

Confidentiality concerns delay UK patient data system

In light of patient confidentiality concerns, the United Kingdom is delaying plans to start uploading patient data to care.data, the new national health record system designed to provide data from physicians' electronic medical record systems to researchers and commercial buyers.

Instead of launching in April, the system will now get underway in October, while the government makes good its promise of enacting legislation to reinforce patient confidentiality. The decision to delay care.data follows pressure from patient and medical groups, including the Royal College of General Practitioners, the British Medical Association and UK Information Commissioner Christopher Graham. The system "was put on hold because a significant number of patients were asserting their right to stay in control of their information," Graham explained in a statement on Feb. 28. "We should see these developments as a line in the sand."

Designed to amass health information from physicians' files on England's 55 million residents (Scotland and Wales are not participating), care.data is central to the conservative government's aims to bolster the UK's life sciences industry through research-based innovation.

"The end result will be that every willing patient is a research patient," British Prime Minister David Cameron explained when the system was introduced.

Although participation in the new records scheme will not be compulsory, patients' right to opt out of care.data was poorly communicated, critics charge. Leaflets mentioning the opt-out provision were sent to 26 million homes, but according to a poll conducted for the British Broadcasting Corporation last month, only 30% of people recalled receiving one. "We don't feel the opt-out has been explained as clearly as we expected," a senior official in the Information Commissioner's Office explained in a Feb. 11 blog posting. "We are looking to see that addressed."



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The UK's care.data is designed to amass health information from physicians' files on England's 55 million residents.

Patient advocates are angry. "The care.data concept has little to do with patient care," says Phil Booth, coordinator of medConfidential, a London-based group advocating for patient confidentiality. "This is all about making patient data available for secondary users in industry." Physicians, Booth warns, "face an appalling situation where on the one hand they must upload patient data in identifiable form, while on the other hand they have a duty to patients to protect their confidentiality."

If care.data is introduced, says Booth, patients should be encouraged to opt in to participate, rather than being allowed to opt out.

But an opt-in model may mean a substantial minority of the population never makes a choice, which means the data cannot be used, says Dipak Kalra, professor of health informatics at University College London. "This will greatly degrade the quality management and research value of the data." In addition, if there are selection biases in who responds promptly or slowly or never to the oppor-

tunity to opt in, says Kalra, "the data may be pretty unusable even if more than half the population eventually says yes."

The government's acknowledgement that the UK Society of Actuaries purchased hospital patient information from the National Health Service (NHS) to guide insurance companies about premium calculations has further inflamed public doubts about the care.data system.

The Health and Social Care Information Centre, which will manage the care.data system, now says that, in the future, data from hospitals will only be supplied for use by "health organizations to improve their ability to carry out their role; or to improve the quality of health care management or service delivery in England."

A privacy impact assessment released by the NHS in January acknowledges that care.data should be managed carefully lest patients lose trust in the confidential nature of health services. — Paul Christopher Webster, Toronto, Ont.

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