

1 **Accelerometer and survey assessed Physical Activity in Children with**
2 **Epilepsy (PACE): A case-controlled study**

3

4 **Keywords:** epilepsy, children, physical activity, quality of life

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26 **Abstract**

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28 **Purpose:** Anecdotal evidence suggests that children with epilepsy (CWE) are limited
29 in the frequency of their daily physical activity (PA). However, there is limited research
30 utilising device-based measures of PA. We compared levels of PA and sedentary
31 behaviour in CWE (11-15 years) and age- and gender-matched healthy controls.

32 **Method:** Participants (n=60 CWE (25 males, 35 females) and n=49 controls (25
33 males, 24 females)) wore a Actigraph accelerometer (GT3X or GT3X+) for 7
34 consecutive days during waking hours and self-reported their PA and sedentary
35 behaviours. CWE were compared to control children on time spent in different
36 intensities of PA and on self-reported PA and sedentary behaviour. **Factors**
37 **associated with PA were analysed using linear regression.**

38 **Results:** CWE spent less time in accelerometer assessed light (189.15 vs 215.01
39 min/day $p<0.05$) and vigorous PA (35.14 vs 44.28 min/day $p<0.05$) on weekdays
40 compared with weekends. **There were no significant differences between CWE and**
41 **control participants in accelerometer assessed time spent sedentary or time spent in**
42 **PA on weekends.** Among CWE, older children engaged in more reported sedentary
43 behaviour and younger children spent more time in most domains of PA ($p<0.05$).
44 Furthermore, CWE reported less PA than controls ($p=0.006$). Sixteen percent of
45 controls met WHO PA guidelines compared to 10% of CWE. There was a positive
46 relationship between accelerometer assessed PA and quality of life for CWE.

47 **Conclusion:** CWE spent less time in light and MVPA on weekdays. Further research
48 is needed to understand reasons for these differences.

49

50

51 Introduction

52 During childhood and adolescence, lifestyles that include adequate levels of physical
53 activity (PA) and low levels of sedentary time are essential to support growth, maintain
54 positive physical and mental health, prevent chronic disease and promote healthy
55 weight trajectories [11,38,40]. However, many young people are insufficiently active
56 (i.e., do not meet the World Health Organization (WHO) recommended minimum of an
57 average of 60 minutes of moderate-to-vigorous-physical activity (MVPA) per day) [8]
58 and spend prolonged periods of time sedentary (e.g., sitting at school and during
59 leisure time) [43]. Low levels of PA are of particular concern for young people living
60 with disabilities and chronic medical conditions [9], not least because of the power of
61 PA in improving health and overall well-being.

62

63 Epilepsy is the most common serious neurological condition in childhood. It is a
64 disease of the brain typically defined by the presence of two unprovoked (or reflex)
65 seizures occurring > 24 h apart or the presence of an epilepsy syndrome [22]. The
66 prevalence of epilepsy in children ranges from 3.2–5.5/1,000 children in developed
67 countries and 3.6 – 44/1,000 children in underdeveloped countries [21]. In addition
68 to epileptic seizures, many children with epilepsy (CWE) have co-occurring
69 neurodevelopmental and mental health difficulties including an increased risk for
70 intellectual disability, difficulties with motor coordination autism, ADHD, depression
71 and anxiety [12,39]. Therefore, it is important to consider these difficulties is possible
72 contributors to levels of PA in children with epilepsy. Additionally, previous research
73 suggests that seizure related factors may be related to levels of PA in some children
74 with epilepsy [29]. Previous studies have also shown that age, gender, sleep and BMI
75 are associated with levels of PA in children in the general population [6,17,32,33,44]

76 and in some survey based studies of PA in children with epilepsy [29]. Parental mental
77 health difficulties are more common in children with epilepsy than parents of healthy
78 children [28,20]. Additionally, parental mental health problems have been associated
79 with reduced physical activity in children with some chronic health conditions [16] and
80 therefore, it is important to consider parental mental health when exploring contributors
81 to PA in CWE.

