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**Article:**

Jarvis, S., Parslow, R.C., Hewitt, C. et al. (2 more authors) (2020) GPs' role in caring for children and young people with life-limiting conditions: a retrospective cohort study. *British Journal of General Practice*, 70 (693). e221-e229. ISSN 0960-1643

<https://doi.org/10.3399/bjgp20x708233>

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## GPs' role in caring for children and young people with life-limiting conditions:

a retrospective cohort study

### Abstract

#### Background

GPs are rarely actively involved in healthcare provision for children and young people (CYP) with life-limiting conditions (LLCs). This raises problems when these children develop minor illness or require management of other chronic diseases.

#### Aim

To investigate the association between GP attendance patterns and hospital urgent and emergency care use.

#### Design and setting

Retrospective cohort study using a primary care data source (Clinical Practice Research Datalink) in England. The cohort numbered 19 888.

#### Method

CYP aged 0–25 years with an LLC were identified using Read codes (primary care) or *International Classification of Diseases 10<sup>th</sup> Revision* (ICD-10) codes (secondary care). Emergency inpatient admissions and accident and emergency (A&E) attendances were separately analysed using multivariable, two-level random intercept negative binomial models with key variables of consistency and regularity of GP attendances.

#### Results

Face-to-face GP surgery consultations reduced, from a mean of 7.12 per person year in 2000 to 4.43 in 2015. Those consulting the GP less regularly had 15% (95% confidence interval [CI] = 10% to 20%) more emergency admissions and 5% more A&E visits (95% CI = 1% to 10%) than those with more regular consultations. CYP who had greater consistency of GP seen had 10% (95% CI = 6% to 14%) fewer A&E attendances but no significant difference in emergency inpatient admissions than those with lower consistency.

#### Conclusion

There is an association between GP attendance patterns and use of urgent secondary care for CYP with LLCs, with less regular GP attendance associated with higher urgent secondary healthcare use. This is an important area for further investigation and warrants the attention of policymakers and GPs, as the number of CYP with LLCs living in the community rises.

#### Keywords

child; continuity of care; emergency healthcare use; general practice; life-limiting condition; primary health care.

### INTRODUCTION

There are more than 40 000 children and young people (CYP) living with a life-limiting condition (LLC) in England.<sup>1,2</sup> Almost 400 diagnoses are considered as life limiting in children.<sup>3</sup> These include conditions for which there is no reasonable hope of cure and from which the CYP will die, and conditions for which curative treatment may be feasible but can fail, such as cancer or heart failure. Severe static neurodisability, such as cerebral palsy and severe congenital anomalies, are also included.

CYP with an LLC typically have complex healthcare needs, and during childhood tertiary or community paediatricians provide their care. The role of GPs in their care is an area that requires further consideration, particularly for children with cancer.<sup>4</sup> Regional analyses in the West Midlands estimated that the numbers of CYP with an LLC may be almost double the number of GPs.<sup>5</sup> However, GPs are rarely actively involved in the provision of health care to CYP with LLCs. This raises particular problems when these CYP develop minor childhood illness, require primary care review, or have other chronic conditions, such as asthma, that require regular medication.<sup>6</sup> Furthermore, many of these CYP are transferred back to the GP to coordinate their care when they become too old for paediatric services.<sup>7</sup>

There is evidence, from the US, of high numbers of hospital admissions for this population,<sup>8,9</sup> and a lack of confidence among general physicians in caring for them;<sup>10</sup> however, there is no UK-based research that has quantified the role of the GP in the care of CYP with LLCs. Increasing GP understanding of these conditions and involvement in the care of CYP with complex needs is being referred to in national strategy and guidance documents,<sup>11,12</sup> and by the organisations that campaign for and support these families.<sup>13</sup>

This study aimed to assess the association between face-to-face GP surgery consultations and emergency healthcare use in CYP with an LLC in a nationally representative data source.

### Patient and public involvement

Parents of CYP with an LLC identified this topic area<sup>14</sup> as they felt that their GP lacked sufficient knowledge of their child's condition, and, therefore, always contacted the hospital or went to A&E rather than their GP. They also described difficulties with the transition process to adult services, mainly around lack of coordination of care.

