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

Ross Anderson argues that the national electronic database of patients' records is not fit for purpose and illegal, but **Mark Walport** believes that it will make valuable contributions to better care

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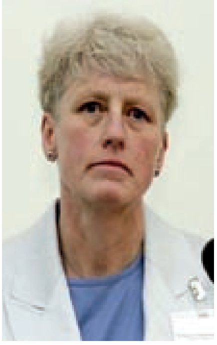
- Research: Adoption and non-adoption of a shared electronic summary record in England (*BMJ* 2010;340:c3111)
- News: Future of NHS summary care record hangs in balance (*BMJ* 2010;340:c3230)
- News: NHS puts brake on roll-out of summary care records (*BMJ* 2010;340:c2158)



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Listen to Trisha Greenhalgh, lead author of the mixed-method case study on adoption and non-adoption of a shared electronic summary record in England, talk about the study's findings at www.bmj.com/podcasts

All references are in the version on bmj.com

WHERE DO YOU STAND ON THE ISSUE?
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YES

A digital 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. It must be abandoned—for reasons of safety, functionality, clinical autonomy, patient privacy, and human rights.

The summary care record 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 record doesn't have everything accident and emergency 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 summary care record 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

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

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NO

I recently received a leaflet from my local NHS updating me about changes to the way my health information will be stored and giving me the opportunity to opt out of the summary care record. I wouldn't dream of opting out of this. I am delighted to see progress—eventually—being made towards introducing a joined up system for electronic patient records.

It is impossible to be a patient or to practise medicine without being frustrated about incomplete and lost health records, difficulty in communications among the extended healthcare team, and needless clinical errors and failure to implement best practice guidelines. Good information technology has the capacity to be transformational. I shall never forget the dramatic improvement to the quality of service to patients and staff that followed the introduction of the first x ray picture archiving system in the UK at Hammersmith Hospital.

Better care

As the leaflet makes clear, the summary care record will provide my healthcare team with quicker access to more reliable information that should help my treatment. If I go under a bus in Birmingham, the local accident and emergency department will be able to access my records in London to check whether I have any allergies and what drugs I am already taking—information that could be lifesaving.

The primary purpose of electronic patient records is to improve patient care. As a patient I expect the following: that my records will be accurate and that I can work with my carers to improve their accuracy; that they will be treated confidentially; that they will be shared between the members of the healthcare team that collectively look after me in primary care and in hospital; and that they will provide a basis for accountability for the quality of my health care. In addition I would hope that my records could be linked to "expert systems" that would minimise the chance of treatment errors and maximise the chance of my being prescribed the best treatment.

Wider research

There is another huge potential benefit of a nationwide electronic patient record system, to improve treatment through research. Research provides the evidence that medical treatments work or, equally importantly, that they don't. It is 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 one of the authors of an independent report on the summary care record by University College London, Emma Byrne, has written that the record was "not much use" and "not particularly effective at improving health care."[3,4]

In an attempt to make the summary care record 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.[5] 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 has 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.

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an integral part of the best health systems.

The foundation for much of this research is information contained in patients' records. This information allows us to discover the factors that determine health and disease, to monitor the safety of drugs, and to study the effectiveness of treatments. Medical records can also be used to identify patients who might be suitable to take part in a clinical study, in order to invite them to take part.

Of course, medical records are both personal and sensitive, and everyone agrees there must be safeguards for confidentiality and consent. But the majority of the public is in favour of using anonymised records to facilitate research. A survey conducted by the Wellcome Trust last year asked 1179 people, "How willing or unwilling would you be to take part in a medical research project which involved allowing access to your personal health information, that is, your medical records, on an anonymous basis?"[1] Seventy four per cent responded that they would be very or fairly willing. As a patient with cancer commented, giving her anonymous data for research is "the most painless way she can help others get better."

> **"the summary care record will provide my healthcare team with quicker access to more reliable information that should help my treatment"**

Safeguarding data

But we cannot avoid the fact that sometimes researchers working as part of clinical teams will need to access data from which it may be possible, directly or indirectly, to identify a patient. For example, a study of 33 000 children showed that those who lived close to a power line at birth had an increased risk of leukaemia.[2] This study involved information that a child of a particular age lived at a particular postcode. Together, these two pieces of information could lead to the identification of individual children, but it would not have been feasible—or proportionate—to seek individual consent from all 33 000 families.

In our 2008 review of data sharing, the former information commissioner, Richard Thomas, and I, set out specific recommendations to enable researchers to access this type of identifiable information for research purposes, while ensuring appropriate safeguards and sanctions are in place.[3] The last government accepted these recommendations, but we have yet to see them introduced in the health arena. We must have action now to implement them.

The new coalition government, coupled with the economic crisis, means that the future is uncertain for Connecting for Health. I do not believe that Connecting for Health has been marketed well to either patients or the medical profession. There has been much too much about its use as a management tool and too little about its primary aim, which should be to improve care. It may be that it would be better implemented as a more federated programme, ensuring common standards to allow interoperability. A key aim must be integration of records and communication across primary and secondary care.

But one thing is certain—the best care requires the best medical records. A world class NHS demands a world class infrastructure. The future for medical records is digital.

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RESEARCH, p 1399