

# Using linked health and education data for research on outcomes of children with chronic conditions: lessons from the ECHILD database in England

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Leong Centre Rounds Seminar  
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## Overview of the talk

- What is ECHILD database?
- What are we doing with ECHILD?
  - HOPE study
  - Adolescent health and education trajectories
  - A Process and Impact Evaluation of the Generation Study
- Lessons learnt from working with ECHILD
- What's coming next?

# ECHILD IN A NUTSHELL

**Education and Child Health Insights from Linked Data**

led by Profs Katie Harron, Ruth Gilbert and Dr Ruth Blackburn

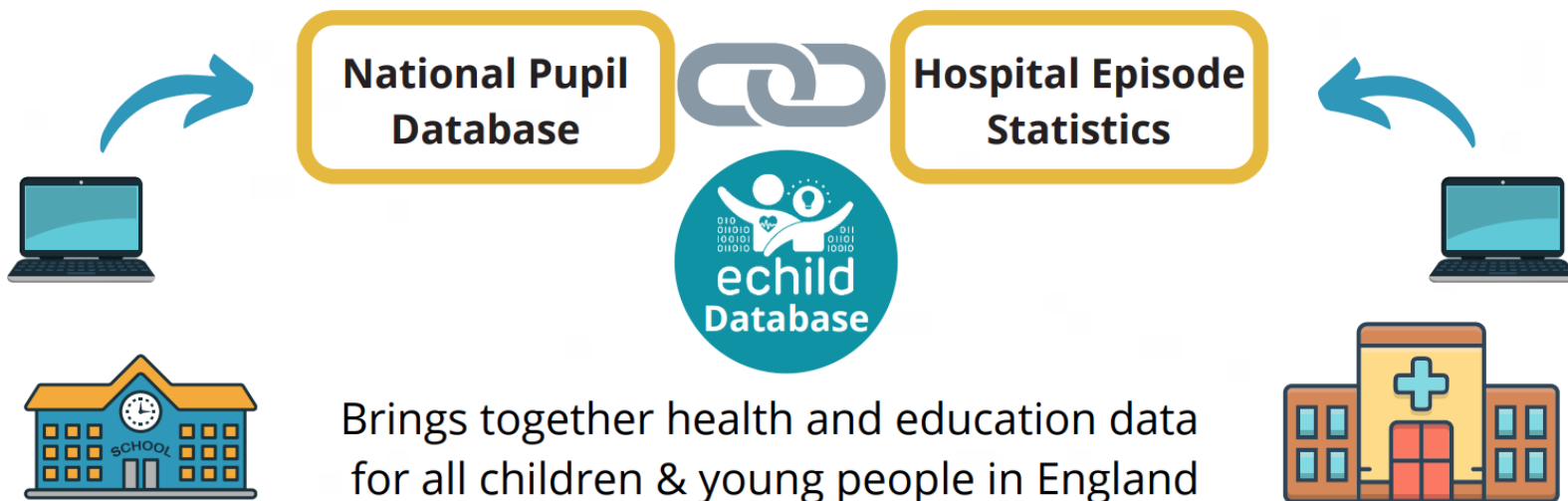




Department for Education



England



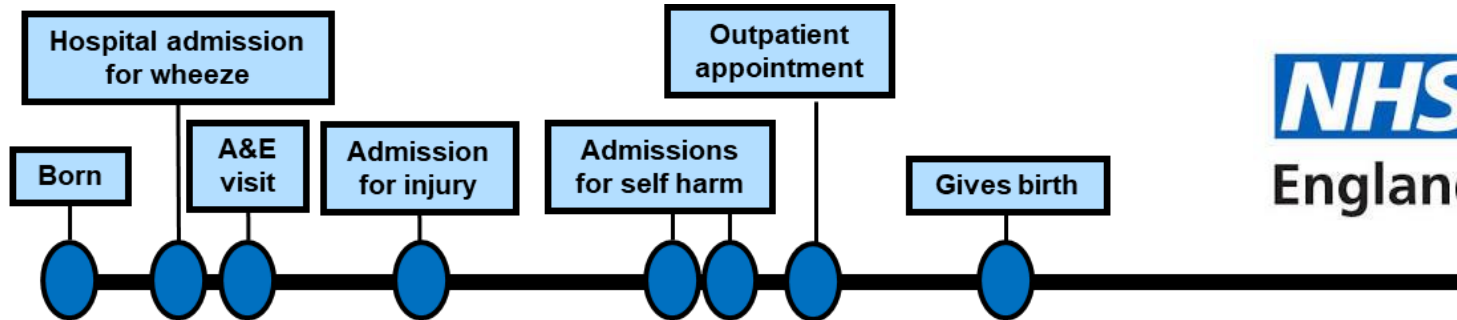
The ECHILD Database is **DE-IDENTIFIED**