### METHOD

#### Participants

*Datasets.* All Clinical Practice Research Datalink (CPRD)<sup>15</sup> Gold primary care (2000–

**S Jarvis**, PhD, research fellow, Department of Health Sciences, University of York, York, and Martin House Research Centre, York. **RC Parslow**, PhD, senior lecturer, Martin House Research Centre, York, and Leeds Institute of Cardiovascular and Metabolic Medicine, University of Leeds, Leeds. **C Hewitt**, PhD, professor, Department of Health Sciences, University of York, York. **S Mitchell**, MSc, FRCGP, GP, Warwick Medical School, Coventry. **LK Fraser**, PhD, senior lecturer, Department of Health Sciences, University of York, York, and Martin House Research Centre, York.

#### Address for correspondence

Lorna Fraser, Department of Health Sciences, Area 2 Seebohm Rowntree Building, Heslington, York YO10 5DD, UK.

**Email:** lorna.fraser@york.ac.uk

**Submitted:** 31 July 2019; **Editor's response:** 10 September 2019; **final acceptance:** 9 October 2019.

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This is the full-length article (published online 11 Feb 2020) of an abridged version published in print. Cite this version as: **Br J Gen Pract 2020**; DOI: <https://doi.org/10.3399/bjgp20X708233>

## How this fits in

Children with life-limiting conditions (LLCs) are high users of health care. GPs have a key role in the management of patients with LLCs and complexity, including children. However, children's health care is often specialist led and GPs are less involved. Primary care studies in adult populations demonstrate the value of continuity of care. This has been compromised by changes in the organisation of GP services, including out-of-hours provision and GP contracting. This study suggests that the consistent and regular involvement of a GP in the care of children with an LLC is associated with reduced emergency secondary care use. This is the first study of its type to examine the potential impact of regular GP attendance and continuity of care with a GP for paediatric patients with LLCs.

2015), Hospital Episodes Statistics Admitted Patient Care (HES APC) (2000–2015), and accident and emergency (A&E, 1 April 2007 to 31 March 2015) records were requested from CPRD for individuals matching the cohort definition (see Supplementary Figure S1). The datasets were linked by CPRD using NHS number, sex, date of birth, and postcode.<sup>15</sup> Denominator population data were provided by CPRD.

**Cohort identification.** A Read code framework was developed using similar methods to a previously developed *International Classification of Diseases 10th Revision (ICD-10)*<sup>16</sup> coding framework<sup>2</sup> for identifying LLCs. A retrospective cohort

was constructed including all CYP (aged 0–25 years) with an LLC recorded in either their primary care record (Read code) or hospital episodes admitted patient care dataset (HES; ICD-10 codes; 2000–2015).

**Data management.** Sex and year of birth (and month of birth if <16 years old) were provided in CPRD data. Deprivation category (split into five groups using the Index of Multiple Deprivation 2010, based on the last known address of the individual<sup>17</sup>) was provided as linked data. Ethnic group (11 categories: black African, black Caribbean, black other, Chinese, Bangladeshi, Indian, Pakistani, other Asian, white, mixed, or other)<sup>18</sup> was recorded in the linked HES data; where an individual had more than one ethnic group provided, it was set by CPRD to the most commonly recorded value, excluding unknown.<sup>15</sup>

The LLC diagnoses were assigned into 11 diagnostic groups: circulatory, congenital, gastrointestinal, genitourinary, haematology, metabolic, neurology, oncology, perinatal, respiratory, and other. The commonest diagnostic group in the individual's records was assigned as the main diagnostic group. If there was a tie then older records were progressively ignored until there was a most common diagnostic group.

## Statistical analysis

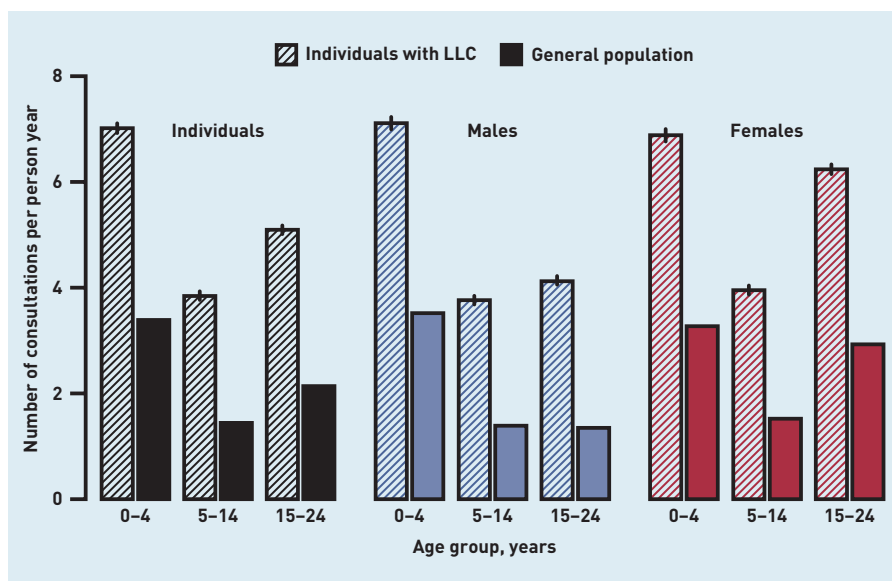
Data analyses were performed using Stata version 15.

