

Press Release

Foundation for Information Policy Research

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On Thursday, the Department of Health will launch the long-awaited report by Professor Trisha Greenhalgh into the Summary Care Record (SCR). This report, whose contents have been widely trailed and leaked (see Tony Collins' blog in *Computer Weekly*), will show that the SCR does not deliver much benefit to the health service; that it does not work very well; and that it was yet another spectacularly badly-managed public-sector IT project. It cost a lot of money, and is not much used. The Foundation for Information Policy Research calls for the SCR project to be abandoned.

Last year, The Joseph Rowntree Reform Trust published a report, 'Database State', written by FIPR members. This report looked at 46 large public-sector IT systems that hold information on all of us, or at least on a substantial minority of us. It rated eleven as 'red', meaning that they were almost certainly illegal under human-rights law; most of the others were 'amber' meaning that they had serious privacy or safety problems.

The SCR was rated 'amber' in the Database State report. However, in view of Professor Greenhalgh's findings, it should now be rated as 'red', said the report's lead author, Ross Anderson, Professor of Security Engineering at Cambridge University. It brings very few benefits and has the potential to do serious harm.

The SCR will make medical information about tens of millions of patients in England available to over 800,000 NHS staff. The information will initially consist of prescriptions and allergies, but the record will be rapidly 'enriched' with all sorts of other data, becoming in time a shared electronic health record. A similar project in Scotland, the Emergency Care Record (ECR), suffered serious privacy failure when an NHS employee improperly accessed the records of Gordon Brown, Alex Salmond, and other celebrities.

Human-rights law requires that sensitive information should in general only be shared with the consent of the data subject. The BMA has long argued that patients should have to opt in to the SCR, so that their consent was unambiguous. But the Department of Health insisted on an opt-out model; it believed that if patients had to opt in, not enough of them would bother to do so for the system to be viable. The new study shows that very few doctors ever use the SCR, and that the opt-out consent model is not working.

Quotes

'The consent mechanisms in the SCR are broken', said Professor Ross Anderson. 'Although mailshots have been sent to millions of patients, most of them have never heard of it. Also, it's really hard to ask for consent in busy A&E departments where a patient may be seen by a dozen staff one after another. And children are not being asked for their consent at all.'

‘The SCR is dangerous because no one doctor is responsible for it’, he continued. ‘Your GP updates your GP record whenever you visit her, and she’s got an incentive to do that because she relies on it. But the SCR takes partial information from your GP, hospital visits, out-of-hours, and bundles it all up together. It’s no-one’s job to keep it accurate.’

Professor Anderson has an op-ed in the British Medical Journal tomorrow urging that the SCR project be abandoned. This article follows and may be cited.

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‘Database State’ coauthor William Heath said ‘The new Coalition has inherited the beginnings of a decent policy on public data. But the big challenge remains a proper policy on personal data. Public services must respect people's dignity and privacy, and as far and as fast as possible restore control over personal data to the individual’

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In April 2006, 23 Professors wrote to the Health Select Committee to say that the project was showing the signs of failure and calling for an independent review. This was vetoed by the Department of Health.

Martyn Thomas CBE FREng, spokesman for the 23 Professors, said ‘There should be an open inquiry into how this flawed project was allowed to continue for so long, and why the recommendation by independent experts in computing and systems was overruled by the Minister against the advice of Connecting for Health.’

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– Notes for editors –

(1) The ‘Database State’ report can be found at

<http://www.jrrt.org.uk/uploads/Database%20State.pdf>

(2) The ‘Computer Weekly’ blog can be found at

http://www.computerweekly.com/blogs/tony_collins/2010/06/highlights-of-confidential-ucl.html

(3) The BMJ article follows. It is also available under embargo from

<http://press.psprings.co.uk/bmj/june/anderson.doc>

while mark Walport’s op-ed in favour of the SCR is available under embargo from

<http://press.psprings.co.uk/bmj/june/walport.doc>

and a summary of the Greenhalgh report is available under embargo from <http://press.psprings.co.uk/bmj/june/scr.pdf>

The URLs from which these articles may be downloaded after the embargo are <http://www.bmj.com/cgi/doi/10.1136/bmj.c3020>
<http://www.bmj.com/cgi/doi/10.1136/bmj.c3022>
<http://www.bmj.com/cgi/doi/10.1136/bmj.c3111>

“In no other safety-critical system would people just heap up data and hope that someone will deal with it.”

Do summary care records have the potential to do more harm than good? **Yes**

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Ross Anderson argues that the national electronic database of patient records is both unnecessary and illegal, but **Mark Walport** (doi:[10.1136/bmj.c3022](https://doi.org/10.1136/bmj.c3022)) believes that it will make valuable contributions to better care

I agree with Mark that the future of medical records is digital. A medical record system that shared information when appropriate between care providers, and was dependable and safe, would be of great value. However, the Summary Care Record isn't it. The SCR must be abandoned—for reasons of safety, functionality, clinical autonomy, patient privacy, and human rights.

