Data Protection Impact Assessment for
National Asthma and COPD Audit Programme (NACAP)

Document control:

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Organisation's ICO registration number can be found at https://ico.org.uk/esdwebpages/search	Z7085833	

Date Completed	Version	Summary of changes
12 April 2018	V1.0	HQIP template
30 April 2018	V4.0	Initial drafts and changes made as result of consultation
25 July 2018	V5.0	Changes made as requested by Public Benefit and Privacy Panel, Scotland
31 July 2018	V5.2	Further changes made as requested by Public Benefit and Privacy Panel, Scotland
03 August 2018	V5.3	Further changes made as requested by Public Benefit and Privacy Panel, Scotland
06 August 2018	V5.4	Further changes made as requested by Public Benefit and Privacy Panel, Scotland
4 February 2019	V5.5	DPIA reviewed and updated (routine 6-monthly process)
18 October 2019	V5.6	DPIA reviewed and updated (routine review)
19 February 2020	V5.7	DPIA reviewed and updated
01 June 2020	V8.1	DPIA reviewed and updated in light of changes to data flows and IG amendments made in May – June 2020
19 April 2021	V8.2	DPIA reviewed and updated made in April 2021
20 October 2021	V8.3	DPIA reviewed and updated made in October 2021

Contents

Screening questions

Please complete the following checklist:

	Section	Yes or No	N/A	Comments
1.	Does your project involve any automated decision making, evaluation or scoring including profiling and predicting using information about a person? Does the outcome from your project decide who gets access to services?	No		
2	Does your project involve any sensitive information or information of a highly personal nature?	Yes		Secondary care components (adult asthma, children and young people asthma and COPD) includes the collection of patient identifiable information. Approval to do this is gained via: **England and Wales** Section 251 application and approval process (approval numbers for adult asthma and COPD audits: CAG 8-06 (b) 2013; paediatric audit: 19/CAG/0061). Subsequent to this, local Caldicott Guardian approval is obtained for each participating hospital. All secondary care audits require identifiable hospital staff user information. Users voluntarily register themselves on the NACAP web-tool in order to participate in the audits.
				The pulmonary rehabilitation component includes the collection of patient identifiable information via a patient consent model. **England and Wales** Section 251 for England and Wales is not required for this audit component. Caldicott Guardian approval is obtained. This audit requires identifiable PR service staff user information. Users voluntarily register themselves on the NACAP web-tool in order to participate in the audit.

3.	Does the proposal involve any data concerning vulnerable individuals who may be unable to easily consent or oppose the processing, or exercise their rights? This group may include children, employees, mentally ill persons, asylum seekers, or the elderly, patients and cases where there is an imbalance in the relationship between the position of the individual and the controller.	Yes		The audit programme will involve collection of data for: **Children**; the children and young people asthma audit collects data pertaining to children and young people, aged 1-18 inclusive who are admitted to hospital for an asthma attack. Data will only be collected to assess the extent to which the care received meets guidelines and standards to enable services to improve care.
4.	Does your project involve any innovative use or applying new technological or organisational solutions? This could include biometric or genetic data, the tracking of individuals' location or behaviour?	No		
5.	Does your project match data or combine datasets from different sources?	Yes		**England and Wales** Patient identifiers are used to link with HES Admitted Patient Care (APC) dataset (for admission and readmission data for England), ONS (for mortality data) (via NHS Digital) and PEDW (via DHCW) for admission and readmission data for Wales.
6.	Does your project collect personal data from a source other than the individual without providing them with a privacy notice ('invisible processing')?	No		Information is gathered from hospitals, GP practices and pulmonary rehabilitation services but posters and patient information flyers are provided and detail how and why data is used and what security measures are taken to ensure its security. A privacy notice is available on the NACAP webpages.
7.	Does your project process data that might endanger the individual's physical health or safety in the event of a security breach?	No		
8.	Is this a new project? Or have the requirements for your project changed since its initiation? Are you sharing new information or linking to new datasets that were not part of the original project specification? Have you added any new audit streams to your project?	No		**This DPIA has been updated to reflect a contract extension.** NACAP audit continues to run as per previous versions of this document. **Hospital and service user details** These audits (COPD, asthma and PR)

				continue to require hospital and PR service user information as data must be entered and signed off by clinical staff. Users voluntarily register themselves on the NACAP web-tool in order to participate in the audits.

Data Protection Impact Assessment

This Data Protection Impact Assessment (DPIA) template and guide is a tool which can help organisations identify the most effective way to comply with their data protection obligations and meet individuals' expectations of privacy. This tool will help organisations which process personal data to properly consider and address the privacy risk that this entails.

DPIA can be used alongside existing project management and risk management methodologies. Conducting a DPIA is now a legal requirement under the GDPR (General Data Protection Regulation) which will start on the 25th May 2018 and the new UK Data Protection Act. By completing a DPIA, this will help to ensure that your project is compliant with GDPR and UK data protection legislation. This document will be updated if further ICO guidance is published or there is change in legislation.

A DPIA is the basis of a "privacy by design" approach, to help meet privacy and data protection expectations of customers, employees and other stakeholders. A DPIA is intended to be prospective and proactive and should act as an early warning system by considering privacy and compliance risks in the initial design and throughout the project.

Purpose and benefits of completing a DPIA

- A DPIA is a process which assists organisations in identifying and minimising the privacy risks of new projects or policies.
- Conducting a DPIA involves working with people within the organisation, with partner organisations and with the people affected to identify and reduce privacy risks.
- The DPIA will help determine the appropriate controls needed to protect personal data i.e. technical, procedural and physical.
- The DPIA will help to ensure that potential problems are identified at an early stage, when addressing them will often be simpler and less costly.
- Conducting a DPIA should benefit organisations by producing better policies and systems and improving the relationship between organisations and individuals.
- The ICO may often ask an organisation whether they have carried out a DPIA. It is often the most effective way to demonstrate to the ICO how personal data processing complies with Data Protection legislation.

Supplementary guidance

- Data Protection Impact Assessment under GDPR guidance
- ICO's conducting privacy impact assessments code of practice
- The ICO's Anonymisation: managing data protection risk code of practice may help organisations to identify privacy risks associated with the use of anonymised personal data.
- The ICO's Data sharing code of practice may help organisations to identify privacy risks associated with sharing personal data with other organisations.
- The ICO's codes of practice on privacy notices, as well as other more specific guidance, will also help an organisation to focus DPIAs on those issues.
- The Government Data Programme has developed a Data Science Ethical Framework to help organisations understand the benefits and risks of using personal data when developing policy. The Framework can be used as part of the process to help you describe information flows and identify privacy risks and solutions.

DPIA methodology and project information.

At what stage in the project did you conduct this DPIA? E.g. planning stage, changes to the existing project, in retrospect.

> This DPIA was originally completed in April 2018 and has been updated several times since (currently on version 8.2). The original draft was completed both in retrospect (in terms of the secondary care COPD continuous clinical audit component of NACAP, which started in February 2017) and at the planning stage (in terms of the asthma and PR audits). The adult asthma audit launched in November 2018 and PR and children and young people asthma audits launched in March and June 2019 respectively.

