National Respiratory Audit Programme (NRAP)

Children and young people asthma audit: Information Governance Frequently Asked Questions

Version 1.0: August 2023

A general FAQ document is available separately.

1. Who is involved in running the audit?

- The audit is managed and operated by the Royal College of Physicians, London (RCP) in collaboration with the following:
    - Healthcare Quality Improvement Partnership (HQIP) – commissions the audit and is data controller for all NRAP audit data.
    - Crown Informatics – provide the audit web tool and data management services.
    - Imperial College London – provide statistical data analysis services.
- The Royal College of Physicians, Crown Informatics and Imperial College London are all data processors for the audit.

2. Has the audit got approval to collect identifiable information?

The Children and young people asthma audit will collect the following patient identifiable/potentially patient identifiable information: NHS number; date of birth; home postcode; gender; date of death.

a. England and Wales

- This audit has Section 251 approval for England and Wales from Health Research Authority Confidential Advisory Group (CAG) to collect the below patient identifiable information without the patient's explicit consent. The CAG reference number is 19/CAG/0001.
- Each participating hospital Caldicott Guardian is required to provide written approval before any data can be entered into the audit.

3. What are hospitals required to do?

Children and young people asthma audit: Information Governance Frequently Asked Questions | Version 1.0: August 2023
National Respiratory Audit Programme (NRAP)
asthma@rcp.ac.uk | 020 3075 1526
www.rcp.ac.uk/nrap

- Although patients do not need to be asked for their consent to be included in the audit, hospitals must carry out fair processing activities. These include the following:
  - Displaying the patient information poster in all areas where patients with asthma may be treated.
  - If a patient or their parent/carer asks for further information, they must be provided with a copy of the most relevant patient/parent/carer information leaflet.
  - Copies of both the poster and patient information leaflets are available to download from the Children and young people asthma audit resources page.
- If a patient informs you that they do not wish to be included in the audit or have opted out under the National opt out Policy, please make this clear in the patient's notes and do not enter their data into the audit.

4. What is the protocol for managing differing views between patients and their parents around the inclusion of information within the audit?

- England and Wales do not have a specified age at which a child is considered to be competent to provide their own consent to data processing. Parents or other carers are only allowed to exercise data protection rights on behalf of a child if the child authorises them to do so, when the child does not have sufficient understanding to exercise their rights themselves, or when it is evident that this is in the best interest of the child.[1] However, NHS Digital, which operate the National Data Opt-Out programme for England, wrote to patients aged 13 years and over with information about opting out of secondary data usage. Any patient in England over the age of 13 is able to set up their own National Data Opt-Out request. It is the responsibility of each hospital or 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.

---

1 Information Commissioner's Office, Guide to the General Data Protection Regulation – Children and the GDPR. Available at https://ico.org.uk/media/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/children-and-the-gdpr-1-0.pdf Accessed 11 February 2019

- Consequently (i.e. due to the lack of explicit guidance), any decisions around whose choice to respect, and the subsequent entry of any data will be at the discretion of the local clinical lead that has been identified for the audit. It would be suggested that considering guidance from the Information Commissioner's Office, any dispute between parents and children with regards to submitting data to the audit should be resolved in favour of the child's decision, unless the child is deemed incompetent to make their own decision.

- Patient information should be provided to ensure that patients/parents/carers are provided with the opportunity to make an informed choice as to the inclusion of that child's personal information in the audit.

5. What are the data flows?

- The Children and young people asthma data flows are publicly available on the resource webpage, but these are also summarised below.

- Approved users at each registered hospital enter data into a bespoke web tool hosted by Crown Informatics. This can be accessed via www.nrap.org.uk.

- Personal Identifiable Data (PID) from each unit is only visible to authorised users within that hospital according to the audit profile. It is also visible to Crown Informatics for web tool and data management purposes. Crown Informatics only access the data on very rare occasions, examples of which are listed below:

  - System 'de-bugging' investigations – if problems are experienced with processes where PID is involved. Examples might include duplicate checks, readmission processing and validation processing. Note, wherever possible, system tests are undertaken on test systems using dummy/fake PID. However, processing of live data may have to be examined in detail in rare and limited circumstances.

  - Data linkage exercises to validate linkage success – these are usually limited spot checks. Bulk access to PID is necessary to undertake linkage exercises (i.e. to prepare the files for transfer to NHS England or Data Health and Care Wales (DHCW)).

  - Subject access requests - when a patient requests their audit details.

