**National Data Opt-Out**

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**National Data Opt-Out & Practices**

**What is the national data opt-out?**

It is a service that enables the public to opt out of their confidential patient information being used for purposes beyond their individual care and treatment.

It was introduced for the health and social care system in England on 25 May 2018.

The public can change their national data opt-out choice at any time via [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters), or by calling the NHS Digital contact centre on 0300 3035678.

**Which practices need to comply with national data opt-out policy?**

The national data opt-out applies to data for patients where their care is provided in England by a publicly funded organisation or the care has been arranged by a public body such as the NHS or a Local Authority, it does not apply to data related to private patients/clients at private providers.

In summary the national data opt-out applies to:

* all NHS organisations (including private patients treated within such organisations)
* all Local Authorities providing publicly funded care
* adult social care providers where the care provided is funded or arranged by a public body
* private or charitable healthcare providers providing NHS funded treatment or arranged care

**When do practices need to comply?**

The Department of Health and Social care require all health and adult social care organisations to comply with the policy by March 2020 as set out in the information standard: [DCB3058 Compliance with National Data Opt-outs.](https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb3058-compliance-with-national-data-opt-outs) Compliance by this date also ensures organisations can complete the evidence item ‘compliance with national data opt-out policy’ in the [Data Security and Protection toolkit](https://www.dsptoolkit.nhs.uk/) for 2019/20.

**What do practices need to do?**

Put processes and procedures in place, by March 2020, to be able to assess any current or future uses of confidential patient information prior to disclosure to consider and apply national data opt-outs where necessary, in accordance with [national data opt-out operational policy.](https://digital.nhs.uk/services/national-data-opt-out-programme/operational-policy-guidance-document)

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 Spine.

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.

**National Data Opt-Out & Patients**

**Patients who can choose to set a national data opt-out**

Anyone who has an NHS number and has registered for care or treatment with the NHS in England can set an opt out if they wish to, even if they don’t currently live in England.

**Patient who can set an opt out choice for themselves**

If the patient is aged 13 or over, they can set their own opt-out choice using the online service, the telephone service, the NHS App, or ‘print and post’, completing a form by hand and sending it in.

**Patients who can set an opt-out choice on behalf of someone else**

Someone can set an opt-out choice on behalf of a patient, by proxy, if:

* they are the parent or legal guardian of the patient, who is a child aged 12 or under
* they have a formal legal relationship with the patient, for example legal power of attorney or are a court-appointed deputy.

They can only do this using the ‘print and post’ service.

**Changing an opt-out**

An opt-out choice can be changed at any time by the patient or their proxy.

**Using the online service**

Patients can set their own opt-out choice by visiting [www.nhs.uk/your-nhs-data-matters](https://www.nhs.uk/your-nhs-data-matters/) using any internet enabled device. So that the service can confirm their identify, they will need to provide:

* their NHS number, or their postcode ( as registered with the GP practice)
* their mobile phone number or email address provided previously at a GP practice or other NHS service

The online service is available 24 hours a day, 7 days a week.

**Using the NHS App**

Patient who have registered for the [NHS App](https://digital.nhs.uk/services/nhs-app) using NHS login can set a national data opt-out using the app.

**Using the telephone service**

Patients can set their own opt-out choice by calling 0300 303 5678.

Calling this number should cost no more than calls to a normal landline number.

The telephone service is available 9am to 5pm, Monday to Friday, apart from on English bank or public holidays.

**Using ‘print-and-post’**

If a patient is unable to use the online or telephone service, or would prefer not to, they can complete a paper form and post it.

The form can be downloaded from [www.nhs.uk/your-nhs-data-matters](https://www.nhs.uk/your-nhs-data-matters/) or requested by calling the telephone service on 0300 303 5678

**Patients in prison or secure settings**

There are special arrangements for patients in prison or other similar secure settings, known as detained and secure estates. A health and care professional can help register a patient’s opt-out choice. See[Guidance for detained and secure estates](https://digital.nhs.uk/services/national-data-opt-out/guidance-for-health-and-care-staff#guidance-for-detained-and-secure-estates).

