



Education & Child Health Insights from Linked Data



An Introductory Guide for Researchers



<Version 2.0>

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Acronyms

A&E	Accident and Emergency
ADR UK	Administrative Data Research UK
AOC	Assured Organisational Connectivity
AP	Alternative Provision
APC	Admitted Patient Care
aPMR	anonymised Pupil Matching Reference
CC	Critical Care
CIN	Children in Need
CLA	Children Looked After
CPP	Child Protection Plans
CSDS	Community Services Data Set
DEA	Digital Economy Act
DfE	Department for Education
ECHILD	Education & Child Health Insights from Linked Data
EHC	Education, Health and Care
EYFSP	Early Years Foundation Stage Profile
FAE	Finished Admission Episodes
FCE	Finished Consultant Episode
FE	Finished Episode
FSM	Free School Meals
GIAS	Get Information about Schools
GP	General Practitioner
HES	Hospital Episode Statistics
ICD	International Classification of Diseases
ILR	Individualised Learner Record
KS	Key Stage
MHMDs	Mental Health Minimum Data Set
MHSDs	Mental Health Services Data Set
MPS	Master Person Service
MSDS	Maternity Services Data Set
NCCIS	National Client Caseload Information
NEET	Not in Education, Employment or Training
NHSE	National Health Service England
NIHR	National Institute for Health and Care Research
NPD	National Pupil Database
ONS	Office for National Statistics
OP	Outpatient
OPCS	Office of Population Censuses and Surveys
PPiE	Public and Patient Involvement and Engagement
PRU	Pupil Referral Unit
PVI	Private Voluntary and Independent
RAP	Research Accreditation Panel
SEN	Special Educational Needs
SRS	Secure Research Service
TPI	Token Person ID
UPN	Unique Pupil Number

1 Introduction

Education & Child Health Insights from Linked Data (ECHILD)

This guide introduces researchers to the **ECHILD** database by providing a broad overview of its coverage, content and creation. ECHILD is a linkable collection of longitudinal, administrative datasets from NHS hospitals, all state school education and children's social care services for the whole population of children and young people in England.

The administrative datasets from education, social care and hospital contacts that have been brought together in ECHILD are well-documented by data providers and the research community. This user guide does not duplicate existing detailed information about these source datasets. Instead, we highlight key aspects that have implications for the potential uses, strengths and limitations of ECHILD. Variables that are included in ECHILD are available separately in the ECHILD Data Catalogue; [Appendix 1](#) lists some useful resources related to the constituent datasets.

1.1 Partnerships

The creation of [ECHILD](#) was led by University College London in partnership with NHS England (NHSE) and the Department for Education (DfE), and funded by ADR UK.[1, 2]

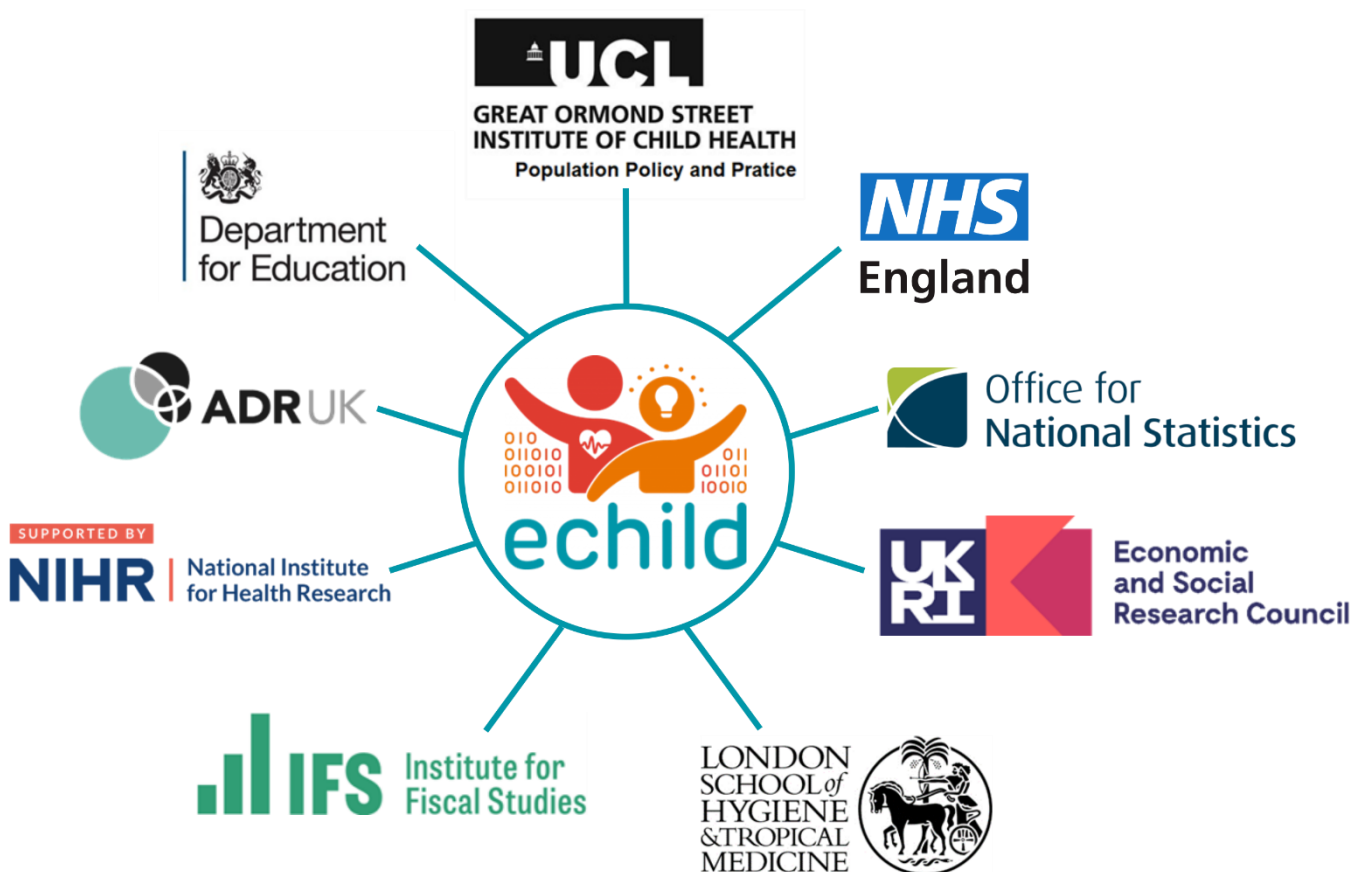


Figure 1.1 ECHILD project stakeholders

Approvals to create and evaluate ECHILD as reported in this user guide were granted by DfE (DR200604.02) and NHSE (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 21/SW/0159) and is overseen by the UCL Great Ormond Street Institute of Child Health's Joint Research and Development Office (20PE16). Further details, including the associated privacy notice, are on the [ECHILD](#) website. ECHILD is available for re-use through the Office for National Statistics Secure Research Service (ONS SRS).

2 ECHILD

2.1 Information Scope

In England, information on a child's journey through education and social care is recorded in administrative records held by the Department for Education (the National Pupil Database; NPD). NHS England holds information about all NHS hospital contacts (captured in Hospital Episode Statistics; HES). HES records are generated for the purposes of service delivery, e.g., to support financial reimbursement for treatment relating to a hospital stay.

