care.data

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

This site tells you all about care.data.

It's a detailed and comprehensive site, with links and references.

If you just want the basic facts - the bare essentials - look at: brief.care-data.info

If you've already decided that you want to opt-out, then look at: optout.care-data.info

If you're still unsure about opting out then maybe look at this flowchart.

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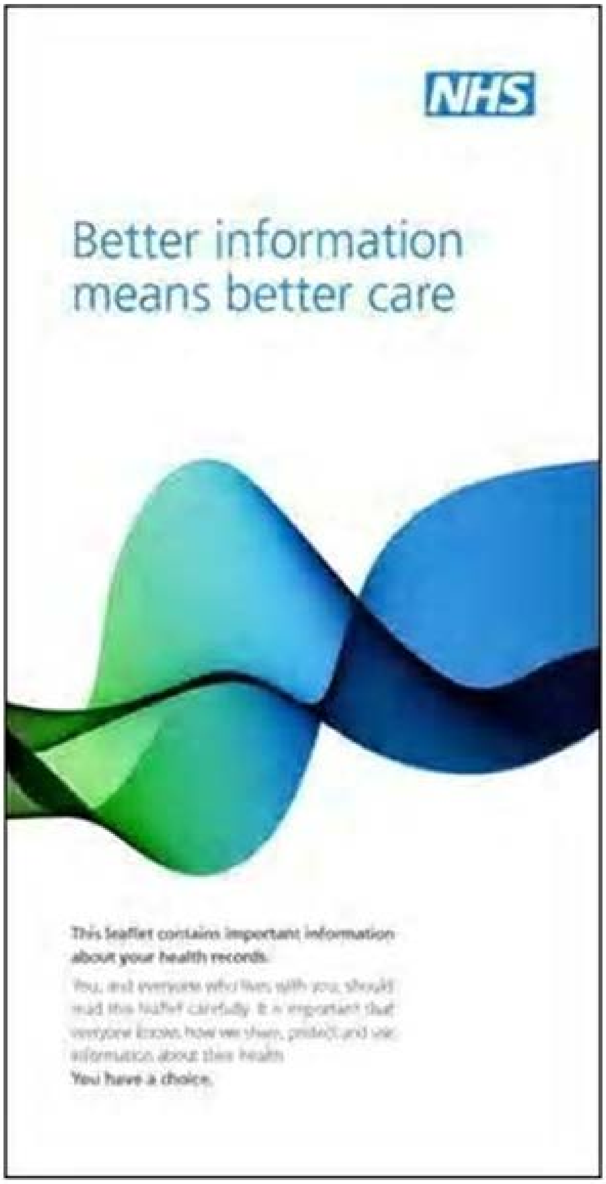
This web site

care.data is going to begin soon, and it will affect every man, woman and child in England and their confidential medical records.

All households in England should have received a junk mail leaflet through their letterbox about this programme, entitled "*Better information means better care*" .



Better information means better care

This leaflet contains important information about your health records.

You, and everyone who lives with you, should read this leaflet carefully. It is important that everyone knows how we share, protect and use information about their health.

You have a choice.

This leaflet is *not* about sharing your medical information with doctors, nurses and other health professionals outside of your GP surgery.
It's *not* about the ways in which your GP shares information about you as part of providing essential medical care.
It's *not* about ensuring that hospital specialists have the information that they need when you are referred to see them.
And it's *not* about submitting information so that GP surgeries and hospitals are paid appropriately for the care that they provide.

This leaflet is about care.data .

Not that you'd know, since "care.data" is never mentioned in the leaflet.

And if you have registered with Royal Mail's Door to Door junk mail opt-out then you will not have received the leaflet at all.

The Health and Social Care Information Centre (HSCIC) is not asking for your permission to extract and upload your data - they're forcibly taking your information.

Your information is not going to "the NHS" - it's going to a single organisation, the HSCIC.
They alone determine what happens to it next - *not you*.

There is no consent with care.data - the decision has been made for you, and your GP surgery, by the HSCIC.
All you have is the *right to object* and reverse the decision affecting your medical information.

care.data - another policy decision made for you, without you.

You have to act if you wish to preserve your confidentiality. Unless you do, care.data will go ahead and involve *your* GP records by default.

And you have to act **fast**, because once your data is uploaded you can **never** get it removed from the HSCIC databases.

Many *might* be happy to allow information from their GP record to be shared if they were asked first, if their data was completely anonymised before upload, if their data was only used within the NHS, and if their data was only used for the purpose of medical research. But, as you will discover, care.data respects none of that.

This website aims to provide information to everyone about care.data so that you can make an *informed* decision about opting out or not.

You'll know an awful lot more about care.data after reading this site than you did after just reading that junk mail leaflet. And you'll be in a much better position to make that decision.

If you do decide to opt-out, this site will tell you how to do so and the opt-out options that you have.

This website provides **facts, not opinion**. It's for **you** to decide whether to opt-out or not. This site will tell you what will be happening to your medical information and what control you have over the data flows to and from the HSCIC databases.

If you want to read about why NHS England and the HSCIC believe that you should not opt-out of care.data, then please visit their sites (links below).

The information provided on this site is designed to complement, not replace, any guidance or advice about care.data provided by your own GP surgery.

It is easy to opt out of care.data

Please do not make an appointment with your GP, or ring your surgery, just to opt-out. You do not need to.

Just hand in, post, or fax an opt-out form or a letter to your GP surgery.

That's it. Simple. No questions asked.

Don't forget to opt-out your children as well.

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care.data in a nutshell....

- care.data is *not* anonymous
- Sensitive and identifiable information is going be extracted from your GP records and uploaded to Health and Social Care Information Centre (HSCIC) databases
- Sensitive and identifiable information *has already been extracted*, and will continue to be extracted from your hospital records and uploaded to HSCIC databases
- You will *not* be asked for your explicit permission or consent before these extractions take place
- The two sets of your information will be combined into one database and subsequently released, in various formats, to organisations within and outside of the NHS, for the purposes of administration, healthcare planning and research
- The HSCIC charges for releasing information to organisations, especially identifiable information - it sells data
- The information is *not* going to be available to doctors and nurses, and so will not be used to provide direct medical care
- The HSCIC will keep your uploaded information *indefinitely* - it will never be deleted, but continuously added to
- You *cannot* prevent the HSCIC from releasing information uploaded about you in anonymised or potentially identifiable formats
- You *cannot* control when, to whom, for what purposes, and what specific

information the HSCIC releases about *you* from *your* care.data record
- Opting out, with either or both of the opt-out options, is the *only* way to have any control at over how the HSCIC use, or will use, your personal data
- Your GP surgery *cannot* stop this extraction - but you, as an individual, can
- You *can* prevent the extraction and uploading of *any* data from your GP record to the HSCIC by asking your GP surgery to put a special code in your GP records
- You *can* prevent the release of your *clearly identifiable* data from the HSCIC by asking your GP surgery to put an additional special code in your GP records
- If you opt-out of care.data (now), you can opt back in at any time in the future
  There is no deadline by which you must opt back in by
- care.data is *not* the same as the Summary Care Record - opting out of one does *not* mean that you have automatically opted out of the other

You *can* control your GP records - if you know how.

See this chart (tinyurl.com/mygprecords) for guidance, and contact your GP surgery if you need further information about any of the data flows.

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care.data - what is going to happen?

GP practices nationwide will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC).

Under the Health and Social Care Act 2012, GP practices have no choice but to allow the HSCIC to extract this information.

The Act removes any requirement to seek the consent of either patients or GPs before extracting and uploading the data.

This project, called *care.data*, is administered by the HSCIC using software and services provided by a private sector company (ATOS).

When will this take place?

The HSCIC states that care.data extractions will now start from GP surgeries in Autumn 2014 (it has been delayed twice now).

How much is care.data costing the taxpayer?

No one knows. The HSCIC has refused to detail the full costs of the programme to date.

A business case for the care.data programme has not yet been submitted to HM Treasury.

It is likely to cost in excess of £50 million though.

ATOS are being paid about £8 million, over 5 years, to provide the infrastructure (known as GPES) to extract care.data from GP systems.

Where's my data going and what's its purpose?

The data will be stored on HSCIC national servers and not on GP systems.

The HSCIC will administer the data, and states it intends to use it "for planning health services and for research".

This is known as "secondary uses" of your medical records.

How does the HSCIC think that care.data will be of benefit to the NHS?

The HSCIC believes that care.data will help:

- find more effective ways of preventing, treating and managing illnesses
- guide local decisions about changes that are needed to respond to the needs of local patients
- support public health by anticipating risks of particular diseases and conditions, and help to take action to prevent problems
- improve the public's understanding of the outcomes of care, giving them confidence in health and care services
- guide decisions about how to manage NHS resources so that they can best support the treatment and management of illness for the benefit of patients

Will doctors and nurses treating me have access to this information?

NO.

Medical staff treating you in GP surgeries, hospitals, A&E, pharmacies and GP out-of-hours centres will not use, or be able to use, this database.

care.data is not about information sharing between healthcare professionals.

It is about data extraction, linkage and analysis: in other words, *data mining.*

Will medical staff with an NHS Smartcard be able to access my uploaded care.data?

NO.

NHS Smartcards are used to access software systems that help provide direct clinical care, for example the Summary Care Record, the Personal Demographics Service, Choose & Book and the Electronic Prescription Service.

NHS Smartcards will not permit access in any way to care.data uploaded to the HSCIC.

care.data is not about the provision of direct medical care by clinical staff.

A bit about data

care.data is *not* anonymous.

The identifiable information uploaded from your GP records is known as the **Primary Care Dataset**.

Once uploaded, information *released* about you can be divided into three main formats:

Anonymised and aggregate data, or as the HSCIC refers to it, **Green data**, is de-identified, so cannot be traced back to an individual. This is the only type of data that will be published openly by the HSCIC, on its website for example.

Pseudonymised data, or as the HSCIC refers to it, **Amber data**, is *potentially* identifiable. Pseudonymisation is a procedure by which the most identifying fields within a data record are replaced by one or more artificial identifiers, or pseudonyms. The pseudonyms render the data record *less identifying* whilst allowing tracking back of the data to its origins. There is a risk, small but real, that pseudonymised data could identify you, especially if that data is provided to organisations that already hold other data about you and can link the pseudonymised data to it. And especially if the pseudonymised data contains very large amounts of information, or very detailed and rich information - just like care.data does.

Clearly identifiable data, or as the HSCIC refers to it, **Red data**, is as its name suggests - clearly identifiable. The identifiers with the data mean that it is obvious that the data refers to you. This data is also known as **personal confidential data, or PCD**.

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The data uploaded from your GP records

Will my Primary Care Dataset be anonymised before it is uploaded from my GP surgery?

NO.

The information will be extracted from your GP surgery in a form that can clearly identify you as the patient that the data refers to.
It is personal confidential data.

In other words, *it will not be anonymised, pseudonymised or de-identified before it is uploaded*.

- If it was anonymised, you wouldn't be able to opt-out
- If it was anonymised, the leaflet wouldn't state "*If you do not want information that identifies you to be shared outside your GP practice, please ask the practice to make a note of this in your medical record*"
- If it was anonymised, the HSCIC wouldn't be able to easily link it to further identifiable data about you that it holds extracted from hospitals - the whole objective of care.data
- If it was anonymised, you wouldn't be able to make a Subject Access

Request for information that the HSCIC holds about *you*

And if it was anonymised, your GP would not be able to inspect *your* individual primary care dataset prior to upload to the HSCIC (and he/she can).

The identifiers (NHS number, DOB, postcode & gender) are *not* "stripped" - not before upload and not after your information arrives at the HSCIC.

Can I request that only anonymised information about me is uploaded to care.data?

NO.

There is no "anonymised" or "trimmed" option for GP care.data uploads.

It's the full, clearly identifiable data upload or nothing.

What information will be extracted from my medical records?

The data extracted - your **Primary Care Dataset** - will include the following:

- Your NHS number
- Your date of birth
- Your postcode
- Your gender
- Your ethnicity
- The date you registered with your GP surgery
- Your medical diagnoses (including cancer and mental health) and any complications
- Your referrals to specialists
- Your prescriptions
- Your family history
- Your vaccinations and screening tests
- Your blood test results
- Your body mass index (height/weight)
- Your smoking/alcohol habits

This information is clearly identifiable - the NHS number alone *uniquely identifies* you.

Certain "sensitive" data will not be extracted in the initial upload (so-called **Release 1** of care.data).

For example:

- Details of infertility and assisted conception, such as IVF
- Sexually transmitted infections, including HIV, genital herpes, genital warts, chlamydia
- Abortions
- Gender identity matters, including reassignment
- Domestic, emotional, physical and sexual abuse

But it has already been stated that "this list might be reconsidered for a future phase of care.data".

Be aware that prescription items that could reveal sensitive data, such as medication for HIV or chlamydia, or hormonal treatment for infertility, *will* be uploaded.

Comprehensive details about the information to be extracted can be found within this HSCIC document.

Can my GP surgery refuse to supply information to care.data?

NO.

GPs are legally compelled to upload to care.data. They cannot refuse to comply.

But this isn't new, is it - GPs have been uploading and sharing data like this for years?

NO.

Absolutely not.

GPs *do* share information about patients as part of providing excellent clinical care, for example:

- Personal information about you and your medical history, when needed for your direct care, e.g. referral to hospital consultants, district nurses, health visitors, midwives, counsellors
- Limited patient identifiable information to public health, in order to arrange programmes for childhood immunisations, communicable diseases, cervical smears and retinal screening

- With your explicit consent, personal information to other organisations outside the NHS, e.g. insurance companies, benefits agencies, solicitors
- Limited information about you, if relevant and necessary, to protect you and others, e.g. to social services child protection investigations
- Under certain acts of parliament to protect you and others e.g. court order
- Summary information which is *completely anonymised* (collected at an aggregate level) e.g. quality and outcome frameworks (QoF), medical research and clinical audit

GPs do extract and send or upload anonymised/aggregated data about patients, sometimes voluntarily and sometimes compulsorily.

But the NHS does not upload vast amounts of personal, confidential and identifiable information about you, from your GP record, forcibly and without your explicit consent, to databases out with your GP surgery, into the hands of different data controllers, for purposes unrelated to your direct medical care.

Until now, that is.

care.data and QOF

All GP surgeries in England collect and store clinical information about patients, and submit that information to NHS England, via the HSCIC, in order to get paid. That information collection programme is known as the Quality and Outcomes Framework. GPs are incentivised to investigate, manage and monitor medical conditions according to clinical guidelines, and to encourage people to attend screening programmes (such as cervical smears) and general health checks (such as blood pressure tests). The information collected is very detailed and the data collected is similar in many ways to that forcibly extracted by care.data (unless you opt-out of course).

However, the information submitted by your GP surgery is *completely anonymised and aggregated* and consists of numbers and percentages only. In stark contrast to care.data, no identifiable information whatsoever about you is submitted as part of QOF.

You can see what the information uploaded under QOF looks like here.

GPs are quite rightly concerned that patients might begin to refuse to attend their surgery for essential investigations, monitoring and management of medical problems, both new and ongoing, out of fear that the subsequent information collected will be uploaded in an identifiable format under care.data.

And in all honesty, such information *will* be uploaded as part of care.data unless you do opt-out.

So please be reassured of the following:

Opting out of care.data will have *no effect whatsoever* on QOF. It will neither affect the recording of clinical information about you by your GP, if appropriate, nor the completely anonymised and aggregated data that your GP submits in order to get paid.

Opting out of care.data should (I hope) give you absolute confidence that you can see your GP, about any matter, without worrying that identifiable information about that consultation, and any necessary investigations or follow-up, will be uploaded to the HSCIC and subsequently passed or sold to other organisations.

Can I limit the information uploaded about me under care.data, e.g. not include certain diagnoses or my smoking/alcohol habits?

NO.

It's the full, clearly identifiable data upload or nothing.

Will happens to my uploaded information then?

This extracted data will be combined with, or linked to, data extracted from any information about you held by hospitals, such as A&E attendances, operations or out-patient appointments, and which has already been uploaded to the HSCIC. The identifiable hospital data is known as Hospital Episodes Statistics (HES).

From April 2014, the data that HES contains will be greatly expanded, to include hospital tests and results, investigations performed, medications prescribed, as well as nursing observations.

In addition, data from other settings where you may have received NHS care will, in due course, be added:

- community care

mental health
- social care

There is talk of genomic records (genetic or DNA data) being linked with care.data in the future.

This combined database will be known as Care Episodes Statistics (CES), and data from this can be released to organisations in green, amber and red data formats, that is in aggregated formats, anonymised formats, pseudonymised formats and clearly identifiable formats (under s251 of the NHS Act 2006, as detailed below).

CES (or more accurately, the CES linked dataset) is the care.data database - *your care.data record*.

Once your full care.data record, containing your GP data plus your hospital data, has been created then your primary care dataset is destroyed, leaving the identifiable and combined care.data record (if you're technically minded, see this diagram).

Will it be a one-off upload of my data?

NO.

Your GP data will continue to be uploaded, initially on a monthly basis, and added to the CES, effectively updating it. So any new diagnoses, medication prescriptions and results will be automatically uploaded and added to your care.data record at the HSCIC.

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Your data - disseminated

Who will have access to my uploaded data?

Information from your care.data record will be made available to organisations both within the NHS, such as NHS commissioning bodies (e.g. CCGs), but also outside of the NHS, such as :

- Pharmaceutical companies

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

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Your data - sold

sell (verb) \'sel

: to exchange (something) for money
: to make (something) available to be bought
: to be able to be bought for a particular price

The HSCIC charges money in exchange for providing data that it holds, especially if it contains personal confidential data.

How much will organisations have to pay to get hold of my personal data?

It depends on the format of your data.

The full HSCIC price list - the "menu" - is here.

Aggregate data (Green), published on the HSCIC website as "Open data" is, obviously, free.

A statistical table of aggregate data (Green) costs approx. £800 - £1200.

Pseudonymised (Amber) data extracts cost approx. £900 - £1800.

Personal confidential data (Red) extracts cost approx. £1700 - £2000.

Certain PCD (Red) extracts can cost as much as £12000.

The HSCIC state that they will not make a profit from selling your data, that they operate a cost recovery scheme only. However many of the companies that they will sell your data to *will* be profit-making.

Who won't have access to my uploaded and combined care.data?

GPs, hospital doctors, nurses, physiotherapists, pharmacists and all the other clinical staff involved in providing your direct medical care will **not** have access.

care.data is not about information sharing for the purposes of direct medical care.

Who will be the data controller for my extracted information?

Once the data has been extracted, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared, sold, or who has access to it.

Your GP will neither be the data controller nor any sort of "data controller in common" (with the HSCIC) for your uploaded information.

The HSCIC and NHS England will be *joint data controllers* for your uploaded information and will have total control over it.

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Anonymised or aggregate information - your Green data

Can I object to my data being provided or sold to organisations in an aggregated or anonymised format?

NO.

You cannot prevent, or control in *any* way, the release or sale of aggregated or anonymised, or **Green**, information from your care.data record, or from any other datasets that the HSCIC holds about you.

Green data is special. Because it is de-identified, it no longer counts as personal data and so falls outside of the Data Protection Act. That means the HSCIC can give or sell *any* Green information extracted from your care.data record, when it likes, to *anyone* it chooses, for *any* purpose, and for whatever price.

"Notably, some of the data the Information Centre will provide to others won't fall under the Data Protection Act. This is because it will be anonymised. This is crucial, as once an individual can no longer be identified from information, either alone or in combination with other information, the law no longer considers it to be personal data. That means that the Data Protection Act no longer applies to it, so it doesn't impose any limitations on what can now be done with it."

ICO blog
NHS patient information: the Information Centre and the DPA

You can, however, opt-out using the 9Nu0 code - this will ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Green data.

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Pseudonymised information - your Amber data

Can I object to my data being provided or sold to organisations in a pseudonymised format?

NO.

You cannot prevent, or control in *any* way, the release or sale of pseudonymised, or **Amber**, information from your care.data record, or from any other datasets that the HSCIC holds about you, even though such data is potentially identifiable.

Although pseudonymised data is *potentially identifiable*, you cannot stop the HSCIC from releasing or selling it to organisations in this format.
Nor can you insist that it must not be released or sold to organisations *that may hold other information about you*.

Access to pseudonymised (potentially identifiable or Amber) information extracts have *no* legal requirement for independent advisory group consideration and approval, or independent oversight and scrutiny.

Sometimes the HSCIC sell your potentially identifiable information after approval from its own in-house advisory group, known as DAAG (see below), sometimes just under a "memorandum of understanding" with the buyer.

You can, however, opt-out using the 9Nu0 code - this will ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be sold as Amber data.

"pseudonymised or de-identified data may be very valuable to researchers because of its individual-level granularity and because pseudonymised records from different sources can be relatively easy to match."

ICO
Anonymisation: managing data protection risk code of practice

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Personal confidential data - your clearly identifiable Red data

In Release 1 of care.data, this information will only be released or sold to those requesting it in an aggregated, anonymised or pseudonymised form, but a bit later on, from Release 2 of care.data onwards, it could be clearly identifiable as *your* information, and you will not be asked for your permission before your "Red" data is distributed.

While the Health and Social Care Act 2012 empowered the HSCIC to collect and hold confidential data compulsorily from GP surgeries, this did not include the power to distribute this data in a clearly identifiable form without a legal justification such as individual patient consent or Section 251 of the NHS Act 2006.

Section 251 can and will inevitably be used to disseminate clearly identifiable information from care.data to other organisations - so bypassing any requirement to seek your consent. It grants the Secretary of State for Health the legal authority to do this, for both research and non research purposes.

The HSCIC *already* uses s251 exemptions to allow clearly identifiable data, currently from HES, to be disseminated to commissioning groups and to other organisations, without seeking explicit patient consent.

The regulations that enable and control Section 251 are called the Health Service (Control of Patient Information) Regulations 2002.

Currently, the Confidentiality Advisory Group (CAG) meets to consider applications for access to clearly identifiable data without patient consent under Section 251, as empowered by Regulation 5a of the Regulations, and makes recommendations to the SoS for Health for research applications. Releases under Reg 5a *require* both the approval of the SoS for Health *and* CAG.

However, Section b of Regulation 5 allows the Secretary of State to have sole power to release sensitive medical and personal information, which would include that sourced from care.data, for *non research purposes*. He/she may seek the advice of a research ethics committee, such as CAG, *but is under no obligation to*.

The largest application for identifiable data ever received by CAG was from the HSCIC in November 2013, and was for the disclosure of the majority of "all data from primary and secondary care for all patients" (see p31 here).

At present, it remains uncertain as to whether there will be truly independent scrutiny for applications to extract and buy clearly identifiable information from your care.data records without your explicit consent. Approval for research purposes *might* be considered by the CAG, but might well be considered by the HSCIC's own in-house advisory group, The Data Access Advisory Group (DAAG).

Researchers may well be "approved" - but they won't be approved by *you*.

"There will be no identifiable disclosures in version 1"

"expect to return with proposals for version 2, with treatment of legal basis and handling of patient objections "

care.data and GP extract
GPES IAG Feb 2013

When can we share something that is confidential?

When the patient has clearly said that we can do it (i.e. when a patient has given their consent)

Where we have to do it by law (for example, in a public health emergency like *an epidemic)*

Where the recipient has approval to receive it under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 (anecdotally known as 'section 251 support').

HSCIC
Rules for sharing information

Is the combined CES database (my care.data record) identifiable or completely anonymised?

care.data is clearly identifiable, although the HSCIC separate the clinical data from the identifying fields (such as NHS number, DOB). These are recombined when pseudonymised data or clearly identifiable data is released, such as under section 251.

The identifiers are not destroyed once your data is with the HSCIC, merely *separated* from, but still "linked to" the clinical data.

If the HSCIC only held completely anonymised care.data:

- There would be no need for the 9Nu4 opt-out code (and we have and can apply this code)
- There could be no pseudonymised (Amber) releases of your data to organisations (and there will be)
- There could be no s251 releases of your clearly identifiable (Red) data to organisations (and there can and, in due course, will be)
- You wouldn't be able to make a Subject Access Request for the care.data information that the HSCIC holds about *you* (and you can)

Will I be informed when my personal confidential data is released or sold to an organisation under Section 251?

NO.

Can I select or approve the particular organisations that my personal confidential data is released or sold to under Section 251?

NO.

You cannot select who the HSCIC disseminates your care.data information to under section 251.

Any organisation - a government department, university researcher, pharmaceutical company or insurance company - can apply to the HSCIC to buy your care.data, including for Red data under Section 251 (although their application may not be successful of course). The decision whether to release or sell your information - what information, to whom, in which format, at what price, and for what purpose - is made by the HSCIC, *not you*.

The HSCIC believes that "it would be wrong to exclude private companies simply on ideological grounds" from applying to buy information from your care.data record.

The HSCIC would determine whether the reasons for any organisation wanting the data were acceptable, stating that they should be "to improve NHS patient care".

"We have private hospitals and companies like Virgin who are purchasing NHS patient care now. This is a trend that will continue. As long as they can show patient care is benefiting then they can apply." the HSCIC states.

Organisations that have been previously granted access to sensitive identifiable health data held by the HSCIC include the Cabinet Office, Dr Foster Ltd, Capita PLC and BUPA.

Can I insist that that my personal confidential data is not released or sold to insurance companies under Section 251?

NO.

You cannot select who the HSCIC disseminates your care.data information to under section 251.

Can I request that my personal confidential data is only released or sold for research purposes under Section 251?

NO.

You cannot control the purposes for which your identifiable information is released.

Section 5 of the Health Service (Control of Patient Information) Regulations 2002 allows the release of identifiable information from your care.data record, as legally authorised by Section 251, for research *and* non research purposes.

Can I request that certain aspects of my personal confidential data is not released or sold under Section 251?

NO.

You cannot control which aspects of your identifiable information the HSCIC releases.

Can I prevent all Section 251 releases of my personal confidential data from the HSCIC?

YES.

The action of the 9Nu4 opt-out code is to prevent clearly identifiable releases of *your* personal confidential data (Red data) from the HSCIC under Section 251/Reg 5, whether for research or non research purposes.

And of course, you can also opt-out using the 9Nu0 code - this will ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Red data.

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Red, Amber, and Green data

Can I object to particular aspects of my data (anonymised or otherwise), such as certain diagnoses, being provided or sold to organisations?

NO.

You cannot control or select which areas of your care.data information the HSCIC disseminates.

Can I object to my data (anonymised or otherwise) being provided or sold to particular organisations, or for particular research, that I find ethically unacceptable?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I object to my data (anonymised or otherwise) being provided or sold to organisations based overseas?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I object to my data (anonymised or otherwise) being provided or sold to organisations who might already hold other information about me?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I request that my data (anonymised or otherwise) is provided only for health research and NHS planning, and not given or sold to commercial companies?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I request that my data (anonymised or otherwise) is provided or sold only to organisations within the NHS?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

How will the HSCIC ensure that organisations given my care.data will process it lawfully and ethically?

The HSCIC is responsible for ensuring that its customers, those that it provides your personal data to, comply with standard data processing guidelines. Effectively, it asks organisations to "promise" to handle the data properly.

The HSCIC states that:

"Customers accessing data through our service are required to sign a data sharing contract before any data is supplied. This contract regulates how the data is shared, used and managed and includes storage security requirements and restrictions on onward sharing or publication. The data sharing contract states that customers must not attempt to link the data with other data sources such that individuals might be re-identified."

So will the HSCIC audit these organisations to ensure that they are complying with the rules, not onward sharing my information and not linking my data?

NO.

The HSCIC does not routinely audit these organisations.

So tell me again - will my information "always be anonymised before being shared with third parties, such as research organisations, universities and private companies"?

NO.

Your data may be released or sold to organisations in an aggregated form, an anonymised form, a pseudonymised form, or a clearly identifiable form under s251 approval.

But *you* have absolutely no say in what information is released, to whom, for what purpose, or, for that matter, how much it's going to cost to obtain your data.

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Insurance companies and access to care.data

The HSCIC also says that clearly identifiable (Red) data will, from Release 2 of care.data onwards, be available to insurance companies - as long as those companies promise that they will not use it "for the purposes of selling or administering any kind of insurance", and as long as their reason for wanting the data was "to improve NHS patient care".

There is *no* legal obstacle to the HSCIC releasing or selling information, whether in Green, Amber or Red formats, to insurance companies.
It has done so before (it has been selling HES data for years) and it will do again (with both HES and care.data).

In addition, anonymised and pseudonymised (Green and Amber) data *should* be given to insurance companies as:

they "can make good use of the data", and it will

"enable insurance companies to accurately calculate actuarial risk so as to offer fair premiums to its customers"

HSCIC
Information Governance Assessment - care.data addendum

And certainly, your HES data has been sold to insurance companies for just this purpose, in this case **Amber data** without DAAG or CAG approval, not for genuine medical research or to benefit NHS care, but simply to increase the profits of those organisations.

If the possibility of your care.data being given or sold to insurance companies is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes.

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to any such organisation.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to any such organisation.

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Pharmaceutical companies and care.data

Pharmaceutical companies would *love* to get their hands on your care.data .

According to the Competition Commission, a company known as i4Health will "offer access to NHS prescription data". One of the aims of this firm is to allow drug companies to get together to access medical information easier than if they applied to the HSCIC for care.data on an individual basis.

The HSCIC confirmed that i4Health had been looking to sign a Memorandum of Understanding with it last year to reduce delays in purchasing patient information from care.data. A sort of fast-track business deal.

> *"Now we find pharmaceutical companies are queuing up behind so-called not-for-profit front companies to spy on what pills we take to get better. The whole care.data scheme is starting to look like nothing more than a giant medical data-laundering machine."*
>
> ***Phil Booth, medConfidential***
> ***The Guardian, February 2014***

If the possibility of your care.data being given or sold to pharmaceutical companies is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes.

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to any such organisation.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to any such organisation.

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Government departments and access to care.data

In June 2013, the HSCIC waved through an application from the Cabinet Office to allow the government to examine the "sensitive" medical records of individual teenagers who took part in the Prime Minister's volunteering project, the National Citizen's Service.

The data was extracted from HES, without consent, and without DAAG approval.

Government departments are just as eligible as any other organisation to apply to obtain your care.data information. In this case, even the supposed safeguard of DAAG consideration was ignored.

The Department of Work and Pensions (DWP) tried, unsuccessfully, to obtain access to confidential patient information, seeking approval under s251 from the then ECC (now CAG), in 2012.

If government access to your GP data from the HSCIC is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to anyone.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to government departments.

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Police access to care.data

Before care.data, police wanting access to your GP records would have to approach your GP or GP surgery and request the information, no doubt quoting section 29(3) of the Data Protection Act 1998 as justification for not seeking your consent first. s29 of the DPA means that information can be disclosed, without a breach of the Act occurring, *but it does not compel disclosure*.

Your GP - a doctor - would be mindful of the GMC's guidance on confidentiality, particularly in relation to disclosures in the public interest. Paragraph 37 of this guidance states that personal information can be disclosed in the public interest without consent, or if consent has been withheld, if the benefits to society outweigh the patient's interests in keeping the information confidential. Generally, this means for the prevention or investigation of a serious crime, or to prevent a terrorist offence.

Your GP is likely to resist simply handing over the information, and may well insist on trying to seek your consent first, or refusing to do anything until presented with a court order compelling release of the relevant information.

Once your identifiable GP data has been uploaded to care.data, and especially once combined with your hospital data, the police *might* approach the HSCIC as an alternative way to obtain GP information about you.

How robustly the HSCIC would resist such an attempt to obtain your information, whether they would insist on seeking your consent first, or require a court order before release, is anyone's guess.

If police access to your GP data from the HSCIC is of concern to you, then be aware of the following.

The 9Nu4 opt-out code would *not* prohibit release of your clearly identifiable data by the HSCIC in such circumstances.

However, the 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to anyone.

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Your data - overseas?

Principle 8 of The Data Protection Act states that *"Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights* *and freedoms of data subjects in relation to the processing of personal data"*.

Information extracted from your care.data record in an anonymised or aggregated way, that is, **Green** data, could certainly be sent or sold directly to an organisation based overseas.

Because Green data it is de-identified, it no longer counts as personal data and so falls outside of the Data Protection Act. That means the HSCIC can give or sell *any* Green information extracted from your care.data record, when it likes, to *anyone* it chooses, *in any country*, for *any* purpose, and for whatever price.

Remember, you cannot prevent, or control in *any* way, the release or sale of aggregated or anonymised, or Green, information from your care.data record, or from any other datasets that the HSCIC holds about you.

It is *possible* that your **Amber** data could be sent to organisations overseas, especially if the HSCIC felt, and could justify to the ICO if challenged, that the data had been pseudonymised to a level where re-identification would be very difficult, that it's own in-house DAAG had "approved" it, and if it was being provided to a country which fufilled the ICO's criteria for "an adequate level of protection".

Remember, you cannot prevent, or control in *any* way, the release or sale of pseudonymised, or Amber, information from your care.data record, or from any other datasets that the HSCIC holds about you, even though such data is potentially identifiable.

It is *unlikely*, but not impossible, that your clearly identifiable, **Red**, personal confidential, data would be sent or sold *directly* to an organisation based overseas. At least, not for research purposes as CAG would be extremely unlikely to approve it.

What is certain though is that your data can and will be given and sold to organisations based in this country. It may well be that once that organisation has the information, it is transferred overseas - without you, the HSCIC, NHS England or the ICO ever finding out.

The HSCIC recently signed a Memorandum of Understanding with the United States of America, in order to facilitate sharing of health data.

If the possibility of your care.data being sent overseas is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes.

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to anyone, in any country.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to anyone, in any country.

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The law and misuse of care.data

Misusing your care.data, whether that is unlawfully obtaining it from the HSCIC, re-identification, disseminating it (overseas, for example), or re-selling it, is a breach of section 55 of the Data Protection Act.

Policing of this falls to the Information Commissioner, but he has pretty limited powers. For example, he has prove in court that "substantial damage and distress had been caused" by the misuse of the data.

The ICO can only bring *monetary penalties*. Even the criminal offence of unauthorised disclosure or obtaining of personal information, as under Section 55 of the Data Protection Act, carries only a fine and is often dealt with by a magistrate.

More serious cases of information theft are dealt with in crown courts, which can impose unlimited monetary penalties. But jail sentences - which information commissioners have called for since 2006 - are not able to be imposed.

"The track record in the magistrates court is pretty pathetic."

"If people don't think this sort of thing matters and if you get to the magistrates court you will be fined about £120, not surprisingly the public doesn't have great confidence that their personal information will stay secure."

Christopher Graham, Information Commissioner
The Independent, February 2014

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Hospitals and other sources of care.data

Can I stop care.data from extracting and uploading my personal information from non-GP sources, such as HES, social care and psychiatric care?

NO.

At present, you cannot object to this data being extracted by the HSCIC.

Can hospital trusts and other non-GP organisations refuse to supply information to care.data?

NO.

The non-GP data that is linked to your GP records to form the combined care.data is sourced from the SUS data warehouse (see below), and all such organisations are mandated to supply information to this database.

Can I stop organisations, such as hospital trusts, from sending my identifiable information to HES in the first place?

YES.

Though it's not easy.

Routine collection of data from hospitals predates the Data Protection Act, but all patients can object to their data being used in this way.

You will have to contact each organisation on an individual basis (your GP surgery cannot do this), requesting that they do not send your personal and identifiable information to the SUS data warehouse (from which the HSCIC extracts HES data). They still have to send information, but all data about you then sent to SUS will be completely anonymised.

At a patient's request, hospital trusts are required to *remove* all patient identifiable data (NHS number or name/address, local patient identifier (hospital number), DOB, postcode) from any SUS submission (CDS file) and render it *anonymised and not pseudonymised*.

Hospital trusts already have strong anonymisation procedures that are currently used for sensitive cases (e.g. IVF), and that can be extended to include patients who have requested that their identifiable information is not sent to SUS.

Guidance on how trusts should achieve this has been published by the HSCIC and can be found here.

Can I prevent the HSCIC from releasing my HES data to organisations?

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your HES record.

You cannot prevent, or control in *any* way, the release sale of pseudonymised, or **Amber**, information from your HES record.

You cannot control when, to whom, or for what purpose, the HSCIC releases or sells personal, clearly identifiable and confidential, or **Red**, information from your HES record.

But you *can* prevent *all* releases of Red, or personal confidential, information from your HES record by means of the **9Nu4** opt-out code

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care.data and medical research

Opting out of care.data will have no effect on *completely anonymised* information about you being shared within the NHS to help medical research.

As it always has been.

Opting out of care.data **in no way** prevents you from agreeing - with your *explicit consent* - to partake in high-quality medical research based at your GP surgery, particularly if your surgery is a Research Ready accredited practice.

Participation in such research is only ever with your full, explicit consent, and *you* choose the type of research that you wish to be contribute to, and the organisation that *you* allow your medical information to be shared with.

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care.data and your direct medical care

Opting out of care.data will have *no effect* on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

Opting out of care.data will have *no effect* on your GP surgery and the way that it is paid by the NHS or on the services that it provides.

Opting out of care.data will have *no effect* on the way that any hospital is paid by the NHS for treating you (PbR).

Neither of the two opt-out codes will affect any of the above.

Will opting out of care.data prevent medical staff in A&E, GP out of hours centres, or hospital out-patient departments having access to my medical information?

NO.

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.

care.data has absolutely nothing to do with information sharing between healthcare professionals or with access of your electronic records by medical staff.

Will opting out of care.data prevent or hinder my GP looking after me?

NO.

Opting out of care.data will have **absolutely no effect whatsoever** on the way that your GP provides your medical care.

It will not affect your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.

It will not stop the NHS organising programmes such as diabetic retinopathy screening, as these are *not* secondary uses of your data but primary uses required for your direct clinical care.

If you opt-out of care.data, you can still be referred to a specialist under Choose & Book, your surgery can still manage your prescriptions via the Electronic Prescription Service, you can continue to request your prescriptions online, continue to email your GP or surgery and continue to access your medical records online (if you are offered that facility).

Opting out of care.data will have no effect whatsoever on your relationship with your GP surgery.

I am part of the UK Biobank project - will my care.data opt-out impact on this?

NO.

Neither the 9Nu0 nor the 9Nu4 code block the extraction of data from your GP records, that you have *explicitly consented to*, if you have signed up to this project.

The 9Nu0 code only blocks the extraction of GP data where your explicit consent has *not* been sought - **such as care.data** .

Will my GP mind if I opt-out?

NO.

Whether or not you opt-out is immaterial to your GP.

And you certainly don't need your GP's approval or permission to opt-out of care.data .

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Subject Access Requests

Can I see what data the HSCIC has extracted from my GP records into care.data?

YES.

The information that the HSCIC holds about you, whether your HES data, your uploaded GP data, or your combined care.data record, is identifiable (i.e. not anonymised) and so information relating to just *you* can be identified, extracted and provided to you.

Everyone has the right to make a request for personal information from a data controller under the Data Protection Act 1998.

You have the right to make a Subject Access Request (SAR) to the HSCIC.

The HSCIC have produced guidance about subject access requests.

A form that you can apply on is here.

The HSCIC holds your extracted health data in an *exclusively* electronic form (as compared with your GP, who holds your information in both electronic and non-electronic (Lloyd George envelope) forms).

Nevertheless, ensure that you request your health records as held *electronically* by the HSCIC.

You will be supplied with a permanent copy of the relevant information, within 40 calendar days.

The maximum fee payable to the HSCIC for the SAR will be £10, regardless of the number of pages the information comprises.

