|  |  |
| --- | --- |
|  |  |

You will have been given this leaflet because you are thinking of opting out of care.data. Deciding whether to opt out is an important decision and we want you to make the right choice and will support you in the choice you make.

What is care.data?

Hopefully you have already read the leaflet that came through your door but we wanted to be sure you understood everything before making a choice.

Care.data is a record of when you visit your GP, the main illnesses you have, the medications you take and the tests you have had. Only the problem titles are shared NOT the notes your GP writes. Sexual health & preference, abortions, fertility treatments, and anything related to criminal record or abuse are automatically excluded. Only your NHS number, gender, date of birth and postcode will be extracted, not your name or full address. All the information is stored securely in a UK data warehouse.

What will happen to my data?

1. Some will be used to produce statistics—eg 100,000 people in Birmingham have diabetes
2. Some will have the NHS number, date of birth etc removed and be used by approved organisations, under a legal contract. This will only be allowed if direct benefit to the NHS can be demonstrated. It will not be given for the purposes of insurance or marketing.
3. In rare circumstances, and only if required by law or with the approval of an independent advisory group, the data will be shared with the NHS Number and date of birth still attached. This will only be done if the data has to be identifiable and there is no way that patient consent could be gained.

Hasn’t Care.data already happened?

Some time ago you will have had the option to opt out of the Summary Care Record (SCR). This is completely separate and is only used for directly providing you with care and, except in emergencies, can only be seen with your consent at the time. Irrespective of the choice you made with that you still need to respond to care.data.

There is another project in Birmingham, Sandwell and Solihull called Central Care Record (CCR) which is currently being rolled out. It is a local project between GPs, hospitals and other care organisations to have a detailed health record for all patients that can be seen by any healthcare professional looking after you. An enhanced version of the Summary Care Record (SCR). You will have the option to opt out, and your information will only be viewed by those directly involved in your care and with your permission. It has nothing to do with care.data and any decision you make about care.data will not affect this.

Whilst sharing this data won’t benefit you directly it will help at a local and national level to ensure quality and safety are maintained in the NHS, to enable planning to meet the needs of all patients and to enable research for better treatments in the future. This is all about improving patient care.

No system is perfect but HSCIC have put in several layers of security to try to ensure that the data can’t fall into the wrong hands. The majority of people using this data won't have any information that could be used to work out who you are (and to try to do so would be illegal). HSCIC (and it’s predecessors) have had this kind of data from hospitals for 25 years and there have been no recorded breeches of this data.

Can I get more information?

Below are listed a number of ways in which you can find out more about care.data.

* Call the national helpline on 0300 456 3531
* Email enquiries@hscic.gov.uk with ‘care.data-GP’ in the subject line
* Visit [www.england.nhs.uk/care.data](http://www.england.nhs.uk/care.data)

I still want to opt out

Thank you for taking the time to read this leaflet and considering whether to opt out. Please complete the form below and we will ensure the right codes are added to your record so you are opted out. Please note that you can change your mind at any point.

Care.Data “Opt Out” form

I confirm that I know enough about the various data extractions in place or proposed. Please block data extraction from the *patient* whose details appear below. I specify the precise areas I wish to block below:

|  |  |  |
| --- | --- | --- |
| A. | Please tick this box if you do not want your GP to release any of your GP record to theHealth and Social Care Information Centre for purposes of the care.data system.  |  |
| B. | Please tick this box if you do not want the Health and Social Care Information Centreto disclose to any accredited third parties any information they hold on you (from any NHS source). Please note that, in general, such data would only be made available to accredited third parties in anonymised, pseudonymised or aggregated form.  |   |
| C. | Please complete in BLOCK CAPITALSTitle: Surname / Family Name: Forename: Date of Birth Address: Postcode: Phone No: Signature: Date:  |
| D. | If you are filling out this form on behalf of another person or a child, their registered GP willconsider this request. Please ensure that you fill out their details in section C and your details in section D.Your Name: Your Signature: Relationship to Patient: Date:  |

|  |  |  |
| --- | --- | --- |
| Area involved | *Practice use**Only (Read V2) (EMIS/Vision etc)* | *Practice use**Only: (CTV3 SystmOne)* |
| Opt out from secondary use of GP patient identifiable data ( Box A) | *9Nu0* | *XaZ89* |
| Opt out from disclosure of personal confidential data by Health and Social Care Information Centre ( Box B) | *9Nu4* | *XaaVL* |

For Practice Use

PLEASE RETURN THIS FORM TO YOUR PRACTICE RECEPTION