



# CYP and NHS health data linkage

An overview of planned analysis of children on waiting lists for ADHD/ASD diagnosis

Public Health  
& Communities



CYP Intelligence Hub

# What we'll cover today

- Linking Suffolk County Council's children's data with health datasets – the strategic context
- Why is linking children's data so important?
- Project overview – where are we now
- Governance and data security
- The first use case – Autism waiting lists
- Next steps and further opportunities

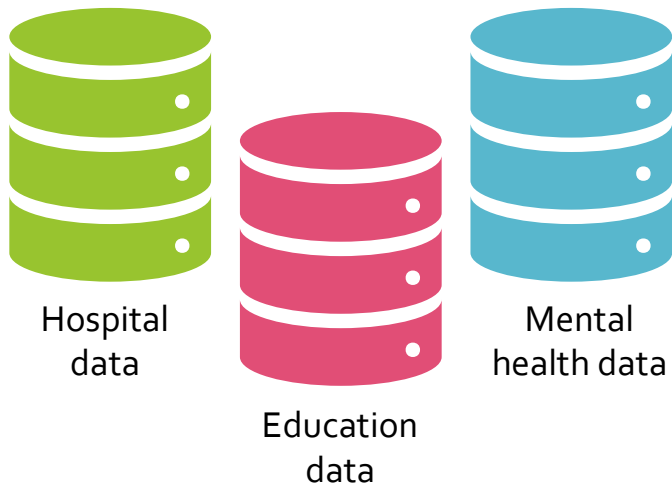


**CONTEXT AND  
STRATEGIC  
IMPORTANCE**

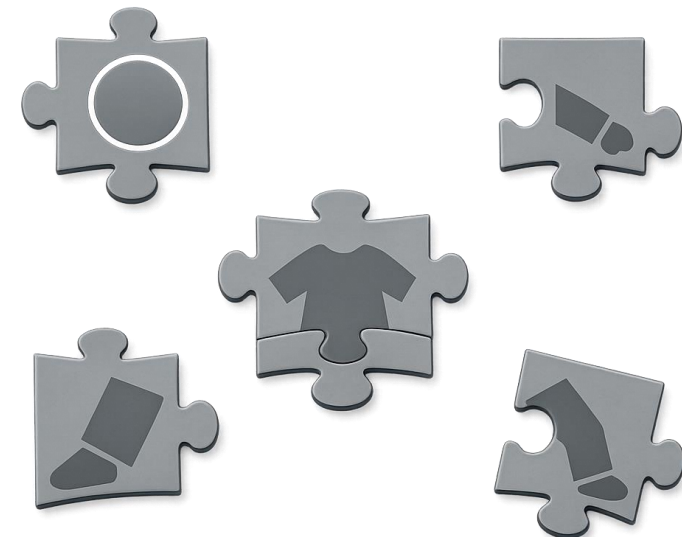
# Setting the scene: why this matters now

- Joint working and using data effectively to deliver SEND services are key focus areas for the Suffolk SEND Local Area Partnership Priority Action Plan.
- We recognise as a system that we need to develop the way we work in order to improve outcomes for children and young people.

In the past information about children has been held in data 'silos', only usually accessible within organisations, and difficult to combine to see a holistic picture of a child.



Fragmented datasets across education, health, and social care can hinder collaborative working, only by bringing these together can we see the whole picture.



# Linking CYP data: making a case for change

Early last year, Suffolk County Council and Suffolk & North East Essex ICB sought authorisation from NHS England to link education, social care and health datasets at child level. A task and finish group was established with representatives from across the system, including CYP i-Hub, Public Health & Communities, IT, SODA, Data protection and the ICB.



This came alongside a paper from The [Children's Commissioner](#) stating that 'Secure, planned and routine sharing of data on groups of children can improve services by better understanding user needs and journeys through health, education and other services'.

The Children's Commissioner recommends that the NHS number is used as a consistent unique reference number to link children's records.

[Recommendation of this approach to linking children's health and care data](#) has also been made by the Department for Education. Suffolk's approach to data sharing and linking will use the NHS number to link records, in line with these national recommendations.

Permission was granted, making us the second system in the country to achieve this.