Can I see what data the HSCIC already holds about me, such as in SUS or Hospital Episodes Statistics (HES)?

YES.

The procedure is exactly as above, just state that you wish for your personal SUS or HES data to be provided to you.

After my GP records have been uploaded to care.data, can I see what data the HSCIC then holds about me as Care Episodes Statistics (CES)?

YES.

You can request your "full", linked, care.data record, exactly as above.

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care.data and the Summary Care Record

care.data and the Summary Care Record (SCR) are two *entirely separate* projects.

The Summary Care Record (SCR) is a national centralised database of medical information (allergies and medication, initially) extracted and uploaded from patients' GP records. This project's aims are to make this information potentially available to emergency doctors (in A&E and GP out-of-hours centres countrywide).

For further information about the Summary Care Record, please see my other site.

As regards the Summary Care Record:

- It concerns *direct clinical care*
- You may have recently received a *personalised* letter from your local CCG about the Summary Care Record
- Your GP surgery may not be able to tell you exactly *when* they will commence uploading Summary Care Records

care.data is very different to the Summary Care Record:

- The information extracted for care.data **far exceeds** just allergies and medication

- The information uploaded to care.data will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- care.data does **not** concern clinical care, it is an administrative and research database
- Patients will **not** be written to individually about care.data, although a national leaflet drop is underway (see below)
- We know that this project **will** go ahead everywhere shortly, with data extractions planned for "Autumn 2014"

You will still need to opt-out to prevent care.data uploads even if you have already opted out of The Summary Care Record.

Summary Care Record opt-outs will not prevent care.data uploads.

Opting out of one database does not mean that you have automatically opted-out of the other.

The Department of Health have reneged on a pledge made in April 2013 that patients who opted-out of the Summary Care Record would not have to opt-out again for care.data.

"We're not going to cancel the opting out that's already happened. There may be a process of recontacting people to explain the new arrangements and that's a detail which we'll work through in operational terms. But we will respect people who have already said they wish to opt out of NHS sharing."

"We will respect those who have already opted out."

Jeremy Hunt
on care.data, April 2013

Can I have a Summary Care Record but opt-out of care.data?

YES.

Can I agree to care.data extractions but opt-out of the Summary Care Record?

YES.

- You can both have a Summary Care Record and allow care.data extractions
- You can opt-out of both databases and allow neither

- Or you can opt-out of one but allow the other

Opting out of either database, or both, will not in any way affect the medical care that you receive from your GP surgery.

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Public awareness about care.data

Do GP surgeries have to ensure patients are aware of care.data and of their right to opt-out?

YES.

Your GP surgery is the data controller for your medical records. Whilst it is legally obliged to release the information to the HSCIC without your explicit consent, unless you opt-out, the surgery has an obligation to provide fair processing information to its patients, making them aware of care.data and of their right to object.

As the organisation with primary responsibility for their patients' data, GP surgeries have an obligation to ensure that information about the use of their data is actively communicated to patients, by any and all reasonable means.

What is NHS England and the HSCIC doing to make patients aware of care.data?

In January 2014, a household leaflet drop, reaching approximately 24 million homes, should have explained data sharing for patients and the public. The leaflet should have made it clear that everyone has a right to object to their confidential data being shared in certain ways.

The cost of the NHS England leaflet drop to households in England was approximately £1.2 million.

Did the leaflet include an opt-out form?

NO.

That would have made it very easy for people to opt-out.

Did the leaflet include the phrase "care.data", even once?

NO.

Was the leaflet personally addressed to me?

NO.

The leaflet was simply pushed through your letterbox.

In other words, junk mail?

YES.

He is critical of the NHS's efforts to explain the care.data system, saying the ICO had advised individual letters to all patients.

"They said 'No, we're going to do a leaflet.' I never received my leaflet," he says.

Christopher Graham, Information Commissioner
The Independent, February 2014

We know that very many patients did not receive it (you are allowed to opt out of unsolicited leaflets via Royal Mail), did not read it (binning it or recycling it immediately), or understand its significance.

Between January and March 2005, 750,000 leaflets of a similar type were delivered by Royal Mail to households within Hampshire and the Isle of Wight outlining the Hampshire Health Record (HHR), another massive medical database. This was supposedly to provide comprehensive information to the entire population of Hampshire & IOW and (just like care.data) was based on an opt-out.

The leaflets were unsolicited junk mail then, and they were again for care.data .

The HHR's attitude to 'obtaining consent' in that way was heavily criticised by the Department of Health.

"We have learnt from what Hampshire did, because we believe that it did not go to every person who needed to learn about it, and I have learnt more about the junk mail rule than I ever want to know, but it exists and you need to send to every addressed adult in order for it not to get thrown away if you have got Safeways or Tescos trying to tell somebody something at the same time."

Connecting for Health
***Oral evidence to the HSC Enquiry into the EPR*, Question 61**

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Where can I get more information about care.data?

There is a lot of information available about care.data, other than this site, which you may choose to refer to before you decide on whether you wish to opt out or not.

NHS England / HSCIC

- Patient information booklet ("Better information means better care")
- Patient "FAQs"
- Web site

EMIS National User Group

- Patient information booklet
- Web site

medConfidential

- Patient information booklet
- "Keep My Secrets" (video)
- Web site

Patient.co.uk

- Patient information booklet

- Web site

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So can I opt-out of care.data?

So can I stop care.data from extracting personal information from my GP records?

YES.

Although GP practices cannot object to this information leaving the practice, individual patients and their families can instruct their practice to prohibit the transfer of their data, i.e. **you have the right to opt-out**.

Not objecting to care.data is akin to 'donating' your medical records.

What If I do not opt-out?

If you do nothing, i.e. you do not opt-out, then your medical information will be extracted and uploaded to the HSCIC.

Naturally, we were all denied an opt-out from care.data to start with.

As far back as 2009, those now in charge of care.data were arguing than no-one should be able to object to sharing of their medical records.

"But no one who uses a public service should be allowed to opt out of sharing their records. Nor can people rely on their record being anonymised - at the moment sexual health services can be anonymous, and as a result there are almost no measures of performance in that sector."

Tim Kelsey, co-founder of Dr Foster, now NHS England's director of patients and information
"Long live the Database State"

Back in February 2013, the HSCIC had argued that patients should have *no right whatsoever* to opt-out of care.data extractions.

"The legal basis for the disclosure from general practice systems is statute. As a result, there is no legal necessity to allow patients to opt out of the extraction."

HSCIC
Information Governance Assessment, February 2013

And indeed, that is true. There is no "legal" requirement for an opt-out, because no such requirement exists within the Health and Social Care Act.

But it was made very clear to the HSCIC, by the IAG and the BMA, that not allowing an opt-out from care.data would be in violation of both the NHS Constitution and the GPES Principles (the rules governing the software system, managed by ATOS, that will extract care.data from GP records).

"You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered, and where your wishes cannot be followed, to be told the reasons including the legal basis"

The NHS Constitution

"Where data are extracted for secondary purposes, no patient data will be extracted if the general practice has recorded a patient's objection to disclosures of patient identifiable data from the general practice for secondary uses even where Section 251 approval has been given"

General Practice Extraction Service (GPES), Information Governance Principles

And so, begrudgingly, the HSCIC were forced to concede an opt-out.

Patient control of information

If you do not want information that identifies you to be shared outside your GP practice, please ask a member of staff at your practice to make a note of this in your medical record. This note will prevent your confidential information from being used other than in special circumstances required by law, such as a public *health emergency.*

Information from other places where you receive care, such as hospitals and community services is collected nationally by the Health and Social Care Information Centre. The Health and Social Care Information Centre only releases this information in identifiable form where there is legal approval for doing so, such as for medical research.

If you object, this type of information will not leave the Health and Social Care Information Centre. The only exceptions are very rare circumstances such as a civil emergency or a public health emergency. Please inform your GP practice if you want to object.

HSCIC
Rules for sharing information (current website)

Remember that you *cannot* prevent the HSCIC releasing Green and Amber data that it holds about you, whether uploaded from your GP record or acquired from other places where you receive care, such as hospitals and community services. The 9Nu4 code will prevent the release of Red data from all these sources though.

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Deleting your uploaded data

How long will the HSCIC keep my uploaded data for?

Indefinitely.

The HSCIC have no intention of *ever* deleting your care.data. In fact, your personal data will be added to on a regular basis by ongoing uploads from your GP records (unless you opt-out).

Can I ever get my uploaded data deleted?

NO.

Once uploaded, you will never be able to get this data deleted by the HSCIC.

Can get my uploaded data deleted if I make a Section 10 DPA request?

NO.

Section 10 of the Data Protection Act gives an individual a limited right to ask a data controller (organisation) to stop processing information about them if it is causing them unwarranted and substantial damage or substantial distress.

Section 10 does not give an individual the right of deletion or removal of data.

So who can help me get my uploaded information deleted?

In personal communication, the ICO have stated the following:

As regards a Section 10 DPA application to the HSCIC, *"In order for such a request to be considered, unwarranted and substantial damage or distress would need to be quantified, rather than a just a simple objection because someone does not agree with the processing or has changed their mind."*

The HSCIC will almost certainly reject all such applications.

And if you were to complain to the ICO:

"I can also confirm that in relation to the ICO. If requested (via a complaint) we can only look at the process of s10, this is where such a request has not been responded to within the time scale of 21 days. We cannot look at a response where an individual does not agree with the outcome. In such a case, the individual would need to apply to a court for a decision to be made as to whether their objection is justified. The court would then order what action, if any, must be taken.

So, when it comes to trying to get your uploaded information deleted:

- The Data Protection Act cannot help you
- Your GP cannot help you
- The ICO will not help you

Your only option will be an expensive legal challenge.

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When can I opt-out of my GP data upload?

You can request that the codes are added right now, *before* extractions and uploads to care.data have begun, or you can request that the codes are added at any time thereafter.

The 9Nu0 opt-out

If the 9Nu0 opt-out code is added *before* your initial GP dataset upload (provisionally scheduled for Autumn) then:

- *No data whatsoever* from your GP record will be uploaded to care.data
- *No data whatsoever* from your GP record will be present within your care.data record
- As long as that opt-out code (9Nu0) remains in force, no *further* data from your GP record will be uploaded to care.data
- But you can never put yourself into the position that you would have been had you opted out *before* uploads commenced

If the 9Nu0 opt-out code is added *after* your initial GP dataset upload (after March), or subsequent to any monthly GP uploads to your care.data record, then:

- Identifiable data from your GP record *will* be present within your care.data record
- The uploaded identifiable data will *never* be deleted
- That data will always be able to be released or sold in Green, Amber and (unless you have the 9Nu4 in force) Red formats
- There is absolutely nothing you can do about your data, Red, Amber or Green, that has *already* been given or sold to other organisations
- But as long as that opt-out code (9Nu0) remains in force, no *further* data from your GP record will be uploaded to care.data

The 9Nu4 opt-out

Your personal confidential data, as held by the HSCIC, and from whatever source, *can* be released, *is already being released*, and *will* be released in a clearly identifiable format (PCD or "Red" data), as detailed above.

As soon as the 9Nu4 opt-out code is added to your GP record and transmitted to the HSCIC, then *no further clearly identifiable data releases about you will occur from the HSCIC*.

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An opt-out *now* means an opt-in - when *you* want

If you opt-out now, you can opt-in at any time in the future, if *you* want, when *you* want, at a time of *your* choosing.

Perhaps *if and when* care.data has been changed so that :

- people are asked for their *explicit consent* before their personal information is uploaded: an *opt-in*
- all your data will be completely anonymised *before* upload
- all information about you is completely anonymised *before* release by the HSCIC
- your information will *only* be released by the HSCIC to organisations within the NHS
- your information will *only* be released by the HSCIC to publicly funded and not-for-profit research organisations
- your information will *only* be released by the HSCIC for limited or strictly defined medical research purposes
- your information will *never* be released by the HSCIC to 3rd parties such as commercial organisations, pharmaceutical firms and insurance companies
- your information will *not* be released by the HSCIC to organisations who are looking to take over and privatise existing NHS services
- your information will *not* be sold
- any uploaded information about you can be deleted *at your request and at any time*
- you can *genuinely* control how your uploaded information will be used - to whom it is given, in what format, for what purpose, and for how long

When any, or all, of the above, or any other requirements that *you* want met are reliably in place, then *you* can choose to opt back in.

Until then, opting out will ensure that your GP information will not be used in ways that are unacceptable to you.

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The second "6 month pause" - what will change?

Absolutely nothing.

care.data may well be delayed again, but after 6 months:

- You will still have to opt-out to protect your personal confidential information
- Your information will still be uploaded in an identifiable dataset
- Your personal information will still be sold in green, amber and red formats, to 3rd parties within and outside of the NHS, for purposes other than genuine medical research
- You will still have no control over your uploaded information, other than to opt-out
- And you will still be unable to delete your uploaded information - unable to change your mind

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So how do I opt-out?

If you have decided to opt out of care.data then it's very easy to do so.

First, download an opt-form:

- Here is a .pdf leaflet, which can be printed double-sided and folded (fits in a DL envelope)

- Here is a .doc leaflet, which can be filled in on your PC and either printed or emailed to your GP surgery (if they allow you to email them)

- An opt-out form available in .pdf, .doc or .rtf format is available from medConfidential

- Your GP surgery may have its own opt-out form downloadable from its website.

There is no "official" or mandatory opt-out form that you are obliged to use, whether produced by the HSCIC or anyone else.

It doesn't matter which form you use.

Make sure that you **haven't** been given, or downloaded, a Summary Care Record opt-out form by mistake.

Fill a form in, and hand it into, post it to, or fax it to your GP surgery.

You do not, however, have to fill in a form to opt-out of care.data .

You can just write a letter to your practice:

- State that you wish to opt-out of care.data
- Request that both the **9Nu0 and 9Nu4** codes are added to your GP records
- Remember to include full names and DOBs (and your address if you are happy to)

If you think that you GP surgery might not be fully aware of their obligations under care.data then add this to your letter:

"Please see the 'BMA FAQs - care.data guide for GP practices' document, at ***www.tinyurl.com/cdgpfaqs*** *, for information about care.data and the relevant read codes"*

If your GP surgery has enabled you to use EMIS Access, then you can use the secure messaging system within that to let your GP know that you wish to opt-out of care.data .

Alternatively, you can tell your GP that you wish to opt-out the next time that you see him or her (if you have an appointment planned for the near future). (Don't make an appointment to see him or her just to opt-out though, please!)

Remember to opt-out your children, or those for whom you have parental responsibility, as well.

Ensure that you make your opt-out wishes known to your GP surgery. No-one else can add the electronic flags to your GP records.

Do not send your opt-forms or letters to the HSCIC.

Do I have to give any reasons for my opt-out?

NO.

Absolutely not.

What about my children's records?

The HSCIC is taking **everyone's** medical records, no matter how young or old you are. As soon as newborn children are registered at their GP surgery, their data will be uploadable.

Your children's medical records will be uploaded too unless you opt them out.

When your children reach their 16th birthdays, they will *not* be automatically written to about care.data and their uploaded information.

But when your children are old enough to understand and make a decision for themselves about the storage and use of their data in his way, they will *never* be able to get that information deleted should they wish.

You do not need to see, discuss with or seek the permission of your GP (or anyone else for that matter) before opting your children out of care.data.

If I opt-out, what will my GP do to my records to prevent care.data processing?

Your GP will add two electronic flags, known as read codes, to your records.

One flag, known as 9Nu0, will ensure that no data whatsoever from your GP record will be uploaded to the HSCIC and released or sold, in any format (Green, Amber or Red)

The other flag, known as 9Nu4, will ensure that *any* data held by the HSCIC, whether extracted from your GP record or other sourced data (such as HES, mental health, social care), will not be released to any organisation in a *clearly identifiable (Red) format*.

The 9Nu4 flag is important if you wish to control how the HSCIC releases information held about you, particularly from organisations other than your GP surgery. Section 251 cannot be used to override patient dissent, so if you have indicated that you do not want your information to be shared in this way, by the presence of the 9Nu4 code, then section 251 *cannot* be used to override this - other than in the most exceptional circumstances, e.g. serious public safety concerns or civil emergency.

Be aware that the 9Nu4 code does *not* stop the release or sale of:

- anonymised/aggregate, or Green, data
- pseudonymised (potentially identifiable), or Amber, data

To prevent those, you must ensure that no GP information whatsoever is uploaded to the HSCIC *in the first place* - by means of the 9Nu0 code.

care.data only affects England. If you are registered with a GP in Scotland, Wales or Northern Ireland then you do not need to opt-out, as no data will be extracted from your GP record under this project.

care.data will only be extracted from the GP record held by the surgery that you are *currently* registered with. So you do *not* need to opt-out at all your previous GP surgeries.

If you have moved abroad then it depends on whether you are still registered with an English GP surgery (you shouldn't be). If you are still registered with a GP surgery in England then either de-register, by informing the surgery that you have moved away, or request that the codes are added and then de-register, if you prefer.

If I opt-out, can I allow uploads to care.data but prohibit release of identifiable information from the HSCIC?

YES.

You can ask your GP to *just* add the read code 9Nu4 to your records, if you so wish.

This will allow identifiable data from your GP records to be *uploaded*, but no information, from whatever source, *released or sold* to organisations in a clearly identifiable form (Red data).

If I opt-out, can I change my mind and opt back in?

YES.

If you opt-out now you can opt-in at at any time in the future - *if* you are happy to, *when* you are happy to, and at a time of *your* choosing. It's your data, you should be in control.

Once you opt back in, your GP will add different electronic flags that will permit uploading to care.data and/or the release of other clearly identifiable information from the HSCIC to organisations.

How can I be certain that my opt-out has been actioned by my surgery, and the codes added to my record?

If your opt-out form, letter, or fax has clearly stated your wish to opt-out of care.data, the codes that you want added, and your name/DoB, then your surgery *will* action your request appropriately, otherwise it would be in breach of the Data Protection Act and you would have every right to make a formal complaint.

You do not *need* to confirm that your opt-out has been registered, but if you are concerned that your surgery may not fully understand the process then the easiest way would be to:

- contact your surgery's practice manager (*not your GP*).
- request that she/he confirms that the opt-out codes have been added to your GP record - email confirmation would probably be easiest

If all else fails, you are entitled to make a subject access request (SAR) to look at your GP records yourself.

Because:

- your GP records are not exclusively electronic records, and
- the codes should have been added to during the 40 days preceding the SAR

your GP surgery must offer you the opportunity to inspect (i.e. view on a computer screen) your records free of charge, rather than providing you with a permanent copy of the records for a fee. Your GP surgery is also obliged to help you access the information within your record that you are looking for.

Faced with having to organise all of that, most surgeries will quickly confirm that the codes have been added.

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In summary

Consent plays no part in care.data .
All you have is the right to object: the right to opt-out.It is the *only* way to have any control over your information.

You cannot modify in *any* way, the **Primary Care Dataset** extracted from your GP record and uploaded to care.data .
The information uploaded from your GP record is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.

Information from your combined care.data record may be released to organisations in an aggregated or anonymised form, a pseudonymised form, or a clearly identifiable form.

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your care.data record.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot prevent, or control in *any* way, the release sale of pseudonymised, or **Amber**, information from your care.data record.
Amber data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot control when, to whom, or for what purpose, the HSCIC releases or sells personal, clearly identifiable and confidential, or **Red**, information from your care.data record.

Red data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You *can* additionally prevent *all* releases of your personal confidential data: by means of the 9Nu4 opt-out code.
The 9Nu4 code will block the release or sale of personal confidential data from *any* source of information that the HSCIC has about you, such as HES.

So what do I need to do to ensure the maximum protection for my personal and confidential medical information?

Ask your GP surgery to add both the 9Nu0 and the 9Nu4 codes to your GP records.

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If I'm still unsure about whether to opt-out or not...?

Look at this flowchart.

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Press articles regarding care.data

- NHS data row shows rising public unease, information chief warns (GUARDIAN)
- Care.data is in chaos. It breaks my heart (GUARDIAN)
- Care.Data: picking up the pieces (NATIONAL VOICES)
- Information Commissioner warns that 'line in the sand' shows people recognise the value of their data (ICO)
- Patients need to have control over their own information if care.data is to

work (GUARDIAN)
- What's wrong with care.data? (POLICYEXCHANGE)
- NHS data blunders mean you can't trust Care.data (WIRED)
- Atos to manage NHS care.data project despite ongoing 'mess' over disability benefit assessments (INDEPENDENT)
- NHS data: take more care (GUARDIAN)
- Remote control - why the government has hit pause on the Care.data project (GUARDIAN)
- Atos awarded contract for NHS records (TELEGRAPH)
- Patient data scheme handling a 'masterclass in incompetence' (BBC)
- Care:crash (FOIMAN BLOG)
- NHS data-sharing project at risk, say MPs (BBC)
- Care.data should be opt-in - Jarman (EHI)
- Firm linked to drug makers sought pact on access to patient records database (GUARDIAN)
- Patient records should not have been sold, NHS admits (TELEGRAPH)
- Medical records rules broken, NHS admits (BBC)
- Hospital records of 47m NHS patients obtained by insurance society (GUARDIAN)
- The insurance firms who bought data on every NHS patient - and used it to push up premiums (DAILY MAIL)
- Hospital records of all NHS patients sold to insurers (TELEGRAPH)
- The NHS plan to share our medical data can save lives - but must be done right (GUARDIAN)
- NHS plans leave 'anonymous' medical data vulnerable (NEW SCIENTIST)
- Victory for privacy as NHS database is delayed (INDEPENDENT)
- Controversial plan to share medical records across NHS is put on hold for six months (DAILY MAIL)
- NHS in England delays sharing of medical records (GUARDIAN)
- Care.data delayed (EHI)
- NHS medical records database halted amid concerns (TELEGRAPH)
- NHS England delays care.data scheme to 'build understanding' of benefits (PULSE)
- NHS crisis talks over introduction of patients' records database (TELEGRAPH)
- Care.data: a media.disaster (EHI)
- Doctors raise fears over sharing NHS patient records (INDEPENDENT)
- GPC calls for urgent talks over public awareness of care.data scheme (PULSE)
- 8 in 10 GPs baffled by plan to harvest patients' records (DAILY MAIL)
- MPS surveys of GPs and public reveal lack of information around care.data (MPS)
- NHS admits news medical records database could pose privacy risk

(TELEGRAPH)

- Two-thirds of public yet to receive care.data information leaflet (PULSE)
- Adults 'unaware of NHS data plans' (BBC)
- Charities lobby Department of Health over care.data (COMPUTING)
- Crisis of confidence in care.data - RCGP (EHI)
- GPs voice fears over giant patient records database (BBC)
- MPs voice concerns over care.data in Parliamentary debate (COMPUTING)
- RCGP demands new publicity campaign to address 'crisis in confidence' over care.data scheme (PULSE)
- This call may be recorded... (PULSE)
- Hack attack on NHS data 'is inevitable' (DAILY MAIL)
- When is an opt-out not an opt-out? When it's a care.data opt-out (COMPUTING)
- A question of trust (DAILY MAIL)
- The brave doctor taking on Big Brother (TELEGRAPH)
- Your NHS data is completely anonymous - until it isn't (THE CONVERSATION)
- Ignore NHS snoops (EXPRESS)
- 'Big Brother' database will grab children's health records but parents are being kept in the dark (DAILY MAIL)
- Doctor knows best (2040 INFORMATION LAW BLOG)
- MPH Student Presentations on the NHS Care.Data Programme (IMPERIAL COLLEGE)
- Insurers 'could use new NHS database to track you down within two hours' (DAILY MAIL)
- GP revolt against sale of patient data gathers pace as health trusts threaten the sack (COMPUTING)
- Big Brother's grab for your health secrets (DAILY MAIL)
- NHS bosses are bullying GPs into sharing their patients' data, say MPs: Scheme described as a 'frankly disgraceful' treatment of patient confidentiality (DAILY MAIL)
- Police will have 'backdoor' access to health records despite opt-out, says MP (GUARDIAN)
- I won't give in to the NHS Thought Police who want to sell your private medical records: GP threatened by health chiefs hits back (DAILY MAIL)
- GPs revolt on patient records: Growing anger at NHS plan to harvest private data (DAILY MAIL)
- MP makes formal complaint to ICO over care.data patient records "grab" (COMPUTING)
- NHS 'bullies' threaten to axe GP for keeping his patients' records private: He opts his entire practice out of scheme to harvest medical data (DAILY MAIL)
- NHS must do more to prove that patient data is safe (CH4)

- 'Maybe we haven't been clear enough about med records opt-out', admits NHS data boss (REGISTER)
- Care.data opt-out 'not clear' - ICO (EHI)
- Giant patient records database 'should be delayed' (BBC)
- GP hit with contract notice over plan to opt all patients out of care.data (PULSE)
- NHS admits it should have been clearer over medical records-sharing scheme (GUARDIAN)
- What price our NHS medical records? (GUARDIAN)
- Giving away your data: from Galton and Google to care.data (GUARDIAN)
- What's so interesting? (PULSE)
- No mandate for care.data grab (PULSE)
- Why we should opt out of the Government's new patient database (GUARDIAN)
- We now trust no one with our data - not even our doctors (GUARDIAN)
- GP survey reveals extent of care.data ignorance among patients and staff (PULSE)
- GPs bear brunt of care.data confusion (PULSE)
- The Government must rethink the risks of this flawed data-sharing scheme (PULSE)
- Privacy under the knife (COMPUTING)
- Care.data: a row waiting to happen (EHI)
- Patients may lose trust in NHS if care.data scheme goes ahead, admits NHS England risk analysis (PULSE)
- 'This goes to the very heart of the doctor-patient relationship' (PULSE)
- Are your medical records in danger? (BBC)
- Sledgehammers and nuts: opt-outs and data sharing concerns for the NHS? (SHA)
- An intelligent, grown-up debate (2040 INFORMATION LAW BLOG)
- 40 per cent of GPs plan to opt out of the NHS big data sweep, due to a lack of confidence in the project (INDEPENDENT)
- Four in 10 GPs to opt out of NHS database (TELEGRAPH)
- Over 40% of GPs intend to opt themselves out of care.data scheme (PULSE)
- MP tables motion to halt care.data rollout as 2,400 patients call helpline (PULSE)
- Don't mislead us about our NHS medical records (TELEGRAPH)
- NHS already handing out private data on thousands of patients: Details given to universities, hospitals and watchdogs without checking for consent (DAILY MAIL)
- Why you should be angry about changes to NHS patient data policy (GUARDIAN)
- Patients will be identifiable when firms are given access to confidential NHS

data, experts warn (INDEPENDENT)
- NHS patient data to be made available for sale to drug and insurance companies (GUARDIAN)
- Independent experts overseeing care.data have approved 31 releases of identifiable patient data since April (PULSE)
- Experts overseeing care.data have been approving releases of identifiable patient data (CWUK)
- Care.data business case needs approval (EHI)
- Should GPs fear sharing NHS data? (GP)
- Power to the people (NATURE)
- Making a choice on the data sharing of medical records (GOVERNMENT COMPUTING)
- Patients urge caution over GP data sharing (GP)
- Health records of every NHS patient to be shared in vast database (TELEGRAPH)
- GPs held responsible for patient complaints over NHS data-sharing project, says ICO (PULSE)
- Concerns Heightened About Opt-Out Central Database For UK Patients' Health Data (INFOSECURITY)
- Care.data campaign leaflet slammed (EHI)
- NHS carelessly slings out care.data plans to 26.5 million Brits (REGISTER)
- Your life in their hands: is the care.data NHS database a healthy step or a gross invasion of patient privacy? (INDEPENDENT)
- GP rebellion over plan to share millions of patients' data (DAILY MAIL)
- NHS England's wholly inadequate leaflet drop (BIG BROTHER WATCH)
- GPs urged to 'proactively' support NHS data-sharing publicity campaign starting next week (PULSE)
- By the way... Your medical notes aren't private now (DAILY MAIL)
- Biggest risk to care.data scheme is potential loss of GP 'confidence' in benefits of scheme (PULSE)
- GP extract to care.data starts in March (EHI)
- Patient confidentiality in a time of care.data (BMJ)
- Fears grow over open access to patient records (GUARDIAN)
- What does the NHS's new IT plan really want to extract from us? (REGISTER)
- Second GP decides to opt all patients out of records extraction as care.data rebellion grows (PULSE)
- Why I'm opting patients out of the care.data scheme (PULSE)
- GP takes 'unlawful' decision to opt patients out of care.data programme (PULSE)
- College GP challenges government proposals (THE OXFORD STUDENT)
- GP: 'Why does the NHS need to obtain so much data from patients?' (COMPUTING)

- care.data: the creep begins (MEDCONFIDENTIAL)
- Big data = big deal (PULSE)
- SCR opt-out does not apply to care.data (EHI)
- Care.data campaign - not off to a flyer (COMMISSIONING.GP)
- GPs should use repeat prescriptions to inform patients about care.data, says new guidance (PULSE)
- NHS climbdown over 'big brother' database (DAILY MAIL)
- Anger over medical records sold to private firms (THISISDERBYSHIRE)
- Big data: unthinking, ignorant and callous (HSJ)
- NHS preps spammy mailshots advertising 'BIGGEST medical data grab in HISTORY' (REGISTER)
- £1m national leaflet drop on care.data (EHI)
- UK push to open up patients' data (NATURE)
- NHS England bows to confidentiality concerns and launches £2m national publicity campaign on care.data (PULSE)
- Care.data project to collate all NHS patients' records (INDEPENDENT)
- Care.data: the latest threat to patient privacy? (COMPUTING)
- 'We've not had the time to inform patients about this' (OXFORDMAIL)
- Essex GP demands more time to warn patients about data extraction (GP)
- Medical records may be 'shared around' (BIGGLESWADE CHRONICLE)
- Campaigners claim GPs could face £500k fines over data protection (GP)
- Care.data extractions on hold (EHI)
- Eight weeks to inform patients their data is going to be harvested, GPs warned (PULSE)
- 2020health calls for care.data to be postponed and replaced by an opt-in system (2020HEALTH)
- NHS data extraction programme poses 'enormous threat' to privacy (PULSE)
- Wirral Euro MP warns of NHS 'data grab' (WIRRALGLOBE)
- GPs unable to object to patient data being shared, warns GPC (PULSE)
- Care.data publicity 'not adequate' (EHI)
- GPs threaten to boycott 'Big Brother' NHS database which would force them to send confidential patient records to private firms (DAILY MAIL)
- GP leaders consider boycott of NHS England's data extraction programme (PULSE)
- Hunt's 'paperless', data-pimping NHS plan gets another £240m (REGISTER)
- Hunt announces new push to create database of NHS patients' records (GUARDIAN)
- Kelsey Uncut: Tweet 'n' delete (HSJ)
- Anger in East Lancashire over plans to sell patient data (LANCS TG)
- Your confidential medical records for sale... at just £1 (DAILY MAIL)
- Jeremy Hunt plans sale of confidential patient medical records to private firms (TELEGRAPH)

- GP group does care.data campaign (EHI)
- NHS England to begin extracting data from GP records (PULSE)
- Database of patient information takes first steps (TELEGRAPH)
- £140 could buy private firms data on NHS patients (GUARDIAN)
- U-turn over NHS database opt-out: Victory for privacy campaign as Hunt backs down (DAILY MAIL)
- NHS patient confidentiality 'at risk' from central database records (GUARDIAN)
- Millions of patients' data to be sold off for research after Cameron announces radical plan to change NHS constitution (DAILY MAIL)

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Contact me

Feel free to send me *constructive* comments about this site.

Neil.Bhatia@nhs.net

I will read every comment sent, though please do not be offended if I do not reply to your message.

Privacy policy: I will not sell, trade or otherwise transfer to any third parties your personally identifiable information (your email address or the content of your email)

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

Last updated: 28.02.14

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This website does not accept or host any advertising.

This website does not use cookies.

care.data - the brief version

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

This site gives you the bare essentials about care.data .

Much more detailed information about care.data, including links and references, can be found on my other webpage, care-data.info

Please refer to it if you need more detail or explanation about any of the sections detailed below, or if you really want to know the full facts about this project.

If you've already decided that you want to opt-out, then look at: optout.care-data.info

If you're still unsure about opting out then maybe look at this flowchart.

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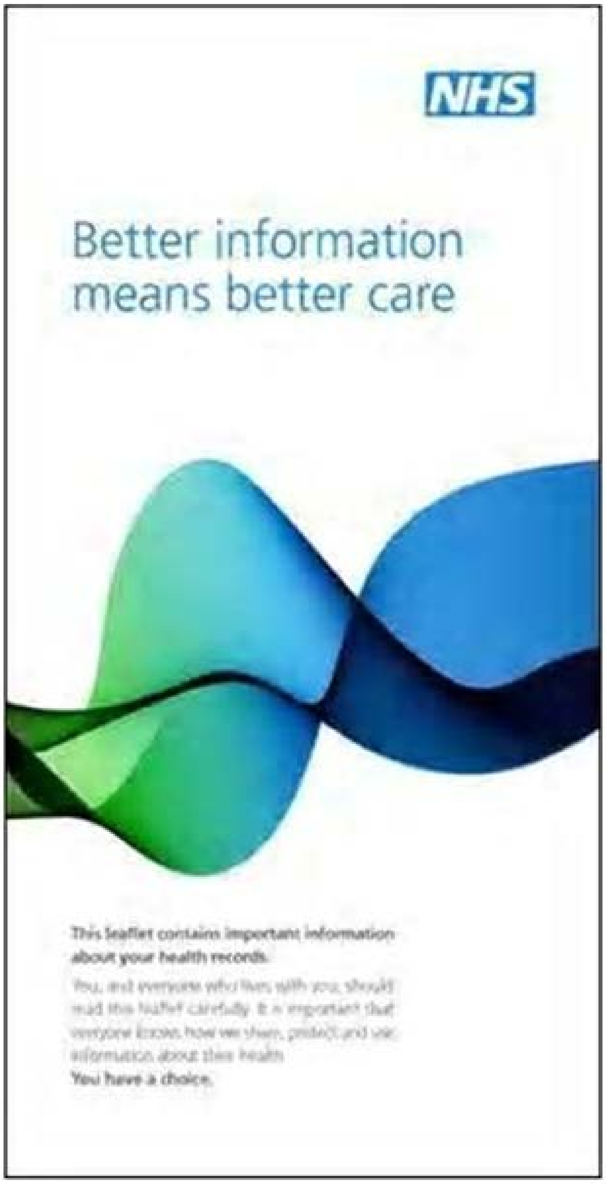
care.data is going to begin soon, and it will affect every man, woman and child in England and their confidential medical records.

All households in England were supposed to have received a junk mail leaflet through their letterbox about this programme, entitled "*Better information means better care*" .



Better information means better care

This leaflet contains important information about your health records.

You, and everyone who lives with you, should read this leaflet carefully. It is important that everyone knows how we share, protect and use information about their health.

You have a choice.

This leaflet is *not* about sharing your medical information with doctors, nurses and other health professionals outside of your GP surgery.
It's *not* about the ways in which your GP shares information about you as part of providing essential medical care.
It's *not* about ensuring that hospital specialists have the information that they need when you are referred to see them.
And it's *not* about submitting information so that GP surgeries and hospitals are paid appropriately for the care that they provide.

This leaflet is about care.data .

This website aims to provide straightforward information to everyone about care.data so that you can make an *informed* decision about opting out or not.

You'll know a lot more about care.data after reading this site than you did after just reading that junk mail leaflet. And you'll be in a much better position to make that decision.

If you do decide to opt-out, this site will tell you how to do so and the opt-out options that you have.

This website provides **facts, not opinion**. It's for **you** to decide whether to opt-out or not. This site will tell you what will be happening to your medical information and what control you have over the data flows to and from the HSCIC databases.

The Health and Social Care Information Centre (HSCIC) is not asking for your permission to extract and upload your data - they're forcibly taking your information.

Your information is not going to "the NHS" - it's going to a single organisation, the HSCIC.
They alone determine what happens to it next - *not you*.

There is no consent with care.data - the decision has been made for you, and for your GP surgery, by the HSCIC.
All you have is the *right to object* - the right to opt-out - and reverse the decision affecting *your* medical information.

care.data - another policy decision made for you, without you.

And you have to act **fast**, because once your data is uploaded you can **never** get it removed from the HSCIC databases.

Many *might* be happy to allow information from their GP record to be shared if they were asked first, if their data was completely anonymised before upload, if their data was only used within the NHS, and if their data was only used for the purpose of medical research. But, as you will discover, care.data respects none of that.

What's happening?

GP practices nationwide will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC).

Under the Health and Social Care Act 2012, GP practices have no choice but to allow the HSCIC to extract this information.

The Act removes any requirement to seek the consent of either patients or GPs before extracting and uploading the data.

This project, called *care.data*, is administered by the HSCIC using software and services provided by a private sector company called ATOS.

The HSCIC states that care.data extractions will now start from GP surgeries in Autumn 2014.

The HSCIC will administer the data, and states it intends to use it "for planning health services and for research".

This is known as **secondary uses** of your medical records.

Medical staff treating you in GP surgeries, hospitals, A&E, pharmacies and GP out-of-hours centres will not use, or be able to use, this database.

care.data is not about information sharing between healthcare professionals.

It is about data extraction, linkage and analysis: in other words, *data mining.*

A bit about data

care.data is *not* anonymous.

The identifable information uploaded from your GP records is known as the **Primary Care Dataset**.

Once uploaded, information *released* about you by the HSCIC can be divided into three main formats:

Anonymised and aggregate data, or as the HSCIC refers to it, **Green data**, is de-identified, so cannot be traced back to an individual. This is the only type of data that will be published openly by the HSCIC, on its website for example.

Pseudonymised data, or as the HSCIC refers to it, **Amber data**, is *potentially* identifiable. Pseudonymisation is a procedure by which the most identifying fields within a data record are replaced by one or more artificial identifiers, or pseudonyms. The pseudonyms render the data record *less identifying* whilst allowing tracking back of the data to its origins. There is a risk, small but real, that pseudonymised data could identify you, especially if that data is provided to organisations that already hold other data about you and can link the pseudonymised data to it. And especially if the pseudonymised data contains very large amounts of information, or very detailed and rich information - just like care.data does.

Clearly identifiable data, or as the HSCIC refers to it, **Red data**, is as its name suggests - clearly identifiable. The identifiers with the data mean that it is obvious that the data refers to you. This data is also known as **personal confidential data, or PCD**.

What information will be extracted from my medical records?

The data extracted - your **Primary Care Dataset** - will include the following:

- Your NHS number
- Your date of birth
- Your postcode
- Your gender
- Your ethnicity
- The date you registered with your GP surgery
- Your medical diagnoses (including cancer and mental health) and any complications
- Your referrals to specialists
- Your prescriptions
- Your family history
- Your vaccinations and screening tests
- Your blood test results
- Your body mass index (height/weight)
- Your smoking/alcohol habits

This information is clearly identifiable - the NHS number alone *uniquely identifies* you.

The identifiers (NHS number, DOB, postcode & gender) are *not* "stripped" - not before upload and not after your information arrives at the HSCIC.

Certain "sensitive" data will not be extracted in the initial upload (so-called **Release 1** of care.data).

For example:

- Details of infertility and assisted conception, such as IVF
- Sexually transmitted infections, including HIV, genital herpes, genital warts, chlamydia
- Abortions
- Gender identity matters, including reassignment
- Domestic, emotional, physical and sexual abuse

But it has already been stated that "this list might be reconsidered for a future phase of care.data".

Be aware that prescription items that could reveal sensitive data, such as medication for HIV or chlamydia, or hormonal treatment for infertility, *will* be uploaded.

