

medConfidential Briefing for Lords Report of the Digital Economy Bill

The Government's amendments make a flawed Bill out of a deeply flawed Bill - there's more work to do, mostly filling in the blind spots the Government has willfully ignored in their current amendments.

medConfidential has 2 comments on current amendments:

1. **We strongly support Baroness Finlay's amendment to exclude medical records**, and propose an amendment to ensure transparency over what data that is shared to whom.
2. **There must be a requirement on the face of the Bill that details of what data is shared with whom is published.** But yet again, there isn't.

Clause 31 and Medical Records

While the Draft Regulations do not cover bodies of the Secretary of State for Health, following Committee stage, we now understand from the Department of Health that the Regulations when laid will include Health, on the basis that the NHS will by then have put care.data behind it. While we welcome DH's eternal commitment to the triumph of political hope over real world experience, it directly contradicts an explicit statement from the Cabinet Office last summer.¹

Unamended, the Bill bundles medical records with other data and delivers the Prime Minister's belief that any data that can be available, should be available, for any decision; even decisions that are catastrophic to the intent of the original data collection, and which generate adverse externalities. With DEFRA data, this might be inconvenient; with health data, it may be fatal.

The Cabinet Office deems all data the same, and their deeply flawed PIA process² can not be considered acceptable for medical records - tone deaf as it is to any form of concerns that are not the policy intent of a siloed civil servant.

We strongly support Baroness Finlay's amendment on clause 36.³

¹ <https://medconfidential.org/2016/2016-digital-economy-bill/>

² <https://medconfidential.org/2016/data-in-the-rest-of-government-the-cabinet-office-data-programme/>

³ [https://www.publications.parliament.uk/pa/bills/lbill/2016-2017/0102/17102-l\(Rev\)\(e\).pdf](https://www.publications.parliament.uk/pa/bills/lbill/2016-2017/0102/17102-l(Rev)(e).pdf)

There is No Transparency

Government amendments continue to allow for data sharing to be secret. They change “specified objective” to be “an objective which is a specified objective in relation to each of those persons”. It’s longer, but no safer, and it’s still secret, it’s still invasive, and can be used for the most nasty interpretations of Government will.

This should be corrected using medConfidential Amendment 1 which requires that all data sharing agreements be published in a Register. Government is continuing to insist on demanding Parliament grant it the ability to copy data anywhere it wishes; it is up to Parliament whether it will be able to do so in secret.

The Government’s suggestion in Commons Committee that citizens can use Freedom of Information Act requests to find out who has shared their data received the guffaws it deserved - but this Government appears to have been serious.

The Code of Practice is now on the face of the Bill - that’s the one change. It still allows data to be copied across the public services in bulk and in secret. This is not permitted in any of the later Chapters, but continues in the civil service chapters (Part 5, Chapters 1 & 2).

The campaign against ID cards was as much about the database it created; 10 years on, this Bill gives them the power to secretly copy the data they’ve always wanted.

When the UK gave up ID cards in the 1950s, the records were removed from the Home Office and shortly after became the central NHS register, this Bill enables a copy to be taken back to the Home Office.

medConfidential Amendment 1

Require a public register of disclosures under this Part - thereby covering all Chapters (3,4,5, and 7 already have some form of transparency from existing culture and processes; 1 & 2 have none).

Insert at end of clause 39:

() Any Code of Practice under this Part shall include a public register of parties disclosing and receiving personal information, a description of the information, and the purposes for which it was disclosed.

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