**Confirmation**

During the process of setting their opt-out choice, the patient can choose their preferred communication method:

* email
* SMS text
* Letter

Once the process has been completed, the patient will receive a confirmation that their national data opt-out choice has been set.

**Before you start**

The flowchart below is a high level view of the actions required to become compliant with national data opt-out policy.



**Compliance with national data opt-out policy**

GP practices must comply with the national data opt-out policy by March 2020.

To comply, practices need to have procedures in place to identify when they need to apply national data opt-outs so that the records for patients with a national data opt-out are removed before any data is disclosed.

To help GP practices to become compliant and to apply national data opt-outs, the four principal GP IT system suppliers are implementing new functionality in the reporting and search modules within their clinical systems. The functionality will enable practices to easily remove the records of patients who have registered a national data opt-out from data disclosures when the practice decides the opt-out applies.

Practices will need to ensure that any clinical system report (or search) used to generate that data disclosure is configured to remove national data opt-outs – using the new functionality when available.

*If the disclosure is generated from a pre-existing report (one which was created prior to the new functionality being available), it’s the responsibility of the practice, as data controller, to ensure that the report is edited to apply national data opt-outs before it is next run.*

*If a new report is required, the practice must ensure that national data opt-outs are applied as appropriate when it is created.*

*If the report used to generate the disclosure is one that the practice does not ‘own’ and is unable to edit (for example, one created or published by another organisation or system supplier), the practice must contact the owner or publisher to ensure that national data opt-outs are applied before data is disclosed.*

Each supplier will provide guidance to their practices about how to use their new functionality, as the functionality is deployed.

**The IG Team have contacted NHS Digital on when the functionality will be available, the response was, and they are hoping the service will be in placed early in the New Year for TPP and February for EMIS.**

**NHS Digital have asked if any practices would like to be involved in testing the functionality to let Priscilla know, who will pass on your details.**

**Preparing practices for the national data opt-out**

* New posters and handouts with information on obtaining supplies are being supplied by the NHS and should be displayed. Old ones, for example, previous privacy notices or material relating to care data should be removed

<https://digital.nhs.uk/services/national-data-opt-out/supporting-patients-information-and-resources>

* The type 2 objection will no longer apply, so all reference to this needs to be removed from patient literature. The practices' privacy notices will also need to be updated to ensure they are applicable with the changed opt out arrangements
* Anyone with a type 2 in place will have had it automatically converted to a national data opt-out which will be respected by NHS Digital, so wishes will still be respected
* The type 1 objection remains in place at least until March 2020 and all literature should reflect this
* All practice staff need to be aware that there is a change in patients’ opt out options. They need to know where to direct patients for further information and to be aware of the need to ensure all documentation being supplied to patients is accurate and up to date
* As the digital channel uses email or telephone details for verification purposes, practices should maintain their efforts to keep this information current on their system and up to date with PDS

**Compliance Implementation Guide - Checklist**

Completion of this checklist will help your surgery to ensure you are ready to declare compliance with the national data opt-out policy.

You should read this in conjunction with the detailed actions and guidance in the Compliance Implementation Guide at <https://digital.nhs.uk/services/national-data-opt-out-programme/compliance-with-the-national-data-opt-out>

**1. Assess data disclosures and update procedures**

|  |  |
| --- | --- |
|  | Current data disclosures assessed to identify any within the scope of national data opt-out policy |
|  | Process for handling new disclosure requests has been updated to make sure national data opt-out policy is considered before data disclosures take place |

**2. Need to apply national data opt-outs?**

**If ‘Yes’ follow actions 3 and 4 to implement the technical solution\* and processes**

*(\*The technical solution is being implemented by the GP systems suppliers within their systems. If you are a GP practice or another organisation using a TPP SystmOne module you will not need to set up the MESH service separately and can go to action 4, unless you use other IT systems to create data disclosures.)****\*\*As a CCG we assume it means ALL systems and not just systmone***

