reliably and consistently over time.

- The PETS-stroke is easy to use for stroke survivors.

- PETS-stroke will allow researchers to measure the treatment burdens associated with stroke treatments, for example those being tested in clinical trials. This is important because treatments that are burdensome may negatively impact quality of life after stroke.

WHAT DID THE STUDY INVOLVE?

- A Research Advisory Group including stroke survivors and unpaid carers helped to advise on recruitment, reviewing patient-facing documents and aiding interpretation of results.

- We adapted an existing questionnaire that measures treatment burden, the Patient Experience of Treatments and Self-Management (PETS), to make it stroke specific, using information from our previous research with stroke survivors. The new questionnaire is called PETS-Stroke.

- A group of 15 stroke survivors reviewed the PETS-stroke and provided feedback on wording, relevance and importance of items.

- A postal survey was completed and returned by 381 stroke survivors from Scotland and Wales. The survey pack included the PETS-stroke and 3 other measures (of stroke illness, readiness to self-manage and satisfaction with care). A second PETS-stroke was also completed and returned 2-4 weeks later.

- Statistical testing examined if the measure is accurate and reliable.

- Telephone interviews with 31 participants examined if the measure was easy to use.

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

- Participants were slightly younger, more affluent and more able bodied than the average Scottish stroke survivor, but a wide range of disabilities were reported including speech problems, arm weakness and difficulty walking.

- PETS-stroke is a valid and reliable measure. It measures treatment burden consistently and patients found it easy to use.

- Treatment burden, measured by PETS-stroke, was significantly associated with higher stroke illness, lower readiness to self-manage and lower satisfaction with care. This helps to reassure us that PETS-stroke measures treatment burden accurately, as these results are what we would expect to find.

- Higher treatment burden was significantly associated with lower sociodemographic status (less affluence) in 8 out of 10 treatment burden categories.

Medical Information
Care Planning
Medications
Medical appointments
Keeping Healthy
Living at Home with Stroke
Relationships with Others
Difficulty with Healthcare Services
Role Limits
Mental Fatigue (single item)

The 34 items in the PETS - stroke are grouped into these 10 categories (9 groups of items and 1 single item).

WHAT IMPACT COULD THE FINDINGS HAVE?

- Treatment burden is important because it can negatively impact peoples' lives after stroke.

- PETS-stroke can be used in clinical trials of stroke treatments to examine the impact that new treatments or therapies have on people.

- Knowledge of any potential treatment burdens will allow a more informed discussion between healthcare professionals and patients and can also inform policy decisions.

- Further testing of the measure will include examination of how well it can detect any changes in treatment burden experienced by a person.

HOW WILL THE OUTCOMES BE DISSEMINATED?

- Findings have been presented at conferences e.g. The UK Stroke Forum Meeting 2023. Results will be published in a peer reviewed journal. The protocol paper is published (Protocol for the development and validation ... | Health Open Research).

- We created a boardgame about treatment burden after stroke which we showcased at the Glasgow Science Festival in June 2023.

- A public dissemination event was held in association with The Scottish Stroke Research Network in April 2024. Around 40 people with lived experience of stroke attended the event at The Grand Central Hotel in Glasgow alongside stroke researchers, stroke clinicians, representatives from CSO, The Stroke Association, Chest Heart and Stroke Scotland, and the Scottish National Advisory Committee for Stroke. This was an enjoyable, interactive and productive event during which we discussed the findings of our research and received insightful feedback from stroke survivors and carers. Feedback on the research was collated and will be utilised to inform future grant applications. Feedback on the event will inform the design of future events.

CONCLUSION

We have developed and tested the PETS-stroke, a 34-item patient-reported measure of treatment burden after stroke. Future funding applications will support use of the measure in clinical trials of stroke treatments. Measuring treatment burden when testing stroke treatments allows consideration of the impact of treatments on the person alongside how effective they are.

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Additional Information
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