Healthcare Improvement Scotland | SHTG Advice on health technologies

SHTG Assessment
October 2022

In response to an enquiry from Paediatric Neurology Services and Paediatric Psychology and Liaison Services, Royal Hospital for Children and Young People, NHS Lothian.

The Psychology Adding Value – Epilepsy Screening (PAVES) and early intervention for children and young people with epilepsy at risk of mental health problems

What were we asked to look at?

The Scottish Health Technologies Group (SHTG) was asked to assess the cost effectiveness of Psychology Adding Value – Epilepsy Screening (PAVES) and early intervention, compared with onward referral to Child and Adolescent Mental Health Services (CAMHS) for children and young people identified, without formal screening by clinicians, as being at risk of mental health problems. PAVES and early intervention includes mental health screening, using the Strengths and Difficulties questionnaire (SDQ) and, if required, provides access to a tailored early intervention pathway for children and young people with epilepsy.
We were not asked to look at the clinical effectiveness of PAVES and early intervention.

Why is this important?

Children and young people with epilepsy are at an increased risk of developing social, emotional, behavioural and learning difficulties, compared with peers who do not have an epilepsy diagnosis. Without early identification and intervention, this can lead to increased morbidity, reduced quality of life, poorer treatment outcomes and lower educational attainment.[1]

A rise in the number of people requiring mental health support has increased pressure on CAMHS, and patients face increased waiting times to commence treatment. Treatment delays

mean that an individual's mental health difficulties can worsen and it may be harder, or take longer, for them to recover. The PAVES and early intervention project, set up in NHS Lothian in 2016, aims to ease service pressures on CAMHS by providing alternative intervention for children and young people with epilepsy.

What was our approach?

We conducted an economic evaluation of the PAVES and early intervention project. The costs and outcomes for patients on the PAVES pathway were compared with standard care, where patients were assumed to undergo either onward referral to CAMHS or no treatment (depending on their screened SDQ score as well as clinical judgement). The evaluation was based on screening and referral data from the PAVES project, and cost estimates were based on published data and staff experience of the resources required to run the intervention components following PAVES screening.

We were asked to carry out a budget impact analysis to inform the roll-out of PAVES and early intervention beyond NHS Lothian. We also explored the literature on the relationship between SDQ scores and longer-term outcomes for patients to determine whether sufficient data exist to extrapolate the economic evaluation over a longer time horizon. Insufficient data were available to reach conclusions for both analyses, and the summaries are presented in *Appendix 1.*

What next?

SHTG's assessment will be used by colleagues in NHS Lothian to inform the future delivery of services in their paediatric neurology department. The findings will be available to paediatric neurology departments across Scotland for their service delivery consideration.

Key Findings

Using PAVES and early intervention pathway can avoid referrals to CAMHS and so is likely to be a cost-effective intervention. In a cohort of 100 patients, 78 became eligible for PAVES over 3 years. Twenty-six referrals to CAMHS were avoided, most in the first year of providing PAVES. The additional cost to the NHS of providing PAVES was £718 for every avoided referral to CAMHS.

Uncertainties include:

- the proportion of people in the standard of care (comparator) pathway that would be referred to CAMHS. This affects the circumstances under which PAVES could be both cheaper than current care in addition to avoiding CAMHS referrals
- the longer-term impact of the PAVES pathway, making the level of recurring costs, savings or benefits unclear
- the clinical effectiveness of PAVES in terms of improving patients' mental health has not been formally quantified in the evaluation. The model can be assumed to be conservative in that is does not capture any expected patient benefits
- whether PAVES is suitable for spread and scale up beyond local paediatric neurology services, to help ease pressure on CAMHS services across other long-term conditions for children.

Contents

Introduction

Epilepsy is one of the most prevalent neurological conditions, affecting approximately one in every 220 children in the UK. It can develop at any age[2] and has a high rate of comorbidity with neurodevelopmental disorders such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).[3]

Children and young people with epilepsy can experience higher levels of anxiety and depressive disorders than the general population and people with chronic illnesses.[4] Studies have shown that rates of mental health problems in children and young people with epilepsy (37%) were significantly higher than in children with diabetes (9%) or healthy peers (7%). The impact of this can permeate every aspect of a child's life, making them vulnerable to emotional and behavioural difficulties, [5, 6] lowering their self-esteem (Shiu, 2004), or limiting their ability to partake in activities, socialise and school attendance.[7] These outcomes have a detrimental effect on health-related quality of life (HRQoL).[8-10]

Children and young people with epilepsy may be particularly vulnerable to mental health problems for a number of reasons. For example, as a result of medication side effects, neurobiology, [11] or the impact of epilepsy on cognitive functioning and development.[12] Reduced cognitive functioning is predictive of poor HRQoL in children and young people with epilepsy.[13]

Epilepsy can affect the family of children and young people with epilepsy, with mothers be significantly more vulnerable to anxiety and depression than mothers of children with neurodisabilities.[14] When observed in the family context, emotional and behavioural difficulties in children and young people with epilepsy have been linked to increased family stress[15] and significantly more permissive parenting styles compared to control groups.[16] The Scottish Intercollegiate Guidelines Network (SIGN) recommends that healthcare professionals should routinely enquire about depression and anxiety symptoms in all children and young people with epilepsy.[17]

The availability of mental health services specifically for children and young people with epilepsy is not always standard and/or timely. A Royal Collage of Paediatrics and Child Health (RCPCH) audit of paediatric epilepsy services across England and Wales found that mental health services are only available via 12.8% of clinics.[18] The National Institute for Health and Care Excellence (NICE) recommends that psychological issues are covered in all epilepsy care plans.[19] To achieve this, the RCPCH states that one full time mental health practitioner is required per 250 children in a clinic.[18] There is evidence to suggest that group psychosocial interventions are effective at improving mood, epilepsy understanding and HRQoL in children and young people with epilepsy.[21]

Research question

What is the cost effectiveness of the PAVES and early intervention pathway compared with the standard of care pathway of no PAVES and either onward referral to CAMHS or no intervention?

Health technology description

PAVES and early intervention pathway

The PAVES and early intervention project began in 2016 with the introduction of a mental health screening tool and early intervention pathway for children and young people with epilepsy. The SDQ screening tool aims to provide an early indication of which patients may be experiencing mental health problems or at risk of soon experiencing mental health problems. Initially the screening tool was printed and given to patients and their parents/carers during their visit(s) to the outpatient clinic. Patients and their parents/carers can now complete the tool online. Screening is based on a traffic light categorisation system, using the patient's SDQ scores. Clinicians review the completed SDQ for combinations of responses that constitute a 'red', 'amber' or 'green' risk categorisation. Clinical judgement is still required as there is no set threshold for these risk categories.