Describe the overall aim of the project and the data processing you carry out

> **Aim**
>
> The overall aim of NACAP is to improve the care, experiences and outcomes of patients with asthma and COPD. It provides (or will provide) healthcare services with the information and tools they need for quality improvement and service development to ensure that patient care and experience is of the highest possible standard.
>
> The RCP will aim to capture <u>all patients</u>:
>
> 1) Admitted to hospitals (in England and Wales):
> - With asthma attacks:
>   a) The children and young people asthma audit will collect data on:
>   - patients aged between 1 and 5 (admitted for asthma attack or wheeze)
>   - patients aged between 5 and 16
>   - patients aged between 16 and 18 who are *treated on paediatric wards*.
>   b) The adult asthma audit will collect data on:
>   - patients aged over 18
>   - patients aged between 16 and 18 who are *treated on adult wards*.
> - With exacerbations of COPD (above the age of 35)
>
> 2) Referred and assessed for pulmonary rehabilitation in England and Wales
> 3) With asthma and COPD registered at a GP practice in Wales
>
> between the launch of the audits (which were staggered) and the programme end (currently February 2023.
>
> **Data processing**
> **Secondary care and pulmonary rehabilitation components**
> Data is currently collected for all admissions to hospital for acute exacerbation of COPD, adults with asthma and children and young people with asthma in England and Wales, on a continuous basis from those hospitals who have agreed to take part in NACAP. The pulmonary rehabilitation audit launched in March 2019; and collects information on patients with COPD referred to and assessed for PR in England and Wales.
>
> Local sites will enter audit data for appropriate patients via a bespoke web-tool hosted by Crown Informatics ([www.nacap.org.uk)](www.nacap.org.uk), which provide real-time, benchmarked data at site level, displayed as run charts, to support local quality improvement.

Patient identifiable data is only visible to individual sites and to Crown Informatics, if required for administrative purposes. Please note, Crown 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 patient identifiable data is involved. Examples might include duplicate checks, re-admission processing, and validation processing. Note, wherever possible, system tests are undertaken on test systems using dummy/fake patient identifiable data. However, processing of live data may have to be examined in detail in rare but limited circumstances.
- Data linkage exercises to validate linkage success - this is usually limited spot checks. Bulk access to patient identifiable data is necessary to undertake linkage exercises (i.e. to prepare the files for transfer to NHS Digital or DHCW).
- Subject access requests - when a patient requests their audit details.

No other organisation or individual will be able to access these identifiable data.

Once a year, Crown Informatics will extract patient-level data from the web-tool for the purpose of the annual national report. Reporting cohorts are determined by the date of the patient's discharge (in secondary care) or of assessment/commencement of a programme (in PR). For example, a report will contain the cohort discharged from hospital/who commenced PR between 1 June and 30 November 2019 in England and Wales. Sites will have 6 weeks from the end of the patient cohort period to enter the data prior to it being extracted by Crown. For PR services this is 18 weeks to ensure patients have enough time to complete their PR programme. This is communicated to them on the log-in page of the web-tool, but also via email. This delay ensures that the hospitals/services have had the time to a) retrieve notes, if necessary and b) manually enter the data into the system.

Once extracted, Crown will anonymise these data using the following methods:

- NHS number will be replaced by study ID
- Postcode will be reduced to the first 4 digits (also known as 'Lower Super Output Area (LSOA)', needed for derivation of deprivation indices)
- Date of birth will be transformed to month and year of birth

Once the data have been anonymised, Crown will transfer patient-level (anonymised) data for the full report cohort (England and Wales) to Imperial College London (ICL) for data cleaning and analysis. Crown operate a 'encrypted/electronic only' data transfer policy for all patient level data using HTTPS 'web file transfer' protocols (256 Bit SSL) and store data on secure end points. Data is protected in AES-256 bit encrypted ZIP files and stored in password protected file transfer databases, which operate under secure access protocols, access logging/tracking and authentication mechanisms. Decryption password dissemination/management operates under a defined identity policy and is given or received orally by a suitably trained and IG trained senior operatives. Use of portable storage media and email is prohibited. Data processing assets are operated in secure locations.

Following the cleaning and analysis of data, aggregated (i.e. analysed and non-identifiable) data will be transferred from Imperial College London to the RCP to provide commentary for, and then publish, audit programme outputs (e.g. national reports, site level reports) all of which will allow hospitals to gain an understanding of the extent to which the care they deliver is similar to that delivered by their peers.

In addition, once a year Crown Informatics will securely transfer identifiable data (NHS number, DOB and postcode) to NHS Digital and DHCW in order to link to HES, ONS and PEDW datasets. This will allow understanding of the longer-term outcomes for the audit cohort, namely admission/readmission and mortality rates and 1 month and 3 months (secondary care) or 3 and 6 months (pulmonary rehabilitation) post discharge from hospital/completion of pulmonary rehabilitation.

The cohort transferred to these organisations will be the same as that extracted for the purpose of the annual national report (i.e. so that a later report detailing their medium-to-long term outcomes can be published). NHS Digital and DHCW will return patient level pseudonymised linked data (with identifiers removed, but the unique audit identifier retained) to Imperial College London in its role as the organisation responsible for analysis of the data. Imperial will combine the validated identifiers, outcomes data and the relevant audit data.

Following the cleaning and analysis of data, aggregated (i.e. analysed and non-identifiable) data will also be transferred from Imperial College London to the RCP to provide commentary for, and then publish, outcome-related audit programme outputs (e.g. national reports, health board reports).

NACAP also publishes six-monthly regional reports, however, these aggregated reports will be run automatically by Crown Informatics and will not require access to identifiable data by any party (including Crown).

Primary care component
Primary care data are extracted from GP practices in Wales (following an opt-in model). Data is anonymised at source (no identifiable data leaves the GP practice). This data accessed via the Secure Anonymised Information Linkage (SAIL) databank and their WLGP (Welsh Longitudinal General Practice) and WDSD (Welsh Demographics Services Dataset) datasets. Data is accessed by Imperial College London, via the SAIL's secure servers, for analysis, and then national, local health board (LHB) and cluster level data is sent to the Royal College of Physicians for commentary and reporting. National and local level reporting outputs are produced. Examples of these, from previous audit rounds can be found at www.rcp.ac.uk/pc2020. Practice level results are produced by DHCW and are made available via an on-line portal. Practices can access their own data (only) and compare it to national and LHB averages for quality improvement (QI) purposes.

Third party applications for data
Third party applications for data must be approved by both the RCP and HQIP. Once approved, Imperial College London transfer anonymised data (patient level or aggregate data, depending on the request) to the third party. The third party analyse the data and publishes its research findings.

Should an approved third party applicant organisation require both audit data and outcome data (i.e. linked data) for the purpose of audit, service evaluation or research, these identifiers will be sent from Crown Informatics to NHS Digital and/or DHCW for the purposes of data linkage (with e.g. HES or ONS) with subsequent flow of a linked (de-identified) dataset from NHS Digital and/or DHCW to the applicant organisation.

Retention of data
All data will be destroyed in line with the 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), which specifies that clinical audit records must be kept securely for a minimum period of 5 years after a the audit has been completed. This will potentially allow post-audit queries to be answered, outstanding longitudinal analyses to be completed and for third party data requests to be approved and completed. Once the point of the audit closure has been reached, any need for retention of patient identifiable data during this period will be assessed by the funders (NHS England and Welsh Government) and the outcome of this assessment will be informed to CAG and subject to extension/amendment requests as required. The NACAP contract date currently runs until 28 February 2023.

DPIA Consultation

We advise you to consult with as many relevant people as possible (both internal and external stakeholders) while conducting this assessment, consultation is an important part of a DPIA and allows people to highlight privacy risks and solutions based on their own area of interest or expertise. Consultation can take place at any point in the DPIA process and may include the project management team, Data Protection Officer, designers, IT provider, procurement team, data processors, communications team, patients, stakeholders, corporate governance and compliance teams, researchers, analysts, statisticians and senior management.

You must consult with the Data Protection Officer regarding the impacts on privacy. Please state below that you have.

If you decide against seeking the views of data subjects or their representatives e.g. this would be disproportionate or impracticable, then the justification must be made clear in the box below.

In the box below name the stakeholder group, date consulted and how consulted. Please insert another box if you consulted with many different stakeholder groups.

Project management team, Data Protection Officer, Senior Management, IT (webtool) provider, sub-contractor for analysis and methodology.

Publishing your DPIA report

Publishing a DPIA report is not a legal requirement but you should consider publishing this report (or a summary or a conclusion) and you should send it to your stakeholders. Publishing the DPIA report will improve transparency and accountability, and lets individuals know more about how your project affects them. Though there may be a need to redact/remove sensitive elements e.g. information on security measures.

