

# IMPORTANT CHANGES TO YOUR MEDICAL RECORDS

## *care.data*

GP practices nationwide will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC). Uploads are planned to begin soon, and all households should have received the HSCIC patient information booklet ("*Better information means better care*") through their letterbox in January. This information will be extracted from the practice in a form that **could** identify you, and will include your NHS number, date of birth, postcode, gender and ethnicity, together with your medical diagnoses (including cancer and mental health), their complications, referrals to specialists, your prescriptions, your family history, details of your vaccinations and screening tests, your blood test results, your body mass index, and your smoking/alcohol habits.

Under the Health and Social Care Act 2012, GP practices have **no** choice but to allow the HSCIC to extract this information. The programme, called *care.data*, is administered by the HSCIC using software and services provided by a private sector company (ATOS). The data will be stored on HSCIC national servers and not on GP systems. The HSCIC will administer the data, and states it intends to use it "for planning health services and for research". This is known as "secondary uses" of your medical records. Medical staff treating you in GP surgeries, hospitals, A&E and out-of hours centres **will not use, or be able to use**, this database. However, the uploaded data is likely to be made available to organisations outside of the NHS, such as universities and commercial organisations. Initially, in "Release 1" of *care.data*, this information will be released to those requesting it in an anonymised form, but a bit later on, in "Release 2" of *care.data*, it will be identifiable as *your* information, and you will *not* be asked for your permission before your data is distributed.

Once the data has been extracted, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared or who has access to it. The HSCIC will be the data controller for your uploaded information and will have total control over it. Although GP practices cannot object to this information leaving the practice, individual patients and their families can instruct their practice to prohibit the transfer of their data, i.e. **you have the right to opt-out**. Opting-out will have no effect on the medical care that you receive either from the Practice or from anywhere else within the NHS or private sector.

**If you do nothing, i.e. you do not opt out, then your medical information will be extracted and uploaded to the HSCIC. Once uploaded, you will not be able to get this data deleted by the HSCIC. So if you want to opt-out, you need to opt-out soon.** You will still need to opt out to prevent *care.data* uploads even if you have already opted out of the NHS Database (The Summary Care Record). *The two databases are very different.* We have produced a leaflet outlining those differences, please see 'The Summary Care Record and *care.data*: two very different databases'.

### ***How do I opt out?***

Fill in the opt-out form and return the form to reception (or hand it to the doctor or nurse that you are consulting with).

### ***Information about care.data***

#### ***NHS England/HSCIC***

Patient information booklet ("*Better information means better care*")

<http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx>

If you have further concerns or questions regarding *care.data* or opting out then please contact Katie Francis, Practice Manager and Caldicott Guardian for the Beauchamp House Surgery.

## The Summary Care Record and *care.data*: two very different databases

### The Summary Care Record (SCR)

This is a national centralised database of medical information (allergies and medication only) extracted and uploaded from patients' GP records. This aims to make this information potentially available to emergency doctors (in A&E and GP out-of-hours centres countrywide) should the need arise and the patient allows the information to be viewed. As a result, it concerns *direct clinical care*.

### *care.data*

This is a different national database that has been launched. This database aims to upload very large amounts of medical information from patients' GP records, again to a centralised database.

#### **care.data is very different to the Summary Care Record:**

- The information extracted for *care.data* **far exceeds** just allergies and medication
- The information uploaded to *care.data* will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- *care.data* does **not** concern clinical care, it is an administrative and research database

#### **Opting-out of one database does not mean that you have automatically opted-out of the other**

You can both have a Summary Care Record and allow *care.data* extractions

You can opt-out of both databases and allow neither

Or you can opt-out of one but allow the other

**Opting-out of either database, or both, will not affect the medical care that you receive from the surgery**