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Putting together the data jigsaw:

The extent of the linking of administrative datasets on children by Integrated Care Boards (ICBs) in England. Responses to a Freedom of Information request

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Acronyms

A&E	Accident and Emergency
AP	Alternative Provision
CAMHS	Child and Adolescent Mental Health Services
CCG	Clinical Care Group
CiN	Children in Need
CSDS	Community Services Dataset
CYPS	Children and Young People's Services
DfE	Department for Education
FOI	Freedom of Information
GP	General Practice
HES	Hospital Episode Statistics
ICB	Integrated Care Board
IG	Information Governance
LA	Local Authority
NHS	National Health Service
PHE	Public Health England
SEND	Special Educational Needs and Disabilities
SUS	Secondary Uses Services

Glossary of Terms

Child and Adolescent Mental Health Services (CAMHS)	The name for the NHS services that assess and treat young people with emotional, behavioural, or mental health difficulties.
Clinical Commissioning Groups (CCGs)	Groups of GP Practices that are responsible for commissioning most health and care services for patients as set out in the Health and Social Care Act 2012. These were replaced by ICBs in 2022.
Children in Need (CiN)	A group of children assessed as needing help and protection because of risks to their health or development.
Community Services Datasets (CSDS)	Child-level longitudinal administrative data from community health services in England since 2015, containing data on health visiting activity for individual children across each child's preschool period.
Children and Young People's Services (CYPS)	Typically, an organisation that provides a range of specialist emotional wellbeing and mental health services for all children and young people aged under 18 who are registered with a GP These services may be provided by different organisations depending on the region.
Data Linkage	Data linkage is a method of bringing information about the same person or entity together from different sources to create a new, richer dataset. This study explores linkage of healthcare, social care, and education datasets.
Freedom of Information (FOI) Request	The Freedom of Information Act 2000 provides public access to information held by public authorities. It states that members of the public are entitled to request information from public authorities.
Integrated Care Board (ICB)	Statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget, and arranging for the provision of health services in a geographical area.
Local Authority (LA)	Statutory organisation that is responsible for governing an area of the country. A Local Authority can either be a county council, borough council, metropolitan area council, or a district council.

Summary

The aim of this research was to investigate the extent of data linkage of children and young people's data in Integrated Care Boards (ICBs) across England. The research questions were explored using a Freedom of Information (FOI) request submitted to all 42 ICBs in England. 31 of 42 ICBs responded to the FOI request (73.8%).

The ICBs reported that they were frequently engaging in data linkage between health datasets. Secondary Uses Services (SUS), Accident and Emergency (A&E), Primary care, and Community Services Datasets (CSDS) were the most frequently linked health datasets. However consistent with the authors' previous publication on local authority (LA) data linkage practices, ICBs were rarely linking their health data with LA datasets (social care and education).

Primarily, if ICBs were linking data, they were doing so for all children and young people in their area. However, some suggested they could not specifically undertake data linkage for certain groups of children, such as those with Special Educational Needs and Disabilities (SEND) and Looked after children, because these vulnerabilities were not always flagged in their health datasets.

ICBs were most likely to be using linked data to undertake strategic planning and populate data dashboards. This echoes the findings from the publication on LA data linkage practices, however the ICBs were also often using the linked data for population health management.

This study suggests that ICBs, similar to LAs, frequently link internal datasets, but face greater challenges with regards to external data linkage. This barrier between healthcare data and LA data on social care and education is a hinderance to multi-agency efforts to meet the needs of disabled children and their families as mandated by the Children and Families Act. Recommendations informed by this research are presented at the end of this briefing.

Policy context

The SEND and Alternative Provision (AP) Improvement Plan (Her Majesty's Government, 2023) proposed national and local inclusion dashboards to 'provide a basis for measuring whether we are achieving our mission of improved outcomes, better experiences and a financially sustainable system' (p. 71). The Independent Review of Social Care (MacAlister, 2022) recommended that the Department for Education (DfE) adopt a proactive data strategy for children's social care, including data linking with education, hospital, and justice data. A "consistent identifier" was suggested to "easily, quickly, and accurately link" data (p. 62). The Department for Education (DfE) strategy (2023) Stable homes, built on love: children's social care strategy and consultation recognises that data is not consistently available to support practitioners, setting out their intentions to deliver social care dashboards by the end of this Parliament. The consultation recognises that there are 'data gaps' and burdens on councils that prevent better use of data, and includes plans for a strategy to address this to be published by the end of 2023.

Parliamentary debate on the Health and Care Act 2022 prompted a Government commitment to develop proposals to improve data-sharing between health and social care to safeguard children and to explain their approach to implementing a consistent child identifier. The subsequent report to Parliament (DfE, 2023) is cautiously supportive of using the NHS number as a consistent child identifier, proposing regional pilots and further work to improve the 'interoperability' of data systems and to build practitioners' confidence in sharing information.

