**National Data Opt-Out Guidance**

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# Introduction

## Guidance statement

This guidance provides outline advice on the National Data Opt-Out (NDO-O) policy with which general practice is required to comply by the revised date of 31 July 2022. It covers the procedures that need to be in place to enable organisations to identify when patient data needs to be removed before it is disclosed to certain third parties in line with [operational policy guidance](https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document).

The choice to opt in or out applies only to the healthcare system in England. It does not apply to health and social care services accessed in Scotland, Wales or Northern Ireland.

It should be noted that NDO-O now replaces the previous type 2 opt-out codes which can no longer be used, although any type 2 opt-outs that have previously been submitted to NHS Digital have been automatically converted to NDO-O.

Sheerwater Health Centre is required to ensure that any such data contained in a report or search generated by EMIS web clinical system or by any other means has the data removed that belongs to patients who have chosen to opt out.

The Data Protection Officer (DPO) at Sheerwater Health Centre is [insert name and role]. Their advice must always be sought and followed regarding NDO-O matters.

Sheerwater Health Centre and all staff are to ensure compliance with all requirements of the NDO-O policy. Failure to comply with the policy and any associated [breaches](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-law-enforcement-processing/personal-data-breaches/) of patient data or confidentiality could lead to prosecution or imposition of [penalties](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-law-enforcement-processing/penalties/) by the Information Commissioners Office (ICO).

## Status

The organisation aims to design and implement policies and procedures that meet the diverse needs of our service and workforce, ensuring that none are placed at a disadvantage over others, in accordance with the [Equality Act 2010](https://www.legislation.gov.uk/ukpga/2010/15/contents). Consideration has been given to the impact this policy might have regarding the individual protected characteristics of those to whom it applies.

This document and any procedures contained within it are contractual and therefore form part of your contract of employment. Employees will be consulted regarding any modifications or change to the document’s status.

This document applies to all employees of the organisation and other individuals performing functions in relation to the organisation such as agency workers, locums and contractors.

# Requirements

## Compliance and understanding the National Data Opt-Out

NHS Digital provides [information for GP practices](https://digital.nhs.uk/services/national-data-opt-out/information-for-gp-practices) regarding compliance with and [understanding of the National Data Opt-Out](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out). The main points are detailed in this chapter.

## Setting or changing an opt-out choice

The NDO-O 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.

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 do not currently live in England. A patient must register their choice to opt out only once, and that registration applies to all healthcare settings and organisations, not just general practice. An opt out choice can be changed at any time by the patient or their proxy.

Opt-outs can be notified using one of the following:

* [Online service](https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/) – Patients registering need to know their NHS number or their postcode as registered at their GP organisation.
* Telephone service **0300 303 5678** which is open Monday to Friday between 0900 and 1700
* [NHS App](https://www.nhs.uk/apps-library/nhs-app/) – for use by patients aged 13 and over (95% of surgeries are now connected to the NHS App). The app can be downloaded from the [App Store](https://apps.apple.com/gb/app/nhs-app/id1388411277) or [Google play](https://play.google.com/store/apps/details?id=com.nhs.online.nhsonline)
* [‘Print and post’ registration form](https://assets.nhs.uk/nhsuk-cms/documents/Make_and_manage_your_choice_or_your_childs_choice_PDF_224kb.pdf). It can take up to 14 days to process the form once it arrives at National Data Opt Out, Contact Centre, NHS Digital, HM Government, 7 and 8 Wellington Place, Leeds, LS1 9TZ
* Getting a healthcare professional to assist patients in prison or other secure settings to register an opt-out choice. For patients detained in such settings [Guidance](https://digital.nhs.uk/services/national-data-opt-out/guidance-for-detained-and-secure-estates) is available on NHS Digital and a [Proxy form](https://digital.nhs.uk/binaries/content/assets/website-assets/services/national-data-opt-out/guidance-for-health-and-care-staff/non-digital-proxy-opt-out-form-detained-and-secure-estate-v1.1.pdf) is available to assist in registration.

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

A third party 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 they have legal power of attorney or are a court appointed deputy

They can only do this using the [‘print and post’ service](https://assets.nhs.uk/nhsuk-cms/documents/Make_and_manage_a_choice_for_someone_else_PDF_154kb.pdf).

## Upholding the opt-out and declaring compliance

As the NDO-O policy applies to nearly all organisations, they need to [uphold patient choices to opt out](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out#upholding-the-opt-out-and-declaring-compliance) by removing the records of any patient before using or disclosing information other than for the purpose of that patient’s immediate healthcare.

The Data Security and Protection (DSP) Toolkit includes an item on compliance with the NDO-O. This requires organisations to self-declare their compliance (or otherwise) with the policy and provide a clear public statement to this effect.

Further reading can be sought in the [Data Security and Protection Handbook](https://practiceindex.co.uk/gp/forum/resources/data-security-and-protection-toolkit-handbook-ms-word-version.1908/).

## Compliance and implementation guide

[The national data opt-out compliance and implementation guide](https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out/compliance-implementation-guide) takes users through the steps they need to follow to achieve compliance by the revised date of 31 July 2022.