Patients who score amber or red are eligible for the early intervention pathway. Early intervention options depend on the needs of the patient, and include referral to third sector services, a workshop for parents/carers of children and young people with epilepsy, printed self-directed support materials and a six-week, face-to-face, therapeutic group intervention for adolescents. All face-to-face components of the intervention took place before the first COVID-19 lockdown (that is, before March 2020).

All children and young people with epilepsy on the PAVES pathway are reassessed by the screening tool at subsequent outpatient appointments and may still be referred to CAMHS, for example, if their SDQ score continues to be categorised as red during subsequent outpatient appointments.

Standard of care pathway (pathway prior to PAVES and early intervention)

Prior to the existence of the PAVES pathway, children and young people with epilepsy identified during paediatric neurology clinic visits as potentially having mental health problems would be referred to CAMHS for further support. The cohort of patients referred to CAMHS represents a subset of all patients who receive the PAVES intervention. We have no data on the proportion of patients who would previously have been referred to CAMHS, but clinicians working in the epilepsy clinic advised that it would be equivalent to being

categorised as red by the screening tool within PAVES. Children and young people with epilepsy categorised as amber would be eligible for the PAVES intervention.

For the standard of care pathway, a cut-off of red screening risk was used in the evaluation. For patients screened as amber or green, no further health and care intervention was assumed, unless their risk changed during subsequent outpatient appointments, which take place approximately every six months.

Not all patients referred to CAMHS are accepted onto the CAMHS waiting list. Each referral is reviewed by the CAMHS team and some may be rejected. Patients accepted onto the waiting list are offered an initial appointment with CAMHS where it is agreed between the patient (and family if required) and clinician whether further appointments are needed, at which point the patient would then go onto a further CAMHS waiting list for treatment.

Economic evaluation – methods

Care pathways

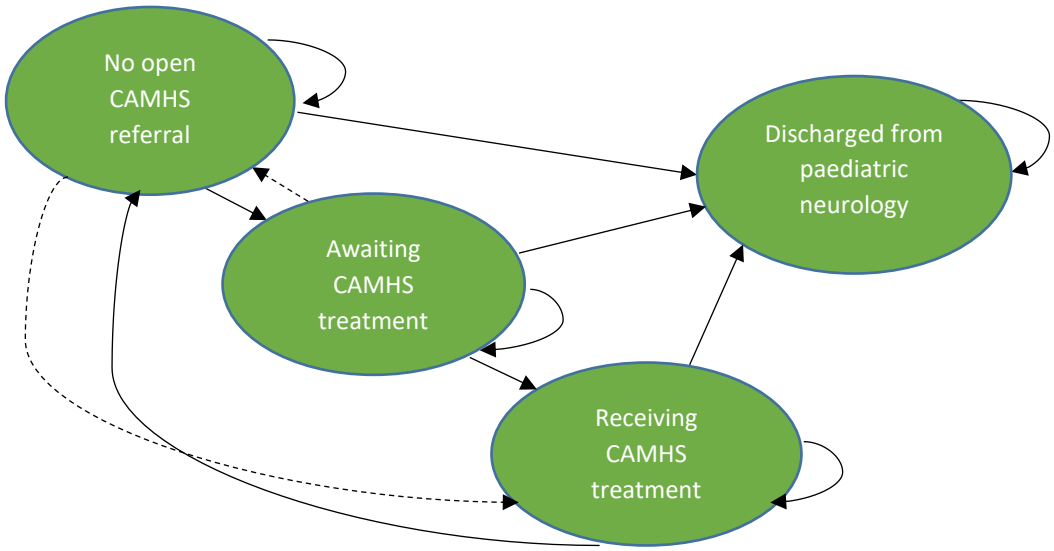
A cohort state transition model has been built based on observed data for 234 patients on the PAVES pathway in NHS Lothian during the period between January 2017 and January 2020. A depiction of the care pathway for patients is shown in *Figure 1*, where hypothetical cohorts of patients are followed up from the point where first screening categorises their risk level as red, amber or green. The model has a 3-year time horizon to reflect likely follow up from first screen, capturing any subsequent CAMHS treatment, and is based on cycles of 6 months to reflect the gap between screenings at the epilepsy clinic.

The model is structured as follows:

- all patients start off in the 'no open CAMHS referral state', (see *Figure 1* below) where they remain if screened as either green or amber or move to 'awaiting CAMHS treatment' if screened as red. The relative proportions are based on the proportion of patients screened as red under the standard of care pathway. Transition data for the PAVES pathway are based on the observed number of CAMHS referrals in any given 6-month cycle of the model
- if a referral is rejected by CAMHS the patient returns to the 'no open CAMHS referral' state. The proportion of CAMHS referrals rejected (23.7%) is available from routine data[22] which is concurrent with the observed CAMHS referrals for the PAVES cohort that were rejected (21.6%), though this is based on a much smaller number of observations
- patients who have their referrals accepted by CAMHS remain in the 'awaiting CAMHS treatment' state for a period of time reflecting the distribution of observed CAMHS waiting times for the PAVES pathway cohort of patients

- thereafter, patients will either move to the 'receiving CAMHS treatment' state where patients remain for a distribution that reflects observed CAMHS treatment durations seen in clinical practice for the PAVES cohort
- patients will return to the 'no open CAMHS referral' state upon discharge from CAMHS
- if a patient becomes old enough to be discharged from paediatric services, they enter the 'discharged from paediatric neurology services' state. In clinical practice, these patients are referred to adult mental health services
- the analysis assumes that patients can be referred to CAMHS treatment only once as there are no data on the proportion of CAMHS referred patients who were later re-referred
- allowing the 'Awaiting CAMHS treatment' state to only be entered once enables the follow up of completed CAMHS patient journeys for this cohort, as all patients are followed up until either they have reached either the 'no open CAMHS referral' state or 'discharged from paediatric neurology' state.

Figure 1: Modelled care pathway for paediatric neurology children and young people with epilepsy experiencing the PAVES pathway or standard of care pathway



Note: Dotted lines represent the possibility that a clinician could need to refer a patient to CAMHS for emergency assessment/treatment, bypassing the standard referral process to allow the patient to be seen as soon as possible. We therefore modelled that in the next cycle they would be receiving CAMHS treatment. It is expected to be needed very rarely (hence shown as a dotted line).

Outcomes

The primary outcome following the introduction of the PAVES pathway was a reduction in the number of CAMHS referrals.

