**The Integrated Care System as a key site**

**for private companies’ access to patient data**

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 sought data is our personal health data. EY, the global corporation, describes patient data as “a valuable intangible asset desired by multiple stakeholders”.[[2]](#footnote-2) It estimates that the NHS’s 55 million patient records “may have an indicative market value of several billion pounds to a commercial organisation”, with pharmaceutical, biotechnology, medical technology and insurance companies among customers eager for the insights that our data can provide.

Until now, personal health data has belonged to a special category[[3]](#footnote-3) requiring extra protections, yet there’s a risk that safeguards will be weakened in the interests of government, the private sector and economic growth. This is clear from proposed legislation, such as the Police, Crime, Sentencing and Courts Bill 2021, and current government strategies and proposals, including the Life Sciences Industrial Strategy Update;[[4]](#footnote-4) the National Data Strategy;[[5]](#footnote-5) and the National AI Strategy.[[6]](#footnote-6) Besides these, the Health and Care Bill 2021, if passed, will “put beyond doubt NHS Digital’s power to share data in connection with health care or adult social care”.[[7]](#footnote-7)

One of the key sites where our personal health data will flow from the NHS to the private sector is within the 40 or so semi-autonomous NHS organisations known as Integrated Care Systems (ICSs or ‘systems’) that are replacing a nationally cohesive health service across England. ICSs’ *modus operandi* depends on vast patient data sets and the private companies that can process these.

**ICSs as sites of data extraction**

Third party use of NHS data is not new. A Financial Times analysis of the NHS Data Release Register,[[8]](#footnote-8) for instance, shows that over the five-year period of available records, sensitive patient data was shared not just with public bodies for planning and research purposes, but also with 43 commercial organisations such as McKinsey, Experian, and KPMG. The health data company i5, for example, received 135 data releases between April and October in 2019. What’s more, the FT found there was little control of what happened to this data once it left the NHS’s servers.

NHS England (NHSE) promised the public that in the drive to digitalise the NHS, patients’ privacy and control of their personal data would be a key priority.[[9]](#footnote-9) However, this assurance has proved pretty worthless. Comprehensive personal health data has been extracted, stored and, in some cases, sold even when patients have chosen to ‘opt out’ of allowing their data to be shared:[[10]](#footnote-10) FT researchers found that the NHS passed on 84% of pseudonymised patient data to external organisations, even where patients had opted out.[[11]](#footnote-11)

Commercial access to confidential patient data has intensified during the Covid pandemic under emergency powers,[[12]](#footnote-12) [[13]](#footnote-13) raising concerns that this precedent will be used to justify a more permanent and extensive flow of health data between the NHS and the private sector.[[14]](#footnote-14) In fact, the transformation of the English NHS into ICSs is dependent on such a flow.

ICSs are essentially NHS bodies required to work in partnership with local councils and ‘others’ (including private companies) to coordinate services within a particular geographical footprint; manage performance; save money and improve the health of its population. This population is largely comprised of people registered with local GPs – it does not necessarily include everyone within an ICS’s footprint. In this way, ICSs share some resemblance to the private health organisations in the USA that provide services for their members rather than the local population.[[15]](#footnote-15)

The Health and Care Bill, if enacted, will allow an ICS’s Board (ICB)[[16]](#footnote-16) to delegate its powers to ‘provider collaboratives’. These organisations – again potentially including private companies - are collectively charged with designing an ICS’s health and care services[[17]](#footnote-17) and able “to decide what, where and how services will be provided”.[[18]](#footnote-18)

Ominously, some NHS leaders suggest that, over time, a much wider range of an ICB’s responsibilities, such as strategy, could also be passed to these collaboratives and the part played by the ICS scaled back. For example, Penny Dash, Chair of North West London ICS and a previous McKinsey partner, argues that if strong provider collaboratives are put in place, ICSs might become organisationally “tiny”, if not “cease to exist”. In which case, she asks, “Why do you need an ICS?”[[19]](#footnote-19) One answer is to generate valuable data.

**Population health management**

ICSs don’t just fragment the NHS as a national health service: they shift it from a universal, comprehensive healthcare system to one based on ‘integrated care’ that relies on data to redesign services and manage cost. This new approach is heavily reliant on Population Health Management (PHM): you could say ‘integrated care’ and PHM are two sides of the same coin.

