

This is a repository copy of *Outpatient appointment non-attendance and unplanned health care for children and young people with neurological conditions: a retrospective cohort study*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/134965/>

Version: Accepted Version

Article:

Jarvis, Stuart William orcid.org/0000-0001-8447-0306, Livingston, John, Childs, Anne-Marie et al. (1 more author) (2018) Outpatient appointment non-attendance and unplanned health care for children and young people with neurological conditions: a retrospective cohort study. *Developmental Medicine and Child Neurology*. pp. 1-7. ISSN 1469-8749

<https://doi.org/10.1111/dmcn.14070>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

Non-attendance at outpatient appointments is associated with increased unplanned healthcare for children and young people with neurological conditions

Stuart Jarvis¹, John Livingston², Anne-Marie Childs², Lorna Fraser¹

¹ *Department of Health Sciences, University of York, United Kingdom*

² *Department of Paediatric Neurology, Leeds Children's Hospital, United Kingdom*

Corresponding Author:

Dr Lorna K Fraser

lorna.fraser@york.ac.uk

Department of Health Sciences

Area 2, Seebohm Rowntree Building

University of York

Heslington

YORK

YO10 5DD

Tel: 01904 321889

Abstract

Aim

To test the hypothesis that children and young people with neurological conditions who missed outpatient appointments have more emergency inpatient admissions and accident and emergency (A&E) visits than those who missed none.

Method

Retrospective cohort of 0-19 year olds with neurological conditions, identified from routine hospital data in England from 1 April 2003 to 31 March 2015 using an International Classification of Diseases, Version 10, coding framework. Counts of emergency inpatient admissions and A&E visits per person per year were modelled (random intercept negative binomial regression) with outpatient attendance the independent variable of interest.

Results

The cohort numbered 524,613 individuals. Those who missed outpatient appointments had 19% (95% CI 18-19%) more emergency inpatient admissions and 16% (95% CI 15-17%) more A&E visits per year than those who missed none. 'Did not attends' had a larger increase in unplanned care than patient or provider cancellations. If no appointments were missed, the models predict there would have been 107,000 fewer A&E visits from 2007/08 to 2014/15 and 104,000 fewer emergency inpatient admissions from 2003/04 to 2014/15.

Interpretation

Missed outpatient appointments were associated with increased unplanned care. Improving outpatient attendance may have the potential to reduce emergency inpatient admissions and A&E visits.

What this paper adds

- Missed outpatient appointments are associated with increased unplanned care
- Both emergency inpatient admissions and accident and emergency visits are increased
- 'Did not attends' are more strongly associated with unplanned care than cancellations

Missed outpatient appointments, whether not attended or cancelled by the provider, represent a cost to the NHS,¹ waste staff time or cause patients to seek other care, such as visiting accident and emergency (A&E) centres. They can also have consequences for patients' future care as those not attending appointments may ultimately be discharged from care, although this should not happen automatically after a single non-attendance.² There are many potential reasons for non-attendance, including chaotic family circumstances, competing priorities and barriers to accessing services.³⁻⁵ Various approaches have been used to try and reduce non-attendance, with some positive results,⁵ but rates remain high.¹

Neurological conditions (those that, depending on severity, may require an individual to be seen by a paediatric neurologist e.g. epilepsy, cerebral palsy, Duchenne muscular dystrophy, Batten disease) are a major and increasing⁶ cause of hospitalisation among children and young people, accounting for 5-10% of their admissions, around 20% of costs and 14% of bed days in the United States.^{6,7} In the UK, neurological conditions account for 30-40% of deaths in children aged 1-19 years,⁸ 8.8% of bed days for 0-14 year olds⁹ and are the third commonest primary reason for Paediatric Intensive Care Unit admission.¹⁰ Children and young people with neurological conditions often have scheduled outpatient appointments to manage their condition and any comorbidities; good management of conditions should reduce A&E visits and emergency hospital admissions.

This study aimed to test the hypothesis that there is an association between missed outpatient appointments and unplanned healthcare use among children and young people with neurological conditions. A secondary aim was to explore whether any association differed between modes of non-attendance: provider cancellation of appointment (PCA); patient could not attend (CNA – patient cancelled appointment); and patient did not attend (DNA – patient did not cancel but did not attend).

Methods

Participants

Cohort identification

An ICD10¹¹ coding framework for neurological conditions (see supplement) was developed with a consultant paediatric neurologist (JL). A retrospective cohort was constructed, including all individuals aged 0-19 years with at least one episode in the Hospital Episode Statistics (HES) Admitted Patient Care (APC) dataset between 1/4/2003 and 31/3/2015 with one of the framework diagnostic codes. Individuals were included from the first inpatient admission with one of the framework diagnostic codes and removed when 20 years old or at date of death (if known, from the APC records, to have died).

Datasets

All HES APC (1/4/2003-31/3/2015), A&E (1/4/2007-31/3/2015) and outpatient (1/4/2003-31/3/2015) records were requested from NHS Digital for individuals matching the cohort definition (Figure 1). Data access was granted by NHS Digital (ref: NIC-371031-B8K6D). Ethical approval was not required for the use of pseudonymised data. The datasets were linked using patient HESID.¹²

Data management

The APC data were preferred for determination of demographics as they were the most complete. Information from the A&E and outpatient datasets was used when APC data were missing.

In each record, ethnicity was assigned to one of eight groups: White, Indian, Pakistani, Bangladeshi, Black, Chinese, Mixed or Other. Each individual's ethnic group was set as the most commonly recorded, excluding missing values. Gender was set as the most commonly recorded, excluding missing.

For variables that could change over time (age, Government Office Region of residence (GOR), and deprivation score¹³), the first recorded value was used in each financial year. Deprivation scores were grouped into five categories from 1 (most deprived) to 5 (least deprived), with approximately 20% of the population of England in each, using published populations¹⁴ and Index of Multiple Deprivation 2004¹⁵ rankings¹⁶ for Lower Super Output Areas.

Based on ICD10 chapters, seven diagnostic groups were defined for the conditions included in the ICD10 coding framework (see supplement): malignant neoplasms (C), benign neoplasms (D), metabolic conditions (E), mental or behavioural conditions (F), nervous system conditions (G), congenital conditions (Q) and other conditions (R). Each record was assigned one or more diagnostic groups based on diagnoses present. The commonest diagnostic group in the individual's records over the study period was assigned as the main diagnostic group. If there was no commonest group, the commonest group associated with primary diagnoses was used. If there was still no commonest group, older records were progressively ignored (assuming that diagnoses become more certain over time) until there was a commonest group.

Outpatient attendance was categorised (successful; PCA; CNA; DNA) for each appointment; appointments scheduled during an inpatient admission were excluded.

Statistical analysis

Data analyses were performed using Stata V.14 (StataCorp. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP, 2015).

Outpatient attendance

Outpatient attendance and modes of non-attendance were tabulated by year, by gender, ethnic group, age group, main diagnostic group, deprivation category and GOR.

Emergency inpatient admissions

Emergency inpatient admissions (for any reason) were tabulated over the whole period by gender, ethnic group, age group, main diagnostic group, deprivation category and GOR and, each year, by category of outpatient attendance.

Numbers of emergency inpatient admissions per cohort member per year were analysed using a two level random intercept negative binomial model. The random intercept accounted for clustering in individuals (many individuals appeared in multiple years). A negative binomial model was used as the outcome were count data and over-dispersed.¹⁷ The independent variable of interest was outpatient attendance at level 1 (per person per year), categorical with three possible values: (i) attended all appointments, (ii) missed appointment(s) (for any reason) and (iii) no appointments. The other variables were, at level 1, age group, deprivation category and GOR; at level 2 (per

person), gender, ethnic group and main diagnostic group. The variables included have been shown to predict levels of unplanned care for children with complex conditions,¹⁸ except GOR included to explore geographical variations. Time at risk was included in the model.

A secondary analysis explored differences between modes of non-attendance for cohort members with at least one outpatient appointment in the year. The three level categorical independent variable for attendance was replaced with three independent binary variables, respectively indicating presence, 1, or absence, 0, of at least one CNA, DNA or PCA in the year. The count of attended outpatient appointments in the year was added as a possible proxy for condition severity. All other variables were unchanged.

Accident and Emergency visits

A&E visits (for any reason) were tabulated over the whole period by gender, ethnic group, age group, main diagnostic group, deprivation category, GOR and, each year, by category of outpatient attendance. The proportion of visits converting to inpatient admissions (those with an inpatient admission on the same day with either the A&E record showing transfer to inpatient admission or inpatient record showing admission from A&E) was also determined.

