



Data Sharing at Tudor Practice

The Tudor 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, dob, address etc.) as well as basic medical information about you, (initially just drugs taken, documented allergies and any “End of life” decisions) would be stored and made accessible to anyone needing it within the NHS (for example if you were seen in a Casualty department in another area of the country. 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, which will help them look after you, particularly if you are brought in unconscious. Many GP Practices would recommend to their patients that they should not block SCR data extraction to take place.

Local Care Records (Identifiable data)

Many areas of the country and Clinical Commissioning groups (CCG’s) are now starting to establish their own local databases of patient information, to try to improve communication between different services (such as Health Service and Social Services) and to help plan local care. They bring together information held on computers in Health care 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, rather 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 not able to give vital information in a critical situation.

You can opt out of having your medical records extracted and uploaded to any such local database and 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, **GP's 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. A Dr or nurse will often add to the coded data in your record, for example, after adding a Depression code, the Dr might type in: "Depressed after wife's death, weepy with some thoughts of ending it all". Free text often contains a lot of personal information and it is important to understand that for the Care-data project, **none** of this "free text" would be extracted from a patient's record. *Also, certain "sensitive" parts of your record will automatically be excluded from extraction, if present. This includes anything related to infertility treatment, history of Sexually transmitted diseases, Abortions, Gender identity issues and any Domestic violence or abuse.* The coded data will be sent, initially, to a large organisation called the HSCIC (Health and 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 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 Tudor Surgery 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 Accident and Emergency 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, Kidney disease, Dementia etc. a separate code needs to be added to your GP record to block extraction of data related to any of these audits and, again, details are below.

Patients whose GP practice uses the “SystmOne” Computer system:

If your GP practice or other provider sites in your locality use a Clinical computer system called “SystmOne”, you may have other decisions to make from time to time. SystmOne has a sharing protocol called eDSM, which stands for “enhanced Data Sharing Model”. This is a neat way of sharing medical information between healthcare workers in different sites (eg – your practice, casualty, etc). Under eDSM each patient has a central pool of their own information, which no-one else is allowed to see, or to add to, unless the patient agrees.

eDSM allows your healthcare workers to share data about you *into* and *out of* your ‘pool’. At each of these units you can ask them to “share out” the data they hold on you into your pool and you can also specify that information in your pool can be “shared in”. You might understand this better if you replace the word “share” with “allow”.

(You can also specify with each unit that certain individual pieces of information are NOT released, even though the rest is. For example, you could block details of adoptions, terminations, drug abuse etc. from being added to the *pool* of information that other provider sites can read.

Providing that you understand the system, many SystmOne GP practices would *strongly* suggest that you agree to sharing your information in this way — it is in your personal interests to allow each of your healthcare workers to have access to as much information about you as possible.

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. However, consent under eDSM is slightly different, because here you have to 'opt in' at each provider site — you will be asked about this the first time you go to a particular provider site (eg. Your GP, casualty, etc).

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, each of the codes that can be added by your GP practice has certain blocking effects, but blocking all types of data **extraction** from your *own* GP record will require more than one code to be added to your record. For example, one particular code blocks the **care.data scheme** from *extracting data* from your record. It also blocks the national clinical audits and any other Section 251 data extractions. Blocking any **local care record** scheme from *extracting* data will require yet another code, as will wanting to block the **Summary Care Record** data *extraction*.

Finally, if you wish to prevent the HSCIC *releasing / sharing* non-identifiable data on you - both the care.data they themselves have extracted from your GP record and also data sent to them about you by *other* sources (like hospitals), to other agencies (a process called "**secondary use**") then a further code will need to be added.

Are there other implications of refusing these data extractions?

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

- Have any effect on the medical care that you are entitled to receive from your GP surgery or from anywhere else within the NHS or private sector
- Have any effect on your GP surgery and the way that it is paid by the NHS or on the services that it provides
- Have any effect on the way that hospitals are paid for treating you.
- Have any effect on your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.
- Prevent your GP from either referring you to a specialist under Choose and Book or managing your prescriptions via the Electronic Prescription Service.
- Prevent you from requesting your prescriptions online, emailing your GP or surgery, or accessing your medical records online (if available to you).
- Prevent 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 GP's to engage with future data extractions and sharing may be subject to change, as stipulated by NHS England or other statutory bodies.