

Data sharing and extraction from The Manor Practice

This document is designed to help NHS patients and others understand more about the various local & national data extractions from patients' confidential medical records that are either already taking place or are scheduled to do so in the near future.

The Manor Practice and its doctors and staff, working as part of the NHS, need and want to share data in various ways but we also want to protect your confidential and personal information. Data about health can be used for various reasons, both internally within the practice, and externally with other services.

In the last few years there have been a number of national schemes in addition to an increasing number of independently and separately organised *local* schemes proposed and implemented where data will be automatically extracted from GP computer systems and sent elsewhere, unless the patient has opted out. Further data extractions for new purposes are due to occur soon. Some of these data extractions are to help the patient if they are seen elsewhere in the country. Some are purely for analysis of health care to improve the NHS services.

For many of these schemes, GP practices have a legal obligation to allow their data to be extracted. The only power we have as the data controllers of your medical record is to try to ensure that you are aware of where your medical records may be sent and *why*. *Patients* however *can* block their data from being extracted in most if not all cases. This document tries to explain the main purposes of data extraction and how you can selectively prohibit this if you wish.

The Summary Care Record (SCR) (identifiable data)

This is a national database that is intended to provide basic health information to all providers who need it. This is currently being rolled out across the country. It is intended that your demographics (personal details such as name, date of birth, address) as well as basic medical information about you (initially just drugs taken, documented allergies) would be stored and made accessible to anyone needing it within the NHS. You can ask to 'opt out' of the SCR if you wish by asking the practice to amend your records. See below for how to do this. However, you need to think carefully before opting out here — the SCR allows doctors throughout the country to access your basic information if they need it, which will help them look after you particularly if you are, for example, brought into an Accident & Emergency department unconscious and hence unable to give any information about yourself. Many GP practices would recommend to their patients that they should not block SCR data extraction taking place.

Local Care Records (identifiable data)

Many areas of the country and Clinical Commissioning Groups (CCGs) are now starting to establish their own local databases of patient information, to try to improve communication between different services (such as Health Service & Social Services) and to help plan local care. They bring together information held on computers in healthcare and in social care. They are designed to give staff working in these areas faster access to relevant patient information. Anyone accessing a patient's records will have their details recorded so it's possible to see who has opened each record. In Birmingham, somewhat confusingly, this local care record is called the 'Central Care Record'.

Key benefits of these schemes are hoped to be things such as:

- Safeguarding Children - poor information sharing has been highlighted as a significant risk in recent cases
- Frail elderly - sharing information when someone is vulnerable
- Urgent care - if someone is unable to give vital information in a critical situation

You can opt out of having your medical records extracted & uploaded to any such local database & information on how to do this is shown below.

Care.data (identifiable data) - rolling out nationally from spring 2014

In 2013 the government proposed to extract large sections of data from GP practices to form a national database from which they intend to analyse health needs across the country and also locally. This has not yet been implemented and we need to wait to see the details. However, when it is implemented, **GPs will not have a choice about this extraction** and it will be universal, to help support NHS planning.

After serious expressions of concern from the medical profession, the Government has finally agreed to a national mail shot in an attempt to ensure that you have a chance to block the initial extraction of your personal data from your GP records. You will have had a leaflet arrive at your home during January 2014. Although you can object to data extraction even after the initial data is extracted, it's not clear what would happen to any of your record that might have already been extracted. It is important to understand that this project will extract most coded data from your record. Only 'coded' data, like symptoms, diagnoses, drugs, lab results etc. is extracted. It is important to note that no 'free text' written by a GP during a consultation would be extracted from a patient's record. The coded data will be sent, initially, to a large organisation called the HSCIC (Health & Social Care Information Centre) where it will be held securely. This data will then, it is claimed, be anonymised so that it would not be possible to work out whose data was whose. It could then be passed on later to other agencies, including commercial organisations.

The practice cannot control or protect how that information is used, shared or who has access to it. But you do have a choice: **you have a right to opt out.**

The official guide to the care data project is available here:

<http://www.england.nhs.uk/ourwork/tsd/care-data/>

The Independent Newspaper's summary of the Care.data scheme is available here:

<http://tinyurl.com/p548me6>

An alternative and slightly more concerning analysis of the Care.data project, written by a knowledgeable GP, is available here: <http://care-data.info/>

Although we at The Manor Practice cannot block the upload of our patient data to the HSCIC, ***you can block your own data being uploaded***, if you wish. Details on how to do this are at the end of this piece.