State in the box below if you are going to publish your DPIA. If so, please provide hyperlink to the relevant webpage if this has been done already or insert the date you intend to publish it.

https://www.rcplondon.ac.uk/projects/outputs/national-asthma-and-copd-audit-programme-nacap-resources Version 8.2 will be published in May 2021.

Data Information Flows

Please describe how personal information is collected, stored, used and deleted. Use your data flow map and information asset register to help complete this section. Explain what personal information is used, what it is used for, who it is obtained from and disclosed to, who will have access and any other necessary information. Completing this section can help identify potential 'function creep', unforeseen or unintended uses of the data for example data sharing.

The NACAP has data flow charts for all its audit components. These can be found below.

Primary care (asthma and COPD) – Legal basis = anonymised at source

PC_Data
Flow_v5_September 2

Stage 1 (data extraction): Primary care data is accessed in a pseudonymised form (no identifiable information leaves the practice) from GP practice systems in Wales. NHS number is replaced by study ID, postcode is transformed into WIMD index, date of birth transformed to age and date of death is transformed into age at death.

Pseudonymised data held in the Secure Anonymised Information Linkage (SAIL) SFTP.

Stage 2 (data analysis and management): Pseudonymised data is access by Imperial College London (via the SAIL WLGP (Welsh Longitudinal General Practice) and WDSD (Welsh Demographics Services Dataset) datasets) for analysis purposes.

Stage 3 (reporting): Imperial College London transfer aggregate (analysed) data (national, local health board (LHB) and cluster level data only) to Royal College of Physicians for commentary and national and Local Health Board reporting. Digital Health and Care Wales (DHCW) receive practice level aggregated data for the DHCW GP portal (which is then made available at practice (practices can access their own data only), local and national level). Imperial publishes research findings using the aggregated data. Small numbers are suppressed throughout.

Stage 4 (third party applicants): Imperial College London transfer anonymised, aggregated data onto third party once application has been approved by HQIP and RCP. Third party analyse this data and publish their research findings. Small numbers are supressed throughout.

Continued from above

Secondary care – COPD and adult asthma

Legal basis:

o   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.
o   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.

AA_Data
Flow_v7_Oct 21 FINAl

COPD_Data
Flow_v7_FINAL_Oct 2

Stage 1 (data entry and pseudonymisation): Local sites (i.e. clinicians, members of the audit team) enter audit data (including patient identifiable data – PATIENT IDENTIFIABLE DATA) for appropriate patients via a bespoke web-tool hosted by Crown Informatics (www.nacap.org.uk).

Crown anonymises data (audit and linked). Date of birth transformed to age, date of death is transformed into survival at x days and postcode is transformed into LSOA.

Stage 2 (audit data analysis and management): Pseudonymised patient level data is sent to Imperial College London for data cleaning and analysis.

Stage 3 (report writing): aggregated data is sent to Royal College of Physicians to draft audit outputs (e.g. national reports).

Stage 4 (linkage): Crown sends identifiable data to NHS Digital and DHCW for linkage purposes and asthma/COPD data is combined with HES, PEDW and ONS. All patient level pseudonymised linked data is returned to Imperial College London.

Imperial College London will combine the validated identifiers, NHS Digital and DHCW data and the relevant audit data.

Stage 5 (linked data analysis and management): Anonymised patient level data is securely transferred to Imperial College London for data cleaning and analysis. Following the cleaning and analysis of data, aggregated (i.e. analysed and non-identifiable) data will also be transferred from Imperial College London to the RCP to provide commentary for, and then publish, outcome-related audit programme outputs (e.g. national reports, health board reports).

Stage 6 (outcome report writing): aggregated data is sent to Royal College of Physicians to draft audit outputs (e.g. national reports).

Hospital level real-time run charts are made available via the Crown web-tool and updated every 15 minutes. Hospitals can only see their own run charts.

Imperial publishes research findings using the aggregated data. Small numbers are suppressed throughout.

Stage 7 (third party applicants): Imperial College London transfer anonymised, aggregated data onto third party once application has been approved by HQIP and RCP. If application requires it Crown, NHS Digital and DHCW (and is

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granted following application to DARS for latter three) patient level audit data is sent to third party. Third party analyse this data and publish their research findings. Small numbers are supressed throughout.

Secondary care – Children and young people asthma

Legal basis:

o   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.

o   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.

CYA_Data
Flow_v7_FINAL_Oct 2

As above.

Pulmonary rehabilitation

Legal basis:

o   Article 6 (1) (a) the data subject has given consent to the processing of his or her personal data for one or more specific purposes

o   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.

o   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.

PR_Data
Flow_v4_FINAL_Oct 2

Web-tool users (secondary care and pulmonary rehabilitation)
Web-tool users (those who enter and sign-off the data) register themselves (legal basis = consent) on the web-tool. Details (including name, job title, email address, place of work and contact number) are kept on the NACAP web-tool and are accessible to the NACAP team for administrative purposes (chasing, communication activities, reporting etc.).

Transferring personal data outside the European Economic Area (EEA)

If personal data is being transferred outside of the EEA, describe how the data will be adequately protected (e.g. the recipient is in a country which is listed on the Information Commissioner's list of "approved" countries, or how the data is adequately protected).

No personal data is transferred outside of the EEA.

Privacy Risk Register
Justification for collecting personal data

Personal data must be adequate, relevant and limited to what is necessary in relation to the purposes for which those data are processed. In certain circumstances it may be unlawful to process information not described in the transparency information (privacy notice/fair processing material) which informs individuals how their personal data is being used.

It may not be necessary to process certain data items to achieve the purpose. They may be irrelevant or excessive leading to risk of non-compliance with the Data Protection Act.

In the tables below list and justify personal data items needed to achieve the lawful aim of a project that requires information on individuals and their personal characteristics. Insert as many more lines that you need. Work through the table of items and decide whether or not you should be collecting the information, examine each data field and decide if you need it.

There are two sections in the table below, one for personal data and one for personal sensitive data items.

Data Categories [Information relating to the individual's]	Is this field used?	N/A	Justifications [there must be justification for collecting the data items. Consider which items you could remove, without compromising the needs of the project]
Personal Data			
Name		N/A	
NHS number (England and Wales)	Yes		Enables linkage with externally held national datasets for exploration of patient outcomes (readmissions and mortality). Also ensures automated duplicate checks can be carried out (i.e. within the web-tool). NHS number, postcode and date of birth are all collected for triangulation purposes. They enable the linkage service to link the correct data in a situation where one of the identifiers might be incorrect.
Address		N/A	
Postcode	Yes		As above and also enables exploration of social and economic deprivation (using Index of Multiple Deprivation (IMD) and Welsh Index of Multiple Deprivation (WIMD)). NHS number, postcode and date of birth are all collected for triangulation purposes. They enable the linkage service to link the correct data in a situation where one of the identifiers might be incorrect.
Date of birth	Yes		As above and also enables exploration of equity of care (i.e. whether different cohorts of patients – in this case patients of different ages - receive the same level of, and access to, care). NHS number, postcode and date of birth are all collected for triangulation purposes. They enable the linkage service to link the correct data in a situation where one of the identifiers might be incorrect.
Date of death	Yes		Collected to ascertain the extent to which the patient's care impacts upon the key outcome of mortality.
Age		No	We collect date of birth and compute age ourselves using in-built web-tool validations.
Sex	Yes		The primary care report collects sex. This enables exploration of equity of care, i.e. whether different cohorts of patients receive the same level of,