Within ECHILD, healthcare, education and social care records have been linked to create a longitudinal database that follows children over time. The database is very useful for research as health, education and social care trajectories are strongly interrelated from childhood to adulthood. ECHILD provides a valuable opportunity to explore these relationships and to generate evidence for policy and practice.[3]

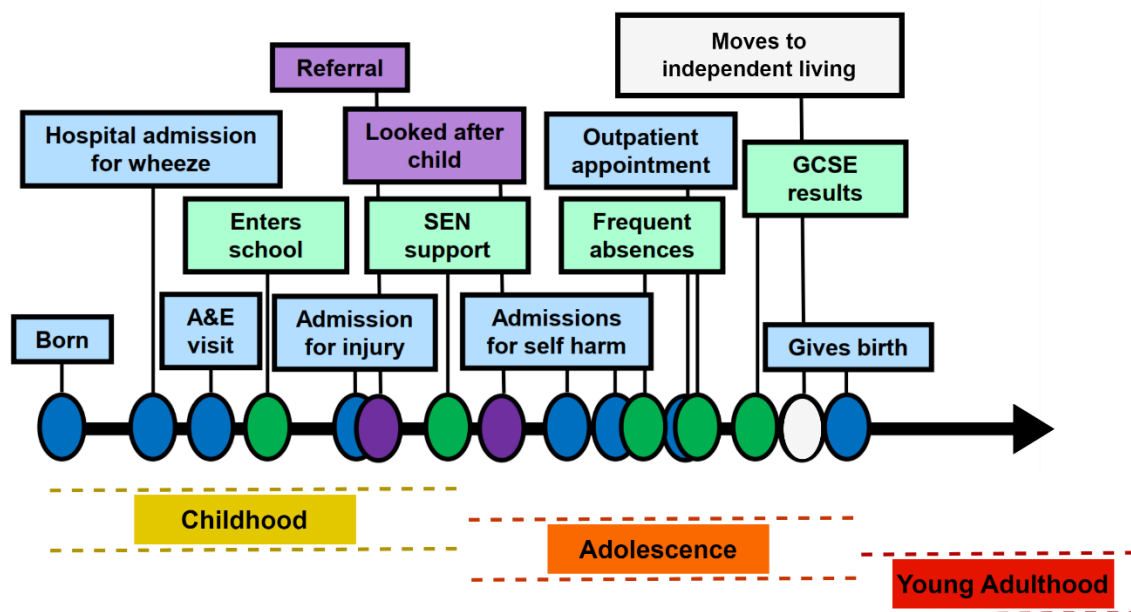


Figure 2.1 Education, Social Care & Health data captured throughout the life of a hypothetical female

2.2 Key research purposes

ECHILD will only be used for research that has a clear public benefit in England and Wales to improve the health and well-being of children and young people accessing health, education and social care services. The specific research purposes (permitted uses) are below (in bold) with examples of relevant research questions.

1.	Informing preventative strategies by Healthcare and Education services e.g., do disabled children attending schools, or living in areas that provide a good level of disability support in school or through social care services, have lower rates of unplanned hospital contacts compared with less supportive schools/areas?
2.	Informing children and their parents e.g., about variation in special educational needs support and outcomes for children with chronic health conditions or disability.
3.	Informing education and clinical practice e.g., investigating whether associations between chronic health conditions and lower school attainment are explained by school absence.
4.	Identifying groups who could benefit from intervention e.g., what are the health outcomes of children post age 16 who have contact with social care services or have special educational needs?
5.	Understanding the most effective methods for working with linked health and education data e.g., what are the most effective methods for working with linked health and education data?

2.3 ECHILD Overview

Key features

- ❖ Population-based cohort of children & young people in England born between 01/09/1984 to date (with annual updates).
- ❖ Longitudinal data from birth to mid-adulthood or the most recent year available, e.g., children born in 1984 will be aged 38 in HES records in 2022.
- ❖ Pseudonymised datasets that do NOT include any identifiable information (name, address, postcode, date of birth, Unique Pupil Numbers or NHS numbers).
 - De-identified NHSE Hospital Episode Statistics administrative datasets (listed in Section 3).
 - DfE National Pupil Database, including the Children Looked After Return and Children in Need Census.
 - ONS Mortality data.
- ❖ Linkage rates
 - of births in 1996/7, 94% of children in the National Pupil Database linked to a hospital record.
 - of births in 2004/05, 98% of children in the National Pupil Database linked to a hospital record.
- ❖ Linked data for an estimated 20 million individuals.

ECHILD includes information from Hospital Episode Statistics (HES), including mortality data provided by the Office for National Statistics (ONS). It also contains education and social care information from the National Pupil Database (NPD). Two pseudonymised IDs are included, one specific to HES data, the other specific to NPD, and individuals are linked across multiple records over time using these IDs. Both the HES IDs and NPD IDs are mapped together and stored within a 'Pseudonymised Bridging file' located within the ONS SRS.[4]

ECHILD can only be accessed by approved researchers in the ONS SRS, and researchers are not permitted to try to re-identify individuals. Furthermore, any results of analyses (tables or figures) are checked by ONS staff for potential disclosure risk before they can be exported from the ONS SRS.

Figure 2.2 presents an overview of how the ECHILD database is structured, with further details about the linkage algorithm provided in [Appendix 2](#) and information about the 'Attribute Data' for HES and NPD provided in Section 3.

2.3.1 Education dataset pseudo-identifier

When a pupil first attends a state-funded school in England e.g., nursery or primary school, or has an education, health and care (EHC) plan put in place [5] they are allocated a 'Unique Pupil Number' (UPN), which remains with the pupil throughout their school career regardless of any change in school or local authority. Social care data is included in the NPD for children who have a UPN. Children receiving social care preschool entry who never have social care during their school years are therefore not included in ECHILD. UPNs facilitate the transfer of school-based education and attainment data between schools, local authorities and central government and are stored within the NPD. Within ECHILD, a nationally unique and anonymised child-level identifier called the 'Anonymised Pupil Matching Reference (aPMR)' can be used to link data across different years of data collection.[5, 6]

2.3.2 Healthcare dataset pseudo-identifier

The pseudonymised linkage spine is generated by NHS England. NHS England receives real-world identifiers provided by the DfE (name, date of birth, sex, postcode) and the aPMR. The real-world identifiers from education and NHS healthcare data are linked separately from any health or education information.[7] For each matched pair of identifiers from education and health, NHS England attaches a pseudonymised ID called a 'Token Person ID' (TPI).[8] The TPI is created specifically for ECHILD and cannot be used to identify anyone.

2.4 ECHILD database structure

Overview of processes involved in the creation of the ECHILD database.

