Opting out of NHS Central Databases

The Government proposes to collect all the nation’s medical records into central NHS databases. The British Medical Association (BMA) has serious reservations; the medical profession has long believed that, in general, data should only be shared with patient consent.

GPs are asked to create a 'summary care record' from your medical notes and upload this to the NHS ‘Spine’ during 2007. The summary will contain your current prescriptions and any allergies. The intention is to upload the rest of your record (the ‘detailed care record’) either at the same time or later.

If you wish to opt out of uploading, please fill in your name, address and date of birth overleaf, and hand the form to your GP.

The Department of Health (DoH) has argued that by having your details uploaded to the NHS ‘spine’, they will be available in an emergency. You may indeed wish to consider this if you have a medical condition such as penicillin allergy. However A&E Departments do work to established clinical protocols for patients for whom they have no medical history, and a dependable centralised database seems unlikely to exist for some time. If you do have such a condition, you should continue to carry a card or a bracelet with you anyway, even if you do consent to the creation of a summary record. Please speak to your doctor if you have any questions.

In November 2006, a Medix poll showed that 52% of GPs did not plan to upload their patients’ data without prior consent – just 13% said they would upload without any consent at all. A Joseph Rowntree Reform Trust survey released in the same month showed that 53% of patients oppose ‘Requiring everyone’s medical records to be stored in a centralised database for access by civil servants and government officials, with no right to opt out’. Just 27% of the public were in favour.

In 1998, the Icelandic Medical Association opposed an attempt by the government there to build a central medical database, by providing opt-out leaflets in surgeries. After 11% of the population opted out, the database scheme was made opt-in instead. That resolved the political and ethical problems. We hope that a similar solution can be found in the NHS in England.

For more information, please check out www.TheBigOptOut.org online or call our help and advice line on 01494 882 458, Monday to Friday, 9am to 5pm.
Exercising my Right to Opt Out

Dear Doctor,

I would be grateful if you would ensure that none of my records held by you are uploaded to the national system. Would you please also file or scan a copy of this letter in my records and also record my dissent by entering the Read code ‘93C3 - Refused consent for upload to national shared electronic record’ into my computer record. I am aware of the implications of this request and will notify you should I change my mind.

This request is itself confidential. Please do not divulge my decision, in an identifiable manner, to anyone other than to clinicians who are providing care to me and who might otherwise place information about me on the national care records service.

Further information for GPs is available online at www.TheBigOptOut.org/for_GPs

Yours sincerely,

(signed)

(name)

(date of birth)

(address)