**GP attendance.** The number of GP attendances (face-to-face surgery consultations) per person were calculated by year, sex, ethnic group, age group, main diagnostic group, and deprivation category. These were compared with previously published levels in the general population,<sup>19</sup> and confidence intervals (CIs) for the cohort figures were determined by bootstrapping with 10 000 samples.

**Consistency of GP seen.** Consistency of GP seen was determined for each CYP each year by calculating the usual provider of care (UPC) index (the proportion of a patient's face-to-face surgery consultations with the most regularly seen GP).<sup>20</sup> A minimum of two GP attendances in 1 year were required for this value to be calculated.

**Regularity of GP attendance.** Regularity of GP attendance was determined for each cohort member each year by calculating the mean and standard deviation of the gap between GP attendances (including

**Figure 1. Face-to-face GP consultations per cohort member per year compared with those for the general population in financial year 2013/2014.<sup>a</sup>**  
<sup>a</sup>Vertical lines are bootstrapped 95% confidence intervals for the cohort. LLC = life-limiting condition.



attendances in the year and the gap from the last attendance of the previous year, if there was one, to the first attendance of the year under consideration). The coefficient of variation (the standard deviation of consultation gaps divided by the mean of consultation gaps<sup>21</sup>) was used to describe regularity. A minimum of two gaps between GP attendances (including the gap from last attendance of the previous year) were required for this value to be calculated.

**Outcome measures.** The number of emergency inpatient admissions and A&E attendances was calculated per individual by year, sex, ethnic group, age group, main diagnostic group, and deprivation category, and was compared with levels in the general population.<sup>22,23</sup> CIs for the cohort figures were determined by bootstrapping with 10 000 samples.

**Multivariable models.** Four multivariable models were undertaken, two for each outcome measure (emergency inpatient admissions and A&E attendances). All used a two-level random intercept (to account for clustering at individual patient level) negative binomial model because of overdispersion of these data.<sup>24</sup>

The independent variable of interest in the first pair of models was UPC index at level 1 (per person per year). This was split into three categories with: less than half of appointments with the most commonly seen GP (that is, there was no 'normally seen' GP), half or more but less than two-thirds of appointments with the most commonly seen GP, and two-thirds or more of appointments with the most commonly seen GP. The other variables were: at level 1, age group; at level 2 (per person), sex, ethnic group, deprivation category, and main diagnostic group. The variables included have been shown to predict levels of unplanned care for children with complex conditions.<sup>25</sup> Time at risk was included in the model. In the second pair of models, the independent variable of interest was coefficient of variation at level 1 (per person per year). This was split into four categories with approximately equal numbers of cohort members in each. The other variables were the same as for the first pair of models.

## RESULTS

There were 19 888 individuals identified with an LLC in this cohort, rising per year from 2293 in 2000 to a high of 9055 in 2013 (see Supplementary Table S1). There were more males (53.7%,  $n = 10\ 666$ ) than females (46.3%,  $n = 9222$ ) and the predominant

ethnic group was white (81.6%). The commonest main diagnostic groups were congenital (33.6%,  $n = 6741$ ) and oncology (20.2%,  $n = 4051$ ). More cohort members lived in areas of highest deprivation (20.7%,  $n = 4222$ ) than in areas of lowest deprivation (18.9%,  $n = 3774$ ).

### Missing data

There were no missing data for sex, month, and year of birth. Nineteen individuals had unknown deprivation category (<1%) and 845 had unknown ethnic group (4.2%).

### GP attendance

The number of face-to-face GP surgery consultations per person year reduced over the study period, from a mean of 7.12 per person year in 2000 to 4.43 in 2015 (see Supplementary Table S1). Those <1 year old had the most consultations per year; rates decreased through early years of age to a low at 11 years of age before increasing (see Supplementary Figure S2). CYP with an LLC had more GP attendances than members of the general population in the same age groups in 2013/2014 (Figure 1).

**Consistency of GP seen.** Mean UPC index increased from age 1 year to age 10 years, before plateauing between 0.52 and 0.55 (Figure 2a). Between 29% and 44% of cohort members in each year did not have a UPC index calculated because of having <2 consultations in the year.