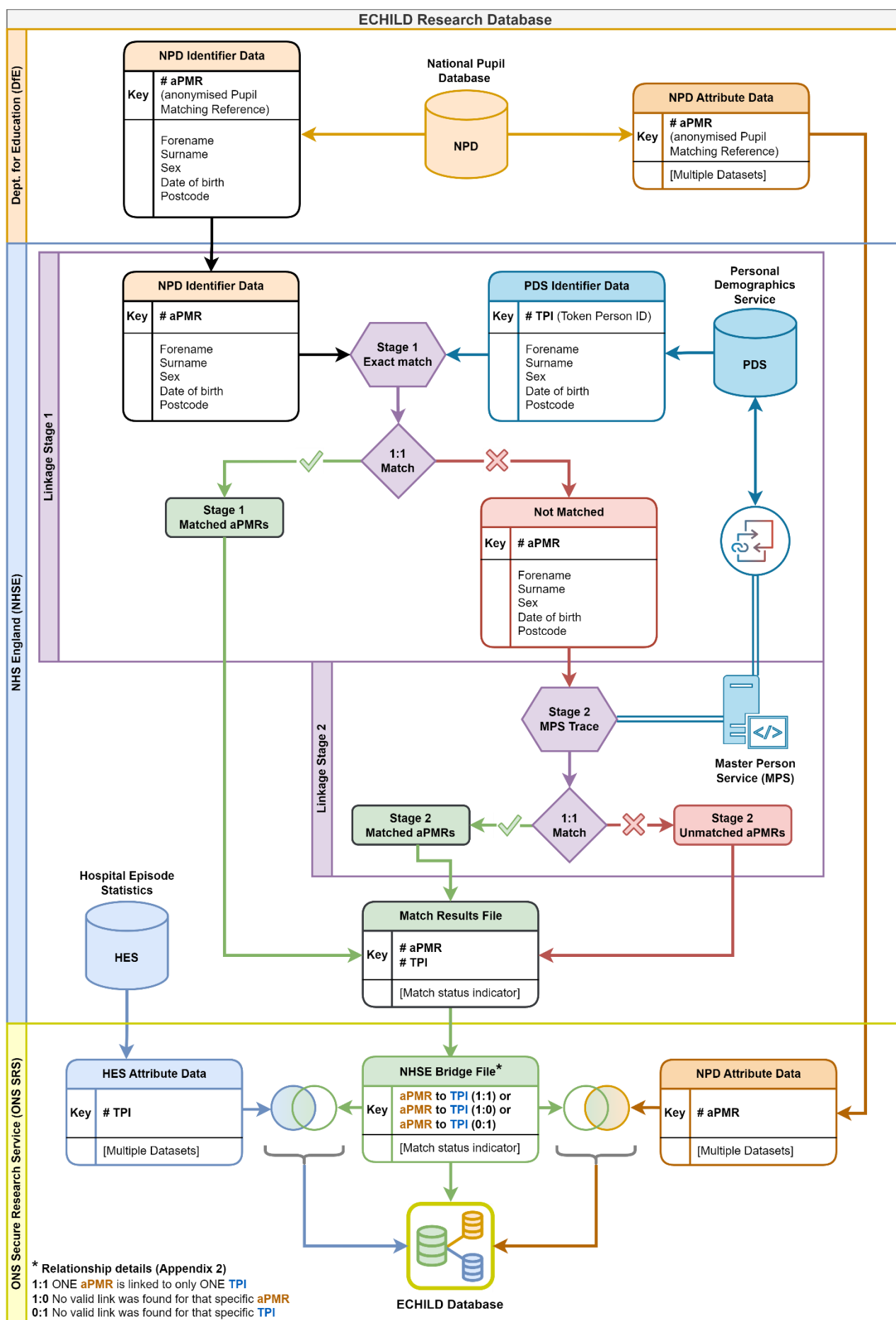


Figure 2.2 Formation of the ECHILD database

3 ECHILD Attribute data

For all students in English state schools, administrative data are routinely collected about their education (stored within NPD), as is information on all contacts with healthcare services (stored within HES). ECHILD is a collection of themed datasets, or ‘Attribute data,’ comprised of multiple tables that span multiple years, stored as separate files that are linkable using the aPMR, TPI and NHSE ‘Pseudonymised Bridging file’.

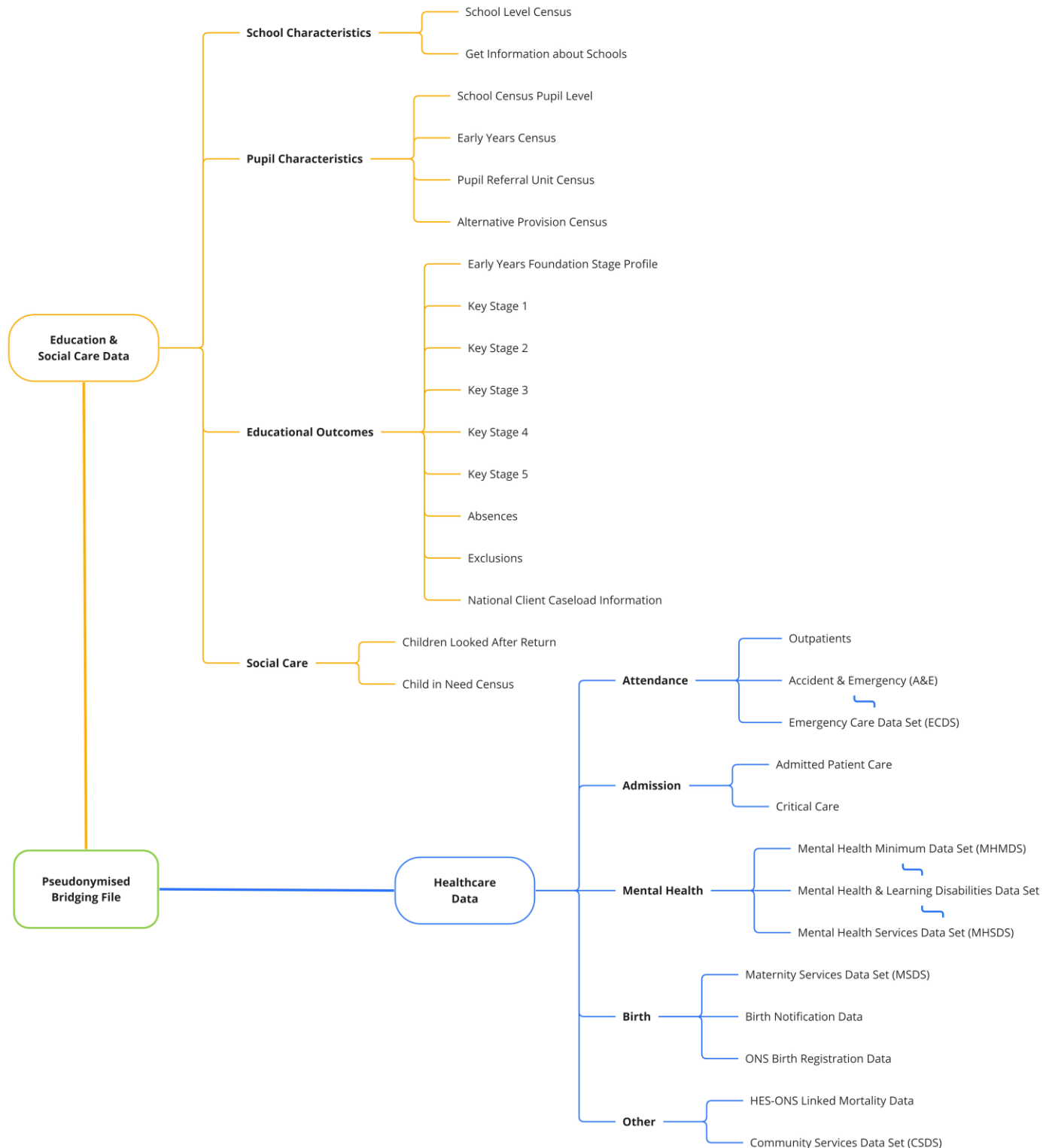


Figure 3.1 Conceptual representation of ‘Attribute data’ available within ECHILD

3.1 Data coverage (years)

Coverage of the Attribute data currently available within ECHILD (years of follow-up).

