

National Respiratory Audit Programme (NRAP)

Children and young people asthma audit: Fair Processing Information/privacy policy

The <u>Healthcare Quality Improvement Partnership (HQIP)</u> and <u>National Health Service England (NHSE)</u> are the joint data controllers for English service users and HQIP and <u>Digital Health Care Wales (DHCW)</u> are the joint data controllers for Welsh service users for data collected and reported on by the NRAP children and young people asthma audit. All data collected by the audit programme is processed to ensure patient confidentiality is maintained. Data processors include:

- **Crown Informatics** who provide the audit web tool and data management services.
- Imperial College London who provide statistical data analysis services.
- **Royal College of Physicians** who run the audit and produce national and local reporting outputs.

Approvals and legal basis

Common Law Duty of Confidentiality

- This audit has been given Section 251 approval for England and Wales by the Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group (CAG). This enables NRAP to collect patient identifiable information without patient consent - <u>CAG reference number</u> 19/CAG/0001:
- The Children and young people asthma audit collects the following patient identifiable items:
 - o NHS number
 - o date of birth
 - o home postcode
 - o date of death (if death occurred during admission).

More information about the audit data flows (also outlined below) and the full dataset is available via the <u>support for services page</u>. Patient information sheets and posters are also available via the 'downloads' page of the <u>audit web tool</u>.



For more information about Common Law Duty of Confidentiality, how it applies to NRAP, and other organisations who request NRAP data, see this <u>short video</u> from the <u>Understanding Health Data Access</u> (UHDA) project.

General Data Protection Regulations (GDPR)

The Children and young people asthma audit's legal basis under GDPR is:

- Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. This is justified through commissioning arrangements which link back to NHS England, Welsh Government and other national bodies with statutory responsibilities to improve quality of health care services.
- Article 9 (2) (h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3.
- Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy. This is justified as the children and young people asthma audit aims to drive improvements in the quality and safety of care and to improve outcomes for asthma patients.

Main data flows

Since 1 June 2019, identifiable patient data has been entered into an online data collection web tool managed by Crown Informatics. This data is entered by selected and authorised hospital users at local sites in England and Wales. Raw, unadjusted data at site-level (non-patient identifiable) are presented on run charts in near to real time (one month after data submission). These are publicly available and support local quality/healthcare improvement.



Periodically, these data will be sent to Imperial College London by Crown Informatics in a completely anonymised, patient level format for analysis. Imperial College London will then send analysed and aggregated data to the NRAP team at the Royal College of Physicians in order to write and publish national and local reports. Only aggregate data will be presented, and no information will be released that could be used to identify individuals.

Linkage

England and Wales

The audit information will be linked with data already held by NHS England and Data Health and Care Wales (DHCW): namely, the Hospital Episodes Statistics (HES) and Patient Episode Database for Wales (PEDW) datasets and the Office of National Statistics (ONS) mortality data. HES is a record of all hospital admissions in England, PEDW records all episodes of inpatient and day-case activity in NHS Wales hospitals, while ONS mortality data is sourced from civil registration data. NHS England and DHCW will receive patient identifiable information (NHS number, date of birth, postcode, and date of death (if death occurred during admission)) from Crown Informatics to link the audit data to these sources.

Once the data has been linked, NHS England and DHCW will remove all patient identifiable information, leaving only the unique audit identifier. Imperial College London will then be sent the pseudonymised patient level record files for the patients that participated in the audit from HES, PEDW and ONS (cause of death, and date of death will be provided to Imperial College London from ONS mortality data). Imperial will then send analysed and aggregated data to the NRAP team at the Royal College of Physicians so that we can write and publish a supplement to the national clinical reports. Only aggregate data will be presented, and no information will be released that could be used to identify individuals.

Third party data requests

Third party data requests are not currently permissible under the non-research Section 251 approval for this audit. NRAP are in the process of applying for research Section 251 approval for this audit. When approved, third party organisations may request to use data for research, audit and service evaluation purposes. The main use of data will always be to improve care and services for children and young people with asthma. NRAP will not share any of this data unless the appropriate legal, ethical and security arrangements are in place to keep it safe and secure.

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Data retention

Data will be retained by NRAP over the period that the audit continues to operate. This will allow post-audit queries to be answered, outstanding longitudinal analyses to be completed and for third party data requests to be approved and completed. In addition, the <u>Information Governance Alliance (IGA)'s Records</u> <u>Management Code of Practice for Health and Social Care 2016</u> specifies that clinical audit records must be kept securely for a minimum period of 5 years after the audit has been completed and if the NRAP closes in the future, this requirement will be considered by NHS England and the Welsh Government and appropriate arrangements made as required.

Saying 'no thank you'

In England, patients who have chosen to opt out of their confidential data being used for purposes other than their own care and treatment (<u>National Data Opt-out Programme</u>) will not be included in this audit. Wales does not operate a national data opt-out programme, but patients are still able to opt out of individual audits, such as this one.

National clinical audit works best when it includes information about as many patients as possible. Patients should speak to a member of their clinical team if they do not want their information to be included. Saying this will not affect the care or treatment they receive in any way. Healthcare services should then ensure their information is not included in the audit and should note this for the future on their patient database. If a patient thinks their information has been submitted to the audit and they would prefer to have it removed, they should contact the hospital where they were treated or the audit team.

Right to complain to a supervisory body

If a patient, or their parent/carer, thinks that their information is being used inappropriately, they have the right to complain to the Information Commissioners Office (ICO).

If you have any queries regarding the processing of data as part of this audit, please contact the NRAP audit team at asthma@rcp.ac.uk.