You cannot modify in *any* way, the **Primary Care Dataset** extracted from your GP records and uploaded to care.data .
You cannot limit the information uploaded about you, e.g. not include certain diagnoses, or your smoking/alcohol habits, or certain medications.
You cannot "anonymise" the upload by removing the fields that identify you.

It's the full, *clearly identifiable* data upload - or nothing.

This extracted data will be combined with, or linked to, data extracted from any information about you held by hospitals, such as A&E attendances, operations or out-patient appointments, and which has already been uploaded to the HSCIC. The identifiable hospital data is known as Hospital Episodes Statistics (HES).

In addition, data from other settings where you may have received NHS care will, in due course, be added:

- community care
- mental health
- social care

This combined database will be known as Care Episodes Statistics (CES) and data from this can be released to organisations in green, amber and red data formats, that is in aggregated formats, anonymised formats, pseudonymised formats and clearly identifiable formats (under s251 of the NHS Act 2006, as detailed below).

CES (or more accurately, the CES linked dataset) is the care.data database - *your care.data record*.

Your GP data will continue to be uploaded, initially on a monthly basis, and added to the CES, effectively updating it. So any new diagnoses, medication prescriptions and results will be automatically uploaded and added to your care.data record at the HSCIC.

Your care.data record is *not* anonymised on storage at the HSCIC - it remains clearly identifiable as *your* information.

Your data disseminated - and sold

Information from your care.data record will be made available to organisations both within the NHS, such as NHS commissioning bodies (e.g. CCGs), but also outside of the NHS, such as :

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

The HSCIC charges money in exchange for providing data that it holds, especially if it contains personal confidential data - it *does sell* your information (the price list is here).

Once your data has been extracted and uploaded, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared or who has access to it.

Your GP will neither be the data controller nor any sort of "data controller in common" (with the HSCIC) for your uploaded information.

The HSCIC and NHS England will be *joint data controllers* for your uploaded information and will have total control over it.

Information from your care.data record may be released or sold to organisations in an aggregated form, an anonymised form, a pseudonymised form, or a clearly identifiable form under s251 approval.

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your care.data record, or from any other datasets that the HSCIC holds about you (such as HES).

Green data is special. Because it is de-identified, it no longer counts as personal data and so falls outside of the Data Protection Act. That means the HSCIC can give or sell *any* Green information extracted from your care.data record, when it likes, to *anyone* it chooses, for *any* purpose, and for whatever price.

You can, however, opt-out using the 9Nu0 code - this will ensure that

***no data whatsoever* is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Green data.**

You cannot prevent, or control in *any* way, the release or sale of pseudonymised, or **Amber**, information from your care.data record, or from any other datasets that the HSCIC holds about you (such as HES), even though such data is potentially identifiable.
Nor can you insist that it must not be released or sold to organisations *that may hold other information about you*.

You can, however, opt-out using the 9Nu0 code - this will ensure that *no data whatsoever* is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Amber data.

While the Health and Social Care Act 2012 empowered the HSCIC to collect and hold confidential data compulsorily from GP surgeries, this did not include the power to distribute this data in an identifiable form (i.e. as **Red data**) without a legal justification such as individual patient consent or Section 251 of the NHS Act 2006.

Section 251 can and will inevitably be used to disseminate clearly identifiable information from care.data to other organisations - so bypassing any requirement to seek your consent. It grants the Secretary of State for Health the legal authority to do this, for both research and non research purposes.

You cannot control when, to whom, at what price, or for what purpose, the HSCIC releases or sells personal, identifiable and confidential, or **Red**, information from your care.data record, or from any other datasets that the HSCIC holds about you (such as HES).

You can, however, *completely* block the release or sale of any of your HSCIC-held personal confidential data (see below).

And you can also opt-out using the 9Nu0 code - this will ensure that *no data whatsoever* is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Red data.

Any organisation - a government department, university researcher, pharmaceutical company or insurance company - can apply to the HSCIC to buy your care.data, including Red data under Section 251 (although their application may not be successful of course). The decision whether to release or sell your information - what information, to whom, in which format, at what price, and for what purpose - is made by the HSCIC, *not you*.

Organisations that have been previously granted access to sensitive identifiable health data held by the HSCIC include the Cabinet Office, Dr Foster Ltd, Capita PLC and BUPA.

No control without opt-out

For all three classes of data release, anonymised, pseudonymised and clearly identifiable:

- You will not be informed when *your* data has been shared or sold by the HSCIC
- You cannot approve or select the organisations that the HSCIC gives or sells your information to
- You cannot prohibit the release or sale of your information to non-NHS organisations, such as commercial or insurance companies
- You cannot select what information from your care.data record is released or sold, and what is not
- You cannot specify that information from your care.data record is only used for research purposes
- You cannot object to your information being provided or sold to particular organisations, or for particular research, that you find ethically unacceptable
- You cannot object to your information being provided or sold to organisations who might already hold other information about you

The *only* control that you have over data that the HSCIC holds, or might hold, about you is to opt-out of care.data.

When you opt-out, your GP will add either or both of two codes, "electronic flags", to your GP records, known as 9Nu0 and 9Nu4.

One flag, known as **9Nu0**, will ensure **no information whatsoever** from your GP record is *uploaded* to care.data.

With this flag in place, **no data whatsoever** from your GP record will be uploaded to the HSCIC, and so no data from your GP record can be released or sold, in any format (Green, Amber or Red).

The other flag, known as **9Nu4**, will ensure that *any* data held by the HSCIC, whether extracted from your GP record (if you haven't opted out) or other sourced data (such as HES, mental health, social care), will not be released or sold to any organisation in a *clearly identifiable (Red) format*.

Be aware that the 9Nu4 code does *not* stop the release or sale of:

- anonymised/aggregate, or Green, data
- pseudonymised (potentially identifiable), or Amber, data

To prevent those, you must ensure that no GP information whatsoever is uploaded to the HSCIC *in the first place* - by means of the 9Nu0 code.

You cannot, however, prevent the release or sale of Green or Amber data from your HES record.

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care.data and medical research

Opting out of care.data will have no effect on *completely anonymised* information about you being shared within the NHS to help medical research.

As it always has been.

Opting out of care.data **in no way** prevents you from agreeing - with your *explicit consent* - to partake in high-quality medical research based at your GP surgery, particularly if your surgery is a Research Ready accredited practice.

Participation in such research is only ever with your full, explicit consent, and *you* choose the type of research that you wish to be contribute to, and the organisation that *you* allow your medical information to be shared with.

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care.data and your direct medical care

Opting out of care.data will have *no effect* on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

Opting out of care.data will have *no effect* on your GP surgery and the way that it is paid by the NHS or on the services that it provides.

Opting out of care.data will have *no effect* on the way that any hospital is paid by the NHS for treating you.

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.

Opting out of care.data will have **absolutely no effect whatsoever** on the way that your GP provides your medical care.

It will not affect your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.

It will not stop the NHS organising programmes such as diabetic retinopathy screening, as these are *not* secondary uses of your data but primary uses required for your direct clinical care.

If you opt-out of care.data, you can still be referred to a specialist under Choose & Book, your surgery can still manage your prescriptions via the Electronic Prescription Service, you can continue to request your prescriptions online, continue to email your GP or surgery and continue to access your medical records online (if you are offered that facility).

Opting out of care.data will have no effect whatsoever on your relationship with your GP surgery.

Whether or not you opt-out is immaterial to your GP.

And you certainly don't need your GP's approval or permission to opt-out of care.data .

Can I get my uploaded information deleted?

If you do nothing, i.e. you do not opt-out, then your medical information *will* be extracted and uploaded to the HSCIC.

The HSCIC has no intention of *ever* deleting your care.data. In fact, your care.data record will be added to on a regular basis by ongoing uploads from your GP records (unless you opt-out).

You *cannot* - ever - get your uploaded data deleted.

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care.data and the Summary Care Record (SCR) are two entirely separate projects

The Summary Care Record (SCR) is a national centralised database of medical information (allergies and medication, initially) extracted and uploaded from patients' GP records. This project's aims are to make this information potentially available to emergency doctors (in A&E and GP out-of-hours centres countrywide).

For further information about the Summary Care Record, please see my other site.

As regards the Summary Care Record:

- It concerns *direct clinical care*
- You may have recently received a *personalised* letter from your local CCG about the Summary Care Record
- Your GP surgery may not be able to tell you exactly *when* they will commence uploading Summary Care Records

care.data is very different to the Summary Care Record:

- The information extracted for care.data **far exceeds** just allergies and medication
- The information uploaded to care.data will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- care.data does **not** concern clinical care, it is an administrative and research database
- Patients will **not** be written to individually about care.data, although a national leaflet drop is underway (see below)
- We know that this project **will** go ahead everywhere shortly, with data extractions planned for "Autumn 2014"

You will still need to opt-out to prevent care.data uploads even if you have already opted out of The Summary Care Record.

Summary Care Record opt-outs will not prevent care.data uploads.

Opting out of one database does not mean that you have automatically opted-out of the other.

You can have a Summary Care Record but opt-out of care.data

You can agree to care.data extractions but opt-out of the Summary Care

Record

- You can both have a Summary Care Record and allow care.data extractions
- You can opt-out of both databases and allow neither
- Or you can opt-out of one but allow the other

Opting out of either database, or both, will not in any way affect the medical care that you receive from your GP surgery.

Opting out of care.data

When can I opt-out of my GP data upload?

You can request that the codes are added right now, *before* extractions and uploads to care.data have begun, or you can request that the codes are added at any time thereafter.

The 9Nu0 opt-out

If the 9Nu0 opt-out code is added *before* your initial GP dataset upload (provisionally scheduled for Autumn) then:

- *No data whatsoever* from your GP record will be uploaded to care.data
- *No data whatsoever* from your GP record will be present within your care.data record
- As long as that opt-out code (9Nu0) remains in force, no data whatsoever from your GP record will *ever* be uploaded to care.data

If the 9Nu0 opt-out code is added *after* your initial GP dataset upload (after March), or subsequent to any monthly GP uploads to your care.data record, then:

- Identifiable data from your GP record *will* be present within your care.data record
- The uploaded identifiable data will *never* be deleted
- That data will always be able to be released or sold in Green, Amber and (unless you have the 9Nu4 in force) Red formats
- There is absolutely nothing you can do about your data, Red, Amber or Green, that has *already* been given or sold to other organisations
- As long as that opt-out code (9Nu0) remains in force, no *further* data from your GP record will be uploaded to care.data
- But you can never put yourself into the position that you would have been had you opted out *before* uploads commenced

The 9Nu4 opt-out

Your personal confidential data, as held by the HSCIC, and from whatever source, *can* be released, *is already being released*, and *will* be released in a clearly identifiable format (PCD or "Red" data), as detailed above.

As soon as the 9Nu4 opt-out code is added to your GP record and transmitted to the HSCIC, then *no further clearly identifiable data releases about you will occur from the HSCIC*.

An opt-out *now* means an opt-in - when *you* want

If you opt-out now, you can opt-in at any time in the future, if *you* want, when *you* want, at a time of *your* choosing.

Perhaps *if and when* care.data has been changed so that :

- people are asked for their *explicit consent* before their personal information is uploaded
- all your data will be completely anonymised *before* upload
- all information about you is completely anonymised *before* release by the HSCIC
- your information will *only* be released by the HSCIC to organisations within the NHS
- your information will *only* be released by the HSCIC to publicly funded and not-for-profit research organisations
- your information will *only* be released by the HSCIC for limited or strictly defined medical research purposes
- your information will *never* be released by the HSCIC to 3rd parties such as commercial organisations, pharmaceutical firms and insurance companies
- your information will *not* be released by the HSCIC to organisations who are looking to take over and privatise existing NHS services
- your information will *not* be sold
- any uploaded information about you can be deleted *at your request and at any time*
- you can *genuinely* control how your uploaded information will be used - to whom it is given, in what format, for what purpose, and for how long

When any, or all, of the above, or any other requirements that *you* want met are reliably in place, then *you* can choose to opt back in.

Until then, opting out will ensure that your GP information will not be used in ways that are unacceptable to you.

How do I opt-out?

If you have decided to opt out of care.data then it's very easy to do so.

First, download an opt-form:

- Here is a .pdf leaflet, which can be printed double-sided and folded (fits in a DL envelope)
- Here is a .doc leaflet, which can be filled in on your PC and either printed or emailed to your GP surgery (if they allow you to email them)
- An opt-out form available in .pdf, .doc or .rtf format is available from medConfidential
- Your GP surgery may have its own opt-out form downloadable from its website.

There is no "official" or mandatory opt-out form that you are obliged to use, whether produced by the HSCIC or anyone else.

It doesn't matter which form you use.

Make sure that you **haven't** been given, or downloaded, a Summary Care Record opt-out form by mistake.

Fill a form in, and hand it into, post it to, or fax it to your GP surgery.

You do not, however, have to fill in a form to opt-out of care.data .

You can just write a letter to your practice:

- State that you wish to opt-out of care.data
- Request that both the **9Nu0 and 9Nu4** codes are added to your GP records
- Remember to include full names and DOBs (and your address if you are happy to)

If you think that you GP surgery might not be fully aware of their obligations under care.data then add this to your letter:

"Please see the 'BMA FAQs - care.data guide for GP practices' document, at ***www.tinyurl.com/cdgpfaqs*** *, for information about care.data and the relevant read codes"*

If your GP surgery has enabled you to use EMIS Access, then you can use the secure messaging system within that to let your GP know that you wish to opt-out of care.data .

Alternatively, you can tell your GP that you wish to opt-out the next time that you see him or her (if you have an appointment planned for the near future). (Don't make an appointment to see him or her just to opt-out though, please!)

Remember to opt-out your children, or those for whom you have parental responsibility, as well.
Your children's medical records will be uploaded too unless you opt them out.

Ensure that you make your opt-out wishes known to your GP surgery. No-one else can add the electronic flags to your GP records.

Do not send your opt-forms or letters to the HSCIC.

Remember: if you opt-out now you can opt-in at at any time in the future - *if* you are happy to, *when* you are happy to, and at a time of *your* choosing. It's your data, you should be in control.

If you do opt back in to care.data, your GP will add different electronic flags that will permit uploading to care.data and/or the release of other clearly identifiable information from the HSCIC to organisations.

In summary

Consent plays no part in care.data .
All you have is the right to object: the right to opt-out.It is the *only* way to have any control over your information.

You cannot modify in *any* way, the **Primary Care Dataset** extracted from your GP record and uploaded to care.data .
The information uploaded from your GP record is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.

Information from your combined care.data record may be released to organisations in an aggregated or anonymised form, a pseudonymised form, or a clearly identifiable form.

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your care.data record.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot prevent, or control in *any* way, the release sale of pseudonymised, or **Amber**, information from your care.data record.
Amber data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot control when, to whom, or for what purpose, the HSCIC releases or sells personal, clearly identifiable and confidential, or **Red**, information from your care.data record.
Red data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You *can* additionally prevent *all* releases of your personal confidential data: by means of the 9Nu4 opt-out code.
The 9Nu4 code will block the release or sale of personal confidential data from *any* source of information that the HSCIC has about you, such as HES.

If you're still unsure about what to do...look at this flowchart.

Feel free to send me *constructive* comments about this site.

Neil.Bhatia@nhs.net

I will read every comment sent, though please do not be offended if I do not reply to your message.

Privacy policy: I will not sell, trade or otherwise transfer to any third parties your personally identifiable information (your email address or the content of your email)

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

Detailed information about care.data can be found at www.care-data.info

Last updated: 28.02.14

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How to opt-out of care.data

If you have decided to opt out of care.data then it's very easy to do so.

But **do not delay**, because once your data is uploaded you can never get it removed from the HSCIC databases.

First, download an opt-form:

- Here is a .pdf leaflet, which can be printed double-sided and folded (fits in a DL envelope)

- Here is a .doc leaflet, which can be filled in on your PC and either printed or emailed to your GP surgery (if they allow you to email them)

- An opt-out form available in .pdf, .doc or .rtf format is available from medConfidential

- Your GP surgery may have its own opt-out form downloadable from its website.

There is no "official" or mandatory opt-out form that you are obliged to use, whether produced by the HSCIC or anyone else.

It doesn't matter which form you use.

Make sure that you **haven't** been given, or downloaded, a Summary Care Record opt-out form by mistake.

Fill a form in, and hand it into, post it to, or fax it to your GP surgery.

If you prefer, you can just write a letter to your surgery.

- State that you wish to opt-out of care.data
- Request that both the **9Nu0 and 9Nu4** codes are added to your GP records
- Remember to include full names and dates of birth (and your address if you are happy to)

That's it. Simple.

The two opt-codes (**9Nu0 and 9Nu4**) will be added to your GP record by your surgery.

Remember to opt-out your children, or those for whom you have parental responsibility, as well.
Your children's medical records will be uploaded too unless you opt them out.

If you think that your GP surgery might not be fully aware of their obligations under care.data then add this to your letter:

*"Please see the 'BMA FAQs - care.data guide for GP practices' document, at **www.tinyurl.com/cdgpfaqs** , for information about care.data and the relevant read codes"*

Please:

- Do not make an appointment with your GP
- Do not arrange to see your GP surgery's Practice Manager
- Do not ring your GP or GP surgery

just to opt-out.

You do not need to.

Remember: **if you opt-out now you can opt-in at any time in the future** - *if* you are happy to, *when* you are happy to, and at a time of *your* choosing. There is no deadline to opt-in by.

It's your data, you should be in control.

The NHS England care.data leaflet entitled *"Better information means better care"* that all households were supposed to receive by junk mail **deliberately did not include an opt-out form**.

Do print off copies of an opt-out form and give to your family, friends and colleagues, or email it to them, send them the link to this site (or to medConfidential), or share this information on social media sites.

This site is also available as a simple Facebook page.

It should be as easy as possible for everyone who wishes to opt-out of care.data to do so.

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

Detailed information about care.data can be found at care-data.info

The bare essentials about care.data can be found at brief.care-data.info

The "I'm still really confused" flowchart.

Last updated: 26.02.14

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IMPORTANT CHANGES TO YOUR MEDICAL RECORDS

GP practices across England will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC).

The data upload is due to commence in March 2014 and all households should receive a leaflet ('Better information means better care') through their letterbox about this in January.

Details from your medical record will be extracted from the practice in a form that can identify you, and will include your NHS number, date of birth, postcode, gender and ethnicity, together with your medical diagnoses (including cancer and mental health), their complications, referrals to specialists, your prescriptions, your family history, details of your vaccinations and screening tests, your blood test results, your body mass index, and your smoking/alcohol habits.

This programme is called **care.data**, and the information uploaded will be used for purposes *other than your direct medical care* (so-called "secondary uses").

Medical staff treating you in GP surgeries, hospitals, A&E and out-of-hours centres will not use, or be able to use, this database. However, the uploaded data is likely to be made available to organisations outside of the NHS, such as universities and commercial organisations.

Under the Health and Social Care Act 2012, GP practices have **no** choice but to allow the HSCIC to extract this information.

Once the data has been extracted, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared or who has access to it.

Although GP practices cannot object to this information leaving the practice, individual patients and their families can instruct their practice to prohibit the transfer of their data, i.e. **you have the right to opt-out.**

If you do nothing, i.e. you do not opt out, then your medical information *will* be extracted and uploaded to the HSCIC.

Once uploaded, you *will not* be able to get this data deleted by the HSCIC. So if you want to opt out, you need to act now.

To opt out, simply fill in your details on the form to the right of this page, cut it out and post it or drop it in to your GP practice, marked for the attention of your GP. If you wish to opt out your children or other members of your family for whom you are responsible, you can add their details on the back of the form.

This is not the Summary Care Record. The two databases are very different. Opting out of one database does not mean that you have automatically opted out of the other.

Further information about the care.data programme is available online - details overleaf.

Dear Doctor,

I am writing to give notice that I refuse consent for my identifiable information and the identifiable information of those for whom I am responsible [delete as appropriate] **to be transferred from your practice systems for any purpose other than our medical care.**

Please take whatever steps necessary to ensure my confidential personal information is not uploaded and record my dissent by whatever means possible.

This includes adding the '**Dissent from secondary use of GP patient identifiable data**' code (Read v2: 9Nu0 or CVT3: XaZ89) to my record as well as the '**Dissent from disclosure of personal confidential data by Health and Social Care Information Centre**' code (Read v2: 9Nu4 or CTV3: XaaVL).

I am aware of the implications of this request, understand that it will not affect the care we receive and will notify you should I change my mind.

Signature: ______________________________

Full name: ______________________________

Address: ______________________________

____

____

Postcode: ______________________________

Date of birth: ______________________________

NHS number (if known): ______________________________

Space for additional patient details overleaf

Additional patient details

Please take whatever steps necessary to ensure the following people's confidential personal information is not uploaded from your practice and record my dissent on their behalf by whatever means possible.

Patient's full name: ______________________________

Address (if different): ______________________________

____

____

Postcode: ______________________________

Date of birth: ______________________________

NHS number (if known): ______________________________

Patient's full name: ______________________________

Address (if different): ______________________________

____

____

Postcode: ______________________________

Date of birth: ______________________________

NHS number (if known): ______________________________

You can provide details of other family members you wish to opt out on a seperate sheet, but make sure this form is attached.

FIND OUT MORE

This leaflet was written with the help of Dr Neil Bhatia, GP. We recommend you visit his website **www.care-data.info** which provides a more comprehensive view of the care.data programme than the 'Better information means better care' leaflet you may have seen.

NHS England does provide some more details at **www.nhs.uk/caredata** and the Health and Social Care Information Centre also has a page describing how it handles your confidential medical information at **www.hscic.gov.uk/patientconf**

Opting out will have no effect on your medical care. If you are unsure what to do, **opt out now**. You can discuss this with your doctor at your next appointment and, if you are satisfied, you can opt back in at any point.

Copies of this leaflet for you to print or e-mail to friends and family can be downloaded from **http://optout.care-data.info**

NOTES

IMPORTANT CHANGES TO YOUR MEDICAL RECORDS

Please read — you may need to act NOW

How to opt-out of care.data

If you have decided to opt out of care.data then it's very easy to do so.

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It doesn't matter which form you use.

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If you prefer, you can just write a letter to your surgery.

- State that you wish to opt-out of care.data
- Request that both the **9Nu0 and 9Nu4** codes are added to your GP records
- Remember to include full names and dates of birth (and your address if you are happy to)

That's it. Simple.

The two opt-codes (**9Nu0 and 9Nu4**) will be added to your GP record by your surgery.

Remember to opt-out your children, or those for whom you have parental responsibility, as well.
Your children's medical records will be uploaded too unless you opt them out.

If you think that your GP surgery might not be fully aware of their obligations under care.data then add this to your letter:

"Please see the 'BMA FAQs - care.data guide for GP practices' document, at ***www.tinyurl.com/cdgpfaqs*** *, for information about care.data and the relevant read codes"*

Please:

- Do not make an appointment with your GP
- Do not arrange to see your GP surgery's Practice Manager
- Do not ring your GP or GP surgery

just to opt-out.

You do not need to.

Remember: **if you opt-out now you can opt-in at any time in the future** - *if* you are happy to, *when* you are happy to, and at a time of *your* choosing. There is no deadline to opt-in by.

It's your data, you should be in control.

The NHS England care.data leaflet entitled *"Better information means better care"* that all households were supposed to receive by junk mail **deliberately did not include an opt-out form**.

Do print off copies of an opt-out form and give to your family, friends and colleagues, or email it to them, send them the link to this site (or to medConfidential), or share this information on social media sites.

This site is also available as a simple Facebook page.

It should be as easy as possible for everyone who wishes to opt-out of care.data to do so.

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

Detailed information about care.data can be found at care-data.info

The bare essentials about care.data can be found at brief.care-data.info

The "I'm still really confused" flowchart.

Last updated: 26.02.14

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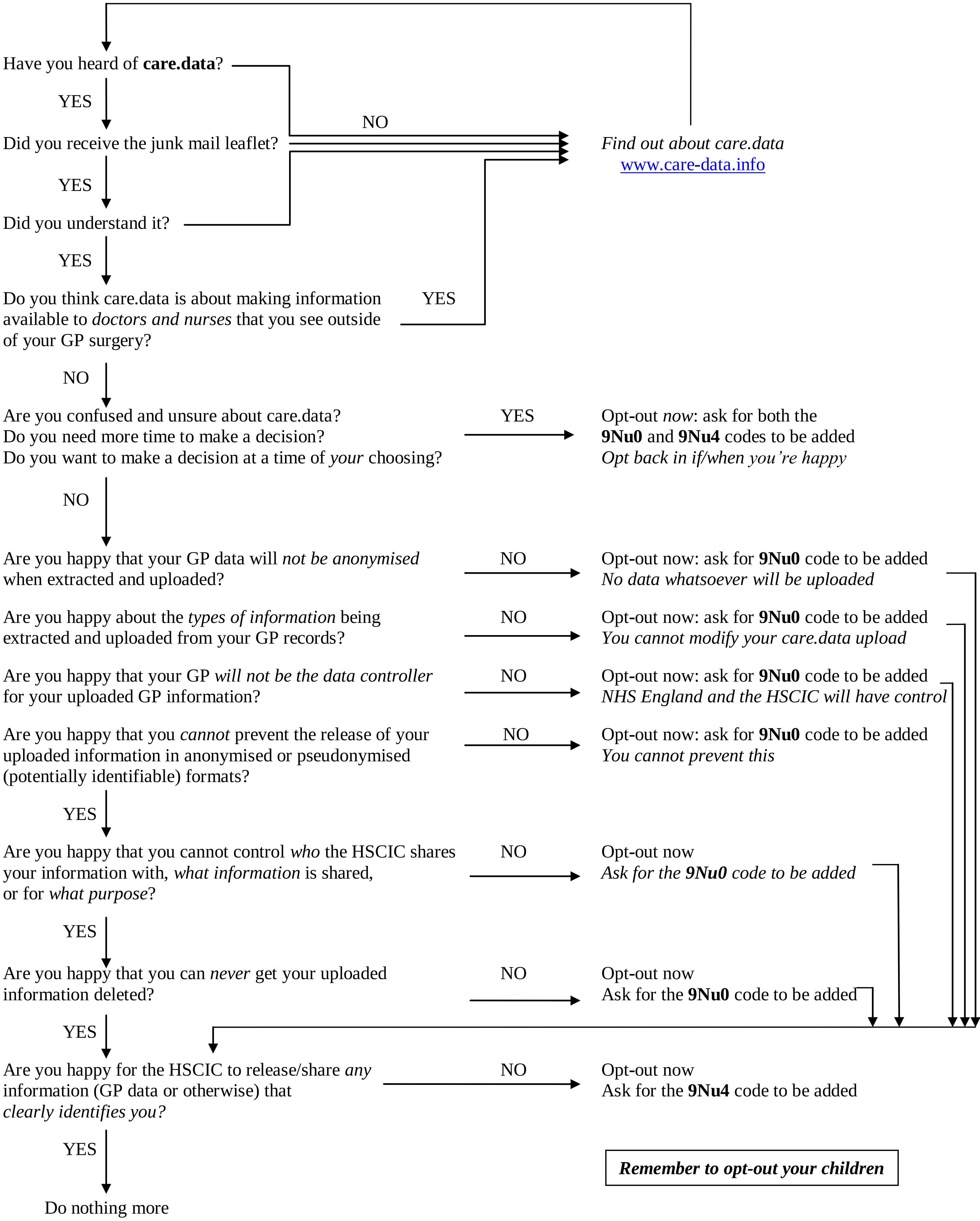
This website does not use cookies.

care.data

what should I do ?



Have you heard of **care.data**?

YES

Did you receive the junk mail leaflet?

YES

Did you understand it?

YES

Do you think care.data is about making information available to *doctors and nurses* that you see outside of your GP surgery?

YES

NO

Find out about care.data
www.care-data.info

NO

Are you confused and unsure about care.data?
Do you need more time to make a decision?
Do you want to make a decision at a time of *your* choosing?

YES

Opt-out *now*: ask for both the **9Nu0** and **9Nu4** codes to be added
Opt back in if/when you're happy

NO

Are you happy that your GP data will *not be anonymised* when extracted and uploaded?

NO

Opt-out now: ask for **9Nu0** code to be added
No data whatsoever will be uploaded

Are you happy about the *types of information* being extracted and uploaded from your GP records?

NO

Opt-out now: ask for **9Nu0** code to be added
You cannot modify your care.data upload

Are you happy that your GP *will not be the data controller* for your uploaded GP information?

NO

Opt-out now: ask for **9Nu0** code to be added
NHS England and the HSCIC will have control

Are you happy that you *cannot* prevent the release of your uploaded information in anonymised or pseudonymised (potentially identifiable) formats?

NO

Opt-out now: ask for **9Nu0** code to be added
You cannot prevent this

YES

Are you happy that you cannot control *who* the HSCIC shares your information with, *what information* is shared, or for *what purpose*?

NO

Opt-out now
*Ask for the **9Nu0** code to be added*

YES

Are you happy that you can *never* get your uploaded information deleted?

NO

Opt-out now
Ask for the **9Nu0** code to be added

YES

Are you happy for the HSCIC to release/share *any* information (GP data or otherwise) that *clearly identifies you?*

NO

Opt-out now
Ask for the **9Nu4** code to be added

YES

Do nothing more

Remember to opt-out your children

care.data - the brief version

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

This site gives you the bare essentials about care.data .

Much more detailed information about care.data, including links and references, can be found on my other webpage, care-data.info

Please refer to it if you need more detail or explanation about any of the sections detailed below, or if you really want to know the full facts about this project.

If you've already decided that you want to opt-out, then look at: optout.care-data.info

If you're still unsure about opting out then maybe look at this flowchart.

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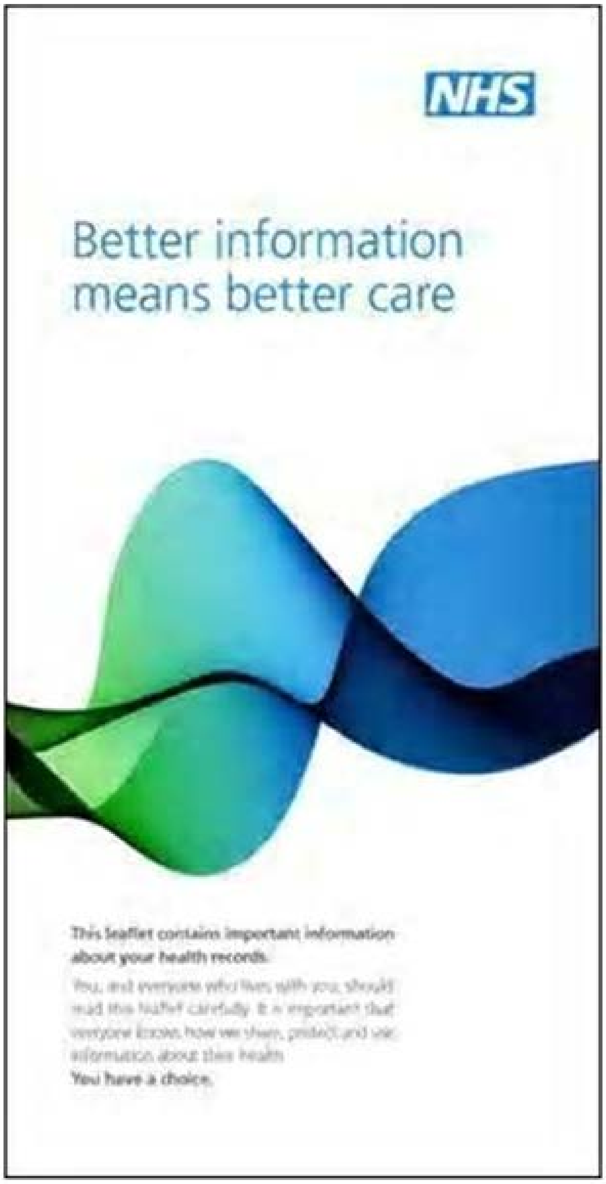
care.data is going to begin soon, and it will affect every man, woman and child in England and their confidential medical records.

All households in England were supposed to have received a junk mail leaflet through their letterbox about this programme, entitled "*Better information means better care*" .



Better information means better care

This leaflet contains important information about your health records.

You, and everyone who lives with you, should read this leaflet carefully. It is important that everyone knows how we share, protect and use information about their health.

You have a choice.

This leaflet is *not* about sharing your medical information with doctors, nurses and other health professionals outside of your GP surgery.
It's *not* about the ways in which your GP shares information about you as part of providing essential medical care.
It's *not* about ensuring that hospital specialists have the information that they need when you are referred to see them.
And it's *not* about submitting information so that GP surgeries and hospitals are paid appropriately for the care that they provide.

This leaflet is about care.data .

This website aims to provide straightforward information to everyone about care.data so that you can make an *informed* decision about opting out or not.

You'll know a lot more about care.data after reading this site than you did after just reading that junk mail leaflet. And you'll be in a much better position to make that decision.

If you do decide to opt-out, this site will tell you how to do so and the opt-out options that you have.

This website provides **facts, not opinion**. It's for **you** to decide whether to opt-out or not. This site will tell you what will be happening to your medical information and what control you have over the data flows to and from the HSCIC databases.

The Health and Social Care Information Centre (HSCIC) is not asking for your permission to extract and upload your data - they're forcibly taking your information.

Your information is not going to "the NHS" - it's going to a single organisation, the HSCIC.
They alone determine what happens to it next - *not you*.

There is no consent with care.data - the decision has been made for you, and for your GP surgery, by the HSCIC.
All you have is the *right to object* - the right to opt-out - and reverse the decision affecting *your* medical information.

care.data - another policy decision made for you, without you.

And you have to act **fast**, because once your data is uploaded you can **never** get it removed from the HSCIC databases.

Many *might* be happy to allow information from their GP record to be shared if they were asked first, if their data was completely anonymised before upload, if their data was only used within the NHS, and if their data was only used for the purpose of medical research. But, as you will discover, care.data respects none of that.

What's happening?

GP practices nationwide will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC).

Under the Health and Social Care Act 2012, GP practices have no choice but to allow the HSCIC to extract this information.

The Act removes any requirement to seek the consent of either patients or GPs before extracting and uploading the data.

This project, called *care.data*, is administered by the HSCIC using software and services provided by a private sector company called ATOS.

The HSCIC states that care.data extractions will now start from GP surgeries in Autumn 2014.

The HSCIC will administer the data, and states it intends to use it "for planning health services and for research".

This is known as **secondary uses** of your medical records.

Medical staff treating you in GP surgeries, hospitals, A&E, pharmacies and GP out-of-hours centres will not use, or be able to use, this database.

care.data is not about information sharing between healthcare professionals.

It is about data extraction, linkage and analysis: in other words, *data mining.*

A bit about data

care.data is *not* anonymous.

The identifable information uploaded from your GP records is known as the **Primary Care Dataset**.

Once uploaded, information *released* about you by the HSCIC can be divided into three main formats:

Anonymised and aggregate data, or as the HSCIC refers to it, **Green data**, is de-identified, so cannot be traced back to an individual. This is the only type of data that will be published openly by the HSCIC, on its website for example.

Pseudonymised data, or as the HSCIC refers to it, **Amber data**, is *potentially* identifiable. Pseudonymisation is a procedure by which the most identifying fields within a data record are replaced by one or more artificial identifiers, or pseudonyms. The pseudonyms render the data record *less identifying* whilst allowing tracking back of the data to its origins. There is a risk, small but real, that pseudonymised data could identify you, especially if that data is provided to organisations that already hold other data about you and can link the pseudonymised data to it. And especially if the pseudonymised data contains very large amounts of information, or very detailed and rich information - just like care.data does.

Clearly identifiable data, or as the HSCIC refers to it, **Red data**, is as its name suggests - clearly identifiable. The identifiers with the data mean that it is obvious that the data refers to you. This data is also known as **personal confidential data, or PCD**.

What information will be extracted from my medical records?

The data extracted - your **Primary Care Dataset** - will include the following:

- Your NHS number
- Your date of birth
- Your postcode
- Your gender
- Your ethnicity
- The date you registered with your GP surgery
- Your medical diagnoses (including cancer and mental health) and any complications
- Your referrals to specialists
- Your prescriptions
- Your family history
- Your vaccinations and screening tests
- Your blood test results
- Your body mass index (height/weight)
- Your smoking/alcohol habits

This information is clearly identifiable - the NHS number alone *uniquely identifies* you.

The identifiers (NHS number, DOB, postcode & gender) are *not* "stripped" - not before upload and not after your information arrives at the HSCIC.

Certain "sensitive" data will not be extracted in the initial upload (so-called **Release 1** of care.data).

For example:

- Details of infertility and assisted conception, such as IVF
- Sexually transmitted infections, including HIV, genital herpes, genital warts, chlamydia
- Abortions
- Gender identity matters, including reassignment
- Domestic, emotional, physical and sexual abuse

But it has already been stated that "this list might be reconsidered for a future phase of care.data".

Be aware that prescription items that could reveal sensitive data, such as medication for HIV or chlamydia, or hormonal treatment for infertility, *will* be uploaded.

You cannot modify in *any* way, the **Primary Care Dataset** extracted from your GP records and uploaded to care.data .
You cannot limit the information uploaded about you, e.g. not include certain diagnoses, or your smoking/alcohol habits, or certain medications.
You cannot "anonymise" the upload by removing the fields that identify you.

It's the full, *clearly identifiable* data upload - or nothing.

This extracted data will be combined with, or linked to, data extracted from any information about you held by hospitals, such as A&E attendances, operations or out-patient appointments, and which has already been uploaded to the HSCIC. The identifiable hospital data is known as Hospital Episodes Statistics (HES).

In addition, data from other settings where you may have received NHS care will, in due course, be added:

- community care
- mental health
- social care

This combined database will be known as Care Episodes Statistics (CES) and data from this can be released to organisations in green, amber and red data formats, that is in aggregated formats, anonymised formats, pseudonymised formats and clearly identifiable formats (under s251 of the NHS Act 2006, as detailed below).

CES (or more accurately, the CES linked dataset) is the care.data database - *your care.data record*.

Your GP data will continue to be uploaded, initially on a monthly basis, and added to the CES, effectively updating it. So any new diagnoses, medication prescriptions and results will be automatically uploaded and added to your care.data record at the HSCIC.

Your care.data record is *not* anonymised on storage at the HSCIC - it remains clearly identifiable as *your* information.

Your data disseminated - and sold

Information from your care.data record will be made available to organisations both within the NHS, such as NHS commissioning bodies (e.g. CCGs), but also outside of the NHS, such as :

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

The HSCIC charges money in exchange for providing data that it holds, especially if it contains personal confidential data - it *does sell* your information (the price list is here).

Once your data has been extracted and uploaded, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared or who has access to it.

Your GP will neither be the data controller nor any sort of "data controller in common" (with the HSCIC) for your uploaded information.

The HSCIC and NHS England will be *joint data controllers* for your uploaded information and will have total control over it.

Information from your care.data record may be released or sold to organisations in an aggregated form, an anonymised form, a pseudonymised form, or a clearly identifiable form under s251 approval.

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your care.data record, or from any other datasets that the HSCIC holds about you (such as HES).

Green data is special. Because it is de-identified, it no longer counts as personal data and so falls outside of the Data Protection Act. That means the HSCIC can give or sell *any* Green information extracted from your care.data record, when it likes, to *anyone* it chooses, for *any* purpose, and for whatever price.

