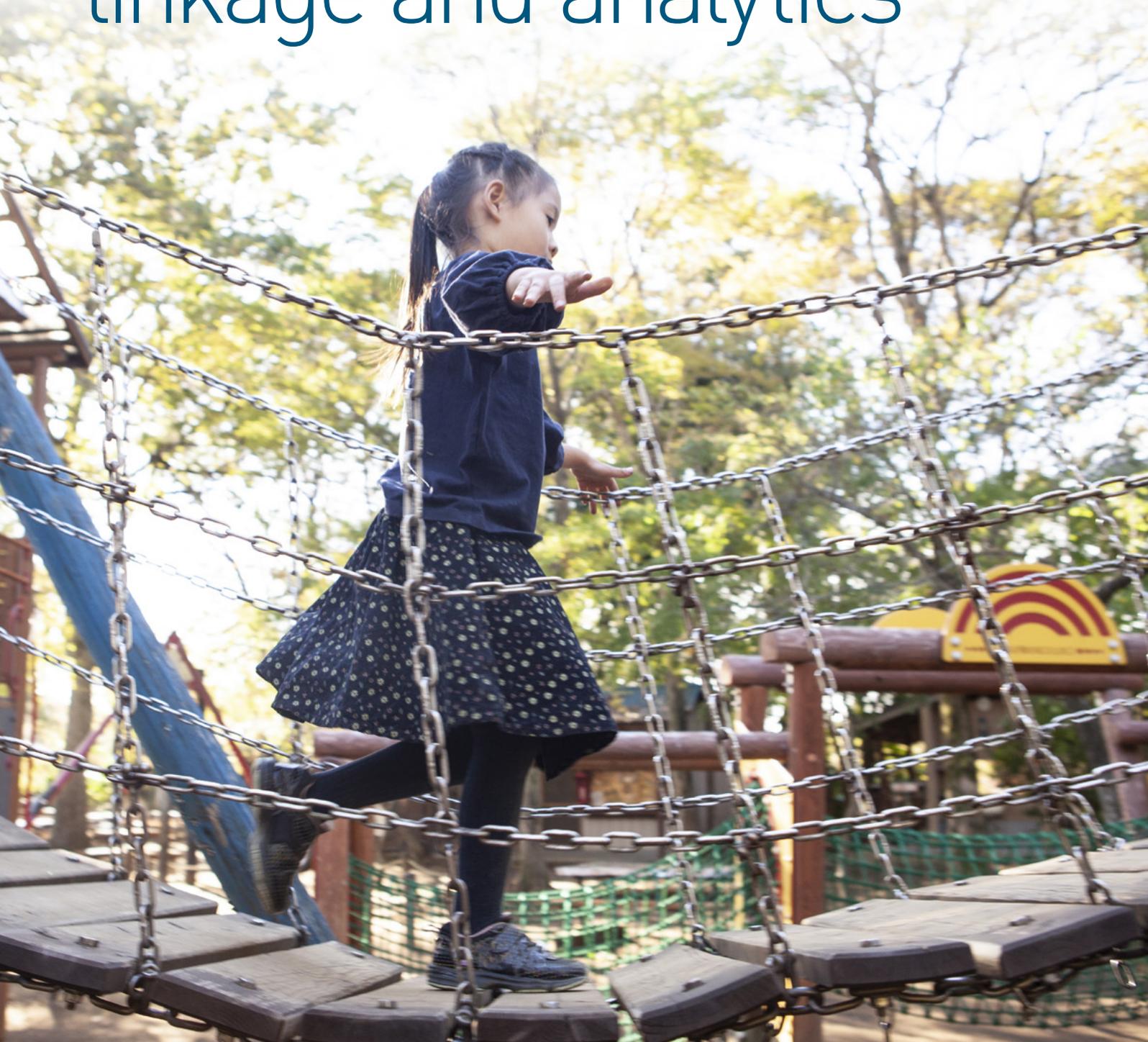


Parents' views on administrative data linkage and analytics



CONTEXT

This study fills a vital gap in knowledge about trust for operational data linkage and analytics among parents of dependent children, in a context where policy developments, and data practices to inform services interventions are moving ahead of public knowledge and consent. We have commissioned a UK wide representative survey of parents, conducted focus group discussions with subgroups of parents and have interviewed family service users. Evidence from our research has shown public confidence in administrative data practices to be weak.

“More effort needs to be made to enforce data rights and transparency if social legitimacy and trust is not to be further undermined.”

KEY MESSAGES

- 1. Transparency and informed consent matter to parents.** Most do not feel they have enough information about administrative data processes to properly assess their legitimacy and they expressed a strong view that parents should be asked for permission before administrative records are linked together.
- 2. There is no social legitimacy accorded to private sector access to and involvement in public sector administrative data sharing and analytics.** More broadly, there is little public support for any flexibility in data protection. Trust is dependent on there being strong and binding levels of regulation and safeguarding in place.
- 3. Trust in the linking and analysing of administrative data among marginalised population groups is precariously fragile.** Concerns over potential data sharing has prevented some parents from using services. Only a minority of parents felt confident that families would not be discouraged from seeking help from a service that links data.
- 4. Parents expressed considerable mistrust about the accuracy and fairness of predictive analytics and highlighted the risk of errors and misinterpretations.** Widespread experiences of administrative data inaccuracies and service misconceptions stoked concerns about potential negative consequences for families.
- 5. Parental support for the linking and analysis of administrative data to identify families in need of support was dependent on the availability and proper resourcing of services.** Where parents thought that data linkage and analytics might be beneficial to families, they did not feel there was sufficient capacity in service provision for this to be realised.