82

83 A recent systematic review found, based on self- or parent-report data, that children
84 and adults with epilepsy engage in less PA than their peers [29]. CWE who are
85 physically active have better physiological and psychological profiles than those with
86 epilepsy who are not active [13]. However, there is evidence that CWE are often
87 subjected to restrictions on PA participation because of parental concerns about injury,
88 concerns about safety in relation to the occurrence of seizures, and a lack of
89 understanding of the benefits and risks associated with PA participation [50].

90

91 Children and adolescents with epilepsy are at increased risk of social isolation [36]
92 and PA could play a role in improving quality of life and social integration. However, to
93 better understand PA levels and the outcomes associated with PA among CWE, so
94 that PA can be promoted, it is essential to accurately measure the behaviour. To date,
95 few studies have utilised more objective devices (such as accelerometers) to assess
96 PA among CWE. Studies have shown that pedometers are feasible to assess step
97 counts among CWE [15,49] but to date there are no studies utilising accelerometers.
98 Accelerometers are able to provide more robust and detailed information on time spent
99 in different intensities of PA.

100

101 The Physical Activity in Children with Epilepsy (PACE) study is an observational study
102 of PA levels among young adolescents (11-15) with 'active' epilepsy and age matched
103 peers. The aim of this study is to compare levels of PA among children with 'active'
104 epilepsy (CWE), and age- and gender-matched healthy controls, using both
105 accelerometers and survey methods. Furthermore, this study aims to examine factors
106 (e.g., age, gender, BMI, seizure related factors, sleep, behaviour-emotional
107 functioning, motor coordination and parent wellbeing) associated with accelerometer
108 assessed PA in CWE, and to examine the associations between PA and quality of life
109 (QoL).

110

111

112 **Methods**

113 Study Procedure

114 Following ethical approval from the XXXX Research Ethics Committee, cross-
115 sectional data were collected between March 2020 and June 2022. Recruitment to the
116 study began in March 2020, but was subsequently put on hold due to COVID-19
117 restrictions. The study re-opened in April 2021 and a blended approach to recruitment
118 was adopted where potential participants could either self-refer via an online portal
119 (which was advertised via [PACE Study Flyer \(thechannel.org.uk\)](https://thechannel.org.uk), or were referred to
120 the study from two participating hospitals. Once CWE had registered their interest in
121 the study, they were then contacted by the research team via telephone or video-call
122 and introduced to the study. Digital written consent from caregivers and assent from
123 children was then taken before participation in the study could commence. Those who
124 had provided consent to take part in the study received a package through the post

125 containing questionnaires for completion at home and an accelerometer to wear for
126 days.

127

128 To be eligible for the study, CWE needed to have 'active' epilepsy (i.e., currently taking
129 anti-seizure medicine (ASM) and/or had a seizure within the last 12 months). Parent
130 reported epilepsy diagnoses were validated against medical records provided via a
131 clinical extraction document completed by the children's general practitioner or
132 paediatrician (see supplement 1). Control participants were children matched on age
133 with the participants with epilepsy. Children in both groups with significant
134 physical/motor impairment that restricted ability to participate in PA were excluded.
135 This was formally defined as having a Gross Motor Function Classification System
136 (GMFCS) greater than level 2. Children at GMFCS Levels 1 and 2 could be included.
137 The children in both groups had to be attending secondary school in England and be
138 aged between 11 and 15 years at the time of participation.

139

140 Recruitment

141 Figure 1 shows recruitment in PACE study

142

143 **Figure 1: Recruitment in PACE study**

144

145 In total 94 CWE expressed an interest in participating (n=79 from Mainstream school
146 and n=15 from Special schools). Eighteen participants dropped out before providing
147 consent, 13 withdrew after providing consent, and three did not complete the
148 assessments. One of the primary reasons for withdrawal (n=10) was concerns about
149 wearing the accelerometer, a particular concern was that it would be visible to others.