Numbers of A&E visits per year for each cohort member were analysed in the same way as emergency inpatient admissions in a two level random intercept negative binomial model, with the same independent variables. Due to potential overlap with the modelling of emergency inpatient admissions (some A&E visits result in an emergency inpatient admission) a sensitivity analysis was performed, modelling only the number of A&E visits not converting to inpatient admission.

A secondary analysis was completed to explore differences between modes of non-attendance and numbers of A&E visits, using the same independent variables as for emergency inpatient admissions.

Results

There were 524,613 cohort members in total, rising from 52,373 in 2003/04 to 298,332 in 2014/15 (Table 1). There were few missing data for gender (<0.05%), none for age group and GOR and in most years few for deprivation category. Ethnic group was unknown for 8.3% of cohort members in 2003/04, dropping to 1.5% in 2014/15. 0.5% of outpatient appointments had unknown outcome.

Outpatient attendance

There were over 12 million outpatient appointments over the study period; 9.4 million (77%) were successful (Table 1). There were 0.86 million PCAs (7% of total), 0.70 million CNAs (6%) and 1.2 million (10%) DNAs. Successful attendance dropped from 80.9% (2003/04) to 76.6% (2014/15), driven by increases in PCAs (4.2% in 2003/04; 8.2% in 2014/15) and CNAs (3.7% in 2003/04; 9.0% in 2014/15). DNAs fell, from 10.6% in 2003/04 to 9.0% in 2014/15.

Variations in outpatient attendance by cohort demographics and diagnoses are summarised in the supplement.

Emergency inpatient admission

Cohort members had 1.3 million emergency inpatient admissions over the study period (Table 1). These fell from 1.30 per person per year (2003/04) to 0.49 (2014/15).

Univariable analyses

Cohort members with complete outpatient attendance had fewer emergency inpatient admissions than those with missed appointments (2014/15: 0.36 per person per year versus 0.62, Table 2).

Those with no outpatient appointments had similar levels of emergency admissions to those with complete attendance (2014/15: 0.33). Rates of emergency inpatient admission per person per year were similar across the modes of outpatient non-attendance (Table 2).

Variations in emergency inpatient admissions with cohort demographics and diagnoses are discussed in the supplement.

Multivariable models

Missed appointments were associated with a 19% (95%CI 18-19%) increase in emergency inpatient admissions compared to complete attendance (Table 3). Those with no appointments also had more emergency admissions (by 17% compared to complete attendance).

Females had 13% more emergency admissions than males. Non-White cohort members generally had fewer emergency admissions than White cohort members, but those in the Pakistani ethnic group had 11% (95%CI 9-13%) more. Compared to 5 to 9 year olds, all other age groups had more emergency admissions (under 1 year olds: 5.30 times as many, 95%CI 5.25-5.34; 1 to 4 year olds 1.82 times, 95%CI 1.80-1.83; 10 to 14 year olds 1.12 times, 95%CI 1.12-1.13; 15 to 19 year olds 1.20 times, 95% CI 1.19-1.21). Compared to cohort members with nervous system conditions, those with malignant CNS tumours (by 66%, 95%CI 61-71%) and metabolic conditions (by 35%, 95%CI 31-39%) had more emergency admissions; those in other diagnostic groups had fewer, by 36% for benign CNS tumours, 13% for mental and behavioural conditions, 34% for congenital abnormalities and 33% for other conditions. The least deprived group had 11% (95%CI 10-12%) fewer emergency admissions than the most deprived. All GORs had similar or lower levels of emergency admissions compared to the North West (London had least, with 25% (95%CI 24-26%) fewer emergency admissions).

To put these differences in context, if no appointments had been missed and there is a causal relationship between missed outpatient appointments and emergency inpatient admissions, the model predicts there would have been over 104,000 (7%) fewer emergency inpatient admissions from 2003/04 to 2014/15.

When modes of outpatient non-attendance were included in the model (Table S2, supplement), a larger association was apparent for DNAs (16%, 95%CI 16-17%, more emergency admissions for those with DNAs than those without) than for PCAs (3%, 95%CI 3-4%) or CNAs (3%, 95%CI 2-4%).

A&E visits

Cohort members had 1.6 million A&E visits from 2007/08 to 2014/15. These increased from 0.75 per person per year in 2007/08 to 0.95 in 2014/15 (Table 1). A quarter of cohort A&E visits converted to inpatient admissions (Table S1, supplement). Under 1 year olds were more likely to be admitted than other age groups (41% of under 1 year olds visiting A&E were admitted).

Univariable analyses

Cohort members with complete outpatient attendance had fewer A&E visits than those with missed appointments (e.g. 2014/15: 0.76 per person per year versus 1.01, Table 2). Those with no outpatient appointments had more A&E visits (e.g. 2014/15: 1.27). Rates of A&E visits were similar

for cohort members with PCAs and CNAs (2014/15: 1.03 and 1.02, respectively) but higher for those with DNAs (2014/15: 1.12).

Variations in A&E visits with cohort demographics and diagnoses are discussed in the supplement.

Multivariable models

Missed appointments were associated with a 16% (95%CI 15-17%) increase in A&E visits compared to complete attendance (Table 3). Those with no outpatient appointments had more emergency admissions (by 71%, 95%CI 70-72%, compared to those with complete attendance).

Females had 3% more emergency admissions than males. The Indian (by 6%), Bangladeshi (by 6%) and Chinese (by 7%) ethnic groups had fewer A&E visits than White cohort members; other ethnic groups had similar levels. Under 1 year olds had 1.82 (95%CI 1.81-1.84) times more emergency admissions than 5 to 9 year olds. 1 to 4 year olds (1.37 times, 95%CI 1.37-1.38), 10 to 14 year olds (1.14 times, 95%CI 1.14-1.15) and 15 to 19 year olds (1.26 times, 95% CI 1.26-1.27) also had more emergency admissions. Cohort members in all other main diagnostic groups had fewer emergency admissions than those with nervous system conditions (fewest: congenital abnormalities, 31% lower). The least deprived group had 20% (95%CI 19-21%) fewer A&E visits than the most deprived. There were variations between Government Office Regions, with most regions having lower levels of A&E visits than the North West, by up to 19% (the South West). Cohort members in London had more A&E visits (by 10%, 95%CI 9-11%) than those in the North West.

Illustrating the size of these associations at the cohort level, the model predicts that, if all individuals with missed appointments had had complete attendance and there is a causal relationship between missed appointments and A&E attendances, there would have been over 107000 (7%) fewer A&E attendances from 2007/08 to 2014/15.

Restricting the model to A&E visits that did not convert to an inpatient admission, the associations were very similar (table S3, supplement) except that under 1 year olds were less different to other age groups (1.31, 95%CI 1.30-1.33 times as many visits as 5 to 9 year olds for A&E visits not converting to inpatient admissions, compared to 1.82, 95%CI 1.81-1.84 times more emergency admissions than 5 to 9 year olds for all A&E visits).

When modes of outpatient non-attendance were considered (table S2, supplement), a larger association was apparent for DNAs (13%, 95%CI 12-14%, more emergency admissions for those with DNAs than those without) than for PCAs (5%, 95%CI 4-6%) or CNAs (6%, 95%CI 5-6%).

Discussion

Children with neurology diagnoses who missed outpatient appointments had higher levels of emergency inpatient admissions (by 19%) and A&E visits (by 16%) compared to children who attended all their outpatient appointments. These associations were stronger for 'did not attend' than for 'could not attend' or 'provider cancelled' appointments. DNAs have multiple reasons including unpredictability in the condition causing non-attendance or patients/carers forgetting to attend, previously shown to be the most common reason in an adult neurological outpatient clinic.¹⁹ Within paediatric care, where attendance is dependent on carers bringing at least younger children to appointments, DNAs have been linked with chaotic family circumstances, which may be related to

severity of condition or poor compliance with treatment, but also with carer perceptions of need and practical barriers to attendance such as transportation.³ In short, DNAs may occur for a number of reasons, including forgetting the appointment or a last-minute decision not to attend due to competing priorities or barriers. DNAs may therefore differ from CNAs (where, by definition an advance decision is taken to not attend, possibly suggesting a carer's assessment of low need for the appointment in relation to other competing priorities) or PCAs (where hospitals may target cancellation to those considered most stable). Therefore, it is plausible that patients with DNAs may be at greater need of attendance than those with CNAs or PCAs and more likely to subsequently visit A&E or have an emergency inpatient admission.

