STUDY PROTOCOL

Planned and unplanned hospital admissions and health-related school absence rates in children with neurodisability: Protocol for a population-based study using linked education and hospital data from England. [version 1; peer review: 1 approved, 3 approved with reservations]

Laura Gimeno[1,2], Ania Zylbersztejn[1,3], Ayana Cant[1], Katie Harron[1], Ruth Gilbert[1]

[1]Great Ormond Street Institute of Child Health, University College London, London, England, WC1N 1EH, UK
[2]Centre for Longitudinal Studies, Social Research Institute, University College London, London, England, WC1H 0NU, UK
[3]NIHR Great Ormond Street Hospital Biomedical Research Centre, Great Ormond Street Hospital Children's Charity, London, England, WC1N 3JH, UK

v1 **First published:** 01 May 2024, **4**:26
https://doi.org/10.3310/nihropenres.13558.1
Latest published: 01 May 2024, **4**:26
https://doi.org/10.3310/nihropenres.13558.1

Abstract

Background

Neurodisability describes a broad set of conditions affecting the brain and nervous system which result in functional limitations. Children with neurodisability have more hospital admissions than their peers without neurodisability and higher rates of school absence. However, longitudinal evidence comparing rates of hospital admission and school absence in children with neurodisability to peers without neurodisability throughout school is limited, as is understanding about whether differences are greatest for planned care (e.g., scheduled appointments) or unplanned care. This study will describe rates of planned and unplanned hospital admissions and school absence due to illness and medical reasons throughout primary school (Reception to Year 6, ages 4 to 11 in England) for children with neurodisability and all other children, using linked individual-level health and education data.

Methods

Open Peer Review

Approval Status ? ? ✓ ?

	1	2	3	4
version 1 01 May 2024	? view	? view	✓ view	? view

1. **Laura Cowley**, Swansea University, Swansea, UK
2. **Rachael Marpole**, Perth Children's Hospital Foundation, Perth, Australia
3. **Rachel Knight Lozano**, University of Plymouth, Plymouth, UK
4. **Simon Paget**, The University of Sydney, Sydney, Australia

Any reports and responses or comments on the article can be found at the end of the article.

We will use the ECHILD (Education and Child Insights from Linked Data) database, which links educational and health records across England. We will define a primary school cohort of children who were born in National Health Service-funded hospitals in England between 1st September 2003 and 31st August 2008, and who were enrolled in Reception (age 4/5) at state-funded schools. We will use hospital admissions records to identify children who have recorded indicators of neurodisability from birth up to the end of primary school (Year 6, age 10/11).

Results

We will describe rates of planned and unplanned hospital admissions and health-related school absence for three groups of children: those with a neurodisability indicator first recorded before beginning primary school, those with neurodisability first recorded during primary school, and those without a record of neurodisability before end of primary school.

Conclusions

We will further explore whether differences between these group vary across primary school years and by socioeconomic and demographic characteristics.

Plain English summary
Neurodisability encompasses a range of health conditions which affect the brain and nervous system and result in difficulties with everyday activities, including learning. Children with neurodisability are more likely to be admitted to hospital and spend longer periods of time in hospital than children without neurodisability. They are also more likely to be absent from school. Yet, in England, these is a lack of evidence comparing admissions and absence rates in children with and without neurodisability throughout their school years. Evidence is also lacking on whether differences are greatest for planned care (e.g., scheduled appointments) or unplanned care. We will use hospital and education records from state-funded hospitals and schools in England to describe rates of hospital admission and school absences for children with and without neurodisability during their primary school years.

Keywords
neurodisability, school absence, hospital admissions, electronic health records, linked data

Corresponding author: Laura Gimeno (l.gimeno@ucl.ac.uk)

Author roles: Gimeno L: Conceptualization, Methodology, Writing – Original Draft Preparation, Writing – Review & Editing; **Zylbersztejn A**: Conceptualization, Methodology, Writing – Review & Editing; **Cant A**: Conceptualization, Methodology, Writing – Review & Editing; **Harron K**: Conceptualization, Funding Acquisition, Methodology, Resources, Writing – Review & Editing; **Gilbert R**: Conceptualization, Funding Acquisition, Methodology, Resources, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: This study is part of the HOPE project (Health Outcomes of young People in Education), which is funded by the National Institute for Health and Care Research (NIHR) under its Programme Grants for Applied Research Programme (grant number NIHR202025). RG is supported by a NIHR Senior Investigator award. This research was supported by Health Data Research UK (grant number LOND1), which is funded by the Medical Research Council and eight other funders. ECHILD is supported by ADR UK (Administrative Data Research UK), and the Economic and Social Research Council (part of UK Research and Innovation) (ES/V000977/1, ES/X003663/1, ES/X000427/1). Research at UCL Great Ormond Street Institute of Child Health is supported by the NIHR Great Ormond Street Hospital Biomedical Research Centre. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.
The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

How to cite this article: Gimeno L, Zylbersztejn A, Cant A *et al.* **Planned and unplanned hospital admissions and health-related school absence rates in children with neurodisability: Protocol for a population-based study using linked education and hospital data from England. [version 1; peer review: 1 approved, 3 approved with reservations]** NIHR Open Research 2024, **4**:26 https://doi.org/10.3310/nihropenres.13558.1

First published: 01 May 2024, **4**:26 https://doi.org/10.3310/nihropenres.13558.1

Introduction

Neurodisability encompasses a range of "congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations"[1]. Neurodisability includes neurodevelopmental disorders such as learning disability, autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD), neurological conditions such as epilepsy and cerebral palsy, and a broad set of other conditions affecting learning and brain development (e.g., chromosomal anomalies, paediatric stroke, and brain tumours).

