

Privacy Vs Improved Care

COMMENT: After nearly 20 years of co-ordinated efforts to computerise the NHS, something new is in the air, says Michael Cross. For the first time, a strategy for health and social care is emerging as a response to top level government policy rather than being driven by IT enthusiasts.



The snag is that the strategy will attract infinitely more mainstream political attention than its predecessors in 1992, 1998 and 2002. Especially as its core proposal - for patients to have online access to their own records by the end of this parliament - potentially affects every resident of England.

At the beginning of January the Department of Health said that the delayed information strategy for health and social care in England would be published in April.

The strategy will aim to implement the ideas set out in last year's NHS Information Revolution consultation paper - essentially that information in electronic medical records be opened up to put patients in charge of their care. The direction of travel was set last month by the government's response to a report by the NHS Future Forum, a body put together last year to provide a reality check to Andrew Lansley's reforms to the NHS in England.

After the initial phase in its consultation, the forum decided (correctly) that the Lansley reforms would get nowhere without a leap in information-handling. As a result, information was one of four themes in the second phase of the forum's work (the others were public health, integration and education and training). Its report, published last month, claims there is real demand from the front line for the information revolution.

The inquiry "heard very clearly that people want more control over their health, through better information, better communication and a louder voice. We heard a strong consensus that 'it's the patient's data', not 'the system's data'. We heard of huge frustration with the obstacles to capturing and sharing information that get in the way of delivering high quality, integrated care."

Controversially, it also found "a consensus that current information governance procedure does not get the best balance between protecting patient confidentiality and sharing information to ensure high quality care."

The forum's central recommendation is that health and social care should be integrated

around the patient, not the system. "Every individual should own their own patient record and be able to share it as they wish. All care records should be electronic and accessible at the point of care throughout the whole care journey, regardless of sector or provider."

The report also endorses the commitment, set out in the chancellor's autumn statement, for patients to have online access to their own health records. However it gently warns that the target date of 2015 appears optimistic. "We support this commitment as a first step, but the information strategy must now make clear how this will be achieved, recognising that there is both a financial and time burden to GP practices and by providing meaningful help and support to them."

It urges the government to invite the Royal College of General Practitioners, in partnership with the British Medical Association, together with NHS Commissioning Board and "relevant patient organisations", to develop a plan to make it happen. The plan will have to deal with technical practicalities (at the moment, only one GP record system, from EMIS, allows online access), education and training and - crucially - what the forum calls "a proper consent process".

It calls for a review of the current information governance rules and of their application, to report during 2012. If the promise of integration is real, this review will have to cover the governance of information from social care as well as NHS records.

The review will also have to take in to account the government's policy on information transparency, and the re-use of data extracted from records. Although the concept is not new - many of the first generation of GP computer systems were installed free in exchange for access to anonymised data about prescribing habits - the new programme is on an entirely different scale.

In a well-trailed announcement at the end of last year, the prime minister said that he would amend the NHS constitution to make data extracted from health records available for research unless patients actively opt out. Acknowledging "a little bit of controversy"

over the issue of confidentiality, he said, "It is simply a waste to have a health system like the NHS and not to do this kind of thing."

Despite the Future Forum's claim of consensus, he can expect a rough ride from professional and civil liberties bodies as well as opponents of private firms entering the market in NHS services.

Recent academic studies have warned that anonymised data may need to be protected as rigorously as identifiable data to remain on the right side of the law. Last year a study commissioned by the Cabinet Office as part of the government's transparency programme warned of a "potential clash" over the use of anonymised data in publicly available releases of data. The problem is that in small datasets, such as from individual surgeons' outcomes, it might be possible to identify individuals despite anonymisation. The study - Transparent Government, Not Transparent Citizens, by Kieron O'Hara, senior research fellow at Southampton University - warns: "There are no complete legal or technical fixes to the de-anonymisation problem" and "It is essential that policymakers, data managers, data controllers, privacy officers, and lawyers do not automatically assume that anonymised data cannot be used to re-identify people."

Meanwhile, a study by three experts in privacy law concluded that in data protection law, anonymised data remain technically "personal data" and are subject to UK and European data protection rules. This would require that all processing of an individual's data (including the act of anonymisation in the first place) must be carried out with consent.

In its response to the Future Forum's report, the government says "We will consider how best to achieve an appropriate balance between the protection of patient information, and the use and sharing of information to improve care."

But with NHS information strategy now so tightly bound to controversial government policies, this "appropriate balance" will be tricky to find.