You can, however, opt-out using the 9Nu0 code - this will ensure that

***no data whatsoever* is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Green data.**

You cannot prevent, or control in *any* way, the release or sale of pseudonymised, or **Amber**, information from your care.data record, or from any other datasets that the HSCIC holds about you (such as HES), even though such data is potentially identifiable.
Nor can you insist that it must not be released or sold to organisations *that may hold other information about you*.

You can, however, opt-out using the 9Nu0 code - this will ensure that *no data whatsoever* is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Amber data.

While the Health and Social Care Act 2012 empowered the HSCIC to collect and hold confidential data compulsorily from GP surgeries, this did not include the power to distribute this data in an identifiable form (i.e. as **Red data**) without a legal justification such as individual patient consent or Section 251 of the NHS Act 2006.

Section 251 can and will inevitably be used to disseminate clearly identifiable information from care.data to other organisations - so bypassing any requirement to seek your consent. It grants the Secretary of State for Health the legal authority to do this, for both research and non research purposes.

You cannot control when, to whom, at what price, or for what purpose, the HSCIC releases or sells personal, identifiable and confidential, or **Red**, information from your care.data record, or from any other datasets that the HSCIC holds about you (such as HES).

You can, however, *completely* block the release or sale of any of your HSCIC-held personal confidential data (see below).

And you can also opt-out using the 9Nu0 code - this will ensure that *no data whatsoever* is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Red data.

Any organisation - a government department, university researcher, pharmaceutical company or insurance company - can apply to the HSCIC to buy your care.data, including Red data under Section 251 (although their application may not be successful of course). The decision whether to release or sell your information - what information, to whom, in which format, at what price, and for what purpose - is made by the HSCIC, *not you*.

Organisations that have been previously granted access to sensitive identifiable health data held by the HSCIC include the Cabinet Office, Dr Foster Ltd, Capita PLC and BUPA.

No control without opt-out

For all three classes of data release, anonymised, pseudonymised and clearly identifiable:

- You will not be informed when *your* data has been shared or sold by the HSCIC
- You cannot approve or select the organisations that the HSCIC gives or sells your information to
- You cannot prohibit the release or sale of your information to non-NHS organisations, such as commercial or insurance companies
- You cannot select what information from your care.data record is released or sold, and what is not
- You cannot specify that information from your care.data record is only used for research purposes
- You cannot object to your information being provided or sold to particular organisations, or for particular research, that you find ethically unacceptable
- You cannot object to your information being provided or sold to organisations who might already hold other information about you

The *only* control that you have over data that the HSCIC holds, or might hold, about you is to opt-out of care.data.

When you opt-out, your GP will add either or both of two codes, "electronic flags", to your GP records, known as 9Nu0 and 9Nu4.

One flag, known as **9Nu0**, will ensure **no information whatsoever** from your GP record is *uploaded* to care.data.

With this flag in place, **no data whatsoever** from your GP record will be uploaded to the HSCIC, and so no data from your GP record can be released or sold, in any format (Green, Amber or Red).

The other flag, known as **9Nu4**, will ensure that *any* data held by the HSCIC, whether extracted from your GP record (if you haven't opted out) or other sourced data (such as HES, mental health, social care), will not be released or sold to any organisation in a *clearly identifiable (Red) format*.

Be aware that the 9Nu4 code does *not* stop the release or sale of:

- anonymised/aggregate, or Green, data
- pseudonymised (potentially identifiable), or Amber, data

To prevent those, you must ensure that no GP information whatsoever is uploaded to the HSCIC *in the first place* - by means of the 9Nu0 code.

You cannot, however, prevent the release or sale of Green or Amber data from your HES record.

care.data and medical research

Opting out of care.data will have no effect on *completely anonymised* information about you being shared within the NHS to help medical research.

As it always has been.

Opting out of care.data **in no way** prevents you from agreeing - with your *explicit consent* - to partake in high-quality medical research based at your GP surgery, particularly if your surgery is a Research Ready accredited practice.

Participation in such research is only ever with your full, explicit consent, and *you* choose the type of research that you wish to be contribute to, and the organisation that *you* allow your medical information to be shared with.

care.data and your direct medical care

Opting out of care.data will have *no effect* on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

Opting out of care.data will have *no effect* on your GP surgery and the way that it is paid by the NHS or on the services that it provides.

Opting out of care.data will have *no effect* on the way that any hospital is paid by the NHS for treating you.

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.

Opting out of care.data will have **absolutely no effect whatsoever** on the way that your GP provides your medical care.

It will not affect your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.

It will not stop the NHS organising programmes such as diabetic retinopathy screening, as these are *not* secondary uses of your data but primary uses required for your direct clinical care.

If you opt-out of care.data, you can still be referred to a specialist under Choose & Book, your surgery can still manage your prescriptions via the Electronic Prescription Service, you can continue to request your prescriptions online, continue to email your GP or surgery and continue to access your medical records online (if you are offered that facility).

Opting out of care.data will have no effect whatsoever on your relationship with your GP surgery.

Whether or not you opt-out is immaterial to your GP.

And you certainly don't need your GP's approval or permission to opt-out of care.data .

Can I get my uploaded information deleted?

If you do nothing, i.e. you do not opt-out, then your medical information *will* be extracted and uploaded to the HSCIC.

The HSCIC has no intention of *ever* deleting your care.data. In fact, your care.data record will be added to on a regular basis by ongoing uploads from your GP records (unless you opt-out).

You *cannot* - ever - get your uploaded data deleted.

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care.data and the Summary Care Record (SCR) are two entirely separate projects

The Summary Care Record (SCR) is a national centralised database of medical information (allergies and medication, initially) extracted and uploaded from patients' GP records. This project's aims are to make this information potentially available to emergency doctors (in A&E and GP out-of-hours centres countrywide).

For further information about the Summary Care Record, please see my other site.

As regards the Summary Care Record:

- It concerns *direct clinical care*
- You may have recently received a *personalised* letter from your local CCG about the Summary Care Record
- Your GP surgery may not be able to tell you exactly *when* they will commence uploading Summary Care Records

care.data is very different to the Summary Care Record:

- The information extracted for care.data **far exceeds** just allergies and medication
- The information uploaded to care.data will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- care.data does **not** concern clinical care, it is an administrative and research database
- Patients will **not** be written to individually about care.data, although a national leaflet drop is underway (see below)
- We know that this project **will** go ahead everywhere shortly, with data extractions planned for "Autumn 2014"

You will still need to opt-out to prevent care.data uploads even if you have already opted out of The Summary Care Record.

Summary Care Record opt-outs will not prevent care.data uploads.

Opting out of one database does not mean that you have automatically opted-out of the other.

You can have a Summary Care Record but opt-out of care.data

You can agree to care.data extractions but opt-out of the Summary Care

Record

- You can both have a Summary Care Record and allow care.data extractions
- You can opt-out of both databases and allow neither
- Or you can opt-out of one but allow the other

Opting out of either database, or both, will not in any way affect the medical care that you receive from your GP surgery.

Opting out of care.data

When can I opt-out of my GP data upload?

You can request that the codes are added right now, *before* extractions and uploads to care.data have begun, or you can request that the codes are added at any time thereafter.

The 9Nu0 opt-out

If the 9Nu0 opt-out code is added *before* your initial GP dataset upload (provisionally scheduled for Autumn) then:

- *No data whatsoever* from your GP record will be uploaded to care.data
- *No data whatsoever* from your GP record will be present within your care.data record
- As long as that opt-out code (9Nu0) remains in force, no data whatsoever from your GP record will *ever* be uploaded to care.data

If the 9Nu0 opt-out code is added *after* your initial GP dataset upload (after March), or subsequent to any monthly GP uploads to your care.data record, then:

- Identifiable data from your GP record *will* be present within your care.data record
- The uploaded identifiable data will *never* be deleted
- That data will always be able to be released or sold in Green, Amber and (unless you have the 9Nu4 in force) Red formats
- There is absolutely nothing you can do about your data, Red, Amber or Green, that has *already* been given or sold to other organisations
- As long as that opt-out code (9Nu0) remains in force, no *further* data from your GP record will be uploaded to care.data
- But you can never put yourself into the position that you would have been had you opted out *before* uploads commenced

The 9Nu4 opt-out

Your personal confidential data, as held by the HSCIC, and from whatever source, *can* be released, *is already being released*, and *will* be released in a clearly identifiable format (PCD or "Red" data), as detailed above.

As soon as the 9Nu4 opt-out code is added to your GP record and transmitted to the HSCIC, then *no further clearly identifiable data releases about you will occur from the HSCIC*.

An opt-out *now* means an opt-in - when *you* want

If you opt-out now, you can opt-in at any time in the future, if *you* want, when *you* want, at a time of *your* choosing.

Perhaps *if and when* care.data has been changed so that :

- people are asked for their *explicit consent* before their personal information is uploaded
- all your data will be completely anonymised *before* upload
- all information about you is completely anonymised *before* release by the HSCIC
- your information will *only* be released by the HSCIC to organisations within the NHS
- your information will *only* be released by the HSCIC to publicly funded and not-for-profit research organisations
- your information will *only* be released by the HSCIC for limited or strictly defined medical research purposes
- your information will *never* be released by the HSCIC to 3rd parties such as commercial organisations, pharmaceutical firms and insurance companies
- your information will *not* be released by the HSCIC to organisations who are looking to take over and privatise existing NHS services
- your information will *not* be sold
- any uploaded information about you can be deleted *at your request and at any time*
- you can *genuinely* control how your uploaded information will be used - to whom it is given, in what format, for what purpose, and for how long

When any, or all, of the above, or any other requirements that *you* want met are reliably in place, then *you* can choose to opt back in.

Until then, opting out will ensure that your GP information will not be used in ways that are unacceptable to you.

How do I opt-out?

If you have decided to opt out of care.data then it's very easy to do so.

First, download an opt-form:

- Here is a .pdf leaflet, which can be printed double-sided and folded (fits in a DL envelope)
- Here is a .doc leaflet, which can be filled in on your PC and either printed or emailed to your GP surgery (if they allow you to email them)
- An opt-out form available in .pdf, .doc or .rtf format is available from medConfidential
- Your GP surgery may have its own opt-out form downloadable from its website.

There is no "official" or mandatory opt-out form that you are obliged to use, whether produced by the HSCIC or anyone else.

It doesn't matter which form you use.

Make sure that you **haven't** been given, or downloaded, a Summary Care Record opt-out form by mistake.

Fill a form in, and hand it into, post it to, or fax it to your GP surgery.

You do not, however, have to fill in a form to opt-out of care.data .

You can just write a letter to your practice:

- State that you wish to opt-out of care.data
- Request that both the **9Nu0 and 9Nu4** codes are added to your GP records
- Remember to include full names and DOBs (and your address if you are happy to)

If you think that you GP surgery might not be fully aware of their obligations under care.data then add this to your letter:

"Please see the 'BMA FAQs - care.data guide for GP practices' document, at ***www.tinyurl.com/cdgpfaqs*** *, for information about care.data and the relevant read codes"*

If your GP surgery has enabled you to use EMIS Access, then you can use the secure messaging system within that to let your GP know that you wish to opt-out of care.data .

Alternatively, you can tell your GP that you wish to opt-out the next time that you see him or her (if you have an appointment planned for the near future). (Don't make an appointment to see him or her just to opt-out though, please!)

Remember to opt-out your children, or those for whom you have parental responsibility, as well.
Your children's medical records will be uploaded too unless you opt them out.

Ensure that you make your opt-out wishes known to your GP surgery. No-one else can add the electronic flags to your GP records.

Do not send your opt-forms or letters to the HSCIC.

Remember: if you opt-out now you can opt-in at at any time in the future - *if* you are happy to, *when* you are happy to, and at a time of *your* choosing. It's your data, you should be in control.

If you do opt back in to care.data, your GP will add different electronic flags that will permit uploading to care.data and/or the release of other clearly identifiable information from the HSCIC to organisations.

In summary

Consent plays no part in care.data .
All you have is the right to object: the right to opt-out.It is the *only* way to have any control over your information.

You cannot modify in *any* way, the **Primary Care Dataset** extracted from your GP record and uploaded to care.data .
The information uploaded from your GP record is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.

Information from your combined care.data record may be released to organisations in an aggregated or anonymised form, a pseudonymised form, or a clearly identifiable form.

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your care.data record.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot prevent, or control in *any* way, the release sale of pseudonymised, or **Amber**, information from your care.data record.
Amber data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot control when, to whom, or for what purpose, the HSCIC releases or sells personal, clearly identifiable and confidential, or **Red**, information from your care.data record.
Red data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You *can* additionally prevent *all* releases of your personal confidential data: by means of the 9Nu4 opt-out code.
The 9Nu4 code will block the release or sale of personal confidential data from *any* source of information that the HSCIC has about you, such as HES.

If you're still unsure about what to do...look at this flowchart.

Feel free to send me *constructive* comments about this site.

Neil.Bhatia@nhs.net

I will read every comment sent, though please do not be offended if I do not reply to your message.

Privacy policy: I will not sell, trade or otherwise transfer to any third parties your personally identifiable information (your email address or the content of your email)

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

Detailed information about care.data can be found at www.care-data.info

Last updated: 28.02.14

This website does not accept or host any advertising.

This website does not use cookies.

Data Linkage and Extract Service

Service Charges 2013/14

Introduction

The HSCIC is publicly funded and we therefore operate on a cost recovery basis. We do not charge for data itself but we do apply charges to cover the costs of processing and delivering our service. Where possible, HSCIC data is made available as open data.

Product descriptions

The table below provides a brief description of the products we provide. Further details are available via our web page at www.hscic.gov.uk/dles

Product	**Description**
Tabulation	A statistical table of aggregate data.
Bespoke extract - pseudonymised	A one-off extract tailored to the customer's requirements of specified data fields containing no patient identifiable or sensitive data.
Bespoke extract - containing personal confidential data	A one-off extract tailored to the customer's requirements of specified data fields containing patient identifiable data, sensitive data items or both.
Standard extract	Cumulative data for the financial year to date, delivered on a monthly basis via a subscription service. Users sign up to receive a year's worth of data, delivered in monthly increments
Bespoke data linkage	A bespoke service linking one or more data sets held by the HSCIC to data supplied by the customer.
Patient status and/or tracking	Products designed to enable customers to receive one-off or on-going notifications of mortality and morbidity events affecting a specified patient cohort.
List cleaning	Validating demographic data to ensure it is accurate and improve linkage outcomes.

Charges

Charges vary according to the type of product and the data sets required as these factors determine the amount of effort and approvals required.

The table below provides indicative charges for the different elements of each product. Actual costs will be confirmed during the application process and formally agreed before processing work commences.

To discuss your requirements and gain advice on making an application, please contact the HSCIC contact centre, tel: 0845 300 6016 or email: enquiries@hscic.gov.uk.

Charges list

Product	Application and Set Up[1]		Annual Service Charge[2]		Processing		Report	
Tabulation	£630		£0		Simple[3] [Complexity]	£198	£0	
					Medium[4]	£318		
					Complex[5]	£516		
Standard extract – no personal confidential data	No ONS data	£630	£0		Single data set	£9,565	£0	
	Including ONS data	£948			Per additional data set	£1,894		
	Including MHMDS data	£1130						
Standard extract – containing personal confidential data	No ONS data	£1,094	£0		Single data set	£10,453	£0	
	Including ONS data	£1,412			Per standard data set	£2,782		
	Including MHMDS data	£1594						
Bespoke extract – no personal confidential data	No ONS data	£630	No ONS data	£0	Per data set for 1 year[6]	£262	£0	
	Including ONS data	£948	Including ONS data	£300	Per additional year (per data set)	£64		
					Premium for SUS-PBR data only	£250		
					Premium for MHMDS data only	£500		
Bespoke extract – containing personal confidential data	No ONS data	£1,094	£300		Per data set per year	£262	£0	
	Including ONS data	£1,412			Per additional year (per data set)	£64		
Bespoke data linkage	No ONS data	£832	£300		Standard automated linkage (per file)[7]. A bespoke extract processing fee may also apply.	£247	£0	
	Including ONS data	£1,150			Per data set for 1 year	£262		
					Per additional year (per data set)	£64		
List cleaning	No ONS data	£1,346	£0		Standard automated linkage (per file)	£247	£0	
	Including ONS data	£1,664			Manual match (per record)	£2.26		
Patient status	No ONS data	£1,346	No ONS data	£50	Standard automated linkage (per file)	£247	Cohort event notification report	£0
	Including ONS data	£1,664	Including ONS data	£100	Manual match (per record)	£2.26	Cause of death report	£45.45
					Ad hoc trace (per record)	£3.78		
Patient tracking	No ONS data	£1,346	£300		Standard automated linkage (per file)	£247	Cohort event notification report (per report)	£52.09
	Including ONS data	£1,664			Manual match (per record)	£2.26	Cause of death report (per report)	£45.45
					Ad hoc trace (per record)	£3.78		
Amendment to patient tracking requirements	£324		£0		£0		£0	

Notes:

1. These fees will be charged for all new requests requiring a Data Sharing Contract (DSC) or other formal agreement such as a Data Reuse Agreement (DRA). Amendments to existing orders or additional reports provided under existing contracts will not incur these charges a second time unless a new DSC/DRA is required as a consequence. If multiple products are being requested simultaneously (e.g. Patient Tracking with cohort linkage to other data sets such as HES, or Standard Extract with Bespoke Extracts to obtain backdated data from previous years), only one application and set up fee will be applied. In circumstances where a new DSC/DRA is not required, an amendment fee may be applied.

2. Where a fee is indicated, this is payable on an annual basis until the data supplied by the HSCIC (including all hard or soft copies of the same) has been destroyed and certified as such by returning a Certificate of Destruction to the HSCIC. This fee is to recover the administrative costs of maintaining approvals for the on-going provision of and/or the on-going reuse of data supplied by the HSCIC.

3. A request is classed as ‘simple’ if specification, production and checking are expected to take less than 5 hours.

4. A request is classed as ‘medium’ if specification, production and checking are expected to take less than 7 hours but more than 5.

5. A request is classed as ‘complex’ if specification, production and checking are expected to take less than 12 hours but more than 7.

6. Most data sets comprise of yearly sub-sets (normally April-March) and customers must specify the years they require. Processing charges are applied per data set and per year required from each data set. Typically the first year of each data set is charged at £262 and subsequent years are charged at a discounted rate. ONS mortality data is one of the exclusions as that data set is not separated into sub-sets by year.

7. This covers the cost of linkage to the HESID index to which other data sets are routinely linked.

Other fees that may be applied include:

Product	**Cost**	**Explanation**
ICD coding	£1.40 per case	For death records not coded to the International Statistical Classification of Diseases and Related Health Problems (ICD) 10th revision, the HSCIC can facilitate the manual coding by ONS. The fee charged per record coded by ONS is recharged to the customer by the HSCIC.
Cross-border linkage (Scotland)	Fees charged by NHS Central Register Scotland will be recharged to the customer by the HSCIC.	For patient status and patient tracking, cross-border linkage enables seamless coverage of cohort members whether registered in England and Wales or Scotland.
DVD production and delivery	£300	Our standard practice is to dispatch data using a Secure Electronic File Transfer system. If there are legitimate reasons why data should be loaded onto a DVD, this fee will be charged covering the production process and secure delivery.
Postage costs	As per Royal Mail charges	Our standard practice is to dispatch data using a Secure Electronic File Transfer system. Should your request involve outputs being issued via post, we will recharge postage costs incurred.
Professional effort	Provided on request	The costs of ad hoc activities not covered in the product list above.

You will be notified in advance if any such fees apply to the product(s) you request.

Royal Mail contract for care.data junk mail leaflet

Phil Booth made this Freedom of Information request to NHS England

The request was **successful**.

From: Phil Booth

1 February 2014

Dear NHS England,

I would like to make a request under the FOI Act.

For the purposes of the Act, please take the date of your receipt of this request as 1st February 2014.

Please would you provide the following:

1) A copy of NHS England's contract with the Royal Mail for delivering the junk mail leaflet 'Better information means better care' to households across England;

2) Documentary evidence that NHS England engaged the "exceptional circumstances" referred to on the webpage http://www.royalmail.com/personal/help-a... in order to override the preferences of those people who had opted out of receiving Royal Mail direct mail.

I would be grateful if you would send me the requested information promptly and in any event not later than the twentieth working day following the date of receipt of my request.

If my request is denied in whole or in part, or specific items within the responses are withheld from disclosure, then you must justify all deletions by reference to specific exemptions of the Act, as per Section 17 of the Act. Where you rely on a qualified exemption to withhold disclosure, you are obliged to consider the public interest in your decision and the refusal notice must explain not only which exemption applies and why, but also the public interest arguments addressed in reaching the decision.

Yours faithfully,

Follow this request

There are 2 people following this request

Follow

RSS feed of updates

Offensive? Unsuitable?

Requests for personal information and vexatious requests are not considered valid for FOI purposes (read more).

If you believe this request is not suitable, you can report it for attention by the site administrators

Report this request

Act on what you've learnt

Tweet this request

Start your own blog

Get help investigating

Write to your politician

Pledge with others

Similar requests

Patient involvement in

Phil Booth

From: Contactus England (HEALTH AND SOCIAL CARE INFORMATION CENTRE)

3 February 2014

Thank you for contacting NHS England.

Your Freedom of Information (FOI) request, which we received on 1 February 2014 has been allocated a reference number of SDR 205033. Please quote this reference in any further communication regarding this matter.

Your FOI request has been passed to the Case Management Team and a Case Officer will acknowledge your request within two working days. We will respond to your FOI request within 20 working days in line with the FOI Act 2000.

If you require any further information or wish to speak to someone about your request, please contact NHS England at the email address and telephone number shown below.

Yours Faithfully

NHS England

PO Box 16738 | Redditch | B97 9PT

0300 3 11 22 33

[1][email address]

[2]www.england.nhs.uk

show quoted sections

From: FOI England (NHS ENGLAND)

3 February 2014

Our reference: SDR-205033: Acknowledgement

the co-design of care.data

To NHS England by Phil Booth 30 January 2014

Qu 1 of 2 re NHS Choices Care Connect service: cost

To NHS England by William 4 January 2014

Data security

To NHS England by Norman barrett 30 January 2014

Inquest Data

To NHS England by fiona bell 26 January 2014

Agency spend for admin and clerical staff april 2013- present

To NHS England by Jessica Keen 14 January 2014

Prison Health Performance and Quality Indicators

To NHS England by Steve Joseph 29 January 2014

NHS procurement

To NHS England by Altaf 28 May 2013

Devon Health Ltd

To NHS England by Bianca Haworth 18 June 2013

Treatment protocol supplemental guidelines

To NHS England by Henry Hall 1 August 2013

SUS Data Protection Compliance

To NHS England by Tim Turner 4 February 2014

More similar requests

Event history details

Are you the owner of any commercial copyright on this page?

Dear Mr Booth,

Thank you for your Freedom of Information (FOI) request, dated 1 February 2014.

Please be assured that your request is being dealt with under the terms of the Freedom of Information Act 2000 and will be answered within twenty working days.

If you have any queries about this request or wish to contact us again, please email [1][email address] and the message will be forwarded appropriately. Please remember to quote the above reference number in any future communications.

Please do not reply directly to this email. This message has been sent from a central mailbox and incoming messages will not be received.

Yours sincerely,

Michelle Butterworth

Freedom of Information

NHS England

Tel: 0300 311 2233

Email: [2][email address]

Website: [3]www.england.nhs.uk

Address: NHS England, PO Box 16738, REDDITCH, B97 9PT

show quoted sections

References

Visible links
1. mailto:[email address]
2. mailto:[email address]
3. http://www.england.nhs.uk/

From: FOI England (NHS ENGLAND)

20 February 2014

Dear Mr Booth,

Re: Freedom of Information request (Our Ref: SDR 205033)

Thank you for your Freedom of Information (FOI) request dated 1 February 2014.

Your exact request was:-

1) A copy of NHS England's contract with the Royal Mail for delivering the junk mail leaflet 'Better information means better care' to households across England;

2) Documentary evidence that NHS England engaged the "exceptional circumstances" referred to on the webpage [1]http://www.royalmail.com/personal/help-a...

in order to override the preferences of those people who had opted out of receiving Royal Mail direct mail."

NHS England holds some information relevant to your request.

In response to Question 1, NHS England contracted The Leaflet Company to arrange the Royal Mail door drop distribution. This was bound by the Royal Mail's Terms & Conditions, which we have attached for you reference.

In response to Question 2, NHS England did not seek for the leaflet to be classified as being 'exceptional circumstances' as we understood that the leaflet would not qualify. This means that the leaflet has not been delivered to households that have registered with the Royal Mail's 'door to door opt-out'. The leaflet has been delivered to households where an individual has registered with the Mail Preference Service.

I hope this information is helpful. However, if you are dissatisfied, you have the right to ask for an internal review by writing to us, within two months of the date of this letter, to:

NHS England

PO Box 16738

REDDITCH

B97 9PT

Email: [2][email address]

Please quote the reference number SDR 205033 in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner's Office (ICO) can be contacted at:

The Information Commissioner's Office

Wycliffe House

Water Lane

Wilmslow

Cheshire

K9 5AF

Telephone: 0303 123 1113

Email: [3][email address].uk

Website: [4]www.ico.gov.uk

Please note there is no charge for making an appeal.

Please do not reply directly to this email. This message has been sent from a central mailbox and incoming messages will not be received.

Yours sincerely,

Michelle Butterworth

Freedom of Information

NHS England

Tel: 0300 311 2233

Email: [5][email address]

Website: [6]www.england.nhs.uk

Address: NHS England, PO Box 16738, REDDITCH, B97 9PT show quoted sections

References

Visible links
1. http://www.royalmail.com/personal/help-a...
2. mailto:[email address]
3. mailto:[email address]
4. http://www.ico.gov.uk/
5. mailto:[email address]
6. http://www.england.nhs.uk/

Things to do with this request

Anyone:

- Add an annotation (to help the requester or others)
- Download a zip file of all correspondence

Phil Booth only:

- Write a reply
- Update the status of this request
- Request an internal review

NHS England only:

- Respond to request

Health & Social Care
Information Centre

1Trevelyan Square
Boar Lane
Leeds
LS1 6AE

Tel: 0845 300 6016
Fax: 0113 254 7239

enquiries@hscic.gov.uk
www.hscic.gov.uk

16th December 2013

Our ref: NIC-235118-Y6V0P

Dear Dr Bhatia,

Re: Information Request – Freedom of Information Act (FOIA) 2000

I can confirm that the Health and Social Care Information Centre (HSCIC) has considered your query dated the 22nd November 2013.

Please could you provide me with an estimate of the total cost of the care.data programme, to date.

Thank you for your request. Section 12 of the FOIA provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit. The Fees Regulations state that this cost limit is £450 (or 18 hours) for public authorities such as the HSCIC.

The HSCIC is in the process of agreeing the scope of the care.data programme and the associated funding required with NHS England (as the lead commissioner) and with the wider members of the Informatics Services Commissioning Group. The programme will bring together activity that to date has been spread across a number of existing projects and operational teams within the HSCIC and it is estimated that to locate, extract and retrieve the requested information would require more than 18 hours work.

Therefore, in this case, the HSCIC is exempt from the obligation to answer any further aspects of your request under Section 12 of the FOIA, as to do so would exceed the 18 hour cost limit.

If you are able to modify or limit your request in any way which would allow us to extract the information you require, please resubmit your request.

I hope you understand the reasons why we are unable to supply the information requested. However, if you are not satisfied, you may request a review from a suitably qualified member of staff not involved in the initial query, via the enquiries@hscic.gov.uk e mail address or by post at the above postal address.

Yours sincerely

James Smith
Higher Information Governance Officer

Further information about your right to complain under the Freedom of Information Act is available from the Information Commissioner's Office, Wilmslow, Cheshire, and on The Information Commissioner's website www.ico.gov.uk.

The Health and Social Care Information Centre values customer feedback and would appreciate a moment of your time to respond to our Freedom of Information (FOI) Survey to let us know about your experience. Please access the survey through this link: https://www.surveymonkey.com/s/HSCIC_FOI_Feedback

hscic Health & Social Care Information Centre

1Trevelyan Square
Boar Lane
Leeds
LS1 6AE

Tel: 0845 300 6016
Fax: 0113 254 7239

enquiries@hscic.gov.uk
www.hscic.gov.uk

Our ref: **NIC-239330-P9L3R** 17th January 2014

Dear Dr Bhatia

Re: Information Request – Freedom of Information Act (FOIA) 2000

I can confirm that the Health and Social Care Information Centre (HSCIC) has considered your query dated the 18th December 2013.

“Please could you kindly send me the business case for the care.data programme, as submitted to HM Treasury.”

Thank you for your enquiry. I can confirm that a business case for the care.data programme has not been submitted to HM Treasury as yet.

In line with the Information Commissioner’s directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the HSCIC website.

I hope you understand the reasons why we are unable to supply the information requested. However, if you are not satisfied, you may request a review from a suitably qualified member of staff not involved in the initial query, via the enquiries@hscic.gov.uk e mail address or by post at the above postal address.

Yours sincerely,

Julie Shippen
Higher Information Governance Officer

Further information about your right to complain under the Freedom of Information Act is available from the Information Commissioner’s Office, Wilmslow, Cheshire, and on The Information Commissioner’s website www.ico.gov.uk.

The Health and Social Care Information Centre values customer feedback and would appreciate a moment of your time to respond to our Freedom of Information (FOI) Survey to let us know about your experience. Please access the survey through this link

https://www.surveymonkey.com/s/HSCIC_FOI_Feedback

care.data

This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

This site tells you all about care.data.

It's a detailed and comprehensive site, with links and references.

If you just want the basic facts - the bare essentials - look at: brief.care-data.info

If you've already decided that you want to opt-out, then look at: optout.care-data.info

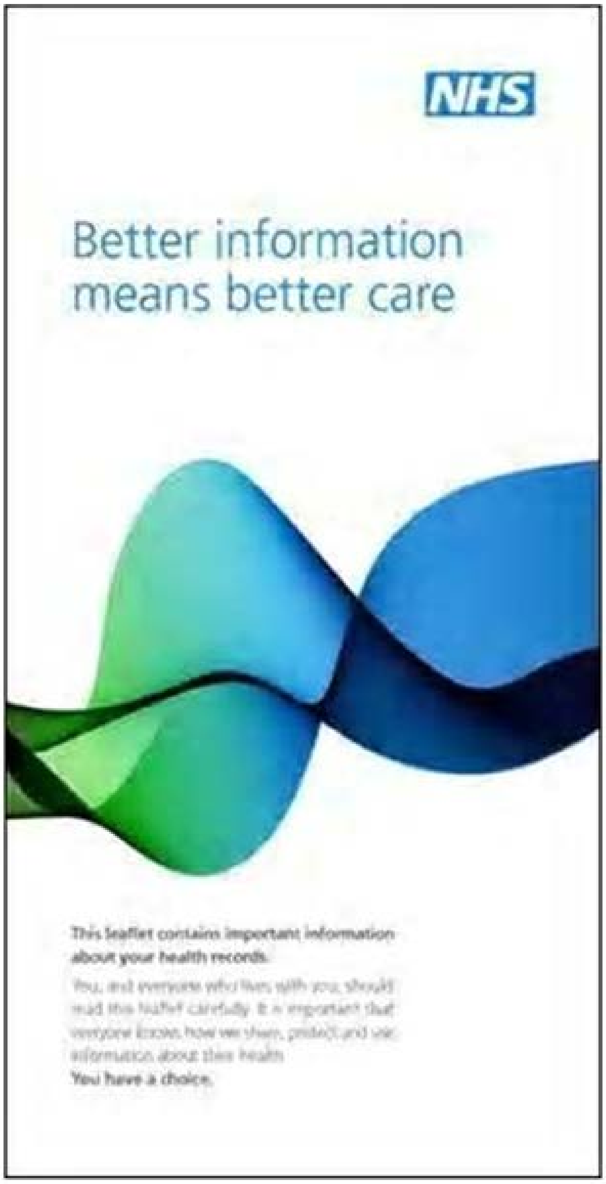
If you're still unsure about opting out then maybe look at this flowchart.

Index to sections

This web site

care.data is going to begin soon, and it will affect every man, woman and child in England and their confidential medical records.

All households in England should have received a junk mail leaflet through their letterbox about this programme, entitled "*Better information means better care*" .



NHS

Better information means better care

This leaflet contains important information about your health records.

You, and everyone who lives with you, should read this leaflet carefully. It is important that everyone knows how we share, protect and use information about their health.

You have a choice.

This leaflet is *not* about sharing your medical information with doctors, nurses and other health professionals outside of your GP surgery.
It's *not* about the ways in which your GP shares information about you as part of providing essential medical care.
It's *not* about ensuring that hospital specialists have the information that they need when you are referred to see them.
And it's *not* about submitting information so that GP surgeries and hospitals are paid appropriately for the care that they provide.

This leaflet is about care.data .

Not that you'd know, since "care.data" is never mentioned in the leaflet.

And if you have registered with Royal Mail's Door to Door junk mail opt-out then you will not have received the leaflet at all.

The Health and Social Care Information Centre (HSCIC) is not asking for your permission to extract and upload your data - they're forcibly taking your information.

Your information is not going to "the NHS" - it's going to a single organisation, the HSCIC.
They alone determine what happens to it next - *not you*.

There is no consent with care.data - the decision has been made for you, and your GP surgery, by the HSCIC.
All you have is the *right to object* and reverse the decision affecting your medical information.

care.data - another policy decision made for you, without you.

You have to act if you wish to preserve your confidentiality. Unless you do, care.data will go ahead and involve *your* GP records by default.

And you have to act **fast**, because once your data is uploaded you can **never** get it removed from the HSCIC databases.

Many *might* be happy to allow information from their GP record to be shared if they were asked first, if their data was completely anonymised before upload, if their data was only used within the NHS, and if their data was only used for the purpose of medical research. But, as you will discover, care.data respects none of that.

This website aims to provide information to everyone about care.data so that you can make an *informed* decision about opting out or not.

You'll know an awful lot more about care.data after reading this site than you did after just reading that junk mail leaflet. And you'll be in a much better position to make that decision.

If you do decide to opt-out, this site will tell you how to do so and the opt-out options that you have.

This website provides **facts, not opinion**. It's for **you** to decide whether to opt-out or not. This site will tell you what will be happening to your medical information and what control you have over the data flows to and from the HSCIC databases.

If you want to read about why NHS England and the HSCIC believe that you should not opt-out of care.data, then please visit their sites (links below).

The information provided on this site is designed to complement, not replace, any guidance or advice about care.data provided by your own GP surgery.

It is easy to opt out of care.data

Please do not make an appointment with your GP, or ring your surgery, just to opt-out. You do not need to.

Just hand in, post, or fax an opt-out form or a letter to your GP surgery.

That's it. Simple. No questions asked.

Don't forget to opt-out your children as well.

Back to index

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care.data in a nutshell....

- care.data is *not* anonymous
- Sensitive and identifiable information is going be extracted from your GP records and uploaded to Health and Social Care Information Centre (HSCIC) databases
- Sensitive and identifiable information *has already been extracted*, and will continue to be extracted from your hospital records and uploaded to HSCIC databases
- You will *not* be asked for your explicit permission or consent before these extractions take place
- The two sets of your information will be combined into one database and subsequently released, in various formats, to organisations within and outside of the NHS, for the purposes of administration, healthcare planning and research
- The HSCIC charges for releasing information to organisations, especially identifiable information - it sells data
- The information is *not* going to be available to doctors and nurses, and so will not be used to provide direct medical care
- The HSCIC will keep your uploaded information *indefinitely* - it will never be deleted, but continuously added to
- You *cannot* prevent the HSCIC from releasing information uploaded about you in anonymised or potentially identifiable formats
- You *cannot* control when, to whom, for what purposes, and what specific

information the HSCIC releases about *you* from *your* care.data record
- Opting out, with either or both of the opt-out options, is the *only* way to have any control at over how the HSCIC use, or will use, your personal data
- Your GP surgery *cannot* stop this extraction - but you, as an individual, can
- You *can* prevent the extraction and uploading of *any* data from your GP record to the HSCIC by asking your GP surgery to put a special code in your GP records
- You *can* prevent the release of your *clearly identifiable* data from the HSCIC by asking your GP surgery to put an additional special code in your GP records
- If you opt-out of care.data (now), you can opt back in at any time in the future
  There is no deadline by which you must opt back in by
- care.data is *not* the same as the Summary Care Record - opting out of one does *not* mean that you have automatically opted out of the other

You *can* control your GP records - if you know how.

See this chart (tinyurl.com/mygprecords) for guidance, and contact your GP surgery if you need further information about any of the data flows.

Back to index

care.data - what is going to happen?

GP practices nationwide will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC).

Under the Health and Social Care Act 2012, GP practices have no choice but to allow the HSCIC to extract this information.

The Act removes any requirement to seek the consent of either patients or GPs before extracting and uploading the data.

This project, called *care.data*, is administered by the HSCIC using software and services provided by a private sector company (ATOS).

When will this take place?

The HSCIC states that care.data extractions will now start from GP surgeries in Autumn 2014 (it has been delayed twice now).

How much is care.data costing the taxpayer?

No one knows. The HSCIC has refused to detail the full costs of the programme to date.

A business case for the care.data programme has not yet been submitted to HM Treasury.

It is likely to cost in excess of £50 million though.

ATOS are being paid about £8 million, over 5 years, to provide the infrastructure (known as GPES) to extract care.data from GP systems.

Where's my data going and what's its purpose?

The data will be stored on HSCIC national servers and not on GP systems.

The HSCIC will administer the data, and states it intends to use it "for planning health services and for research".

This is known as "secondary uses" of your medical records.

How does the HSCIC think that care.data will be of benefit to the NHS?

The HSCIC believes that care.data will help:

- find more effective ways of preventing, treating and managing illnesses
- guide local decisions about changes that are needed to respond to the needs of local patients
- support public health by anticipating risks of particular diseases and conditions, and help to take action to prevent problems
- improve the public's understanding of the outcomes of care, giving them confidence in health and care services
- guide decisions about how to manage NHS resources so that they can best support the treatment and management of illness for the benefit of patients

Will doctors and nurses treating me have access to this information?

NO.

Medical staff treating you in GP surgeries, hospitals, A&E, pharmacies and GP out-of-hours centres will not use, or be able to use, this database.

care.data is not about information sharing between healthcare professionals.

It is about data extraction, linkage and analysis: in other words, *data mining.*

Will medical staff with an NHS Smartcard be able to access my uploaded care.data?

NO.

NHS Smartcards are used to access software systems that help provide direct clinical care, for example the Summary Care Record, the Personal Demographics Service, Choose & Book and the Electronic Prescription Service.

NHS Smartcards will not permit access in any way to care.data uploaded to the HSCIC.

care.data is not about the provision of direct medical care by clinical staff.

A bit about data

care.data is *not* anonymous.

The identifiable information uploaded from your GP records is known as the **Primary Care Dataset**.

Once uploaded, information *released* about you can be divided into three main formats:

Anonymised and aggregate data, or as the HSCIC refers to it, **Green data**, is de-identified, so cannot be traced back to an individual. This is the only type of data that will be published openly by the HSCIC, on its website for example.

Pseudonymised data, or as the HSCIC refers to it, **Amber data**, is *potentially* identifiable. Pseudonymisation is a procedure by which the most identifying fields within a data record are replaced by one or more artificial identifiers, or pseudonyms. The pseudonyms render the data record *less identifying* whilst allowing tracking back of the data to its origins. There is a risk, small but real, that pseudonymised data could identify you, especially if that data is provided to organisations that already hold other data about you and can link the pseudonymised data to it. And especially if the pseudonymised data contains very large amounts of information, or very detailed and rich information - just like care.data does.