Data Categories [Information relating to the individual's]	Is this field used?	N/A	Justifications [there must be justification for collecting the data items. Consider which items you could remove, without compromising the needs of the project]
			and access to, care.
Marital Status		N/A	
Gender	Yes		Enables exploration of equity of care (i.e. whether different cohorts of patients receive the same level of, and access to, care).
Living Habits	Yes		Information on smoking and exposure to secondhand smoke are collected as they are key contributing factors in the care and management of COPD and asthma patients.
Professional Training / Awards		N/A	
Income / Financial / Tax Situation		N/A	
Email Address		N/A	
Physical Description		N/A	
General Identifier e.g. Hospital No		No	
Home Phone Number		N/A	
Online Identifier e.g. IP Address/Event Logs	Yes		Collected for users of the web-tool (i.e. not the patients that make up the audit cohort) due to the make-up of the NACAP web-tool (how the equipment needs to work with the internet) but this information is not accessed or used in anyway.
Website Cookies		N/A	
Mobile Phone / Device No		N/A	
Device Mobile Phone / Device IMEI No		N/A	
Location Data (Travel / GPS / GSM Data)		N/A	
Device MAC Address (Wireless Network Interface)		N/A	
Sensitive Personal Data			
Physical / Mental Health or Condition	Yes		Enables exploration of equity of care and parity of esteem (i.e. whether patients with different co-morbidities receive care of different standards). This will be: • extracted for the Primary Care audit, • obtained via linkage to HES and PEDW for the asthma audits and COPD audits
Sexual Life / Orientation		N/A	
Family / Lifestyle / Social Circumstance		N/A	
Offences Committed / Alleged to have Committed		N/A	
Criminal Proceedings / Outcomes / Sentence		N/A	

Data Categories [Information relating to the individual's]	Is this field used?	N/A	Justifications [there must be justification for collecting the data items. Consider which items you could remove, without compromising the needs of the project]
Education / Professional Training		N/A	
Employment / Career History		N/A	
Financial Affairs		N/A	
Religion or Other Beliefs		N/A	
Trade Union membership		N/A	
Racial / Ethnic Origin	Yes		Only the PR audit collects ethnic background to enable assessment of equity of care across race and ethnic origin.
Biometric Data (Fingerprints / Facial Recognition)		N/A	
Genetic Data		N/A	
Spare			
Spare			
Spare			

Data quality standards for personal data

In the box below, describe how you will ensure that personal data is accurate and kept up to date.

Streamlining of datasets will help minimise data entry omissions. Comprehensive validation rules are built into the web-tool to ensure that incorrect, conflicting and/or illogical data cannot be saved. Pop-up warnings appear for values that are plausible, but rare.

Comprehensive helpnotes for each question will be provided and the questions themselves reviewed annually in order to ensure they are clear. The central team will operate a helpdesk to answer queries that arise. FAQ documents will be available for all audits. Once data entry periods have closed, data will be exported and checked centrally for any inappropriate cases or illogical data before analysis.

For the primary care audit, robust rules will be applied to data cleaning to ensure that erroneous values are removed prior to analysis.

Details of registered webtool users will be audited periodically to ensure that we do not have out of date details. People who have signed up for information/newsletters will be contacted annually to ensure that they wish to remain on the distribution list.

Individual's rights

If your project uses personal data you must complete this section.

If your project uses personal data you must state how fairness and transparency will be achieved e.g. privacy notices on websites, posters, and leaflets. The information must be provided in a concise, transparent, intelligible and easily accessible form, using clear and plain language. Any information provided to children should be in such a clear and plain language that the child / vulnerable person can easily understand.

In the box below, please define the way you have ensured that individuals are aware of the rights, if they request those rights how will they achieve them? For example if an individual requests a copy of their information held by you, describe how you would do this. You can insert any relevant policy or process guides in the appendix at the end of this document if they are not already available on your website. This section does not refer to the personal information held about your audit staff.

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
Individuals are clear about how their personal data is being used.	**Audit data** A privacy notice is available covering the whole programme. Fair processing notices are available for each audit component on the NACAP webpages as they launch. Posters and patient information leaflets are made available at all necessary healthcare services (primary, secondary care and pulmonary rehabilitation) to ensure patients are aware of their data being used and for what purpose. **Web-tool users** Web-tool users voluntarily register themselves on the web-tool and are clear on the purposes	**Audit data** All (privacy notice, fair processing notices, posters and patient information leaflets) are available via the NACAP webpages (www.rcp.ac.uk/nacap) as the different audit components launch – audit materials will not be available prior to this point. Posters are sent to all GP practices and hospitals and patient information leaflets made available via URL. Posters and leaflets are also made available via the webpages. Where necessary, patient information leaflets have been made available for different age ranges and groups (for example adults, children (4-7 years and 8+ years) and parents so all necessary people have access to this information. **Web-tool users** Web-tool users voluntarily register themselves on the	**Audit data** **Example - Link to full secondary care COPD fair processing notice.** https://www.rcp.ac.uk/projects/outputs/national-asthma-and-copd-audit-programme-nacap-secondary-care-workstream-copd **Web-tool users/contacts** Upon registering new users receive an automated email to inform them that their registration request will be shared with the approver for their service (often a clinical lead) as part of one of the web-tool security measures.

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
	for which their information will be used by the NACAP team (administrative only). This is done via: • Automated emails during the registration process • NACAP fair processing and privacy policies • Crown privacy policies	web-tool and are clear on the purposes for which their information will be used by the NACAP team (administrative only). Automated emails are sent at different points during the registration process to keep new users up to date. User details are not used outside of programme administrative activities (chasing and audit communication).	
Individuals can access information held about them	This is included in the [privacy notice](#). Identifiable information is not accessible by the audit team but is available to key personnel at Crown Informatics. All access requests will be directed to Crown Informatics once received at the audit helpdesk. This does not apply to the primary care audit where the data is anonymised at source.	We would not be able to provide the information held but would put the person in touch with Crown Informatics who would be able to help.	Privacy Notice: *The right of access* You have the right to see what information is held about you. Crown Informatics are the only organisation in the clinical audit programme that receives personal data and this is anonymised as soon as possible. If you are a patient, we don't use names and addresses so you would have to know your NHS number. Once the data has been anonymised it would not be possible to identify if you were included in the audit sample. You have the *right to rectify* any data that is incorrect but rectifying it with us would not change the information in your health record and you may want to contact your healthcare provider directly.
Request erasure (right to be forgotten) in certain circumstances, making clear that it does	This is included in the [privacy notice](#). **Audit data** All fair processing information and patient information leaflets provide	**Audit data** Fair processing information, posters and patient information leaflets as the different audit components launch – audit materials will not be available prior to this. Can be accessed via the	Privacy notice: *The right to erasure* You can request that we don't use personal information about you in our studies and we will ensure that any of your information we hold is destroyed. This will need to be done on a study by study basis otherwise the only way we could remove you from all studies would be to hold personal data about you to

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
not apply to an individual's health or care record, or for public health or scientific research purposes	individuals with the right to have their information removed from or not included in the audit. The section in the patient information is called 'Saying no thank you'. **Web-tool users** NACAP web-tool users can request that their information is removed from the web-tool as and when necessary. They can either do this via their own account or make a request via the NACAP helpdesk which is then communicated to Crown.	NACAP webpages (www.rcp.ac.uk/nacap) and via the necessary healthcare services (GP practice, hospitals or pulmonary rehabilitation service). **Web-tool users** User account deletion/ modification information can be accessed by logged-in users via the NACAP web-tool (www.nacap.org.uk).	compare with the patient information that we receive. You also have the right to restriction of processing and to object to processing. We treat these the same way as the right to erasure and remove all information about you. If you decide that you would prefer that your information is not used please let us know by contacting us in writing at the postal address or use this email: nacap@rcplondon.ac.uk. **Audit data** **Example from the secondary care COPD patient information sheet** ## Saying 'no thank you' 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. In the future there will be other national COPD audits taking place in different places and different times, such as in pulmonary rehabilitation services and at GP practices. Asking not to be included in this audit does not automatically remove you from future audits. When they take place you will have the opportunity to ask for your details not to be included in them, if you wish. If you think information about you has been submitted to the COPD audit and you would prefer to have it removed, please contact the hospital that treated