Many of the individual conditions encompassed under this definition of neurodisability are rare. For instance, 2–3 livebirths per 1000 are affected by cerebral palsy[2], and 1.2 livebirths per 1000 by Down syndrome[3]. This relatively small group of children have a much greater need for healthcare compared to their peers. For example, in Northern Ireland, children with cerebral palsy make up only 0.3% of the population aged 0–24 years, but account for 1.6% of all hospital admissions and outpatient appointments in this age-group[4]. A number of record linkage studies, both within the UK (England, Wales, Scotland) and internationally (Australia) have shown that children with a variety of neurodisability subtypes, including neurological conditions such as cerebral palsy and epilepsy[4–8], Down syndrome[9], and neurodevelopmental conditions, such as ADHD[10,11], ASD, and learning disabilities[12], are more frequently admitted to hospital and for a longer duration than their peers without neurodisability.

Children with neurodisability are also more likely to be absent from school[8,11,13,14]. There is some evidence among children with learning difficulties and ASD that these higher rates of absence may be driven by their greater need for healthcare[15], resulting in more time away from school. However, this evidence is cross-sectional, based on published aggregate statistics, and relies on children being in receipt of Special Educational Needs support to be identified as having learning difficulties or ASD, which not all children with neurodisability receive. Longitudinal evidence on how health-related school absence rates change over the course of primary school for children with neurodisability more generally is limited. While evidence for the role of school absence as a mediator for associations between chronic health conditions like neurodisability and school attainment is weak[16], education remains a key social determinant of many health and socioeconomic outcomes in adulthood. It is therefore important to understand how the complex healthcare needs of children with neurodisability affect schooling.

In this study, we will use linked education and hospital records to quantify rates of planned and unplanned hospital admissions and health-related school absence during primary school (age 4/5 to 10/11 years) in England, for children with and without neurodisability. Little research has explored whether differences in admissions and absences between children with neurodisability and their peers are greatest for planned care, reflecting proactive management of the complex medical conditions of children with neurodisability, or unplanned care. We will also explore whether differences in admission and absence rates between children with neurodisability and their peers differ by school year and by socioeconomic and demographic characteristics (area-level deprivation, recorded eligibility for free school meals, ethnicity, geographic region, and month of birth).

This study is part of the wider Health Outcomes of young People in Education (HOPE) research programme, which aims to understand the impact of Special Educational Needs (SEN) provision of children and young people's health and education outcomes. The umbrella protocol for the HOPE research programme has been published elsewhere[17].

Methods

Ethics and dissemination

Permissions to use linked, de-identified data from Hospital Episode Statistics and the National Pupil Database were granted by the Department for Education (DR200604.02B) and NHS Digital (DARS-NIC-381972). Ethical approval for the ECHILD project was granted by the National Research Ethics Service (17/LO/1494), NHS Health Research Authority Research Ethics Committee (20/EE/0180), and UCL Great Ormond Street Institute of Child Health's Joint Research and Development Office (20PE06). Access to the ECHILD database is approved by the ECHILD team (ich.echild@ucl.ac.uk) for proposals and projects using ECHILD.

Findings will be disseminated to stakeholders (including academics, government departments, service users, and service providers) through seminars, workshops, and peer-reviewed publications. We will publish the code used for analysis in an open-source repository to enable others to replicate and build upon our work using ECHILD.

Study type

This is an observational study, using linked health and education records to conduct a population-based birth cohort study.

Dataset and linkage

The ECHILD (Education and Child Health Insights from Linked Data) database contains linked administrative data on health and education for approximately 14.7 million children and young people born in England between 1st September 1995 and 31st August 2020 from age 0 to 24[18].

Health data comes from Hospital Episode Statistics (HES) for England, a database which records contacts with all National Health Service (NHS) funded hospitals. In this study we will use HES Admitted Patient Care (APC) datasets, which record all inpatient episodes in NHS-funded hospitals since 1997[19]. HES records contain basic demographic information and information of diagnoses (coded using International Classification of Diseases 10th Revision (ICD-10) codes) and procedures (coded using Office of Population Censuses and Surveys Classification of Interventions and Procedures (OPCS-4) codes). HES APC contains information on birth admissions

which can be used to construct birth cohorts from administrative data. NHS England produces study-specific pseudonymised patient identifiers which can be used to link hospital admissions in the same individual over time, through further admissions and access to other health services. Coverage of HES is high, since most secondary care in England occurs in NHS or NHS-funded hospitals (98–99%), and nearly all children born in England (97%) have a birth record in HES[19]. In the ECHILD database, HES data is linked to Office for National Statistics (ONS) Mortality Data for deaths from 1st January 1998 onwards, enabling us to capture deaths that occur outside of the hospital (in hospital deaths are captured in HES).

Education data comes from the National Pupil Database (NPD), which contains information of registration, attainment, absences, and exclusions of children attending state-funded schools in England[20]. The Department for Education (DfE) produces study-specific anonymised Pupil Matching Reference (aPMR) numbers which can be used to link education records for the same individual across their school careers. During primary school years (Reception to Year 6 in England), NPD only captures children who are registered at state-funded schools. It is estimated that 7% of children in school each year in England attend independently funded (private) schools[20], and that 0.5-1% are home-schooled[21,22].