The SCR was marketed to the public as a way for accident and emergency staff to check up on unconscious patients. According to Tony Blair, if you ended up in hospital in Bradford, doctors could look up your records with your general practitioner in Guildford. But this is nonsense. Very few patients have conditions that must be made known to emergency staff; for those that do, the properly engineered solution is MedicAlert.[1] Unconscious patients often can't be reliably identified, so a database is less robust than a tag or card; the SCR doesn't have everything A&E staff might want to see; and it is not even available in Scotland (let alone on a beach in Turkey).

The truth is that the SCR was designed to accumulate large amounts of data about patients from multiple sources. Many patients' records will start with a hospital discharge summary rather than a general practice summary, while plans are afoot to include medical images and even ambulance messages.[2]

Lack of control

This rapid increase in scope creates a serious hazard: a multicontributor record for which no individual clinician is responsible. Transfers of data between general practices have thrown up serious difficulties about the different ways in which data are classified. Adding other providers will make this worse; experience with the electronic discharge letter suggests that hospital data also vary from poor to dangerously incomplete. In a clinical context, weak controls on quality and consistency may be offset by the effort clinical owners make to organise the data on which they rely. But with no-one motivated to curate the data, responsibility for it will be diffuse. This is a known hazard in medicine, and applies to other systems too. In no other safety critical system would people just heap up data and hope that someone will deal with it.

Functionality and clinical autonomy are related to safety. Experience shows that clinical systems bought by doctors generally work, while those bought by civil servants generally don't. A good case history is the GPASS system in Scotland—a well-meaning attempt to save money by providing general practices with a common publicly-funded computer system left them instead with systems unresponsive to clinical needs. Without clinical ownership of a system's specification and evolution, it is unlikely to remain fit for purpose.

So it is not surprising that the Department of Health is sitting on an independent report on the SCR by University College London; nor that one of the report's authors, Emma Byrne, has written that the summary care record was “not much use” and “not particularly effective at improving health care.”[3]

In an attempt to make the SCR appear a success in other ways, there was a frantic push before the election to increase the number of records uploaded. Yet despite Connecting for Health breaking an agreement with the BMA on pausing uploads and a deceptive and coercive patient information campaign, only 240 practices are uploading data. In Bolton, where the summary care record was piloted over three years ago, only 25 practices out of 56 are uploading; in Bradford it's 20 out of 83; and in Somerset, 9 out of 76.

Breach of human rights

The showstopper though is privacy. In 2008, the European Court of Human Rights decided the case *I v Finland*. Ms “I” was a nurse in Helsinki, and HIV positive; the systems at her hospital let her managers find out about her status, and they hounded her out of her job. The court awarded her compensation, finding that we have a right to restrict our personal health information to the clinicians involved directly in our care. Other staff must be unable to access records, not just “not allowed.” In 2009, colleagues and I wrote a report for the Joseph Rowntree Reform Trust, examining the impact of this and other cases on UK central government systems and concluded that the summary care record had serious legal problems.[4] With the additional data being added, it is now clearly unlawful.

Furthermore, the summary care record’s consent procedures are completely unsatisfactory; sharing medical data requires informed consent, yet large numbers of patients are unaware that the record even exists. Expecting patients to be aware of it, and to opt out every time they interact with health care, is ridiculous; just how do you get consent from an intoxicated teenager who’s turned up to get emergency contraception? In fact, children are not being offered an opt-out at all.

There are two larger points here. The first is that to escape the Finland judgment, the UK would have to abrogate the European Convention on Human Rights, withdraw from the Council of Europe, and almost certainly leave the European Union. Second, this is not just a matter of law but goes to the heart of the relationship between patients and doctors. The summary care record and the national information technology plan will make even highly sensitive information such as mental health records available by default to hundreds of thousands of people—and not just in the core NHS but in Whitehall, local authorities, and research laboratories. This is totally at odds with the expectations of patients, with safe systems engineering, and with prudent clinical practice, as well as with human rights law. We do need to automate medical records – but we need to do it right.

Competing interests: None

Provenance and peer review: Commissioned; not externally peer reviewed.

1 MedicAlert. Response to summary care record. www.medicalert.org.uk/pages/response-to-summary-care-record.html.

2 NHS Connecting for Health. National Clinical Reference Panel. Minutes, November 2009. www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/advis/ncrp.

- 3 Byrne E. Privacy is not just a technical problem—the NHS needs to change the way it thinks about our data. 21 May 2010. www.openrightsgroup.org/blog/2010/privacy-is-not-just-a-technical-problem.
- 4 Anderson R, Brown I, Dowty T, Heath W, Inglesant P, Sasse A. Database state. Joseph Rowntree Reform Trust, 2009. www.jrrt.org.uk/uploads/Database State.pdf.

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