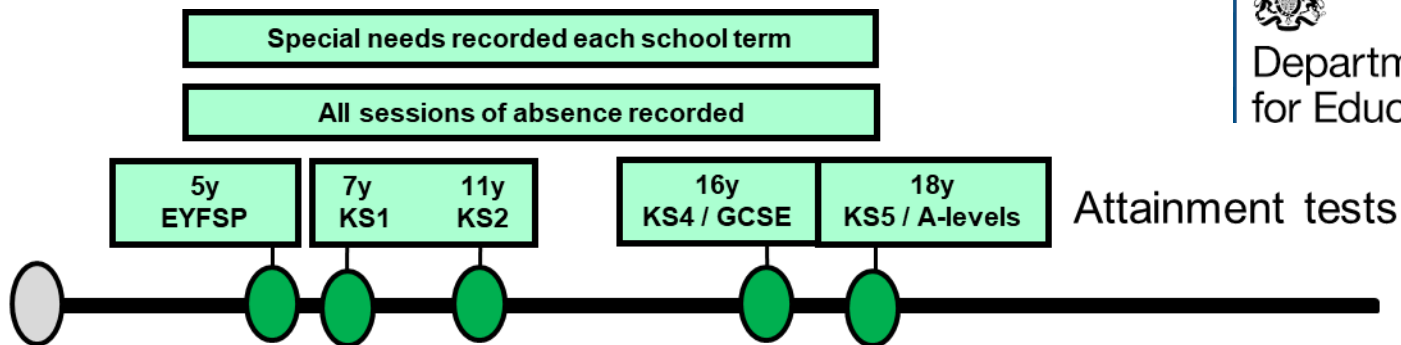
Linked data for **20 million pupils**



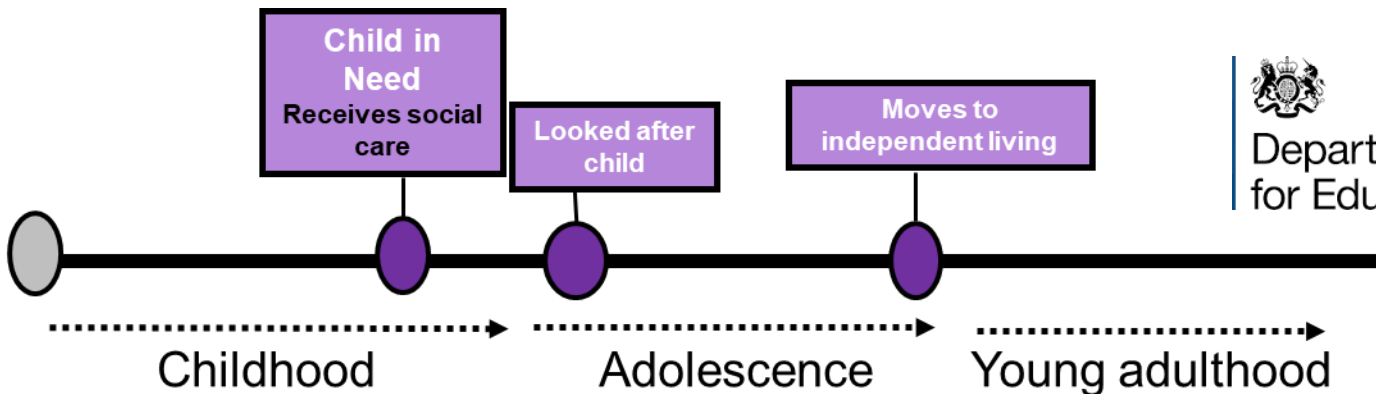
## HEALTH CARE

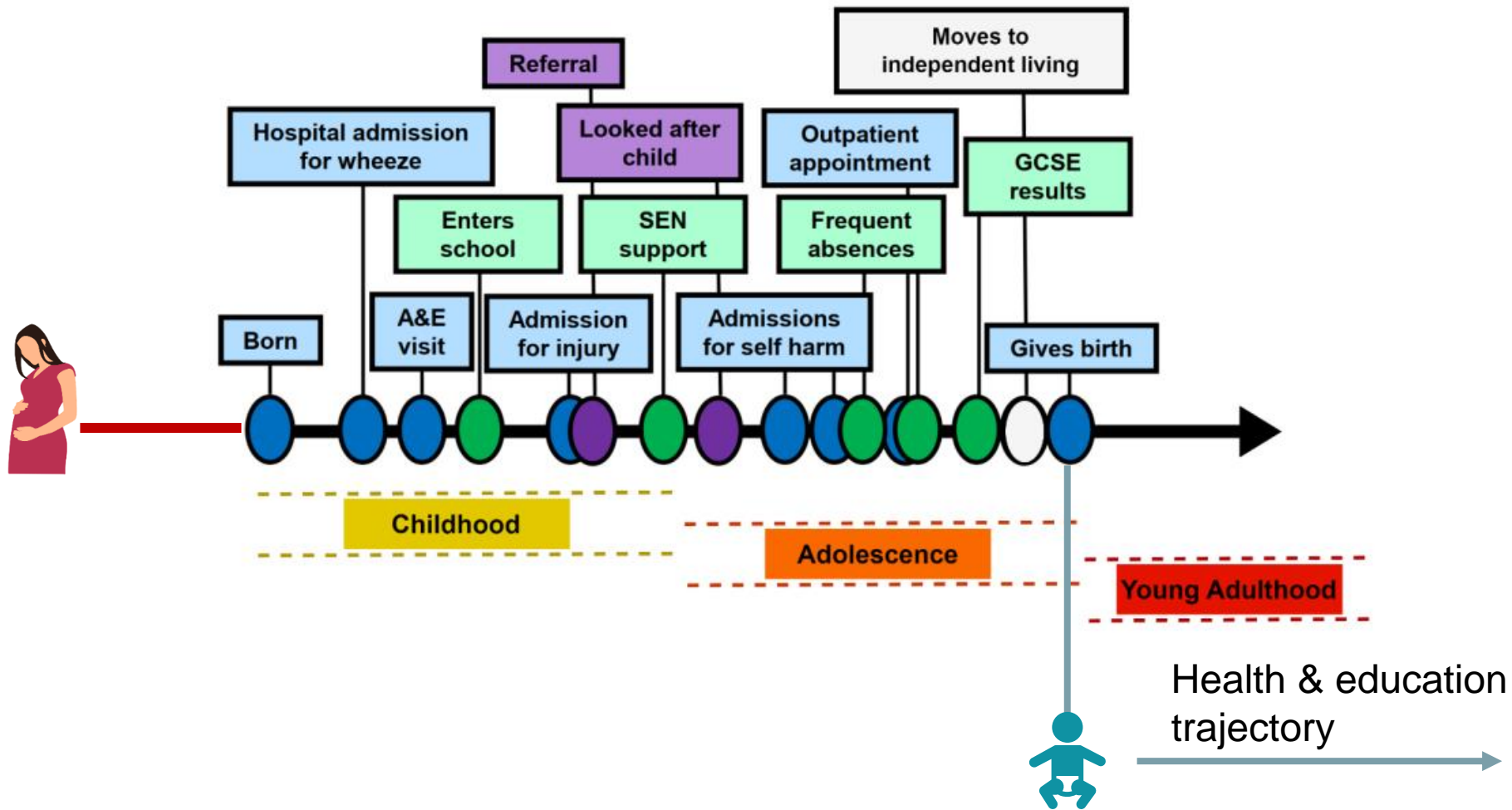


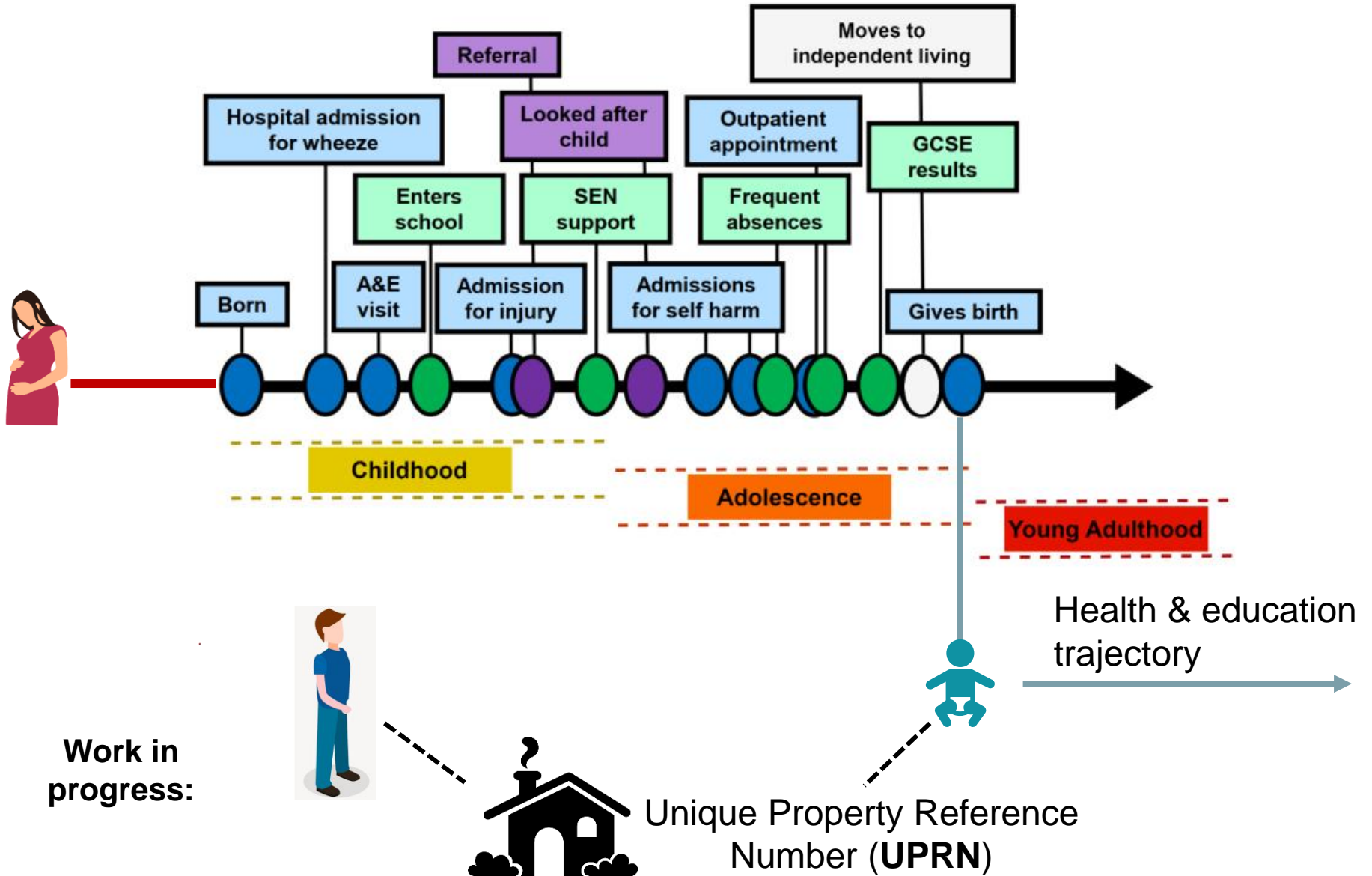
## SCHOOLS



## SOCIAL CARE









# THE HOPE STUDY: HEALTH OUTCOMES FOR YOUNG PEOPLE THROUGHOUT EDUCATION

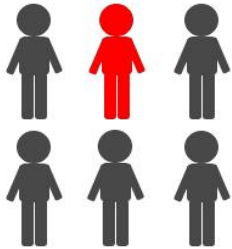
**Overall aim:** to explore variation in special educational needs (SEN) provision and its impact on health and education outcomes





