





## RESEARCH ARTICLE

# Health care utilization and mortality for people with epilepsy during COVID-19: A population study

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## Abstract

**Objective:** This study was undertaken to characterize changes in health care utilization and mortality for people with epilepsy (PWE) during the COVID-19 pandemic.

**Methods:** We performed a retrospective study using linked, individual-level, population-scale anonymized health data from the Secure Anonymised Information Linkage databank. We identified PWE living in Wales during the study “pandemic period” (January 1, 2020–June 30, 2021) and during a “prepandemic” period (January 1, 2016–December 31, 2019). We compared prepandemic health care utilization, status epilepticus, and mortality rates with corresponding pandemic rates for PWE and people without epilepsy (PWOE). We performed subgroup analyses on children (<18 years old), older people (>65 years old), those with intellectual disability, and those living in the most deprived areas. We used Poisson models to calculate adjusted rate ratios (RRs).

**Results:** We identified 27 279 PWE who had significantly higher rates of hospital (50.3 visits/1000 patient months), emergency department (55.7), and outpatient attendance (172.4) when compared to PWOE (corresponding figures: 25.7, 25.2, and 87.0) in the prepandemic period. Hospital and epilepsy-related hospital admissions, and emergency department and outpatient attendances all reduced significantly for PWE (and all subgroups) during the pandemic period. RRs [95% confidence intervals (CIs)] for pandemic versus prepandemic periods were .70 [.69–.72], .77 [.73–.81], .78 [.77–.79], and .80 [.79–.81]. The corresponding rates also reduced for PWOE. New epilepsy diagnosis rates decreased during the pandemic compared with the prepandemic period (2.3/100 000/month cf. 3.1/100 000/month, RR = .73, 95% CI = .68–.78). Both all-cause deaths and deaths with epilepsy recorded on the death certificate increased for PWE during the pandemic (RR = 1.07, 95% CI = .997–1.145 and RR = 2.44, 95% CI = 2.12–2.81).

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When removing COVID deaths, RRs were .88 (95% CI = .81–.95) and 1.29 (95% CI = 1.08–1.53). Status epilepticus rates did not change significantly during the pandemic (RR = .95, 95% CI = .78–1.15).

**Significance:** All-cause non-COVID deaths did not increase but non-COVID deaths associated with epilepsy did increase for PWE during the COVID-19 pandemic. The longer term effects of the decrease in new epilepsy diagnoses and health care utilization and increase in deaths associated with epilepsy need further research.

#### KEYWORDS

deaths, health care utilization, real world evidence, routinely collected data, status epilepticus

## 1 | INTRODUCTION

Coronavirus disease 2019 (COVID-19), caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has caused significant morbidity and mortality worldwide.<sup>1,2</sup> There is increasing evidence that people with epilepsy (PWE) are more susceptible to severe COVID-19, having an increased risk of being hospitalized with, or dying from, COVID-19.<sup>3–6</sup>

Significant changes in global health care provision and behavior, from the onset of the COVID-19 pandemic in early 2020, have affected people with many conditions, including epilepsy.<sup>7</sup> Health care professionals providing epilepsy care were redeployed to COVID-19 work, and epilepsy consultations and investigations were canceled.<sup>8,9</sup> There was a significant shift toward virtual clinic appointments.<sup>10</sup> Health care behavior changed in the UK as well as other countries, with people being deterred from seeking medical attention for non-COVID-19 illnesses due to perceived COVID-19 risk.<sup>11,12</sup>

Nonpharmaceutical interventions to reduce the transmission of SARS-CoV-2 have included social distancing, school and workplace closures, and prohibiting public gatherings. All of these changes may have affected PWE in negative ways, which may increase seizure frequency, for example, increased psychological distress, reduced contact with families and carers, reduced sleep, and difficulties in accessing epilepsy medication.<sup>13–15</sup> These changes may have had greatest negative impact on those with particular vulnerabilities such as children, patients with intellectual disability (ID), and those living in areas of highest deprivation. There might also have been positive effects, including more time at home with family, less stress at work, and fewer difficulties in traveling to (virtual) appointments.

The World Health Organization declared an end to COVID-19 as a public health emergency in May 2023.<sup>16</sup> Despite this, and the high levels of vaccination and

#### Key Points

- People with epilepsy have increased rates of hospital, emergency department, and outpatient attendance when compared to people without epilepsy.
- These rates (and rates of new epilepsy diagnoses) reduced significantly during our pandemic study period (January 1, 2020–June 30, 2021).
- Rates of status epilepticus did not change during the pandemic period.
- All-cause non-COVID deaths did not increase for people with epilepsy.
- There was a small increase in non-COVID deaths with epilepsy listed as a cause for people with epilepsy.

immunity, it is still a global threat, and significant impacts of the pandemic are still being felt in health systems worldwide.<sup>16</sup> Therefore, it is important to understand the impact COVID-19 has had on people with chronic conditions such as epilepsy. For example, changes in health care utilization, mortality, or diagnosis rates for specific subgroups of PWE would help identify those most vulnerable and inform targeting of limited resources for specific groups postpandemic and for future similar pandemics. Understanding the impact of COVID-19 can help develop health care services for people with long-term conditions such as epilepsy that are more resilient to the challenges posed by future COVID-19 and other pandemics.

As part of the COVID-19 and Epilepsy in Wales (CoVEW) project, we have previously shown an increased COVID-19 vaccine uptake in PWE and a small increased risk of COVID-19 hospitalizations and deaths for PWE in Wales.<sup>6,17</sup> In a previous study on epilepsy deaths at the beginning of the pandemic (to the end of 2020), we found

no overall increase in deaths for PWE or non-COVID deaths in PWE.<sup>18</sup> To our knowledge, there have been very limited epilepsy-specific, population-level studies on the effect of COVID-19 on health care utilization and mortality. As part of the CoVEW project, our aim in this study was to extend our previous work and investigate the indirect effects of COVID-19 for PWE in Wales by comparing outcome rates during the pandemic with corresponding prepandemic rates.

