But will doctors elsewhere have the courage to publish their patient survey results?

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- 1 Cleary PD. The increasing importance of patient surveys. *BMJ* 1999; 319:720-1.
- 2 Rao M, Clarke A, Sanderson C, Hammersley R. Patients' own assessments of quality of primary care compared with objective records based measures of technical quality of care: cross sectional study. *BMJ* 2006;333: 19-22.
- 3 Ramsay J, Campbell JL, Schroter S, Green J, Roland M. The general practice assessment survey (GPAS): tests of data quality and measurement properties. *Fam Pract* 2000;17:372-9.
- 4 Coulter A. What do patients and the public want from primary care? *BMJ* 2005;331:1199-201.

- 5 GfK NOP Social Research. *Annual tracking survey*. London: General Medical Council, 2006.
- 6 Vingerhoets E, Wensing M, Grol R. Feedback of patients' evaluations of general practice care: a randomised trial. *Qual Health Care* 2001;10:224-8.
- 7 Wensing M, Vingerhoets E, Grol R. Feedback based on patient evaluations: a tool for quality improvement? *Patient Educ Couns* 2003;51:149-53.
- 8 Greco M, Sweeney K, Broomhall J, Beasley P. Patient assessment of interpersonal skills: a clinical governance activity for hospital doctors and nurses. *Journal of Clinical Excellence* 2001;3:117-24.
- 9 Greco M, Brownlea A, McGovern J. Impact of patient feedback on the interpersonal skills of general practice registrars: results of a longitudinal study. *Med Educ* 2001;35:748-56.
- 10 Leeper MK, Veale JR, Westbrook TS, Reed K. The effect of standardized patient feedback in teaching surgical residents informed consent: results of a pilot study. *Curr Surg* 2003;60:615-22.
- 11 Leddy KM, Wolosin RJ. *Patient satisfaction with pain control during hospitalization. Improving health care quality and safety*. Oak Brook, IL: Joint Commission Resources, 2005.
- 12 Gillies RR, Shortell SM, Casalino L, Robinson JC, Rundall TG. How different is California? A comparison of US physician organisations. *Health Aff* 2003; Suppl Web Exclusives:W3-492-502. (doi 10.1377/hlthaff.W3.492.)

Soft paternalism and the ethics of shared electronic patient records

It's ethically sound for patients to opt out

The NHS is planning to make patients' health records more easily accessible using a network of integrated databases.¹ This will, we may reasonably expect, improve quality of care and efficiency, reduce paperwork, and sometimes even save lives. The ultimate aim is to benefit patient health and welfare.²

Easier access to medical data from a "single resource shared by everyone" also makes patients vulnerable. Patient records contain sensitive private information that can, if not handled correctly, harm the patient. Should all citizens by default be included in the new electronic records service with the possibility to "opt out" if they prefer, or should people be asked to "opt in" only if they want to? The Royal College of General Practitioners strongly recommends "opt in" with reference to the ethical principle of informed, explicit consent, whereas Connecting for Health, the agency building the new electronic records service, recommends "opt out."³

To impose electronic records on members of the population against their will may be unduly paternalistic even if we assume that all the technical, legal, and organisational safeguards are in place and that the system, on balance, promotes health and welfare. A policy counts as paternalistic if it "attempts to influence the choices of affected parties in a way that will make choosers better off."⁴ Should we not all accept a policy that makes everyone better off? Defenders of liberty and autonomy disagree. One of the lessons learnt from the history of medical ethics is that efforts to promote the common good must be constrained by liberty and informed consent: those affected have the right to accept or reject a programme which will have a direct impact on their legitimate interests. Patients have a legitimate interest in privacy and preventing third parties gaining access to sensitive material—this is a concern in legislation everywhere.⁵⁻⁸

Standard medical ethics suggests that when people disagree about whether a programme is acceptable, the public should be fully informed about its implications and included only if they give explicit consent.⁹ Those affected

know best whether it is good for them. For shared, electronic patient records "opt in" with explicit informed consent is therefore the only acceptable solution.

Or so the argument goes. Recent advances in ethics, law, and behavioural economics on the understanding of "bounded rationality" suggest an alternative way of protecting freedom: soft paternalism.¹⁰ Consider an example. Suppose the director of the cafeteria in your hospital knows that customers, including doctors and nurses, have a tendency to choose more of the foods placed at the beginning of the counter. If the director offers the healthy food first, she maximises the chance of customers making healthy choices. If she places the less healthy food first, the opposite will happen.⁴ What is the right thing to do?

People do not always make the choices that are best for them. Employees offered a wide range of pension saving plans (including plans that are good for them in the long run) on average make poorer choices than employees who are offered a good plan as a default but who are free to opt out.¹¹

The choice of the default rule in organisational systems powerfully affects people's choice for two reasons. Firstly, people are not always rational.¹² Inertia prevents people from making the best choices, collecting all the information is costly and takes time, weakness of will affects all of us, and people do not always have stable and well formed preferences within the range of choices open to them. Secondly, as the cafeteria example shows there is, in many cases, no neutral freedom of choice. Soft paternalism recommends mildly steering choices in a direction that makes people better off, while preserving freedom of choice.

