

Strand Medical Group

DATA SHARING

The **Strand Medical Group** 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 local and national schemes proposed and implemented where data will be compulsorily extracted from GP computer systems and sent elsewhere. 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*, in some cases, prohibit their data from being extracted. 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 and allergies) 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.

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 allow Health and Social care staff 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.

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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 (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 but also down to local assessments. This has not yet been implemented and we need to wait to see the details.

However, if 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. This will be a one off chance and you can expect a leaflet through your door soon.

Patients cannot object to the extraction of data if it is anonymised, when it's not possible to identify the person involved. However, the Care.data project will be extracting **identifiable** data. This 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, or sold on, 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 scary view, written by a knowledgeable GP, is available here:

<http://care-data.info/>

Although we at Strand Medical Group cannot block the upload of our patient data, *you can block your own data being uploaded*, if you wish. If you wish to do so, read how to do so at the end of this leaflet.

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Other data held on you in other databases:

There are several other agencies, including parts of the NHS, that will hold data on you, for example, local A and E departments, local hospitals, Mental Health trusts 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 prohibit its onward transmission to other agencies for “secondary use”. This is done by asking us to add a specific code to your GP record. (When the HSCIC interrogate your GP record to check permission to extract your data, it will then “see” this code - whether or not you have also had the code added to prohibit extraction for “care-data” purposes). See below for details.

Section 251:

Section 251 of the NHS Act 2006 allows the Secretary of State for Health to make regulations to ignore the usual requirement for Medical records to remain confidential but only for defined medical purposes.

Section 251 came about because it was recognised that there were essential activities of the NHS, and important medical research, that required the use of **identifiable** patient information – but, because patient consent had not been obtained to use people’s personal and confidential information for these other purposes, there was no secure basis in law for these uses. So Section 251 was established to enable disclosure of confidential patient information for medical purposes, where it was not possible to use anonymised information and where seeking consent was not practical, having regard to the cost and technology available. In other words, it overrode the Data Protection Act.

More information on this is available here: <http://tinyurl.com/o6wzvpc>

Summary of these various types of data extraction:

A useful flowchart of the various control codes, including possible extraction of identifiable data together with an explanation of what adding each code *does and does not do* is available here:

<http://tinyurl.com/o4pzhk8>. Note however that it was written for a specific area of the country so refers to some local data sharing that will not be relevant to most readers.

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. Simply complete the form at the end of this document and give it to the receptionists at the surgery or email it to us.

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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 any hospital is paid by the NHS 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.

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DATA SHARING "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:

Name	
Surname	
Forename	
Address	
Phone No. (mobile if possible)	
Date of Birth	
Signature (unless a child aged under 18)	
Date	

If completing this on behalf of a child, please also complete below:

Name (BLOCK CAPITALS)	
Signature	
Relationship to the patient	

Please tick any or all of the 4 areas detailed below that you wish to prohibit data extraction to:

<u>Area involved</u>	<u>Tick those from which you wish to prohibit use of your <u>data</u></u>	<u>Practice use <u>only</u></u>
1. Summary Care Record (SCR)		9Ndo
2. Any local (e.g. CCG) Care Record		9Ndj
3. National "Care.Data" scheme (including Section 251)		9Nu0
4. Use of your data from other sources: (AandE, Hospitals etc)		9Nu4

PLEASE RETURN THIS FORM TO PRACTICE RECEPTION