

YOUR MEDICAL RECORDS – YOUR DECISION

The government proposes to collect everyone's medical records into centralised databases. The British Medical Association (BMA) and many doctors have serious reservations; the medical profession has made it clear for several years now that patient medical records should only be uploaded with the explicit consent of patients.

A new NHS computer system is being rolled out across England, called the Summary Care Record (SCR). GPs are being asked to create a summary of

your medical notes and upload this to the centralised system known as NHS 'Spine'. 12-16 weeks before your details are due to be uploaded you should receive a letter about this. **If you do not respond in time, you will be assumed to have given your consent**.

The Summary Care Record initially contains your personal details, your medications and any allergies or adverse reactions. However, later on as the NHS Spine develops, many people who work in the NHS will be able to access it and much more: e.g. information from hospitals, blood tests, x-rays and specialists' letters. Access <u>without your permission</u> will be allowed in a clinical emergency, if required by law (as with much government data-sharing) or a court order, or if it is considered to be "in the public interest" – which might include medical research.

If you wish to opt out of having your medical records uploaded, please fill in your name and other details overleaf, and send or hand in the form to your GP practice. You can always change your mind and opt in later.

Connecting for Health (CfH), the government agency responsible for the Summary Care Record, argues that by having your details uploaded they will be available in an emergency. You may indeed wish to consider this if you have a medical condition such as diabetes or penicillin allergy. However A&E Departments do work to established clinical protocols for patients for whom they have no medical history, and are unlikely to rely only on a centralised database in critical situations. If you do have such a condition, you should continue to carry a card or MedicAid bracelet with you anyway, even if you do consent to the creation of a Summary Care Record. **Please speak to your doctor if you have any questions.**

The purpose of this fact sheet is to inform you about your right to control what happens to your medical records. Connecting for Health has agreed with doctors' leaders that patients newly registering with a GP practice should have absolute control over whether or not their records go onto SCR. But patients already registered with a practice will be assumed to want a Summary Care Record unless they actively opt out. We believe everyone should have the same control.

What are my options?

- If you want to have a Summary Care Record, and are happy for your records to be sent to it TAKE NO ACTION; your records will be uploaded in due course.
- If you do not want a Summary Care Record, and aren't happy for your records to be sent to it OPT OUT NOW. You can change your decision later, but once your SCR has been viewed you will not be able to have any data already uploaded to it deleted.
- If you don't know whether you want a Summary Care Record, and want to decide later OPT OUT NOW. You will be able to have a SCR created at a later date, when you've found out more.

To opt out, simply fill in the form on the reverse of this sheet and return it to your GP practice. If you have any concerns about medical confidentiality, you can visit **www.TheBigOptOut.org** online or call their help and advice line on **01494 882 458**, Monday to Friday, 9am to 5pm.

Connecting for Health should send you a letter via your Primary Care Trust; the patient information they send doesn't include a direct link to their own opt out form but if you prefer to use that one, you can download a copy from here (the form is on page 3):

http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/optout.pdf

Request for all clinical data to be withheld from the Summary Care Record

Dear Doctor,

I am exercising my right to opt out, and would be grateful if you would ensure that none of my records held by you are entered onto a Summary Care Record.

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' (or equivalent) 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,

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Information to help identify my records (please complete in BLOCK CAPITALS)

Title		Surname / Family name	
Forename(s)			
Address			
Postcode			
Date of birth			
NHS number (if	known)		