Benefits of linking data

The merits of data linking from public services are well documented (Downs et al., 2016). Linked data can be a means of identifying those at risk of negative outcomes to target early intervention and gathering information about specific groups (Atherton et al., 2015; Sohal et al., 2022; ADR UK, 2023). For example, linking data between healthcare and education datasets provides ways of examining the impact of mental health and illness on academic achievement (Downs et al., 2019). However, the findings of the recent FOI request indicated that, for LAs, targeted interventions were a less common use of linked data than data dashboards and strategic planning (Martin-Denham et al., 2023). The research also found that 75.8% of LAs were not yet linking internal with external health datasets.

Examining the impact of mental health and illness on academic achievement

Useful in identifying those at risk of negative outcomes

Target early interventions

Barriers to data linking

Barriers to data linkage include issues of consent, the capacity required for thorough analysis of linked data, a lack of understanding of where the data originates, and the quality of this data (Atherton et al., 2015). Inadequate data capture in individual services has also been known to hinder data linkage efforts e.g., in health, lacking the facility to easily capture data at each point of care; in education, a strong focus on the perceived primary need of each child, instead of all their needs (Martin-Denham et al., 2023, Pinney, 2017, p.19). The situation is not helped by the different definitions, scope, and purpose of health, education, and children's social care data sets (Pinney, 2017, p.9, p.19). Moreover, a unique personal identifier is needed to enable linking data from different administrative sources with marginal error. Some Scandinavian countries have national legislation that requires such an identifier to be used in all administrative contexts (health care, education, military, etc.) (Ludvigsson et al., 2009). This is not currently the case for the UK, however the recent DfE report to Parliament (July 2023, p.11) acknowledges that "Whilst this is not the panacea, using the NHS number would allow data to be shared more efficiently and accurately."

Table 1. Responses to FOI as of July 6th 2023

Requests and responses	ICB Responses	% of Total
Total FOIs attempted	42	N/A
Full responses	31	74%
Responded with queries	4	9.5%
Awaiting response	3	7.1%
Incomplete response	2	4.8%
Do not hold info requested	2	4.8%

Aim and objectives

Aim: To investigate the extent of data linkage of children's data at the ICB level in England and to:

1. Identify which LAs are linking data sets.

2. Determine which datasets LAs are linking.

3. Investigate how LAs are using linked data.

Methods

Between May and July 2023, FOI requests were made to 42 ICBs. The response rate was 31/42 for complete responses (Table 1). There were two incomplete responses that were not included in the analysis. The data was analysed using descriptive statistics. For ease of reading, 'children' is used to include 'children and young people'.

Findings

The findings are presented in order of the FOI questions. Percentages are rounded to one decimal place.

① Do you link health datasets for children and young people accessing health services? (n=38)

As shown in Figure 1, 22 ICBs (57.9%) reported that they were linking health data for children and young people. Ten ICBs (26.3%) reported that this was in development and six (15.8%) were not yet linking data.

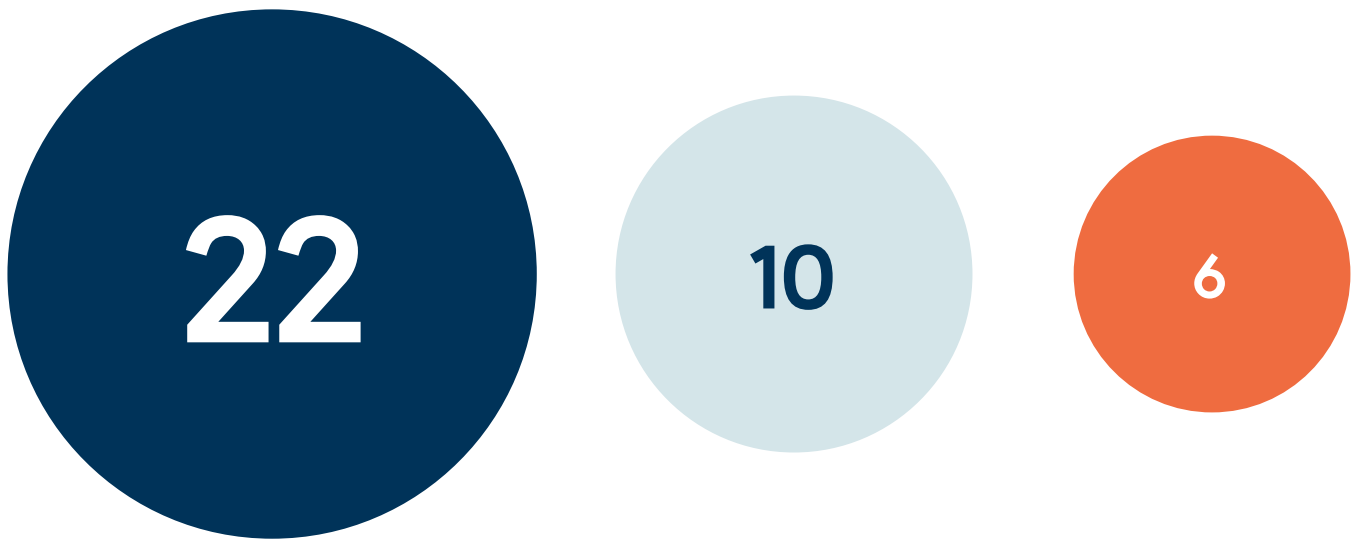**Key:** Bubble size representative of number of responses ● Yes ● In development ● No

