Letters

To opt in or opt out of electronic patient records?

Isle of Wight and Scottish projects are not opt out schemes

EDITOR—Watson and Halamka debate whether patients should have to opt in or out of the national electronic care record.[1] However, the Isle of Wight and Scottish electronic emergency care summary models cannot be truly compared with that proposed for the NHS summary care record because patients control access to their data in both, which makes them nearer to opt in systems. In the Isle of Wight and Scotland data are initially collected under opt out arrangements, but they are accessed only with active patient consent once collected and held on the common repository—that is, under opt in rules. The fact that the initial collection operates on presumed consent is only part of the overall process. The overall system is opt in for record access.

JOHN HELLER/AP

In the proposed NHS summary care record data will be accessed once collected with no further input from the patient. This distinction is profound, causes the medical profession concern (as evidenced by the motions passed supporting opt in at the BMA's annual representative meeting), and is not being made sufficiently clear to the public.

The complex issues in this debate are not helped by the counter intuitive labelling of the so called opt in and opt out positions. The key is that patients and clinicians must have confidence that information will be secure and shared only with patient consent.

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Competing interests: PRC owns GePmail, a clinical communications software supplier.

1 Watson N, Halamka JD. Patients should have to opt out of national electronic care records [with commentary by J Wilkinson]. *BMJ* 2006;333:39-43. (1 July.)

Integration technology is key to success

EDITOR—Watson's case that patients should have to opt out of national electronic care records is compelling.[1] In the Hampshire and Isle of Wight's successful records service, however, the key feature was the use of computer integration software (XML Graphnet), which provided a breakthrough in confidentiality while linking diverse and unrelated systems together.

The alternative method of trying to achieve joint working is to scrap all existing systems and force all services to use the same system. This approach was tested in Dorset as part of an NHS pilot scheme during 2001-3 by the Information Authority at the same time as the Hampshire scheme. It hit massive problems with data migration, confidentiality, and a revolt by general practitioners against the imposition of new software that did not work as well as their advanced surgery systems. This is the route chosen by Connecting for Health. The Dorset site recorded delays and escalating costs before abandoning rigid centralisation and adopting the same integration technology as Hampshire.

When we asked patients contacting the out of hours service for permission to look at their integrated record they universally agreed and were surprised that we could not already do this across the whole NHS.

After the National Audit Office report Lord Warner announced a review and proposal to look at the Veterans' Administration system in the United States and pilot sites in 2007.[2] The lessons are already here: Hampshire and Dorset piloted two methods of building the national system. Integration technology is the key to rapid progress. It is cost effective and rapidly reproducible, and it works.

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Competing interests: In 2003 JMO used a Graphnet solution but now has no commercial interest.

1 Watson N, Halamka JD. Patients should have to opt out of national electronic care records [with commentary by J Wilkinson]. *BMJ* 2006;333:39-43. (1 July.)
2 National Audit Office. *The national programme for IT in the NHS: report by the Comptroller and Auditor General.* London: NAO, 2006.

Electronic patient record is incompatible with confidentiality

EDITOR—From the website of the General Medical Council on the duties of registered doctors:

> Doctors hold information about patients which is private and sensitive. This information must not be given to others unless the patient consents or you can justify the disclosure.
>
> Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care.
>
> Many improper disclosures are unintentional. You should not discuss patients where you can be overheard or leave patients' records, either on paper or on screen, where they can be seen by other patients, unauthorised health care staff or the public. You should take all reasonable steps to ensure that your consultations with patients are private.

The electronic patient record will allow a summary care record on every patient to be available from every NHS computer terminal.[1] I look forward to the day when patient notes are legible, devoid of repetition, and contain results of relevant investigations. The electronic patient record might achieve this and improve patient care, although at a significant financial cost. Unfortunately, it is also a direct and serious threat to patient confidentiality.

Many hospitals already have electronic access to laboratory records and radiological images. Passwords are sometimes shared, screens left on in open view. Insufficient attention is paid to confidentiality and security, even though staff can be disciplined for breaching rules on electronic data protection. When the medical history of the whole population becomes available on a central computer the potential for loss of confidentiality is obvious.