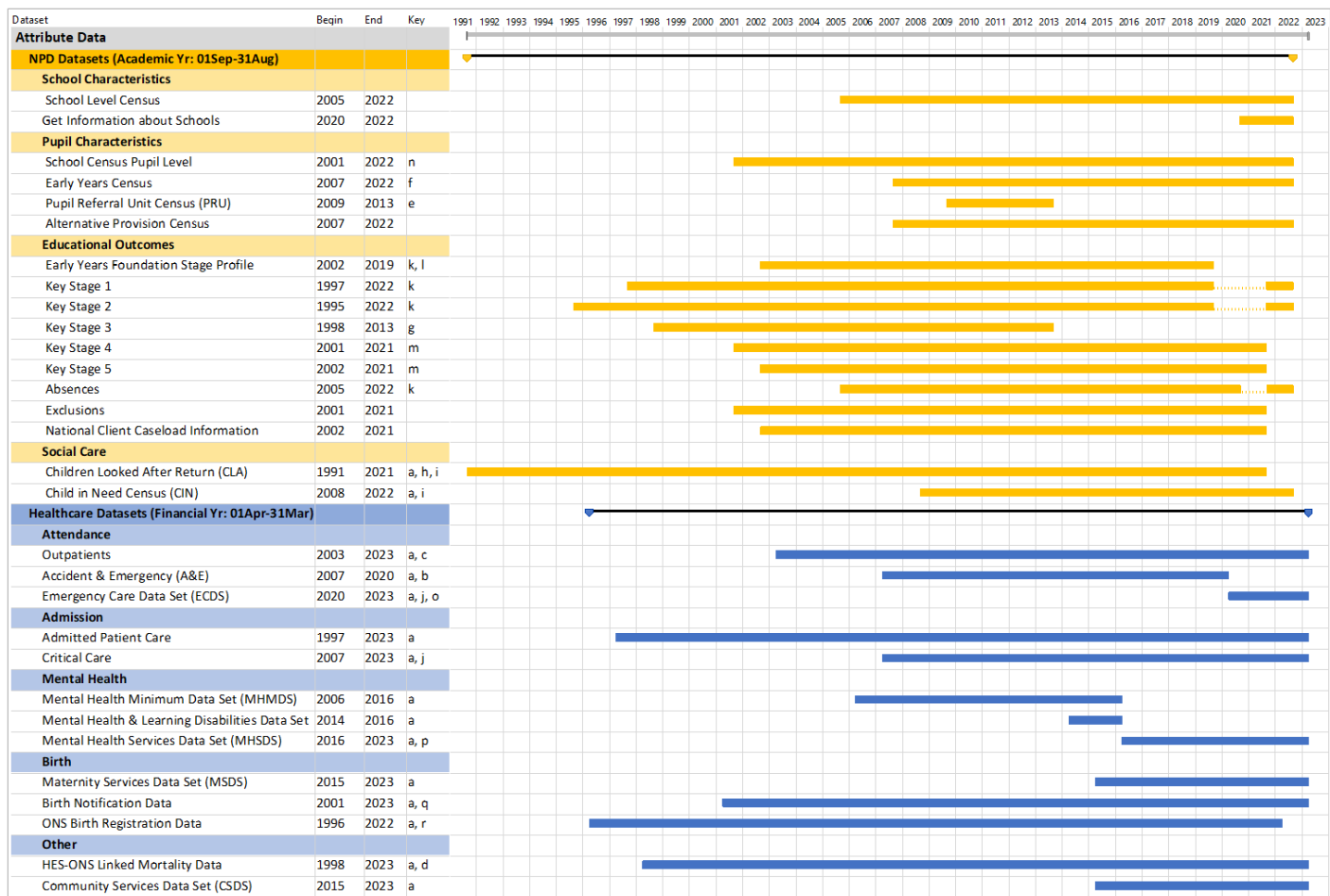


Figure 3.2 Timespan (years) covered by the Attribute data.

Key	Detail
a	HES data are collated by financial year (1st Apr to 31st Mar), which partially covers an academic year (1st Sep to 31st Aug).
b	Partial coverage as HES A&E data were experimental and did not have full national coverage.
c	Partial coverage as HES Outpatient data were experimental and did not have full national coverage.
d	Partial coverage of an academic year as ONS Mortality data were first linked to HES in January 1998.
e	The PRU Census were subsumed into the School Census Pupil Level from 2013/14.
f	The Early Years Census included 3- to 4-year-olds between 2007/08 and 2012/13. From 2013/14 it includes 2- to 4-year-olds.
g	Key Stage 3 assessments ceased after 2012/13.
h	Partial coverage of population as between 01/04/1992 & 31/03/2003, CLA data were only collected for a one-third sample (i.e., children with a day of birth divisible by 3).
i	Linkage between Education & Social Care modules of NPD began in April 2006 for CLA and April 2009 for CIN (partially complete until 2012, mainly applies to under 5-year-olds).
j	Not yet ingested to ONS SRS.
k	Not collected to help reduce the burden on educational and care settings during the coronavirus (COVID-19) pandemic.
l	Partial coverage as between the 2002/3 and 2005/6 academic years, data only on a 10% sample of children.
m	Not provided with standard institutional identifiers in 2019/20 and 2020/21 as evaluation of individual institutional performance during the pandemic years is not permitted.
n	From 2001/02 to 2004/05 annual census exists, from 2005/06 onwards census data are termly.
o	ECDS data from October 2017 to 2019/20 are considered pilot data, with ECDS formally replacing HES A&E in 2020/21.
p	MHSdS: v1.5 (from 2015/16 to 2018/19) up to v5.0 (from Oct 2021 to Mar 2022).
q	Data from October 2002.
r	Data from January 1996.

3.2 Hospital Episode Statistics

HES contains hospital records for all NHS patients in England, including patient demographics and standardised codes for diagnoses, symptoms and procedures relating to the care they have received.[9] The datasets are collected by NHSE from hospital care providers and curated on an ongoing basis. However, data from other health providers such as General Practitioners (GPs) or pharmacies are not included. HES datasets are collated by financial year and following processing and quality assessment, the finalised datasets are released for secondary use and remain unchanged thereafter.[10]

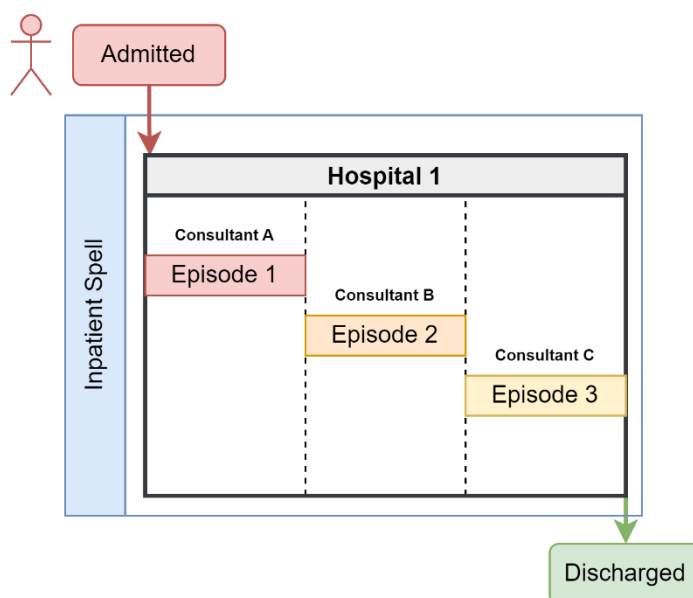
3.2.1 Admitted Patient Care

Records within the Admitted Patient Care (APC) dataset are called ‘hospital episodes’, and each episode relates to a period of care for a patient under a single consultant (consultant episode) within one hospital provider. The time from initial admission to discharge is called a ‘spell’, defined as ‘periods of continuous care in one provider institution’ and each admission spell can be made up of many episodes. APC data contain ‘Finished Admission Episodes’ (FAEs) which is the first episode in a spell of care, and ‘Finished Consultant Episodes’ (FCEs), which is a continuous period of care under one consultant.[10, 11] Only FCEs occurring within the financial year (up to midnight on 31st Mar) are included. Patients with an unfinished consultant episode in the current financial year will have their record represented as a finished episode in the next financial year of HES data.[12]

Inpatient spell (single hospital)

A hospital admission commences when a patient is initially admitted for care and ends when a patient is discharged, transferred, or dies.

One spell of admission encompasses multiple episodes of care under a different consultant.



Continuous Inpatient spell (across multiple hospitals)

In some instances, admitted patients that require specialised treatment may be transferred from one hospital to another more specialist hospital, e.g., transfer to a Children’s hospital.