Clearly identifiable data, or as the HSCIC refers to it, **Red data**, is as its name suggests - clearly identifiable. The identifiers with the data mean that it is obvious that the data refers to you. This data is also known as **personal confidential data, or PCD**.

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The data uploaded from your GP records

Will my Primary Care Dataset be anonymised before it is uploaded from my GP surgery?

NO.

The information will be extracted from your GP surgery in a form that can clearly identify you as the patient that the data refers to.
It is personal confidential data.

In other words, *it will not be anonymised, pseudonymised or de-identified before it is uploaded*.

- If it was anonymised, you wouldn't be able to opt-out
- If it was anonymised, the leaflet wouldn't state "*If you do not want information that identifies you to be shared outside your GP practice, please ask the practice to make a note of this in your medical record*"
- If it was anonymised, the HSCIC wouldn't be able to easily link it to further identifiable data about you that it holds extracted from hospitals - the whole objective of care.data
- If it was anonymised, you wouldn't be able to make a Subject Access

Request for information that the HSCIC holds about *you*

And if it was anonymised, your GP would not be able to inspect *your* individual primary care dataset prior to upload to the HSCIC (and he/she can).

The identifiers (NHS number, DOB, postcode & gender) are *not* "stripped" - not before upload and not after your information arrives at the HSCIC.

Can I request that only anonymised information about me is uploaded to care.data?

NO.

There is no "anonymised" or "trimmed" option for GP care.data uploads.

It's the full, clearly identifiable data upload or nothing.

What information will be extracted from my medical records?

The data extracted - your **Primary Care Dataset** - will include the following:

- Your NHS number
- Your date of birth
- Your postcode
- Your gender
- Your ethnicity
- The date you registered with your GP surgery
- Your medical diagnoses (including cancer and mental health) and any complications
- Your referrals to specialists
- Your prescriptions
- Your family history
- Your vaccinations and screening tests
- Your blood test results
- Your body mass index (height/weight)
- Your smoking/alcohol habits

This information is clearly identifiable - the NHS number alone *uniquely identifies* you.

Certain "sensitive" data will not be extracted in the initial upload (so-called **Release 1** of care.data).

For example:

- Details of infertility and assisted conception, such as IVF
- Sexually transmitted infections, including HIV, genital herpes, genital warts, chlamydia
- Abortions
- Gender identity matters, including reassignment
- Domestic, emotional, physical and sexual abuse

But it has already been stated that "this list might be reconsidered for a future phase of care.data".

Be aware that prescription items that could reveal sensitive data, such as medication for HIV or chlamydia, or hormonal treatment for infertility, *will* be uploaded.

Comprehensive details about the information to be extracted can be found within this HSCIC document.

Can my GP surgery refuse to supply information to care.data?

NO.

GPs are legally compelled to upload to care.data. They cannot refuse to comply.

But this isn't new, is it - GPs have been uploading and sharing data like this for years?

NO.

Absolutely not.

GPs *do* share information about patients as part of providing excellent clinical care, for example:

- Personal information about you and your medical history, when needed for your direct care, e.g. referral to hospital consultants, district nurses, health visitors, midwives, counsellors
- Limited patient identifiable information to public health, in order to arrange programmes for childhood immunisations, communicable diseases, cervical smears and retinal screening

- With your explicit consent, personal information to other organisations outside the NHS, e.g. insurance companies, benefits agencies, solicitors
- Limited information about you, if relevant and necessary, to protect you and others, e.g. to social services child protection investigations
- Under certain acts of parliament to protect you and others e.g. court order
- Summary information which is *completely anonymised* (collected at an aggregate level) e.g. quality and outcome frameworks (QoF), medical research and clinical audit

GPs do extract and send or upload anonymised/aggregated data about patients, sometimes voluntarily and sometimes compulsorily.

But the NHS does not upload vast amounts of personal, confidential and identifiable information about you, from your GP record, forcibly and without your explicit consent, to databases out with your GP surgery, into the hands of different data controllers, for purposes unrelated to your direct medical care.

Until now, that is.

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care.data and QOF

All GP surgeries in England collect and store clinical information about patients, and submit that information to NHS England, via the HSCIC, in order to get paid. That information collection programme is known as the Quality and Outcomes Framework. GPs are incentivised to investigate, manage and monitor medical conditions according to clinical guidelines, and to encourage people to attend screening programmes (such as cervical smears) and general health checks (such as blood pressure tests). The information collected is very detailed and the data collected is similar in many ways to that forcibly extracted by care.data (unless you opt-out of course).

However, the information submitted by your GP surgery is *completely anonymised and aggregated* and consists of numbers and percentages only. In stark contrast to care.data, no identifiable information whatsoever about you is submitted as part of QOF.

You can see what the information uploaded under QOF looks like here.

GPs are quite rightly concerned that patients might begin to refuse to attend their surgery for essential investigations, monitoring and management of medical problems, both new and ongoing, out of fear that the subsequent information collected will be uploaded in an identifiable format under care.data.

And in all honesty, such information *will* be uploaded as part of care.data unless you do opt-out.

So please be reassured of the following:

Opting out of care.data will have *no effect whatsoever* on QOF. It will neither affect the recording of clinical information about you by your GP, if appropriate, nor the completely anonymised and aggregated data that your GP submits in order to get paid.

Opting out of care.data should (I hope) give you absolute confidence that you can see your GP, about any matter, without worrying that identifiable information about that consultation, and any necessary investigations or follow-up, will be uploaded to the HSCIC and subsequently passed or sold to other organisations.

Can I limit the information uploaded about me under care.data, e.g. not include certain diagnoses or my smoking/alcohol habits?

NO.

It's the full, clearly identifiable data upload or nothing.

Will happens to my uploaded information then?

This extracted data will be combined with, or linked to, data extracted from any information about you held by hospitals, such as A&E attendances, operations or out-patient appointments, and which has already been uploaded to the HSCIC. The identifiable hospital data is known as Hospital Episodes Statistics (HES).

From April 2014, the data that HES contains will be greatly expanded, to include hospital tests and results, investigations performed, medications prescribed, as well as nursing observations.

In addition, data from other settings where you may have received NHS care will, in due course, be added:

- community care

mental health
- social care

There is talk of genomic records (genetic or DNA data) being linked with care.data in the future.

This combined database will be known as Care Episodes Statistics (CES), and data from this can be released to organisations in green, amber and red data formats, that is in aggregated formats, anonymised formats, pseudonymised formats and clearly identifiable formats (under s251 of the NHS Act 2006, as detailed below).

CES (or more accurately, the CES linked dataset) is the care.data database - *your care.data record*.

Once your full care.data record, containing your GP data plus your hospital data, has been created then your primary care dataset is destroyed, leaving the identifiable and combined care.data record (if you're technically minded, see this diagram).

Will it be a one-off upload of my data?

NO.

Your GP data will continue to be uploaded, initially on a monthly basis, and added to the CES, effectively updating it. So any new diagnoses, medication prescriptions and results will be automatically uploaded and added to your care.data record at the HSCIC.

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Your data - disseminated

Who will have access to my uploaded data?

Information from your care.data record will be made available to organisations both within the NHS, such as NHS commissioning bodies (e.g. CCGs), but also outside of the NHS, such as :

- Pharmaceutical companies

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

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Your data - sold

sell (verb) \'sel

: to exchange (something) for money
: to make (something) available to be bought
: to be able to be bought for a particular price

The HSCIC charges money in exchange for providing data that it holds, especially if it contains personal confidential data.

How much will organisations have to pay to get hold of my personal data?

It depends on the format of your data.

The full HSCIC price list - the "menu" - is here.

Aggregate data (Green), published on the HSCIC website as "Open data" is, obviously, free.

A statistical table of aggregate data (Green) costs approx. £800 - £1200.

Pseudonymised (Amber) data extracts cost approx. £900 - £1800.

Personal confidential data (Red) extracts cost approx. £1700 - £2000.

Certain PCD (Red) extracts can cost as much as £12000.

The HSCIC state that they will not make a profit from selling your data, that they operate a cost recovery scheme only. However many of the companies that they will sell your data to *will* be profit-making.

Who won't have access to my uploaded and combined care.data?

GPs, hospital doctors, nurses, physiotherapists, pharmacists and all the other clinical staff involved in providing your direct medical care will **not** have access.

care.data is not about information sharing for the purposes of direct medical care.

Who will be the data controller for my extracted information?

Once the data has been extracted, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared, sold, or who has access to it.

Your GP will neither be the data controller nor any sort of "data controller in common" (with the HSCIC) for your uploaded information.

The HSCIC and NHS England will be *joint data controllers* for your uploaded information and will have total control over it.

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Anonymised or aggregate information - your Green data

Can I object to my data being provided or sold to organisations in an aggregated or anonymised format?

NO.

You cannot prevent, or control in *any* way, the release or sale of aggregated or anonymised, or **Green**, information from your care.data record, or from any other datasets that the HSCIC holds about you.

Green data is special. Because it is de-identified, it no longer counts as personal data and so falls outside of the Data Protection Act. That means the HSCIC can give or sell *any* Green information extracted from your care.data record, when it likes, to *anyone* it chooses, for *any* purpose, and for whatever price.

"Notably, some of the data the Information Centre will provide to others won't fall under the Data Protection Act. This is because it will be anonymised. This is crucial, as once an individual can no longer be identified from information, either alone or in combination with other information, the law no longer considers it to be personal data. That means that the Data Protection Act no longer applies to it, so it doesn't impose any limitations on what can now be done with it."

ICO blog
NHS patient information: the Information Centre and the DPA

You can, however, opt-out using the 9Nu0 code - this will ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Green data.

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Pseudonymised information - your Amber data

Can I object to my data being provided or sold to organisations in a pseudonymised format?

NO.

You cannot prevent, or control in *any* way, the release or sale of pseudonymised, or **Amber**, information from your care.data record, or from any other datasets that the HSCIC holds about you, even though such data is potentially identifiable.

Although pseudonymised data is *potentially identifiable*, you cannot stop the HSCIC from releasing or selling it to organisations in this format.
Nor can you insist that it must not be released or sold to organisations *that may hold other information about you*.

Access to pseudonymised (potentially identifiable or Amber) information extracts have *no* legal requirement for independent advisory group consideration and approval, or independent oversight and scrutiny.

Sometimes the HSCIC sell your potentially identifiable information after approval from its own in-house advisory group, known as DAAG (see below), sometimes just under a "memorandum of understanding" with the buyer.

You can, however, opt-out using the 9Nu0 code - this will ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be sold as Amber data.

"pseudonymised or de-identified data may be very valuable to researchers because of its individual-level granularity and because pseudonymised records from different sources can be relatively easy to match."

ICO
Anonymisation: managing data protection risk code of practice

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Personal confidential data - your clearly identifiable Red data

In Release 1 of care.data, this information will only be released or sold to those requesting it in an aggregated, anonymised or pseudonymised form, but a bit later on, from Release 2 of care.data onwards, it could be clearly identifiable as *your* information, and you will not be asked for your permission before your "Red" data is distributed.

While the Health and Social Care Act 2012 empowered the HSCIC to collect and hold confidential data compulsorily from GP surgeries, this did not include the power to distribute this data in a clearly identifiable form without a legal justification such as individual patient consent or Section 251 of the NHS Act 2006.

Section 251 can and will inevitably be used to disseminate clearly identifiable information from care.data to other organisations - so bypassing any requirement to seek your consent. It grants the Secretary of State for Health the legal authority to do this, for both research and non research purposes.

The HSCIC *already* uses s251 exemptions to allow clearly identifiable data, currently from HES, to be disseminated to commissioning groups and to other organisations, without seeking explicit patient consent.

The regulations that enable and control Section 251 are called the Health Service (Control of Patient Information) Regulations 2002.

Currently, the Confidentiality Advisory Group (CAG) meets to consider applications for access to clearly identifiable data without patient consent under Section 251, as empowered by Regulation 5a of the Regulations, and makes recommendations to the SoS for Health for research applications. Releases under Reg 5a *require* both the approval of the SoS for Health *and* CAG.

However, Section b of Regulation 5 allows the Secretary of State to have sole power to release sensitive medical and personal information, which would include that sourced from care.data, for *non research purposes*. He/she may seek the advice of a research ethics committee, such as CAG, *but is under no obligation to*.

The largest application for identifiable data ever received by CAG was from the HSCIC in November 2013, and was for the disclosure of the majority of "all data from primary and secondary care for all patients" (see p31 here).

At present, it remains uncertain as to whether there will be truly independent scrutiny for applications to extract and buy clearly identifiable information from your care.data records without your explicit consent. Approval for research purposes *might* be considered by the CAG, but might well be considered by the HSCIC's own in-house advisory group, The Data Access Advisory Group (DAAG).

Researchers may well be "approved" - but they won't be approved by *you*.

"There will be no identifiable disclosures in version 1"

"expect to return with proposals for version 2, with treatment of legal basis and handling of patient objections "

care.data and GP extract
GPES IAG Feb 2013

When can we share something that is confidential?

When the patient has clearly said that we can do it (i.e. when a patient has given their consent)

Where we have to do it by law (for example, in a public health emergency like *an epidemic)*

Where the recipient has approval to receive it under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 (anecdotally known as 'section 251 support').

HSCIC
Rules for sharing information

Is the combined CES database (my care.data record) identifiable or completely anonymised?

care.data is clearly identifiable, although the HSCIC separate the clinical data from the identifying fields (such as NHS number, DOB). These are recombined when pseudonymised data or clearly identifiable data is released, such as under section 251.

The identifiers are not destroyed once your data is with the HSCIC, merely *separated* from, but still "linked to" the clinical data.

If the HSCIC only held completely anonymised care.data:

- There would be no need for the 9Nu4 opt-out code (and we have and can apply this code)
- There could be no pseudonymised (Amber) releases of your data to organisations (and there will be)
- There could be no s251 releases of your clearly identifiable (Red) data to organisations (and there can and, in due course, will be)
- You wouldn't be able to make a Subject Access Request for the care.data information that the HSCIC holds about *you* (and you can)

Will I be informed when my personal confidential data is released or sold to an organisation under Section 251?

NO.

Can I select or approve the particular organisations that my personal confidential data is released or sold to under Section 251?

NO.

You cannot select who the HSCIC disseminates your care.data information to under section 251.

Any organisation - a government department, university researcher, pharmaceutical company or insurance company - can apply to the HSCIC to buy your care.data, including for Red data under Section 251 (although their application may not be successful of course). The decision whether to release or sell your information - what information, to whom, in which format, at what price, and for what purpose - is made by the HSCIC, *not you*.

The HSCIC believes that "it would be wrong to exclude private companies simply on ideological grounds" from applying to buy information from your care.data record.

The HSCIC would determine whether the reasons for any organisation wanting the data were acceptable, stating that they should be "to improve NHS patient care".

"We have private hospitals and companies like Virgin who are purchasing NHS patient care now. This is a trend that will continue. As long as they can show patient care is benefiting then they can apply." the HSCIC states.

Organisations that have been previously granted access to sensitive identifiable health data held by the HSCIC include the Cabinet Office, Dr Foster Ltd, Capita PLC and BUPA.

Can I insist that that my personal confidential data is not released or sold to insurance companies under Section 251?

NO.

You cannot select who the HSCIC disseminates your care.data information to under section 251.

Can I request that my personal confidential data is only released or sold for research purposes under Section 251?

NO.

You cannot control the purposes for which your identifiable information is released.

Section 5 of the Health Service (Control of Patient Information) Regulations 2002 allows the release of identifiable information from your care.data record, as legally authorised by Section 251, for research *and* non research purposes.

Can I request that certain aspects of my personal confidential data is not released or sold under Section 251?

NO.

You cannot control which aspects of your identifiable information the HSCIC releases.

Can I prevent all Section 251 releases of my personal confidential data from the HSCIC?

YES.

The action of the 9Nu4 opt-out code is to prevent clearly identifiable releases of *your* personal confidential data (Red data) from the HSCIC under Section 251/Reg 5, whether for research or non research purposes.

And of course, you can also opt-out using the 9Nu0 code - this will ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can then be released or sold as Red data.

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Red, Amber, and Green data

Can I object to particular aspects of my data (anonymised or otherwise), such as certain diagnoses, being provided or sold to organisations?

NO.

You cannot control or select which areas of your care.data information the HSCIC disseminates.

Can I object to my data (anonymised or otherwise) being provided or sold to particular organisations, or for particular research, that I find ethically unacceptable?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I object to my data (anonymised or otherwise) being provided or sold to organisations based overseas?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I object to my data (anonymised or otherwise) being provided or sold to organisations who might already hold other information about me?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I request that my data (anonymised or otherwise) is provided only for health research and NHS planning, and not given or sold to commercial companies?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

Can I request that my data (anonymised or otherwise) is provided or sold only to organisations within the NHS?

NO.

You cannot control or select who the HSCIC disseminates your care.data information to.

How will the HSCIC ensure that organisations given my care.data will process it lawfully and ethically?

The HSCIC is responsible for ensuring that its customers, those that it provides your personal data to, comply with standard data processing guidelines. Effectively, it asks organisations to "promise" to handle the data properly.

The HSCIC states that:

"Customers accessing data through our service are required to sign a data sharing contract before any data is supplied. This contract regulates how the data is shared, used and managed and includes storage security requirements and restrictions on onward sharing or publication. The data sharing contract states that customers must not attempt to link the data with other data sources such that individuals might be re-identified."

So will the HSCIC audit these organisations to ensure that they are complying with the rules, not onward sharing my information and not linking my data?

NO.

The HSCIC does not routinely audit these organisations.

So tell me again - will my information "always be anonymised before being shared with third parties, such as research organisations, universities and private companies"?

NO.

Your data may be released or sold to organisations in an aggregated form, an anonymised form, a pseudonymised form, or a clearly identifiable form under s251 approval.

But *you* have absolutely no say in what information is released, to whom, for what purpose, or, for that matter, how much it's going to cost to obtain your data.

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Insurance companies and access to care.data

The HSCIC also says that clearly identifiable (Red) data will, from Release 2 of care.data onwards, be available to insurance companies - as long as those companies promise that they will not use it "for the purposes of selling or administering any kind of insurance", and as long as their reason for wanting the data was "to improve NHS patient care".

There is *no* legal obstacle to the HSCIC releasing or selling information, whether in Green, Amber or Red formats, to insurance companies.
It has done so before (it has been selling HES data for years) and it will do again (with both HES and care.data).

In addition, anonymised and pseudonymised (Green and Amber) data *should* be given to insurance companies as:

they "can make good use of the data", and it will

"enable insurance companies to accurately calculate actuarial risk so as to offer fair premiums to its customers"

HSCIC
Information Governance Assessment - care.data addendum

And certainly, your HES data has been sold to insurance companies for just this purpose, in this case **Amber data** without DAAG or CAG approval, not for genuine medical research or to benefit NHS care, but simply to increase the profits of those organisations.

If the possibility of your care.data being given or sold to insurance companies is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes.

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to any such organisation.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to any such organisation.

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Pharmaceutical companies and care.data

Pharmaceutical companies would *love* to get their hands on your care.data .

According to the Competition Commission, a company known as i4Health will "offer access to NHS prescription data". One of the aims of this firm is to allow drug companies to get together to access medical information easier than if they applied to the HSCIC for care.data on an individual basis.

The HSCIC confirmed that i4Health had been looking to sign a Memorandum of Understanding with it last year to reduce delays in purchasing patient information from care.data. A sort of fast-track business deal.

> *"Now we find pharmaceutical companies are queuing up behind so-called not-for-profit front companies to spy on what pills we take to get better. The whole care.data scheme is starting to look like nothing more than a giant medical data-laundering machine."*
>
> ***Phil Booth, medConfidential***
> ***The Guardian, February 2014***

If the possibility of your care.data being given or sold to pharmaceutical companies is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes.

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to any such organisation.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to any such organisation.

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Government departments and access to care.data

In June 2013, the HSCIC waved through an application from the Cabinet Office to allow the government to examine the "sensitive" medical records of individual teenagers who took part in the Prime Minister's volunteering project, the National Citizen's Service.

The data was extracted from HES, without consent, and without DAAG approval.

Government departments are just as eligible as any other organisation to apply to obtain your care.data information. In this case, even the supposed safeguard of DAAG consideration was ignored.

The Department of Work and Pensions (DWP) tried, unsuccessfully, to obtain access to confidential patient information, seeking approval under s251 from the then ECC (now CAG), in 2012.

If government access to your GP data from the HSCIC is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to anyone.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to government departments.

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Police access to care.data

Before care.data, police wanting access to your GP records would have to approach your GP or GP surgery and request the information, no doubt quoting section 29(3) of the Data Protection Act 1998 as justification for not seeking your consent first. s29 of the DPA means that information can be disclosed, without a breach of the Act occurring, *but it does not compel disclosure*.

Your GP - a doctor - would be mindful of the GMC's guidance on confidentiality, particularly in relation to disclosures in the public interest. Paragraph 37 of this guidance states that personal information can be disclosed in the public interest without consent, or if consent has been withheld, if the benefits to society outweigh the patient's interests in keeping the information confidential. Generally, this means for the prevention or investigation of a serious crime, or to prevent a terrorist offence.

Your GP is likely to resist simply handing over the information, and may well insist on trying to seek your consent first, or refusing to do anything until presented with a court order compelling release of the relevant information.

Once your identifiable GP data has been uploaded to care.data, and especially once combined with your hospital data, the police *might* approach the HSCIC as an alternative way to obtain GP information about you.

How robustly the HSCIC would resist such an attempt to obtain your information, whether they would insist on seeking your consent first, or require a court order before release, is anyone's guess.

If police access to your GP data from the HSCIC is of concern to you, then be aware of the following.

The 9Nu4 opt-out code would *not* prohibit release of your clearly identifiable data by the HSCIC in such circumstances.

However, the 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to anyone.

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Your data - overseas?

Principle 8 of The Data Protection Act states that *"Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights* *and freedoms of data subjects in relation to the processing of personal data"*.

Information extracted from your care.data record in an anonymised or aggregated way, that is, **Green** data, could certainly be sent or sold directly to an organisation based overseas.

Because Green data it is de-identified, it no longer counts as personal data and so falls outside of the Data Protection Act. That means the HSCIC can give or sell *any* Green information extracted from your care.data record, when it likes, to *anyone* it chooses, *in any country*, for *any* purpose, and for whatever price.

Remember, you cannot prevent, or control in *any* way, the release or sale of aggregated or anonymised, or Green, information from your care.data record, or from any other datasets that the HSCIC holds about you.

It is *possible* that your **Amber** data could be sent to organisations overseas, especially if the HSCIC felt, and could justify to the ICO if challenged, that the data had been pseudonymised to a level where re-identification would be very difficult, that it's own in-house DAAG had "approved" it, and if it was being provided to a country which fufilled the ICO's criteria for "an adequate level of protection".

Remember, you cannot prevent, or control in *any* way, the release or sale of pseudonymised, or Amber, information from your care.data record, or from any other datasets that the HSCIC holds about you, even though such data is potentially identifiable.

It is *unlikely*, but not impossible, that your clearly identifiable, **Red**, personal confidential, data would be sent or sold *directly* to an organisation based overseas. At least, not for research purposes as CAG would be extremely unlikely to approve it.

What is certain though is that your data can and will be given and sold to organisations based in this country. It may well be that once that organisation has the information, it is transferred overseas - without you, the HSCIC, NHS England or the ICO ever finding out.

The HSCIC recently signed a Memorandum of Understanding with the United States of America, in order to facilitate sharing of health data.

If the possibility of your care.data being sent overseas is of concern to you, then opt-out using both the 9Nu0 and 9Nu4 codes.

The 9Nu0 opt-out code *would* ensure that **no data whatsoever** is uploaded to the HSCIC from your GP record, and so no data from your GP record can be released by the HSCIC - to anyone, in any country.

The 9Nu4 opt-out code *would also* prohibit release of your clearly identifiable data, from whatever source, under s251, by the HSCIC, to anyone, in any country.

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The law and misuse of care.data

Misusing your care.data, whether that is unlawfully obtaining it from the HSCIC, re-identification, disseminating it (overseas, for example), or re-selling it, is a breach of section 55 of the Data Protection Act.

Policing of this falls to the Information Commissioner, but he has pretty limited powers. For example, he has prove in court that "substantial damage and distress had been caused" by the misuse of the data.

The ICO can only bring *monetary penalties*. Even the criminal offence of unauthorised disclosure or obtaining of personal information, as under Section 55 of the Data Protection Act, carries only a fine and is often dealt with by a magistrate.

More serious cases of information theft are dealt with in crown courts, which can impose unlimited monetary penalties. But jail sentences - which information commissioners have called for since 2006 - are not able to be imposed.

"The track record in the magistrates court is pretty pathetic."

"If people don't think this sort of thing matters and if you get to the magistrates court you will be fined about £120, not surprisingly the public doesn't have great confidence that their personal information will stay secure."

Christopher Graham, Information Commissioner
The Independent, February 2014

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Hospitals and other sources of care.data

Can I stop care.data from extracting and uploading my personal information from non-GP sources, such as HES, social care and psychiatric care?

NO.

At present, you cannot object to this data being extracted by the HSCIC.

Can hospital trusts and other non-GP organisations refuse to supply information to care.data?

NO.

The non-GP data that is linked to your GP records to form the combined care.data is sourced from the SUS data warehouse (see below), and all such organisations are mandated to supply information to this database.

Can I stop organisations, such as hospital trusts, from sending my identifiable information to HES in the first place?

YES.

Though it's not easy.

Routine collection of data from hospitals predates the Data Protection Act, but all patients can object to their data being used in this way.

You will have to contact each organisation on an individual basis (your GP surgery cannot do this), requesting that they do not send your personal and identifiable information to the SUS data warehouse (from which the HSCIC extracts HES data). They still have to send information, but all data about you then sent to SUS will be completely anonymised.

At a patient's request, hospital trusts are required to *remove* all patient identifiable data (NHS number or name/address, local patient identifier (hospital number), DOB, postcode) from any SUS submission (CDS file) and render it *anonymised and not pseudonymised*.

Hospital trusts already have strong anonymisation procedures that are currently used for sensitive cases (e.g. IVF), and that can be extended to include patients who have requested that their identifiable information is not sent to SUS.

Guidance on how trusts should achieve this has been published by the HSCIC and can be found here.

Can I prevent the HSCIC from releasing my HES data to organisations?

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your HES record.

You cannot prevent, or control in *any* way, the release sale of pseudonymised, or **Amber**, information from your HES record.

You cannot control when, to whom, or for what purpose, the HSCIC releases or sells personal, clearly identifiable and confidential, or **Red**, information from your HES record.

But you *can* prevent *all* releases of Red, or personal confidential, information from your HES record by means of the **9Nu4** opt-out code

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care.data and medical research

Opting out of care.data will have no effect on *completely anonymised* information about you being shared within the NHS to help medical research.

As it always has been.

Opting out of care.data **in no way** prevents you from agreeing - with your *explicit consent* - to partake in high-quality medical research based at your GP surgery, particularly if your surgery is a Research Ready accredited practice.

Participation in such research is only ever with your full, explicit consent, and *you* choose the type of research that you wish to be contribute to, and the organisation that *you* allow your medical information to be shared with.

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care.data and your direct medical care

Opting out of care.data will have *no effect* on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

Opting out of care.data will have *no effect* on your GP surgery and the way that it is paid by the NHS or on the services that it provides.

Opting out of care.data will have *no effect* on the way that any hospital is paid by the NHS for treating you (PbR).

Neither of the two opt-out codes will affect any of the above.

Will opting out of care.data prevent medical staff in A&E, GP out of hours centres, or hospital out-patient departments having access to my medical information?

NO.

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.

care.data has absolutely nothing to do with information sharing between healthcare professionals or with access of your electronic records by medical staff.

Will opting out of care.data prevent or hinder my GP looking after me?

NO.

Opting out of care.data will have **absolutely no effect whatsoever** on the way that your GP provides your medical care.

It will not affect your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.

It will not stop the NHS organising programmes such as diabetic retinopathy screening, as these are *not* secondary uses of your data but primary uses required for your direct clinical care.

If you opt-out of care.data, you can still be referred to a specialist under Choose & Book, your surgery can still manage your prescriptions via the Electronic Prescription Service, you can continue to request your prescriptions online, continue to email your GP or surgery and continue to access your medical records online (if you are offered that facility).

Opting out of care.data will have no effect whatsoever on your relationship with your GP surgery.

I am part of the UK Biobank project - will my care.data opt-out impact on this?

NO.

Neither the 9Nu0 nor the 9Nu4 code block the extraction of data from your GP records, that you have *explicitly consented to*, if you have signed up to this project.

The 9Nu0 code only blocks the extraction of GP data where your explicit consent has *not* been sought - **such as care.data** .

Will my GP mind if I opt-out?

NO.

Whether or not you opt-out is immaterial to your GP.

And you certainly don't need your GP's approval or permission to opt-out of care.data .

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Subject Access Requests

Can I see what data the HSCIC has extracted from my GP records into care.data?

YES.

The information that the HSCIC holds about you, whether your HES data, your uploaded GP data, or your combined care.data record, is identifiable (i.e. not anonymised) and so information relating to just *you* can be identified, extracted and provided to you.

Everyone has the right to make a request for personal information from a data controller under the Data Protection Act 1998.

You have the right to make a Subject Access Request (SAR) to the HSCIC.

The HSCIC have produced guidance about subject access requests.

A form that you can apply on is here.

The HSCIC holds your extracted health data in an *exclusively* electronic form (as compared with your GP, who holds your information in both electronic and non-electronic (Lloyd George envelope) forms).

Nevertheless, ensure that you request your health records as held *electronically* by the HSCIC.

You will be supplied with a permanent copy of the relevant information, within 40 calendar days.

The maximum fee payable to the HSCIC for the SAR will be £10, regardless of the number of pages the information comprises.

Can I see what data the HSCIC already holds about me, such as in SUS or Hospital Episodes Statistics (HES)?

YES.

The procedure is exactly as above, just state that you wish for your personal SUS or HES data to be provided to you.

After my GP records have been uploaded to care.data, can I see what data the HSCIC then holds about me as Care Episodes Statistics (CES)?

YES.

You can request your "full", linked, care.data record, exactly as above.

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care.data and the Summary Care Record

care.data and the Summary Care Record (SCR) are two *entirely separate* projects.

The Summary Care Record (SCR) is a national centralised database of medical information (allergies and medication, initially) extracted and uploaded from patients' GP records. This project's aims are to make this information potentially available to emergency doctors (in A&E and GP out-of-hours centres countrywide).

For further information about the Summary Care Record, please see my other site.

As regards the Summary Care Record:

- It concerns *direct clinical care*
- You may have recently received a *personalised* letter from your local CCG about the Summary Care Record
- Your GP surgery may not be able to tell you exactly *when* they will commence uploading Summary Care Records

care.data is very different to the Summary Care Record:

- The information extracted for care.data **far exceeds** just allergies and medication

- The information uploaded to care.data will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- care.data does **not** concern clinical care, it is an administrative and research database
- Patients will **not** be written to individually about care.data, although a national leaflet drop is underway (see below)
- We know that this project **will** go ahead everywhere shortly, with data extractions planned for "Autumn 2014"

You will still need to opt-out to prevent care.data uploads even if you have already opted out of The Summary Care Record.

Summary Care Record opt-outs will not prevent care.data uploads.

Opting out of one database does not mean that you have automatically opted-out of the other.

The Department of Health have reneged on a pledge made in April 2013 that patients who opted-out of the Summary Care Record would not have to opt-out again for care.data.

"We're not going to cancel the opting out that's already happened. There may be a process of recontacting people to explain the new arrangements and that's a detail which we'll work through in operational terms. But we will respect people who have already said they wish to opt out of NHS sharing."

"We will respect those who have already opted out."

Jeremy Hunt
on care.data, April 2013

Can I have a Summary Care Record but opt-out of care.data?

YES.

Can I agree to care.data extractions but opt-out of the Summary Care Record?

YES.

- You can both have a Summary Care Record and allow care.data extractions
- You can opt-out of both databases and allow neither

- Or you can opt-out of one but allow the other

Opting out of either database, or both, will not in any way affect the medical care that you receive from your GP surgery.

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Public awareness about care.data

Do GP surgeries have to ensure patients are aware of care.data and of their right to opt-out?

YES.

Your GP surgery is the data controller for your medical records. Whilst it is legally obliged to release the information to the HSCIC without your explicit consent, unless you opt-out, the surgery has an obligation to provide fair processing information to its patients, making them aware of care.data and of their right to object.

As the organisation with primary responsibility for their patients' data, GP surgeries have an obligation to ensure that information about the use of their data is actively communicated to patients, by any and all reasonable means.

What is NHS England and the HSCIC doing to make patients aware of care.data?

In January 2014, a household leaflet drop, reaching approximately 24 million homes, should have explained data sharing for patients and the public. The leaflet should have made it clear that everyone has a right to object to their confidential data being shared in certain ways.

The cost of the NHS England leaflet drop to households in England was approximately £1.2 million.

Did the leaflet include an opt-out form?

NO.

That would have made it very easy for people to opt-out.

Did the leaflet include the phrase "care.data", even once?

NO.

Was the leaflet personally addressed to me?

NO.

The leaflet was simply pushed through your letterbox.

In other words, junk mail?

YES.

He is critical of the NHS's efforts to explain the care.data system, saying the ICO had advised individual letters to all patients.

"They said ‘No, we're going to do a leaflet.' I never received my leaflet," he says.

Christopher Graham, Information Commissioner
The Independent, February 2014

We know that very many patients did not receive it (you are allowed to opt out of unsolicited leaflets via Royal Mail), did not read it (binning it or recycling it immediately), or understand its significance.

Between January and March 2005, 750,000 leaflets of a similar type were delivered by Royal Mail to households within Hampshire and the Isle of Wight outlining the Hampshire Health Record (HHR), another massive medical database. This was supposedly to provide comprehensive information to the entire population of Hampshire & IOW and (just like care.data) was based on an opt-out.

The leaflets were unsolicited junk mail then, and they were again for care.data .

The HHR's attitude to 'obtaining consent' in that way was heavily criticised by the Department of Health.

"We have learnt from what Hampshire did, because we believe that it did not go to every person who needed to learn about it, and I have learnt more about the junk mail rule than I ever want to know, but it exists and you need to send to every addressed adult in order for it not to get thrown away if you have got Safeways or Tescos trying to tell somebody something at the same time."

Connecting for Health
Oral evidence to the HSC Enquiry into the EPR, Question 61

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Where can I get more information about care.data?

There is a lot of information available about care.data, other than this site, which you may choose to refer to before you decide on whether you wish to opt out or not.

NHS England / HSCIC

- Patient information booklet ("Better information means better care")
- Patient "FAQs"
- Web site

EMIS National User Group

- Patient information booklet
- Web site

medConfidential

- Patient information booklet
- "Keep My Secrets" (video)
- Web site

Patient.co.uk

- Patient information booklet

- Web site

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So can I opt-out of care.data?

So can I stop care.data from extracting personal information from my GP records?

YES.

Although GP practices cannot object to this information leaving the practice, individual patients and their families can instruct their practice to prohibit the transfer of their data, i.e. **you have the right to opt-out**.

Not objecting to care.data is akin to 'donating' your medical records.

What If I do not opt-out?

If you do nothing, i.e. you do not opt-out, then your medical information will be extracted and uploaded to the HSCIC.

Naturally, we were all denied an opt-out from care.data to start with.

As far back as 2009, those now in charge of care.data were arguing than no-one should be able to object to sharing of their medical records.

"But no one who uses a public service should be allowed to opt out of sharing their records. Nor can people rely on their record being anonymised - at the moment sexual health services can be anonymous, and as a result there are almost no measures of performance in that sector."

Tim Kelsey, co-founder of Dr Foster, now NHS England's director of patients and information
"Long live the Database State"

Back in February 2013, the HSCIC had argued that patients should have *no right whatsoever* to opt-out of care.data extractions.

"The legal basis for the disclosure from general practice systems is statute. As a result, there is no legal necessity to allow patients to opt out of the extraction."

HSCIC
Information Governance Assessment, February 2013

And indeed, that is true. There is no "legal" requirement for an opt-out, because no such requirement exists within the Health and Social Care Act.

But it was made very clear to the HSCIC, by the IAG and the BMA, that not allowing an opt-out from care.data would be in violation of both the NHS Constitution and the GPES Principles (the rules governing the software system, managed by ATOS, that will extract care.data from GP records).

"You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered, and where your wishes cannot be followed, to be told the reasons including the legal basis"

The NHS Constitution

"Where data are extracted for secondary purposes, no patient data will be extracted if the general practice has recorded a patient's objection to disclosures of patient identifiable data from the general practice for secondary uses even where Section 251 approval has been given"

General Practice Extraction Service (GPES), Information Governance Principles

And so, begrudgingly, the HSCIC were forced to concede an opt-out.

Patient control of information

If you do not want information that identifies you to be shared outside your GP practice, please ask a member of staff at your practice to make a note of this in your medical record. This note will prevent your confidential information from being used other than in special circumstances required by law, such as a public *health emergency.*

Information from other places where you receive care, such as hospitals and community services is collected nationally by the Health and Social Care Information Centre. The Health and Social Care Information Centre only releases this information in identifiable form where there is legal approval for doing so, such as for medical research.

If you object, this type of information will not leave the Health and Social Care Information Centre. The only exceptions are very rare circumstances such as a civil emergency or a public health emergency. Please inform your GP practice if you want to object.

HSCIC
Rules for sharing information (current website)

Remember that you *cannot* prevent the HSCIC releasing Green and Amber data that it holds about you, whether uploaded from your GP record or acquired from other places where you receive care, such as hospitals and community services. The 9Nu4 code will prevent the release of Red data from all these sources though.

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Deleting your uploaded data

How long will the HSCIC keep my uploaded data for?

Indefinitely.

The HSCIC have no intention of *ever* deleting your care.data. In fact, your personal data will be added to on a regular basis by ongoing uploads from your GP records (unless you opt-out).

Can I ever get my uploaded data deleted?

NO.

Once uploaded, you will never be able to get this data deleted by the HSCIC.

Can get my uploaded data deleted if I make a Section 10 DPA request?

NO.

Section 10 of the Data Protection Act gives an individual a limited right to ask a data controller (organisation) to stop processing information about them if it is causing them unwarranted and substantial damage or substantial distress.

Section 10 does not give an individual the right of deletion or removal of data.

So who can help me get my uploaded information deleted?

In personal communication, the ICO have stated the following:

As regards a Section 10 DPA application to the HSCIC, *"In order for such a request to be considered, unwarranted and substantial damage or distress would need to be quantified, rather than a just a simple objection because someone does not agree with the processing or has changed their mind."*

The HSCIC will almost certainly reject all such applications.

And if you were to complain to the ICO:

"I can also confirm that in relation to the ICO. If requested (via a complaint) we can only look at the process of s10, this is where such a request has not been responded to within the time scale of 21 days. We cannot look at a response where an individual does not agree with the outcome. In such a case, the individual would need to apply to a court for a decision to be made as to whether their objection is justified. The court would then order what action, if any, must be taken.

So, when it comes to trying to get your uploaded information deleted:

- The Data Protection Act cannot help you
- Your GP cannot help you
- The ICO will not help you

Your only option will be an expensive legal challenge.

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When can I opt-out of my GP data upload?

You can request that the codes are added right now, *before* extractions and uploads to care.data have begun, or you can request that the codes are added at any time thereafter.

