**medConfidential briefing on the Data Protection Bill (second reading)**

The stated intent[[1]](#footnote-0) of DCMS is to change as little as possible - as an act of bureaucratic indifference, it almost succeeds. This is not necessarily entirely positive.

**Clause 15 must be amended so Regulations can only allow processing where it was already being lawfully processed prior to this Act, and where it does not otherwise breach the new DPA.**[[2]](#footnote-1) Allowing Ministers to issue Regulations setting aside data protection law at will is an dramatic and significant change to data protection in the UK. It does not reflect the DCMS stated intent.

The Data Protection Bill is a Government manifesto commitment, which was immediately followed in the manifesto by a commitment to place the National Data Guardian (for Health and Social Care) on a statutory footing. That is a commitment this Bill fails to do meet,[[3]](#footnote-2) and which should be considered at Third Reading.

The NHS has also committed to informing patients how their medical records are used. The legal protections in the Bill against “enforced Subject Access Request” should also apply to such information. At committee stage, it will be necessary to seek clarification from the Government that it c172(1) supplies this protection (possibly via a missing 172(1)(c) “consists of information associated with that record”).

**Academic Peer Review and the new Re-identification Offence (c162)**

The policy intent of DCMS was to change as little as possible from the status quo. This Offence is one of the few areas where it has done so. This was an active choice.

In principle, the re-identification clause had the prospect of damaging legitimate research, and the solution to that is novel, and on the face of it at least, may be effective.

The effects of retroactive immunity for researchers (via clause 162(4)(b)(iii)) should be fully worked through with the relevant data authorising bodies. In what may likely be the full glare of public interest, a post-event authorisation, where a researcher by definition will not have followed all the rules (if they had, it would have been a pre-event request), is likely to put unusual stresses on the authorisation processes for research.

**As drafted, this law will require a peer reviewer to make a decision which either gives a fellow researcher immunity from prosecution, or undermines their legal defence, based on actions that have already been taken and are known to be flawed.** That is not a question peer review was designed to answer, nor one peer reviewers necessarily expected to sign up for.

Given the flaws in the design and structure of the offence, to resolve this structural problem would probably require a radically different approach to defining the Offence.

**Does the Re-identification Offence apply to likely NHS data scenarios? (c162)**

The HES dataset is the consolidated medical history of England covering nearly 30 years - it contains over 1.5 billion hospital events, which are all dated, and linked to individual. However, every individual within that dataset has had their name/NHS number replaced with a pseudonym to link their medical history.

medConfidential supports an offence that penalises an individual who abuses this dataset. The dataset will protect events such as date of birth, but it leaves entirely unprotected other dates, such as the dates of maternity events of a mother. If a woman has 2 children, and someone knows their birth dates, they are 99% likely to be uniquely identifiable from those the events that occurred on those two dates. The medical history can be read for someone who the individual already knows.

In the event of a leak of the HES dataset, that is the risk that the public are extremely concerned about, and 162(1) and c162(2) do not appear to be engaged.

The offence does cover blatant reidentification at large scale. But that is not a realistic or likely outcome for medical data as disseminated by the NHS. What is more realistic, is that the pseudonymised data is leaked, and because of pre-existing knowledge - either the dates of birth of children, or the date that someone had an unusual or publicised event - that single information can act as a key to read the rest of their medical history. No “more”(162(2)(a)) information is needed to be added to the dataset.

We do not doubt that the Government will concoct a scenario where this offence engages - but in the event of a leak of “de-identified”(162(2)(a)) data, the majority of harm will come from gossip, and the fear of gossip, rather than about random unknown individuals.

When the former Leader of the Opposition successfully had a minor operation,[[4]](#footnote-3) the date was published, as was the fact that it was the only operation of that type in that hospital on that date. That information can not be secret.

When someone is involved in a traffic accident, those are often written up in local newspapers, with the victim usually named, alongside the area they come from, and the date of the event. Traffic accidents are fortunately relatively rare, but that does provide a key into the data which does not depend on re-identification as defined by the offence.[[5]](#footnote-4)

We welcome the intent of the Offence; it is just far from clear whether as written, a breach of the data disseminated by the NHS would likely be prosecutable. It is unclear whether this was intentional.

**Interaction between the research and freedom of expression exceptions**

Defamation law has shown there is an overlap between research and freedom of expression. The Bill as drafted ignores such an overlap (Schedule 2 - Part 5). To clarify, the freedom of expression exemption should use and refer to the definitions used in (section 6 of) the Defamation Act 2013. This will also remove any ambiguity between Defamation and Data Protection law, as they will use the same definitions, and have been well considered and strongly tested by the research community.

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1. Some constitutional law specialists question whether this actually the case: <https://ukconstitutionallaw.org/2017/09/28/oliver-butler-the-data-protection-bill-and-public-authority-powers-to-process-personal-data-resurrecting-clause-152-of-the-coroners-and-justice-bill-2009/> [↑](#footnote-ref-0)
2. such as s47 of the Statistics and Registration Services Act. [↑](#footnote-ref-1)
3. A Presentation Bill has been laid in the House of Commons, although it is unclear whether it will receive Government time to progress. It will be clearer on/after October 20th. [↑](#footnote-ref-2)
4. [http://www.telegraph.co.uk/news/politics/ed-miliband/8666354/Ed-Miliband-undergoes-successful- nose-operation.html](http://www.telegraph.co.uk/news/politics/ed-miliband/8666354/Ed-Miliband-undergoes-successful-nose-operation.html) [↑](#footnote-ref-3)
5. Only You, Your Doctor, and Many Others May Know: <https://techscience.org/a/2015092903/> [↑](#footnote-ref-4)