**Keeping patient data safe / National Opt out**

We are committed to protecting of patient data, making sure it is handled securely, and only used for the good of health and care, and that patient data is always protected. We comply with the [national data opt-out policy](https://www.nhs.uk/your-nhs-data-matters/). We also provide advice to the health and care sector on keeping data safe.

1. **Overview**

Your health records contain a type of data called confidential patient information. This data can be used to help with research and planning.

You can choose to stop your confidential patient information being used for research and planning. You can also make a choice for someone else like your children under the age of 13.

Your choice will only apply to the health and care system in England. This does not apply to health or care services accessed in Scotland, Wales or Northern Ireland.

1.1 **What is confidential patient information**

Confidential patient information is when 2 types of information from your health records are joined together.

The 2 types of information are:

* something that can identify you
* something about your health care or treatment

For example, your name joined with what medicine you take.

Identifiable information on its own is used by health and care services to contact patients and this is not confidential patient information.

**1.2 How we use your confidential patient information**

**Your individual care**

Health and care staff may use your confidential patient information to help with your treatment and care. For example, when you visit your GP they may look at your records for important information about your health.

**Research and planning**

Confidential patient information might also be used to:

* plan and improve health and care services
* research and develop cures for serious illnesses

**Your choice**

You can stop your confidential patient information being used for research and planning. Find out [how to make your choice](https://www.nhs.uk/your-nhs-data-matters/manage-your-choice).

If you’re happy with your confidential patient information being used for research and planning you do not need to do anything.

Any choice you make will not impact your individual care.

1. **Health and care information**

Information about you and your health is recorded when you receive health care or social care, to help with your care and treatment. This is what most people call your medical records. Each organisation you have contact with keeps its own records on you. Information includes:

* your name, date of birth, address and contact details
* your [NHS number](https://digital.nhs.uk/services/nhs-number), which makes sure your records are linked to you and you alone
* details of health conditions and illnesses
* medicines and other treatments
* records of contact you've had with doctors and other health and care workers

Good care requires good information about you, so it's very important that this information is recorded. But it's also very personal - so you need to be confident that it's looked after securely and in line with the law.

**Why we collect some information from your health and care records**

Each health and care organisation you have contact with holds its own records on you. We collect and store some information from everyone's health and care records because of our role managing your health care

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**Improving your individual care**

**Y**our health information will be held in our systems to help us improve your care. Some information is shared to help improve your care, eg:

* the [NHS Spine](https://digital.nhs.uk/services/spine) is a central IT system that links your records to your NHS number and makes sure this important information is never lost, wherever you are treated
* your [Summary Care Record](https://digital.nhs.uk/services/summary-care-records-scr/summary-care-records-scr-information-for-patients) stores vital medical information including medicines you take and your allergies, giving health professionals important and sometimes life-saving information when you are being treated away from your usual doctor's surgery
* your prescriptions can be sent direct to a pharmacy through our [Electronic Prescription Service](https://digital.nhs.uk/services/electronic-prescription-service), saving you time and improving your care
* when your GP has made a referral you can book an appointment on line at a time to suit you, using the [e-Referrals Service](https://digital.nhs.uk/services/e-referral-service)
* you will be called for routine screenings, for example for cervical or bowel cancer, based on information we hold about you in our central systems

1. **Summary Care Record**

Your Summary Care Record is a short summary of your GP medical records. It tells other health and care staff who care for you about the medicines you take and your allergies. This means they can give you better care if you need health care away from your usual doctor's surgery. Everyone has one by default, but you can decide to opt out. You can also choose to add more information to it to improve your care. Read more about [Summary Care Records and your choices](https://digital.nhs.uk/services/summary-care-records-scr/summary-care-records-scr-information-for-patients).

1. **National data opt-out**

All health and care organisations in England are required to apply your national data opt-out in line with the policy by March 2020, including hospitals and GP practices. Your type 2 opt-out only applied to confidential patient information being shared by NHS Digital.