## 2 | MATERIALS AND METHODS

### 2.1 | Study design and data sources

This observational cohort study used the Secure Anonymised Information Linkage (SAIL) databank, which contains anonymized individual-level, population-scale, routinely collected electronic health record data sources.<sup>19</sup> These include hospital admission and demographic data for the complete Welsh population (3.1 million) and primary care records for 86% of the Welsh population.<sup>20,21</sup> We used the Controlling COVID-19 Through Enhanced Population Surveillance and Intervention (Con-COV) project dataset within SAIL (Project 0911).<sup>22</sup>

### 2.2 | Setting

For this study, we defined a pandemic period from January 1, 2020 to June 31, 2021. This study period was prespecified and based on the data available at the beginning of the project. We defined the prepandemic period from January 1, 2016 to December 31, 2019 as a reference period. We identified PWE living in Wales and diagnosed with epilepsy before June 31, 2021. We used a previously validated method to define PWE as having a primary care diagnosis of epilepsy (defined using Read codes used in primary care) and prescription of at least two antiseizure medications.<sup>23</sup>

### 2.3 | Outcomes

Using primary care (general practice), hospital care, outpatient, intensive care, and emergency department data alongside Office for National Statistics mortality data, we defined various outcomes for PWE as follows: new diagnosis of epilepsy, episodes of *status epilepticus* (Read or International Classification of Disease [ICD] diagnosis codes for status epilepticus), *hospital visits* (for an epilepsy-related reason or any reason), *outpatient*

*appointments* (any hospital in Wales for any reason), *emergency department attendances* (for any reason), and *deaths* (deaths due to any reason or deaths with epilepsy recorded on the death certificate [deaths associated with epilepsy]). We included both measures of mortality to compare with epilepsy mortality in other populations. We defined COVID-19-related deaths as having ICD-10 codes for COVID-19 on death certificates (in any position, e.g., primary or secondary cause of death) or occurring within 28 days of a positive SARS-CoV-2 polymerase chain reaction (PCR) test.

We also performed a subgroup analysis for children (people aged <18 years), older people (aged >65 years), and people with an ID. We defined a person as having an ID if they had a primary care diagnosis code (Read code) for ID.

### 2.4 | Covariables and matching

We compared these outcomes for PWE (after their diagnosis date) during the pandemic period with those in the prepandemic period, as well as comparing relevant outcomes for a matched comparator group of people without epilepsy (PWOE) and the whole Welsh population in the pandemic period with those in the prepandemic period. We created the matched comparator group of PWOE using exact 5:1 matching on sex, age, and socioeconomic deprivation quintile measured using the Welsh Index of Multiple Deprivation 2019 (WIMD). WIMD uses weighted scores from eight domains to form a score for small geographical areas or Lower-layer Super Output Areas (LSOAs). WIMD scores for each LSOA are then grouped into quintiles, with Quintile 1 being the most deprived and Quintile 5 being the least deprived.<sup>22</sup>

### 2.5 | Statistical methods

We used Poisson models to calculate rate ratios with corresponding confidence limits for pandemic versus prepandemic periods. We used R (version 4.1.3) for statistical analysis.

### 2.6 | Patient and public involvement

We collaborated with Epilepsy Action, a leading UK epilepsy charity, and research volunteers with epilepsy, who were part of the project from the onset. We discussed the project design, results, and this article with volunteers with epilepsy. We produced a video that showed some of the views of people living with epilepsy on their

experiences of the effects of COVID-19.<sup>24</sup> The original Con-COV (Project 0911) cohort was developed with input from members of the SAIL Databank Consumer Panel.

## 2.7 | Ethical approval

This study was approved by the SAIL independent Information Governance Review Panel (Project 0911). The Research Ethics Service has previously confirmed that SAIL projects using anonymized, routinely collected data do not require National Health Service research ethics committee approval.

## 3 | RESULTS

In the prepandemic period, we identified 29 840 PWE (149 200 matched comparators) and in the pandemic period we identified 27 279 PWE (136 395 matched comparators). For demographic characteristics of the prepandemic and pandemic epilepsy and whole Wales populations, see Table 1.

Table 2 shows mean monthly outcome rates and rate ratios when comparing prepandemic and pandemic periods. PWE had double the number of emergency department attendances, hospital admissions, and outpatient appointments when compared to the comparators in the prepandemic period (rate ratios [95% confidence intervals (CIs)] = 2.36 [2.34–2.38], 2.08 [2.06–2.10], 1.92 [1.91–1.93]). PWE had a higher mortality rate in the prepandemic period when compared to the comparators (2.0 compared with 1.0 deaths/month/1000; rate ratio = 1.99, 95% CI = 1.91–2.09; Table S1).

In the pandemic period, there were significantly fewer emergency department attendances, hospital admissions, and outpatient appointments for the epilepsy and comparator groups. There were also fewer hospital attendances for epilepsy and fewer new epilepsy diagnoses, although the rates of status epilepticus did not change (Table 2). There was a greater reduction in hospital admissions and emergency department attendance rates for PWE in Wales when compared to the whole Welsh population and comparator group during the pandemic period (Tables 2 and S2; Figures 1A,C, S1, and S7).

Figures 1 and S1–S12 show the monthly variation in outcome rates during the pandemic period compared to prepandemic monthly averages. For hospital admissions, outpatient appointments, and emergency department and epilepsy hospital attendances (Figure 1A–D), there are noticeable reductions around the time of the first and second “waves” of COVID-19 in Wales (April 2020 and January 2021).

The supplementary figures show changes in outcome rates for our subgroup analysis (children, older adults, those with ID, and those living in the two most deprived quintiles). The subgroup results are broadly comparable to the whole epilepsy group. However, children had greater reductions in all hospital visits, hospital visits because of epilepsy, and emergency department visits during the pandemic (Figures S2, S8, and S11). PWE with ID also seemed to have greater reductions in emergency department visits during the pandemic period (Figure S8).

All-cause deaths for PWE did not increase significantly during the pandemic, and all-cause deaths excluding COVID deaths for PWE reduced during the pandemic. This contrasted to all-cause deaths for the comparator group and whole Welsh population, which increased during the pandemic (but deaths excluding COVID for the comparator group and whole Welsh population did not increase).