150 Eighty-eight children expressed an interest in participating in the control group (84
151 mainstream school and 4 special school). Twenty-eight controls dropped out before
152 providing consent, and a further five dropped out after providing consent. A further six
153 participants did not complete the full assessment process. In total 60 CWE completed
154 the assessment and 49 control participants. One epilepsy and one control participant
155 completed the surveys measures but did not provide accelerometer data.

156

157

158 **Measures**

159 Accelerometer assessed physical activity and sedentary behaviour

160 All participating children received an Actigraph accelerometer (GT3X or GT3X+) in the
161 post with detailed instructions on how to wear it. All children were asked to wear the
162 accelerometer on an elasticated belt, over their right hip for seven consecutive days
163 during waking hours. Children were instructed to remove the devices when sleeping
164 or during water-based activities to limit discomfort and potential device damage.
165 Actigraph accelerometers are an established measure of PA and sedentary time
166 among all populations [26,41].

167

168 Accelerometers were initialised to collect data at 100 Hz using ActiLife version
169 (Version 6.13.4), and the data were re-integrated into 15 second epochs and
170 processed using Kinesoft (version 3.3.20, XXXXXX UK. <http://www.kinesoft.org>).

171 Periods of ≥ 60 minutes of consecutive zeros (with a tolerance of two minutes of non-
172 zero interruptions) were classified as non-wear time and excluded, as was the period
173 12am to 7am to minimise possible misclassification of overnight wear/sleep as
174 sedentary time.

175

176 A day was defined as valid when participants had worn the accelerometer for at least
177 480 minutes. All participants with at least 3 valid days were included in the analyses.
178 Accelerometer data were expressed as average counts per minute (CPM), which is
179 the total counts per valid day, divided by valid monitor wear time per day. Sedentary
180 time (ST) was considered when CPM were less than 100, light physical activity (LPA)
181 when CPM were between 101 and <2995, moderate physical activity (MPA) when
182 CPM were between 2995 and <4012, and vigorous physical activity (VPA) when CPM
183 were 4012 or more, following established cut-points by Evenson [18].

184

185

186 Survey Measures of Physical Activity

187 All participants were asked to complete the Physical Activity Questionnaire for
188 Adolescents (PAQ-A), a 7-day recall used to assess general PA levels [30] (see
189 supplement 2). The PAQ comprises 13 validated questions relating to PA undertaken
190 in the previous week and is designed for school-age children and young people. Each
191 question is scored out of five and a final score is calculated as the mean of all nine
192 responses; higher scores indicate higher activity.

193

194 The original questions were validated for a Canadian population and so minor
195 revisions were made in terms of sporting activities and phrasing to adjust for cultural
196 and sporting preferences in the UK. In particular, question 1 lists 22 sports that
197 respondents are asked to quantify involvement in over the preceding week; in place
198 of floor hockey, street hockey, ice hockey, ice skating, baseball and Canadian football,
199 we inserted tennis, athletics, cricket, rugby, martial arts and gymnastics. Previous

200 studies conducted in the UK and other countries have shown that the revision of
201 questions to suit the local population provides satisfactory results and validity
202 [27,3,46,1]. Questions 2–10 relate to activity at specific times of the day and question
203 11 asks how often PA was performed for each day of the preceding week. Question
204 12 and 13 focus on injuries which may have impeded engagement in PA.

205

206 Participants were also asked to complete the Adolescent Sedentary Activity
207 Questionnaire (ASAQ) [24], (see supplement 3) which focusses on self-reported
208 weekday and weekend sedentary behaviours (outside of school). Participants
209 reported the duration of time they engaged in a variety of sedentary behaviours in their
210 free time on a typical weekday and weekend day. The ASAQ measures 11 sedentary
211 behaviours across 5 different domains: small screen recreation (SSR) (TV,
212 videos/DVDs, computer for fun), education (doing homework with/without a computer,
213 being tutored), travel (seated in a vehicle), cultural (reading, playing an instrument,
214 crafts or hobbies), and social (sitting around with friends, talking on the telephone,
215 religious activities). Time spent in each domain was calculated. Totals from the five
216 categories were then summed to yield three outcomes; total time spent in sedentary
217 behaviour on weekdays, total time spent in sedentary behaviour on weekend days,
218 and total time spent in sedentary behaviour during the week (i.e., weekdays +
219 weekends).

