

IMPORTANT CHANGES TO YOUR MEDICAL RECORDS (Care.Data)

Please read you may need to act NOW

GP practices across England 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). The data upload is due to commence in March 2014 and all households should receive a leaflet ('Better information means better care') through their letterbox about this in January.

Purpose of this leaflet:

We feel it is vital that you, as our patient, are made aware of these changes. This leaflet has been produced to help you understand what currently happens to information you share with your health professional and how that information may be used outside of your direct care.

The majority of patients come to their GP Practice when they have something wrong with them. Problems discussed are usually of a personal nature and patients expect that the information they are sharing will remain confidential. This confidentiality is central to the trust between healthcare professionals and you as our patient. Without doctor-patient confidentiality, you may be reluctant to disclose information of a personal nature that we may need to help provide you with the best possible healthcare.

What we record at the Practice:

Healthcare professionals in our practice record information about the care we provide. The type of information that is recorded includes the following:

- Demographics, e.g. address, telephone number, e-mail, date of birth, gender etc
- What you tell us when you see us in consultations, e.g. about your physical and psychological health and social circumstances
- Diagnosis, investigations, treatments, referrals, family background
- Social information, e.g. housing status, alcohol, smoking status
- Third party sources, e.g. hospital letters, A&E attendances, relatives, carers, insurance companies, solicitors

What we already share about you:

We share different types of information about our patients. These include:

- Personal information about you and your illness, when needed for your direct care, e.g. referral to Hospital Consultants, District Nurses, Health Visitors, Midwives, Counsellors, the summary care record
- Patient identifiable information to public health, in order to arrange programs for childhood immunisations, communicable diseases, cervical smears and retinal screening
- **With explicit consent**, personal information to other organisations outside the NHS, e.g. insurance companies, benefits agencies
- Limited information about you, if relevant, to protect you and others, e.g. to social services child protection investigations
- Anonymised (non identifiable data) summary information for quality and outcome frameworks (QoF), medical research and clinical audit

It is also important to understand that currently a limited amount of patient information or data is used mostly at local level to help design health services or undertake clinical audit the majority of this information is anonymised.

How we protect your personal information:

Currently, your GP is responsible for protecting your information and to do this they comply with the Data Protection Act 1998 (DPA). As part of the DPA, all healthcare professionals have an

obligation to only share information on a need to know basis. For further information on the DPA please see the following link: <http://www.legislation.gov.uk/ukpga/1998/29/contents>.

The physical storage of information is on secure servers which are protected by firewalls. Access to the information is by strong authenticated password. The number of people who have access to your information is limited to members of the practice team and in a few instances some pre agreed data is shared with health care profession e.g. District Nurses but on a need to know basis.

So what is changing?

Under the Health and Social Care Act 2012 the Health & Social Care Information Centre (HSCIC) on behalf of NHS England (the body responsible for commissioning health services across England) details from your medical record will be extracted from the practice in a form that can 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.

This programme is called care.data, and the information uploaded will be used for purposes *other than your direct medical care* (so-called "secondary uses"). 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.

Under the Health and Social Care Act 2012, GP practices have no choice but to allow the HSCIC to extract this information. 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.

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.**

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 act now.

What you need to do:

To opt out, simply fill in your details on the form to the right of this page, cut it out and post it or drop it in to your GP practice, marked for the attention of your GP. If you wish to opt out your children or other members of your family for whom you are responsible, you can add their details on the back of the form.

This is not the Summary Care Record (more information on the summary care record is available online at www.nhscarerecords.nhs.uk). The two databases are very different. Opting out of one database does not mean that you have automatically opted out of the other. Further information about the care.data programme is available online:

www.care-data.info

www.nhs.uk/caredata

www.hscic.gov.uk/patientconf

Opting out will have no effect on your medical care. If you are unsure what to do, **opt out now.** You can opt back in at any point.

Dissent from secondary use of patient identifiable data

If you wish to opt out, please complete and return to the Practice

Dear Doctor,

I am writing to give notice that I refuse consent for my identifiable information and the identifiable information of those for whom I am responsible [*delete as appropriate*] to be transferred from your practice systems for any purpose other than my medical care.

Please take whatever steps necessary to ensure my / our confidential personal information is not uploaded and record my dissent by whatever means possible.

I am aware of the implications of this request, understand that it will not affect the care I / we receive and will notify you should I change my mind.

Yours sincerely,

Signature _____ Date _____

Name:	
Date of Birth:	
NHS Number: (if known)	
Address:	
<i>Please tick the box of your choice</i>	
I do not want my personal data to go from the GP Practice to the HSCIC (Dissent from secondary use of GP patient identifiable data) Code: 9Nu0	
I am happy for my data to go to the HSCIC but I do not want it disclosed to other organisations (Dissent from disclosure of personal confidential data by Health and Social Care Information Centre) Code: 9Nu4	

Space for additional patient details overleaf

Additional patient details [please complete in BLOCK CAPITALS]

Dear Doctor, please take whatever steps necessary to ensure the following people's confidential personal information is not uploaded from your practice and record my dissent on their behalf by whatever means possible.

Patient's full name: _____

Address: _____

Postcode: _____
Date of birth: _____
NHS number (if known): _____

Patient's full name: _____

Address: _____

Postcode: _____
Date of birth: _____
NHS number (if known): _____

Patient's full name: _____

Address: _____

Postcode: _____
Date of birth: _____
NHS number (if known): _____

Patient's full name: _____

Address: _____

Postcode: _____
Date of birth: _____
NHS number (if known): _____

You can provide details of other family members you wish to opt out on a separate sheet, but make sure the signature sheet is attached.