



National Asthma and COPD Audit Programme (NACAP)

NACAP: National data opt-out

Version 3: October 2021

All patients have the right to decide whether or not information about them and their healthcare is used for research and planning. The National data opt-out allows information to be held on the NHS Spine against an individual's NHS number indicating whether they are happy to for their data to be used. This allows data to be removed from data collections before submission to national clinical audits, registries, confidential enquiries etc.

What happens if patient decides to opt-out of NACAP audits?

- It is the responsibility of each hospital or NHS Trust in England to ensure that information is not entered into the web tool for patients that have a national data opt-out in place. Patient notes should be checked before entering data into the web tool to see whether or not they have chosen to opt out of confidential patient information being used for research and planning purposes.
- If a patient decides during their treatment that they would like to opt-out, their data should not be entered into the NACAP web tool and they should be provided with necessary National data opt-out information to formally log their opt-out preference (see below for this information).
- If a patient wishes to opt out but their treatment has already taken place and the record for that episode of care already entered onto the NACAP web tool, we recommend that they contact the hospital that treated them or the audit team to discuss this. Please note however, that national data opt-out preferences do not apply retrospectively (to data already submitted and used for research and planning purposes).
- If a patient thinks that their information is being used inappropriately, they have the right to complain to the [Information Commissioners Office](#) (ICO).

What information should I be providing to patients who wish to opt-out of their data being used for planning and research purposes?

More information on the National data opt-out is available at <https://digital.nhs.uk/services/national-data-opt-out> or www.nhs.uk/your-nhs-data-matters.

These web pages will provide the patient with:

- information on what is meant by confidential patient information
- finding examples of when confidential patient information is used for individual care and examples of when it is used for purposes beyond individual care
- finding out more about the benefits of sharing data
- understand more about who uses the data
- finding out how their data is protected
- being able to access the system to view, set or change their opt-out setting
- finding the contact telephone number if you want to know any more or to set/change your opt-out by phone seeing the situations where the opt-out will not apply

Patients can also find out more about how patient information is used at:

<https://www.hra.nhs.uk/information-about-patients/> (which covers health and care research); and
<https://understandingpatientdata.org.uk/what-you-need-know> (which covers how and why patient information is used, the safeguards and how decisions are made)

More information about how NACAP uses patient data, including 'how to say no' to being included, can be found at the following audit workstream links:

COPD: www.rcp.ac.uk/nacap-copd-resources

Adult Asthma: www.rcp.ac.uk/nacap-adult-asthma-resources

Children and young people's asthma: www.rcp.ac.uk/nacap-paediatric-asthma-resourcecs

Patients can change their mind about their choice at any time.