HES and NPD records are deterministically linked by NHS England using an algorithm which uses identifiable information (including name, date of birth, sex, and postcode) to create a bridge file allowing researchers to link pseudonymised patient identifiers and aPMRs[18], enabling the creation of longitudinal educational and healthcare histories for each individual in our study cohort. The linkage rate between HES and NPD is high and has improved with time (94–98%)[18].

Study population

The study population consists of all singleton children born in NHS-funded hospitals in England between 1st September 2003 and 31st August 2008 (academic years 2003/4 to 2007/8) who were linked to NPD and recorded as enrolled in Reception at state-funded schools (age 4/5) in the January (Spring) School Census. We focus on children born during this period since these children would be expected to have completed primary school (end of Year 6, age 10/11) by 31st August 2019 (Table 1). This was the last academic year that was unaffected by the COVID-19 pandemic, which began in March 2020. Lockdowns during the COVID-19 pandemic affected children's access to school, and the frequency of planned admissions and outpatient appointments reduced substantially during the pandemic[23,24]. We use the January School Census since it is used for the allocation of school funding (and so is assumed to be the most complete). While mandated primary school begins in Year 1 (age 5/6) in England, most children are also enrolled in Reception, beginning school at age 4/5.

Children will be excluded from the study cohort if their NHS record does not link to NPD (likely indicating they did not attend state-funded school in England, that they died or emigrated before primary school age, or a missed link)[25], or if they did not appear in Reception (age 4/5) in any January School Census. We will also exclude children who are registered two or more years outside of their expected school year, based on their year of birth.

Table 1. Timeline for primary school cohort.

		Academic Calendar Year															
		2003/4	2004/5	2005/6	2006/7	2007/8	2008/9	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
Academic Year of Birth	2003/4	**0**	1	2	3	4	5	6	7	8	9	10	**11**	12	13	14	15
	2004/5		**0**	1	2	3	4	5	6	7	8	9	10	**11**	12	13	14
	2005/6			**0**	1	2	3	4	5	6	7	8	9	10	**11**	12	13
	2006/7				**0**	1	2	3	4	5	6	7	8	9	10	**11**	12
	2007/8					**0**	1	2	3	4	5	6	7	8	9	10	**11**

Legend:

Birth record
Reception
Primary school

Note: The number in each box indicates the how old a child would turn on their birthday in given academic year. Mandated primary school years are Year 1 to Year 6, although many children enter in the year they turn five (referred to as Reception year). Academic years are from 1st September to 31st August the following year.

Follow-up

Children will be followed from Reception (age 4/5) until the end of primary school (Year 6, age 10/11), death, or the end of the study (31st August 2019), whichever occurred first. Follow-up time will be split by school year (from 1st September to 31st August).

For hospital admissions, we will follow children across the whole of their primary school years, from Reception until end of Year 6 or death. Children's hospitalisation rates can be characterised across their primary school years whether they are in state-funded school (and so feature in a school census in NPD) or not. Loss to follow-up from HES can occur because of emigration, but due to a lack of data on migration, a limitation of this study is that we will not be able to censor emigrants.

For absences, outcome data is only available for those enrolled in a state-funded school in a given academic year. A child initially enrolled in state-funded Reception, and so part of the primary school cohort, may not appear in NPD in subsequent years for a variety of reasons including emigration, transition to home-schooling or independent non-state schooling, off-rolling, or death before the end of primary school. We will split follow-up time by school year, and for each school year consider only children who are enrolled. If a child subsequently reappears in a school census having been previously missing (provided a death has not been recorded), then they will be reincorporated into the analytical sample for that school year. We will provide information on the percentage of children in the primary school cohort who are recorded in NPD for each school year, and so factor into absence rate calculations for that year.

Exposure: neurodisability

We will use children's hospital admission and mortality records from birth up to the 31st August of Year 6 (age 10/11) to identify children with neurodisability based on ICD-10 diagnostic codes and OPCS-4 procedural codes. The codes used to identify cases were collated from published papers and code lists and compiled in collaboration with clinicians. The methods used to identify children with neurodisability in HES according to these code lists will be published elsewhere[26], and the code lists themselves will be made available in an online repository. Using these codes, we will create three exposure groups: children who had an indicator of neurodisability first recorded before the start of primary school (i.e., before 1st September of Reception), children who had a first record of neurodisability during primary school (i.e., between 1st September of Reception and 31st August of Year 6), and those who had no recorded codes indicating neurodisability before the end of primary school.

The definition of neurodisability in our study follows the consensus definition proposed by Morris and colleagues: "Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour"[1]. Following this definition, conditions identified as a neurodisability include neurodevelopmental disorders (e.g., learning difficulties, ASD, ADHD), neurological disorders (epilepsy, cerebral palsy), genetic conditions likely to affect learning (e.g., Down syndrome, sex chromosome anomalies), musculoskeletal disorders (e.g., spina bifida and anomalies of the spinal cord), and conditions which affect the brain (e.g., paediatric stroke, hydrocephalus, inflammation of the brain, brain tumours), and perinatal conditions affecting the brain (e.g., neonatal abstinence syndrome/foetal alcohol syndrome, perinatal brain injury). Our definition excludes traumatic brain injuries and other acquired injuries to the head since head injury is common, but severity and resulting functional limitations are not well captured in hospital records.

Outcome: planned and unplanned hospital admission

Our analysis will focus on planned and unplanned hospital admissions to state-funded hospitals in England. Our outcome therefore reflects more severe healthcare contacts: planned interventions requiring admission to hospital (rather than planned care received in the community, primary care, or at hospital outpatients), and unplanned health events resulting in hospital admission (rather than any contact with emergency departments).

