

## The Current State of Medical Records Sharing - following events at TPP<sup>1</sup> and DeepMind<sup>2</sup>, no response to Caldicott 3, and Government comments at Report Stage in the House of Lords of the Digital Economy Bill

The Government has admitted its intent to share medical records as equivalent to any other data under the Digital Economy Bill. When asked to comment on that, the Government responded: “We are not there yet”<sup>3</sup>

So when will we be there?

The Draft Regulations to the Digital Economy Bill do not include the Secretary of State for Health. Will Parliament get a vote on whether future Regulations will do so? This could easily happen as part of a future Bill around data, such as the forthcoming Data Protection Bill.

Given the breadth of current legislation, it is unlikely that Parliament will be given an opportunity to revisit this issue. The National Data Guardian Bill – currently indefinitely delayed in the Commons – is extremely narrow in its scope. It places the NDG on a statutory footing, but does not specify anything about what data should be copied, by whom, what for, or where.

TPP chose to share data on 26 million GP patients across its care provider customers, without those care providers understanding that TPP was acting as a data controller, which meant that care providers were inadvertently sharing the records of which they thought *they* were data controller with anyone with equivalent access, logged in at any other TPP-serviced care context. It’s still unclear whether Google DeepMind had any legal basis (they claim only ‘direct care’) for accessing 1.6 million patients’ medical records to build a smartphone app.

Despite their failures, neither of these organisations appears to have had harmful intent; they were trying to do the right thing, albeit with a rather narrow short-term goal. The fundamental problem is that, in focussing on that goal – and possibly distracted by some longer-term commercial considerations – they failed to spot the failures that would occur. Some consideration of the bigger picture, and a proper appreciation of the law, might have helped.

The Digital Economy Bill takes that same failure of thinking – exemplified by care.data – and spreads it across the public sector. It is not those with good intentions that are the biggest problem; the real risk come from those who don’t consider the effects of their intentions.

The BMA, minded of the failures of care.data, other projects, and its responsibility to its members and medical ethics, has seen the damage that unfettered copying can cause. Whereas the Royal Statistical Society has taken the position that, so long as research and statistics get ‘their’ data under some safeguards, the civil service can do whatever it likes with citizens’ data *without* safeguards; the Wellcome Trust has not publicly deviated from that view.

Only last week, NHS Digital ‘announced’ there will be a new programme to copy patients’ GP data, for which it is seeking approval by the end of 2017.<sup>4</sup> While as yet officially unnamed, in practice this programme is nothing less than “care.data 2”.

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<sup>1</sup> <http://www.telegraph.co.uk/news/2017/03/17/security-breach-fears-26-million-nhs-patients/>

<sup>2</sup> <https://www.law.cam.ac.uk/press/news/2017/03/julia-powles-publishes-google-deepmind-and-healthcare-age-algorithms>

<sup>3</sup> <https://www.theyworkforyou.com/lords/?id=2017-03-20b.94.0#g114.1>

<sup>4</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/603002/20170328\\_NHSD\\_Digital\\_Board\\_Papers\\_P art\\_1\\_WEB.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/603002/20170328_NHSD_Digital_Board_Papers_P art_1_WEB.pdf) - Page 56 - line C4.

## Future choices

This is about data sharing for purposes beyond direct care to non-NHS bodies. Government has been clear - medical records held by Government should be as poorly protected as data held by the Department for Transport or DEFRA. HMRC records get statutory protection, NHS records do not. Without a statutory bar, one end state of the Cabinet Office thinking is the American situation, where a public body can routinely and wrongly make re-identifiable treatment records available under their Freedom of Information Act.<sup>5</sup>

The Data Protection Bill provides a vehicle for cleaning up the catastrophic mess of section 31. Whatever happens, the Government should not bring forth any regulations around s31 (including commencement) or health data until after the National Data Guardian has been placed on a statutory footing – the Government’s oft-stated but never-delivered promise for nearly 3 years.

Opposing the inclusion of health data under s31 does not prevent health data being shared,<sup>6</sup> it simply requires bodies to do what they should already be doing: be careful, and stay within the law. Section 31 shows Government has entirely ignored the lessons of care.data, and intends doing the same thing all over again, expecting a different result.

Written over a year ago, Caldicott 3 has aged well,<sup>7</sup> but the Government has still not responded to its recommendations – even as events have moved on, and GPs begin to tell their patients how data is being used.

While Caldicott 3 left open whether a patient’s GP records could be copied at will, the recent finding by the ICO that TPP’s approach was unlawful hopefully illustrates the fatal flaw in that particular folly. NHS England’s continuing interest in a “National Data Lake” seems, at best, wilfully ignorant in this context.<sup>8</sup>

The Government Transformation Strategy<sup>9</sup> tries to move to a “single government department” view of data – with a ‘Data Controller in Chief’ copying data at will.<sup>10</sup> The Digital Economy Bill gives effect to this world view.

As we move into a Brexit world, with regard to medical records, does “We’re going to make a success of it” mean unfettered copying at the whim of a civil servant, or lawful respect for informed patient choice?

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<sup>5</sup> <http://techscience.org/a/2015092903/>

<sup>6</sup> <https://medconfidential.org/2016/data-in-the-rest-of-government-the-cabinet-office-data-programme/>

<sup>7</sup> <https://medconfidential.org/2016/caldicott-review-1-the-good/>

<sup>8</sup> <https://www.digitalhealth.net/2017/01/new-national-nhs-patient-data-lake-proposed-based-on-stps-2/>

<sup>9</sup> <https://medconfidential.org/2017/response-to-government-transformation-strategy-2017-to-2020/>

<sup>10</sup> <http://www.governmentcomputing.com/blogs/government-computing-network-blog/privacy-groups-urging-dropping-entire-digital-economy-bill-data-clause>