

Fracture Liaison Service Database (FLS-DB)

FLS-DB: National data opt-out (NDOO) – Frequently Asked Questions

Version 1: November 2022

Overview

The mandatory implementation of the National Data Opt-Out (NDOO) was extended until 31 July 2022. Therefore, organisations within England (NDOO does not apply to Wales) have been expected to take note of this deadline, ensuring that they are taking the relevant steps implementing the opt-out.

The FLS-DB was not granted exemption from the NDOO, therefore patients who have opted-out **cannot** be included in the audit.

Question	Answer
What is the National Data Opt-out (NDOO) and where do I go to find out more information?	<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 which came into place on 31 July 2022 (www.digital.nhs.uk). (approximately 6% of patients on average)</i></p> <p><i>In the first instance we would advise that you speak with your Information Governance team (or similar) to find out how your local processes work – there are examples below</i></p> <p><i>To find out more information about the NDOO for your self here are some specific links for patients and healthcare services below.</i></p> <p><i>For patients - https://digital.nhs.uk/services/national-data-opt-out</i></p> <p><i>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>
Where can I find information of patients that have opted-out?	<i>Your organisation will be able to run a check on any patients to identify whether they are currently opted-out. Check with your organisation's Information Governance team about the policy and procedures for how you check the NDOO status of your patients.</i>
Do I ask individual patients in England if they want to opt-out?	<i>You should not ask individual patients whether they wish to opt-out of having their data used for FLS-DB. Patients should have already applied an NDOO preference prior to attending your service. Patients can check on their NHS app if they have opted out.</i>
What process do I follow to a) identify patients who have set a NDOO preference and b) uphold that preference?	<p><i>a) Your Organisation's Information Governance team will have a system for identifying whether a patient has opted-out. A patient's NHS number must be screened against their NDOO response and then, either be included or excluded in accordance with their response BEFORE uploading to FLS-DB.</i></p> <p><i>b) You will not have any choice regarding upholding their preference, if they have applied the NDOO they must be removed and not entered into the audit. You should follow your service's process and policy.</i></p>

Can FLS-DB apply an NDOO preference on behalf of a patient?	<i>The FLS-DB cannot apply an NDOO preference on behalf of a patient; only Individual patients (13 years and above), can apply an NDOO preference.</i>
Can a patient opt back in? If so, how long does it take?	<i>A patient has the right to opt back in. it can take up to 21 days for a change in NDOO preference to be recorded and applied to data uses or disclosures (fair processing period). This is a great website you can share with patients who want more information: https://www.nhs.uk/your-nhs-data-matters/</i>
What happens if I submit a record to FLS-DB for a patient that has opted out?	<i>It is your responsibility to ensure that patients who have opted out are not entered into the audit 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 – we will produce a guide for doing this retrospectively in 2023. Using the webtool, you will have access to your patients in the audit. You can select the patient record and delete them from the audit manually.</i>
Will the data set be changing to include the consent question?	<i>We will not be changing the data set as it is the service's responsibility to apply their national data opt out policy</i>
Does it apply to historic audit patients?	<i>It only applies to patient records SUBMITTED to the audit after 31st July onwards If a patient has opted out;</i> <ul style="list-style-type: none"> <i>any data that has been uploaded before 31st July is OK</i> <i>any data that is submitted after 31st July needs to be NDOO checked and not uploaded (e.g 12 month monitoring data)</i>
Can FLS-DB check a patient's "Opt-out" status?	<i>The FLS-DB does not have access to patient identifiable information, therefore we are unable to provide this information. Check with your Information Governance team regarding local processes for screening for patients who have applied an NDOO.</i>
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 FLS-DB audit?	<i>If they have applied 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 FLS-DB audit. 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>
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.	<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 The FLS-DB estimate on average 6% will have opted out. We are currently discussing appropriate mechanisms to adjust the KPI to fairly represent participants entered into the audit.</i>
If a Welsh service has treated a patient from England who has opted out, what process should the Welsh site follow?	<i>The national data opt out is a provision that is only applicable to patients that attend a hospital in England. Whilst Welsh sites may see a patient from England, as they are not set up to apply the NDOO, they don't need to apply it for these patients.</i>