

## **Data Sharing in Herefordshire**

Herefordshire practices, their doctors & staff, working as part of the NHS, need and want to share patient data in various ways in order to improve the services and care that we provide. But we also want to ensure we continue to protect your confidential and personal information.

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 & implemented where data will be automatically extracted from GP computer systems & 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 they have as the data controllers of your medical record is 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 & how you can selectively prohibit this if you wish.

### **1. The Summary Care Record (SCR)**

This is a national database that is intended to provide basic health information to all providers who need it. 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 as 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.

### **2. Risk Stratification**

We (Herefordshire Clinical Commissioning Group) are introducing a system called Risk Stratification within Herefordshire GP practices. This system uses confidential information from your medical record to identify patients who may need more care and support. We particularly want to be able to identify people at high risk of emergency hospital admission so we can offer more care to help improve their health and try to avoid a hospital admission. Identifying each person's risk of future admission is called Risk Stratification.

The information from your record along with your postcode and NHS number will be sent to a secure system where it can be linked with information from hospitals if you have been in hospital recently. Your personal results can only be seen by those caring for you in your own GP practice. Anonymised information which does

not identify you can also be used to help those planning NHS services in Herefordshire – but they will not be able to link this information to you as an individual in any way.

### **3. Local Health Record Network (LHRN)**

GP practices in many areas of the country and many 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 Services & Social Services, in order 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 needing to see your record will ask you first. You must agree before your record can be seen and this occurs each time you are seen. In addition anyone accessing a patient's records will have their details recorded so it's possible to see who has opened each record. In Hereford this is known as the "Local Health Record Network" provided by Taurus Healthcare Ltd.

Key benefits of this scheme 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 & uploaded to any such local database and information on how to do this is shown below. And if you have not opted out you still need to give consent each time your record is accessed.

### **4. care.data - nationally from autumn 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 & 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 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. 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 doctor 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". Uncoded notes like this are called "free text". 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 & any domestic violence or abuse.

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 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>

Although we 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.

### **5. 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 & 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. Please see below for details.

### **6. 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.

### **7. 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 & 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 for research purposes with no immediate benefit to you.

### **8. 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.

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 data that care.data 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.

### **9. 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 & 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 in this document was correct at the time of writing (April 2014, updated January 2016) but guidance given to 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.

**Data Sharing in Herefordshire - Opt Out form.**

Please block data extraction from the patient whose details appear below:

Title of PATIENT (Mr/ Mrs etc)	
Forename and Surname 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 (Gillick/Fraser competence). In this case, please also complete below:

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

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

<b>Area involved</b>	<b>Tick those you wish to block</b>	<b>Practice use (Read codes)</b>
Summary Care Record (SCR)		9Ndo
Local Risk Stratification scheme (Aristotle)		9Oh5
Local Care Record (Taurus) and Aristotle		93C1
National care.data scheme, all national clinical audits, and any Section 251 approved reasons		9Nu0
Release/sharing by the HSCIC of data coming from any source (GP care.data, A&E, hospitals etc) to other agencies		9Nu4
All National Clinical Audits		9M1..
National Diabetes Clinical Audit		9M10.

**PLEASE RETURN THIS FORM TO PRACTICE RECEPTION. THANKS**

## RISK STRATIFICATION OPT-OUT FORM

We are introducing a system called Risk Stratification within Herefordshire GP practices. This system uses confidential information from your medical record to identify patients who may need more care and support. We particularly want to be able to identify people at high risk of emergency hospital admission so we can offer more care to help improve their health and try to avoid a hospital admission. Identifying each person's risk of future admission is called Risk Stratification.

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Please note that this local use of information for Risk Stratification is NOT the same as the Summary Care Record which is a national shared record, neither is it the same as the local sharing of records in the Local Health Record Network.

### You have a choice.

If you are happy for your information to be used in this way you do not have to do anything.

If you DO NOT want your records to be used for Risk Stratification locally please fill out the form on the previous page and leave it at reception

I am happy to be contacted in future to discuss my decision if there are changes made to the system: Yes / No

For practice use only

Actioned by practice: Yes / No

Date .....