**If ‘No’ go straight to action 5 – communications and compliance**

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**3. Set up technical solution**

|  |  |
| --- | --- |
|  | Messaging Exchange for Social Care and Health (MESH) client software is installed |
|  | MESH mailbox in place that can be used with the Check for National Data Opt-outs service |
|  | Process in place for creating a list of NHS numbers that need to be checked from the data prepared for disclosure |
|  | Process in place for creating the files to be sent to the MESH service |
|  | Process in place to use the returned files to create an updated set of data to be disclosed, with national data opt-outs removed |
|  | Process in place to confirm opt-outs have been applied and that data can now be disclosed |

**4. Implement new processes**

|  |  |
| --- | --- |
|  | Data Protection Impact Assessment (DPIA) completed |
|  | New processes documented and included in Standard Operating Procedures or equivalent written instructions |

**5. Communications and declaring compliance**

|  |  |
| --- | --- |
|  | Internal communications complete |
|  | Patient communications are ready |
|  | Communications for other organisations are ready |
|  | Date to declare compliance decided |

**You are ready to declare compliance**

**Recommended text for privacy notices**

Recommended text to include in your practices patient privacy notice.

**Privacy Notice – Template Transparency Statement, (version 2)**

The following is a recommended set of text to reference the wider use of a patient’s health and care data by local and national NHS and care organisations that can be added to an organisation’s website alongside the organisation’s Privacy Notice. It is intended to provide a simple easy to understand message about the wider uses of data, drawing upon the language used in other materials which has been tested with patients and the public. The intention of the Template Transparency Statement is to point patients to the national online resources that have been created to support this communication to patients, and to ensure they are aware that they have a choice about the use of confidential patient information about them being used for purposes beyond their individual care.

This is not intended to replace the practice’s own Privacy Notice which needs to be specific to the organisation.

Practices are reminded that they need to update their Privacy Notices (or ‘Fair Processing’ material) to satisfy the General Data Protection Regulation (GDPR) and data protection legislation. The key points to note are that the GDPR strengthens the requirements on organisations as data controllers to provide clear and concise information to patients in order to be fairly and lawfully processing information, being clear about what data is collected and how it is processed. This information should be described accurately and clearly within the organisation’s Privacy Notice along with the identity and contact details of the data controller and made available to patients. Further information and guidance about Privacy Notices under GDPR is available from the Information Commissioner’s Office (ICO) at: <https://ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/privacy-notices-under-the-eu-general-data-protection-regulation/>.

**Recommended text for transparency statement to be added alongside the organisation’s Privacy Notice.**

 It is recommended that this is included to be clear to patients whether your own organisation is currently compliant with the policy for applying national data opt-outs”

**How the NHS and care services use your information**

[Insert practice] is one of many practices working in the health and care system to improve care for patients and the public)[[1]](#footnote-1).

Whenever you use a health or care service, such as attending Accident & Emergency or using Community Care services, important information about you is collected in a patient record for that service. Collecting this information helps to ensure you get the best possible care and treatment.

The information collected about you when you use these services can also be used and provided to other organisations for purposes beyond your individual care, for instance to help with:

• improving the quality and standards of care provided

• research into the development of new treatments

• preventing illness and diseases

* monitoring safety

• planning services

This may only take place when there is a clear legal basis to use this information. All these uses help to provide better health and care for you, your family and future generations. Confidential patient information about your health and care is **only used** like this where allowed by law.

Most of the time, anonymised data is used for research and planning so that you cannot be identified in which case your confidential patient information isn’t needed.

You have a choice about whether you want your confidential patient information to be used in this way. If you are happy with this use of information you do not need to do anything. If you do choose to opt out your confidential patient information will still be used to support your individual care.

