



National respiratory audit programme (NRAP)

Pulmonary Rehabilitation audit: National data opt-out (NDOO) – Frequently Asked Questions

Version 1.1 March 2024

Overview

The mandatory implementation of the **National Data Opt-Out (NDOO)** came into effect on 31 July 2022. This requires all healthcare services within England (NDOO does not apply to Wales) to ensure that they are taking the relevant steps in implementing the opt-out.

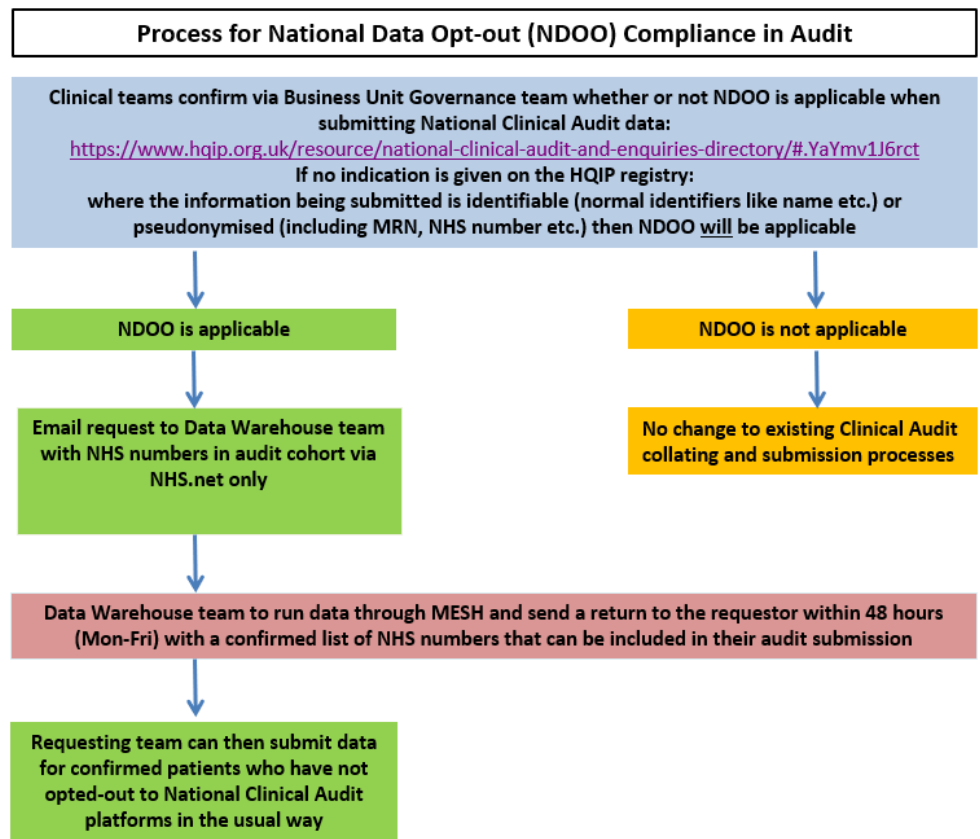
For patients assessed **from 1 April 2024** onwards, PR services in England must apply the National Data Opt-Out. This means you do not need to get explicit patient consent, but instead must ensure National Data Opt-Out is applied.

Patients assessed for PR **before 1 April 2024** should be asked for explicit consent and therefore are **not subject** to opt-out.

Below are some frequently asked questions that the programme has received over the last few months:

Question	Answer
What is the National Data Opt-out (NDOO) and where do I go to find out more information?	<p>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).</p> <p>In the first instance we would advise that you speak with your Business Intelligence or Information Governance team (or similar) to find out your processes – see below example process.</p>

WORKING EXAMPLE



On an individual basis, the easiest way to find out about the NDOO 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.

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/>

For services - <https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out/compliance-implementation-guide#actions-to-take-to-achieve-compliance>

My service is based in Wales, what process do I need to follow?

Wales does not operate a national data-opt out service. Patients are still able to opt-out of individual audits, such as this one. Services in Wales will therefore need to follow their local patient opt-out procedures.

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

Trusts are required to have in place a technical solution to manage NDOO. Most have an agreed process or Standard Operating Procedure in place for identifying whether a patient has opted-out for you to follow. A patient's NHS number will need to be screened against their NDOO response and then be included or excluded from the PR audit. Trusts will have access to a mechanism that can screen for NDOO, such as MESH (Message exchange for Social Care and Health).

If a patient has applied the NDOO they must be removed and not entered into the audit. You should follow your organisation's process and policy – see previously shared flow chart.

I don't know what our local process is. What should I do?

Reach out to your trust's Business Intelligence team and/or Information Governance team, who will be able to advise. As other NRAP secondary care audits have been using NDOO since 2022, you may find it helpful to connect with those teams locally to understand their experiences.

The person I've spoken to in my hospital/trust doesn't know what NDOO is and/or is obstructing us making this change. What should I do?

We recommend that you escalate this to a senior colleague, such as your Caldicott Guardian.

Our BI team in the trust have said they will not be able to cope with the amount of requests, what do we do?

The NDOO has been mandatory for trusts since 31 July 2022, and is in place for other audits, including other NRAP audits. As such, your trust should already have a process in place to manage this. If other teams or colleagues are preventing you from following this process, we recommend that you escalate this to a senior colleague, such as your Caldicott Guardian.

We are a private provider, where can we find patients' NDOO preferences?