Figure 1. Number of ICBs linking health datasets

Two ICBs whose linkage of health data was in development elaborated on their responses. Coventry and Warwickshire disclosed that they were in the process of linking data, with the first phase of linked primary and secondary care data scheduled for September 2023 in the form of a linked data platform. Before conducting additional data linking and establishing the South Yorkshire Data Centre, Doncaster is investigating the Community Services Dataset (CSDS) accuracy and completeness.

2 Which health datasets are you linking? (n=38)

SUS (also known as Hospital Episode Statistics (HES)), A&E, Primary care, and CSDS were the most frequently linked health datasets, as depicted in Figure 2. These were the only datasets that were linked by >50% of ICBs. ICBs were less likely to link CAMHS, CYPS, and Births and Deaths datasets. Only two ICBs were linking Child Health records.

The present study's accompanying publication on LA data linkage (Martin-Denham et al., 2023) found that many LAs were unfamiliar with CYPS as a service. CYPS is a service that is not offered in every region, and sits under the larger umbrella of Children and Young People's Mental Health Services (CYPMHS). CAMHS also sits under this umbrella, but is a nationally-available NHS service, unlike CYPS. However, some ICBs reported that the information they received from CAMHS was covered by the CSDS, which negated the need to link the former.

Key: ■ Yes ■ No

Number of ICB responses

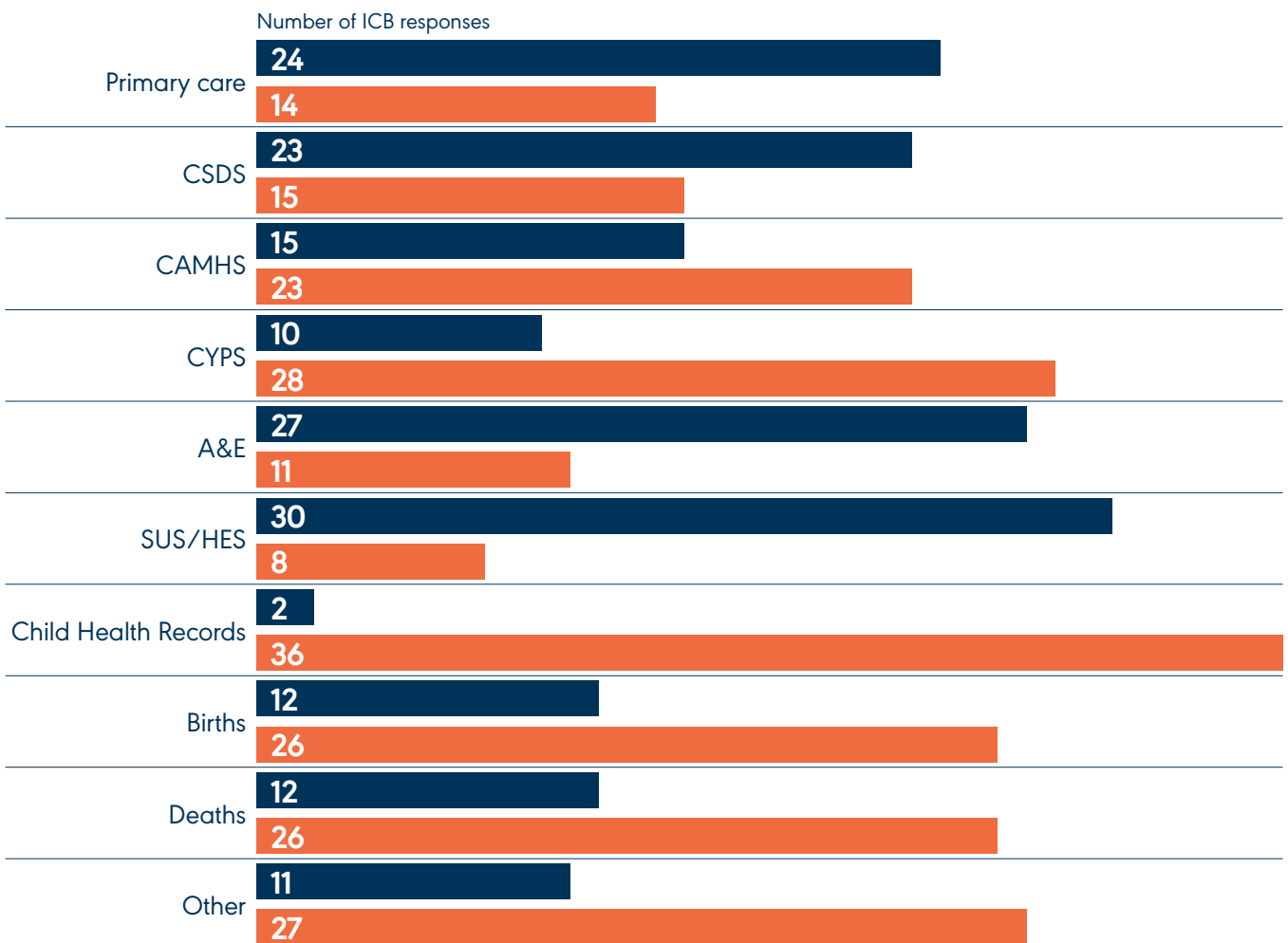| Dataset	Yes	No
Primary care	24	14
CSDS	23	15
CAMHS	15	23
CYPS	10	28
A&E	27	11
SUS/HES	30	8
Child Health Records	2	36
Births	12	26
Deaths	12	26
Other	11	27

