What is epilepsy
Epilepsy is a common condition where sudden bursts of electrical activity in the brain cause seizures or fits. There are lots of possible symptoms of epilepsy seizures, including uncontrollable shaking or losing awareness of things around you. Treatment to help people have fewer seizures, or to stop having seizures completely, include medication and surgical procedures.

People who have epilepsy may be at a greater risk of having mental health difficulties. This could be: related to how epilepsy affects the brain, a side effect of medication, or a result of having to live with an epilepsy diagnosis because it is a long-term condition that can, in some cases, be fatal.

What is PAVES?
Psychology Adding Value – Epilepsy Screening (PAVES), is a service for children and young people with epilepsy who experience mental health issues.

Those who are identified as potentially eligible for the service are asked to attend their local paediatric epilepsy outpatient clinic for assessment. They are asked to complete questionnaires that help clinicians decide whether or not they need mental health support. They are supported in filling in the questionnaire by parents or carers where appropriate.

The need for mental health support is categorised using a traffic light system (“red” for greatest need for support, “green” for no need and “amber” for in between). Previously, all patients who were in the “red” category would have been referred to local Child and Adolescent Mental Health Services (CAMHS). PAVES lets them, and their families/carers, try different forms of mental health support first instead.

These forms of support include reading resources, a face to face support group for young people every week for six weeks, and a workshop for parents and/or carers.
Why is this important?

By providing earlier access to support for young people with epilepsy who have mental health difficulties, PAVES can help reduce the risk of young people with epilepsy developing more severe mental health difficulties in the future, and any subsequent problems related to this, for example, social, emotional or behavioural difficulties.

This is particularly important right now because CAMHS services in Scotland are busy. Patients can face long waiting times before they start treatment. During this time their mental health may deteriorate making recovery more difficult or making it take longer.

It is important to note that clinicians would still make referrals to CAMHS services where needed, but that PAVES offers a way to support patients in the meantime, either until they can access CAMHS services, or as an alternative, depending on each patient’s circumstances.

What we did

We looked at whether or not using PAVES would save NHSScotland money and resources compared with what used to happen before PAVES began, which was that everybody who was found to be in the “red” category after completing the questionnaires at the paediatric epilepsy outpatient clinic would be referred to CAMHS.

We did this by comparing what we expect the costs and the outcomes to be for a group of patients who would be treated with PAVES and those who would be treated only by CAMHS.

What we found

In a sample of 100 patients whose mental health difficulties were identified at the paediatric epilepsy outpatient clinic using the questionnaire, we estimate that twenty six referrals to CAMHS would be avoided, mostly in the first year. PAVES did incur an additional cost of £718 per person.

It may be possible to adapt or expand access to PAVES to ease pressure on CAMHS services across other long-term conditions in paediatrics, but further research is needed to explore this. It was also not clear whether PAVES can significantly help improve patients’ mental health scores on the questionnaire. The benefits of PAVES explored in our work was predominantly the efficiency of the NHS in terms of avoided CAMHS referrals, rather than the benefits of PAVES to patients’ mental health.

The value of PAVES in helping the NHS with epilepsy patients who have mental health difficulties will depend on how frequently these difficulties recur, and what proportion of new patients to the clinic are screened and found to have mental health difficulties. We did not have sufficient data to explore these issues.
What is our conclusion?
There was evidence to show that PAVES is cost effective for the NHS.

What next?
This report will be published on our website in 2022.

This plain language summary has been produced based on SHTG Assessment
October 2022