The 9Nu0 opt-out

If the 9Nu0 opt-out code is added *before* your initial GP dataset upload (provisionally scheduled for Autumn) then:

- *No data whatsoever* from your GP record will be uploaded to care.data
- *No data whatsoever* from your GP record will be present within your care.data record
- As long as that opt-out code (9Nu0) remains in force, no *further* data from your GP record will be uploaded to care.data
- But you can never put yourself into the position that you would have been had you opted out *before* uploads commenced

If the 9Nu0 opt-out code is added *after* your initial GP dataset upload (after March), or subsequent to any monthly GP uploads to your care.data record, then:

- Identifiable data from your GP record *will* be present within your care.data record
- The uploaded identifiable data will *never* be deleted
- That data will always be able to be released or sold in Green, Amber and (unless you have the 9Nu4 in force) Red formats
- There is absolutely nothing you can do about your data, Red, Amber or Green, that has *already* been given or sold to other organisations
- But as long as that opt-out code (9Nu0) remains in force, no *further* data from your GP record will be uploaded to care.data

The 9Nu4 opt-out

Your personal confidential data, as held by the HSCIC, and from whatever source, *can* be released, *is already being released*, and *will* be released in a clearly identifiable format (PCD or "Red" data), as detailed above.

As soon as the 9Nu4 opt-out code is added to your GP record and transmitted to the HSCIC, then *no further clearly identifiable data releases about you will occur from the HSCIC*.

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An opt-out *now* means an opt-in - when *you* want

If you opt-out now, you can opt-in at any time in the future, if *you* want, when *you* want, at a time of *your* choosing.

Perhaps *if and when* care.data has been changed so that :

- people are asked for their *explicit consent* before their personal information is uploaded: an *opt-in*
- all your data will be completely anonymised *before* upload
- all information about you is completely anonymised *before* release by the HSCIC
- your information will *only* be released by the HSCIC to organisations within the NHS
- your information will *only* be released by the HSCIC to publicly funded and not-for-profit research organisations
- your information will *only* be released by the HSCIC for limited or strictly defined medical research purposes
- your information will *never* be released by the HSCIC to 3rd parties such as commercial organisations, pharmaceutical firms and insurance companies
- your information will *not* be released by the HSCIC to organisations who are looking to take over and privatise existing NHS services
- your information will *not* be sold
- any uploaded information about you can be deleted *at your request and at any time*
- you can *genuinely* control how your uploaded information will be used - to whom it is given, in what format, for what purpose, and for how long

When any, or all, of the above, or any other requirements that *you* want met are reliably in place, then *you* can choose to opt back in.

Until then, opting out will ensure that your GP information will not be used in ways that are unacceptable to you.

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The second "6 month pause" - what will change?

Absolutely nothing.

care.data may well be delayed again, but after 6 months:

- You will still have to opt-out to protect your personal confidential information
- Your information will still be uploaded in an identifiable dataset
- Your personal information will still be sold in green, amber and red formats, to 3rd parties within and outside of the NHS, for purposes other than genuine medical research
- You will still have no control over your uploaded information, other than to opt-out
- And you will still be unable to delete your uploaded information - unable to change your mind

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So how do I opt-out?

If you have decided to opt out of care.data then it's very easy to do so.

First, download an opt-form:

- Here is a .pdf leaflet, which can be printed double-sided and folded (fits in a DL envelope)
- Here is a .doc leaflet, which can be filled in on your PC and either printed or emailed to your GP surgery (if they allow you to email them)
- An opt-out form available in .pdf, .doc or .rtf format is available from medConfidential
- Your GP surgery may have its own opt-out form downloadable from its

website.

There is no "official" or mandatory opt-out form that you are obliged to use, whether produced by the HSCIC or anyone else.

It doesn't matter which form you use.

Make sure that you **haven't** been given, or downloaded, a Summary Care Record opt-out form by mistake.

Fill a form in, and hand it into, post it to, or fax it to your GP surgery.

You do not, however, have to fill in a form to opt-out of care.data .

You can just write a letter to your practice:

- State that you wish to opt-out of care.data
- Request that both the **9Nu0 and 9Nu4** codes are added to your GP records
- Remember to include full names and DOBs (and your address if you are happy to)

If you think that you GP surgery might not be fully aware of their obligations under care.data then add this to your letter:

"Please see the 'BMA FAQs - care.data guide for GP practices' document, at ***www.tinyurl.com/cdgpfaqs*** *, for information about care.data and the relevant read codes"*

If your GP surgery has enabled you to use EMIS Access, then you can use the secure messaging system within that to let your GP know that you wish to opt-out of care.data .

Alternatively, you can tell your GP that you wish to opt-out the next time that you see him or her (if you have an appointment planned for the near future). (Don't make an appointment to see him or her just to opt-out though, please!)

Remember to opt-out your children, or those for whom you have parental responsibility, as well.

Ensure that you make your opt-out wishes known to your GP surgery. No-one else can add the electronic flags to your GP records.

Do not send your opt-forms or letters to the HSCIC.

Do I have to give any reasons for my opt-out?

NO.

Absolutely not.

What about my children's records?

The HSCIC is taking **everyone's** medical records, no matter how young or old you are. As soon as newborn children are registered at their GP surgery, their data will be uploadable.

Your children's medical records will be uploaded too unless you opt them out.

When your children reach their 16th birthdays, they will *not* be automatically written to about care.data and their uploaded information.

But when your children are old enough to understand and make a decision for themselves about the storage and use of their data in his way, they will *never* be able to get that information deleted should they wish.

You do not need to see, discuss with or seek the permission of your GP (or anyone else for that matter) before opting your children out of care.data.

If I opt-out, what will my GP do to my records to prevent care.data processing?

Your GP will add two electronic flags, known as read codes, to your records.

One flag, known as 9Nu0, will ensure that no data whatsoever from your GP record will be uploaded to the HSCIC and released or sold, in any format (Green, Amber or Red)

The other flag, known as 9Nu4, will ensure that *any* data held by the HSCIC, whether extracted from your GP record or other sourced data (such as HES, mental health, social care), will not be released to any organisation in a *clearly identifiable (Red) format*.

The 9Nu4 flag is important if you wish to control how the HSCIC releases information held about you, particularly from organisations other than your GP surgery. Section 251 cannot be used to override patient dissent, so if you have indicated that you do not want your information to be shared in this way, by the presence of the 9Nu4 code, then section 251 *cannot* be used to override this - other than in the most exceptional circumstances, e.g. serious public safety concerns or civil emergency.

Be aware that the 9Nu4 code does *not* stop the release or sale of:

- anonymised/aggregate, or Green, data
- pseudonymised (potentially identifiable), or Amber, data

To prevent those, you must ensure that no GP information whatsoever is uploaded to the HSCIC *in the first place* - by means of the 9Nu0 code.

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care.data only affects England. If you are registered with a GP in Scotland, Wales or Northern Ireland then you do not need to opt-out, as no data will be extracted from your GP record under this project.

care.data will only be extracted from the GP record held by the surgery that you are *currently* registered with. So you do *not* need to opt-out at all your previous GP surgeries.

If you have moved abroad then it depends on whether you are still registered with an English GP surgery (you shouldn't be). If you are still registered with a GP surgery in England then either de-register, by informing the surgery that you have moved away, or request that the codes are added and then de-register, if you prefer.

If I opt-out, can I allow uploads to care.data but prohibit release of identifiable information from the HSCIC?

YES.

You can ask your GP to *just* add the read code 9Nu4 to your records, if you so wish.

This will allow identifiable data from your GP records to be *uploaded*, but no information, from whatever source, *released or sold* to organisations in a clearly identifiable form (Red data).

If I opt-out, can I change my mind and opt back in?

YES.

If you opt-out now you can opt-in at at any time in the future - *if* you are happy to, *when* you are happy to, and at a time of *your* choosing. It's your data, you should be in control.

Once you opt back in, your GP will add different electronic flags that will permit uploading to care.data and/or the release of other clearly identifiable information from the HSCIC to organisations.

How can I be certain that my opt-out has been actioned by my surgery, and the codes added to my record?

If your opt-out form, letter, or fax has clearly stated your wish to opt-out of care.data, the codes that you want added, and your name/DoB, then your surgery *will* action your request appropriately, otherwise it would be in breach of the Data Protection Act and you would have every right to make a formal complaint.

You do not *need* to confirm that your opt-out has been registered, but if you are concerned that your surgery may not fully understand the process then the easiest way would be to:

- contact your surgery's practice manager (*not your GP*).
- request that she/he confirms that the opt-out codes have been added to your GP record - email confirmation would probably be easiest

If all else fails, you are entitled to make a subject access request (SAR) to look at your GP records yourself.

Because:

- your GP records are not exclusively electronic records, and
- the codes should have been added to during the 40 days preceding the SAR

your GP surgery must offer you the opportunity to inspect (i.e. view on a computer screen) your records free of charge, rather than providing you with a permanent copy of the records for a fee. Your GP surgery is also obliged to help you access the information within your record that you are looking for.

Faced with having to organise all of that, most surgeries will quickly confirm that the codes have been added.

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In summary

Consent plays no part in care.data .
All you have is the right to object: the right to opt-out.It is the *only* way to have any control over your information.

You cannot modify in *any* way, the **Primary Care Dataset** extracted from your GP record and uploaded to care.data .
The information uploaded from your GP record is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.

Information from your combined care.data record may be released to organisations in an aggregated or anonymised form, a pseudonymised form, or a clearly identifiable form.

You cannot prevent, or control in *any* way, the release or sale of aggregated/anonymised, or **Green**, information from your care.data record.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot prevent, or control in *any* way, the release sale of pseudonymised, or **Amber**, information from your care.data record.
Amber data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You cannot control when, to whom, or for what purpose, the HSCIC releases or sells personal, clearly identifiable and confidential, or **Red**, information from your care.data record.

Red data is *not* anonymised.
You *can* ensure that no information whatsoever is uploaded to care.data from your GP record: by means of the 9Nu0 opt-out code.
There will be no information from your GP record to release or sell, in *any* format.

You *can* additionally prevent *all* releases of your personal confidential data: by means of the 9Nu4 opt-out code.
The 9Nu4 code will block the release or sale of personal confidential data from *any* source of information that the HSCIC has about you, such as HES.

So what do I need to do to ensure the maximum protection for my personal and confidential medical information?

Ask your GP surgery to add both the 9Nu0 and the 9Nu4 codes to your GP records.

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If I'm still unsure about whether to opt-out or not...?

Look at this flowchart.

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- Information Commissioner warns that 'line in the sand' shows people recognise the value of their data (ICO)
- Patients need to have control over their own information if care.data is to

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- What's wrong with care.data? (POLICYEXCHANGE)
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- The insurance firms who bought data on every NHS patient - and used it to push up premiums (DAILY MAIL)
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- Two-thirds of public yet to receive care.data information leaflet (PULSE)
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- Crisis of confidence in care.data - RCGP (EHI)
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Contact me

Feel free to send me *constructive* comments about this site.

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I will read every comment sent, though please do not be offended if I do not reply to your message.

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This non-commercial website was written by Dr Neil Bhatia, a GP and Caldicott Guardian in Hampshire.

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The Summary Care Record

forward to Page 2 - Alternatives to the Summary Care Record

This non-commercial website represents the personal views of Dr Neil Bhatia, GP and Caldicott Guardian for the Oaklands Practice in Yateley.

Page 1 - The basics

This website aims to provide information to everyone about The Summary Care Record (SCR) so that you can make an *informed* decision about opting-in or opting-out.

Much of the information and guidance on this site was extracted from sources via the Freedom of Information Act.

The information provided on this site is designed to complement, not replace, any guidance or opinion about The Summary Care Record provided by your own GP surgery.

The official DoH Summary Care Records website is here.

You *can* control your GP records - if you know how.

See this chart (tinyurl.com/mygprecords) for guidance, and contact your GP surgery if you need further information about any of the data flows.

Summary Care Records in a nutshell....

- Medical information is going be extracted from your GP records and uploaded, on a continuous basis, to a central database run by the Department of Health (DoH)
- You will *not* be asked for your permission before this extraction take place, but you should have been (or should be) informed that it is taking place
- The information extracted will (initially) be your medication (past and current) and your allergies (if you have any)
- Your information will theoretically be available across England, in hospitals and GP out of hours centres, to doctors, nurses and other staff (both clinical and non-clinical)
- However *anyone* with an NHS Smartcard and the appropriate electronic permissions can access your Summary Care Record, though you should be asked for your permission first
- Your GP will *not* be the data controller for the uploaded information - the Secretary of State for Health will be
- Your GP surgery *cannot* stop this extraction - but you, as an individual, can (if you so wish)
- The Summary Care Record is voluntary - *you are under no obligation to allow your records to be*

processed in this way, and you have the right to opt-out
- You *can* stop the extraction of this data from your GP records by asking your GP to put a special code in your GP records
- If you opt-out of the Summary Care Record (now), you can opt back in at any time in the future
- The Summary Care Record is *not* the same as care.data - opting out of one does *not* mean that you have automatically opted out of the other

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The details....

Summary Care Records - what is going to happen ?

You may have received a letter from your local CCG (or, previously, PCT) about the Summary Care Record (it looks like this).

A new central NHS computer system is being gradually introduced across England called the Summary Care Record (often referred to as the "NHS Database"). The Summary Care Record is meant to help emergency doctors and nurses help you when you contact or see them when your GP surgery is closed.

Medical data from your GP records will be extracted and uploaded, on a continuous basis, to a central database run by the Department of Health (DoH). The data will then be made available to those who have access to the Summary Care Record by means of an NHS Smartcard.

Your data will be uploaded by default, unless you actively object – an "opt-out" mechanism:.

That is, if you do and say nothing, your data *will* be uploaded.

The DoH believes that everyone should be assumed to be happy to have their information uploaded and be required to formally object if not.

When is this all happening ?

The Summary Care Record is an ongoing project. It is live in some areas of the country, and within those areas in some (but not all) GP surgeries.

In November 2013, the government announced that *all* surgeries in England *must* upload Summary Care Records by then end of March 2015, at the latest.

However, your GP surgery may not yet be able to tell you *exactly when* they will commence uploading Summary care Records.

Can GP surgeries refuse to upload records to the Summary Care Record without their patients' explicit consent ?

NO.

The Department of Health is forcing *all* GP surgeries to upload Summary Care Records, under an opt-out system, by the end of March 2015.

Who will be the data controller for my uploaded records ?

The data extracted for the Summary Care Record will be stored on Deparment of Health national servers and not on GP systems.

The Secretary of State for Health is the data controller for all data stored in Summary Care Records.

As the data controller, he and he alone decides the purposes for which your uploaded data is, or will be, processed and the way in which your uploaded data is, or will be, processed. He alone decides who has access to your records, and whether or not to seek your consent for any such release.

Whilst your GP controls your medical records as held by your surgery, your GP is *not* the data controller for any records uploaded and stored in your Summary Care Record.

Your GP will **not** be able to:

- Control who has access to your uploaded records
- Control how your uploaded records will be shared or disseminated
- Control whether your consent is sought for any sharing or distribution of your uploaded records
- Control which other databases your uploaded records may be linked to
- Tell you who has accessed your uploaded records, and when
- Monitor or investigate who has inappropriately or illegally accessed your uploaded records
- Get your uploaded data completely deleted from the Summary Care Record should you wish

What information will be extracted from my medical records ?

At first, the data uploaded from your GP records will comprise of "core" data, and this phase is known as the *initial summary*. This will occur if you have either opted-in, or have not specifically opted-out.

If you have opted-out, no clinical information whatsoever is uploaded and a completely blank record is created instead.

Demographic data (your name, address, DOB, telephone number, GP details etc) has already been uploaded.

"Core" data consists of:

- All repeat medications which have not been discontinued and are not more than 18 months past their review date. This also includes items which are recorded on the system but which are prescribed elsewhere (e.g. hospital or special clinic) or OTC (Over The Counter) drugs taken by the patient and recorded on the system
- All repeat medications which have been discontinued in the last 18 months
- All acute medication prescribed in the last 6 months. This includes medication prescribed elsewhere and OTC drugs
- Suspected adverse reactions and allergies including allergies to drugs, foods and any other substances

Core data is the *minimum* data that will be uploaded to the Summary Care Record.
More data can and will be uploaded to it if you should want - *or if you're not careful*.

The core data will be updated in your Summary Care Record automatically as your GP prescribes further medication, or if you develop allergies or adverse reactions to medicines. It is then known as your "GP summary".

You cannot stop a record of the medication that your GP prescribes from being automatically uploaded to the Summary Care Record, even if this is medication clearly used to treat sensitive or embarrassing conditions, and nor can your GP stop this upload. It is often easy to deduce a patient's diagnosis from the medication being used to treat him or her.

The Summary Care Record was never - ever - going to be just a "summary".

Immediately after this initial upload further data can and will be added, such as major diagnoses, past operations and procedures, hospital letters etc. This process of uploading further data to your record is known as "enrichment" or "enhancement".

Additional (or "supplementary") data from your GP record can be uploaded to the Summary Care Record. This will then result in an *enriched GP Summary*.

The additional data that can be uploaded to the Summary Care Record by your GP is vast.
The GP Summary can hold data under some or all of the following headings:

- Allergies and Adverse Reactions
- Repeat Medications
- Acute Medications
- Discontinued Repeat Medication
- Risks to Care professional or Third Party
- Diagnoses
- Problems and issues
- Clinical Observation and Findings
- Treatments
- Investigations
- Provision of Advice and Information to Patients and Carers
- Personal Preferences
- Social and Personal Circumstances
- Services and Care Professionals and Carers
- Lifestyle
- Family History

Since October 2010, the government has stated that patients must give their explicit consent before any enrichment by their GP occurs.

If you are asked by your GP before further information about you is uploaded, then you can request that the information is not sent. You may wish for sensitive information, for example relating to mental or sexual health or certain infections, to be witheld from your enriched Summary Care Record.

Following the recommendations made in the Ministerial Review of the Summary Care Record, which reported in October 2010, the only enrichment of the Summary Care Record will be with additional information added from your GP records.

No other organisations (e.g. hospital trusts, A&E) are now permitted to upload additional information to the

Summary Care Record.

How do I control enrichment of my Summary Care Record ?

There exists a setting or flag that controls what data, if any, is stored within a given SCR. This is known as the *National Summary Preference, or SCR Preference* flag.

The flag can be set in a number of ways. It can be set by your GP (using the existing surgery software) if your surgery is enabled to do so, or it can be set by your GP adding a specific read code (or electronic "flag") to your GP-held electronic record.

If you have opted-out, then no Summary Care Record (or actually, a blank one) will be created for you. Obviously, no enrichment can take place by your GP. Your GP will have added the opt-out read codes *93C3 or 9Ndo* to your GP record, or may have set the flag directly. Setting the flag adds the read code and vice versa.

The SCR Preference flag is set as *Express dissent (opted out) - Patient does not want to have a Summary Care Record*

The remaining settings determine whether GP enrichment can take place or not.

The default setting is implied consent for a core SCR. Whilst this setting remains in force, *only* a core GP summary will be uploaded and your SCR *cannot* be enriched by your GP.

If you say or do nothing as regards opting-out of the SCR then your preference flag *may* remain on this setting. It is the assumption made if you do not opt-out.

The SCR Preference flag is set as *Implied consent for medication, allergies and adverse reactions only*

The other setting that prevents enrichment is express consent for a core SCR. Whilst this setting remains in force, again *only* a core GP summary will be uploaded and your SCR *cannot* be enriched by your GP.

This is set if you *tell* your GP that you only want a core SCR.

The SCR Preference flag is set as *Express consent for medication, allergies and adverse reactions only*

The final setting is express consent for an enriched SCR.

This is set if you *tell* your GP that you acually want an enriched SCR.

The SCR Preference flag is set as *Express consent for medication, allergies and adverse reactions, AND additional information*

If this setting is set then:

- The initial summary is created ready for upload
- The Summary Care Record *can* be enriched by your GP
- Enrichment to a GP summary can occur *before* the initial upload occurs, so an enriched GP Summary may be uploaded right from the start

Express consent to have an enriched SCR can be set in a number of ways:

- The flag may be set by your GP using the existing GP software, if the surgery is so enabled
- The flag may be set by the presence of the specific electronic code *9Ndn* in your GP-held elctronic record

Be aware of the implications of having an enriched Summary Care Record.

So what are my choices if I want to have a Summary Care Record ?

If you want a Summary Care Record (SCR) then you need to decide whether you want your SCR limited to basic core data (allergies, medications and bad reactions) only, automatically updated from your GP surgery, or whether you want your SCR to be *enriched* with further data from your GP record.

If you want your SCR to remain as the default, that is core data only, and not enriched with further data from your GP record, then you need to tell your GP.

Your GP will then :

- Delete any opt-out read codes from your record (if you have previously opted-out, or if your practice is running an opt-in scheme)
- Change your preference setting to *Express consent for medication, allergies and adverse reactions only*, if and when your surgery is enabled, or
- Add the read code *9Ndm* to your GP record

If you want your SCR to be *enriched* with further data from your GP record, then you need to tell your GP.

Your GP will then :

- Change your preference setting to *Express consent for medication, allergies and adverse reactions, AND additional information*, if and when your surgery is enabled, or
- Add the read code *9Ndn* to your GP records

The choice is yours - take control of your medical data if you choose to have a Summary Care Record.

Make sure your GP knows what type of Summary Care Record you want. Do not leave it to chance.

Can I change from a core SCR to an enriched one ?

YES.

It is easy to make your basic (core) SCR into an enriched one. Just ask your GP.

Your GP will simply change your preference flag, or add the *9Ndn* read code to your records.

Can I change from an enriched SCR to a core one ?

YES.

It is easy to revert your enriched SCR back to a basic (core) one. Just ask your GP.

- Ask your GP to delete all instances of the opt-out read codes (if your have previously opted out), and
- Ask your GP to delete all instances of the *9Ndn* read code, and
- Ask your GP to set your preference flag to *Express consent for medication, allergies and adverse reactions only*

Be aware however that this procedure will not *delete* your previously uploaded, enriched data.

What about my children's records ?

The Department of Health is uploading **everyone's** medical records, no matter how young or old you are.

Your children's medical records will be uploaded too unless you opt them out.

Children under the age of 16 years old will *not* be written to about the Summary Care Record before their records are uploaded; it will be up to their parents or guardians to decide whether to discuss it with them or not.

The uploaded data may refer to confidential data which the child provided to their GP perfectly legitimately without parental knowledge.

When your children reach their 16th birthdays, they will *not* be automatically written to about the Summary Care Record and their uploaded data.

But when your children are old enough to understand and make a decision for themselves about the storage of their data in his way, they will *not* be able to get those records completely deleted should they want.

Do I need my GP's permission before oping-out my children ?

NO.

Absolutely not.

You do not need to see, discuss with or seek the permission of your GP (or anyone else for that matter) before opting your children out of the Summary Care Record.

The decision to opt-out your children (or opt-in to it) is yours to make, after discussion with your children as appropriate.

In exceptional circumstances, your GP might contact you, as a parent/guardian, to discuss whether opting-out is in the child's best interests. But (in my opinion) this would be extremely rare.

If your child's medical history was so complex, serious or life-threatening then almost certainly other methods of making your child's medical information available to others will already have been considered.

If you are uncertain about opting your children in to, or out of the Summary Care Record then you are welcome to discuss it with your GP. But you are under no obligation to.

New babies will automatically get a Summary Care Record when they register at the GP practice.

You will need to opt-out your newborn if you do not want them to have Summary Care Record.

Can I get my uploaded data deleted from the Summary Care Record?

NO.

Once your medical data has been uploaded to the Summary Care Record, it will be extremely difficult, if not impossible, to get your data completely deleted.

If you decide you no longer want your medical records on this database, or if you discover that your records have been uploaded without your knowledge or your understanding or your consent, you will find it virtually impossible to get your data deleted. Your "visible" record can be blanked out or masked, but your medical records - and your childrens' records - will still be stored intact and indefinitely on the Summary Care Record database.

If your records are "accidentally" uploaded, your GP will not be able to get them deleted for you. Your GP will not be able to put things right.

When your children are old enough to understand about the Summary Care Record, they will not be able to get their uploaded data deleted if they want.

If your Summary Care Record has ever been accessed by a health professional (GP, Nurse, A&E doctor, Medical Student, Pharmacist, Health care Assistant, Phelbotomist, Optician, Dentist etc. etc.), or "should have been accessed" then you *cannot* get your data deleted, only "masked".

If you present to A&E and you are asked if your SCR can be looked at, and you say no (perhaps because this is the first time that you realise that your data has been uploaded) then your data "should have been accessed" and you *cannot* get your data deleted.

The Department of Health has produced no guidance to indicate when a SCR "should have been accessed".

Nevertheless, if you *want* to try to get a SCR deleted:

- You will need to fill in a SCR Deletion Form and hand this to your GP
- The form is downloadable here
- You will have to opt-out of the Summary Care Record (if you haven't already) by stating this to your GP
- Your GP will send your SCR Deletion form to the local CCG who will initiate the deletion assessment with the Department of Health

Very,few requests to have a SCR deleted will be accepted.

But can I opt-out a a later date, after my SCR has been created ?

YES.

The very same code that is added to prevent the uploading of medical records to the SCR in the first place is used to "blank" or "mask" a "visible" SCR (so called "logically deleted").

Your GP will either add the appropriate read code to your GP-held records or your GP can set your decision to no longer have a Summary Care Record directly via the surgery GP preference flag software.

This will limit those who could clincally access your data, but all your uploaded data will remain intact and archived on the Summary Care Record database forever (i.e. not "physically deleted").

Can I opt back in, at a later date, if I have opted-out ?

YES.

You can opt back in at any time and have a Summary Care Record created.

For example, you can choose to opt-out now and only opt-in once you are certain that your local Accident & Emergency department and your local GP out of hours centre are both accessing and viewing Summary Care Records.

Will I be asked for my permission before my Summary Care Record is looked at ?

YES.

Well, you *should* be. This is known as "permission to view".

In certain situations though, known as "Emergency Access", your permission isn't required, as long as whoever is accessing your data states that they feel that it is "in the public interest" not to ask you, or if your consent cannot be provided (if you are in a coma, for example).

You should be asked *every time* your SCR is accessed.

Be absolutely sure that your "permission to view" status (otherwise known as your *SCR consent value*) remains permanently at *Patient must be asked every time for permission to view their Summary Care Record*.

Just one mouse-click by the doctor or nurse looking at your SCR can change this consent status to *Patient need not be asked again for permission to view their Summary Care Record*.

And then you won't be asked for your permission ever again.

Can I find out who has accessed my uploaded SCR, and when ?

YES.

But it's not easy.

If you agree to have your records uploaded to the Summary Care Record then you will *not* be informed each and every time anyone accesses your medical record, or informed at regular intervals as to how many times your record has been accessed and by whom. The NHS will not volunteer this information to you. You will have to ask.

The Data Protection Act gives you the right to find out this information. But it will be time consuming, and you will have to do this regularly if you wish to monitor and protect your uploaded data.

You will have to apply to the Department of Health for this information, under a DPA subject access request.

Your GP cannot apply on your behalf, not can your GP tell you the number of times that your uploaded data was accessed and by whom.

The from that you need to use to make your request is available here.

You will provide your name, date of birth, current address and possibly your previous address.

You will need to provide for identity purposes a copy of any one of the following documents:

- Photocopy of passport
- Original copy of electricity bill
- Original copy of gas bill
- Original copy council tax bill
- Original copy of any other bill in your full name

You will need to send your request to:

The Data Protection Manager
Department of Health
Room 334B Skipton House
80 London Road
London SE1 6LH

It may take up to 40 days for your requested information to be received from the DoH.

Who has access to my Summary Care Record ?

Anyone with an NHS smartcard and the appropriate permissions (RBAC roles B0257, B0264, B0370) on the card can access any Summary Care Record.

The NHS Smartcard works just like the chip and pin bankcards.

Summary Care Records can be accessed within GP practices directly (via their system software) or, via a web-based application, anywhere across England where there is an NHSnet connection.

Anyone can have the appropriate RBAC permissions added to their smartcard.

Access to the Summary Care Record is not restricted to doctors and nurses working in Accident & Emergency departments or GP out of hours centres.

Almost any department or ward within a hospital, and any staff member within those areas, can be authorised to access your Summary Care Record, including managers, support workers, helpers and technicians.

Soon, even pharmacies across England could have access, which you may or may not welcome.

Your GP does not authorise them - CCGs, hospital trusts and organisations do. Your GP cannot stop those activity codes being added to any smartcard.

In order to view a Summary Care Record, the user has to declare that they have a reason to access the record - that is, that they have a "Legitimate Relationship" with the patient.

When your Summary Care Record is accessed, the user is asked to declare the "self-claiming" Legitimate Relationship via a mouse-click. They then have access to your record.

The SCR is supposedly policed by means of "privacy alerts", sent to an organisation's privacy officer when, for example, a self-claiming legitimate relationship is generated. The privacy officer is then supposed to investigate all such alerts to see whether any unwarranted access to the SCR has occurred.

When a legitimate relationship is set up (by a receptionist) for an entire department - for example, when you attend Accident & Emergency - then everyone in that department (who has an appropriate smartcard) can access your record without needing to self-claim. They all then have *unrestricted* access to your Summary Care Record for the next 6 months. No one needs to declare a "self-claiming" Legitimate Relationship - and that means no privacy alerts.

However, the privacy officer policing your Summary Care Record will *not* be your GP.

Will my Summary Care Record be downloaded when viewed - and will this download be deleted ?

When your SCR is looked at in an Accident & Emergency department (or other hospital department running the *Ascribe Symphony software*) a copy of your SCR (as it is at that moment in time, a snapshot) is downloaded and stored indefinitely on the organisation's local computer system.

You cannot prevent this download nor can you get this downloaded copy deleted should you wish.

However, when you visit a GP out of hours centre, the majority of which run software by *Adastra*, a snapshot of your SCR is *not* downloaded and stored indefinitely.

A copy of the SCR is temporarily cached on the Adastra system when a clinician accesses the SCR so it can be viewed by them. This copy is automatically deleted by the system once the case has been closed.

Will anyone actually look at my Summary Care Record if I attend Accident & Emergency or a GP out of hours centre ?

The probability of your Summary Care Record being accessed, looked at and used within a consultation in any given setting somewhere in England is very, very low at present.

Very few organisations across England are actually set up to access and use the Summary Care Record.

Many hospital trusts neither use the Summary Care Record nor have plans to.

In some hospital trusts, the Accident & Emergency department isn't set up to use the Summary Care Record, although other departments are. And within those departments, doctors are not enabled to access the Summary Care Record.

Even in those GP out of hours centres set up to use the Summary Care Record, official figures have shown that in areas where records have been uploaded, they are accessed for less than 1% of calls.

A current (5th November 2013) list of organisations who are *capable* of viewing the SCR can be found here, although it is not clear which departments (such as Accident & Emergency) within those hospital trusts are actually and reliably looking at Summary Care Records.

You can ask your GP whether doctors and nurses at your local Accident & Emergency department or GP out of hours centre are actually using the Summary Care Record.

If not, you may wish to wait until they are before allowing your records to be uploaded. The upload serves no purpose otherwise.

In North East Hampshire, not one of the four local Accident and Emergency departments (Frimley, Reading, Basingstoke and Guildford) are either viewing Summary Care Records or, seemingly, have any plans to do so at present.

Do I need to agree to have a Summary Care Record before I can email my GP or surgery, request a repeat prescription by email or online, book an appointment with my GP online or look at my medical records ?

NO.

You can do all of those without having a Summary Care Record.

Is care.data the same as the Summary Care Record ?

NO.

care.data and the Summary Care Record (SCR) are two entirely separate projects.

For further information about care.data, please see my other site.

As regards the Summary Care Record:

- It concerns *direct clinical care*
- You may have recently received a *personalised* letter from your local CCG about the Summary Care Record
- Your GP surgery may not be able to tell you exactly *when* they will commence uploading Summary Care Records

care.data is very different to the Summary Care Record:

- The information extracted for care.data **far exceeds** just allergies and medication

- The information uploaded to care.data will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- care.data does **not** concern clinical care, it is an administrative and research database
- Patients will **not** be written to individually about care.data, although a national leaflet drop is planned (see below)
- We know that this project **will** go ahead everywhere shortly, with data extractions planned for "Spring 2014"

You will still need to opt-out to prevent a Summary Care Record upload even if you have already opted-out of care.data .

Summary Care Record opt-outs will not prevent care.data uploads.

care.data opt-outs will not prevent Summary Care Record uploads.

Opting-out of one database does not mean that you have automatically opted-out of the other.

Can I have a Summary Care Record but opt-out of care.data ?

YES.

Can I agree to care.data extraction but opt-out of the Summary Care Record ?

YES.

- You can both have a Summary Care Record and allow care.data extractions
- You can opt-out of both databases and allow neither
- Or you can opt-out of one but allow the other

Opting-out of either database, or both, will not in any way affect the medical care that you receive from your GP surgery.

What happens if I neither opt-in nor opt-out ?

If you do nothing, your GP will have to assume that you want a Summary Care Record.

Hopefully, you will just have a basic, core SCR (though that is by no means certain).

Unless your surgery clearly states that it will automatically create only basic, core SCRs, then you should opt-in and make your preference known to your GP.

So if I am happy to have a Summary Care Record, how do I opt-in ?

If you are certain that you want a Summary Care Record (if you are unsure then please discuss it with your

GP) then you can opt-in by giving your explicit consent to your GP.

If you are certain that you would like your data uploaded then you simply have to state this to your GP. You can see your GP, ring your GP or write to your GP. If your GP allows you to email him/her then you could give your explicit consent in this way.

You have the right to see a copy of your medical data *before* it is uploaded by your GP surgery to the Summary Care Record.

This will allow you to check the following:

- That the medications that you are being prescribed are recorded correctly and are up to date
- That the allergies or adverse reactions to medicines (if any) that you have are recorded accurately and in full
- That the main illnesses or diagnoses in your medical record are accurate and comprehensive, if you are intending to have an enriched SCR

before the information is uploaded.

If you do wish to have a Summary Care Record, make sure:

- You tell your GP whether you want your SCR to be a basic SCR (consisting of core data only) or an enriched one
- Your SCR preference setting remains permanently at *Express consent for medication, allergies and adverse reactions only*, if you just want a basic SCR
- Your SCR "permission to view" status remains permanently at *Patient must be asked every time for permission to view their Summary Care Record*

I have created a simple opt-in form for use at any GP surgery:

Download the generic opt-in form in PDF format

Download the generic opt-in form in DOC format

Download the generic opt-in form in RTF format

Please note that this form states that you want a basic SCR, with core data only uploaded.

You can opt-in using this simple form:

- You can hand your opt-in form in to your GP surgery
- You can post your opt-in form to your GP surgery
- You can fax your opt-in form to your GP surgery
- You can email your opt-in form to your GP or GP surgery (if they have an email address)
- The same form can be used for your children (or for any children under the age of 16yrs for whom you have parental responsibility)
- If you prefer, just write a letter to your GP stating that you are giving your explicit consent for a Summary Care Record to be created from your medical records.

Do NOT send your opt-in form to your local CCG. The CCG is not the data controller for your medical

records, your GP is.

You can opt-in verbally (without an opt-in form or letter) by:

- Stating your wish to opt-in to your GP the next time that you see him/her
- Stating your wish to opt-in to your GP the next time that you speak with him/her on the telephone
- Stating your wish to opt-in to your GP the next time that you email him/her

ANY communication (in person, by letter, email, fax, or telephone) to your GP stating your wish to opt-in is valid.

I don't wish to have a Summary Care Record - how do I opt-out ?

Opting out of the Summary Care Record is quick and easy.

You do not have to wait until the Summary Care Record goes live in your area to opt-out. You can opt-out right now and your wishes will be recorded by your GP and will ensure that your data is not uploaded if and when the programme does go live for your surgery.

You are under *no obligation whatosever* to fill in the official opt-out form in order to prevent your data from being uploaded, though you can if you wish.

And when the Summary Care Record does go live in your area and for your surgery, you will *not* have to opt-out a second time.

Your GP will either add the appropriate read code (9Ndo) to your GP-held records or your GP can set your decision to refuse to have a Summary Care Record directly via the surgery GP software (the so-called "Summary Care Record preference flag").

ANY communication (in person, by letter, email, fax, telephone or text) to your GP stating your wish to opt-out is valid.

I have created a generic opt-out form for use at any GP surgery:

Download the generic opt-out form in PDF format

Download the generic opt-out form in DOC format

Download the generic opt-out form in RTF format

You can opt-out in writing:

- You can hand your opt-out form in to your GP surgery
- You can post your opt-out form to your GP surgery
- You can fax your opt-out form to your GP surgery
- You can email your opt-out form to your GP or GP surgery (if they have an email address)
- The same form can be used for your children (or for any children under the age of 16yrs for whom you have parental responsibility)
- If you prefer, just write a letter to your GP stating your wish to opt-out

Do NOT send your opt-out form to your local CCG. The CCG is not the data controller for your

medical records, your GP is.

You can opt-out verbally (without an opt-out form or letter) by:

- Stating your wish to opt-out to your surgery in person
- Stating your wish to opt-out to your GP the next time that you see him/her
- Stating your wish to opt-out to your GP the next time that you speak with him/her on the telephone
- Stating your wish to opt-out to your GP the next time that you email him/her

Do NOT ring, email or attend your local CCG to opt-out. The CCG is not the data controller for your medical records, your GP is.

You do **not** need:

- To wait until the Summary Care Record goes live in your area to opt-out. You can opt-out right now.
- To opt-out in person.
- To make an appointment with your GP (or practice manager) to opt-out.
- Your GP's permission to opt-out.
- Your GP's permission to opt-out your children (or any children under the age of 16yrs for whom you have parental responsibility).
- To give any reasons why you wish to opt-out.
- To "discuss" your opt-out with your GP, your surgery, your CCG or with anyone else.

How will opting-out affect my medical care ?

Opting-out will have no effect on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

Healthcare professionals will treat you in exactly the same way, whether you have a Summary Care Record or not. Your entitlement to medical care is unaffected.

If medical staff are authorised to access your *electronic hospital records* (if any exist at a given hospital) then your opt-out of The Summary Care Record will have **absolutely no effect on that whatsoever, in any way**.

Opting-out will have no effect on your GP surgery and the way it provides services.

It will have **absolutely no effect whatsoever** on the way your GP records are stored or accessed electronically by your surgery.

It will not affect your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.

If you opt-out of The Summary Care Record, you can still be referred to a specialist under Choose & Book, your surgery can still manage your prescriptions via the Electronic Prescription Service, you can continue to request your prescriptions online, continue to email your GP or surgery and continue to access your medical records online (if you are offered that facility).

Opting out of The Summary Care Record will have no effect whatsoever on your relationship with your GP surgery.

Will my GP mind if I opt-out ?

NO.

Whether or not you opt-out is immaterial to your GP.

And you certainly don't need your GP''s approval or permission to opt-out of the Summary Care Record.

Feel free to send me *constructive* comments about this site.

Neil.Bhatia@nhs.net

I will read every comment sent, though please do not be offended if I do not reply to your message.

Privacy policy: I will not sell, trade or otherwise transfer to any third parties your personally identifiable information (your email address or the content of your email)

This non-commercial website represents the personal views of Dr Neil Bhatia, GP and Caldicott Guardian for the Oaklands Practice in Yateley..

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The Summary Care Record

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This non-commercial website represents the personal views of Dr Neil Bhatia, GP and Caldicott Guardian for the Oaklands Practice in Yateley.