Figure 2. Which health datasets are being linked by ICBs?

Eleven ICBs identified the 'other' datasets they were linking in their response to Question 2 (Table 2).

Table 2. The 'Other' reported datasets from Q2

ICB	Other
Bath and North East Somerset, Swindon and Wiltshire	Ambulance NHS 111 Monthly Mental Health Minimum Data Set (MHMDS)
Buckingham, Oxfordshire and Berkshire West	Ambulance NHS 111
Cambridgeshire and Peterborough	Ambulance (MDS) Improving Access to Psychological Therapies (IAPT) Maternity Services Dataset (MSDS) Mental Health Services Dataset (MHSDS) Secondary Care Drugs and Devices Contract Monitoring Waiting List (WLMDS)
Cornwall and Isles of Scilly	Prescribing
Gloucestershire	MHSDS Personal Demographic Service (PDS)
Hampshire and Isle of Wight	Direct feed from acute, mental health and community providers[2]
North East London	Diagnostic Imaging-Dataset (DIDS) IAPT MHMDS Waiting Lists
Nottingham and Nottinghamshire	Alcohol Dependence Continuing Health Care (CHC) Child and Young People Health Service (CYPHS) COVID-19 Ethnic Category Data Set COVID-19 Vaccination Status DIDS e-Referral System Dataset (eRSDS) IAPT MSDS MHSDS National Cancer Waiting Times Monitoring Dataset (CWT) National Diabetes Audit (NDA) Out-of-Hours Emergency Care Providers Patient Reported Outcome Measures Dataset (PROMS) Patient Demographics Service (PDS) Summary Hospital Mortality Indicator Dataset (SHMI) Tobacco Dependence
South West London	NHS 111
Suffolk and North East Essex	Ambulance NHS 111

3 Which groups of children and young people do you link health data on? (n=38)

30 ICBs (78.9%) were linking, or developing the capacity to link health data on all children and young people in their area (Figure 3). One ICB was only linking health data for children and young people with SEND, those on the Children in Need register, and those eligible for free school meals.
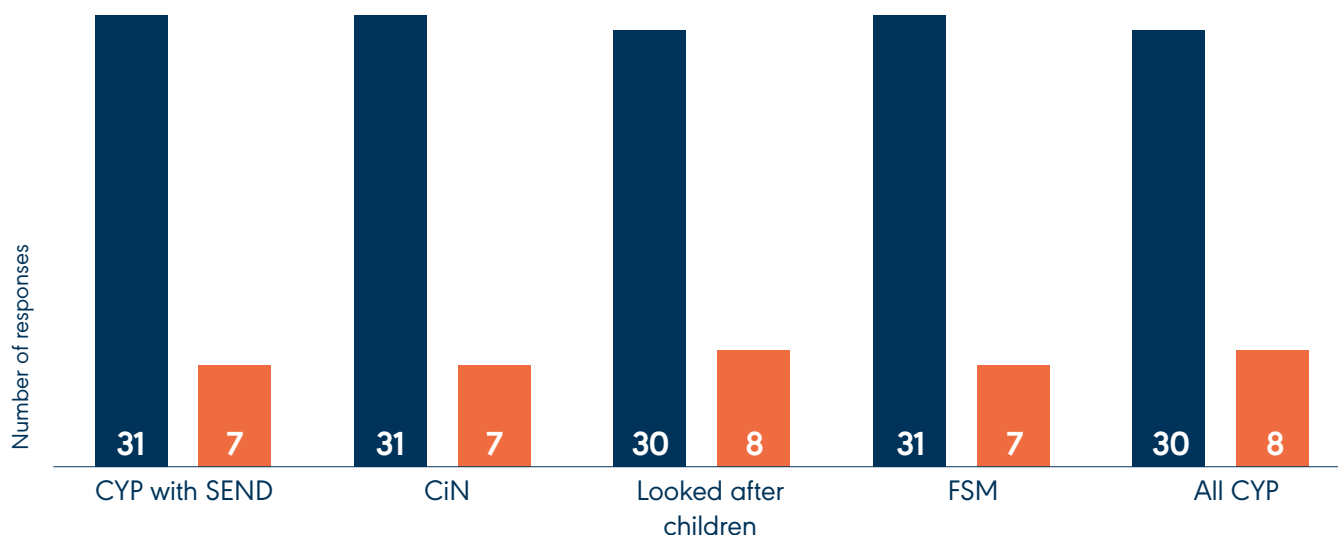
Key: ■ Yes ■ No