Workers in hospitals or general practice surgeries might seek inappropriate access to medical records because of curiosity or malice, commercial gain, or simple error. If screens are left on in open areas or passwords compromised, tracing of access for disciplinary purposes would be difficult. If challenged after a breach of security one could argue that data were requested accidentally. I occasionally enter a wrong number into the radiology viewing system and see unwanted images. Such errors are inevitable.

The GMC clearly advises doctors that patients should be asked before entrusting their confidential medical records to others; this must mean that explicit consent is required to enter their data into a national computer system. The electronic patient record, whatever its political or bureaucratic attractions, is intrinsically incompatible with a confidential relationship between doctor and patient and we should advise our patients of this. The huge sums of money being invested in its development might be more usefully spent on improving patient care than on compromising their privacy.

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Competing interests: None declared.

1 Norheim OE. Soft paternalism and the ethics of shared electronic patient records. *BMJ* 2006;333:2-3. (1 July.)

Poor training of locums in using hospital computer systems poses risk

Editor—Norheim highlights the expansion of computerised health care.[1] Having undertaken several locum doctor appointments while undertaking a higher degree, we have noticed some serious failings in training for locum doctors in using hospital computer systems. Frequently doctors share passwords for electronic patient records and hospital computer systems as it is difficult and often time consuming to attain their own passwords, especially when very short term locums are being undertaken. This should be avoided at all costs as it compromises data security.

Locum doctors should ensure that they are given basic training in using these systems as part of their induction at a new hospital, as well as individual passwords. This may be achieved through the information technology department or the clinical risk manager for out of hours duties. If necessary, locums should turn up before the start of their shift for such training. In the future, doctors could be assigned a universal password for use in all centres they work in; however, they would still require training for each different system used.

Ensuring adequate training at this stage in developing computerised health care is crucial to its eventual success.

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1 Norheim OE. Soft paternalism and the ethics of shared electronic patient records. *BMJ* 2006;333:2-3. (1 July.)

Analogy for soft paternalism in shared electronic records is flawed

Editor—There is a flaw in Norheim's argument using the analogy of managing a hospital cafeteria for soft paternalism in shared electronic patient records.[1] If the manager of the hospital cafeteria decides to put healthy food at the beginning of the counter the worst that can happen is that customers eat more healthily without consciously deciding to do so. If patients' health records are made universally available confidentiality is put at risk and the potential consequences are serious.

When serious harm can result from a course of action explicit consent is required. The Royal College of General Practitioners is right to insist on opting in.

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1 Norheim OE. Soft paternalism and the ethics of shared electronic patient records. *BMJ* 2006;333:2-3. (1 July.)

NHS has not learnt IT lessons from 1999

Editor—The first report of the UK government's public accounts in 1999 summed up the problems of large government information technology (IT) projects[1]:

Unrealistic
Unmanageable
Unconsidered
Unauditable
Uncostable
Unstoppable.

Lessons failed to be learnt from this report. The problems just repeat themselves time and time again. No wonder people walk away from these projects.[2]

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Competing interests: None declared.

1 House of Commons. Public Accounts—first report. Session 1999-2000. www.publications.parliament.uk/pa/cm199900/cmselect/cmpubacc/65/6502.htm (accessed 6 Jul 2006).
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Hip fracture: heparin is for thromboembolic prophylaxis

Editor—Thromboembolic prophylaxis for hip fracture is contentious, as Parker and Johansen state in their review of hip fracture.[1] Well might eyebrows be raised, however, by their failure to recommend any form of low molecular weight heparin thromboprophylaxis contrary to the latest American and British guidelines.[2] The current debate, driven by epidemiological data and recent clinical trials, is not the benefit of low molecular weight heparin preparations at proved doses but the likely inadequacy of typical courses of five to 10 days compared with longer and more inconvenient courses of 28 days or more.[3]

The authors further seem to imply that with heparin it is best to give nothing because of the risk of bleeding complications. Their referenced 2002 Cochrane review states there is a lack of power to identify outcomes of clinical importance apart from a reduction in deep vein thrombosis. There are currently concerns about wound infection rates in patients taking low molecular weight heparin,[4] but no reason to be concerned about bleeding complications in the context of the entire evidence base and correctly timed thromboprophylaxis doses of heparin, taking into account spinal anaesthesia. Given that clinicians tend to undertreat with anticoagulants patients such as the elderly at highest risk of thromboembolism and overtreat patients at low risk such as the fit young coming in for elective operations,[5] the article does a gross disservice to an important issue.

