

National Asthma and COPD Audit Programme (NACAP)

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

Version 1: October 2022

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.

NACAP'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.

NACAP's pulmonary rehabilitation audit is consent-based and therefore the NDO does not apply to this audit. Because patients are explicitly asked the question 'do you consent to your data being included in NACAP PR audit?', all patients can be included unless they have expressly advised to the contrary.

Below is a copy of the letter that was sent to services in August 2022, responding to several queries relating to NDO.



NDO response from
NACAP V1.1.pdf

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

Question	Answer
<p>What is the National Data Opt-out (NDO) and where do I go to find out more information?</p>	<p><i>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).</i></p> <p><i>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.</i></p> <p style="text-align: center;">WORKING EXAMPLE</p> <div style="text-align: center; border: 1px solid black; padding: 5px; margin-bottom: 10px;"> Process for National Data Opt-out (NDOO) Compliance in Audit </div> <div style="background-color: #e1eef6; padding: 10px; margin-bottom: 10px;"> <p>Clinical teams confirm via Business Unit Governance team whether or not NDOO is applicable when submitting National Clinical Audit data: https://www.hqip.org.uk/resource/national-clinical-audit-and-enquiries-directory/#.YaYmv1J6rct If no indication is given on the HQIP registry: where the information being submitted is identifiable (normal identifiers like name etc.) or pseudonymised (including MRN, NHS number etc.) then NDOO <u>will</u> be applicable</p> </div> <div style="display: flex; justify-content: space-around; margin-bottom: 10px;"> <div style="text-align: center;"> <div style="background-color: #90c17e; padding: 5px; margin-bottom: 5px;">NDOO is applicable</div> <div style="background-color: #90c17e; padding: 5px; margin-bottom: 5px;">Email request to Data Warehouse team with NHS numbers in audit cohort via NHS.net only</div> <div style="background-color: #e17777; padding: 5px; margin-bottom: 5px;">Data Warehouse team to run data through MESH and send a return to the requestor within 48 hours (Mon-Fri) with a confirmed list of NHS numbers that can be included in their audit submission</div> <div style="background-color: #90c17e; padding: 5px;">Requesting team can then submit data for confirmed patients who have not opted-out to National Clinical Audit platforms in the usual way</div> </div> <div style="text-align: center;"> <div style="background-color: #f1c232; padding: 5px; margin-bottom: 5px;">NDOO is not applicable</div> <div style="background-color: #f1c232; padding: 5px;">No change to existing Clinical Audit collating and submission processes</div> </div> </div> <p><i>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.</i></p> <p><i>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/</i></p> <p><i>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</i></p>
<p>Where can I find information of patients that have opted-out?</p>	<p><i>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.</i></p>

<p>Do I ask individual patients in England if they want to opt-out?</p>	<p><i>You do not need to ask individual patients whether they wish to opt-out of having their data used for NACAP. 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.</i></p>
<p>What process do I follow to a) identify patients who have set a NDO preference and b) uphold that preference?</p>	<p><i>Your service will have a system for identifying whether a patient has opted-out. 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.</i></p>
<p>Can NACAP apply an NDO preference on behalf of a patient?</p>	<p><i>NACAP 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.</i> https://www.nhs.uk/your-nhs-data-matters/</p>
<p>Can a patient opt back in? If so, how long does it take?</p>	<p><i>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.</i></p>
<p>What happens if I submit a record to NACAP for a patient that has opted out?</p>	<p><i>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. NACAP does not have access to this part of the webtool as it holds identifiable data.</i></p>
<p>Does it apply to historic audit patients? Will the data set be changing to include the consent question?</p>	<p><i>No, it doesn't apply to patient records for the audit before 31/07/22.</i></p> <p><i>We will not be changing the data set as it is the hospital's responsibility to apply their national data opt out policy.</i></p>
<p>Will opt-out affect Best Practice Tariff (BPT)? CPD and adult asthma secondary care audits only</p>	<p><i>If an NDO preference has been set for their data not to be used, the patient's details cannot be entered into the audit and therefore will not be included in the BPT calculation for that Trust.</i></p> <p><i>Depending on the number of patients from that area who have opted out, this has the potential to impact BPT results.</i></p>

<p>Can NACAP check a patient's "Opt-out" status?</p>	<p><i>NACAP does not have access to patient information, therefore we are unable to 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.</i></p>
<p>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 NACAP audit? And if so, what would be considered appropriate confirmation of that decision?</p>	<p><i>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 NACAP audit.</i></p> <p><i>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.</i></p>
<p>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.</p>	<p><i>Unfortunately, there is no way to work around this issue without the service keeping a record of the number of opted-out patients which you can refer to when analysing your data.</i></p> <p><i>This is a risk to audit entry. We are currently discussing appropriate mechanisms so as to be able to fairly represent participants entered into the audit.</i></p>