220

221 Body Mass Index (BMI) was calculated using the NHS healthy weight calculator
222 (<https://www.nhs.uk/live-well/healthy-weight/bmi-calculator/> accessed 12th November
223 2022), BMI was determined for each participant based on their height and weight. This
224 calculator is based on the measurements found within the UK national growth charts⁴⁵.

225 The calculator provides BMI scores as a percentile, with percentiles then falling into
226 four categories, underweight (on the 2nd percentile or below), healthy weight (between
227 the 2nd and 91st percentile), overweight (on the 91st percentile or above), very
228 overweight (on the 98th percentile or above).

229

230 Epilepsy variables

231 In the CWE we collected data on clinical parameters (e.g., seizure frequency via a
232 seizure diary, current epilepsy medication, age of epilepsy onset, number of seizure
233 types) and current educational provision from medical records (see supplement 1) and
234 parent report.

235

236 Deprivation

237 Index of Multiple Deprivation (IMD) was calculated for each participant based on their
238 home post codes. This is an indicator of area level deprivation, using the IMD 2019
239 rankings (Department of Communities and Local Government), English indices of
240 deprivation. Retrieved from [http:// imd-by-postcode.opendatacommunities.org/](http://imd-by-postcode.opendatacommunities.org/)
241 (Accessed during study period)). Lower scores are associated with lower deprivation.

242

243 Measures of child behaviour and caregiver wellbeing.

244 The children and caregivers in both groups completed the following assessments:
245 Strengths and Difficulties Questionnaire (SDQ) – a measure of child behaviour/mental
246 health [23], PEDs QL - Self-report– a measure of quality life in children [47] and the
247 Insomnia Severity Index – a measure of sleep difficulties [2]. The primary caregiver of
248 the CWE and controls also completed the Developmental Coordination Disorder
249 Questionnaire (DCDQ) [51] – a measure of child motor coordination. Additionally, all

250 primary caregivers completed the Depression Anxiety Stress Scale [25] which is a
251 measure of parental mental health.

252

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254

255 **Analyses**

256 Descriptive statistics were used to characterise the participants. Time spent in
257 sedentary, light, moderate and vigorous PA on weekdays and weekend days were
258 compared between the epilepsy group and control groups using independent sample
259 t-tests. Regarding gender, between group differences were also explored using
260 independent t-tests. We compared total score and individual question scores on the
261 PAQ-A and subscales on the ASAQ between the 2 groups using sample
262 independent t-tests.

263

264 Univariable linear regression was used to identify factors associated with sedentary
265 behaviour and activity levels on weekdays and weekend days. Factors associated at
266 the $p < 0.200$ level on univariable analyses were included in multivariable linear
267 regression modelling [34]. Factors considered were epilepsy variables (e.g., seizure
268 frequency, age of first seizure, Antiseizure Medicine (ASM) status,) and child factors
269 (e.g., gender, age, socioeconomic status (via IMD data), sleep, emotional
270 behavioural difficulties, coordination difficulties, school placement) and caregiver
271 mental health. All analyses were done with IBM SPSS version 28.0 (IBM
272 Corporation, Armonk, NY, USA).

273

274

275 **Results**276 **Demographics of children with epilepsy and children in the control group**

277 Table 1 shows the characteristics of the CWE and the participants in the control group.

278 There was no significant difference between the two groups with respect to gender,
279 age, school type, ethnicity, deprivation, and Body Mass Index.