It was the World Economic Forum, an international organisation that provides a platform for the world’s leading 1,000 companies, which first promoted the idea of ‘integrated care’. Its 2012 report on the financial sustainability of publicly provided health services, such as the NHS, maintained that - in the face of growing elderly populations, an increase in chronic conditions and restricted funding - integrated care was “necessary to identify patients most at risk, proactively plan and manage their care, and prevent escalation to higher cost settings”.[[20]](#footnote-20) PHM provides the means to achieve this – as NHSE says, it’s “the critical building block for integrated care systems”.[[21]](#footnote-21) PHM, in turn, is reliant on ICSs, as it requires multiple health and care settings to work together in order to provide the necessary big data and analytics at-scale.[[22]](#footnote-22)

Doing nothing to quell fears that the NHS is heading towards becoming a privately insured health system,[[23]](#footnote-23) the concept of ‘population’ in PHM “typically refers to individuals who are covered by a health insurance plan, or the patients of a health care delivery organisation”.[[24]](#footnote-24) And rather like 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.”[[25]](#footnote-25) 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 may be monitored by staff who often have only basic training and increasingly rely on standardised decision-making techniques, such as algorithms.

**Big data:: big tech**

ICSs’ reliance on PHM and ‘big data’ means a dependence on the technology companies that have the means for collecting and analysing the volume of information involved. With this in mind, NHSE has accredited hundreds of organisations to join what’s called the Health Systems Support Framework (HSSF).

The HSSF is a ‘one-stop shop’ enabling access to support services from third party suppliers that have signed up to pre-negotiated standard terms and conditions. The focus is on services that can support the move to ICSs and PHM.[[26]](#footnote-26) [[27]](#footnote-27) The Framework is essentially a directory of predominantly private providers, divided into different service categories or Lots. For example, in 2021 the category of ‘Population Health Intelligence’[[28]](#footnote-28) listed 45 organisations, six of which were NHS bodies while the rest were private companies, such as multinational giants Deloitte, EY, IBM, 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.[[29]](#footnote-29) It also will be more difficult to protect personal health data if current government plans for increased sharing of data between the public and private sectors are confirmed.

**Loss of data protections**

For now, our personal health data is offered some protection by the Data Protection Act (2018) and the UK General Data Protection Regulation (UK GDPR), governing how personal data can be gathered, processed, used and stored.[[30]](#footnote-30) However, there are strong indications that this protection will be seriously threatened as data is seen as increasingly important to the NHS and the economy more broadly.[[31]](#footnote-31)

For example, responding to an invitation by the Prime Minister to “look at ways to refresh the UK’s approach to regulation”, a Taskforce on Innovation, Growth and Regulatory Reform[[32]](#footnote-32) calls for a new, ‘agile’ approach to regulation that will allow data to flow more freely and so provide “a cutting-edge business landscape”. This will require amending existing data legislation, and ‘cutting red tape’ by introducing a new Proportionality Principle that claims to protect citizens’ privacy while the real priority is ”to boost economic competitiveness” (Para 47).

At the same time, the Department for Digital, Culture, Media and Sport (DDCMS) described their recent consultation (‘Data: A new direction’) as “the first step in the process of reforming the UK’s regime for the protection of personal data”.[[33]](#footnote-33) Far from improving data protection, it proposes to muzzle the watchdog for data privacy (the Information Commissioner’s Office); reduce safeguards; and increase access to personal health data by third parties, whether government departments, public bodies or the private sector.[[34]](#footnote-34)

**The broader context**

The current plans for data are alarming in their scope and intent. Not least, access to personal health data without due consent, especially where this allows private gain, is at odds with the ethos of social solidarity that underpins the NHS. Fears of such access are known to damage patients’ trust in healthcare professionals and turn people against the use of their data for *bone fide* research carried out in the public interest.

Already, data-driven digital technologies are creating new health ecosystems that need stronger, rather than weaker regulation. As a joint Lancet and Financial Times Commission put it,

“… weak governance of digital transformations[[35]](#footnote-35) has led to uneven effects globally, endangering democracy, limiting the agency of patients and communities, increasing health inequities, eroding trust, and compromising human rights, including in the field of health.”[[36]](#footnote-36)

Their report calls for a new approach to the collection and use of health data based on a concept of data solidarity that simultaneously promotes the public good potential of data, protects individual rights, and builds a culture of data justice and equity. This is what we should be campaigning for.