Deaths associated with epilepsy (deaths where epilepsy was mentioned on the death certificate) increased during the pandemic period for PWE, even when COVID deaths were excluded (Table 2). This was also the case in our subgroup analysis for older people, those with ID, and those living in the two most deprived quintiles (Figure 3). There were no deaths in children, and so we did not perform subgroup analysis in this group.

Figure 2 compares the monthly death rates for PWE during the pandemic and prepandemic period. Peaks in all deaths occurred during the first and second “waves” of COVID-19 in Wales (March 2020 and January 2021). Although all-cause non-COVID-19 deaths in PWE remained on or below prepandemic levels throughout the pandemic period (Figure 2A), non-COVID-19 deaths associated with epilepsy were higher than prepandemic levels from July–November 2020 (Figure 2B).

## 4 | DISCUSSION

### 4.1 | Main findings

In this large population-level study, of more than 27 000 PWE, we compared health care utilization, status epilepticus rates, and mortality rates for PWE during the first 18 months of the COVID-19 pandemic with prepandemic rates.

We found that PWE had approximately double the rate of emergency department, inpatient, and outpatient attendances when compared to matched comparators and the whole population in the prepandemic period. This is probably because of the need for outpatient visits in most people with a chronic disease as well as hospital and emergency department attendances because of breakthrough

**TABLE 1** Characteristics of study cohorts with numbers in each category (corresponding percentages for each category in parentheses).

	Prepandemic		Pandemic	
	Epilepsy	Comparator	All Wales	All Wales
Total	29 840	149 200	3 113 137	3 037 156
Male	14 657 (49.1)	73 285 (49.1)	1 553 022 (49.9)	1 151 169 (49.9)
Female	15 183 (50.9)	75 915 (50.9)	1 560 115 (50.1)	1 521 987 (50.1)
Age				
<18 years	3342 (11.2)	16 710 (11.2)	614 063 (19.7)	620 339 (20.4)
18–65 years	20 025 (67.1)	100 125 (67.1)	1 885 695 (60.6)	1 816 167 (59.8)
65+ years	6473 (21.7)	32 365 (21.7)	613 379 (19.7)	600 650 (19.8)
WIMD				
1	8070 (27.0)	40 350 (27.0)	631 590 (20.3)	623 773 (20.5)
2	6874 (23.0)	34 370 (23.0)	619 460 (19.9)	607 600 (20.0)
3	5396 (18.1)	26 980 (18.1)	625 583 (20.1)	603 509 (19.9)
4	4913 (16.5)	24 565 (16.5)	616 861 (19.8)	597 899 (19.7)
5	4587 (15.4)	22 935 (15.4)	619 643 (19.9)	603 188 (19.9)
Intellectual disability	4632 (15.5)	2460 (1.6)	46 191 (1.5)	54 865 (1.8)
Positive SARS-CoV-2 PCR test at end of study	–	–	–	183 341 (6.0)
			1941 (7.1)	9021 (6.6)

Note: Prepandemic period is defined as January 1, 2016–December 31, 2019. Pandemic period is defined as January 1, 2020–June 30, 2021. WIMD 1, most deprived quintile; WIMD 5, least deprived quintile.

Abbreviations: PCR, polymerase chain reaction; WIMD, Welsh Index of Multiple Deprivation.

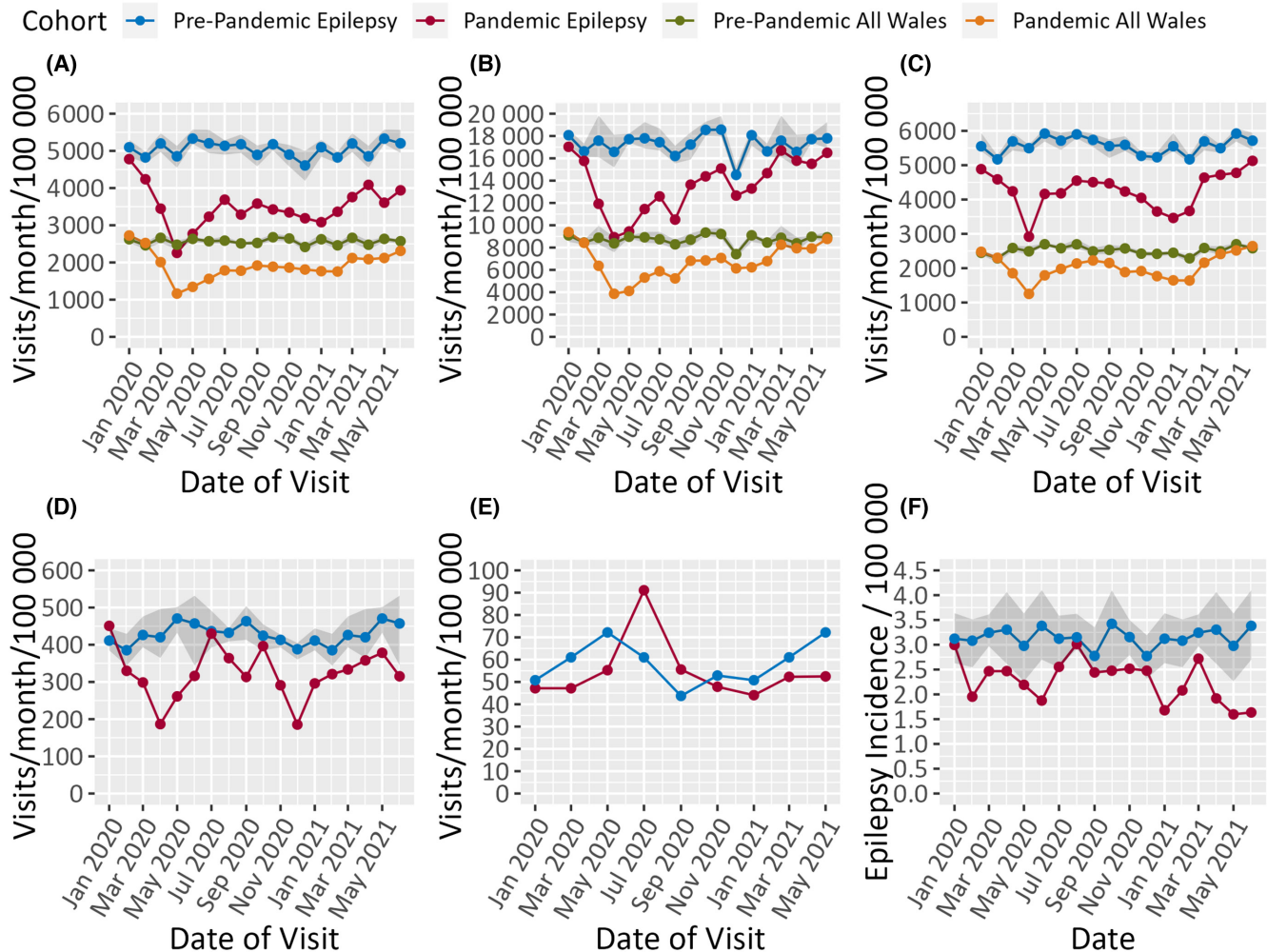
**TABLE 2** Mean monthly rates (per 1000 people) of key outcomes before and during the COVID-19 pandemic.