280

281 **Table 1:** Characteristics of Children in PACE study

	Participants with Epilepsy (n=60)	Controls (n=49)	p Value
School Type			
Mainstream	53	47	0.139
Special	7	2	
Age in years (M, SD)	12.9 (1.41)	12.8 (1.39)	0.815
Range	11 – 16 years	11-15 years	
Gender			
Female	25 (41.7%)	25 (51%)	0.330
Male	35 (58.3%)	24 (49%)	
Ethnicity			
White	52 (86.7 %)	41 (83.7%)	0.660
Non-White	8 (13.3%)	8 (16.3%)	
Index of Multiple Deprivation, M (SD)	5.9 (3.02)	6 (3.03)	0.977
Low (1-5)	28	23	
High (6-10)	32	26	

Body Mass Index Centile Categories			
Underweight	3 (5%)	2 (4.1%)	NA
Healthy Weight	40 (66.7%)	34 (69.4%)	
Overweight	11 (18.3%)	9 (18.4%)	
Very overweight	6 (10%)	4 (8.2%)	
Body Mass Index Categories			
Healthy weight	40 (66.7%)	34 (69.4%)	
Unhealthy weight	20 (33.3%)	15 (30.6%)	0.762
Reported Neurodevelopmental Diagnosis			
ADHD	4	1	0.376
Autism	10	0	0.002
DCD	1	0	1.000
	11	1	0.011
Seizure frequency			
Weekly or more often	26 (43.3%)	NA	NA
Monthly or less often.	34 (56.7)	NA	NA
Seizure Type			
1 seizure type	27	NA	NA
2 seizure type	18	NA	NA
3 seizure type	15		
Seizures reported whilst wearing activity tracker			
Yes	14 (23.3%)	NA	NA
No	46 (76.7%)	NA	NA
Age of Onset of epilepsy (Years) M (SD)	8.05 (3.93)	NA	NA

Range	0.01 – 15	NA	NA
Number of current ASMs			
M (SD)	1.72 (1.12)	NA	NA
Range	1-5	NA	NA
Polypharmacy (prescribed more than one Antiseizure Medicine (ASM))			
Yes	30 (50%)	NA	NA
No	30 (50%)	NA	NA

282 M= Mean, SD= SD, ADHD= Attention Deficit Hyperactivity Disorder, DCD=

283 Developmental Coordination Disorder.

284

285 The control group were similar to the general population with respect to ethnicity
 286 (control group white/non-white 84%/16% and general population in England
 287 white/non-white 82%/18%) (<https://www.ethnicity-facts-figures.service.gov.uk/>
 288 accessed October 17th 2023). In the control group 47% of children were in the lowest
 289 5 deciles (most deprived) and 53% were in the highest 5 deciles (least deprived) of
 290 the IMD index and thus similar to the proportions in the general population.

291

292 Comparison between children with epilepsy and children in control group regarding
 293 sedentary behaviour and physical activity

294 Table 2 shows a comparison between the two groups with respect to accelerometer
 295 measured sedentary time and PA during weekdays and weekend days.

296 **Table 2.** Accelerometer data for Children with Epilepsy (CWE) and controls on
 297 weekdays (n=51 CWE and n=38 control) and weekend days (n=47 CWE and n=33
 298 control)

	CWE Mean (SD)	Control Mean (SD)	P value	Mean Difference	Effect Size Cohens d 95% CI
Weekday Wear minutes/day	802.31 (117.70)	822.09 (79.45)	0.374	-19.779	-0.612 to 0.230
Weekend day Wear minutes/day	736.81 (140.83)	767.41 (108.22)	0.297	-30.600	-0.684 to 0.209
Weekday sedentary minutes/day	577.29 (115.59)	561.83 (78.879)	0.480	15.456	-0.269 to 0.572
Weekend day sedentary minutes/day	526.59 (136.04)	534.17 (109.03)	0.791	-7.580	-0.505 to 0.385
Weekday Light Physical Activity minutes/day	189.15 (51.74)	215.01 (53.94)	0.024*	-25.864	-0.916 to - 0.630
Weekend day Light Physical Activity minutes/day	181.30 (58.71)	202.98 (64.58)	0.123	-21.683	-0.802 to 0.095
Weekday Moderate Physical Activity minutes/day	18.10 (7.01)	21.20 (8.09)	0.057	-3.098	-0.837 to 0.012
Weekend day Moderate Physical Activity minutes/day	13.13 (8.76)	13.64 (11.86)	0.825	-0.511	-0.495 to 0.395-
Weekday Vigorous Physical Activity minutes/day	17.04 (11.53)	23.08 (14.60)	0.032*	-6.04	-0.892 to - 0.040
Weekend day Vigorous Physical Activity minutes/day	15.00 (14.61)	15.97 (25.24)	0.776	-0.965	-0.510 to 0.381
Weekday MVPA minutes/day	35.14 (16.87)	44.28 (19.27)	0.020*	-9.14	-0.935 to - 0.082

