

Saying 'no thank you'

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the study to be reliable and accurate. If you withdraw from the study, we may need to keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

National clinical audit works best when it includes information from as many patients as possible. However, if you would rather your information wasn't included in this audit, please speak to your consultant or member of the respiratory team. They will ensure your information is not entered onto the secure database. Saying this will not affect the care or treatment you receive in any way.

If you think information about you has already been submitted to the National Audit Community Acquired Pneumonia Audit 2018-19 and you would prefer to have it removed, please contact the hospital that treated you or the BTS audit team on the numbers listed below. If it is still possible to identify your information we will remove it from our records. We only keep your NHS number for a limited period of time and once this has been deleted it will not be possible to identify your information.

BTS may run further Pneumonia audits in future. Asking not to be included in this audit does not automatically remove you from future audits. If further Pneumonia audits do take place which include confidential information, you will have the opportunity to ask for your details not to be included in them, if you wish.

How can I find out more about the National Pneumonia Audit 2018-19?

You can find out more about how we use your information at:

<https://www.brit-thoracic.org.uk/standards-of-care/audit/>

Or contact the BTS audit team:

Email: audittools@brit-thoracic.org.uk or

Telephone: 020 7831 8778 option 2.

National Adult Community Acquired Pneumonia Audit 2018-19

Patient Information Leaflet (v 0.1)

What is the National Adult Community Acquired Pneumonia Audit?

This study collects information about the quality of care for adults admitted to hospital with Pneumonia. NHS hospitals in the UK that provide care for people with Pneumonia are able to take part.

Who is responsible for the audit?

The British Thoracic Society (BTS) is the sponsor for this study based in the United Kingdom. We will be using information from your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. BTS will keep identifiable information about you for 1 year after the study has finished.

What information is collected?

BTS will collect information about you for this study from your hospital. This information will include your NHS number, home postcode, sex, date of birth and health information, which is regarded as a special category of information. We will use this information to highlight areas where care for Pneumonia patients is good, and where improvements need to be made. Hospitals can then make changes to improve their standards of care. The audit will also help to make sure that information on the quality of care is available to the public.

Information will be collected on patients admitted with Pneumonia between 1 December 2018 and 31 January 2019. For further details of what information is collected, please visit our website: <https://www.brit-thoracic.org.uk/standards-of-care/audit/>.

Why is it necessary to collect this information?

NHS numbers are needed so information collected by this audit can be linked with other sources (see 'Where does my information go?'). We do this so we can follow your care after you are discharged from hospital. We also want to understand differences in patient populations across the county – home postcode, sex and date of birth are used to test any variations that are seen between hospitals.

Where does my information go?

There are very strict rules about what happens to your information. The hospitals taking part in this audit will enter information about your care, along with your NHS number and other information, into a highly secure online database provided by BTS and Westcliff Solutions Ltd. The online database is managed by staff at BTS and Westcliff Solutions Ltd, who will only see personal details for database administration and have to follow strict confidentiality rules. Both BTS and Westcliff Solutions Ltd follow best practice in data protection and security.

Westcliff will send information collected through the audit (including NHS number, home postcode, sex, date of birth and admission dates) to NHS Digital so that it can be linked to other information. NHS Digital has a record of all hospital admissions from the Hospital Episode Statistics (HES) dataset. NHS Digital will provide date and cause of death information for audit participants, sourced from civil registration data, on behalf of the Office for National Statistics (ONS). NHS Digital will be able to link this data to the individual patients in the audit. This linked data will be sent to Westcliff to remove all patient identifiable information, before being sent to BTS and the University of Nottingham for analysis and reporting. Linking the data in this way allows us to look at more aspects of your care without asking hospitals to enter extra information into our database.

How do we keep your information safe?

There are very strict NHS regulations and standards in place to ensure the confidentiality and security of patient information. All organisations involved in handling data for this audit are required to comply with these to ensure your information is stored safely.

How will my information be used?

The information collected is used to provide each participating hospital with reports about the standards of care they deliver to Pneumonia patients, and how these compare with other hospitals in the UK. This helps hospitals to see where they can improve. National reports are also published on the BTS websites and are accessible to the public. No reports contain NHS numbers or any other information that can be used to identify you.

The data collected through this audit may also be used to produce academic papers, but these would not include any information that can be used to identify individual patients. Any such use of the data will always be in line with the overall aims of improving care and services for Pneumonia patients and improving the information recorded about Pneumonia patients.

Will my information be provided to anyone else?

Information about your health and care may be provided to researchers running other research studies in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Why haven't hospital staff asked for permission to use my information?

This audit has been given special legal permission to collect confidential information without asking for consent from individual patients. This is because it can be difficult to ask patients for their permission when they have Pneumonia. Some patients may find it hard to communicate and some won't have relatives with them who can communicate wishes on their behalf. Being in hospital with Pneumonia is a very distressing time for patients, and asking them about this at this time would not be the most important priority.