To find out more or to register your choice to opt out, please visit [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters). On this web page you will:

* See what is meant by confidential patient information
* Find examples of when confidential patient information is used for individual care and examples of when it is used for purposes beyond individual care
* Find out more about the benefits of sharing data
* Understand more about who uses the data
* Find out how your data is protected
* Be able to access the system to view, set or change your opt-out setting
* Find the contact telephone number if you want to know any more or to set/change your opt-out by phone
* See the situations where the opt-out will not apply

You can also find out more about how patient information is used at:

[https://www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/%20) (which covers health and care research); and

<https://understandingpatientdata.org.uk/what-you-need-know> (which covers how and why patient information is used, the safeguards and how decisions are made)

You can change your mind about your choice at any time.

Data being used or shared for purposes beyond individual care does not include your data being shared with insurance companies or used for marketing purposes and data would only be used in this way with your specific agreement.

Health and care organisations have until 2020 to put systems and processes in place so they can be compliant with the national data opt-out and apply your choice to any confidential patient information they use or share for purposes beyond your individual care. Our organisation ‘is / is not currently’ compliant with the national data opt-out policy.[[2]](#footnote-2) “

**National Data Opt-Out Guidance**

**To prevent use of type 2 opt-out codes and identify if they have been used in error**

<https://digital.nhs.uk/services/national-data-opt-out/information-for-gp-practices/prevent-type-2-opt-out-code-use-in-tpp-systmone>

<https://digital.nhs.uk/services/national-data-opt-out/information-for-gp-practices/prevent-type-2-opt-out-code-use-in-emis-web>

<https://digital.nhs.uk/services/national-data-opt-out/information-for-gp-practices/prevent-type-2-opt-out-code-use-in-vision>

<https://digital.nhs.uk/services/national-data-opt-out/information-for-gp-practices/prevent-type-2-opt-out-code-use-in-microtest>

**Patient who previously had a type 2 opt-out**

Where a patient had a type 2 opt-out registered on or before 11 October 2018, this was automatically converted to a national data opt-out and if they were aged 13 or over they were sent a[**personal letter explaining the change**](https://digital.nhs.uk/binaries/content/assets/website-assets/services/national-data-opt-out/patient-type-2-opt-out-transition-letter-v1.0.pdf)and ahandout with more information about the national data opt-out.

Patients can be reassured that their choices will continue to be respected. If they want to change their choice, they can use the[**national data opt-out service**](https://www.nhs.uk/your-nhs-data-matters/)to do this.

**Patients who have a type 1 opt-out**

Some patients will have a type 1 opt-out registered with their GP practice, which indicates they do not want their confidential patient information leaving the practice for research and planning purposes. These existing type 1 opt-outs will continue to be respected until 2020, when the Department of Health and Social Care will consult with the National Data Guardian on their removal.

**National data opt-out operational guidance document**

<https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document>

**Compliant with the national data opt-out policy**

<https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out>

**National data opt-out: compliance implementation guide**

<https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out/compliance-implementation-guide>

**Supporting your patients – resources and guidance**

<https://digital.nhs.uk/services/national-data-opt-out/information-for-gp-practices>

Practices should make sure staff are aware of the national data opt-out so they can support your patients.

The [Royal College of General Practitioners](https://www.rcgp.org.uk/) has published a [Patient Data Choices toolkit](https://www.rcgp.org.uk/patientdatachoices) for GPs and practice staff, and training materials in their [RCGP e-learning module](https://www.rcgp.org.uk/patientdatachoices).

[Resources](https://digital.nhs.uk/services/national-data-opt-out/supporting-patients-information-and-resources) are available for practice staff to share with patients if they have any questions. When patients ask about opting out:

* refer them to the website nhs.uk/your-nhs-data-matters
* it's helpful to make sure they know their NHS number
* ensure they have an up-to-date email address or mobile phone number in their GP practice record, as this will be used to verify their identity when they use the service
1. This paragraph to be inserted by national organisations such as ALBs [↑](#footnote-ref-1)
2. [↑](#footnote-ref-2)