## Background: what is SEN provision?

**SEN provision:** extra adjustments/adaptations to meet the needs of children who have health, learning or behavioural problems, which impact their ability to learn



**1 in 6** children receive any SEN provision each year;

**1 in 3** children have a record of any SEN provision at least once during their time in education

SEN provision **varies** across the country, between schools & by pupil characteristics and is widely regarded as inequitable



Children with SEN have worse health and education outcomes but there is little evidence that SEN provision improves health and/or educational outcomes

**Overall aim:** to explore variation in SEN provision and its impact on health and education outcomes

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**WP1:** Do outcomes vary compared to peers?

**Health phenotypes:**

- Neurodisability
- Major congenital anomalies
- Gestational age



**Health and education outcome, eg:**

- Planned / unplanned healthcare contacts
- Attainment
- Absences and exclusions

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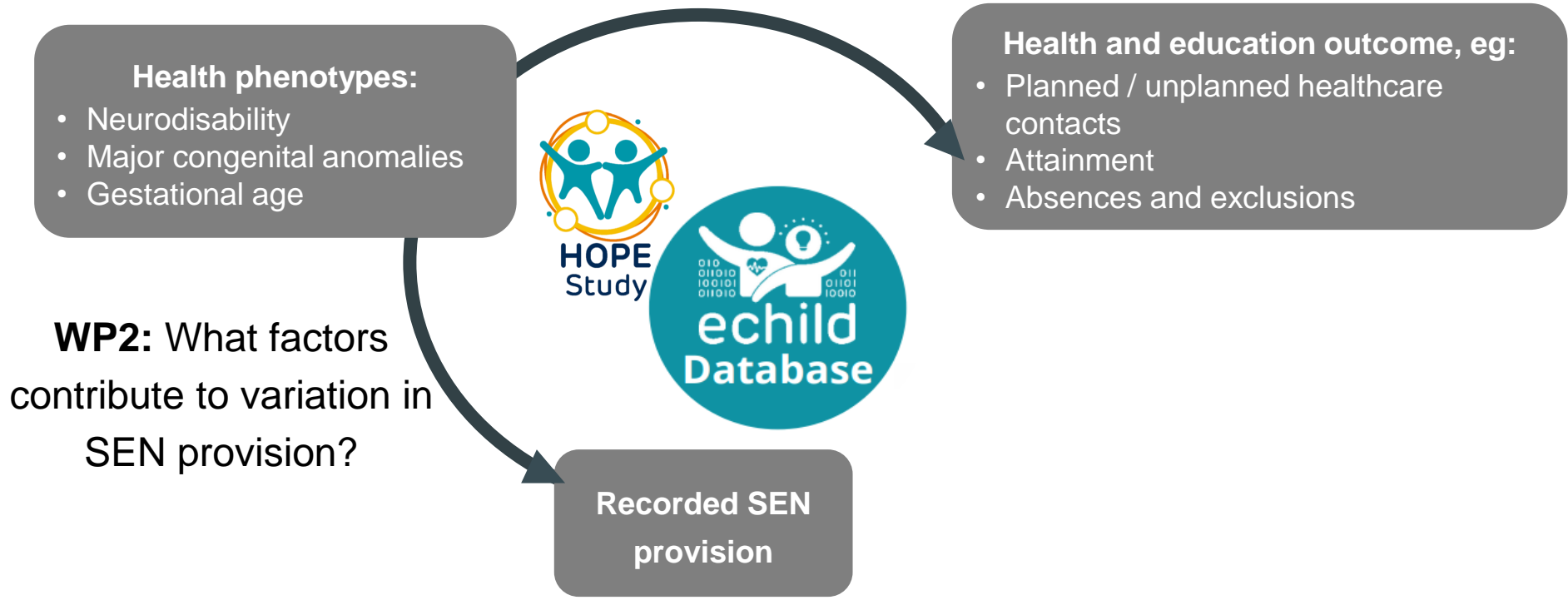


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**WP2:** What factors contribute to variation in SEN provision?