Secondary outcomes were as follows:

- improvement in assigned category of risk over time (for example, red to amber/green and amber to green for improvement or green/amber to red and green to amber for deterioration)
- improvement in SDQ score(s) for patients whose categorisation did not change
- reduction in the required duration of CAMHS treatment.

Secondary outcomes were summarised narratively as change in SDQ category does not influence the CAMHS referral process in the model beyond identifying which patients under current practice would be referred to CAMHS (upon their first red screen). Change in duration of CAMHS treatment was tested in sensitivity analysis.

Costs

The economic model captures the total costs associated with the PAVES pathway and the total costs associated with the standard of care pathway, taking into account the cost of PAVES early intervention and the cost of CAMHS services.

The cost of screening is not included in the model, on the basis that paediatric neurology clinicians would have previously identified the vast majority of cases that should be referred to CAMHS through their own clinical judgement.

PAVES early intervention costs

The PAVES early intervention comprises three components: patient groups that meet once a week for 6 weeks, with blocks run twice per year; a one-off parent/carer education workshop that is run seven times per year; and self-directed support, printed in advance and provided to patients.

The patient group requires two staff members (either two clinical psychologists at Band 7 or one clinical psychologist or a nurse who are both at Band 7) to run the group. The time commitment required to organise and provide sessions is 2-3 half-day sessions each week during the 6-week duration of the patient group course, run twice per year. The estimated total cost was calculated as £15,600 based on a £65 per working hour cost of each staff member's time.[23] As eight patients attended the patient group courses, the average cost per attending patient was £1,950 per annum. Demand for the course was tested in sensitivity analysis (that is, fewer courses run per annum in subsequent years).

The parent/carer education workshop requires two staff members (either two clinical psychologists at Band 7 or one clinical psychologist and a nurse who are both at Band 7) to run each session and the time commitment required to organise and provide sessions is 2-3 half-day sessions for each of the seven instances of the workshop per year. The estimated

total cost was calculated as £9,100 based on a £65 per working hour cost of each staff member's time.[23] As 29 patients' family members attended the workshop, the average cost per attending parent/carer was £314 per annum. Demand for the course was tested in sensitivity analysis (that is, fewer sessions provided in subsequent years).

The Personal Social Services Research Unit (PSSRU) Unit Costs of Health and Social Care include administration costs required for printing materials within working hour costs. The cost of printing self-directed support materials was not included in the base case on the basis that these costs would be incorporated during the allocated sessions set aside for PAVES as described above, and the materials provided to patients at their next paediatric neurology appointment. This assumption was tested in sensitivity analysis, whereby we estimated the cost of printing self-directed support materials at 4 hours per annum for a staff member at Band 4 with a working hour cost of £33 per hour (as we assumed this task could be delegated if it could not be done by the relevant PAVES staff members during their allocated time to work on PAVES).

The cost of venues for face-to-face sessions were not included in the base case analysis because during the intervention period no cost was incurred by staff running the sessions. This assumption was tested in sensitivity analysis, based on the Public Health Scotland average cost per square metre for property maintenance in teaching hospitals (£38)[24] and the (estimated) number of square metres utilised during the provision of the face-to-face PAVES components (25 m^2 for the patient intervention and 20 m^2 for the parent/carer workshops).

In the economic model the cost of the PAVES intervention is assigned to proportion of patients not classified as green in the 'no open CAMHS referral' health state. In the PAVES cohort it is possible that components of PAVES would be taken up after 6 months (for example, when some patients may have moved into the 'awaiting CAMHS treatment' state), but for simplification we assumed patients would receive PAVES components upon their first red or amber screen.

<u>CAMHS service costs</u>

For CAMHS appointments, no specific unit costs per contact, or per patient are available from routinely published information from Public Health Scotland. Acute outpatient and inpatient costs are available from the Public Health Scotland Cost Book, but it was felt that most services would be provided outwith hospital settings and so hospital data may overestimate CAMHS costs. Total expenditure on CAMHS is available via the Public Health Scotland (PHS) Costs Book.[25] An approximate cost of a CAMHS contact in Scotland was derived from total expenditure data, and the total costs for community-based contacts in England (£463,858,462) is similar to Scotland (£46,512,731) given comparative population sizes.[25, 26] Average costs were similar between the countries for outpatient activity (£262 and £282 in Scotland and England respectively) and inpatient activity (£894 in Scotland compared with £771 in England), although the amount of hospital based care provided varied considerably between the countries. NHS Reference Costs were adjusted for community-based contacts in

England (£221), to account for differences in the average costs of CAMHS inpatient and outpatient-based contacts between the countries and derive an overall estimate for all CAMHS contacts in Scotland, which was £283. These figures were tested within sensitivity analysis by using the NHS Reference Costs directly (£271 for all CAMHS contacts).[26]

CAMHS contacts costs were assumed not to include the costs associated with making the initial referrals from paediatric neurology to CAMHS, or the CAMHS case reviews during which decisions are made about whether to accept or reject referrals onto the CAMHS waiting list.

Paediatric neurology time was estimated as 15 minutes of a hospital consultant paediatric neurologist's time, at a unit cost of £123 per working hour[23] which works out at £31 per CAMHS referral.

CAMHS referral decisions were expected to include 3 to 4 clinicians from the local CAMHS multidisciplinary team reviewing each case for approximately 15 minutes. The most likely CAMHS local multidisciplinary team composition in NHS Lothian was estimated from PHS's CAMHS characteristics of the workforce supply, [27] and used to cost 15 minutes for each staff member including one nurse (50% of a Band 6 cost and 50% Band 7) a psychologist (50% Band 7 and 50% Band 8a), an occupational therapist (50% of a Band 6) and 50% of a consultant's time. Unit costs were taken from community-based PSSRU costs, except for the consultant, where hospital costs were used and the total costs for 15 minutes was £55.

Data are available on the number of CAMHS referrals where a review took place following triage, whereby the patient (and their family if necessary) are offered a screening appointment and case review for 1 to 2 hours by one clinician, the patient is then either added to the CAMHS waiting list or discharged to paediatric neurology without further intervention by CAMHS. These reviews did not occur in all cases but a unit cost was applied where relevant. Reviews were assumed to be conducted by either a consultant, a nurse (Band 7) or a psychologist (Band 8a). The average cost for the review was assumed on the basis of 2.5 hours availability at £221 per review.

Patients who were discharged from paediatric neurology services while in the 'awaiting CAMHS treatment' state were assumed to incur the cost of a re-referral to adult mental health services. This was assumed to involve the same process as for CAMHS (a 15-minute referral from a neurologist followed by a multidisciplinary discussion by mental health staff and, if necessary, a review with the patient). The same costs as for CAMHS (described above) were used.