	Prepandemic			Pandemic			Pandemic vs. prepandemic rate ratios (95% CI) <i>p</i>		
	Epilepsy	Comparator	All Wales	Epilepsy	Comparator	All Wales	Epilepsy	Comparator	All Wales
Status epilepticus	.284	-	-	.274	-	-	.95 (.78-1.15) <i>p</i> = .6	-	-
Emergency admissions, any	55.69	23.60	25.18	42.67	20.12	20.42	.78 (.77-.79) <i>p</i> < .0001	.87 (.86-.88) <i>p</i> < .0001	.81 (.81-.81) <i>p</i> < .0001
Hospital admissions, any	50.33	24.16	25.65	35.04	19.33	19.18	.70 (.69-.72) <i>p</i> < .0001	.82 (.81-.83) <i>p</i> < .0001	.75 (.75-.75) <i>p</i> < .0001
Hospital admissions, epilepsy	4.27	-	-	3.24	-	-	.77 (.73-.81) <i>p</i> < .0001	-	-
Outpatient appointments	167.72	89.68	87.01	139.74	70.07	67.42	.80 (.79-.81) <i>p</i> < .0001	.80 (.79-.80) <i>p</i> < .0001	.77 (.77-.77) <i>p</i> < .0001
New epilepsy diagnoses	.031	-	-	.023	-	-	.73 (.68-.78) <i>p</i> < .0001	-	-
Deaths, all	2.01	1.00	.83	2.14	1.27	.94	1.07 (1.00-1.15) <i>p</i> = .06	1.27 (1.22-1.33) <i>p</i> < .0001	1.11 (1.10-1.12) <i>p</i> < .0001
Deaths, all, excluding COVID-19 <sup>a</sup>	2.01	1.00	.83	1.76	1.03	.75	.88 (.81-.95) <i>p</i> = .0008	1.03 (.99-1.08) <i>p</i> = .17	.89 (.88-.90) <i>p</i> < .0001
Deaths associated with epilepsy	.30	-	-	.43	-	-	1.48 (1.25-1.75) <i>p</i> < .0001	-	-
Deaths associated with epilepsy, excluding COVID-19 <sup>a</sup>	.30	-	-	.37	-	-	1.29 (1.08-1.53) <i>p</i> = .005	-	-

Note: Prepandemic period is defined as January 1, 2016–December 31, 2019. Pandemic period is defined as January 1, 2020–June 30, 2021. Significant rate ratios are shown in bold.

Abbreviation: CI, confidence interval.

<sup>a</sup>COVID-19 deaths were defined as having International Classification of Disease-10 codes for COVID-19 on death certificates (in any position, e.g., primary or secondary cause of death) or occurring within 28 days of a positive SARS-CoV-2 polymerase chain reaction test.



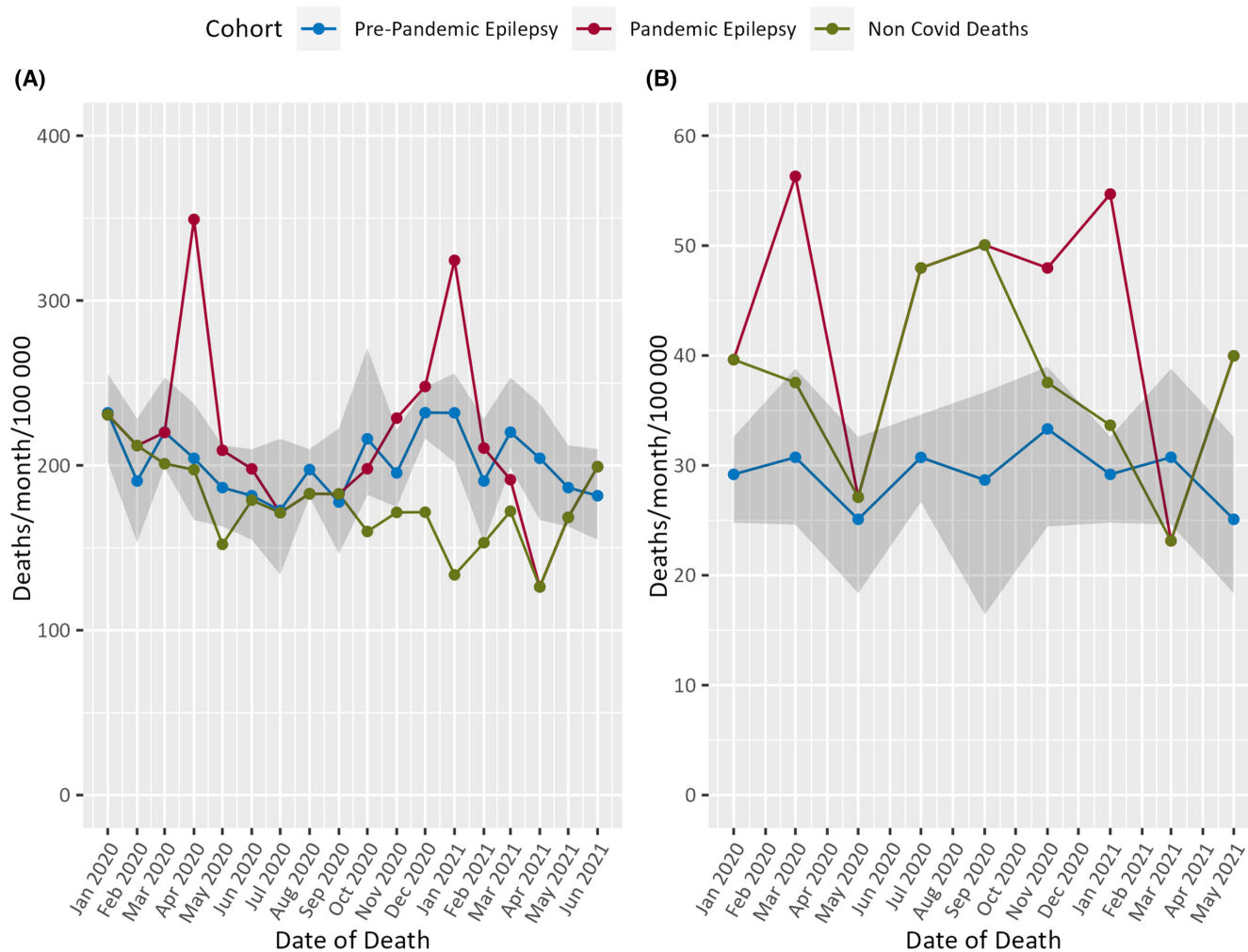
**FIGURE 1** Graphs comparing mean monthly (A) hospital visits, (B) outpatient visits, (C) emergency hospital visits, (D) epilepsy hospital visits (hospital visits with epilepsy coded as the main reason for admission), (E) hospital visits with status epilepticus in the pandemic period (January 2020–June 2021), and (F) new epilepsy diagnoses. The corresponding monthly mean (or 2-monthly mean) is shown for the pre-pandemic period (2016–2019). The gray shading around the pre-pandemic lines represents the range of visits per month during the pre-pandemic years (2016–2019).

