

IMPORTANT CHANGES TO THE WAY YOUR PERSONAL DATA IS HANDLED

Under a new scheme called care.data, your GP will soon be required to supply confidential information from your medical records to a central database at the Health and Social Care Information Centre (HSCIC).

Details from your medical record will be extracted in a form that can identify you – including your NHS number, date of birth, postcode, gender and ethnicity – as well as your medical diagnoses (including cancer and mental health), their complications, referrals to specialists, your prescriptions, vaccinations and screening tests, your family history, your blood test results, your body mass index and your smoking/alcohol habits.

The information uploaded will be used for purposes other than your direct medical care and the intention is to make it available – with some of the identifying information removed, but not always – to organisations outside of the NHS including universities, commercial companies, medical researchers and ‘information intermediaries’.

Your practice has no choice but to allow HSCIC to extract this information and once your data has been extracted, your GP cannot control or protect how that information is used, shared or who has access to it. But you do have a choice: YOU HAVE THE RIGHT TO OPT OUT.

The NHS Constitution says that patients can simply instruct their doctor or GP practice to stop the transfer of information from their own medical record, and information from the records of those for whom they are legally responsible, e.g. children. You don’t have to make an appointment to do this – please speak to one of the receptionists – there is an ‘opt out’ form for you to sign: Care Data Opt Out Form.

Official information is somewhat limited; the ‘Better information means better care’ leaflet that may have dropped through your letterbox does not even mention care.data. **If you do nothing – i.e. you do not opt out – then your medical information will be extracted and uploaded to HSCIC monthly from March 2014. Once uploaded, you will not be able to get this data deleted. So if you want to opt out, you need to act NOW.**

For official NHS information, visit www.nhs.uk/caredata.