Page 2 - Other ways to make your information available

If you do not want a Summary Care Record but would still like to consider ways in which you could make your medical information accessible if you ended up in A&E, or if you needed to see an out-of-hours GP, then read on.

These ways are capable of providing information that :

- Is far more comprehensive than the Summary Care Record
- Allows you to provide information on non-prescription medication that you take, and medication prescribed by a doctor other than your GP
- Ensures that *you* remain in total control of the information
- Ensures that *you* control who sees your information, and when
- Ensures that the information will be available to medical staff *instantly*
- Ensures that your information is *guaranteed* to be seen by medical staff
- Ensures that your information is available even if the IT/computers/phones aren't working
- Ensures that your information is available even if the A&E, or out-of-hours GP, isn't yet connected to the Suumary Care Record, or clinical saff are not using it
- Ensures that your information will be available *world-wide* should you choose so
- Ensures that *you* (+/- your GP) decide the information that you want to be made available, or ought to be available
- Ensures that *you* (+/- your GP) can keep the information accurate, up to date and relevant
- Ensures that your information will *not* be widely shared or disseminated

Is there a need ?

First of all, have a think as to whether or not you even need to consider this. For the vast majority of children, teenagers and young adults - that is, the generally healthy population with little or no relevant medical history that would prove useful in an emergency - there is unlikely to be any material benefit from making your medical information available in any of the ways described below. If you are unsure as to whether your history or medication is of such significance then the best thing to do is to discuss this with your GP when you next see him or her.

Doctors spend years in training to be proficient at assessing patients without knowing any of their medical history, including unconscious patients or patients unable to communicate by virtue of their illness, and to administer appropriate and in some cases life-saving treatment confidently. That is how doctors are trained and that is why the training to be a doctor is so long and so demanding.

Information is already shared

If you become unwell and see your GP in your local surgery (or your GP visits you at home) and you are ill enough to need to be admitted to hospital then your GP (or surgery) will ensure that the hospital doctors have your relevant medical details either by speaking directly to the hospital staff, listing your details in a letter that you take with you to hospital, or by faxing those details straight to the hospital.

If you become unwell during working hours and end up in A&E then the hospital medical staff will not hesitate to ring your GP surgery for information if needed. Equally, your GP surgery will not hesitate to pass on full and detailed information (from one doctor to another) about any patient in that situation. GP surgeries can instantly fax printed details straight to the A&E department.

If you become unwell when your GP surgery is shut (for example, at night) then the hospital medical staff will not hesitate to ring your GP surgery for information the next working day if needed. Once again, your GP surgery will not hesitate to pass on full and detailed information about any patient in that situation.

Your surgery details

One of the simplest things that you can do it to keep a small business card or piece of paper in your wallet, purse or handbag detailing the name of your GP surgery, the surgery telephone number and the surgery fax number (see alert cards, below). If you are admitted to hospital then the medical staff will be able to contact your GP surgery easily.

Know your own history

The vast majority of patients presenting to A&E or an out-of-hours GP are adults perfectly capable of stating their own medical history, medications and allergies to medical staff, or are children accompanied by parents or guardians who can do so on their behalf. Know your own medical history, your medications, and your allergies. If you're not sure, ask your GP for a summary (see below) the next time that you see him or her.

Make sure someone else knows your history

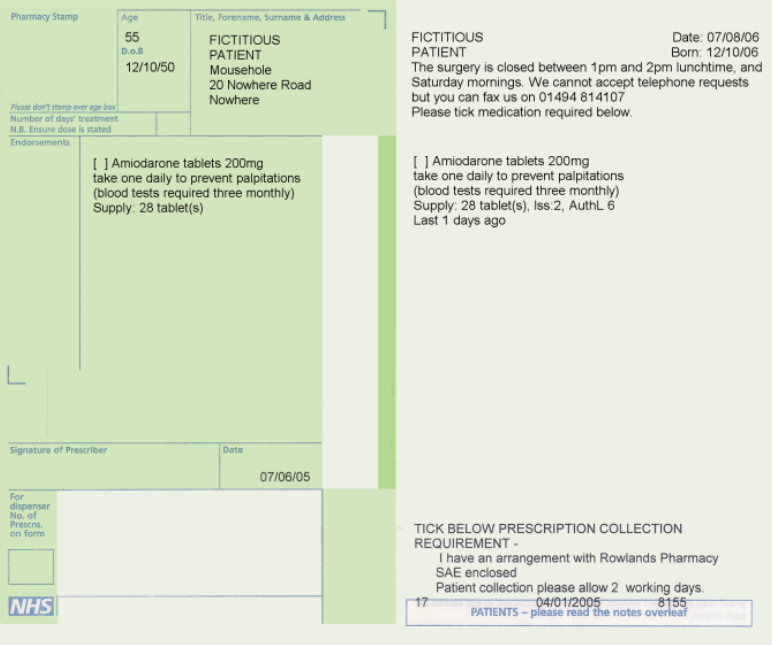
If you have a significant medical history - perhaps you have had multiple or serious medical problems, are on certain medications (see below), or would have difficulties communicating your medical details (for example, you have had a stroke affecting your speech) - then it is always advisable to ensure that someone else (such as a son or daughter, parent, relative, friend or neighbour) could detail your medical history if required. In an emergency, medical staff will always try to contact someone for more information. The easiest way would be to give a copy of your medical history (such as a brief summary, described below) to a trusted person. They could then read out details to medical staff if contacted, or even fax the summary straight to the hospital A&E department if they own a fax machine or PC.

And of course, many patients - particularly children and the elderly - are accompanied to hospital by parents, relatives, carers, friends or neighbours.

Repeat prescription

One of the easiest way to ensure that relevant information is easily to hand is to carry a simple summary of your medical history with you, for example in your wallet, purse or handbag. And one of the easiest ways to do this is to ask your GP or surgery for a duplicate copy of your repeat prescription request (the one that you tick and hand in to your surgery when you need more medication). Add to this page any significant allergies that you have and any significant past medical events or operations - all this information can be obtained from your GP the next time that you see him or her. Add next of kin details, your NHS number (your surgery can give you this) and ask your GP surgery to stamp it so that your surgery address and telephone number are there too. Keep that piece of paper (about ¼ of the size of an A4 sheet) with you, folded up in your wallet, purse or handbag. If you are visited at home by an out-of-hours GP then that information might be useful to the visiting doctor. Medical staff in hospitals are trained to check personal effects for such information when patients are admitted in an emergency.

All GP practices can add significant diagnoses within repeat prescriptions, making it clear both to patients and to other healthcare professionals the reasons for that medication being used. Instead of just prescribing the medication as "take one tablet daily", the GP adds "to lower blood pressure" or "to prevent angina", as can be seen in the picture below:



Pharmacy Stamp
Age
55
D.o.B
12/10/50
Title, Forename, Surname & Address
FICTITIOUS
PATIENT
Mousehole
20 Nowhere Road
Nowhere
Please don't stamp over age box
Number of days' treatment
N.B. Ensure dose is stated
Endorsements

[ ] Amiodarone tablets 200mg
take one daily to prevent palpitations
(blood tests required three monthly)
Supply: 28 tablet(s)

Signature of Prescriber
Date
07/06/05
For dispenser No. of Prescns. on form
NHS

FICTITIOUS
PATIENT
Date: 07/08/06
Born: 12/10/06
The surgery is closed between 1pm and 2pm lunchtime, and Saturday mornings. We cannot accept telephone requests but you can fax us on 01494 814107
Please tick medication required below.

[ ] Amiodarone tablets 200mg
take one daily to prevent palpitations
(blood tests required three monthly)
Supply: 28 tablet(s), Iss:2, AuthL 6
Last 1 days ago

TICK BELOW PRESCRIPTION COLLECTION REQUIREMENT -
I have an arrangement with Rowlands Pharmacy
SAE enclosed
Patient collection please allow 2 working days.
17 04/01/2005 8155
PATIENTS – please read the notes overleaf

A few GP practices routinely add medication allergies to the repeat prescription sheet.

"Brief Summary"

GP computer systems can easily print out a short summary (sometimes called a "Brief Summary") of important and relevant medical information for any of the practice's patients in a few seconds. This summary would include name, address, DOB, NHS number, diagnoses, medication, allergies and certain immunisations (such as tetanus). To this the surgery contact details could be added, as well as next of kin details. The printout is usually on an A4 piece of paper, and you would need to ask your GP in person for this. Once again, keep this summary with you, folded up in your wallet, purse or handbag. Give a copy to your trusted next of kin, relative, friend or neighbour.Again, if you are visited at home by an out-of-hours GP then that information might be useful to the visiting doctor, and medical staff in hospitals are trained to check personal effects for such information when patients are admitted in an emergency.

An example of a brief summary can be seen here.

A brief summary could be saved onto an encrypted USB stick as a .txt, .doc, .rtf or .pdf file.

Access your own information

More and more surgeries are offering their patients the ability to access and view their own records online -

an example is EMIS Patient Access.

Online Electronic Health Record Access

Allergies

29/04/2009 Adverse reaction to Penicillins

Current Medication

Repeat (Long Term Prescriptions)

09/07/2008 Cetirizine Hydrochloride Tablets 10 mg
ONE TO BE TAKEN DAILY

Active or Significant Clinical Problems in Date Order

29/04/2009 Hay fever
16/04/2007 Refused consent for upload to national shar electronic rec

Active or Significant Clinical Problems by Body System

Chest system

29/04/2009 Hay fever

Administration

16/04/2007 Refused consent for upload to national shar electronic rec

Family Health History

You have no family history items recorded

Most recent entry on your health record

29/04/2009 Hay fever

Most Recent Results

29/04/2009 Alcohol 21 units/week
23/03/2006 Height 165 cm
23/09/2008 Wt. 71.4 Kg
14/04/2008 B.M.I. 26.1
27/07/2004 Microbiology, Normal

If your surgery offers this, and you have asked to be granted access in this way, then in an emergency you could allow medical staff access to your records on a temporary basis, or a relative or friend could do this for you. No information is uploaded to the Summary Care Record for this. More details can be found in a factsheet that I have written for my own patients. EMIS is one GP software system that offers this, but other systems are doing this as well.

Zaptag is another example of online health records access. Information from your GP surgery is securely uploaded to the Zaptag server and available to you (or any medical staff you choose) as required. Once again, no information is uploaded to the Summary Care Record for this.

Philip Steven's Health Account

Records By Date

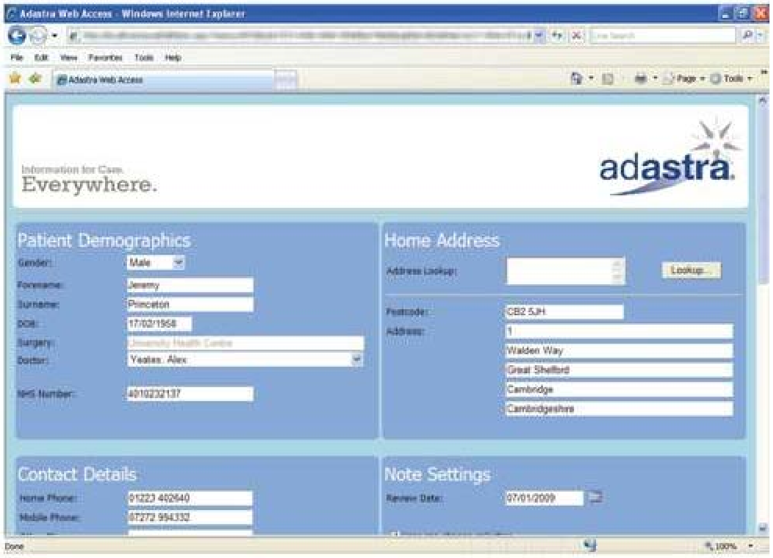
Date	Description	Author	View	Edit	Delete	Status
01/01/2012	**Condition:** Broken Leg **On-set Date:** 01/01/2012 **Status:** broken **Last Episode:** 01/01/2012	Self				
01/01/2012	**Allergy Name:** Bee Stings **Reaction:** Red Rash **First Observed:** 01/01/2012	Self				
01/01/2012	**New Passport** -	Self				

My Health Providers

Emergency GP to GP information

All GP surgeries have mechanisms in place to send a brief summary about certain patients to the local out-of-hours GP organisation, so that if patients present there, or is visited at home, then the doctors and nurses already have information to hand. This is commonly done for patients with very complex medical problems, for those patients who are terminally ill, and for patients who are predicted to become unwell when their GP surgery is shut. An example of a form used to notify an out-of-hours organisation of such patients can be found here. If your medical history warrants passing information proactively to the out-of-hours organisation then your GP will discuss this with you.

GPs can also add information directly to the local out-of-hours database via a secure web portal, using Adastra's Web Access software (Adastra is the biggest provider of clinical systems to GP out-of-hours organisations). With the explicit consent of patients, GPs can login securely and add information directly to the database instead of faxing it through as previously mentioned. The out-of-hours database is only accessible by staff working in the local out-of-hours centre, and has nothing whatsoever to do with the NHS Database.



Patient Demographics

Gender: Male
Forename: Jeremy
Surname: Princeton
DOB: 17/02/1958
Surgery: University Health Centre
Doctor: Yeates, Alex
NHS Number: 4010232137

Home Address

Address Lookup:
Postcode: CB2 5JH
Address: 1
Walden Way
Great Shelford
Cambridge
Cambridgeshire

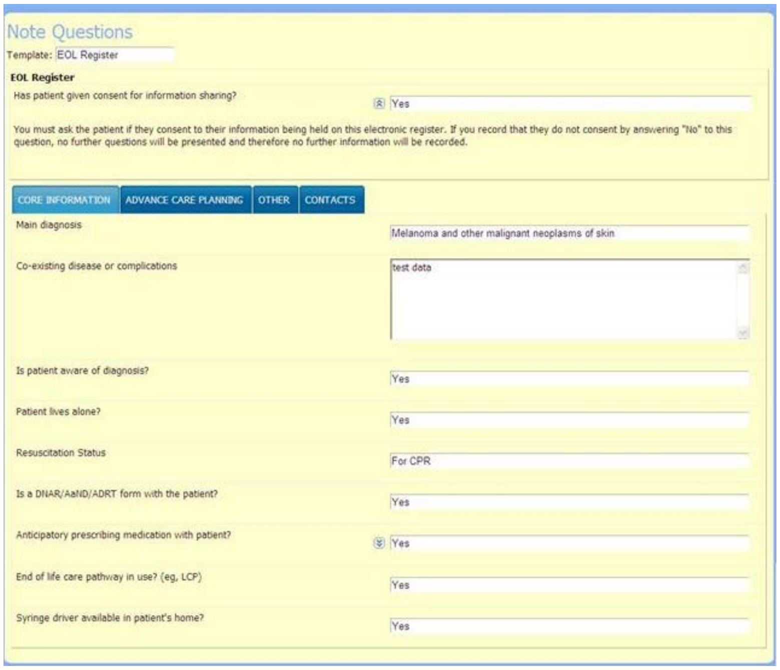
Contact Details

Home Phone: 01223 402640
Mobile Phone: 07272 994332

Note Settings

Review Date: 07/01/2009

Adastra also offers their End of Life Care Register, a more detailed version of Web Access but specifically for terminally ill patients. This may allow Advance Statements and Advance Decisions to be made available in detail to local out-of-hours clinicians, and once again has nothing whatsoever to do with the NHS Database.



Note Questions

Template: EOL Register

EOL Register

Has patient given consent for information sharing? Yes

You must ask the patient if they consent to their information being held on this electronic register. If you record that they do not consent by answering "No" to this question, no further questions will be presented and therefore no further information will be recorded.

Main diagnosis	Melanoma and other malignant neoplasms of skin
Co-existing disease or complications	test data
Is patient aware of diagnosis?	Yes
Patient lives alone?	Yes
Resuscitation Status	For CPR
Is a DNAR/AaND/ADRT form with the patient?	Yes
Anticipatory prescribing medication with patient?	Yes
End of life care pathway in use? (eg, LCP)	Yes
Syringe driver available in patient's home?	Yes

Alert Cards

Simple credit-card sized cards can be used to store medical details (including GP contact details), for example:

MediPAL® 0845 603 4604

Cardholder Name: JOHN A. SMITH.

Emergency Contact: Eve Smith 01234 56789 (M) 07799988801

Date of Birth: 16/02/1950

Current DAILY Medication:

3 x 10units NOVORAPID INSULIN

1 x 20units LEVIMIR INSULIN

2.5 mg VENTOLIN INHALER

1 x 100mcg LEVOTHYROXINIE

1 x 2.5mg LISINOPRIL

1 x 40mg FUROSEMIDE

1 x 20mg SIMVASTATIN

1 x 75mg ASPIRIN

1 x 20mg RAMIPRIL

1 x 25mg ATENOLOL

Copyright © 2009

Data correct as at: 20/01/2009

The Data Protection Act 1998
Reg. No Z8558147

Brief Medical History:
ALLERGIC TO PENICILLIN
DIABETES TYPE 1 - TAKES INSULIN
ATRIAL FIBRILATION - Nov 2001
HIGH BLOOD PRESSURE
EPILEPTIC – Since Sept 2003
BLOOD GROUP A Rh Negative
NHS No. - 050 6366 22 33
GP DETAILS:
Doctor A. Brown
+ 44 (0) 1234 56789
The Surgery, 15 Sunny Days, Anywhere, AB1 1CD (UK)

There are a few medications that could be particularly useful for an A&E or an out-of-hours doctor to know about. Carrying information on you at all times that states this medication that you are taking is important, and nearly everyone prescribed such drugs will already have (or should have) such "alert cards" either from their GP, hospital specialist or pharmacist. A few examples are:

Corticosteroids: patients should carry a steroid alert card (an example is shown here).

Warfarin: patients should carry an anticoagulant alert card (an example is shown here).

Biological therapy: e.g. for arthritis, again an alert card (an example is shown here).

Alert cards can also be used for those suffering with rare or complex medical disorders (an example is here.)

Medical Alert Devices

Medical alert devices provide a potentially life-saving identification and information system for individuals. Usually, people with serious medical problems (e.g. haemophilia or type I diabetes), severe and life-threatening allergies (e.g. peanuts or penicillin) or on long-term medication (such as warfarin) wear these devices, which take the form of bracelets, necklets, dog tags and even watches, inscribed with, or containing, the essential medical information, a unique ID, and a 24 hour telephone number for a call centre holding even more details about the person.

The two most widely used and recognised devices are:

MedicAlert

SOS Talisman

Extensive information about medical alert devices can be found on these two websites.

All medical staff are trained to search for, recognise and use these alerts. They really are the best way to ensure medical staff have - quite literally - instant access to important medical information (as well as being able to identify you in the absence of any other form of ID). MedicAlert is endorsed by (amongst others) The British Association for A&E Medicine and The Royal College of General Practitioners.

Once again, if you think that a medical alert device would be appropriate for you then it is worth discussing this with your GP the next time that you see him or her.

Remember

- **You do not have to upload your medical records to the Summary Care Record to make information available to medical staff in an emergency - there are other options.**
- **Your GP will always be able to advise you as to any true need to consider making information**

available in those ways, given your particular medical circumstances.

- **Simple ways, such as brief summaries and alert cards, are easy to implement.**
- **Medical alert devices provide the most secure and guaranteed way to enable medical staff to instantly access essential medical information about you, should your circumstances warrant it.**

But after considering everything you do decide that the Summary Care Record really is the best option for you, then tell your GP and *give your explicit consent* for your records to be uploaded.

This non-commercial website represents the personal views of Dr Neil Bhatia, GP and Caldicott Guardian for the Oaklands Practice in Yateley.

Last updated: 30.10.13

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The Summary Care Record

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forward to Page 2 - Alternatives to the Summary Care Record

This non-commercial website represents the personal views of Dr Neil Bhatia, GP and Caldicott Guardian for the Oaklands Practice in Yateley.

Page 1 - The basics

This website aims to provide information to everyone about The Summary Care Record (SCR) so that you can make an *informed* decision about opting-in or opting-out.

Much of the information and guidance on this site was extracted from sources via the Freedom of Information Act.

The information provided on this site is designed to complement, not replace, any guidance or opinion about The Summary Care Record provided by your own GP surgery.

The official DoH Summary Care Records website is here.

You *can* control your GP records - if you know how.

See this chart (tinyurl.com/mygprecords) for guidance, and contact your GP surgery if you need further information about any of the data flows.

Summary Care Records in a nutshell....

- Medical information is going be extracted from your GP records and uploaded, on a continuous basis, to a central database run by the Department of Health (DoH)
- You will *not* be asked for your permission before this extraction take place, but you should have been (or should be) informed that it is taking place
- The information extracted will (initially) be your medication (past and current) and your allergies (if you have any)
- Your information will theoretically be available across England, in hospitals and GP out of hours centres, to doctors, nurses and other staff (both clinical and non-clinical)
- However *anyone* with an NHS Smartcard and the appropriate electronic permissions can access your Summary Care Record, though you should be asked for your permission first
- Your GP will *not* be the data controller for the uploaded information - the Secretary of State for Health will be
- Your GP surgery *cannot* stop this extraction - but you, as an individual, can (if you so wish)
- The Summary Care Record is voluntary - *you are under no obligation to allow your records to be*

processed in this way, and you have the right to opt-out
- You *can* stop the extraction of this data from your GP records by asking your GP to put a special code in your GP records
- If you opt-out of the Summary Care Record (now), you can opt back in at any time in the future
- The Summary Care Record is *not* the same as care.data - opting out of one does *not* mean that you have automatically opted out of the other

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The details....

Summary Care Records - what is going to happen ?

You may have received a letter from your local CCG (or, previously, PCT) about the Summary Care Record (it looks like this).

A new central NHS computer system is being gradually introduced across England called the Summary Care Record (often referred to as the "NHS Database"). The Summary Care Record is meant to help emergency doctors and nurses help you when you contact or see them when your GP surgery is closed.

Medical data from your GP records will be extracted and uploaded, on a continuous basis, to a central database run by the Department of Health (DoH). The data will then be made available to those who have access to the Summary Care Record by means of an NHS Smartcard.

Your data will be uploaded by default, unless you actively object – an "opt-out" mechanism:.

That is, if you do and say nothing, your data *will* be uploaded.

The DoH believes that everyone should be assumed to be happy to have their information uploaded and be required to formally object if not.

When is this all happening ?

The Summary Care Record is an ongoing project. It is live in some areas of the country, and within those areas in some (but not all) GP surgeries.

In November 2013, the government announced that *all* surgeries in England *must* upload Summary Care Records by then end of March 2015, at the latest.

However, your GP surgery may not yet be able to tell you *exactly when* they will commence uploading Summary care Records.

Can GP surgeries refuse to upload records to the Summary Care Record without their patients' explicit consent ?

NO.

The Department of Health is forcing *all* GP surgeries to upload Summary Care Records, under an opt-out system, by the end of March 2015.

Who will be the data controller for my uploaded records ?

The data extracted for the Summary Care Record will be stored on Deparment of Health national servers and not on GP systems.

The Secretary of State for Health is the data controller for all data stored in Summary Care Records.

As the data controller, he and he alone decides the purposes for which your uploaded data is, or will be, processed and the way in which your uploaded data is, or will be, processed. He alone decides who has access to your records, and whether or not to seek your consent for any such release.

Whilst your GP controls your medical records as held by your surgery, your GP is *not* the data controller for any records uploaded and stored in your Summary Care Record.

Your GP will **not** be able to:

- Control who has access to your uploaded records
- Control how your uploaded records will be shared or disseminated
- Control whether your consent is sought for any sharing or distribution of your uploaded records
- Control which other databases your uploaded records may be linked to
- Tell you who has accessed your uploaded records, and when
- Monitor or investigate who has inappropriately or illegally accessed your uploaded records
- Get your uploaded data completely deleted from the Summary Care Record should you wish

What information will be extracted from my medical records ?

At first, the data uploaded from your GP records will comprise of "core" data, and this phase is known as the *initial summary*. This will occur if you have either opted-in, or have not specifically opted-out.

If you have opted-out, no clinical information whatsoever is uploaded and a completely blank record is created instead.

Demographic data (your name, address, DOB, telephone number, GP details etc) has already been uploaded.

"Core" data consists of:

- All repeat medications which have not been discontinued and are not more than 18 months past their review date. This also includes items which are recorded on the system but which are prescribed elsewhere (e.g. hospital or special clinic) or OTC (Over The Counter) drugs taken by the patient and recorded on the system
- All repeat medications which have been discontinued in the last 18 months
- All acute medication prescribed in the last 6 months. This includes medication prescribed elsewhere and OTC drugs
- Suspected adverse reactions and allergies including allergies to drugs, foods and any other substances

Core data is the *minimum* data that will be uploaded to the Summary Care Record.
More data can and will be uploaded to it if you should want - *or if you're not careful*.

The core data will be updated in your Summary Care Record automatically as your GP prescribes further medication, or if you develop allergies or adverse reactions to medicines. It is then known as your "GP summary".

You cannot stop a record of the medication that your GP prescribes from being automatically uploaded to the Summary Care Record, even if this is medication clearly used to treat sensitive or embarrassing conditions, and nor can your GP stop this upload. It is often easy to deduce a patient's diagnosis from the medication being used to treat him or her.

The Summary Care Record was never - ever - going to be just a "summary".

Immediately after this initial upload further data can and will be added, such as major diagnoses, past operations and procedures, hospital letters etc. This process of uploading further data to your record is known as "enrichment" or "enhancement".

Additional (or "supplementary") data from your GP record can be uploaded to the Summary Care Record. This will then result in an *enriched GP Summary*.

The additional data that can be uploaded to the Summary Care Record by your GP is vast.
The GP Summary can hold data under some or all of the following headings:

- Allergies and Adverse Reactions
- Repeat Medications
- Acute Medications
- Discontinued Repeat Medication
- Risks to Care professional or Third Party
- Diagnoses
- Problems and issues
- Clinical Observation and Findings
- Treatments
- Investigations
- Provision of Advice and Information to Patients and Carers
- Personal Preferences
- Social and Personal Circumstances
- Services and Care Professionals and Carers
- Lifestyle
- Family History

Since October 2010, the government has stated that patients must give their explicit consent before any enrichment by their GP occurs.

If you are asked by your GP before further information about you is uploaded, then you can request that the information is not sent. You may wish for sensitive information, for example relating to mental or sexual health or certain infections, to be witheld from your enriched Summary Care Record.

Following the recommendations made in the Ministerial Review of the Summary Care Record, which reported in October 2010, the only enrichment of the Summary Care Record will be with additional information added from your GP records.

No other organisations (e.g. hospital trusts, A&E) are now permitted to upload additional information to the

Summary Care Record.

How do I control enrichment of my Summary Care Record ?

There exists a setting or flag that controls what data, if any, is stored within a given SCR. This is known as the *National Summary Preference, or SCR Preference* flag.

The flag can be set in a number of ways. It can be set by your GP (using the existing surgery software) if your surgery is enabled to do so, or it can be set by your GP adding a specific read code (or electronic "flag") to your GP-held electronic record.

If you have opted-out, then no Summary Care Record (or actually, a blank one) will be created for you. Obviously, no enrichment can take place by your GP. Your GP will have added the opt-out read codes *93C3 or 9Ndo* to your GP record, or may have set the flag directly. Setting the flag adds the read code and vice versa.

The SCR Preference flag is set as *Express dissent (opted out) - Patient does not want to have a Summary Care Record*

The remaining settings determine whether GP enrichment can take place or not.

The default setting is implied consent for a core SCR. Whilst this setting remains in force, *only* a core GP summary will be uploaded and your SCR *cannot* be enriched by your GP.

If you say or do nothing as regards opting-out of the SCR then your preference flag *may* remain on this setting. It is the assumption made if you do not opt-out.

The SCR Preference flag is set as *Implied consent for medication, allergies and adverse reactions only*

The other setting that prevents enrichment is express consent for a core SCR. Whilst this setting remains in force, again *only* a core GP summary will be uploaded and your SCR *cannot* be enriched by your GP.

This is set if you *tell* your GP that you only want a core SCR.

The SCR Preference flag is set as *Express consent for medication, allergies and adverse reactions only*

The final setting is express consent for an enriched SCR.

This is set if you *tell* your GP that you acually want an enriched SCR.

The SCR Preference flag is set as *Express consent for medication, allergies and adverse reactions, AND additional information*

If this setting is set then:

- The initial summary is created ready for upload
- The Summary Care Record *can* be enriched by your GP
- Enrichment to a GP summary can occur *before* the initial upload occurs, so an enriched GP Summary may be uploaded right from the start

Express consent to have an enriched SCR can be set in a number of ways:

- The flag may be set by your GP using the existing GP software, if the surgery is so enabled
- The flag may be set by the presence of the specific electronic code *9Ndn* in your GP-held elctronic record

Be aware of the implications of having an enriched Summary Care Record.

So what are my choices if I want to have a Summary Care Record ?

If you want a Summary Care Record (SCR) then you need to decide whether you want your SCR limited to basic core data (allergies, medications and bad reactions) only, automatically updated from your GP surgery, or whether you want your SCR to be *enriched* with further data from your GP record.

If you want your SCR to remain as the default, that is core data only, and not enriched with further data from your GP record, then you need to tell your GP.

Your GP will then :

- Delete any opt-out read codes from your record (if you have previously opted-out, or if your practice is running an opt-in scheme)
- Change your preference setting to *Express consent for medication, allergies and adverse reactions only*, if and when your surgery is enabled, or
- Add the read code *9Ndm* to your GP record

If you want your SCR to be *enriched* with further data from your GP record, then you need to tell your GP.

Your GP will then :

- Change your preference setting to *Express consent for medication, allergies and adverse reactions, AND additional information*, if and when your surgery is enabled, or
- Add the read code *9Ndn* to your GP records

The choice is yours - take control of your medical data if you choose to have a Summary Care Record.

Make sure your GP knows what type of Summary Care Record you want. Do not leave it to chance.

Can I change from a core SCR to an enriched one ?

YES.

It is easy to make your basic (core) SCR into an enriched one. Just ask your GP.

Your GP will simply change your preference flag, or add the *9Ndn* read code to your records.

Can I change from an enriched SCR to a core one ?

YES.

It is easy to revert your enriched SCR back to a basic (core) one. Just ask your GP.

- Ask your GP to delete all instances of the opt-out read codes (if your have previously opted out), and
- Ask your GP to delete all instances of the *9Ndn* read code, and
- Ask your GP to set your preference flag to *Express consent for medication, allergies and adverse reactions only*

Be aware however that this procedure will not *delete* your previously uploaded, enriched data.

What about my children's records ?

The Department of Health is uploading **everyone's** medical records, no matter how young or old you are.

Your children's medical records will be uploaded too unless you opt them out.

Children under the age of 16 years old will *not* be written to about the Summary Care Record before their records are uploaded; it will be up to their parents or guardians to decide whether to discuss it with them or not.

The uploaded data may refer to confidential data which the child provided to their GP perfectly legitimately without parental knowledge.

When your children reach their 16th birthdays, they will *not* be automatically written to about the Summary Care Record and their uploaded data.

But when your children are old enough to understand and make a decision for themselves about the storage of their data in his way, they will *not* be able to get those records completely deleted should they want.

Do I need my GP's permission before oping-out my children ?

NO.

Absolutely not.

You do not need to see, discuss with or seek the permission of your GP (or anyone else for that matter) before opting your children out of the Summary Care Record.

The decision to opt-out your children (or opt-in to it) is yours to make, after discussion with your children as appropriate.

In exceptional circumstances, your GP might contact you, as a parent/guardian, to discuss whether opting-out is in the child's best interests. But (in my opinion) this would be extremely rare.

If your child's medical history was so complex, serious or life-threatening then almost certainly other methods of making your child's medical information available to others will already have been considered.

If you are uncertain about opting your children in to, or out of the Summary Care Record then you are welcome to discuss it with your GP. But you are under no obligation to.

New babies will automatically get a Summary Care Record when they register at the GP practice.

You will need to opt-out your newborn if you do not want them to have Summary Care Record.

Can I get my uploaded data deleted from the Summary Care Record?

NO.

Once your medical data has been uploaded to the Summary Care Record, it will be extremely difficult, if not impossible, to get your data completely deleted.

If you decide you no longer want your medical records on this database, or if you discover that your records have been uploaded without your knowledge or your understanding or your consent, you will find it virtually impossible to get your data deleted. Your "visible" record can be blanked out or masked, but your medical records - and your childrens' records - will still be stored intact and indefinitely on the Summary Care Record database.

If your records are "accidentally" uploaded, your GP will not be able to get them deleted for you. Your GP will not be able to put things right.

When your children are old enough to understand about the Summary Care Record, they will not be able to get their uploaded data deleted if they want.

If your Summary Care Record has ever been accessed by a health professional (GP, Nurse, A&E doctor, Medical Student, Pharmacist, Health care Assistant, Phelbotomist, Optician, Dentist etc. etc.), or "should have been accessed" then you *cannot* get your data deleted, only "masked".

If you present to A&E and you are asked if your SCR can be looked at, and you say no (perhaps because this is the first time that you realise that your data has been uploaded) then your data "should have been accessed" and you *cannot* get your data deleted.

The Department of Health has produced no guidance to indicate when a SCR "should have been accessed".

Nevertheless, if you *want* to try to get a SCR deleted:

- You will need to fill in a SCR Deletion Form and hand this to your GP
- The form is downloadable here
- You will have to opt-out of the Summary Care Record (if you haven't already) by stating this to your GP
- Your GP will send your SCR Deletion form to the local CCG who will initiate the deletion assessment with the Department of Health

Very,few requests to have a SCR deleted will be accepted.

But can I opt-out a a later date, after my SCR has been created ?

YES.

The very same code that is added to prevent the uploading of medical records to the SCR in the first place is used to "blank" or "mask" a "visible" SCR (so called "logically deleted").

Your GP will either add the appropriate read code to your GP-held records or your GP can set your decision to no longer have a Summary Care Record directly via the surgery GP preference flag software.

This will limit those who could clincally access your data, but all your uploaded data will remain intact and archived on the Summary Care Record database forever (i.e. not "physically deleted").

Can I opt back in, at a later date, if I have opted-out ?

YES.

You can opt back in at any time and have a Summary Care Record created.

For example, you can choose to opt-out now and only opt-in once you are certain that your local Accident & Emergency department and your local GP out of hours centre are both accessing and viewing Summary Care Records.

Will I be asked for my permission before my Summary Care Record is looked at ?

YES.

Well, you *should* be. This is known as "permission to view".

In certain situations though, known as "Emergency Access", your permission isn't required, as long as whoever is accessing your data states that they feel that it is "in the public interest" not to ask you, or if your consent cannot be provided (if you are in a coma, for example).

You should be asked *every time* your SCR is accessed.

Be absolutely sure that your "permission to view" status (otherwise known as your *SCR consent value*) remains permanently at *Patient must be asked every time for permission to view their Summary Care Record*.

Just one mouse-click by the doctor or nurse looking at your SCR can change this consent status to *Patient need not be asked again for permission to view their Summary Care Record*.

And then you won't be asked for your permission ever again.

Can I find out who has accessed my uploaded SCR, and when ?

YES.

But it's not easy.

If you agree to have your records uploaded to the Summary Care Record then you will *not* be informed each and every time anyone accesses your medical record, or informed at regular intervals as to how many times your record has been accessed and by whom. The NHS will not volunteer this information to you. You will have to ask.

The Data Protection Act gives you the right to find out this information. But it will be time consuming, and you will have to do this regularly if you wish to monitor and protect your uploaded data.

You will have to apply to the Department of Health for this information, under a DPA subject access request.

Your GP cannot apply on your behalf, not can your GP tell you the number of times that your uploaded data was accessed and by whom.

The from that you need to use to make your request is available here.

You will provide your name, date of birth, current address and possibly your previous address.

You will need to provide for identity purposes a copy of any one of the following documents:

- Photocopy of passport
- Original copy of electricity bill
- Original copy of gas bill
- Original copy council tax bill
- Original copy of any other bill in your full name

You will need to send your request to:

The Data Protection Manager
Department of Health
Room 334B Skipton House
80 London Road
London SE1 6LH

It may take up to 40 days for your requested information to be received from the DoH.

Who has access to my Summary Care Record ?

Anyone with an NHS smartcard and the appropriate permissions (RBAC roles B0257, B0264, B0370) on the card can access any Summary Care Record.

The NHS Smartcard works just like the chip and pin bankcards.

Summary Care Records can be accessed within GP practices directly (via their system software) or, via a web-based application, anywhere across England where there is an NHSnet connection.

Anyone can have the appropriate RBAC permissions added to their smartcard.

Access to the Summary Care Record is not restricted to doctors and nurses working in Accident & Emergency departments or GP out of hours centres.

Almost any department or ward within a hospital, and any staff member within those areas, can be authorised to access your Summary Care Record, including managers, support workers, helpers and technicians.

Soon, even pharmacies across England could have access, which you may or may not welcome.

Your GP does not authorise them - CCGs, hospital trusts and organisations do. Your GP cannot stop those activity codes being added to any smartcard.

In order to view a Summary Care Record, the user has to declare that they have a reason to access the record - that is, that they have a "Legitimate Relationship" with the patient.

When your Summary Care Record is accessed, the user is asked to declare the "self-claiming" Legitimate Relationship via a mouse-click. They then have access to your record.

The SCR is supposedly policed by means of "privacy alerts", sent to an organisation's privacy officer when, for example, a self-claiming legitimate relationship is generated. The privacy officer is then supposed to investigate all such alerts to see whether any unwarranted access to the SCR has occurred.

When a legitimate relationship is set up (by a receptionist) for an entire department - for example, when you attend Accident & Emergency - then everyone in that department (who has an appropriate smartcard) can access your record without needing to self-claim. They all then have *unrestricted* access to your Summary Care Record for the next 6 months. No one needs to declare a "self-claiming" Legitimate Relationship - and that means no privacy alerts.

However, the privacy officer policing your Summary Care Record will *not* be your GP.

Will my Summary Care Record be downloaded when viewed - and will this download be deleted ?

When your SCR is looked at in an Accident & Emergency department (or other hospital department running the *Ascribe Symphony software*) a copy of your SCR (as it is at that moment in time, a snapshot) is downloaded and stored indefinitely on the organisation's local computer system.

You cannot prevent this download nor can you get this downloaded copy deleted should you wish.

However, when you visit a GP out of hours centre, the majority of which run software by *Adastra*, a snapshot of your SCR is *not* downloaded and stored indefinitely.

A copy of the SCR is temporarily cached on the Adastra system when a clinician accesses the SCR so it can be viewed by them. This copy is automatically deleted by the system once the case has been closed.

Will anyone actually look at my Summary Care Record if I attend Accident & Emergency or a GP out of hours centre ?

The probability of your Summary Care Record being accessed, looked at and used within a consultation in any given setting somewhere in England is very, very low at present.

Very few organisations across England are actually set up to access and use the Summary Care Record.

Many hospital trusts neither use the Summary Care Record nor have plans to.

In some hospital trusts, the Accident & Emergency department isn't set up to use the Summary Care Record, although other departments are. And within those departments, doctors are not enabled to access the Summary Care Record.

Even in those GP out of hours centres set up to use the Summary Care Record, official figures have shown that in areas where records have been uploaded, they are accessed for less than 1% of calls.

A current (5th November 2013) list of organisations who are *capable* of viewing the SCR can be found here, although it is not clear which departments (such as Accident & Emergency) within those hospital trusts are actually and reliably looking at Summary Care Records.