Weekend day MVPA minutes/day	28.13 (22.04)	29.61 (25.45)	0.783	-1.476	-0.508 to 0.383
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299 MVPA: moderate-to-vigorous-physical-activity

300 *p<0.05

301

302 Fifty-one CWE and 38 controls had valid data from the accelerometer for weekdays
303 and 47 CWE and 33 controls had valid data for the weekend days. CWE wore the
304 accelerometer for just over 13 hours on a weekday and around 12 hours on a weekend
305 day. The control participants wore the accelerometers for approximately 20 minutes
306 more than CWE on a weekday and 30 minutes more on a weekend day (Table 2).
307 CWE spent 71% of their weekday and weekend day sedentary, whereas control
308 participants spent 68.5% of their wear time sedentary. There were no significant
309 differences between CWE and control participants in time spent sedentary on
310 weekdays or weekend days (Table 2). CWE spent significantly less time in light,
311 vigorous and moderate-vigorous PA on a weekday (Table 2). Sixteen percent of
312 control children met the World Health Organization (WHO) PA guidelines ([Physical
313 activity \(who.int\)](#) accessed 24th April 2024) compared to 10% of CWE.

314

315 **Factors associated with accelerometer assessed sedentary time and physical activity**

316 Table 3 shows the factors significantly associated (p<0.05) with accelerometer
317 assessed sedentary time and PA in the multivariable analysis. All considered factors
318 and associated p values are in supplement 4a (Epilepsy group) and supplement 4b
319 (Control group).

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337 **Table 3:** Factors significantly associated with sedentary behaviour and Physical Activity in children with epilepsy (*) and children in
338 control group (*) on multivariable analysis. (p values in brackets) (Regression coefficient and 95% Confidence Interval (CI))

Variable	Sedentary weekday	Sedentary weekend	Light PA Weekday	Light PA weekend	Moderate PA Weekday	Moderate PA Weekend	Vigorous PA Weekday	Vigorous PA Weekend
Participant Age	* (0.001) 37.444 (95%CI 15.881 to 59.007)	* (0.021) 32.875 (95%CI 5.249 to 60.500)	* (0.006) -14.147 (95%CI - 24.391 to - 4.443) * (0.003) -16.428 (95%CI - 26.298 to - 5.928)	(<0.001)* -21.706 (95%CI - 32.840 to - 10.573)		* (0.001) -2.775 (95% CI - 4.413 to - 1.136)		* (0.017) -3.708 (95%CI - 6.720 to - 0.695)
Gender			* (0.007) -39.854 (95%CI - 68.104 to - 11.604)		* (0.048) -5.171 (95%CI - 10.284 to - 0.059)			
School Type					* (0.028) -6.876 (95%CI - 12.991 to - 0.762)	* (0.009) -9.003 (95% CI - 15.653 to - 2.352)		

Mental health/behaviour				* (0.044) -3.247 (95%CI - 6.409 to - 0.085)				
Motor Coordination			* (0.045) 1.024 (95%CI 0.025 to 2.024)				* (0.040) 0.347 (95% CI 0.017 to 0.676)	
Age of seizure onset					* (0.037) -0.059 (95%CI -1.084 to - 0.035)		* (0.004) -1.229 (95%CI - 2.036 to - 0.423)	
No. of seizure types								
Epilepsy medication			* (0.027) -30.371 (95% CI -57.141 to - 3.600)				* (0.007) -6.337 (95% CI - 10.848 to - 1.27)	