CAMHS treatment costs are likely to be dependent on an individual's needs and so highly variable. PAVES data were used to estimate a distribution for the average CAMHS treatment length in terms of 6-month cycles. Owing to a lack of data on the number of contacts with CAMHS within any given period of time, the following assumptions were made (tested in sensitivity analysis):

- for treatment durations less than 6 months, a patient would have six contacts with CAMHS
- for treatment durations of 6 months to less than 12 months, a patient would have 12 contacts
- for treatment durations of 12 months to less than 18 months, a patient would have 18 contacts
- for treatment durations of 18 months to less than 2 years, a patient would have 24 contacts
- for treatment durations of 2 years (the maximum duration in the model) a patient would have 30 contacts.

Patients moved through the model only once with rejected referrals returning to either the 'no open CAMHS referral' state or 'discharged from paediatric neurology.' This was a simplifying assumption as we have no data on repeat referrals to CAMHS.

It was necessary to account for the effect of a rejected referral to CAMHS if it meant that a patient had their treatment delayed significantly by requiring a re-referral and eventual treatment. Forty percent of the rejected referrals were assumed to incur the cost of CAMHS treatment based on the proportion of red screening patients in the PAVES cohort who went on to have a subsequent red screen at remaining visits up to the end of the 3-year follow up. It was hypothesised that because of the delay in receiving treatment caused by the referral being rejected, these patients would incur repeat costs of a CAMHS referral as well as a one-off cost that represented eventual CAMHS treatment over a higher-than-average number of cycles (the 75th percentile was used, that is, three cycles). This assumption was tested in the sensitivity analysis (median CAMHS treatment duration, lower quartile of initial CAMHS treatment duration).

A summary of the costs used in the model are provided in *Table 1.*

Table 1: Costs included in the model

Resource	Amount of resource required	Unit cost of resource used	Total cost
PAVES patient group (6-week course)	1x Psychologist (Band 7) 1x Psychologist or Nurse (Band 7)	£65 per Band 7 hour x 4 (hours per session) x 2.5 (sessions needed) x 6 (weeks of course) x 2 (iterations of course per year)	£15,600 per year
PAVES parent/carer group (one-off workshop)	1x Psychologist (Band 7) 1x Psychologist or Nurse (Band 7)	£65 per Band 7 hour x 4 (hours per session) x 2.5 (sessions needed) x 7 (iterations of course per year)	£9,100 per year

Resource	Amount of resource required	Unit cost of resource used	Total cost
PAVES self-directed support (sensitivity analysis only)	1 x Administrator (Band 4)	£33 per Band 4 hour x 4 hours per year	£132 per year
PAVES venue (sensitivity analysis only)	1 x 20m^2 room 1 x 25m^2 room	£38 per m^2 per year £38/365.25 x 12 = £38/365.25 x 7 =	£25 (patient group costs per year) £18 (parent/carer workshop costs per year) £43 total per year.
Referral to CAMHS/re-referral to adult mental health services	1 x Consultant paediatric neurologist	£123 per working hour x 0.25 hours	£31 per referral (based on observed proportion – PAVES group and all 'red' screened patients for current practice group)
CAMHS review/re-review by adult mental health services	0.5 x Nurse (Band 6) 0.5 x Nurse (Band 7) 0.5 x Psychologist (Band 7) 0.5 x Psychologist (Band 8a) 0.5 x Occupational therapist (Band 6) 0.5 x Consultant	£220 per working hour x 0.25 hours	£55 per review
CAMHS treatment	1 x CAMHS contact	£283 based on NHS Reference Costs (England) and PHS (Scotland) CAMHS activity and cost data. A beta distribution α=3.0345 β=3.6733 simulated the number of cycles of treatment before discharge (min=0 max=5) and total contacts were based on the number of cycles of treatment from <6 months to >2 years.	£283 per CAMHS contact

Transition probabilities

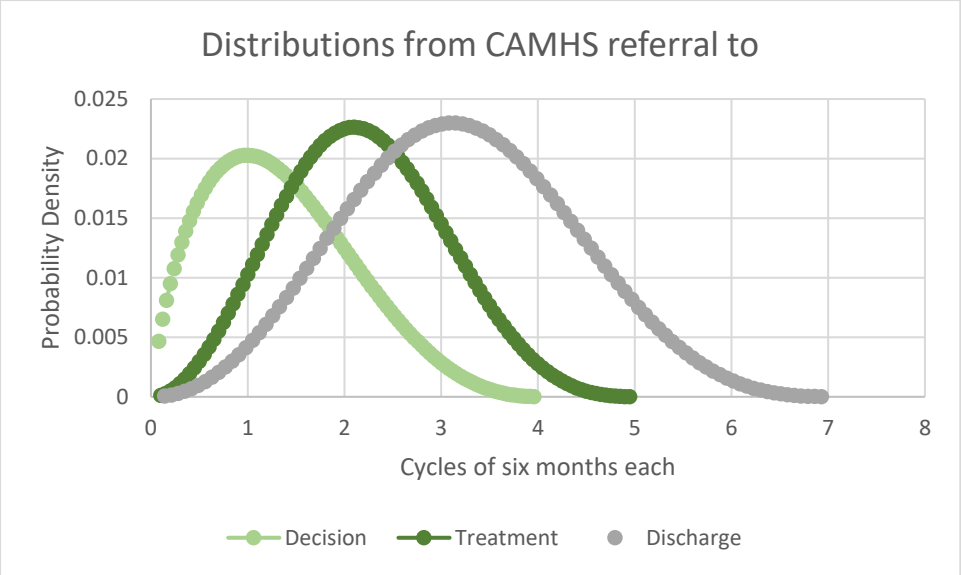
Data to inform the transitions with the model were drawn from anonymised summary statistics from the PAVES pathway project in NHS Lothian, alongside routinely available healthcare data from Public Health Scotland.[22] A summary of the data is shown in *Table 2.* Important assumptions included:

- PAVES eligibility fluctuated over time. Patients could screen as red or amber at one screen, and green the next, then re-enter PAVES eligibility again with a further red or amber screen. In total, approximately 70% of the sample had at least one cycle of PAVES eligibility
- for patients who screened as red, if they had screened red in any cycle previously, a new CAMHS referral was not made as it was assumed this was already being progressed in the standard of care pathway
- the model structure accounted for the (rare) possibility that a patient could bypass the referral system if their need for CAMHS treatment was urgent. A constant probability was assumed based on expected proportion of 0.46% patients being affected in any given cycle as it was observed in the cohort only once
- the proportion of referrals rejected by CAMHS was estimated from the observed number of patients for whom referral (and/or review) data were available without any treatment or discharge data from the PAVES cohort. This is a simplifying assumption, and it may be that patients did not receive treatment for other reasons, but the observed proportion of patients affected (21.6%) among the PAVES cohort was broadly in line with routine data for NHS Lothian (23.1%) over the period of data collection (January 2017 to January 2020)[22]
- for patients in specific states in the model, time duration in that state was simulated using beta distributions for the number of cycles before i) an accepted decision is made following referral, ii) treatment is commenced for all accepted referrals and iii) patients are discharged following treatment (see *Figure 2*). Distributions were only used if the patient was referred to CAMHS (to capture time to decision), did not have a rejected referral (to capture time to treatment) or subsequently entered the 'receiving CAMHS treatment' in the model (time to discharge from this state). These events did not happen for all simulated patients in the model.