# Benefits of linking data together include...

1. Organisations will be able to understand and **address system-wide issues**, identifying areas for improvement.
2. Better **Coordination of Services**
3. **Data-driven decision** making (Informed Policy and Practice, Evidence-Based interventions)
4. Inform **sufficiency planning** and resource allocation
5. Reduced duplication and **improved efficiency**
6. **Increased accountability** and transparency (Ability to track outcomes)
7. Enable **early risk** identification and proactive action
8. Increased understanding of the **inequalities** which impact children in Suffolk and the ability to take action to reduce disparities.
9. A holistic view children's needs will be possible, enabling professionals to offer **timely tailored support** and interventions in geographical locations where need is highest.
10. **The overarching aim will be to better meet the needs and to achieve better outcomes for children and young people.**



# **PROJECT OVERVIEW AND GOVERNANCE**

# Where are we now?

## Data is now flowing

As of early January the first sets of SCC CYP data are now linked with health data and held in a secure 'Population Health Management' (PHM) dataset. The wider PHM dataset has been linking and holding adult social care and health data safely and effectively for two years. The PHM data is hosted by the ICB and accessible by SCC analytical teams.

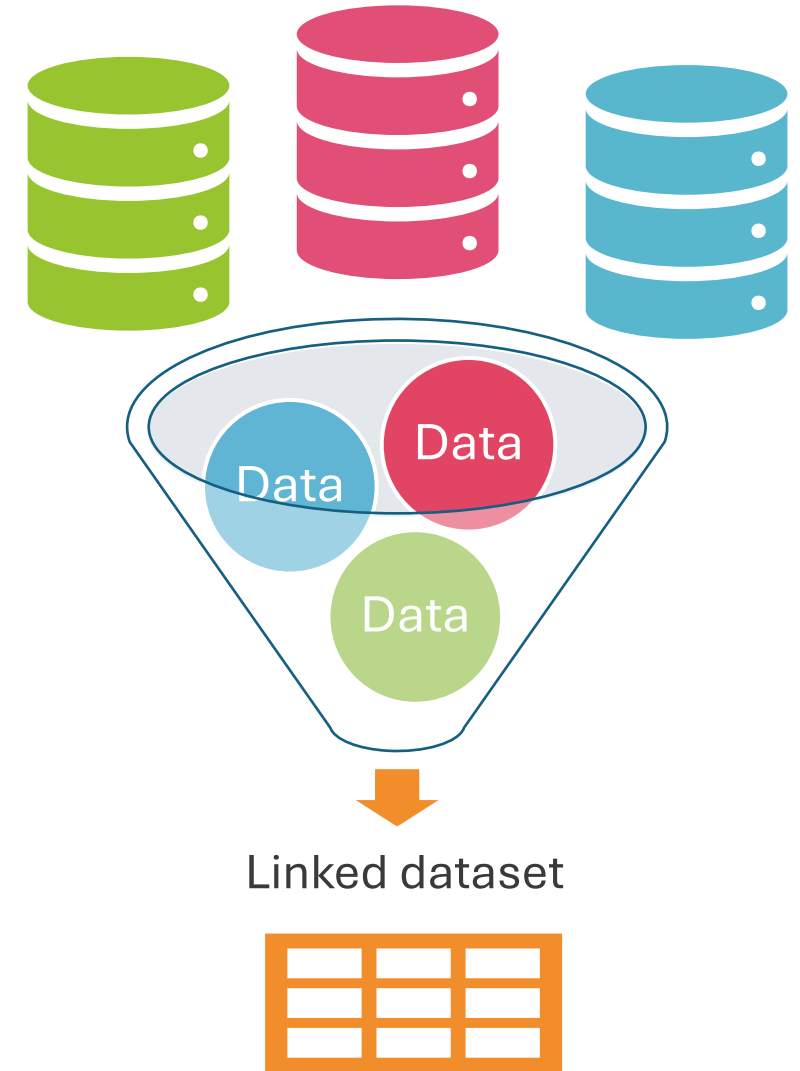
The dataset currently includes the following CYP data:

- NHS health data
- Children's social care
- Early Help
- Unaccompanied Asylum Seeking Children (UASC)
- Youth Justice
- SEND/EHCP (including Primary Need)
- Exclusions/Suspensions
- Home Education
- Free School Meals
- NEET/Post-16

Next month we are hoping to have incorporated the final datasets:

- SEN Support
- School Absence
- School Registrations

The data is in **indicator format** e.g Does the child have an EHCP – Yes/No



# Complex multi-organisational work has been ongoing to enable the data linkage to ensure that...



The linkage takes place within legal frameworks including the Data Protection Act 2018 GDPR, the Health and Care Act 2022 and the Children Act 2004



The data is safe, secure and only accessible to those with a need to see it.



