

National respiratory audit programme (NRAP)

NRAP: National data opt-out (NDO) – Frequently Asked Questions

Version 2.5: March 2024

Overview

The mandatory implementation of the National Data Opt-Out (NDO) came into effect on the 31 July 2022.

This requires all healthcare services within England (NDO does not apply to Wales) to ensure that they are

taking the relevant steps in implementing the opt-out.

NRAP's COPD, adult asthma and CYP asthma secondary care audits are not NDO exempt, therefore

patients who have applied the NDO, and do not wish their data to be used must not be included in the

audit.

NRAP's pulmonary rehabilitation (PR) audit gained Section 251 approval from the Health Research

Authority's (HRAs) Confidentiality Advisory Group (CAG) to collect patient identifiable data for patients

assessed for PR from 1 April 2024 onwards. Patients assessed for PR before 1 April 2024 should be asked

for explicit consent and therefore are **not subject** to opt-out.

A copy of the letter that was sent to services in August 2022, responding to several queries relating to

NDO, is available here.

Below are some frequently asked questions that the programme has received:

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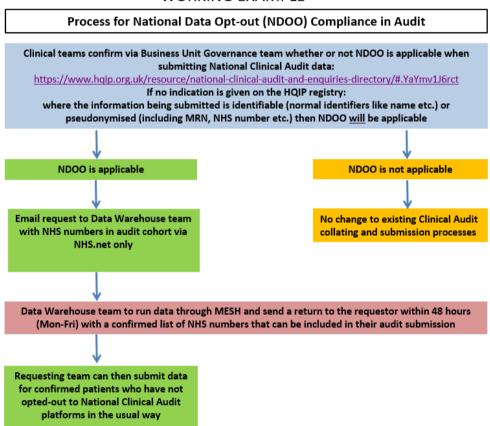


Question Answer

What is the National Data Optout (NDO) and where do I go to find out more information? The national data opt-out is a service that allows patients in England to opt-out of their confidential patient information being used for research and planning purposes (www.digital.nhs.uk).

In the first instance we would advise that you speak with your Business Unit Governance team (or similar) to find out your processes – see below example process.

WORKING EXAMPLE



On an individual basis, the easiest way to find out about the NDO is to use a web search engine and type in 'national data opt-out'. To help we have provided some specific links for patients and healthcare services below.

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www.rcp.ac.uk/nrap



For patients - https://digital.nhs.uk/services/national-data-opt-out
https://www.england.nhs.uk/contact-us/privacy-notice/how-the-nhs-and-care-services-use-your-information-the-national-opt-out/
https://digital.nhs.uk/services/national-opt-out/
https://digital.nhs.uk/services/national-data-opt-out/compliance-implementation-quide#actions-to-take-to-achieve-compliance

Where can I find information of patients that have opted-out?

Your organisation will be able to run a check on any patients to identify whether they are currently opted-out. You will need to check with your organisation's policy and procedure for checking NDO status of your patients.

Do I ask individual patients in England if they want to opt-out?

You do not need to ask individual patients whether they wish to opt-out of having their data used for NRAP. Patients should have already applied an NDO preference prior to attending hospital. Remember that your patients may be very unwell, their care should take priority. Information regarding the NDO and how to apply a preference if they wish to do so should be on display within your healthcare setting.

What process do I follow to a) identify patients who have set a NDO preference and b) uphold that preference?

Your service will have a system for identifying whether a patient has optedout. A patient's NHS number must be screened against their NDO response and then be included or excluded in accordance with their response.

You will not have any choice regarding upholding their preference, if they have applied the NDO they must be removed and not entered into the audit. You should follow your organisation's process and policy – see previously shared flow chart.

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Can NRAP apply an NDO preference on behalf of a patient?

NRAP cannot apply an NDO preference on behalf of a patient. Only Individual patients (13 years and above), parents or carers of children can apply an NDO preference.

https://www.nhs.uk/your-nhs-data-matters/

Can a patient opt back in? If so, how long does it take?

A patient has the right to opt back in, allowing their data to be used across all audits. It can take up to 21 days for a change in NDO preference to be recorded and applied to data uses or disclosures. This is known as a 'fair processing' period. This would mean that if a patient changed their choice whilst they were in hospital, they wouldn't be able to be included in the audit, as their change had not taken effect by the time they were discharged.

What happens if I submit a record to NRAP for a patient that has opted out?

First and foremost, it is your responsibility to ensure that patients who have opted out are not entered into the audit. You must abide by your organisation's policy and process. If a unit discovers they have entered a patient into the audit that they shouldn't have, they can delete that patient to remove them from the audit. You will have access to the patients in the audit via the webtool. You can go back in and select the participant and delete from the audit. NRAP does not have access to this part of the webtool as it holds identifiable data.

Does it apply to historic audit patients? Will the data set be changing to include the consent question?

No, it doesn't apply to patient records for the audit before 31 July 2022 for COPD, adult asthma and CYP asthma secondary care audits. For the PR audit, it does not apply to patient records for the audit before 1 April 2024.

We will not be changing the data set as it is the hospital's responsibility to apply their national data opt out policy.

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Will opt-out affect Best Practice	If an NDO preference has been set for their data not to be used, the patient's
Tarif (BPT)?	details cannot be entered into the audit and therefore will not be included in
COPD and adult asthma	the BPT calculation for that Trust.
secondary care audits only	
	Depending on the number of patients from that area who have opted out, this
	has the potential to impact BPT results.
Can NRAP check a patient's	NRAP does not have access to patient information, therefore we are unable to
"Opt-out" status?	provide you with the access you require. You should check with your business
	governance team regarding processes for screening for patients who have
	applied an NDO.
If a patient has opted-out via	If the patient has applied a National Data Opt-out at any point (GP practice or
their GP, is it acceptable for our	service level), then it is a 'blanket' opt out and they cannot be used in the
clinical team to ask if they are	NRAP audit.
willing for their data to be used	
for the purposes of the NRAP	You should not ask a patient of their opt-out status. This should be
audit? And if so, what would be	determined by your service running an opt-out status check against their NHS
considered appropriate	number.
confirmation of that decision?	
If a patient has opted out how	Unfortunately, there is no way to work around this issue without the service
can this be shown to not affect	keeping a record of the number of opted-out patients which you can refer to
our audit numbers? When you	when analysing your data.
pull data it may look like we	
have missed patients when in	This is a risk to audit entry. We are currently discussing appropriate
fact they have opted out.	mechanisms so as to be able to fairly represent participants entered into the
	audit.

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