Those with no outpatient appointments also had more emergency inpatient admissions and, to a greater extent, A&E visits than those with complete attendance: those without outpatient contact may be more likely to attend A&E with a deteriorating condition than address it through planned healthcare. Parents unfamiliar with outpatient services may misunderstand the role of A&E or there may be poor availability or accessibility of primary care services when they require medical assistance for their child.

The youngest and oldest cohort members received more unplanned care than 5 to 9 year olds and under 1 year olds had a higher conversion rate from A&E attendance to inpatient admission. For the very young, with less predictable condition trajectories, this may reflect increased caution among parents and healthcare professionals. For the older groups, it may reflect increased condition severity or other reasons, such as trauma. Teenage years are often the time when compliance with treatment, including epilepsy medications, decreases and risk taking behaviours such as alcohol use increase, potentially resulting in worse control of underlying neurological conditions. The oldest and youngest neurology patients are known to have the highest rates of hospitalisation.⁷

Children from most minority ethnic groups had less unplanned healthcare than the White cohort members, the main exception being the Pakistani ethnic group (10% higher incidence of emergency inpatient admission than White cohort members). This may reflect differing conditions within diagnostic groups or different healthcare seeking behaviours within these populations.²⁰

In the current study unplanned healthcare use was lowest in the least deprived group, similar to previous studies which have demonstrated greater numbers of A&E visits for more deprived households.^{21,22} This may reflect differences in access to alternatives, such as GP services or more understanding of the roles of A&E amongst less deprived families. While more deprived groups may have both lower outpatient attendance (particularly DNAs) and greater numbers of A&E visits and emergency inpatient admissions, potential confounding has been addressed in the multivariable analyses through inclusion of deprivation category as an independent variable.

Although the results are consistent with the hypothesis that missed outpatient appointments result in more unplanned care, causation is not demonstrated. Unplanned care may itself cause some non-completed appointments (a patient may miss an outpatient appointment due to A&E attendance; the alternative scenario of missing an appointment due to being an inpatient is mitigated by excluding from the analyses appointments falling within inpatient stays) It is also possible that an unplanned inpatient stay may lead to cancellation of an appointment scheduled shortly afterwards. Both missed outpatient appointments and unplanned care may be driven by condition severity. An attempt to mitigate for this has been made by including successful outpatient appointment count in

the secondary multivariable analyses. Heightened condition severity should either not affect PCAs or reduce them (in most cases where providers consider need for individuals who have not recently had an emergency admission - the exception being that a provider may cancel an appointment shortly after an emergency care episode), but PCAs were still associated with increased emergency admissions and A&E visits. Further research is needed to establish whether the observed associations between missed outpatient appointments and increased levels of unplanned care are present in other patient groups.

In addition to any causal link between missed outpatient appointments and unplanned hospital care, missed appointments have other consequences, including direct costs to the NHS¹ and possible consequences for future care of patients, as they may be discharged after multiple DNAs.² Service providers should consider the family perspective and barriers to attendance when seeking to reduce outpatient non-attendance.⁴

Strengths and limitations

The study utilised routinely collected, national level healthcare data. For the analyses, diagnoses have been grouped by ICD10 chapter, but the ICD10 coding system does not always provide sufficient granularity so diagnoses within a chapter may have very different care needs, affecting levels of unplanned care. As the cohort was identified from inpatient admissions, cohort members present in the first year all had an inpatient admission that year, whereas not all cohort members had inpatient admissions in later years. This may explain some of the observed decrease in rates of emergency inpatient admissions over the study period.

When counting A&E attendances and emergency inpatient admissions, these were not limited to those with a recorded neurological diagnosis. This was because while the proximal cause for admission or attendance is likely to be recorded, any relation to an underlying neurological condition may not be and there are difficulties in determining whether or not some unplanned care events are related to the underlying neurological condition. Some included events included may therefore be unrelated to the underlying condition, but it is expected that these are a minority.

The large datasets used mean that, in the models, some small differences are statistically significant and these may not always be sufficiently large to have clinical significance. However, applying the models at the population level helps to give an illustration of the potential relevance of the observed associations.

Few data were missing for most variables, but recording of ethnic group was poor in earlier years. Data were more complete from 2007/08 onwards (under 5% missing). A sensitivity analysis building the emergency inpatient admission multivariable model on only 2007/08-2014/15 (supplemental table S4, not repeated for A&E visits as this model was already restricted to 2007/08-2014/15) supports the main finding of incomplete outpatient attendance being associated with increased emergency inpatient admissions. Nonetheless, associations between ethnic group and the number of emergency inpatient admissions or A&E visits should be treated with caution. The routine data used in this study does not contain information on key interventions such as emergency health care plans which have been shown to reduce hospital admissions or bypassing A&E straight to inpatient care when appropriate.²³

Finally, this is a quantitative study using routinely collected data. It is able to show an association between outpatient non-attendance and A&E attendance and emergency inpatient admissions, but not the reasons for these associations nor the reasons for outpatient non-attendance. This should be addressed through a future qualitative study.

Conclusions

This study showed an association between outpatient non-attendance and increased levels of A&E attendances and emergency inpatient admissions. If these are causally linked, thousands of A&E attendances and emergency inpatient admissions could be avoided each year if individuals with missed appointments had complete attendance. As there are direct costs to the NHS of missing appointments, improving outpatient attendance should be a priority for healthcare providers. The implications on unplanned healthcare use for NHS trusts which have policies on not offering further appointments for repeat DNA patients should be examined and mechanisms for improving outpatient attendance prioritised.

Acknowledgements

This paper is independent research arising from a Postdoctoral Fellowship (LF) supported by the National Institute for Health Research. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

Data access was funded by the Paediatric Neurology Charitable Trust, Leeds Teaching Hospitals Charity.

References

- 1 Morse A. *NHS waiting times for elective care in England*. London: National Audit Office; 2014.
- 2 NHS Standard Contract Team. NHS Standard Contract 2017/18 and 2018/19 General Conditions (Full Length) May 2018 edition, page 59. <https://www.england.nhs.uk/wp-content/uploads/2018/05/3-nhs-standard-contract-2017-19-particulars-general-conditions-may-2018.pdf> (accessed 30 July 2018)
- 16-3 Cameron E, Heath G, Redwood S, et al. Health care professionals' views of paediatric outpatient non-attendance: implications for general practice. *Fam Pract* 2013; **31**: 111-7.
- 4 Ballantyne M, Benzies K, Rosenbaum P, Lodha A. Mothers' and health care providers' perspectives of the barriers and facilitators to attendance at Canadian neonatal follow-up programs. *Child Care Health Dev* 2015; **41**: 722-733
- 5 Arai L, Stapley S, Roberts H. Child 'Did not attends'. *Child Care Health Dev* 2014; **40**: 797-805
- 6 Berry JG, Poduri A, Bonkowsky JL, et al. Trends in Resource Utilization by Children with Neurological Impairment in the United States Inpatient Health Care System: A Repeat Cross-Sectional Study. *PLOS Med* 2012; **9**: e1001158.
- 7 Moreau JF, Fink EL, Hartman ME, et al. Hospitalizations of children with neurological disorders in the United States. *Pediatr Crit Care Med* 2013; **14**: 801-10.