**Regularity of GP attendance.** Children aged <1 year had the greatest regularity of face-to-face consultations (mean coefficient of variation 0.82; median 0.81, Figure 2b). Between 37% and 46% of cohort members in each year did not have a coefficient of variation calculated because of having <2 gaps between consultations in the year.

### Emergency inpatient admission

The mean number of emergency inpatient admissions per person year decreased over the study period, from 0.94 in 2000 to 0.55 in 2015 (see Supplementary Table S1). Cohort members had more emergency inpatient admissions than the general population, across all groups from age 0–25 years (Figure 3a).

**Multivariable models.** The UPC index was not significantly associated with incidence of emergency inpatient admission (Table 1). Children aged <1 year had the most emergency admissions: 3.52 (95% CI = 3.33 to 3.72) times as many as 1–5-year-olds. Emergency admissions decreased with

**Table 1. Associations between consistency of GP seen and emergency inpatient admissions and A&E attendances for the cohort: multilevel random intercept negative binomial regression models for years 2000–2015 (inpatient admissions) and 2008–2015 (A&E attendances)<sup>a</sup>**

	Emergency inpatient admission			A&E visit				
	Incidence rate ratio	95% CI		P-value	Incidence rate ratio	95% CI		P-value
<b>Usual provider of care index</b>								
<1/2	1 (ref)				1 (ref)			
≥1/2, <2/3	1.01	0.98	1.05	0.40	0.95	0.91	0.98	<0.01
≥2/3	1.03	0.99	1.07	0.18	0.90	0.86	0.94	<0.01
Undefined (<2 consultations in year)	1.02	0.98	1.06	0.35	0.80	0.76	0.83	<0.01
<b>No. of consultations in year</b>								
Year	1.04	1.03	1.04	<0.01	1.03	1.03	1.03	<0.01
Year	0.96	0.95	0.96	<0.01	1.03	1.03	1.04	<0.01
<b>Sex</b>								
Male	1 (ref)				1 (ref)			
Female	1.03	0.99	1.07	0.20	0.94	0.91	0.98	0.01
<b>Ethnic group</b>								
Black African	1.12	0.96	1.31	0.15	1.06	0.92	1.22	0.45
Black Caribbean	1.30	1.04	1.63	0.02	1.50	1.19	1.89	<0.01
Black other	1.38	1.07	1.77	0.01	1.49	1.19	1.88	<0.01
Bangladeshi	1.16	0.84	1.60	0.38	0.91	0.68	1.23	0.56
Chinese	0.83	0.56	1.23	0.37	1.05	0.72	1.54	0.80
Indian	0.86	0.73	1.01	0.07	0.93	0.79	1.08	0.34
Pakistani	1.07	0.94	1.22	0.31	0.99	0.87	1.12	0.88
Other Asian	1.35	1.13	1.61	<0.01	1.24	1.05	1.46	0.01
White	1 (ref)				1 (ref)			
Mixed	1.24	1.08	1.42	<0.01	1.16	1.02	1.32	0.02
Other	1.09	0.93	1.27	0.30	1.19	1.03	1.38	0.02
<b>Age group, years</b>								
<1	3.52	3.33	3.72	<0.01	1.94	1.78	2.10	<0.01
1–5	1 (ref)				1 (ref)			
6–10	0.47	0.45	0.49	<0.01	0.66	0.63	0.69	<0.01
11–15	0.45	0.42	0.47	<0.01	0.70	0.66	0.74	<0.01
16–20	0.44	0.42	0.46	<0.01	0.73	0.69	0.77	<0.01
21–25	0.44	0.41	0.46	<0.01	0.81	0.76	0.85	<0.01
<b>Main diagnostic group</b>								
Circulatory	1.79	1.56	2.06	<0.01	1.22	1.06	1.39	0.01
Congenital	1 (ref)				1 (ref)			
Gastrointestinal	2.82	2.38	3.35	<0.01	1.32	1.12	1.55	<0.01
Genitourinary	3.07	2.79	3.38	<0.01	1.65	1.50	1.82	<0.01
Haematology	1.85	1.68	2.04	<0.01	1.19	1.08	1.31	<0.01
Metabolic	1.99	1.79	2.21	<0.01	1.34	1.20	1.49	<0.01
Neurology	1.71	1.60	1.82	<0.01	1.33	1.25	1.41	<0.01
Oncology	1.95	1.83	2.08	<0.01	1.02	0.96	1.08	0.58
Perinatal	0.88	0.75	1.04	0.14	0.96	0.83	1.12	0.64
Respiratory	2.29	2.12	2.46	<0.01	1.28	1.19	1.38	<0.01
Other	1.53	1.23	1.90	<0.01	1.22	1.00	1.49	0.05
<b>Deprivation category</b>								
1 (least deprived)	0.72	0.67	0.77	<0.01	0.63	0.59	0.67	<0.01
2	0.75	0.70	0.80	<0.01	0.66	0.62	0.71	<0.01
3	0.82	0.77	0.88	<0.01	0.78	0.73	0.83	<0.01
4	0.95	0.89	1.01	0.10	0.86	0.80	0.91	<0.01
5 (most deprived)	1 (ref)				1 (ref)			
<b>Model parameters</b>								
Degrees of freedom	38				38			
Log likelihood	-91 308.9				-63 513.0			
BIC	183 056.2				127 447.1			