**Recorded SEN provision**



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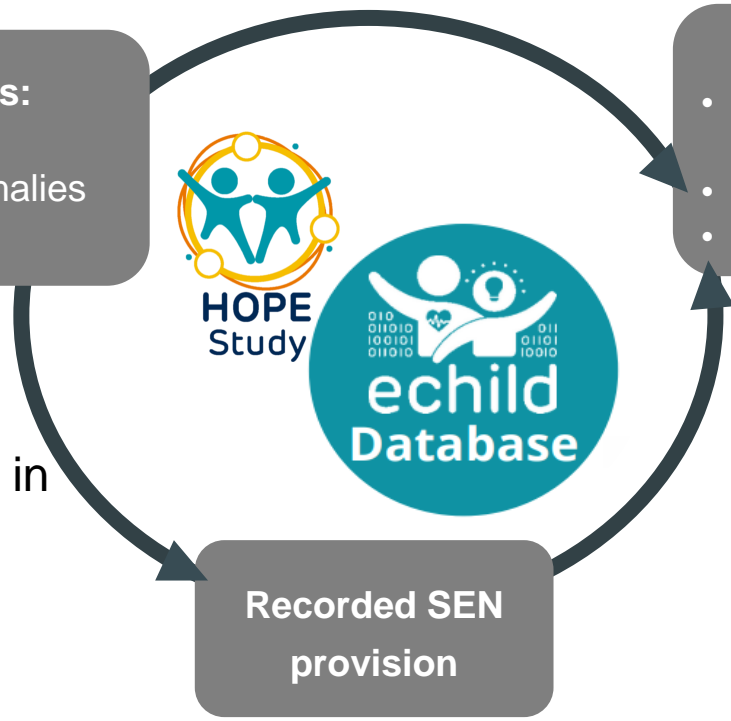
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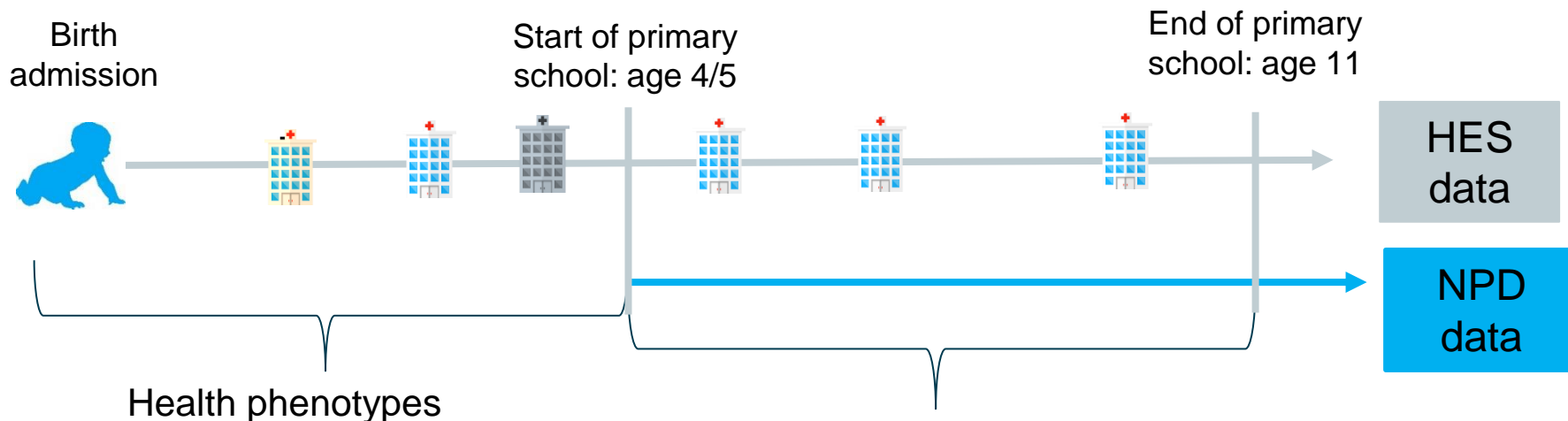
**WP3:** What is the impact of SEN provision?

**Underlying process of SEN provision – identification of need, assessment, and actual provision**

**WP4:** What are the experiences of SEN provision?

# How do we use ECHILD for WP1-WP3?

- Focus on **primary school**
- Standardise definitions (cohorts/ phenotypes / outcomes / SEN provision)



- Neurodisability
- Major congenital anomalies
- Gestational age

### SEN provision:

- Attending special school
- Education, Health and Care Plan (EHCP, a legal document which sets out support arranged by local authorities)
- SEN support (arranged by the school as part of school's usual curriculum)

Health and education outcomes



## **WP1:**

- (a) define a range of 'health phenotypes'
- (b) describe their association with health and educational outcomes

## Children with neurodisability in ECHILD

*‘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. (...) The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour’.[1]*

- include conditions where >50% of children are likely to have neurodisability

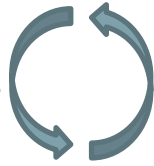


## Children with neurodisability in ECHILD

### Literature reviews:



- To identify relevant health conditions
- To identify diagnostic and procedure codes for each set of conditions



### Input from experts



discussion with experts on which conditions to consider



### Develop a whole-country cohort of primary-school children from ECHILD:

- **Inclusion:**
  - singleton live births in 2003/4-2008/9
  - Recorded in school census in Year 1
- **Follow-up:** until end of primary school