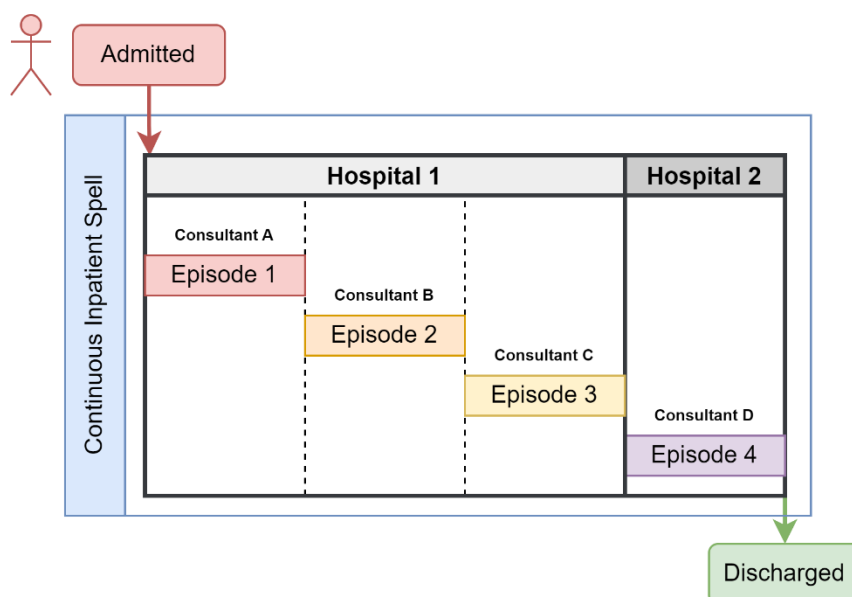


Figure 3.3 Hospital admission spells and episodes

3.2.2 Attribute data: Hospital attendance

Table 3.1 Overview of HES Attendance datasets

Dataset	Years	Details
Outpatients (OP) ¹	2003 to 2023	Outpatient appointments at English NHS hospitals and NHS-commissioned activity in the independent sector (regardless of whether the appointment was attended or not).[13] In 2003/04, the OP module was considered experimental and did not have complete coverage as not all providers completed data submissions.[14]
Accident & Emergency (A&E) ²	2007 to 2020	Attendance level dataset collecting information about the treatment received by patients attending A&E Departments, Minor Injury Units and Walk-In Centres, in England.
Emergency Care Data Set (ECDS) ²	2020 to 2023	In 2018, the A&E dataset was replaced by the ECDS which is now the national dataset for Urgent & Emergency care.[15, 16]

3.2.3 Attribute data: Admission

Table 3.2 Overview of HES Admission datasets

Dataset	Years	Details
Admitted Patient Care (APC) ¹	1997 to 2023	Episode-level dataset of patients admitted for treatment (i.e., requiring the use of a hospital bed), at NHS hospitals in England; includes delivery and birth data, up to 20 diagnostic codes per episode and procedure codes.[11]
Critical Care (CC) ¹	2007 to 2023	<p>Episode-level dataset of patients admitted for treatment and receiving Critical Care (intensive care or high dependency care) at NHS hospitals in England.</p> <p>Treatment in adult designated wards where constant support and monitoring are required to maintain at least one organ (i.e., an Intensive Care or High Dependency Unit).[17]</p>

¹ Diagnoses are recorded using the International Classification of Disease (ICD) version 10 and procedures are recorded using the Office of Population Censuses and Surveys (OPCS) version 4. Diagnoses and procedures have very low levels of completeness in the outpatient module (5% and 26%, respectively).[10]

² Bespoke codes are used to record diagnoses and treatments [18]; however, these are much more limited than ICD-10 and OPCS-4 codes. Prior to 2012/13, the A&E module was considered experimental and did not have complete coverage as not all providers completed data submissions.[19]

3.2.4 Attribute data: Mental Health

Table 3.3 Overview of Mental Health datasets

Dataset	Years	Details
Mental Health Services Data Set (MHSDS)	2016 to 2023	Patient-level dataset that records all activity relating to patients who receive assessments and treatment from Mental Health Services in England, where the patient has (or is thought to have): either a mental health condition; a need for support with their mental well-being; a learning disability; autism; or any other neurodevelopmental condition.[20]
Mental Health & Learning Disabilities Data Set	2014 to 2016	The Mental Health & Learning Disabilities Data Set Data is collected from the health records of individual children, young people and adults who were in contact with mental health services.[21]
Mental Health Minimum Data Set (MHMDS)	2006 to 2016	<p>The MHMDS was the preliminary dataset capturing data about the use of Mental Health Services in England.</p> <p>However, the MHMDS was superseded by the Mental Health & Learning Disabilities Data Set, which in turn was superseded by the MHSDS.</p>

3.2.5 Attribute data: Birth

Table 3.4 Overview of Birth datasets

Dataset	Years	Details
Maternity Services Data Set (MSDS)	2015 to 2023	The MSDS is a patient-level dataset that captures information about activity carried out by Maternity Services relating to a mother and baby(ies), from the point of the first booking appointment until the mother and baby(ies) are discharged from maternity services. The MSDS collects records of each stage of the maternity service care pathway in NHS-funded maternity services and includes information not recorded in HES.[22, 23]
Birth Notification Data	2001 to 2023	Birth notification is a document completed by the doctor or midwife present at birth occurring in an NHS facility in England, Wales and the Isle of Man. The baby's NHS Number is issued as part of the 'statutory notification of birth'. Birth notification data includes information that is not found in the birth registration data such as gestation age and ethnicity of the baby as stated by the mother.[24]
ONS Birth Registration Data ¹	1996 to 2022	ONS Birth Registration Data includes information recorded when live births and stillbirths are registered as part of civil registration, a legal requirement, in England and Wales. The registration of births is a service carried out by the Local Registration Service in partnership with the General Register Office (GRO), in England and Wales. All registered births are included except very late registrations received more than 14 months after the end of each reference year (there are fewer than 100 of these for any given year).[25]

¹ Inclusion of dataset within ECHILD is pending confirmation

3.2.6 Attribute data: Other

Table 3.5 Overview of Linked Mortality and Community Service datasets

Dataset	Years	Details
HES-ONS Linked Mortality Data	1998 to 2023	<p>Since January 1998, HES data have been routinely linked to mortality data as recorded by the Office of National Statistics,[26] and this information is also included in ECHILD.</p> <p>Mortality data contains information taken from the death certificate for all deaths registered in England and Wales and includes cause of death, date and place of death. Information related to stillbirths is not available in this dataset.[26]</p>
Community Services Data Set (CSDS)	2015 to 2023	<p>The CSDS captures activity data about children and adults collected by Community Services, including health visiting teams. Such activities may take place in settings such as Health centres; Day care facilities; Schools or Community centres; Mobile facilities, or a patient's own home.[27]</p> <p>Data are collected about children and adults e.g., personal, demographic or social circumstances; breastfeeding and nutrition; long-term conditions (disabilities), diagnoses and scored assessments.</p> <p>The CSDS is comprised of patient-level data from all publicly funded community services providers e.g., Foundation or Non-Foundation Trusts; Acute Trusts; Mental health Trusts, Community Healthcare Trusts, Independent sector providers and Local Authorities.</p>

3.3 National Pupil Database

The NPD was formally established in 2002 based on including a pupil census record for every child in state education. Prior to 2002, key stage test results were recorded from 1995/6 (for KS2) which is linkable to the pupil census. The NPD database is curated by the Department for Education (DfE). The NPD is made up of modules of data that are collected by the DfE from schools, local authorities and exam-awarding organisations on an ongoing and statutory basis.[28] Information collected as part of NPD is used for funding purposes, policy-making, generating statistics and research. The NPD modules included in ECHILD can be broadly grouped as pupil characteristics, educational outcomes and social care.

