

Workshop report: Improving Data Sharing and Linkage

Background

The British Academy of Childhood Disability Strategic Research Group (BACD SRG) is working with the Council for Disabled Children, part of the National Children's Bureau, on the opportunities and challenges for research using linked datasets derived from health, education, social care and other public services. This work is funded by The Castang Foundation.

The Children's Wellbeing and Schools Bill includes specific measures to improve the sharing of information about children between different agencies where it is in their best interests to do so. This includes introducing a Single Unique Identifier (SUI), which would require services to use a consistent code across the different data systems for which they are responsible and when sharing information about an individual child. However, the current provisions in the Bill do not make it explicit that the SUI can be used for reasons beyond operational safeguarding and welfare purposes. This has raised concerns, specifically, around whether or not the SUI can be used for research.

What is the problem?

Health, education, social care and other public services individually have large amounts of data that exist within their own organisations. At present, sharing and linking data about large numbers of children for *research purposes* is challenging for legal and practical reasons. Most data sharing and linkage takes many years to achieve. This reduces opportunities for the use of population level data held by public services from being safely used for timely research to improve the wellbeing and lives of children and families.

A workshop focusing on the potential for a Single Unique Identifier in improving data sharing and linkage for research was conducted in March 2025. The workshop was attended by 15 participants from 11 organisations (listed in Appendix); all had experience and expertise of linking data or working with linked data. The workshop findings are summarised below.

Report recommendations

1. An SUI should be able to be used in the sharing and linkage of agencies data for research that could improve the lives of children and families. There should be a clear statement about this in legislation. In this context the existing legal and data protection frameworks would still need to be followed.
2. Following legislation, there should be meaningful public engagement to help improve public trust and reduce privacy concerns. Engagement activities need to include those populations for whom good quality data are currently lacking.

Benefits of a SUI for Research Purposes

Increased accuracy and efficiency: Improves accuracy of record matching, reducing errors in identifying children. Implications for improved individual care, operational aspects, and research data use.

Reduced costs and administrative burdens: Saves time and resources currently spent on complex probabilistic matching methods. May reduce some of the current delays in accessing data, and therefore staff costs.

Improved confidence in legitimacy of data sharing: A clear statement in legislation that data shared and linked can be used for research would facilitate use of SUI for research purposes, and reduce the concerns of data controllers.

Better policy and service planning underpinned by research: Enables researchers to better support high quality care through operational initiatives to improve the lives of children and families. Longitudinal tracking would be enabled, providing a clearer understanding of cohorts and informing service development that meet children's changing needs over time.

Enhanced research and operational insights: Allows early identification of groups or populations of children at risk (including intersectionality of vulnerabilities), creating opportunities for further research leading to the development of effective intervention strategies. Better ability to visualise the 'whole' of a situation would remove challenges associated with piecing together all the different data needed to understand complex issues under current linkage systems.

Reduced data sharing risks: Would necessitate less identifiable data to be shared, as matching and linkage would be streamlined by use of SUI, reducing some privacy concerns.

Reduced need for individuals to re-share traumatising information for research purposes.

Opportunities for UK to become leaders in use of data for real world public good: Publicly funded services that are free to the population at the point of care means that UK is a leader in data sources, the quality of data and opportunities for linkage. In the future, this can be harnessed to improve the health and wealth of the nation e.g. AI technologies supporting delivery of high-quality care.

Examples of existing data linkage systems

Some successful linkage systems do exist (e.g., [E-CHILD](#), [Born in Bradford](#), [Cadre](#), [SAIL Databank](#)) and function without a SUI, though they require extensive legal, technical, and financial support and are time consuming.

Current barriers to data sharing and linkage

Lack of a SUI: Current data linkage relies on complex matching processes, leading to data errors. These errors are compounded for vulnerable children for whom baseline data quality is poor (e.g., children of asylum seekers, adopted children, children from ethnic minorities, those who frequently change address, children of sex workers). Current data linkage algorithms are based on white populations – this compounds inaccuracies in data from particular populations. These errors lead to lack of confidence in linked data, especially about the children who face the greatest challenges.

Governance complexities: Researchers face challenges accessing data due to unclear data ownership and restrictions on data sharing across organisations.

Public trust and privacy concerns: Certain communities distrust government data use, fearing misuse (e.g., displaced persons, people from minority ethnic groups). Past initiatives have raised privacy concerns, particularly in relation to the potential sharing of GP records.

Data quality issues: Inconsistencies in local authority systems and case management software across health, social care and education hinder effective linkage. The accuracy of data within each sector varies, limiting the accuracy and value of linked data.

Legislative and policy inconsistencies: Different legal frameworks exist for health, social care, and education data, creating bureaucratic challenges, which can create challenges for the timely provision of data.

Appendix

Organisers and report authors

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Workshop attendees

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