

NHS Data and the Effects of the Data Protection and Digital Information Bill (Part 1)

Every interaction across the NHS will need assessing to discover who holds what data, and what they can do with it under the new regime envisaged by this Bill (it's not just data contracts).

(Scope: UK-wide): Clause 1¹ of the Bill would move “pseudonymised” identifiable data subject to a contract would be considerable as “anonymous” under the law, and any breach of that “anonymous” data would be outside of the ICO's remit (as the data was “anonymous” on first processing, even if subsequent processing made it once again fully identifiable).

(UK) Other provisions (cl 2,3,6) in the Bill mean that any data available for one purpose can be reused for commercial research, and there is no “public interest” requirement for any uses other than public health (cl 2(4)(b)).

(UK) Individual rights to object, and the right to find out what data is held and how it is used, are restricted by clauses 8, 9, 17. How would curtailing these rights have affected victims of the Post Office scandal, and other data scandals, who need them to discover why/how things happened.

(AI) Taken together, this Bill maximises data and minimises governance of data fed to AIs.

(England) The [Goldacre Review](#) is clear that “pseudonymised but readily re-identifiable data” is a major category largely ignored by HMG policy creating described as the “misunderstanding has been pivotal in a range of problematic decisions around risk management.”

(England) Identifiable patient data is sent by DHSC bodies overseas on the basis that it's “Anonymised – ICO code compliant” and “protected by contract”, and when that data reaches overseas, there will be no recourse if it is shared again, potentially including back into the UK.

(UK) The narrow definition of “identifiability” in the Bill means data that a company has access to in the course of their normal business can be reused if they deliberately ignore attention to details. This is likely to cause a high risk to every contract the NHS has, especially those in which data has previously been unmentioned due to the soon to be repealed protections of the Data Protection Act. Additionally, the proposal that the UK also [moves](#) into the US led [Cross Border Privacy Regime](#) means every such contract will now be even more ambiguous.

(England) As visible in the official [data usage registers](#), or more comprehensibly at [TheySoldItAnyway.com](#), NHS England policy is that when data is deemed “anonymous” in NHS England's view, the choice of patients to dissent from those uses is ignored.

(Scotland, Wales, NI): Scotland, Wales and NI do not have the (English) national data opt out, so any use of data on similar lines covers the entire population.

(US) if HMG wishes to move towards US style data protection regime, does that also mean a move to [US-style HIPAA](#) disclosure for breaches (with liability)? Or is the Bill a move towards a free for all against patients?

(UK) The [identity provisions](#) were supposed to put the existing legal framework on a statutory footing, a framework the Home Office simply refuse to believe applies to them. Are the Home Office going to break the law, or will DeSIT give in and amend to add a framework after most scrutiny is done? (as happened with [s191-194](#) of the 2018 Data Protection Act)

¹ All clauses are against the latest published text of the Bill at the end of Committee, which is: <https://publications.parliament.uk/pa/bills/cbill/58-03/0265/220265v2.pdf>

(Westminster) While this Bill may move many dodgy uses of data outside of the data protection regime, and outside of ICO responsibility, it will not, and can not, move *political* responsibility for abuses of NHS data away from Ministers and Government. Ministers will remain accountable to the House for the actions of data DHSC and associated public bodies collect and share, only now it will be at higher risk of scandal with reduced punishments for misuse, especially around medical records.

(Home Office) We would also seek clarity on whether Bill committee debate suggested that wider reuse of information will be another way for the Home Office to acquire identifiable NHS data for Home Office public tasks.

Examples

(UK) Facebook's tracking cookies have been used to advertise to patients who visit the websites of [NHS hospitals](#) and [mental health charities](#), what (deregulatory) changes under the Bill?

(England) Education data suggests that such risks are a deliberate government policy. High risk dissemination without scope for dissent [under the Bill](#) also includes all school records of children collected since the late 1990s via the National Pupil Database.

(England, Babies) Baby blood spot tests are retained beyond the 5 years² parents may have given consent for, with no recourse or redress to prevent data being used for purposes they did not expect, such as "research" by [Chinese military-linked firms](#), because, "scientific research only uses anonymised data". This Bill legalises such retention, transfers, and broad uses.

(England, commerce) The "Our Future Health" project is a private biobank for commercial entities³ advertising under an NHS logo, marketed by a charity, claims it has anonymous data which can be shared outside the UK, and should someone misuse it, patients and the NHS will have no recourse under UK law. It is unclear if this is by design.

(England, NHS) None of the above should be a surprise, as the evidence session for Bill Committee included this: (emphasis added)

[Q85](#) Sir John Whittingdale: Can you say a little about the extent to which you have been a contributor to the design of the new provisions in the Bill and whether you are happy with the outcome of that?

Jonathan Sellors [UK Biobank]: The short answer would be yes. **I was contacted by NHS England about the wording of some of the consent aspects**, some of the research aspects **and particularly some of the pseudonymisation aspects**, because that is an important wall. **Most research conducted is essentially on pseudonymised rather than identifiable data.** ...

As a result of that contact, we expect NHS England should be able to answer any questions you have about the implications of the Bill.

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² [Code of Practice \(2018\) "Under Review" Ref: PHE gateway number 2017684](#)

³ The specific, clear, and ethical statements about ethics and research from "the biobank" contrast clearly with the focus grouped script from OFH which advertises under NHS logo without giving too many details of what they'll do with the genetic data they take, and who'll make money off it.