<sup>a</sup>No. of consultations in year\* and Year\* are continuous variables — incident rate ratios indicate the expected proportional change in outcome rate for one additional consultation and 1 year later in time. A&E = accident and emergency. BIC = Bayesian information criterion.

Figure 2. (a) Consistency of GP seen (usual provider of care index) for cohort members with  $\geq 2$  face-to-face GP consultations in a year and (b) variability of gaps between GP consultations (coefficient of variation) for cohort members with  $\geq 2$  gaps between consultations defined in a year.

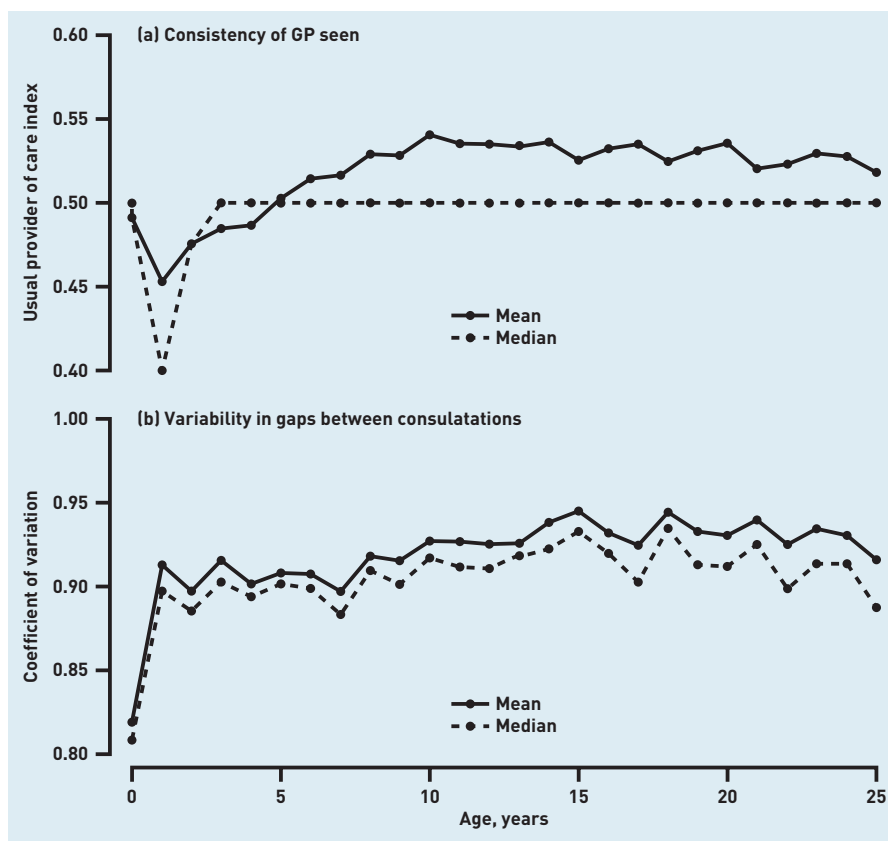
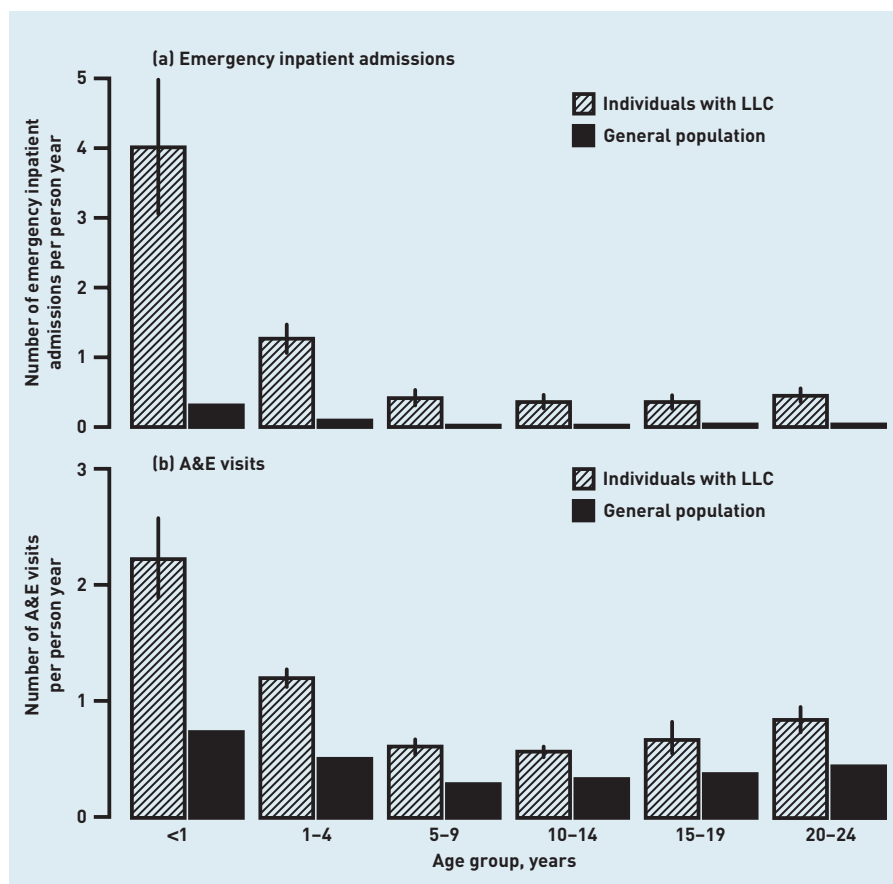