Failing to make recommendations consistent with international guidelines in a review article on managing hip fracture could unnecessarily help perpetuate the undertreatment of one of the groups of patients at highest risk of thrombotic complications.

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Competing interests: None declared.

1 Parker M. Johansen A. Hip fracture. *BMJ* 2006;333:27-30. (1 July.)
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Patient involvement in health care will improve quality

Editor—Coulter suggests that patients should be asked to provide detailed reports of their experiences of clinical care during a particular consultation and that they should be asked about what actually occurred rather than to evaluate what occurred.[1] We agree that it is a generalisation too far by Rao et al to state that patients are unable to assess the quality of care they receive.[2]

A more useful approach may be building working partnerships for care. Coulter mentions this when she stated that most patents prefer doctors who involve them in treatment decisions and those who respect patients' dignity.[3] There is much scope for incorporating into routine health care, patients' views on their health needs and their assessment of progress towards treatment goals, particularly in chronic

disease. Encouraging patients to become active participants who take responsibility for working towards their treatment goal—for example, by ensuring that their blood pressure is regularly checked—could contribute towards improving quality. In this way partnership between patients and doctors drives the quality agenda.

We recently followed up a cohort of 1000 patients with schizophrenia by assessing patients' views in a structured format. Although treatment alliances are often thought to be more problematic in mental health, we found that patients could contribute accurate information to their care plans on needs and accurately comment on clinical outcomes.[4] Furthermore, by using patient centred assessment tools, effective alliances developed between clinicians and patients that were associated with reduced admission and other improved pragmatic outcomes. Such approaches are much more likely to improve clinical quality than relying on patient assessed measures of quality in rating-style questionnaires.

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Competing interests: None declared.

1 Coulter A. Can patients assess the quality of health care? *BMJ* 2006;333:1-2. (1 July.)
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Cholesterol and risk of stroke

Cholesterol, stroke, and age

Editor—Ebrahim et al studied whether blood cholesterol concentrations are predictive for haemorrhagic and ischaemic stroke in a large cohort of young and middle aged Korean civil servants.[1] They found that low concentrations of cholesterol were associated with haemorrhagic stroke while high concentrations were associated with ischaemic stroke.

The incidence of stroke rises sharply with increasing age. The overwhelming majority of all strokes occur in subjects aged 70 and over. The mean age of the participants in this study was about 42 (SD 9). This means that 95% of study participants were under 60 at baseline and therefore under 70 at end of follow-up. This is important since the predictive value of total cholesterol concentration for cardiovascular mortality is heavily dependent on age. After 70 there seems to be no association with cardiovascular mortality,[2] while after 80 high total cholesterol concentration might even be beneficial.[3 4] A similar pattern with age probably also holds for cholesterol and risk of stroke.[5]

We agree with the authors that the burden of stroke is becoming greater as the population ages, making its prevention a priority. However, in this case it is not possible to simply transpose the findings from young and middle aged people to the elderly population at risk. Therefore, the study by Ebrahim et al does not contribute significant knowledge whether total cholesterol concentration is a risk factor for the vast majority of strokes.