- 8 Hardelid P, Dattani N, Davey J, Pribramska I, Gilbert R. Overview of child deaths in the four UK countries. *Child Health Reviews - UK* London: Royal College of Paediatrics and Child Health; 2013.
- 9 Jarvis SW, Livingston J, Childs A-M, Fraser LK. The impact of neurological disorders on healthcare for children and young people. *International Journal for Population Data Science* 2018; **3**(7).
- 10 PICANet. PICANet 2015 Annual Report. 2015. <https://www.picanet.org.uk/annual-reporting-and-publications/annual-report-archive/> (accessed 30 July 2018)
- 11 World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems*. Geneva, Switzerland: World Health Organisation; 1992.
- 12 Health & Social Care Information Centre. Methodology for creation of the HES Patient ID (HESID). 2014.
- 13 Noble M, Wright G, Dibben C, et al. *The English Indices of Deprivation 2004*. London: ODPM Publications; 2003.
- 14 Department for Communities and Local Government. SOA level 2001 population estimates - rounded. London: Department for Communities and Local Government; 2004. <http://webarchive.nationalarchives.gov.uk/20100410180038/http://www.communities.gov.uk/archived/general-content/communities/indicesofdeprivation/216309/> (accessed 30 July 2018)
- 15 Department for Communities and Local Government. Index of Multiple Deprivation 2004. https://data.gov.uk/dataset/imd_2004 (accessed 30 July 2018)
- 16 Department for Communities and Local Government. SOA level ID 2004. <http://webarchive.nationalarchives.gov.uk/20100410180038/http://www.communities.gov.uk/archived/general-content/communities/indicesofdeprivation/216309/> (accessed 30 July 2018)
- 17 Bland M. Dealing with counts: Poisson regression and negative binomial regression. An introduction to medical statistics. Oxford University Press (UK); 2015. 240-4.
- 18 Jarvis S, Parslow RC, Carragher P, Beresford B, Fraser LK. How many children and young people with life-limiting conditions are clinically unstable? A national data linkage study. *Arch Dis Child* 2017; **102**: 131-138.
- 19 Roberts K, Callanan I, Tubridy N. Failure to attend out-patient clinics: is it in our DNA? *Int J Health Care Qual Assur* 2011; **24**: 406-12.
- .
- 20 Cooper H, Smaje C, Arber S. Use of health services by children and young people according to ethnicity and social class: secondary analysis of a national survey. *BMJ* 1998; **317**: 1047-51.
- 21 Beattie TF, Gorman DR, Walker JJ. The association between deprivation levels, attendance rate and triage category of children attending a children's accident and emergency department. *Emerg Med J* 2001; **18**: 110.
- 22 Hendry SJ, Beattie TF, Heaney D. Minor illness and injury: factors influencing attendance at a paediatric accident and emergency department. *Arch Dis Child* 2005; **90**: 629.
- 23 Jaffer F, Reilly MM, Quinlivan Ret al. Emergency neuromuscular admissions are avoidable: a regional audit of unplanned hospital admissions of neuromuscular patients 2009-2011: final results and recommendations. *J Neurol Neurosurg Psychiatry* 2013; **84**: e2.

Figure 1: Construction of the cohort and datasets used.

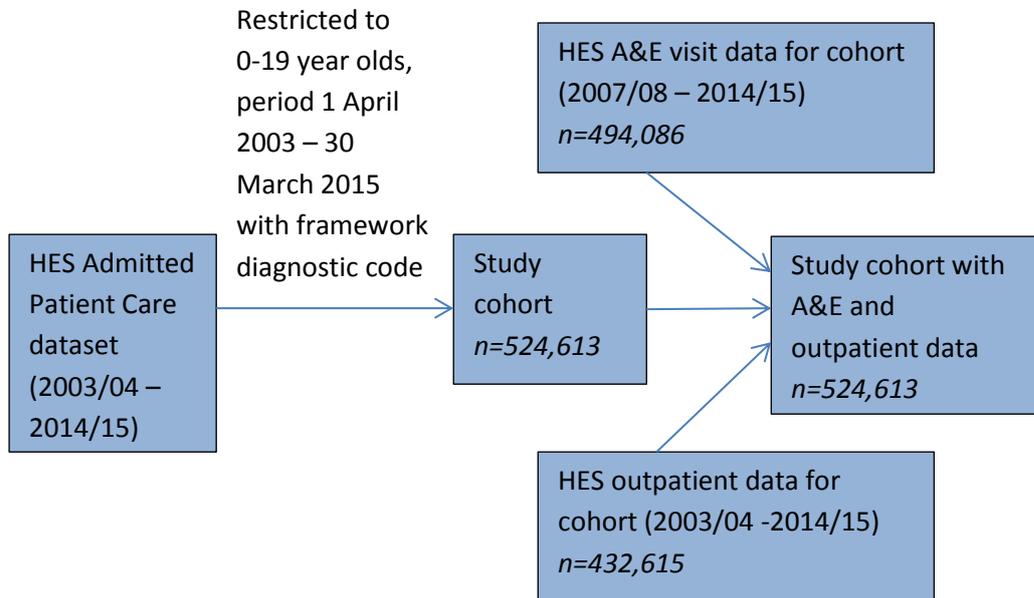


Table 1: Study cohort and outpatient, emergency inpatient and A&E activity.

	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	Total
Individuals	52,373	77,909	100,809	119,965	142,900	163,411	182,717	205,267	226,013	247,054	273,464	298,332	524,613
Gender													
Female	22,552	33,506	43,228	51,368	60,802	69,093	76,670	85,530	94,027	102,553	113,180	122,713	224,061
Male	29,810	44,395	57,574	68,582	82,090	94,308	106,027	119,704	131,976	144,485	160,258	175,583	300,352
Unknown	11	8	7	15	8	10	20	33	10	16	26	36	200
Ethnic group													
White	40,409	60,703	78,976	94,335	112,426	128,824	144,016	161,748	177,741	193,202	212,438	230,050	398,887
Indian	877	1,356	1,772	2,183	2,705	3,159	3,592	4,117	4,515	5,023	5,682	6,246	10,489
Pakistani	2,071	3,202	4,214	5,103	6,188	7,202	8,200	9,295	10,410	11,455	12,709	14,087	21,380
Bangladeshi	541	855	1,166	1,393	1,667	1,939	2,255	2,650	2,959	3,283	3,669	4,042	6,381
Black	1,882	2,983	4,105	5,116	6,430	7,608	8,908	10,337	11,761	13,307	15,071	16,586	27,662
Chinese	100	146	210	253	313	355	417	480	547	598	728	804	1,349
Mixed	911	1,473	2,030	2,605	3,311	4,068	4,756	5,701	6,575	7,649	8,881	10,107	15,484
Other	1,247	1,914	2,555	3,300	4,103	4,886	5,759	6,817	7,959	9,138	10,520	11,826	19,483
Unknown	4,335	5,277	5,781	5,677	5,757	5,370	4,814	4,122	3,546	3,399	3,766	4,584	23,498
Age group													
Under 1	10,071	11,840	12,941	13,937	14,735	16,070	16,674	17,796	17,349	17,370	18,813	19,015	N/A
1 to 4	11,718	17,868	23,148	27,297	32,886	36,424	39,473	43,507	47,670	52,491	57,708	62,139	N/A
5 to 9	11,207	17,589	23,520	28,714	34,523	40,128	46,252	53,023	59,662	66,542	74,525	82,310	N/A
10 to 14	10,516	16,257	21,287	25,344	30,357	35,346	39,563	45,275	50,992	55,697	61,942	69,031	N/A
15 to 19	8,861	14,355	19,913	24,673	30,399	35,443	40,755	45,666	50,340	54,954	60,476	65,837	N/A
Main diagnostic group													
Malignant neoplasms (C)	832	1,080	1,326	1,483	1,626	1,742	1,877	1,982	2,046	2,034	2,107	2,118	4,363
Benign neoplasms (D)	64	112	162	187	212	237	245	246	286	295	304	323	666
Metabolic (E)	960	1,336	1,720	1,971	2,200	2,420	2,662	2,860	3,002	3,137	3,294	3,398	5,606

