

Why is the NHS Summary Care Records programme such a bad idea?

1) Once on the system, your medical information is no longer secure: it will be accessible to hundreds of thousands of people across the NHS, not just those directly involved in your care – and many others besides. Connecting for Health (CfH) rules state that your permission will NOT be asked for any access made “in the public interest”, “by statute” or “by Court Order”. Any such access to your details will NOT result in an alert being sent to the Privacy Officer (staff involved in safeguarding the privacy of patients), as would be the case for a genuine clinical emergency, i.e. they won’t be checking up on bureaucrats, researchers, police and immigration officers.

2) Once on the system, it may be almost impossible to get off. Though you can in theory ‘opt out’ after a record has been created for you, Connecting for Health has said that a Summary Care Record (SCR) will not be deleted if it has been viewed even once. As CfH is using an ‘implied consent’ model to initiate upload and has not directly informed anyone under 16 that an SCR will be created for them, this means that any person under the age of 16 – and many others besides – will effectively have no choice. Their record will be viewed before they even know they’ve got one, and they’ll never get it off.

3) The ‘summary’ is just the beginning: once a record on you has been created, it will be added to indefinitely. Patients are being told that the medical information on the SCR will be limited to allergies and medications only. This is untrue. The ‘summary’ information is simply what will be uploaded initially. After that, your record can be ‘enriched’ with more medical details – e.g. GP diagnoses or hospital visits – at any point. And even worse, the way that the system has been designed means that sensitive information can be added to your record automatically, without your explicit consent. Though CfH claims your permission will be sought before further details are added, it has built a single ‘flag’ on the system that once set will permit “passive enrichment”, i.e. automatic additions to your record, for the rest of your life.

(For a flowchart to help you understand your options regarding SCR opt in and ‘enrichment’, see <http://www.neilb.demon.co.uk/download/algo.pdf>)

4) Summary Care Records undermine the very basis of medical confidentiality. In addition to the reasons above, at the point your details are uploaded your GP ceases being the ‘data controller’ – the person responsible in law for protecting your data. The data controller for the SCR is the Secretary of State which, in practice, means the Department of Health. Civil servants, not doctors or you the patient, will be in control. This represents a fundamental shift in the basis of patient-doctor confidentiality, something that is absolutely essential if people are to disclose things about themselves for their own treatment and well-being, and for the wider public health.

5) If you have a life-threatening condition, you shouldn’t just rely on SCR. Over two years’ independent research has shown little evidence of the claimed benefits, and the system will never be perfect. We all know that computers and networks go down from time to time, it may be difficult to identify your record – especially if you are unconscious, confused or in distress – and sometimes information will be incorrect or out-of-date. In reality, there are already long-standing protocols in place for dealing with people in medical emergencies and people with serious allergies or chronic conditions know to wear a MedicAlert bracelet or equivalent.