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1 Ebrahim S, Sung J, Song YM, Ferrer RL, Lwalor DA, Davey Smith G. Serum cholesterol, haemorrhagic stroke, ischaemic stroke, and myocardial infarction: Korean national health system prospective cohort study. *BMJ* 2006;333:22-7. (1 July.)
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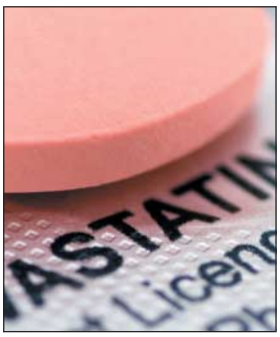
Study lumps apples and oranges

Editor—The statement by Ebrahim et al, that "preventive strategies that include lowering blood cholesterol should not be tempered because of concerns about a possible increased risk of haemorrhagic stroke" is too general and does not acknowledge that their study population did not include patients with symptomatic vascular disease, the population most often aggressively treated with statins, with resultant low cholesterol concentrations.[1]



GEOFF KIDD/SPL

These patients frequently have cerebral vessels diseased with atherosclerosis, and evidence of silent cerebral infarcts.[2] Indeed, the only randomised trial to evaluate an intensive statin treatment strategy in patients primarily with ischaemic stroke noted a higher incidence of haemorrhagic stroke among those who received the high dose statin.[3] In another study there was a trend towards increased haemorrhagic stroke with statin use among those who had had a cerebrovascular event.[4]

Another limitation of their study is the lack of information on low density lipoprotein cholesterol concentrations, the primary treatment target in guideline recommendations.[5]

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1 Ebrahim S, Sung J, Song YM, Ferrer RL, Lwalor DA, Davey Smith G. Serum cholesterol, haemorrhagic stroke, ischaemic stroke, and myocardial infarction: Korean national health system prospective cohort study. *BMJ* 2006;333:22-7. (1 July.)
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The Japanese comparison

Editor—Yet again, a potential relation between low cholesterol concentrations and haemorrhagic stroke is dismissed.[1] Yet again, a causal relation between high cholesterol concentrations, ischaemic stroke, and coronary heart disease is (apparently) confirmed.

Yet data from Japan directly contradicts Ebrahim et al's conclusions. From 1958 to 1995 fat consumption increased from 5% to 20% of the total daily energy consumption, and cholesterol concentrations rose from 3.9 mmol/l to 5.0 mmol/l.[2] During this period the rate of stroke (combined) fell from 1344/100 000/year to 205/100 000/year in those aged 60-69. This is a 6.5-fold reduction in the rate of stroke.[3] (There was also a decrease in death rate from coronary heart disease.)

The possibility that increased fat consumption was the causal factor in reducing the rate of stroke is strongly supported by a study in *Stroke*, which concluded that: "A high consumption of animal fat and cholesterol was associated with a reduced risk of cerebral infarction death."[4]

A low cholesterol concentration has been found to be associated with an increased risk of haemorrhagic stroke in many different studies. And when cholesterol concentrations rose dramatically in Japan the rate of stroke plummeted.

A low cholesterol concentration may well be a "causal" risk factor for haemorrhagic stroke, and the connection cannot be dismissed by this study.

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Competing interests: MEK is a member of the international network of cholesterol sceptics (THINCS).

1 Ebrahim S, Sung J, Song YM, Ferrer RL, Lwalor DA, Davey Smith G. Serum cholesterol, haemorrhagic stroke, ischaemic stroke, and myocardial infarction: Korean national health system prospective cohort study. *BMJ* 2006;333:22-7. (1 July.)
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Thinking the unthinkable: selling kidneys

Editor—Roff's personal view on selling kidneys generated discussion during our morning round in an intensive care unit among 10 doctors, including two nephrologists.[1] Only four were against the regulated selling of kidneys for renal transplantation, the nephrologists taking opposing views. We offer several points in favour of the regulated sale of kidneys.

Firstly, regulated sale will bridge the gap between demand and supply of kidneys for transplantation.

Secondly, it will reduce if not abolish the rampant illegal kidney trade. Most doctors are aware of this illegal trade but rarely become involved in it. We know that patients from rich countries visit poor countries for purchase of kidneys and renal transplantation. Some poor villages in south India have a sizeable population of people who have sold their kidney and are called "kidneypakkam."