Mental/behavioural (F)	7,662	11,376	15,332	18,763	22,805	27,158	31,552	37,286	42,810	49,256	56,527	63,521	103,075
Nervous system (G)	31,429	46,737	59,377	69,551	82,076	92,159	101,190	111,061	120,446	128,966	139,994	150,333	284,962
Congenital (Q)	8,158	12,424	15,985	19,114	22,253	25,111	27,780	30,620	33,124	35,583	38,365	40,591	58,989
Other (R)	3,268	4,844	6,907	8,896	11,728	14,584	17,411	21,212	24,299	27,783	32,873	38,048	66,952
Deprivation category													
1 (most deprived)	15,827	22,980	29,414	34,997	42,239	47,736	53,135	59,679	65,842	71,714	79,307	86,740	N/A
2	11,045	16,558	21,391	25,528	30,237	34,653	38,793	44,241	49,030	53,994	59,959	65,348	N/A
3	9,234	13,750	17,963	21,432	25,276	28,821	32,548	36,384	40,720	44,673	49,707	54,099	N/A
4	8,353	12,594	16,250	19,501	22,735	26,223	29,181	32,238	35,691	38,956	42,798	46,789	N/A
5 (least deprived)	7,900	11,980	15,748	18,465	22,075	25,052	28,085	31,638	34,730	37,717	41,693	45,356	N/A
Unknown	14	47	43	42	338	926	975	1,087	0	0	0	0	N/A
Government Office Region of residence													
North East	3,209	4,748	6,181	7,409	8,837	10,061	11,050	12,276	13,367	14,372	15,361	16,229	N/A
North West	8,426	12,155	15,533	18,718	22,572	25,929	28,405	32,008	34,996	38,015	41,378	44,975	N/A
Yorkshire and Humber	5,444	8,031	10,157	12,061	14,127	16,250	18,143	20,241	22,293	24,141	27,173	29,284	N/A
East Midlands	4,672	6,881	8,679	10,107	12,324	13,863	15,397	16,944	18,191	19,551	21,167	23,152	N/A
West Midlands	5,695	8,425	11,067	13,497	16,282	18,907	21,103	23,541	25,872	28,224	31,587	34,341	N/A
East of England	5,115	7,568	9,747	11,326	13,392	15,039	17,171	19,324	21,401	23,952	26,774	29,368	N/A
London	6,811	10,470	13,929	16,720	20,066	22,686	25,746	29,657	33,435	37,424	41,585	45,684	N/A
South East	7,848	11,836	15,556	18,270	21,598	24,677	27,902	31,258	34,456	37,468	41,969	46,530	N/A
South West	5,153	7,795	9,960	11,857	13,702	15,999	17,800	20,018	22,002	23,907	26,470	28,769	N/A
Outpatient activity													
All appointments (mean per person per year)	264345 (5.0)	397226 (5.1)	532393 (5.3)	638963 (5.3)	753701 (5.3)	896607 (5.5)	1053414 (5.8)	1202739 (5.9)	1354181 (6.0)	1517229 (6.1)	1698087 (6.2)	1905339 (6.4)	12214224 (N/A)
Successful (%)	213843 (80.9)	315807 (79.5)	423766 (79.6)	501254 (78.4)	585366 (77.7)	689007 (76.8)	790445 (75.0)	903875 (75.2)	1019776 (75.3)	1157399 (76.3)	1302490 (76.7)	1451957 (76.2)	9354985 (76.6)
PCAs (%)	11071 (4.2)	19200 (4.8)	25587 (4.8)	32096 (5.0)	43262 (5.7)	52716 (5.9)	72512 (6.9)	87964 (7.3)	110461 (8.2)	116903 (7.7)	130499 (7.7)	156492 (8.2)	858763 (7.0)
CNAs (%)	9679 (3.7)	15584 (3.9)	20975 (3.9)	25958 (4.1)	38542 (5.1)	50306 (5.6)	67778 (6.4)	78953 (6.6)	83376 (6.2)	88889 (5.9)	101450 (6.0)	115611 (6.1)	697101 (5.7)

DNAs (%)	27998 (10.6)	43963 (11.1)	59164 (11.1)	73328 (11.5)	83604 (11.1)	96785 (10.8)	116149 (11.0)	125241 (10.4)	135587 (10.0)	143501 (9.5)	154410 (9.1)	170988 (9.0)	1230718 (10.1)
Unknown outcome (%)	1754 (0.7)	2672 (0.7)	2901 (0.5)	6327 (1.0)	2927 (0.4)	7384 (0.8)	6128 (0.6)	6319 (0.5)	4562 (0.3)	6990 (0.5)	8438 (0.5)	7939 (0.4)	64341 (0.5)
Emergency inpatient admissions (mean per person per year)	68143 (1.30)	76717 (0.98)	88592 (0.88)	92710 (0.77)	98259 (0.69)	105581 (0.65)	113319 (0.62)	122390 (0.60)	125336 (0.55)	133208 (0.54)	139310 (0.51)	146048 (0.49)	1309613
A&E visits (mean per person per year)	N/A	N/A	N/A	N/A	107266 (0.75)	131701 (0.81)	161714 (0.89)	189605 (0.92)	213651 (0.95)	236645 (0.96)	257718 (0.94)	283758 (0.95)	1582058

Table 2: Emergency inpatient admissions and A&E visits by category of outpatient attendance. Figures in parentheses are mean values per person per year.

Outpatient attendance	Emergency inpatient admissions (per person per year)											
	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
Complete	28007	31717	35425	34360	34979	35650	33033	36393	35317	38630	38675	38820
	(1.18)	(0.86)	(0.74)	(0.62)	(0.57)	(0.53)	(0.48)	(0.48)	(0.42)	(0.41)	(0.38)	(0.36)
Incomplete	30843	36020	43444	48541	52863	59236	68984	74208	78544	82444	88102	94587
	(1.52)	(1.10)	(0.99)	(0.88)	(0.80)	(0.77)	(0.75)	(0.71)	(0.68)	(0.67)	(0.64)	(0.62)
No appointments	9293	8980	9723	9809	10417	10695	11302	11789	11475	12134	12533	12641
	(1.11)	(1.10)	(1.10)	(1.02)	(0.65)	(0.57)	(0.53)	(0.48)	(0.43)	(0.40)	(0.36)	(0.33)
≥1 PCAs	9914	12055	14840	16129	21182	25047	31425	35707	41599	43755	47669	52705
	(1.60)	(1.14)	(1.07)	(0.91)	(0.89)	(0.87)	(0.84)	(0.80)	(0.77)	(0.75)	(0.73)	(0.71)
≥1 CNAs	9616	11313	13858	14972	19679	23826	29663	33025	33868	35482	39572	43702
	(1.58)	(1.17)	(1.1)	(0.94)	(0.88)	(0.84)	(0.81)	(0.77)	(0.74)	(0.73)	(0.71)	(0.70)
≥1 DNAs	23595	27039	33286	37107	39216	43347	50165	52308	54312	56277	59597	64302
	(1.58)	(1.13)	(1.03)	(0.92)	(0.85)	(0.82)	(0.8)	(0.77)	(0.74)	(0.73)	(0.71)	(0.70)
Outpatient attendance	A&E visits (per person per year)											
	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
Complete	N/A	N/A	N/A	N/A	37696	45126	49249	57963	63856	72548	77424	83027
					(0.62)	(0.67)	(0.71)	(0.76)	(0.77)	(0.78)	(0.76)	(0.76)
Incomplete	N/A	N/A	N/A	N/A	53229	66147	87623	101869	115470	124738	137403	152580
					(0.81)	(0.86)	(0.95)	(0.98)	(0.99)	(1.01)	(1.00)	(1.01)
No appointments	N/A	N/A	N/A	N/A	16341	20428	24842	29773	34325	39359	42891	48151
					(1.02)	(1.08)	(1.17)	(1.21)	(1.29)	(1.31)	(1.25)	(1.27)
≥1 PCAs	N/A	N/A	N/A	N/A	20874	26495	37858	44733	54863	60175	67555	76774
					(0.88)	(0.92)	(1.01)	(1.00)	(1.01)	(1.03)	(1.03)	(1.03)
≥1 CNAs	N/A	N/A	N/A	N/A	18594	24483	35328	42073	46378	50513	56916	63792
					(0.83)	(0.87)	(0.97)	(0.98)	(1.01)	(1.04)	(1.02)	(1.02)
≥1 DNAs	N/A	N/A	N/A	N/A	39774	48854	64277	72736	80552	85666	92536	103242
					(0.86)	(0.92)	(1.03)	(1.08)	(1.1)	(1.11)	(1.11)	(1.12)

Table 3: Associations between outpatient attendance and emergency inpatient admissions and A&E visits for the cohort. Multilevel random intercept negative binomial regression models for all years from 2003/04 to 2014/15 (inpatient admissions) and 2007/08 to 2014/15 (A&E visits).