seizures and problems associated with the increased comorbidities in PWE.

During the pandemic, there were fewer emergency department attendances, hospital admissions, and outpatient appointments for PWE and the whole Welsh population. The most likely explanation for this reduction in hospital and emergency visits during the pandemic period was that people seemed to be deterred from coming to hospital for non-COVID-19 reasons due to both concerns about contracting COVID-19 and not wanting to put a strain on health services. This pattern has been seen in other parts of the UK as well as other countries.<sup>25–28</sup> In line with this, there seemed to be a greater reduction in hospital and emergency department attendances around the time of the first and second “waves” of COVID-19 in Wales. In the UK, as in other countries, there was a dramatic shift from “in-person” to “virtual” outpatient

appointments during the pandemic. It may have been that many virtual appointments took place at the onset of the pandemic without being recorded while appropriate systems were being developed.

We have recently found that PWE were more at risk from hospitalization and death from COVID-19 in Wales<sup>6</sup> despite higher vaccination rates, and overall PWE in this study had more confirmed SARS-CoV-2 PCR tests.<sup>17</sup> Despite this, we found that there was a greater reduction in hospital admissions and emergency department attendances for PWE when compared to matched comparators during the pandemic (rate ratios of .70 [95% CI = .69–.72] and .78 [95% CI = .77–.70], respectively, in PWE and .82 [95% CI = .81–.83] and .87 [95% CI = .86–.88] in comparators). There were also fewer hospital attendances specifically for epilepsy (rate ratio = .77, 95% CI = .73–.81). The reasons for this are



**FIGURE 2** Deaths per month per 100 000 people with epilepsy: (A) all deaths and (B) deaths associated with epilepsy (AWE). Deaths AWE are deaths in people with epilepsy where epilepsy is mentioned on the death certificate in any position. Pre-pandemic monthly mean rates are shown (2016–2019), and gray shading represents the range of visits per month during the pre-pandemic years (2016–2019). Due to low numbers (and potential reidentification issues), rates are presented every 2 months for deaths AWE.

not entirely clear. It may be that PWE were proportionally more deterred from attending hospital during the pandemic when compared to people without epilepsy. PWE may have had fewer seizures outside their home environment during the pandemic because of social isolation rules and therefore were less likely to be brought to hospital by unfamiliar bystanders.

