**NHS data, Integrated Care Systems**

**and the Data Protection and Digital Information Bill**

**Background**

In a world where “data is now the driving force of the world’s modern economies,”[[1]](#footnote-1) the free flow of data between the public and private sectors is a top priority for our current government.

The most highly prized data is our personal health data. EY, the global corporation, **The Data Protection and Digital Information Bill** estimates that the NHS’s 55 million patient records have an “indicative market value of several billion pounds [annually] to a commercial organisation”, such as those within the pharmaceutical, biotechnology, medical technology and insurance sectors.[[2]](#footnote-2) The NHS database, with its exceptional granularity and longitudinal completeness, is unmatched elsewhere. This has prompted the government to support a market in NHS data, arguing that this will turn the UK into a ‘science superpower’ and increase economic growth.[[3]](#footnote-3)

Until now, personal health data has belonged to a special category[[4]](#footnote-4) requiring *extra* protections, yet existing safeguards are being weakened. This is clear from recent legislation, such as the Police, Crime, Sentencing and Courts Act 2022; current government strategies and proposals, including the Life Sciences Industrial Strategy Update;[[5]](#footnote-5) and the National Data Strategy.[[6]](#footnote-6) The Health and Care Act (2022) “put[s] beyond doubt NHS Digital’s power to share data in connection with health care or adult social care”,[[7]](#footnote-7) and safeguards will be further undermined by the Data Protection and Digital Information Bill, currently passing through Parliament (more on this later).

**NHS data and Integrated Care Systems**

One of the key sites where our personal health data will flow from the NHS to the private sector is within the 42 semi-autonomous NHS organisations known as Integrated Care Systems (ICSs or ‘systems’) that were brought in by the recent Health and Care Act. ICSs are replacing a nationally cohesive health service across England, and paving the way for a private insurance model. Their *modus operandi* depends on vast patient data sets and the private companies that can process these.

ICSs fragment the NHS as a national health service but, in addition, they shift it from a universal, comprehensive healthcare system to one based on ‘integrated care’ that relies on data to redesign services and cut costs. In the context of growing numbers of older people, an increase in chronic conditions and restricted funding, integrated care has been seen as “necessary to identify patients most at risk, proactively plan and manage their care, and prevent escalation to higher cost settings”.[[8]](#footnote-8)

This approach is heavily reliant on Population Health Management (PHM). According to NHS England (NHSE), PHM is “the critical building block for integrated care systems”:[[9]](#footnote-9)PHM and ICSs are two sides of the same coin. With echoes of the health insurance industry, PHM uses vast data sets to segment an ICS’s population according to health risk and cost. It then intervenes “to balance the health risk of the population segment and likelihood of impact, and the expense of implementing identified solutions.”[[10]](#footnote-10) Those individuals considered to be at less risk (in effect, the majority) are, for the most part, expected to ‘self-care’ using advice from websites and apps, or they may be monitored by staff with basic training and increasingly reliant on standardised decision-making techniques, such as algorithms.

**ICSs and commercial access to personal health data**

Lack of investment has prevented the NHS from developing its own platforms and software, and from training its own data analysts. This lack, and ICSs’ reliance on ‘big data’ and PHM in order to function, has created a dependence on technology companies with the capacity to collect and analyse the volume of information involved. NHSE’s response has been to accredit hundreds of organisations to join what is called the Health Systems Support Framework (HSSF), a ‘one-stop shop’ facilitating access to support services from third party suppliers that have signed up to pre-negotiated standard terms and conditions. The Framework’s focus is largely on services that can support the move to ICSs and PHM.[[11]](#footnote-11) In essence, it provides a directory of predominantly private providers, such as multinational giants Deloitte, EY, IBM, Oracle, Cerner, Atos, McKinsey and Co, Palantir, and PriceWaterhouseCooopers.