Figure 3. Emergency care use for cohort members compared with the general population by age group. (a) Emergency inpatient admissions in 2015; (b) A&E visits in 2013–2015. Vertical lines are bootstrapped 95% confidence intervals for the cohort. A&E = accident and emergency, LLC = life-limiting condition.



increasing age. Incidence of emergency admissions differed by main diagnostic group, with those with a genitourinary diagnosis having most: 3.07 (95% CI = 2.79 to 3.38) times as many as those with a congenital main diagnosis. There was a gradient by deprivation category, with the least deprived having 28% (95% CI = 23% to 33%) fewer emergency admissions than the most deprived.

Less regular GP consultations were associated with more emergency admissions, with those having most variation having 15% (95% CI = 10% to 20%) more emergency admissions than those with least variation (Table 2).

Those children with too few GP consultations to be assigned a coefficient of variation also had significantly more emergency admissions (by 24%; 95% CI = 19% to 29%). The other variables were similar to the previous model.

#### A&E attendances

A&E attendances per person year increased over the study period, from 0.60 in 2008 to 0.76 in 2015 (see Supplementary Table S1). Cohort members had more A&E attendances than the general population, across all age groups (Figure 3b).

**Table 2. Associations between regularity of GP appointments and emergency inpatient admissions and A&E attendances for the cohort: multilevel random intercept negative binomial regression models for all years 2000–2015 (inpatient admissions) and 2008–2015 (A&E attendances)<sup>a</sup>**

