Digital Economy Bill - Problematic Principles in Part 5 MedConfidential Briefing for 2nd Reading in the House of Lords

Part 5 Chapter 1 is the return of what was s152 of the Coroners and Justice Bill 2009, which was thrown out.¹

Government advocacy around Part 5 Bill cites appropriate uses of data.² The Bill text goes far broader than that. Attempts to have a dialogue with the Cabinet Office of this Government on the intent and language go entirely ignored - they simply do not reply.³

The text of the Bill allows for copying of any data by anyone fulfilling a public service. There is no legal requirement for transparency. In the Commons Committee, the Government said that citizens should make Freedom of Information Act requests for the agreements and Privacy Impact Assessments made under this Bill. Besides the burden placed on bodies, it places a high burden on citizens to know that these agreements can exist and to ask for them, even if the idea itself was not preposterous.

There should be a legal requirement that all agreements⁴ to share/copy/access data should be published in a register⁵ of such agreements. If Government insists on copying data wherever it likes, for whatever reason it likes, it should simply explain why, publicly. The Government Digital Service talks about better ways of using data, with APIs to access only the data needed, as necessary,⁶ but this Bill does not deliver on what they say. It is more of the same: copying. Digital idealism ignores the practical reality in Departments.

The principle of this Bill should be that data should be used transparently - if Government wishes to copy, share, or access citizen data, it should be willing to proactively say why.

The string of broken promises around health data copying

In 2014 "this Government decided that people should be able to opt out from having their anonymised data used"⁷ and 1.2 million people took up the offer. In 2016, it emerged that the Secretary of State had changed his mind,⁸ and ignored the opt out, in secret.

The Data Protection Act allows a change in process, but public bodies doing so in secret, against their previous public statements, undermines public confidence in providing information to Government, and how data is used. It will actively dissuade those who would most benefit from such proposals to receive the help that they offer.

⁶ https://gds.blog.gov.uk/2016/12/08/now-we-are-5/

¹ <u>http://www.statewatch.org/news/2009/feb/uk-ml-convention-clause-152-briefing.pdf</u>

² And elsewhere, e.g. <u>https://gds.blog.gov.uk/2016/12/08/now-we-are-5/</u>

³ There was a civil society open policy making process which ran 2011 - 2014. The existence of these clauses was categorically denied at the time (later confirmed in conversation), and the outcomes and findings of that process have been entirely ignored.

⁴ Under the forthcoming General Data Protection Regulation, there is an expectation that Privacy Impact Assessments will be published.

⁵ Of this kind: <u>https://gds.blog.gov.uk/2015/09/01/registers-authoritative-lists-you-can-trust/</u>

⁷ Secretary of State for Health <u>https://www.theyworkforyou.com/debates/?id=2014-02-25c.146.9#g148.0</u>

⁸ http://www.digitalhealth.net/analytics/48338/nhs-digital-sees-off-patient-privacy-challenge

Just as patients should know how their medical records have been used, Citizens should know how their personal data has been used by Government.⁹ Instead, the new head of the Government Digital Service uses, "as an example, that both DWP and the NHS have large databases of citizen records, and that "we really need to be able to match those".¹⁰

Medical Records are included in the copying

The stated intent of the Bill is to exclude health data, pending other work by the Department of Health. The method Cabinet Office chose to do this is via the exclusion of the Secretary of State for Health from Schedule of bodies covered by the Bill.

Unfortunately, all this achieves in practice is a demonstration that the Cabinet Office doesn't understand the effects of their own Bill - an example of the lack of attention to detail throughout Part 5. The Bill includes all health data that individuals are required to share with other departments (such as DWP), and which they can then onwardly share. The effect of this manner of exclusion is that the most vulnerable in society - and those who have the most to gain from appropriate sharing - will be put at most risk of harm.

With the above mandated secrecy about agreements, groups who work to aid those communities will be entirely in the dark.

Civil Registration databases - Part 5 Chapter 2.

If the stated intent of Chapter 2 is not to allow the copying in bulk of population registration databases, why is that not on the face of the Bill?

We accept the General Register Office's need for a clear statutory basis to, with the consent of a citizen, confirm digitally to a department the details provided by that citizen are accurate. Individual digital services, with consent, are uncontroversial.

If that is all the case, given the Government's reliance on the open policy making process in other areas of the bill, why did the Government never mention these proposals then?¹¹

Bulk copying of civil registration databases is a very different matter to individual consent, and a very different principle. As all acts of civil registration start with an act by a responsible citizen (marriage, death, birth), they can all be done using consent that is provided at that time - bulk copying on an unconsented basis is entirely unnecessary, unless the purposes are not those being claimed.

If the Government were to introduce identity cards by the back door, this is the clause they would use, cloaked in the secrecy that pervades this Part.

⁹ <u>https://medconfidential.org/2015/implementing-data-usage-reports/</u>

¹⁰ https://www.publictechnology.net/articles/news/kevin-cunnington-reveals-his-'cunning-plan'-future-gds

¹¹ <u>https://www.theyworkforyou.com/pbc/2016-17/Digital_Economy_Bill/09-0_2016-10-25a.330.3#g330.6</u>

Summary

Given the obstinacy of the Cabinet Office, Part 5 of this Bill has been offered on a take or leave it basis to Parliament. If it is not improved at Committee stage, we suggest you leave it.

A major hospital in London has a deal with Google to produce an app to tell doctors which patients are in the most urgent need.¹² This is a good thing. But to produce it, Google insisted on having a copy of main dataset covering every patient in the hospital, which is only available up until the end of the previous calendar month. The appropriate way to get the information needed, was to get up to the minute information on the patient whose details they were going to display. However, Google wanted all the data, and insisted on it if the hospital wanted to work with them.

It's not the creation or production of a pretty app that's the problem - it's the demand for excessive data in return for using the app. It's entirely rational for the hospital to accept the app as it may lead to marginally better care for their patients; but the price is being paid in their patients' data. The Bill applies this principle across Government: third parties want the benefits of having the data, because this Bill does not require any protections.

The Minister was asked a simple question about safeguards: "Could you explain where they are and what they look like?"¹³ and no answer - because there are none.

Characterising Chapters 1 and 2, it can be said they *"will have the effect of removing all barriers to data-sharing between two or more persons, where the sharing concerns at least in part the sharing of personal data, where such sharing is necessary to achieve a policy objective…"*¹⁴

Unfortunately for the Government, that characterisation is quoting from the Government's explanatory notes for s152 of the Coroners and Justice Bill. Nothing has changed in Government thinking since 2009, when the House of Lords threw out that clause.

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¹² <u>https://www.newscientist.com/article/2086454-revealed-google-ai-has-access-to-huge-haul-of-nhs-patient-data/</u>

¹³ <u>https://www.theyworkforyou.com/pbc/2016-17/Digital_Economy_Bill/02-0_2016-10-11a.60.5#g70.6</u>

¹⁴ paragraph 962 <u>http://www.publications.parliament.uk/pa/cm200809/cmbills/009/en/2009009en.pdf</u>