NPD does not include information on pupils within private schools, or those being home-schooled, except in relation to public examinations (key stage 4 and 5). Approximately 7% of children [6] are enrolled in a private school each year with up to 11% ever enrolled in a private school during their school career.[29]

3.3.1 Attribute data: Pupil Characteristics

Table 3.6 Overview of Pupil characteristics datasets

Dataset	Years	Details
School Census Pupil Level ^{1,2}	2001 to 2022	<p>Information on pupils enrolled in state-funded schools, including local-authority-maintained schools, academies, free schools, city technical colleges and special schools. Data collected termly: Autumn (October); Spring (January); Summer (May). From Spring 2013/14, the school census also includes pupils enrolled in Pupil Referral Units (previously collected in a separate census).</p> <p>The census does not contain information for pupils:</p> <ul style="list-style-type: none"> Enrolled in hospital schools or non-maintained independent schools (e.g., private schools). Who pursue an apprenticeship, traineeship, training, or work as part of their post-16 options.
Early Years Census ^{2,3}	2007 to 2022	Children (all 2- to 4-year-olds) in state-funded early years care in any private, voluntary, and independent (PVI) sector nursery, with one or more children receiving funding from DfE. Data collected annually (January).
Pupil Referral Unit Census (PRU) ²	2009 to 2013	Information on pupils enrolled in PRUs (a form of school for pupils unable to attend mainstream schools due to factors such as behavioural issues). Data collected annually until January 2013. From Spring 2013/14, this data is collected as part of the School Census.
Alternative Provision Census (AP) ²	2007 to 2022	An annual census (collected in January) of pupils who are educated in alternative provision placements. Provision must be arranged by the local authority or school otherwise the child would not receive suitable education e.g., due to illness or if they received a fixed-term exclusion.

¹After KS4, the School Census Pupil Level module only contains information for young people who continue in full-time post-16 education in schools or colleges.

²The census modules of the NPD are recorded at enrolment level. Children who are registered in more than one educational setting will have multiple records in a census. The census modules of the NPD contain information such as age, gender, ethnicity, special educational needs (SEN) support, first language and free school meals (FSM) eligibility.

³The Early Years Census only collects information for children who are taking up a government-funded place.[30] All 3- and 4-year-olds in England are entitled to government funding; however, funding for 2-year olds is only for specific groups of children, such as those who are in care, who have an education, health and care plan, or whose parents are in receipt of certain benefits. Early years settings that do not have any children who receive direct government funding are not required to submit information via the Early Years Census.

3.3.2 Attribute data: School Characteristics

Table 3.7 Overview of School Characteristics datasets

Dataset	Years	Details
School Level Census	2005 to 2022	Collects information from primary schools, secondary schools, special schools, maintained nurseries and academies and pupil referral units three times a year, however, private schools are not included.[31]
Get Information about Schools (GIAS)	2020 to 2022	GIAS (formerly 'Edubase') is the DfE's public register or dataset containing school characteristics. GIAS is updated whenever a school updates their details. GIAS also maintains information for several organisation types and is used by the DfE to contact establishments, update systems, perform analysis and inform policy decisions.[32]

3.3.3 Attribute data: Educational Outcomes

Table 3.8 Overview of Educational Outcomes datasets

Dataset	Years	Details
Early Years Foundation Stage Profile (EYFSP)	2002 to 2019	Early Years Foundation Stage Profile data. Has information on statutory assessment of children in the final year of the Foundation Stage (Reception year).
Key Stage 1 (KS1)	1997 to 2022	Key stage 1 attainment data. Has information on assessment of learners by the end of year 2 of schooling (age 7).
Key Stage 2 (KS2)	1995 to 2022	Key stage 2 attainment data. Has information on assessment of learners by the end of year 6 of schooling (age 11).
Key Stage 3 (KS3)	1998 to 2013	Key stage 3 attainment data. Has information on assessment of learners by the end of year 9 of schooling (age 14).
Key Stage 4 (KS4) ¹	2001 to 2021	Key stage 4 attainment data (all methodologies). Has information on the assessment of learners by the end of year 11 of schooling (age 16).
Key Stage 5 (KS5) ¹	2002 to 2021	Key stage 5 attainment data. Has information on post-16 assessment of learners in school, sixth forms and Further Education colleges.
Absences ²	2005 to 2022	Has information on authorised and unauthorised absences, including reasons for absence, derived from the termly School Census, for 4- to 15-year-olds.
Exclusions ³	2001 to 2021	Has information on pupil fixed term and permanent exclusions as collected in the termly School Census.
National Client Caseload Information (NCCIS) ⁴	2002 to 2021	Has information from the National Client Caseload Information System on employment destinations.

¹Attainment data are collected for all pupils when they complete nationally recognised assessments at KS4 and KS5, including those in private schools and further education state sector colleges.[28]

²Absence data are not recorded for boarding pupils.[33] Schools may provide information about the reasons for absences (e.g., due to illness, medical appointments, etc) or just the number of absences overall.[28] Absence data were first collected for 4-year-olds in the 2012/13 academic year. In 2012/13, the period of collection of absence data was also extended to the end of the summer term. In previous years, absence data were only collected for the first half of the summer term. Absence data include 'persistently absent' indicators (the threshold for which varies by academic year).[34]

³Compared to other modules of the NPD, there is a lag in data availability related to exclusions. Data are made available in the summer for the preceding academic year; for example, data for the academic year 2017/18 is released in summer 2019.[28]

⁴Unlike the School Census Pupil Level module (which only contains information for young people who continue in full-time education post-16), NCCIS includes information about the post-16 activities of all young people aged 16 to 19 years (or aged 16 to 24 years for young people with a current Education, Health and Care (EHC) plan).[35] This activity information is collected by local authorities and used by the DfE to estimate Not in Education, Employment or Training (NEET) rates for young people in England.

3.3.4 Attribute data: Social Care

Table 3.9 Overview of Social Care datasets

Dataset	Years	Details
Children Looked After Return (CLA)	1991 to 2021	Has information on children looked after by a local authority in England for a period of at least 24 hours. The data include information on date and type of placement, use of respite care, and exiting from care, including through adoption. Does not include information on informal fostering arrangements.
Children in Need Census (CIN)	2008 to 2022	Has information covering all children who are referred to children's social care services, including information on whether they were assessed and found to be in need. The CIN census also contains information on children who are subject to a Child Protection Plan (CPP).

The CLA and CIN modules of the NPD include an encrypted version of the identifier assigned by the local authority (child ID) that allows social care records for the same individual to be linked over time. However, this identifier is local authority specific and so it is not possible to link records for the same individual across different local authorities.[36, 37]

UPNs have been returned to DfE by local authorities in the CLA module from 1st April 2005 and in the CIN module from 1st April 2009 (i.e., from when the CIN census began). Where a UPN is returned, the aPMR is available, enabling linkage to the NPD education records. Before April 2005, it is not possible to link education and the CLA datasets. It is also not possible to link social care and education records for children who were only in contact with children's social care services before their UPN was assigned (e.g., for children who were a child in need or looked after before school age). Previous research has shown that 20% of children who are ever looked after during childhood are only looked after before age 5.[38]

3.3.5 Individualised Learner Record

Training providers within the Further Education (FE) and skills sector in England use the 'Individualised Learner Record' (ILR) to collect information about each of the learners in their sector, the learning undertaken, and the learning outcome, e.g., sectors include Adult skills, Community Learning, Skills Bootcamps, 16-19 (excluding Apprenticeships).