340 In the epilepsy group, the factor most consistently associated with sedentary time and
341 PA was age. Older children accumulated significantly more sedentary time, and
342 younger children spent significantly more time in most types of PA. Children in special
343 schools engaged in significantly less moderate PA than children in mainstream
344 schools on both weekdays and weekends. Additionally, children with an earlier onset
345 of seizures engaged in significantly less moderate and vigorous PA on weekdays than
346 children with a later onset of seizures. In contrast to the epilepsy group, younger age
347 was only associated with increased light PA on weekdays in the control group.
348 Additionally, being female was associated with less light PA on weekdays and less
349 moderate PA on weekends in the control group.

350

351 Gender - between group analysis on accelerometer

352 Males with epilepsy engaged in more sedentary behaviour and less physical activity
353 than males in the control group. However, the only statistically significant difference
354 was for light weekday physical activity ($p=0.35$) (see supplement 4c). For females,
355 the epilepsy group engaged in more sedentary behaviour than the control group, but
356 the differences did not reach statistical significance. For physical activity, females in
357 the epilepsy group engaged in less activity than the control group for most intensities
358 but there were no statistically significant differences between the groups.

359

360 Comparison between children with epilepsy and children in control group on survey 361 measures

362 CWE reported less physical activity (PAQ-A total score) than participants in the control
363 group ($p=0.006$). At the individual question level CWE reported less physical active
364 for: 'Active travel to school' ($p<0.001$) 'Active during physical education classes

365 (p=0.014) and 'Active travel from school' (See supplement 5a). There were no
366 differences between the groups regarding the domains of activities engaged in
367 (supplement 5a). There were also no significant differences on the report time in any
368 of the subdomains of sedentary behaviours (ASAQ) for weekdays or weekends (see
369 supplement 5b).

370

371 Quality of Life for children with epilepsy and children in control groups

372 There was a positive correlation between PA (of all intensities) and self-reported
373 quality of life in CWE. Lower quality of life was associated with higher sedentary
374 behaviour. For weekend MVPA the relationship reached statistical significance
375 (p=0.008) (see supplement 6). Similar relationships were found for participants in the
376 control group. A positive relationship was also noted between survey measured PA
377 on the PAQ-A and quality of life in CWE (p=0.002) and the control group (p=0.012).

378

379 **Discussion**

380 This study provides novel pilot data on accelerometer assessed PA in secondary
381 school-aged CWE in comparison with age and gender-matched controls, as well as
382 data on factors associated with PA in this age group. Data from the accelerometers
383 indicate that young people with epilepsy engage in less PA than peers across a range
384 of PA intensities. The survey data also revealed less self-reported PA among the
385 CWE. Chronological age would appear to be an important factor for PA in CWE, such
386 that PA levels reduce with increasing age, even after considering other possible
387 contributory factors.

388

389 This is one of the first studies to provide accelerometer measured PA in CWE and thus
390 comparisons with previous studies are difficult. The fact that young people with
391 epilepsy of secondary school age engage in less accelerometer assessed PA than
392 their peers has potential negative implications. Physical inactivity is associated with
393 many non-communicable diseases and has significant economic costs for healthcare
394 systems and wider society [14,31]. Additionally, research has established that levels
395 of PA in childhood track into adulthood [45], highlighting the need to facilitate
396 behaviour change as early as possible. In addition to the physical benefits [48],
397 engaging in PA is also associated with improvements in cognitive functioning [5] and
398 has mental health benefits [4], both of which are often challenges for young people
399 with epilepsy.