Figure 3. The groups of children whose data are being linked

Some ICBs elaborated that, while they could link data on all children, they did not yet have the capability to link data on specific groups of children. For example, Cheshire and Merseyside ICB answered "There is the ability in data sets across Cheshire & Merseyside ICB to link all children and young people, but the ability to link those with Special Educational Needs and Disabilities, Looked after children, or those in need is dependent on records being identified (or 'flagged') as such in the original data set."

Other ICBs reported that the ability to link data for specific groups of children and young people varied across the area they covered. North East and North Cumbria ICB reported that the ability to link data for Children in Need and Looked after children was only possible in some areas. Suffolk and North East Essex were only linking data for children who had accessed health services.

4 How are you using the linked data? (n=38)

The majority of the ICBs were using linked data for strategic planning (63.2%) and/or data dashboards (57.9%). Joint commissioning (50%), service review (44.7%), and targeted interventions (44.7%) were less common (Figure 4).
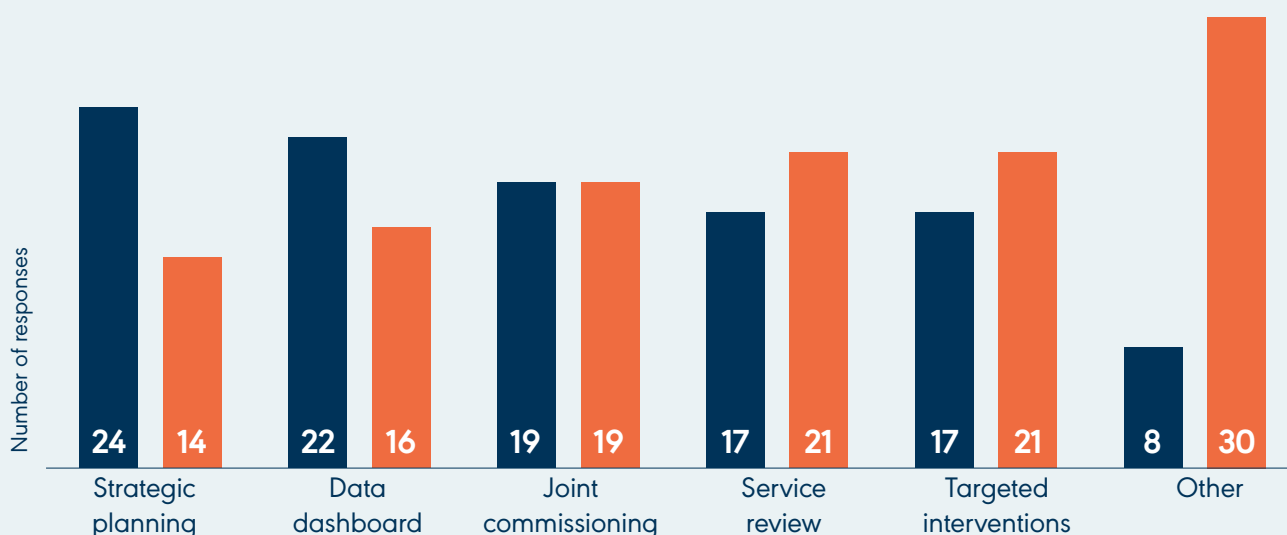
Key: ■ Yes ■ No

Figure 4. How ICBs are using linked data

The comments from the eight ICBs who reported using data linkage for 'Other' purposes suggest some were actually using the linked data for strategic planning (as shown in Table 3). Some referred to population health management, which the NHS defines as "a way of working to help frontline teams understand current health and care needs and predict what local people will need in the future." This could likely fall under the umbrella of strategic planning, however, the additional detail provided in these responses is nonetheless useful.

Table 3. The 'Other' reported uses of linked datasets from Q3

ICB	Other
Black Country	Inferential statistics and capacity/demand modelling utilising 'System Dynamics & Discrete Event' modelling
Cornwall and Isles of Scilly	Population health management
Coventry and Warwickshire	Direct Patient Care and Population Health Management
Gloucestershire	Identifying potential or emerging health inequalities Service transformation/improvement
Hertfordshire and West Essex	Segmentation modelling
Northamptonshire	Currently working with the children and young people collaborative to better understand their data/reporting requirements
North West London	Population health management Pathway analysis
Sheffield	Reviews for specific conditions

5 · Do you currently link local health datasets with any LA datasets? (n=38)

Only a minority (15.8%) of ICBs were linking local health datasets to LA datasets (such as school census and Children in Need datasets). This process was in development for 28.9% of ICBs, while the majority of ICBs (55.3%) had made no progress towards linking these datasets.