FINDINGS

Transparency and consent

Our survey shows that parents do not feel they know or understand how their records are being used (82%). Most parents know that administrative records are collected and digitally stored about them (72%), but only just over half know that digital administrative records from different sources can be linked together to find out more about individual families (53%). There is overwhelming agreement that Government should publicise how they link and use families' data (81%). There is also strong view that parents need to be asked permission for administrative records about their family to be shared and linked together, at 60% overall and 66% among parents from marginalised groups. Only around half of parents overall trust Government and services to share administrative records.

Private sector involvement

A majority of parents were against the sharing of data with the commercial sector, at 55%, and rising to >60% among parents from marginalised groups. There was considerable suspicion expressed about the involvement of private companies in administrative data linkage, with a majority of parents against this among all social groups, at 55%, and rising to >60% among parents from marginalised groups. This concern was backed up in our focus group discussions

“I’m quite negative about [private data analytics companies working with public administrative records] to be honest. Because I would be interested to know like what is the prerequisite for the people that are working for these private companies? Like how are they vetted? ... Like no, I'm not comfortable with that at all. That needs to be seriously regulated.” Mother

Mistrust and service avoidance

There is a particularly worrying level of distrust towards government and public services among social groups with protected characteristics, such as Black parents, and those on low incomes, young parents, and large families. Only 28% of Black parents had trust in the linking of police and criminal justice data. More broadly, a minority of all surveyed parents were sure that they would not avoid a service that linked data (just 35%) and even fewer (15%) were sure that other families would not avoid services for this reason. Interviews with family service users confirmed this, with several parents admitting that they had avoided seeking help because they did not want a digital record to be linked and shared.

*“I hear from a lot of parents, as a parent peer support and as a parent of a kid..I don't want to take my child to the doctor, because then they think this'..... There's dozens of forums online, where parents are telling other parents, 'Don't ask for help because it will be used against you.' That's a big risk, we could end up with children who are actually getting hurt because their parents are too scared that they might lose them if they ask for help”
Mother and family service user*

Predictive analytics, error and risk

Focus groups and individual interviews revealed a broad scepticism about the predictive capacity of algorithms. Few parents believed that past actions could or should be used to predict future behaviour and many expressed alarm at the prospect.



“Individuals that might be victim of circumstance, at that point in time, had to get in debt just to put food on the table. And that’s a moment in time. Is that going to be reflected? Then you’re taking raw data and creating a meaning without having all the information to hand, which I think, potentially, could be quite dangerous...” *Father*

Parents were particularly concerned about the risk that data errors posed. A high proportion had encountered administrative data errors themselves, and in many cases had struggled to get them corrected.

Data targeting and service capacity

Some parents in the focus groups and individual interviews supported the principle of using data linkage and analytics to direct early help to families, but they were concerned that without extra resourcing, this could do more harm than good.

“If we’re not going to put the resources into supporting these things properly, you can have all the information you want in the world, but if it’s not backed up by a really holistic service that’s fully funded, then you could be opening wounds for people or creating issues for people and then not supporting them.” *Mother*

Service users in particular expressed doubt as to whether data practices would lead to earlier and more effective family intervention, with some questioning whether this was the real motive

“Being cynical, I don’t think it’s the way, you know, there are many other ways they could prevent escalations or provide support to families which are not in crisis mode already without sharing information. People are asking already for help but they don’t meet thresholds, they don’t meet criteria. So how are they going to do it, make it better sharing information?” *Mother*

RECOMMENDATIONS

for Government and public services data handlers

- Seek explicit and properly informed parental consent to link data at regular intervals by providing clear and personalised report. This should include details of how and for what length of time family data will be stored and information on which organisations might use it and for what purpose. Consider using different levels of consent to enact this.
- Provide a straightforward and enforceable right to view all personal data held in online in local authority databases, data warehouses and lakes. Provide robust systems that allow parents to report data errors and ensure these are quickly investigated and corrected.
- Operate a straightforward and enforceable right to opt out of data sharing, except where information has a clear relevance to child protection concerns.
- Where commercial companies have been contracted as data handlers or analysts of family data, make details about the work and its objectives publicly available alongside a rigorous data risk assessment.
- Data algorithm registers, used in EU cities like Amsterdam, Helsinki and Barcelona can be introduced to promote transparency (see <https://www.algorithmregister.org/>).
- Publish regular independent assessments of the accuracy and utility of predictive models.

ABOUT THE PROJECT

The Parental social licence for data linkage for service intervention research project is providing a comprehensive understanding of the social legitimacy of and trust in operational data linkage and analytics as a basis for intervention in family lives.

The research fills a vital gap in knowledge about the dynamics of social legitimacy and trust among parents of dependent children, in a context where policy developments and data processing practices to inform services interventions may be moving ahead of public knowledge and consent.

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Find out more

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