We will extract data on all hospital admissions for all children in the cohort during their primary school years: from 1st September of Reception (age 4/5) to 31st August of Year 6 (age 10/11), or death. Admissions are continuous periods in hospital that could consist of several finished consultant episodes (a period of hospital stay under a single consultant). Admissions within one day of each other (discharged and re-admitted on the same or following day) or admissions that included a hospital transfer will be considered as a single admission. We will classify admissions into planned (elective) and unplanned (emergency) admissions using the admission method of the first episode within the admission.

Outcome: school absence

Data on number of absent sessions are collected every term throughout primary school. For the purposes of this study, we will not differentiate between authorised and unauthorised absences. Instead, we will count total absences, measured as a percentage of available school half days that the pupil was absent, and persistent absence (absent from ≥10% of possible sessions during the school year)[28]. We will also analyse the subgroup of health-related absences, recorded as "due to a doctor or dentist's appointment" (henceforth referred to as medical absences), or "due to illness".

Additional variables

Results will be presented stratified by sex at birth recorded in HES and school year (the academic year runs from 1st September to 31st August the following year). School year

will be determined based on the school year indicator recorded in each January School Census: Reception (age 4/5) to Year 6 (age 10/11). We will assume that the small number of children with missing data on school year are in the expected school year for their date of birth.

In secondary analyses, we will explore whether differences in hospital admission and absence rates between children with neurodisability and their peers vary by five socioeconomic and demographic characteristics, measured at school entry (January School Census of Reception, age 4/5). If data are missing in Reception, we will use the earliest complete recoding available in any subsequent January School Census (usually Year 1), under the assumption that these characteristics are unlikely to change during primary school. Considered sociodemographic indicators are:

1. Income Deprivation Affecting Children Index (IDACI) quintile associated with the pupil's residential address. IDACI is an area-level measure of the proportion of children under the age of 16 living in low-income households. We will retain a separate category for children with missing IDACI.
2. Whether a pupil was recorded as eligible for free school meals (yes/no).
3. Government Office Region of residence associated with the pupil's residential address (North East, North West, Yorkshire and the Humber, East Midlands, West Midlands, East of England, London, South East, South West, or missing).
4. Mode of ethnicity across School Censuses (Asian or Chinese, Black, Mixed, White, any other ethnic group, or unclassified).
5. Child's birth month, using birth date recorded in HES birth admissions.

Statistical analysis

Descriptive analysis. We will describe the characteristics of the primary school cohort in Reception (age 4/5) for each exposure group (i.e., children with neurodisability first recorded before primary school, those with neurodisability first recorded during primary school, and those with no recorded neurodisability from birth to the end of primary school). We will give further information on the distribution of children with neurodisability in the cohort by neurodisability subtype recorded in health records (e.g., ASD, cerebral palsy, perinatal conditions affecting the brain, chromosomal anomalies).

For children with and without neurodisability, we will describe the proportion of children in the primary school cohort who appear in NPD for each school year, and the percentage of children who died before the end of primary school (31st August of Year 6, age 10/11, ascertained through linkage to ONS mortality data or discharge method in HES).

Planned and unplanned admissions. Results for children with neurodisability recorded before start of primary, during primary school and with no record of neurodisability before end of primary school will be presented by school year (Reception to Year 6), overall and stratified by sex.

We will calculate rates of planned and unplanned hospital admissions by dividing the total number of planned and unplanned admissions during a given school year by total person-time at risk (expressed in days) in the academic year. For each cohort member, time at risk during a given academic year is the number of days between 1st September and the earliest of either 31st August the following year or death, minus time spent in admitted patient care (APC). We discount time spent in APC since a child cannot be at risk of readmission to hospital if they are already admitted.

We will calculate the proportion of children with ≥1 planned and ≥1 unplanned hospital admission, by sex and school year, by dividing the number of children with at least one admission during that school year by the total number of children alive at the start of the school year.

Finally, we will calculate the proportion of all days that children spend in hospital during primary school (for planned and unplanned admissions) which are contributed by children with neurodisability.

In addition to visualising these outcomes, we will use regression models to quantify relative differences in planned and unplanned hospital admission between children with neurodisability (recorded before primary school and during primary school) and their peers without recorded neurodisability, adjusting for socioeconomic and demographic characteristics and school year. In secondary analyses, we will explore whether differences between these groups widen or narrow over the course of primary school by testing for interaction between neurodisability and school year. Finally, we will describe whether differences between children with and without neurodisability vary by socioeconomic and demographic characteristics, by testing for interactions between indicators for these characteristics and neurodisability.

Absences. Results for children with neurodisability recorded before start of primary school, during primary school and with no record of neurodisability before end of primary school will be presented by school year (Reception to Year 6), overall and stratified by sex.

We will calculate rates of school absence (overall, medical, due to illness, and health-related) by dividing the number of absences in the school year by the total possible number of sessions among enrolled children during that school year.

We will calculate the proportion of children with persistent absence (≥10% of absent sessions) by dividing the number of children with a flag for persistent absence by the number of children registered in that school year in the January School Census.

As well as visualising these outcomes, we will use regression models to quantify relative differences in absence rates between children with neurodisability (recorded before primary school and during primary school) and their peers without neurodisability, adjusting for socioeconomic and demographic characteristics and school year. As described for hospital admissions, we will also explore whether differences in absence rates between these groups widen or narrow over the course of primary school, and whether they vary by socioeconomic and demographic characteristics.