The same kind of reasoning can form the basis of the suggested NHS information technology programme, using "opt out." People are free to protect their interests if

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they strongly disagree with the policy. Logistically this also makes sense. The transactional costs of an “opt in” policy will be formidable. If too few patients are included, the potential benefits of the programme will be lost.

The essence of the ethical dilemma is that explicit informed consent preserves freedom of choice at the cost of less health and welfare while strong paternalism, without the possibility to opt out, promotes health and welfare at the cost of freedom. Soft paternalism—in this case accepting the default policy—preserves freedom of choice and promotes health and welfare for all.

I have three caveats to this conclusion, however. The NHS must convincingly show that technical, organisational, and legal safeguards will be implemented in its information technology programme. These safeguards must include strict and transparent rules of access to health records, mechanisms of complaint, and open understandable information about the programme and its implications.

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- 1 Cross M. Keeping the NHS electronic spine on track. *BMJ* 2006;332:656-8.
- 2 Department of Health. *Making a difference: safe and secure data sharing between health and adult social care staff*. London: Department of Health, 2006.
- 3 Cross M. GPs' leader sets conditions for electronic care records. *BMJ* 2006;332:627, doi:10.1136/bmj.332.7542.627-b.
- 4 Sunstein CR, Thaler RH. Libertarian paternalism is not an oxymoron. *University of Chicago Law Review* 2003;70:1159-202.
- 5 Beardwood JP, Kerr JA. Coming soon to a health sector near you: an advance look at the new Ontario Personal Health Information Protection Act (PHIPA). *Healthcare Q* 2004;7(4):62-7.
- 6 Adalsteinsson R. Human genetic databases and liberty. *Jurid Rev* 2004;2004: 65-74.
- 7 Conti A. The recent Italian Consolidation Act on privacy: new measures for data protection. *Med Law* 2006;25:127-38.
- 8 Choi YB, Capitan KE, Krause JS, Streeter MM. Challenges associated with privacy in health care industry: implementation of HIPAA and the security rules. *J Med Syst* 2006;30:57-64.
- 9 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 2nd ed. Oxford: Oxford University Press, 1983.
- 10 Davis JK. The concept of precedent autonomy. *Bioethics* 2002;16:114-33.
- 11 Thaler RH, Benartzi S. Save more tomorrow: using behavioral economics to increase employee saving. *Journal of Political Economy* 2004;112: 164-87.
- 12 Elster J. *Sour grapes: studies in the subversion of rationality*. Cambridge: Cambridge University Press, 1983.

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The NHS programme for information technology

This massive natural experiment needs evaluating and regulating

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The NHS National Programme for IT in England is one of the largest information technology programmes in the world.¹ The programme has been subjected to hostile media coverage in its four year history, and it has been difficult to know how much of this is justified. The publication of the National Audit Office report on the programme gives both supporters and critics food for thought.² The audit office finds that elements of the programme are progressing well, but also points to key challenges over the next few years—in ensuring that the promised systems are delivered and that NHS staff are engaged with the programme.³

The report contains a wealth of detail, but doctors should pay particular attention to two issues. Firstly, the report notes that the Department of Health has failed to show benefits of the programme that will justify its costs and that the Treasury accepts this and is content for the programme to proceed. The difficulty in identifying benefits is not surprising, given that systematic reviews show relatively modest benefits associated with information technology projects,^{4 5} and the audit office stresses the need for high quality empirical evidence about the programme. To place the issue in context, the audit office estimates that the total costs of the programme to 2014 will be around £12.4bn (€18bn; \$23bn). This is a big number but equates to only about 1-1.5% of NHS expenditure a year. Doctors need to judge, therefore, whether the programme will improve services and patient outcomes by an equivalent amount.

From a researcher's perspective, the programme is a massive natural experiment which offers a unique opportunity to capture good observational evidence about the costs, risks, and benefits of large scale investments in information technology. It is not necessary to

stop the programme—this is not practicable now anyway—but the Department of Health should move quickly to commission studies that will generate robust, useful results in the next 12 months and beyond.

The second issue concerns the ways in which doctors and other clinicians engage with suppliers in the new electronic environment. In the early phase of the programme centralisation was justified. The audit office concluded that the processes for central procurement of infrastructure were well managed and that contracts have been managed in a way that protects NHS interests. Individual NHS organisations—and private firms providing NHS services—do not typically have the skills or the political clout to manage large contracts for building infrastructure. There are outstanding questions about the technological solutions favoured by the programme, but a review—prompted by an open letter from 23 academic computer scientists to the House of Commons Health Committee⁶—should provide a better understanding of those issues.

The process had relatively little clinical involvement early on, and this has led to criticisms that the programme is not doctor friendly. Staff working on the programme nationally now seem to appreciate that clinicians and suppliers need to work closely together if the more ambitious elements of the programme—notably the shared electronic health and social care record—are to be successful. The NHS does not want or need products imposed on it, whether on time or years late, and then be locked into them until a company chooses to develop replacements. Rather, a

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