Data is held in pseudonymised form and can only be re-identified to practitioners with a legitimate health or care relationship with the child



Small numbers are suppressed in analytical outputs to avoid the risk of disclosure





**FIRST USE CASE:  
AUTISM (ASD)  
WAITING LISTS**

# The first use case for the data will be to understand more about children on the the Autism (ASD) and ADHD assessment waiting list.

The project has been scoped in partnership with Harriet Wakeling in CYP and Jamie Mills in SNEE ICB.

## Purpose of the request

- To identify children and young people living in Suffolk who are currently on waiting lists for potential Autism (ASD) and ADHD and to understand their education, health and social care status.

## Objectives

- To gain an understanding of the vulnerability profile of these individuals and enable a holistic view of the support they are already receiving, or may benefit from.

## Impacts

- Understanding the effect on key vulnerability markers such as persistent absence or truancy, expulsion, NEET or involvement with Youth Justice.
- Exploring further possibilities for supporting these CYP effectively.

## Outputs

- Analytical report with visualisations, map and narrative insights.
- Tables and charts summarising wait times, education and social care markers.
- Potential conversion to a Power BI dashboard at a later date.



# The focus questions are:

<b>Key focus question</b>	Which children living in Suffolk are currently on the Autism (ASD) and ADHD assessment waiting list and are most vulnerable due to social care involvement, adverse educational markers and other risk factors?
Waiting times	What is the total number of children on the ASD and ADHD waiting list? How is the waiting time distributed ( 0–13 weeks, 13+ weeks, 1+ years, 3+ years)?
Demographics	What are the demographic patterns (e.g. by age group, ethnicity or sex)?
Service involvement	What proportion are open to children’s social care, youth justice, or early help services?
Absence	What proportion have experienced permanent exclusion, suspension, or are on part-time timetables?
SEND	What is their SEND status (EHCP, ECNA, SEND support), and what are their primary/secondary needs?
Education	How many are home educated, young carers, or NEET (not in education, employment, or training)?
Geography	Are there geographic patterns or hotspots (e.g. by MSOA) in the distribution of children on the waiting lists?



# Project timeline

	Mid Dec-25	Late Dec-25	Mid Jan-26	Late Jan-26	Mid Feb-26
<b>Phase 1: Project Initiation</b> Define project scope, objectives, stakeholders, and governance requirements to ensure clarity and compliance					
<b>Phase 2: Data Collection &amp; Linkage</b> Gather and link relevant datasets (MHSDS, PHM CYP, education, social care) to build a comprehensive view of children and young people on ASD waiting lists.					
<b>Phase 3: Analytical Assessment</b> Analyse waiting list demographics, vulnerability markers, and support status using statistical and mapping tools to identify key patterns and risk factors.					
<b>Phase 4: Reporting &amp; Visualisation</b> Produce analytical reports, tables, charts, and narrative insights; prepare for potential conversion to a Power BI dashboard for stakeholder review					
<b>Phase 5: Review, Feedback &amp; Action Planning</b> Share findings with stakeholders, gather feedback, address risks/issues, and develop recommendations for improved support and future monitoring					



# Initial findings

Will be available for the SEND Improvement Board meeting on 29<sup>th</sup> Jan



**NEXT STEPS AND  
FURTHER  
OPPORTUNITIES**

# Next steps and further opportunities



Linkage of the final 3 datasets and completion of the analysis to answer all focus questions



'Batch tracing' process with NHS England to obtain the NHS number for CYP where SCC don't already hold it – this will enable linkage of all records



Wider comms to stakeholders



Identification of further use cases – current suggestions include:

- Understanding how many children have medical needs in schools
- Analysis of how many persistently absent children are open to mental health services
- Understanding the NHS service usage of children not in education, employment or training (NEET)

The overarching opportunity is to use this data collectively to answer new questions which enable us to work more effectively as a system to support children and young people