Bias

In some cases, children with neurodisability may be misclassified, since we assume that if a child does not have a code indicative of neurodisability in their hospital records before the end of Year 6 (age 10/11), they do not have neurodisability and are included in the 'all other children' comparator group. We also note that children whose codes indicating neurodisability that are first recorded in HES during primary school may have been diagnosed before primary school.

In both instances, children with neurodisability who are misclassified are more likely to be those with milder forms of neurodisability who are likely to receive diagnosis and healthcare in primary care and community paediatrics settings. Since we expect that children with neurodisability (even in its milder forms) are likely to have worse outcomes than their peers without neurodisability, we expect that our analysis may underestimate the difference between children with neurodisability and all other children. Rates of hospital admission and school absence themselves may be overestimated, since children included in the neurodisability group are likely to have more severe versions of neurodisability than those who were not identified.

Sensitivity analyses

We will provide additional information on the characteristics of children in the primary school cohort compared to all children born in English NHS-funded hospitals between 1st September 2003 and 31st August 2008. We will also explore whether results differ when further stratifying by academic year of birth, to check whether improvements in coding and diagnosis of disability across cohorts have substantially affected our findings.

Strengths, limitations, and opportunities for further research

Strengths of this study will include its use of linked health and education data covering a large number of children born in England across several years (forming several school year cohorts). Linkage of health and education data means that children with neurodisability can be identified by their hospital records. The large sample size means that differences in admissions and absence rates between children with and without neurodisability recorded before end of primary school can be stratified by socioeconomic and demographic indicators.

This study will also has limitations. Our analysis will focus on hospital admissions, rather than healthcare contacts more widely. Not all healthcare contacts resulting in health-related absences are recorded in HES. While outpatient data has been recorded since 2003/2004 and is available in HES, many other types of planned care are not included. Contacts with primary care and community paediatrics will not be recorded in HES, and children with neurodisablity attending special schools may receive additional care at school, which will also be missed. Accident and Emergency (A&E) data in HES was experimental until 2012/2013, and the percentage of attendances captured remained <85% until 2014/15[27], such that no cohort included in our study had A&E data available from Reception. Since our analysis focuses on hospital admissions, reflecting more serious planned interventions or unplanned health problems which are not easily dealt with in primary care, rather than healthcare contacts more generally, interpretation of our results is less impacted by certain types of care not being recorded in HES. However, since this study treats health-related school absence as an outcome, the impact of healthcare contacts beyond hospital admissions on education will still be captured to some extent.

Finally, our research will describe differences between children with neurodisability and their peers for hospital admissions and absences separately. Further research may seek to explore the extent to which health-related absences in NPD can be explained through hospital contacts captured in HES.

Data availability statement

No data are associated with this article.

Acknowledgements

We would like to acknowledge all children and families whose de-identified data are used in this research. We would also like to acknowledge the contribution of the wider HOPE Study team to this work: Sarah Barnes, Kate Boddy, Kristine Black-Hawkins, Lorraine Dearden, Bianca De Stavola, Johnny Downs, Martin Doyle, William Farr, Tamsin Ford, Lucy Karwatowska, Kate Lewis, Matthew Lilliman, Stuart Logan, Jacob Matthews, Vincent Nguyen, Jugnoo Rahi, Jennifer Saxton, Joachim Tan, and Isaac Winterburn. We thank Ruth Blackburn, Matthew Jay, Farzan Ramzan, and Antony Stone for ECHILD database support. Thank you to Kate Lewis and Vincent Nguyen for their feedback on an early version of this protocol.

References

1. Morris C, Janssens A, Tomlinson R, *et al.*: **Towards a definition of neurodisability: a Delphi survey.** *Dev Med Child Neurol.* 2013; **55**(12): 1103–1108.
PubMed Abstract | Publisher Full Text

2. Surveillance of Cerebral Palsy in Europe: **Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE).** *Dev Med Child Neurol.* 2000; **42**(12): 816–824.
PubMed Abstract

3. Public Health England: **National congenital anomaly and rare disease registration service: congenital anomaly statistics 2018.** London: Public Health England, 2020.
Reference Source

4. Carter B, Bennett CV, Jones H, *et al.*: **Healthcare use by children and young adults with cerebral palsy.** *Dev Med Child Neurol.* 2021; **63**(1): 75–80.
PubMed Abstract | Publisher Full Text

5. Meehan E, Reid SM, Williams K, *et al.*: **Hospital admissions in children with cerebral palsy: a data linkage study.** *Dev Med Child Neurol.* 2017; **59**(5): 512–519.
PubMed Abstract | Publisher Full Text

6. Meehan E, Williams K, Reid SM, *et al.*: **Comparing emergency department presentations among children with cerebral palsy with general childhood presentations: a data linkage study.** *Dev Med Child Neurol.* 2017; **59**(11): 1188–1195.
PubMed Abstract | Publisher Full Text

7. Paget SP, Mcintyre S, Schneuer FJ, *et al.*: **Outpatient encounters, continuity of care, and unplanned hospital care for children and young people with cerebral palsy.** *Dev Med Child Neurol.* 2023; 1–11.
PubMed Abstract | Publisher Full Text

8. Fleming M, Fitton CA, Steiner MFC, *et al.*: **Educational and health outcomes of children and adolescents receiving antiepileptic medication: Scotland-wide record linkage study of 766 244 schoolchildren.** *BMC Public Health.* 2019; **19**(1): 595.
PubMed Abstract | Publisher Full Text | Free Full Text