Before doing so, it presents a [checklist](https://digital.nhs.uk/binaries/content/assets/website-assets/services/national-data-opt-out/compliance/cig-checklist-v3-.docx) of the process and advises that users should consider:

* How long it will take to be compliant (the advice and guidance of the organisation’s DPO will be invaluable in making this assessment)
* Who should be involved in the implementation

[The guide](https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out/compliance-implementation-guide#assess-data-disclosures-and-update-procedures) outlines the five steps that need to be taken to achieve compliance. However, as step 2, implementing a technical solution, will be carried out by clinical system suppliers on behalf of GP organisations, they do not need to implement step 3, i.e., set up the technical solution and use the Message Exchange for Social Care and Health (MESH) which accesses the [Check for National Opt-Outs Service](https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out/check-for-national-data-opt-outs-service).

Step 1 Assess data disclosures and update procedures.

Step 2 Decide whether to implement a technical solution. Note the four principal GP system suppliers have been commissioned to assist GP organisations to comply with the NDO-O by developing and embedding a technical solution in their systems.

Step 3 Set up the technical solution and use the Message Exchange for Social Care and Health (MESH) which accesses the Check for National Opt-Outs Service. Organisations only need to consider doing this if they hold and generate patient data reports using a system/software other than their clinical system.

Step 4 Implement new processes. This suggests that a Data Protection Impact Assessment (DPIA) should be completed using the format shown at the link which is based on the [ICO template](https://ico.org.uk/media/about-the-ico/consultations/2258461/dpia-template-v04-post-comms-review-20180308.pdf). It is strongly advised that completion of the DPIA is left to the organisation’s DPO.

Step 5 Plan communications and declare compliance. This step requires organisations to consider communications and to declare compliance:

* Internally with all staff
* Externally with patients including updating the [organisation's website and privacy notice](https://digital.nhs.uk/binaries/content/assets/website-assets/services/national-data-opt-out/supporting-patients---information-and-resources/pn-template-text-v2.0-191218.docx) using a suggested wording
* With other organisations with which the organisation works who may be affected by the organisation becoming compliant with the NDO-O
* Decide the date to declare compliance
* Declare compliance

## Understanding if the data you use or disclose is in scope

This understanding is covered by a series of 10 questions that organisations need to ask themselves:

1. Is the use or disclosure for [individual care or research and planning](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](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/confidential-patient-information)?
3. Does the organisation have explicit [consent for the use or disclosure](https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/when-does-a-national-data-opt-out-not-apply#6-1-consent)?

Note that the NDO-O does not apply where explicit consent has been obtained from the patient for a specific purpose and that there are also three other main exemptions:

* + Communicable diseases and risks to public health, such as the COVID-19 pandemic
  + Overriding public interest
  + Information required by law or court order

1. Is the disclosure for the [purpose of the monitoring and control of communicable disease](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out#is-the-disclosure-for-the-purpose-of-monitoring-and-control-of-communicable-disease-or-other-risks-to-public-health-) or other risks to public health? If it is, NDO-O does not apply
2. Is the information being disclosed [because of a legal requirement](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/legally-required-data-disclosures)?
3. Is the use or disclosure in the [overriding public interest](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out#is-the-use-or-disclosure-in-the-overriding-public-interest-)?
4. Is the legal basis for the [use of disclosure Section 251 approval](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out#is-the-legal-basis-for-the-use-or-disclosure-section-251-approval-)?
5. Is the use or disclosure to an [arms-length body](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out#is-the-use-or-disclosure-to-a-national-or-arms-length-body-)?
6. Is the disclosure to [NHS Digital](https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/policy-considerations-for-specific-organisations-or-purposes#7-10-nhs-digital)?
7. Is the use or disclosure to [support payment and invoice validation](https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out#is-the-use-or-disclosure-to-support-payment-and-invoice-validation-)?

# Resources to inform patients of their opt-out choices

## General resources

To assist organisations, resources are available to download from the [NHS Digital – Supporting your patients – information and resources](https://digital.nhs.uk/services/national-data-opt-out/supporting-patients-information-and-resources) pages. A4 posters and patient hand-outs should already be displayed and available in patient waiting areas.

## Accessible resources

These accessible resources include:

* [British Sign Language video](https://www.youtube.com/watch?v=0BwUsKDqPQ8&feature=youtu.be) of the patient hand-out
* [Audio version](https://s3.eu-west-2.amazonaws.com/files.digital.nhs.uk/assets/Your+Data+Matters+-+Sign+Language+Version+AUDIO+ONLY.wav) of the patient hand-out
* Braille version of the patient hand-out which can be ordered from [NHS England Health Publications](https://www.healthpublications.gov.uk/Home.html)
* An easy read booklet of the patient hand-out for patients with learning disabilities as well as a larger print version can be downloaded from the resources for patients [NHS Digital web page](https://digital.nhs.uk/services/national-data-opt-out/supporting-patients-information-and-resources)

## Tailored resources

These tailored resources, which can also be downloaded from the same link to the NHS Digital web page in the preceding paragraph, include guidance for:

* Black and minority (BME) patients
* Carers
* Young people
* Patients with a previous type 2 opt-out

## 4.4 Other languages

A patient hand-out in 11 languages is available from the [NHS Digital web page](https://digital.nhs.uk/services/national-data-opt-out/supporting-patients-information-and-resources).

# Summary

This guidance enables member organisations to understand the NDO-O policy with which general practice is required to comply by 31 July 2022. It covers the requirements and procedures that need to be in place to enable organisations to identify when patient data needs to be removed before it is disclosed to certain third parties.

Additionally, it identifies the sources where they can access and download resources to enable them and their patients to understand and follow the guidance required to fulfill their obligations as required by the National Data Guardian.

At the time of publication, all key documents have been referenced in this guidance.