ILR data are used to ensure public money distributed through the Education & Skills Funding Agency is being spent in line with government targets, for quality, value for money, planning and supporting future initiatives.[39]

An ILR 'Year' of data, typically runs from 1st August to 31st July and in May 2023, the ECHILD project acquired ILR data from 2000/01 to 2021/22 containing an aPMR identifier matched to the NPD – thereby facilitating linkage to the existing NPD datasets in ECHILD and adding another dimension to the potential for analyses.

3.4 Mother-baby Linkage in ECHILD

The ECHILD team are in the process of creating a 'mother-baby' link, whereby HES delivery and birth records for both mother and baby will be linked together using a probabilistic linkage algorithm.[40] In summary, the probabilistic linkage approach uses 'indirect identifiers', i.e., information from the maternity and baby tails within HES (such as gestational age and birth weight) to link together mother-baby dyads. Previous work has demonstrated high linkage rates using this approach.[41] The mother-baby linkage means that it is possible within ECHILD to look at how maternal characteristics (including those captured in health, education and social care datasets) are related to child outcomes.

4 Accessing ECHILD

ECHILD is available to researchers through the [ONS SRS](#) [42], which follows the [Five Safes](#) Framework:

1.Safe People	2.Safe Projects	3.Safe Settings	4.Safe Outputs	5.Safe Data
Accredited Researchers	Ethical & benefits public	Secure technology	Non-identifiable outputs	Use de-identified data

4.1 ECHILD cannot be linked to other data sources without further approval

Researchers wishing to link additional datasets to ECHILD will need permission from the data controllers i.e., NHSE and DfE. In addition, the ECHILD team will consider the feasibility of such requests on a case-by-case basis and encourage researchers to contact the team for further discussion.

4.2 Ethics Self-Assessment

It is important to consider the ethical aspects of any study involving secondary analysis of de-identified administrative data; although the data are de-identified, no study is free of risk. Researchers applying to use ECHILD will be asked to complete a [Self-Assessment](#) form [43] to assess compliance of their proposed project with the ethical principles developed by the National Statistician's Data Ethics Advisory Committee.

4.3 Access Conditions

Researchers will have to demonstrate how their research will benefit the health and well-being of children and young people accessing health, education and social care services. More specifically, projects will have to fall under at least one of the agreed five research purposes described in Section 2.2. We do not have approval for non-UCL PhD students without a substantial contract at an applying institution to access ECHILD.

Researchers will be expected to:

1. State their use of ECHILD in any publication/presentation and acknowledge the ECHILD team in publications and reports, including the following acknowledgements/notes where possible: *"We would like to acknowledge the contribution of the wider ECHILD Database support and programme management."*
2. Undertake appropriate Public and Patient Involvement and Engagement (PPIE) activities.
3. Refer to ONS [guidance](#) regarding pre-publication, publication and code file clearance.
4. Notify and provide details in writing of all publications to UCL 14 days in advance of publication.
5. Notify and provide draft publications to the Department for Education 14 days in advance of any publication.
6. Include the following data sharing and funding statements in publications as defined by NHS England, the Department for Education, the ONS and ECHILD Database funders:
 - a) "The ECHILD Database uses data from the Department for Education (DfE). The DfE does not accept responsibility for any inferences or conclusions derived by the authors."
 - b) "This work uses data provided by patients and collected by the National Health Service as part of their care and support. Source data can also be accessed by researchers by applying to NHS England."
 - c) "We are grateful to the Office for National Statistics (ONS) for providing the Trusted Research Environment for the ECHILD Database. ONS agrees that the figures and descriptions of results in the attached document may be published. This does not imply ONS' acceptance of the validity of the methods used to obtain these figures, or of any analysis of the results."
 - d) "The views in this publication do not necessarily reflect the views of UCL."
7. Report how data quality issues were addressed.
8. Share their code/script for data processing and analysis.
9. Prepare and send an annual report to the ECHILD team on the benefits of the research undertaken.

4.4 Process to access ECHILD

Step	Task
1.	Contact ECHILD Team: ich.echild@ucl.ac.uk
2.	Complete ethics self-assessment
3.	Submit an application form to UCL
4.	Obtain approval from UCL on feasibility and purpose
5.	Submit the UCL-approved application form to ONS Research Accreditation Panel (RAP)
6.	Obtain approval from RAP for release under Digital Economy Act (DEA)
7.	Sign Data Access Agreements with UCL & ONS Accredited Researcher Assurance Registration (ARAR) form.
8.	UCL instructs ONS to provide access to a specified extract of ECHILD to named user(s)

4.5 Accredited Research Status

To access ECHILD researchers must become fully [Accredited Researchers](#) under the Digital Economy Act 2017 (DEA) as this enables researchers to carry out analysis and produce outputs on projects within a Trusted Research Environment such as the ONS Secure Research Service (SRS). To be a fully accredited researcher, individuals must have an undergraduate degree (or higher), including a significant proportion of maths or statistics. Otherwise, they must be able to demonstrate at least three years of quantitative research experience.[42]

4.6 Assured Organisational Connectivity (AOC)

An [AOC](#) is an agreement between your organisation and the ONS concerning how your organisation meets the required physical and system security standard to directly allow access to the SRS from your organisation or your home office space. All AOC agreements must be approved by the ONS and it is the responsibility of the researcher to check if an institutional AOC is in place before applying for access to ECHILD.[44]

5 ECHILD database strengths and limitations

5.1 Strengths

5.1.1 Includes information related to health, education & social care

HES and NPD are well-established administrative datasets for health, education and social care in England. These datasets act as an evidence base to inform policy: they are used to produce national statistics by government departments and for wider research purposes by the academic community. However, the lack of a common identifier in these administrative datasets has limited the potential for wide-scale analysis across domains. By linking health, education and social care datasets, ECHILD presents a unique and valuable opportunity to explore how children's health affects their education, and how their education affects their health.

5.1.2 Longitudinal data resource for a whole population-based cohort of children & young people

All children and young people in England who were born between 01/09/1984 to date (updated annually) are eligible for inclusion in ECHILD. Overall, the dataset contains linked health and education records for approximately 20 million individuals. The large sample size and long follow-up period will enable research into long-term outcomes and less common exposures. The ambition is for ECHILD to be updated in the future to include more recent years of data as they become available. This would extend the length of follow-up for cohort members who were born more recently.

5.1.3 Comprises well-documented administrative datasets

The constituent datasets within ECHILD are well-documented by data owners[9, 45] and the research community.[6, 10, 46-49] For example, details about how information in the datasets is collected, what variables they contain and how coding has changed over time are readily available to researchers. Appendix 1 highlights some key resources for researchers.

5.1.4 Provides timely access to administrative data for research purposes

Negotiating access with multiple administrative data providers is time-consuming and resource intensive, particularly when it involves the transfer of identifiable information for linkage purposes.[50] Governance arrangements for the re-use of the de-identified ECHILD data for research purposes via the ONS SRS are now established. This will avoid the need for repeated transfer and use of identifiable information to link HES and NPD data for individual research projects.

5.2 Limitations

5.2.1 Administrative data are not collected for research purposes

Administrative datasets are not specifically collected for research purposes, which has implications for the type of research that can be carried out and how research findings are interpreted.[51] For example, HES data are primarily used for reimbursement of costs and so there may be differences in the frequency and quality of the information that is recorded based on the impact it has on payment. Researchers who intend to carry out secondary analysis of ECHILD must familiarise themselves with the constituent datasets to understand the potential limitations and caveats of their proposed analyses.