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
			you or the COPD audit team on the numbers listed below. **Web-tool users/contacts** User account deletion modification information can be found via the NACAP web-tool (www.nacap.org.uk). They can either do this via their own account or make a request via the NACAP helpdesk which is then communicated to Crown. **Patient information from the webtool**: Crown has ability to search by identifier and delete with permanency. Obtained from Crown System Level Security Policy (SLSP) 13.2 Data Disposal When the system or its data has completed or is no longer needed, the following methods will be adopted to dispose of equipment, back-up media or other stored data: • Disposal/erasing of data will be performed in accordance with any regulations or legislative requirements, but information will be wiped from all digital media using a recognised erasing tool to ensure that data is not recoverable. • Data no longer required will be erased from the system and the space reused. • Back-up tapes will be overwritten or destroyed. • If the machine is no longer required, the data storage drives will be removed and physically destroyed and the remaining components will be disposed of.
Rectification of inaccurate information	This is included in the privacy notice.	We can rectify inaccurate information but would recommend that people contact the health provider	Privacy Notice: You have the right to see what information is held about you. Crown

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
		that supplied the information to rectify at source.	Informatics are the only organisation in the clinical audit programme that receives personal data and this is anonymised as soon as possible. If you are a patient, we don't use names and addresses so you would have to know your NHS number. Once the data has been anonymised it would not be possible to identify if you were included in the audit sample. You have the *right to rectify* any data that is incorrect but rectifying it with us would not change the information in your health record and you may want to contact your healthcare provider directly
Restriction of some processing	This is included in the privacy notice. **Audit data** All fair processing information and patient information leaflets provide individuals with the right to have their information removed from or not included in the audit. The section in the patient information is called 'Say no thank you'. **Web-tool users** NACAP web-tool users can request that their information is removed from the web-tool as and when necessary. They can either do this via their own account or make a request via the NACAP helpdesk which is then	**Audit data** Fair processing information, posters and patient information leaflets as the different audit components launch – audit materials will not be available prior to this. Can be accessed via the NACAP webpages (www.rcp.ac.uk/nacap) and via the necessary healthcare services (GP practice, hospitals or pulmonary rehabilitation service). **Web-tool users** User account deletion/ modification information can be accessed by logged-in users via the NACAP web-tool (www.nacap.org.uk).	Privacy notice: You also have the right to restriction of processing and to object to processing. We treat these the same way as the right to erasure and remove all information about you. All existing and future fair processing (including privacy notices) and patient information does or will include details of how patients can have their information removed or not included in the audits. **NACAP web-tool user** NACAP web-tool users can request that their information is updated from the web-tool/changed as and when necessary. They can either do this via their own account or make a request via the NACAP helpdesk which is then communicated to Crown.

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
	communicated to Crown.		
Object to processing undertaken on some legal bases	This is included in the [privacy notice](). **Audit data** There is a National Data Opt-Out Programme which runs in England and enables patients residing or being treated in England to apply a blanket 'opt-out' to their identifiable healthcare data being used for secondary purposes (such as audit and research). All fair processing information and patient information leaflets provide individuals with the relevant information on how to have their information removed from or not included in the audit. The section in the patient information is called 'Say no thank you'.	**Audit data** Fair processing information, posters and patient information leaflets as the different audit components launch – audit materials will not be available prior to this. As and when these are launched they will be able to be accessed via the NACAP webpages (www.rcp.ac.uk/nacap) and via the necessary healthcare services (GP practice, hospitals or pulmonary rehabilitation service). See information to the left on how the objection is applied for each of the different countries (England and Wales).	Privacy notice: You also have the right to restriction of processing and to object to processing. We treat these the same way as the right to erasure and remove all information about you. All NACAP documentation explains/will explain the National Data Opt-Out Programme (NDOP) in England and how this differs to how objections are applied for Scotland and Wales (and individual opt-outs in England). In addition, the information makes it clear that for Scotland and Wales objecting to one audit component does not automatically remove them from another of the NACAP components. They can, therefore, object to one audit but still be included in others. The adult asthma 'saying no thank you' section currently reads: **Saying 'no thank you'** National clinical audit works best when it includes information about as many patients as possible. However, please speak to a member of your clinical team if you do not want your information to be included. Saying this will not affect the care or treatment you receive in any way. They will ensure your information is not included in the audit. If you think your information has been submitted to the audit and you would prefer to have it removed, please contact the hospital that treated you or the audit team. In England, patients who have chosen to opt-out of their confidential

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
			data being used for purposes other than their own care and treatment (National Data Opt-out Programme) will not be included in this audit. Wales does not operate a national opt-out programme, but patients are still able to opt-out of individual audits, such as this one.
Complain to the Information Commissioner's Office;	This is included in the privacy notice.	Contact details for the ICO are provided.	**Contact the Information Commissioner's Office** If you are unhappy with the way we handle your data or have dealt with a request, you have the right to lodge a complaint with the Information Commissioner's Office at https://ico.org.uk/concerns/ or telephone 0303 123 1113.
Withdraw consent at any time (if processing is based on consent)	This is included in the privacy notice. **Audit data** This is included in the fair processing information for the pulmonary rehabilitation component of NACAP which operates under a consent model. **NACAP web-tool users** NACAP web-tool users can request that their information is removed from the web-tool as and when necessary. They can either do this via their own account or make a request via the NACAP helpdesk which is then	**Audit data** Fair processing information which is available via the NACAP webpages (www.rcp.ac.uk/nacap). **NACAP web-tool users** User account deletion/ modification information can be accessed by logged-in users via the NACAP web-tool (www.nacap.org.uk).	Privacy notice: *Consent* Where people sign up to receive newsletters and updates, attend events or work with NACAP consent is received for us to store and process personal data. The Pulmonary Rehabilitation clinical audit collects patient data by obtaining consent from patients, as well as using Public Task and Special Categories of Data (ensuring high standards of healthcare). Information about the audit is provided to help clinicians obtain informed consent from patients. The consent material for PR is available at: https://www.rcp.ac.uk/projects/outputs/national-asthma-and-copd-audit-programme-nacap-pulmonary-rehabilitation-workstream The relevant section from the PR information sheet is below: *If you have given permission for your information to be included in this audit but you later change your mind, please let you PR service know. However, if data has already been extracted for reporting,*

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
	communicated to Crown.		*your data will be included in the report in an aggregated and anonymous format.* **NACAP web-tool user** NACAP web-tool users can request that their information is deleted from the web-tool as and when necessary. They can either do this via their own account or make a request via the NACAP helpdesk which is then communicated to Crown.
Data portability (if relevant)	This is included in the privacy notice.	N/A	Privacy notice: *The right to data portability* If we do have information held about you and you wish to see it, we will provide your data in a format that you will be able to use, such as Microsoft Word, Excel or CSV.
Individual knows the identity and contact details of the data controller and the data controllers data protection officer	**Audit data** This information is given within all fair processing notices. **NACAP web-tool users** Information on the identity and contact details of the data controller and their data protection officers can be found within the NACAP web-tool information.	**Audit data** Fair processing notices are available via the NACAP webpages (www.rcp.ac.uk/nacap) **NACAP web-tool users** User account deletion/ modification information can be accessed by logged-in users via the NACAP web-tool (www.nacap.org.uk).	**Audit data** **Example from secondary COPD audit fair processing information** *The Healthcare Quality Improvement Partnership (HQIP) are the data controllers for all data collected and reported on by the National COPD Audit Programme. All data collected by the audit programme is processed to ensure patient confidentiality is maintained.* **NACAP web-tool user** Information from the NACAP web-tool for users. The programme has been commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and currently covers England and Wales only. The audit programme is led by the Royal College of Physicians (RCP). For more information on the National Asthma and COPD Audit Programme please visit: www.rcplondon.ac.uk/nacap.