Key: Bubble size representative of number of responses ● Yes ● In development ● No
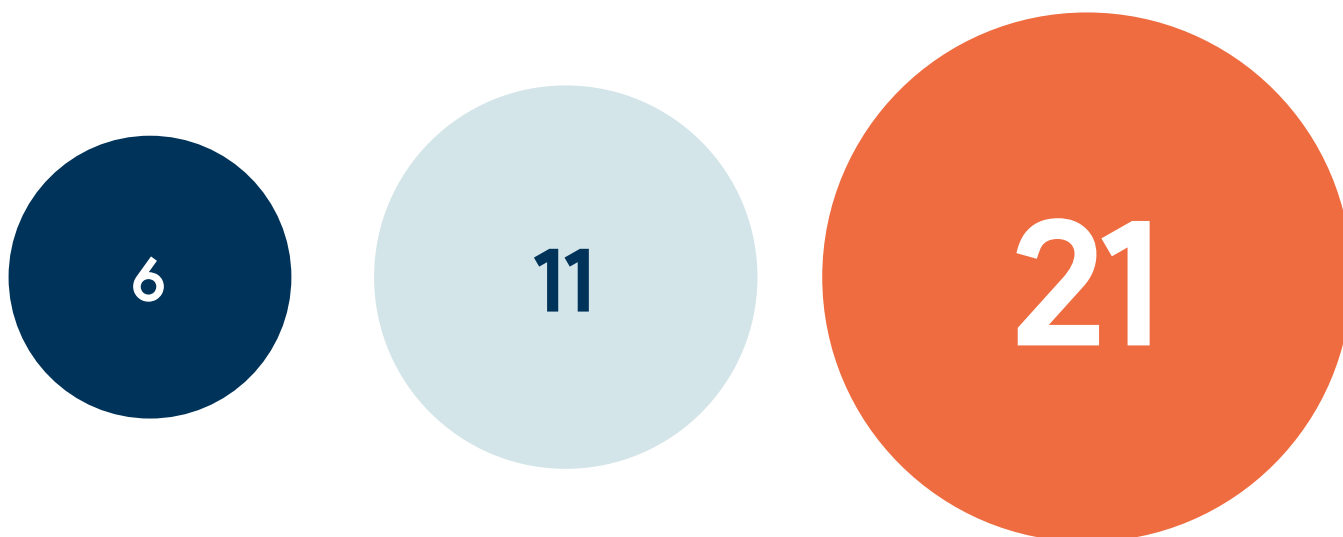

Figure 5. ICB reported linking of health and LA datasets

Seven ICBs shared reasons why data linkage of health and LA data was in development or not occurring at all (Table 4). The reasons included: only receiving LA data; information governance barriers; and lack of data flow.

Table 4. ICB reported reasons data linkage of health and LA datasets was in development or not taking place

ICB	Other
Cambridgeshire and Peterborough	We have just added Social Care Packages to the warehouse but it is still in development in terms of usage
Cheshire and Merseyside	Linkage with Social Care data is in place in some geographic areas in Cheshire & Merseyside ICB, but not all currently
Gloucestershire	No linking of Children's data from the LA with Health Care data sets
Leicester, Leicestershire and Rutland (LLR)	At present the LLR ICB do not link local health data sets with the LAs and work is in early stages of development
North East London	Information Governance is not in place to share LA with health yet
North West London	In development and working with LAs to get children & young people LA data flows in place
South West London	Nothing currently available, however programmes are in place to onboard Children looked after return SSDA903

