

## Written evidence submitted by Professor Rosalind Edwards, Professor Val Gillies and Dr Sarah Gorin (DDA0005)

### Executive summary:

In response to this call for evidence on the right to privacy by the House of Commons Science and Technology Committee we address the following elements in the terms of reference:

- the potential benefits, including to research, to effectively use and share data between and across Government, other public bodies, research institutions and commercial organisations, and the existing barriers to such data sharing;
- the extent to which data issues are appropriately addressed by the Government's National Data Strategy, its draft strategy, data saves lives: reshaping health and social care with data, and its consultation Data: a new direction; and
- the extent to which appropriate safeguards and privacy are applied in the usage and sharing of individuals' data.

More specifically, below we provide evidence and policy recommendations in relation to:

- the risks of data sharing across and between Government and industry
- the key issue of public trust and the need for transparency with respect to how individual's data is used and shared

While Government recognises the need for high levels of public trust and transparency in the data regime, public concerns and caveats are not acknowledged.

Findings from our Economic and Social Research Council-funded project Parental Social Licence for Data Linkage for Service Intervention<sup>1</sup> show that:

#### 1. Representative survey findings:<sup>2</sup>

- *There is little public support for any flexibility in data protection requirements; rather public trust is dependent on there being strong levels of regulation and safeguarding in place.*
- *Public trust in sharing administrative data and data analytics among marginalised population groups is already fragile. Their concerns need to be addressed if social legitimacy and trust is not to be further undermined, with consequences for a cohesive and equal society.*
- *There is no social legitimacy accorded to industry access to and involvement in public sector administrative data sharing and analytics.*

#### 2. Freedom of Information requests returns:<sup>3</sup>

- *local authorities are not transparent about their use of operational data linking and matching and the application of predictive analytics, providing incomplete,*

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<sup>1</sup> <http://generic.wordpress.soton.ac.uk/parentdata/>

<sup>2</sup> <https://www.cambridge.org/core/journals/data-and-policy/article/data-linkage-for-early-intervention-in-the-uk-parental-social-license-and-social-divisions/2FE85AD3BF7925609251D3940E184BC8>

<sup>3</sup> <http://generic.wordpress.soton.ac.uk/parentdata/2021/11/04/generating-transparency-where-none-exists-just-how-are-data-analytics-used-in-childrens-services/>

*insufficient, irrelevant and ambiguous information even when it is clear they are using data analytics.*

On the evidence we provide, we call for Government to:

- **Pay heed to the evidence on public trust and press pause on the data sharing and Artificial Intelligence (AI) systems for public services.**
- **Put strong regulatory measures in place before consulting on further reform.**
- **Go beyond top-down awareness-raising and transparency strategies, to enter into robust discussions about the risks as well as the benefits of data sharing and linkage to consider the unintended social consequences.**

#### **Response authors:**

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#### **About the *Parental Social Licence for Data Linkage for Service Intervention* research project**

The Parental Social Licence research project fills a vital gap in knowledge about the dynamics of social licence and trust for operational data linkage and analytics among parents of dependent children, in a context where policy developments, and data linkage and analytics practices to inform services interventions may be moving ahead of public knowledge and consent.

The project is funded by the Economic and Social Research Council (ESRC) under grant number ES/T001623/1.

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1. Our *Parental Social Licence for Data Linkage for Service Intervention* project finds little social legitimacy and trust for data sharing among public services, nor for private sector involvement in data analytics.

We commissioned a representative probability-based survey of parents of dependent children across the UK, which shows that:

- Only around half of parents overall said they trusted Government and services to share administrative records. Marginalised social groups, such as Black parents, low income families, young parents, and large families, show particularly low levels of trust in data linkage by many public services. Notably only 28% of Black parents had trust in sharing police and criminal justice data. This points to a worrying level of distrust toward government and public services among those in society who are most marginalised.
- Transparency and informed consent to use of their administrative records is important for parents. There is a 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.
- There is no social legitimacy for data sharing with industry, with a majority of parents against this among all social groups, at 55%, and rising to >60% among parents from marginalised groups.

2. Our focus group discussions underline our survey findings:

*"I think that this whole sharing of information and data is fundamentally wrong without consent because it's my data. It belongs to me, this information. It is not information that should be sold or shared with any other agency without my consent."* (Mother)

*"When [our support organization] deal with individuals that might be victim of circumstance, that, at that point in time, they had to get in debt just to, kind of, put food on the table. And that's a moment in time. Is that going to be reflected? And if it's not, 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 ... A moral and ethical private business that fundamentally protects individuals' data at the expense of shareholders' returns doesn't exist, because they would be out of business, by definition. So, I, on a personal level, am wary."* (Father)

*"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)

3. Our *Parental Social Licence for Data Linkage for Service Intervention* project found that local authorities are not transparent about their use of operational data linking and matching, the application of predictive analytics, or involvement of industry in this

We submitted Freedom of Information requests to 220 UK Local Authorities in the UK, asking about their use of data linking, automated intelligence, algorithms and predictive analytics, and involvement of industry, in family services.

- The 149 English councils participating in the 'Troubled Families' (now Supporting Families) programme must, by necessity, link and analyse data sets to identify

'troubled' households and claim payment by results from central government. Yet only 76 responded that they used data analytics. The remainder responded 'no' to all the FoI questions about their use or claimed their systems did not meet our definition.

- Councils claiming they did not use data linkage were vague and evasive, such as positioning family work as separate from children's services, or by using the term 'data matching' instead. Yet our subsequent internet searches established that many of them do use systems with predictive analytic capacity.
- A wide range of data 'solutions' are drawn on by local authorities to classify, flag, target and intervene in families, yet parents are not generally informed of how their information is being used and for what purposes. It is difficult, even for researchers using Freedom of Information requests, to establish this, let alone transparent informing of parents and the general public.

4. The DCMS consultation *Data: A New Direction* refers to Centre for Data Ethics and Innovation polling data (chapter 4, p.103). This data shows that the public is looking for strong controls to be in place.

On data sharing between departments and between organisations, the highest responses on the Likert scales used in the survey (7.0+) concern:

- Strict controls on who can access the information and how it is used
- Heavy fines and possible prison sentences for anyone caught misusing the information
- Being informed of exactly who the information is being shared with
- The option to opt-out of the local council sharing the information
- Only the minimum necessary information is shared with central government

The CDEI polling data and our own research findings do not endorse the proposed measures for reforming the use of data in public services, and raise serious concerns about public trust and the social legitimacy of data sharing, data linkage and data analytics.

The recent United Nations High Commissioner of Human Rights' report calls for a pause in the use of data sharing and AI systems for profiling, automated decision-making and machine learning, on the basis of concerns about individual rights to privacy.

It is vital that Government pays heed to the evidence on public trust and to the UN High Commissioner's call for a moratorium so that robust measures to build and maintain social legitimacy for access to and use of administrative data are put in place before consultation with the public on the acceptability of any data reforms.

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