400

401 The survey data, provides novel contextual information on PA and suggests that young
402 people with epilepsy may not be engaging in PA to the same degree as peers, which
403 is in line with a previous survey-based study of CWE compared to peers [37] and
404 sibling controls [52]. Differences were noted surrounding activity during travel to and
405 from school, and during physical education classes. Regarding travel to school, it may
406 be that caregivers are reluctant to let CWE walk/cycle to school unaccompanied due
407 to the perceived risk of having seizures. A potential solution would be to travel with a
408 caregiver or peers, however, or look to 'compensate' (i.e., fit in extra PA) elsewhere in
409 the day. Regarding physical education classes in school, extra training may be needed
410 for school staff so that they understand that CWE can engage in the same activities
411 as peers once an appropriate risk assessment has been undertaken. **The differences**
412 **noted in the survey data for travel to school and physical education classes might at**
413 **least partly explain the lack of significant differences between CWE and control**

414 participants in time spent on accelerometer measured physical activity at weekends.
415 However, more research is needed to explore why differences exist between weekday
416 and weekend activity levels.

417

418 This study also reports on factors which are associated with PA. We observed a
419 negative association between age and PA in CWE. This reduction in PA with age has
420 also been noted in the general population of adolescents [19] regarding MVPA and
421 thus it will be important to see if there are epilepsy specific issues at play and if the
422 reduction in PA of all intensities happens at a similar rate. It might be that as
423 sports/activities become more formalised during the adolescent years, young people
424 with epilepsy are restricted from accessing these more structured sporting activities
425 due to barriers including lack of knowledge of epilepsy and seizure management. The
426 data from the measure of quality of life suggests that engaging in more PA is
427 associated with better quality of life, this is an observation seen in other clinical and
428 non-clinical populations [35]. Given that quality of life is so reduced in young people
429 with epilepsy [42] increasing PA is likely to have benefits across a range of quality-of-
430 life domains.

431

432 In terms of feasibility, data from the current study suggests that using accelerometers
433 is a feasible way to measure PA in young people with epilepsy. This is line with a
434 previous study which suggests that CWE would wear pedometers to measure PA
435 [7,49]. However, the fact that 10 CWE dropped out from the study after expressing
436 interest, citing wearing of the accelerometer as an explanation, means alternative
437 methods should be explored. The literature has seen a move towards wrist worn
438 accelerometry in part because it is less visible and has shown high compliance with

439 adolescence [10]. Thus, future research in CWE should consider using wrist worn
440 accelerometers.

441

442 Study Limitations

443 There are several limitations that should be considered when interpreting the
444 findings of the current study. Firstly, we had difficulties recruiting CWE and controls
445 who attend special schools. Our limited sample size should be considered when
446 interpreting the results of our statistical analysis. In order to account for the potential
447 impact of COVID-19 restrictions we used a healthy control group. Despite this it is
448 still possible that COVID-19 restrictions impacted on the groups differently. We had
449 also initially hoped to assess the children's cognitive abilities via formal cognitive
450 testing. Unfortunately, this proved impossible as we had to abandon in-person visits
451 in order to adhere to COVID-19 guidelines at the time of testing. Furthermore, the
452 analyses were unable to consider the potential impact of variation in biological
453 maturity status of the children had on the results of the study. Strengths of this study
454 included age and gender matched controls and the use of accelerometers to assess
455 physical activity.

456

457 **Clinical Implications and Future Research**

458 Clinicians (e.g., paediatricians, paediatric neurologists and epilepsy nurses) working
459 with the paediatric epilepsy population should routinely ask about levels of PA in CWE
460 and potential barriers for participating. There is also a clear need for epilepsy
461 professionals to liaise with parents and schools to ensure that CWE can engage in PA
462 outside and inside schools so that CWE are not excluded from PA.

463

464 There is a need for more data on PA with larger samples but also considering younger
465 children and children attending special schools. In terms of CWE attending special
466 schools it is likely that to gather this data there we will need to further engage with
467 special schools regarding recruitment and consider whether waist worn
468 accelerometers are the most appropriate way to collect data in this group.
469 Interventions to promote PA in children with epilepsy should be developed with the
470 young people and outcome measures should include not only PA measures but also
471 quality of life and mental health measures.

472

473 **Conclusion**

474 Secondary school age CWE (aged 11-15 years) in the UK engaged in less PA than
475 peers across a range of intensities on weekdays. There is a need for further research
476 to better understand PA in CWE across the age ranges to inform the development of
477 interventions to increase PA in this group.

478

479

480

481

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488

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