Table 2: Data used to inform probabilities and other model parameters

Treatment group	% of cohort (Cycle 1)	% of cohort (Cycle 2)	% of cohort (Cycle 3)	% of cohort (Cycle 4)	% of cohort (Cycle 5)	% of cohort (Cycle 6)
New/re-entry to PAVES eligibility this cycle	60.5%	19.1%	12.9%	8.6%	0.0%	14.3%
Referred to CAMHS this cycle (PAVES)	7.7%	3.4%	1.0%	1.0%	2.1%	1.0%
Newly screening as 'red' this cycle (current practice CAMHS referrals)	66.7%	37.8%	57.5%	46.8%	8.0%	6.3%
Number of model cycles till CAMHS decision	Beta distribution α=1.666666667, β=3.333333333, min=0, max=4					
Referrals rejected by CAMHS	21.6%					
Moving directly to CAMHS treatment	0.46%					
Number of model cycles till start of treatment	Beta distribution α=2.830666667, β=3.701641026, min=0, max=5					
Number of model cycles till discharge from CAMHS	Beta distribution α=3.034499514, β=3.673341517, min=0, max=7					
Discharged from paediatric neurology this cycle	5.1%	3.5%	10.0%	10.9%	7.1%	8.3%

Figure 2: Distributions of the number of model cycles that the simulated cohort takes from CAMHS referral to decision, treatment and discharge



CAMHS referral rates

The CAMHS referral rates assumed in the standard of care cohort are based on expert opinion that any patient screened as red would previously have been referred to CAMHS. This assumption was tested in scenario analysis (any red or amber screen, two red screens at any point, two consecutive red screens only, three red screens at any point, or three consecutive red screens), but it has the following effects:

- an initial surge in the number of patients moving from the 'No open CAMHS referral' state to the 'awaiting CAMHS treatment' state. Owing to the fact their first ever categorisation is red, subsequent categorisations even if they remain red, the CAMHS referral has already been made following the first screen and so is not repeated. Therefore, referrals to CAMHS in subsequent cycles affect a lower proportion of patients.
- using the available data which only come from the PAVES eligible cohort (all of whom received at least self-directed support), creates a risk that the true number of non-PAVES patients who would move from having 'no open CAMHS referral' to 'awaiting CAMHS treatment' may be higher than observed among PAVES patients, particularly if the self-directed support component of PAVES can alone prevent patients from reaching red risk. This was tested in sensitivity analysis by varying the eligibility for CAMHS referral to include both red and amber screens. Further research on the comparative effectiveness of the individual components of the PAVES intervention would provide better estimates.
- in clinical practice, it may be expected that patients at high or red risk would already be known to CAMHS, and referrals would be on going. It is also expected that there

may be additional elements of clinical judgement involved in making a CAMHS referral besides a red screen. However, there were insufficient data available to generate a more steady-state model structure (for example, a Markov model) or a dynamic model that could account for the mental health of new patients entering paediatric neurology clinics upon an epilepsy diagnosis. Summary data were available on patient demographics, for example, patient's current age, epilepsy severity, Scottish Index of Multiple Deprivation (SIMD). A more in-depth analysis is required to incorporate them fully into an economic evaluation.

- all data had been collected prior to the first COVID-19 lockdown in March 2020, and the impact of COVID-19 on a) subsequent patient categorisations from SDQ scores, and b) other factors influencing CAMHS referrals, waiting times and treatment durations, is unclear.

Economic evaluation – results

Summary data

Data were available for 234 participants screened for PAVES. Demographic summary characteristics are shown in *Table 3*.

Table 3: PAVES cohort summary data

Characteristic	Result
N – total sample (%)	234 (100%)
N with data for >1 screen	160 (68.4%)
Age (mean, SD)	10.6 (3.49)
Gender (n, % female)	120 (51.3%)
SIMD 1	39 (16.7%)
SIMD 2	51 (21.8%)
SIMD 3	36 (15.4%)
SIMD 4	34 (14.5%)
SIMD 5	72 (30.8%)
SIMD missing	2 (0.8%)
Received self-directed support from PAVES	234 (100%)

Attended patient group component	8* (3.4%)
Parent(s)/carer(s) attended workshop	29 (12.4%)
Referred to CAHMS	37 (15.8%) **

*Four patients attended along with a parent/carer
**Sometimes only discharge data were available from CAMHS, and a referral is assumed.

No follow-up screening data were available beyond the initial screen for 74 of the 234 patients, however the model was still informed by subsequent CAMHS referrals for these patients. For 55 of these cases lost to follow up, the patients would have been eligible for PAVES based on their only available screening categorisation, and so they would be expected to have at least received self-help materials prior to being lost to follow up.

Of the remaining 160 patients for whom at least one or more follow-up data were collected, 50 patients (31.3%) were screened as only ever being in the green SDQ risk category, that is, at no point did they become eligible for PAVES early intervention throughout the model.

The proportion of patients screening as red, amber and green over time is shown in *Table 4*.

Table 4: Screening results over time

Result	Screen 1	Screen 2	Screen 3	Screen 4	Screen 5	Screen 6
Screened red	94	44	31	30	13	5
Of which new to red	94	9	7	2	1	0
Screened amber	47	30	37	25	16	9
Of which new to amber	47	22	13	7	1	1
Screened green	92	78	50	20	10	2
Of which new to green	92	16	15	7	3	0
Total eligible for PAVES early intervention	141	81	56	46	22	9
Of which new to PAVES eligibility	141	12	8	3	0	1

Observed CAMHS referrals occurred for 37 of the 234 people in the PAVES pathway (15.8%). On the basis of a patient having at least one red screen, a total of 113 (48.3%) CAMHS referrals would have otherwise been expected in the standard of care pathway over the follow-up timeframe.