	Emergency inpatient admission				A&E visit			
	Incidence rate ratio	95% confidence interval		P value	Incidence rate ratio	95% confidence interval		P value
Outpatient attendance								
Complete	1 (ref)				1 (ref)			
Incomplete	1.19	1.18	1.19	< 0.01	1.16	1.15	1.17	< 0.01
No appointments	1.17	1.16	1.18	< 0.01	1.71	1.70	1.72	< 0.01
Gender								
Male	1 (ref)				1 (ref)			
Female	1.13	1.12	1.14	< 0.01	1.03	1.02	1.03	< 0.01
Ethnic group								
White	1 (ref)				1 (ref)			
Indian	0.97	0.94	0.99	0.01	0.94	0.92	0.96	< 0.01
Pakistani	1.11	1.09	1.13	< 0.01	1.00	0.98	1.01	0.69
Bangladeshi	0.94	0.91	0.97	< 0.01	0.94	0.92	0.97	< 0.01
Black	0.95	0.93	0.96	< 0.01	0.98	0.97	1.00	0.01
Chinese	0.92	0.86	0.99	0.02	0.93	0.88	0.99	0.02
Mixed	0.90	0.88	0.92	< 0.01	1.02	1.00	1.04	0.03
Other	0.97	0.96	0.99	0.01	1.03	1.02	1.05	< 0.01
Age group								
Under 1	5.30	5.25	5.34	< 0.01	1.82	1.81	1.84	< 0.01
1 to 4	1.82	1.80	1.83	< 0.01	1.37	1.37	1.38	< 0.01
5 to 9	1 (ref)				1 (ref)			
10 to 14	1.12	1.12	1.13	< 0.01	1.14	1.14	1.15	< 0.01
15 to 19	1.20	1.19	1.21	< 0.01	1.26	1.25	1.27	< 0.01
Main diagnostic group								
Malignant neoplasms (C)	1.66	1.61	1.71	< 0.01	0.78	0.75	0.81	< 0.01
Benign neoplasms (D)	0.64	0.58	0.71	< 0.01	0.75	0.68	0.82	< 0.01
Metabolic (E)	1.35	1.31	1.39	< 0.01	0.89	0.86	0.91	< 0.01
Mental/behavioural (F)	0.87	0.87	0.88	< 0.01	0.88	0.87	0.89	< 0.01
Nervous system (G)	1 (ref)				1 (ref)			
Congenital (Q)	0.66	0.66	0.67	< 0.01	0.69	0.68	0.70	< 0.01
Other (R)	0.67	0.67	0.68	< 0.01	0.90	0.89	0.91	< 0.01
Deprivation category								
1 (most deprived)	1 (ref)				1 (ref)			
2	0.98	0.97	0.99	< 0.01	0.94	0.93	0.95	< 0.01
3	0.96	0.95	0.97	< 0.01	0.88	0.87	0.88	< 0.01
4	0.93	0.92	0.94	< 0.01	0.83	0.83	0.84	< 0.01
5 (least deprived)	0.89	0.88	0.90	< 0.01	0.80	0.79	0.81	< 0.01

Government Office Region of Residence

North East	1.01	1.00	1.03	0.14	0.93	0.92	0.95	< 0.01	
North West	1 (ref)								
Yorkshire and Humber	0.93	0.91	0.94	< 0.01	0.87	0.86	0.88	< 0.01	
East Midlands	0.88	0.87	0.89	< 0.01	0.86	0.85	0.87	< 0.01	
West Midlands	0.93	0.92	0.95	< 0.01	0.91	0.90	0.93	< 0.01	
East of England	0.88	0.86	0.89	< 0.01	0.83	0.82	0.84	< 0.01	
London	0.75	0.74	0.76	< 0.01	1.10	1.08	1.11	< 0.01	
South East	0.91	0.90	0.92	< 0.01	0.83	0.82	0.84	< 0.01	
South West	0.87	0.86	0.88	< 0.01	0.82	0.81	0.83	< 0.01	

Model parameters

Degrees of freedom	35	35
Log likelihood	-1966752	-2113332
BIC	3934012	4227165

Supplement

ICD10 coding framework for neurological conditions

The following ICD10 codes (and all subdiagnoses) were included in the neurological coding framework:

- C70-C72 – malignant neoplasms of meninges, brain, spine or other parts of central nervous system
- D32-D33 – benign neoplasms of meninges, brain or other parts of central nervous system
- E71, E72, E75 –E77, E79.1, E79.8, E79.9, E83.0, E88.9 – disorders of amino-acid, sphingolipid, glycosaminoglycan, glycoprotein, purine and pyrimidine or copper metabolism, Lesch-Nyhan syndrome, unspecified metabolic disorders
- F02.8 – dementia in: cerebral lipidosis, epilepsy, hepatolenticular degeneration, hypercalcaemia, hypothyroidism, intoxications, multiple sclerosis, neurosyphilis, niacin deficiency, polyarteritis nodosa, systemic lupus erythematosus, trypanosomiasis, uraemia, vitamin B12 deficiency
- F05-F07 – Delirium, not induced by alcohol and other psychoactive substances, Other mental, personality and behavioural disorders due to brain damage and dysfunction and to physical disease
- F70-F79 – Mental retardation
- F80-F89 – Disorders of psychological development
- F95 – Tic disorders
- G00-G99 – Diseases of the nervous system
- Q00-Q07 – Congenital malformations of the nervous system
- Q85, Q87 – Phakomatoses, Other specified congenital malformation syndromes affecting multiple systems
- Q90-93 – Trisomies, monosomies and deletions from the autosomes
- R25-R27 – abnormal involuntary movements, abnormalities of gait and mobility and other lack of coordination

Detailed results

Outpatient attendance

Univariable analyses

Univariable analyses of outpatient attendance and modes of non-attendance are presented in Table S1.

Levels of outpatient attendance and reasons for non-attendance were similar for males and females.

There were some variations by ethnic group, with those in the Chinese ethnic group having the greatest proportion of successful attendance (80.5%); Bangladeshi cohort members had the lowest rate of successful attendance (70.9%). PCAs were highest for those in the Bangladeshi ethnic group (11.0%) and lowest for those in the Pakistani group (5.0%). CNAs were highest for White cohort members (6.0%) and lowest for those in the Pakistani group (3.7%). DNAs were highest for Black cohort members (14.0%) and lowest for those in the Chinese group (6.8%).

Under 1 year olds had the greatest proportion of successful appointments (81.5% compared to 75.4% for 15 to 19 year olds) and the lowest percentage of PCAs, CNAs, and DNAs. Differences between the other age groups were small.

Cohort members with malignant CNS tumours were most likely to successfully attend appointments (83.8%) and had the lowest numbers of PCAs (6.0%, although those with benign tumours or metabolic conditions had similar rates: 6.2% and 6.1%), CNAs (3.7%) and DNAs (5.9%).

Gradients were observed with deprivation category. The most deprived were less likely to successfully attend (75.7%) than the least deprived (78.3%). However, the most deprived had fewer PCAs (6.4% versus 7.4% for the least deprived) and CNAs (4.5% versus 6.8%), but approaching twice as many DNAs (13.0% versus 6.9%).

There were wide variations by GOR, with cohort members in the West Midlands having most successes (84.3%) and those in the East Midlands having the fewest (69.8%). These two regions also showed the greatest difference in PCAs (West Midlands: 2.7%; East Midlands 11.0%). The West Midlands also had the lowest level of CNAs (2.4%; highest: 9.2%, East Midlands). For DNAs, the North West had the highest proportion (12.1%) and East of England the lowest (8.3%).

Table S1: Outpatient attendance, emergency inpatient admissions and A&E visits by cohort demographics and main diagnostic groups.

		Outpatient attendance				Emergency inpatient admissions (mean per person per year)	A&E visits (mean per person per year)	Proportion of A&E visits converting to inpatient admissions
		Success (%)	PCA (%)	CNA (%)	DNA (%)			
Gender								
	Female	4099396 (76.8)	372476 (7.0)	303888 (5.7)	533865 (10.0)	589500 (0.67)	691389 (0.95)	26%
	Male	5255589 (76.4)	486287 (7.1)	393213 (5.7)	696853 (10.1)	720065 (0.59)	890669 (0.88)	25%
Ethnic group								
	White	7346943 (76.8)	672466 (7.0)	572241 (6.0)	918364 (9.6)	1018450 (0.62)	1213418 (0.89)	25%
	Indian	198795 (77.3)	19476 (7.6)	13794 (5.4)	23499 (9.1)	26434 (0.64)	31866 (0.91)	27%
	Pakistani	499592 (79.2)	31313 (5.0)	23060 (3.7)	73688 (11.7)	80054 (0.85)	76608 (0.96)	29%
	Bangladeshi	117491 (70.9)	18219 (11.0)	9422 (5.7)	19542 (11.8)	17151 (0.65)	23447 (1.04)	25%
	Black	442830 (73.1)	46661 (7.7)	26970 (4.5)	84975 (14.0)	62587 (0.60)	97483 (1.08)	27%
	Chinese	25273 (80.5)	2199 (7.0)	1620 (5.2)	2148 (6.8)	3067 (0.62)	3924 (0.93)	29%
	Mixed	269966 (75.1)	26482 (7.4)	20094 (5.6)	40000 (11.1)	36118 (0.62)	51451 (1.01)	26%
	Other	337184 (75.9)	33083 (7.5)	22164 (5.0)	48914 (11.0)	44102 (0.63)	65083 (1.07)	26%
	Unknown	116911 (75.9)	8864 (5.8)	7736 (5.0)	19588 (12.7)	21650 (0.38)	18778 (0.53)	21%
Age group								
	Under 1	896535 (81.5)	62815 (5.7)	44378 (4.0)	89071 (8.1)	297656 (1.6)	176057 (1.28)	42%
	1 to 4	2301569 (76.2)	215009 (7.1)	169482 (5.6)	318754 (10.5)	327567 (0.72)	381743 (1.03)	27%
	5 to 9	2363642 (76.1)	227433 (7.3)	177391 (5.7)	318780 (10.3)	213600 (0.4)	310703 (0.68)	21%
	10 to 14	2065926 (76.6)	194957 (7.2)	161653 (6.0)	255676 (9.5)	209196 (0.45)	307420 (0.79)	22%
	15 to 19	1727313 (75.4)	158549 (6.9)	144197 (6.3)	248437 (10.8)	261594 (0.58)	406135 (1.06)	22%
Main diagnostic group								
	Malignant neoplasms (C)	236220 (83.8)	16800 (6.0)	10527 (3.7)	16569 (5.9)	29227 (1.44)	10020 (0.65)	34%
	Benign neoplasms (D)	13457 (80.0)	1048 (6.2)	792 (4.7)	1484 (8.8)	1274 (0.48)	1534 (0.71)	24%