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
In which countries the data controller is processing their personal data. For data transfers outside the EU, a description of how the data will protected (e.g. the recipient is in an 'adequate' country / how a copy of the safeguards can be obtained.	N/A	N/A	N/A
To know the legal basis under which their information is processed. Is there a clear legal basis for the processing of personal data? If so, what is the legal basis?	This is included in the privacy notice, fair processing notices and the patient information leaflets.	Both the fair processing notices and patient information leaflets for each audit component can be found via the NACAP webpages (www.rcp.ac.uk/nacap). Patient information leaflets are also made available via a URL in the posters.	**Example from the adult asthma clinical audit patient information leaflet** *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 an asthma attack**. Some patients may find it hard to communicate and some won't have relatives with them who can communicate wishes on their behalf. An asthma attack is a very distressing time for patients, and asking them about this audit at this time would not be the most important priority.* **Example from COPD fair processing notice**

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
			This audit has been granted Section 251 approval by the NHS Health Research Authority (CAG reference: CAG 8-06(b)/2013) for England and Wales, meaning that we are allowed to collect patient-identifiable data without patient consent. More information about the data items collected, as well as about the data flows outlined below, is available in our patient information sheet as part of the audit resources for the secondary care workstream. **Example from the primary care patient information leaflet** ***Why haven't the practice staff asked for my permission to use my information?*** *This doctor's surgery has agreed to take part in the audit. The audit will not collect any identifiable information. This means it is not necessary to ask for permission from each from each individual patient.* From the Privacy Notice: **Our legal basis for collecting information** The legal bases for collecting and using personal data are: *Public Task* We collect only the information that is necessary to carry out our function and avoid collecting information that will not be used. This is received from healthcare providers, such as NHS Trusts and Health Boards. To see what information is held in your healthcare record please contact your local Trust or Board. 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. *Consent* Where people sign up to receive newsletters and updates, attend events

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
			or work with NACAP consent is received for us to store and process personal data. The Pulmonary Rehabilitation clinical audit collects patient data by obtaining consent from patients, as well as using Public Task and Special Categories of Data (ensuring high standards of healthcare). Information about the audit is provided to help clinicians obtain informed consent from patients. *Contract* For example, this is the basis we use when it is necessary for us to take specific steps before entering into a contract with you to supply you a service or vice versa. *Legal obligation* For example, this is the basis we use when it is necessary for us to comply with the law (not including contractual obligations) because we are required to keep documentation to produce in court proceedings. *Legitimate interests* This basis is used to allow us to hold information as evidence should we need it in the future, for example, if you ask us to unsubscribe you from our newsletter. *Common Law Duty of Confidentiality* We apply the Common Law Duty of Confidentiality to all data we hold. Article 9 condition for processing special category data: • 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.

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
To know the purpose(s) for the processing of their information.	This is included in the privacy notice, the fair processing notices and patient information leaflets include information on this.	The fair processing notices, privacy notice and patient information leaflets for each audit component can be found via the NACAP webpages (www.rcp.ac.uk/nacap) as the different audit components launch – audit materials will not be made available prior to this point. Patient information leaflets are also made available via a URL in the posters.	**Example from adult asthma clinical audit patient information leaflet** *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.* From the privacy notice: **How and why we use the information**
Whether the provision of personal data is part of a statutory obligation and possible consequences of failing to provide the personal data.	N/A	N/A	N/A
The source of the data (where the data were not collected from the data subject)	The patient information leaflets provide this information.	Patient information leaflets are made available via URL (in the posters) and PDF on the NACAP webpages (www.rcp.ac.uk/nacap)	**Example from adult asthma clinical audit patient information leaflet** *Where does my confidential information go?* *The **hospitals taking part** in this audit will **enter information about your care, along with your confidential information, into a highly secure online database**. This is held by Crown Informatics, which follows best practice in data protection and security. **It will be held for the duration of the audit. Should the audit come to an end, it will be held for a further 5 years.** Staff at Crown Informatics will only see personal details for database administration and have to follow strict confidentiality rules.*

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
Categories of data being processed	Datasets and data flows.	Audit datasets and data flows are, or will be made (as audits launch), available on the NACAP webpages (www.rcp.ac.uk/nacap)Data flows are colour coded to enable easy identification of what category of information each flow falls into (identifiable, anonymised, anonymised and aggregated).	Please note the following: COPD, adult and children and young people asthma, pulmonary rehabilitation and primary care audit information are available at www.rcp.ac.uk/nacap. Information will include datasets and data flows which will outline all categories of data being processes by NACAP.
Recipients or categories of recipients	Datasets and data flows.	Data flows are, or will be made, available on the NACAP webpages (www.rcp.ac.uk/nacap)All data flows include information on data processes and controllers for each stage of the process.	COPD, adult and children and young people asthma, pulmonary rehabilitation and primary care audit information are available at www.rcp.ac.uk/nacap. Information includes data flows which will outline all recipients or categories of recipients who receive audit data.
The source of the personal data	The privacy notice and patient information leaflets provide this information.	Patient information leaflets are made available via URL (in the posters) and PDF on the NACAP webpages (www.rcp.ac.uk/nacap)	**Example from adult asthma clinical audit patient information leaflet** **Where does my confidential information go?** The hospitals taking part in this audit will enter information about your care, along with your confidential information, into a highly secure online database. This is held by Crown Informatics, which follows best practice in data protection and security. It will be held for the duration of the audit. Should the audit come to an end, it will be held for a further 5 years. Staff at Crown Informatics will only see personal details for database administration and have to follow strict confidentiality rules. Example from the privacy notice: The audit information will be linked with data already held by NHS Digital and Data Health and Care Wales (DHCW): namely, the Hospital Episodes Statistics (HES) and Patient Episode Database for Wales

Individuals rights (where relevant)	Describe how you ensure individuals are aware of these rights	Describe how you would do this	Please copy and paste section of document that states the individuals rights
			(PEDW) datasets and the Office of National Statistics (ONS) mortality data.
To know the period for which their data will be stored (or the criteria used to determine that period)	As above	As above	As above
The existence of, and an explanation of the logic involved in, any automated processing that has a significant effect on data subjects (if applicable)	N/A	N/A	N/A

Privacy Risks

Types of Privacy risks

- Risks affecting individuals or other third parties, for example; misuse or overuse of their personal data, loss of anonymity, intrusion into private life through monitoring activities, lack of transparency.
- Compliance risks e.g. breach of the GDPR
- Corporate risks (to the organisation), for example; failure of the project and associated costs, legal penalties or claims, damage to reputation, loss of trust of patients or the public.

Risks affecting individuals

Patients have an expectation that their privacy and confidentiality will be respected at all times, during their care and beyond. It is essential that the impact of the collection, use and disclosure of any patient information is considered in regards to the individual's privacy.

In the box below insert the number of individuals likely to be affected by the project. This could be the number of unique patient records your project holds now and how many more records you anticipate receiving each year.

Secondary care components

All patients admitted to hospital with an acute exacerbation of COPD or an acute asthma attack are included in the scope of the audit.

COPD

There are currently over 100,000 COPD clinical records on the NACAP webtool. There are an estimated 115,000 admissions to hospital as a result of COPD each year. The aim is for 100% case ascertainment, therefore, we would hope the dataset would increase by approximately 115,000 per annum.

Potential number of affected patients = 345,000 by 2021 with a 100% CA

Asthma

Approximately 60,000 people (adult and children and young people) are admitted to hospitals for acute asthma attacks each year. The aim will be for 100% case ascertainment, although this is unlikely for the first 2-3 years.
Impact: that all patients within this audit component would be at risk.

