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Care.data Relaunch Held Back

The rescheduled roll-out of the Government's Care.data scheme is likely to be delayed beyond September. The original launch in April was postponed for six months following threatened legal action and a campaign for a mass opt-out .

The Care.data scheme will combine people's surgery and hospital records within a central database. Public concern has centred on the sale of people's records for commercial purposes and lack of adequate safeguards against individuals being identified. Last year's Health and Social Care Act requires NHS information to be made freely available to commercial bodies.

Care.data boss Tim Kelsey and new head of NHS England Simon Stevens have now both said that the delayed roll-out will not be tied to "artificial deadlines". However, Kelsey said pilot uploading of patients' data from 500 surgeries would begin in the autumn.

Many GPs are unhappy that their enforced involvement in Care.data could undermine patients' trust. The National Conference of Local Medical Committees, representing GPs, recently backed a call for patients' records only to be uploaded if individuals agree by opting in. NHS England only offers a right of opt-out, and even this was only included in the scheme as an after thought.

Postponement of Care.data has been promoted as giving time to educate the public after a population-wide leaflet fiasco in February. NHS England has not changed the scheme beyond claiming that data will only be released where patients will benefit and not to insurance companies or for marketing purposes.

The Government passed up a chance to build confidence in its plans during a House of Lords debate in early May. It persuaded peers to vote down an amendment to the Care Bill from the respected cross-bencher Lord David Owen which would have given statutory power over the scheme to the Independent Information Government Oversight Panel.

Lord Owen argued that the sharing of Care-data could be crucial for medical research but was being undermined by distrust.

Data insecurity

Two million "serious data breaches" of NHS patient records have been logged by the watchdog, the Information Commissioner, since 2011. Care.data comes under the authority of NHS's England's Health & Social Care Information Centre which has a gung-ho approach to patient information.

Last February HSCIC admitted handing the insurance industry the records of millions of patients to aid the compiling of actuarial tables. The data given to the insurance industry was "pseudonymised", meaning patients' names had been removed. Care.data would be similarly

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pseudonymised. The process is readily reversible if the dataset is combined with data from another source containing names and basic personal details.

NHS England and the Government have refused to apply an irreversible process of “anonymisation” to Care.data. They say de-pseudonymising Care.data would be unlawful and organisations receiving the data would have to promise not to do it.

Care.data boss Kelsey is an evangelist for so-called “open data” who will struggle to reassure critics that he cares about data security. According to the Register website, he wrote in 2009: “No one who uses a public service should be allowed to opt out of sharing their records. Nor can people rely on their record being anonymised.”

A former journalist, Kelsey set up the Dr Foster company which pioneered comparison of hospital statistics. In 2006 he profited from the Department of Health paying £12 million for a stake in a joint venture with Dr Foster. The payment was criticised by the National Audit Office and the Commons Public Accounts Committee.

Care.data should not be confused with patients’ summary care records and other sharing of information within local health services. In a me-too development, HMRC (formerly Inland Revenue) is causing outrage with plans to sell tax records.