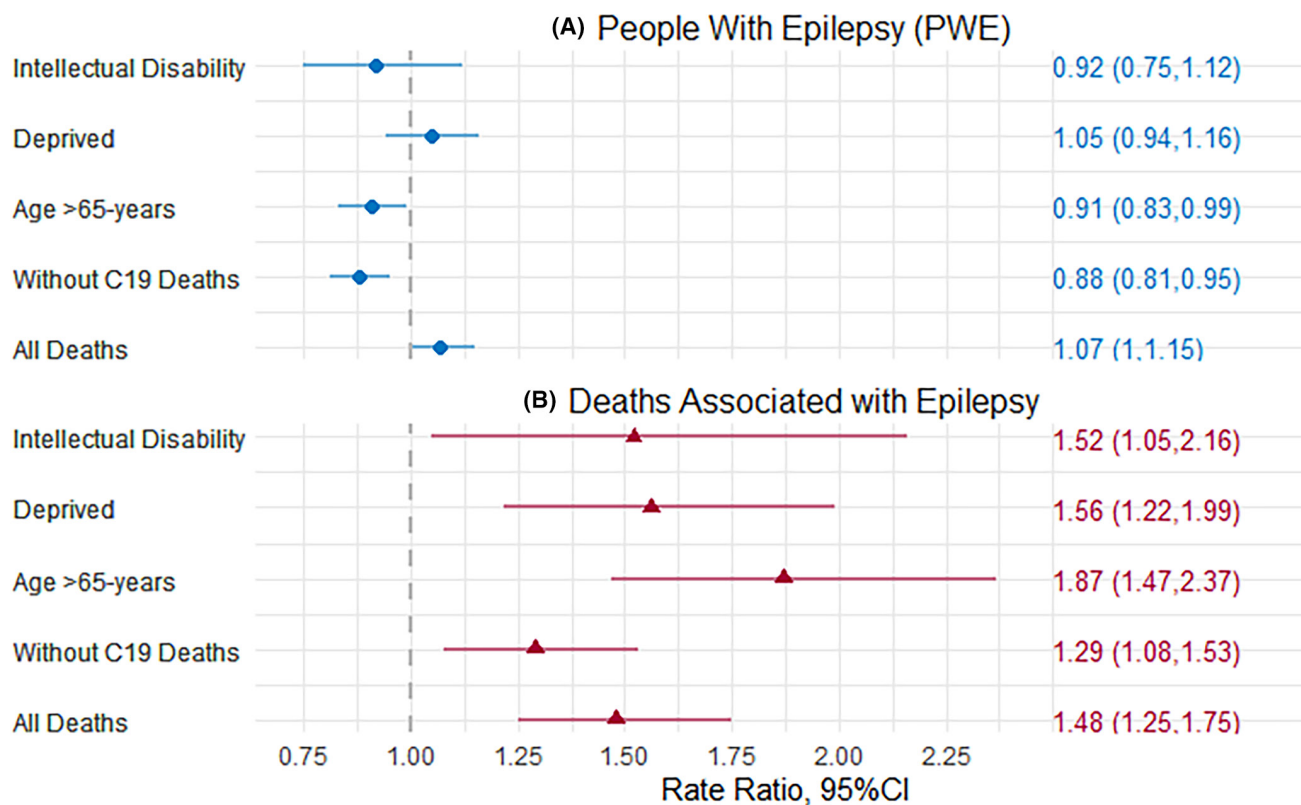
PWE may also have had fewer breakthrough seizures during the pandemic, resulting in fewer emergency department and hospital attendances. For example, due to public health measures such as social isolation, greater attention to hand hygiene, and wearing masks, there were fewer bacterial respiratory and gastrointestinal infections during the pandemic.<sup>29,30</sup> These are known triggers for breakthrough seizures.

We found no change in the overall rates of status epilepticus during the pandemic (apart from a possible increase during the summer of 2020; Figure 2E). If the

underlying rates of status epilepticus were unchanged, then this is reassuring, as it meant that PWE in Wales were still attending hospital for episodes of status epilepticus in Wales despite an overall reduction in hospital attendances. However, it is possible that there was an increase in underlying status epilepticus rates and proportionally fewer PWE attended hospital with status epilepticus given the overall decrease in hospital attendances during the pandemic.

New epilepsy diagnosis decreased during the pandemic (rate ratio .73, 95% CI = .68–.78). It is possible that this represents a real decrease in new cases of epilepsy, although it more likely represents a reduction in new diagnoses being made. This could have been due to a reduction in outpatient appointments or a possible increase in unwitnessed seizures. There have also been reductions in the incidences of other diseases during the pandemic.<sup>31</sup> We did not observe a “catch-up” in





**FIGURE 3** Rate ratios of deaths in the pandemic (January 2020–June 2021) versus prepandemic (2016–2019) period. The bars indicate 95% confidence intervals (CIs). (A) All deaths in people with epilepsy. (B) Deaths in people with epilepsy where epilepsy is mentioned in any position on the death certificate (deaths associated with epilepsy). Deprived = people living in the two most deprived quintiles as measured by the Welsh Index of Multiple Deprivation. C19, coronavirus disease 2019.

epilepsy diagnoses at the end of the pandemic period, although this might take a few years to notice. The impact of this reduction in diagnoses might be felt in the next few years with potentially fewer PWE on treatment and having specialist care for their epilepsy. This might lead to increased hospital admissions and deaths, and health care planners should be aware of this, given the increased pressure on UK and other health care systems postpandemic.

Reassuringly, all-cause deaths for PWE (and PWE with ID, older PWE, and more deprived PWE) did not increase significantly during the pandemic, in contrast to the comparator group and whole Welsh population (Figure 3). This is despite the slightly increased risk of COVID-related deaths in PWE.<sup>6</sup> All-cause deaths (excluding COVID-19 deaths) for PWE (and the whole Welsh population) reduced during the pandemic. This reduction in non-COVID-19 deaths during the pandemic has been found in other (but not all) populations.<sup>32–34</sup> Possible reasons for this include some “COVID-19 deaths” being due to other causes but having incidental COVID-19 or COVID-19 recorded on death certificates (particularly with increased immunity toward the end of the pandemic); people who would have died from

other causes dying earlier from COVID-19; and a reduction in infections normally associated with deaths such as influenza.<sup>29,30,32</sup>

Deaths associated with epilepsy (DAE), where epilepsy was recorded on the death certificate, increased slightly for PWE (and PWE with ID, older PWE, and more deprived PWE), even when COVID-19 deaths were excluded. The rate ratios for DAE were not significantly different between PWE with ID, older PWE and more deprived PWE. The increase in DAE could have been because of more deaths directly related to epilepsy such as trauma and sudden unexpected death in epilepsy (SUDEP) or because PWE were having more seizures around the time of death. Changes in the death registration process or heightened awareness of seizures during the pandemic might have made it more likely that epilepsy was recorded on death certificates. It is also possible that health care changes during the pandemic may have contributed to this change, amplifying preexisting health care shortfalls for PWE.

It is important to note that even though DAE increased slightly, they still accounted for the minority of deaths in PWE during the pandemic (.43 deaths/month/1000 PWE compared with 2.14 deaths/month/1000 PWE overall).