	Emergency inpatient admission				A&E visit			
	Incidence rate ratio	95% CI		P-value	Incidence rate ratio	95% CI		P-value
<b>Coefficient of variation for gaps between consultations</b>								
<0.75	1 (ref)				1 (ref)			
≥0.75, <0.95	1.05	1.01	1.09	0.01	1.01	0.97	1.05	0.63
≥0.95, <1.20	1.07	1.03	1.12	<0.01	1.04	0.99	1.08	0.10
≥1.20	1.15	1.10	1.20	<0.01	1.05	1.01	1.10	0.03
Undefined (<2 consultation gaps in year)	1.24	1.19	1.29	<0.01	0.91	0.88	0.95	<0.01
<b>No. of consultations in year</b>	1.04	1.04	1.04	<0.01	1.03	1.03	1.03	<0.01
<b>Year</b>	0.96	0.95	0.96	<0.01	1.03	1.03	1.04	<0.01
<b>Sex</b>								
Male	1 (ref)				1 (ref)			
Female	1.04	1.00	1.08	0.08	0.95	0.91	0.99	0.02
<b>Ethnic group</b>								
Black African	1.11	0.95	1.30	0.17	1.06	0.92	1.22	0.43
Black Caribbean	1.31	1.04	1.64	0.02	1.49	1.19	1.88	<0.01
Black other	1.39	1.09	1.79	0.01	1.50	1.19	1.89	<0.01
Bangladeshi	1.16	0.84	1.61	0.37	0.92	0.68	1.24	0.58
Chinese	0.83	0.56	1.23	0.35	1.06	0.72	1.55	0.78
Indian	0.86	0.73	1.01	0.07	0.93	0.79	1.08	0.34
Pakistani	1.07	0.94	1.22	0.30	0.99	0.87	1.13	0.89
Other Asian	1.36	1.14	1.61	<0.01	1.24	1.06	1.46	0.01
White	1 (ref)				1 (ref)			
Mixed	1.24	1.08	1.42	<0.01	1.16	1.02	1.32	0.02
Other	1.08	0.92	1.27	0.33	1.19	1.03	1.38	0.02
<b>Age group, years</b>								
<1	3.48	3.29	3.68	<0.01	1.94	1.79	2.11	<0.01
1–5	1 (ref)				1 (ref)			
6–10	0.46	0.45	0.48	<0.01	0.65	0.62	0.68	<0.01
11–15	0.44	0.42	0.46	<0.01	0.69	0.65	0.73	<0.01
16–20	0.44	0.41	0.46	<0.01	0.72	0.68	0.76	<0.01
21–25	0.43	0.41	0.46	<0.01	0.80	0.75	0.84	<0.01
<b>Main diagnostic group</b>								
Circulatory	1.79	1.56	2.06	<0.01	1.22	1.06	1.39	0.01
Congenital	1 (ref)				1 (ref)			
Gastrointestinal	2.80	2.36	3.32	<0.01	1.32	1.12	1.56	<0.01
Genitourinary	3.05	2.78	3.36	<0.01	1.65	1.51	1.82	<0.01
Haematology	1.84	1.67	2.03	<0.01	1.19	1.08	1.31	<0.01
Metabolic	1.97	1.78	2.19	<0.01	1.34	1.20	1.49	<0.01
Neurology	1.70	1.60	1.81	<0.01	1.33	1.25	1.41	<0.01
Oncology	1.93	1.82	2.06	<0.01	1.01	0.95	1.08	0.68
Perinatal	0.89	0.76	1.05	0.17	0.97	0.83	1.12	0.65
Respiratory	2.29	2.12	2.47	<0.01	1.29	1.19	1.39	<0.01
Other	1.53	1.23	1.90	<0.01	1.23	1.01	1.50	0.04
<b>Deprivation category</b>								
1 (least deprived)	0.72	0.67	0.77	<0.01	0.63	0.59	0.67	<0.01
2	0.75	0.70	0.80	<0.01	0.66	0.62	0.71	<0.01
3	0.82	0.77	0.88	<0.01	0.78	0.73	0.83	<0.01
4	0.95	0.89	1.01	0.10	0.86	0.80	0.91	<0.01
5 (most deprived)	1 (ref)				1 (ref)			
<b>Model parameters</b>								
Degrees of freedom	39				39			
Log likelihood	-91 244.5				-63 549.9			
BIC	182 939.0				127 531.9			

<sup>a</sup> 'No. of consultations in year' and 'Year' are continuous variables — incident rate ratios indicate the expected proportional change in outcome rate for one additional consultation and 1 year later in time. A&E = accident and emergency. BIC = Bayesian information criterion.

**Multivariable models.** Children with an LLC who saw the same GP for two-thirds or more of visits had 10% (95% CI = 6% to 14%) fewer A&E attendances than those seeing the same GP for under half of attendances (Table 1). Children <1 year old had most A&E attendances: 1.94 (95% CI = 1.78 to 2.10) times as many as 1–5-year-olds. Numbers of A&E attendances varied between main diagnostic groups, with those with a genitourinary main diagnosis having most: 1.65 (95% CI = 1.50 to 1.82) times as many as those with a congenital main diagnosis. There was a gradient by deprivation category, with the least deprived having 37% (95% CI = 33% to 41%) fewer A&E attendances than the most deprived.

Children with less regular GP consultations also had increased numbers of A&E attendances, with those with most variation having 5% more (95% CI = 1% to 10%) compared with those with most regular GP consultations (Table 2). The group with too few GP visits to have a coefficient of variation assigned had 9% fewer A&E visits (95% CI = 5% to 12%). The other variables were similar to the previous model.

