**SUMMARY OF THE CASE STUDY OF THE SOUTH EAST LONDON INTEGRATED CARE SYSTEM (ICS):**

**AN EXAMPLE OF HOW ICSs ARE USING PATIENT DATA**

**Keep Our NHS Public Health Data Working Group**

**May 2023**

**Introduction**

The collection, analysis and sharing of patients’ data is fundamental to the functioning of Integrated Care Systems (ICS);[[1]](#footnote-1) this data informs direct patient care, the commissioning and planning of services (including cuts), Population Health Management (PHM) and workforce planning. Patients’ data is also a highly valuable resource, with some ICS ‘partners’ and sub-contractors keen to exploit this.

Current laws provide protection for our personal data but this is not well enforced and will be weakened by forthcoming legislation favouring the interests of Business. It has never been more important for health campaigners/data subjects to know and able to challenge what is happening to patient data.

With this in mind, the KONP Data Working Group, in collaboration with South East London Save Our NHS, looked into the way that one ICS (South East London ICS), collected and used patients’ data. Our aims were to understand how best to monitor and, if necessary, challenge the way personal data is being used, and to provide information for other health campaign groups wishing to investigate their local ICB’s use of data.

The issues we found concerned lack of clarity about data governance arrangements, legal issues, the use of data without consent, risks to confidentiality, lack of patient/citizen engagement and the fast growing role of the private sector.

**Findings**

Findings are organised into five themes:

**Theme 1: Data governance**

While ICBs are accountable in law for the data that they handle and process, where this accountability lies, or how it is performed in practice is not always clear. In SEL, the organisational bodies that deal with patients’ data often had to be teased out by searching Board papers or submitting questions to the Board. Almost all of these bodies were without lay representation (other than Healthwatch) and the only publicly accessible meetings or papers were those of the IC Board.

**Theme 2: Data usage**

Along with other ICSs, the SEL ICS uses the London Care Record (LCR) that collects data from primary, secondary and urgent care providers and makes this available to all health care professionals on a view-only basis for informing direct care. The LCR is hosted by the Discovery Data Service (DDS), which hosts the patient databases of its three founding ICSs (including SEL). These can be accessed, subject to data sharing agreements, for purposes such as research, quality and care improvement, health and care commissioning, and population health management (PHM). The governance of these arrangements rests with the parties to any data sharing agreement. We could find nothing about the governance of the DDS itself, or about its current funding.

Our enquiries raised concerns about the use of patients’ data, such as for Population Health Management (PHM) and risk stratification[[2]](#footnote-2) purposes. The combination of different data sets that this involves poses a considerable risk of patient identification. The use of PHM is also worrying as it uses personal data for purposes that patients may not support, such as the rationing of treatments or cutting of services to meet constrained budgets. Although we found a data privacy notice on the ICS website informing patients how their data is used for these purposes, and their right to object, we found no indication of how the ICB ensured patients were made aware of this.[[3]](#footnote-3)

**Theme 3: Legal basis for the use of patients’ data**

The Common Law Duty of Confidentiality (CLDC) and legislation such as the UK General Data Protection Regulation (GDPR) are meant to protect the use of personal data such as health records, yet responses toFreedom of Information requests indicate that public bodies (such as ICSs) can process data for multiple secondary purposes without our knowledge or consent when this is judged to be ‘in the public interest’ (including by non-health professionals), provided that approval is obtained from an independent Confidentiality Advisory Group.

**Theme 4: Patient and citizen engagement**

In the SEL context, if not elsewhere, lip service is paid to patient and citizen engagement. Even though its digital strategy aims to “deliver person centred care informed by systematic patient engagement and involvement of the service user”, engagement is essentially with Healthwatch. The SEL ICB frequently appears to be evading answers to important questions from the public or responds using opaque language.

**Theme 5: Private company involvement**

Private companies, whether providing technology (such as data platforms) or processing and analytic services, are heavily involved in the collection and use of patient data and increasingly embedded within the infrastructure of the ICS. It is a matter of concern that a significant number of the multinationals providing data and digital services to the NHS now have multiple work-related legal violations recorded in the US.

**Conclusion**

 It is surprising and worrying that the governance of patient data use is not more of a priority for this and possibly other ICBs, especially as it appears that confidential patient information can be legally accessed for purposes beyond patient care, and some organisations do not even appear to follow the law as it currently exists. Meanwhile, private sector involvement in the provision of data services is growing at pace without clarity about the access that companies may have to individuals’ records.

 The forthcoming Data Protection and Digital Information Act is likely to make these issues worse. For now, at least, it seems that the most effective way of countering the growing access to our data is to understand and insist on the protections that we have, and to demand transparency: such demands may at least help to ensure that ICSs carefully consider their actions.

1. For clarification, we use the term *Integrated Care System* to refer to the totality of the organisations within an individual ICS, while *Integrated Care Board* (ICB) refers not simply to the IC Board itself but to the various committees, sub-committees and groups that carry out the work of the Board. [↑](#footnote-ref-1)
2. Risk stratification is often used to assign a risk status to patients, then using this information to direct care. [↑](#footnote-ref-2)
3. <https://www.selondonics.org/wp-content/uploads/SEL-ICB-Privacy-Notice-Data-Service-v2.0.pdf> [↑](#footnote-ref-3)