Metabolic (E)	204789 (78.6)	16012 (6.1)	12243 (4.7)	26087 (10.0)	34851 (1.2)	20681 (0.9)	38%
Mental/behavioural (F)	1604073 (76.1)	145183 (6.9)	127342 (6.0)	214696 (10.2)	180659 (0.47)	280576 (0.85)	23%
Nervous system (G)	4846889 (76.4)	453402 (7.1)	360468 (5.7)	652617 (10.3)	761687 (0.67)	910127 (0.98)	26%
Congenital (Q)	1922712 (76.5)	181397 (7.2)	147063 (5.8)	247709 (9.9)	190187 (0.62)	178001 (0.7)	28%
Other (R)	526845 (76.9)	44921 (6.6)	38666 (5.6)	71556 (10.4)	111728 (0.53)	181119 (0.96)	21%
Deprivation category							
1 (most deprived)	2592712 (75.7)	217833 (6.4)	152863 (4.5)	444162 (13.0)	415424 (0.68)	540184 (1.07)	25%
2	1995195 (75.6)	191805 (7.3)	147301 (5.6)	289699 (11.0)	288717 (0.64)	367287 (0.98)	25%
3	1714584 (76.8)	162681 (7.3)	137140 (6.1)	206048 (9.2)	229533 (0.61)	266929 (0.85)	25%
4	1541544 (77.7)	143125 (7.2)	128548 (6.5)	157544 (7.9)	194581 (0.59)	215316 (0.78)	26%
5 (least deprived)	1510454 (78.3)	143269 (7.4)	131226 (6.8)	133183 (6.9)	181125 (0.57)	192267 (0.72)	26%
Unknown	496 (76.0)	50 (7.7)	23 (3.5)	82 (12.6)	233 (0.07)	75 (0.02)	40%
Government Office Region of residence							
North East	566591 (77.8)	54515 (7.5)	35045 (4.8)	67862 (9.3)	80530 (0.65)	95694 (0.94)	22%
North West	1271044 (81.1)	47566 (3.0)	54509 (3.5)	189430 (12.1)	232579 (0.72)	271192 (1.01)	27%
Yorkshire and Humber	870311 (75.4)	85923 (7.4)	75485 (6.5)	121303 (10.5)	128984 (0.62)	148472 (0.86)	27%
East Midlands	718030 (69.8)	113674 (11.0)	94834 (9.2)	97573 (9.5)	105850 (0.62)	117008 (0.83)	25%
West Midlands	1140561 (84.3)	36433 (2.7)	32589 (2.4)	138379 (10.2)	150233 (0.63)	181640 (0.91)	26%
East of England	952190 (74.6)	114957 (9.0)	96090 (7.5)	106298 (8.3)	124380 (0.62)	130366 (0.78)	27%
London	1444913 (72.6)	185302 (9.3)	116130 (5.8)	228320 (11.5)	168178 (0.55)	298032 (1.16)	24%
South East	1423107 (76.7)	140981 (7.6)	113279 (6.1)	163916 (8.8)	198108 (0.62)	204614 (0.77)	25%
South West	968238 (76.7)	79412 (6.3)	79140 (6.3)	117637 (9.3)	120771 (0.59)	135040 (0.8)	24%

Emergency inpatient admission

Univariable analyses

Females had more emergency inpatient admissions than males (0.67 compared to 0.59 per person per year, Table S1). There were only minor variations between most ethnic groups, but cohort members in the Pakistani ethnic group had more emergency inpatient admissions (0.85) per person per year than other groups (next highest: Bangladeshi, 0.65). Under 1 year olds had many more emergency admissions (1.60 per person per year) than other age groups; 5 to 9 year olds (0.40) and 10 to 14 year olds (0.45) had fewest. Cohort members with an oncology (1.44) or metabolic main diagnosis (1.20) had more emergency admissions than other groups (next highest, nervous system conditions, 0.67). The most deprived had more emergency admissions (0.68) than the least deprived (0.57) and there were geographical variations (highest: North West, 0.72; lowest: London 0.55).

A&E visits

Univariable analyses

Females had more A&E visits than males (0.95 per person per year compared to 0.85, Table S1). Cohort members in minority ethnic groups had more A&E visits per person per year than White cohort members (0.89), particularly those in the Other (1.07) and Black (1.08) groups. Under 1 year olds had the highest rate of A&E visits (1.28) compared to 1 to 4 year olds (1.03), 5 to 9 year olds (0.68), 10 to 14 year olds (0.79) and 15 to 19 year olds (1.06). Those with an oncology main diagnosis had fewer A&E visits (0.65) than those in other groups (highest: nervous system conditions, 0.98). The most deprived had more A&E visits (1.07) than the least deprived (0.72) and there were variations by GOR (highest: London, 1.16; lowest: South East, 0.77).

There were only minor differences between genders in the proportion of A&E visits converting to inpatient admissions (Table S1). Conversion rates were also similar for most ethnic groups, ranging from 25% (White, Bangladeshi) to 29% (Pakistani, Chinese). Those with unknown ethnic group had fewer conversions (21%). Under 1 year olds were much more likely to be admitted following an A&E visit (41%) than other age groups (21-27%). Children and young people with a CNS tumour or metabolic condition were more likely to be admitted (respectively 34% and 38%) than those with other conditions (21-28%). There were not clear differences in admission rates between deprivation categories (although the small number unknown deprivation category had a greater proportion of admissions, 40%, 95%CI 29-50%). Variations in admission rates from A&E were also small between government office regions of residence, from 22% (North West) to 27% (North East, Yorkshire & Humber, East of England).

Secondary analysis – unplanned care and modes of outpatient non-attendance

Table S2: Associations between hospital cancellation of outpatient appointments and patient cancellation or non-attendance and unplanned inpatient admissions and A&E visits for members of the cohort with at least one scheduled outpatient appointment. Multilevel random intercept negative binomial regression model for all years from 2003/04 to 2014/15 (inpatient admissions) and 2007/08 to 2014/15 (A&E visits).

		Emergency inpatient admission				A&E visit			
		Incidence rate ratio	95% confidence interval		P value	Incidence rate ratio	95% confidence interval		P value
PCAs									
	None	1 (ref)				1 (ref)			
	One or more	1.03	1.03	1.04	< 0.01	1.05	1.04	1.06	< 0.01
CNAs									
	None	1 (ref)				1 (ref)			
	One or more	1.03	1.02	1.04	< 0.01	1.06	1.05	1.06	< 0.01
DNAs									
	None	1 (ref)				1 (ref)			
	One or more	1.16	1.16	1.17	< 0.01	1.13	1.12	1.14	< 0.01
Outpatient activity level									
	Per successful outpatient appointment	1.03	1.03	1.03	< 0.01	1.02	1.02	1.02	< 0.01
Gender									
	Male	1 (ref)				1 (ref)			
	Female	1.12	1.11	1.12	< 0.01	1.03	1.02	1.03	< 0.01
Ethnic group									
	White	1 (ref)				1 (ref)			
	Indian	0.97	0.95	1.00	0.03	0.92	0.90	0.95	< 0.01
	Pakistani	1.10	1.08	1.12	< 0.01	0.98	0.97	1.00	0.04
	Bangladeshi	0.97	0.94	1.00	0.06	0.94	0.91	0.96	< 0.01
	Black	0.97	0.96	0.99	< 0.01	0.98	0.97	1.00	0.04
	Chinese	0.88	0.82	0.95	< 0.01	0.89	0.83	0.96	< 0.01
	Mixed	0.92	0.90	0.94	< 0.01	1.02	1.00	1.04	0.04
	Other	0.97	0.95	0.99	< 0.01	1.03	1.01	1.05	< 0.01
Age group									
	Under 1	5.49	5.43	5.54	< 0.01	2.23	2.21	2.25	< 0.01
	1 to 4	1.79	1.78	1.81	< 0.01	1.43	1.42	1.44	< 0.01
	5 to 9	1 (ref)				1 (ref)			
	10 to 14	1.11	1.10	1.12	< 0.01	1.16	1.15	1.17	< 0.01
	15 to 19	1.18	1.16	1.19	< 0.01	1.29	1.28	1.30	< 0.01
Main diagnostic group									
	Malignant neoplasms (C)	1.40	1.35	1.45	< 0.01	0.66	0.63	0.68	< 0.01
	Benign neoplasms (D)	0.63	0.56	0.70	< 0.01	0.72	0.65	0.79	< 0.01