Other data held on you in other databases

There are several other agencies, including parts of the NHS, which will hold identifiable data on you, for example, local A&E departments, local hospitals, Mental Health trusts, Social Services etc. These various agencies will also be sending 'patient identifiable' data to the HSCIC. Although you cannot stop these agencies from sending data on you to the HSCIC, you can block its onward transmission to other agencies for 'secondary use'. Your GP practice does this by adding a specific code to your GP record. *(Then, when the HSCIC interrogates your GP record to check permission to extract your data for care.data purposes, it will 'see' this secondary use blocking code and will therefore block the sending of data on you from them to other agencies - whether or not you have also had the code added to prohibit extraction for 'care.data' purposes).* If you ask your GP practice to add the blocking code for this 'secondary use' purpose, not only will it prevent data on you held by other places (like hospitals) being used for secondary purposes but it will also block the data on you held in your GP practice from being used for these purposes as well. See below for details.

National Audits

The HSCIC is also overseeing a number of nationally run data extractions to help with various specific disease areas such as diabetes and kidney disease. A separate code needs to be added to your GP record to block extraction of data related to any of these audits; again, details below.

Summary of these various types of data extraction

Dr Neil Bhatia's useful flowchart of the various control codes, showing what each code actually does when present in your record is available here: www.tinyurl.com/o4pzhk8 . Note however that it was written for a particular part of the country and so refers to some local data sharing that will not be relevant to most readers. The flowchart also refers to something called s251 (Section 251 of the NHS act 2006). If you are sufficiently interested, more information on this is available here: www.tinyurl.com/o6wzvpc .

This document does not (at present) cover the national diabetes retinal screening data extraction, due to lack of information on whether and how patients could block data extraction for this purpose.

Opting out from any of these schemes

It is possible to 'opt out' from any or all of the data sharing projects if you wish. For most of the data extraction schemes described above, simply complete the form at the end of this document and give it to your GP practice.

Do think carefully about each scheme as to whether you really want to block each one. For example, the Summary Care Record and also some local schemes are designed to help health care workers and sometimes social services to look after you better, sometimes in emergency situations; whereas Care.data is purely for research purposes with no immediate benefit to you.

Will opting out from one of these data extractions block them all?

No. For example, if a patient has requested that the HSCIC should not extract data under the Care.data scheme, but has not prohibited anything else, there is no block to disclosure of personal confidential data under the Summary Care record, Section 251, or the Health & Social Care Act for national clinical audits and so data would be extracted for these purposes despite blocking the care.data extractions.

Are there other implications of refusing these data extractions?

No. Asking for any of these extractions to be blocked will NOT have any impact on:

- the medical care that you are entitled to receive from your GP surgery or from anywhere else within the NHS or private sector
- your GP surgery and the way that it is paid by the NHS or on the services that it provides
- the way that hospitals are paid for treating you
- your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists
- your GP in terms of either referring you to a specialist under Choose & Book or managing your prescriptions via the Electronic Prescription Service
- you in terms of requesting your prescriptions online, emailing your GP or surgery, or accessing your medical records online (if available to you)
- your GP from sharing your data within the NHS, where appropriate, for the purposes of your direct medical care

Disclaimer

All information contained in this document was correct at the time of writing. (January 2014). But guidance given to GP practices and requirements of GPs to engage with future data extractions and sharing may be subject to change, as stipulated by NHS England or other statutory bodies.

Opt out form can be found overleaf.....

The Manor Practice Data sharing "Opt Out" form

I confirm that I have read and understood 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:

Title of PATIENT (Mr/ Mrs etc)	
Surname of PATIENT	
Forename of PATIENT	
Patient's Address	
Phone No. (Mobile if possible)	
Date of Birth.	
Patient's Signature (unless you have parental responsibility & you are signing on behalf of your child)	
Date	

If you have parental responsibility for a child, for whom you are completing this form, you should believe that the child is not competent to make his/her *own* decision. In this case, please also complete below:

Your name (BLOCK CAPITALS)	
I do not feel the person named above, for whom I have parental responsibility, has the capacity to decide these issues him/herself. Your signature:	
Your relationship to the patient	

Tick any or all of the 6 areas detailed below that you wish to block data extraction to:

<u>Area involved</u>	<u>Tick those from which you wish to block use of your data</u>	<u>Practice use Only (Read V2) (EMIS/Vision etc)</u>
1. Dissent from secondary use of general practitioner patient identifiable data		9Nu0
2. Dissent withdrawn for secondary use of general practitioner patient identifiable data		9Nu1
3. Dissent from disclosure of personal confidential data by Health and Social Care Information Centre		9Nu4
4. Dissent withdrawn from disclosure of personal confidential data by Health and Social Care Information Centre		9Nu5
5. All national clinical audits		9M1..
6. National diabetes clinical audit		9M10..
7. Express dissent for Summary Care Record dataset upload		9Ndo

PLEASE RETURN THIS FORM TO PRACTICE RECEPTION