### Draft code lists for health phenotypes



**Analysis:** for each health phenotype we used the data to describe:

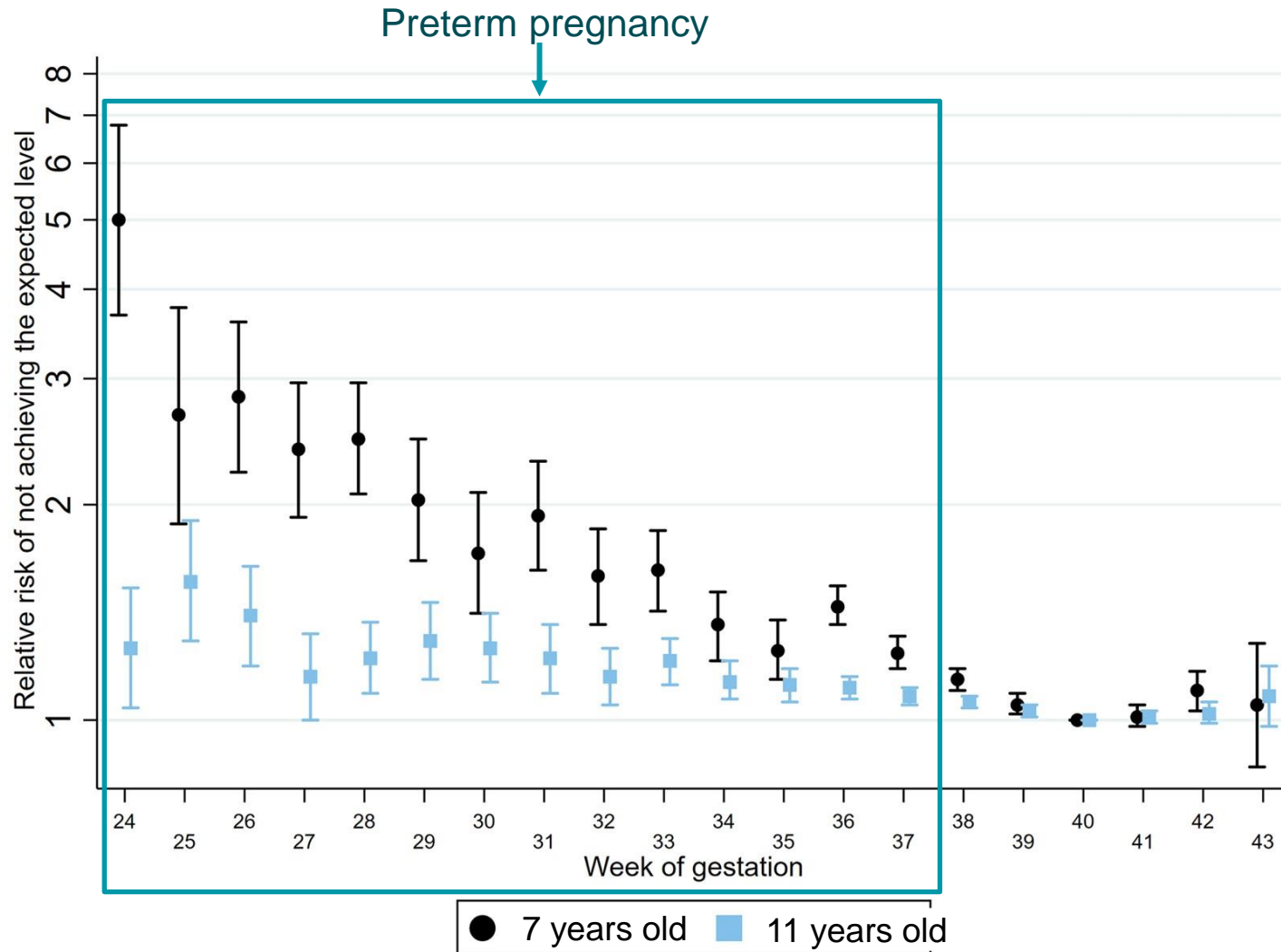
- Cumulative incidence of neurodisability by age (<1yo, <5yo, <11yo)
- **Characterise cohort:** rates of preterm birth, low birth weight
- **Overview of health outcomes:** rates of planned / unplanned hospitalisations
- **Overview of SEN provision:**  
Cumulative incidence, incidence in year 1 (age 5yo), year 3 (age 7yo), year 6 (age 11yo)

## Children with neurodisability in ECHILD

### Work in progress:

- Iterative process – refine the code list, cross-validate, finalise
  - Examine prevalence of specific conditions compared to external references
- Examine outcome trajectories across primary school compared to peers:
  - Educational attainment  
(Ayana Cant, study protocol <https://openresearch.nihr.ac.uk/articles/4-28/v1>)
  - Hospital admissions and school absences  
(Laura Gimeno, study protocol <https://openresearch.nihr.ac.uk/articles/4-26/v1>)

## Educational attainment by week of gestation

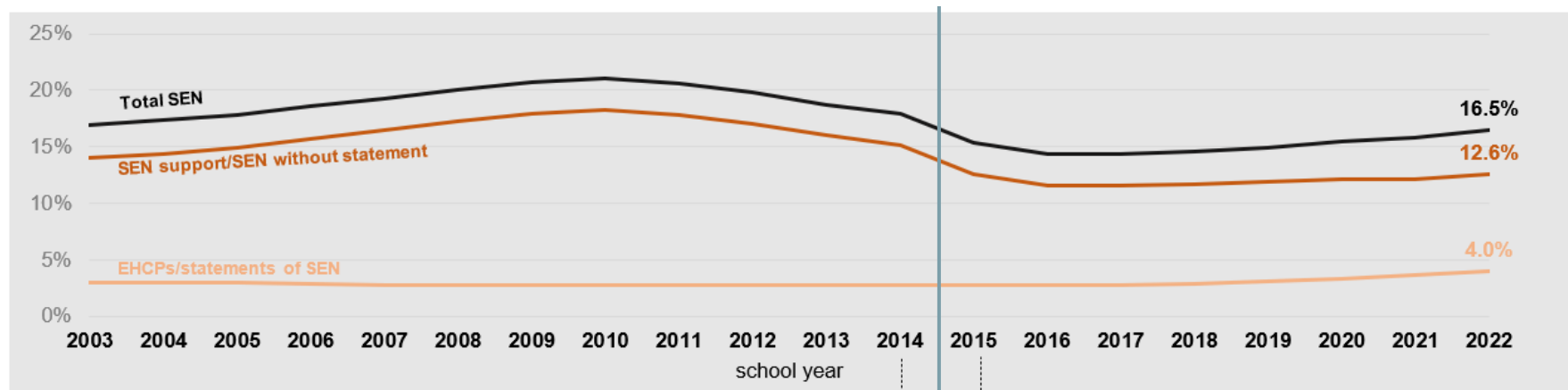


568,035  
children born in  
England 2004/5



**WP2:** What factors contribute to variation in SEN provision?

## Variation in SEN provision for children with major congenital anomalies: by policy period



**2014: Children and Families Act**  
 Legislation on rights of children, families, and people with special educational needs or disabilities