5.2.2 Potential for linkage error

Firstly, there may be errors in the linkage of records within HES (by TPI) or NPD (by aPMR). As previously outlined, TPI and aPMR are derived using linkage algorithms that use various combinations of identifiable information, including name, date of birth, postcode and NHS number or UPN. Secondly, there may be errors in the linkage between HES and NPD that was carried out to create the ECHILD database. Initial evaluation of linkage quality found that approximately 97% of children recorded in NPD matched to a HES record, but that minority ethnic groups and pupils from more disadvantaged neighbourhoods were less likely to be linked.[52]

5.2.3 Constituent datasets in ECHILD have different structures

Both HES and NPD contain individual-level data; however, the structure of the dataset modules varies between (and within) HES and NPD. For example, HES is an episode-level dataset where each row represents a period of continuous care from a consultant, outpatient appointment or A&E attendance, depending on the data module. NPD, CIN and CLA are also episode-level data modules where each row represents a referral to Children's Social Care services (within which there is a significant degree of duplication) or a period of time a child was looked after under a specific legal status and in a specific placement setting, respectively. NPD census modules contain enrolment-level information which means that children who are simultaneously enrolled in more than one educational setting will have multiple rows of information recorded. These differences in data structure mean that researchers will need to carry out substantial dataset manipulation prior to their analyses.

Appendix 1. Resources

Additional resources

1. Department for Education National Pupil Database: Data collection and censuses for schools [53]
2. National Pupil Database online data dictionary [54]
3. National Pupil Data User Group [55]
4. Children's Social Care User Group [56]
5. NHSE documentation related to Hospital Episode Statistics [9]
6. Hospital Episodes Statistics online data dictionary [18]

Articles

7. Data Resource Profile: HES APC [46]
8. Data Resource: National Pupil Database [6]
9. Cohort Profile: Children in Need Census [47]
10. Data Resource Profile: Children Looked After Return [48]
11. GUILD: GUIDance for Information about Linking Data sets [57]
12. REporting of studies Conducted using Observational Routinely-collected health Data [58]

Key ECHILD Publications

Authors	Article
Blackburn, R et al. (2022)	COVID-19-related school closures and patterns of hospital admissions with stress-related presentations in secondary school-aged adolescents: weekly time series.[59]
Nguyen V G et.al (2022)	SEN support from the start of school and its impact on unplanned hospital utilisation in children with cleft lip and palate: a demonstration target trial emulation protocol using ECHILD.[60]
Blackburn, R et al. (2021)	Hospital admissions for stress-related presentations among school-aged adolescents during term time versus holidays in England: weekly time series and retrospective cross-sectional analysis.[61]
Libuy, N et al. (2022)	Gestational age at birth, chronic conditions and school outcomes: a population-based data linkage study of children born in England.[62]
Mc Grath-Lone L et al. (2022)	Changes in adolescents' planned hospital care during the COVID-19 pandemic: analysis of linked administrative data.[63]
Etoori, D et al (2021)	Deficits in hospital care among clinically vulnerable children aged 0 to 4 years during the COVID-19 pandemic.[64]
Mc Grath-Lone L et al. (2021)	Ethnic bias in data linkage.[65]
Mc Grath-Lone L et al. (2021)	Data Resource Profile: The Education and Child Health Insights from Linked Data (ECHILD) Database.[4]
Mc Grath-Lone L et al. (2022)	What makes administrative data research-ready? A systematic review and thematic analysis of published literature.[66]
Libuy, N., et al. (2021)	Linking education and hospital data in England: linkage process and quality.[52]

Appendix 2. Linkage process

This section provides an overview of the linkage process (Figure 2.2) used to create the ECHILD database.

Data sources

The Department for Education's National Pupil Database

The Department for Education (DfE) collates and manages data on school children in England in a resource known as the National Pupil Database (NPD).[6] For the purposes of the ECHILD linkage, salient points are described below.

Within NPD, each record is associated with natural identifiers (forename, surname, gender, date of birth, postcode) relating to the pupil's details as known by the submitting organisation at the time the data were submitted. DfE additionally assigns each record in NPD an anonymised Pupil Matching Reference (aPMR). An aPMR is an identifier which is not in itself meaningful: it does not reveal the identity of the pupil. aPMRs are assigned to all records in NPD such that one aPMR should represent one pupil and each pupil should have only one aPMR. This allows records for each pupil to be identified across NPD, both between different datasets and over time, without revealing their identity. As a result, NPD contains a longitudinal record of pupils' names, addresses, and (potentially) genders over time.

NHS England's Personal Demographics Service and Master Person Service

NHS England operates the Personal Demographics Service (PDS), a national electronic database of demographic data for patients accessing care in England or services funded by the NHS in England. PDS contains natural identifiers (forename, surname, gender, date of birth, postcode) and NHS number. Each person is assigned a distinct NHS number at birth if born in England, or at the first time of accessing NHS services in England if not otherwise registered. PDS holds a longitudinal record of name and address changes made to NHS services in England over time. This means there may be many records for each person in PDS but all records for a person should be assigned the same NHS number (with some exceptions, see reference [67]).

The Master Person Service (MPS), managed by NHS England,[68] takes a record of natural identifiers and attempts to match this to a PDS record allowing for some errors and missingness in the recording of the natural identifiers. If this fails and the natural identifiers are sufficiently complete, MPS attempts to match records against a secondary store (MPS bucket) of natural identifiers of persons who previously had contact with the NHS in England and do not have an NHS number, these persons are assigned an 'MPS ID'.

The MPS returns a "Person ID" using either:

1. NHS number, if a valid match is found in PDS; or,
2. MPS ID if no match is found in PDS but a valid match is found in the MPS bucket; or,
3. No value if no match is found in either PDS or the MPS bucket.

The Person ID is then encrypted to generate a Token Person ID (TPI), which is not meaningful and does not reveal the person's identity.

Person IDs, enabling the assignment of Token Person IDs, are also recorded throughout NHS England's standard data collections, including Hospital Episode Statistics datasets, Emergency Care Datasets, Mental Health Services Datasets, and Community Services Datasets. The 'Person ID' or 'TPI' are primarily the only means to identify records belonging to a single patient amongst data held by NHS England.

Linking DfE NPD aPMRs to NHS England TPIs

For the purposes of the ECHILD linkage, four simplifying assumptions were made:

1. Each aPMR represents precisely one “real” person within NPD;
2. Each “real” person represented within NPD has precisely one aPMR;
3. Each TPI represents precisely one “real” person within NHS England data collections;
4. Each “real” person represented within NHS England data collections has precisely one TPI.

The linkage task resulted in a ‘one-to-one’ match, linking each aPMR to a single TPI.

DfE supplied a ‘linkage dataset’ to NHS England, comprising the natural identifiers (forename, surname, gender, date of birth, postcode) and an aPMR for each record in its NPD.

Linkage Stage 1: Exact link

An initial, simple, linkage stage was used to avoid over-burdening the more resource-intensive MPS trace. Each valid record (e.g., no blank entries) in the linkage dataset was compared to all records in a prepared extract from PDS.

A record was deemed “linked” if compared records matched on the following criteria:

1. First four characters of forename;
2. Full surname;
3. Full date of birth;
4. Full postcode; and,
5. Gender.

An aPMR was considered ‘matched’ if it had a one-to-one link to a TPI.

Linkage Stage 2: MPS Trace

Records with aPMRs that were not ‘matched’ in Linkage Stage 1 were submitted to MPS.

Again, an aPMR was considered ‘matched’ if it had a one-to-one link to a TPI.

Linkage Outputs: Pseudonymised Bridging file

NHS England produced a Pseudonymised Bridging file consisting of all aPMRs in the DfE-supplied linkage dataset and their “matched” TPI. All aPMRs that were not matched after Linkage Stage 2 were included in this file but did not have an assigned TPI. An additional variable indicating at what stage each aPMR was linked was also present in the NHS England bridge file.

Disclaimer

Although every effort has been made to provide complete and accurate information at the time of publication (June 2023), the authors make no warranties, express or implied, or representations as to the accuracy of content in this guide. The authors assume no liability or responsibility for any error or omissions in the information contained in the guide.

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