You can ask your GP whether doctors and nurses at your local Accident & Emergency department or GP out of hours centre are actually using the Summary Care Record.

If not, you may wish to wait until they are before allowing your records to be uploaded. The upload serves no purpose otherwise.

In North East Hampshire, not one of the four local Accident and Emergency departments (Frimley, Reading, Basingstoke and Guildford) are either viewing Summary Care Records or, seemingly, have any plans to do so at present.

Do I need to agree to have a Summary Care Record before I can email my GP or surgery, request a repeat prescription by email or online, book an appointment with my GP online or look at my medical records ?

NO.

You can do all of those without having a Summary Care Record.

Is care.data the same as the Summary Care Record ?

NO.

care.data and the Summary Care Record (SCR) are two entirely separate projects.

For further information about care.data, please see my other site.

As regards the Summary Care Record:

- It concerns *direct clinical care*
- You may have recently received a *personalised* letter from your local CCG about the Summary Care Record
- Your GP surgery may not be able to tell you exactly *when* they will commence uploading Summary Care Records

care.data is very different to the Summary Care Record:

- The information extracted for care.data **far exceeds** just allergies and medication

- The information uploaded to care.data will **not** be made available to health professionals providing your treatment, but to universities, pharmaceutical companies and commercial organisations
- care.data does **not** concern clinical care, it is an administrative and research database
- Patients will **not** be written to individually about care.data, although a national leaflet drop is planned (see below)
- We know that this project **will** go ahead everywhere shortly, with data extractions planned for "Spring 2014"

You will still need to opt-out to prevent a Summary Care Record upload even if you have already opted-out of care.data .

Summary Care Record opt-outs will not prevent care.data uploads.

care.data opt-outs will not prevent Summary Care Record uploads.

Opting-out of one database does not mean that you have automatically opted-out of the other.

Can I have a Summary Care Record but opt-out of care.data ?

YES.

Can I agree to care.data extraction but opt-out of the Summary Care Record ?

YES.

- You can both have a Summary Care Record and allow care.data extractions
- You can opt-out of both databases and allow neither
- Or you can opt-out of one but allow the other

Opting-out of either database, or both, will not in any way affect the medical care that you receive from your GP surgery.

What happens if I neither opt-in nor opt-out ?

If you do nothing, your GP will have to assume that you want a Summary Care Record.

Hopefully, you will just have a basic, core SCR (though that is by no means certain).

Unless your surgery clearly states that it will automatically create only basic, core SCRs, then you should opt-in and make your preference known to your GP.

So if I am happy to have a Summary Care Record, how do I opt-in ?

If you are certain that you want a Summary Care Record (if you are unsure then please discuss it with your

GP) then you can opt-in by giving your explicit consent to your GP.

If you are certain that you would like your data uploaded then you simply have to state this to your GP. You can see your GP, ring your GP or write to your GP. If your GP allows you to email him/her then you could give your explicit consent in this way.

You have the right to see a copy of your medical data *before* it is uploaded by your GP surgery to the Summary Care Record.

This will allow you to check the following:

- That the medications that you are being prescribed are recorded correctly and are up to date
- That the allergies or adverse reactions to medicines (if any) that you have are recorded accurately and in full
- That the main illnesses or diagnoses in your medical record are accurate and comprehensive, if you are intending to have an enriched SCR

before the information is uploaded.

If you do wish to have a Summary Care Record, make sure:

- You tell your GP whether you want your SCR to be a basic SCR (consisting of core data only) or an enriched one
- Your SCR preference setting remains permanently at *Express consent for medication, allergies and adverse reactions only*, if you just want a basic SCR
- Your SCR "permission to view" status remains permanently at *Patient must be asked every time for permission to view their Summary Care Record*

I have created a simple opt-in form for use at any GP surgery:

Download the generic opt-in form in PDF format

Download the generic opt-in form in DOC format

Download the generic opt-in form in RTF format

Please note that this form states that you want a basic SCR, with core data only uploaded.

You can opt-in using this simple form:

- You can hand your opt-in form in to your GP surgery
- You can post your opt-in form to your GP surgery
- You can fax your opt-in form to your GP surgery
- You can email your opt-in form to your GP or GP surgery (if they have an email address)
- The same form can be used for your children (or for any children under the age of 16yrs for whom you have parental responsibility)
- If you prefer, just write a letter to your GP stating that you are giving your explicit consent for a Summary Care Record to be created from your medical records.

Do NOT send your opt-in form to your local CCG. The CCG is not the data controller for your medical

records, your GP is.

You can opt-in verbally (without an opt-in form or letter) by:

- Stating your wish to opt-in to your GP the next time that you see him/her
- Stating your wish to opt-in to your GP the next time that you speak with him/her on the telephone
- Stating your wish to opt-in to your GP the next time that you email him/her

ANY communication (in person, by letter, email, fax, or telephone) to your GP stating your wish to opt-in is valid.

I don't wish to have a Summary Care Record - how do I opt-out ?

Opting out of the Summary Care Record is quick and easy.

You do not have to wait until the Summary Care Record goes live in your area to opt-out. You can opt-out right now and your wishes will be recorded by your GP and will ensure that your data is not uploaded if and when the programme does go live for your surgery.

You are under *no obligation whatosever* to fill in the official opt-out form in order to prevent your data from being uploaded, though you can if you wish.

And when the Summary Care Record does go live in your area and for your surgery, you will *not* have to opt-out a second time.

Your GP will either add the appropriate read code (9Ndo) to your GP-held records or your GP can set your decision to refuse to have a Summary Care Record directly via the surgery GP software (the so-called "Summary Care Record preference flag").

ANY communication (in person, by letter, email, fax, telephone or text) to your GP stating your wish to opt-out is valid.

I have created a generic opt-out form for use at any GP surgery:

Download the generic opt-out form in PDF format

Download the generic opt-out form in DOC format

Download the generic opt-out form in RTF format

You can opt-out in writing:

- You can hand your opt-out form in to your GP surgery
- You can post your opt-out form to your GP surgery
- You can fax your opt-out form to your GP surgery
- You can email your opt-out form to your GP or GP surgery (if they have an email address)
- The same form can be used for your children (or for any children under the age of 16yrs for whom you have parental responsibility)
- If you prefer, just write a letter to your GP stating your wish to opt-out

Do NOT send your opt-out form to your local CCG. The CCG is not the data controller for your

medical records, your GP is.

You can opt-out verbally (without an opt-out form or letter) by:

- Stating your wish to opt-out to your surgery in person
- Stating your wish to opt-out to your GP the next time that you see him/her
- Stating your wish to opt-out to your GP the next time that you speak with him/her on the telephone
- Stating your wish to opt-out to your GP the next time that you email him/her

Do NOT ring, email or attend your local CCG to opt-out. The CCG is not the data controller for your medical records, your GP is.

You do **not** need:

- To wait until the Summary Care Record goes live in your area to opt-out. You can opt-out right now.
- To opt-out in person.
- To make an appointment with your GP (or practice manager) to opt-out.
- Your GP's permission to opt-out.
- Your GP's permission to opt-out your children (or any children under the age of 16yrs for whom you have parental responsibility).
- To give any reasons why you wish to opt-out.
- To "discuss" your opt-out with your GP, your surgery, your CCG or with anyone else.

How will opting-out affect my medical care ?

Opting-out will have no effect on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

Healthcare professionals will treat you in exactly the same way, whether you have a Summary Care Record or not. Your entitlement to medical care is unaffected.

If medical staff are authorised to access your *electronic hospital records* (if any exist at a given hospital) then your opt-out of The Summary Care Record will have **absolutely no effect on that whatsoever, in any way**.

Opting-out will have no effect on your GP surgery and the way it provides services.

It will have **absolutely no effect whatsoever** on the way your GP records are stored or accessed electronically by your surgery.

It will not affect your prescriptions, vaccinations, screening procedures, investigations, monitoring of chronic conditions or referrals to specialists.

If you opt-out of The Summary Care Record, you can still be referred to a specialist under Choose & Book, your surgery can still manage your prescriptions via the Electronic Prescription Service, you can continue to request your prescriptions online, continue to email your GP or surgery and continue to access your medical records online (if you are offered that facility).

Opting out of The Summary Care Record will have no effect whatsoever on your relationship with your GP surgery.

Will my GP mind if I opt-out ?

NO.

Whether or not you opt-out is immaterial to your GP.

And you certainly don't need your GP"s approval or permission to opt-out of the Summary Care Record.

Feel free to send me *constructive* comments about this site.

Neil.Bhatia@nhs.net

I will read every comment sent, though please do not be offended if I do not reply to your message.

Privacy policy: I will not sell, trade or otherwise transfer to any third parties your personally identifiable information (your email address or the content of your email)

***This non-commercial website represents the personal views of Dr Neil Bhatia, GP and Caldicott Guardian for the Oaklands Practice in Yateley.*.**

Last updated: 01.12.13

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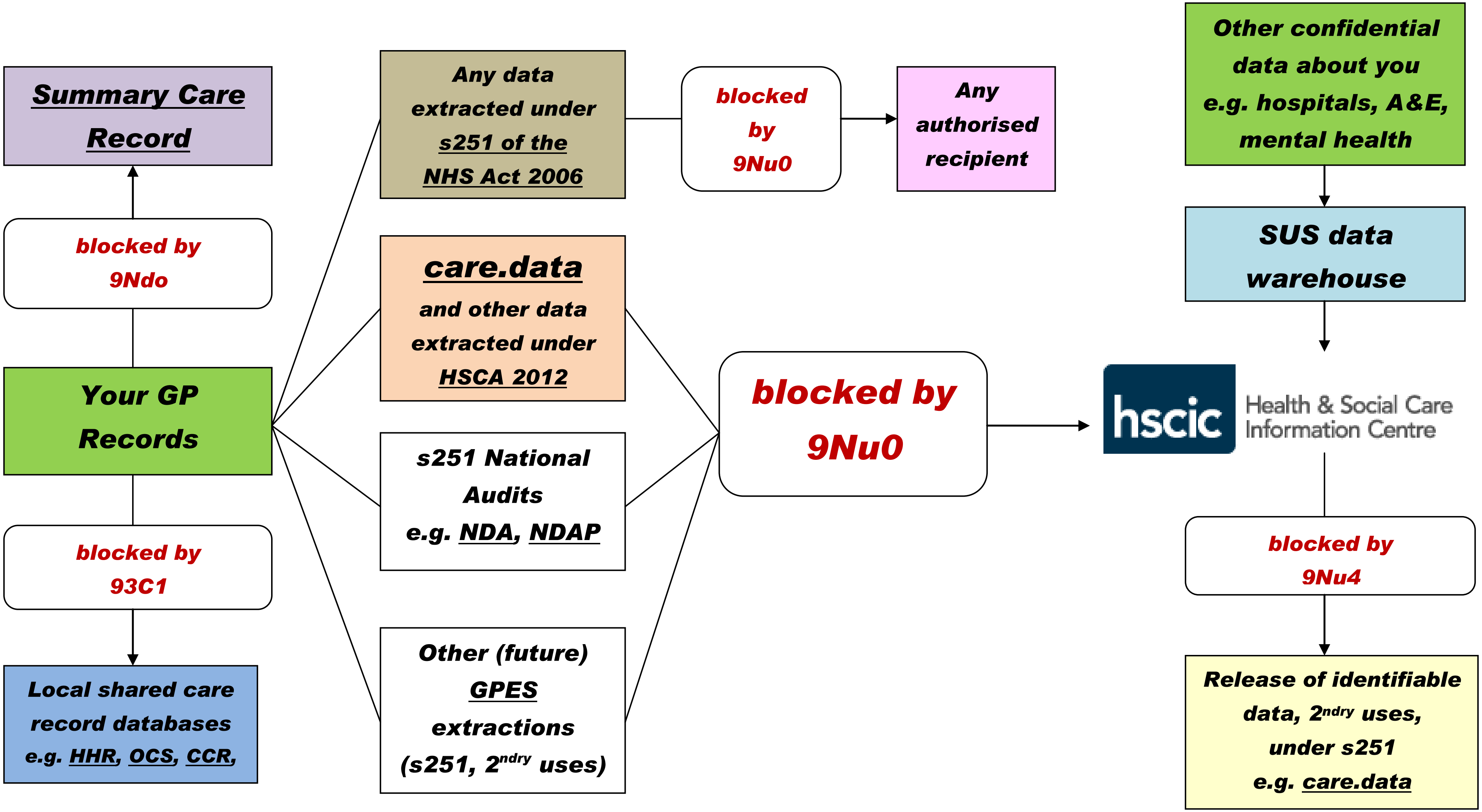
How your GP can help you control your personal and confidential information

- The diagram below shows some of the potential flows of your confidential and identifiable information, *without your express consent,* within the NHS
- You *cannot* prohibit flows of *effectively anonymised* information about you.
- You *can* contact your surgery and request that your GP adds any or all relevant Read codes (electronic “flags”), 9Ndo/9Nu0/9Nu4/93C1, to your GP records to prevent your data being processed in a particular way (i.e. you can “opt-out” of these types of data sharing)
- The Read codes have no function other than to tell software systems not to extract and/or send your data
- Any opt-out can be easily reversed (i.e. you can opt back in) *at any time* should you change your mind
- Make sure you understand what you are opting out of (follow the links)



Summary Care Record

blocked by 9Ndo

Your GP Records

blocked by 93C1

Local shared care record databases e.g. HHR, OCS, CCR,

Any data extracted under s251 of the NHS Act 2006

blocked by 9Nu0

Any authorised recipient

care.data and other data extracted under HSCA 2012

s251 National Audits e.g. NDA, NDAP

Other (future) GPES extractions (s251, 2ndry uses)

blocked by 9Nu0

Other confidential data about you e.g. hospitals, A&E, mental health

SUS data warehouse

hscic Health & Social Care Information Centre

blocked by 9Nu4

Release of identifiable data, 2ndry uses, under s251 e.g. care.data

The **9Nu0** code added to your GP records will:	The **9Nu4** code added to your GP records will:	The **9Ndo** code added to your GP records will:	The **93C1** code added to your GP records will:
• Prevent *care.data* extractions • Prevent data extractions for purposes other than your direct medical care where your explicit permission is not being sought (s251) • Prevent data extractions for national audits where your explicit permission is not being sought (s251)	• Prevent data about you, as held by the HSCIC, from being released to organisations in an identifiable format	• Prevent your data being uploaded to the national Summary Care Record database	• Prevent your data being uploaded to local shared care record databases (e.g. the Hampshire Health Record, Oxfordshire Care Summary, Central Care Record)
It will **not**:	It will **not**:	It will **not**:	It will **not**:
• Prevent your data being uploaded to the national Summary Care Record database • Prevent your data being uploaded to local shared care record databases • Prevent data about you, as held by the HSCIC, from being released to organisations in an identifiable format	• Prevent your data being uploaded to *care.data* • Prevent your data being uploaded to the national Summary Care Record database • Prevent your data being uploaded to local shared care record databases • Prevent s251 data extractions from your GP records	• Prevent your data being uploaded to *care.data* • Prevent your data being uploaded to local shared care record databases • Prevent s251 data extractions from your GP records • Prevent data about you, as held by the HSCIC, from being released to organisations in an identifiable format	• Prevent your data being uploaded to *care.data* • Prevent your data being uploaded to the national Summary Care Record database • Prevent s251 data extractions from your GP records • Prevent data about you, as held by the HSCIC, from being released to organisations in an identifiable format

The 9Nu0, the 9Nu4, the 9Ndo or the 93C1 code 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 & 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

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Health and Social Care Act 2012

2012 c. 7 ▸ **Table of Contents**

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Changes to legislation: There are outstanding changes not yet made by the legislation.gov.uk editorial team to Health and Social Care Act 2012. Those changes will be listed when you open the content using the Table of Contents below. Any changes that have already been made by the team appear in the content and are referenced with annotations.

Collapse all -

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NHS INFORMATION CENTRE AWARDS ATOS CONTRACT FOR NEW GENERAL PRACTICE EXTRACTION SERVICE

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NHS Information Centre awards Atos contract for new General Practice Extraction Service

Supporting the future information needs of the NHS to further improve patient care

London, 20th December 2011

Atos, an international IT services company, today announed that it has been awarded a five-year contract worth £8 million by the NHS Information Centre to supply technical components needed to implement the General Practice Extraction Service (GPES). Specifically, Atos will supply the software system that will produce the queries required to extract specified data from the range of GP practice systems across England.

GPES is a new service managed by the NHS Information Centre and sponsored by the Department of Health that will be able to extract data from GP practice systems across England for specific purposes that will support better patient care.

The launch of GPES means that, for the first time ever, it will be possible for the NHS to harness the full potential that primary care data offers for reducing inequalities, tackling inefficiencies and delivering best-quality local care. GPES will also play a key role in the proposed new process for providing payments to GPs and clinical commissioning groups.

Chief executive of the NHS Information Centre Tim Straughan said:"GPES will offer an unprecedented, standardised picture of primary care information across England, while protecting patient confidentiality, through robust information governance principles, and minimising administrative burdens for GPs and practice staff."

Ursula Morgenstern, UK CEO, Atos said: "We have worked closely with the NHS Information Centre to fully understand their needs and believe that our solution meets all the requirements, offers value for money and is low risk. We are committed to its success and to ensuring it becomes the single source for usable primary care information within the NHS."

Atos will develop and build the solution in compliance with all security standards. It will then manage the day to day operations from the UK , ahead of when the service begins to produce its first major deliverable – Quality and Outcomes Framework data from April 2013.

About Atos
Atos is an international information technology services company with annual revenues of €8.6 billion and 74,000 employees in 42 countries. Serving a global client base, it delivers hi-tech transactional services, consulting and technology services, systems integration and managed services. Atos is focused on business technology that powers progress and helps organizations to create their firm of the future. It is the Worldwide Information Technology Partner for the Olympic and Paralympic Games and is quoted on the Paris Eurolist Market. Atos operates under the brands Atos, Atos Consulting & Technology Services, Atos Worldline and Atos Worldgrid.

About the NHS Information Centre
The NHS Information Centre is England's authoritative, independent source of health and social care information. It works with a wide range of health and social care providers nationwide to provide the facts and figures that help the NHS and social services run effectively. Its role is to collect data, analyse it and convert it into useful information which helps providers improve their services and supports academics, researchers, regulators and policymakers in their work. The NHS Information Centre also produces a wide range of statistical publications each year across a number of areas including: primary care, health and lifestyles, screening, hospital care, population and geography, social care and workforce and pay statistics.

Contact us

Tessa David
UK PR Manager

» E-mail Tessa
+44 (0)20 7830 1977

About GPES

The NHS Information Centre's General Practice Extraction Service (GPES) will provide a standardised picture of primary care information across England, while protecting patient confidentiality and minimising administrative burdens for practice staff. The service will be operational from September 2012 and its first major deliverable will be to extract data from GP systems for QOF to CQRS in April 2013. All requests for data extractions will need the approval of an independent advisory group which will include GP and patient representatives. Data extractions will only take place if they adhere to strict information governance rules that have been approved by the National Information Governance Board, the medical ethics committee of the British Medical Association and the Royal College of General Practitioners. More information about GPES is at www.ic.nhs.uk/gpes

More on : Deals & Contracts Press Releases | United Kingdom |

NHS Connecting for Health ceased to exist on 31st March 2013. This website is therefore not being updated. For up to date information about systems and services visit the Health and Social Care Information Centre website at www.hscic.gov.uk/systems

Registration Authorities and Smartcards — NHS Connecting for Health

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Registration Authorities and Smartcards

Registration Authorities – Operating Guidance 2013-2014

The Operating Guidance for Registration Authorities (PDF, 165.8kB) from 1st April 2013 has now been published.

This document is relevant for any organisations involved in the provision or delivery of Registration Authority services. It explains the future RA model given the changing organisational structure of the NHS, resulting from the Health and Social Care Act 2012.

For queries contact cfh.accesscontrol@nhs.net

Forward notice of invitation to local authorities, independent sector and other non-NHS organisations to host Registration Authorities (RA)

Following the change to policy to permit local authorities, independent sector and other non-NHS organisations to host Registration Authorities (RAs) further information and guidance will be published shortly to invite organisations to apply to become a pilot RA. The guidance will explain the criteria in respect of governance, operation and external monitoring and audit required by a RA and how HSCIC will be selecting pilot RAs.

Read full notice.

Access Controls - Smartcards

Related links

NHS Care Record Guarantee

NHS systems and related services like Choose and Book or the Electronic Prescription Service increasingly use a common approach to protect the security and confidentiality of every patient's personal and healthcare details. NHS electronic staff records also use this common approach to protect the security and confidentiality of staff employment records. Please see the Electronic Staff Record website for further information.

That approach includes a rigorous identity check of all those who may have access to those records, and careful control of what access any individual should have. The NHS has set out the principles that will govern how patient information in particular is held in the NHS, and the way it can be shared.

These are set out in the NHS Care Record Guarantee which is reviewed by an independent body, the National Information Governance Board, at least every twelve months.

Registration Authorities

Organisations that deliver NHS care and need to access patient information within NHS systems and other national services must set up Registration Authorities to manage this process. The roles and responsibilities of Registration Authorities are defined by NHS policy. Their key tasks are first to verify the identity of all healthcare staff who need to have access to sensitive data, and second to establish and provide only the degree of access they need to do their jobs.

The identity check is to a very high standard (the government recommended standard 'e-GIF Level 3') and includes a mandatory face-to-face meeting. It requires the individual to provide at least three forms of evidence (photo and non-photo), including proof of address. Once their identity is confirmed healthcare staff are issued with a Smartcard and a passcode by the Registration Authority.

They have to use their Smartcard and passcode each time they log on to access and use information.

The Registration Authority will also determine the level of access the individual should have. That information is on a data base which is interrogated every time the individual logs on, and the appropriate access is granted. In this way the individual has no way of changing the level of access that they have been granted.

Smartcards

Smartcards and passcodes are similar to a chip and PIN credit or debit card, but are more secure, as there is no account information on the Smartcard and the passcode is more complex. A user's Smartcard is printed with their name, photograph and unique user identity number. The photograph is stored centrally, and is always available for an organisation to verify that the Smartcard holder is indeed the person to whom it was issued. All NHS healthcare staff know that it is a disciplinary offence to tamper with Smartcards, share passcodes, or use a Smartcard that doesn't belong to them, and that they may lose their jobs if they do so. Individuals are granted access to patient information based on their work and level of involvement in patient care. This means that, for example, someone working in an administrative role rather than a clinical one might only be able to see the demographic information needed to process an appointment, not the full clinical record.

Increasingly with new applications Registration Authorities will also be able to determine which records an individual might routinely be able to access. Some healthcare staff might on rare occasions need to access data for a patient they don't routinely expect to see – those in A&E for example - and they are specifically enabled to do so.

Most however only need to see data on patients with whom they have a "legitimate relationship" and Registration Authorities will be able to set boundaries around the records of groups of patients for particular users, for the duration of an episode of care.

As more new systems are introduced, every time someone accesses a patient's record, it is being recorded, along with how they used it and this will form an important audit trail which cannot be provided with paper records.

Staff will also continue to be bound by their own professional codes of conduct, local regulations and contractual requirements, the Data Protection Act and the NHS Code of Confidentiality.

There will be occasions when NHS care is provided outside the NHS or is provided jointly, with a local authority for example, and staff, in order to provide that care, will need access to information as would NHS healthcare staff. They have to go through exactly the same steps as NHS healthcare staff to get that access, and are subject to all the same controls, requirements and sanctions as NHS healthcare staff.

Queries on the role of Registration Authorities, Smartcards and process, can be directed to cfh.accesscontrol@nhs.net

Smartcards - innovative, extended use. NHS Lincolnshire case study

NHS Lincolnshire implemented extended use of Smartcards for a range of innovative uses and the benefits they have seen.

In addition, it includes a menu of solutions to provide organisations with a more informed view when considering this type of solution.

Download Smartcards - innovative, extended use. NHS Lincolnshire case study. (PDF, 270.5kB)

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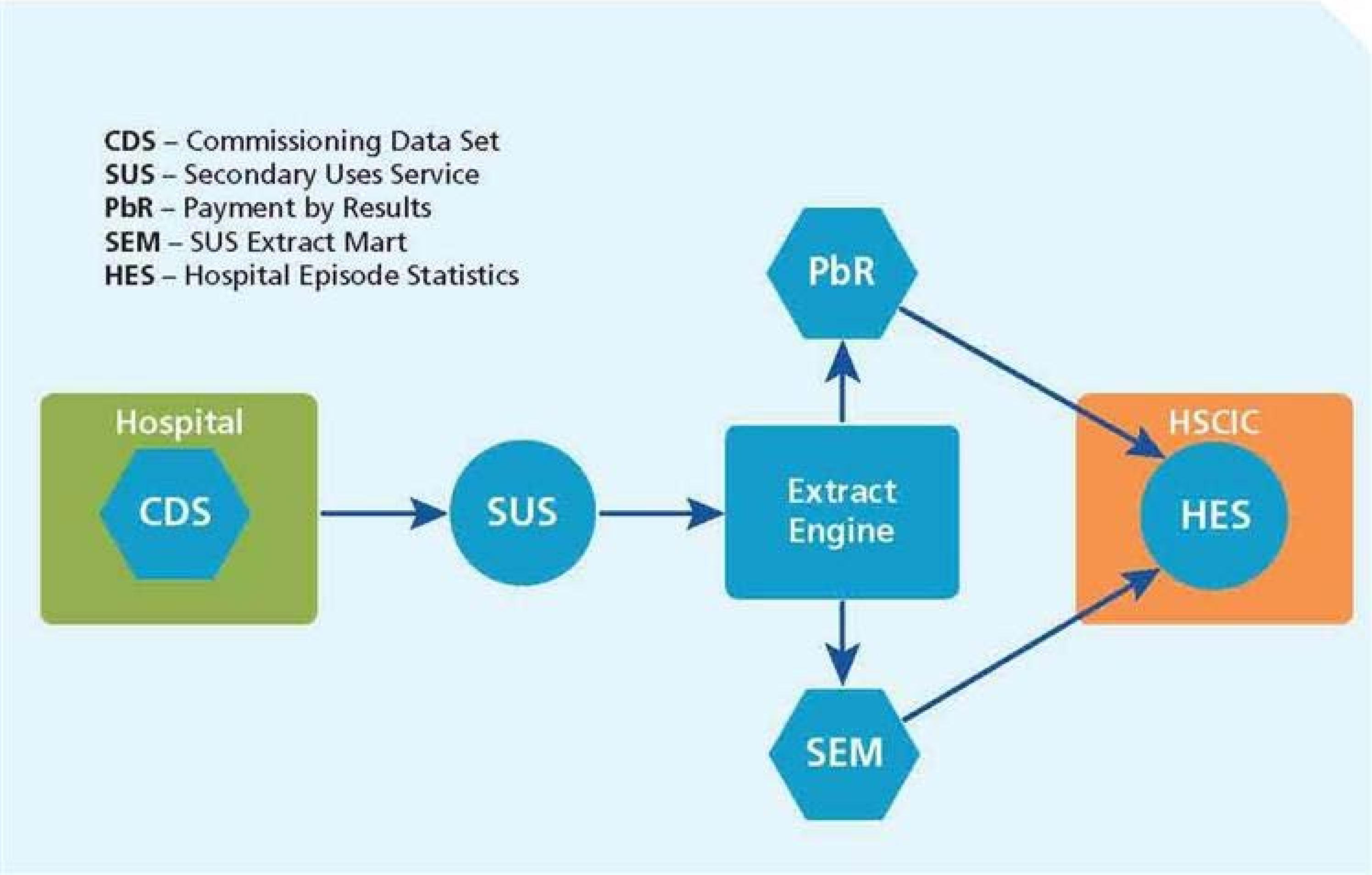
CDS – Commissioning Data Set
SUS – Secondary Uses Service
PbR – Payment by Results
SEM – SUS Extract Mart
HES – Hospital Episode Statistics
Hospital
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HES

Information Commissioner's Office

The UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.

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ICO blog: NHS patient information: the Information Centre and the DPA

By Dawn Monaghan
11 February 2014

In my last blog, I wrote about how the Data Protection Act applies to information from medical records going from GPs in England to the Health and Social Care Information Centre. I committed to writing a second blog giving some explanation of how the Act applies to personal data once it arrives at that Information Centre. So here goes…

In many respects, this is a simpler explanation than my previous blog. The exemptions to aspects of the Data Protection Act provided by the Health and Social Care Act 2012 end once the Information Centre takes receipt of the personal data. And with that in mind, the Information Centre must then treat that information as any other data controller would do.

This means that they are responsible for ensuring what they do with the data (using it, sharing it, storing it, disposing of it etc), complies with the Data Protection Act.

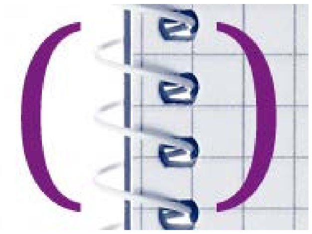
First of all, let's cover what information patients are given. While their personal data will have been taken directly from GPs under the Health and Social Care Act, patients must be told what that data will be used for. The Information Centre should take active steps to make sure that this information is provided, so all patients are easily able to find out what is happening to their data.

In terms of how the information is used, the rules are also clear. When you provide an organisation with your personal data, that organisation must normally tell you what it plans to use that information for, and if it later decides it wants to use your information for a different reason, it would usually need to come back to you.

In the case of the Information Centre, even though you are not providing your information directly, similar principles apply. It must only use the data for the purposes it has been 'directed' to do by NHS England and that it is responsible for as an organisation.

There are exceptions in the Act to how information can be used. These would apply to the Information Centre as to any other data controller, including sharing the information for certain purposes to do with criminal justice or the taxation system, as well as where they're obliged to by law or a court order, or where they go back to the patient and get their consent to share it more widely.

Notably, some of the data the Information Centre will provide to others won't fall under the Data Protection Act. This is because it will be anonymised. This is crucial, as once an individual can no longer be identified from information, either alone or in combination with other information, the law no longer considers it to be personal data. That means that the Data Protection Act no longer applies to it, so it doesn't impose any limitations on what can now be done with it.



In this section

Key battle won in war against forced subject access request

NHS patient information and the Data Protection Act

NHS patient information: the Information Centre and the DPA

Related items

What are health records?

Another hot topic of discussion since my last blog has been around how to opt out. Any opt outs the NHS chooses to provide are up to them, and do not fall under the Data Protection Act (as explained in our last blog). But providing a clear explanation to patients of the options open to them does fall under the Data Protection Act. We've been clear the communications plans we have seen would be likely to meet the fair processing requirements under the law. But we don't feel the opt out has been explained as clearly as we expected, and so we are looking to see that addressed. This seems likely to be a topic we'll return to in a future blog.

Dawn Monaghan
Strategic Liaison Group Manager
11 February 2014

If you'd like to get in touch with feedback or comments please find us on Twitter @ICOnews or email blog@ico.org.uk.

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medConfidential
KEEP MY SECRETS

How to opt out

THE OPT OUTS ARE NOW FIXED, 26/2/14

You can read more about what happened by following the link above, but on 25 February the Secretary of State for Health confirmed to us in writing the operation of the opt out codes. The way the codes work has been fixed, and HSCIC has now published a page explaining exactly how they will work:

http://www.hscic.gov.uk/article/3915/What-we-will-collect-from-GP-records-under-caredata

Also, as of 18 February, care.data uploads have been **delayed for a further 6 months** until September 2014. A number of 'pilot' practices – locations as yet unknown – may begin uploading patient data before then.

If you have any concerns about care.data – and if you haven't done so already – our advice continues to be to **opt out now**. The latest delay changes nothing about the scheme, and NHS England seems to believe that its only problem is that it has failed to 'communicate the benefits' clearly enough!

N.B. As well as opting out, you may want to write to your MP about this. The

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Our newsletter is sent using MailChimp. We won't share your details with anyone else.

KEEP MY SECRETS

Health Select Committee is now conducting an inquiry into care.data, and we gave evidence to its first session.

Opt out form

In January 2014, NHS England sent out a leaflet entitled *Better information means better care* (2MB PDF) via junk mail. It was not addressed directly to you as a patient and it deliberately didn't include an opt-out form. The leaflet says you should "speak to your GP practice" if you want to opt out. This is misleading and could waste your time and potentially waste valuable GP appointment time as well.

All you actually need do is write a letter or download a simple form (link below) instructing your doctor to opt you out, which you can fill in and post or drop into your surgery reception for their attention.

If you have any problems getting your surgery to understand what you are opting out of, or if they hand you an opt out form for something else, e.g. the Summary Care Record, then let us know using our handy *formFix* tool – you tell us, and we'll send them some details.

Dr Neil Bhatia, a Hampshire GP, has written the text of a leaflet with a tear-off form that you can use for yourself, your children and anyone for whom you hold lasting power of attorney:

Opt out form (PDF)

Please do take a few moments to e-mail this PDF to your family, friends and colleagues, or send them the link to this page – **www.medconfidential.org/how-to-opt-out** – or share it on social media. You might even print off copies of the form (which conveniently prints double-sided and folds to fit in a DL envelope) to give to others who may not have heard about what's going to happen to their medical records, and won't know what they can do.

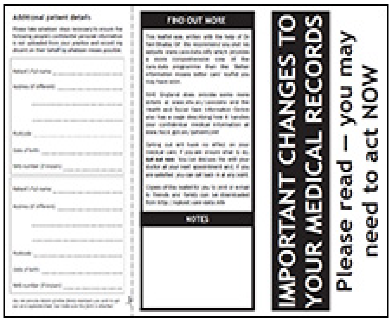
Dr Bhatia also provides more information on the care.data scheme on his website: www.care-data.info

What's happening?

Under changes to legislation, your GP can now be required to upload

Search

DOWNLOAD AN OPT OUT FORM:



IMPORTANT CHANGES TO YOUR MEDICAL RECORDS
Please read – you may need to act NOW

Opt out form (PDF)

DOWNLOAD AN OPT OUT LETTER:

Opt out letter (PDF)
Opt out letter (MS Word)

For more information, see How to opt out and What's the story?

Tweets by @medConfidential

personal and identifiable information from the medical record of every patient in England to central servers at the Health and Social Care Information Centre. Once this information leaves your GP practice, your doctor will no longer be in control of what data is passed on or to whom.

This information will include diagnoses, investigations, treatments and referrals as well as other things you may have shared with your doctor including your weight, alcohol consumption, smoking and family history. Each piece of information will be identifiable as it will be uploaded with your NHS number, date of birth, post code, gender and ethnicity.

NHS England – the body now in charge of commissioning primary care services across England – will manage and use the information extracted by the Health and Social Care Information Centre for a range of purposes, none of which are to do with your direct medical care. Though the official leaflets talk a great deal about research, these 'secondary uses' for which your data may be used include patient-level tracking and monitoring, audit, business planning and contract management.

In September 2013, NHS England applied to pass on your information in a form it admits "could be considered identifiable if published" to a whole range of organisations that include – but are not limited to – research bodies, universities, think tanks, "information intermediaries", charities and private companies.

Though you may be told that any data passed on will be 'anonymised', no guarantees can be given as to future re-identification – indeed information is to be treated so that it **can** be linked to other data at patient level – and NHS England has already been given legal exemptions to pass *identifiable* data across a range of regional processing centres, local area teams and commissioning bodies that came into force on April 1st 2013. The Health and Social Care Information Centre already provides access to patient data, some in identifiable form, to a range of 'customers' outside the NHS, including private companies.

So what can I do?

ACT NOW! If you do not want confidential, identifiable information from your medical records to be uploaded and passed on for purposes other than your medical care you can opt out by telling your doctor. You don't have to book

RECENT POSTS

Opt out fixed… for now
PRESS RELEASE: medConfidential responds to announcement of a 6 month delay to care.data uploads
Keep My Secrets

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England: NHS care.data project postponed to autumn 2014 | Churchmouse Campanologist on How to opt out
Sasha on formFix: help protect your GP from NHS England's data protection fines
Keeping your medical records safe? They don't give ATOS… | The Wolf of Bridge Street on How to opt out

an appointment to do this, you can simply send a letter.

As an alternative to the form above, we provide a letter in Microsoft Word (.doc) format, editable Rich Text (.rtf) format and as an Adobe Acrobat (.pdf) PDF for you to fill in and send to your doctor. **We have updated this letter so that you can use it to opt out your children or adults for whom you are legally responsible as well.**

Simply click on one of the links below to download and print off a copy, fill in your details and the details of anyone else you are opting out, sign it and send it to your GP:

Opt out letter (PDF)

Opt out letter (MS Word)

Opt out letter (Rich Text)

Opting out will not affect the care you receive and you can change your mind at any point and opt back in if you like. Opting out will not prevent your GP from being paid for care provided – information needed for those payments should only leave the practice in summary (i.e. anonymous) form.

If you have any specific concerns, we recommend you speak with your GP.

As you will see from the letter, there are TWO codes that your doctor will need to add to your record – one to prevent your information being uploaded from the GP practice, and one to stop the Health and Social Care Information Centre from passing on any identifiable data it gathers from any other care context, e.g. hospital records or clinics.

As of 25 February, we are confident the opt out codes have been fixed and will work as they should have done from the very beginning. To keep informed about ongoing issues, e.g. the location of the 'pilot' practices as that becomes known, please:

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Our newsletter is sent using MailChimp.

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67 thoughts on "How to opt out"

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Pingback: Are you happy for big business to have your confidential medical records? | Vox Political

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Comments are closed.

Dissent from secondary use of patient identifiable data

Dear Doctor,

I am writing to give notice that I refuse consent for my identifiable information and the identifiable information of those for whom I am responsible [*delete as appropriate*] to be transferred from your practice systems for any purpose other than my medical care.

Please take whatever steps necessary to ensure my / our confidential personal information is not uploaded and record my dissent by whatever means possible.

This includes adding the '**Dissent from secondary use of GP patient identifiable data'** code (Read v2: 9Nu0 or CTV3: XaZ89) to my record as well as the '**Dissent from disclosure of personal confidential data by Health and Social Care Information Centre**' code (Read v2: 9Nu4 or CTV3: XaaVL).

I am aware of the implications of this request, understand that it will not affect the care I / we receive and will notify you should I change my mind.

Yours sincerely,

Signature ______________________________ Date ______________

Information to help identify my records [*please complete in BLOCK CAPITALS*]

Title _______ Surname / Family name ______________________________

Forename(s) ____

Address ____

____

Postcode ____________________

Date of birth ____________________

NHS number (if known) ____________________________

Space for additional patient details overleaf

More copies of this letter can be downloaded from **www.medconfidential.org/how-to-opt-out**

Additional patient details [*please complete in BLOCK CAPITALS*]

Dear Doctor, please take whatever steps necessary to ensure the following people's confidential personal information is not uploaded from your practice and record my dissent on their behalf by whatever means possible.

Patient's full name: ____________________
____
Address: ________________________________
____
____
____
Postcode: ______________________________
Date of birth: ___________________________
NHS number (if known): __________________

Patient's full name: ____________________
____
Address: ________________________________
____
____
____
Postcode: ______________________________
Date of birth: ___________________________
NHS number (if known): __________________

Patient's full name: ____________________
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Address: ________________________________
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Postcode: ______________________________
Date of birth: ___________________________
NHS number (if known): __________________

Patient's full name: ____________________
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Address: ________________________________
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____
Postcode: ______________________________
Date of birth: ___________________________
NHS number (if known): __________________

You can provide details of other family members you wish to opt out on a separate sheet, but make sure this letter is attached.

Customisable copies of this letter can be downloaded from **www.medconfidential.org/how-to-opt-out**