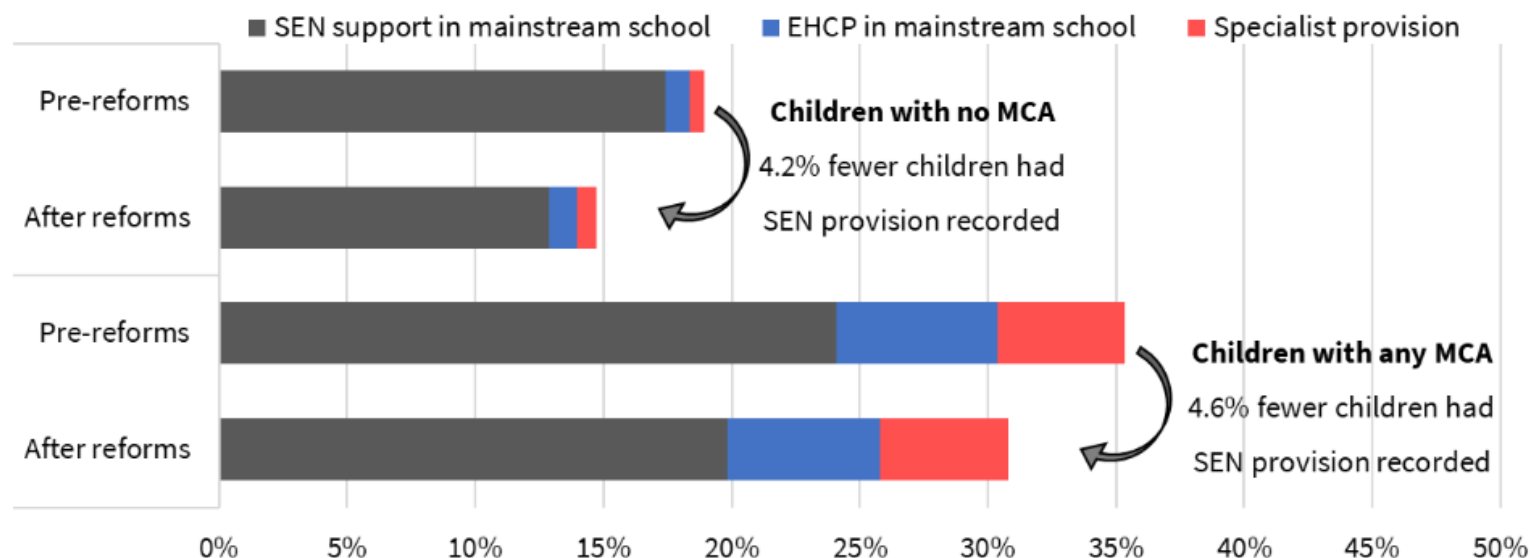
**2015: SEND Code of Practice: 0 to 25 years**  
 statutory guidance for organisations working with young people with SEND. Introduced Education, Health and Care Plans (EHCPs) instead of Statements of SEN.

Was the impact of these policy changes different for children with major congenital anomalies (MCA) compared to their peers?

## Variation in SEN provision for children with major congenital anomalies: by policy period

### Study Cohort:

- 5,189,922 children born in England & attending state-funded primary school between 2008-2019
- **3.5%** had an indication of MCA in hospital records
- **42%** of children with MCA had any SEN provision (vs **26%** of peers)
  - rates varied by MCA type, highest for chromosomal and neurologic anomalies



# **HEALTH OUTCOMES ACROSS SECONDARY SCHOOL AND EARLY ADULTHOOD (11-24 YEARS OLD)**

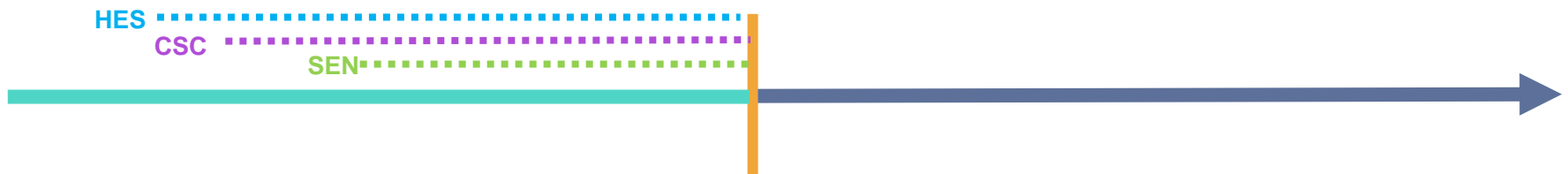
## Adolescent cohorts

ECHILD enables us to develop study cohorts of adolescents using school enrolment data as denominator