6 **Which LA datasets are you linking to health datasets? (n=38)**

As shown in Figure 6, only 18.4% of LAs were able to name the specific datasets that were being linked. This was consistent with responses to our FOI request to LAs (Martin-Denham et al. 2023) which showed that there were few LAs linking their social care and education data with health data.
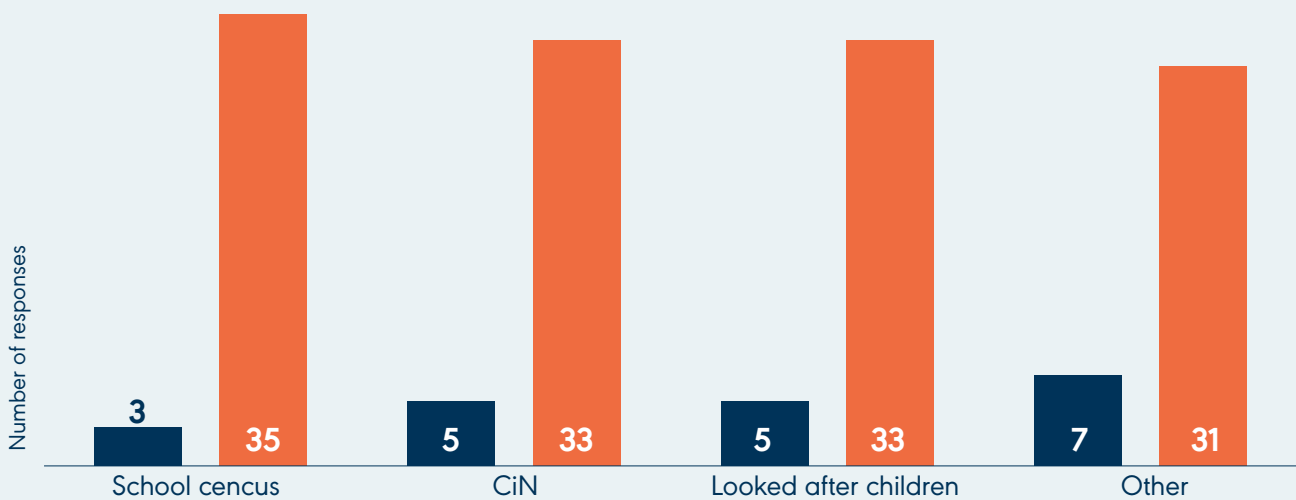
Key: ■ Yes ■ No

Figure 6. The LA datasets linked to health datasets

Of the ICBs that linked 'Other' datasets, two linked adult social care data only (Table 5), and did not engage in data linkage between LA and health data on children in their area.

Table 5. The 'Other' LA datasets linked to health datasets

ICB	Other
Bath and North East Somerset, Swindon and Wiltshire	Social care data
Cambridgeshire and Peterborough	Social care packages
Cheshire and Merseyside	Social care records
Cornwall and Isles of Scilly	Adult social care datasets
Doncaster	National Child Measurement Programme
South East London (Central Analytics)	National Child Measurement Programme, the ICB is in the exploratory stage of accessing patient level data from LAs/PHE
Suffolk and North East Essex	Currently only Adult Social Care

Discussion

The aim of this research was to investigate the extent of data linkage of children's data at the ICB level in England with three objectives, as follows.

Determine which ICBs are linking children and young people's data

The majority (57.9%) of ICBs in this study were linking their internal health datasets. 26.3% of ICBs stated that data linkage efforts were 'in development' while the remaining 15.8% were not linking children's data and did not provide any rationale.

While the majority of ICBs were linking internal health datasets, only a small minority (18.4%) of ICBs were linking health and LA data. Some ICBs provided rationale, referring to a lack of Information Governance (IG) arrangements, and a lack of data flow. References were made to 'onboarding' certain social care datasets in the future, however, there was scarce evidence that ICBs in England are engaged or are developing systems to allow for the linking of health datasets and LA datasets on children. This was particularly true of linking health data with education data, with no reference made to the latter in any responses from ICBs.

In the previous publication on LA data linkage, a similar pattern was observed. LAs were frequently linking their own internal datasets but were unlikely to be linking these with any healthcare datasets (Martin-Denham et al. 2023).

Determine which datasets ICBs are linking

For ICBs that were linking health datasets, the most commonly linked datasets were SUS, A&E, Primary care, and CSDS. Some secondary care datasets like CAMHS and CYPS were being linked by a minority of ICBs, as were Birth and Death records. Child Health Records were only being linked by two ICBs.

Evidence regarding LA datasets that are being linked to health datasets by ICBs was in short supply. Of the three datasets provided as options (School census, CiN, Looked after children), each was being linked by fewer than 12% of ICBs in this study. When ICBs answered that they were linking 'Other' LA datasets,

they usually mentioned social care data packages and adult social care, highlighting the lack of data linkage occurring across ICBs regarding children's data held by LAs.

It is encouraging to find that there is data linkage occurring between the CSDS and other health datasets, as the previous publication reported that only three LAs were linking this dataset to their social care and education data (Martin-Denham et al., 2023). However, it is concerning that a considerable number of ICBs are not linking other health data to the CSDS, as the CSDS is a vital dataset for identifying trends in childhood disability data. This may give more credence to the suggestion in the previous publication that the CSDS is not flowing adequately in certain regions; the Doncaster branch of the South Yorkshire ICB stated that they could not link the CSDS until they assessed its 'accuracy and completeness'.

Identify how ICBs are using linked data

When ICBs were engaged with children's data linkage, they were using it to inform strategic planning and populate data dashboards. The extent to which ICBs were using data linkage for strategic planning is likely to be understated by the responses, as many who gave a response labelled as 'Other' mentioned population health management, which is itself a form of strategic planning. Half of the ICBs were using linked data for joint commissioning, while a smaller proportion were using linked data for service review and targeted interventions. It is interesting to note the amount of joint commissioning occurring in ICBs, as one might expect this to be more prevalent in LAs' use of linked data, however, this was not the case (Martin-Denham. 2023).

