

## 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.<sup>1</sup> 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.<sup>2</sup>

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."<sup>3</sup>

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."<sup>4</sup> 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.<sup>5-8</sup>

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.<sup>9</sup> 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.<sup>10</sup> 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.<sup>4</sup> 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.<sup>11</sup>

The choice of the default rule in organisational systems powerfully affects people's choice for two reasons. Firstly, people are not always rational.<sup>12</sup> 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 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.

Competing interests: None declared.

- 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). *Healthc 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, Streeper 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.

doi 10.1136/bmj.38890.391632.68

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