Potential number of affected patients = Approx. 305,000 by 2021 with a 65% CA

Pulmonary rehabilitation component

There were 7,476 patient records entered for the 2017 snapshot PR clinical audit on the NACAP web-tool. As of March 2019, all patients assessed for and who complete pulmonary rehabilitation are included in the scope of the audit (continuously). This is approximately 46,000 per year although estimates for the audit are 30,000 per year for the first 2 year (65% case ascertainment).

Potential number of affected patients = Approx. 70,000 by 2021 with a 65% CA.

TBC:

Primary care components

The 2017 primary care audit was conducted on COPD patients only. This audit captured 82,696 COPD patient records in this audit cycle. There are 260,000 people in Wales with asthma which will be included in the 2018, 2019 and 2020 audit cycles for primary care.

Potential number of affected patients = Approx. 340,000 patients with close to 100% CA.

Number of individuals (users and contacts) on NACAP web-tool = 1578 unique users/contacts currently. This is likely to double by the time recruitment to the asthma audits is completed.

Please complete the table below with all the potential risks to the Individuals of the information you hold on them, your corporate risks and compliance risks.

When completing the table you need to consider if:

- Inadequate disclosure controls increase the likelihood of information being shared inappropriately.
- The context in which information is used or disclosed can change over time, leading to it being used for different purposes without people's knowledge.
- Measures taken against individuals as a result of collecting information about them might be seen as intrusive.
- The sharing and merging of datasets can allow organisations to collect a much wider set of information than individuals might expect.
- Identifiers might be collected and linked which prevent people from using a service anonymously.
- Vulnerable people may be particularly concerned about the risks of identification or the disclosure of information.
- Collecting information and linking identifiers might mean that an organisation is no longer using information which is safely anonymised.
- Information which is collected and stored unnecessarily, or is not properly managed so that duplicate records are created, presents a greater security risk.
- If a retention period is not established information might be used for longer than necessary.

Corporate and compliance risks

In the table, list the corporate risks to your organisation which could include reputational damage, loss of public trust, financial costs and data breaches. Below these, insert any compliance risks.

Possible corporate risks include:

- Non-compliance with the DPA or other legislation can lead to sanctions, fines and reputational damage.
- Problems which are only identified after the project has launched are more likely to require expensive fixes.
- The use of biometric information or potentially intrusive tracking technologies may cause increased concern and cause people to avoid engaging with the organisation.
- Information which is collected and stored unnecessarily, or is not properly managed so that duplicate records are created, is less useful to the business.
- Public distrust about how information is used can damage an organisation's reputation and lead to loss of business.
- Data losses which damage individuals could lead to claims for compensation.

Examples of compliance risks include:
- Non-compliance with the common law duty of confidentiality
- Non-compliance with the GDPR.
- Non-compliance with the Privacy and Electronic Communications Regulations (PECR).
- Non-compliance with sector specific legislation or standards.
- Non-compliance with human rights legislation.

Managing Privacy and Related risks

There are many different steps you can take to reduce a privacy risk. For example
- Devising retention periods which only keep information for as long as necessary and planning secure destruction of information.
- Implementing appropriate technological security measures.
- Ensuring that staff are properly trained and are aware of potential privacy risks.
- Developing ways to safely anonymise the information when it is possible to do so.
- Producing guidance for staff on how to use new systems and how to share data if appropriate.
- Using systems which allow individuals to access their information more easily and make it simpler to respond to subject access requests.
- Taking steps to ensure that individuals are fully aware of how their information is used and can contact the organisation for assistance if necessary.
- Selecting data processors that will provide a greater degree of security and ensuring that agreements are in place to protect the information which is processed on an organisation's behalf.
- Producing data sharing agreements which make clear what information will be shared, how it will be shared and who it will be shared with.

Use your project plan and a detailed explanation of information flows to identify more precisely how a general risk may occur. For example, there may be particular points in a process where accidental disclosure is more likely to happen.

The DPIA actions should be added to into your project plan and risks added to your contract review documentation.

Privacy Risks and Actions Table

Please see appendix 2 for additional guidance on completing this table

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
Illegitimate access	1	5	5	Reduced	Crown Informatics Ltd holds all identifiable information on behalf of NACAP. The NACAP team/other sub-contractors do not have access to these identifiers. **Data security at Crown** (web-tool in use for secondary care). Only nominated individuals have access to the data, and only the individual units themselves can see the patient identifiable data of their own patients. Access to data is via	**Crown** have an excellent reputation for data security. Their security systems ensure that all data is held safely and the risk of breach is an absolute minimum. Annual checking of DSPT is undertaken by the programme **Imperial College London** takes all necessary measures to ensure that the data they hold is secure and		

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					secure client software, operating over secure VPN firewalled networks using secondary application layer security provided by IBM. Data is stored and processed at a secure data centre; this operates to ISO 27001 certification (2015). **Data security at Imperial College London** (only have pseudonymised data) Primary care data: On an encrypted hard drive locked in a safe which is bolted to the wall. Secondary care and pulmonary rehabilitation	inaccessible to anyone not authorised to access it. Annual checking of DSPT is undertaken by the programme		

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What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					data: On a password protected computer on an encrypted internal hard drive which sits in a locked room. The datasheets themselves are also password protected individually as well as the computer. Data is regularly backed up on a server, and access to servers are certified to ISA 7001, the recognised standard for data security.			
Undesired modification	1	4	4	Reduced	As above	As above		
Disappearance of data	1	3	3	Reduced	**Crown Informatics Ltd** (sub-contract who hold all patient level and identifiable information.	**Crown** have an excellent reputation for data security. Their		

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					Backups are encrypted at AES256, held in dual copies, and stored securely. As above for **Imperial College London**.	security systems ensure that all data is held safely and the risk of disappearance or loss of information is at an absolute minimum. **Imperial College London** take all necessary measures to ensure that the data they hold is secure and inaccessible to anyone not authorised to access it. All data is backed up on an secure server.		

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
Network failure (RCP)	1	5	5	Reduced	**Data security at RCP.** Data is regularly backed up on a server, and access to both servers are certified to ISA 7001. This will ensure that despite a network failure access can still be gained to key information.	This ensures that even if a network failure is experienced all information remains safe and unharmed.		
Sub-contractor network failure or cyber-attack	1	5	5	Reduced	**Crown Informatics Ltd** holds all identifiable information on behalf of NACAP. The NACAP team and all other sub-contractors do not have access to this. Data security at Crown (web-tool in use for secondary care). Only nominated individuals have access to the data, and only the individual	**Crown** have an excellent reputation for data security. Their security systems ensure that all data is held safely and the risk of breach is an absolute minimum. All the necessary fire walls and precautions are in place to deal		

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What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					units themselves can see the patient identifiable data of their own patients. Access to data is via secure client software, operating over secure VPN firewalled networks using secondary application layer security provided by IBM. Data is stored and processed at a secure data centre; this operates to ISO 27001 certification (2015). Backups are encrypted at AES256, held in dual copies, and stored securely. As above for Imperial College London.	with and avoid with cyber events. **Imperial College London** take all necessary measures to ensure that the data they hold is secure and inaccessible to anyone not authorised to access it. All data is backed up on a secure server.		

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What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
Data breach	1	5	5	**Reduced**	The audit programme is subject to comprehensive data regulations, and will do the following to both reduce and transfer the risk of a data breach: - Legal basis. The audit programme will ensure that the secondary care audits are covered under Section 251 of the Health and Social Care Act (reference: CAG 8-06 (b) 2013, 19/CAG/0061). - Data security at Crown (web-tool in use for secondary care). Only nominated individuals have access to the data, and only the individual units themselves can see	These measures ensure that the risk of a data breach is extremely low. They ensure the security of all information (identifiable and anonymised).		

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					the patient identifiable data of their own patients. Access to data is via secure client software, operating over secure VPN firewalled networks using secondary application layer security provided by IBM. Data is stored and processed at a secure data centre; this operates to ISO 27001 certification (2015). Backups are encrypted at AES256, held in dual copies, and stored securely. Data security at RCP and ICL. Data is regularly backed up on a server,			

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What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					and access to both servers are certified to ISA 7001, the recognised standard for data security.

