

# Care.data quick reference guide

This guide will help you to speak to patients about care.data and direct them to other sources of information. It will also explain some of the key things that general practice staff need to know, including how to manage the opt-out process.

## How patients are affected

To support care.data, patients will receive a letter and booklet about information sharing and an opt-out form in the post; these can also be downloaded from NHS Choices. If patients don't want identifiable information from their GP record to be used for purposes beyond their direct care, they can opt out.

It is important to note that if a patient opts out, they are opting out of *all of* their identifiable GP information being used for purposes beyond their direct care. Care.data is just one data flow of this type. You must understand and be able to speak to patients about all of the data sharing that is happening at your practice, not just the care.data element.

## Care.data help for practice staff

General practice staff can seek information from:

**Visit:** NHS England care.data website

**Call:** GP helpline **0300 303 5678**

**Email:** [care.data@hscic.gov.uk](mailto:care.data@hscic.gov.uk)

### Key reading

Detailed information about the topics covered in this guide can be found on the care.data pathfinder pages of the NHS England website.

The documents 'Legal guidance for GPs and practice staff in pathfinder practices' and 'Data governance guidance for GPs and practice staff in pathfinder practices' are essential reading for practices.

## Care.data help for patients

The following support is available for patients:

**Visit:** NHS Choices [www.nhs.uk/datasharing](http://www.nhs.uk/datasharing)

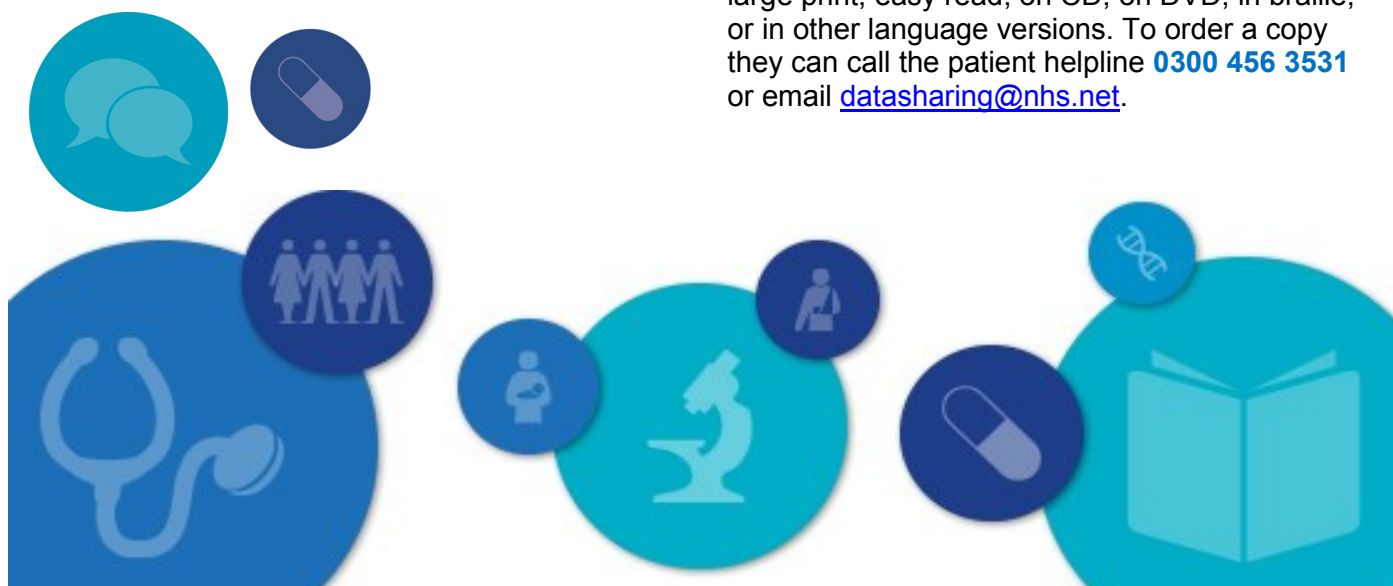
**Call:** Patient helpline **0300 456 3531**  
Open Monday – Friday 09:00 to 17:00

A text phone service is also available on 0333 003 1799

**Email:** [datasharing@nhs.net](mailto:datasharing@nhs.net)

### Information in different formats

The patient information leaflet is available from [www.nhs.uk/datasharing](http://www.nhs.uk/datasharing) in easy read, a British Sign Language (BSL) video (with subtitles), audio formats, and other language versions. Patients can also ask for a copy to be posted to them in large print, easy read, on CD, on DVD, in braille, or in other language versions. To order a copy they can call the patient helpline **0300 456 3531** or email [datasharing@nhs.net](mailto:datasharing@nhs.net).



## Fair processing and informing patients about data sharing

### Your responsibilities as a data controller

General practices are the data controllers for their patients' records. As such, you are responsible for ensuring that information is readily available to patients about what you will do with their information and who it may be shared with.