NHSE states that these companies will only have access to ‘de-identified’ or anonymous patient data – that is, data that is not considered ‘sensitive’ and not covered by data protection legislation. However, ensuring that patient data is de-identified (i.e. stripped of details such as age, gender or NHS number) becomes increasingly difficult when, as in the case of PHM, it’s combined with other data sets.[[12]](#footnote-12) In addition, the Data Protection and Information Bill, if passed, will allow personal data to be subjectively reclassified by data controllers so that it can be treated as if anonymous data and therefore beyond legal safeguards.

Of course, NHS data – if appropriately shared - is invaluable for service planning, improving patient care, and developing new treatments. But safeguarding the confidentiality of patients’ data is also vitally important, not least to ensure patients continue to have trust in their healthcare professionals, and have trust in the use of their data for bone fide research carried out in the public interest.

NHSE has promised the public that, in the drive to digitalise the NHS, patients’ privacy and control of their personal data will be a key priority[[13]](#footnote-13) and, for now, the Data Protection Act (2018) and the UK General Data Protection Regulation (UK GDPR) provides support for this. However, the Data Protection and Digital Information Bill includes measures to significantly threaten existing protections for personal data; to reduce regulatory ‘burdens’ on business that currently ensure their compliance with data legislation; and to muzzle the data watchdog, the Information Commissioner.[[14]](#footnote-14)

**What needs to happen**

This dangerous Bill needs to be defeated and the drive to allow commercial access to personal health data must be stalled.

The stewardship and use of personal health data should rest with the NHS, supported by proper, state-funded investment that would allow it to develop the relevant technologies and staff training.

There should be transparency allowing the public to know who is using their data, on whose say so, for what purpose, and how such use is being monitored.

The recommendations of the Goldacre Review[[15]](#footnote-15) for Trusted Research Environments (where users can view but not extract data and where data use can be properly monitored) should be implemented, including for data held by ICSs.

The independence of the Information Commissioner’s Office should be strengthened, not brought under political control.

The potential of NHS data should be used for patients and the NHS, not profit.

1. Oliver Dowden, then Secretary of State for Digital, Culture, Media, and Sport, <https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy> [↑](#footnote-ref-1)
2. <https://assets.ey.com/content/dam/ey-sites/ey-com/en_gl/topics/life-sciences/life-sciences-pdfs/ey-value-of-health-care-data-v20-final.pdf> [↑](#footnote-ref-2)
3. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1022315/Data_Reform_Consultation_Document__Accessible_.pdf> [↑](#footnote-ref-3)
4. ‘Special category data’ is particularly sensitive data, access to which could create significant risks to a person’s fundamental rights and freedoms. <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/special-category-data/what-is-special-category-data/#scd2> [↑](#footnote-ref-4)
5. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857348/Life_sciences_industrial_strategy_update.pdf> published in 2020 by the Office for Life Sciences (part of the Department of Health and Social Care) and Department for Business, Energy and Industrial Strategy). [↑](#footnote-ref-5)
6. <https://www.gov.uk/government/publications/uk-national-data-strategy> [↑](#footnote-ref-6)
7. Health and Care Bill Explanatory Notes <https://publications.parliament.uk/pa/bills/cbill/58-02/0140/en/210140en.pdf> (EN-1032). [↑](#footnote-ref-7)
8. <https://www3.weforum.org/docs/WEF_HE_SustainabilityHealthSystems_Report_2012.pdf> [↑](#footnote-ref-8)
9. <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/phm/> [↑](#footnote-ref-9)
10. <https://www2.deloitte.com/content/dam/Deloitte/uk/Documents/public-sector/deloitte-uk-public-sector-population-health-management.pdf> [↑](#footnote-ref-10)
11. <https://www.england.nhs.uk/hssf/background/> [↑](#footnote-ref-11)
12. <https://www.chino.io/blog/what-is-anonymous-data-according-to-gdpr/> [↑](#footnote-ref-12)
13. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> [↑](#footnote-ref-13)
14. https://keepournhspublic.com/data-protection-bill-risk/ [↑](#footnote-ref-14)
15. https://www.goldacrereview.org [↑](#footnote-ref-15)