Metabolic (E)	1.27	1.23	1.31	< 0.01	0.84	0.81	0.87	< 0.01
Mental/behavioural (F)	0.84	0.83	0.85	< 0.01	0.88	0.87	0.89	< 0.01
Nervous system (G)	1 (ref)				1 (ref)			
Congenital (Q)	0.63	0.63	0.64	< 0.01	0.66	0.65	0.67	< 0.01
Other (R)	0.75	0.74	0.76	< 0.01	0.96	0.95	0.97	< 0.01
Deprivation category								
1 (most deprived)	1(ref)				1(ref)			
2	0.98	0.97	0.99	< 0.01	0.93	0.92	0.94	< 0.01
3	0.95	0.94	0.96	< 0.01	0.86	0.85	0.87	< 0.01
4	0.92	0.91	0.93	< 0.01	0.81	0.80	0.82	< 0.01
5 (least deprived)	0.87	0.86	0.88	< 0.01	0.77	0.76	0.78	< 0.01
Government Office Region of Residence								
North East	0.99	0.97	1.01	0.26	0.91	0.90	0.93	< 0.01
North West	1 (ref)				1 (ref)			
Yorkshire and Humber	0.93	0.91	0.94	0.00	0.86	0.85	0.87	< 0.01
East Midlands	0.88	0.87	0.89	0.00	0.84	0.82	0.85	< 0.01
West Midlands	0.89	0.88	0.91	0.00	0.89	0.88	0.91	< 0.01
East of England	0.86	0.84	0.87	0.00	0.80	0.79	0.81	< 0.01
London	0.73	0.72	0.74	0.00	1.07	1.06	1.08	< 0.01
South East	0.91	0.89	0.92	0.00	0.80	0.79	0.81	< 0.01
South West	0.85	0.83	0.86	0.00	0.79	0.78	0.80	< 0.01
Model parameters								
Degrees of freedom	37				37			
Log likelihood	-1718313				-1805566			
BIC	3437159				3611658			

Sensitivity analysis – A&E visits not converting to an inpatient admission

Table S3: Associations between outpatient attendance and A&E not converting to an inpatient admission for the cohort. Multilevel random intercept negative binomial regression model for 2007/08 to 2014/15.

		A&E visit not leading to admission			
		Incidence rate ratio	95% confidence interval		P value
Outpatient attendance					
	Complete	1 (ref)			
	Incomplete	1.16	1.15	1.16	< 0.01
	No appointments	1.81	1.80	1.82	< 0.01
Gender					
	Male	1 (ref)			
	Female	1.01	1.01	1.02	< 0.01
Ethnic group					
	White	1 (ref)			
	Indian	0.92	0.90	0.94	< 0.01
	Pakistani	0.98	0.97	1.00	0.02
	Bangladeshi	0.95	0.92	0.98	< 0.01
	Black	0.96	0.95	0.98	< 0.01
	Chinese	0.91	0.85	0.97	< 0.01
	Mixed	1.02	1.00	1.04	0.04
	Other	1.02	1.00	1.04	0.02
Age group					
	Under 1	1.31	1.30	1.33	< 0.01
	1 to 4	1.29	1.28	1.29	< 0.01
	5 to 9	1 (ref)			
	10 to 14	1.15	1.14	1.16	< 0.01
	15 to 19	1.29	1.28	1.30	< 0.01
Main diagnostic group					
	Malignant neoplasms (C)	0.68	0.66	0.71	< 0.01
	Benign neoplasms (D)	0.78	0.71	0.86	< 0.01
	Metabolic (E)	0.80	0.78	0.83	< 0.01
	Mental/behavioural (F)	0.88	0.88	0.89	< 0.01
	Nervous system (G)	1 (ref)			
	Congenital (Q)	0.73	0.72	0.73	< 0.01
	Other (R)	0.98	0.97	0.99	< 0.01
Deprivation category					
	1 (most deprived)	1(ref)			
	2	0.93	0.93	0.94	< 0.01
	3	0.86	0.85	0.87	< 0.01
	4	0.81	0.80	0.82	< 0.01
	5 (least deprived)	0.77	0.76	0.78	< 0.01

Government Office Region of Residence

North East	0.97	0.95	0.98	< 0.01
North West	1 (ref)			
Yorkshire and Humber	0.88	0.87	0.89	< 0.01
East Midlands	0.88	0.87	0.90	< 0.01
West Midlands	0.93	0.92	0.95	< 0.01
East of England	0.84	0.83	0.85	< 0.01
London	1.18	1.16	1.19	< 0.01
South East	0.86	0.85	0.87	< 0.01
South West	0.85	0.84	0.86	< 0.01

Model parameters

Degrees of freedom	35
Log likelihood	-1813446
BIC	3627393

Sensitivity analysis – emergency inpatient admissions and outpatient attendance in years with more complete ethnicity data

Table S4: Associations between outpatient attendance and unplanned inpatient admissions for the cohort. Multilevel random intercept negative binomial regression model 2007/08 to 2014/15 (sensitivity analysis for years with more complete ethnicity data).

		Emergency inpatient admission			
		Incidence	95% confidence		P value
		rate ratio	interval		
Outpatient attendance					
	Complete	1 (ref)			
	Incomplete	1.25	1.24	1.26	< 0.01
	No appointments	1.14	1.13	1.15	< 0.01
Gender					
	Male	1 (ref)			
	Female	1.14	1.13	1.15	< 0.01
Ethnic group					
	White	1 (ref)			
	Indian	0.98	0.95	1.01	0.17
	Pakistani	1.14	1.12	1.16	< 0.01
	Bangladeshi	0.96	0.93	1.00	0.04
	Black	0.99	0.97	1.01	0.17
	Chinese	0.96	0.89	1.03	0.27
	Mixed	0.94	0.92	0.96	< 0.01
	Other	1.02	1.00	1.04	0.11
Age group					
	Under 1	5.66	5.60	5.72	< 0.01
	1 to 4	1.84	1.82	1.85	< 0.01
	5 to 9	1 (ref)			
	10 to 14	1.15	1.13	1.16	< 0.01
	15 to 19	1.26	1.25	1.28	< 0.01
Main diagnostic group					
	Malignant neoplasms (C)	1.66	1.61	1.71	< 0.01
	Benign neoplasms (D)	0.64	0.58	0.71	< 0.01
	Metabolic (E)	1.35	1.31	1.39	< 0.01
	Mental/behavioural (F)	0.87	0.87	0.88	< 0.01
	Nervous system (G)	1 (ref)			
	Congenital (Q)	0.66	0.66	0.67	< 0.01
	Other (R)	0.67	0.67	0.68	< 0.01
Deprivation category					
	1 (most deprived)	1(ref)			
	2	0.98	0.97	0.99	< 0.01
	3	0.96	0.95	0.97	< 0.01
	4	0.93	0.92	0.94	< 0.01

5 (least deprived)	0.89	0.88	0.90	< 0.01
<hr/>				
Government Office Region of Residence				
North East	0.99	0.97	1.01	0.28
North West	1 (ref)			
Yorkshire and Humber	0.91	0.90	0.93	< 0.01
East Midlands	0.86	0.84	0.87	< 0.01
West Midlands	0.92	0.91	0.94	< 0.01
East of England	0.87	0.86	0.88	< 0.01
London	0.72	0.71	0.73	< 0.01
South East	0.91	0.89	0.92	< 0.01
South West	0.86	0.84	0.87	< 0.01
<hr/>				
Model parameters				
Degrees of freedom	35			
Log likelihood	-1536433			
BIC	3073368			