9. Esperanza RA, Evans A, Tucker D, *et al.*: **Hospital admissions in infants with Down syndrome: a record-linked population-based cohort study in Wales.** *J Intellect Disabil Res.* 2022; **66**(3): 225–239.
PubMed Abstract | Publisher Full Text | Free Full Text

10. Prasad V, Rezel-Potts E, White P, *et al.*: **Use of healthcare services before diagnosis of attention-deficit/hyperactivity disorder: a population-based matched case-control study.** *Arch Dis Child.* 2024; **109**(1): 46–51.
PubMed Abstract | Publisher Full Text | Free Full Text

11. Fleming M, Fitton CA, Steiner MFC, *et al.*: **Educational and health outcomes of children treated for attention-deficit/hyperactivity disorder.** *JAMA Pediatr.* 2017; **171**(7): e170691.
PubMed Abstract | Publisher Full Text | Free Full Text

12. Bebbington A, Glasson E, Bourke J, *et al.*: **Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983-1999: a population-based cohort study.** *BMJ Open.* 2013; **3**(2): e002356.
PubMed Abstract | Publisher Full Text | Free Full Text

13. Fleming M, Salim EE, Mackay DF, *et al.*: **Neurodevelopmental multimorbidity and educational outcomes of Scottish schoolchildren: a population-based record linkage cohort study.** *PLoS Med.* 2020; **17**(10): e1003290.
PubMed Abstract | Publisher Full Text | Free Full Text

14. John A, Friedmann Y, DelPozo-Banos M, *et al.*: **Association of school absence and exclusion with recorded neurodevelopmental disorders, mental disorders, or self-harm: a nationwide, retrospective, electronic cohort study of children and young people in Wales, UK.** *Lancet Psychiatry.* 2022; **9**(1): 23–34.
PubMed Abstract | Publisher Full Text | Free Full Text

15. Hatton C: **School absences and exclusions experienced by children with learning disabilities and autistic children in 2016/17 in England.** *Tizard Learn Disabil Rev.* 2018; **23**(4): 207–212.
Publisher Full Text

16. Jay MA, Sanders-Ellis D, Blackburn R, *et al.*: **Umbrella systematic review finds limited evidence that school absence explains the association between chronic health conditions and lower academic attainment.** *Front Public Health.* 2023; **11**: 1122769.
PubMed Abstract | Publisher Full Text | Free Full Text

17. Zylbersztejn A, Lewis K, Nguyen V, *et al.*: **Evaluation of variation in special educational needs provision and its impact on health and education using administrative records for England: umbrella protocol for a mixed-methods research programme.** *BMJ Open.* 2023; **13**(11): e072531.
PubMed Abstract | Publisher Full Text | Free Full Text

18. Mc Grath-Lone L, Libuy N, Harron K, *et al.*: **Data resource profile: the Education and Child Health Insights from Linked Data (ECHILD) database.** *Int J Epidemiol.* 2022; **51**(1): 17–17f.
PubMed Abstract | Publisher Full Text | Free Full Text

19. Herbert A, Wijlaars L, Zylbersztejn A, *et al.*: **Data resource profile: Hospital Episode Statistics Admitted Patient Care (HES APC).** *Int J Epidemiol.* 2017; **46**(4): 1093–1093i.
PubMed Abstract | Publisher Full Text | Free Full Text

20. Jay MA, Grath-Lone LM, Gilbert R: **Data resource: the National Pupil Database (NPD).** *Int J Popul Data Sci.* 2019; **4**(1): 1101.
PubMed Abstract | Publisher Full Text | Free Full Text

21. Department of Education: **Elective home education: call for evidence 2018. government consultation response.** London: Department of Education; 2019.
Reference Source

22. Long D, Danechi S: **Home education in England.** London: House of Commons Library; Report No.: 05108, December, 2013.
Reference Source

23. Mc Grath-Lone L, Etoori D, Gilbert R, *et al.*: **Changes in adolescents' planned hospital care during the COVID-19 pandemic: analysis of linked administrative data.** *Arch Dis Child.* 2022; **107**(10): e29.
PubMed Abstract | Publisher Full Text | Free Full Text

24. Etoori D, Harron KL, Mc Grath-Lone L, *et al.*: **Reductions in hospital care among clinically vulnerable children aged 0–4 years during the COVID-19 pandemic.** *Arch Dis Child.* 2022; **107**(10): e31.
PubMed Abstract | Publisher Full Text | Free Full Text

25. Libuy N, Harron K, Gilbert R, *et al.*: **Linking education and hospital data in England: linkage process and quality.** *Int J Popul Data Sci.* 2021; **6**(1): 1671.
PubMed Abstract | Publisher Full Text | Free Full Text

26. Zylbersztejn A, Cant A, Gimeno L, *et al.*: **Phenotyping neurodisability in hospital admissions records in England: a descriptive study of a national birth cohort.** In preparation. 2024.

27. Medicines & Healthcare products Regulatory Agency, Clinical Practice Research Datalink: **Hospital Episode Statistics (HES) Accident and Emergency and CPRD primary care data Documentation (Set 21).** London: Medicines & Healthcare products Regulatory Agency; Report No.: 1.8. March, 2021.
Reference Source

28. Department of Education: **Pupil absence statistics: methodology.** 2023; [cited 2024 Feb 26].
Reference Source

Open Peer Review

Current Peer Review Status: ? ? ✔ ?

