Care.data

This is the government’s scheme to collect information about individual patients from GP and hospital records to create a nationwide database which can be used for service planning, research and by commercial organisations. Despite the name, it has nothing to do with caring for individual patients. It has enormous potential for making research easier and cheaper and the scheme is supported by many organisations. It may also allow easy follow-up of patients previously recruited for research trials, for example to look at the long term effects of a treatment researched some years ago. However there are also many people who are concerned about the way the data is being collected. People can opt out of the system but if they do nothing they will automatically be included. Critics argue that most of the public are not sufficiently informed to make a decision about having their data included, and will not opt out due to ignorance rather than choice.

Personal and sensitive information such as diagnoses, referrals, medication etc. will be included in care.data. The data will be aggregated and various reports generated: most reports will probably consist of data on large populations and so have no “personal” data disclosed to third parties; but it will also be possible for organisations to apply for data which contains enough information to identify individuals (known as “Red data”). The HSCIC (Health & Social Care Information Centre) will decide who can and cannot buy such data, but individual patients will have no say in this. The data is not for health professionals to look after individual patients.

You can ask your GP to enter a code in your GP records (“Read Code 9Nu0”) which will prevent your personal GP data from being included in care.data. However, hospital (including mental health) and social care data on all patients is already being uploaded and there is no mechanism to opt out of this, other than to write to each organisation treating you requesting that only anonymous data is provided- GPs are not allowed to do this for you. However it is possible to ask your GP to enter a code on your GP records (“Read Code 9Nu4”) which stops your personal data being released to any third party (with a few exceptions, such as the police).

There is a separate “Summary Care Record” (SCR) which can be accessed by NHS professionals to help look after individual patients (the SCR currently contains only limited information i.e. medication and allergies/drug reactions). In Oxfordshire, there is also an Oxfordshire SCR which also contains a summary of the main diagnoses on your GP record: this information is potentially available to the Out-Of-Hours GPs, ambulance service and A&E dept- in order to help individual patient care. This data is not made available to third parties outside the NHS, but is widely accessible within the NHS. You may remember having been sent a leaflet inviting you to opt out of the SCR too- but it is an entirely separate matter and opting out of the SCR does not mean you are opted out of care.data.

It is possible to have a SCR but to opt out of care.data: opting out of care.data will not affect your GP records, hospital records, and electronic transmission of referrals or booking appointments etc., only the transfer of your records to care.data.


Those who are happy to be included in care.data need do nothing. For those who want to opt out, a form is printed below, but it is not compulsory to use this form, as there is no standard format for such requests.

College Doctors

Drs Judith Bogdanor, Laurence Leaver & Mark O’Shea, Jericho Health Centre

February 2014
Opt-Out Form for “care.data”
NB you do not need to use a specific form to opt out, but this is provided to help anyone who does want to opt out. Please fill out a separate request for any/each dependent(s) if appropriate.

To: Dr Bogdanor & Partners
Jericho Health Centre, New Radcliffe House, Walton St. Oxford OX2 6NW

Full Name

Date of Birth

NHS number (if known)

Contact number (in case of query)

Signature  Date

I have read and understood enough information to make an informed decision to opt out as follows:

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<tr>
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<th>Yes (opt me out)</th>
<th>No (include me)</th>
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<tr>
<td>I would like to opt out of my GP records being used by care.data, (enter code 9Nu0)</td>
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<td>I would like to prevent care.data from releasing any personally identifiable (“Red”) data collected from any source (enter code 9Nu4)</td>
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