Where CAMHS services were required for 37 patients, 10 (27%) had received either/both patient group and/or parent/carer workshop components rather than self-directed support

alone. No CAMHS involvement was noted for the remaining 197 patients, of whom 23 (11.7%) had received either/both patient group and/or parent/carer workshop components, rather than self-directed support alone.

There was overlap in the average duration of CAMHS involvement among those receiving self-directed support only compared with those who also received any/both additional PAVES components with 168 days (IQR 85.25 to 385.25 days) for those receiving only self-directed support and 249 days (IQR: 155 to 305 days) for those receiving more PAVES components.

Base case results

An economic evaluation simulated the progress of 100 paediatric neurology patients, representing the number of patients on the PAVES pathway each year. Patients were followed up over cycles of 6 months, reflecting the median number of days (189 days, IQR: 147 to 273) between each observed screening period. The evaluation took an NHS and social care perspective and compared PAVES with current practice to estimate the additional cost per CAMHS referral avoided. Cost and effects were discounted at 3.5% per annum, after the first year. Results are shown in *Table 5.*

The additional cost of PAVES for each CAMHS referral that was avoided compared to standard care, was £718. The total cost of current practice was £103,199 and the total cost of PAVES was £121,657, so while PAVES cost an additional £18,457 to provide, it also avoided 26 referrals that would have progressed to CAMHS under standard care.

Table 5: Base case results

Strategy	Total costs	Total CAMHS referrals	Incremental costs of PAVES	Incremental CAMHS referrals	ICER (Additional cost per CAMHS referral avoided)
PAVES	£121,657	23	£18,457	26	£718
Current practice	£103,199	49			

Sensitivity analysis

The sensitivity analysis was limited to scenario analyses of parameters of interest. Descriptions of the changed variables in the model compared to their base case inputs, and subsequent change to the base case results are shown in *Table 6* below.

Table 6: Scenario analysis results

Scenario Number	Scenario	Value In Base Case	Value In Scenario Analysis	Revised ICER Result
NA	Base case	£718	NA	£718
1a	Include separate cost of self-directed materials	NA	£132 per year	£732
1b	Include additional venue costs	NA	£43 per year	£722
1c	Including both self-directed support costs and additional venue costs	NA	£175 per year	£737
2	Rejected CAMHS referral patients would not incur treatment costs	2.5	0	£754
3	Provide PAVES only in the first year of eligibility (requires fewer sessions to be organised in subsequent years)	2x patient group and 7x parent/carer workshop per year	1x patient group and 2x parent/carer workshop after year 1	PAVES is dominant
4	Use NHS Reference Costs for unit cost of a CAMHS contact	£283	£271	£801
5a	Duration of CAMHS treatment (fewer cycles)	0 to 7 cycles (median 3)	0 to 5 cycles (median 2) Beta distribution α= 2.830666667 β= 3.701641026	£911
5b	Duration of CAMHS treatment (more cycles)	0 to 7 cycles (median 3)	0 to 9 cycles (median 4). Beta distribution α= 3.143804298 β=3.646812986	£781
5c	Half CAMHS contacts per duration	<1 cycle=6 1 cycle=12 2 cycle=18 3 cycle=24 4 cycle=30	<1 cycle=3 1 cycle=6 2 cycle=9 3 cycle=12 4 cycle=15	£1682

Scenario Number	Scenario	Value In Base Case	Value In Scenario Analysis	Revised ICER Result
		etc.	etc.	
5d	Double CAMHS contacts per duration	<1 cycle=6 1 cycle=12 2 cycle=18 3 cycle=24 4 cycle=30 etc.	<1 cycle=12 1 cycle=24 2 cycle=36 3 cycle=48 4 cycle=60 etc.	PAVES is dominant
5e	Reduced CAMHS treatment contacts and duration	See 5a and 5c	Combine changes made for analysis 5a and 5c	£1779
5f	Increased CAMHS treatment contacts and duration	See 5b and 5d	Combine changes made for analysis 5b and 5d	PAVES is dominant
6a	Current practice only: red or amber referrals lead to a CAMHS referral (as % of all PAVES eligible)	Cyc1=0.67 Cycl2=0.09 Cycl3=0.06 Cycl4=0.01 Cycl5=0.01 Cycl6=0.0	Cycl1=1 Cycl2=1 Cycl3=1 Cycl4=1 Cycl5=1 Cycl6=1	PAVES is dominant
6b	Current practice: Two screens of red needed to initiate a CAMHS referral (as % of all PAVES eligible)	Cyc1=0.67 Cycl2=0.09 Cycl3=0.06 Cycl4=0.01 Cycl5=0.01 Cycl6=0.0	Cyc1=0.0 Cycl2=0.36 Cycl3=0.06 Cycl4=0.04 Cycl5=0.01 Cycl6=0.01	£37,459
6c	Current practice: two consecutive screens of red needed to initiate a CAMHS referral	Cyc1=0.67 Cycl2=0.09 Cycl3=0.06 Cycl4=0.01 Cycl5=0.01 Cycl6=0.0	Cyc1=0.0 Cycl2=0.36 Cycl3=0.02 Cycl4=0.03 Cycl5=0.00 Cycl6=0.01	PAVES is dominant
6d	Current practice: three screens of red needed to initiate a CAMHS referral	Cyc1=0.67 Cycl2=0.09 Cycl3=0.06 Cycl4=0.01 Cycl5=0.01 Cycl6=0.0	Cyc1=0.0 Cycl2=0.0 Cycl3=0.14 Cycl4=0.06 Cycl5=0.03 Cycl6=0.00	PAVES is dominant

Scenario Number	Scenario	Value In Base Case	Value In Scenario Analysis	Revised ICER Result
6e	Current practice: three consecutive screens of red needed to initiate a CAMHS referral	Cyc1=0.67 Cycl2=0.09 Cycl3=0.06 Cycl4=0.01 Cycl5=0.01 Cycl6=0.0	Cyc1=0.0 Cycl2=0.0 Cycl3=0.14 Cycl4=0.01 Cycl5=0.01 Cycl6=0.00	PAVES is dominant

Secondary outcomes

For those eligible for PAVES:

- six patients improved from red to green) upon receipt of PAVES, sustained until final available follow up. A further 28 improved from red to amber, or from amber to green
- there was either no overall change (no change or a mix of improvement followed by deterioration or in SDQ categorisation vice versa) for 57 PAVES eligible participants
- ten participants showed only deterioration in their SDQ categorisation (moving from green to amber or from amber to red). Severe deterioration (moving directly from green to red) is not possible within the PAVES eligible subsample because by default the starting point for severe deterioration (green) is outwith PAVES eligibility.