Speak to your trust's Business Intelligence or Information Governance team and ask which system should be used to find patients' NDOO preferences.

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

It is your responsibility to ensure that patients who have opted out are not entered into the audit. However, if a service 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 you've entered into the audit via the webtool. You can go back in, select the participant and delete them from the audit. NRAP does not have access to this part of the webtool to delete records for you.

What do I do with patients who were assessed prior to 1 April 2024?

You must continue to record explicit consent for everyone assessed before 1 April 2024. This will remain an option on the webtool.

Does the NDOO apply to historic audit patients?

No, it doesn't apply to patient records for the audit before 1 April 2024. For patients entered into the audit up to and including 31 March 2024, the previous model of explicit patient consent should be used.

What happens if someone's opt-out status changes during the process of entering them into the audit?	<p><i>A patient has the right to change their opt-out preferences. It can take up to 21 days for a change in NDOO preference to be recorded and applied to data uses or disclosures. This is known as a 'fair processing' period.</i></p> <p><i>However, the national data opt-out does not apply retrospectively so, for instance, data disclosed before a patient set an opt-out should not be recalled to have the national data opt-out applied. Patients do not need to confirm their NDOO preference with you.</i></p>
Can NRAP check a patient's "Opt-out" status?	<p><i>NRAP does not have access to any patient information, therefore we are unable to check patients' NDOO preferences. You should check with your Business Intelligence team regarding processes for screening for patients who have applied an NDOO.</i></p>
Can NRAP apply an NDOO preference on behalf of a patient?	<p><i>NRAP cannot apply an NDOO preference on behalf of a patient. Only Individual patients (13 years and above), parents or carers of children can apply an NDOO preference.</i></p> <p><i>https://www.nhs.uk/your-nhs-data-matters/</i></p>
Does this mean we will have to enter more patients into the audit?	<p><i>The application of NDOO has been implemented to address the existing requirement to enter more patients via the expanded dataset for all respiratory conditions. The import function remains on the website and can be a useful option for services.</i></p>
When is the right time to do the NDOO check?	<p><i>Whatever process works for you locally is the correct time. Feedback from secondary care services is that periodically pulling a list of patients for the audit > submitting list to screening team > entering patients who are eligible from list works well.</i></p>

You can enter records into the PR audit as draft > submit the list to screening team > delete any ineligible records once you've received the cleaned data – but having to remove ineligible records is an additional step.

Other audits are exempt from NDOO. Is this possible for NRAP?

We have previously applied for exemption for all audits in NRAP, but we were unsuccessful due to our level of case ascertainment. We'll continue to review whether we can reapply for exemption as we work to improve case ascertainment.

It will take our service more time to enter patients into the audit now. What should I do?

The import guidance on the NRAP webtool can be a helpful way to streamline data entry. If your local SOP requires you to wait for a period of time while your list of patients is screened, you could request patient lists in bulk and instead schedule time later in the week to enter the records.

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 can apply their NDOO preference at any time. Information regarding the audit, NDOO and how to apply a preference is available on our PR audit poster, which should be on display within your healthcare setting.

How will patients know that they are part of the audit if we do not discuss it with them?

You do not need to verbally inform patients about the PR audit. We have a poster that we will be sharing with services to be displayed in assessment areas that advises patients that their data will be used in the NRAP pulmonary rehabilitation audit unless they have applied an NDOO.

If a patient has opted-out via their GP, is it acceptable for our clinical team to ask if they are willing for their data to be used for the purposes of the NRAP audit? And if so, what would be

National Data Opt-out preferences are stored centrally. If the patient has applied a National Data Opt-out at any point (GP practice or service level), then it is a 'blanket' opt out and they cannot be used in the NRAP audit.

If a patient's record indicates they do not wish to take part in audits then you should uphold their preference and not enter them into the audit.

considered appropriate confirmation of that decision?

You should not ask a patient of their opt-out status. This should be determined by your service running an opt-out status check against their NHS number.

If a patient has opted out how can this be shown to not affect our audit numbers? When you pull data it may look like we have missed patients when in fact they have opted out.

A service is welcome to keep a record of the number of opted-out patients which you can refer to when analysing your data locally.

What if I have a patient who explicitly tells me they do not want their data to be part of the audit?

In the rare instance that a patient tells you they wish to opt in or out of the audit, in contrast to their NDOO preference, then the patient's choice should take priority. We would suggest that you establish and maintain an internal process for logging that choice, which will override NDOO preferences, e.g. adding a note to the patient's internal record. You should discuss this with your Information Governance team locally.

Should we keep hold of old, completed consent forms, or can they be destroyed once entered into the audit?

Please store and archive the consent forms following the guidance in your existing data retention policy.

Do we need to check the NDOO status for a patient each time they are re-referred for PR?

Yes, you should check the NDOO status each time a patient is re-referred into the service, when they begin the process of being assessed for PR.



If we do not submit data to the audit until 6 weeks after initial PR assessment, do we need to re-check the NDOO status for patients?

No, it is only necessary to check the NDOO status once at the start of the PR process. There is no need to re-check during treatment.

Which stage is classed as initial assessment for PR, and therefore determines whether the NDOO applies or not?

This may vary between services and is the first date the patient was assessed with the view of enrolling them onto a PR programme. This may be an in-person assessment but could also be a telephone call during which there is a clinical interaction with a healthcare professional. Telephone calls that are exclusively to book an assessment appointment should not be classed as initial assessment.