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1. Oliver Dowden, 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. ‘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-3)
4. <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-4)
5. <https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy> [↑](#footnote-ref-5)
6. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1020402/National_AI_Strategy_-_PDF_version.pdf> [↑](#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://www.ft.com/content/6f9f6f1f-e2d1-4646-b5ec-7d704e45149e?accessToken=zwAAAXrS748okc9vn28f4tFGRtO17H1wTkUUng.MEUCIQCxFsI-luw05Kf9DtMZIwot1ylLoZDLHThQDY4-Clhu1AIgUYny6kSD4MtupnKMk4ANCYz9qRuMUsfjOAflRsFk01g&sharetype=gift?token=411a1633-2d5e-4b8c-915a-491018a9e465> [↑](#footnote-ref-8)
9. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> [↑](#footnote-ref-9)
10. <https://www.nhs.uk/using-the-nhs/about-the-nhs/opt-out-of-sharing-your-health-records/> [↑](#footnote-ref-10)
11. <https://www.ft.com/content/6f9f6f1f-e2d1-4646-b5ec-7d704e45149e?accessToken=zwAAAXrS748okc9vn28f4tFGRtO17H1wTkUUng.MEUCIQCxFsI-luw05Kf9DtMZIwot1ylLoZDLHThQDY4-Clhu1AIgUYny6kSD4MtupnKMk4ANCYz9qRuMUsfjOAflRsFk01g&sharetype=gift?token=411a1633-2d5e-4b8c-915a-491018a9e465> [↑](#footnote-ref-11)
12. <https://www.nhsx.nhs.uk/covid-19-response/data-and-covid-19/information-governance/copi-notice-frequently-asked-questions/> [↑](#footnote-ref-12)
13. Palantir, for example, was contracted to build the NHS Covid-19 Data store with Big Tech companies like Google and Amazon holding contracts to work on the platform. [↑](#footnote-ref-13)
14. <https://www.thebureauinvestigates.com/stories/2020-05-07/the-tech-firms-getting-their-hands-on-nhs-patient-data-to-fight-coronavirus> [↑](#footnote-ref-14)
15. <https://www.theguardian.com/commentisfree/2021/dec/07/public-nhs-the-new-health-and-care-bill-alarm-bells-privatisation> [↑](#footnote-ref-15)
16. Each ICS is led by an Integrated Care Board (ICB), a statutory body with responsibility for NHS functions and the ICS’s budget. [↑](#footnote-ref-16)
17. <https://www.england.nhs.uk/wp-content/uploads/2021/06/B0754-working-together-at-scale-guidance-on-provider-collaboratives.pdf> [↑](#footnote-ref-17)
18. <https://www.theguardian.com/commentisfree/2021/dec/07/public-nhs-the-new-health-and-care-bill-alarm-bells-privatisation> [↑](#footnote-ref-18)
19. <https://www.hsj.co.uk/integrated-care/icss-may-cease-to-exist-after-setting-up-strong-provider-groups/7031201.article> [↑](#footnote-ref-19)
20. <https://www3.weforum.org/docs/WEF_HE_SustainabilityHealthSystems_Report_2012.pdf> The team behind the report, dominated by senior representatives from multinational corporations, especially McKinsey, was steered by Simon Stevens (then President of the giant US corporation, UnitedHealth Group, but subsequently head of NHSE). [↑](#footnote-ref-20)
21. <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/phm/> [↑](#footnote-ref-21)
22. For example, according to Deloitte, NHSE’s Long Term Plan (2019) marked a policy shift from what it called ‘reactive care’ to a ‘proactive, integrated approach’ that embodied PHM, and that ICS’s would be the main mechanism for achieving this. <https://blogs.deloitte.co.uk/health/2019/03/the-transition-to-integrated-care-why-population-health-management-is-critical-to-the-future-sustain.html> [↑](#footnote-ref-22)
23. <https://www.bmj.com/content/345/bmj.e5128/rr/654254> [↑](#footnote-ref-23)
24. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6422602/> [↑](#footnote-ref-24)
25. <https://www2.deloitte.com/content/dam/Deloitte/uk/Documents/public-sector/deloitte-uk-public-sector-population-health-management.pdf> [↑](#footnote-ref-25)
26. <https://www.england.nhs.uk/hssf/background/> [↑](#footnote-ref-26)
27. Although the HSSF’s scope has been expanded more recently to include workforce and HR services. [↑](#footnote-ref-27)
28. ‘Population Health Intelligence’ covers informatics and analytics to support PHM, whole system planning, strategy development, management, assurance and evaluation. [↑](#footnote-ref-28)
29. <https://www.chino.io/blog/what-is-anonymous-data-according-to-gdpr/> [↑](#footnote-ref-29)
30. The GDPR was part of EU legislation that was retained in our domestic law following Brexit, but is now open to review. [↑](#footnote-ref-30)
31. <https://www.opendemocracy.net/en/ournhs/what-the-tories-want-to-do-with-our-health-data-and-why-we-need-to-stop-them/> [↑](#footnote-ref-31)
32. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/994125/FINAL_TIGRR_REPORT__1_.pdf> May 2021 Duncan Smith, T Villiers, and G Freeman. [↑](#footnote-ref-32)
33. <https://www.gov.uk/government/consultations/data-a-new-direction> [↑](#footnote-ref-33)
34. <https://www.openrightsgroup.org/blog/new-uk-data-laws-are-govt-revenge-against-nhs-patients/> [↑](#footnote-ref-34)
35. By which they mean “the multifaceted processes of integration of digital technologies and platforms into all areas of life, including health”. [↑](#footnote-ref-35)
36. <https://els-jbs-prod-cdn.jbs.elsevierhealth.com/pb-assets/Lancet/stories/commissions/governing-health-futures-2030/GHF-Executive_Summary-English-1636647203407.pdf> [↑](#footnote-ref-36)