When we include all follow-up points (not just the time points where participants were PAVES eligible):

- five patients improved from red to green and 20 improved from red to amber or amber to green
- there was no overall change for 108 participants
- 23 patients deteriorated from green to 'amber' or 'amber' to 'red' and in only four cases did patients deteriorate severely, for example directly from 'green' to 'red'.

Given that there are only three possible SDQ categories and so patients may improve or deteriorate without changing category, we explored change in the original SDQ scores for those patients who showed inconsistent (that is, improvement followed by deterioration to original value by end of follow up or vice versa) or no change in category. Results are shown in *Table 7* below.

Table 7: SDQ scores for patients whose SDQ categorisation did not show consistent change

SDQ Categorisation	SDQ Score Shows	SDQ Score (Patient)	SDQ Impact Score (Patient)	SDQ Score (Parent/Carer)	SDQ Impact Score (Parent/Carer)
No overall change in SDQ categorisation over time (PAVES eligible) N=57	Improvement	10	5	21	17
	No change/inconsistent change	2	14	5	18
	Deterioration	16	8	31	20
No overall change in SDQ categorisation over time (Total cohort) N=108	Improvement	16	5	35	18
	No change/inconsistent change	11	36	10	62
	Deterioration	24	8	61	23

Discussion

In a modelling cohort of 100 patients, 26 CAMHS referrals are predicted to be avoided, indicating that the PAVES and early intervention pathway is likely to be a cost-effective intervention. The additional cost of introducing the service is £718 per avoided referral. .

The results are sensitive, particularly to the assumption in the standard of care pathway of referring all patients with one red SDQ screen to CAMHS. If the referral pathway was more stringent (for example, two or more red screens needed before a CAMHS referral is initiated) then PAVES would result in more referrals than current care and be more costly (that is, PAVES would be dominated). If the referral pathway were assumed to be more conservative (for example, all red or amber screened patients referred to CAMHS) there would be fewer CAMHS referrals which would be less costly (that is, PAVES would be dominant).

PAVES also has the potential effective than current care in terms of CAMHS referrals avoided, and so cost less, if offered to patients and their families once in the first year of eligibility, and if the number of contacts per treatment course is increased, alone or in combination with a longer treatment duration.

There were no data on any variation in attendance at the patient group sessions over time, which is important to ensure patients are receiving the full benefit of the PAVES intervention. In addition, PAVES may be considered by patients and their families/carers as potentially less intrusive than a referral to CAMHS, but we have no information on this. The lived experience of patients who receive PAVES was outwith the scope of this report. However, we acknowledge the increased psychological impact of epilepsy for children and young people with the condition, and that seizure control (and/or perception thereof), medication side effects and neurobiology may all exacerbate mental health difficulties compared to the impact of other childhood chronic illnesses.

No additional staff are employed to support PAVES and so the time to prepare must account for other duties staff could have undertaken during those hours (this is the opportunity cost of providing PAVES). It may be that the costs of providing PAVES have been overestimated for example, if, over time, clinicians' familiarity with preparing the required workshops and literature reduces the hours needed to organise these parts of the process. These data were collected prior to the COVID-19 pandemic and because of the growth in being able to facilitate meetings online, implementation costs could be shared across NHS Boards to meet demand. Although the time investment required by staff to run PAVES sessions would be expected to be the same and so it may not improve the cost effectiveness of PAVES.

The effectiveness of PAVES relates specifically to its capability to reduce CAMHS referrals, a service delivery outcome, rather than showing the effect on patients' health outcomes. Further research should document the health outcomes of PAVES.

A person's mental health status is affected by multiple factors, for example, circumstances affecting the patient's daily life, the underlying severity of their condition and/or comorbidities or complications such as learning disabilities. As this model was specifically

designed to look at CAMHS outcomes, it was not possible with the available data to explore the impact of these factors, or identify subgroups for whom PAVES may be most effective. It is important to consider the possibility that PAVES, while cost-effective, may not show relevant clinical benefits for patients.

The uptake of the more intensive PAVES components (the patient group and parent/carer workshops) was low. Any positive effect of the PAVES component on service delivery is relevant for CAMHS services at present, given the significant pressures in terms of their capacity to treat the numbers of patients being referred. These issues may have been exacerbated by the COVID-19 pandemic, as available data pre-date the first lockdown of March 2020.

The model structure could be simplified with additional data. Further research could consider a matched study to compare against the observed rate of CAMHS referrals prior to PAVES being introduced (particularly given that the model results are particularly sensitive to the rate of CAMHS referrals in current practice) but using historical controls may be particularly problematic if service arrangements would likely be different from the previous service provided before PAVES.

Conclusions

Using PAVES and early intervention pathway can avoid referrals to CAMHS and so is likely to be a cost-effective intervention. The additional cost of introducing the service is £718 for every CAMHS referral avoided.

There is uncertainty about whether PAVES:

- could be shown to cost less than current care as well as avoiding CAMHS referrals
- leads to recurring savings for the NHS
- can lead to clinically effective changes in patients' mental health
- could ease pressure on CAMHS services across other long-term conditions in paediatrics as well as neurology.

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Appendix 1: Additional analyses

We undertook a budget impact analysis in an attempt to inform the roll-out of PAVES and early intervention beyond NHS Lothian. We also explored the literature on the relationship between SDQ scores and longer-term outcomes for patients to determine whether sufficient data exist to extrapolate the economic evaluation over a longer time horizon. Insufficient data were available to reach conclusions for both analyses.