Concluding remarks

There appears to be a vast difference between internal and external data linkage across ICBs. For example, Nottingham and Nottinghamshire are linking upwards of 20 health datasets, but these are not linked to any LA datasets. These findings are mirrored in the previous publication, which showed that LAs frequently linked their own datasets, but seldom engaged in external data linkage with health datasets (Martin-Denham et al. 2023).

Linked data also has the potential to provide richer evidence on trends in prevalence (as expected in the SEND Review, p. 30 & 76) than is possible through analysis of SEND primary needs data alone (Pinney, 2017, p.18-19). In particular, paediatric disability data in the Community Services Data Set provides rich evidence of the multi-faceted needs of children and families, in areas where NHS providers comply with the mandate (in place since November 2015) to report.

Until health, education, and social care datasets are more widely linked, there will be limited scope for engaging in robust multi-agency planning, review, and joint commissioning to meet needs of disabled children and their families in the integrated fashion expected by the Children and Families Act (sections 25 & 26).

National recommendations

a. Opportunities for LAs and health partners to share learning through a grants programme on how they have successfully linked health and LA data to improve outcomes for children.

b. Best practice guidance and IG templates to make it easier for ICBs and LAs to develop data-sharing protocols and processes.

c. For LAs to add NHS numbers to children's EHC plans and datasets to provide an accurate, efficient field for data linkage with NHS/health datasets, as suggested by the Council for Disabled Children (CDC, 2021).

d. A consistent data capture interface to improve reporting of paediatric disability data to the Community Services Data Set, a key dataset for understanding trends in SEND and the multi-faceted needs of disabled children and their families.

e. Data capture at all points of care and services across agencies needs to be in place to ensure that quality data are available to link and analyse to improve children's outcomes.

Future research

Future studies should investigate and report examples of how local data linkage across health, education, and social care has improved outcomes for children and their families. It is important to showcase the potential of data linkage as a tool for identifying and addressing the needs of disabled children, as this may lead to improvements in commissioning and further funding towards robust data linkage practices across ICBs as well as LAs.

Furthermore, it is concerning to find that some ICBs are not able to identify children with specific vulnerabilities, such as SEND and Looked after children, in all of their health datasets. Future research should discriminate between whether ICBs/LAs are merely capable of linking data for these children, or whether they are able to specifically identify these groups of children in their data linkage.

Limitations

There are a number of potential limitations of this research. First, not all ICBs have provided a response to the FOI request. Four responded with queries that have not yet been addressed, three are yet to respond, two provided incomplete responses and two suggested that they did not hold the information that was requested in the FOI. With more time and resources, it would be possible to increase the number of completed responses, and a higher response rate would allow for more valid generalisations about data linkage practices in England.

Second, the responses to Question 3 did not provide sufficient insight. Question 3 asks 'Which groups of children and young people do you link data on?' If an ICB answered that they linked data on each of the subcategories of children and young people (children and young people with SEND, CiN, Looked after children, children and young people on free school meals), as well as 'All children and young people', the authors were unable to discern whether, for example, the ICB was specifically linking records for children and young people with SEND. Rather, it could be the case that all children and young people with SEND would be included in region-wide data linkage practices that would not necessarily be addressing the specific needs of children and young people with SEND. Splitting this section of the FOI request into multiple questions may have been preferable, for example:

Question 3a: Do you link data for all children and young people? Yes/No

Question 3b: Do you perform data linkage on any specific groups of children and young people, and if so, what are the groups?

- Children in Need
- Looked after children
- Children and young people on free school meals
- Other (specify)
- We do not perform data linkage on specific groups of children and young people

Third, some ICBs did not feel that one response from the whole ICB would give an accurate representation of data linkage practices in the region (possibly reflecting fairly recent health service restructuring with the move from CCGs to ICBs). Instead, the ICB of South East London gave one response for their Central Analytics team, and another for Lewisham's place-based population health management centre. West Yorkshire ICB gave five separate responses, each for a different area of the region:

a. Leeds
b. Bradford district and Craven
c. Calderdale
d. Kirklees
e. Wakefield

Yorkshire ICB gave five separate responses, each for a different area of the region:

a. Sheffield
b. Barnsley and Rotherham
c. Doncaster

These discrepancies suggest that regional variation in data linkage practices cannot be evaluated solely through differences between ICBs, as there are additional differences within ICBs. While the present study did not have the resources to investigate the structure of each ICB or account for multiple parties involved in data linkage within individual ICBs, an exhaustive investigation of variations in data linkage practices across England cannot take place without considering these supplemental details.

Fourth, as mentioned in the findings, the low rate of data linkage reported for the CYPS dataset does not suggest that this data is being omitted from all data linkage. Rather, different regions of England use a different name for this service and data, an incongruence which is characteristic of the challenges involved in linking data between different services and regions.

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