In accordance with advice from National Data Guardian, Dame Fiona Caldicott, general practices must make it clear to patients which local and national organisations are receiving their GP data, and for what purposes.

All GP data sharing should be explained to them, not just the data shared with the HSCIC for care.data. It is recommended that this information is placed on the practice's website.

Practices should make it clear to patients what opt outs are available and what they mean. To help support this, the care.data programme is mailing a letter, information booklet and opt-out form to registered patients on your behalf.

When carrying out their fair processing responsibilities, general practices should use several forms of communication to achieve maximum coverage. For example:

- Individual communications (e.g. letter, telephone, text or email).
- Providing information to patients at reception or by clinical staff.
- Including information with repeat prescriptions, and
- Placing information on your practice website and online appointment booking pages.

### Update patient information on GP systems

The names and addresses for the mailing are taken from the registration data that is routinely collected from your system. It is vital, therefore, that your systems are updated with changes of address, deaths and new registrations as soon as you are notified. You should provide prominent reminders to patients to update you with any new details (e.g. a change of address). Practices could also use email and/or SMS messages to help.

## Opting out

### Key facts about opting out

It is vital to remember that the opt-out applies to *all* sharing of identifiable information for purposes beyond a patient's direct care from the general practice, not just the care.data information flow.

Key things that practices need to know:

- Opting out is a patient's right.
- They don't need to give a reason.
- They can opt in or out at any time, and can change their mind as many times as they like.
- The pathfinder stage of the care.data programme uses the same codes as the postponed roll-out in 2014. If a patient has already registered one or both of the objections, their opt-out will be respected and no further action is needed.
- A Summary Care Record opt out does not cover patients for this too.
- The information that supports a patient's direct care is not affected and will continue to flow.
- The opt-out doesn't cover information collected about a patient outside the general practice.
- Parents, guardians or carers can opt out on behalf of children under the age of 16 (unless the child is competent to make the decision themselves).
- Those with a Lasting Power of Attorney can opt out for those they are responsible for.
- New patients and young people turning 16 should also be given the opportunity to opt out.



# How to manage opt-outs and patient preferences

## 1) Establish a process

The practice should agree an internal process and an owner (or owners) for managing opt-out requests, including the channel and method that will be used for handling acknowledgments that the opt-out has been applied.

## 2) Perform the opt-out against *all* applicable data flows

If a patient wants to opt out of their identifiable GP data being used for purposes beyond their direct care, you must apply an opt-out code to their medical record as detailed in the table below.

Read v2	CTv3	SNOMED CT	Rubric
9Nu0.	XaZ89	827241000000103	Dissent from secondary use of GP patient identifiable data

The above process will ensure that no GP data is collected for that patient for care.data.

Carrying out the opt-out as described above *will not* automatically opt the patient out of *all* local and national flows of patient identifiable data for purposes other than direct care.

To respect the patient's wishes fully, the practice must identify all other flows of data of this nature and apply the opt-out accordingly. If the opt-out cannot be applied to any of the data flows, the patient should be informed. Your CCG and Caldicott Guardian can help you to identify local and national information flows so that you know where to apply the opt-out. For more information please read the section on requirements for data controllers in the data governance guidance document.

## 3) Confirm that the opt out is recorded

If a patient has asked for confirmation that their request has been carried out, the practice should text, email or write to them when the opt-out has been applied to their record.

# Questions patients might ask you

## Questions about care.data

In this section we cover the most likely questions that patients might ask about care.data. You can also direct patients to the information line on **0300 456 3531** (Monday - Friday 09:00 to 17:00). There is also a detailed set of frequently asked questions about care.data on NHS Choices.

## Questions about other data flows

The following questions only cover care.data, but patients might ask you about other types of GP data sharing too. It is your responsibility as data controller to know where to direct patients for information about every flow of data that leaves your practice.

## 1) Why does the NHS share information?

The NHS in England uses information for two different purposes:

**To support direct care** by providing information that is vital to a patient's personal care and treatment. For example, a GP sharing information with a specialist to help them make a diagnosis. Summary Care Records use information in this way, to support direct care.

**For purposes beyond direct care**, where it is used to help plan services, create statistics and support research. Care.data uses information for this purpose.

## 2) What is care.data?

Care.data is a programme of work that aims to increase the range of information collected across all NHS funded services for purposes beyond direct care.

Information gathered from different care settings will be connected and made available to those who can use it to improve health and care. For example, those who plan NHS services, researchers, medical charities and businesses that help the NHS to improve its services.

During the first phase of care.data the Health and Social Care Information Centre will collect information about the care provided at general practices across England, and connect this with information already collected from hospitals.

## 3) Why does the NHS need care.data?

At the moment, the NHS in England doesn't have a complete, 'big picture' view of the care it delivers because it doesn't have joined-up data from everywhere a patient is treated.

As a result, there is no way of analysing what's happening to patients as they travel through the health and care system.