Budget impact

The roll-out of PAVES and early intervention beyond NHS Lothian

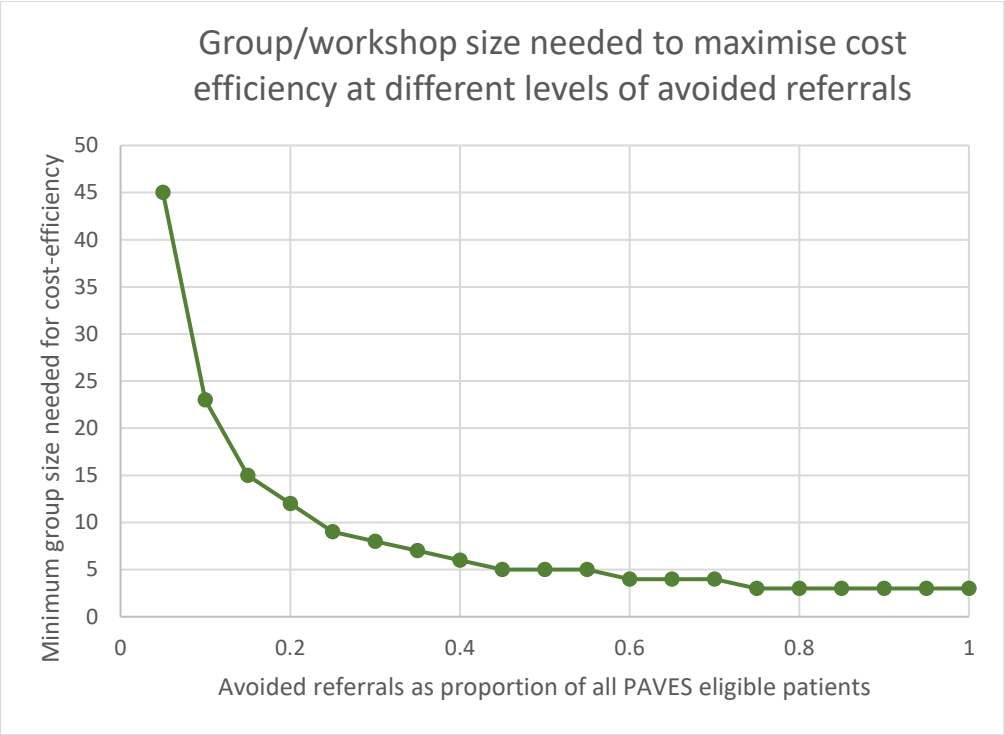
The economic analysis explored the cost effectiveness of PAVES based on data provided by NHS Lothian. Paediatric neurology is a specialist service. Further research is needed to quantify how PAVES can be rolled-out across NHS Scotland, given that elements of service provision between other paediatric neurology services and CAMHS may be organised differently, and this could affect both costs and effects. PAVES may also have a value for other specialties beyond paediatric neurology, particularly if CAMHS services are experiencing capacity issues. However, it has not been possible to complete our original objective to include a budget impact analysis for the roll-out of PAVES here, because there remain several key uncertainties, including:

- The 'steady-state' average annual rate of avoided referrals compared with PAVES eligibility (observed data indicate 28% in year 1, 8% in year 2 and 1% in year 3).
- The relationship between uptake of the more costly PAVES components (patient group and parent/carer workshop) and the avoidance of a CAMHS referrals (observed data suggest that those who attended the group and/or workshop) were more likely to have a CAMHS referral but their motivation to attend the group and/or workshop may have been motivated by the severity of the young person's mental health in the first place.
- Economies of scale – bigger centres across Scotland may have more staff available to provide PAVES components to patients more rapidly or frequently per annum; and vice versa (smaller departments may need to invest more in order to provide a PAVES service).

PAVES cannot be provided on a per patient cost because it is unlikely that the workshops and patient groups would be run for only one attendee. The minimum level at PAVES can be provided and still offer a potential cost saving is illustrated below, for various estimates of avoided referrals per PAVES eligible patients being offered the intervention. This is based on the modelled average cost of contacts needed to treat one patient who is successfully referred to CAMHS was £4,623 (that is, not including the referral costs and subsequent assumptions about the eventual costs associated with rejected CAMHS referrals etcetera). Under these circumstances the absolute minimum number of CAMHS patients/parent(s) and carers needed per group/workshop is three and the maximum is 45. The median group size

needed for cost effectiveness was five participants (IQR: 3.0 to 8.2). It seems feasible that such a group size could be managed in clinical practice, but it is noteworthy that for the observed cohort, avoided referrals per PAVES eligible patients was low (range: 1% to 28%, with a median of 8%) which would necessitate higher minimum numbers per group if these rates are generalisable; it may not be possible to provide the required level of support under the current staffing arrangements.

Figure 3: Minimum group sizes for PAVES to be cost minimising at all rates of avoided referrals expressed as a proportion of PAVES eligible patients (that is, 1/NNT)



Literature search

Exploring the relationship between SDQ scores and longer-term outcomes

An exploratory literature search was conducted using MEDLINE to explore the use of the SDQ in studies that had looked at long-term outcomes for children and young people with epilepsy. It was hoped that the published literature could be used to extrapolate data beyond the period of the PAVES pilot to estimate potential longer-term impacts arising from early intervention to prevent deteriorating mental health among children and young people with epilepsy based on their corresponding SDQ scores.

The search identified 11 studies which demonstrate the positive impact of the 'Triple P' Positive Parenting Programme (PPP) versus a control group, using SDQ as the measurement tool either on completion of the PPP intervention, or at follow-up assessment intervals.

Regardless of follow-up period, the studies demonstrated improvements in outcomes in the PPP group versus a control group measured by SDQ. Improvements in outcomes for the PPP intervention group are maintained over longer-term follow up.

The PsycINFO database was searched, and six similar studies were identified which demonstrated the positive impact of PPP as an intervention on SDQ-measured outcomes over an extended period of time (follow-up periods between 3 months to 2 years). One study in Glasgow[28] used teacher rated SDQ measurements to assess the impact of PPP on children's mental health over a period of 6 years. The study concluded that PPP in Glasgow City appears to have had no impact on early child mental health problems over this 6-year period. Thus PPP, implemented on an entire population level, is unlikely to produce measurable benefits in terms of child mental health.

In terms of studies which identified the use of SDQ as a predictor of longer-term societal outcomes, only one paper[29] used the SDQ to measure psychological distress and depressive symptoms in 13- to 14-year-old pupils in three London boroughs. Scores were linked to the pupils' GCSE performances at age 16. The study found that the overall SDQ score for psychological distress was negatively associated with achievement at GCSE for both boys (OR = 0.41, 95% CI 0.24-0.69) and girls (OR = 0.60, 95% CI 0.41-0.87). This led the authors to conclude that psychological distress was associated with educational achievement. Low achievement at school can have a substantial effect on opportunities in adult life.

Although evidence was found to demonstrate the value of early intervention (specifically, PPP) towards improved mental health outcomes, it was concluded that there was insufficient evidence available on the use of SDQ to predict longer-term societal outcomes to extrapolate SDQ data from the observed PAVES pilot, over the longer term.

Appendix 2: table of abbreviations

CAMHS	Child and Adolescent Mental Health Services
HRQoL	Health-Related Quality of Life
ICER	Incremental cost-effectiveness ratio
PAVES	Psychology Adding Value – Epilepsy Screening
PPALS	Paediatric Psychology and Liaison Services
SDQ	Strengths and Difficulties questionnaire
SHTG	Scottish Health Technologies Group