

## **medConfidential: background briefing on Questions to the Health Secretary & NHS Chief Executive regarding care.data and related matters - December 2014**

### **The National Data Guardian**

On 13th November, appointing Dame Fiona Caldicott as the first National Data Guardian, the Secretary of State said “I intend to put the National Data Guardian on a legal footing at the earliest opportunity”<sup>1</sup>. Jeremy Lefroy MP’s Private Members’ Bill is such an opportunity, given the explicit focus on the use of NHS numbers across Health and Social Care: where the NHS number is used, or must not be used, must clearly be within the remit of the National Data Guardian.

medConfidential has proposed an amendment (see PMB Committee briefing attached) which would facilitate the display of cross-party opinion in a discussion of - and, if incorporated, deliver on - the Secretary of State for Health’s commitment, given because, in his words, “we need to be as determined to guarantee personal data is protected as we are enthusiastic to reap the benefits of sharing it. Dame Fiona will oversee the safe use of people’s personal health and care information and hold organisations to account if there is any cause for concern, ensuring public confidence.”<sup>2</sup>

The Private Members’ Bill Committee is meeting on Wednesday afternoon. The Health Select Committee may wish to offer comment and (we hope) support for Dame Fiona Caldicott’s new role being quickly put onto a statutory footing.

### **Missing: Care Act Regulations and new Directions to NHS England/HSCIC on patient consent**

NHS England claims in public that ‘legislation has fixed everything’, but despite repeated promises to Parliament, citizens, patients and professionals, no stakeholders have seen drafts or any details of either the Regulations to the Care Act, or new Directions on patient consent. All parties remain entirely in the dark.

Absent the crucial definitions of “the promotion of health”, sanctions for misuse and the rules and operation of the Confidentiality Advisory Group in these Regulations, promises made to patients and GPs in the care.data ‘pathfinders’ will not be true. And without Directions, the patient opt-out will still be in the gift of the Secretary of State - not on a statutory basis, not even in tertiary legislation - with potentially devastating consequences for public confidence.

We have no idea of the answer to this question: “How are they going, Mr Hunt?”

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<sup>1</sup> <https://www.gov.uk/government/news/national-data-guardian-appointed-to-safeguard-patients-healthcare-information>

<sup>2</sup> *ibid*

## **Consent and hospital data**

The Health and Social Care Information Centre's new Code of Practice<sup>3</sup> requires it to honour patient dissent/consent where Directed or otherwise legally required to do so. This therefore requires that the Directions to HSCIC (and possibly NHS England) on patient consent are explicit and unambiguous, and thereby transfers responsibility for the detail from HSCIC to the Department of Health. We hope such Directions will be as clear as the Secretary of State's comments when accepting the Caldicott2 report last year - such Directions must be followed.

It was in fact the uses of hospital data that caused most public controversy earlier in the year. In January and February, an opt-out code for data collected from non-GP care providers - hospitals, screening, clinics, etc. - was promoted to patients (9Nu4, or 'Type 2 objection'). Given the thousands of care providers, their data would generally go from the provider to HSCIC, where the HSCIC would be prevented from including the information of those who had opted out in any onward data flows.

There is a distinct lack of clarity over when the 9Nu4 opt-out code will be implemented for ongoing data flows such as Hospital Episode Statistics (HES). Indeed, current draft communications to patients for the care.data 'pathfinder' stage have dropped this option entirely. medConfidential has seen no clear and effective consent mechanism proposed for non-GP records other than the 9Nu4 process. If patients' right to opt out of secondary uses of their GP records is to be respected, this right must clearly also be respected by other parts of the system.

The 9Nu4 process takes advantage of the strengths of having a National Health Service. Will NHS England ensure that it is clearly included in the care.data communications, and that the legal requirements regarding consent be fully Directed by DH and implemented across the NHS?

### **[To NHS England CEO] care.data Communications**

NHS England's CEO is due to sign off the care.data patient communications this month.

While the patient communications published at the care.data Advisory Group public meeting in Manchester on 26 November are clearly not ready, in rushing to deliver something by an arbitrary deadline of Christmas the programme is in danger of even more seriously compromising public confidence and failing to deliver its promised objectives.

Is the NHS Chief Executive clear that the current design of the care.data programme meets the business case for the investment of reputation, patient trust and resources being deployed?

### **[To all] care.data Communications**

Will witnesses give an undertaking that no care.data communications will occur during purdah?

medConfidential

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<sup>3</sup> [https://medconfidential.org/wp-content/uploads/hscic/2014-november/HSCIC140705a\\_Draft%20Code%20of%20Practice.pdf](https://medconfidential.org/wp-content/uploads/hscic/2014-november/HSCIC140705a_Draft%20Code%20of%20Practice.pdf)