## 4.2 | Comparison with other studies

Other studies have found similar results. In Ontario, Canada, there was a decrease in hospitalizations, emergency department attendances, and outpatient attendances during the first year of the pandemic (March 2020–March 2021) for seven ambulatory care sensitive conditions including epilepsy.<sup>35</sup> Across all age groups in the USA, there was a reduction in emergency department visits for seizures and/or epilepsy.<sup>36</sup> There was a significant reduction in emergency department visits and an increase in all-cause mortality for PWE in Hong Kong in 2020.<sup>37</sup> A study using routinely collected data in a region of Scotland, UK, included 4285 PWE during the pandemic until November 2021.<sup>38</sup> The authors found a reduction in overall, as well as epilepsy-related, mortality, emergency department, and hospital attendances.<sup>38</sup>

In a smaller, previous study (pandemic period up until the end of 2020), specifically looking at mortality, we found no significant change in overall mortality for PWE but an increase in deaths associated with epilepsy.<sup>18</sup> A population study of mortality in Scotland, UK up until the end of 2020 did not find an overall increase in deaths associated with epilepsy but found a small increase in deaths associated with epilepsy in women in 2020.<sup>39</sup>

## 4.3 | Strengths

We have performed one of the largest population-level studies of health care utilization and mortality in PWE during the COVID-19 pandemic, including more than 27 000 PWE, covering the first 15 months of the pandemic (including both largest waves). We have used a previously validated method of epilepsy-case ascertainment and used a large age-, sex-, and deprivation-matched comparator group as well as being able to compare to prepandemic data. We have also specifically measured rates of status epilepticus at a population level.

## 4.4 | Weaknesses

We have not accounted for temporal or geographical variation in COVID-19 prevalence or circulating variants or health care provision. Although our comparator group was matched for age, sex, and deprivation, we did not match for comorbidities in this group. We could not account for the increased virtual contact with PWE that was being made, particularly at the beginning of the pandemic. We did not specifically measure causes of death and could not specifically measure SUDEP using the routinely collected

data in this study. SUDEP is also poorly recorded in death certificate data in the UK. We also did not measure important outcome measures for PWE such as quality of life, mental health, and seizure frequency that could have changed during the pandemic.

Our prespecified study end point was the end of June 2021. At this time, the COVID-19 pandemic was ongoing, although increased immunity, due to vaccination and previous infections, and a greater range of available COVID-19 treatments were reducing the effect of the pandemic.

## 4.5 | Conclusions

Hospital admissions, emergency department attendances, and outpatient attendances fell significantly for PWE in Wales during the COVID-19 pandemic. There were also significantly fewer new diagnoses of epilepsy. Although all-cause mortality for PWE did not increase and there was reduction in non-COVID-19 deaths, there was a slight increase of epilepsy-associated deaths. With increasing strain on health care services in the postpandemic recovery period, these findings could have implications for PWE, health care professionals, and health care providers.

## AUTHOR CONTRIBUTIONS

Huw Trafford performed primary data and statistical analysis. William O. Pickrell and Richard F. Chin conceived, designed, and coordinated the study. Michael P. Kerr, Richard F. Chin, H. Robert Powell, and Ronan A. Lyons provided senior clinical advice. Joe Hollinghurst and Alan Watkins provided statistical advice. Jan Paterson and Daniel Jennings provided public and patient involvement advice. All authors were part of the project team reviewing results and progress. Huw Trafford and William O. Pickrell drafted the manuscript. All authors reviewed and edited the manuscript.

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#### CONFLICT OF INTEREST STATEMENT

The authors confirm that they have no conflicts of interest.

#### ETHICS STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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#### REFERENCES

1. WHO. WHO Coronavirus (COVID-19) Dashboard. 2022 [cited 2022 15/12/2022]; Available from: <https://covid19.who.int/>
2. Wang H, Paulson KR, Pease SA, Watson S, Comfort H, Zheng P, et al. Estimating excess mortality due to the COVID-19 pandemic: a systematic analysis of COVID-19-related mortality, 2020–21. *Lancet*. 2022;399(10334):1513–36.
3. Hippisley-Cox J, Coupland CAC, Mehta N, Keogh RH, Diaz-Ordaz K, Khunti K, et al. Risk prediction of covid-19 related death and hospital admission in adults after covid-19 vaccination: national prospective cohort study. *BMJ*. 2021;374:n2244.
4. Muccioli L, Zenesini C, Taruffi L, Licchetta L, Mostacci B, di Vito L, et al. Risk of hospitalization and death for COVID-19 in persons with epilepsy over a 20-month period: the EpiLink Bologna cohort, *Italy*. *Epilepsia*. 2022;63(9):2279–89.
5. Yoo J, Kim JH, Jeon J, Kim J, Song TJ. Risk of COVID-19 infection and of severe complications among people with epilepsy. A nationwide cohort study. *Neurology*. 2022;98(19):e1886–e1892.
6. Strafford H et al. Epilepsy and the risk of COVID-19 related hospitalisations and deaths, a population study. *Epilepsia*. 2023; <https://doi.org/10.1111/epi.17910>
7. Moynihan R, Sanders S, Michaleff ZA, Scott AM, Clark J, To EJ, et al. Impact of COVID-19 pandemic on utilisation of healthcare services: a systematic review. *BMJ Open*. 2021;11(3):e045343.
8. Ahrens SM, Ostendorf AP, Lado FA, Arnold ST, Bai S, Bensalem-Owen MK, et al. Impact of the COVID-19 pandemic on epilepsy center practice in the United States. *Neurology*. 2022;98(19):e1893–e1901.
9. Cross JH, Kwon CS, Asadi-Pooya AA, Balagura G, Gómez-Iglesias P, Guekht A, et al. Epilepsy care during the COVID-19 pandemic. *Epilepsia*. 2021;62(10):2322–32.
10. Klein BC, Busis NA. COVID-19 is catalyzing the adoption of telemedicine. *Neurology*. 2020;94(21):903–4.
11. The Health Foundation. Non-COVID-19 NHS care during the pandemic. 2020 Available from: <https://www.health.org.uk/news-and-comment/charts-and-infographics/non-covid-19-nhs-care-during-the-pandemic>
12. Government, W. NHS activity and capacity during the coronavirus (COVID-19) pandemic: 11 February 2021. 2022 Available from: <https://www.gov.wales/nhs-activity-and-capacity-during-coronavirus-covid-19-pandemic-11-february-2021-html>
13. Reilly C, Muggerridge A, Cross JH. The perceived impact of COVID-19 and associated restrictions on young people with epilepsy in the UK: young people and caregiver survey. *Seizure-Eur J Epilep*. 2021;85:111–4.
14. Abokalawa F, Ahmad SF, al-Hashel J, Hassan AM, Arabi M. The effects of coronavirus disease 2019 (COVID-19) pandemic on people with epilepsy (PWE): an online survey-based study. *Acta Neurol Belg*. 2022;122(1):59–66.
15. Giordano A, Siciliano M, de Micco R, Sant'Elia V, Russo A, Tedeschi G, et al. Correlates of psychological distress in epileptic patients during the COVID-19 outbreak. *Epilepsy Behav*. 2021;115:107632.
16. Wise J. Covid-19: WHO declares end of global health emergency. *BMJ*. 2023;381:p1041.
17. Strafford H, Lacey AS, Hollinghurst J, Akbari A, Watkins A, Paterson J, et al. COVID-19 vaccination uptake in people with epilepsy in Wales. *Seizure-Eur J Epilep*. 2023;108:49–52.
18. Daniels H, Lacey AS, Mikadze D, Akbari A, Fonferko-Shadrach B, Hollinghurst J, et al. Epilepsy mortality in Wales during COVID-19. *Seizure-Eur J Epilep*. 2022;94:39–42.
19. Databank, T.S.A.I.L. *SAIL Databank*. 2023 [cited 2023 11th March]; Available from: <https://saildatabank.com/>
20. Jones KH, Ford DV, Thompson S, Lyons R. A profile of the SAIL databank on the UK secure research platform. *Int J Popul Data Sci*. 2020;4(2):1134. <https://doi.org/10.23889/ijpds.v4i2.1134>
21. Ford DV, Jones KH, Verplancke JP, Lyons RA, John G, Brown G, et al. The SAIL databank: building a national architecture for e-health research and evaluation. *BMC Health Serv Res*. 2009;9:157.
22. Lyons J, Akbari A, Torabi F, Davies GI, North L, Griffiths R, et al. Understanding and responding to COVID-19 in Wales: protocol for a privacy-protecting data platform for enhanced