Version 1

Reviewer Report 14 August 2024

https://doi.org/10.3310/nihropenres.14717.r32442

?

Simon Paget
The University of Sydney, Sydney, New South Wales, Australia

Thank you for the opportunity to review this manuscript. The authors describe a protocol for a data linkage study to examining relationships between (planned and unplanned) hospital admissions and school absences in primary school-aged children with and without neurodisabilities.

The protocol is well written, and generally clear and easy to follow.

The methodology to ascertain the population (i.e., children born in an NHS hospital between 1/9/2003 and 31/8/2008, and enrolled at (state-funded) school at age 4/5) using administrative data appears robust, and the small number of children missed in this way (e.g., through migration, private school) are unlikely to negatively impact the study's findings.

Identifying children with neurodisability from this population will be more challenging using the proposed methodology i.e., ICD-10 codes from hospital admission data. It seems likely that many of the children in the (total population) with more common neurodisabilities (e.g., learning disabilities, attention deficit hyperactivity disorder (ADHD), autism spectrum disorders) may have either never been admitted to hospital during the study period (e.g. ADHD), or have been admitted for another reason, in which case the ICD-10 codes may not be accurate (i.e., diagnoses missed) (e.g. a child with ADHD admitted with appendicitis). As the authors note, this methodology is likely to skew to a more severe neurodisability population (e.g. see a recent article on CP = Paget SP, McIntyre S, Lain S, Goldsmith S, Nassar N. A comparison of cohorts of children with cerebral palsy from a population register and hospital admission data: A data linkage study. Paediatr Perinat Epidemiol. 2024; 38: 22-30. doi:10.1111/ppe.13024), and perhaps not ascertain comorbidities well. Of note here, the most common causes of hospitalisation here often are unrelated to the neurodisability but are due to common comorbidities (e.g., greater risk of respiratory illnesses, epilepsy). I note the plan to index the code lists, which is welcome.

I think that one issue that the authors should consider more is to explicitly state the specific research question this study aims to answer. This doesn't feel clearly articulated in the protocol at

present. For example, the abstract and introduction provide evidence that children with neurodisability are already known to have a higher frequency of hospital admissions and school absences than the general population, so the rationale to repeat that in this study is perhaps unclear. The Methods section suggests two outcomes i.e., hospital admissions (planned / unplanned), and school absence. The introduction (to my reading) sets up for a study that will test associations between hospital admissions (independent variable) and school absences (dependent variable), but Methods suggests a range of potentially exploratory analyses. A couple of additional points here. I wonder whether classifying neurodisability as early or later (therefore creating three groups including the general population) adds a more complexity that is warranted. Secondly, there are, of course, known associations of socioeconomic disadvantage and frequency of hospital admissions. I'd suggest that the authors consider adjusting for these as socioeconomic variables as covariates in their proposed analysis. Of course, there are more disruptions to education because of health care other than hospital admissions. Primary care, disability related allied health interventions, and outpatient appointments are likely more numerous and potentially impacting - however, I think there is value in quantifying the impact of hospital admissions as an area that can potentially be avoided / minimised with good care (this is noted in the limitations).

Some explanation of how the temporal relationships between hospital admissions and school absences are going to be considered would also be helpful. If a hospital admission happens on a weekend or during a school holiday. Or are hospital admissions going to used as a proxy for ill health?

Abstract
- A clear statement of the research question would be helpful here.
Introduction
- Also would benefit for clear statement of research question.
Methods
- Generally clear and well written.
- Clarifying research question would help perhaps clarifying exposures (neurodisability, admissions?), covariates (sex, measures of socioeconomic disadvantage) and outcomes (school absences?).
- As above, I'm not clear that splitting groups based on timing of neurodisability first admission is particularly meaningful (but happy to be educated).
- Further thought about how to categorise the main outcome variable would be useful (is this going to be linear regression, poisson or logistic?)

I look forward to hearing more about your project as it progresses, and will be interested in the results.

Is the rationale for, and objectives of, the study clearly described?

Partly

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?
Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Paediatrics, disability, data linkage, health services research

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 08 August 2024

https://doi.org/10.3310/nihropenres.14717.r31663

Rachel Knight Lozano
University of Plymouth, Plymouth, England, UK

This paper describes the protocol for an England-based observational data linkage study of health and educational outcomes in primary school children with neurodisability.

The rationale for this study is clear, well-reasoned and compelling, acknowledging key issues of time spent in hospital and participation in school for children with neurodisability. The background highlights an important gap in record data linkage literature, in which healthcare usage and school attendance in children with neurodisability are each considered in isolation. Authors seek to address this through an observational study of health and educational outcomes. Although a clear aim of the wider research programme is stated, clear objectives of this specific observational study would add value to this protocol and support readers to align these with the proposed method and data analysis.

The method is well written, structured through a clear framework of population, exposure and outcomes. Authors consider a range of relevant and inclusive health and educational records for data collection whilst acknowledging the anticipated limitations of data coverage beyond NHS-funded health and state-funded education. Alongside the outcomes of interest, authors consider important socioeconomic and demographic variables both in their data collection and analysis plan that may impact on their outcomes of interest in children with neurodisability.

The timeframe for data collection appears well-reasoned, with consideration of the COVID pandemic and its impact on outcomes of health and education. It is not clear to the reader why the population age addresses primary school only; the health database records provide data sets from 1995 (ECHILD), 1997 (HES) and 1998 (mortality data), which presents an opportunity to extend the upper age limit age beyond 10/11, capturing important secondary school data as well. It would be useful to further understand the author's reasoning for this.