- All members of the audit team have data protection training on an annual basis.

Removal of data if requested by a patient Crown has ability to search by identifier and delete with permanency. Obtained from Crown System Level Security Policy (SLSP)

When the system or its data has completed or is | | | |

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What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					no longer needed, the following methods will be adopted to dispose of equipment, back-up media or other stored data: • Disposal/erasing of data will be performed in accordance with any regulations or legislative requirements, but information will be wiped from all digital media using a recognised erasing tool to ensure that data is not recoverable.			

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					• Data no longer required will be erased from the system and the space reused. • Back-up tapes will be overwritten or destroyed. • If the machine is no longer required, the data storage drives will be removed and physically destroyed and the remaining components will be disposed of. Posters, patient information leaflets and fair processing information are made			

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What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					widely available to ensure that patients are aware of the audit and how and why their data is used. There is the option for them to ask for their information not to be included in the audit if they do not wish it to be.			
Corporate risks & compliance risks section								
National Data Opt-out risk (England only)	2	4	8	**Accepted**	There is a risk that patients who have opted-out of having their patient identifiable information used for audit/research/planning purposes will be incorrectly entered onto the audit webtool. Other			

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					than ensuring that information on this is included in the audit guidance there is nothing the audit can do as it will not have access to the central spine repository where this information is held. Responsibility for not entering that patients' data is solely with the hospital/health and social care service who are entering the data. This has been put as a 2 as with the introduction of this on 25 May 2018, this is a very new process and issues cannot be pre-empted at this point. This does not apply to Wales.			

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					NACAP and Crown are in regular discussions with HQIP regarding compliance and to ensure a consistent approach across the programme			
Section 251 annual reviews – not submitted	1	4	4	Reduce	The majority of the legal basis requirements involve an annual review of the approval – particularly section 251. There is a risk that these are delayed or not submitted and NACAPs legal basis is not valid for a time period. All senior programme staff (clinical leads, programme and project managers) are to have an awareness of	With all senior team members knowing the details and dates of these that the likelihood of them being missed is significantly reduced.		

What are the potential risks to the individuals whose personal data you hold?	Likelihood of this happening 1 Very unlikely 2 Unlikely 3 Possible 4 Likely 5 Very Likely (See guidance below for definition))	Impact 1 -Insignificant 2-Minor 3-Moderate 4-Major 5-Catastrophic (See guidance below for definition)	Overall risk score (likelihood x impact = score)	Will risk be accepted, reduced or eliminated?	Mitigating action to reduce or eliminate each risk OR Where risk is accepted give justification.	Explain how this action eliminates or reduces the risk	Expected completion date	Responsible owner
					these process and the dates that they are due. Reminders are placed in calendars and in project plans to ensure all necessary team members are aware of the requirement to update these essential documents and approvals.			

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Regularly reviewing the DPIA

DPIA should be an ongoing process and regularly reviewed during the lifecycle of the project or programme to ensure

- Risks identified are still relevant
- Actions recommended to mitigate the risks have been implemented and mitigating actions are successful

You must add to your DPIA every time you make changes to the existing projects, send an updated version to your HQIP project manager and ensure that you incorporate any identified risks/issues to your risk/issue registers of the project contract review form.

Appendix 1 Submitting your own version of DPIA

If submitting your own version of DPIA please ensure it includes the following items. If any items are missing please add this to your DPIA and then submit it. You must also complete the screening questions above.

	Checkbox – Please tick	Evidence – Page number and section in your DPIA
Confirmation of advice /consultation sought from Data Protection Officer whilst completing the DPIA	Yes	This was done via CQID senior management.
Name of DPO	Pamela Forde	
Name and role of person approving completion of DPIA form. This must not be the same person that completes the form.	Pamela Forde Royal College of Physicians Data Protection Officer	This was done via CQID senior management but no queries or concerns were raised on return.
Will the DPIA be published or part of it such as the summary or conclusion (not essential but encouraged). If so, where is it published?	Yes	Page 12
Does it include a systematic description of the proposed processing operation and its purpose?	Yes	See page 8-10
Does it include the nature, scope, context and purposes of the processing	Yes	See page 8-10
Does it include personal data, recipients and period for which the personal data will be stored are recorded	Yes	See page 8-10
Does it include the assets on which personal data rely (hardware, software, networks, people, paper or paper transmission channels)	No	
Does the DPIA explain how each individual's rights are managed? See section on individuals rights	Yes	See pages 19 - 32
Are safeguards in place surrounding international transfer? See section on	N/A	

sending information outside the EEA		
Was consultation of the document carried out and with whom?	Yes	RCP Data protection officer CQID senior management NACAP programme manager NACAP web-tool provider NACAP data analysis lead
Organisations ICO registration number	Yes	See front page
Organisations ICO registration expiry date	Yes	See page 2
Version number of the DPIA you are submitting	Yes	See page 2
Date completed	30 April 2018 Revised 25 July 2018 Revised 4 February 2019 Revised 19 February 2020 Revised 1 June 2020 Revised 19 April 2021	See page 2

Appendix 2 Guidance for completing the table

What are the potential risks to the individuals whose personal data you hold?	See examples above		

	Likelihood score	Description	Example
Likelihood of this happening (H,M,L)	1	Very unlikely	May only occur in exceptional circumstances
	2	Unlikely	Could occur at some time but unlikely
	3	Possible	May occur at some time
	4	Likely	Will probably occur / re-occur at some point
	5	Very likely	Almost certain to occur / re-occur

	Impact scores	Description	Example
Impact (H,M,L)	1	Insignificant	No financial loss; disruption to day to day work manageable within existing systems, no personal data loss/ no breach of confidentiality
	2	Minor	Minor (<£100k) financial loss / disruption to systems; procedures require review but manageable; limited slippage in work activity, breach of confidentiality where < 20 records affected or risk assessed as low where data pseudonymised/files encrypted and no sensitive data
	3	Moderate	Disruption to financial systems (<£250k); significant slippage in work activity or resources e.g. delay in recruiting staff; procedures and protocols require significant review, breach of confidentiality/ loss personal data where < 100 records involved and no sensitive data
	4	Major	Major financial loss (£500k); large scale disruption to deliverables & project plans; business activity severely undermined, wasting considerable time / resources; poor quality report leading to loss of confidence in provider / HQIP / NHSE, breach of confidentiality/loss of personal sensitive data or up to 1000 records
	5	Catastrophic	Huge financial loss (>£500k); significant threat to viability of the organisation in total or in part; huge disruption to business activity; almost total lack of confidence in project provider / HQIP / NHSE, serious

	breach of confidentiality/loss of personal sensitive data >1000 records involved
Risk score (calculated field)	Please multiply the likelihood by the severity (likelihood x severity = risk score). This score will help to rank the risk so the most severe risks are addressed first
Will risk be accepted, reduced or eliminated? (where risk is accepted give justification)	A = Accepted (must give rationale/justification) R = Reduced E = Eliminated
Mitigating action to reduce or eliminate each risk	Insert here any proposed solutions – see managing privacy and related risks section above OR If a risk has been accepted please give justification here (The purpose of the DPIA is to reduce the risk impact to an acceptable level while still allowing a useful project to be implemented.)
Explain how this action eliminates or reduces the risk	Describe how your proposed action eliminates or reduces the possible risk. You may want to assess the costs/resource requirements (i.e. purchasing additional software to give greater control over data access and retention) and balance these against the benefits, for example the increased assurance against a data breach, and the reduced risk of regulatory action and reputational damage.
Expected completion date	What is the expected completion date for your proposed action? Ensure that DPIA actions are integrated into the project plan. You should continue to use the PIA throughout the project lifecycle when appropriate. The DPIA should be referred to if the project is reviewed or expanded in the future.
Action Owner	Who is responsible for this action?