### Exposures:

- **SEN:** Any SEN provision in primary school
- **CSC:** a record of being looked after or other interactions with social care
- **HES:** chronic conditions

**Inception:**  
enrolment  
in school  
e.g: in Year 7  
(aged 11yo)



### Outcomes:

- Hospital contacts during transition from paediatric to adult care
- Mortality
- Attainment
- Absences across secondary school
- Post-16 destinations



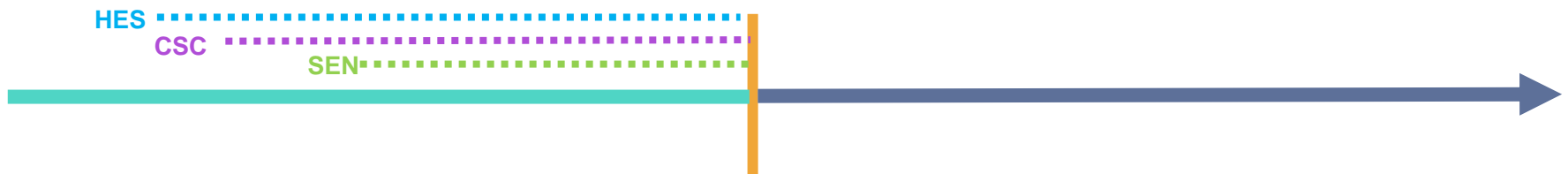
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### Outcomes:

- Hospital contacts during transition from paediatric to adult care
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## Health trajectories of young people with statutory support from education, social care or both

By the time young people turn 18:

- 1 in 3 children receive some SEN provision at some point in school
- 1 in 3 ever receive an intervention from social care services
- ~ 3-4% are ever placed in out of home care
  
- Social care and educational needs are often inextricably linked
- How do longer-term outcomes compare for young people with different levels of statutory support from education and social care compared to their peers?

2 ongoing studies comparing outcomes for adolescents receiving different levels of SEN provision and/or social care intervention and their peers:

1. Trends in planned and unplanned hospital admissions by age, as young people transition out of school and from pediatric to adult health services (11-23 years old)
2. 10 year risk of death in adolescents (13-23 years old)

# ECHILD AS A SOURCE OF POPULATION CONTROL / COMPARISON GROUPS



# A Process and Impact Evaluation of the Generation Study

## The Generation Study:

- Aims to explore the possibility of using genomic newborn screening (gNBS) to expand current newborn screening programmes
- Sequence the genomes of 100,000 newborn babies in 2024/25
- Run by Genomics England

## A Process and Impact Evaluation team:

- independent mixed-methods evaluation of the Generation Study
- 7 studies, aiming to examine:
  - Feasibility
  - Acceptability
  - **Clinical utility**
  - Cost effectivenessof gNBS in England



# A Process and Impact Evaluation of the Generation Study

Generation Study will involve linkage to administrative health records

Outcomes: hospital contact and mortality rates

We will compare outcomes for:

- Children with confirmed diagnosis (from Generation Study) vs children with similar conditions diagnosed via clinical practice
  - Use linked admin data from Generation Study to derive clinical code algorithm to characterise children with rare conditions in Hospital Episode Statistics
  - Apply this algorithm to ECHILD
- Children with 'condition suspected' results (false positive) vs control groups:
  - (a) children who test negative
  - (b) the general population of children in England (ECHILD)



## Lessons learnt

- Descriptive work is important!
- Qualitative work and engaging with schools to learn about education
  - Recorded SEN doesn't mean there was an intervention
  - Implications for causal questions
  - Visiting schools and learning about situation “on the ground”
- Working with experts in education was key
  - Other researchers with relevant expertise on the team
    - Variation in provision between school type, importance of month of birth for educational attainment scores in early years
- COVID – changes in data availability
  - Schools stopped collecting data
  - Huge impact on hospitalisations – affecting studies relying on ICD-10 codes (e.g. prevalence of chronic conditions)

# Lessons learnt – Team science!



## Watch this space – ongoing / future projects:

- Health and education outcome trajectories in adolescents with chronic conditions
  - Outcomes post-16
- Mental health – Ruth Blackburn
- Cost trajectories across health, education and children’s social care (Ruth Gilbert)
- Linking UPRN to enable examining household structures (Ruth Blackburn)
- Environmental exposures – Pia Hardelid
- Maternal exposures & childhood outcomes (Katie Harron)
- Newborn adverse health & early education outcomes in England and Ontario (Rashmi D'Souza)
- Proof of concept causal inference work
  - HOPE study (Bianca De Stavola, Lorraine Dearden, Kate Lewis, Vincent Nguyen)
  - Mediating effect of school absences (Matt Jay)
  - Impact of school placement type (mainstream/special) on outcomes of children with Down Syndrome (Julia Shumway)



**Study team:** Kate Lewis, Bianca De Stavola, Pia Hardelid, Ruth Gilbert, Ruth Blackburn, Matthew Lilliman, Farzan Ramzan, Milagros Ruiz, Tony Stone, Louise Mc Grath Lone, Matt Jay, Nicolas Libuy, Vincent Nguyen, Lorraine Dearden, Ayana Cant, Katie Harron, Laura Gimeno, Joachim Tan

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**For ECHILD updates:** <https://www.ucl.ac.uk/child-health/research/population-policy-and-practice-research-and-teaching-department/cenb-clinical-epidemiology>



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