## DISCUSSION

### Summary

Overall, the number of face-to-face consultations with a GP had decreased for these children and their families over the period from 2000 to 2015. However, CYP with LLCs who consulted their GP more regularly had fewer emergency hospital admissions and A&E attendances than those with less regular consultations. CYP with an LLC who saw the same GP more often had fewer A&E attendances than those who had less consistency.

### Strengths and limitations

This study used a nationally representative sample of primary and secondary care data with robust and transparent statistical techniques. The study is limited by the observational study design and therefore causation cannot be assessed. There are no measures of disease severity or complexity in these data.

The UPC index measure has limitations. Any individuals with <2 consultations per year do not have UPC defined and the group of individuals with two consultations per year have possible values of only 0.5 or 1.0, with 0.5 falling in the middle group in the analyses presented here. This was because including 0.5 in the middle group seemed appropriate for those with a larger number of consultations (for example, for those

with two out of four consultations with the same GP). Sensitivity analyses were used with (1) a 2-year period for the outcomes and UPC calculations and (2) requiring three consultations per year for UPC to be defined. Similar associations between UPC and the outcomes were observed in these analyses and they present their own problems, in case (a) the <1-year age group, which differs from other groups, is not defined consistently as individuals cannot be in that age group for 2 years, and in case (b) the group with defined UPC reduces in size.

### Comparison with existing literature

There are no comparable studies assessing the regularity of GP visits. However, a US study has shown that children with medical complexity often did not have their annual well child checks, but those who did had reduced hospital admissions.<sup>26</sup> There are similar results for adult patients, where higher continuity of care by GPs has been associated with fewer emergency department attendances<sup>27</sup> and lower mortality.<sup>28</sup>

### Implications for research and practice

The 2012 Chief Medical Officer's report<sup>11</sup> recommended that CYP with long-term conditions should have a named GP who coordinates their care. Furthermore, CYP and families have expressed preferences for care to be provided at home<sup>29</sup> and there is policy emphasis on providing care at home and avoiding hospital admissions.<sup>30</sup> The findings of this study highlight the role of GPs and primary care teams as an important area for consideration in the care of this population. Research into the relationship between GPs, CYP with LLCs, and their family members would be of value to better understand these associations. Previous research has suggested that the response of GPs to care of CYP with palliative care needs in cancer can be highly variable, with issues of training and time resource for GPs.<sup>6,31</sup>

These study findings show that the GP attendance rate for CYP with LLCs is decreasing. This may relate to difficulty accessing GP services in a timely fashion and the specialist-led nature of their care. Further consideration of the role and value of GPs and primary care teams in the management of this population is warranted as the number of CYP with LLCs is rising, and more of these CYP are living into young adulthood than ever before. The GP can become the main healthcare provider when these young people are discharged



from paediatric services. GPs are also in a unique position as a healthcare provider for the whole family,<sup>32</sup> which includes bereavement<sup>6,33</sup> if a CYP dies.

Opportunities to see more of CYP with LLCs in primary care already exist, with chronic disease reviews, learning disability checks, and quality improvement initiatives.<sup>34</sup> This study highlights the potential importance of GP continuity of care for CYP with LLCs and their families, alongside care provided by specialist paediatricians. The provision of truly integrated care in the community for CYP with LLCs requires further consideration. Communication between paediatricians and their primary

care colleagues would need to improve, including sharing electronic records. Understanding the role that each member of the integrated team can play in the health care of the CYP is also key and worthy of consideration as both the primary care and paediatric workforce requires innovation.<sup>35</sup> In other countries, paediatricians work in primary care providing care to these children in combination with specialists.<sup>36</sup> The evaluation of initiatives in the UK to integrate primary and secondary care for children, including those with chronic or complex conditions, is currently underway (<https://www.cyphp.org/>).

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### Funding

This research was undertaken as part of the Martin House Research Centre, which is supported by Martin House Hospice Care for Children and Young People and the University of York. Stuart Jarvis is funded by a National Institute for Health Research (NIHR) Doctoral Research Fellowship (award: DRF-2018-11-ST2-013) for this research project. Lorna Fraser is funded by an NIHR Career Development Fellowship (award: CDF-2018-11-ST2-002) for this research project. This publication presents independent research funded by the NIHR. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

### Ethical approval

Data access and protocol were approved by the Independent Scientific Advisory Committee (ref: 16\_277R). CPRD has ethical approval for observational research using pseudonymised data.

### Provenance

Freely submitted; externally peer reviewed.

### Competing interests

The authors have declared no competing interests.

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