You do not need to do anything if you are happy about how your confidential patient information is used. You can change your choice at any time.

**Type 1 opt-out: medical records held at the GP practice**

You can tell us if you do not want your confidential patient information held in your medical record to be used for purposes other than your individual care. This is commonly called a **type 1 opt-out**. This opt-out request can only be recorded by the GP practice.

**Type 2 opt-out: information held by NHS Digital**

Previously you could tell your us if you did not want NHS Digital to share confidential patient information that is collected from across the health and care service for purposes other than your individual care. This was called a type 2 opt-out.

The type 2 opt-out was replaced by the **national data opt-out**. Type 2 opt-outs recorded on or before 11 October 2018 have been automatically converted to national data opt-outs.

**How can can I opt out?**

National data opt-outs are not recorded at the GP practice and instead you can change your national data opt-out using the [online service](https://www.nhs.uk/your-nhs-data-matters/) or by calling our NHS Digital contact centre.

Young adults from the age of 13 can set and change their own national data opt-out.

You can choose whether your confidential patient information is used for research and planning. To find out more visit [nhs.uk/your-nhs-data-matters](https://www.nhs.uk/your-nhs-data-matters/).

[Read more about the collection and conversion of type 2 opt-outs](https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information/your-information-choices/how-opt-outs-work).

**National Data Opt-Out Compliance Policy**

**Summary**

The national data opt-out applies to the disclosure of confidential patient information for purposes beyond individual care across the health and adult social care system in England.

This document provides operational guidance to understand when the national data opt-out must be applied along with the exemptions when it will not apply.

The national data opt-out applies to data that originates within the health and adult social care system in England and is applied by health and care organisations that subsequently process this data for purposes beyond individual care.

The opt-out does not apply to data disclosed by providers of health and care services outside of England or to children’s social care services.

The national data opt-out is aligned with the authorisation used for sharing a patient’s data in accordance with the common law duty of confidentiality (CLDC). In broad terms the national data opt-out applies unless there is a mandatory legal requirement or an overriding public interest for the data to be shared. The opt-out does not apply when the individual has consented to the sharing of their data or where the data is anonymised in line with the Information Commissioner’s Office (ICO) Code of Practice on Anonymisation.

A member of the public is able to set an opt-out via a number of channels that include online, digitally assisted and non-digital channels. Any person registered on the Personal Demographic Services (PDS) and who consequently has an NHS number allocated to them is able to set a national data opt-out. The opt-out is stored in a central repository against their NHS number on the Spine1.

NHS Digital and Public Health England are applying the national data opt-out to any in scope data releases and are compliant with this policy. Other relevant organisations are required to be compliant with the opt-out by March 2020.

The opt-out applies regardless of the format of the data and this includes structured and unstructured electronic data and paper records. When the opt-out is applied, the entire record (or records) associated with that individual must be fully removed from the data being disclosed. The NHS number is used as the identifier for the removal of the records.

A national data opt-out publication provides statistics on the national data opt-out against various dimensions, including age and geography to help organisations to understand the impact of the opt-out on their data. Related documents that set out requirements and guidance on the application of the national data opt-out include the Data Security and Protection Toolkit (DSPT), the forthcoming Information Standard on Compliance with the National Data Opt-out and the NHS Digital Code of Practice on Confidential Information. Further information and guidance on the opt-out is available from the national data opt-out programme webpages.

**Setting or changing an opt-out choice**

The national data opt-out allows a patient to choose if they do not want their confidential patient information to be used for purposes beyond their individual care and treatment - for research and planning. Patients, or people acting for them by proxy, have control over setting or changing their own opt-out choice, and can change their mind at any time. In most cases health and care staff won't be involved - but it's helpful to understand how the process works so you can tell patients where to find out more about their choices.

[Read more about how patients can opt out, including special arrangements for people in secure settings](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/setting-or-changing-a-national-data-opt-out-choice).