Thirdly, monetary compensation of donors is well known and well accepted. We have seen brothers and sisters demanding and taking money for the so called voluntary donation.

Fourthly, a collateral benefit of the regulated kidney trade may be redistribution of some wealth in this seemingly unjust world. There may be movement of kidneys from poor countries with population explosions to rich nations. $40 000 seems fair compensation and tempting even to us.

Dealing in human spare parts superficially seems to be indecent and immoral. But how can denying the sale of a part of a human body be denied in a world where body and soul are sold and resold daily? With proper and honest checks, this business has the potential of producing more benefit than harm.

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1 Roff SA. Thinking the unthinkable: selling kidneys. *BMJ* 2006;333:51. (1 July.)

Say no to the market

Time to mobilise in the political arena

Editor—It has been an enduring puzzle to me that the medical profession can be in large measures of agreement over the folly of successive governments' policies but the option of direct political action is almost never discussed.[1]

Much of that which is happening to the NHS is almost wholly condemned by those who work in it, but the BMA response is routinely nicely measured, delivered with restrained eloquence, and characterised by a remorseless reasonableness.

I believe that the next election will be the last at which any substantial impact can be made and that we as doctors should mobilise now, with other concerned groups such as the Royal College of Nursing, and have pro-NHS candidates in every constituency. Dr Richard Taylor MP, for example, has been elected twice on a health ticket.

A colleague recently remarked: "The world is run by those who turn up." We are all concerned, we command the confidence of a far larger section of the electorate than many, we can be articulate, we could be a very effective parliamentary influence, and we might even win. Why don't we mobilise politically? I'm game. Anyone else?

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1 Godlee F. Editor's choice. Say no to the market. *BMJ* 2006;333. (1 July.)

Say yes to the market

Editor—In her Editor's choice "Say no to the market" Godlee argues that performance and quality are key to developing our vision for a future healthcare system.[1] I agree that quality and performance measures are crucial but disagree with her and the BMA because if we are serious about performance and quality then the market is a necessity.

In an NHS monopoly providers can deliver good or bad services, safe in the knowledge that commissioners cannot go elsewhere for their services. In a market, organisations have to stand up and account for what they have done with funding and what they propose to do in the future, not in isolation but in competition with other providers. Thus commissioners can base choices on quality and performance, making these factors prime drivers for change.

We all know excellent NHS services. We also know of poorly performing services. The monopoly NHS inadvertently provides safety and security for both types of service. The market provides a way of comparing services and choice for commissioners that is most worrying for people working in poorly performing services. A commissioner seeking quality who also has a choice of providers can ensure that the people who stand to profit the most from the market are the patients.

Say yes to quality, say yes to the market.

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1 Godlee F. Editor's choice. Say no to the market. *BMJ* 2006;333. (1 July.)

Might as well say no to the weather

Editor—Godlee does not define market but exhorts us all to say no to it.[1]

The market—a recognition that services, providers, consumers will all interact, and usually at a price—is as unavoidable as the weather. The NHS buys drugs largely from private companies, at considerable cost. NHS hospitals are built with public money by private building firms. Nurses, doctors, cleaners, and patient managers all look at alternative employment options outside the NHS. The BMA attempts to exert a trade union pressure to exact a price for doctors' labour. Medical schools train generations of doctors, who may or may not find work in the United Kingdom. Even the *BMJ* comes at a price.

Having recognised the pointlessness of saying no to the market, let us agree these principles of the NHS:

- Free at the point of use (in Wales, no prescription charge)
- Funded entirely from general taxation (with extra taxes on smokers and drinkers)
- Universal in its cover (everybody can have anything but may have a long wait).

Nowhere is there a law that says NHS contracts for cataracts cannot be given to private ophthalmologists. Bring on the tariff, I say—and let's get competitive in our service quality and delivery. Indeed, we general practitioners have had mixed fortunes over 50 or more years, varying this form of private provider and public payment contract, while dentists have largely given up on it. But did patients have their needs met as best the country could afford?

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1 Godlee F. Editor's choice. Say no to the market. *BMJ* 2006;333. (1 July.)

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