The authors are very transparent about the risk of bias and limitations of this study. However, this observational study has potential to provide a platform for future research in the field of both health and educational neurodisability research, which is somewhat under-emphasised. More detail regarding anticipated opportunities for future research would add value to this protocol.

Is the rationale for, and objectives of, the study clearly described?
Partly

Is the study design appropriate for the research question?
Yes

Are sufficient details of the methods provided to allow replication by others?
Yes

Are the datasets clearly presented in a useable and accessible format?
Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: childhood neurodisability; chest health outcomes; prevention of chest-related illness; chest-related health usage

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 08 August 2024

https://doi.org/10.3310/nihropenres.14717.r32443

?

Rachael Marpole
Perth Children's Hospital Foundation, Perth, Western Australia, Australia

Article on school absences in children with neurodisability from hospital admissions.

Introduction
- Third paragraph: Change in school absences over time? (Early primary versus upper primary) - Is this being assessed as well?

- Fourth paragraph: Will you look at neurodisability (diagnosed at any time) versus no neurodisability? Many of these conditions are present from birth, i.e. Autism, ADHD, and learning disability, it doesn't matter when their diagnosis is first recorded. Internalised autism is diagnosed

later and not necessarily because it is less severe.

Methods - Study population
- Why just singletons? Is it because it will be difficult to link hospitals with school data as they have the same birthdate and address? Multiples are more likely to be premature and have cerebral palsy and other complications.

Methods - Follow up
- Will the dates of admissions be looked at? As most admissions happen in winter and more likely to be unplanned.

Methods - Exposure - neurodisability
- This will miss children with neurodisability who are never admitted. Could you cross-reference with the school data to add children who are receiving special educational needs support?

Methods - Outcomes -planned and unplanned hospital admissions
- Will admission days on weekends and school holidays be counted? As school can't be missed if it is not on.

Is the rationale for, and objectives of, the study clearly described?
Yes

Is the study design appropriate for the research question?
Yes

Are sufficient details of the methods provided to allow replication by others?
Yes

Are the datasets clearly presented in a useable and accessible format?
Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Cerebral palsy, Respiratory disease in neurodisability, paediatrics

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 30 May 2024

https://doi.org/10.3310/nihropenres.14717.r31671

?

Laura Cowley
Swansea University, Swansea, Wales, UK

This is a well-written and well-thought out study protocol that describes in detail a planned data linkage study to examine hospital admissions and school absences amongst children with neurodisability in England. I have a few suggestions which may improve the clarity of the manuscript.

Abstract
In my opinion the background section of the abstract lacks detail on why the research questions are important to address (see also my comments on the Introduction, below). Similarly, the conclusions section of the abstract could state how the findings might contribute to policy and practice in the health and education fields for children with neurodisability. The word "group" should be "groups".

Introduction
In general the introduction gives a good and succinct overview of the previous literature and the problem to be addressed, however I think what is missing is why this work is important and how the findings will help children with neurodisability to get better healthcare and education? It seems obvious and a bit of a foregone conclusion that children with neurodisability will have both a greater number of hospital admissions and a greater number of school absences compared to their non-disabled peers. The authors touch on why it is important to understand how health needs affect schooling, but there is a lack of detail about why it is important to compare hospital admissions for the two groups, and why it may be important to differentiate between planned and unplanned hospital admissions. How will knowing about these potential differences help to inform policy and practice and healthcare for children with neurodisability?

Last sentence - "provision of" should read "provision on"

Methods
My first thought is that one of the outcomes is hospital admissions, but neurodisability will be identified using ICD-10 codes, so by definition, children will have to have been admitted to hospital in order to be recorded as having a neurodisability. Is there circular reasoning here and can the authors comment on this? Is neurodisability more likely to be recorded in GP data than hospital data? Is it possible to also look at whether neurodisability is recorded in the education data, and to compare the diagnoses across the two datasets?

The datasets, linkage and study population are all well-described and I like Table 1 to describe the cohort. Although there is justification for the end date of the cohort (2008) I might add in a justification for the start date (2003) too, for completeness. I am a little confused by the following sentence: "Children's hospitalisation rates can be characterised across their primary school years whether they are in state-funded school (and so feature in a school census in NPD) or not." Surely

this is not relevant, since children are only included in the cohort if their NHS record links to NPD, and NPD only includes state-funded schools anyway? The authors mention that they cannot see emigration in the data, but is it possible to see transition to home-schooling, independent non-state schooling or off-rolling in the data? Or is this just assumed by non-enrollment in a given year?

The sentence beginning "HES and NPD records" is very long, consider splitting it.

The authors mention that "the codes used to identify cases were collated from published papers", please reference each of the papers that you sourced codes from. It is great to see that the code lists will be made available.

It would be good to see a bit more detail on the statistical analysis techniques that will be used. The authors mention regression, but what type of regression will be used? Logistic, Cox, Poisson?

Strengths, etc.
I'm not sure I understand the following sentence: "Linkage of health and education data means that children with neurodisability can be identified by their hospital records." Neurodisability will only be defined using hospital records, you don't need to link to education data to do this?

"This study will also has limitations" - "has" should be "have".

Is the rationale for, and objectives of, the study clearly described?
Partly

Is the study design appropriate for the research question?
Yes

Are sufficient details of the methods provided to allow replication by others?
Partly

Are the datasets clearly presented in a useable and accessible format?
Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Children's health and social care, data linkage, administrative data

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.