[Find a range of resources you can use to inform patients about their opt-out choice](https://digital.nhs.uk/services/national-data-opt-out/supporting-patients-information-and-resources).

**How opt-outs are recorded**

When a patient sets an opt-out choice, it is recorded against their NHS number on the Spine. It will remain unless the patient changes their mind, even after they have died.

[Read more about how NHS Digital records and manages opt-out choices](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/how-opt-outs-are-recorded).

**National Opt Out Compliance**

To be to compliant we must assess if data disclosures are within scope of the national data opt-out policy.

**1. Is the use or disclosure for individual care or research and planning?**

The national data opt-out policy does not apply where information is being used or shared for an individual patient's care. It only applies to use or disclosure of data for purposes beyond individual care such as research and planning.

[Find out more about individual care and research and planning purposes](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/individual-care-and-research-and-planning-uses-of-data).

**2. Is the use or disclosure confidential patient information?**

Data is recorded whenever a patient has contact or interaction with the health and care system. The opt-out only applies to confidential patient information (CPI) - data that includes both:

* information that identifies or could be used to identify the patient
* information about their health, care or treatment

The national data opt-out does not apply to information that is anonymised in line with the Information Commissioner’s Office (ICO) Code of Practice (CoP) on Anonymisation or is aggregate or count type data.

[Read more about confidential patient information and anonymised data](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/confidential-patient-information).

If the use or disclosure is CPI, you need to determine how the common law duty of confidentiality is being met.

**3. Do we have explicit consent for the use or disclosure?**

If a patient has agreed to a specific use of data, after being fully informed, then the national data opt-out does not apply. Even patients who have registered a national data opt-out can agree to take part in a specific research project or clinical trial, by giving their explicit consent.

**4. Is the disclosure for the purpose of monitoring and control of communicable disease or other risks to public health?**

The national data opt-out does not apply to disclosure of confidential patient information if it is being used to protect public health, for example to:

* diagnose communicable diseases
* control or prevent their spread
* deliver and monitor vaccination programmes
* manage risks of infection from food or water supplies or the environment

**5. Is the information being disclosed because of a legal requirement?**

When there is a legal requirement to disclose information that sets aside the common law duty of confidentiality, the national data opt-out policy does not apply.

[Find out more about legally mandated data disclosures](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/legally-required-data-disclosures).

**6. Is the use or disclosure in the overriding public interest?**

There are a small number of exceptional circumstances where clinicians, Caldicott Guardians and managers can decide to share information based on public interest, and in these cases the national data opt-out does not apply. These kinds of decisions about disclosures are made on a case-by-case basis and carefully consider the circumstances involved.

Data controllers should have their own arrangements in place to apply the public interest test where necessary.

**7. Is Section 251 approval being relied upon the legal basis for the use or disclosure Section 251 approval?**

The Confidentiality Advisory Group (CAG) considers applications for the use of confidential patient information without consent under the following regulations of Control of Patient Information Regulations 2002 , Section 251 of the NHS Act 2006:

* Regulation 2 – for diagnosis and treatment of cancer
* Regulation 5 – for general medical and research purpose

Both regulations are also subject to regulation 7, which sets out that the data must not be processed further than for the permitted purpose.

If the data use or disclosure has Section 251 support obtained under regulation 2 or 5, it is in scope of the policy, and national data opt-outs **must** be applied before the disclosure takes place.

This applies unless CAG have determined, in limited and exceptional circumstances, that the standard condition to support opt-outs has been waived, or that another specific opt-out will apply to the approval.

**Declaring compliance**

If you have worked out that the national data opt-out policy applies to your change of use or disclosure of data, you need to apply national data opt-outs by removing the records of anyone who has an opt-out registered before you use or disclose the information.

For further details please refer to NHS Digital [National data-opt-out operational policy guidance document](https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document) for complete policy guidance.