- epidemiology and evaluation of interventions. *BMJ Open*. 2020;10(10):e043010.
23. Fonferko-Shadrach B, Lacey AS, White CP, Powell HWR, Sawhney IMS, Lyons RA, et al. Validating epilepsy diagnoses in routinely collected data. *Seizure-Eur J Epilep*. 2017;52:195–8.
  24. Action, E. *Living with epilepsy during COVID-19*. 2023; [Film describing people's experiences of living with epilepsy during COVID-19]. Available from: <https://youtu.be/GhwCGKNGm14>
  25. Santi L, Golinelli D, Tampieri A, Farina G, Greco M, Rosa S, et al. Non-COVID-19 patients in times of pandemic: emergency department visits, hospitalizations and cause-specific mortality in northern Italy. *PloS One*. 2021;16(3):e0248995.
  26. Vollmer MAC, Radhakrishnan S, Kont MD, Flaxman S, Bhatt S, Costelloe C, et al. The impact of the COVID-19 pandemic on patterns of attendance at emergency departments in two large London hospitals: an observational study. *BMC Health Serv Res*. 2021;21(1):1008.
  27. Reschen ME, Bowen J, Novak A, Giles M, Singh S, Lasserson D, et al. Impact of the COVID-19 pandemic on emergency department attendances and acute medical admissions. *BMC Emerg Med*. 2021;21(1):143.
  28. Birkmeyer JD, Barnato A, Birkmeyer N, Bessler R, Skinner J. The impact of the COVID-19 pandemic on hospital admissions in the United States. *Health Aff*. 2020;39(11):2010–7.
  29. Tanislav C, Kostev K. Fewer non-COVID-19 respiratory tract infections and gastrointestinal infections during the COVID-19 pandemic. *J Med Virol*. 2022;94(1):298–302.
  30. Shaw D, Abad R, Amin-Chowdhury Z, Bautista A, Bennett D, Broughton K, et al. Trends in invasive bacterial diseases during the first 2 years of the COVID-19 pandemic: analyses of prospective surveillance data from 30 countries and territories in the IRIS consortium. *Lancet Digit Health*. 2023;5(9):e582–e593.
  31. Qi C, Osborne T, Bailey R, Cooper A, Hollinghurst JP, Akbari A, et al. Impact of COVID-19 pandemic on incidence of long-term conditions in Wales: a population data linkage study using primary and secondary care health records. *Br J Gen Pract*. 2023;73(730):e332–e339.
  32. Tallack CKH. What has happened to non-COVID mortality during the pandemic. London: The Health Foundation; 2021.
  33. Catalano R, Casey JA, Gemmill A, Bruckner T. Expectations of non-COVID-19 deaths during the pre-vaccine pandemic: a process-control approach. *BMC Public Health*. 2023;23(1):155.
  34. Silverio-Murillo A, Balmori de la Miyar JR, Martínez-Alfaro A. Non-COVID-19 deaths in times of pandemic. *J Public Health (Oxf)*. 2023;45(2):e196–e203.
  35. Kendzerska T, Zhu DT, Pugliese M, Manuel D, Sadatsafavi M, Povitz M, et al. Trends in all-cause mortality and inpatient and outpatient visits for ambulatory care sensitive conditions during the first year of the COVID-19 pandemic: a population-based study. *J Hosp Med*. 2022;17(9):726–37.
  36. Sapkota S, Caruso E, Kobau R, Radhakrishnan L, Jobst B, DeVies J, et al. Seizure or EPilepsy related emergency department visits before and during the COVID-19 pandemic—United States, 2019–2021. *MMWR Weekly*. 2022;71:703–8.
  37. Wai AKC, Wong CKH, Wong JYH, Xiong X, Chu OCK, Wong MS, et al. Changes in emergency department visits, diagnostic groups, and 28-day mortality associated with the COVID-19 pandemic: a territory-wide, retrospective, cohort study. *Ann Emerg Med*. 2022;79(2):148–57.
  38. Marshall AD, Leach JP, Mackay D, Heath CA. The impact of the COVID-19 pandemic on a cohort of adults with epilepsy. *Seizure-Eur J Epilep*. 2023;111:191–5.
  39. Mbizvo GK, Schnier C, Ramsay J, Duncan SE, Chin RF. Epilepsy-related mortality during the COVID-19 pandemic: a nationwide study of routine Scottish data. *Seizure*. 2023;110:160–8.

## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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