This means the NHS is unable to compare things like referral times, or the treatment provided in different areas. If this information was available, the NHS could identify where improvements can be made. The care.data programme will address these gaps by providing connected information from other places that a patient has received care.

Information sharing of this type could lead to:

- Better prevention of disease.
- Earlier diagnosis of conditions.
- Safer and more effective treatments.
- More effective integrated care pathways.
- A reduction in health inequalities.
- A greater understanding of how to use NHS funding most effectively, and
- A better understanding of improvements that can be made in the NHS.

## 4) What will my information be used for?

In short, it will help the NHS to provide everyone with better treatment and services. Connected GP and hospital information is very useful to the NHS and medical researchers. It will be used to help the NHS plan its services more effectively and to help researchers gain a better understanding of medicines and treatments for people across the country.

Examples of things it will allow the NHS to do:

- Highlight areas of the country with the most effective levels of care (so that others can learn from them).
- Understand the reasons why different groups of people, such as the elderly or those in certain parts of the country, may experience differences in the quality of care they receive.
- Diagnose serious conditions sooner, and
- Understand which groups are most at risk of developing certain diseases and conditions.

## 5) Who will use my information?

By law, the Health and Social Care Information Centre can only share information for the benefit of health and care. This means that decisions about who can receive patient information are based on what they want to use it for and not what type of organisation they are. It is expected that the information will mostly be used by:

- Medical researchers at universities.
- People who plan NHS services.
- Companies who want to monitor how existing drugs work, or develop new drugs, and
- Charities (e.g. Macmillan Cancer Support and Asthma UK).

Information will never be shared with organisations that want to use it solely for commercial purposes such as insurance or direct marketing. So, for example, a private healthcare provider may use it for health research purposes but not for insurance purposes.

## 6) Will the NHS and companies use my information to make a profit?

### The NHS

The Health and Social Care Information Centre charges a fee to cover its costs. This is in accordance with rules set by the Treasury. It does not aim to make a profit from providing this information.

### Companies

The law states that commercial companies cannot use your information solely for commercial purposes, such as for insurance or direct marketing. Commercial companies can use patient information to make a profit, but only if it will benefit health and care (e.g. companies developing new drugs). Anyone applying for information must demonstrate how it will do this.



## 7) Can I be identified?

It is very unlikely that you will be identified from the information that has been collected about you. As the information does not contain your name or full address, anyone attempting to identify you would need to go to great lengths to do it. Trying to identify individuals in this way is forbidden by the data sharing agreements that recipients have to sign and could be a breach of Data Protection law.

Identifying information is removed during the process.

The Health and Social Care Information Centre needs to collect information that might identify you so that it can match up (and connect together) your GP information with information from your hospital records. But once your records have been matched together, any information that could identify you will be removed and replaced by pseudonyms. Pseudonymisation is a process used to protect patients' identity. It involves replacing identifiers in a record (such as your NHS number) with an alternate identifier (e.g. a random number).

## 8) Will my information be safe?

The Health and Social Care Information Centre is absolutely committed to keeping patients' information safe and secure and takes every appropriate step to protect confidentiality. It has responsibilities under the Data Protection Act to protect patient information and is legally accountable for its safety and security. Key measures to protect confidentiality include:

- Very secure IT systems and services.
- A strict approvals process for people who want to use the information.
- Legally binding data sharing contracts with people who want to use the information.
- Auditing and monitoring organisations that have received patient information.
- For now, information can only be seen in person at a secure data facility, and
- A cyber security programme allows HSCIC to react quickly to security threats.

## 9) What about other places that I've received treatment? Can I opt out there too?

If you do not want identifiable information that other health organisations (such as hospitals) hold about you to be shared for reasons beyond your direct care, you need to ask them how to opt out.

## About the data extraction

### What will be collected for care.data?

During the pathfinder stage HSCIC is collecting:

- ✓ NHS number, date of birth, gender, postcode and ethnicity (known as 'identifiers').
- ✓ Information recorded in the previous four months about prescriptions, referrals and diagnoses. This information is collected as codes (e.g. code C10EL for diabetes).

### What will not be collected for care.data?

HSCIC is **not** collecting:

- × Name, full address or telephone number.
- × Notes such as conversations between the GP and the patient.
- × Information about sexual orientation, marital status, employment, use of illegal substances, sexually transmitted infections, domestic violence, convictions, or terminations.

You can find detailed information about the data to be collected in the data governance document.

A full list of the codes HSCIC will extract is contained within the care.data technical specification, which is available on its website.

### Data will be collected using the General Practice Extraction Service

If the General Practice Extraction Service (GPES) is already in use at the practice there are no additional actions required. For more about GPES visit [www.hscic.gov.uk/gpes](http://www.hscic.gov.uk/gpes)

## Information Governance level 2 compliance

It is expected that practices implementing care.data should have achieved or be working towards achieving Information Governance level 2 compliance. The IG Toolkit and further information can be found at <https://www.igt.hscic.gov.uk>