- Non-identifiable patient level data is sent from Crown Informatics to Imperial College London for statistical analysis purposes.

- Following analysis, non-identifiable, aggregated patient data is sent from Imperial College London to the audit team (at the Royal College of Physicians) for audit administration and reporting.

- Non-identifiable patient level data may also be shared with third-parties for research, audit and service evaluation under Data Sharing Agreements (DSAs), which are arrangements agreed separately as required, according to IG recommendations.

6. Who has access to the data?

a. Patient identifiable data

- Only nominated individuals at each hospital and Crown Informatics can see any patient related identifiable data. Access to data is carried out for necessary administrative purposes only by named, trained, and certified individuals.

- Crown Informatics has a Data Security and Protection Toolkit (DSPT) rating of Standards Exceeded (ODS code: 8J157) and meets all NHS guidelines and requirements.

- They are also registered with the Data Protection Authorities (DPA) under reference: Z3566445.

- Access to data is via secure client software that operates over secure encrypted firewalled networks using secondary application layer security.

b. Non- identifiable patient data

- Only members of the Imperial College London analysis team will have access to anonymised patient level data sent to them by Crown Informatics.

- Imperial College London has a DSPT rating of Standards Met (ODS code: EE133887-SPHTR) and meets all NHS guidelines and requirements.

- They are also registered with the Data Protection Authorities (DPA) under reference: Z5940050.

Children and young people asthma audit: Information Governance Frequently Asked Questions | Version 1.0: August 2023
National Respiratory Audit Programme (NRAP)
asthma@rcp.ac.uk | 020 3075 1526
www.rcp.ac.uk/nrap

- Data Sharing and Transfer Agreements duly authorised by the audit commissioners (HQIP) will govern the transfer of non-identifiable patient data to any approved third parties.

c. Anonymised and aggregated level data
- Members of the NRAP team at the Royal College of Physicians receive anonymised and aggregated data from Imperial College London.
- The Royal College of Physicians has an DSPT rating of Standards Met (ODS code: 8J008-CSD) and meets all NHS guidelines and requirements.
- Royal College of Physicians is also registered with the Data Protection Authorities (DPA) under reference: Z7085833.

7. How is data transferred?

- Data is collected over secure web/internet-based systems using high strength TLS (SSL) protocols (256 bit, SHA256 signatures and 4096 bit certificates. The web tool SSL certificate is 'organisationally verified' (OV) and issued by an established respected global certifier).

8. How and where is the data stored?

a. Crown Informatics
- Data is stored and processed at a secure UK based ISO 27001 certified data centre.
- The servers are owned and operated by Crown Informatics and are held in a secure locked rack, accessible to named individuals. All access is logged, managed and supervised.
- Data is stored in secure encrypted databases.
- Backups are encrypted (AES256), held in dual copies, and stored securely.

b. Imperial College London

Children and young people asthma audit: Information Governance Frequently Asked Questions | Version 1.0: August 2023
National Respiratory Audit Programme (NRAP)
asthma@rcp.ac.uk | 020 3075 1526
www.rcp.ac.uk/nrap

- Data is stored on a password protected computer on an encrypted internal hard drive which sits in a locked room. Datasheets themselves are also password protected individually.
- Data is regularly backed up and access to servers is certified to ISO 27001.

9. What is the data retention schedule?

- Data will be retained for the duration of the audit in order to complete longitudinal analyses, including assessing long-term outcomes for children and young people who have asthma attacks.
- All data will be destroyed in line Information Governance Alliance (IGA)'s Records Management Code of Practice for Health and Social Care 2016 (available at: https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/codes-of-practice-for-handling-information-in-health-and-care/records-management-code-of-practice-for-health-and-social-care-2016) which requires that clinical audit records must be kept securely for a period of 5 years after a clinical audit has been completed. This will enable the RCP to answer any post-closure queries.
- This retention schedule has been approved by the CAG.

The National Respiratory Audit Programme (NRAP) has been funded by HQIP until 31 May 2026, at which point a decision will be taken about the future of the work.

Children and young people asthma audit: Information Governance Frequently Asked Questions | Version 1.0: August 2023
National Respiratory Audit Programme (NRAP)
asthma@rcp.ac.uk | 020 3075 1526
www.rcp.ac.uk/nrap

Children and young people asthma audit: Information Governance Frequently Asked Questions | Version 1.0: August 2023
National Respiratory Audit Programme (NRAP)
asthma@rcp.ac.uk | 020 3075 1526
www.rcp.ac.uk/nrap