

Patient Health Records February 2014 Briefing Paper



Introduction

In the past few weeks, individuals have been receiving a leaflet (often along with junk mail) from their local NHS entitled: Better Information Means Better Care. The leaflet explains that you have a choice as to whether or not you wish your health records and care information to be shared, not only across the NHS, but also for purposes other than care. This briefing paper has been prepared by the NPC's Health Working Party and seeks to provide clarification as to what is going on, rather than advising people whether or not they should or shouldn't opt in or out of sharing their medical data.

What is the difference between this and the previous opt out?

There are two separate systems of recording data and information. An earlier opt out was related to the Summary Care Records <http://systems.hscic.gov.uk/scr>; the purpose of which is to share clinical information between individual patients and the professionals who provide care to them. For example, if you live in London but are knocked down by a bus in Leeds, it should be possible for people treating you to have access to clinical information which would help them provide the care you need. There are no plans to alter these records.

However, this latest leaflet relates to a second system of data storage known as *care.data*.

The care.data system

Under the terms of this new leaflet, if individual choose not to opt out, information from their *care.data* record will be made available to organisations both within the NHS, such as NHS commissioning bodies (eg. CCGs), but also to outside of the NHS, such as:

- Pharmaceutical companies
- Health charities
- Universities and other academic organisations
- Medical Royal Colleges
- Information intermediaries
- Think-tanks
- Commercial companies

You can opt out in the four weeks after receipt of your leaflet, and if you change your mind you are able to opt in whenever you wish, however once the data has been uploaded it will, as far as we have been told, not be erased.

Some people are understandably concerned that opting out of *care.data* will prevent medical staff in A&E, GP out of hours centres, or hospital out-patient departments having access to their medical information? **This is simply not the case.**

If medical staff are authorised to, and have access to that information (for example if they are enabled to, and are using the Summary Care Record, and you have agreed to have a Summary Care Record created for you) then your opt-out of *care.data* will have absolutely no effect on that whatsoever.

If medical staff are authorised to access your electronic hospital records (if any exist at a given hospital) then your opt-out of *care.data* will have absolutely no effect on that whatsoever.

Opting out of *care.data* will have absolutely no effect whatsoever on the way your GP records are stored or accessed electronically by your surgery, and *care.data* has absolutely nothing to do with information sharing between healthcare professionals or with access of your electronic records by medical staff.

You can find the full and accurate version of all this and the opt-out letter and form at <http://www.care-data.info/> and <http://medconfidential.org/>.

Summary

Of course it comes down to individual choice as to whether or not someone wishes to opt in or out. If most people opt in, future research and planning for public health will be easier for the authorities than at present. For more information see the Health and Social Care Information Centre at <http://www.hscic.gov.uk/article/3525/Caredata> and NHS England at <http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx>.

Alternatively, the information provided will include your date of birth, postcode, and national insurance number, which some fear would make individuals identifiable. There is also concern about the security and storage of this data. The French firm Atos have won the contract. It is valuable, for example to insurance companies and may be therefore, of interest to hackers. The government will also be selling the information to interested parties. Whilst they are currently emphatic that this will only be for genuine and ethical reasons, there is the potential for future pressures or changes in the legal system to cause problems sometime in the future.

There also appears to be a lot of uncertainty and lack of information both on the public side and from GPs themselves, which the leaflet does not properly explain. For example, one member went to her local GP practice and explained she wanted to opt out, but was given misleading information and was handed completely the wrong form for this particular opt out. She was given a form to sign which was only to do with the Summary Care record (mentioned above) and not the *care.data* one. Therefore if you wish to opt out – make sure you are signing the correct form.

If you are happy for your information to be used then you do not need to do anything. But if you have concerns or if you do not want information that identifies you from being shared outside your GP practice, as described here, inform a member of staff at your practice. They will make a note of this in your medical record. You will also be able to restrict the use of information held by other places you receive care from. However, this will not affect the care you receive. You can change your mind at any time and as many times as you wish. Just inform your GP practice and ask them to record your wishes.

